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### "TREATING THE WHOLE PERSON:" AN ETHNOGRAPHIC STUDY OF AN INTEGRATIVE MEDICINE PAIN CLINIC

by

# LINDSEY ANN MARTIN

### DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

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MAJOR: ANTHROPOLOGY

Approved by:

Advisor

Date

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2012

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## DEDICATION

In memory of my father John Martin and my grandparents William and Betty Belter You are with me in spirit...always

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iii

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iv

Dedicationii
Acknowledgementsiii
List of Tablesix
List of Schemesx
Chapter 1: Introduction1
Prologue1
The Research Problem3
Study Aims & Scope6
Conceptual Framework7
Medical Pluralism in the U.S. Healthcare System7
Multidisciplinary Pain Clinics16
Description of Study Chapters
Chapter 2: Methods & Participants32
Sample & Recruitment 32
Research Design & Methods36
Research Design36
Research Methods36
Data Management & Analysis44
Chapter 3: Research Site45
Site Selection45
The Metropolitan Region & Local Community where the IMPC is Located47
A Brief History of the Detroit Metropolitan Area47

# TABLE OF CONTENTS

A Brief History of Waterview	51
The Integrative Medicine Pain Clinic	53
Outside the Clinic	54
Inside the Clinic	55
A Tour through the IMPC	57
Chapter 4: Dr. Bennett's Dream	75
Dr. Bennett & His Career	75
Dr. Bennett & the Making of the IMPC	79
Jasmine	84
Adding to the Dream	89
The IMPC's Culture: The Idea of "Being a Family"	
Creating the "Family:" The Hiring Process	98
The IMPC Staff	101
Chapter 5: The IMPC's Pain Management Approach	124
"Treating the Whole Person"	
Identifying the Cause of the Patient's Pain	
Developing the Patient's Treatment Plan	
Customizing the Patient's Treatment Plan	131
Discussion	141
Chapter 6: Patients' Stories & Their Experiences at the IMPC— Part I	147
Betty's Story: Being an Active & Independent Older Adult	148
Discussion	156
Robin's Story: Experiencing a Lifetime of Pain	159

Discussion17	70
Christina's Story: Longing for "My Old Life"17	73
Discussion18	32
Natalie's Story: Controlling My Body & My Life18	34
Discussion19	92
Chapter 7: Patients' Stories & Their Experiences at the IMPC— Part II	96
Linda's Story: Dealing with a Degenerative Condition	6
Discussion20	9
Stella's Story: Desiring a Healthy Life21	4
Discussion22	5
Julia's Story: Fighting to Get what I Need22	27
Discussion23	37
Paul's Story: Doing What Works for Me24	40
Discussion25	1
Chapter 8: Conclusion25	7
The Real Work of Healing at the IMPC2	57
Conceptualizing Integrative Medicine25	58
Beyond Blending: Social Relationships in IM Practice	64
Integrative Medicine at the IMPC: Relationship-Based Care	35
Future Directions27	74
Concluding Thoughts2	79
Appendix A: Table of Measures28	31
Appendix B: Staff Interview Protocol	32

Appendix C: Patient Interview Protocol—Interview #1	284
Appendix D: Patient Interview Protocol—Interview #2	285
Appendix E: The IMPC's Treatment Options	287
References	.290
Abstract	305
Autobiographical Statement	307

# LIST OF TABLES

Table 1:	Clinic Practitioners and Staff that Participated in the Study	33
Table 2:	Summary of Treatments Observed during the Co-Created Clinical Encounters	.39
Table 3:	Self-Reported Characteristics of Patients that Participated in Interviews	42
Table 4:	Key Demographic Characteristics of Detroit and Waterview	.50
Table 5:	Comparison of Jobless Rates 2008-2011	.51

## LIST OF SCHEMES

Scheme 1: The IMPC's Physical Environment57	.57
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#### CHAPTER 1

### INTRODUCTION

### PROLOGUE

I was 31 years old, sitting across the table from a young, passionate woman named "Julia" who was only three years older than me at the time. Julia described to me in harrowing detail how years of debilitating, chronic pain that she felt was like "a railroad tie through your head, or your eye....That somebody kind of lit on fire." She talked about how she had "lost everything"—her independence, her ability to work, money, dreams, and aspirations, and that she had to become "fully dependent really quickly on a lot of people."

Julia described how her experiences with chronic pain enveloped both her body and mind as "sometimes you feel like you body's ruling...everything." She talked about trying to get order back in her life—to "get the control back with your head instead of letting your body rule." Julia embarked on a years-long health-seeking process where she said that she was dehumanized by many of her doctors, and was even accused of being a "drug seeker." Julia desperately tried to find pain relief through any means possible that included pain medication and even life threatening surgery. She also tried complementary and alternative therapies like energy medicine that she first thought "was a bunch of crap" until she realized that they were having health benefits for her. Julia had all of these experiences and she was only 34 years old.

Yet, despite her pain and her problems seeking treatment, Julia spoke about how she changed as a person from her experiences as she had a new appreciation for life and those closest to her, noting that "I'm probably nowhere near the person I was, which you know is probably good and bad....everything in your life changes." Although on this day Julia sat across the table from me in pain, she radiated a sense of optimism and strength to overcome adversity that she expressed with these powerful, moving words: "trust me I've had my times where I've been tired of fighting, but that doesn't mean you can stop."

As I sit here now, having recently turned 34, I cannot begin to fathom what it must have been like for her at that age to have her life consumed by chronic pain—to have "lost everything" you have worked towards in life, and to have your dreams suddenly "change." Given our closeness in age, Julia's story struck particularly close to home for me. Sadly it was only one of many that I heard during my fieldwork in a pain clinic. Patients of different ages had their bodies and minds battered by their experiences with chronic pain; many wondered out loud if they will ever have a pain-free moment in their lives again and if they can find a clinic to help manage their pain. This dissertation will take you on a journey to a pain clinic where you will get to know its staff, meet their patients and hear their stories about using an integrative medicine approach to pain management. You will hear their ideas about what it takes to start to heal bodies, and begin piecing lives back together.

### THE RESEARCH PROBLEM

Medical anthropologists have had a longstanding interest in examining the pluralistic nature of certain health care systems (e.g. Baer 1995; Baer 2001; Baer 2004; Baer 2005; Baer 2008; Barnes 2005; Crandon-Malamud 1993; Janzen 1978; Last 1996; Salkeld 2004; Salkeld 2008; Whitaker 2003). Several major works have specifically examined U.S. medical pluralism in depth and these authors found that while historically U.S. health care delivery was once very pluralistic, a biomedical approach came to dominate over time (Baer 2001; Porter 2004; Starr 1982). Yet, the growing practice of integrative medicine (IM) in the past two decades highlights how U.S. health care is once again becoming increasingly pluralistic (Baer 2004; Caspi, et al. 2003).

Although official definitions of IM are still debated (Caspi, et al. 2003; Salkeld 2008), IM is commonly conceptualized as complementary and alternative medicine (CAM)<sup>1</sup> (e.g. massage or acupuncture) and biomedical treatments (e.g. prescription medications) being used together (Baer 2004:xiv; Caspi, et al. 2003). What Baer (2004:xiv) describes as a "blend" of modalities. For instance, the National Center for Complementary and Alternative Medicine (NCCAM) conceptualizes IM as "a practice that combines both conventional [i.e. biomedical] and CAM treatments for which there is evidence of safety and effectiveness" (2010:1). Ethnographic approaches are well suited to study IM and explore the diverse ways it is operationalized, practiced and "blended" within clinical settings (e.g. Boon and Kachan 2008; Gaboury, et al. 2009;

<sup>&</sup>lt;sup>1</sup> Complementary and Alternative Medicine or CAM is defined by the National Center for Complementary and Alternative Medicine (NCCAM) as "a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. Conventional medicine (also called Western or allopathic medicine) is medicine as practiced by holders of M.D. (medical doctor) and D.O. (doctor of osteopathy) degrees and by allied health professionals, such as physical therapists, psychologists, and registered nurses. The boundaries between CAM and conventional medicine are not absolute, and specific CAM practices may, over time become widely accepted" (National Center for Complementary and Alternative Medicine, 2010).

Salkeld 2004; Salkeld 2008), and how an IM approach to care can be used to address patients specific health conditions (e.g. Koithan, et al. 2007a).

Pain has been increasingly recognized as a significant and critical contemporary health issue in the United States in the past decade in need of further research (Institute of Medicine 2011; National Center for Health Statistics-Centers for Disease Control and Prevention 2006). The number of individuals living in chronic pain has now reached a staggering number—over 100 million reported by the Institute of Medicine (2011). The Institute of Medicine's (IOM) report from the Committee on Advanced Pain Research, Care, and Education calls for an urgent need to improve pain management in the U.S. and writes:

Everyone is at some risk of acute or chronic pain arising from an illness, an injury, or an array of other factors....Pain is a universal experience but unique to each individual. Across the life span, pain—acute and chronic—is one of the most frequent reasons for physician visits, among the most common reasons for taking medications, and a major cause of disability. Severe chronic pain affects physical and mental functioning, quality of life, and productivity. It imposes a significant financial burden on affected individuals, as well as their families, their employers, their friends, their communities, and the nation as a whole (2011:1-1).

The IOM's (2011) report describes pain as a condition that affects people—physically, socially and psychologically—yet there is variability in how the experience of pain impacts people's lives.

Medical anthropologists are interested in examining both the individual and collective experiences of living with pain. They have documented in specific cultural contexts some of the complexities associated with this condition (Good 1994; Good, et al. 1992; Greenhalgh 2001; Jackson 2000; Jackson 2005; see also Jackson 2011; Kleinman 1988). The classic anthropological distinction made between disease (i.e. the physiological problem) and illness (i.e. the subjective "lived experience") is highly useful

when thinking about the complexity of pain (Crowley-Matoka, et al. 2009; Kleinman, et al. 1978). For instance, the use of the solely disease-based biomedical model for the management of pain does not adequately address the subjective nature of this condition (Kleinman, et al. 1992). Kleinman et al. note:

Chronic pain has an anomalous status in biomedicine largely because it is so baffling to clinicians and academic physicians. The pain is seldom adequately accounted for by physiological lesions; its course and outcome do not conform to any known biochemical or mechanical process (1992:4).

Kleinman et al. also note how a particularly tenuous relationship exists between the U.S. health care delivery system and chronic pain patients: "Chronic pain patients and their families are dissatisfied, often vehemently so, with the health-care system, every component of which has failed them" (1992:6-7). Consequently, chronic pain and its related health-seeking are often highly disruptive life experiences for patients (Good 1994; Good, et al. 1992; Greenhalgh 2001; Honkasalo 2001; Jackson 2000; Kleinman 1988). Seeking relief for chronic pain is often a full-time pursuit that consumes much of patients' lives (Good 1994; Greenhalgh 2001). Additionally, larger political economic issues are also related to pain treatment, according to Good, who writes:

for many chronic pain suffers, conforming to the schedule of the health care system and attempting to negotiate the irrationality of the American welfare and insurance bureaucracies came to be a world of its own, replacing the everyday world which had preceded it (1994:127).

These kinds of health-seeking experiences significantly impact the lives of patients and amplify the overall chronic pain experience (Good 1994; Greenhalgh 2001).

Since the exclusive use of a biomedical model for the treatment of this condition is not necessarily the only or most effective way to manage it (e.g. Crowley-Matoka, et al. 2009; Good 1994; Greenhalgh 2001), it is necessary to further anthropologically explore other ways of handling chronic pain. Using an IM approach to manage pain is gaining increasing acceptance in the U.S. as seen in a recent report by the U.S. Army Surgeon General (2010), which highlights the prevalence of pain in the U.S. population in general, and specifically among U.S. military personnel and veterans. This report recommends:

a holistic, patient-centered approach [to pain management] which employs all modes of therapy—from more conventional means which rely upon the use of [prescription] drugs, to complementary and alternative modes such as acupuncture, meditation, biofeedback, yoga and others (U.S. Army Surgeon General 2010).

Given the pressing need to improve the management of pain, and growing interest in using an IM approach to do so, I chose to focus specifically in this dissertation research on how patients experiencing chronic pain engage with an IM approach to care in a U.S. based multidisciplinary pain clinic.

### Study Aims & Scope

The purpose of this study was to describe a key area of increasing contemporary medical pluralism in the U.S.—the practice of integrative medicine (IM)—by ethnographically studying an IM clinic, and identifying how this clinic applies their integrative approach to the treatment of chronic pain. The aims of this study were:

- 1) To identify and describe the history of this IM clinic, including the development of its IM approach in general and for pain treatment specifically;
- 2) To identify and describe the roles of the clinic's practitioners and staff, as well as their education, training, treatment approaches and professional experiences;
- 3) To document and describe patients' experiences with integrative medicine and pain treatment through the collection of life histories and illness narratives;
- 4) To ethnographically document the co-created integrative medicine clinical encounter and examine how pain treatment approaches are enacted and perceived.

#### CONCEPTUAL FRAMEWORK

This study draws upon the scholarly literature, emerging debates and key concepts in the anthropological and social scientific literature on U.S. medical pluralism and multidisciplinary pain clinics. This conceptual framework provides the structure in which to understand how the pain clinic studied both conceptualizes and practices their particular integrative medicine approach to chronic pain management. Importantly, a series of contrasting ideas-mind/body, care/cure. biomedicine/CAM, and disease/illness—are often discussed in these literatures as various authors show how over time these ideas have shaped Western medicine generally as well as integrative medicine and pain treatment specifically (e.g. Baer 2004; Baszanger 1998; Caspi, et al. 2003; Chrisman and Johnson 1996; Crowley-Matoka, et al. 2009; Gordon 1988; Jackson 2000; Lock and Scheper-Hughes 1996; Salkeld 2004).

#### Medical Pluralism in the U.S. Healthcare System

In the following discussion of U.S. medical pluralism, I will first describe how the pluralistic attitude towards health care lessened with increasing biomedical authority in the U.S. (Porter 2004; Starr 1982), and a separation of body from mind began to take hold (Gordon 1988). I will then discuss a gradual resurgence of medical pluralism as well as the power relations that oftentimes emerge in the dialogue between biomedicine and CAM. I will also consider how these discussions contributed to the conceptualization of IM in U.S. health care in the past several decades (Baer 2004; Bauer 2010; Caspi, et al. 2003; Consortium of Academic Health Centers for Integrative Medicine 2009; Salkeld 2004; Salkeld 2008). Lastly, I will present an ethnographic example from a local level IM clinical practice that highlights some of these power

7

relations regarding when the blending of biomedicine and CAM appear in action (Salkeld 2004; Salkeld 2008).

The medical form that is most commonly associated with U.S. health care today is biomedicine. However, biomedicine was not always the predominate form of medical care, and the United States historically has been a very medically pluralistic country (Porter 2004; Starr 1982). The history of U.S. medicine is long and complex. Hence, I will focus mainly on key aspects to situate complementary and alternative medicine, and integrative medicine in the context of U.S. health care over time<sup>2</sup>.

Paul Starr's (1982) influential book *The Social Transformation of American Medicine* discusses in detail how many forms of medical knowledge and medical practices existed throughout American history that included, lay (popular) medicine, home-based medical care, physician provided medicine, homeopathy, osteopathic medicine, chiropractic medicine and Christian Science. He writes that over time each of these various forms of medical care were subordinated in favor of a biomedical model. Starr also describes how medical knowledge moved from the hands of the layperson mainly into the domain of the physician over time. Starr talks about how the professionalization of biomedicine was vital to gaining power and becoming the predominant form of medical care in the U.S. He noted how the American Medical Association (AMA) had an influential role in this process as well as the organization of medical practitioners. Starr also explains that the AMA became a powerful organization at the center of U.S. medicine and took the lead in restructuring how medical practitioners were trained by the beginning of the 20<sup>th</sup> century.

<sup>&</sup>lt;sup>2</sup> See Starr (1982) for a more comprehensive history of the development of U.S. biomedicine and Baer (2001) for a history of alternative medicine in the United States.

Key to the AMA's restructuring process was the politically powerful 1910 *Flexner Report* that found many medical schools in disarray and provided the rationale for strengthening the biomedical model of medicine (Starr 1982; Torrens 2002). The *Flexner Report* highlighted the need for changes in U.S. medical education making the case that "America was oversupplied with badly trained practitioners" (Starr 1982:120). Starr writes that a push existed to close many schools and for those that remained open, they needed to gain university affiliation and follow in the footsteps of the Johns Hopkins University medical school which "embodied a conception of medical education as...rooted in basic science and hospital medicine" (1982:115). The Johns Hopkins method of training medical students became the norm in the U.S. and a priority was placed on a curriculum based on objective scientific knowledge across the board. In short, Starr depicted a climate in which medical knowledge became more privileged, difficult to attain, and used objective science as its educational foundation in the wake of the *Flexner Report*.

This focus on "objective science" has important implications for understanding how biomedical treatments and related medical education are structured (Gordon 1988). In "Tenacious Assumptions in Western Medicine" Gordon (1988) describes how Western biomedical epistemology is driven by Cartesian thinking where the human body is divided from the mind. Gordon describes how this separation focuses biomedical attention on the tangible rather than the intangible. In other words, what is seen on the body or in the body is separate (and treated as such) from what exists in the mind (Lock and Scheper-Hughes 1996:46-51). Hence, biomedicine focuses on a patient's "objective" disease rather than their subjective illness experience as noted by Chrisman and Johnson:

disease is tied to the perspective of the professional [medical] sector and its practitioners. In the Western world, disease is a perspective of sickness that refers to some biophysiological abnormality that can be objectively demonstrated by Western scientific means (1996:106).

Biomedicine's influence as the predominant form of medical practice in U.S. healthcare remains (Gordon 1988; Porter 2004; Starr 1982). Yet, the 1960s and 1970s saw a resurgence in explaining health in a more holistic versus objective scientific approach in the U.S. where many alternative approaches suppressed by biomedicine (e.g. homeopathy) were given the opportunity to once again grow (Baer 2001; Baer 2004; Lowenberg 1989). In the past two decades, evidence of this resurgence can be seen with the increasing popularity of CAM therapies in the U.S., and the development of an IM model of care (Barnes, et al. 2008; Barnes, et al. 2004; Caspi, et al. 2003; Eisenberg, et al. 1998).

Anthropologists and social scientists are becoming increasingly interested in the study of CAM and IM, and a large literature has developed in this area. This scholarly research and commentary often focuses on the ongoing relationship between CAM and biomedicine, including how biomedical and CAM treatment modalities and theories of healing are informally (i.e. by patients themselves) or formally (i.e. in a clinical setting) integrated, and the primacy of biomedicine in this integration process (e.g. Adler 1999; Adler 2002; Adler, et al. 2009; Anderson 1999; Baer 2002; Baer 2004; Baer 2008; Barnes 2005; Barrett, et al. 2003; Barry 2006; Boon and Kachan 2008; Caspi, et al. 2003; Gaboury, et al. 2009; Hollenberg 2006; Koithan, et al. 2007a; McGuire 2002; Micozzi 2002; Salkeld 2004; Salkeld 2008; Templeman and Robinson 2011). For medical anthropologists interested in the study of IM practice, they have often taken a

critical approach when examining the ongoing power struggle between biomedicine and CAM in negotiating what this practice should be (e.g. Baer 2004; Baer 2008; Salkeld 2004; Salkeld 2008).

Although there are some established macro-level (i.e. health-systems) definitions of IM (e.g. Bauer 2010; Consortium of Academic Health Centers for Integrative Medicine 2009), multiple definitions, perspectives and misinterpretations of IM have been proposed (Caspi, et al. 2003; Salkeld 2008). From this macro-level perspective, Baer (2004) argues that term "integrative medicine" is really biomedicine's way of legitimizing and subordinating CAM therapies within its own dominant model of health care. Importantly, this legitimization and subordination of CAM by biomedicine can occur through language (Anderson 1999; Caspi, et al. 2003:59), which evident in the following definitions of IM presented below.

The Consortium of Academic Health Centers for Integrative Medicine, a grouping of medical schools and centers that are encouraging a shift in the delivery of health care from a solely biomedical model to a more integrative one writes that integrative medicine is:

the practice of medicine that reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals and disciplines to achieve optimal health and healing (Consortium of Academic Health Centers for Integrative Medicine 2009).

The Mayo Clinic, a preeminent biomedical institution in the U.S. and also part of this

Consortium, developed the following definition of IM:

Integrative medicine describes an evolution taking place in many health care institutions: to treat the whole person—mind, body and spirit—not just the disease. This is done by combining the best of today's high-tech medicine with

the best of non-traditional practices—products and therapies that have some high-quality evidence to support their use (Bauer 2010:10).

The Mayo Clinic's also adds that "the doctor and patient relationship is more of a partnership" in their conceptualization of this form of medical practice (2010:11).

As we can see, it is clearly evident that both of these conceptualizations demand for the use of "evidence" as an important aspect of legitimizing an IM approach (Bauer 2010; Consortium of Academic Health Centers for Integrative Medicine 2009). The way the Mayo Clinic frames "evidence," for example, is in the terms of "objective science" on which biomedicine is premised. However, some authors have argued that the "evidence" used to evaluate the effectiveness of CAM therapies cannot and should not be determined simply through the use of biomedical science (Barry 2006; Micozzi 2002). Rather, other forms of "evidence" should be used according to Barry who writes:

the evidence needed is that which investigates not whether a therapy is working according to biomedical and scientific criteria, but whether it is making a difference to the bodies, beliefs, social and cultural experiences of its clients and whether patients keep coming back (2006:2655).

This debate over the use of "evidence" in an IM approach is particularly relevant for this dissertation. As we will see later, in chapter 4 I describe how the pain clinic that I ethnographically studied does not frame "evidence" solely in terms of biomedical "objective science" when they evaluate the legitimacy of CAM therapies to be used and blended in their particular IM treatment approach for pain management.

Also, both the Mayo Clinic and the Consortium emphasize some of the same basic key features in their conceptualizations of IM such as having a holistic (i.e. "whole person") view of the patient, developing relationships or "partnerships" with them, and the combination of treatments and theories of healing (Bauer 2010:10-11; Consortium of Academic Health Centers for Integrative Medicine 2009). However, Caspi et al. (2003:61) would argue that such definitions of IM like those described above are too multi-focal and misinterpret the true cornerstone of this type of approach—the patient themselves. They argue that IM approaches simply need to stay focused on "putting the patient at the center of the therapeutic relationship" rather than getting caught up in the treatments and integration of them (Caspi et al. 2003:61).

Although these macro-level definitions espouse the need for forming a strong relationship with patients in the practice of IM—evident through such language as "the importance of the relationship between practitioner and patient," "partnership," and "therapeutic relationship" (Bauer 2010:11; Caspi, et al. 2003:61; Consortium of Academic Health Centers for Integrative Medicine 2009)—these definitions fail to adequate explain what they mean by this language. Consequently, because of the broad-level nature of these conceptualizations, they fall short of describing how these relationships form between the practitioner and patient in IM practice, their significance for our understanding of IM, as well as their role in patients healing with an IM approach. Some literature does focus either in part or whole on the significance of these social relationships for IM practice (e.g. Adler, et al. 2009; Koithan, et al. 2007a; Koithan, et al. 2007b; Mulkins and Verhoef 2004; Salkeld 2004; Steinsbekk and Launso 2005), but more research is needed in local level IM clinical practice in order to more adequately explore this domain.

While the definitions presented above focus on defining IM on a macro or health systems level (Bauer 2010; Caspi, et al. 2003; Consortium of Academic Health Centers for Integrative Medicine 2009), Salkeld went further and studied the integration process(es) in a local level U.S. Midwestern clinical setting and notes: "A key component of the definition of 'integrative' medicine is the process by which clinicians introduce CAM therapies into their practice" (2008:21). She discusses how what is known as IM is not yet clearly understood and complex; it is an ongoing epistemological negotiation between biomedicine and CAM that occurs among the various actors at the clinic level (Salkeld 2008). Taking a critical approach in her examination of IM practice, Salkeld (2004; 2008) applied Foucault's theories of power/knowledge and bio-power to study the relationships between the clinic's holistic medical doctors and staff (e.g. CAM practitioners, nurses), and between these doctors and the clinic's patients.

Salkeld's (2004:79-80, 82) close observations of her IM clinic's holistic treatment approach indicated that the clinic's doctors retained a biomedically-oriented authoritative role in this setting and held the exclusive knowledge about how biomedicine and CAM practices and ideas were to be integrated in the customization of patient's treatment plans. She found that the "evidence" the doctors used to determine the efficacy of their approach was whether the patient responded successfully to their treatment plan (Salkeld 2008:29). Oftentimes a patient's diagnosis and subsequent treatment(s) shifted towards CAM with each unsuccessful protocol, but Salkeld notes how in numerous instances the clinic's doctors shut out the CAM practitioners from this customization "process:"

Although many clients received treatment from CAM practitioners during their course of treatment at the clinic, therapists generally did not confer with physicians about clients. CAM providers were not included in the initial diagnostic process; rather...physicians functioned as "gatekeepers" in the selection of CAM therapies to recommend (2008:30).

14

Salkeld's findings on the power relations between biomedicine and CAM, involved in her clinical setting, informed my thinking in designing this study of a local level IM pain clinic when I also discuss their "process" of integrating biomedicine and CAM both in the making of their approach and the customization of patient's treatment plans.

Additionally, when discussing the practitioner-patient relationship in this particular IM clinical setting, Salkeld (2004) draws attention to the concept of "patient responsibility," which was strongly emphasized in her fieldsite. Salkeld defines this concept of "patient responsibility" in this particular context as "the idea that patients have responsibility for maintaining their own health through seeking medical care, following clinical advice and not 'sabotaging' their health through behavior which is counterproductive to good health" (2004:149). Since Salkeld (2004:38) found that her clinic's doctors retained an "authoritative" position in the practitioner-patient relationship, they believed their expertise as physicians most fundamentally mattered. In short, the clinic's doctors felt their expertise should be valued and utilized by their patients if they wanted to remain healthy. This concept played a key role the interactions between the practitioner and patient in this setting. Consequently, Salkeld's findings on patient responsibility will be important to keep in mind later on when I discuss how the integrative medicine pain clinic I studied approaches this concept in the making and enactment of their particular treatment approach for chronic pain management.

This section provided an initial overview of U.S. medical pluralism where we saw the way medical knowledge and practices have been shaped and prioritized in the U.S. health care system over time, and the various power relations involved in this process. We can see from this literature that a key question often addressed is whether

15

biomedicine is still the master narrative in the way IM is conceptualized and practiced. I provided examples of how IM is conceptualized both from macro (e.g. the Mayo Clinic) and micro-level (e.g. Salkeld's local level IM clinic) perspectives that indicate the primacy of biomedicine in this integration process. Interestingly, what emerged from this discussion is the much lesser addressed issue regarding the role of social relationships in IM practice. Later on we will see that while these power relations between biomedicine and CAM are evident in the way IM is conceptualized and enacted in the clinic ethnographically studied for this dissertation, these social relationships emerged as an integral aspect of how they approach pain management with an integrative approach.

### **Multidisciplinary Pain Clinics**

I will next discuss how pain has been conceptualized and treated in a variety of Western pain clinics and how those treatment processes have been represented in the ethnographic literature.

The study of pain has long been a topic of interest in the social sciences and humanities as traced in numerous works (e.g. Baszanger 1998; Good 1994; Good, et al. 1992; Greenhalgh 2001; Jackson 2000; Kleinman 1988; Morris 1991; Rey 1995; Scarry 1985; Thernstrom 2010). For their part, social scientists emphasize how individual experiences with pain and related treatment strategies must also be interpreted within larger cultural, social and historical contexts. One of the most extended discussions of this issue is found in Isabelle Baszanger's (1998) *Inventing Pain Medicine: From the Laboratory to the Clinic*. As we will see, in the second half of the 20<sup>th</sup> century, Dr. John Bonica played an important role in the conceptualization and organization of the pain

medicine specialty (Baszanger 1998; Meldrum 2003). Baszanger (1998) discusses Bonica's work extensively for several reasons: 1) a focus on linking body and mind in pain treatment approaches, 2) his idea for a multidisciplinary approach to addressing pain that would be enacted in a new type of setting, the specialty "pain clinic," and 3) his dedicated efforts in bringing international attention to pain as a critical health issue that lacked adequate research and treatment.

Baszanger (1998) describes how around the time of the Second World War, Bonica, a doctor specializing in anesthesia, desired to improve how pain was managed as he felt that treatments were inadequate at the time. Baszanger notes: "Bonica found himself helpless when faced with patients suffering from complex pain....His interest in pain and the concept of 'pain clinic' originated during this encounter with individuals in severe pain and the lack of medical solutions to treat them" (1998:21). To address such "complex pain" cases, Bonica set in motion a unified approach to treat the patient's pain as he had multiple specialists (e.g. orthopedics, psychiatry, neurosurgery) combine their expertise and work together towards a common goal of helping the patient. This process shifted pain treatment from only one specialty to multiple as noted by Baszanger: "This was the first instance of the conception and implementation of a multidisciplinary—and interdisciplinary—approach to pain" (1998:22).

Bonica (1953) continued his work along these lines and his important medical text called *The Management of Pain* was published (Baszanger 1998). His "pain clinic" model, presented in this book, illuminated his belief that pain is an experience linking both body and mind, and needed to be treated that way (Baszanger 1998:24). Baszanger reports that Bonica's conceptualization of the multidisciplinary pain clinic

emerged as a gold-standard or "model" for practitioners to build on when developing their own clinics (1998:81). She describes the tenets of Bonica's "model" below:

The rule, adopted directly from Bonica's work, was that effective treatment of chronic pain must take into account its physical and psychological components and requires the use of different therapeutic techniques. Each of these techniques, or groups of techniques, was mastered by a group of specialist physicians or nonphysicians, and the originality of a particular pain clinic resides in the way in which these techniques are integrated in a therapeutic program proposed by the multidisciplinary team. At the same time, each technique, whether chemical, physical, surgical, or psychological, received sustained attention and benefited from exchanges between "its" specialists, the result of which was a significant increase in overall clinical knowledge (Baszanger 1998:82).

Yet Baszanger highlights how Bonica's "model" varied greatly in terms of how practitioners conceptualized this approach and put it into practice: "The practice of pain medicine took shape through local groupings of people from different origins in combinations that also differed from one group to another. In each case, the specific nature of these groupings influenced the practice in very different directions" (1998:81).

After tracing the historical development of the "pain clinic" concept and Bonica's important role in this process, Baszanger (1998) presents her own comparative ethnographic study of two pain clinics located in France and analyzes how each developed their own treatment approach for a multidisciplinary pain clinic. These clinics both treat patients with highly complex pain issues that had yet to find relief after much health-seeking, in what Baszanger calls the "more 'difficult' patients, in the sense that they have already benefited from virtually every therapeutic means possible" (1998:236). For each of these clinical settings, I will summarize Baszanger's discussion of 1) how pain is conceptualized and treated, 2) the practitioner-patient relationship formed in this setting and 3) whether or not the patients in these clinical settings felt

these treatment approaches worked for them (i.e. were efficacious).

In the first pain clinic, pain is conceptualized as a physiological issue with the body and the physicians first try to identify an "organic" or physical cause (Baszanger 1998:126). Once a physical cause is identified, they try to "objectify" the patient's pain through the use of body maps, diagrams and graphs to explain to the patient their condition, and how the clinic's various physiological treatment options will attempt to "cure" their pain (Baszanger 1998:146, 156). In this setting, patients' self-described experiences living with pain are not an influential factor in how the physicians conceptualize the patient's condition or in their diagnosis or treatment as Baszanger notes below:

What is remarkable...is that the physician hardly ever asks any questions about the patient's life, what has changed for the patient because of this pain...nor about work, what the patient can or cannot still do....Many patients talk about the impact of pain on their lives and family relations....Though they listen, physicians are not led to open a new field for treatment as long as they can decipher the case with other resources....These elements [of the patient's life] are not considered irrelevant....However, their status is more fragile than that of physical evidence because their validity as facts is open to question (1998:150).

Baszanger observed that this clinic's physicians chose not to emphasize the patient's experiences living with pain as these lived experiences cannot be measured or tested. Instead, they give priority to finding a physiological cause of the patient's pain. Importantly, Baszanger documents that only when all physiologically-based treatments have been exhausted are patients referred for psychiatric treatment because at that point, the physicians believe that the etiology of their pain is psychiatric in nature.

Baszanger concludes that this first clinic's approach to pain is very fragmented, describing it as "a two-tier approach, the first being purely medical and somatic and a possible second phase which is psychiatric" (1998:126). Therefore, although this clinic

considers its approach multidisciplinary given the various types of specialists on staff (e.g. neurosurgery, anesthesia, rheumatology, neurology and psychiatry), it is not interdisciplinary as the medical specialists and psychiatric specialists do not work together when treating the patient's pain (Baszanger 1998:127). In addition, Baszanger (1998:161-164, 184) characterizes the practitioner-patient relationship in this first pain clinic as a divided one. In other words, doctor and patient do not work together in the clinical encounter as Baszanger observes that "the physician refers physician and patient to their respective universe, each with his/her own task to accomplish: the physician as a skilled scientist, an operator; the patient is an enlightened consumer who must decide his/her own fate" (1998:162). For example, the doctor develops the treatment plan and provides the treatments; the patient's role in the clinical encounter is to receive said treatments. Importantly in this first clinical setting, Baszanger notes that there is little or no room for negotiation or questioning by the patient about their treatment plan, and in general the doctor will not acquiesce to the patient's wants and needs.

In contrast, the second pain clinic Baszanger (1998) studied conceptualizes pain as an experience that envelopes body with mind at once, meaning that they believe both physical and psychological components of the patient's pain are integrated. Hence, patient's experiences with pain and their life histories are therefore important for the doctor to learn about as "an explanation for their pain is woven by constructing a link between [physical] pain and the patient's personal circumstances (depression, unemployment, bereavement, divorce, and so on)" (Baszanger 1998:175). Baszanger notes that physicians take this wider view of the patient because they believe "everything the patient brings to the consultation is important, [so] the physician's gaze has to be multifocal. While looking at the patient's body, the physician must concentrate on exploring the patient's biography and ideas about pain" (1998:167). Therefore, this second pain clinic approaches treatment in an "integrated" fashion that includes the use of physiological treatments and psychological ones in order to manage rather than "cure" the patient's pain (Baszanger 1998:129, 131).

In addition, Baszanger (1998) describes the practitioner-patient relationship in this second pain clinic as more of a working relationship where the doctor and patient are actively integrating their efforts in carrying out the treatment plan. While the patient in this second pain clinic has a role to play along with the doctor in the treatment process, a division in the relationship is still evident: "The physician must, so to speak, establish a 'we-at-work' relationship which in no way implies equality between physician and patient or erasure of the dimensions of the physician's expertise" (Baszanger 1998:177). In other words, the physician still has an elevated status in the doctorpatient relationship as they hold the knowledge or "expertise" that the patient does not have. Yet, Baszanger (1998:180) observes that there is more room for negotiation of the treatment approach between the doctor and patient in this second pain clinic as the doctor will, at times, acquiesce to the patient's desires even if it somehow challenges their medical "expertise."

Important to note, in both these clinical settings, the treatment approaches did not work for every patient (Baszanger 1998:235-296). Yet, Baszanger believed few patients openly challenged these treatment approaches in the clinical encounter in either setting given the "largely asymmetric relationship between physician and patient. The patient has very limited room for maneuvering [in the clinical encounter] and most often expresses reticence by silence or by default, so to speak, by not returning to the center" (1998:235). Baszanger does note one exception when patients did openly challenge their doctors in both of these settings and writes: "[patient] disagreements [with their doctors] are related to a wider, more fundamental aspect. In most cases they reflect a divergence, or at least an absence of overlap, between the conception of pain held by patient and by physician" (1998:235-236). For example, the patient may believe that their pain is the result of an entirely organic or physical cause that the doctor cannot find. Hence, if pain is deemed by the doctor to be more psychological than physical in nature, the patient may not agree with that assessment and consequently not engage with the treatment plan.

In conceptualizing this dissertation it was very helpful to understand the history that Baszanger (1998) presented in the literature about the development of the multidisciplinary specialty "pain clinic" model. She highlighted Bonica's ideas that pain is a mind and body experience, and a critical health issue that requires a multidisciplinary treatment approach to be enacted in the making of specialty pain clinics. Baszanger's descriptions of the treatment approaches employed in her two clinical settings investigated will provide useful points of comparison when I later discuss the treatment approach of the pain clinic that I studied. I will now highlight other relevant ideas brought up in some contemporary ethnographies written by anthropologists interested in pain treatment settings.

Jackson (2000) conducted an ethnographic study of an in-patient multidisciplinary pain clinic in the U.S. I will review Jackson's discussion of 1) how the

22

clinic conceptualized pain and the course of action taken to treat it, 2) their particular blend of biomedical and CAM treatment modalities used in this setting (which is also influenced by power relations among the clinic's practitioners), and 3) issues of responsibility that arose in terms of who must do what in the enactment of this pain treatment approach for an efficacious result, and the power relations involved in this process. I will also show why Jackson's findings matter for understanding the pain clinic that I ethnographically studied.

In the U.S. clinic that Jackson studied, pain is conceptualized from a "holistic" mind and body perspective, and was treated that way as she notes below:

For them, holistic medicine meant looking at the big picture, at an entire life rather than a body part; trying to handle the problem without narcotics or surgery; and looking to the body and the mind for healing...rather than depending on conventional medicine—in other words working *with* the body rather than *on* the body (2000:29, emphasis added).

The aim of the clinic's treatment approach was to help the "whole person" better manage their pain as it "stressed healing, not cure" (Jackson 2000:58, 25). The essence of their approach to pain management was for the patient to change their conceptualization of pain from an all-encompassing, life-altering problem to one that they could better cope with and therefore reduce its impact on their daily lives (Jackson 2000:25). Jackson describes this central objective as "the goal of changing that person's behavior and attitude toward pain—and perhaps diminishing the amount of pain" (2000: 58).

In line with their "holistic" treatment approach, various treatment modalities that addressed both the mind and body aspects of pain were blended that drew from both biomedicine and CAM such as psychotherapy, biofeedback, massage and exercise (Jackson 2000). Psychotherapy was particularly encouraged to allow the patient to identify and possibly work through what could be the emotional aspects associated or causing their pain and negative thoughts that could impede their abilities to manage it (Jackson 2000:78). Also, Jackson found that "educating patients—about pain itself, about various pain-managing modalities, about depression and other emotions" (2000:58) was an important aspect of their approach to pain treatment. Importantly, carrying out this holistic approach required the staff to work together as a team. However, "staff turnover" affected this teamwork approach as new staff members did not always embrace providing patient care in this way (Jackson 2000:31).

In implementing the clinic's "holistic" treatment approach, Jackson notes there was some disagreement between clinic staff members over the use of some treatments that were considered alternatives to more biomedically-based treatments (2000:27-29, 31). Some staff members believed more than others in the use of these types of

alternative treatments as Jackson notes:

During my study, biofeedback, autogenics (a relaxation practice), hypnosis, acupuncture, therapeutic touch, movement therapy, pain imaging and reflexology (foot massage to alleviate pain in another area of the body)—all somewhat marginal in mainstream medicine—were practiced or at least discussed favorably during formal sessions with patients....[The clinic's medical director, a dual-specialized medical doctor in neurology and psychiatry] was not persuaded of the value of some of these therapies (he dismissed acupuncture as a form of hypnosis) and apparently did not know of others (e.g. reflexology) that were practiced [in the clinic] (2000:28-29).

Although the medical director was in charge of the clinic, other staff members often told their patients about or utilized these biomedical alternatives "behind closed doors" (Jackson 2000:29).

Another key aspect of the "holistic" pain treatment approach in Jackson's clinic

was the use of "confrontation therapy" with their patients that "was targeted at reducing maladaptive, self-defeating behavior....[The clinic's medical director] said he 'simply and directly' confronted patients with the fact that 'they must give up life-styles and identities built around full-time suffering'" (2000:68) such as their dependency on pain medication. The clinic's medical director often utilized confrontation with the clinic's patients. Jackson notes that when the staff members engaged in this confrontational aspect of their treatment approach, they had to eschew any appearance of sympathy for the patient for it to be effective.

The clinic's treatment approach resulted in "asymmetrical" practitioner-patient relationships to be formed in this setting, according to Jackson, as staff members held authoritative roles over the patients: "authority was very asymmetrically distributed and very inflexible. Few mechanisms existed for challenging the structure or contesting ideology. Oftentimes, dissent [on the part of the patient] was redefined as further evidence of a patient's personality and emotional problems" (2000:79). Accordingly, Jackson noted how "the program did not try to be user-friendly" (2000:80), making assessments of efficacy for this particular treatment approach difficult as some patients chose to engage more fully with it than others. For instance, some patients did not find the treatment approach helpful and criticized it (e.g. calling it "brainwashing") (Jackson 2000:79), while others so fully engaged that Jackson "compared [them] to religious converts" (2000:141). Jackson concludes that the efficaciousness of her clinic's approach is highly subjective: "what made...[the clinic's approach] work, when it did, was that people confronted their pain (what this meant differed for each patient). Those who improved significantly were able...to turn an anomaly into something normal, or at least significantly more normal, and feel more in control of their situation" (2000:142). Jackson's work is important to consider for this dissertation research on an integrative medicine pain clinic as it shows another distinct approach to "holistic" pain treatment, and illustrates how there are various ways to go about "blending" elements of biomedicine and CAM.

Another way anthropologists have approached the study of treatment approaches for pain is through documenting different kinds of individuals' healthseeking experiences (e.g. Good 1994; Good, et al. 1992; Greenhalgh 2001; Kleinman 1988). Among this body of work, I chose Greenhalgh's (2001) auto-ethnography as an illustrative example as it describes her own harrowing illness experience as a fibromyalgia patient that highlights 1) how the overall treatment approach a patient utilizes matters for understanding their health-seeking experiences, 2) the way patients can go about informally blending biomedicine and CAM treatment modalities in the process of managing their conditions and 3) how the power relations evident in the practitioner-patient relationship can influence the efficacy of particular pain treatment approach utilized.

Greenhalgh (2001) describes her complex health-seeking process where she experienced the physical pain from her condition, side effects from her treatments, depression and a very difficult relationship with her doctor where she felt powerless to challenge his authority for most of the time she was under his care. Greenhalgh kept a journal to help her cope with this relationship, and she expressed in it what she could not openly discuss with her doctor during their encounters:

Through her [i.e. Greenhalgh] writing, she challenged her doctor's discourses of objectification by restoring the wholeness he had shattered when he split her

body from her mind and emotions and by recovering her own authority to know and to speak about her body. This authority had been denied when her doctor made himself the expert on her body (2001:165).

Although Greenhalgh followed her doctors' treatment plan, pain relief was elusive. Independently from her doctors' care, she also briefly utilized alternative treatments that she read about (e.g. meditation) to help with her depression. But these alternative treatments also were harmful for Greenhalgh in their own particular way, which contributed to her already depressed mental state:

[Greenhalgh] believed that her mind and emotions were deeply implicated in her bodily ills. Internalizing the cultural blame that [alternative medicine] books like these placed on her, implicitly if not explicitly, she felt blamed for her illness and blamed for her failure to heal it (2001:225).

Only after Greenhalgh was well into her health-seeking process for fibromyalgia did she learn from a doctor she previously sought care from that she was misdiagnosed. She ultimately confronted her main doctor over this misdiagnosis and his treatment approach, only to hear him justify his actions. Greenhalgh poignantly described what this negative health-seeking experience did to her life: "She [Greenhalgh] had rid herself of the harmful doctor, but she was left with the aftereffects of his 'care' on her body and soul" (2001:273).

Greenhalgh's (2001) work provides a vivid account of how she engaged with a particular treatment approach, and how this approach was not efficacious for her, but rather further disrupted her life. Greenhalgh's descriptions of her doctor's authoritative role in their encounters (where she felt powerless to voice her concerns over her lack of improvement with his treatment plan) are highly relevant to consider for this dissertation when I later discuss the type of practitioner-patient relationship formed in the carrying out the particular treatment approach documented in the pain clinic studied. Additionally, Greenhalgh's choice to seek out alternative therapies is also important to consider as it provides a window into some of the drawbacks of patients informally "blending" biomedicine and CAM independently, and alludes to the need for more coordinated and integrative approaches for pain management.

While Greenhalgh's (2001) auto-ethnography has been critiqued for its limited focus in only covering her own chronic pain experience, it was still instructive for me to read in planning this study due to its visceral writing about her "lived experience" of pain, health-seeking journey, and the impact of her condition upon her life. Additionally, Greenhalgh's work stands among social science literature that highlights the role of gender in women's chronic pain experiences, including the practitioner-patient relationship (e.g. Skuladottir and Halldorsdottir 2008; Werner, et al. 2004; Werner and Malterud 2003). Although gender was not the focus of this study and is beyond its current scope, we will see the impact of chronic pain upon patient's gender identities (e.g. mother, grandmother, wife, breadwinner, etc.) in the patient narratives presented in chapters 6 and 7 of this dissertation. In the conclusion of this dissertation, I will return to the issue of gender and chronic pain to discuss how viewing my data through a gendered theoretical lens is a topic worthy of future exploration.

In closing this section, it is important to consider Crowley-Matoka et al.'s (2009) recent work that extends the line of argument why ethnography is of value for studying pain treatment settings. After an extensive literature review on both medical and social scientific studies on pain treatment, they found a "prioritization in biomedical culture of body over mind, disease over illness, and cure over care" that influences how this health condition is conceptualized and treated by U.S. practitioners (Crowley-Matoka et

al. 2009:1320). They strongly argue that the use of ethnographic methods are appropriate in the study of pain clinics to help us see how these contrasting ideas play out in various treatment approaches, and how such findings would better inform our thinking on this subject and subsequently improve how pain is managed in the United States.

In Crowley-Matoka et al.'s (2009:1314) analysis they argue that the Western cultural dualism that separates body from mind is still pervasive in pain treatment approaches as biomedical practitioners continue to focus their efforts on trying to treat the patient's pain as a physical issue (i.e. there is something wrong with the body), largely unconnected to possible psychological components of pain such as depression. The authors also note that pain treatment approaches still focus on patient's "diseases" and not enough on the illness experience:

Patients' illnesses...encompass not only the physical causes and manifestations of disease but also the psychosocial context in which they occur and the impact they have on patients' lives and relationships. The biomedical focus on disease tends to limit consideration of a wide range of social determinants of illness and suffering, thus decontextualizing and oversimplifying what patients actually experience....decontextualization of the illness experience and emphasis on the physical manifestations can also cause a disconnect between what the patient and the physician consider important and "real" (Crowley-Matoka, et al. 2009:1315).

Also some pain treatment approaches still try to "fix" or "cure" pain (Crowley-Matoka et al. 2009:1315). The authors believe that physicians approach the concept of "pain management" (i.e. caring for patients in pain) with caution as they are oftentimes unaccustomed to treating non-curative health conditions and the greater amount of time often involved in this process (Crowley-Matoka, et al. 2009:1315). These contrasting dualisms that Crowley-Matoka et al. identified in their review of pain treatment settings

will be important to keep in mind later on in this dissertation. We will see how the ethnographic methods utilized in this study revealed these ideas in the clinic's treatment approach that will be described in chapter 5, and how these ideas are negotiated in this particular integrative pain treatment setting.

In summary, these ethnographic works of pain treatment settings discussed above highlight several relevant issues that emerge throughout this dissertation. They draw attention to the importance of conceptualizing pain as a mind and body issue, the significance of taking a multidisciplinary and teamwork oriented approach to patient care, and the role of patient responsibility in the enactment of pain treatment approaches. They also point out the differences that exist in the types of practitionerpatient relationships formed in various pain treatment settings, and how these relationships often influence how patients experience and perceive treatment. As we can see from this body of literature, the way these issues emerge and are dealt with in these various settings often influences the overall efficacy of the treatment approach utilized. Consequently, these ethnographies underscore Baszanger's (1998) conclusion that not all ways of treating pain are appropriate and successful for every patient.

#### **Description of Study Chapters**

Chapter 2 presents the sample and recruitment procedures, research methods, and data analysis. Chapter 3 discusses the site selection process, provides background on the metropolitan region and community where this research took place, and an in-depth description of the IM pain clinic that was studied. Chapter 4 profiles the clinic's founder and medical doctor, and his dream to open an integrative medicine pain clinic. Next it describes his wife and business partner, and how together they made this dream of an IM pain clinic a reality. The clinic's "family-like" culture and its staff are also described in this chapter. In chapter 5 the clinic's staff explains their particular IM treatment approach to managing pain, and I discuss the various ways in which their treatment approach negotiates the mind/body, care/cure, biomedicine/CAM and disease/illness dualisms evident in studies of medical pluralism and multidisciplinary pain clinics. Chapters 6 and 7 provide a series of patient narratives where we see the clinic's approach enacted, and how it is perceived by patients in this particular setting. These chapters present a continuum of patient experiences as patients' faith in and commitment to the clinic's treatment approach varies, as does their ability to move forward in their lives. Chapter 8 concludes this dissertation. In this chapter I argue how the real work of healing with this clinic's approach resides not in the integration of treatment modalities, but rather in the social relationships formed between the practitioners and patients in this particular IM pain treatment setting. I will also discuss some of the limitations of this study, future directions and concluding thoughts.

#### **CHAPTER 2**

#### **METHODS & PARTICIPANTS**

This methods chapter will describe 1) the study sample and recruitment procedures including the inclusion and exclusion criteria as well as ethical considerations of this study, 2) the research design and methods, and 3) data management procedures and data analysis. Multiple data collection strategies were employed and multiple forms of analysis in this in-depth ethnographic study of an IM pain clinic. Being in this research setting for a full year was a rich experience that gave me the opportunity to build strong rapport with the staff and patients, and collect much detailed ethnographic data. Data was provided by participant-observation of the daily workings of the clinic, direct observation of staff and patient co-created clinical encounters and interviews with staff as well as patients<sup>3</sup>.

#### SAMPLE & RECRUITMENT

The study sample included staff (N=10), and English speaking adult patients (N=40) who were able to give consent. I approached the staff directly at the beginning of the study for their permission to be observed throughout the study period and also interviewed. I was able to obtain written consent from eight of the clinic's ten staff during the first staff meeting I attended in September 2008. I later approached other staff that were not at this meeting on an individual basis to introduce the study and obtain written consent (see Table 1: Clinic Practitioners and Staff that Participated in the Study). Two of the clinic's practitioners chose not to participate, and I respected their

<sup>&</sup>lt;sup>3</sup> This study received Institutional Review Board (IRB) approval from the Wayne State University Human Investigation Committee (HIC) on August 28, 2008. Written consent forms were used for the clinic staff and patients. Staff and patients were not compensated for participation in this study. To maintain confidentiality of all participants, pseudonyms are utilized.

voluntary right not to consent. One of these practitioners was a CAM practitioner who was only called in upon patient request, and therefore at the clinic infrequently.

Study Participants	Staff Designation	Gender	Race or Ethnicity	Education
Dr. William Bennett <sup>4</sup>	Medical Doctor and	Male	African American	Doctor of Medicine (M.D.)
	clinic founder			Medical Board Certifications: Physical Medicine and Rehabilitation; Pain Management
				Certified in Medical Acupuncture
Roxy	Massage Therapist	Female	White	Massage Therapy School <sup>5</sup> — 800 hours (House Bill No. 5651)
Elizabeth	Massage Therapist	Female	White	Nursing—Bachelors; Registered Nurse Massage School—500 hours
Erica	Massage Therapist	Female	White	Massage School—650 hours
Michael	Physical Therapist	Male	African American	Physical Therapy—Masters
Jennifer	Physical Therapy Assistant	Female	White	Applied Sciences in Physical Therapy—Associates
Jasmine	Practice Administrator and Dr. Bennett's	Female	Hispanic	Health Services Administration— Bachelors and Masters Applied Sciences in Physical
	wife			Therapy—Associates
Nicole	Medical Biller	Female	White	Anthropology—Bachelors On the job training
Joan	Medical Assistant	Female	White	On the job training
Pamela	Office Manager	Female	White	Medical Billing—Diploma On the job training

Table 1: Clinic Practitioners and Staff that Participated in the Study

 <sup>&</sup>lt;sup>4</sup> All staff members are referred to on a first-name basis with their pseudonyms except the clinic's Medical Doctor. "Dr. Bennett" is given this distinction with his pseudonym as all staff members refer to him as "Dr. Bennett" or by his initials "DWB" in both formal and informal settings, including his wife Jasmine.
 <sup>5</sup> The clinic's massage therapists are certified. The State of Michigan did not introduce formalized licensing requirements until January 2009 (State of Michigan House Bill No. 5651).

I had two research design changes to my recruitment procedures. First, I originally intended and had Institutional Review Board (IRB) approval to conduct direct person-to-person recruitment of clinic patients. However, I learned early on that this direct person-to-person approach would not be met with success in this fieldsite as staff wanted to tell their patients about the study. I contacted the IRB about my proposed recruitment procedures and they suggested having someone in a direct clinical relationship with the patient introduce me as a researcher conducting a study at the clinic, and then I could formally introduce the study to the patient. Elizabeth, one of the clinic's massage therapists, said that she felt this change in recruitment procedures allowed her to transfer the trust and rapport she developed with her patients over to me. It also highlighted the staffs' professional judgments as they considered the well-being of their patients by assessing their pain levels and comfort level with a researcher being in the room. If patients were interested in participating, I utilized a written consent form for the observation and interviews<sup>6</sup>.

This change in recruitment procedure also allowed me the opportunity to develop a good relationship with the staff. Roxy emerged as a key staff member in this recruitment process, and provided me with the greatest access to the co-created clinical encounters. The number of clinical encounters I was able to observe over the research period during specific weeks varied based on multiple factors including staff member availability to screen potential patients, the patient's schedule, cancellations and noshows, the time of year (e.g. holidays), and patient interest in the study. However, the clinical encounters I had access to were very informative and provided a rich data set to

<sup>&</sup>lt;sup>6</sup> Given that this was an ethnographic study on chronic pain and IM that utilized narrative methods, Protected Health Information (PHI) under the Health Insurance Portability and Accountability Act (HIPAA) was not included in the study design.

complement the patient interviews. Both of these types of data are presented in the patient narratives in chapters 6 and 7.

The second recruitment change involved originally excluding massage therapy patients from the study as I felt my presence in the room would be disruptive for such a quiet (and potentially private) treatment modality. Upon starting this research, I learned early on from Roxy and Elizabeth, two of the massage therapists at the clinic, that they felt their patients would be very interested in participation, and that my presence would not disrupt the treatments. I therefore filed an amendment to the IRB to remove this exclusion from my protocol based on the feedback of these specific practitioners at the research site. Massage became an important data source as will be discussed in greater detail in the patient narratives in chapters 6 and 7. Massage was a more lengthy form of treatment in which patients often discussed pain management and other life issues with practitioners in-depth in this setting.

An informational flyer on what this study was about and who to contact for further information was also used to recruit and introduce the study to potential patients. Dr. Bennett, the clinic's Medical Doctor, and Jasmine, the clinic's practice administrator gave me permission to leave informational flyers about the study in the waiting room. The availability of a study flyer provided the opportunity for patients to also contact me independently.

Given the small size of the clinic, great care was taken to ensure the confidentiality of the staff and patients. All consenting participants were informed that all research data is confidential, that no identifying information will be revealed in the research data, and that pseudonyms or code numbers will be used in all research data and publications. All research materials gathered during this study are kept in a secure location.

#### **RESEARCH DESIGN & METHODS**

#### **Research Design**

This research was designed as a 12 month (August 2008-August 2009) study. This study was in part modeled on Salkeld's (2004) ethnographic study of an integrative medicine clinic. While her ethnographic study employed a different theoretical perspective, I based my design and methods for this ethnographic study on what she found feasible for a dissertation project in an IM clinic, and in a similar time frame. The specific research design and methods choices for studying the treatment and management of pain in this IM clinic setting will be detailed below.

#### **Research Methods**

Three types of methods were utilized in this study: 1) participant-observation of the daily workings of the clinic, 2) direct observation of staff and patient co-created clinical encounters, and 3) interviews with staff and patients (see Table of Measures Appendix A).

#### Participant-Observation of the Daily Workings of the Clinic

I engaged in participant-observation of the clinic for approximately 12 to 17 hours per week on average over the course of the fieldwork year. I was on site most weeks for three to four days per week to observe the staff's daily activities on both full schedule and lighter schedule days with seeing patients in the clinic. I had greater access to talk with the clinic's staff on lighter schedule days; such days gave me the opportunity to observe in greater depth their interaction with one another, and have informal conversations/interviews with them on a variety of topics. Clinic staff was willing for me to be on site as needed during business hours throughout the whole study period.

In getting started with participant-observation, I initially considered how Salkeld (2004) approached this aspect of her data collection in her IM clinical fieldsite. She was able to choose particular locations in her clinic that she found best to observe daily activities. I followed this approach and chose areas of the clinic that were optimal for observation, and where I would not be in the way of the staff as they went about their daily activities. Given Dr. Bennett's role as the clinic founder and Jasmine's as the clinic's overall practice administrator, I consulted with them regarding issues of clinic access for my observations. In general, I was granted access to many of the clinic's areas and free to move about these areas throughout the day. I also arranged with the individual practitioners where I would observe them with their patients in their own treatment rooms.

By conducting participant-observation of the staff's daily activities, I was able to document and describe their specific roles and duties in the clinic, and how each of their positions fits into the overall clinic structure and IM pain management approach. In addition, I also conducted participant-observation of the clinic's staff meetings where I documented the content of these meetings. Over the research period, I was able to observe six (N=6) of these larger staff meetings that took place on an as needed basis. These meetings took place on Fridays and started at lunch time and ran up to three hours in length. All the full time staff members attended these meetings, and occasionally the contracted staff did as well if they were not seeing patients at the time. These meetings began with lunch and then proceeded to discuss a variety of issues.

37

The staff meetings started with Jasmine, the clinic's practice administrator, going over several agenda items, and then opening up the meeting to other staff members by going around the table and having everyone share any updates or issues they may have. Some important things I learned from these staff meetings that contributed to a better understanding of the clinic's culture are described in chapter 4.

Another aspect of the clinic's activities I was interested in observing when possible was their relationship with the general public and surrounding community. The main way I observed this was through the clinic's website, and their participation in a community charity event in August 2009<sup>7</sup>.

#### Direct Observation of the Co-Created Clinical Encounters

I engaged in direct observation of the co-created clinical encounters to observe how the IMPC's pain management approach is enacted and perceived. Over the research period I gained access to 40 of these co-created clinical encounters and observed a variety of different types of treatments (N=40). (See Table 2: Summary of Treatments Observed during the Co-Created Clinical Encounters). Nine of the patient's that I observed during these co-created clinical encounters also consented to the indepth interviews that I will discuss below.

<sup>&</sup>lt;sup>7</sup> The IMPC also offered free information seminars as a public outreach effort, but these seminars were cancelled due to lack of registration. The staff attributed these cancellations to the time of year when the seminar was offered (e.g. winter), the economy (e.g. patients may not have the money to afford the services or supplements discussed in the seminar), or the public was not ready to accept the IMPC's IM approach to pain management.

Type of Treatment	Staff Member Administering Treatment	# of Treatments Observations
Trigger Point Injections	Dr. Bennett	2
Medical Acupuncture		1
Intramuscular Stimulation (IMS)		1
Nerve Block		1
Prolotherapy		1
Massage <sup>8</sup>	Roxy	28
	Elizabeth	3
Physical Therapy Evaluation <sup>9</sup>	Michael	1
Physical Therapy	Jennifer	2
		Total: 40

# Table 2: Summary of Treatments Observed during the Co-Created Clinical Encounters

Access to the co-created clinical encounters was based on the discretion of the clinic's individual practitioners who screened their patients before allowing me access as they considered how the patient was feeling on specific occasions, their pain levels, and whether they felt up to the research. There were a few disadvantages to this screening process such as not being able to gain access to new patient consultations with Dr. Bennett and (except for one instance) other new patient appointments with the clinic's other practitioners. As a result, I was unable to document how the clinic's practitioners established their initial rapport with their patients.

# Staff Interviews

I conducted a formal semi-structured open-ended interview with eight of the ten clinic staff members to supplement long-term observation of clinic activities (see staff

<sup>&</sup>lt;sup>8</sup> One massage was of one of the clinic's staff members.

<sup>&</sup>lt;sup>9</sup> This physical therapy evaluation was of one of the clinic's staff members.

interview protocol Appendix B). Formal interviews ranged from approximately 20 minutes to one hour and 20 minutes in length and took place in the privacy of the clinic's conference room. These interviews were scheduled to fit into the practitioner and staff members' busy schedules. Originally, I had planned on beginning these interviews early in the study period to help me get to know the staff as individuals, to build rapport, and understand how they go about their daily activities. However, once in the field I felt it would be better to wait to begin most of these formal interviews until the halfway point of my data collection. I felt it was important to get to know the staff on more of an informal basis first, develop a stronger rapport, and wait until they felt very comfortable with my presence in the clinic.

The staff interview began with open-ended questions about their career choice, educational experiences, motivations that led to their chosen occupation, and why they chose to work at this particular IM clinic. By asking consenting staff members to tell me about their career choices in such a format, salient aspects of their life histories emerged that directly relate to their chosen career. These interviews also included specific questions that covered a wide range of topics that included having the staff member describe in their own words the care and services offered at this IM clinic; discuss their opinions regarding the growth and future directions of this clinic; marketing; clinic design and layout (both the public areas and individual practitioners treatment rooms); their specific roles in the clinic, what it was like working in this setting and any comments regarding their professional experiences in this setting; and their views on the emerging field of IM generally and for pain management specifically. The open-ended nature of these interviews shed light on staff members' significant life experiences and motivations to work in an IM environment. These interviews were audio recorded and transcribed.

Throughout the course of the research period, I documented short, informal interviews/conversations I had the opportunity to have with the various staff members on an ongoing basis. As I moved around the different clinic areas, I often got into conversations with the staff about their daily work. For example, oftentimes the massage therapists would come into the conference room and share their experiences they had working with patients or talk about different techniques they decided to try in particular situations (e.g. biofeedback, hot stone therapy). These conversations helped me gain further understanding about the clinic's overall IM pain management approach, and individual practitioners' treatment strategies and work experiences. These informal interviews/conversations were recorded in my daily field notes. Over time, staff members talked freely around me about a variety of topics during both formal and informal interviews. If needed, they felt comfortable asking me to keep some sensitive or private issues "off the record" and knew that I would honor that request.

## Patient Interviews

I recruited 11 patients for the in-depth interviewing component of the study (see Table 3: Self-Reported Characteristics of Patients that Participated in Interviews).

Study Participants	Age	Gender	Race or Ethnicity	Marital Status	Education	Socio- economic Status
Julia	34	Female	White	Divorced	Some College	Poor
Denise	44	Female	White	Married	Some College	Middle-class
Paul	44	Male	Not Reported	Divorced	Associate Degree	Unemployed
Natalie	44	Female	White	Married	Trade School	Middle-class
Christina	49	Female	White	Married	Some College	Middle-class
Tim	52	Male	White	Married	Some College	Middle-class
Kathleen	53	Female	Not Reported	Married	Bachelor Degree	Middle-class
Linda	56	Female	White	Married	High School	Not Reported
Stella	59	Female	African American	Separated	Masters Degree	Middle-class
Robin	60	Female	Native American	Single	Some college	Not Reported
Betty	89	Female	White	Single	Masters Degree	Middle-class

# Table 3: Self-Reported Characteristics of Patients that Participated in Interviews

I chose to conduct formal patient interviews to more fully explore pain as a significant life experience; each patient completed a formal semi-structured life history and illness narrative interview. The study design allowed for the administration of both of these interviews in one longer session to accommodate the patients pain levels and time. Administration of the full interview protocol lasted between 50 minutes to two hours. The interviews took place in the clinic's conference room that allowed for maximum privacy and comfort of the patient.

The life history interview consisted of three components (see Appendix C). The first component consisted of some general demographic questions that included age,

gender, marital status, educational level, as well as also asking patients to describe in their own words their socioeconomic status and race or ethnicity. The second component utilized the Self-Rated Health (SRH) measure to ask the patients about their general health and how their health is in relation to others in their particular age group (Idler and Benyamini 1997; Idler, et al. 1999). I drew upon Luborsky's (1987; 1990; 1993) Sequence and Templates in Narratives (STN) life history method as a model for the third component of this interview as it allowed for patients to talk about their life histories in an open-ended format.

Given how anthropologists have identified how chronic pain and its related health-seeking can have a great impact upon one's life (e.g. Good 1994; Greenhalgh 2001; Jackson 2000), I conducted an illness narrative interview to learn more about patient's specific conditions and health-seeking processes (see Appendix D). For example, the clinic utilized an "objective" pain scale to have patient's rate their pain (from one to ten with ten being the highest level of pain), so I was interested in capturing more subjective descriptions of patient's pain. Therefore, I asked the patients to describe how they would communicate to someone else what their pain experience is like (i.e. a song, particular metaphor, picture, etc.), and to discuss the ways pain impacts their life, and the role they feel pain will play in their futures. Additional interview domains included, for example, patient experiences at this clinic, types of treatments they received, obstacles or challenges in getting the care that they needed, and what they felt this clinic could do to improve their patient care.

# **DATA MANAGEMENT & ANALYSIS**

I converted all hand written field notes from my participant-observation of the daily workings of the clinic, direct observations of staff and patient co-created clinical encounters, and informal interviews with staff into typewritten full field notes. All formal staff and patient interview data was downloaded from the digital voice recorder to my password protected computer, and transcribed.

I analyzed all data inductively looking for key topics and themes that emerged (Luborsky 1994). Preliminary data analysis occurred throughout the research period as I entered my daily field notes into the computer, and as I transcribed the interviews. This preliminary analysis identified early themes in the research data, and these themes were confirmed during formal data analysis. I conducted two types of formal analyses. The first was a thematic, open-coding process of the data from participant-observation of the daily workings of the clinic, and both informal and formal interviews with staff. Key findings from this phase of analysis will appear in chapters 4 and 5. The second type of analysis I conducted was in-depth case study analyses of patient interview data and their corresponding clinical encounter observations that will be discussed in chapters 6 and 7.

#### **CHAPTER 3**

### **RESEARCH SITE**

# The "little gem in Waterview" (Nicole, Clinic Staff)

This chapter discusses the fieldsite selection process, and the metropolitan region and local community where this research took place. It provides a detailed description of the Integrative Medicine Pain Clinic's (IMPC) physical environment as well as the different sections within it.

### SITE SELECTION

In preparation for the selection of a dissertation fieldsite, I attended two events that brought together leaders and practitioners who work in the field of integrative medicine. The first event was a weekend conference in May 2006 on the use of IM in end-of-life care that I learned about from an end-of-life researcher. The second event was a one-day IM health exposition in January 2007 that I learned about through an article in a local newspaper. Attending these events provided opportunities to informally network with practitioners and learn about local IM clinics. Through connections made at these events, I learned about two feasible fieldsites for this research that differed greatly from one another in scale. One was a large hospital-based integrative medicine center where a variety of different health issues were treated. The other was a small, private integrative medicine practice that specialized specifically in outpatient pain management.

As I developed ideas for my research proposal, I communicated with and met the leadership at both of these sites about the possibility of conducting my dissertation research with them. However, this small IM pain clinic expressed particular interest in being considered as a fieldsite for my ethnographic study during initial meetings in the summer of 2007. During these meetings I learned more information about their integrative medicine approach to pain management, and I provided the clinic with information about myself, my educational background, and my research interests. I also discussed specific aspects of the proposed dissertation research that included the ethnographic methods I would be utilizing during the study. I was also asked where I saw my research going, what my future plans were, and what my research will contribute. The clinic expressed no reservations about me conducting my research at the clinic or any objections about the research methods I would be using. They not only gave me permission, but enthusiastic support as well. After these initial meetings, I kept in contact with the clinic over the next year as I prepared my dissertation proposal<sup>10</sup>.

This clinic fit closely with my research interests for two reasons. First, their focus on pain management and rehabilitation permitted an in depth examination of how an integrative medicine approach addresses pain as a specific health. Second, this clinic had recently increased the number of integrative medicine services just prior to the research period. I believed this increase in services would afford me the opportunity to observe in greater detail the growth and development of integrative medicine in this local context. I selected this clinic as the dissertation fieldsite and informed them of my choice. They were highly pleased and eager for me to begin the research in their clinic setting. I will next describe the metropolitan area and the community where this research took place.

<sup>&</sup>lt;sup>10</sup> The clinic went through some significant remodeling, and hired additional staff between my initial contact with them and the beginning of my dissertation research. These remodeling and staff changes will be discussed later in this chapter and in chapter 4.

# THE METROPOLITAN REGION & LOCAL COMMUNITY WHERE THE IMPC IS LOCATED

The IMPC is located in "Waterview," a largely white, middle class suburban community located just outside of Detroit, Michigan. Although this research took place in Waterview, it is important to conceptualize the entire Detroit metropolitan region as a whole as the city of Detroit and its suburban neighbors are connected not only geographically, but also economically and socially (Farley, et al. 2000; Sugrue 2005). The following discussion not only provides the cultural context for this research, but the background necessary to contextualize and understand some of the experiences and political economic struggles experienced by the IMPC staff, and their patients who are drawn from around the Detroit metropolitan area. The Detroit metropolitan region is largely segregated by race, and race relations and social class are two defining (and oftentimes not mutually exclusive) factors in the history of this metropolitan area (Farley, et al. 2000; Hartigan 1999; Sugrue 2005). Although issues of race and social class were not the focus of this study and beyond its current scope. I will return to them in the concluding chapter of this dissertation where I will indicate how they are a potential route for future exploration with my data.

#### A Brief History of the Detroit Metropolitan Area

Detroit's history has been a tumultuous one over the centuries. The city was known for fur trading when it was originally founded in the early 1700s, but experienced some of its greatest changes as it became the heavily industrialized "Motor City" during the 20<sup>th</sup> century (Farley, et al. 2000; Hivert-Carthew 1994). The growth of the automotive industry led to a significant increase of Detroit's white and black populations over time, and by mid-century racial tension mounted, including racial segregation that

overtook Detroit's city neighborhoods (Farley, et al. 2000:34-35). Detroit began to experience a demographic shift from 1950 onwards as many of Detroit's white residents began to leave the city to live and work in the suburban areas in increasing numbers; this "white flight" changed the city's population (Farley, et al. 2000:49-50; Sugrue 2005:8, 149, 162). Sugrue describes how Detroit changed racially and socioeconomically: "As Detroit's population shrank, it also grew poorer and blacker" (2005:149). Detroit's racial tension came to a breaking point in July 1967 when the city experienced a major race riot (Farley, et al. 2000:43). Additionally, the city became characterized as "unsafe," according to Farley et al. (2000:47) who noted increasing crime rates within the city.

Importantly, the downfall of Detroit's automotive industry became a defining feature in the region's history from the 1970s to present day (Gallagher 2010; Maynard 2003). Farley et al. (2000) points out that unlike other U.S. cities, Detroit relied solely on the automotive companies as its economic base so when workers lost their jobs, there was no other industry they could turn to for employment. Most recently, the economic recession that began in 2008 was the final breaking point for the Detroit's automotive industry, leading all but Ford Motor Company to declare bankruptcy in 2009 (Gallagher 2010:36-37, 119).

Today, Detroit is an urban city with a largely African American population, a relatively low median household income, and a very high poverty rate, especially when compared to the suburban Waterview (see Table 4: Key Demographic Characteristics of Detroit and Waterview below). Importantly, U.S. census figures show significant depopulation in the city of Detroit in past ten years with a loss of over 200,000 residents

(U.S. Census Bureau: State and County QuickFacts). Even though foreclosure rates for the entire metropolitan region have slightly improved according to the Southeast Michigan Council of Governments (2011), a high foreclosure rate still plagues Detroit with an average of one home in foreclosure out of every 30.<sup>11</sup> Additionally, Detroit's official jobless rate greatly increased during the recession (the numbers were far higher than both state and national averages), and has only slightly improved according to the most recent figures (see Table 5: Comparison of Jobless Rates 2008-2011 below)<sup>12</sup>. While the city of Detroit is still struggling, recent headlines in the *Detroit Free Press* convey some hope that Michigan's economy is slowly improving, in part to the automotive industry hiring once again (Gardner 2011; Yung 2011). This is an ironic twist of fate considering the significant role this industry had in the Detroit metropolitan area's economic decline.

<sup>&</sup>lt;sup>11</sup> Average based on the 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> quarter of 2010 and the 1<sup>st</sup> quarter of 2011.

<sup>&</sup>lt;sup>12</sup> It is important to note that data from the U.S. Bureau of Labor Statistics illustrates a larger national trend of much higher jobless rates for African Americans compared to whites. <u>http://www.data.bls.gov/</u>

Demographic Characteristics	Detroit	Waterview
Population	713,777	59,715
One Race/Ethnicity:		
White	75,758	55,373
Black/African American	590,226	2,350
Asian	7,559	614
Hispanic/Latino	48,679	1,040
Sex:		
Male	337,679	28,527
Female	376,098	31,188
Median Age:	34.8	44.2
Household Income (Median):	\$25,787	\$51,243
Individuals Below Poverty Line:	37.6%	8.4%
Educational Level		
(% of Population 25 years +):		
High School/GED	32.8%	32.5%
Some College	26.4%	27.6%
Associate's	6.2%	8.0%
Bachelor's	7.0%	16.3%
Graduate/Professional	4.9%	7.7%
Employment Sector		
(% of Population 16 years +):		
Education/Health Care/Social	26.0%	22.0%
Assistance		
Manufacturing	12.4%	15.1%
Retail	9.9%	11.2%
Professional/Scientific/Management/	10.4%	12.7%
Administrative/Waste Management		
Arts/Entertainment/Recreation/	11.6%	8.7%
Accommodation/Food Service		

Table 4: Key Demographic Characteristics of Detroit and Waterview<sup>13</sup>

<sup>&</sup>lt;sup>13</sup> The population, race/ethnicity and median age categories are from the U.S. Census Bureau's 2010 Census. The Household income, poverty rate, education level and employment sector categories for Detroit are based on the 2010 American Community Survey 1-Year estimates from the U.S. Census Bureau; for Waterview the 2008-2010 American Community Survey 3-Year Estimates from the U.S. Census Bureau. All data accessed from the U.S. Census Bureau website <a href="http://factfinder2.census.gov/main.html">http://factfinder2.census.gov/main.html</a>.

	2008 (Annual)	2009 (Annual)	2010 (Annual)	2011 (Annual)
Detroit	16.1	25.0	22.7	20.2
Waterview	9.3	16.6	14.4	12.3
Michigan	8.3	13.3	12.5	10.4
U.S.	5.8	9.3	9.6	8.9

# Table 5: Comparison of Jobless Rates 2008-2011<sup>14</sup>

Additionally, Detroit (and Michigan overall) has also struggled with a reputation as being an unhealthy place to live (Michigan Department of Community Health 2005). For example, Detroit was labeled one of the nation's "fattest cities," a moniker bestowed by popular health and fitness magazines (e.g. Colletti and Masters 2010; Men's Fitness Magazine 2009; Michigan Department of Community Health 2005). Detroit has since improved in its ranking in these sources of popular media, but in 2010 *Men's Health* still gave the city of Detroit a low "D+" rating on their "A+" (i.e. the "fittest" city) to "F" (i.e. the "fattest city") scale partly due to the city's rates of obesity (Colletti and Masters 2010; Michigan Department of Community Health 2005). Detroit's ongoing reputation as an unhealthy place to live will be important to keep in mind later on in this dissertation. In chapter 4 we will see how Dr. Bennett emerges as the antithesis of the stereotypical portrayal of "unhealthy" Detroit area residents when we learn about his own beliefs that stress the importance of wellness and healthy living, and the way in which these beliefs emerge in the clinic's more flexible view of patient responsibility discussed in chapter 5.

# A Brief History of Waterview

Like Detroit, Waterview experienced a fair amount of demographic and economic change throughout the 20<sup>th</sup> century. A historical account authored by the Waterview Historical Commission (2001) describes in detail how this rural farming community grew

<sup>&</sup>lt;sup>14</sup> All data is from the Michigan Department of Technology, Management & Budget Labor Market Information website <u>http://milmi.org/cgi/dataanalysis</u>. All rates are not seasonally adjusted.

in population, and transitioned over time into a suburban community with movie theaters, restaurants, markets and parks. While 1950s Detroit was losing its population due to the "white flight" to the suburbs (Sugrue 2005), Waterview's population greatly increased during this period as thousands moved into this rapidly developing (and largely white) Detroit suburb ("Waterview" Historical Commission 2001). The Historical Commission noted: "It was a time of unparallel growth for the city—hundreds of new subdivisions, thousands of new homes, and miles of new water mains, sewer lines, and paved streets" (2001:8). The 1970s saw Waterview's population peak at approximately 93,000, but the city began a steady trend of population loss thereafter: "Due to an aging population and a decrease in family size, situations that were occurring in all of Detroit's older suburbs, the city's population fell to 76,210 in 1980, 68,107 in 1990, and to 63,096 in the year 2000" ("Waterview" Historical Commission 2001:8).

Today Waterview is a suburban city with a majority white population, a higher median household income, and a relatively low rate of poverty when compared to the city of Detroit (see Table 5: Key Demographic Characteristics of Detroit and Waterview above). Most recent U.S. Census figures show Waterview's 2010 total population at 59,715 residents, indicating its continued depopulation (U.S. Census Bureau: State and County QuickFacts). Interestingly, while Waterview is still a majority white suburban city, it appears to be becoming more racially integrated (along with other Detroit suburbs) (Wisely 2011); a significant demographic trend given the Detroit metropolitan area's long history of racially segregated communities. A comparison of 2000 and 2010 U.S. Census figures shows that while Waterview's total population dropped (there are fewer whites, Asians and Hispanics), the area's African American population increased

from only 435 residents in 2000 to a notable 2,350 in 2010 (U.S. Census Bureau).

While the effects of the recent 2007-2009 economic recession affected the city of Detroit on a larger scale, Waterview was not spared from its effects and struggles with some of the same issues. For example, Waterview's unemployment increased during the recession, and while not as high as the city of Detroit, is still higher than state and national averages (see Table 6: Comparison of Jobless Rates 2008-2011 above). Although elevated, Waterview's foreclosure rate stands at one home out of every 45, which is better than the city of Detroit according to a report by the Southeast Michigan Council of Governments (2011).<sup>15</sup> To help reduce the number of foreclosed homes, one of Waterview's city council member encouraged residents to foster their civic pride by endorsing their city as an enjoyable place to live: "I am personally asking you to become an ambassador for your City....Together we can attract families to our empty houses....Our strong community is exactly what many are looking for—they just don't know about us."<sup>16</sup>

#### THE INTEGRATIVE MEDICINE PAIN CLINIC

I will next describe the immediate neighborhood where the IMPC is located and the building that houses the clinic, and then take you on a walking tour inside the various clinic spaces to highlight how it resembles in some respects a more "typical" biomedical doctor's office, and in other respects a more tranquil, spa-like complementary medicine setting.

<sup>&</sup>lt;sup>15</sup> Average based on the 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> quarter of 2010 and the 1<sup>st</sup> quarter of 2011.

<sup>&</sup>lt;sup>16</sup> "Waterview" May 2011 newsletter will not be formally cited due to issues of confidentiality.

# **Outside the Clinic**

Waterview is a small community that is only 11.5 square miles, and comprised mostly of residential neighborhoods<sup>17</sup> of well kept homes and streets.<sup>18</sup> A few major thoroughfares lined with various businesses run through the city, and the IMPC is located on one of these busy city streets. Some of the small businesses that are near the IMPC include a florist, kitchen improvement store, a nursery, a greeting card store, a sports memorabilia shop, a pizza chain restaurant, a dance studio and a banquet hall. The IMPC is located between a bank and a popular ethnic restaurant in the Waterview area. Oftentimes the IMPC staff uses this restaurant as a landmark when they are directing patients to the clinic's location. If the wind is blowing in the right direction, you can even smell the enticing aromas of the restaurant's food in the IMPC's parking lot.

To access the IMPC, you turn down a dead-end street to get to the parking lot in the back of the building.<sup>19</sup> The IMPC's parking lot is small and only comprised of 13 parking spaces (including one handicapped spot), and parking can be a challenge at times given the number of staff and patients relative to the limited number of spaces. On most days, the staff parks furthest away from the entrance to allow patients to park closest to the door.<sup>20</sup> As the founder of the clinic, Dr. Bennett almost always parks in the space next to the door for likely symbolic and practical reasons (he has a large,

<sup>&</sup>lt;sup>17</sup> "Waterview" promotional flyer will not be formally cited due to issues of confidentiality.

<sup>&</sup>lt;sup>18</sup> Residents are strongly encouraged to abide by "ordinances" as well as "City codes" to maintain the outward appearance of their homes and property. According to the Waterview city website, the city has a "Code Enforcement Officer" that investigates ordinance and code violations and issues citations if need be. The "Waterview" city website will not be formally cited with its own URL due to issues of confidentiality.

<sup>&</sup>lt;sup>19</sup> In addition to the back entrance that faces the clinic's parking lot, there is a front entrance that faces the busy thoroughfare. This front entrance is always locked (a sign is posted that says "please use the back door") and is not utilized given its distance from the parking lot. <sup>20</sup> The clinic also has an agreement with the bank across the street for some staff to park in their lot.

heavy briefcase and several other items he brings with him on a daily basis and it is a sign of respect and ownership for the clinic's founder).

The type of building that houses the IMPC—a small one-story square brick building—is commonplace in the Waterview community. A large teal and dark blue sign (that lights up at night) sits on top of a tall black pole is advantageously positioned in front of the clinic to grab the attention of passersby. In the top half, the sign has the clinic's name in black letters with "Comprehensive Pain Management" below in large white letters to provide emphasis. Dr. Bennett's name is written in smaller white letters inside a black stripe that divides the sign into two halves. The specialties of the clinic are then listed in the second half of the sign in white letters; the conventional biomedical specialties (and those most likely to be covered by a patient's health insurance) are listed first (pain management and physical therapy) while the complementary specialties (medical acupuncture and massage) follow. The clinic's phone number is in large white numbers at the very bottom of the sign. I will now take you inside the IMPC and highlight the key features of the clinic's physical environment.

## **Inside the Clinic**

When Dr. Bennett moved his practice to this building in August 2003, he only occupied one half of this building and another business occupied what later became the "therapy side" of the clinic. In 2007, the clinic underwent extensive renovations that allowed Dr. Bennett to integrate the building's two separate halves and expand the kinds of treatments he offered such as massage therapy, and physical therapy. The IMPC now has a larger-than-it-looks feel thanks to these renovations that resulted in entire walls being moved in the newly acquired half of the building, as well as fresh paint

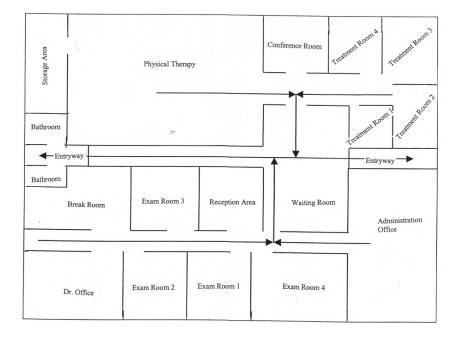
and new carpet that was put down throughout the entire building to create the clinic that exists today.

Immediately upon entering the IMPC you can see some of the thought that went into creating the appearance and mood of the IMPC's physical environment. The IMPC's décor in the public spaces share certain characteristics such as the emphasis on nature<sup>21</sup>. There are framed prints of flowers and plants, numerous silk plants and trees, and light green painted walls in all of the clinic's public rooms such as the waiting room and various treatment rooms. The carpet coordinates with the walls, and is a greenish berber-style. The practice administrator and Dr. Bennett's wife Jasmine took the recommendation of the clinic's contracted Reiki and medical hypnotherapy practitioner to paint the walls this particular green color. Jasmine explained to me that she originally opted for an "orangey-bronze look," however, Jasmine learned that this orange color "is a warm color and so when people are in pain they're already warm so you need to have them cool and calm, and blue or green would be more of a cool and calming [color]." Jasmine, who has received compliments on how her choices for the physical environment, also explained the rationale for the silk plants scattered throughout: "[It's] just part of wanting people to feel comfortable and at home, you know, 'cause you go to a doctor's office and it's like so gray and stale and sterile looking andand yeah sterility and cleanliness is clean but I wanted people to feel calm and at home and peaceful." The use of calming colors and plant-life are reminiscent of the Orient, giving the IMPC's physical environment an almost "exotic" vibe for its location in the heavily industrialized Detroit metropolitan area.

<sup>&</sup>lt;sup>21</sup> The clinic also decorated the waiting room and other public spaces for holidays like Halloween and Christmas.

# A Tour through the IMPC

I will now take you on a tour through the IMPC to better understand how the clinic is spatially arranged (see Diagram 1: The IMPC's Physical Environment below). I will begin with the waiting room that connects what the staff informally refers to as the "medical side" and "therapy side" of the clinic.



# Scheme 1: The IMPC's Physical Environment<sup>22</sup>

# The Waiting Room

Staff and patients enter the IMPC through their back entrance by the parking lot. Upon opening the glass door and entering the building, there is a very short entryway and a large wooden door that opens into a hallway that leads to the clinic's waiting room. There is a brass plaque with Dr. Bennett's name on this wooden door that again symbolizes his role as the founder of this clinic. Once through this wooden entry door, one leaves the busy, high traffic zone of the major road and shopping district found outside and enters the more peaceful environment of the IMPC's waiting room. Every

<sup>&</sup>lt;sup>22</sup> The arrows in Scheme 1 denote the IMPC's emergency exit strategy.

so often one can hear an ambulance siren as it is speeding down the street or the loud music coming from someone's car radio, but for the most part the IMPC is insulated against the noise pollution outside. On most days, jazz music from a local Detroit area radio station is softly playing in the waiting room from a small boom box that sits on the floor, and the soothing smell of essential oils (emanating from the massage rooms and a room diffuser) fills the air.

The waiting room is filled with various types of literature that has a twofold purpose. It is available for patients to read to educate them about different facets of the pain management approach offered here, and to market the practice as well. Jasmine believes if patients are educated about acupuncture, for example, they are more likely to benefit from it and "are more likely to utilize it," which helps the clinic financially.

Immediately upon entering the clinic's hallway that leads to the waiting room you encounter a sizeable literature stand with a sign on top in bold lettering that reads: "Please Help Yourself to the <u>FREE</u> literature." Jasmine explains the purpose of the unit was to house all in one place the numerous pamphlets on the various whole food supplements that the IMPC currently sells. However, Jasmine describes this unit as underutilized by patients and the clinic decided to discontinue many of these supplements (with reduced pricing specials) as patients were not buying them, which the staff attributed to the current economic conditions affecting the entire area.<sup>23</sup> This literature stand also houses copies of the clinic's informational newsletter they publish called the "Integrative Health Advisor" with various articles on, for example, their available treatments, how these treatments can help relieve the pain associated with

<sup>&</sup>lt;sup>23</sup> The clinic will still continue to carry some of the whole food supplements they believe will sell such as the detoxification kit that is heavily marketed to patients; several of the IMPC staff (including Dr. Bennett) have used this kit and strongly endorse it for weight loss.

patient's health conditions, and de-stressing. Two free natural health magazines are also housed in this stand. A plethora of other pamphlets on the IMPC's practitioners and various treatment options are also placed around the rectangular shaped waiting room.<sup>24</sup>

To keep patients occupied while they wait for their appointments, there is a tall, skinny magazine rack that contains other types of magazines. The types of magazines are what you would typically find at doctors' offices such as automotive magazines, popular culture magazines, and a magazine for children, as well as a magazine published by the Internet medical website WebMD®. In addition to these types of magazines, you also find a natural heath magazine that the IMPC subscribes to.

The waiting room also contains a television and DVD player that for the most part is not used except to play the occasional DVD. The staff initiates the use of the television and DVD player, and some of the DVD's the clinic has played include one on the whole food supplements they sell in the clinic, a medical talk show that aired on public TV where Dr. Bennett was a guest, and a DVD on various stretching exercises they received from one of the pharmaceutical representatives that visited the office.

The waiting room also showcases several of Dr. Bennett's professional accomplishments on the walls. For example, a bronzed version of Dr. Bennett's medical degree that is fastened to a wood plaque hangs in the waiting room as well as two large framed certificates both from the American Board of Physical Medicine and

<sup>&</sup>lt;sup>24</sup> Also located in this hallway is a wooden wall display case with a glass front. The content included seasonal specials on services like massage or on products like the discounted whole food supplements. There is also information about the IMPC's comprehensive website, positive patient comments taken from the clinic's patient satisfaction survey forms, and occasionally an "about us" section that profiles one of the IMPC's staff that includes a written biography of the individual with their photo.

Rehabilitation. One signifies Dr. Bennett's role as a Board diplomat, and the other indicates his subspecialty in pain medicine. The location of these biomedical credentials in the waiting room provides an immediate air of legitimacy for him as a qualified physician. On another wall, various awards presented to Dr. Bennett are also presented as well as a framed copy of the local newspaper article mentioned above about the CAM and IM health exposition that profiled Dr. Bennett and the IMPC. None of the other IMPC staff have their credentials or accomplishments showcased in this particular public space, another indicator of Dr. Bennett's pre-eminent role as the founder of the IMPC.

In finishing off describing this area of the clinic, there is an interesting anecdote to report. As we learned above, Jasmine had a large role in creating the clinic's overall appearance. However, some of the staff rearranged the waiting room furniture part way through the research period.<sup>25</sup> Interestingly, the staff made these changes when Dr. Bennett and Jasmine were away on vacation. One of the biggest changes involved moving a large display stand of therapeutic water filled pillows (it now stands next to the "therapy side" doorway). Staff members observed that individuals with assistive devises did have some difficulty navigating around this display stand that was originally positioned right as the hallway opened up into the waiting room. Other changes made the space more open and uncluttered. The fieldnote below describes a conversation I had with Joan, the IMPC's medical assistant, about the changes the staff made:

I mentioned [to Joan] that the office looked nice; the furniture had been rearranged a bit [in the waiting room]. The medical assistant [i.e. Joan] said that it's the ADHD [i.e. Attention Deficit Hyperactivity Disorder] coming out in us [i.e. the staff]. I said that the MD will be happy when he returns. Joan said either that

<sup>&</sup>lt;sup>25</sup> The descriptions of the waiting room described in this chapter reflect the changes the staff made.

or the practice administrator [i.e. Jasmine] will freak out...one of the two [scenarios] (Fieldnotes March 26, 2009).

Joan's statement showed how the staff was interested in changing the environment and motivated to do it in order to improve the physical space for the IMPC's patients. However, Joan's statement also indicated how the staff was unsure if it was their role or "place" to make these changes. In the end, Jasmine and Dr. Bennett welcomed the changes when they returned from their trip. However, this anecdote illustrates a hierarchy in decision-making in the clinic culture that I will describe further in the next chapter. I will next describe where Dr. Bennett practices in the clinic, what the staff informally called the "medical side."

# The "Medical Side:" Where Dr. Bennett Practices

Coming from the waiting room into the "medical side" one will see the administrative room, the four exam rooms, Dr. Bennett's office, the break room and the reception desk are all located on the "medical side" of the clinic. It is important to note that while Dr. Bennett's side of the clinic is informally referred to by the staff as the "medical side," this term refers to Dr. Bennett's continuous presence in this section of the clinic, not that strictly biomedical treatments are done here. Dr. Bennett performed both biomedical pain management treatments like trigger point injections on this side, and complementary treatments such as medical acupuncture in this section of the clinic as well.<sup>26</sup> Dr. Bennett explained why he localizes his treatments on the "medical side" of the clinic:

it's mainly me on that [i.e. medical] side. Okay. So I'm over there and I'm doin' acupuncture, but it doesn't make sense for me to do acupuncture on that [i.e. the therapy] side and do it on this [i.e. the medical] side...it doesn't make sense for me to have massage therapists in a room next to me [i.e. on the medical side]

<sup>&</sup>lt;sup>26</sup> The IMPC's treatments are described in Appendix E.

while I'm...seein' a patient for a regular patient encounter, and the person next door...is havin' a massage and they want it quiet.

Jasmine described the "medical side" as much louder than the "therapy side" (that will be described next in this chapter). She said the "therapy side" was intentionally created as a quieter environment that is isolated from noises such as the phone calls being made from the administrative area, and the loud Aqua Massage machine also located in the administrative room. This is a key separation of Dr. Bennett's practice from that of the therapists as indicated in his statement "it's mainly me on that side," and could be another visual indicator of his authority in this setting as he utilizes the most space—the four exam rooms and his personal office—compared to the clinic's other massage and physical therapy practitioners.

The "medical side" is accessed from a door in the waiting room. This door is almost always closed and locked for privacy, and patients have to be called into Dr. Bennett's side of the office by clinic staff (usually Joan, the medical assistant), much like what you would encounter in a typical biomedical office. This aspect of the IMPC's environment is another indicator of Dr. Bennett's status as the founder of the clinic, and the staff acknowledges his role by serving as gatekeepers. Once through this door, a narrow hallway connects the different rooms found in this side of the clinic, and Dr. Bennett's framed residency certificates (more visual symbols of his medical authority and ownership of the clinic) can be found hanging throughout this hallway. The administrative room, Dr. Bennett's treatment rooms, his personal office, the staff breakroom, and the reception desk are also located on this side of the clinic.

Turning left as you exit the doorway, the administrative room is at the end of the hallway and is one of the larger rooms at the IMPC. This room is the hub of business

operations as the medical billing and other administrative aspects of running the IMPC are performed here. There are three desks with computers, one occupied by Pamela, the office manager, one by Nicole, the medical biller, and one used by Jasmine the practice administrator. Although these are mainly dedicated workspaces of certain people, the other clinic staff is allowed to use each other's desks and computers if needed. For example, if Jasmine is not at the clinic, one of the massage therapists is free to use her desk and computer to record their patient notes.

The administrative room has a very busy atmosphere with multiple activities often going on at the same time. Staff may be on the phone with insurance companies or patients, making appointment reminder phone calls, or using the computers all with a steady hum of the computers and IMPC's server in the background. A large wall calendar is tacked to the back of the administrative room door that is used to keep track of vacation schedules, days off, staff meetings (and also indicative of their family-like culture, staff birthdays) as well as during my fieldwork the weekly countdown to the much anticipated Florida IMPC sponsored staff vacation that took place at the end of July 2009.

The administrative room also houses the clinic's Aqua Massage machine. The administrative room is the only location in the IMPC where the Aqua Massage machine can be placed given that it was built in this room before the clinic expanded and cannot be moved. This large machine occupies almost the entire length of one wall. The Aqua Massage machine allows a patient to have a water massage while remaining fully clothed. Given that this machine uses water powered jets for a massage, it is very loud and when turned on can be heard through many rooms in the IMPC. While this is an atypical placement for the Aqua Massage machine, it is accepted and tolerated here by both staff and patients.

A large portion of the medical side is devoted to the four exam rooms. All the exam rooms contain mostly the same furniture (e.g. exam table, chair) and related nature décor such as the silk plants and framed prints of flowers and plants. While all of the rooms can be used for patient consultations and treatments thanks to a rolling supply cart that will be described below, exam room four appeared to be the preferred and most utilized for treatments<sup>27</sup>. Exam room four is the largest of the exam rooms, and contains a mixture of biomedical and complementary elements. The clinic's EMG machine that is used for nerve testing is in this room along with Dr. Bennett's acupuncture certification, which is hanging on the wall with a plastic model of a human body with the acupuncture points sitting nearby. This exam room also houses medical supplies for biomedical and CAM treatments on a rolling two tiered supply cart that can be wheeled to the other three exam rooms if needed, but is mostly kept in exam room four that contained syringes, gauze, bottles of injection liquids, and a container of disinfecting wipes.

Dr. Bennett's personal office is also located in this side of the clinic and is an eclectic mix of décor. The door to his office is mostly left open and has a large biomedically oriented poster attached to it with the title "The Management of Persistent and Breakthrough Pain" that includes scientific diagrams of the human brain. His office has a very casual, "lived-in" feel and contains a large wooden desk, his chair, and two additional chairs across from this desk that can be used to accommodate visitors. On the corner of his desk sits a small talking Yoda from the Star Wars movies that he

<sup>&</sup>lt;sup>27</sup> Almost all of the co-created clinical encounters I observed with Dr. Bennett occurred in this room.

occasionally turns on and takes great amusement in when it starts talking. Framed pictures of President Obama are also hanging on the walls. In chapter 4, I will further discuss how the personalization of Dr. Bennett's office reflects his personality.

Across the hall from Dr. Bennett's office is the clinic's breakroom that is used for multiple purposes. The breakroom stores items such as drug samples brought to them by pharmaceutical representatives and various cleaning supplies. However, the clinic staff uses the room mostly to take their breaks throughout the day and it is one of the clinic's most communal locations. Oftentimes, staff will "break bread" in this room as it is a lunch or snack-time gathering place as it has a kitchenette with a microwave, toaster oven, small refrigerator, sink and storage cupboards. Occasionally, staff will bring in food such as cakes to celebrate birthdays, and other assorted sweet and savory items to share, and these items always find a home in the breakroom. The breakroom is also a social venue for informal conversation and has a more casual, lived in atmosphere than the rest of the clinic. A gray folding table is placed up against the wall with stools or chairs around it, with room for additional chairs to be added when the food/social gatherings grow in size. It is interesting to note that this room is directly across from Dr. Bennett's office where his door is usually left open. Oftentimes, he participated in these informal conversations and kept a hand in what was going on there. Given the communal nature of this room, the door is left open. If a staff member preferred to take a break privately or have a private conversation, they utilized the conference room or an unoccupied treatment or therapy room where they could close the door.

Next to breakroom is a small area that houses the IMPC's reception desk. This area of a hub of activity as the clinic's fax and copy machine are located here, as well as a large desk with a phone and computer that Joan, the IMPC's medical assistant, uses to schedule patient appointments. Like many doctor's offices, this area is partially enclosed by a glass partition. However, at the IMPC, two sides of the reception desk area are enclosed by glass giving this small space a more open feel, and allowing Joan greater visibility into the waiting room in order to greet patients immediately upon their arrival.

## The "Therapy Side:" Where the Physical Therapists & Massage Therapists Practice

Many of the IMPC's patients move between the "medical side" and "therapy side" depending on their treatment plan. For example, a new patient comes in and first sees Dr. Bennett on the "medical side." Once a treatment plan has been decided upon, the patient may then receive their trigger point injections one day over on the "medical side," and later that week receive massage or physical therapy over on the "therapy side" of the clinic. Access to this side of the clinic is much less formal than the "medical side" as the door that connects this side of the clinic to the waiting room is always left open. The physical therapists and massage therapists usually come to the open doorway and call their individual patients back to their respective treatment rooms. The door being left open caused a few problems for the therapists as some patients mistakenly thought this open door meant they could freely walk into the treatment rooms without the therapist's permission where another patient might be preparing for or in treatment. While there was talk about closing the "therapy side" door, the temporary

use of signage let patients know they had to wait to be called back by their therapist and solved the problem for the most part.

As we learned earlier, Jasmine envisioned the "therapy side" to be quieter and she noted when it was designed how "I wanted it to have a more quiet spa feel." The therapy side is comprised of different types of rooms in terms of their functions: the large physical therapy room, the smaller physical therapy evaluation room, the three massage rooms, a supply room, and the conference room or my "perch" as it was called by Dr. Bennett during my dissertation research.<sup>28</sup> The conference room was an advantageous location as I was able to observe the Massage Therapists and talk with them on an informal basis. For me, the conference room also provided a private work space to write-up my fieldnotes, and a quiet spot to conduct interviews.

The conference room has a large wooden table that takes up almost all of the available space in this small room, and is surrounded by several chairs that are upholstered in a colorful jewel-toned fabric. This room has many purposes from holding meetings, hosting lunches that were brought in often from various pharmaceutical company representatives, a quiet spot for staff members to have lunch, and a place for staff members to spread out and work if they need additional space. Staff meetings were held in this room during the first few months of my fieldwork, but given the number of new staff that had been hired, these meetings quickly outgrew this room. Since the staff felt the space was too small to fit everyone comfortably, the large physical therapy room was used for meetings to give everyone a chance to spread out around a large folding table that was brought out specifically for these meetings.

<sup>&</sup>lt;sup>28</sup> This was a fitting term as the term "perch" is defined as "a resting place or vantage point" (Merriam-Webster 1981) both of which accurately describe this room for me.

The large physical therapy room is at the very end of the hallway as you turn left once you enter the therapy side. Interestingly, while Jasmine envisioned this side of the clinic to be the quietest and have a "spa feel," the physical therapy room still has a very biomedical atmosphere.<sup>29</sup> Instead of the framed artwork of flowers and plants on the walls seen in many of the other public spaces of the clinic, there are framed posters of nature scenes with motivational sayings such as "perseverance," "challenge," and "attitude" that are indicative of attention being paid to creating what is considered to be an encouraging rehabilitative environment. Another element contributing to the more biomedical feel of this room is a large, highly detailed anatomic wall chart of the human muscular system.

This room contains a pulley operated weight machine, a cardio machine that exercises the arms and legs, inflatable exercise balls of varying colors that are stacked up in the corner of the room, a dark green padded physical therapy table, dumbbells, and a purified water system for staff and patient use. A large wood desk with a phone and a computer (used to record patient notes and check the clinic's centralized scheduling system) serves as the communal workspace of the physical therapist, physical therapy assistant, and massage therapists (and, at times, the resident anthropologist). A large floor-to-ceiling shelving unit contains various items such as brightly colored exercise bands, towels, disinfecting wipes, a clock, and a radio that is set to a local rock station. While this room was designed to be a very high energy atmosphere with the use of motivational posters and rock music playing in the background, a drawback to this space (that has been noted by the clinic's practitioners)

<sup>&</sup>lt;sup>29</sup> According to Jasmine, when the IMPC gained access to the half of the building that houses physical therapy and massage therapy, they needed a very large room to accommodate the physical therapy equipment needed, and the size of this room fit well with their needs.

is the lack of sunlight as there are no windows in this room. Connected to this room is the IMPC's laundry room/supply storage area. This small room with unfinished walls contains a washer and dryer, a cordless rechargeable vacuum (popular with staff because of its portability), and a large shelving unit for storing paper goods and cleaning supplies.

Physical therapy evaluations, an evaluation takes place before the actual manual therapy begins, are conducted in the much smaller treatment room one just down the hallway from the large physical therapy room. Jasmine explained how Dr. Bennett visualized this smaller treatment room as a "more private" space for patients to be evaluated by the physical therapist rather than having the evaluations take place in the high-traffic, larger physical therapy room (where treatments, computer usage, and use of the clinic's laundry/supply room all be taking place at the same time creating a noisier environment). This "more private" space is also utilized by the physical therapy assistant for ultrasound treatments (the small ultrasound machine can be wheeled from its home in the physical therapy room to this smaller evaluation room). Patients are able to rest and relax more by receiving their ultrasound treatments in this more quiet space.

Located down the hallway are the clinic's three massage therapy rooms, treatment rooms two, three and four, one for each therapist on staff. The massage therapy rooms have the same color walls, carpet, and nature décor as seen in many of the clinic's other spaces, but as we will see, the therapists added some personal touches to their rooms, and positioned the massage tables and furniture to their liking. These rooms also differ in how they were personalized, which presents a nice contrast showing how each therapist customizes the environment they want to create for their patients.

The majority of the massages I observed at the IMPC occurred in treatment room three that is the most spacious of all of these rooms. Although this room faces the busy thoroughfare, only the most extreme street noises could be heard such as an ambulance siren or a very loud car that stopped at the drive-thru ordering station at the Mexican restaurant next door. Thanks to heavy, dark brown curtains that cover the windows, very little light streams in from the outside. Jasmine said that a decision was made to give Roxy this larger room as she is their only full time massage therapist. Importantly, because Roxy works long hours, she had to create an environment that not only benefits the patient, but her as well: "I'm in that room for eight hours. It better be comfortable...and feel good to me because I'm the one who has to be in there the whole day...and it obviously has to be comfortable for the...patient...because that's a huge part of it."

Roxy explained how her "personality" is evident in her treatment room. She strongly believed in fate, and because of Roxy's beliefs, a sense of calm emanated from her. This calmness is reflected in the space Roxy intentionally created: "I like mine [i.e. my room] just very calming and soothing, which you've [i.e. Lindsey] even said when you've come into my room that's—you feel that. So that's important to me." Not only did I notice the calming effects of the room, but one of her patients aptly portrayed it to me as "peaceful" (Fieldnotes October 22, 2008).

Roxy noted how lighting and music are important elements of personalization of her treatment room, and I found that both added to this "calming and soothing" environment she desired. The lighting of the room is very soft, and this softness is achieved with different lamp styles she utilizes. Sitting on a desk that is positioned in one corner of her room, Roxy had a small table lamp that she turns on very low. Also on this desk, she placed a small salt lamp which is a large chunk of whitish colored salt illuminated by a tiny light placed inside. Later in my fieldwork, she added a tall pole lamp in another corner of her room that cast low light up towards the ceiling. In the opposite corner of the room, there is a tall dresser where she stores her linens and her CD player sits on top. Roxy chose very peaceful sounding instrumental pieces year round, but at Christmastime, she changed her music to instrumental holiday pieces. Much thought went into the music Roxy chose as she considered it an extension of her: "my music is a huge reflection of who I am. My music is a lot different than Erica's and it's a lot different than Elizabeth's...it comes from my heart. That's—that's an expression of me, music's a huge deal to me."

Roxy was knowledgeable in many different massage therapy techniques and uses them when she deems appropriate (e.g. hot stones, aromatherapy, reflexology). Roxy also personalized her room with the massage therapy tools she frequently utilized. On the corner of her desk she has a heater that warms water for hot stone therapy<sup>30</sup>. On the dresser, Roxy has her aromatherapy bottles, and a large tub of the over-the-counter pain relieving gel the clinic sells.

Roxy also had specific reasons behind the positioning her massage table in her room:

<sup>&</sup>lt;sup>30</sup> The stones are placed in this hot water bath that slowly warms them. The stones are removed with tongs to prevent contamination of the water, and then used by Roxy during a patient's treatment. Roxy also explained that the stones can be used cold as well.

LM: How have you set up...your treatment room? Is there a particular reason why you set it up that way...?

Roxy: Like with my table on an angle? ...it just—it flows well to me. It has like a flow, a feel to it....I have a heating pad on the table. Electrical blanket....I moved the table around to where I could get to an outlet. But I just—I liked the way it [i.e. the room] flows....I've read the Feng Shui books and technically it's not a good idea to have their [the patient's] head facing the door...it actually makes them feel more private—privacy [to have their head facing away from the door]....So if their feet are there—I mean they're covered the entire time, but it's just more of a mental thing just—just to make them feel a little more safe. So that's one of the reasons.

In Roxy's room, the front of the massage table where the patient places their face points

toward the windows, and their feet are facing the doorway as she described above.

Roxy has achieved the "flow" she desired as the positioning of her table allows her to

effortlessly move around the entire table to give a full body massage, and have easy

access to her hot stones, aromatherapy bottles, and the pain relieving gel that she

applies to many patients at the end of their treatment.

Roxy always ensured the room was prepared before the patient entered the

space. However, one day, Roxy was unnerved as her room was not as prepared as

she would have liked for the clinical encounter as seen in the fieldnote below:

Roxy apologized to the patient for not having eucalyptus in the face cradle. Roxy said that the clinic has ordered more [because she has run out]. Roxy also had to restart her CD player, which is always playing when a patient is in the room. For some reason today, the CD player was off. Roxy expressed concern because she has it set to continuously play all day (Fieldnotes July 15, 2009).

I wrote the following commentary in my fieldnotes about what I had observed:

Commentary: These two issues signify how much pride Roxy places in the environment she has created in her massage room. Roxy has told me before how important it is to set the environment ahead of time and always makes sure she is early to get the room ready for the patient. She was clearly concerned when she noticed that her music wasn't playing. She expressed in her interview how important her music is to her in the massage encounter. (Fieldnotes July 15, 2009)

In addition to ensuring that the massage table was prepared with clean linens, Roxy always knew the personal preferences of each of her patients, and for this patient in particular she always placed the aromatherapy scent of eucalyptus in the face cradle. On this day, Roxy had run out of this scent, and her CD player had malfunctioned causing her music to stop playing. In short, Roxy believed all of these elements for creating a proper tranquil environment were extremely important for helping the patient relax and release his or her tension. In this particular instance, she felt treatment was somewhat compromised without these elements being set up correctly for the arrival of the patient.

In contrast treatment room four—Elizabeth's room—is smaller than Roxy's, has no windows, but does have a large storage closet where she stores her massage supplies and linens. While this room is smaller than Roxy's, it has an airy, spacious feel thanks to Elizabeth's minimalist approach to her personalization:

I wanted it to be very...restful. And I didn't want sensory overload. I didn't want clutter....I wanted everything to be as monochromatic as possible so that when a patient came in, they again wouldn't be distracted by...bright colors...loud noise...visual distractions or—I wanted it to be...a feeling of restful...sensory...you know, calm, you know, that kind of thing.

The room is clutter-free as she added little décor to what was already in the room (a silk plant and framed floral picture), and there are only a few pieces of furniture such as a massage therapy stool for Elizabeth to sit on if she needs to (she may sit during a portion of her massage to target a specific area like the neck, for example), a small bench for sitting or for the patient to place their clothing<sup>31</sup>, and a petite cabinet with a small table lamp and a CD player on top. This rectangular lamp emits very soft light

<sup>&</sup>lt;sup>31</sup> Elizabeth also hung decorative clothes hangers on the back of her treatment room door to give the patient the option to hang their clothing if they prefer.

through a mosaic of colored or stained glass, and she uses her CD player to play soothing nature sounds such as ocean waves. Elizabeth believes that the sound of ocean waves help to relax the body, as I recorded in the following fieldnote: "She [i.e. Elizabeth] said it was important 'to incorporate all the [body's] senses' [like hearing, smell, etc.] when trying to relieve pain...to relax the whole body with sounds such as ocean waves" (Fieldnotes September 16, 2008).

Interestingly, Elizabeth's massage table is not positioned in the center of the room, but rather slightly off center as it runs close to one of the room's walls (despite its proximity to the wall, Elizabeth had ample room to move around her table when giving a full body massage). Elizabeth never explained to me the specific reasons for positioning her table this way, but given the smaller size of this room, I noticed that placing the table in this way prevents it from being directly in front of the doorway. Elizabeth's table also runs horizontal to this wall so the patient's feet, rather than their head, point towards the doorway.

This chapter has discussed the site selection, provided a brief overview of the Detroit metropolitan region, and described the IMPC's physical environment. The following chapter discusses the IMPC's staff and the clinic's culture.

### **CHAPTER 4**

### DR. BENNETT'S DREAM

"I always wanted to open up a kind of complementary [medicine] center and this is my dream" (Dr. Bennett, Clinic Founder)

As a specialist in physical medicine, rehabilitation and pain management, Dr. Bennett had a dream to help patients live healthier and more pain-free lives by opening a clinic that provided more than just the standard biomedical treatment options. His wife and business partner Jasmine joined in this dream by providing the economic management savvy needed to make it a reality. As the clinic grew both in physical size and number of staff over the years, the IMPC developed a family-like culture where the long-term staff for the most part shares in and helps to sustain this dream. This chapter describes Dr. Bennett's development as a health care professional, his dream to open an IM pain clinic, and the making of the IMPC. The role of Jasmine in the realization of what became their shared dream, and how adding staff to the "IMPC healthcare family" are then described.

#### **DR. BENNETT & HIS CAREER**

Dr. Bennett is a 41 year old African American doctor with strong ties to the Detroit metropolitan area. He received his undergraduate and medical degrees from universities in the city of Detroit, and spent his early career working in the city and later its surrounding suburbs. Dr. Bennett decided to become a physiatrist, a doctor who

specializes in the area of physical medicine and rehabilitation (PM & R)<sup>32</sup>, because he said:

I saw physical medicine as a situation where people were kinda like downtrodden at the worst they could possibly be...living I guess, in pain, not walking...disabilities and things like that. And it gave me an opportunity to help people come from the bottom up to a more functional level.

After finishing medical school, Dr. Bennett traveled to Illinois for his PM & R residency

that he completed at a Chicago area hospital, and then returned to Michigan to work at

a hospital in a city north of Detroit. After that, he began working in the neurosurgery

department at one of Detroit's largest and most well known hospitals.

Dr. Bennett said he "created a job" in this neurosurgery department by focusing specifically on the field of pain medicine<sup>33</sup>, a subspecialty of PM & R in which he later received board certification. Dr. Bennett blended these two areas of specialization in his hospital job. He first evaluated the neurosurgery patients to see which patients were

Due to issues of confidentiality, the IMPC's website will not be formally cited with its own URL.

<sup>&</sup>lt;sup>32</sup> The IMPC's website defines PM & R in the following way: "Physical medicine and rehabilitation physicians (physiatrists) treat patients in all age groups and treat problems that touch upon all the major systems in the body. They focus on restoring function. Physiatrists treat acute and chronic pain and musculoskeletal disorders. They may see a person with back pain, a patient who sprains an ankle and needs rehabilitation, or an employee who has carpal tunnel syndrome. Physiatrists also treat serious disorders of the musculoskeletal system that result in severe functional limitations. They may treat a patient with a birth defect, someone involved in a car accident, or an elderly person with a broken hip. Physiatrists coordinate the short and long-term rehabilitation process for patients with amputations, spinal cord injuries, stroke or other neurological disorders, brain injuries, and multiple sclerosis."

<sup>&</sup>lt;sup>33</sup> The terms pain medicine and pain management were used interchangeably at the IMPC to refer to this medical specialty. IMPC's website describes Dr. Bennett as a physician specializing in pain management, and describes this specialty in the following way: "Pain Management is the act, manner or practice of managing pain, handling or control of an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder. Treatment for chronic pain is best understood and accomplished by a physician specializing in pain management. A pain management physician can prescribe specific medications to help assist one with problematic pain. They can also help alleviate pain through various physical aids (such as braces, canes, and other modalities), and can furthermore prescribe certain exercise regimes and physical therapy treatment programs to help one with pain management. The additional credentialing in Pain Management provides Dr. [Bennett] with the added skills to treat patients with painful disorders, acute or chronic. The ultimate goal of the pain management physician is to help patients manage persistent pain and resume normal, productive lives."

the best surgical candidates, and he then worked with those patients after surgery to help control their pain, and with their rehabilitation. Unlike the surgeons in his department, Dr. Bennett had a much longer lasting relationship with these patients as he dealt with them before surgery and through their recovery. Working with these neurosurgery patients during their recovery process started Dr. Bennett's interest in complementary medicine where he saw that surgery alone was not often the most successful treatment plan. Dr. Bennett states:

I had several patients that were...they had pain and yet they weren't getting better with the treatments that I had, which was a traditional allopathic treatments. So—they were receiving acupuncture, for example...and this was...done by a physician in Canada...he was getting benefits...with the patients. So they'd [the patients] come back and say "Hey doc [Dr. Bennett], you know, I had this pain in my back...and...I'm getting acupuncture. It's workin'." I was like okay I'd say "Well—well...what do you think? If it's helpin' ya, keep doin' it." So they did the acupuncture, [and were] getting better and it's just not one person, it was several people.

Dr. Bennett's growing interest in the use of complementary medicine to manage pain led him to a prestigious conventional medical school in California in 2001 that offered training in medical acupuncture specifically for biomedically trained physicians. This specialized training involved a combination of distance video training with a short term practical "hands-on" component that Dr. Bennett traveled to California to complete.

After being laid off from the large hospital where he worked, Dr. Bennett began in

private practice in August 2001. This layoff was a motivating factor in his life because it

provided an opportunity for him to "follow his dream" and open his own practice:

I was soon let go from [the hospital] because they had these layoffs during the time, and I was one of the physicians laid off so it started me in private practice, and it was really cool because then it gave me [free] rein to like...to do what I wanted to do. And I always wanted to open up a kind of a complementary [medicine] center and this is my dream.

In private practice, Dr. Bennett now had the opportunity to make his own treatment decisions without some of the constraints present in his prior hospital job. Dr. Bennett's next steps in the realization of this dream were to complete his board certification in pain management, and begin to build a patient base in private practice. Since the costs of starting an independent private practice were high and initial patient volume was low, Dr. Bennett partnered with another physiatrist for two years in the city of Waterview in the beginning rather than try to start out on his own. While this joint practice specialized in PM & R, it was a stepping stone for Dr. Bennett's dream of opening a stand-alone integrative pain management clinic. The opportunity to branch out on his own completely presented itself when the lease ended on the building they shared. At that time, Dr. Bennett had finally established himself in Waterview, and now felt the time was right to purchase his own building (only two miles down the road from his old location) and open the IMPC in August 2003.

In telling this story, Dr. Bennett portrays how he was seen as a physician of last resort by some, and how he developed a positive reputation in the local medical community for being able to handle "difficult" pain cases (i.e. those patients that do not respond well to solely biomedical treatments for pain) through using complementary medicine. Dr. Bennett states:

I started off with one patient...from there it slowly progressed...I had...just [a] few people in the community that was [sic] accepting of acupuncture and as complementary...treatments, but then T spoke to more and more...physicians...they came to...to trust...another physician to deliver these...non-traditional treatments...to their patients. And...they started seein' outcomes with their patients and so, you know, I had the difficult cases [sent to me]. You know, send 'em over to him [Dr. Bennett]. And that's how things kinda got started. And I grew from that one patient to now I can't tell va how many patients have passed through the doors...to this...point.

To this day, other medical doctors will refer patients to the IMPC based on Dr. Bennett's reputation as someone who can "do something" in treating people with difficult pain cases. As we will see in the patient narratives in chapters 6 and 7, several of the patients describe their own scenarios in detail in which they came to see Dr. Bennett because of prior negative health seeking experiences or lack of successful biomedical treatment options for their pain, or both.

#### **DR. BENNETT & THE MAKING OF THE IMPC**

Dr. Bennett has a combination of personality traits that allowed him to achieve the dream of opening the IMPC. Dr. Bennett is a very outgoing and energetic individual. Idle time is Dr. Bennett's enemy and he can be characterized as extremely productive. His Blackberry quickly became a beloved item that was never far from his side, and he listens to audio books or runs errands when not seeing patients.

Dr. Bennett also has an innate sense of optimism seen through his "can do" attitude that things can be better; he has the passion to make it so, and a penchant for "breaking the mold." This penchant for "breaking the mold" is evident in Dr. Bennett's political views as seen in the framed magazine covers of President Obama, the nation's first African American president that are hanging in his office. Dr. Bennett was an early strong supporter of President Obama and his attitude epitomizes President's "Yes we can!" campaign slogan. During this study, Dr. Bennett opted for fashionable dress shirts, ties, sweaters, and shoes rather than wearing the traditional white doctor's coat when seeing patients. His penchant for "breaking the mold" is also evident in his particular approach to pain management (that will be described in chapter 5) that includes his holistic beliefs about wellness and living a healthy life seen in the way he cares for himself.

Dr. Bennett is the antithesis of the stereotypical portrayal of "unhealthy" Detroit area residents. While he leads a busy life, Dr. Bennett values prioritizing wellness that includes finding a healthy balance between work and family time. This balance includes taking time for vacations during the year with his wife Jasmine and their three children. Wellness also includes finding time to relax, as he did during his busy days that included frequently cracking jokes with staff and patients (he is known for his witty sense of humor and ability to laugh at himself), sharing a lunchtime meal with staff, and using the clinic's Aqua Massage machine (keep in mind the image of how unusual it would be in a traditional biomedical office to find the MD in an Aqua Massage machine in the administrative area of his office).

Dr. Bennett's holism also emerges in how he values and actualizes living a healthy life. He embodies this value through his own careful monitoring of his diet that is rich in fruits, vegetables, lean proteins and supplements. Dr. Bennett focuses on healthy eating and occasionally detoxifies his own body with a more strict supplement and diet regimen. However, from time to time Dr. Bennett deviated from this drive to maintain his body and allowed himself to indulge in moderation in sweets or food from some of his favorite area restaurants such as Famous Dave's BBQ or a soul food restaurant in the city of Detroit.

One of Dr. Bennett's greatest passions is exercise, and he can be described as having an athletic build achieved through running (including marathons), playing basketball or using the weight equipment in the clinic's physical therapy room when he is not busy with patients. His enthusiasm for exercise resulted in personal injury on

80

more than one occasion, and he self-admits to "abusing" his body by pushing himself beyond his physical limits. While Dr. Bennett's injuries are indicative of his drive to push himself to extreme physical limits at times, his injuries also highlight what he does when his own body is not well. He truly believes in the form of integrative medicine that he practices. In other words, he treats his own health issues with a similar approach to what he suggests for his patients. For example, he regularly utilizes massage at the IMPC and the fieldnote excerpt below describes my observations of Dr. Bennett while he was receiving a massage from Roxy, the clinic's full-time massage therapist:

The MD's [Dr. Bennett's] mood is different today...a little more laid back than I'm used to seeing him. However, I soon learned that he had a shoulder injury that was pretty painful. He still joked around [with Roxy] and made light of things, but clearly was in pain....Today [he] is more laid back and quiet (Fieldnotes August 21, 2009).

On most days that I observed Dr. Bennett he was extremely upbeat and humorous, but when he was injured, he appeared more laid back. This change in his mood is reflected in the excerpt from the fieldnote of the observed massage after he had sustained a painful injury the day before that he said almost brought him to "tears." It is experiences like this one that provide a window into the empathy he has with his patients, as he has first-hand knowledge of how pain affects a person's body, mind and overall mood.

As he frequently recommends for his patients, Dr. Bennett also uses prolotherapy when he sustains an injury (see The IMPC's Treatment Options in Appendix E for a full description of this treatment). I will summarize prolotherapy briefly: Dr. Bennett describes prolotherapy as a treatment that heals injured areas of the body with a mixture of a sugar solution with Lidocaine® that he believes is safer than a steroid injection. In the interview excerpt below he explains how he felt that this treatment helped heal his knee injury:

Prolotherapy—phenomenal. Phenomenal. I'm tellin' 'ya, I wouldn't do this if I didn't believe in it....and [I'm] actually like...proof that it helps and works. [I've been] havin' problems from my knee um from running because I run marathons every now and then....I told [the physician's assistant] to inject me, and she injected me twice. Knee pain went away....[I'm] Proof on myself that it works....you know, just stuff like that...just shows me that hey, this stuff...it's not just, you know, made up.

Although Dr. Bennett states that the proof that these therapies work is somewhat "anecdotal" in nature, Dr. Bennett does not use the term "anecdotal" negatively. In part, he thoughtfully chose the conventional and complementary medicine treatment options that the IMPC offers by: 1) trusting how his own body responded to these treatments, and 2) by also not dismissing his patients' accounts of their successes with a variety of non-conventional biomedical treatments.

Dr. Bennett imparts his own holistic beliefs in wellness and living a healthy life to others as he oftentimes offered advice about good eating habits, nutrition, detoxification and exercise with the clinic's staff and patients. Elizabeth, one of the IMPC's massage therapists states:

He [Dr. Bennett], you know—you know he's very active. His exercise regimen is very intense and how he takes care of his body with nutrition and water and all that so as they say, he talks the talk and he walks the walk, you know? And I value that about him too. And he's also, you know he'll talk to us too; the employees and he'll say "You know, what types of things do you like to do for exercise? Or how often have you been able to exer[cise]" so I value that too that he is concerned about other people....It was always promoting, encouraging, supportive of what you wanted to do. And I—I just really like that...about this office, you know? You never feel pressured into doing anything, at least I don't. And, you know, I was happy to work under those terms, you know?

Importantly, she felt that Dr. Bennett is highly supportive of staff members regardless of

whether or not they took his advice about healthy eating, exercise, and detoxification.

As we can see from Elizabeth's statement, helping people move towards wellness and living a healthy life does not entail Dr. Bennett actively pushing his beliefs upon others. Rather, it involves providing the knowledge, support and encouragement to the individual, and leaving the decision up to them whether or not they want to accept this advice and find a way to incorporate it into their lives.

The following excerpt from my fieldnotes provides a glimpse at how Dr. Bennett conveys to others the importance of his holistic beliefs of wellness and living a healthy life. These holistic beliefs include effectively managing stress and Dr. Bennett likely has some significant stressors because of operating a private pain practice such as financial solvency, and coping with the effects of treating pain patients upon his own psychological wellbeing. Both Dr. Bennett and his wife Jasmine believe that life experiences are not inherently stressful, but rather it is an individual's response to these experiences that can make them stressful.

One afternoon early into my fieldwork, Dr. Bennett and Jasmine were talking about the negative effects of a stressful life with me in the clinic's breakroom during the lunch hour. Dr. Bennett was reading <u>Power vs. Force: The Hidden Determinants of Human Behavior</u> by psychiatrist Dr. David R. Hawkins (1995), which was the catalyst for our conversation:

We were talking about stress because he [Dr. Bennett] was reading "Power vs. Force" book and there's a chapter...on the effect of stress on the body and disease etiology. The MD [Dr. Bennett] asked about my stressors and how I handle them. Basically, I said, I don't handle my stress well....The MD [Dr. Bennett] and the practice administrator [Jasmine] explained—while making direct eye contact with me—that it's how you perceive the situation that makes it stressful. We create the stressful situation, they said, and if I decide I'm going to make the dissertation process enjoyable and a fun experience rather than a stressful one that I will handle the situation better. I said all the deadlines and paperwork make it stressful [for me], but the MD [Dr. Bennett] said that

regardless of stress, the deadlines will always be there and that paperwork is just paperwork. I add the stress to those situations they said (Fieldnotes October 29, 2008).

In this situation, Dr. Bennett and Jasmine were using my dissertation experience as an example of how I could take what is commonly perceived as a stressful experience, and make it less stressful by changing my perceptions of the process. Importantly, they were doing so in a non-judgmental way using my real-life situation to exemplify their approach to handing stress, and direct eye contact to emphasize their message.

### JASMINE

Jasmine is a 36 year old Hispanic female, and Dr. Bennett's wife. Jasmine is in charge of the IMPC's business operations as their practice administrator. She represents this role through the way she dresses for her busy lifestyle; oftentimes with her curly, dark brown hair tied back, Jasmine is always neatly dressed in attractive business casual wear, and shoes that are cute but comfortable—a necessity as she is always on the go as a working mom. Jasmine's personality differs from her husband's in notable ways as she minces no words and tends to be more direct. Natalie, a long time IMPC patient who also knows Jasmine, describes her as a "tough cookie" and the force behind Dr. Bennett's success as well as the IMPC's growth over the years. Natalie commented:

I think Jasmine has been a great backbone behind his practice....Well what's more important is when I first started seeing Dr. Bennett, he probably had two rooms like this, a desk, and I think the billing shared the front office. They were very small. We were down the street [in another building]....would I think he had done it himself [expand the clinic]? I think he's still be babying that planter's wart on his foot. I'm not saying he couldn't do it himself, but I think it takes—I think Jasmine has done well....He's got the [medical] knowledge, she's got the gall. She's got the push....She's absolutely wonderful. With the patients...with the doctor, with the staff and I don't think this is gonna stop here. I think it's gonna go farther.

84

As Natalie's statement indicated, not only do Jasmine and Dr. Bennett's personalities complement them as a married couple, but as business partners as well. Natalie feels that each brings something particular to the IMPC—Dr. Bennett has "the [medical] knowledge" and Jasmine "the gall" or this economic savvy—that led to the clinic's growth over the years. Jasmine complements her husband by providing a sense of pragmatism to sustain this dream of the IMPC, and weather the economic storms particularly in this area of the country where many in their patient base lack the insurance coverage for these kinds of needed treatments. It is difficult to creatively contemplate how to get their patients to pay "out of pocket" for these desired services, when many are struggling to pay for their basic costs of living such as housing, food and medicine, but Jasmine views herself and others view her as up to the challenge.

Jasmine did not start out in her career in health care management; she first earned her associate's degree in physical therapy and worked as a physical therapy assistant (PTA). Her motivation to study physical therapy was due to a significant life experience when her brother was severally injured in an accident:

I started to get into physical therapy and health care all together when my brother um actually fell off a porch...and he broke many of his bones and was like in one of those whole body casts....He required a lot of therapy and I was there to support him and come to therapy with him. That's how I got into that. And then I got into [health care] management because there was somebody that came to my PTA class and talked about rather that—rather than going into PT as a getting a bachelors in PT, which they don't even offer anymore, she ended up going into management. That's why I ended up going that route.

Jasmine later continued on in college earning a bachelor and masters degree in Health Services Administration, but has never lost touch with the field of physical therapy. To keep active Jasmine attends continuing education courses for PTA's to keep her skills current and to allow her to serve as a fill-in for the clinic's physical therapy services if needed.

Jasmine worked in health care management in a corporate position at the same large and well known Detroit hospital where husband, Dr. Bennett, was practicing. After she had her children Jasmine decided to become a stay at home mom for awhile. However, Jasmine was central to the realization of Dr. Bennett's dream as he came to see that he could not make the clinic a reality on his own and that their skills complemented each other. Jasmine said that "he wanted the support" from her in the making of the IMPC, and she made the decision to come to work with her husband in building his private practice. She worked full-time at first but now mostly on a part-time basis a few days a week. Jasmine and Dr. Bennett work together cohesively as a team—they generally agree on the overall direction for growing the IMPC, but defer to each other's expertise (his in integrative medicine and hers in business).

Due to Jasmine's background in health care management, she serves as the IMPC's practice administrator that includes duties like handling the clinic's supplies and payroll, as well as marketing. While Dr. Bennett is centrally interested in his role as a healer, Jasmine describes how she is "more focused on the more global direction of the practice. In terms of adding services, strategic planning, looking at...you know, is this something of value to us. Is it something that's making a difference for us?" In thinking about what would be an attractive draw to patients, Jasmine spearheaded the transformation of the clinic's physical space to the more spa-like atmosphere that exists today. Jasmine is always focused on adding to the clinics services that Dr. Bennett and the other practitioners want to be able to provide for their patients (e.g. Dr. Bennett had

the desire to add diagnostic ultrasound to his practice), but with a careful eye towards the cost-benefit ratio. She balances the two to ensure that the clinic provides what she calls "the best quality of care available" with the resources they currently have.<sup>34</sup>

It is likely Jasmine's business savvy has contributed to cutting the clinic's operational costs, but at the same time allowing for expansion of treatment services, even in tough economic times. For example, Dr. Bennett and Jasmine added physical therapy to the clinic's available treatment options in an economic moment where there was a deep recession in the Detroit metropolitan area (where many people were losing their jobs and insurance coverage). For Dr. Bennett as the clinic's "healer in chief," physical therapy was an important option to add to the clinic's services as it fits with his more holistic approach to pain management. Jasmine notes her husband's long-standing desire to offer on-site physical therapy:

he always wanted to have physical therapy as...another option because you can more monitor what kind of therapy they [i.e. the patients] [are] getting because oftentimes people are not getting the quality of care that, you know, could be optimal for them [off-site]. So he wanted to be able to monitor it more and so that's why he wanted to have it here [at the IMPC].

For Jasmine, the practice administrator, she justified the financial investment for a different reason:

one of our biggest [business] strategies is diversification... I think diversification leads to being able to stay, you know, above the rest when times are tough... so while me may be slow in the practice [i.e. Dr. Bennett's services], and [his patient] volume down, physical therapy is up [in volume] and so it kinda helps out in the whole.

According to Jasmine, physical therapy was a high volume service that helped provide a

boost to the clinic financially. Physical therapy is also covered by insurance for many,

<sup>&</sup>lt;sup>34</sup> Diagnostic ultrasound has been added to the clinic's services since the completion of my fieldwork.

but not all, of the patients in this study, which most likely justified their investment as well as its therapeutic benefits.

As more new services and related practitioners were added to the IMPC, Jasmine was very protective of the staff and keeping them employed during recent tough economic times. During one of the staff meetings I attended, for example, Jasmine reassured the staff that she will find ways to continue to cut clinic operating costs to ensure they do not lay anyone off because of ongoing recession.

Jasmine has found some especially creative ways to reduce costs-she "breaks the mold" with innovative thinking in this realm. One of the most notable areas where Jasmine and Dr. Bennett had been saving on operating costs was with the cleaning and laundry services. While most private medical practices hire outside contractors for cleaning and laundry services, all IMPC staff (including Dr. Bennett) are responsible for maintaining the clinic's cleanliness (by doing various chores like vacuuming, dusting, and empting trash) and doing laundry (such as patient gowns and sheets from the massage therapy tables). Jasmine's pragmatism emerged in my observations of her as she saved money by regularly purchasing cleaning and other clinic supplies from a bulk warehouse store and drove them to the clinic herself. In short, it is her practical business savvy that has helped keep their dream of running this clinic alive even in one of the most economically depressed areas of the country. Jasmine is extremely passionate about the IMPC dream and helping others live a more pain free life. Thus, she is highly driven, which is seen through her ability to set and realize goals to help the clinic grow, and she has a willingness to "break the mold" to find innovative economic ways to sustain it.

## ADDING TO THE DREAM

### The IMPC's Culture: The Idea of "Being a Family"

In envisioning his dream, Dr. Bennett consciously strove for the IMPC to have a "family-like" environment for staff and patients. Dr. Bennett desired to create a homey feel for the clinic: "I want people [i.e. patients] to feel really relaxed, calm, okay feel like they're comin' to a place that, you know, is like—like home to them where people are warm and friendly and that sort of thing." Dr. Bennett believes that not only is this kind of culture is important for pain patients to make them comfortable in what is commonly associated as an uncomfortable environment, but it is also vital for their staff so that they feel "happy" working at the IMPC.

However, this family-like culture was a conceptual adjustment for Jasmine when she first began working with her husband at the IMPC, according to Pamela, the clinic's office manager and long-time employee: "She [Jasmine] was used to working at [a Detroit hospital] in the corporate environment and it's like okay, [she said to us that] we need to calm the laughing down [at the IMPC]." Pamela went on to say:

[I felt] we need to be on a first name basis with these patients. When the patients come in and say "don't call me Mrs., I'm Pat", "don't call me Mrs., I'm Marie." They want that. They want that next level relationship with us. They wanna hear us laughing and...we've expanded [that kind of relationship] and we've run with it.

Pamela attributed Jasmine's initial hesitancy to envision a culture that fosters connecting with patients on a more personal level (through laughter and calling patients by their first names) to her previous working experiences in corporate health care management. Jasmine eventually came on board with idea of being a family by recognizing the importance of humor for the clinic's social environment. For example,

when I interviewed Jasmine I noted how the IMPC's "patients mention a lot of times [that] they always hear someone [i.e. staff] kinda laughing and [that] they like that [kind of] environment where it's lighthearted." Jasmine replied to me that while "there's still, you know, work that has to get done...there's no reason you can't have a little talk or humor or laugh in the meantime." Jasmine now embraced this idea of being a family as it fostered a positive environment for recruiting and retaining the right kinds of staff, and having patients also develop a closer, ongoing relationship with the IMPC.

Based on the above, one can readily see why in analyzing the IMPC's culture, I found it most productive to use the metaphor of "family." While anthropologists recognize there are certainly many different kinds of families, for this discussion I am going to draw on some widely known cultural ideas associated with "traditional" family structures in U.S. nuclear families. Along these lines, Dr. Bennett and Jasmine set the tone for the IMPC by emerging as the metaphorical "parents" of this family. They can be conceptualized as the parents who are the ultimate decision-makers.

Symbolizing stereotypical gender roles in this context, Dr. Bennett is the "father" and main authority figure at the IMPC. This role and associated responsibilities and privileges are seen when all the staff refer to him by the title of "doctor" or by his initials "DWB" (Dr. William Bennett) versus calling him by his first name. Even his wife Jasmine refers to him as "Dr. Bennett" when they are around the staff, setting this tone of respect for others to follow. Dr. Bennett is also the leader in designing the IMPC's pain management approach. Another symbol of respect, Dr. Bennett's special parking space in the clinic's lot that other staff members do not park in, is like a father in a family who may have a special chair that other family members do not sit in. Jasmine as the "mother" of this family takes care of the day to day running of the clinic that resembles the day to day running of the family. She makes decisions about "household matters" like family responsibilities such as "chores," how the clinic is decorated, and making purchases of everyday supplies. She is also in charge of the clinic's staff meetings.

Dr. Bennett and Jasmine also can be seen as very parent-like as they are responsible for establishing a reward structure for this family. For example, Dr. Bennett's descriptions of major rewarding activities such as he and Jasmine taking staff out to dinner to show "we care," and even paying for an "office trip" to Florida for fulltime staff to "tell 'em how much we love 'em." These rewards are indicative of not only how they want staff to feel "happy," but it shows how they treat them like members of their own family. Again, treating your employees like "family" to this degree "breaks the mold" for ideas about health care staffing and intra-office relationships.

## Teamwork

As the parents of this metaphorical family, Dr. Bennett and Jasmine set the tone and lead by example by communicating certain expectations that include harmony in their relations with one another and the smooth manner by which the family operates and gets the work done. These communal expectations are often embodied in the "family value" of teamwork that helps sustain the IMPC dream by everyone contributing to keeping the clinic running on a day-to-day basis. This teamwork materialized through problem solving, "cross training," and in carrying out certain chores.

Problem solving emerged during clinic staff meetings. While Jasmine developed the agenda for these meetings and ran them, "family members" weighed in on clinic problems, and decisions made about how to address these problems were collective

91

activities. For example, a problem with clinic operations surfaced when the massage therapists had late afternoon or early evening appointments that were after the close of regular clinic business hours. The massage therapists would finish with treating their patients only to emerge from their rooms to find they were left alone in the clinic with their patients at night. To increase their safety, it was collectively decided that adjusting the work schedules for some of the other staff would ensure that someone would always be able to stay late with the massage therapists to accommodate these later appointment times.

In another example of teamwork, several IMPC staff are "cross trained." For example, if Joan, the medical assistant is out sick, other staff members are trained to run the reception desk in her absence. Jasmine is a trained PTA, making her qualified to fill-in for Jennifer, the clinic's PTA if needed. Pamela, the office manager and Roxy, the clinic's full-time massage therapist are trained to use the ultrasound machine to help out Jennifer with her physical therapy patients if she is running behind. As Dr. Bennett notes, "everyone's covering each other...coverin' their back[s]" so the clinic runs smoothly.

Teamwork also included sharing in certain "chores." These "chores" include, for example, vacuuming treatment rooms and all public spaces (e.g. the waiting room), wiping down windows, cleaning the bathroom and stocking its paper products, dusting, cleaning treatment room equipment, laundry, washing dishes in the breakroom kitchen, emptying trash cans, and tidying the waiting room. Importantly, Dr. Bennett and Jasmine share in doing these "chores" with their family members as Jasmine noted below: there's no one person that can have the mentality "that's not my job." You know, you'll see Dr. [Bennett] throwing out the garbage and vacuuming just as well as you'll see me or anybody else...it's important that we all work together cohesively...respecting that you're no better than I am.

Roxy's statement below illustrates how the IMPC "family members" appreciate the

respect conveyed by Dr. Bennett and Jasmine when they share in these chores:

And I'll tell you what, Jasmine and Dr. Bennett, they're the first people I've ever met that honestly will not ask you to do something that they're not willing to do. And I've seen them do it a million times, which is nice. Because even though he's the doctor he doesn't treat you as if you're underneath them and you're less [of a person].

On my very first day of fieldwork I arrived at the clinic to find Dr. Bennett cleaning the outside windows and the glass partition at the reception desk using an all natural window cleaner. I noted my surprise at seeing him cleaning with the following commentary I included in my fieldnotes: "How many M.D.'s do you see cleaning their own offices? This gave me an early idea about the kind of person the M.D. is and how he cares about his practice" (Fieldnotes September 15, 2008).

Interestingly, these "chores" were not stereotypically gender specific (e.g. where only the female staff cleaned while Dr. Bennett, as the only full-time male staff member, made repairs). While I did observe Dr. Bennett making repairs to the clinic like replacing burned out lights outside or water damaged ceiling tiles, it was common to see Roxy, the clinic's full-time massage therapist, carrying her drill or other tools around the clinic to install coat hooks, hang pictures and install the display case in the waiting room.<sup>35</sup>

<sup>&</sup>lt;sup>35</sup> I assisted Roxy with the installation of this display case, which was no easy task given its weight and size! After our initial attempt to anchor it into the wall, the entire display case fell out of the wall and into my hand when the clinic's drywall was unable to support its weight. Roxy moved it down the wall a few feet and anchored the case into a stud with longer screws, which solved the problem.

While the completion of these chores was usually done so in a timely manner, it was not always a perfect system. I noted one instance where "family members" had to remind Dr. Bennett that one of his chores needed to be done. This chore was first brought to light during the November 2008 staff meeting, as indicated in my following fieldnote:

Another issue [brought up by staff] is the lighting situation outside. Light burned out outside and now that daylight savings is over, it's dark on the one side of the parking lot when the massage therapists leave the building, sometimes a few hours after the MD [Dr. Bennett] is done with patients (Fieldnotes November 14, 2008).

The massage therapists were concerned for their safety when leaving the building at

night and entering a darkened parking lot. Making minor building repairs fell under Dr.

Bennett's list of "chores," and a few days after the staff meeting, he had yet to replace

the burned out light in the clinic's parking lot.

I made the following observation in the clinic a few days after this staff meeting,

where an unsigned reminder note was left for Dr. Bennett:

I noticed on one of the exam room doors, in the MD's side of the office, a sign that had "DWB" [Dr. Bennett's initials] written in pen and underneath in big black letters "outside lights, what's up?" Then in pen it was written "status check". The sign was taped to the exam room door at eye level, and when the MD went to go inside the room to see a patient, he noticed the sign and read the words out loud. The sign was taped to the door with scotch tape and at a slight angle. This is in reference to the issue brought up at the staff meeting how, now that daylight savings is over and it's dark much earlier, one of the lights outside in the parking lot is burned out making the lot very dark and unsafe for the massage therapists and their clients to leave if they have late appointments (Fieldnotes November 19, 2008).

Given Dr. Bennett's authoritative role, I interpreted the anonymous nature of this note as

a way for staff member(s) to deal with this yet unresolved issue in a more non-

confrontational way as it obviously was not a minor issue for them. Yet, given that this

note was taped at eye level and at an angle on the exam room door to ensure Dr. Bennett would see it, this note also served as a somewhat firm reminder for him that he had yet to complete this chore. Dr. Bennett noticed the note right away as he stopped short just before going into the exam room to see a patient. However, he appeared to take the note in stride as he stood in the hallway and read the note out loud to himself.

Despite this note, I observed that the repair was not made to the light until November 26<sup>th</sup>, which was the day before Thanksgiving and a very quiet day in the clinic as there were few patients. Dr. Bennett was in a jovial mood on this day as he went about utilizing his "down time" to clean the equipment in one of the exam rooms while occasionally whistling. When he finished cleaning this equipment, Dr. Bennett asked Joan for something he could stand on so he could reach the outside light to make the needed repair.

In this particular occurrence, Dr. Bennett was not too timely in the completion of this particular chore as it was 12 days from the issue first being discussed at the staff meeting to the actual repair to the light. We can speculate that although Dr. Bennett got his chore done, he did so in his timeframe. How the staff negotiated making this repair happen highlights the power relationships at the IMPC. We can speculate that perhaps anonymous nature of the note is indicative of how everyone stayed within their "appropriate" roles, respecting that Dr. Bennett is the lead authority figure. Perhaps Dr. Bennett's felt that his role as this lead authority figure granted him the privilege of delaying some of the more time consuming chores such as building repairs until he had such "down time."

However, my observations of clinic staff indicated that this teamwork system functioned well for the most part, and was essential in how the IMPC represented itself to outsiders. If this teamwork system broke down (e.g. not working together to keep the clinic clean), it would reflect negatively upon Dr. Bennett as he and everyone else in "the family" see him as the "founder" of the IMPC. Dr. Bennett said:

everyone working here...they're a representation of me. When they [i.e. patients] come to the front desk, when you see the biller, when you see a massage therapist, when you see anyone around here, they're a representation of me. Okay. And how that's a representation of me is because when I actually do the hiring, okay, I've chosen that person to be here, okay. And so if I chose a bad person to be here, then I'd chose people to see a bad person. All right? If the waiting room [is] dirty [because it was not cleaned], then that's a representation of me.

Dr. Bennett believed that "one person can actually destroy the whole group" so if "a bad person" is brought into the family it reflected poorly upon Dr. Bennett's role as this leader, and casted doubt on his abilities if he cannot effectively manage the clinic setting. In my conversations with him, Dr. Bennett alluded to a "bad person" as someone who is not a team-player (i.e. not willing to help maintain the clinic's day-today operations). Although teamwork was essential to sustaining the IMPC dream, there were moments of tension among the staff as we will see next.

### "Growing Pains"

Typically, I observed "the family" functioning cohesively. However, Roxy noted that there were "growing pains" because so many new individuals came together for the first time after the clinic expanded to offer more services. Elizabeth too acknowledged how there are these moments of tension:

And even when we have had differences—and there's been a few times that, you know, I've been upset about something or somebody else has been upset about something but we usually manage to work it out. You know it's not a grudge

thing or that we carry on, you know we try to find humor in it or resolve it, you know, and when you figure you've got that many different personalities here, you're bound to have differences of opinion on how things—or even, you know, just different phases of our life. Like, you know, I just turned 61 and I think Jennifer [the IMPC's PTA] is twenty something, 25 or 26....So, you know, she's in a different place in her life than I am. But, you know, we—we find common denominators and—and that's great. You know it's really great.

Importantly, Elizabeth noted how the staff try to work out their differences mostly among themselves and not to hold grudges against one another.

Roxy and Elizabeth, two massage therapists, have very different personalities, are almost 30 years apart in age, and have some differing views about how they practiced. Yet they tried to find a "common denominator" by sharing their knowledge about different massage therapy techniques with each other. However, as happens in families, one person was doing something that someone else found problematic. The issue dealt with climate control on the "therapy side" that has its own thermostat that regulated the temperature in the physical therapy and all the massage therapy rooms. Tension arose as Roxy preferred to have her room much cooler when she worked as the rooms can get quite warm with manual body therapy taking place. She used the air conditioning when it was cold outside to lower the room temperature.<sup>36</sup> However, Elizabeth preferred to have her room much warmer as some of her clients were elderly and very sensitive to cooler temperatures. In a staff meeting in November, Roxy admitted she had been the one responsible for using the air conditioning in the cooler, fall weather. The issue was resolved by communally agreeing at a staff (i.e. "family") meeting to prohibit the use of the air conditioning until the following spring.

<sup>&</sup>lt;sup>36</sup> While Roxy preferred a cooler room to work, she always made sure patients were warm during the massage by using blankets and a heating pad on her massage table.

Keeping conflicts at a minimum was a cultural prioritized value at the IMPC. Dr. Bennett expressed that he wants his staff to be happy to reduce the likelihood of staff turnover: "when...everybody's happy there's less turnover. Like I don't have a lot of turnover with...people [i.e. staff]. Employees come in, employees leavin'. None of that stuff." <sup>37</sup> Jasmine also echoed their strong wish for employees who will stay long-term and act like clinic "family:" "You know, when we get people we...want them to stay. We expect them to stay. But if...they're not doin' a good job obviously they're not going to but that's our expectation—that we want somebody that's gonna stick around." A constant flux of employees would make it difficult to maintain this particular culture that relies on stability to find people who buy into, and have the passion for the IMPC and its "family" concept that is necessary to help "sustain this dream."

## **Creating the "Family:" The Hiring Process**

It is important to point out that Dr. Bennett and Jasmine focused on their hiring practices a lot during their interviews with me. To promote hiring people who fit into this culture and ensure minimal turnover, Dr. Bennett and Jasmine both described a rigorous process they engage in when hiring the clinic's staff. Although the overarching culture is meant to be warm, relaxed and home-like, Dr. Bennett and Jasmine have exacting and specific expectations for the individuals they hire. They do not want someone who does not fit into the IMPC or meet their standards. Jasmine noted: "We hire people that we know will fit...into that culture" and they are highly selective "because you don't wanna mess with that culture that you have," she said. A review of resumes as well as initial phone interviews with candidates takes place before upwards of 20-25 potential candidates are interviewed in-person for each position, which is

<sup>&</sup>lt;sup>37</sup> There was no staff turnover during my fieldwork period.

noteworthy in a small practice such as this one with only 12 employees. The in-person interviews are lengthy (about an hour) and as Jasmine noted: "I interview people very aggressively" for the position. At times she and Dr. Bennett utilize "a working interview where the person comes and tries out the job" to see if the candidate is what they refer to as "the right person" for that position. Jasmine noted that when she was hiring for the physical therapist position, she had one potential candidate characterize their pain management approach as "quackery" when she spoke to them on the phone. As one can guess, that individual was not brought in for an in-person interview.

When fitting into the IMPC family, an individual's personality is key in addition to their own orientation to the IMPC's pain management approach. Dr. Bennett described how a having a complementary personality is what he and Jasmine look for in individuals they are interviewing: "there's a click [when interviewing] that occurs and you say 'Ah, that's the right person' because they kinda fit the same, you know, the personality and things like that." I interpreted Dr. Bennett's statement to mean that the individual he and Jasmine hire must already embody the core values that they associate with the IMPC's culture. From my participant-observation, I interpreted these core cultural values to be a strong sense of optimism, passion, and a willingness to engage with the stance of "breaking the mold." I will introduce these core cultural values next, and in later chapters show how they play a role in patient's treatments.

#### Optimism

Dr. Bennett is inherently optimistic and since he is the "founder" of the clinic, it is not surprising that they would want this value to be embodied by those hired to work in this specialty pain clinic. Dr. Bennett is almost always in a cheerful mood, and his "can

99

do" attitude is likely why in part he has developed a reputation as a healer who can help in "difficult" pain cases. For example, rather than Dr. Bennett seeing his earlier hospital layoff as a negative life event, he utilized it as a motivating factor to venture into private practice full-time, and to begin the process of opening his own stand-alone integrative pain clinic. Key to remaining optimistic is Dr. Bennett's use of humor as he loved joking around with his family and patients. Elizabeth noted how Dr. Bennett "sets the tone" for this use of humor at the IMPC by allowing staff to tease him as well. Laughter was a frequent occurrence at the IMPC, which fostered this cheerful mood and helped mediate conflicts among staff. As we will learn in later chapters, humor also is an aspect of how the IMPC staff approaches managing pain as they believe it helps in the patient's healing process.

#### Passion

Both Dr. Bennett and Jasmine exhibit great passion to help others as seen through their chosen careers and professional development. Their passion is also evident in their combined drive to make the IMPC dream a reality. We also saw Dr. Bennett's passion emerge, for example, in his personal beliefs about wellness and living a healthy life. It also emerged in the compassion and empathy he has for his patients as he actually listens to and is willing to learn from them (such as the surgery patients who turned to acupuncture for relief). Jasmine's passion can be seen in her efforts to keep the clinic going and growing even in the economic downturn when many businesses in the area "went under."

# A Willingness to Break the Mold

Importantly, Dr. Bennett and Jasmine have a willingness to "break the mold" that

100

is evident in their innovativeness; his in having a dream to create a certain kind of clinic based on a more holistic approach to pain management (that will be detailed in the next chapter) and hers in the creative ways she employs to actualize and sustain this dream. They also break the mold by creating an atypical culture for their staff and patients. Dr. Bennett and Jasmine envisioned a different kind of medical practice with a "family-like" culture, which they foster through a teamwork approach to the clinic's day-to-day operations that helps sustain this dream.

#### The IMPC Staff

I will now introduce the members of the IMPC staff or "family." I will discuss who the various staff are and what they do, and provide examples of how they embody various aspects of the above-mentioned IMPC culturally prioritized core values that Dr. Bennett and Jasmine desire. While Dr. Bennett and Jasmine look for those hired to already to embody these core cultural values, as we will soon see, their culture allows for considerable variation in terms of *how* those hired go about enacting these core values.

At the time of my research the clinic staff hired by Dr. Bennett and Jasmine ranged widely in age from mid-20's to early 60's, were mostly female and white except for Michael, the IMPC's physical therapist, who was an African American male. They can be divided into two distinct groups: the administrative staff that I will discuss next that the patients oftentimes first interact with, and the practitioners who provide the specific treatment modalities.

## The Administrative Staff

The administrative staff is responsible for the IMPC's business operations that

include, for example, all the non-treatment related aspects of patient care such as scheduling, billing and insurance reimbursements, and checking patients in when they arrive for their appointments that involves checking vital signs and verifying insurance. The administrative staff is comprised of three individuals: Joan, the medical assistant; Pamela, the office manager; and Nicole, the medical biller. Joan's story of becoming an IMPC employee is presented first as she is oftentimes the first person patients interact with when they arrive at the clinic.

Joan is the spunky, petite, 36 year old medical assistant. Her blond, shoulderlength hair frames her face, and she almost always wears her smart-looking eyeglasses over her contact lenses. On a daily basis, she wears more relaxed fit solid-colored scrubs (and at times a long-sleeved, printed scrub-type jacket over her top to stay warm) and comfortable athletic shoes (a must given the busy nature of her job). She is highly organized and a skilled multitasker as she is oftentimes pulled in multiple directions at once given her particular job duties. She is a long-time employee of the IMPC and began working at the clinic when it opened its doors in August, 2003. Dr. Bennett was looking to hire someone for the IMPC's reception desk, and learned about Joan from the office manager at the medical office where she had been working. Dr. Bennett approached Joan directly about the position:

Dr. [Bennett] actually called me at home and set up the interview for that afternoon, and I just, the energy and values that they have really were exactly what I was looking for. 'Cause it wasn't the cold [im]personal "I am the doctor, you are the employee." You know no God complex. No, you no, no ego involved, you know? Makes a big, big difference.

Joan was immediately drawn to his warm personality that stands in contrast to what she describes as the "cold," egotistical physician stereotype.

102

Joan has a large set of diverse work tasks. A patient's first impression of the clinic oftentimes rests on Joan's shoulders. Joan has an incredible memory where she generally remembers patients' names before they have the chance to sign-in for their appointments. Her ability to remember a patient's name (and calling most of them by their first names) had a favorable impression on many of the patients I spoke to, which fosters this sense of "family." In addition to welcoming patients to the IMPC, Joan's responsibilities also include verifying patient's insurance policies, escorting patients to Dr. Bennett's treatment rooms and recording patient vital signs, handling patient intake as well as patient discharge, and answering the phone. Joan also handles the entire clinic schedule that includes patient appointments and the personal schedule for Dr. Bennett.

While the multiple requirements of Joan's job are highly stressful, it appears she mediates this stress through her positive attitude and great sense of sarcastic humor. Joan can oftentimes be heard bantering with Dr. Bennett and the other clinic staff. On many occasions I had the opportunity to experience firsthand her sarcastic sense of humor. There was a running joke between Joan and me throughout the course of my fieldwork where in order for me to access the medical side of the clinic, Joan had to get up from the reception desk and open the locked door. Many times she would tell me with a straight face that I had to jump through the window at the reception desk (that was a few feet off the floor) if I wanted to gain access! Also, the passion Joan has for her job is evident in her statement below:

I like people [i.e. the patients] to know that it makes a difference that they're here. And that hopefully we make a difference to them that they're here, and that they don't walk into an environment where you can feel tension, and you can tell that people [i.e. the staff] don't like each other or that the doctors treat their staff

103

badly. 'Cause you can tell when you walk into an office where people are unhappy. 'Cause they don't care whether—about the patient. You know and I think this office has demonstrated, as you've probably seen, we care about our patients. You know—you know we treat them as patients, but at the same time they come in here and it's almost like "Okay I'm in pain. It's terrible, but I know I'm gonna get a smile—somebody's gonna make me smile. Somebody's gonna, you know, really care whether my day is going well or not." You know there's compassion and again, just—even with the doctors I go to personally, it's like wow. It's very different.

Joan notes how the IMPC environment is "different" from what a patient may find at

other medical practices because she and the rest of the staff want patients to feel like

they are cared about; she wants to "get a smile" from the patient. Her position at the

IMPC's reception desk is the ideal spot for her to try to make this "difference" as she

goes the extra mile to remember patient's names as they walk through the door.

In addition to Joan's goal to make a "difference" for patients when they arrive at

the IMPC, she helps promote the IMPC "outside work time" because of her strong

personal endorsement of the clinic's particular pain management approach that she

feels sets the IMPC apart:

In fact my boyfriend's, you know, family—his mom and his sister come here. My dad has come here. My stepson has been here. You know so anybody that I see that it's like "Oh well at least come in and give it a try." You know even at my own doctor's office I've taken in referral pads and—'cause they seem to have been interested in, you know, the different care that Dr. Bennett offers. Especially the primary cares [i.e. primary care physicians] don't want to deal with the medication aspect, you know? They like that, you know, we're [i.e. the IMPC] kind of one stop. You know we can do physical therapy and massage therapy, the acupuncture, you know it's all kind of contained, which does make a difference for patients if you don't have to run around all over town to get things that you need.

Not only does Joan recommend the clinic's approach to her family, and at her own primary care doctor's office, she also regularly volunteers to sit at health expos to promote the IMPC. In addition, Joan carries Dr. Bennett's business cards with her on a regular basis to hand out if the moment arises.

Pamela is the IMPC's boisterous and outgoing office manager who describes herself as "friendly" and "loud." Around her mid-30's with long, wavy dark brown hair that cascades over her shoulders, on most days, Pamela can be seen in relaxed-fit, solid colored scrubs, but time to time varies from this look and opts for fashionable, business casual wear. Pamela began working for Dr. Bennett when he shared the first Waterview location with his partner, and moved with him when he opened the IMPC. Pamela was drawn to Dr. Bennett and his partner because she felt "a feeling of mutual respect, and fun, and ease" emanating from them that she felt fit well with her personality. However, Pamela had some hesitations about accepting the position because of the hours involved, and it was Jasmine that convinced her to try the job. Pamela states:

I wasn't going to take this job. I wasn't going to because of the hours and Jasmine said 'Pamela could you just come on [board] and try it and see how it works and...you know the communication...and we just meshed...we just blended....I went ahead and agreed to start at part-time, and...seven years later here I am!

Pamela's story, like Joan's, exemplified Dr. Bennett and Jasmine's determination in not only finding "the right person," but once they see the core values they desire in an individual, they want to ensure over the long-term that steps are taken to see that they are happy in their jobs and stay on at the IMPC. Pamela has held many responsibilities at the clinic and considers herself "the all around person." She handles many administrative aspects including credentialing, some medical billing, and office notation and handling duties at the reception desk when Joan is out of the office. Pamela is almost always in a cheerful mood as often heard through her infectious laugh that carries throughout the entire clinic. Pamela has a strong work ethic where she dedicates herself not only to her job, but also to the emotional connection she makes with the IMPC's patients. Patients are more than just patients as she gets to know many of them personally as some "become [like] family" she said. Pamela does not believe in "having that cold shoulder with the patients" and describes how she gets very close to some of them:

I get very personal....there's certain patients we all connect with and we...listen to their stories, we have their numbers and we talk to them outside of the office and, you know, we kind of counsel them on some level. But we, you know, we...have those friendships with them, and those people a lot of that stems from those situations where...you know, they come to us they're in tears and they're comfortable enough with us to...show and shed their tears.

Pamela's words indicate how forming a more personal relationship with patients is just as important to their care at the IMPC as the specific therapeutic treatments they receive.

An example of Pamela's enthusiasm to help the IMPC's patients, as well as sustain the IMPC financially, emerges in the medical billing aspect of patient care. When I was discussing issues of insurance reimbursement with her she described how "we will fight tooth and nail to try to get things [i.e. treatments] covered" for their patients. She described one case in particular:

we had one of our patients...I mean she was classic textbook case for Botox® injections,<sup>38</sup> and her insurance refused to give us authorization....So, you know, she finally went on ahead and she paid cash for the visit and...by by whatever chance we billed it out anyway and it was paid. They went on ahead and paid it but...I mean it was just awful [what the patient experienced], but we're willing to go and continue to write these letters and repeatedly write these letters—[telling

<sup>&</sup>lt;sup>38</sup> Botox® injections are helpful in treating muscle spasms. Botox® injections as part of the IMPC's available treatments are detailed in Appendix E.

the insurance companies] look they need this [treatment]. This [treatment] is going to help.

This particular case illustrated where fighting with an insurance company worked in the patient's favor. Pamela also described how the IMPC staff goes above and beyond their normal duties by advocating for their patients through writing numerous letters to insurance companies to have their treatments covered.

Nicole is the even-tempered and highly organized medical biller, with short, light sandy-brown hair. Around her mid-30's, she opts for stylish scrubs as her daily wear; solid colored scrub pants, with brightly colored and printed scrub tops that are slightly fitted to her tall frame. Nicole came to the clinic in August 2008, so she was a new addition to the staff when I started my fieldwork. Nicole's duties as medical biller are essential to sustaining the IMPC by not only helping patients get the coverage they need for their treatments, but by getting the IMPC what it needs as well to flourish. At staff meetings, Nicole consistently provided Dr. Bennett and Jasmine a detailed financial picture by preparing reports on insurance reimbursements and claims, and year end totals. Nicole proudly presented these detailed financial reports at these meetings, and one time had even created a detailed pie chart to illustrate what appeared to be the clinic's ratio of settled versus unsettled insurance claims (Fieldnotes July 17, 2009). Most of this chart (that Dr. Bennett likened to "Pak Man" during the meeting) was comprised of these settled insurance claims, which elated the staff (Fieldnotes July 17, 2009).

Nicole noted the positive environment at the IMPC where staff are happy and often laughing. Nicole greatly values family, so working at the IMPC was an ideal fit as

107

it allowed her to work in close proximity to her own family, and also have a "work

family:"

they all care about you and...our happy [happiness], you know you're a part of their [Dr. Bennett and Jasmine's] work family....I mean...I don't get up in the mornings going "Ohhh" [I have to go to work], you know, I like comin' to work. It's fun. We have a lot of fun. I mean we get our work done, but we have...a lot of laughs. I mean we—we laugh like every day.

In addition to being drawn to the clinic's family-like culture, she was drawn to the clinic's

more holistic approach to managing pain:

And I was really excited...when I found this job because...he [Dr. Bennett] has that holistic...you know, part of the whole practice....I just felt well that personality wise for me that was just a really good fit....I mean when I just looked at his website I'm like..."this is where I need to work!"

Nicole most likely felt that her personality fit with the clinic's culture as she shared an open-mindedness to non-traditional methods of pain management, which most likely stems from her personal experiences with "really severe…back issues."

When chiropractic care and what Nicole described as "the traditional route" (e.g. physical therapy and x-rays) did not give her an answer for her back pain, she sought the help of another chiropractor that specialized in kinesiology. Nicole understands first-hand what it is like for an insurance company not to pay for treatment as her provider would not cover the kinesiology therapy. She decided to pay out of pocket for her treatments with this kinesiologist, and now considers herself "cured." Nicole feels that insurance companies are not open-minded enough about what she calls "alternatives," which in her case cost them more money: "the insurance company paid a lot more out [for physical therapy and x-rays] than if they would've opened up their eyes to...other alternatives [like kinesiology]." Nicole's personal experiences of paying out of pocket when "traditional" methods of pain relief were unsuccessful most likely contributed to

her passion to help the IMPC's patients as she can emphasize with them on a more personal level.

Nicole has the least amount of direct contact with the IMPC's patients; however her desire for helping them emerges as she still connects with them on a personal level in another way:

I mean like 'cause I—for those auto or work injuries I'm submitting like the...chart documentation with each [insurance] claim so I—I kinda read through 'em sometimes....I'm like reading through some patients, you know, histories sometimes and...it's surprising...some of this chronic pain it's obviously—I mean it affects their lives tremendously... these people with chronic pain you can see they're not currently working. Or they're currently seeking out disability or, you know. So it—it gets me curious as to, you know, like on medical aspects like—what—okay what is going on with these patients to have this chronic like condition, you know, so....it's interesting for me to...to keep up with some of these patients.

While Joan connects with patients by getting to know them on a first-name basis, and Pamela listens to the personal stories of some of the IMPC's patients, Nicole reads some of the IMPC's patient histories while processing their auto or work insurance claims as a way to connect on this more personal level. She then closely follows the claim process for these patients as her way of showing compassion for them and the disruption to life they have experienced. I will now describe the IMPC's practitioners below. Examples of how they enact the clinic's treatment approach will be further detailed in the next chapter.

# The Practitioners

In addition to Dr. Bennett, the clinic's practitioners who participated in this study include Roxy, the clinic's full-time massage therapist, Elizabeth and Erica, the clinic's two contracted massage therapists, and the physical therapy team comprised of Michael, the physical therapist and Jennifer the physical therapy assistant. I will begin with Roxy whom I observed most frequently and developed a strong rapport. Roxy is the clinic's full-time massage therapist who is in her early-30's, has short-cropped red hair and a big, outgoing personality. She wears fashionable scrubs; solid color pants with colorful and cheery-looking printed short-sleeved scrub tops that frame her strong, powerful arms she developed from spending seven years at her profession. Roxy's specialty is Swedish massage, but her dedication to her work is evident as she took well beyond the required 500 hours in school so she could acquire knowledge in many different massage modalities (e.g. Thai massage, Polarity, reflexology, hot stone, Shiatsu, aromatherapy) so she can incorporate them (and often does) in her Swedish massages.

Roxy is very positive and strongly believes in fate that things will work out as they are meant to, which makes a sense of calm emanate from her. This power of fate emerged in Roxy's story of how she came to work at the IMPC as she feels she was in just the right place at the right time when she needed work:

honestly I feel that somehow the universe just made it happen. I had just moved home from [another state]....My sister and I jumped on [the busy Waterview thoroughfare]; we had to go to the hardware store and I noticed the [IMPC's] sign and I noticed the building seemed new. I didn't remember it being there. I immediately called, and I needed a job, and I'd been home for four days. And it just so happens they were hiring and I ended up having a job within seven days of being home.

Roxy also believes that fate led her to work specifically in the field of pain management:

it wasn't that I was looking for a pain clinic per say [to work at]....'Cause I've worked in physical therapy, I've worked in spas, I've worked for myself, I've done it all. Seen all ends of it. Now to be honest with you, I love, love the atmosphere here...[at the IMPC] because you actually feel like you're making a difference. It's—I joke around—a lot of massage people joke around and call 'em fluff and buffs, the ones [i.e. massages] that are done at the spa, and we actually have to use our minds [here], you know, what can we do for this specific person and their situation. So each massage is totally different. And that's what makes it fun. So

I love being in a pain clinic because then you really are put to the test. So you individualize each case.

While Roxy has done massage therapy in a variety of different work environments like

spas and in physical therapy settings, she enjoys the IMPC's atmosphere because she

uses her skills in new ways.

While Roxy says she loves working in a pain clinic, maintaining a positive attitude

can be difficult in such a setting as she notes below:

the patients—the main thing is is when they walk in the door, they're in pain. This is a pain clinic. So you [the practitioner] have 'ta understand that and be, you know, very in tune with that. They [the patient] don't have time to play around with somebody having a bad day, you know, and they're [the practitioner] in a bad mood therefore they're not gonna take as good care of the patient. You have to leave that at the door. So it's just nice that we all—we pay attention to that too.

Roxy describes below the steps the IMPC staff take to maintain a positive environment

by talking with each other and joking:

our main goal is to make sure they feel better and they are taken care of, the patient. But at the same time we [the staff] also joke with each other, and it's a family environment....I can usually see it in some—one of our co-workers eyes if there's a problem or if they're upset and they—same with them [they can see in my eyes if I have a problem]. I'll be [like], you know, "I'm fine, everything's okay" and they're like "No it's not. Take five minutes and sit down and tell me what's wrong." So it's just so nice to know that you're coming into an area where everybody actually—it's my family away from my family.

If one of the staff experienced a personal crisis during my fieldwork such as the death of

a close family member (as did Joan) or a family member experienced a serious illness

(as did Roxy), everyone rallies together to provide emotional support and maintain this

positive environment.

Roxy has a sometimes sarcastic, but always hilarious sense of humor. For example, she introduced me one time to her patient as the IMPC's own garden "gnome"

that they rub for good luck (a title I assumed that she bestowed upon me given that much like a garden gnome—I had become a fixture at the clinic)! Building off the joke, the following day when Roxy introduced me to her sister who was visiting the clinic, I jumped in and introduced myself as the "resident garden gnome" that caused Roxy to erupt into laughter. Roxy's laughter, much like Pamela's, could often be heard throughout the clinic that greatly contributed to the positive atmosphere at the IMPC. Roxy was always open to a good joke (and even poking fun at herself).

Roxy noted how she is "very proud of what I do," and from my observations this pride emanates from her when she works with the IMPC's patients. Roxy's enthusiasm for the field of massage therapy came from her own life circumstances after she witnessed first-hand the healing power of human touch:

my eight year old had heart surgery when he was three months old and...I noticed that with him touch seemed to help. I didn't know anything about it, I just knew that I couldn't pick him up, I couldn't do anything because he was on all these tubes and vents so I just placed my hand on his foot or on his-on his hand and I talked softly and I-I would watch the monitors 'an he knew I was there....And then eight months later, my husband...he went into a coma, and was in a coma for six weeks and almost died from acute pancreatitis. And he actually came through it, and it was physical therapy and massage therapy that brought him back. They say that for every day that you're down, it takes a week for your body to recover....it should have taken him at least six months to recover from this. And within two and a half months he was back to riding his Harley, and doing things that they [i.e. the doctors] never expected....And he had lost sixty pounds just from being in a coma and it was just-it was a nightmare. And as soon as he recovered, I immediately signed up for school and was in school that fall. So that's what-I would have never in a million years thought I'd be a massage therapist. And usually a lot of massage therapists you'll talk to them and most of the time there's something significant in their life that happens that puts them into that field. Or at least the ones [like me] who stay in it for so long.

It was witnessing her own close family members' recoveries from severe illnesses that

led her to enroll in massage therapy school and she never looked back to her previous

career as an administrative assistant.

Elizabeth, the joyful and soft-spoken contracted massage therapist, is 61 years old but looks much younger than her age. She has chin-length, light brown hair and oftentimes wears khaki pants, sensible shoes, and the more traditional-looking, relaxed fit solid-color scrub top. Despite her part-time status, I did interact with her frequently. Elizabeth entered the health care field by becoming a nurse (as a Licensed Practical Nurse or LPN and then as a Registered Nurse or RN when she completed her bachelor's degree in nursing), and specialized in "postpartum" and "mother-baby" care. She still conducts "community education" programs through Detroit area hospitals in areas of child care such as breast feeding and birthing classes. After working as an RN in this capacity for over ten years, she decided to add massage therapy to her health care background. Elizabeth attended a 500 hour program during the year 2001 of what she described as "basic" training that covered a variety of types of massage including Swedish, trigger point, infant, and sports massage. She also completed two levels of Reiki training, and at the time of my research, Elizabeth also developed a great interest in oncology and entered a specialized program to learn oncology massage. Later on in my research, she also began working for a hospice program providing massage to patients at end-of-life.

Elizabeth worked in an "integrative therapy center" at a small suburban hospital in the Detroit area as a massage therapist prior to coming to the IMPC. When a larger hospital system took over this smaller hospital, Elizabeth did not like the changes that ensued at this center that went against her belief in putting the patient first:

my philosophy of...I was more oriented to the individual...we always had bottled water [available for our patients and I was told], "nope, can't do that." Sometimes I'd make it [i.e. the massage] an hour and 15 minutes if that person had trouble getting on or off the table, [I was told] "Nope. They've gotta be...50 minutes. Get

them in, get them out, get it over with," you know?...And I said I understand you're a business and...they [hospital system administrators]... sat me down and said "If you don't make money, we don't make money."...But my holistic thinking, you know, it just was—the edicts were different.

Elizabeth felt the needs of the individual patient were going to be sacrificed because of the hospital's financial bottom line, and the prospect of making such changes in how she cared for her patients made her uncomfortable. Elizabeth also hoped to be able to visit patients admitted to the hospital to provide massage but this prospect diminished leading Elizabeth to tell the hospital system administrators "I'm not feeling comfortable with this so I'm not going to renew my contract."

When Elizabeth decided to leave the hospital integrative medicine center, she had heard that Dr. Bennett was expanding the IMPC's building that would include additional massage rooms. She applied for a massage therapist position, and was hired. Elizabeth described why she believed staff members were drawn to work at the IMPC:

I think the people that they've [i.e. Dr. Bennett and Jasmine] hired have the same vision [for the IMPC] and it is wonderful and...his mission, I think he [i.e. Dr. Bennett] makes that clear and I think for the most part that everybody does feel that way, you know, as he does. And I see people doing things over and above, you know? Which is really nice so there is that collaborative team over and above the work that you're doing, [and] you're also [made to] feel like you contribute [to the clinic]...[for example] problem solving like of somethin' needs to be hung up, Roxy will bring her drill or...I've brought things in 'cause I thought they'd be helpful or appropriate. Same thing with Erica, you know? So those are the kinda people that he's hired. They're not just here to do a job and leave, you know?

Importantly, Elizabeth feels that she and the rest of the staff do not conceptualize their

employment at the clinic as just "a job," but instead feel they are contributing to Dr.

Bennett's vision for the IMPC.

In addition to Elizabeth being drawn to a work environment where she felt she was doing more than just "a job," she also found a sense of professional autonomy with her work:

I really value the [professional] autonomy. It's, you know, the structure here is very flexible in terms of treatment modality so if I wanted to do deep tissue [massage] because I felt the patient needed it...I don't have to consult with Dr. Bennett necessarily....And I like the fact that he treats us like professionals. He doesn't give us a prescribed "You have to do this, you better do that" kinda thing....he really trusts our professional judgment and—and he values our input too. And I thought that was a really good thing. I really like working under those circumstances, you know?

One area where Elizabeth enjoyed her professional autonomy was with going over the clinic's allotted time limit for massage appointments if she felt the extra time was necessary for her patients. Elizabeth like that at the IMPC she did not have to adhere to "a fixed" schedule like she encountered in the hospital setting where she previously worked.

Elizabeth had such zeal for her work in the health care professions that she described herself as having a "servant's heart," meaning that since childhood she felt she was destined to help others. She describes how her grandmother was her inspiration to have a health care career:

my grandmother was a nurse and when I was five I just knew that that's what I was gonna do. You know I—I didn't know [or understand at that age] what my grandma did, but I knew what I needed to do [to serve others] and I really—I really admired her and I just thought that that was the person that I wanted to be, you know? And I think what's really—this is interesting because I've been trying to get a sense of people that are healers or people that really again have this, again, servant's heart. ...even as [I was] talking to Dr. Bennett, he was exposed to a faith that encouraged service to others. And I think that that—I got that, you know? That was something that—throughout my life service to others, you know? It was, you know, real important.

In addition to sharing a common value with Dr. Bennett's vision of a healer being of "service to others," Elizabeth also identified with him as they both believed in "the totality

of the person" where the body, spirit and mind are integrated:

one of the staff members [at the hospital where I worked] knew of Doctor [i.e. Dr. Bennett]. She had had really sledgehammer headaches, and she had been going to Doctor for acupuncture and she said Dr. [Bennett] is just phenomenal and he has a very holistic approach to healing and I said "Oh that's wonderful because that's my perspective too" that the body has an innate ability to heal itself and that we should be encouraging people to be proactive and not look outside themselves necessarily for resolution of their problem but to know that their body has this ability to—to heal.

Discovering that she shared this holistic mindset with Dr. Bennett piqued Elizabeth's

interest in him before she started working at the IMPC, and appealed to her when she

applied for a massage therapist position at the clinic.

Erica, the IMPC's other part-time contracted massage therapist, is in her mid-

50's, has a tall stature, and short, blond hair. Erica always wore relaxed-fitting scrubs,

and comfortable, Croc®-style shoes. I had the least amount of interaction with Erica in

comparison to Roxy and Elizabeth. For many years Erica was told that she had a

natural ability to be a massage therapist:

And I used to have people say "Oh you should be a massage [therapist]" I mean back when I was 16, 18 years old I went to a muscular dystrophy camp and I was a counselor there....And at night the counselors we would sit in a line on chairs and do neck and shoulder massages on each other....But you had to give one [a massage], you know, for you to get one so we would do this at night while we had our counselor meeting. This is how we'd hold our counselor meeting! So it was kind of interesting. I really got into doing it then, you know? And really enjoyed it, and liked getting massages as well as, you know, giving them and so over the years it just kind of took a backseat until I was 50 years old! And I went to school!

When Erica was around 40 years old, she began periodically calling the local massage

therapy schools and requesting information. She continued to do this over a ten-year

period as various life events such as pregnancy and her divorce prevented her from attending school, she made the decision to enter a program in 2004 and proceeded to attend a yearlong 650-hour program and graduated in 2005.

Unlike the other IMPC staff members, Erica knew Dr. Bennett before she came to work at the IMPC. Dr. Bennett was one of Erica's massage therapy patients at the physical therapist's office where she worked. When Dr. Bennett and Jasmine expanded the IMPC and provided the additional rooms for massage therapy, Dr. Bennett approached Erica to come work at the clinic. She said she "wasn't really ready to jump ship," but was then laid off from this physical therapy office. Erica then came to the IMPC on a contracted basis. During my fieldwork, Erica worked three out of five days a week at the IMPC, and also had her own home massage therapy business.

In the telling of Erica's story, she also felt she helped Dr. Bennett shape his vision for the IMPC's pain management approach. In Erica's statement below, she described a series of events that lead to her thinking that way:

I just fell and I jammed my shoulder and my arm, and I had dislocated the tibia. It was popped out for two days and I worked with it like that, didn't know it until my arm was all ballooned out. But when you go and protect it while you're working 'cause I just thought it was bruised and when they looked they popped it back in and it took, it had to get popped back in daily for about a week to hold it, but you tighten other muscles [when that happens]. And I had tightened [the muscles] up all the way up my arm into my neck. And it couldn't seem to get relieved by massage, [or] by the treatments [I was getting] so when I was working on Dr. Bennett [i.e. doing his massage] one day he said "why don't you follow me back to the office?", and he did and IMS [i.e. intramuscular stimulation] treatment on my neck. That was really an eye opener. I mean it showed me a whole 'nother degree [of pain relief], which I really love it. And then we started working out [my treatments] like I would get a massage like the day after [the IMS] and I was like, you know, that took the effects of the IMS and increased it. You know it would be working and if I got a massage usually that night or the next day, it really made the muscles let loose. So I used to tell him this and so that's when he started doin' a lot more of that with his patients, trying to get them to, you know, do the massage right after, you know, a day or two after [their treatment]....'Cause then

when they [i.e. massage therapists] would work on me, it [i.e. the muscles] would be so much more relaxed. They could get deeper to get into a better, you know, spot. So it [i.e. combining massage with other pain treatments] started with my own therapy.

Thus, when Erica fell and suffered a severe injury to her tibia, her IMS treatments<sup>39</sup>

followed by massage therapy the following day brought her tremendous relief from the

painful effects of this injury. She reported her pain relief to Dr. Bennett, and Erica said it

was at that moment Dr. Bennett started having "a lot more" of his other patients receive

massage therapy following their pain treatments like IMS or injections.

Interestingly, I found Erica's descriptions of the IMPC's work environment more

reserved than the other staff. For example she noted:

It's a really nice staff here. It's a friendly, pretty upbeat, you know, group of people. And then everybody kind of just does their job and goes about their business, you know?! But yet it's a very friendly atmosphere. Kind of in the lighthearted not, you know, you're dealing with people who are in a lot of pain so you can't [be down], but people aren't crabby and cranky here all the time. I think the majority it's an upbeat atmosphere.

While she noted the importance of the IMPC's "upbeat atmosphere" for pain patients,

Erica made reference that everyone keeps to themselves when she felt

"everybody...goes about their business," which downplayed the notion of the family-like

culture that is more apparent in the descriptions made by the other IMPC staff. Erica

also felt differently about the IMPC work environment than other staff because her

position was contract versus full-time:

Being contract, my position is a little different, you know? To be honest, I was just told [by Jasmine] I'm just here to do my massages and make sure my laundry's done. Really I'm not involved in any other part of it. But, you know, when I'm here if someone else needed help. If they're, you know, if Roxy is running behind and, you know she's washing up and her patient walks out and I'm not doing anything, I'll change the sheets in here room 'cause she would do

<sup>&</sup>lt;sup>39</sup> Briefly, the IMPC's website describes IMS as an adaptation of acupuncture. Please see Appendix E The IMPC's Treatment Options for a full description of IMS.

the same for me. You know we do the laundry. It's not like we go "I only wash my sheets."...You know if I'm just standing around doing nothing, I fold the other sheets or, you know, if Jennifer needed help with something, of course I would help her. I don't do some other things strictly because I feel that...it's a taking advantage of a contract person, you know, like emptying trash and doing all these over and aboves.

Due to her contracted status, Erica conceptualized these "chores" as going "over and above" what someone in her part-time position should be required to do. Erica said she was hired only "to do my massages" and does not want to go beyond her "role" as a contracted employee if she engages in these shared chores like the full-time staff (e.g. she would empty the trash in her room, but felt she was not being paid to empty the trash in other locations in the clinic). Erica said when she was younger, she would have gone "over and above" her contracted position, but now that she is older she feels she would be taken advantage of: "probably when I was in my 20's I would have done it all, but I'm not anymore!" Erica even mentioned that she told Elizabeth, the other contracted massage therapist, to "stop doing" these chores because she too was in a contract position.

It became apparent that Erica did not fully buy into the IMPC's family concept for a few factors. First, a different power dynamic existed between Erica and Dr. Bennett. Unlike other IMPC staff members, Erica knew Dr. Bennett before coming to the IMPC, as he was one of her patients. Given this role reversal, perhaps Erica did not see Dr. Bennett as the same kind of authority figure that the others did. Second, Erica noted above how she felt her part-time status exempted her from doing some of chores expected of all the IMPC staff (e.g. cleaning the clinic). Erica conveyed that she was now older and wiser, so to speak, and felt that she would be taken advantage of if she went "over and above" what she felt she was paid to do (e.g. to provide massage and do her own laundry). Thus, Erica did not fully buy into the family concept as she did not want to partake in all aspects of the IMPC's teamwork system.

Despite Erica not fully taking part in the IMPC's "family" concept, she is very enthusiastic about helping others through the practice of massage. For Erica, a big appeal to work at the IMPC was treating pain patients rather than doing "the fluff and buff" massages as she explained here:

I did like what he [i.e. Dr. Bennett] does [at the IMPC] and how he works with his patients is a big, you know, staying in that line of work more than—I just can't picture myself working at a spa. I'll be real honest, I couldn't....probably because I'm capable of doing the deeper massages [i.e. deep tissue massage] and things like that....There's nothing wrong with the Fluff and Buff [massages]—that's what we call it! But it's not real rewarding. I wouldn't think as well as when you're helping somebody who has pain or a problem. I mean I do massages out of my home also so I see all the people for all different reasons. But the majority are coming not just like it's [i.e. the massage] an extra treat. It's more they need it for maintenance purposes, you know? Whether it be emotionally, physically, you know, it's the whole spectrum of that. You know I just can't picture myself just working in a spa-y type atmosphere.

Erica's desire to work with patients that needed more than just the "fluff and buff's" made her a good fit for the IMPC's goal of helping patients live more pain-free lives. Erica also had a strong work ethic as seen through her dedication to her patients. For example, she went the extra mile for one of her patients when she discovered the benefits of biofeedback therapy, and incorporated it into their massage treatment. Not only was she excited over discovering its usefulness in massage, but she was so enthused she shared her new knowledge with me and even had me—the anthropologist—try out the biofeedback unit.

In addition to Dr. Bennett and the clinic's massage therapists, the physical therapy team completes the set of the practitioners who participated in this study. Michael is the clinic's physical therapist. He is a tall, young-looking (I assumed Michael

was in his early 30's as he never told me his age, only that he looks younger than he is) African American man with an athletic build. Always wearing athletic-looking apparel and shoes, he conducted physical therapy evaluations one day a week on patients identified by Dr. Bennett as good candidates for physical therapy, and then devised a treatment plan that Jennifer, the clinic's physical therapy assistant, would carry out. I never had the chance to interview Michael given his very limited schedule at the IMPC. However, patients that I interviewed for this study spoke highly about Michael's care and thoroughness (e.g. Michael discovered that Linda, one of the IMPC's patients whose case will be further described in chapter 7, had dislocated ribs after a fall and he pushed them back into position for her during her evaluation). I also learned that he has been a practicing physical therapist for ten years, and was considering pursuing his physical therapy education at the doctoral level.

Michael was always joking with the staff when he came in to do his weekly evaluations. I had the opportunity to see his sarcastic side when he was evaluating Roxy for physical therapy to help with her neck pain and headaches as they jokingly bantered back and forth during her evaluation (Michael asked Roxy what medications she was taking to help with her headaches and she replied "coke" and "meth"). I was also not spared from his sarcasm during the encounter as it appeared he was feeling me out during my observations:

The PT [Michael] also has a very sarcastic sense of humor and I could sense this by the way he was asking what he should do or how he should act because I'm sitting in the room observing and taking notes....He then asks me if I have any questions [for him], like how long he has been a practicing physical therapist. He answered his own question when he said ten years and then said to me he looks younger than he really is. I then asked him how old he is and was met with no response, I think on purpose! He said his birthday is coming up in a few weeks and I said happy early birthday! I said mine was a few weeks ago and told him

121

that Roxy was mad at me because I didn't tell anyone it was my birthday. He said my birth date would make me a...and I answered an Aquarius. Roxy told him that I baked cupcakes and brought them in for everyone and he responded what are we in 3<sup>rd</sup> grade? (Fieldnotes February 5, 2009).

In addition to poking fun at me for bringing in cupcakes to share with the IMPC staff on

my birthday, Michael's sarcastic humor and inquisitiveness emerges when he starts

asking me questions about anthropology:

This is my first time really getting to know the physical therapist and his personality. I think he was wondering about my background because he asked me how I got interested in anthropology and I told him that I've always been interested in medicine, but couldn't do the chemistry associated with it. I said I turned towards medical anthropology and the study of health and healing systems. He said that even though he didn't like classes like organic chemistry, he just did them to get through it to do what he is doing now. He asked if I had any anatomy classes, etc...I said no...that "I am a social scientist!" I think he was testing me and my personality (Fieldnotes February 5, 2009).

Here Michael's use of sarcasm becomes evident as it appears he is trying to understand my purpose at the clinic, and most likely, tease me for not going into one of the "hard sciences" like he did (he did not like organic chemistry but got through it) as demonstrated by him asking me what different science classes I have taken. However, amid this sarcastic humor, his enthusiasm for the field of physical therapy became evident through his compassion. He was genuinely concerned about finding a solution to address Roxy's headache pain, and was extremely gentle with the manual exam techniques he performed on Roxy during the encounter and his continual reassessment after he completed each one.

Jennifer, the clinic's physical therapy assistant (PTA), is not afraid to let her individual style emerge as she has sections of her short-cropped hair dyed bright colors like pink or purple. In her mid-20's, and always neatly dressed in a sporty look of khaki pants, athletic shoes, a short-sleeved shirt and sweat jacket, she worked at the clinic three days a week. Despite several requests to interview her, Jennifer seemed reluctant to make the time to be interviewed, so I did not want to keep pushing my requests and stopped at that point. Jennifer was more reserved with the IMPC's patients. However, I found that she was more talkative and that her own sense of humor emerged when she was around Roxy (the two became close friends during my fieldwork). The two regularly joked with one another, oftentimes exchanging remarks tinged with profanity that were made safely out of the earshot of patients. When Jennifer and Roxy began to use of profanity around me, I took this as an indicator that both of them were becoming more comfortable incorporating me into the IMPC "family."

In this chapter we learned about Dr. Bennett's dream to open the IMPC, how he and Jasmine gathered their treatment team (i.e. "family"), and their expectations of them. The heart of Dr. Bennett's dream and the subject of the following chapter is the IMPC's pain management approach.

# **CHAPTER 5**

## THE IMPC'S PAIN MANAGEMENT APPROACH

"Our Mission: To have satisfied patients that have benefitted from their treatment plan, received excellent customer service, and refers others to our practice" (IMPC's Mission Statement, framed and prominently displayed in the waiting room)

The IMPC's mission statement reflects their desire to help patients live healthier and more pain free lives through their particular treatment approach, which is the subject of this chapter. The first part of this chapter describes how the IMPC conceptualizes their "treating the whole person" pain management approach. The second part of this chapter examines how the contrasting ideas of mind/body, biomedicine/CAM, care/cure and disease/illness discussed in chapter 1 come to light through practitioners' descriptions of the IMPC's treatment approach.

## **"TREATING THE WHOLE PERSON"**

Pamela summarizes the IMPC's shared vision of patient care as "treating the whole person. Not just well 'you're having leg pain [so] let's treat your knee.' It's more of trying to treat overall health, overall wellness. To treat the mind if need be because...they're all connected." We will next see how the practitioners enact this "whole person" approach by first trying to identify what may be causing the patient's pain. Second, a treatment plan is then developed for the patient to help them better manage their pain condition. Third, the IMPC's practitioners help to customize this treatment plan in order to make it fit with the patient's specific needs and life situation.

#### Identifying the Cause of the Patient's Pain

Dr. Bennett believes that typically there is a specific cause behind the patient's pain that needs to be identified. In the interview excerpt below, Dr. Bennett describes

his perspective, which highlights why he feels pain medication is not an effective form of

pain management simply on its own:

Dr. Bennett: It's like a person comes in with pain. I can give 'em a pain pill. No problem, just write a script, here's a pain pill....I can give you enough pain medication to knock out your pain. So you don't experience pain. But did I treat the problem?

LM: Yeah. It's just masking the symptom, right?

Dr. Bennett: Right. So your symptom is pain, and I gave you somethin' that took care of your pain. Now your pain may have been because...well I don't know, your arm's broken...you know, deformed. It's still deformed, so unless you change the actual...problem, then you're not gonna help with the symptom, and they still keep the problem. Okay, so now you take away the pain pill, the pain's still there because the problem hasn't been fixed. You fix the problem, now you fix the pain. I'm not sayin' I don't give 'em a pain pill to help with their symptoms so that they can function and do everything in life and be comfortable, but you gotta address the actual problem at hand.

Dr. Bennett expresses here that there is something physically wrong with the patient's

body that is causing their pain, and he uses a broken arm as an example in this instance. Therefore, pain is a "symptom," according to Dr. Bennett, of a larger "problem" (e.g. broken arm) with the patient's body. Medication will not "fix the problem" (e.g. mend the broken arm); it serves only as a stop-gap measure to help the patient function while the "problem" is being addressed by other means.

Importantly however, Dr. Bennett also believes that there can be more to the patient's pain than just a physical "problem" with the body as Joan observes: "You know if a patient is having pain because they're having other issues that are maybe that are definitely not so physical and easy to nail down, he [Dr. Bennett] seems to be able to pick up on that." Early on I noticed Dr. Bennett's attentiveness to these "not so physical" causes of chronic pain and how he perceives these issues too as when he told me:

the pain is what the pain is, right?...but then psychologically...you know, things maybe go further in a different direction and maybe generate a little extra pain. Maybe they have more depression that's built in because of this sort of feeling lonely and, you know, "No one else helps me. And no one else knows what I'm goin' through. I can't do this sort of thing."

In Dr. Bennett's words, he states that he sees pain as having both physical and psychological components that need to be addressed such as depression, for example, which can "generate a little extra pain" for the patient.

Since Dr. Bennett views pain as having at the outset a physical cause, he describes the IMPC's approach as taking "a disease focus." In this focus he tries to identify specific diseases like arthritis or fibromyalgia<sup>40</sup> as potential physical causes behind the pain a patient is experiencing. Dr. Bennett speaks using the term "disease" when describing the IMPC's approach, but in my conversations with him, he is also keenly aware of patient's lived experiences of chronic pain and the need to address those aspects in pain treatment. We will see these ideas come to life in the following interview excerpt.

During the course of this particular conversation, an interesting dynamic occurred. Dr. Bennett began to direct the course of our conversation by using an example from my own life's experiences to exemplify his point:

Dr. Bennett [to LM]: You live by yourself?

LM: I'm [living] with my mom right now.

Dr. Bennett: Okay so...imagine...your mom comin' home, you know, imagine your mom wakin' up every day in pain...."Lindsey, I'm hurting."..."I just hurt. I

<sup>&</sup>lt;sup>40</sup> The IMPC's website describes fibromyalgia as "the presence of chronic widespread pain....The defining symptoms of fibromyalgia are chronic, widespread pain and tenderness to light touch. Other symptoms can include moderate to severe fatigue, a heightened and painful response to gentle touch, needle-like tingling of the skin, muscle aches, prolonged muscle spasms, weakness in the limbs, nerve pain, functional bowel disturbances, and chronic sleep disturbances."

don't feel good today." "Oh, I'm in pain so bad I can't—I can't even go to the store. Can you help me? Can you take me to the store?"

LM: she has...pretty severe fibromyalgia and she actually had a spasm in her neck...two years ago and one morning she woke up and she couldn't lift her head up....So it was, you know, she was almost completely crippled at that point.

Dr. Bennett: So how does that affect you?

LM: I didn't know what to do. I mean at that point....I was like, you know, it's overwhelming.

Dr. Bennett: Yeah. So it affects the whole family....You're livin' with someone, and they have pain, it affects not just the person who has the pain, it affected you as well.

LM: Yeah. Caregivers, other family members.

Dr. Bennett: So they have to deal with it. Now here's the other thing that's interesting. You understand somewhat about fibromyalgia. Imagine a family member that doesn't understand.

LM: I've had patients tell me that "Oh, you know, my husband doesn't believe it's real." And—to them that it just—it's denying what they're experiencing so.

Dr. Bennett: Yeah....I mean this—they don't—it's not real to them 'cause they don't have it. See you—it's real for you. See now you have an understanding of fibromyalgia. You've said "Okay, I have an understanding of fibromyalgia. I've never had it...but I have an understanding of it." Having it is different than having an understanding of it. Going through it. Experiencing it. Wakin' up, havin' the pain, going to bed.

LM: Not being able to function.

Dr. Bennett: Yeah and gettin' depressed, you know, feelin' sad. Not being able to function like you said. These are the things that kinda like wow, that's havin' it, right? And so when family members don't understand it, a person may have pain one day and they get upset 'cause their pain...tolerance is low [or] different things...one family member would have said one thing to 'em and—in the past it would have been okay, but they [Dr. Bennett makes yelling noise during the interview] yell at 'em because of this sort of thing....this affects the whole family dynamics. They were working before and now they can't do their job at work anymore. So they can't bring the income to the family. And people at work are on them about this sort of thing. They get depressed because of their situation 'cause they can't do the things they were doin' before....so there's...the medications that they're getting, side effects. They go to multiple doctors, and

the doctors don't understand what they're doin' and they're just givin' 'em medications just to kinda, you know, pass 'em on or whatever, you know. So this person feels like all alone. Nobody to help 'em out. It's pretty bad, yeah.

In this example, Dr. Bennett illustrates what *living* with chronic pain can be like for patients. He drew attention to the loneliness and isolation patients may experience, their anger that causes them to lash out at family members, the loss of their livelihood and subsequent financial burden from not being able to work because of their pain, doctors invalidating their pain experience and "pass 'em on" to other doctors, and the patient feeling as though no one understands them or what they are going through. These are all examples of how a chronic pain condition can affect a patient's life, including their various life roles and associated identities (e.g. employee, mother, wife, etc.), as well as their family dynamics. Thus, Dr. Bennett is very aware of the need to design a treatment approach that takes into account and works at addressing some of these key life issues. Yet, it is interesting to note how his language still employs the "disease" model although his orientation to the "whole person" treatment approach is a much broader conceptualization of the illness experience.

How do the ideas about disease and illness manifest themselves in the following example about diagnosing trigger points? Because of the IMPC's attentiveness to both the physical and psychosocial aspects of chronic pain, I noticed that trigger points were frequently identified among the clinic's patients as one of or sometimes the sole cause of their pain. According to Dr. Bennett, trigger points are often caused by an individual's life circumstances, both physical ones and psychosocial ones such as stress (IMPC website).<sup>41</sup> They are described on the clinic's website "as painful lumps or nodules" that

<sup>&</sup>lt;sup>41</sup> For further in-depth information on trigger points, see Davies and Davies (2004).

form in the body's muscles and can cause a great amount of pain especially if nerves are compressed:

Trigger points develop as a response to muscle overuse, muscle tears, trauma, bruises, surgical incisions, joint problems, or as a result of other medical conditions. They can also be caused by changes in your body resulting from long-term stress. The muscle becomes tightened, inflammatory waste products collect in the muscle tissue, and scar tissue could eventually form to entrap the nerves causing pressure and pain. A trigger point may be painful not only at the area being pressed, but also triggers pain in other parts of the body. This type of pain is called referred pain (IMPC website).

Trigger points are a good example of a physical symptom with a body and mind (e.g. stress) cause. The IMPC believes that trigger points can and should be treated with a holistic approach and they design integrative treatment plans accordingly. Later on, we will see multiple examples in the patient narratives of how the "treating the whole person" approach works for a number of different patients with a trigger point diagnosis.

# **Developing the Patient's Treatment Plan**

Dr. Bennett believed that the best way to address a patient's pain was though an integrative approach as both biomedical and CAM treatments "have somethin' to offer people." Patient's "with the best outcomes" for effective pain management need to have diverse treatment options, according to Dr. Bennett because he felt:

right now there's no...one treatment to fix the problem....So when you're lookin' at someone with chronic pain issues....a integrative approach is the best...option to it, and I think each...each modality, each treatment option...provides a different way of...controllin' their pain....if one aspect helps then you're good, you know? Other one doesn't, then you just try another.

Interestingly, Dr. Bennett described how the use of an integrative approach to pain management has been utilized informally by patients "for years," but in a piecemeal fashion. He discussed how patients had been "runnin' around" on their own to various biomedical and CAM practitioners at different locations. For example, a patient seeking treatment for their trigger points may have visited a CAM practitioner for massage or acupuncture, and a medical doctor for trigger point injections, all at different locations and using different approaches to help them address their underlying pain problem.

However, Dr. Bennett believed "the best option" for such an integrative approach to pain management is for patients to come to one location. At this location, Dr. Bennett described how patients would have a treatment plan developed for them, which would be comprised of a diverse array of integrative treatment options. For instance, a patient could have their trigger points addressed by having their injections as well as massage therapy carried out at this one location. Additionally, the patient would have the benefit of this treatment plan being coordinated by a physician in a clinic with a multidisciplinary orientation to treating pain:

I think that the best options for patients is to be in a setting where they're in a...environment like this [the IMPC] where...things are—are there for them...they don't have to look for...someplace....when you have...physicians, practices or...you know, centers [like the IMPC] where the...integrative treatments are takin' place there, it's sorta like "Okay, now we can coordinate this thing." We can say "Okay, massage seems to be helping." Okay? "Uh no it's not helpin'. Let's back off on that." Okay? "This seems to be helpin', the physical therapy. Ah, no that's not helpin', let's pull that out." Okay? "Let's try acupuncture. Okay that one didn't help, let's try this." Versus the patient runnin' around [to different places for treatments]....So then you coordinate this whole thing by havin' it in one center [like the IMPC].

Dr. Bennett aimed to create such an "environment" with the IMPC where he, as the clinic's medical doctor, can offer each patient a treatment plan consisting of diverse biomedical and CAM treatment options that he can integrate *and* coordinate on-site. Dr. Bennett felt such an "environment" allows him to closely monitor a patient's progress and, if needed, integrate other treatment options as not all modalities will work equally well for every patient, even if they have the same pain condition (e.g. trigger points). Therefore, Dr. Bennett felt he needed to have this diverse array of biomedical and CAM treatment options "on board" for him to draw from depending on the individual patient's needs (See The IMPC's Treatment Options in Appendix E for a more comprehensive listing and description of specific treatment options). However, what is seen by Dr. Bennett as very important in addition to the physician taking an integrative approach is customizing it to each patient's medical and life situation. At that point, after his initial diagnosis phase, he brings in the IMPC's other practitioners that include the physical therapists and massage therapists.

# **Customizing the Patient's Treatment Plan**

Although Dr. Bennett is responsible for diagnosing the patient's pain condition and develops the initial treatment plan, the IMPC's practitioners, including Dr. Bennett, frequently and continually interact with each other and their patients in making treatment decisions in order to customize this treatment plan. Roxy noted an example of how this customization helps to meet the patient's specific needs:

we all work together, you know. I'll sit there and talk to Jennifer and Michael over in physical therapy and find out what can I do on my end to make it easier [for the patient]. Or I sit in on a Botox® injection and watch where he's [i.e. Dr. Bennett]—[where] the injection sites are and then I'm able to work more in those specific areas to make it more...of a specific massage for that person to where we relax the muscles and again it's just—it's all hand in hand. So that's—that's the difference. So it's not like they're [i.e. the patients] coming in and getting one treatment and that's it and they're done. We're all talking together and trying to see what else we can do.

In this example, Roxy mentioned how she may observe Dr. Bennett treating a patient with a Botox® injection, and then later she sees this same patient for a massage. By the practitioners interacting with one another, Roxy is able to then focus her massage

on the specific area that was injected by Dr. Bennett in order to "relax the muscles" around the injection site.

In this setting, professional autonomy among all of the IMPC's practitioners is valued. The practitioners have a considerable degree of flexibility when customizing their particular portion of the patient's treatment plan. Over the course of my fieldwork, I observed how this customization process often occurs during the co-created practitioner-patient encounters. In these encounters the goal is for a warm, collaborative practitioner-patient relationship to develop, which facilitates the patient's abilities to make decisions about their care, alongside their practitioner(s). I will next discuss in more detail how three of the IMPC's practitioners who are featured in the patient narratives in the following two chapters—Dr. Bennett, Elizabeth and Roxy—go about this customization process. Specifically, I will cover how they establish their relationship with their patient, and foster the patient's decision-making capabilities during the co-created clinical encounter.

Dr. Bennett often draws from his professional experiences as a physician with a "blended" background in biomedicine and CAM to help him in developing a rapport with his patients. Key to this process is his belief that he needs to talk with patients and actively listening to their concerns especially in the diagnosis phase:

I could be in a room with a patient and see someone and all they just needed was somebody to talk to 'em....you have to listen to the person and what they need....one medication may be the right fit for a person and another medication may not. No medication may be good for them and they just need acupuncture, you know? But it all depends on—on the person and dynamic and when I go into that room to see 'em, I'm not sittin' here thinkin' to myself I'm gonna treat 'em with this then, and then we're gonna do this, and we're gonna do this, and we're gonna do this. I usually develop it based upon what happened, the dynamics of the room and the encounter at that time.

Because Dr. Bennett is aware of how a pain patient may be depressed or feel socially

isolated, he also personally believes that customizing the use of humor is an important

part of the rapport he develops with his patients:

their [i.e. the patient's] family lives who knows how bad that situation is....they have loved ones that have to deal with their pain. Their kids...they won't understand their pain. And I would imagine that in their households they're not havin' a lot of laughter that's goin' on. They're at work; they're workin' in an environment where it's really...professional. Probably not a lot of laughing and stuff goin' on there....Part of the...the healing process is laughter, you know? They come in [to the IMPC] and they laugh, and that was the first time they laughed all week long....This person's in pain, you know laughin'?...What an oxymoron right?

Dr. Bennett felt that laughter is an important part of the patient's healing process, and

that the IMPC may be the only environment patients are able (and perhaps feel

comfortable) to laugh although they are in pain.

For Dr. Bennett, another essential aspect of customizing patients' treatments is

fostering them to take an active role in their own pain management:

here's a key....if you came in to see me...I'm just a tool...for you to use....Now I—I'm the professional, I know different things that it can help 'ya out...but you direct my treatment....So if—if I say to you "You have to take this, and drink this three times a day—take this pill three times a day", and you don't wanna take this pill, you're not gonna take it....But if we talked together and after we talked based upon what I've explained to you, that you're in agreement with takin' this, you've directed your care....I'm—I'm a tool, and they're usin' my knowledge because I'm the professional to help them, right? But I'm givin' 'em options so that they're involved in it and so now "Hey, this is what we're gonna do." Okay. Now the likelihood of them takin' this and drinkin' or takin' the pill is much greater than me sayin' "Here you have to take it."...So now I'm not the one tellin' you what to do, you're basically tellin' me how we're gonna do it, and we're workin' together.

As we can see, Dr. Bennett conceptualizes himself as "a tool" that the patient can use to help them make decisions about their *own* treatment. Dr. Bennett recommends particular treatment options based on his knowledge as a physician, and then works *with* patients to customize their treatment plan to fit the patient's individual needs. While this situation is what Dr. Bennett views as ideal, given the economic realities of the Detroit metropolitan area, patients may be limited financially (and in other ways) with the costs associated with their treatments. Therefore, a divergence may exist between what Dr. Bennett suggests as an ideal treatment plan versus the reality of patients' individual life circumstances. If a patient is not able to afford certain treatments that are not covered by their health insurance, Dr. Bennett will try to work within their budgets. One way Dr. Bennett achieves this is recommending biomedical pain treatment options first, rather than the CAM options that are not covered by insurance, which Jasmine comments on below:

So sometimes, you know, when it comes to the acupuncture...more often than not he'll [i.e. Dr. Bennett] go with the traditional [biomedical] course first and then say "Well okay these aren't working how about we try acupuncture? <sup>42</sup> How about we try changing this, changing that." So...you know he doesn't always offer that as a first course, you know because, you know insurance doesn't cover it. So that becomes a deterrent for patients, and he's a doctor first and foremost. That's the difference between just coming to a straight acupuncturist versus come to a—a physician, you know?"

If these biomedically-based treatments do not help the patient, Dr. Bennett will then suggest CAM treatment options such as acupuncture.

While it is the belief of Dr. Bennett (and the IMPC's other practitioners) that patients benefit the most from their integrative treatment approach when they make the effort to follow through with the whole thing (e.g. figure out how to pay for it, fit it into their lives, and so forth), they are realistic that not all patients are able or willing to make that level of commitment. Unlike some of the other clinical settings described in the literature review (e.g. Baszanger 1998; Jackson 2000; Salkeld 2004), it is not a "deal breaker" if patients do not subscribe to the "ideal" treatment plan proposed. As we will

<sup>&</sup>lt;sup>42</sup> The numbers of patients opting for acupuncture treatments were down significantly throughout my fieldwork period.

see in the patient narratives in later chapters, patients can still come to the IMPC for treatment even if they decide to adopt a more modified version of the customized approach recommended for them. Pamela even commented how she believes patients are encouraged to come to the IMPC and at least try their approach because of Dr. Bennett's willingness "to work with them" and make "the time" necessary to help them finance their treatments:<sup>43</sup> "When they [i.e. patients] see that he [i.e. Dr. Bennett] is willing to work with them then they're a little bit more willing to come in. You know and [for the patient's] it's like 'okay he's...taken the time [to do this]....Let's try it."

Like Dr. Bennett, Elizabeth also has a blended healthcare background that she often draws from when establishing a rapport with her patients. Elizabeth is trained as a nurse as well as a massage therapist. In some cases, Elizabeth believes that sharing her nursing background with her massage therapy patients helps build "trust" in the practitioner-patient relationship as well as provides a different air of "authority" to the information she shares with them:

And for some patients, I identify myself as a nurse if we're having a discussion on their Parkinson's [disease] and I'm saying, you know, "I've worked with Parkinson's patients before"...I don't identify myself as a nurse for everybody. If somebody's just coming in for a stress relief [massage], but when I feel it's appropriate like when we're talking about medications and side effects and that kind of thing then I say well, "My experience with such and such," you know? So...it's been really helpful [to bring in the nursing background].

In my observations of Elizabeth, she often shared information on wellness and healthy living by talking about exercise and hydration, for example. However, she feels that it is up to the patient to choose if they want to incorporate her advice into their lives. Elizabeth holds the perspective that if a patient does not utilize the knowledge she

<sup>&</sup>lt;sup>43</sup> Dr. Bennett also offers "specials" on treatments not covered by insurance (for example, there were specials on prolotherapy) to bring more CAM treatments into a patient's financial reach during tough economic times.

mentions to them, that perhaps they are not "at that place yet" in their life to incorporate this advice. While it may be true that the patient is not ready to incorporate the advice into their lives, the possibility also exists that the patient may not share the same personal philosophies about prioritizing wellness and healthy living like Elizabeth does.

Elizabeth also mentioned the importance of collaborating with the patient during the clinical encounter, encouraging the patient to be "proactive" in their massage:

I always make it patient centered so I get my cues from what they're saying, how they're feeling, and I find that that's very effective. That they get more out of it 'cause they're more proactive and, for example, if I think hot rocks [i.e. hot stones] might be effective [in their massage] and I explain how that would work and why I think that modality would work, and it's a collaborative thing. The patient would say "Oh sure, I'll try it once" and then throughout the massage I'll say, "You know, how are you feeling? Is that, you know, relaxing these muscles?"

Elizabeth noted that while she may recommend a particular massage modality like using hot stones, it is important for the patient to make the choice if that modality would be something they would like to her to incorporate into their massage experience. Whatever choice the patient makes, Elizabeth supported it and she stated that their choice does not affect the relationship she has formed with them.

Taking a somewhat different approach than Dr. Bennett and Elizabeth, Roxy, the clinic's full-time massage therapist, often draws from her own more personal experiences when establishing a rapport with patients. Roxy felt that she differentiated herself from other massage therapists as she does not put up as many "boundaries" between her life and the patient's life:

I do talk about my personal life; some therapists would not. That's something I do, but it's because I've been through a lot so I'm able to, you know, let them know, given them a little bit of insight on—'yes I can relate with you' because sometimes it's hard for them if they feel that nobody can understand them. But I make sure that, you know, they know just a little bit but not, you know, I'm not

gonna give 'em my social security number, and my kids dates of birth and that that kind of thing.

Connecting with patients on a more personal level helps Roxy begin to address the patient's broader life issues, beyond the physical symptoms of the pain. While Roxy guarded sensitive personal information, she felt that if she was able to provide "a little bit of insight" about a similar life experience she had, she will do so to help the patient feel that someone "can understand them." For example, Roxy would talk about her husband's past health crisis or how she was coping financially during these tough economic times hitting the Detroit metropolitan area. Roxy believed in the use of laughter as a coping mechanism for the adversities she experienced in her own life and she carried this belief into the interactions she had with her patients. Quite often you could hear laughter between Roxy and her patient emanating from her treatment room.

However, Roxy noted that getting too close with her patients caused some negative effects for her:

And that's where you get into the gray area where they're telling you things, you know, in confidence an... about their lives and things like that and it's—it's hard not to take that on. A lot of people ask me "Well are you tired when you're done with all these massages?" Well physically no. I can handle the—the massage part of it. But mentally there's days where I go home and I'm just—I'm done. I just need to go to sleep because it just, you know, you get one after another after another, and there's only so much you can do, and you can't take it personally. You can't take it on, but it's hard not to when you're hearing that 'cause you feel horrible. And you've become very close with them. So trying to set up those boundaries and be professional, but you still care for the person.

Roxy often listened to her patients talk openly "about their lives" and their pain and it caused her to feel mentally drained as she described her tendency to take on the patient's problems.

Additionally, while Roxy reads the patient's medical history, she also felt it is essential to actively listen to the patient's own words as they described how their pain issues were affecting their bodies. Roxy said it is important to listen to the patient because even though two patients may have the same pain condition diagnosed, they most likely will experience this condition differently:

I always am able to read the history on them before I ever walk into their room. I will always know what is going on with them...the specific medical issues that they're having. The second part of it for me anyways is if I've never met them I ask them...you know, I...will say to them "Okay, I know you're here for a massage, but what specific problems are you having?" 'Cause I want to hear it out of their mouth. I can ... read [in their medical] that yes they are having sciatic [nerve] issues<sup>44</sup>....But what does that mean to them?...is their leg going numb [from sciatica]? Or is it—are they feeling more [effects] in their lower back? Because I've showed you [Lindsey] like for instance a sciatic release. Well it could affect either or [the legs or back], or both. I need to know from them what is going on with them. And because of the sciatica, is it now affecting the middle of their back or are they now getting migraines because of the compensation for so many years? I may not know that. So I have to hear from them what is going on. And then as I walk back out of the room to scrub up, and then I think about it and, you know, usually I'll quickly come up with a plan....and then the third part of it is you just feel with your hands. As soon as you start to massage them, you'll start to feel the areas and then you just do it right on the spot. You know whether it be trigger point work-because that's another thing. I could read it in their history, but I have no idea how much...pressure they can tolerate. One persons gonna be totally different than the second person. One person I could probably go in with my elbows and their telling me to use more pressure. The next person I have to go extremely lightly because their pain tolerance is very low. So-you just-it's all play it by ear.

While the patient's own words are important to how Roxy customizes her patient care,

she also uses tactile cues and described how she "listen[s] with my fingers." In other

words, Roxy describes how when her hands touch the patient's body, she has an innate

sense where the problem areas are and adjusts accordingly the amount of pressure she

<sup>&</sup>lt;sup>44</sup> The IMPC's website describes a low back pain problem called sciatica: "Sometimes patients report symptoms of pain traveling down their leg. This is commonly called **sciatica** (emphasis added). It refers to the irritation of the sciatic nerve as pain runs down the leg into the foot." As Roxy noted, pain from the sciatic nerve can be felt in the lower back or in the leg.

uses on the patient's muscle tissue. Customization of massage therapy to a patient's particular needs is especially important, according to Roxy, as not all patients can tolerate the same amount of pressure applied to their muscle tissue.

Roxy also believes in teaching patients to be aware of how their own body responds to the massage. For example, if a patient has numerous trigger points in their muscle tissue, Roxy explains how they may hear audible "crunchy" noises as she breaks down these trigger points. She may also tell the patient how the body continues to process the treatment after the massage for a 48 hour period where a "good sore" or "good hurt" would be felt in their muscles the following day, followed by the full relaxation of the muscles by the second day post-treatment.

I wanna make sure I explain to them what's going on. When we're giving them a massage there's many things that are happening. Between [explaining what] the trigger points [are] and, which I've explained it to you...with their—the process of their body healing with...the fact that it takes up to 48 hours [for the body] to process massage. There's just lots of information. So when the timing's right— 'cause I don't wanna give them too much all at once or else they never remember any of it. So as we're doing the massage, I like to inform them and given 'em some information...and then let 'em process the massage whether that be them talking to me or just relaxing and being quiet and, you know, doing their thing. But I feel that just in case they—they do walk out that door and end up going elsewhere, they need to be aware of their bodies. They need to be aware of what's going on and, you know, if I'm breaking down trigger points, what are those crunchy feelings that they're getting that this is normal.

Importantly, Roxy describes how a patient chooses to allow their body to "process the massage" varies. For example, some patients prefer to be more active and talk throughout the entire treatment about their lives, their pain, their families, jobs, and so forth. In the majority of massages I observed with Roxy, patients chose to "process the massage" in this particular way. However, some patients preferred a more relaxed atmosphere and remained quiet or fell asleep on the massage table while their body

processed the treatment. Either way, Roxy supported the patient's decision and engaged in conversation with them if they chose, or she respected the peaceful atmosphere and went about her work in silence.

Roxy also explained to me another way she believed she differentiated herself from other massage therapists. She felt that the patient is in charge of the massage

therapy session:

they're [i.e. the patient] in control of their session. That that's their hour, not mine. And that's another thing that's really important with massage therapists. A lot of 'em start to feel that they're the ones in control. That they're the therapist and the patient just needs to be quiet and let 'em do their thing. And that is not the case. The patient, it's their session, not mine. I'm facilitating what their body needs to do. And I can't feel what they're feeling so therefore I cannot tell them "No pain, no gain." 'Cause that's not true....I have to respect and honor the fact that they're allowing me into their personal space, and I have to listen whether their speaking it or their just—you can physically see it with the way they're breathing or—or if they're flinching. And respect them and, you know, make sure that they're comfortable at all times. So that's another huge part of it that a lot of therapists overlook. They don't pay attention. They just think "Oh, I'm helping them." So you have to—you have to walk in that room feeling honored that they're allowing you into their space. So that's a huge deal.

Roxy felt she does not have the right to fully control the massage therapy session

because she cannot assume what or how the patient is feeling in terms of their pain.

Therefore, Roxy believed her purpose as a massage therapist was "facilitating what

their body needs to do." Roxy facilitated the session by getting the patient's verbal

feedback during the treatment, and assessing the patient's body language as a non-

verbal cue of whether or not she is applying too much pressure that could cause

additional pain. Thus, facilitating the patient's abilities to control aspects of their

treatment is another way Roxy addresses more than just the patient's physical pain.

## DISCUSSION

I will next analyze how the way in which the IMPC conceptualizes their strategy of "treating the whole person" negotiates the series of contrasting ideas—mind/body, care/cure, biomedicine/CAM and disease/illness—described in chapter 1.

We see the ideas of addressing the mind and body appear when Dr. Bennett first talks about identifying the cause of the patient's pain and the IMPC's overall approach. He believes there is a physical cause; there is some "problem" with the patient's body that results in the patient feeling a sensation of pain. Although Dr. Bennett's language appears from the outset to be drawn from a biomedical model that separates the body from the mind (Gordon 1988), and appears much like the how the physicians in Baszanger's (1998) first pain clinic conceptualize pain, he also wholeheartedly believes that psychological issues such as depression can bring the patient "extra pain" as well. In some of the multidisciplinary pain clinic models from chapter 1, the psychological aspects of chronic pain such as depression, for example, were addressed by staff psychiatrists or psychologists (Baszanger 1998; Jackson 2000). In this case, the IMPC will refer patients to these types of outside specialists when there is a perceived greater need. However, the IMPC's practitioners also regularly try to address psychological issues such as depression and social isolation in their "whole person" approach to chronic pain management. For example, they often rely on the use of humor with patients to make them laugh, or they may break down some of their professional boundaries and share relevant life experiences so patients feel that someone "can understand them."

141

Related to the mind and body discussion above is how notions of "disease" and "illness" are conceptualized at the IMPC. Dr. Bennett initially describes the IMPC's treatment approach as having "a disease focus." In chapter 1 we saw that biomedical practitioners are taught to fundamentally utilize the "disease" concept and therefore its centrality in IM pain treatment is not unexpected (Chrisman and Johnson 1996; Crowley-Matoka, et al. 2009:1318; Gordon 1988). Since Dr. Bennett is a conventionally trained medical doctor, it therefore comes as no surprise that he would think in terms of specific "diseases" like fibromyalgia, for example, in the diagnostic process. Yet, it became evident in my conversations with Dr. Bennett how he is keenly aware of a patient's illness experiences as he described several ways pain can affect a patient's entire life. For instance, we saw him draw attention to how pain affects patients' family relationships, their various life roles and identities, their financial stability, their ability to work, and so forth, which indicates how Dr. Bennett (and the rest of the clinic staff too) do not view patient's only as their "diseases." Similarly, Baszanger (1998) pointed out how the medical doctors in her second pain clinic gained a fuller picture of their patients illness experiences by listening to them talk about how their pain condition has affected their lives. The staff in Jackson's clinic studied was also aware of a patient's illness experience as they described their "holistic" approach as "looking at the big picture, at an entire life rather than a body part" (2000:29). However, how Jackson's clinic then treated the "whole person" differed considerably from some of the other clinics profiled (e.g. through their use of the "confrontation therapy" approach).

The IMPC's treatment approach addresses the issues of "care" and "cure" in the following ways. For example, we saw Dr. Bennett talking about pain medication as an

example of a specific treatment modality that he said will not "fix" (i.e. cure) the patient's pain. On the outset, his language appears to be drawn from a biomedical model to pain treatment, which places emphasis on "fixing" pain (Crowley-Matoka, et al. 2009:1315). However, later on in the same interview with Dr. Bennett, he said "right now there's no...one treatment to fix" chronic pain. Here we can see how he is acknowledging that pain cannot be "fixed" as there is no one cure-all. Dr. Bennett instead talked about how each of the IMPC's treatments "provides a different way" to control the patient's pain. His descriptions highlight how the IMPC's approach takes a pain *management* perspective (the IMPC's focus on *managing* instead of curing pain is evident even in the outside signage that prominently reads "comprehensive pain management"). In this particular respect, the IMPC's approach is similar to other pain clinic models that do claim to "fix" pain, but rather manage it (e.g. Baszanger's second pain clinic and Jackson's as well). We will see how the IMPC goes about caring for their patients through pain management in the narratives presented in the two chapters that follow.

The IMPC's approach to integrative chronic pain management also negotiates the biomedicine/CAM dualism in several ways. I spent some time considering how this dualism emerges in the way the staff interacts with each other in the enactment of this approach. For example, Dr. Bennett saw himself as coordinator of a patient's integrative treatment plan given his role as the IMPC's medical doctor and clinic founder. This role clearly gave him an authority figure status in this IM clinical setting, which on the outset appears much like the elevated status the physicians held in Salkeld's (2004; 2008) IM clinic. Yet, Dr. Bennett also relied very closely on the staff to help him care for the clinic's patients through coordinating their efforts. At the IMPC, while each practitioner (e.g. medical doctor, physical therapists, and massage therapists) has their own role or specialty in the patient's treatment plan, they will often consult with one another to better synchronize their efforts. Roxy noted in chapter 4 that she does not feel as though she is "underneath" Dr. Bennett given her role as a CAM practitioner. Roxy mentioned how it was not uncommon for her to work with Dr. Bennett by sitting in and observing where he is injecting a patient so she can focus her massage around that particular area of the patient's body. Roxy also mentioned working closely with the physical therapists to bring her efforts into line with theirs if they share the same patient case.

As Salkeld (2004; 2008) noted, it is always important to consider power relations in these treatment settings. At the IMPC the emphasis on teamwork often helps with coordinating care across different types of practitioners even when their views may differ regarding the overall treatment plan. Even Erica who had some issues with IMPC management overall liked how she was able to do more than "fluff and buff" massages here, and that she had a degree of professional autonomy to customize her treatments and even utilize biofeedback therapy with some of her patients.

Having shared vision about integrated treatment at the IMPC includes trying to develop a treatment plan that will work and is feasible in a number of senses for the patient. For instance, they may start with biomedically endorsed treatment options that health insurance is more likely to pay for and then incorporate CAM from there. In the patient narratives in following chapters, we will see how the IMPC works with patients to try to help them justify the rationale for their treatment being covered. However, the IMPC staff also makes a point to be flexible and adapt to the reality of the patient's life circumstances and give them as much as they can afford and desire given the political economic realities of the Detroit metropolitan area.

I also found that the biomedicine/CAM dualism appears in the practitioner-patient relationships formed at the IMPC. An IM model of care emphasizes a more balanced relationship between the patient and the practitioner, lessening the practitioners authority during the clinical encounter (e.g. Bauer 2010; Caspi, et al. 2003; Consortium of Academic Health Centers for Integrative Medicine 2009). However, in Salkeld's (2004) IM clinic she found that the doctors still held an "authoritative" role with their patients. Yet, some of the language utilized by the IMPC's practitioners conveys how they see themselves in a less authoritative position. For instance, Dr. Bennett said that patient's "direct" his treatment of them and he is a "tool" that the patient can utilize. Consequently, the IMPC's practitioners emphasize the issue of patient responsibility differently than the doctors in Salkeld's clinical setting. We saw in chapter 1 how the doctors in Salkeld's clinic believed that their patients are not being responsible for improving their health and wellbeing if they do not incorporate the knowledge they provide to them into their lives. At the IMPC, the practitioners do want to know how patients are living their lives (e.g. managing their stress levels), and do offer advice on wellness and healthy living. However, they were somewhat more laid back about the issue of patient responsibility as the patient does not have to adopt this advice if they do not want to and can still be treated in this setting accordingly.

Interestingly, this more flexible attitude towards adopting practitioner advice even extended to me the dissertation researcher when they allowed me to continue on with the work I was doing there even when I did not fully show signs of adopting their advice regarding stress management yet (alas I have yet to incorporate this advice into my life). One has to wonder too if perhaps Detroit's reputation as an "unhealthy" place to live may have influenced the IMPC to take a more flexible view regarding patient responsibility. It appears as though the IMPC believed that providing a more supportive rather than authoritative environment in this regard would be more fruitful for patients to consider adopting their advice on wellness and healthy living.

Importantly, even though the IMPC is more laid back about this issue, the practitioners still at times use language that conveys a sense of biomedical authority. For instance, although Dr. Bennett conceptualized himself as the patient's "tool," he also felt that he was "the professional" who held particular "knowledge" that the patient needed when he said: "they're usin' my knowledge because I'm the professional to help them." Thus even in a setting like this one where there is clearly a stated desire for practitioner-patient autonomy and to truly have a co-created clinical encounter, there is still a power dynamic that remains and must be acknowledged. It must be determined at the IMPC whose knowledge is considered "expert" knowledge in the development and carrying out of patient treatment plans.

This chapter described the IMPC's approach to pain management that is embodied in the idea of "treating the whole person." I then discussed how the IMPC's "treating the whole person" approach negotiates the contrasting ideas of mind/body, biomedicine/CAM, care/cure and disease/illness discussed in chapter 1. The following chapter presents the first four out of eight patient narratives that show how this "treating the whole person" approach is enacted and perceived by the IMPC's patients.

## **CHAPTER 6**

# PATIENTS' STORIES & THEIR EXPERIENCES AT THE IMPC PART I

# "I never realized you can be in pain 24 hours a day, you know, seven days a week" (Christina, IMPC patient)

So far in this dissertation we have learned about the making of the IMPC from the perspective of its staff and practitioners. We have seen how its more "spa-like" physical environment and "family-like" culture provide the foundation for their "treating the whole person" approach to IM chronic pain management. In this chapter and the next, I will present a series of narratives to provide the patient's perspective and show how they connected with the IMPC treatment setting. These chapters present a continuum of these patient narratives showing variability in how they engage with the IMPC's "treating the whole person" approach, from those who more fully engage with it (chapter 6) to those who only do so in part (chapter 7).

These narrative accounts were created from several types of data including indepth interviews conducted with the patients as well as observations of their co-created clinical encounters. In each of their stories, we will learn about the patient's life that includes how their pain has affected their various salient life roles and identities (including their age-related identities like middle-age and older adulthood, and genderrelated identities such as mother, grandmother, wife, daughter, son, breadwinner, etc.), and the political economic struggles related to living in the repressed Detroit metropolitan area that are experienced by some. We will also learn about their healthseeking experiences prior to coming to the IMPC, what motivated them to come to this clinic, and their individual experiences engaging with the clinic's "treating the whole person" approach. Lastly, I discuss what was learned from each patient and what it reveals about the IMPC treatment setting.

Good writes: "Disease occurs, of course, not in the body, but in life. ... Its effect is on the body in the world! ... narratives are central to the understanding of the experience of illness, to placing pain...in relation to other events and experiences in life" (1994:133). For that reason, these patient narratives serve as a tool to help us better understand how the clinic's "treating the whole person" approach impacts the bodies and consequently the lives of their patients (Good 1994). As we have learned, the clinic's approach is comprised of three parts (diagnosis, the treatment plan, and the customization of it to patient's lives), all of which the staff sees as integral to helping patients better manage their pain, and begin to mend their bodies and subsequently their lives. Yet, what emerges from these patient narratives is the central importance of the practitioner-patient relationship to the IMPC's approach. As we will come to learn, what draws patients to this clinic and keeps them coming back, even when they only partially engage with it, are the bonds established between the IMPC's practitioners and patients during the customization of care. These bonds (over and above the diagnosis and treatments patients receive here) are what truly help patients begin to come to terms with how their condition has impacted their lives so they can start down the road to healing.

#### **BETTY'S STORY: BEING AN ACTIVE & INDEPENDENT OLDER ADULT**

Betty is an 89 year old white female of Lebanese descent, and a resident of Waterview. As an otherwise healthy older adult female who only usually experienced mild arthritis pain, her active retirement was suddenly sidelined by the onset of persistent chronic pain. At the IMPC, Betty learned that this chronic pain was due to trigger points that developed from an accumulation of lifelong stress. I had one in-depth interview with Betty, and also observed a co-created clinical encounter between Betty and Elizabeth, one of the massage therapists at the IMPC.

I found this case interesting because Betty described how she experienced age discrimination from the other doctors she visited who dismissed her pain as "just arthritis." Out of frustration with her negative health-seeking experiences as an older woman, Betty found the IMPC in her insurance provider booklet and decided on a whim to make an appointment to see what they had to say. While she expected to be stereotypically treated and told once again she had "just arthritis" pain, what she found instead was an approach to pain management that she felt resolved her acute pain episode. That Betty's pain was largely addressed in a matter of weeks was a huge relief to her in a number of ways. While physical relief was very important to her, so was finding a treatment setting where her concerns were not just dismissed as the "aches and pains of old age" that must be tolerated. Importantly, her fears of losing her independence and becoming a "burden" on her children if her pain could not be adequately managed were addressed. Rather, to her surprise, Betty described how the IMPC enabled her "gutsy" independent personality to emerge in their interactions with her as they sought to address her pain problem.

Betty had many roles throughout her life that included being a devoted daughter to her mother whom she cared for at the end of her mother's life, a wife, a mother to two children, a government worker and now a retiree. Betty oftentimes spoke very directly and used colorful language to talk about her life that she loved, but that also had periods of great stress. Betty grew up poor watching her own mother struggle to raise a family of four girls as a single parent after Betty's father abandoned the family when Betty was nine years old. Consequently, her family struggled through hard times and making ends meet without welfare.

To illustrate the kinds of hard things that she had to do as a child, Betty described how: "I used to stand by the trains when we lived down in Detroit. We lived near the railroad tracks. So we didn't even have a wagon, but boxes so I would go and stand by the train and wait for it to come so the coal could fall off and I could pick it up and carry it 'cause we had coal stoves then [to heat our home]." Betty added that coal stoves were dangerous, but her family had to keep their home warm so she would collect the coal for their stove.

Betty came of age as a young adult during the Great Depression years. At that time Betty began working for various government programs that enabled her to gain skills in business. Betty married but when her children were very young, her husband left her and she had to raise her children as a single parent while working between two to three jobs to support her family. Betty cared deeply for her children and worked hard to ensure they grew into successful adults. She described her 38 years of working for the U.S. military as a civilian employee as a highlight of her life that allowed her to get an education, travel the world, and become fluent in several languages.

Betty devoted herself to her career with the military. She worked in the contract and procurement field in many different locales around the world, and during major conflicts such as the U.S. military involvement in Korea, Vietnam and Desert Storm. A highlight of Betty's career came when she "was stationed in Korea" and worked with an adoption agency to bring Korean children to the U.S. for adoption. Betty worked hard during her career to be able to support herself in retirement because she highly values independence, a value that most likely stems from her life experiences. She never wanted to be in a situation where she was a "burden" and forced to rely on her children for support. Betty noted: "I don't rely on anybody. I don't have to. Made my own way and I can retire very comfortably on my pension."

Until the onset of her acute pain problem, Betty enjoyed a very active and independent life as a retiree. That life included enjoying simple daily pleasures such as eating her favorite food-Burger King cheese Whoppers®-and yard work. Bettv proudly mentioned: "I walk three to five miles a day and I just keep active. I mow my own lawn and do all my garden work and just keep busy." However, Betty unhappily noted that with her age brought age stereotypes where she was treated like she was "stupid" or "senile" which incensed her. She exclaimed: "They don't get away with that with me....Being in [the] service working with the military, sometimes my language....I let it rip! Damn right. This is who I am, you know, take it or leave it." The onset of Betty's pain threatened to derail her active, independent lifestyle she was accustomed to in retirement. Betty was no stranger to pain from an earlier severe pain episode in her life. When Betty was working for the U.S. government in Vietnam she described experiencing severe paralyzing pain until she was treated with acupuncture and cupping that resolved the condition. In 2008, Betty suddenly experienced the onset of what she described as the same type of pain that began in an acute stage and when not resolved by several visits to doctors, became a debilitating pain condition. Betty, a healthy older adult who did not take any medication except an occasional Motrin® or Tylenol® for

headaches, suddenly had her active retirement sidelined by this pain that was "affecting her head." Betty's life became severely disrupted for several months. She lamented: "Now in fact I didn't wanna do anything because everything was just a chore to me. You know if I walked it was painful. So consequently I just sat. During the winter I just sat. Picked up weight. Was terrible."

Betty had several negative health seeking experiences as she felt doctors dismissed her head pain as arthritis, but Betty said that she had never heard of someone having arthritis in the head before. Betty commented: "I say they don't [i.e. the doctors] show me any class....I felt that, you know, when you're old...the first thing they're [i.e. the doctors] gonna say 'Well, you know, it's just arthritis." Worried that her pain was the sign of a serious problem, Betty looked through her insurance provider booklet and found the IMPC, liked the fact the clinic was close to home and decided to "Give it a shot." Figuring she had nothing left to lose, Betty came to the IMPC ready to confront yet another doctor who would dismiss her pain as "just arthritis."

Upon coming to the IMPC, the clinic had an immediate positive impression upon Betty who liked how she was treated with respect that was lacking at all the other doctors she visited for her acute pain. In the interview excerpt below, she described in lively language how, when she met Dr. Bennett for the first time, she assumed he might be another one of those doctors who would disrespect her:

I walked in here [the IMPC] when I first found Dr. Bennett and the first thing I said to him—I had all my medical records with me—and I said to him "Well let's be honest. This is me and if you—I've been through hell and high water with this. Since August I've been in pain, and if you can help me, fine. If you can't just don't waste my time. Don't waste your time. I could give two shits less…!" And I said [to Dr. Bennett] "I'm sorry this is me. Take it or leave it." …He said "Oh you're gutsy!" …he was very nice. I said what I appreciate 'bout—'bout this

place is that no matter how old you are you're treated with respect....There's lots of respect here. To put up with me my God!

The IMPC's holistic approach was vastly different from Betty's other doctors who, based on her age, only saw her as a case of an older person with "arthritis." Betty knew that she had a serious problem and was experiencing way more than just "run of the mill" arthritis pain or pulled muscles. She described her pain as so intense that she wanted to "cut my head right off" and that she would "commit suicide" if she could not find someone to help her. A comment I found surprising for the "gutsy" Betty. Betty stated how the pain "really frightened the hell outta me" because she felt like something was "gonna burst" in her head that could cause her to "lose control" when driving and possibly fatally striking someone.

In thinking about Betty's life issues and pain holistically, Dr. Bennett identified what was causing Betty's pain and developed a treatment plan to address her problem. He felt that Betty's desire to remain independent into older adulthood drove her to work hard her whole life, which caused much tension—including physical tension, specifically in her head and neck. Dr. Bennett and Betty identified that it was this tension that was causing and worsening her pain as she formed trigger points in her body. The IMPC approached Betty's pain by educating her about this condition through the use of diagrams that explained to her how the trigger points affected the nerves, muscles and veins in her head. Betty explained the process of Dr. Bennett teaching her about trigger points:

He [i.e. Dr. Bennett]—he said that it was muscles—muscle, nerves that were on top of each other. And he showed me the diagram and where—where the pain was, and what the pain—he described everything. How the pain reacts to the veins and the muscles in the head. The correlation between that.

Addressing pain for Betty also meant that the IMPC staff had to customize her treatment plan in order to help Betty think about how to best address the tension in her life. Betty's treatments included physical therapy, massage and trigger point injections to help reduce overall levels of tension. This series of activities were undertaken to assist Betty in stress management along with formal and informal conversations during her cocreated clinical encounter.

With Elizabeth, an IMPC massage therapist, I was able to observe a massage therapy session. Both Elizabeth and Betty initiated conversations covering everything from Betty's cooking at home to what was occurring to Betty's body during this massage. The following fieldnote excerpts below demonstrate the importance of these conversations in customizing Betty's treatment plan to her central life goal of desiring to remain independent. In the first excerpt, Elizabeth and Betty talk at the beginning of the massage about how the clinic's treatment plan was addressing her pain:

The massage begins with Elizabeth asking [if] the patient [i.e. Betty] has...seen the doctor since they last worked together. Betty said she saw the doctor on Monday and had [trigger point] injections. She said the injections "unknotted" her. Betty said [to Elizabeth] she feels fine after all these treatments she receives at the clinic. She said she feels like two million, five hundred thousand dollars since coming here for her treatments. Betty said everything is helping, the shots, PT and the massage. Elizabeth [then] describes to Betty, in anatomical and physiological terms, why she gets the pain that she does in her head and neck (Fieldnotes May 22, 2009).

Although Betty initially had the cause of her pain condition explained by Dr. Bennett, we can also see from this excerpt how Elizabeth reinforced this information again during her massage. Betty also demonstrated her growing knowledge about the cause of her pain during the encounter when Betty told Elizabeth how she was starting to catch herself when tensing up.

During this encounter Elizabeth also educated Betty about healthy living that

included encouraging her to drink more water because with advancing age, the body's

tissues and joints "dry out:"

Elizabeth then continued to explain [to Betty] how the fascia connects everything [in the body]. Elizabeth said that the myofascia can become dehydrated. Betty doesn't like water and has to force herself to drink it [she said]. Elizabeth said that as we age, our joints and the fascia dry out. Once Betty found out about this, she said she will start drinking more water. Elizabeth suggested a few ways to the patient to incorporate more water into her diet....Elizabeth tells Betty that water, walking and watching your weight are the "3 W's" and key [to being healthy] (Fieldnotes May 22, 2009).

In addition, Elizabeth provided another healthy living suggestion to Betty by

encouraging her to take senior yoga classes to help address her tension:

Elizabeth suggested to Betty to take yoga classes. Betty said when she was in Florida, she took water ballet. Elizabeth suggested that she visit [a local community center] to take senior oriented classes. However, Elizabeth was sure to tell Betty that this is not the "rocking chair crowd" that she would encounter [at other more senior oriented community centers] (Fieldnotes May 22, 2009).

During this massage, there were numerous instances where Elizabeth asked Betty for

feedback on her treatment to ensure she was not injuring her by applying too much

pressure during the massage. I captured one such interaction in the fieldnote excerpt

below where Betty learned from Elizabeth the difference between feeling "good pain"

and "bad pain" that a patient might experience during a massage:

Elizabeth tells Betty to take a "good breath in from your ribs." Elizabeth then said [to Betty], "Does that hurt? You're making faces at me." Betty said the area is so sore. Elizabeth said that achiness, a "dull achy" feeling is a good thing and means that the area is stretched. She said sharp and burning pain is no[t] good [pain to be feeling] (Fieldnotes May 22, 2009).

At the conclusion of Betty's massage, Elizabeth encouraged her to remain on the massage table so she could continue enjoy its relaxing effect on the body rather than hopping off right away. However, Elizabeth then joked with Betty that she

acknowledged the reality of Betty's personality and that Betty is not one to spend additional time on the massage table after treatment. In fact, Elizabeth laughingly commented that she would most likely be dressed and be out the door quickly in order to resume her day.

When interviewed, Betty spoke highly of her care overall and specifically emphasized how the IMPC staff respected her as an older adult. While this certainly might not be the result for every 89 year old, Betty said her pain had completely resolved itself with her treatment plan. She told Elizabeth that she was "Starting to feel like my old self again." Betty believed that her pain will not return and said: "I'm not worried about it [i.e. the pain] at all. I don't expect it to be back. If I have a pain every now and then or...[muscle] soreness...that's no big deal. I can expect arthritis pain. It's no big deal. I understand that. No. As long as I don't have this [head pain]." Now that Betty said that she knows that tension caused her trigger points, she said she was working on relaxing more: "And I know that I have to...relax. Because I've always had tension all my life so it's my fault too....'Cause I was always in the running. I'm always in a hurry."

## Discussion

What became apparent as Betty told her life story was the strong value she placed on being independent, being her "own person" and doing what it takes to keep that going—even in advanced old age. Several of Betty's life experiences most likely contributed to her independent "gutsy" personality. She grew up impoverished in Detroit where she had to collect coal that fell down by the railroad tracks to help heat the family home. Her father abandoned her family, so her mother raised her and her sisters, and she lived through the Great Depression as a teen and young adult. Mirroring her own mother's life experiences, Betty's husband left her and she had to raise her children on her own as a single parent. She had to work up to three jobs at one time to help support her family. When she worked for the military, she did so during major conflicts, and at the conclusion of her military career she retired fully able to support herself.

However, the severity of her pain that made her want to "commit suicide" challenged her "gutsiness." This pain problem highlighted her deep-seated fears of losing her own independence in old age, whereby her unresolved pain would cause her to be a "burden" on her children, along with the realization that her condition could cause her to accidentally harm someone by losing control of her automobile and more importantly, lose control of her life.

As we learned, Betty's prior biomedical doctors saw her as her case as "just arthritis." The perspective of these doctors were that she had to accept an altered and more frail reality filled with the routine "aches and pains" of old age. According to Betty, these experiences likely eroded her sense of independence and amplified the amount of disruption she was already experiencing in her life. Betty's experience at the IMPC was the opposite of her fear of being treated as a stereotypical old person; rather the clinic staff enabled Betty to be the "gutsy" independent person she was. This validation showed that the IMPC understood the effect that Betty's pain was having on her selfperception and her life overall.

In the process of addressing Betty's pain, the IMPC staff continued to work with Betty to sustain her self-identity as an active older adult. For example, Elizabeth suggested she take senior yoga classes to help with her tension, and suggested a location where she could go and not encounter the "rocking chair crowd." In framing the yoga class in this way, the IMPC continued to enable and acknowledge Betty's "gutsy," active and independent personality. Betty also mentioned how she felt others perceived her as "stupid" or "senile" because of her advanced age. By contrast, Dr. Bennett and Elizabeth did not talk down to Betty, but educated her about her trigger points that caused her pain episode, and how to manage her "tense" life which most likely contributed to the cause of this specific pain condition. Dr. Bennett and Elizabeth's sharing of their medical knowledge with Betty was indicative of how they felt she was capable of understanding this essential information about her health and realizing she had to make some key life changes to try to prevent the pain from returning, like reducing the tension in her life. In my opinion, it was Betty's relationship with the IMPC staff combined with their particular treatment approach that addressed her trigger points approach that moved her towards a more pain-free future.

Betty said that her pain problem was completely resolved and that her treatment experience at the IMPC was entirely satisfactory. Betty's assertion is most likely due to two factors, those being her perceived efficacy of the IMPC's holistic pain management approach and the IMPC staff giving Betty a renewed sense of confidence that she would not have to spend the rest of her life in debilitating pain. One interesting note in retrospect is to wonder if Betty's previous life experience with acupuncture when she was in Vietnam made her more open to the integrative treatments the IMPC utilized to address her chronic pain. Unfortunately, I did not have the opportunity to explore this possible connection further.

# **ROBIN'S STORY: EXPERIENCING A LIFETIME OF PAIN**

Robin is a 60-year-old female of Native American, African and Irish descent. Robin's case differs from most of the other patients interviewed as she described being in pain for her entire life. Robin emphasized the salience of this idea for understanding her life when she exclaimed: "I always say I've been in pain since I was born!" Robin then went on to mention an early incident of being dropped as an infant by a hospital nurse and suffering a broken collar bone. As Robin's narrative unfolds, it becomes evident that understanding her health problems is a predominant theme in understanding her life history. In addition to ongoing pain issues, Robin also experienced some other serious health conditions throughout her life and, as a result, has had few moments where her health has not been a significant issue in her life and affected the various roles she has held in some key ways. I learned about Robin's life story and illness experiences through two in-depth interviews. I also observed a cocreated clinical encounter between Robin and Jennifer, the IMPC's physical therapy assistant (PTA).

Robin had only been a patient at the IMPC for about a month when I interviewed her. However, she was feeling quite positive about the IMPC and said she already experienced a "dramatic improvement" since this clinic had already began to address lingering problems that remained since a 2007 surgery to correct her "twisted and tilted" spine. Although Robin considers that she had mainly successful surgery to address this spine problem, Robin was now seeking treatment at the IMPC to help her with certain aspects of recovery after this surgery resulted in "new pains." Robin's narrative differs from other IMPC patients who spoke about avoiding surgery due to what they feared would be a negative outcome, or had surgery that did not bring about a desired outcome.

I found Robin to be a soft spoken individual with a gentle personality who held a positive attitude about life. She also had a witty sense of humor that I had the opportunity to observe as she was not afraid to joke around with the IMPC staff during treatment sessions. In her life story presented next, we will come to see how Robin's positive demeanor and sense of humor has helped her cope with a lifetime of pain.

Family was very important to Robin as she talked about being a daughter, sister, mother and a grandmother at various times during her interviews. She described coming from a close family and having had a "good life" despite not having a lot of money, and ongoing health issues. Reflecting upon her life she noted: "if I put the pain aside, you know I've had a very good life. I had two great parents and three great sisters." Robin, and her family, lived down South for the first few years of her life. She described happy times living there where her family owned a diner that saw a lot of business from soldiers at the nearby military base. When she was six, her parents decided to move to the Detroit area and she has resided here ever since. Robin's family moved based on the advice of her aunt who was a nurse and living in Detroit at the time. Two of Robin's sisters needed better medical care than what they were receiving down South, and her aunt felt the medical care in Detroit would be better for them.<sup>45</sup>

As one of four siblings, Robin described being particularly close to her one older sister. Robin experienced a devastating loss when this sister passed away when the sister was only in her early 20's. Robin could not recall the exact age she was when her

<sup>&</sup>lt;sup>45</sup> Robin chose not to disclose what her sisters' specific health problems were.

sister passed, but said she was "very young." Robin partially explained the tragedy that befell her sister:

my oldest sister married someone who did not treat her in a good way. He used to drink. Used to fight with her and—and when she was pregnant she was 21 going on 22, he kicked her and her top teeth went through her bottom lip...she ended up losing the baby. And while she was in the hospital she pretty much just gave up and passed.

Robin mentioned with grief how her sister's death greatly affected her, even now: "I still to this day miss her."

Robin affectionately spoke about her parents, mostly in terms of reminiscing about the various occupations they held while she was growing up. After moving to Detroit, Robin said her mother became the "head cook" at the Catholic school that Robin attended for most of her primary and all of her secondary education: "I went from third grade through the 12<sup>th</sup> grade at the same school. Same building. It's like they didn't unlock the door till we graduated!" Her father was mainly involved in carpentry work as she described him in one instance installing new flooring in a church. Robin also mentioned a happy time for her parents when they owned a charter bus company in Detroit, and said this was "good for them." Robin currently describes herself as "single," but she does have a grown child—a son—who is married with children of his own. She did not talk much about her son, but overall spoke positively about their relationship and described him as "a good kid."

Along with Robin's roles as a family member, Robin held two other roles in her life, namely a musician and a patient that she described in detail. Robin's passion for music began when she was four years old and started playing the piano. Her passion for music led Robin to begin playing the organ at a local church where she later learned how to play the guitar for their services. The church gave her a guitar that she still cherishes to this day: "So they had a guitar made for me, which was really great and beautiful guitar. I still have it and still play it." Robin also taught music in the Catholic elementary and middle schools where she would "go around from the class—to the classrooms with my guitar. I'd start playin' the guitar. So I did that. We used to put plays on and I did that for 17 years." Robin moved from teaching to bookkeeping at the Catholic high school for several more years at which time her pain conditions described below interfered with her ability to teach.

As seen in Robin's earlier comment about being in pain from nearly the time she was born, it is not surprising that Robin identified being a patient as a major and ongoing life role for herself. Thinking about this role, she commented: "Cause I—even now I—when I go to the different offices or—or if I'm, you know, lying on the bed waiting for the doctor, I look up at the ceiling and think boy these ceilings never change! Since I was a little kid and to now is just always the same." Robin associated the ceilings in her doctor's offices as a symbol of her lifelong patient role that started in childhood. Robin became ill with rheumatic fever that affected her heart valve and she missed attending the sixth grade at her Catholic school. She had to be tutored at home that year while she recovered from her illness.

Due to these serious problems, Robin confronted the possibility of mortality at a young age and talked about her fears: "I always thought that oh my gosh I won't live till I'm 10 years old, you know?! Always had that fear, but so that was that." When Robin was in her late teens, she also had to have a benign breast tumor removed and has had several different types of surgeries since. After the birth of her son, she had a

hysterectomy due to a "fairly large" benign tumor in her uterus. This operation proved to be very dangerous for her as she almost died during surgery. Other surgeries followed including one on her tear ducts due to severe dry eye, and a yearly surgery to keep her esophagus open due to a diagnosis of Schatzki's ring that caused her esophagus to close to a dangerously narrow point to where she "can't even swallow water." Robin's experiences with her health problems played a predominant role throughout her entire life. However, she especially talked in great detail about the chronic pain she experienced during adulthood, and how it affected her life.

Robin spoke most about three types of painful conditions that plagued her in adulthood. The first involved her diagnosis of trigeminalgia, a chronic painful "facial nerve disorder" Robin suffered from for many years. She described the condition where "you get ticks where your lip goes up and that gets kinda painful, until it relaxes" and "it felt like a 18 wheeler driving on my face." This condition interfered with her career as a music teacher in the Catholic schools, and she described below how she felt when she experienced an acute attack:

Robin: and whenever my face would tick I'd—I—well I—of course I'd warn people ahead of time, you know? "Something's gonna happen. Don't let it scare you!"

LM: You could feel it coming?

Robin: I could feel it coming, yeah and—and then my lip would go up and—like Elvis, that—that type of going up and the people would just sit there and watch [and say] "Wow look at that!"...it used to be embarrassing. I used to teach in school, grade school, and this was when this was coming on, and I was embarrassed by it and would go—I went to the principal and explained it and he says "Well we'll have you do something else besides the teaching. We won't have you teach as much," you know? So I went into—from teaching music to bookkeeping. Yeah so I had an office and that's how the bookkeeping started. Yeah. I miss the teaching, but that was that.

Robin started bookkeeping at the Catholic high school to accommodate her trigeminalgia, but said that medication "pretty much" controlled the condition now. With her condition managed, she was able to return to teaching music part-time at the high school in addition to her bookkeeping job, until the school closed permanently. Robin was very matter-of-fact when she reported how her condition impacted her teaching, but also had a tone of longing in her voice when she described this period in her life.

In addition to her trigeminalgia, Robin described how her spine was "twisted and tilted" instead of straight, a lifelong condition that she began to experience the effects from when she was around 30 years old. The unusual position of her spine caused Robin severe back pain that affected her work where she had to make accommodations to get through the day: "with my jobs I've had to get up and stand against the wall or walk around, you know, massaging my back." Not only did her chronic back pain affect her work life, it affected her leisure pursuits, too. For example, Robin mentioned that one of her leisure pursuits that she gave up was being a clown that visited hospitalized children. Robin learned how to do clown make-up, had her costume and even her clown name (Melody). However, she had to give up this activity shortly after her training due to her intense pain.

In addition to giving up her interest in being a clown, Robin discussed how her pain affected her ability to sing during Sunday church services. She had to find creative ways to accommodate her pain that even included using the church's architecture:

In church on Sundays, we have these small poles in the church, pillars, and whenever I would hurt I would go over there and just stand against the pole. ...and we'd sing with me standing there next to the pole, you know!...It would relieve like the pain. I would push against it [the pole]...I have my favorite pole in church, yeah.

Robin also used church books and placed those behind her back to relieve the pain she was experiencing. Fellow church members also used to see her in pain and would give her massages to bring relief. Robin talked about how the parishioners would come to her aid when they saw how much pain she was in: "there are times a choir member would see that I'm hurting and they would come up and massage the lower back while I'm there playing, and they'd come up and massage it, you know? So they can tell by the way I look that I'm in pain....I used to be able to hide it [being in pain]." Over time though, it had become less possible for Robin to hide her excruciating pain.

Because Robin was eventually unable to hide physically expressing her pain, she opted to have back surgery that she avoided for years out of fear that it would not help her condition. Robin discussed how she reached this breaking point with her severe chronic back pain: "Everybody said 'Don't have surgery,' you know? And I got to the point where I had to do something 'cause it was getting to be too much, you know?" Robin underwent successful back surgery in 2007 and is now off of the powerful pain medication Oxycodone<sup>®</sup>. However, Robin talked about "new pains" that surfaced after her surgery and continued to greatly affect her life as her muscles had to learn to adjust to her spine being in its correct position since this surgery. This new pain was not as severe as the pain Robin experienced prior to her 2007 surgery, and she distinguished it in the following way:

I have pain from my hip to my—to the area where I had the surgery in. But it's all muscular. For so many years I had this [spine] problem, you know, with my back and I moved a certain way and the muscles I guess got used to that way and now that my spine is straight [since the surgery], the muscles have to go back to where they should be....They're knotted up.

Robin had a course of physical therapy after the 2007 back surgery, but by 2009 she needed more comprehensive care to address these pains that would not subside. Robin discussed how her surgeon referred her to Dr. Bennett and the IMPC as the next step in addressing her "new pains:" "He says [i.e. her surgeon] 'I think it's time you saw a physiatrist.'...He says 'I've done my job!...It's time for massage therapy and working with the muscles now.' So that's why I'm here [at the IMPC]. I'm glad I came. Everyone is so nice and helpful." Interestingly, Robin had never heard of the medical specialty of physiatry before her surgeon mentioned it to her and she said she "had no idea what a physiatrist was" or "even know how to pronounce it at first!"

Robin mentioned that she noticed how the IMPC is different from other medical practices by describing the social environment as "like family," and the staff as "cheerful," "nice," "friendly," and "helpful." With her vast experience interacting in different medical practices, Robin noted that these are characteristics "you don't see that often." Robin felt "lucky" to have come to a clinic like the IMPC for her care. Robin perceived the IMPC's clinic environment as having a youthful energy as she described below:

So he came in and—and we're sitting there waiting and I see this young guy walk by [i.e. Dr. Bennett]. He says "Hi. How you doing?" I said "Fine." I didn't know who—who it was! So I'm just looking—looking at a magazine and then they call me in the office and—and this young guy comes in. I [said] "Oh! Are you the doctor?"...[I] said "Wow. This is a young office!" But so friendly. So helpful and, you know, [they said] "We're gonna get ya back on your feet and feeling better and"—and I felt good.

Robin also mentioned how helpful it was to her to have doctors who patiently listened and explained her treatment plan. She described her surgeon in these terms, and Dr. Bennett as well: He [i.e. Dr. Bennett] takes his time! Listens to everything and then he says "Okay you're gonna remember everything I told you?" I said [to Dr. Bennett] "Well I didn't know I was supposed to remember!" And he said [Robin makes a noise of Dr. Bennett pretending being upset] "I'll write it down for you." But he's—he's very good. I—I'm glad to be here.

Not only did Robin find Dr. Bennett to be patient with her and a good listener, her words revealed how she felt comfortable enough to allow her own sense of humor to emerge in her interaction with him. It was her wittiness that prompted Dr. Bennett's sarcastic response back to her where he pretended to be upset with Robin for not remembering what he had just said.

Since her 2007 surgery Robin's spine was now in its correct position, but the muscles that surrounded it had not yet fully adjusted to their new positions. As a result, the tension in these particular muscles caused the formation of numerous trigger points that left Robin with "new pains." Robin described what she felt like when these "new pains" were at their absolute worst: "When it's really, really bad, it's like someone has a—a knife sticking in my lower back...And in the cervical area, it's more like—I'd say maybe driving nails in! You know it's—it's all the pain is sharp pain. It's not like a dull pain. It's all sharp." The IMPC began to address Robin's pain by developing a treatment plan that integrated trigger point injections performed by Dr. Bennett, massage therapy with Elizabeth,<sup>46</sup> and physical therapy with Jennifer the clinic's PTA.

Robin acknowledged that for the clinic to address these "new pains," she must also experience some pain from her treatments. I had the opportunity to observe one of Robin's hour-long physical therapy sessions with Jennifer that showed me the importance of the practitioner-patient relationship of the IMPC's approach and the trust

<sup>&</sup>lt;sup>46</sup> To Robin's surprise, she and Elizabeth had a previous connection with one another; they attended the same Catholic high school and "graduated together." This shared aspect of their past helped them to more quickly forge a therapeutic relationship.

that must be built as treatments to address the pain proceed. In the fieldnote excerpt below, we see how Jennifer and Robin had to work through a process of addressing pain Robin experienced from her physical therapy session as her muscles were trying to adjust to their correct positions.

The patient [i.e. Robin] is now doing pelvic tilts. She is now on her back on top of this long table, with her head resting on a pillow. She raises her pelvis upward and down...the PTA [i.e. Jennifer] has her go from 15 pelvic tilts in previous "I lost count...shoot" Robin says while doing these sessions to 30 now. exercises. Jennifer now has Robin press her back into the [this] table and this causes much pain...Robin rates the pain as a ten on the one to ten (with ten being the worst)...pain scale. Robin said the exercise "smarts". Due to the pain Robin is in, Jennifer changes the [therapy] plan and has her roll a large yellow exercise ball back and forth with her legs while lying back on the table instead of the other painful exercise. Jennifer watches Robin and checks to make sure she is doing the exercises correctly. Jennifer then puts weighted belts on Robin's legs and has her do leg lifts, first with the left leg and then switching to the right She tells Robin that she doesn't have to lift her leg so high for these leg. exercises when she [i.e. Jennifer] notices how high she [i.e. Robin] is going. Jennifer sits on the exercise machine next to the table to observe Robin as she is switching back and forth between her legs for the leg lifts (Fieldnotes February 19, 2009).

Based on feedback from Robin, Jennifer adjusted her therapy plan accordingly to reduce the pain Robin experienced from her treatment, and then monitored her closely once she put this new plan into effect.

Robin's witty sense of humor emerged throughout my observations of this cocreated clinical encounter. Robin said lightheartedly that she has a "strange body," and that "some little man" gets into her body at night and knots up all her muscles. She joked about the number of repetitions she had to do with one of the weight machines, and also stuck her tongue out at me while laying face down on one of the physical therapy tables while having Jennifer was doing manual therapy on her glutes (a spot of "referred pain" Jennifer said, often seen in back pain patients like Robin). Additionally, when Jennifer left the room momentarily and then returned, Robin said in a joking tone "uh oh...she's back!" At the end of Robin's session, Jennifer (who was more reserved with her patients than some of the other IMPC staff) lightheartedly told Robin "I'm done torturing you."

While Robin was still in pain at the time of her interviews, her positive attitude emerged in her assertion about her future: "I anticipate no pain. I'm looking forward to that." Thus, Robin fully anticipated being able to leave the care of the IMPC staff completely pain free one day. Importantly, despite her lingering physical pain, she talked about how she felt "mentally" better since coming to the IMPC:

I—I'm—mentally I'm a lot better, okay? I—and that's important to—even though I have—I always say my new pains, I'm—I'm a lot better. And I believe it and—and I feel it too, so. And I feel that when I walk out—the last day I walk outta here I'm going be perfect. I—I truly believe that. I'm so glad I'm here.

Until the day comes that Robin can "walk outta" the clinic pain free, she continued with her treatment plan that included starting trigger point injections with Dr. Bennett, and exercising at home, which was suggested by the IMPC staff as they provided her with a set of physical therapy exercises she could do on her own.

Robin acknowledged the importance of exercising on her own as part of her treatment plan when she felt she still needed "to move around more" and "walk a little more" when it gets warmer outside (it was February when I interviewed her). However, Robin recognized two realities of her life circumstances that influenced her ability to exercise more: weather and crime. Robin found that the weather in the Detroit metropolitan area, especially in winter with cold temperatures and dampness, elevated her pain levels and she yearned for a "warmer climate" and one that is drier. Robin also felt that her living situation prevented her from exercising more:

Right now in the neighborhood I'm in is not the greatest. Course it's Detroit, but it's not the greatest so I'm hoping in the near future I can be in a safer place and feel good and feel like I can go out and walk around a, you know, walk around the block. Ride a bike around the block without being afraid. And not having to look around every time I open the door!

Thus, not only did Robin desire moving to a "warmer climate", but "a safer place" outside of the city of Detroit where she imagined that she could get more exercise. In addition to Robin's worries about not exercising enough because of weather and crime, she also worried about her ability to continue with the comprehensive level of care she had at the IMPC if she lost her health insurance. She had good health insurance that covered her care, including her massage therapy, and said she is "lucky that way." However, she noted that her financial situation could change at any time due to the bad economy: "I have insurance through [insurance company name] and right now, hopefully things stay as they are. With this economy like it is, I don't know."

Discussion

It became noticeable as Robin told her life story how her positive attitude and witty sense of humor likely helped her cope with her identity as a lifelong patient; a role that began in childhood and continued throughout her adult life to the "new pains" she experienced after her back surgery. Yet, I believe that Robin's ability to remain positive and humorous amid all her numerous health problems helped her take their effects in stride. For example, when she discussed her fears of dying as a young child ("I always thought that oh my gosh I won't live till I'm 10 years old, you know?! Always had that fear, but so that was that") and how her painful neurological disorder forced her to give up her cherished role as a teacher ("I miss the teaching, but that was that"), she ended her discussions about these topics with the phrase "that was that." I perceived Robin's

phrasing as an indicator of how she accepted what had happened to her, adapted her life accordingly, and moved forward to the best of her abilities. When Robin's neurological problem distorted her face and caused her to give up teaching, she became a bookkeeper at the school instead.

Robin clearly felt comfortable in the "cheerful" and "friendly" IMPC environment that she described as "like family." The IMPC's upbeat atmosphere became evident when Robin noted how she immediately felt better when Dr. Bennett assured her "We're gonna get ya back on your feet and feeling better." In this instance we see Dr. Bennett's "can do" attitude emerge in his interactions with Robin. As indicated earlier, Dr. Bennett has a reputation in the medical and local community for being able to handle longstanding complex pain cases. He was not daunted by Robin's medical history, including her pain problem and set out right away to take a new kind of approach than what had been tried before to address the "new" pains resulting from her spine surgery. As well as offering pain treatment services like physical therapy and massage therapy, the IMPC staff really helped Robin envision what a pain-free life could be like for her.

Humor was a core aspect of Robin's personality and most likely was a reason why she liked the clinical environment at the IMPC. Given her unrealized desire to work with hospitalized children as a clown, it appeared Robin realized and respected how humor could be an important aspect of the healing process. The clinic's social environment enabled Robin's humorous side to emerge as seen in the lighthearted banter between her and Dr. Bennett, and with Jennifer during her physical therapy session. As such, she noted that she felt "mentally" better since coming to the IMPC and had a happy demeanor during her interviews. Robin also alluded in her comments to the positive effect her mental state had on her. She had acquired a "sense of hope" because things were going so well with her pain treatment, and had a greater interest in working on her overall health and wellness.

Importantly, the IMPC's approach provided Robin with a sense of confidence that she will be able to "walk outta here [the IMPC]" completely pain free. Robin's belief that she would be a pain free raises interesting questions about her future. A key aspect of Robin's identity was her lifelong role as a patient as seen in her comments about the number of doctors' offices she had visited (and ceilings she stared up at) during her lifetime. Ironically, it was this patient identity that was the one constant throughout her life amid all the problems that her health conditions caused like interfering with some of her personal and professional goals. The prospect that Robin could face a future not only free from physical pain, but free from this patient identity raises interesting questions about her life as she moves forward. Robin was now presented with the possibility of creating a whole new life for herself without this key role that provided a sense of stability for most of her life.

However, as we can see from Robin's story, there are a few factors that could potentially cloud Robin's desire of creating this new, possibly pain-free life. Robin never went into great detail about money issues except to mention growing up without a lot of financial security, and that she lost two jobs. She mentioned having good health insurance, but she worried about the influence that the nation's poor economy might have on her ability to retain her current level of coverage. If Robin were to lose this insurance coverage, this could affect the ability to afford the treatment plan she was undergoing at the IMPC. For example, a change in her coverage could result in the loss of massage therapy as a covered benefit. Robin also acknowledged the importance of taking responsibility for her health such as exercising on her own to help in addressing her pain. Yet, if she is unable to move to a warmer climate or to a safer neighborhood outside of the city of Detroit where there may be less crime, these factors could continue to impede her progress to be completely pain-free, and this new life she so strongly desired.

#### CHRISTINA'S STORY: LONGING FOR "MY OLD LIFE"

Christina is a 49 year old white female who was hit by a drunk driver one night on her way home from work. The sheer impact of the accident began a cycle of chronic and debilitating pain that severely impacted Christina's otherwise very active life. Christina came to the IMPC for treatment very early on in her health seeking based on the suggestion of her family doctor. In her in-depth interview, Christina described not only the intensity of her chronic pain, but the frustration she experienced as she longed to "go back to my old life." Christina told me about how she had been a patient at the IMPC for about six months and was very pleased with her current care and improvement in her overall condition since her accident. She fully engaged with and was committed to the IMPC's pain management approach, which had greatly improved her pain, but she still felt she had a long way to go to reach the "100 percent" she desired. Along with the in-depth interview, I had the opportunity to observe a co-created clinical encounter between Christina and Roxy, a massage therapist at the IMPC.

Christina's story involved overarching political economic issues that she faced as she tried to move forward with her life. Christina's financial situation was not stable. She was constantly threatened by her insurance company refusing to pay for treatments and forcing her to return to work while still not "100 percent." Christina had no choice but to pay for her massage treatments out of pocket but said she will "find a way" to do so. In my conversations with Christina, she came across as a very determined individual who was not afraid to speak her mind. However, another side of Christina that reflected a tenderhearted side of her personality also emerged in our conversations.

Christina was proud of holding a number of key roles in middle age before her auto accident and ensuing pain negatively impacted her ability to hold these roles. Christina had been a foster child, wife, and a mother to three children, a volunteer, as well as a fulltime student who worked two jobs. Christina's early years were spent in four different foster homes: "I don't have just a family; I have many [families]...So it would be many different ethnicities. Different walks of life. Different types of people. It would look like the United Nations!" Despite having such a large number of people who comprised her foster families, Christina grew close to only one of her foster parents that she endearingly called "mama:" "she's [i.e. mama] a black lady and, you know, she actually has baby pictures of me in her album and she tells everyone 'This is my daughter.' And I have pictures of her at home and I [tell people]—this...[is] my mom."

In large part due to her own earlier life experiences with family instability, Christina was deeply devoted to her roles as a wife and mother. Her children were adults with the youngest at 21 years old still living at home with Christina and her husband who worked full time in the automotive industry. Although her children were grown and her husband was employed, Christina constantly worried about them. Her son was serving in the military in Iraq, and her husband had an uncertain job future in this economically challenged region of the country. Christina exclaimed in worried tone: "Our middle son's in Iraq. He's in the Army. Does my husband go to work today or not? You know? It's horrible. I wouldn't recommend this life for anybody! It's like okay do I eat today or not? You know?"

Christina also mentioned suffering from ongoing depression. To help mediate this condition, Christina kept a busy life managing all of her other roles like her volunteering, working and going to school. Christina talked about her depression and why she needed to "keep busy:"

You definitely have some really, really bad days [with the depression]. And then sometimes you have really, really good days so I think that's one of the reasons I keep myself busy. And as bad as the economy is, I still try and give to homeless shelters...taking scarves in the wintertime. Scarves and hats and gloves. A bologna sandwich it's like a whole—they've got a meal there. ...Some people don't eat for days at a time...it bothers me. [Christina chokes up] It shouldn't be like that in this state. It shouldn't be like that anywhere in the United States.

Although Christina worried about her family and her financial situation, she told me that she knew that life can be much worse. By taking food and clothing items to the homeless shelter, Christina felt some aspect of control that she can at least do something to help those less fortunate than her. Christina also helped homeless people who approached her by buying them meals, and worked for several years with an AIDS organization. Her work with this organization was prompted when Christina's son received a blood transfusion at the young age of three years old that she learned was possibly contaminated with the HIV virus. This scary experience raised her awareness of and concern for HIV/AIDS related causes and influenced her interest in volunteering in this area. Christina reported that she had a great work ethic. At the time of her auto accident, Christina had been working two minimum wage jobs to help make ends meet. In addition to working these two jobs, Christina had also started attending school to become a medical assistant. Christina's days were long and hard: "I'm used to getting up at 6 in the morning if not earlier, not going to be till midnight, one o'clock in the morning. You know doing, doing, doing....[And] between the two jobs and school—I would, you know, have like a 12, 15 hour day." However, Christina's busy days involving work and school abruptly ended when the auto accident occurred. Suddenly, Christina became considerably less busy because of the intense pain that resulted from the accident. Due to these stressful circumstances, Christina also began struggling much more with her depression.

One rainy night on her way home from one of her jobs, Christina's busy life literally came to a screeching halt when she was hit by a drunk driver with previous Driving Under the Influence (DUI) charges. Stopped at a red traffic light, Christina saw headlights approaching the back of her truck, but felt that the driver would stop due to the traffic signal. Suddenly, Christina's large truck was struck with such force that windows shattered, the truck's roof collapsed and her vehicle was pushed out of her lane. Christina described the impact: "He hit me so hard—it was a three lane highway. I was in the middle lane. When he hit me, I was facing the opposite way two lanes over." As a result of this impact from the accident, Christina's life became consumed with chronic pain that affects her entire body. Christina said she had not felt "100 percent" since the accident and wondered if she will ever get back to being that way.

Christina's chronic pain as well as numbness in her left arm affected her life in several significant ways. Suddenly, Christina who worked since the age of 14 could no longer do so because her two jobs required both standing and the physical strength to lift heavy items to be stocked on shelves. Christina reflected how her inability to work affected her: "I've been working since I've been 14 years old. That's a lot of time behind my belt there....To go from working to absolutely not being able to do anything it's a crush to a person." Christina's pain has also forced her to suspend her schooling for the time being. Christina also mentioned the pain even affected how she maintained her own home. There were certain chores she was not able to complete like cleaning her floors, or the chores she was able to finish took much longer than they used to. Christina talked about how she felt she was a different person because of the constraints pain placed upon her life: "There's so much that you're limited to do that you can't do....It's very-just downright rude! I feel like my hands are tied. I'm not me. I feel like I'm not me." In this agitated statement, Christina personified her pain by characterizing it as "rude" or disrespectful because of the limits it placed on her life. In addition to her pain so rudely affecting her life, Christina's sense of time was also greatly impacted. This is a common experience among chronic pain patients (Good 1994:126). Christina's long days filled with work, school and chores became filled with nothingness as seen in her following remark: "[There's]...No sense of time either. Because your day is just one big long boring, dot dot dot, nothing." Pain medication did not help Christina feel better since she said the pills made her gain weight, and that she felt like "a veggie" because of their side effects. Since the auto accident prevented Christina from engaging in many of the roles she held at this stage of her life, she said

the "big highlight" of the day was coming to see the staff at the IMPC because it gave her the opportunity to leave her home.

Christina's pain also affected her family relationships. She mentioned how she is not accustomed to asking for help, but now has to have her sister-in-law and her husband assist her at various times. There were times where the pain prevented her from picking up her nephew: "My nephew just had a birthday. Can't pick him up 'cause he's 35 pounds. That doesn't seem like a lot of weight. To me, if it's 35 pounds or three thousand pounds it would be the same to me. I can't do it. It's very upsetting." Her pain also prevented her from going out with her husband, and Christina felt her husband did not comprehend the depth her pain was having on her life right away: "I tell my husband 'You go. I can't go. I'm in pain.' [Christina's husband says to her] 'You're in bed again?' [Christina replies] 'Well, you know, I'm tired of lying on the couch. I can't sit up. I can't lay down. What do you want me to do?''' Christina felt that her pain was also invalidated outside of her home environment because she worried that her insurance company would force her to go back to work before she was "100 percent" if diagnostic testing did not show an observable cause for her pain.

Christina came to the IMPC with high expectations for her care, based on the recommendation of her family physician. The IMPC's holistic approach had an immediate impression upon Christina who described feeling very welcome at the clinic and described the atmosphere as family-like with staff she described as "caring people-persons." Christina described how she was treated by the IMPC's staff as a "whole person" in several ways. She noted how the clinic staff got to know her quickly by name: "I think the second time I was here she's [the IMPC's medical assistant said] 'Oh

[Christina] you don't need to sign in I know who you are.' Wow! I've been to my dentist's office for 15 years and I don't think they know who I am." Christina also noted the importance of the clinic staff simply asking how she felt, an experience she never had before at other doctor's offices: "They get to know who you are....'[Christina], how are you doin'?' Wow. There's just wow. That's all I can say because I've been to doctor's offices where I've never been asked how you feel.'" In addition to the warm welcome she received, Christina's descriptions below show how the IMPC went about identifying the cause of her pain and customizing her treatment plan to address her specific pain condition.

Christina's pain was not focused in one particular part of her body but was more widespread due to what she learned were "knots" or trigger points that formed in various areas of her body. She described the pain from these trigger points as occurring "all over" and used the following analogy to describe how she felt: "I have a screensaver on my laptop and it has music, and it has bursts of color....Like fireworks on a screen, you know? Different spots, different colors. Like red being really owy painful and blue not being so painful." Not only did Christina learn about trigger points at the IMPC, she said all aspects of her treatment plan were fully explained to her, unlike the experience she had with another doctor:

I used to have this doctor that all he wanted to do was write prescriptions. [I asked] "Well why am I feeling this way? Why is this happening?" [The other doctor said] "Oh just take this pill you'll feel better." [Dr. Bennett] explains to you "Okay this is what's gonna happen. This is why you need to do this. This is why you need to do that." I know what I'm doing. And I know why. And I know what the risks are and I know what the good things, you know I know the bad and I know the good. This other doctor that I used to have many years ago never explained anything.

Christina also noted how she learned that all the treatment modalities suggested to her at the IMPC—pain medication, heat, physical therapy stretches, trigger point injections and massage—were meant to work in conjunction with one another.

Problematic to her recovery, Christina described how her health insurance coverage limited what the clinic could do to help her: "my insurance doesn't want to pay for massage. Doesn't want to pay for the physical therapy." However, Christina so strongly desired to return to her "old life" that she was willing to make the financial sacrifice to get the care that she needs as she talked about in the interview excerpt below:

That's why I said—I said "Joan" I said "You know what? They're tellin' me I've got all these knots and everything in my back and in my arms and everything." I said "Book me for a couple of massages. I'll have to pay for 'em out of pocket." You know it's something I've gotta do. Because I—they're tellin' me, you know, this really will help. Really can't afford it, but if it's gonna help me get better and get me back to work and get me back to who I was before the accident, then it—I'll find a way to afford it.

The clinic offered the option of half-hour massages at a lower cost and Christina was willing to pay the out of pocket expense so she can get "back to who I was before the accident."

I had the opportunity to observe her very first massage appointment and witnessed Christina and her massage therapist Roxy start to bond as they developed their practitioner-patient relationship during this co-created clinical encounter. In the fieldnote excerpt below, Roxy inquired at the very beginning of the massage about Christina's auto accident and how she had felt since:

Roxy asks Christina if she saw the accident coming and Christina said that she didn't. Roxy said that this was a good thing [that Christina didn't see the accident coming] because she would have tensed up. Christina said she was taking the drunk driver to court, and Roxy said [unfortunately taking the driver to court]

"doesn't bring your health back."...Roxy asked Christina, "What have you noticed since the accident?" Christina replies, "There is no comfortable way" to sit, lay or stand." Christina also said, "He [the drunk driver] hit me pretty dang hard." ...Roxy uses metaphors to explain procedures, or anatomical issues to patients. Roxy used the following metaphor to explain what trigger points are to Christina: "Imagine [your] tissue [is] like a piece of Saran wrap". She said when you experience physical and mental stressors, the Saran wrap crumples up [forming a trigger point]. Roxy explains the crunching noise Christina hears as she breaks up the trigger points [so the scar tissue can be reabsorbed by Christina's body.] At one point in the massage Christina said, "Wow that is so weird" when she heard the trigger points pop [in her body]....[Later in the massage Roxy told Christina] "It's [i.e. her auto accident] a life changing event and not for the better" (Fieldnotes December 18, 2008).

During this short, half-hour massage encounter, a lot of conversation ensued as Christina and Roxy got to know each other. By Roxy inviting Christina to talk about her accident, she learned directly from her about the auto accident itself and the effect it had on Christina's body. Christina's frustrations over the incident and the effect it had on her body and life more broadly also emerged through her words. For example, she talked about how she filed a lawsuit against the drunk driver who hit her, how the driver hit her "pretty dang hard," and that she was constantly in pain no matter what position she placed her body. Importantly, Roxy also thoroughly explained what was happening to Christina's body during the massage, especially aspects such as the popping noise from her breaking down Christina's trigger points would not come as a surprise. Nontreatment related conversation also took place as Christina and Roxy talked about their husbands and home lives.

At the time I interviewed Christina, she acknowledged that she still had a long road ahead of her, and considered herself to be "ten percent better" with treatment. She stated:

Well I'd probably say I'm ten percent better. I don't think it's because of anything they're doing. I think they're doing everything possibly they can do, that they're allowed to do. They just have so many limits because the insurance company

that I don't think they're able to help me out as much as they can because my insurance company wasn't—just doesn't pay for it.

Christina was frustrated with and blamed her insurance company for not covering treatments that the IMPC staff felt she needed like in-clinic physical therapy. Christina acknowledged, however, that she has to take better care of herself. Christina said that while she likes her candy, smokes and does not exercise regularly, she is working to change her lifestyle that includes eating better to lose weight she put on after the accident.

#### Discussion

The different sides of Christina, including her determination and her tenderhearted nature, can both be seen in how she tells her story. Her warmth emerges in her devotion to her life roles and gender identities as a wife and mother especially. Her tenderhearted nature can be seen as she constantly worried about her husband and her children, especially her son serving in the military in Iraq. In addition, Christina is very concerned about social issues like poverty, homelessness, HIV and sees herself as someone who should engage in helping to improve the lives of those who are less fortunate. In some of her accounts of what is going on in the world and larger social problems, one can see how Christina's tenderhearted nature also likely interacts with and fuels her ongoing depression about how things are going "at large." All of this interacts with Christina's current situation, pain problem and finding a way to go forward.

We can speculate that perhaps the physical pain Christina experienced from her accident also gave her a socially acceptable way to deal with some of the depression that she had experienced throughout her whole life. At the IMPC Christina found a nurturing social environment where she was treated as a "whole person" in several ways: she talked about how important it was to be called by name, and simply being asked how she felt. As the staff began to address the physical pain from Christina's trigger points, they also began to address some of the psychosocial issues that she was dealing with as well that most likely increased her pain. For example, the conversations that ensued during the co-created clinical encounter helped Roxy hear directly from Christina about the physical effects of her pain, and also helped Christina learn about what was occurring to her body during her treatment. These conversations provided Christina with an outlet to talk about the accident and air her frustrations about her pain. Christina's pain was not validated initially by her husband, and never was by her insurance company; experiences that would have made the normally determined Christina feel like less of a person. However, we saw Roxy validate the impact that Christina's pain brought to her life when Roxy acknowledged how Christina's auto accident was "a life changing event and not for the better."

Throughout Christina's life story we can see her desire to get back to her "old life." While Christina still desired her "old life," it appeared that the clinic's treatment approach was having a positive effect that may help her grapple with the idea that now (from mid-life on) she may have to live with some degree of chronic pain, incorporate that into her life and find a way to go forward to find a new "me." She discussed her current understanding of her condition, how it had changed her body, her desire to be more responsible for her own health and wellbeing post-accident, and her commitment to the clinic's pain management approach seen in part through her determination to "find a way" to pay for her ongoing treatment. One wonders given the realities of Christina's life (e.g. her financial instability due to her husband's uncertain job future in the Detroit metropolitan area, her health insurance company refusing to pay for some of her treatments, and the possibility of Christina not being able to work as much as she used to) whether she would have to accept living with a degree of pain for the rest of her life because the IMPC's "ideal" treatment plan proposed for her may be limited because of these political economic realities.

#### NATALIE'S STORY: CONTROLLING MY BODY & MY LIFE

Natalie is a 44-year-old white female who moved to the Waterview area in the late 1980's. In my two interview sessions with Natalie and observation of a massage session with Roxy, I learned that she has been a long-term patient at the IMPC for over nine years. After meeting Natalie I found her to be a highly ambitious and assertive individual. She described in detail taking great pride in her abilities to multitask in life. Due to Natalie's ambitious (and at times pushy) personality, she "ran" the interview sessions I had with her. As a result, there were aspects of her life story I intended to follow-up on, but was unable to. Yet, Natalie's case was too interesting to ignore. Her case had much good material to think with concerning the connection between the physical and psychosocial aspects of pain as Natalie's struggle to control her own stressful life interacted with her "out of control body."

Natalie suffered from chronic headaches for years; in addition she experienced generalized chronic pain resulting from two auto accidents, fluctuating weight, balance problems, suffered from a spontaneous a collapsed lung, and had weakened bones that she attributed to an unspecified form of cancer treatment. She also described leading a highly stressful life seeing to the needs of her children and her husband, at times to the

neglect of her own health. Like the cases presented so far, Natalie's case shows that patients can experience significant relief through the IMPC's pain management approach. However, interesting issues about the long-term effectiveness of the IMPC's approach are raised when a patient is no longer actively in treatment there. When Natalie moved away from Waterview for six months and stopped coming to the IMPC, her pain returned with great fervor and she felt like she was "wilting away" until she returned to the IMPC for treatment again.

Natalie held various roles in her life that included being a hair stylist, a wife and mother to three children. However, being a good mother was Natalie's main role as she spoke at great length about her children, and how she centered her life around them. Natalie took great pride in the educational and athletic accomplishments of children, and her dedication is evident in the amount of time she spent attending to their needs including driving her high school daughter to a local college to attend classes, or to her gymnastics practices. However, as she reported, Natalie's dedication to her children oftentimes came at the sacrifice of her own health.

Because her children were so active both scholastically and with extracurricular activities, Natalie was always "running around" trying to keep up with her children's demanding schedules. She describes how she was physically tired from being so busy: "I'm tired 'cause I take the kids back and forth to college or I take 'em back and forth to school, and you're tired with that. You get a little run down because you're not eating, you're grabbing something quick. You're not doing the balance thing." Natalie acknowledged how her own "stress" and "tension with the kids" were contributing factors to her "serious" migraine headaches. Despite the toll her children's schedules had on her health, Natalie took on the bulk of the childcare responsibilities because her husband worked at night. Next, we will see how Natalie's life as a busy mother was greatly affected by her chronic pain that spiraled out of control.

Natalie's chronic headaches were only part of her pain issues that have occurred over the past several years. In 1997, while Natalie was making peanut butter and jelly sandwiches for her children, she coughed and had a "spontaneous pneumothorax" (collapsed lung). Following what she calls her "pneumo," she was involved in "back to back" auto accidents that left her unable to walk very well and maintain her balance. Not only was walking painful, she suffered from "neck pain" as a result of these accidents in addition to "shoulder pain." Natalie said she was placed on "narcotics" and believed that her liver was unable to properly process these medications because she "wasn't feeling right" while she was taking them.<sup>47</sup> While Natalie did not want to mention the specific type, she also mentioned she was diagnosed with cancer in 2000 and placed on a type of chemotherapy for a year that she received through injections. Natalie only spoke about her cancer in terms of the negative effects her treatment had upon her body that were out of her control: "So now I'm just dealin' with the repercussions...with that [the cancer treatment]. It's a domino effect [in my body]." She described her cancer treatment as "poison" and attributed her body's reaction to her chemotherapy as a contributing factor with the chronic pain she experienced as she believed it "brittled" or weakened her bones.

<sup>&</sup>lt;sup>47</sup> Natalie learned later when she became a patient of Dr. Bennett's that these drugs were causing her more harm as they can cause headaches that she was already prone.

In addition to the effect Natalie's pain had on her body, her inability to control this

pain prevented her from being the mother she wanted to be as depicted in Natalie's

words below:

Well I have three kids and a husband, and three dogs. Have a Chihuini, and she's light. I can pick her up with no pain in the shoulders. I have a Chihuahua that's old that's gotta sit on your lap. And I have a miniature Pincher that has to have 100 percent of your attention all the time. Now add in a husband and three kids that are teenagers that wanna go everywhere and you cannot always get in the car to drive because you hurt. And it's not the dogs. I can handle the dogs 'cause they're lightweight. It's disruptive because there's times that if it's too cold, I can't take you to school, and I know you have to go to college. And I think it's great that they're younger at that age of being a teenager and in college. But I can't get out there in the cold. I have to get my husband up who works nights to go take them to school so I've broken his sleep. There's times I can't, you know, lift certain heavy pots and pans like the big sauce pans for the spaghetti sauce or somethin' like that. And it's not right for the kids to completely wait hand and foot.

Natalie's pain affected her mothering responsibilities that included taking care of the family pets, cooking, and driving her children to where they needed to go. She also mentioned how her pain was exacerbated by cold weather, which prevented her from driving her children to school on cold mornings.

Natalie was referred to Dr. Bennett by her "family doctor" and has found significant relief with the IMPC's pain management approach one time. While Natalie was not completely pain free yet, she credited Dr. Bennett's approach over the past nine years as helping her make significant strides in finding relief: "He's [i.e. Dr. Bennett]—come a long ways with me. Actually, my body's come a long ways with his help." Natalie speculated that without Dr. Bennett's help, "I might be in a wheelchair. Who knows."

Natalie described feeling very comfortable with Dr. Bennett and liked how he was concerned not only about how her pain affected her directly, but how it affected her role as a mother as well. In the interview excerpt below, Natalie recalled one such interaction she had with Dr. Bennett where he showed this type of concern:

Well he [i.e. Dr. Bennett] knew I wasn't walkin' well. He saw the way it'd go up and down, up and down, up and down. I've never been a heavy girl, but I've never been overly skinny and I kept going up and down [with weight] and it really caused a little concern with him. Plus the balance and everything. And he knew I had young kids 'cause they'd sit out here [in the waiting room], and he knew I was running with [my daughter] 'cause she's been in gymnastics since second grade.

Not only was Dr. Bennett concerned about her pain, balance issues and fluctuating weight, but also how these issues would have directly affected the busy life Natalie led. Natalie also conveyed how her relationship with Dr. Bennett had evolved into a very comfortable one over the years where asking about "what's goin' on" in each other's lives was commonplace in their long-term relationship: "Well after ten years<sup>48</sup> it's just like 'Okay what's goin' on? …what's goin' on with your life?!' And that's what I like about him. He just—okay instead of just going in 'Okay what can I do for you today?' and then throw the chart on the table, he's very personable."

Natalie also liked how Dr. Bennett was so willing to experiment with a variety of treatments when customizing her treatment plan to try and address the numerous pain issues she experienced. When Natalie came to see Dr. Bennett, she said she "was havin' a hard time movin'" and described her pain as a powerful "earthquake." When I asked Natalie to elaborate why she felt her pain was like an earthquake she stated very matter-of-factly "Cause I hurt. It hurt to walk. There was times I couldn't walk. I couldn't sit in the car, even if somebody else was drivin'....an earthquake is an earthquake. It happens. When you move it hurts."

<sup>&</sup>lt;sup>48</sup> While Natalie mentions she has known Dr. Bennett for ten years in this statement, she more accurately cites the length of time as being over nine years in other parts of her interview.

To address Natalie's pain that she experienced from her accidents, the residual effects from her collapsed lung, her weakened bones from her cancer therapy, and her chronic headaches, Dr. Bennett worked with her to try various types of treatments. However, Natalie lamented that new pain problems would arise just when she finally felt she and Dr. Bennett had found a successful treatment plan for her existing pain problems: "when I find something [treatment-wise] that works, it seems like something else [pain-wise] ails me." Natalie then described how she and Dr. Bennett would have to start down a new path, and alter her treatment plan to address the new issue that surfaced. Natalie was willing to try a variety of treatments and had previously utilized acupuncture, Intramuscular Stimulation (she referred to the IMS device Dr. Bennett used as a "car battery" that "jumpstarted" her ability to walk with less pain), and trigger point injections.

Natalie conveyed how Dr. Bennett had a deep understanding of her tolerance level for pain. This understanding helped him, according to Natalie, customize her treatment plan so the various treatment modalities would not exceed her pain tolerance level: "He knows all his patients, but I know he knows me. I'm not sittin' there sayin' 'Oh I'm special,' I'm just saying he knows who we are so you're not gonna be giving something that you can't tolerate." For example, Natalie mentioned how Dr. Bennett did not recommend manual bodywork such as massage for many years because he knew her body would not be able to tolerate this type of treatment until recently: "probably within the last two years—because I couldn't be touched—then they decided to go and give it a shot for massage. They actually watched me to make sure I can go that way [with treatment]." Dr. Bennett now believed that Natalie's tolerance level had improved to the point where massage therapy could be was added to her treatment plan in addition to trigger point injections "as needed."

I was able to observe one of Natalie's massage therapy sessions with Roxy, the clinic's full-time massage therapist. In the interview excerpts below, it became evident during this session how Natalie was enabled to direct certain aspects of her care and did direct much of this encounter she had with Roxy. In the first instance, Natalie questioned Roxy about whether she felt the trigger points (i.e. "spots" or "knots") present in her body:

Natalie said to Roxy, "Can you feel" how he [i.e. Dr. Bennett] worked it all [the knots out] with the trigger point injections?...Natalie told Roxy how Dr. Bennett said she hasn't been that bad [with trigger points] in years....Natalie asks Roxy how she and Dr. Bennett know where the spots are that contracted [i.e. trigger points]. Roxy demonstrates on Natalie's back how she can identify the spots by sight by pushing on all the spots [i.e. trigger points] she has found popping out of Natalie's back. Roxy explains to Natalie that after doing massage for so long, she knows where the spots are....With flowing motions, Roxy goes from the top to bottom of her back to using her elbow around the sciatic nerve area. Roxy appears to focus on the paraspinal muscles. Natalie [then] asks Roxy if she can feel the knot in her hip (Fieldnotes June 16, 2009).

Natalie also made affirmative statements during the massage when she felt that

particular massage techniques were helping her. Roxy did not prompt Natalie first with

a question whether these particular techniques were helping her:

Roxy starts with Natalie's left leg by moving the sheet back to expose the leg. She begins by working Natalie's foot and Natalie replies "Oh that takes the pain out of my back" when Roxy does what appears to be some reflexology.... When Roxy worked Natalie's neck, Natalie said "I just love it when" you work my neck and Roxy replied that she remembered [from their last visit]....Roxy puts both of her hands together and lines up her thumbs so they are right next to each other. She uses her thumbs and goes from Natalie's spine vertical down the side of Natalie's back. Natalie said, "I'm just going to melt" into the table (Fieldnotes June 16, 2009).

Again, without a question to prompt her, Natalie mentioned twice to Roxy how she felt

she brought pain upon herself with intense yard work:

Natalie explained how she had been trimming bushes and in more pain because of the intensity of the yard work she had been doing. Roxy switches arms and works up by Natalie's neck and uses three fingers to work up by Natalie's shoulder and traces the area. Roxy switches between using one and two hands when working in this area, and massages down Natalie's arm. Natalie talks again about how she had injured herself trimming bushes and the effect it had on her back....[At the end of the massage] Roxy tells Natalie that she overdoes it with yard work (Fieldnotes June 16, 2009)

At the end of the massage, Natalie requested that Roxy to add a technique to her treatment:

Roxy finishes the massage, but Natalie asks if Roxy can stretch her head. Roxy has to have Natalie flip over on her back and tells her to relax while she cradles her head and stretches the neck (Fieldnotes June 16, 2009).

Interestingly, during Natalie's interview she admitted that stretching techniques help when she felt the onset of one of her headaches, and said she should do the stretching exercises herself at home. However, as we can see from the above fieldnote excerpt, she relied on Roxy mainly to do this stretching during treatment sessions. Natalie confided to me in her interview that she believed Roxy could perform the stretching better than her: "But if you really want to be honest, the massage therapist does stretch the neck, the arms, and sets whatever she has to set. And she's wonderful. So that kinda like saves me."

Natalie self admitted she could help herself with her pain by stretching on her own to prevent her headaches, and limiting herself with the intensity of her physical activities (e.g. she caused more pain for herself by trimming bushes in her yard). According to Natalie: "I've been told...by Dr. Bennett to maintain my stretches with my neck. Don't do anything stupid like back handsprings, back tucks and, you know, try to play gymnastics with my daughter...I know my stops, my limits." However, we can see how Natalie confessed that she does not always adopt this advice to help herself. Additionally, when Natalie moved away from Waterview and stopped coming to the IMPC, her pain level intensified again. Her pain was so debilitating that her family strongly encouraged her to return to the clinic for treatment:

I stopped comin' to Dr. Bennett because I moved out to—40 minutes away. I stopped for six months. My family begged me to go back because they saw me wilting away. I couldn't get up from the table...I couldn't take care of the animals, and they know how I am. I wouldn't even get up to cook. It hurt. It hurts....So we went back to the car battery [i.e. her IMS treatments].

Natalie accepted how she had to return to the IMPC, relying on the "car battery" (i.e. IMS treatments) to bring her relief. Interestingly, while Natalie expressed the desire to be pain free someday, she emphatically felt that she would never be able to leave Dr. Bennett's care: "I like to see an end [to the pain], and I think we're close to it. But even if we are, I'm not leaving Dr. Bennett!"

#### Discussion

Through the telling of Natalie's story, we saw examples of how her ambitious personality and assertiveness emerged multiple times. Natalie drove herself to be the best mother she could be by seeing to the every need of her children. For example, she supported her children's accomplishments by driving them to their classes and numerous sporting events, as well as cooking for them. Natalie expressed much pride in her multitasking abilities, but acknowledged how her "hectic" lifestyle that involved caring to her children's every need made her "tired," stressed and tense. We also learned how she pushed herself in other aspects of her life, such as overdoing it physically with yard work. It became evident through Natalie's life experiences how her

ambition negatively impacted her health, and she self-admitted to not taking care of herself. As Natalie was trying to gain control over the business of her stressful life, she was simultaneously losing control over her body and experiencing chronic pain due to her numerous health issues that emerged.

Natalie's out of control body was aptly depicted in the "earthquake" metaphor she used to describe her chronic pain. Extending this metaphor, Natalie's word choice here was worthy of note as earthquakes are natural disasters that just "happen," meaning they are out of our control and there is no way to prevent them. It seems that Natalie was also acknowledging through this metaphor how her life and her pain were uncontrollable like "an earthquake." Interestingly, just as Natalie and Dr. Bennett found the right combinations of treatments to control her pain, another pain issue would surface that caused Dr. Bennett to seek out a new treatment plan. We can speculate that the moments in Natalie's life when she needed a new treatment plan were perhaps the moments when she was most stressed. Her case shows how Natalie had really come to rely on the IMPC when such situations arose.

It appeared that Natalie's extreme need to be in control attracted her to the clinic's approach that is focused on developing a strong practitioner-patient relationship with patients, which enabled patient's to direct aspects of their care. This type of relationship provided Natalie the opportunity to exert the control that she appeared to desire in her life by controlling numerous aspects of her pain management at the IMPC. I noticed how Natalie's desire for control emerged in her massage therapy session with Roxy. For example, Natalie told Roxy how certain massage techniques felt to her before Roxy had the chance to ask Natalie herself. Natalie also asked Roxy to do

stretches at the end of her massage, exercises that Natalie admitted she should have been doing at home, but felt Roxy could do them better. It often appeared as though Natalie took the aspect of the clinic's pain management approach, where patients "direct" their care, to the extreme.

Natalie's case is also one of contradiction because while she believed that she would eventually be pain free, it appeared as though she wanted to remain a long-term patient at the IMPC as seen in her emphatic statement: "I'm not leaving Dr. Bennett!" For Natalie, it appeared that staying a long-term patient at the IMPC was an essential aspect of ability to control her pain, which helped her better control her busy life. Thus, coming to the IMPC provided Natalie not only relief from her physical pain issues, but acted as a support system as their treatment approach enabled Natalie to better pursue her desired life role as this ambitious super-mom.

The IMPC's goal was to enable their patients to help themselves in maintaining a more pain-free life (e.g. through suggestions on self-care and living a healthy lifestyle), and did so through a more flexible approach to patient responsibility. However, Natalie's case demonstrated the breakdown of this process. She purposefully engaged in activities that brought her stress and tension, and she overexerted herself physically all the while knowing her pain would become exacerbated. Natalie knew from her previous life experiences that if she returned to the IMPC, the staff would work with her again to control her pain. Ironically, issues that Natalie could have controlled like reducing her stress and tension, doing her stretching exercises, and not overexerting herself, she chose not to. In fact, she appeared not willing to make these changes in her life. She would rather have the IMPC deal with the aftereffects of her exacerbated

pain rather than make the changes in her lifestyle to reduce her dependency upon their care. Whereas in Jackson's (2000) clinic this scenario would likely have resulted in "confrontation therapy" or in Salkeld's (2004) clinic perhaps dismissal from care, at the IMPC what happened was re-engagement with the clinic's treatment approach.

#### **CHAPTER 7**

## PATIENTS' STORIES & THEIR EXPERIENCES AT THE IMPC PART II

# "I'm like too young for this crap!" (Linda, IMPC patient)

In this chapter, you will be introduced to four of the IMPC's patients who only partially embraced their treatment approach for various different reasons that include dissatisfaction with certain aspects of their care at the IMPC, not finding the right combination of treatment modalities, a lack of financial resources, and the need for only one particular treatment modality.

### LINDA'S STORY: DEALING WITH A DEGENERATIVE CONDITION

Linda is a 56 year old white female and a resident of Waterview who has lived with chronic pain most of her life due to a degenerative spinal condition that led to an acute pain episode in August 2008. I had two in-depth interviews with Linda, and also observed a co-created clinical encounter between Linda and Roxy, a massage therapist at the IMPC. In telling her story, Linda described how she saw various doctors who failed to address the root cause of this acute episode. Out of desperation, she decided to try the IMPC as a "last resort" approximately six weeks prior to my meeting her. While Linda was very pleased with some initial aspects of her care at the clinic, she had already had a negative experience with the IMPC's physical therapy services. However, her acute episode had been somewhat addressed with a treatment plan that included nerve blocks, pain medication and massage therapy.

In the story that follows, Linda's strong, independent personality and tough exterior (that likely resulted from living a good portion of her life in pain) emerged. Linda

196

was not afraid to say what was on her mind, such as voicing harsh criticisms of the IMPC's physical therapy program. At the same time, Linda also had a softer aspect to her personality that appeared when she was describing her career as a daycare provider, her close family relationships, and in the moments when her pain exposed her vulnerabilities.

Linda was a recent retiree and devoted much of her life to the care of children, not only her own, but those she cared for in her daycare business. Linda estimated that she "probably had over 50 kids in my career. [And] I'm friends with most of 'em still [today]." Linda was married, and both she and her husband entered into their marriage with children from previous relationships. Linda mentioned that her husband formally adopted her daughter who was age seven when they decided to marry. In addition to Linda being a mother and daycare provider, she was now a grandmother to ten grandchildren. She enjoyed spending time with her grandchildren and noted: "my daughter's three kids come over every Sunday for dinner. And my other one...they're very busy with karate and their things so we don't see 'em very often, but [we] talk on the phone, you know?"

In addition to Linda being passionate about the care of young children, she and her husband shared a passion for travel. They traveled together extensively to places such as the Bahamas and Hawaii, and also enjoyed camping. When I first met Linda, she was anxiously awaiting their next trip, a cruise to the Hawaiian Islands. While Linda was enjoying retirement, at this time she was contemplating going back to work parttime for one of the families she had worked for previously. While Linda and her husband shared much of their lives together, she said that she needs some time just for herself with both of them now retired. Linda felt that going back to work part-time during the summer would allow some more personal time in her schedule: "that kinda gives me time to myself. 'Cause 24/7 with your husband after you both retire!" As we will come to see next, Linda's experience with an acute pain episode threatened to derail her plans to return to work.

While Linda led a very busy and active life, she also had been living with a chronic pain condition since she was 22 years old. Linda was originally diagnosed with arthritis, and spent two years in treatment for this pain condition. After two years of arthritis treatment, she later found out she actually had "degenerative disk disease," a diagnosis confirmed by several orthopedic surgeons. Linda's disks were slowly dissolving over her lifetime until she lost all the cushioning in between her vertebra. She described the current condition of her spine as "bare bone grinding on bare bones." Linda's prognosis was grim and her doctors told her "by the time I was 50 I'd be in a wheelchair. Well I'm 56 and I'm still not in a wheelchair."

Linda described the severity of her condition as variable now, given that some days she felt better than others. Rainy weather increased her pain levels, and her degenerative disk condition was now made worse with the development of arthritis at this time in her life. She also suffered from bouts of insomnia that left her feeling tired during the day:

because my back hurts all the time that I can only lay on my side, and I can lay down and in the first ten minutes if I'm not asleep I have to get up. I can't just lay in bed. So there's days I can be exhausted and I'll lay down at ten o'clock and I can't go to sleep. And I'm up till two, three o'clock in the morning until I can't keep my eyes open anymore and that's the only way I can go to bed. On any given day Linda never knew how she would feel. Based on the way she felt on a particular day, Linda would decide whether she should push herself with her activities or not, knowing the likely consequences if she did such as increased pain and stiffness.

Linda opted not to have surgery for her condition and decided to "take my chances" with her disease rather than having her disks fused together and rods inserted

into her back:

I've talked to several doctors...I've had eight...orthopedics and I've probably had eight in my lifetime and they've told me I think five years ago surgery would be—I either can have surgery and it won't work. I can have surgery and be paralyzed. I can have surgery and be in rehab for a year. Or you take your chances. So I decided to take my chances. And everybody I've talked to, I haven't found one person yet that's ever had one back surgery. They go through four, five, six, seven surgeries. I'm not doin' that. Rehab's too hard to keep doin' that....So I just figure whatever happens happens.

Linda left her condition to "fate" and continued to live the life she wanted. Linda expressed that she was waiting until the moment came when she had no choice but to go into a wheelchair: "I'm just not gonna give up. I'm too young, and whenever I go in a wheelchair I go in a wheelchair, you know?"

However, Linda feared living a life in a wheelchair because "I see people that are in their 70's and 80's that have this [condition] and all they do is sit in a [wheel] chair. They won't do anything." Fearing that a wheelchair would cause the loss of her active life, Linda pushed herself with her activities, but paid great consequences: "I still go shopping, but I pay for it at night....at night after I've gone all day it's like once you lay down its like rigamortis sets in. Your muscles are calm and stuff, well then I can't move. I can't get off the bed." When Linda cared for young children in her day care business, she also chose not to take pain medication during the day. Linda indicated that she paid the consequences for this decision as well "because I did day care I never took pain medication during the day and so by the time I got off work I was miserable."

Linda was able to adapt to the limits of her condition, in part, because of her husband. She credited him for doing many household chores that would have been very difficult for her to do, and that she believed could have accelerated her condition such as lifting heavy laundry and having to get down on her "hands and knees" to wash a floor: "I can't get on the floor and wash a floor. I can't—I don't do laundry. My husband does almost everything anyways. He always has and so I benefit greatly that way 'cause he's, you know, really good about that stuff." While Linda felt it was all right that she was dependent upon her husband for these household chores, she greatly fears being completely dependent upon him if she is unable to physically care for herself. This scenario was a potentially real possibility that Linda worried about if, for instance, she became paralyzed from surgery, a risk her doctors discussed with her.

Linda also feared that her condition was prematurely aging her when she emphatically said "I'm like too young for this crap!" and criticized older adults as she felt they complained too much about their pain:

And I'm so tired of hearing seniors say "Oh I hate to be a senior and I hate this and I hate going through this" and I'm like "Try being 57 and doin' it." You know? ...I mean I'm too young. I have grandkids. I have a life. I have loads of years ahead of me, you know? And I—I just feel very angry.<sup>49</sup>

Although Linda mentioned that she accepted the inevitability of wheelchair use in her future, she also negatively linked the use of assistive devices with older age:

See I'm the type of person my husband will say "How come you don't ride the scooter in the store?" And I said "Cause there's always somebody worse off than me," and I see some of these seniors and I just think, you know, let 'em do it. I'll just deal with it! Maybe if I was 80 I'd feel different, but I just you know I

<sup>&</sup>lt;sup>49</sup> Linda misspoke in her statement as her correct age is 56 years old.

try—like I'm supposed to use my walker every day. I should use it to come here. I should use it all the time and it's like I have it in the car if I need it, I'll say I need it. I don't want to be dependent on it because once I use it all the time then I feel that's it. And I don't want to feel like that.

The interview excerpt above showed how Linda was bothered by the possibility of having to use assistive devices when she used phrases like "supposed to" and "should use it" when speaking about her walker. Linda's words underscored her sentiment that once she became "dependent on" these devices such as motorized scooters and walkers that she had become a "senior."

In addition, Linda also suffered from bouts of temporary paralysis. Linda described how when she was at rest, her muscles began to relax and became very stiff to the point where she could not walk. Linda had to make additional accommodations in her life to deal with these bouts of paralysis after she experienced an incident that left her completely helpless:

After awhile my muscles get so relaxed that I can't—I mean there's times I can't even get off my bed. That my husband has to get, you know? And I have to start carrying my cell phone with me all the time 'cause I had a incident a couple years ago. We had our laundry downstairs and my husband would go downstairs, do laundry, watch TV and stay down there. And I don't know what we had been doing all day, but I laid on the couch. Well then your muscles relax and I screamed for two hours trying to get off the couch. I couldn't get off the couch. So I ended up on the floor. Well he still didn't hear me. So when he came upstairs, I'm hysterical because I've been crying for two hours and I'm on the floor. And he said "carry your cell phone and just call me from now on," you know?

While Linda carried her cellular phone in case of emergencies, this plan was not without its problems. Recently, Linda fell down a set of stairs, and even though she said she had her cellular phone "in my hand," the fall left her in a state of shock and unable to speak right after this fall occurred. Fortunately, Linda's husband heard her fall and came to her aid, but she broke her foot and had two dislocated ribs. These incidents highlighted Linda's fears of completely losing her mobility and independence.

While Linda kept the progression of her condition at bay longer than expected by her doctors, she suffered an acute pain episode that began in August 2008. This acute pain episode put her life "on hold," which included postponing any future travel plans. For several months, Linda began going to different doctors to address this "horrendous" pain that started in her back and then moved to and settled in her chest. The area of pain was small, only "about four inches" across her chest, but very intense. Linda exclaimed: "I went to you know all these different doctors and they all just looked at me and said 'I don't see anything on the test." One doctor thought Linda was having a heart attack, but she was cleared of any heart problems. She visited a neurologist who did not find a cause for her pain, and a gastroenterologist because she thought it could be gallstones. Linda was cleared of any neurological and gallbladder issues. Since none of Linda's doctors could "see" her pain, Linda could not get properly diagnosed which she felt contributed to her not being able to function on a daily basis:

And I literally sat in a chair since August 'til I started here...I've sat in a chair and screamed and cried. I just was beside myself. I haven't driven a car since August [and it is now January]. I am very limited to what I can do 'cause the pain was horrendous. And by the time I went through all those doctors, the pain got greater and greater.

Linda's frustration along with her pain grew. She turned to one of her doctors who suggested she try a pain management specialist:

so I called my doctor and I said "Somebody's got to help me. You gotta do somethin' here." And he [i.e. my doctor] says "The only thing I can think of is try pain management." He says "I don't know nothin' about it." He says "But try it." ...I said "Well I think there's a place at the corner of our street." So my husband went online, there's pictures of Dr. Bennett, [the website] tells all about his

schooling, everything about him, and about the certain people that work here and stuff, and so we decided to make a phone call.

The outside signage at the IMPC had caught the attention of Linda and her husband and she was happy that she did not have far to look to find a pain management clinic in which to seek treatment.

When Linda's 2008 acute pain episode began, she was told she would have to wait several weeks to get appointments with specialists. All the while, Linda described that she was writhing in pain and not being able to live the active life she wanted that included spending time with her grandchildren and traveling with her husband. However, Linda experienced something different when she called the IMPC:

what impressed me is that every place I had called, other than this place [i.e. the IMPC], said "Oh I can't get you in for another three weeks" and all this. And I called here [i.e. the IMPC] and they said "Well probably," 'cause it was Christmas, they said "Maybe about a week and a half." And I said [to Joan the medical assistant] "Isn't there any way?" and she come back and she said "I talked to the doctor [i.e. Dr. Bennett] and we can get you in Monday" and that was [in] like four days. And I go, "I'll be there." So it was like they tried, you know? Nobody else wanted to even think about asking anybody. And so that kinda impressed me you know that they were willing to, you know?

Linda described what she said to Joan: "So when I called here, I said 'You're my last resort.' And I said [to Joan] 'So you either help me or you don't help me.' And I think that's why they took me right away 'cause they knew I was like desperate." Linda reported that she was not treated, like she had been by other clinics she phoned, as just another faceless voice on the phone line.

In interviews, Linda indicated how she had at times somewhat contentious relationships with certain doctors over her care. As we have learned, Linda's primary condition was initially misdiagnosed at a young age, and that she vehemently avoided surgery suggested by some of her doctors. Linda even described how one of her

doctors had what she considered a very unrealistic approach to treating her degenerative disk disease:

degenerative disk disease:

I had one doctor years ago said to me "Are you going to do what I tell you to do?" and I said "Well what are you gonna tell me to do?" And he said "I want you to do nothing for six months." I said "Excuse me that means no working, no doing anything or whatever. I'm just gonna sit in a chair?" And he said "Take it or leave it." He says "I want you to do nothing for six months and see how you feel." I said "That's impossible." There's no way you can continue life like that. So I never went back, you know? ...I can't possibly do that!

Linda then commented on how she felt Dr. Bennett treated his patients differently than

the other doctors she had seen:

Like he listens to everything you tell him. And most doctors just kinda like "Yeah okay," you know? And then next week you say somethin' and they don't remember that. And he'll, you know I'll come in and he'll remember from the time before "Well did the shot work? Did you...feel okay?" and stuff like that. So he kinda really listens and wants to know. You know? So that—that's really nice. ...He really wants to be with his patients and wants to kinda be a friend to 'em, you know?

In this instance, Linda noted how Dr. Bennett actually listened to her and asked her how

she felt. Linda valued that Dr. Bennett did not give ultimatums like her other doctors,

but allowed patients to direct the course of their treatments.

Linda arrived at the IMPC for her first appointment and described how she felt that particular day: "I walked in his [i.e. Dr. Bennett's] office crying and screaming." She said the level of pain she was experiencing was like "a 14" on only a ten point scale with ten being the most severe pain. After several months of searching for a cause with other practitioners, Dr. Bennett had a much quicker response to Linda's pain. He immediately told Linda that he believed it was the nerve endings in this area of her chest that led to this acute episode. Dr. Bennett developed Linda's treatment plan with a strategy that included nerve block injections to "deaden" the nerves causing the acute pain in her chest, as well as massage therapy to help with muscle spasms in her back, and physical therapy. Now that she was no longer caring for children on a full-time basis, Linda felt comfortable using pain medication that Dr. Bennett was able to prescribe for her.

While Linda was pleased with Dr. Bennett's care, there was one area of her treatment plan that required some extra doctor-patient negotiation. Despite her treatment plan that called for nerve block injections, Linda was not a fan of getting shots. She recounted a treatment episode when she was a child that made her fearful: "I don't like shots. I had a terrible time when I was a child about six years old. They put a shot in my arm and it hit a bone and ever since then all you have to do is—I can smell it [i.e. the shot] comin' in the room....So it was like a shot in my back? I don't—I don't know about [that]!" When Linda faced her first nerve block at the IMPC, she was worried about the procedure, and the "needles and all this stuff sitting around" the treatment room made her nervous. However, Linda's words below indicated how Dr. Bennett was in tune with her emotional response, and that he was concerned about how Linda felt about undergoing this procedure:

In fact the first time I came I kinda chickened out. They left me in the room for about 15 minutes, and I don't know if you've been in that room, but it has needles and all this stuff sitting around. Well I kept thinkin' about it, thinkin' about it, and when he [i.e. Dr. Bennett] walked in I said "You know I don't really feel like I could do this." And he was the first doctor...and I tell everybody this, I was very impressed that he walked in; he knew I was upset and he said "I don't feel comfortable sticking a needle in your back. And you don't feel comfortable bein' here so we won't do it. And when we make the appointment for the next week in the morning, if you get up and say 'I don't want it done,' we won't do it." No other doctor to me would say that....He didn't feel comfortable. I didn't feel comfortable. Dr. Bennett worked with Linda to give her time to address her fears over her injections. He gave Linda the option of canceling her next appointment if she still felt uneasy over the procedure. Linda's daughter also came with her into the treatment room on her second visit to help her feel at ease. Linda now described being much more comfortable with the procedure and noted: "I've come back a couple times by myself [for shots]."

Linda reported being quite satisfied overall with treatment provided by Dr. Bennett and their doctor-patient interactions. Much like how Dr. Bennett was able to customize Linda's care by addressing her initial concerns about her nerve block injections, Roxy who was Linda's massage therapist, was in tune with how her body responded to touch. During the co-created clinical encounter that I was able to observe between Linda and Roxy, I noted how Roxy tailored Linda's massage treatment to address her body's specific needs as illustrated in the fieldnote excerpt below:

Roxy said she uses effleurage [a Swedish massage technique] which "helps warm up the tissue" and "relax the muscles." Roxy said the saying "No pain no gain" is something she doesn't believe in [when giving a massage]. She said you can be just as effective with lighter techniques versus deep tissue. Roxy said that when she goes deeper on Linda's back, it starts to spasm. This is why she uses lighter techniques and why it's good to know a variety of techniques she said. Roxy moved from the back to the shoulder area of the patient. She then switches and did the same techniques on the other side of Linda's back. Roxy said she uses no heat because Linda is always hot, so there is no electric blanket on the table and Linda is not under any blankets. Roxy said as you get to know a patient you tailor the experience to them (Fieldnotes January 28, 2009).

Unlike many patients I observed, Roxy did not warm the table with an electric blanket or cover Linda's body with additional blankets because she "is always hot." Given that Linda suffered from muscle spasms in her back, Roxy also focused the entire hour on

this problematic area of Linda's body, and used a much lighter touch than with other patients to avoid causing additional spasms.

In contrast to Linda's experiences with Dr. Bennett and Roxy, she recounted a negative experience with the clinic's physical therapy program:

I tried physical therapy here, but I didn't like it....I broke my foot and the day I came in here I have a cast on and she's telling me [Jennifer, the IMPC's physical therapy assistant (PTA)] to use the rowing machine....I complained to them [i.e. the IMPC staff] and they said oh no I shouldn't have even been even touched....He [i.e. Dr. Bennett] said we'll just wait and do the massages and the shots and see what happens.

This negative experience left Linda not wanting to continue her physical therapy at the IMPC. Dr. Bennett addressed Linda's concerns over her therapy by suspending it in order to focus just on her injections and massages. Linda described being unhappy with the physical therapy program for two reasons. First, she felt their physical therapy services were very limited in scope and noted: "I've been to physical therapy places that has like the water aerobics and all the [equipment]—they [i.e. the IMPC] don't have very much at all. So I don't know how they can really help anybody with what they have." Linda said the IMPC lacks enough exercise equipment as well as a pool; she had found that doing exercises in water helps her most. Second, Linda was impressed with Michael, the IMPC's physical therapist who completed her initial evaluation for treatment. Linda developed an immediate rapport with Michael as he realized during her evaluation that she had two dislocated ribs (from her fall down her basement stairs) that he was able to move into proper position.

However, Linda was unhappy when she learned that her actual therapy would be carried out by Jennifer, the physical therapy assistant, rather than Michael. Beyond her overall discontent with the situation, Linda had the following specific complaints about

Jennifer's approach to her care:

But she [i.e. Jennifer] would leave you in the room by yourself and go take care of somebody in the ultrasound, which I don't feel with a broken foot I should've been left in that room doing exercises....And the girl that does my [physical] therapy at the other place told me that when they [i.e. physical therapists] go through training, the first thing they're taught is if you have somebody with a cast on, you're not allowed to touch 'em anywhere. And she never even [gave it a second thought], you know? But she's a young girl.

Despite this negative experience, when Linda reflected on her overall experience

at the IMPC, she attributed a dramatic improvement in her pain and a significant change in her mood to the care she received here: "I'm actually laughing now and being a human being." Linda even mentioned how her daughter noticed this dramatic improvement in her mood since coming to the IMPC:

I don't know if you want this on tape! My daughter said that until I came here I was the biggest bitch in the world. She goes "Mom you've really changed!" 'Cause she knew every time she called me I was so distressed and didn't want to go out. I didn't wanna go anywhere. I didn't want to do anything. And she goes "God what a change!"

Massages were an integral part of Linda maintaining her ability to function with less pain on day-to-day basis. To accommodate Linda's desire to continue traveling despite her condition, Roxy suggested to Linda that she should schedule a massage with her both before and after her upcoming Hawaii trip. Scheduling a massage before and after a long plane trip, where Linda would experience the effects of sitting for a long period of time on her back would help reduce her pain Roxy said. Linda expressed however that she would have to give up massage therapy if she lost her current insurance coverage where massage was a covered benefit:

so far I haven't had to pay for anything so. And I couldn't afford it if I had to; I wouldn't be able to come so. 'Cause he's on—he's on retirement [her husband]

so we only get paid once a month so it's like I don't have any extra money comin' in to be able to do if they—if I had to pay for massages or somethin' I wouldn't be able to do it.

Since Linda and her husband live on a limited income, she said she would have no choice but to give up this particular treatment if she lost her coverage as she and her husband do not have the "extra money."

## Discussion

We can see from Linda's life experiences how she developed her strong personality and tough exterior. Dealing with the pain Linda's chronic degenerative spine condition caused her was challenging enough on its own. Yet, Linda also had to cope with a misdiagnosis of her condition early on in her health seeking, and she faced the grim prospects that her doctors gave her that included the possibility of being in a wheelchair by age 50. Linda appeared to express some pride that she beat the odds of her doctor's prognosis as she is now 56 years old and still not in a wheelchair.

Linda's story also highlighted her somewhat contentious relationships with her doctors, and her assertiveness emerged in how she took control over her care in several ways. First, she decided to "take my chances" with her degenerative disease by living her active life the way she wanted. Linda's active life included running her daycare business and traveling with her husband, and she appeared willing to pay the consequences of this lifestyle with increased levels of pain and stiffness at night. Second, Linda also refused surgery that could have paralyzed her. Third, she resisted using her walker and other assistive devices like motorized scooters. Linda felt once she used this device fulltime, she would become "dependent" and appear old. It should

be noted that this sentiment is not an uncommon feeling among those who use such devices (Becker 1997:88).

Despite Linda's tough exterior, she also had a vulnerable side that emerged in her dependence on her husband to not only do certain household chores, but to help her at a moment's notice when she suffered bouts of temporary paralysis that made her completely helpless. Yet, it was Linda's acute pain episode that left her most vulnerable, as her intense pain that would not subside put her retirement, which included more travel with her husband and some part-time daycare work, "on hold." Linda grew frustrated with her doctors that could not "see" her pain on any objective scientific tests, and she became more desperate for relief as the months progressed. Finally, one of Linda's doctors suggested pain management, a specialty that Linda was not well versed in, but Linda decided to try as a "last resort" in addressing her pain. While Linda did not comment on this particular issue, it was surprising that her doctor did not have some basic knowledge about the specialty of pain management.

Due to Linda's contentious relationships with her doctors, the IMPC's holistic approach where the clinic staff looked at patients as real people experiencing real pain appeared to have appealed to her. Linda noted significant differences between the IMPC and her other doctors, such as Dr. Bennett's willingness to fit Linda into his schedule. This instance showed how the IMPC was more flexible than a conventional medical office by considering the patient's pain situation and level of need. Linda also mentioned how her other doctors often told her what she needed to do for her condition like have dangerous surgery or just "do nothing for six months and see how you feel." However, Linda felt that Dr. Bennett was showing concern for her well-being by truly listening to her and acting as more of a "friend" rather than acting simply as a professional authority figure telling her what she must do to address her condition.

The IMPC addressed Linda's condition by accommodating both Linda's physical and psychological needs for her pain. For example, Roxy customized Linda's massage treatments so she was comfortable. By the IMPC offering massage therapy on site, the therapists are able to get to know their patients, work with their preferences—as in Linda's case no heat—and learn the exact amount of pressure the patient can tolerate during the massage experience. Roxy stated that in Linda's case, lighter pressure was beneficial and reduced the tension in Linda's muscles greatly since her first visit. Dr. Bennett's strong practitioner-patient relationship with Linda helped her face some of her psychological fears over pain injections. Dr. Bennett could sense Linda's apprehension and gave her the time she needed to become comfortable with this procedure that included Linda rescheduling her first appointment and also bringing her daughter with her into the treatment room.

However, Linda was not afraid to speak her mind, and voiced some criticisms she had over the IMPC's approach to her care. Linda noted, for example, how it was not just the pain injections themselves that made her fearful of the procedure, but the IMPC's treatment room itself. The IMPC prided itself on creating a nurturing physical environment to make patients feel comfortable. However, Linda said the injection supplies were left out on a cart that was clearly visible to her in her treatment room, which contributed to her fears.

Linda also did not hold back her criticisms of the IMPC's physical therapy program that she felt were inadequate for her specific needs. Her previous experiences

211

with physical therapy at other locations led Linda to conclude that the IMPC lacked a lot of equipment that these other locations had, such as a pool for aquatic therapy. Although the room for physical therapy at the IMPC is large, there was only room for two main pieces of exercise equipment. Thus, this therapeutic aspect of the IMPC's pain management approach was limited by the spatial constraints of the clinic's building and their current scope of operations.

Linda also was uncomfortable having an assistant perform her physical therapy. She was unable to form a strong practitioner-patient relationship with Jennifer, the clinic's PTA, as Linda felt (and was not afraid to say) that Jennifer was too inexperienced because she was an assistant. It became evident in Linda's interviews that she never had any of her previous physical therapy performed by an assistant and she felt that the clinic's PTA lacked the necessary training to be working with patients without supervision. Linda felt Jennifer should have immediately taken note that she was in a cast, not left her unattended on the equipment with this cast on, and know to suspend physical therapy until Linda's broken foot had healed. Not only was Linda disappointed that what she believed was a less qualified assistant was performing her therapy, but she also felt Jennifer was inexperienced because she was "a young girl."

The IMPC prided itself on their pain management approach that offered several treatment options for patients on-site for their convenience, and to provide continuity of care. However, this approach partially failed for Linda who was unhappy with the clinic's physical therapy services, which caused her to seek this particular type of treatment elsewhere. Linda not only lost the convenience factor of having all of her pain

treatments performed at the same clinic, but also having all of these treatments comprehensively managed by Dr. Bennett and the IMPC staff.

Overall, Linda felt that her treatment plan of injections and massage made her "human" again and that she was no longer the "biggest bitch in the world." It appeared from Linda's story that moving forward in her life was not just contingent on the continued successful management of her pain. For Linda, moving forward also involved putting off going into a wheelchair and becoming more dependent on her walker as she considered using assistive devices as making her appear "old" and disabled. However, there are a few factors that may impede Linda's ability to move forward with her life. Given the inevitability of Linda's condition accelerating, she will most likely need more physical therapy. However, she voiced sharp criticism over the IMPC's program. How effectively the IMPC will be able to provide comprehensive care in Linda's case is yet to be seen if this therapy cannot be monitored in-house along with her other treatments like her injections and massage.

Linda may also eventually face issues regarding the sustainability of her treatments at the IMPC. She said she would be forced to give up her massage therapy if her insurance stopped covering it because she did not have the "extra money." One might ask how important is Linda's pain management to her life if she is unwilling to pay some out of pocket costs? Would Linda be willing to make necessary life adjustments such as reducing the amount she is traveling to have the "extra money" pay for her care? Ironically, Linda's ability to continue traveling—especially long distances—appeared to be contingent on getting massages both before and after her trip to reduce the pain and tension in her muscles. Here the IMPC's more flexible approach to the

issue of patient responsibility does not appear to be as beneficial for Linda's case. While Linda knows from the IMPC staff the importance of massage therapy for her treatment plan to be effective, she does not appear to consider this particular modality a priority in her life given how (at least at this point in time) she is not willing to find a way to pay for it if she loses her insurance coverage.

### STELLA'S STORY: DESIRING A HEALTHY LIFE

Stella is a 59 year old African American female and self described "baby boomer." In Stella's in-depth interviews, she described at length how she has lived on and off with a chronic pain condition affecting her knees and legs. While a surgical procedure addressed the pain for many years, Stella has been living with "unbearable" pain for about a year. Stella came to the IMPC to see Dr. Bennett based on the suggestion of her primary doctor. While she initially had "low" expectations when coming to the clinic based on the negative attitude of some of her other doctors, Stella was relatively pleased with her care overall and described feeling like a "family member" when she came for her appointments. Stella said she had been coming to the IMPC for "about two to three months" for injections in her knee and physical therapy. However, she mentioned that her treatment plan was not entirely effective in relieving her pain. Still, Stella had the interest and financial resources to explore some of the other treatment options at the IMPC and remained optimistic at this point about their potential benefits for her.

In the story presented below, Stella's vivacious personality emerged. She was very fashion conscious and loved to talk about her shopping trips and the latest bargain that she found. Stella was also very open about her life, including both the positive aspects of it as well as her own self-criticisms. According to Stella, perseverance was a defining feature of her personality as she had overcome some significant obstacles that came her way. She also had a spiritual side that appeared when she talked about having "faith" that her pain will subside, and "faith" that Dr. Bennett would eventually be able to help her achieve this goal of being pain free without a knee replacement.

Stella held many roles throughout her life that include being a daughter, a sister, a wife, a mother, and a city employee. She was a devoted daughter and very close to her parents who have since passed away; her father in 2006 at 98 and her mother in 2007 at 89 years of age. While she had a sister and brother, it was Stella who provided the care for her parents through the end of their lives. However, because both of her parents were ill, care giving became overwhelming for Stella: "it just got [to be] too much 'cause I was taking care of two parents that were both ill." Because of the intense care giving her parents needed, they eventually went to live in what Stella described as a "group home."

It appeared from Stella's words that she felt guilt over this move that she believed led to her father's death. Stella felt her father became ill because of his emotional response of moving from his own house to this group home. Stella described the death of her parents as a very "emotional" time for her: "I went into a depression. Anxiety. I had all of it. No thoughts of killing myself though...I was just depressed." At that time, she had also been diagnosed with mild bipolar disorder. Stella said she was going through menopause around the time of her parents' deaths and believed it contributed to her mood swings. Stella noted that she was doing better emotionally since seeing a psychiatrist, and was on medication for her mental health issues, but mentioned her hope "to wean myself" off of these medications.

Despite Stella's stressors, she spoke positively about her health at this point in her life: "I don't think I have any major problems. But I guess for the black community we have problems with high blood pressure. I don't have high cholesterol." Interestingly, Stella contrasts her physical appearance and overall health with that of her brother and sister. She described all three of them as not appearing "old for our age," but Stella used words like "thin," "fit" and "good health" to describe her sister and brother, and the word "fat" to describe her own body. Stella had recently been diagnosed with diabetes with its onset attributed to her weight, but she felt the stress over her parents' deaths was a contributing factor. Stella was on medication for her diabetes, but hoped with exercise, weight loss and better eating habits that she would be able to control her condition without the use of medication. Despite Stella's diabetes, she felt her health was better than many her age because "I don't drink, I don't smoke, I don't do drugs. So, a lot of that I think is the reason why I'm probably not as bad off as some people that I know. In my age group, a lot of them that I went to school with are dead from strokes and heart attacks."

Stella admitted that she briefly experimented with drugs while in college "for a minute and found out it wasn't for me." Her philosophy against drug use led her to leave her first husband whom she described as a "junkie." Stella was young in this relationship, only 24 years old, and described her marriage as very short, not even lasting a year by the time she separated from her husband. Stella exclaimed: "I only stayed married ten months! Found out my husband was a junkie. So I left. We were

separated about ten years and somebody told me that [he] OD'd." Stella remarried, but this second marriage ended amicably, and she described being "friends" with her second husband. The reason that Stella told that she and her second husband separated was so she would not become infected with HIV:

I married a young man who ended up with AIDS. He's doin' very well. But we're legally separated. We thought it would be best at this point. He definitely didn't want to get me infected so. And I'm not very trustworthy of some of these so called birth control. ...I was glad he felt that way about me that he didn't want to infect me so. But he's doin' good and we're friends.

While Stella said her parents' generation believed in the institution of marriage, she said

with the "baby boomer" generation "we don't believe in that."

While Stella acknowledged marriage was not for her, she also admitted that she

had never wanted to take on being a mother in her lifetime. Stella had no desire to

have children and she was told that she was not physically able to become pregnant.

To Stella's surprise, however, when she was in a relationship with another man she

became pregnant and gave birth to her son when she was in her mid-thirties:

Stella: I had a son at 36. First they told me I wasn't able to get pregnant well that panned it out to be a big lie! 36 years old, now that was a shocker. Very much a shocker, believe me. But a woman who said she wasn't gonna have any kids.

LM: So big change in your life?

Stella: Oh big big change. ...Believe it or not I was a little selfish about it because I thought here's this little individual steppin' into my life at a time where I thought I was gonna be able to break loose and do some of the things that I wanted to do. And of course I had to put all that off to raise him as a single mother. I wasn't married to the father. So I raised him, and he's 24. He's been to college. Didn't really wanna go so he went and gotta trade. He's a good kid. Very good kid. He lives with me. Tryin' to get him out!

While Stella described herself as "a little selfish" when she learned the news that she was pregnant, she made great sacrifices to raise her son as a single parent. Stella credited her parenting abilities to the close, supportive relationship she had with her

own parents. Stella provided for her son by giving him an education and a home. While Stella joked that she was "Tryin' to get him [i.e. her son] out!" of the house, she mentioned that her son was providing her some much needed support as she tried to address her serious health problems including her diabetes and pain issues. Stella noted that her son reminded her that she needed to be eating better and going faithfully to her physical therapy appointments at the IMPC.

Reflecting on her work life over time, Stella described trying to follow her father's advice: "His philosophy was to go to school, get an education, get a good job, retire. Enjoy the things you wanna enjoy." When Stella graduated from college, however, she was not able to find a good job and worked as a substitute teacher. Stella discovered that she really did not like teaching in an urban school system: "Kids were so bad. I wasn't used to that kinds of—I just wasn't used to it. Very urban parents, not very—I would say not very interested in the children, or their children." Stella left teaching and held a series of jobs with a city municipal system, first as a corrections officer that she described as a "very, very interesting!" experience and short lived, then with the city housing department where she assisted seniors, and then finally working in a city water department where she used her education background to provide training for the employees on such issues as equipment training and safety. Stella originally had no specific knowledge to train employees in these areas, but said "I learn quickly" and was able to do this job that she enjoyed for many years.

At the time of interviewing Stella, she had only been retired a few months after working 35 years: "Now I'm retired at a young age and everybody's askin' me what am I gonna do. And I said 'quite a bit.' As much as I possibly can. Do some of the things I couldn't do when I was workin'." Stella wanted to travel, and even considered working part-time in the future. She also discovered what she called her "creative" side and enjoyed hobbies such as making jewelry, and being a wedding decorator. She described herself now as "Retired. Happy. Not looking for a husband" and currently "celibate." While Stella was enjoying her retirement and free time, her pain condition threatened her future plans.

Stella was no stranger to pain and when she was in college she developed a condition that threatened to permanently disable her: "I guess I was a sophomore [in college]—I contracted a disease they call polyneuritis...you can't walk. Facial distortion. Diagnosis was that I'd never walk again. But I was like 'Oh yeah! I'm walkin' again.' So I did and I was able to graduate." Stella was able to overcome her polyneuritis that temporarily disabled her in college. However, later on Stella suffered from leg pain due to arthritis and a lack of cartilage in her knee. The condition worsened as she became overweight later in life:

I had arthritis and they said the cartilage was just, well it's not there. So it's bone rubbin' on bone. I had what they call—was it microscopic surgery? They went in and cleaned up the knee, and it got better. And that lasted for years. Even when I got pregnant [at 36 years old] I had no trouble with my knees. They [i.e. her knees] didn't start back [being painful] until, I would say recently. I would say last year I started havin' difficulty walking. I would get real tired and then my legs would ache. And then I couldn't stant for long periods of time.

Stella described how she experienced many years without pain problems with her legs and knees because of her surgery. However, she considered her recent pain that started in her knees and radiated up and down her legs as "unbearable."

Stella began a health seeking journey in hopes of finding pain relief and avoiding a knee replacement that she wants "to avoid" "at all costs." Stella went to an orthopedic doctor for care, but did not find any relief from the treatment she received, only frustration:

So I went to an orthopedic specialist, and he gave me shots. Didn't work. Put me on Celebrex®. Didn't work. And then the next time I went back to him he said "Lose weight." And that's all he said! ... I went back to my doctor and told her what he said and she said "Well oh. Well we don't want to send you back there." So then she sent me over here to Dr. Bennett for—she said for pain management.

Stella acknowledged that she needed to lose weight because it would help alleviate some of her knee and leg pain. However, she also noted how her knees took a lot of abuse over her lifetime, which may have played a role in the pain she was experiencing now. Stella used to be active in playing sports such as volleyball and basketball when she was growing up, and had injuries then that she felt might have contributed to her arthritis now. She also had several slip and fall accidents that occurred during the winter months, and when she was working at her municipal job. Stella also worked during one Christmas season at the U.S. Postal Service sorting packages, a job that required standing the entire time. Because of the grueling nature of this job, when she was asked if she would like to work another holiday season, she replied "Hell to the no." Stella attributed her current problems to stemming, in part, from these earlier life experiences.

Stella was very concerned about her mobility in the future as her pain greatly influenced any activity that required the use of her knees and legs. Stella loved to dance and enjoyed hip hop music, but cannot dance in her current condition. Stella's pain also disrupted one of her passions; she loved to shop and was a self described shopaholic. Recently, however, her "knee just give out" as she walked through a major department store. As mentioned earlier, Stella was looking forward to traveling more in retirement, but described how she is embarrassed by the accommodations she must

make because of her condition like using a wheelchair:

I would travel more. Sitting on the airplanes, they're worse than—they're gettin' smaller and smaller. ...I get on 'em, but woo. I'm like—I have to be the last one to get off. And I do have to—well with the new airport...I have to have a wheelchair to get there 'cause it's a very long walk [through the terminal]. ...I would never make it. ...Last year I had to have a wheelchair, and I—I said it's embarrassing to me. But you do what you have to do.

Stella also enjoyed going to concerts and sporting events, but the arenas were not the

most accessible for someone with severe knee and leg pain. Stella reported that the

seating in these areas was very "uncomfortable" because the seats pushed your knees

upwards, which was awkward and painful for someone with her condition. Stella also

described the difficulty she had using the steps in these arenas:

But baseball games, concerts, I can't do it. And trying to climb the steps and the—it's embarrassing when you go up steps like, you know, step and done, step and done. Not step, step, step. And comin' back down holdin' on to the rail like—like for life. And I normally turn myself around where I'm facin' the rail and I'm going down kinda like sideways because it's less pain.

Despite experiencing these setbacks with her mobility, Stella had "faith" that she one day will be pain free: "I have faith that it's goin' to get better. They just haven't found the right thing yet that's goin' to actually do the job."

Stella described feeling like she was part of a family when she came to the IMPC because the staff showed concern for their patients: "Everybody's [i.e. the entire clinic staff] concerned about your health, the pain. Hoping—I would say moving toward trying to get you better." While Stella did not like going to doctors' appointments, she mentioned that she did not mind coming to the IMPC. Stella emphasized how the IMPC does not feel like her regular doctors' offices, such as her orthopedic doctor, in the example below:

And Dr. Bennett, he doesn't keep you waiting. The appointments, if they give you a 3:30 and you're here at 3:30, it may be like a ten minute wait which is nothing compared to [other doctors]....And when he does [leave you waiting], he comes out. The nurse [i.e. Joan, the IMPC's medical assistant] doesn't come out, he does. And he says "I'm runnin' behind, but I'll get to you within the next few minutes," you know? If you can't stay...you can make another appointment. So that's the difference between him and other doctors I've been to.

Stella conveyed with this example how Dr. Bennett respected his patients by coming into the waiting room, and assuring them that he was aware that their time was valuable. It was because of this difference in how the IMPC interacts with their patients, Stella said with conviction that she would never go back to any of her other orthopedic doctors "if they paid me!" Importantly, as we will come to learn, Stella liked the fact that Dr. Bennett was not "interested in cutting," but instead designing a treatment plan focused on alternatives to surgery.

Stella initially had "low" expectations coming to the IMPC and admitted that she really did not know what she was getting into: "I thought I was comin' to an orthopedic, another orthopedic doctor. My [primary] doctor actually didn't tell me it was a pain specialist." Stella already knew the cause of her pain before she came to the IMPC, and was looking for non-surgical treatment options to alleviate her pain that felt "like somebody was like kickin' me in my knee." Stella was concerned that a knee replacement would not be successful because she had "seen people with replacements and they in the same pain. Or they walk with a limp or whatever."

While Stella mentioned above how she felt the entire IMPC staff was invested in her care, she specifically mentioned how Dr. Bennett was "very nurturing" in comparison to her orthopedic doctor that she described as "cold" and lacking a compassionate "bedside manner." When Stella initially came to see Dr. Bennett, she thought she would encounter "another doctor that was gonna tell me the same thing, but maybe, you know, in a different way!" meaning that her primary focus should be losing weight if she had any expectation for pain relief. Stella recounted the following exchange she had with Dr. Bennett as they began to establish their doctor-patient relationship:

I think I was waiting on him to tell me the same thing that that other doctor told me, lose weight, 'cause I told him when I got here and he examined me, and he said "Well, there's a couple things we can do." And I said "I know, lose weight." He said "No, I'm not talkin' about that!" ... He said "If you choose to lose weight, fine. But we're goin' to try to alleviate the pain." 'Cause you know if I drop ten pounds or 20 pounds, the pain does go away in some sense. But now, you know, my legs are real sore. He said that's tendinitis and he's gonna take care of that too.

Alleviating Stella's pain was Dr. Bennett's primary concern, but she was also interested in exploring various avenues for weight loss. Stella mentioned that Dr. Bennett provided her with "a packet" of materials about the clinic's detoxification program. However, Stella sounded doubtful about the clinic's program that utilized supplements and required the user to make healthful food choices, and cook healthy meals. Stella admitted that she did not enjoy cooking and that she did not "eat right:" "I don't like to cook. I don't like to plan [out my meals]. I've tried it." She preferred to find an easier diet plan where her meals would be pre-made specifically for her nutritional needs.

To address Stella's pain, Dr. Bennett designed a treatment plan that added on steps one-by-one looking for a solution to her pain. Stella said that Dr. Bennett did "a series of" Supartz® injections in each knee that provided relief "for a little while, and then the pain just started...back. So then he [i.e. Dr. Bennett] said 'Well we'll try physical therapy' [next]." When I interviewed Stella, she had tried "about three weeks" of physical therapy at the IMPC, but still said she was in pain. While Stella had "a high tolerance for pain," after she began her physical therapy, her leg pain became so "bad"

that she had no choice but to take pain medication that she considered a "last resort." Regarding her physical therapy Stella said with exasperation: "So I guess they're tryin' to build up the muscles so I can take the pressure away from the knee. It ain't workin!"

While Stella was still searching for pain relief, she believed the IMPC was trying their best to help her find a successful treatment plan and noted: "I think he's [i.e. Dr. Bennett] doin' the right thing. You do the shots. If the shots don't work, go to PT [physical therapy]." Given that Stella was struggling with her physical therapy, she wanted to explore other treatment options available at the IMPC such as massage or acupuncture that could help her find the relief she desired. Massage and acupuncture were two options that Stella was going to discuss during her next visit with Dr. Bennett. Fortunately, Stella had excellent insurance and said massage therapy is a covered benefit, and she hoped regular massages would relieve some of her back pain that resulted from her compensating from the pain she felt in her legs and knees. While acupuncture was not covered under her health plan, she said she will pay out of pocket costs and wanted to explore this option "if all this other stuff doesn't work" such as physical therapy and the Supartz® injections. Stella said: "I know he [i.e. Dr. Bennett] does it [i.e. acupuncture] and [that] its [offered] here, and I'll pay for it. 'Cause I wanna be relieved. And I've heard some good things about acupuncture."

Despite how Stella struggled to find pain relief, she was encouraged to continue her care at the IMPC because of Dr. Bennett's concern over her pain, and that the IMPC has various other non-surgical treatment options available. Stella liked that all these options are located in one clinic as she found it frustrating going "from place to place" trying to get treatment. In addition, Stella described how the IMPC is trying to help address her address her pain by providing self-care information that included doing home physical therapy exercises as well as using heat and cold packs to help her muscles. Stella acknowledged the importance of this advice in helping to alleviate her pain, but admitted she had not been using the hot and cold packs: "Well I don't do the heat [packs] and I don't do the cold [packs] so I'm gonna start doin' that tonight. I'm gonna put cold pack on my knees and see how that works. And then in the morning when I'm stiff, I have a heating pad that's right by my bed. I could just put that right on." Stella admitted that by not using these packs that she could have impeded her progress in finding a successful way to manage her pain.

## Discussion

Stella's life experiences showed her ability to persevere over adversity—to desire more out of life by doing "what you have to do." For instance, Stella was able to muster the strength needed to gain her mobility back after her diagnosis of polyneuritis at a young age, and walk again despite what her doctors were telling her to the contrary. Stella went on to finish college after her polyneuritis, and tried a number of jobs until she found a "good" one that she loved and worked hard at until she retired.

However, Stella's ongoing psychological issues, diagnosis of diabetes and now her chronic pain and unsuccessful health seeking, threatened to wear down her ability to persevere. Importantly, Stella's chronic pain issues were a constant reminder of how her physical condition changed over her lifetime. Stella was not overweight when she was young, and she was active in her youth playing sports. But now Stella was no longer able to travel without assistance or hip hop dance anymore, two cherished activities that require much more mobility than she now had. Stella's slow movements up and down arena stairs and her use of assistive devices like a wheelchair at the airport must have been especially difficult for her given the pride she had in looking younger than her chronological age of 59. For Stella—the "baby boomer"—these instances must have made her feel that she was becoming old.

Now that Stella was retired, she desired a healthier, more pain-free life that would enable her passions of traveling more and shopping. Yet, the attitudes of some of Stella's doctors also worked against her in her efforts to persevere over her pain. Specifically, she mentioned how an orthopedic doctor told her the only way to reduce her pain was to "lose weight." Stella did not appreciate the frankness of her doctor's response, and she expected more of the same type of frank attitude at the IMPC. What Stella found, however, was a supportive atmosphere with a staff that was "concerned about your health, your pain," and non-surgical options for pain relief.

In addressing the disorder that Stella's pain brought to her life, Dr. Bennett took a much less judgmental attitude to address her weight and her pain issues simultaneously. Dr. Bennett did so when he took a more indirect route by not issuing an ultimatum like Stella's orthopedic doctor that any attempt to relieve her pain is solely contingent on her weight loss. While it appeared that Stella acknowledged that a healthy lifestyle included weight loss as an important aspect in her avoiding surgery and finding relief from her pain, Dr. Bennett did not stand in judgment of her or dwell on the issue. Rather, he placed the decision upon Stella and went on in their discussion about what he could do to help her manage her pain with the clinic's various non-surgical options.

It appeared that the IMPC's more flexible approach towards patient responsibility provided the type of supportive atmosphere that Stella needed to start addressing her pain and weight issues. Although Dr. Bennett and Stella had yet to find a fully successful treatment plan to alleviate her pain, she had "faith" in their doctor-patient relationship and Dr. Bennett's abilities to help her. The IMPC's numerous treatment options also gave Stella faith that there were more avenues for pain relief that she and Dr. Bennett had yet to explore. Stella's conversations with Dr. Bennett over her weight also appeared to enable her for the first time to seriously consider her weight loss options. Although Stella conceptually buys into her "ideal" treatment plan (e.g. her willingness to pay treatments like acupuncture, and to start using the heat and cold packs after her physical therapy treatments), it is too early in her health-seeking process to tell whether she will take on more responsibility to incorporate this "ideal" treatment plan more fully into her life.

#### JULIA'S STORY: FIGHTING TO GET WHAT I NEED

Julia is a 34 year old white female whose narrative is distinct in this sample in that her chronic pain condition resulted from a genetic cause that was present from birth, but became a major problem in her twenties. Julia was a new patient at the IMPC and had four or five treatments so far with Dr. Bennett<sup>50</sup>. She was interested in more fully engaging with available treatments at the IMPC, but described two limiting factors. First, she already had a treatment team elsewhere comprised of other biomedical and CAM practitioners she had already established herself with. Second, Julia was limited by her insurance coverage and a lack of financial resources. Importantly, Julia

<sup>&</sup>lt;sup>50</sup> Julia said she suffered from memory problems due to her brain surgery. On the day of her in-depth interview, Julia mentioned some memory problems she was having on that particular day that caused her to have trouble remembering specific details such as her number of treatments, dates and so forth.

wholeheartedly believed in taking a natural approach to pain management when available and financially possible.

Julia had tried numerous alternative, complementary and conventional pain management treatments during her complex health seeking journey to treat her severe pain condition. I had one in-depth interview with Julia, and also observed a co-created clinical encounter between Julia and Dr. Bennett. Although she and Dr. Bennett were still negotiating what their doctor-patient relationship would be, Julia was positive about their relationship, and finding pain relief through the IMPC's approach. As we will see in Julia's story, she described how she was a fighter, an aspect of her personality that stemmed from her life experiences and she based her treatment decision-making on her strong "gut" instincts.

Up until Julia's severe pain began in her early twenties, she led a very active life. Julia grew up as the only child of parents who ran a home-based business together. She described her childhood as a "happy" one, but regretted that she was an only child. Julia excelled in school, took honors level classes and loved to dance, so much so that she even taught dance to children. She married her "high school sweetheart" at "a very young age," but described her marriage as short lived and it "ended very badly." Julia described her ex-husband as "a good person," but with some real problems. For a time, they had a good marriage where they travelled a lot, but he had some severe psychological issues that were not diagnosed until after their divorce. Julia said she and her ex-husband "grew apart" when she "grew up and got a real job" and could no longer "go at a moment's notice" (e.g. to travel, etc.). Since her ex-husband was very unstable, Julia said she "kinda disappeared for awhile," moving to another state for almost a year to impose a physical separation between them.

In Julia's short time being married, she was also a student and an employee during this period of her life. Julia attended college studying occupational therapy and taking pre-med classes, and worked as a waitress and bartender. In her early twenties, after returning from her time out of state, Julia said she held "a couple business jobs" for some time and worked in the accounting field. However, Julia "hated" accounting and wanted to return to school. Despite not enjoying her accounting job, Julia described herself as a "workaholic:" "I was always going. I didn't really ever sleep. I was always going. Always going. You know what I mean? I was an early morning riser and a late night person. And I never napped. It was just like go." Even now with Julia's pain, she was still "going" as much as she could. She loved to learn. Drawing on her more recent life experiences using natural medicine to treat her pain condition that we will learn about next, Julia was in college in an online degree program that will eventually award her undergraduate and graduate degrees in the field of naturopathy.

Julia could not recall her exact age when her severe pain began, but said she was around 23 or 24 years old. The cause of her pain was a chiari malformation, which is defined as "a condition in which brain tissue protrudes into your spinal canal" (Mayo Clinic 2010). Julia said she had this genetic condition her entire life, but never realized it until the malformation started to grow larger inside her head at this time. The ear infections she had as a child were actually symptoms of this condition. Julia later learned that the headaches she attributed to sinus infections were actually frontal migraines also attributed to the malformation growing inside of her head:

I thought I just had a really bad sinus infection...the amount I was working and other stuff, and eye strain...[working in] accounting and you know, lights and everything else. You just kinda blow a lot of that stuff [i.e. symptoms] off. ...But they weren't the kind of migraines where I was throwing up either. ...but it was really like one day somebody basically flipped a switch and this started [i.e. the chiari malformation] and it started growing and every day it was getting worse.

Julia said her severe pain began one Thanksgiving with the onset of a headache that led to her head swelling by early December and blackouts by Christmas of that year. Her pain was so intense that she said "I couldn't handle it" and that she "wasn't sleeping" because of its intensity.

Julia began a very long and complex health seeking journey that led her to see around 80 doctors as well as a stay in nearby hospital pain center that she described as a horrible experience. Julia said she was "blown off" and dehumanized by doctors when she described being treated like a "drug seeker," and how she felt powerless as a patient when she was not allowed to question her doctor's authority. Julia discussed how she coped with these difficulties she had with her doctors:

you really have to follow your gut because if you feel something's wrong, no matter what doctors are telling you, you have to keep on looking. And you have to keep on pressing forward. Because as long as you don't feel you're being a hypochondriac and make sure that you're not, you know? But if you really feel that there's something else there...odds are there is.

It was Julia's "gut" instinct that something was wrong with her body that helped her continue her health seeking, despite being "blown off" by some of her doctors and characterized as a drug addict.

Julia was in tremendous pain and said it was more important to stop the pain than to have a doctor provide her with an actual diagnosis. Julia remarked that finding out an actual diagnosis was important for her father: "my father was a big one pushing for the word—the name of what was causing whatever. He needed a name. I didn't need a name, I just needed some relief. I didn't care where it came from." Julia was tested for a brain tumor as well as meningitis, treated for migraines, and had two near death experiences because of allergic reactions to pharmaceutical drug treatments for her pain.

Ironically, a chiari malformation was a possible diagnosis early on in Julia's health seeking, but "ruled out" she said. However, Julia did not mention the specific reason why this diagnosis was discounted so early. Julia also explained how "scary" it was to be the patient taking possible diagnoses to her doctors:

And a lot of times...you're the one taking things [i.e. possible diagnoses] to your doctor. You know? And that's the scary thing. You're taking, you know, the back and forth of the "Have you heard about this diagnosis? Have you heard about this one? Have you heard about this one?"

By the time the chiari malformation was discovered, this growth "at the base of" Julia's brain had caused a great amount of damage to her body. For example, the malformation blocked her spinal fluid that deteriorated her spine. Her discs bulged and became herniated, which led to intense back pain. The malformation also caused severe debilitating headaches that prohibited her from being able to fully function on a daily basis. Julia decided to undergo dangerous brain surgery to remove her malformation, but later regretted her decision: "So there are plenty of days that I do resent or regret having the [brain] surgery." With her surgery she regained some sensation in her back that she had lost, which caused her to feel even more pain from the damage already done to her spine.

In addition to Julia experiencing debilitating pain from the malformation, she described losing "a lot of" herself because her condition led to a series of ongoing losses in her life. Working was one of Julia's major life roles that was disrupted by her

pain. Julia initially felt that she would be able to return to work: "I really was a lot like other people. I really did feel I was gonna be back to work very quickly. I did." Other losses followed her loss of livelihood, and she described these below:

Yeah I lost everything. I mean I lost my apartment, you know I had to move back in with my parents because I couldn't be left alone because I was blacking out. I couldn't drive right away...you lose your freedom. ...You're fully dependent really quickly on a lot of people. ...You don't get money—you know you don't have money in the bank. If you have it you use it for medical treatment your insurance doesn't cover. ...You lose your savings account and other stuff and yeah I would have to say everything in your life changes.

Julia also lost some control over getting the treatment she needed for her debilitating pain because of restrictions imposed by her insurance company.

Self-describing herself as "poor," when Julia's insurance company refused to pay for certain aspects of her pain treatment, she was forced to pay high out of pocket costs with what little money she had. For example, Julia cited one instance where she had a bad "allergic reaction" to generic Fentanyl® pain patches that resulted in her having to pay \$600 out of pocket for the name brand drug that her insurance company refused to cover. Julia said that her lack of good insurance coverage was a "huge" issue for her in getting the complex care that she needed. She felt that insurance companies oftentimes "dictate" to a patient the treatments they need, with little consideration of what a doctor may have felt was in the patient's best interests: "A lot of times procedures and medicines your doctors want you to have your insurance says no....I think health insurance...I think it dictates [your treatment]—I think it almost becomes your doctor. It overrules your doctor in a lot of senses." Julia also mentioned losing the ability to control how other people perceived her.

Outwardly, she described how others around her did not know the depth of her health

problems, and Julia never considered herself "sick." Yet once other people found out

Julia's diagnosis, she felt she was "characterized by" her pain condition:

But you do get characterized by what you have and that kinda stuff. Even people that don't even know necessarily what it is characterized you as, you know, and they look at you, they give you that look like you're this almost like, you know either you're contagious and you can infect them or you're like the little kid throwing up in a pot, you know, that look. ...It's been hard 'cause you don't look at yourself like that.

Julia described how she started getting "pity looks," and that some of her friends also

perceived her differently upon learning about her diagnosis:

like the last nine years [it] has had its hand [i.e. the chiari malformation] in every aspect of my life. I don't think there's too many relationships that it's not somewhere in. And you really find out who your friends are and I have friends that are distant friends because they can't handle it, but they know they can't. They're very honest about it though that they can't handle the reality of it. It's not that they don't call. It's not that you don't see each other it's just not, you know?

Importantly, Julia noted one positive aspect of her diagnosis being revealed to others-

it gave her an ability to "look at people differently too" as she discovered who were truly

her friends.

Julia also spoke at length about how she lost control over her body and had to

fight to get control back. I asked Julia "Do you feel a lot of times your body's out of

control?" and she replied:

Oh yeah. I think sometimes you feel like you body's ruling every, you know, everything but I think that's—once you get to that point you kinda wake up a little bit and know that you've gotta slowly bring yourself back down and, you know, get the control back with your head instead of letting your body rule, you know what I mean?

For Julia, she came to see her struggles as a fight of mind over body as she had to

battle the effects of her chronic pain upon her body. Even showering—a routine activity

for many—was for Julia a major victory in this fight:

And trust me I've had my times where I've been tired of fighting, but that doesn't mean you can stop. I mean you have to try to find it in you, even if that's all you can do. And sometimes the best you can do is get up and take a shower, and that took all day to do. Sometimes that's a good day. But at least you did it

Julia also described how her body took complete control from her when she gained a

significant amount of weight from her medications despite not being able to eat:

Sometimes it's hard I mean I've thrown up everything I've eaten for a month....I [was] just so dehydrated and everything and I've gained 30 pounds because of medicines that I couldn't keep anything down. Other than you took the medicine. That stayed down and then after that you just threw everything up, and you still gained weight and it's—it's a whole different thing when you're gaining you know 30, 40 pounds, 50 pounds and you didn't eat—overeat to do that. I mean it's bad enough if you gain it, but then at least if you have yourself to blame for it....So you gotta give up all the things like you know what I mean? If you worried about your weight before well you have to monitor it [now]...a lot of things change.

Julia highlighted the difference between gaining weight by one's own doing compared to what she went through gaining weight due to no fault of her own. However, she felt that she had to face the same consequence of monitoring her weight like someone who overeats and is "to blame for it."

Although Julia experienced several major losses in her life because of her diagnosis and chronic pain, she also talked about the positive aspects of these experiences. Julia mentioned how she developed a sense of self-awareness that allowed her to take a hard look at her life, and discover aspects where she lacked appreciation. Julia said she developed a very positive attitude, and that her pain condition taught her to slow down and appreciate the people around her: "I had lost some people very close to me, you know, while I've been sick, which on one hand I was

fortunate enough because I was able to spend more time with them than I would have been able to had I been at work 'cause I was pretty much a workaholic when I was working." While her pain condition disrupted her life in many ways, it also allowed her to spend time with people she was close to that her previously busy "workaholic" lifestyle would have prohibited. In addition, Julia also said she now had a much more "open mind" towards complementary and alternative medicine. For example, she previously thought energy medicine—like Chi Gong—"was a bunch of crap" until she tried it and experienced a period of painlessness. Julia described how it was her open-mindedness and "gut instincts" that led her to seek a new approach to managing her pain at the IMPC.

Ironically, Julia met Dr. Bennett when they were both Erica's massage therapy patients during the time Erica worked at a physical therapist's office before coming to the IMPC. Julia and Dr. Bennett had back-to-back appointments with Erica, and ended up talking "every week" with each other. Julia said she felt comfortable with Dr. Bennett and "had a good gut feeling about him," and was interested in exploring new options for pain relief:

I think I was looking to see what he could offer....I think you almost treat it more like an interview almost when you go to see somebody new after awhile. I mean it's been over ten years for me so I've...you kinda go in and see what somebody has to offer and if you're comfortable....So I think you really kinda see if you click in a way. You know you have to have somewhat similar beliefs or at least a goal, something—something has to be similar.

Julia believed in taking a natural approach to pain treatment when possible, and was impressed by Dr. Bennett's approach where he did not use steroids in his trigger point and nerve block injections, but the natural Sarapin®. In addition, when Julia became Dr. Bennett's patient herself she found that he was respectful of patients, noting that "I don't think he talks down to anybody." A key aspect of how the IMPC began addressing Julia's pain and the impact it brought to her life was by respecting her as a patient who had control over her treatment decisions.

Since Julia's spine had begun deteriorating due to the blockage of her spinal fluid that was caused by her chiari malformation, Dr. Bennett designed a treatment plan of nerve block and trigger point injections to address her intense back pain. Julia discussed how Dr. Bennett "likes to work as a team" with his patients, and that she was looking for a doctor to do her pain relieving injections that would work with her when "making the decision where it's [i.e. the injection] going to be and what level [i.e. strength of the injection solution]." The fieldnote excerpt below documented how Julia and Dr. Bennett entered into a doctor-patient relationship that respected her treatment decision-making abilities:

The MD [i.e. Dr. Bennett] began pushing around the spine as Julia confirmed if there was a sore spot by saying "right there" to the MD and then he also asked Julia "right here...is [the] area" where the pain is? Dr. Bennett prepared Julia [for the injections] by using an alcohol wipe and wiping the [injection] area down. He then took some rubber surgical gloves out of a box on his cart of supplies and used some Betadine® solution on Julia's back. This solution turned the area a brownish color. He used some gauze to spread the solution around in a large area where the injections would be. He then uses another alcohol wipe to clean the Betadine® solution off Julia's back....Dr. Bennett preps the injections by using a large needle to draw out two different solutions that looked to be 1) Lidocaine® and 2) Sarapin® the all natural pain reliever he uses. He then changes the needle to a smaller one once he has the serum prepared. Dr. Bennett then begins the injections by pushing on different areas alongside Julia's spine; Julia guides him along so he knows where to inject. He makes several injections alongside both areas of the spine to complete the nerve block (Fieldnotes March 9, 2009).

Importantly, Julia mentioned how Dr. Bennett "understands that this is your body" and during the clinical encounter I observed he never assumed where Julia's pain was.

Rather, Dr. Bennett asked Julia before he injected her if she felt pain as he touched certain spots on her back.

Julia only received her pain relieving injections at the IMPC and said she came to the clinic "with a team of doctors already [in place], [and] he's [i.e. Dr. Bennett] trying to find his place I think you know in that whole situation." For example, although Dr. Bennett performed prolotherapy at the IMPC, Julia was already established with a doctor in Florida for this particular treatment. Julia also had received massage therapy elsewhere, but had decided to give up this particular treatment given its cost to her. In addition, Julia also did a lot of pain management self-care to reduce her stress such as self-hypnosis and energy work like Chi Gong. Julia believed stress was toxic to the body: "I think anybody that doesn't manage their stress is almost guaranteed to get sick I mean with something you know, and if they let it go too long it's gonna develop into something else." Julia also detoxified herself with supplements and was looking into adopting an anti-inflammatory diet to help manage her pain.

#### Discussion

In the telling of her story, we can see how Julia became a fighter due to the numerous losses she experienced as a result of her chronic pain. Julia quickly lost her independence as went from being a self-sufficient, active young woman to a person who had to rely on others for significant help. She described various life role reversals she dealt with like moving back home with her parents, and temporarily lost her ability to drive, an issue that individuals usually do not grapple with until much later in life. In addition to losing her independence, she also lost financial security as she had to use what was left of her savings to pay for her complex care.

Importantly, Julia also described losing a sense of herself. She described being dehumanized by her doctors (even labeled a "drug seeker"), and how she was treated by some of her friends like she was "sick" despite Julia believing the contrary. Thus, Julia not only had to fight what her pain was doing to her body, but she also had to fight the perceptions others had of her. For instance, Julia's pain was not visible so outside observers had no way of knowing that she was taking pain medication that caused her to gain weight.

Yet despite Julia's losses, she found the positive aspects of her pain experiences that allowed her to find strengths she never had and as a result, she grew as an individual. Julia now paid attention to important relationships in her life, and developed a much more open mind to complementary and alternative therapies for her pain that she previously considered "a bunch of crap." She found a new way to go on with her life, and hoped to become a naturopathic doctor someday. She developed a strong "gut" instinct that provided her with a sense of awareness that allowed her to discover who her friends were truly, and enabled her to take care of getting the health care that she needed.

Julia's positive "gut" response when she met Dr. Bennett may have played a significant role in her choosing to come to the IMPC to seek additional and more natural treatment options for her pain. Dr. Bennett allowing Julia to direct aspects of her treatment is a hallmark of the IMPC's treatment approach that embraces collaboration in the clinical encounter. This aspect of the IMPC's approach provided Julia with a sense of control over her body that she so often lost during her long and complex health seeking. Julia's belief that teamwork is essential during health seeking, and the IMPC's

approach that includes forming a bond with patients illustrated how a patient's personal philosophy and the clinic's pain management approach coalesced.

Importantly for Julia, not only does moving forward for her involve finding a successful way to manage her pain, but we can see how the clinic's pain management approach is also helping her restore some of herself. However, Julia only partially engaged with the IMPC's approach for several reasons. Julia spoke about her limited finances and insurance coverage that "dictates" to her what treatments will be covered, and forced her to pay, at times, high out of pocket costs. Thus, Julia's ability to stay engaged with her treatment plan is uncertain given her political economic realities, along with her current inability to work.

Julia also came to the IMPC with an already established treatment team. The number of years she had been health seeking resulted in Julia forming bonds with other health care providers not affiliated with the IMPC. Julia admitted that Dr. Bennett is still trying to "find his place" within her treatment team meaning Dr. Bennett is still in the process of figuring out what the IMPC can offer her that her other health care providers cannot (or perhaps will not). Although the IMPC aims to provide comprehensive pain management, the complexity of Julia's condition illustrates how aspects of the clinic's approach can be blended with a patient's existing treatment team if needed. Also, the IMPC's treatment approach that provides patients with advice on wellness and healthy living really would not be helpful for Julia. We saw from her story how she prioritized her health long before coming to the IMPC as seen through the various self-care practices she already had in place to help manage her pain like reducing her stress levels with energy work (she even mentioned starting to adopt an anti-inflammatory

diet). Given Julia's self-care practices, it is doubtful that there would be much more the IMPC could suggest to her to help her manage her pain.

# PAUL'S STORY: DOING WHAT WORKS FOR ME

Paul is a 44 year old male and a lifelong Waterview resident who was hit by a drunk driver and sustained injuries that caused him to experience severe chronic pain. Paul only visited the IMPC for nerve block and trigger point injections, treatments that could not be provided by his other physician on as regular a basis as Paul would have liked given the intensity of his chronic pain. I had an in-depth interview with Paul and observed a co-created clinical encounter with Paul and Dr. Bennett. I came to learn that Paul already had a treatment team established and had only been a patient at the IMPC for about two months. He discussed receiving massage therapy, physical therapy and occupational therapy from practitioners not affiliated with the IMPC, and preferred to receive these therapies from these other providers with whom he already had developed a longstanding and trusting relationship. In Paul's candid telling of his story below, he described himself as a very driven individual, but also noted his frustrations over the limits his chronic pain placed upon his life. Paul was also frank in his descriptions of his expectations of the IMPC's approach and the fact he has yet to find the pain relief he was so desperately searching for.

Paul held some key life roles in middle age before being injured in a major auto accident, which led to the onset of debilitating chronic pain. Paul graduated from high school in the Waterview area, and went to college to study accounting but "just did not like it [i.e. accounting] at all" he said. However, Paul continued his degree program and eventually finished earning an associate's degree in business. In general, Paul felt that college was not a good fit for him: "Seriously I didn't think much of college at all. Otherwise, I probably would have gone—gone farther and gotten my bachelors really." After Paul finished his associate's degree, he worked part-time at "a computer store" in management and said he "really enjoyed" working with computers that were becoming popular at the time. Instead of going back to college, Paul learned about computers through "hands on" training, and had worked in the information technology (IT) field ever since. He opened his own IT related business that remained opened for 24 years.

In addition to his work life, Paul also described coming from "a very family oriented family" as he had a sister and two brothers. However, Paul's marriage soon after he graduated from college to a woman "eight years older than I was" caused some family strife as his parents disapproved of his relationship and "pretty much disowned me" he said. Paul was married for 15 years and during that time he and his wife spent 13 of those years breeding show cats and going to cat shows around the country. While Paul and his wife enjoyed traveling and making new friends, showing and breeding cats was "a lot of work," and he described the cat shows as "very political." Paul eventually made the decision that he and his wife should stop showing and breeding cats. Although he never mentioned the specific reason why he made this decision, he did discuss how he wanted his wife to work and "I made her get rid of all the cats, you know, 'cause hey, she couldn't work and do the cats at the same time." As we will see next, Paul's auto accident and subsequent chronic pain disrupted both his work and family life in significant ways.

One day Paul and his wife were in their car waiting at a red light when they were struck by a drunk driver speeding down the road. The back of their car was hit with a great amount of force, and Paul believed the driver was going 45 to 50 miles per hour when he hit the back of their stopped car:

Yeah we were waitin' for the light to turn green basically so we were just sitting there just waiting for the light to turn, and the car basically rear-ended us and just nailed us. ...It was just so much pain on my left side as far as that was concerned. They took me to the—they put me on a gurney, strapped my neck and all that stuff then took me off to the—to the hospital. And they did the MRI's, cat scans and all that stuff as that was concerned. They didn't see anything broken as far as that was concerned. There was a lot of glass and some wounds in my head. ... [Compared to my wife] I pretty much took all the damage [from the accident] as far as anything. But the damage really didn't come until later on.

The damage to Paul's body from this accident started to appear "four or five months"

later and included severe headaches, memory loss and back spasms. Paul said his

memory loss was so bad that he could not find his car in a grocery store parking lot: "I

mean I'd go out and-go out [to] grocery shop and forget where I parked my car.

Literally! [Laughter] There was one time I spent 30 minutes looking for my car outside."

Paul, who described himself as extremely healthy and never going to a doctor before

this life altering experience, now had his life consumed with doctor's visits and taking as

many as 11 types of medications to manage his pain.

Paul's chronic pain disrupted his work life as he was no longer able to keep his

own business open and work the eight to 12 hour days he was accustomed to:

I was very tired, I was—couldn't keep myself going during the day, I—headache pain, medications, you know, the...muscles in my back were just, you know, spasming like crazy, and all that so I was a mess, basically. And I just couldn't work anymore at that point....I had my business for almost...24 years basically and three years ago I had to close the company due to the fact of—of the car accident.

Paul and his wife got divorced after 15 years of marriage, in part over money issues as

she became the sole breadwinner in their relationship as Paul could no longer work:

I couldn't work and everything like that, and then my wife was working at the time...and she got all pissed off and everything as far as that was concerned. ...she was the money maker at that time, not me...her situation was basically... 'Oh this is my money,' not our money.

Paul mentioned how he used make their house payments until he was out of work, and that his wife took issue with her salary being used to make these payments. Paul found the money issue played a significant role in the deterioration of his marriage. Paul described earning "good money" with his own business and felt when you are married the money should be shared no matter who is in the breadwinner position: "[When] you're married, it's [i.e. the money]—it's ours!"

Paul tried going back to work after the accident, but said he was reduced to "doing data entry" work for a real estate agent. Paul found, however, that even working a few hours each day—a far cry from the eight to 12 hour days he was used to working—caused him problems as he said "I could only handle up to three to four hours a day...as far as that was concerned 'cause my neck would just start to freezing right up and stuff." Because Paul could not work full-time, he applied for Social Security Disability (SSD) benefits, but was denied. He was appealing the decision, but Paul felt his age was against him in this process: "But I did file for it [i.e. SSD] four, you know, five years ago. And of course they see a 40, well at that time a 40 year old tryin' to get a—trying to get social security, you ain't gonna win." Paul conveyed his deep concern about his financial security if his lawyer's appeal for benefits on his behalf was denied once again.

Paul also talked about having to rely on other family members for other kinds of help due to his chronic pain. Despite his parents' strong feelings about his marriage, they came to his aid after the accident and his divorce to help him with basic home maintenance and cleaning despite their advanced age: "I mean I can't even cut my grass. My dad's 80 years old and he's cuttin' my grass...you know? My parents come over and clean my house...completely once a month, you know? I can't do that stuff. If I go to do it, you know, it just gives me a headache."

Paul mentioned how his close-knit family had "lot of family functions all the time." Unfortunately for Paul, his chronic pain greatly affected his ability to participate in these functions. For example, Paul described how on the day of his niece's birthday party he "was feeling pretty good." However, he only completed just a few activities on that particular day before he felt a "headache coming on:"

And so I take a Vicodin® when I feel pain headache coming on, and then my niece had a birthday party at five o'clock! So then I had to go to a birthday party with all the people talking and noises and stuff. So I kinda knew it's gonna hit me [a migraine headache]. So what happens then is you...go to these people with all these parties and stuff or if you're in a party atmosphere, you're pretty much fine at that point...as far as that's concerned. And I also bring my meds with me at that point too 'cause if start feeling more pain coming in, I'll pop an Oxycodone® or whatever while I'm at the party. And...so anyways...when I got home about 8:30, my neck was just throbbing and everything as far as that was concerned. And...by the time I went to bed, I had taken an Imitrex® for my migraine 'cause I knew it was gonna come. And by Sunday morning, I had prevented that migraine, but if I wouldn't have taken all of those pills or the Imitrex® the night before, I would've woken up with a migraine headache. And that's throwing up and everything.

Paul was keenly aware of his body's pain signals and how he must medicate himself in order to participate in environments where he encounters pain triggers such as noise that can cause his debilitating headaches. Paul discussed how his pain, as well as the use and timing of his medications, dictated his ability to participate in these family events. He had to limit the amount of time spent with his family because of the noise: "I don't stay around family functions very long. I'll stay a couple hours and that's it 'cause I know if I stay longer I'm just going to pay for it the next day. And my family knows about that stuff. They realize it and everything so."

In addition to extensive use of powerful pain medication, Paul had some prior success with an intense weekly schedule of trigger point injections and nerve blocks at a neurologist's office. However, when Paul's doctor left this office, this new neurologist was unable to accommodate Paul's intense treatment schedule of three visits a week for these injections. While Paul was able to function fairly well at this point in his health seeking, the lapse in the number of treatments he was able to receive at his neurologist's office caused his pain condition to worsen: "So at that point all my headaches and pains just came right back big time....I was workin' two to three hours at least gettin'—when I was gettin' the injections, and at least making something of my life, you know?" One of the doctors at this neurologist's office recommended that Paul visit the IMPC to receive his injections on a more regular basis.

Paul was initially hopeful when he came to the IMPC for treatment. Although he described the IMPC as "just your normal doctor's office," Paul did note how he was treated a little different than other doctors' offices he had gone to for treatment:

I guess they're a little more pleasant up front I guess you'd call it because...she [i.e. Joan, the IMPC's medical assistant] sees me she says "Oh don't even bother signing in." So...they recognize you as a person. As far as that's concerned. Not just a number as far as that's concerned. So I can say that's a little bit different.

While Paul described feeling like he was not "a number" at the IMPC, he discussed an incident that made him "miffed" at how he was treated. Paul took issue with the IMPC's approach where after every 30 days of treatment, patients must be seen for a consultation appointment before continuing with their treatment plan or scheduling any

additional future appointments. Paul felt that because he was going to remain a patient at the IMPC for the long term, these consultation appointments were "a waste of time" for him.

Despite Paul's objections to this aspect of the IMPC's approach, he went ahead and scheduled his consultation appointment anyway. After he had his consultation appointment, Paul went to schedule his injections only to learn that Dr. Bennett's schedule was fully booked. Paul had no choice but to return to his neurologist's office temporarily for these injections. Paul discussed his frustration with the IMPC over this issue:

I told Dr. Bennett I said "You know I'm a little miffed right now." I says "This is what happened." I say "I wanted to make my appointments a week earlier for the week—for the next month," and [Joan, the IMPC's medical assistant] said "No." She said "We don't do it that way." I says [to Joan the IMPC's medical assistant] "Well hey, I'm going to be a patient for yours for awhile here." I says "You need—you've already agreed to me when you first saw me that you'd see me two to three times a week." I says "And then I'm not able to see you for that whole week?" I says "That's not right." He says [i.e. Dr. Bennett] "No no that should never have been." So he fixed it up. And [Joan, the IMPC's medical assistant] didn't talk to me for like two weeks! [Laughter] And I mean I could tell—even I think she's fine with it now I think but I'm sure she got yelled at big time because, you know, hey, he [i.e. Dr. Bennett] lost the money with me going somewhere else to where I was able to come here. 'Cause he even asked me "Where were you last week?" I says "Well I couldn't get appointments."

Paul felt that Joan, who was responsible for the clinic's scheduling, was angry at him when he informed Dr. Bennett of his dissatisfaction over the IMPC's appointmentmaking procedures. After this incident, Dr. Bennett corrected this particular situation for Paul so he would be able to stay on a consistent injection schedule: "at least now what they're doing is they'll put the consultation [appointment] and two more visits [for injections] in that [same] week to continue...what they're doing [for my pain]." However, Paul encountered a second issue when trying to keep his weekly schedule of injections that frustrated him. Dr. Bennett was the only practitioner at the IMPC who was qualified to provide Paul his injections, and he took a week off for vacation. Paul described what happened to his body when he did not receive his weekly injections:

Paul: He [i.e. Dr. Bennett] commented yesterday when he was giving me my injections in my side of my neck he goes—he couldn't believe how hard it was. I said "Well it was because you went off gallivanting to Cancun, you know for one week!" [Laughter] So I mean that's pretty much it though, you know. I've gotta have my injections.

LM: So it has to be every week?

Paul: It's gotta continuously two to three times a week. ...If I get off that schedule, I'm back into headache—I mean I'll—all last week I was pretty much in bed laying—laying around last week. I couldn't do anything. I literally I was pop—up popping the Imatrex's® and Vicoden's® and Oxycodone's® last week.

Since Paul's treatment schedule could not be met the week Dr. Bennett was on vacation, Paul had no choice but to rely on greater quantities of his pain medications for relief. Paul had some issues with both how the IMPC approached his care and also voiced some dissatisfaction over how his particular treatments were carried out.

Paul described having muscle and nerve damage as a result of his auto accident, which included damage to his cervical spine, and the formation of trigger points in his muscle tissues. He described the severity of his pain as like a "thunderstorm" in his head because of the pounding, ringing in his ears, sensitivity to noise and light that he experienced: "the lights [in the room] would be like the lightening hit me you know as far as that's concerned so. Oh yeah. That's why I say it's like a storm." To address the impact that Paul's pain brought to his life, Dr. Bennett alternated between trigger point injections and nerve blocks with his treatment plan. However, Paul noted that the IMPC's treatment plan for these injections differed in two ways from that of his neurologist. At Paul's neurologist's office he would receive a nerve block as well as trigger point injections during the very same visit. Dr. Bennett alternated between nerve blocks and trigger point injections, and used a different solution for these injections. Dr. Bennett preferred to use Lidocaine® with the all natural (steroid-free) Sarapin® in contrast to Paul's neurologist who preferred to use Marcaine® with a corticosteroid called Dexamethasone® that Paul felt was more effective at keeping his pain under control. Paul mentioned that Dr. Bennett's injections only keep his pain "at bay:"

It's his [i.e. Dr. Bennetts] procedure, which is why I'm probably not getting any better truthfully so. Because I need more [nerve] blocks than anything. But yet the trigger [point injections]—as you know the muscles in your shoulder all lead up into your neck. So I—I can see his reasoning why he's doing it [i.e. the trigger point injections]...I just don't know if he's put—if it's the medicine he's using like I said 'cause he's using Lidocaine® where the other doctor's using Marcaine®. See Lidocaine® is only five percent where Marcaine® is ten or 15 percent....The concentration's a lot tougher so. That could be it too...so.

While Paul described that he felt Dr. Bennett's approach to his injections was not providing kind of relief he was hoping for, he did mention that Dr. Bennett's injections were free from steroids that can cause bone and muscle damage over time.

Paul's concern over the treatment plan Dr. Bennett developed emerged during his co-created clinical encounter that I observed. During this encounter, both Dr. Bennett and Paul aired their views about this approach, but eventually negotiated together how to better address Paul's pain:

Once the MD's [i.e. Dr. Bennett's] in the room, the patient [i.e. Paul] says he can't go back to work because of the headaches....Paul tells Dr. Bennett that his other doctor used Marcaine®. Marcaine® is longer lasting Dr. Bennett says and Lidocaine® doesn't last as long as Marcaine®. However, the Sarapin® he uses is a longer lasting agent than Lidocaine® he [i.e. Dr. Bennett] says. Dr. Bennett

tells Paul that he will bring in the Marcaine®. Paul said he has had improvement with Dr. Bennett's approach, but not as much as with his other doctor [i.e. his neurologist] (Fieldnotes September 25, 2008).

During this exchange, Paul did not hesitate to voice his concern that the Lidocaine® is not a strong enough agent in his injection. Dr. Bennett acknowledged that Marcaine® is stronger than the Lidocaine® that he used, but quickly noted that his mixture also used Sarapin® that he believed was a longer lasting pain relief agent than the Lidocaine®. However, Dr. Bennett was willing to customize Paul's treatment plan by bringing in the Marcaine® to use along with the Sarapin® to see if it will help Paul find more relief.

Paul also described how Dr. Bennett helped him cope with some psychological issues related to receiving injections that stemmed from two of Paul's previous life experiences. Paul grew up with a diabetic brother who had to give himself daily injections that gave him an aversion to needles:

My brother's a diabetic and—I couldn't watch him give himself shots every morning when I—when I grew up and everything like that. And I can't stand—I don't like shots either. I—I won't look at a shot. And I just don't like it at all. So when he's givin' me shots, I explained to him when I first saw him I says "Don't tell me you're givin' me injection, just do it." I said "you might hear me just gabbing it off or just talking or whatever, but it's a way to keep my mind off you injecting me." I said "that's just how I do it." I said "I'm in my happy—happy place!" [Laughter] I mean that's what you gotta do as far as that's concerned, you know

In addition, Paul also had a negative experience at his neurologist's office when he received his very first nerve block injection. Paul described being left alone in the treatment room with the needle his doctor was going to be using that was "a good two inches long," and had to endure his doctor explaining the procedure in great detail to his assistants.

Both of these experiences greatly affected Paul who preferred non-treatment related conversation during his injections so he could remain calm. As Paul noted above, he and Dr. Bennett negotiated a customized approach so that treatment specifics are not discussed during the clinical encounter. This customized approach is evident in fieldnote except below that was recorded when Paul was receiving injections

from Dr. Bennett:

The patient [i.e. Paul] lays down on the table, face down using the head rest. The MD [i.e. Dr. Bennett] feels for a spot in the back of the head—the cervical area. Dr. Bennett pushes down with his fingers to find the location of Paul's trigger points. Dr. Bennett asks Paul if he is doing okay while he is giving him the injections and Paul replies, while face down in the head rest, "this is my other world". Once Dr. Bennett injects the area, he uses surgical sponges to cover the injection site and pressed down with all his fingers and rubs, with his fingers, in circular motions and then in back and forth motions to soak up anything that may have seeped out from the injection site. The conversation switches [from Paul's headaches] to politics and Dr. Bennett and Paul are discussing the recent presidential debate [and the current financial crisis in the U.S.] (Fieldnotes September 25, 2008).

As we can see, Paul and Dr. Bennett engaged in conversations that did not focus on the injections themselves. The only procedural aspect that Dr. Bennett discussed with Paul was asking if Paul was feeling okay during the injections. Paul said such non-treatment related conversation allows him to go to his "other world" or "happy place." By this Paul meant he used these conversations as a means to distract himself and focus his mind on something other than the injections themselves.

After two months of trigger point injections, Paul said his expectations that the IMPC's approach would help him find significant relief had not yet been met. Paul conveyed that he remained somewhat positive for significant pain relief, but admitted he had come to terms with the fact that his pain most likely was a chronic, life-long condition:

Unless they—there's somethin' they can do as far as opening me up and doing something with the nerves and stuff in my neck to kill it all, then I wouldn't have the pains. But...this is probably gonna go on for the rest of my life as far as that's concerned so. ...A chronic type thing so I—I picture myself that way, but least able to work—least I'd be able to work part time, you know what I'm sayin'? This is just driving me nuts just at home doin' nothin'. You know I'm just not that type of person.

Paul anticipated that his treatments at the IMPC would enable him to work once again: "it hasn't...been to my expectations, but yet it's kept me at bay. So I'm—I'm happy with the service and everything, but not ecstatic. Ecstatic would be okay good I'm finally well, you know? Where I do—where I can get back to work." For Paul, working again is the main goal that he had identified as a necessary step associated with getting his life back together.

## Discussion

Paul's life experiences reveal the pride he had in himself for developing a successful business in a field that he loved. Book learning did not work for Paul, and he did not like college. Rather, he preferred "hands on" learning and learned all about computers and IT from the ground up by working in a computer store. He turned his passion into a highly successful business that he owned for a number of years. He worked long, hard hours, but made "good money" that provided Paul and his wife with a comfortable lifestyle that included breeding cats and traveling the country to compete in cat shows. The cats were his wife's responsibility, but his financial investment. It appeared from Paul's story that his decision to give up the cats and have his wife get a job began to put a strain on their relationship prior to the car accident they were in together. When the drunk driver hit Paul's car, his life changed in an instant as he sustained injuries that set in motion a cycle of chronic pain.

Paul's chronic pain caused two significant role reversals for such an ambitious middle-aged man. Paul's pain caused him to lose his business as he could no longer accommodate the long hours needed to keep its doors open. As a result, a significant role reversal occurred for him as he lost his breadwinner position in his marriage. Paul had to rely solely on his wife's income that she considered "her money" not "their money." This financial issue was the final blow to his already strained marriage that ended in divorce. In addition, Paul was not caring for his aging parents but rather his parents were caring for him at mid-life by cleaning his home and mowing his lawn, activities that a healthy man at Paul's age would most likely be performing. Paul's descriptions of these role reversals indicated that he was greatly frustrated with the changes to his health and life as a result of the auto accident.

Adding to his frustration and further damaging his pride was the fact that he was reduced to doing data entry work a few hours a day. At age 40, Paul's pride was further eroded when this once self-sufficient man who made "good money" was reduced to applying for Social Security Disability benefits, only to be denied. While never explicitly mentioned by Paul, his comments indicated how he believed he experienced reverse age discrimination by the Social Security Administration because he applied for benefits at an age where it is traditionally expected that most adults are employed and able to support themselves.

Paul's pain also limited his participation in family activities. In order to attend family functions, Paul had to medicate himself with powerful pain medicine just to get through the event. Paul's very sad but well stated comment—"I don't stay around family functions very long. I'll stay a couple hours and that's it 'cause I know if I stay longer I'm just going to pay for it the next day. And my family knows about that stuff. They realize it and everything so"—leads one to speculate on the effect of his limited participation in these family functions. Although Paul said that his family understands the limitations he had due to his pain condition, given the closeness of his family relationships, his limited participation not only affected Paul's life but the lives of his extended family as well.

When Paul came to the clinic for treatment, he came much later in his health seeking process and had already established himself with other practitioners (he already had a massage therapist and physical therapist), which may explain his more limited engagement with the IMPC's pain management approach. His partial commitment may also be explained by Paul not buying into the more holistic aspects of the IMPC's approach. For instance, while Paul noted that while it was nice not to be treated like a "number," this aspect of the IMPC's approach was not highly important to him. Rather, Paul approached the IMPC differently than other patients profiled here in that he was looking for the IMPC to provide the specific treatments he needed (i.e. trigger point and nerve block injections) in the time he needed it (i.e. three times a week).

Yet, perhaps receiving customized treatment is more important to Paul than he realizes. There is much evidence in the narrative presented above of how he would actually like the clinic to customize his treatment selection and treatment modality. For example, Paul discusses at length specific needs as a patient were not always met as there were aspects of the clinic's care that did not work for him. Paul described how his rigorous treatment schedule of two to three visits every week for pain-relieving injections was broken on two occasions. The IMPC's scheduling process, which

prevented Paul from scheduling additional injections until his progress was first evaluated by Dr. Bennett, caused the first break in his injection schedule. Paul reported his dissatisfaction to Dr. Bennett, but he felt Joan, who oversaw this scheduling process, was "miffed" at him (Joan did not talk to Paul for two weeks) after he complained to Dr. Bennett. Dr. Bennett addressed Paul's concern by altering the clinic's scheduling process specifically for him where Paul was able to schedule a consultation appointment and injections the same week.

Paul's treatment schedule was also affected when Dr. Bennett went on vacation, leaving Paul unable to keep up his injections and forcing him to rely heavily on pain medication. Dr. Bennett's specialized role at the IMPC as the only practitioner qualified to administer Paul's injections would mean Paul's treatment schedule would be affected every time Dr. Bennett went out of town. When Paul mentioned the issue to Dr. Bennett, Paul felt it was not adequately addressed as a real concern. It seems like for the IMPC to address Paul's concern, they need to further customize his care and perhaps the care of other patients as well by finding another way for Paul to get his injections while Dr. Bennett is away. Perhaps it would be of benefit for the clinic to have another physician on call or as a referral for patients like Paul that have very complex cases that require such a rigorous treatment plan that cannot be disrupted. For Paul, these two instances where his care was not customized to his liking illustrate how the IMPC did not live up to "treating the whole person" (and was not satisfactory).

Paul's business was the center of his life for over two decades. Thus, working again, at least on a part-time basis, would be a small but significant step for Paul to rebuild his life and mend his pride. Paul had expected that the injections he received at

the IMPC would be able to help him make this step, but he felt that Dr. Bennett's injection solution was not strong enough as it only kept his pain "at bay." However, Paul's doctor-patient relationship with Dr. Bennett allowed for the negotiation of his treatment plan. Paul's concerns about the strength of the injection solution were met by Dr. Bennett as he acquiesced to Paul's request to try a different strategy using Marcaine® that Paul felt might work better in his case. Yet, Paul admitted that while he desired a pain-free future, he felt he would most likely experience pain for the rest of his life. It appeared from Paul's case that Dr. Bennett was helping Paul adjust to this reality somewhat by making the clinical encounter as comfortable as possible by avoiding any conversation about the injection process itself to address Paul's fear of needles.

Importantly, Paul interacted with the IMPC in a different way as he was seeking out a treatment setting looking for a specific type of treatment modality rather than an integrative treatment plan. We must ask the following question about the IMPC's approach. If the clinic's philosophy is "treating the whole person," what happens when there are patient's like Paul whose expectations are not fully aligned with the realities of what the IMPC can provide? Some of the elements of the IMPC's approach such as customized care and the ability for patients to negotiate aspects of their treatment worked in Paul's case. While the IMPC aims for their patients to buy into their entire treatment approach as they believe it will result in the best outcome, patients like Paul can still be treated in this setting even if their own beliefs about how their treatment should be addressed are not completely in line with the IMPC's comprehensive pain management approach. Chapters 6 and 7 presented two sets of patient narratives where we saw the various ways in which different patients engaged with the IMPC's "treating the whole person" approach for the management of chronic pain. The next chapter concludes this dissertation by discussing how these narratives revealed the real work of healing at the IMPC.

## **CHAPTER 8**

## CONCLUSION

### THE REAL WORK OF HEALING AT THE IMPC

Pervading much of current anthropological and social scientific literature, IM practice is oftentimes approached in terms questions about the process(es) behind blending different types of treatment modalities and theories of healing, and the primacy of biomedicine in this integration (e.g. Adler 1999; Adler 2002; Anderson 1999; Baer 2002; Baer 2004; Barrett, et al. 2003; Barry 2006; Boon and Kachan 2008; Caspi, et al. 2003; Hollenberg 2006; Salkeld 2004; Salkeld 2008; Templeman and Robinson 2011). However, I maintain that the real work of healing with an IM approach is not simply situated in the manner in which this blending process occurs. Rather, I found in this study that healing emerges from the social relationships that develop between IM practitioners and their patients. Importantly, I discovered several dimensions involving social relationships that feature not only the interactions between the practitioners and their patients, but also between patients' own biographical pasts, presents, and possible futures.

This ethnographic study of the IMPC provides a window into the significance of these relationships for the practice of IM. I discovered that the real work of healing with the IMPC's treatment approach occurs as the practitioners and their patients develop and grow these social relationships. The interactions found in these relationships not only result in the validation of patients' chronic pain experiences, but also facilitate patients' ongoing efforts in reconstructing their past and present life roles and identities, enabling them to envision their possible future selves. Given the importance of these relationships to the IMPC's "treating the whole person" approach, I argue that more attention is needed in the ethnographic literature on these interactions between IM staff and their patients, and discovering how these social relationships are constructed and negotiated in IM practice.

#### **Conceptualizing Integrative Medicine**

The practice of IM is becoming increasingly widespread, and it is often generally understood as an approach that brings together CAM and biomedicine (Baer 2004; Caspi, et al. 2003; National Center for Complementary and Alternative Medicine 2010). For example, an integrative approach may involve blending biomedically-based treatments such as prescription medication or physical therapy with CAM-based treatments such as massage or acupuncture (Baer 2004; Consortium of Academic Health Centers for Integrative Medicine 2009; National Center for Complementary and Alternative Medicine 2010). IM is also understood to involve blending the epistemologies behind these two forms of healing; for example, blending different beliefs on disease origin (Salkeld 2004; Salkeld 2008). In the anthropological and social scientific literature on IM practice, a debate has emerged about how to conceptualize this approach (Baer 2002; Baer 2004; Baer 2008; Caspi, et al. 2003; Salkeld 2004; Salkeld 2008). Importantly, this debate has led to various interpretations of IM, and what some argue are misinterpretations of this practice (Caspi, et al. 2003; Salkeld 2008).

In much of the literature, a key question oftentimes emerges that asks whether biomedicine is still the master narrative in the practice of IM (e.g. Anderson 1999; Baer 2004; Baer 2008; Barrett, et al. 2003; Barry 2006; Caspi, et al. 2003; Hollenberg 2006; Salkeld 2004; Salkeld 2008). Importantly, it has been found that even in IM clinical settings that aim to be more holistic in nature, biomedicine oftentimes predominates in many respects (e.g. Salkeld 2004; Salkeld 2008). The data from this ethnographic study of an IM pain clinic provides additional support to previous findings in the literature that note the omnipresence of the biomedical model in clinical IM treatment settings. In the forthcoming discussion, I will highlight three key examples from my data that show why this would have been an interesting issue to address with my findings. However, I maintain that my data shows something more profound going on at the IMPC than simply a negotiation between biomedicine and CAM in this particular IM clinic.

To begin, in chapter 3 we learned how the IMPC desired to create an environment that had less of a biomedical or "sterile" feel. Yet, I found that there are still several aspects of the clinic's physical space that indicate the primacy of biomedicine in this IM setting. When looking to the literature for a similar comparison, Salkeld (2004) provides the most detailed anthropological accounting of how an IM clinical space was designed. She argues that biomedicine is given primacy in this physical environment given how the four physicians utilize and control the most clinic space when compared to the CAM practitioners (Salkeld 2004). Similar to Salkeld's setting, I found that Dr. Bennett's services take up half of the clinic space at the IMPC (ironically, the staff describes Dr. Bennett's side of the clinic using the label the "medical side"). Also commonplace in biomedical treatment settings, Dr. Bennett's services are located behind a locked doorway, and patients can only access this side of the clinic via Joan the medical assistant. In contrast, the IMPC's "therapy side," where the massage and physical therapists practice, is left open. Additionally, the physicians in Salkeld's

clinic assert also their authority over this setting given only the presence of their names on the clinic's doorway, much the IMPC where only Dr. Bennett's name is listed on the doorway. Dr. Bennett is also the only practitioner listed on the clinic's large outside sign (that also has the clinic's biomedical specialties listed first with the CAM specialties below), and only his credentials hang in the clinic's public spaces (e.g. on the waiting room walls and one wall in the clinic's "medical side").

Additionally, there were several indicators of biomedical predominance in the clinic's culture and staff relationships that I described in chapter 4. The literature notes that biomedical primacy can often be seen in the relationships between biomedical and CAM practitioners (Boon and Kachan 2008; Gaboury, et al. 2009; Hollenberg 2006; Salkeld 2004; Salkeld 2008). Trust and teamwork are important features related to integrative practitioners working effectively with one another (Boon and Kachan 2008). A key aspect of Dr. Bennett's "dream" was building a staff to support his vision of the IMPC, and there is a strong rhetoric of family and teamwork that creates a bond and sense of trust between Dr. Bennett, Jasmine and the additional IMPC staff. However, despite this strong rhetoric, Dr. Bennett and Jasmine, who both come from biomedical backgrounds, emerge as the key decision-makers and authority figures in this setting.

Also, chapter 5 provides an emic view of the IMPC's treatment approach, and there are several key indicators of the biomedical model in their process of integration. Use of more biomedically-oriented language can be a key indicator of the predominance of this model in integrative treatment approaches (Anderson 1999), which became evident in the IMPC's diagnostic phase described by Dr. Bennett using the term "disease focus." Also, Dr. Bennett described himself as the "coordinator" of the patient's treatment plan as he is the clinic's sole physician. His choice of language is indicative of his authority in this setting and control over key aspects of the patient's treatment process. Additionally, it is also not uncommon for alternative practitioners to utilize more biomedically-oriented language in integrative treatment settings as well (Anderson 1999). Roxy, who is a massage therapist, described how she approached a patient's treatment using anatomical terminology like "sciatic release," for example.

The predominance of the biomedical model in the IMPC's treatment approach is also evident in the clinic's process of integrating biomedicine and CAM treatment modalities. As indicated in the literature, this process can differ depending on the IM clinical setting (Salkeld 2004; Salkeld 2008). For example, in Salkeld's IM clinic, with each unsuccessful protocol the patient's treatments and diagnoses became more CAM oriented. However, the IMPC's process differs as their ability to offer a blended treatment approach was, at times, influenced by the political economic realities of their patients who live in the Detroit metropolitan area (e.g. the breadth of patients insurance coverage; financial strain). Although Dr. Bennett ideally hoped to provide blended treatment plans, he will take a biomedical route first if patients need because of financial issues such as a lack of insurance coverage or a patient's inability to find a way to afford the out-of-pocket costs associated with CAM therapies. It has been noted in the literature that the cost of CAM therapies can be a deterrent for patients (as it appeared to be for some of the IMPC's patients), and some of these modalities are not endorsed by insurance plans (Baer 2004:144-145; Barrett, et al. 2003).

These political economic realities have important implications for the conceptualization and practice of IM as they reinforce the primacy of a biomedical

261

model in blended treatment settings like the IMPC's (Baer 2004:144-145; Barrett, et al. Consequently, the sustainability of approaches like the IMPC's in the 2003). contemporary and increasingly pluralistic U.S. health care environment is called into question. What if large segments of the population are unable to afford the out of pocket costs associated with CAM treatment options like massage or acupuncture? Will the IMPC (and perhaps other clinics like it) be able to continue to sustain itself financially in the current U.S. economic climate with their IM approach? It is quite possible that the IMPC may have no choice but to prioritize more biomedical therapies rather than their ideal blend of biomedicine with CAM in order to sustain itself financially. Unfortunately, this study was limited by not having longitudinal data to explore this political economic reality, and whether the IMPC would have to narrow the scope of the CAM treatment options they offered. Yet, there were several indicators during my fieldwork of this possibility. For example, although nutritional supplements and Reiki were offered at the clinic, these types of CAM treatments were not covered by insurance and perceived by the staff as greatly underutilized by patients. Though the IMPC staff at times attributed this underuse to economic considerations, it would require further investigation to see if this was truly the case.

As we can see, much of my data from the IMPC lends additional support to the anthropological and social scientific literature that approaches the study of IM in terms of questions about how different treatment modalities and theories of healing are blended, and whether biomedicine is still the master narrative in this integration process. I still believe this is an important question to address, especially given the above highlighted political economic issues that are associated with this increasingly pluralistic health care environment. Yet, I maintain that my data indicates that there is something deeper going on at the IMPC.

After analyzing each of the patient's individual stories and their engagement with the IMPC's "treating the whole person" approach in chapters 6 and 7, I came to a realization. Many of the IMPC's patients (perhaps with the exception of Julia who was already well educated on CAM therapies before meeting Dr. Bennett) were seeking a new kind of approach to address their chronic pain, but not one that was specifically "integrative" per say. That is, they were not necessarily searching for an approach that blended biomedicine and CAM, but rather some place that would listen to them and more adequately address their chronic pain needs. In fact some patients, like Betty for example, did not appear to know that the IMPC was indeed an "integrative" clinic. For instance, I asked Betty "Is this the first integrative clinic that brings in massage and PT that you've been to?" She replied, "Yes. ...this [clinic] combines all—everything. ...Whatever it is, is working." Thus, it appeared that many patients that I talked to were not drawn to the clinic for "integrative" pain management.

What then was it about this place that drew these patients (including myself as a researcher) to it, *and* kept them coming back, even if they only partially engaged with their treatment approach? I found that the answer began to emerge in the interactions which occurred between the IMPC's staff and their patients, and the subsequent social relationships that developed and grew between them. In the enactment of the IMPC's treatment approach, I came to discover that it is not the clinic's process of blending treatment modalities where we see the real work of healing. Rather, the clinic's form of relationship-based care is where this healing work takes place.

# **Beyond Blending: Social Relationships in IM Practice**

I contend that a more pressing issue that we need to address in the study of IM, rather than simply focusing on the integration process itself, should center on the significance of these social relationships for this type of blended practice. In chapter 1, I discussed a few of the macro or health systems level conceptualizations of IM that currently exist. Some of these conceptualizations largely focus on the integration process (e.g. the Mayo Clinic), and only touch on the idea of these interactions and social relationships through their use of such concepts as "partnerships" or "therapeutic relationships" (Bauer 2010: 11; Caspi, et al. 2003: 61; Consortium of Academic Health Centers for Integrative Medicine 2009). Consequently, these interactions and social relationships have the tendency to be oversimplified with such concepts that are also not adequately operationalized. For instance, how are these "partnerships" and "therapeutic relationships" formed? What types of interactions are involved? What do these concepts mean in local level IM clinical practice, and what is their influence on the patient's healing process? Accordingly, the significance of these interactions and social relations gets lost in such broad-level IM conceptualizations.

In their studies of IM, some anthropologists and social scientists have discussed these interactions and social relationships between practitioners and patients that have emerged through patient interviews or observations of clinical encounters (Adler, et al. 2009; Koithan, et al. 2007a; Koithan, et al. 2007b; Mulkins and Verhoef 2004; Salkeld 2004; Steinsbekk and Launso 2005). However, there are a few issues to note with this body of literature. First, some of these studies do not take place in formalized IM treatment settings (Adler, et al. 2009; Steinsbekk and Launso 2005). In other words, these studies focus on patients' interactions with their biomedical and CAM practitioners, but patients are informally integrating treatments on their own versus receiving coordinated care in a single treatment setting. Second, some of these studies largely focus on the interactions related to the professional roles, identities and statuses of the practitioners and patients that emerge in the clinical encounter (Adler, et al. 2009; Koithan, et al. 2007a; Salkeld 2004). Third, only a few studies draw attention to the role these social relationships for healing, including how the patient's life has changed as a result of their interactions with their IM practitioners, and their ability to move forward with their lives (Koithan, et al. 2007b; Mulkins and Verhoef 2004). However, only one of these studies collected original data on this topic (Mulkins and Verhoef 2004), and both studies appear to only partially attribute these social relationships as key to the patient's healing process with an integrative approach (Koithan, et al. 2007b; Mulkins and Verhoef 2004).

Therefore, more research is needed to further explore the significance of these social relationships to conceptualizations of IM and how it is practiced. Evidence from my study of the IMPC contributes to this body of knowledge by showing how these social relationships deserve a more central role in our understanding of how healing occurs with an IM approach more generally and in pain management specifically. Importantly, as we will see below, my data indicates how these social relationships can include both the interactions defined by the professional roles of the practitioners and patients, and the interactions between patients' past, present, and future selves.

#### Integrative Medicine at the IMPC: Relationship-Based Care

Consistent with some of the more common and established conceptualizations of

IM practice (e.g. Bauer 2010; Consortium of Academic Health Centers for Integrative Medicine 2009), the IMPC's emic understanding of their "treating the whole person" approach provides patients a more holistic mind and body perspective to their IM care. Specifically, the IMPC begins from a biomedical orientation by identifying the patient's disease. They address the patient's physical body (i.e. the disease) ideally through integrating biomedical and CAM modalities in treatment plans such as trigger point injections and massage, for example. They then customize the patient's treatment plan through their attentiveness to their patient's mental state and unique life circumstances that could impact their care. For example, they acknowledge the more subjective (i.e. illness) aspects of patient's health conditions like the financial impact of it in their lives. Like other more holistically-oriented treatment settings, the IMPC strives to know patients as "real people" who have lives that they yearn to resume (Jackson 2000:29; Steinsbekk and Launso 2005:199). They see themselves as supporting this type of holistic mind and body treatment approach with the "home-like" physical environment that they created, and with what they describe as their "family-like" culture. In short, from the perspective of the IMPC staff, they give equal weight to all three aspects (problem identification, developing the IM treatment plan, and customization of the patient's treatment plan) of their "treating the whole person" approach.

However, from my etic-level analysis of the data, I contend that the real work of healing with the IMPC's approach resides in the interactions between practitioners and patients as they engage in a relationship-building process during the customization of patient care. Yes, the specific treatment modalities and (when possible) the integration of them in the treatment plan are an important aspect in helping patients address their pain. For instance, both trigger point injections and massage were highly beneficial treatment modalities that were integrated in Betty's treatment plan and helped resolve much of her pain. For some patients, the diagnostic phase of the IMPC's approach where they learn the name of the specific "disease" or health condition that is greatly impacting their lives was found to be highly important. For example, a diagnosis was highly important for patients like Betty who felt that the pain she experienced was more than "just arthritis." Christina's diagnosis of trigger points helped her understand why she was in so much pain as a result of her accident. This diagnostic phase was also important for Linda whose other doctors were unable to "see" what was possibly causing her pain on any of her "objective" medical tests.

Yet, my data reveals that what the IMPC excels so well at, and what I contend is the cornerstone to their practice of IM, is forming an intense bond with their patients in this process of customizing the patient's treatment plan. This bond allows for social relationships to develop during the co-created clinical encounter. Importantly, I found two kinds of social relationship structures at the IMPC that feature interactions between the practitioner and patient and their associated professional roles and identities (e.g. doctor, patient), and also interactions between patients' past, present, and future life roles and associated identities (e.g. gender identities, age-related identities).

Conversations between the IMPC's practitioners and their patients are an integral part of this relationship-based care. During the co-created clinical encounters, many formal and informal conversations take place about the patient's pain, their treatment process, and other aspects of their pain and life stories, which facilitates these interactions, and the formation of these social relationships. Conversation during the clinical encounter is therapeutic as it helps them make sense of what has happened in their lives by validating patients' experiences, and helping them come to terms with how chronic pain has changed their bodies and impacted their lives. An important part of this process was the IMPC's practitioners sharing knowledge and advice about wellness and healthy living during these co-created clinical encounters. For example, patients became more self-aware of their bodies, and learned about skills necessary for selfcare such as home physical therapy exercises and lifestyle changes (such as healthy eating and stress reduction) in order to manage pain and its effects upon their lives.

Another essential aspect to the IMPC's ability to form and sustain these interactions and social relationships is their more flexible view regarding patient responsibility. Unlike other clinical settings (both IM and pain oriented) that heavily emphasize patient responsibility and blame if treatment falls short of expectations (Jackson 2000; Jackson 2005:346; Salkeld 2004), the IMPC worked with their patients to help them not blame themselves for the onset of their pain or if the treatment approach was not entirely effective. Additionally, teaching their patients about self-care practices also helps them begin to adjust to the reality of understanding oneself as someone living with a chronic pain condition, and some of the accommodations that can be made to physically and socially to adjust to this new reality. Importantly, the practitioners try to present their self-care suggestions in a non-judgmental way, therefore providing the patient with the knowledge, but also the choice whether or not to incorporate this advice into their lives. In contrast to Jackson's (2000) pain clinic and their use of "confrontational therapy" to change patients' "maladaptive" behaviors, the IMPC's practitioners aim to create a more supportive rather than authoritative

environment. In my interviews, some patients expressed how this kind of nonjudgmental approach was very important and helpful for them.

In multiple patient narratives I saw how these interactions and social relationships allow the patient time to come to terms with their pain condition, and what they may have to change in their lives in order to move forward. For Christina, the IMPC staff validated the magnitude of her pain upon the multiple life roles and identities (e.g. wife, mother, volunteer, student, and employee) she juggled as a busy woman at mid-life. Although she still desired her "old life," she acknowledged that there were things she could do to improve her health such as stopping her smoking habit and eating better so she could work towards a new "me." In Betty's case, the IMPC staff validated her pain as stemming from her lifelong tension and worked with her to treat both her physical pain from her trigger points, but also to find ways (e.g. senior yoga, but not with the "rocking chair crowd") to reduce her tension and prevent her pain from returning that had the real potential of robbing her of her independence that was an essential part of her identity as an older adult. For Robin, her interactions and social relationships with the IMPC staff (e.g. Dr. Bennett, Jennifer and Elizabeth) gave her very real hope that she could have a new life that would be completely different from the patient identity that had come to consume much of her past.

Therefore, integrative medicine at the IMPC is not what integrative medicine is often assumed to be, which as we have seen, so often emphasizes this notion of blending biomedical and CAM treatment modalities and theories of healing (e.g. Baer 2004; Bauer 2010; Caspi, et al. 2003; Consortium of Academic Health Centers for Integrative Medicine 2009). Rather, integrative medicine at the IMPC is based on the interactions and social relationships they form with their patients that integrates the patient's entire life history in the way they envision and enact their "treating the whole person" approach. In reality, while the IMPC frames what they do from a mind and body perspective, I found that they are really taking a more diachronic view of their patients. The clinic bonds with their patients in order to understand who they once were (the patient's past life roles and associated identities), who they are now (their present situation and impact of their pain on these roles and identities), and who they desire to be again (their future selves). I contend that the IMPC's more diachronic view of their patients is particularly good for treating pain as Good writes: "Disease occurs not only in the body—in the sense of an ontological order in the great chain of being—but in time, in place, in history, and in the context of lived experience and the social world" (1994:133). Hence, the IMPC conceptualizes and treats pain as a "lived experience" (Good 1994: 133), rather than simply a mind and body one, which often serves as the foundation of other pain treatment approaches documented in the literature (e.g. Baszanger 1998; Jackson 2000).

For the most part, I found that this relationship-based care at the IMPC is why their approach "works," so to speak compared to pain treatment approaches in other multidisciplinary pain clinic settings (Baszanger 1998; Jackson 2000). Their relationship-based approach to the practice of IM chronic pain management is supported in part, to having a strong charismatic healer with Dr. Bennett at the clinic's helm, and their attentiveness to creating a supportive physical and social environment for their patients through their emphasis on teamwork and family (qualities oftentimes lacking in the clinics described by Baszanger and Jackson). As indicated in patients' narratives, this type of relationship-based care is mostly a good thing as I indicated above with examples from Betty, Christina and Robin's stories that showed in various ways how they were beginning to move forward with their lives. For example, we saw how the IMPC's approach appeared highly effective for Betty who engaged with it fully as she began to deal with her tension that caused her trigger points and began moving forward with her life.

However, as the existing ethnographic literature in this area has shown, not all pain treatment approaches work equally well for all patients (e.g. Baszanger 1998; Jackson 2000). For instance we see in Natalie's story at the end of chapter 6 how this relationship-based care helped her more effectively manage her pain so she could continue to attend to what she identified as her most cherished life role as a mother. Yet, because Natalie developed such strong social relationships with the clinic's practitioners, she became dependent upon them, which prevented her from envisioning her future self free from the continued care of the IMPC. In other words, Natalie always envisioned herself as a patient at the IMPC, evident in her proclamation "I like to see an end [to the pain], and I think we're close to it. But even if we are, I'm not leaving Dr. Bennett!" Additionally, Natalie acknowledged that she knew her physical limits, but continued to push herself anyways; indicating how she was unable to accept the changes she needed to make in her life in order to move forward.

The patient's narratives in chapter 7 largely indicate how this relationship-based care at the IMPC is not a perfect system when patient's only take a piecemeal approach. For example, Linda was unable to effectively interact with Jennifer, and only formed strong social relationships with Dr. Bennett and Roxy. As a result, Linda was not able to take advantage of having a fully coordinated and integrative approach at the IMPC. In addition, Julia was limited financially in the treatments she could afford. For her, political economic aspects prevented her from interacting and developing social relationships with some of the other clinic practitioners. In Stella's case, she formed a strong bond with Dr. Bennett as she appeared to like the clinic's more flexible view of patient responsibility. However, one has to wonder that if the lack of effective treatment modalities will possibly challenge the "faith" she has placed in Dr. Bennett to more effectively manage her pain. In Paul's situation, he purposely chose not to interact with any of the clinic's other practitioners except Dr. Bennett as he had already formed strong relationships with a massage and physical therapist outside of the IMPC. Paul also had some difficulties in his interactions with Dr. Bennett (e.g. Dr. Bennett's vacation schedule caused Paul to miss some treatments; Paul confronted Dr. Bennett over his concerns regarding the strength of the injection solution Dr. Bennett used to treat his trigger points), which caused some tension and Paul to admit that his treatment at the IMPC only kept his pain "at bay." As a result, Paul was unable to fully envision his future self where he was able to work again.

This continuum of patient stories shows how this form of relationship-based care in this IM pain clinic setting can be messy, so to speak, when patients only partially engage, either by choice or due to life circumstances. However, despite this variability in whether people chose to embrace the IMPC's approach in full or part, the patients concur that the IMPC's approach appears to at least be "doing something." It is effective in "meeting them where they're at," so to speak, by working with patients' needs and life circumstances and providing some hope to patients that while their future may not be completely pain-free (like Paul, for example), they can at least use what aspects of the approach work for them in order to start working towards restoring some semblance of order to their lives.

This study was limited by not having longitudinal data to explore the long-term effectiveness of these interactions and subsequent social relationships that are the cornerstone of the IMPC's "treating the whole person" approach. Many of the patients I met were very early in their treatment process at the IMPC, with Natalie's case being the exception in this study. Again, Natalie's case illustrated how the IMPC's more flexible approach to patient responsibility resulted in her becoming dependent on the clinic's care. Consequently, it is hard to know if the IMPC's approach has a higher potential to foster this kind of dependent relationship (at least for some patients) upon their care. Can the IMPC consider it a "good outcome" of their "treating the whole person" approach, which is driven by these social relationships, if patients (like Natalie) keep engaging in behaviors that result in them continually seeking treatment at the IMPC? In moving forward, I hope to design a longitudinal study centering on the interactions between IM practitioners and their patients, and their social relationships in order to better understand its long-term effectiveness for an IM approach overall, and pain management specifically. This study would focus on practitioner and patient interactions around this type of pain treatment, and may shed light on whether patients are better able to self-manage their conditions with such an approach, or if it results in them becoming increasingly dependent upon a clinic's continued care.

In summary, this ethnographic study of an IM clinic set out to identify and describe how they conceptualize integrative medicine and apply it to the management

of chronic pain. When I began this research, my understanding of IM was grounded in the common conceptualization in the literature that IM is a "blended" approach, and one that is often dominated by biomedicine (Baer 2004). However, at the end of writing my dissertation, I realized that there is so much more to an integrative approach than merely conceptualizing it in this way. Integrative medicine at the IMPC is so much more than simply a "blend" of modalities and epistemologies to manage patients' chronic pain The foundation of IM at this particular pain clinic is rooted in these conditions. interactions between practitioners and patients, and the subsequent development of social relationships between them that have the potential to move patients towards healing. Consequently, I contend that a new understanding of IM is needed that directs more attention to these interactions and social relationships. This study shows the value added of an ethnographic approach for studying IM practice as it identified the salience of this relationship-based care for the practice of IM more generally, and its use for the management of complex chronic health conditions like pain more specifically. Additionally, the use of ethnographic methods highlighted how these interactions and social relationships have the potential to foster patients taking a more active role in their health care.

## **FUTURE DIRECTIONS**

As is often the case when conducing ethnographic studies, the richness of the data that has emerged has provided me with numerous opportunities to reengage with my findings, view them through new conceptual lenses and ponder the future directions of this research. One of these areas for future study involves taking a closer look at the role the cultural context of the Detroit metropolitan area played in this research. As

indicated in chapter 3, race and class are important (and not mutually exclusive) issues in the Detroit context (Farley, et al. 2000; Hartigan 1999; Sugrue 2005). Interestingly, I found that these issues emerged implicitly and explicitly throughout various moments of my research. For example, I noticed that when Dr. Bennett, who is African American, and Jasmine who is Hispanic, talked about their lives and who they are as people, they never brought up the issue of race relations in their life stories or in the making of the clinic. In hindsight, Dr. Bennett and Jasmine's own lives as minorities (and especially as minorities in IM health care specifically) would have been an interesting issue to explore further given the cultural context of where the IMPC is located. For example, it would have been particularly interesting to explore with Dr. Bennett how he felt being an African American physician in the largely white suburban Waterview community, and if he ever experienced any issues related to his race while practicing in this area.

Also, only one patient chose to talk about the issue of race even though I did not specifically interview on this topic. Only Betty, an 89 year old white female of Lebanese descent and a Waterview resident, chose to talk about Dr. Bennett as an African American physician. She discussed in her interview how she felt she accidently insulted Dr. Bennett because of his race the first time she met him:

'Cause when he walked in [here] he said [to me] "Hello, how are you?" I said "Fine." I said—I said "Are you the doctor?!" ...And he said "Yeah." I said "Well where's your white coat?!" "I—I don't wear a white coat" [he said]. He said "I have a thing about [it]." I said "Okay," you know? I thought—I thought when I asked the question he might think I asked it because he was black, you know. That's when I thought I said "Oh Jimmy Christmases," you know I hope he doesn't think that.

Since Betty associated the traditional doctor's coat as a cultural symbol of biomedical authority, she expected that the doctor she was about to meet would be wearing one of these traditional coats. When Betty reflected on her comment to Dr. Bennett, she worried that Dr. Bennett may have misinterpreted her statement to mean that she questioned him being the doctor because of his race, and not because of the absence of the traditional doctor's coat. It is not surprising given Betty's direct nature that she explicitly made reference to Dr. Bennett's race. Her comment raises the possibility that other patients may have hinted at this issue more implicitly in their illness narratives.

Additionally, we learned in chapter 3 how the clinic underwent renovations to improve its physical appearance. However, there was still one aspect of the clinic's appearance that one of the IMPC staff members wanted to improve upon as noted in the fieldnote excerpt below:

As the [staff] meeting continued, [a staff member] brought up another topic. She said she wanted the office to "stop being so ghetto"! She felt that the radio sitting on the waiting room floor made them look "ghetto". The clinic is considering and will check the price on getting radio throughout the entire building and getting satellite feed. The radio is believed to be tacky looking as they want the clinic to have a "spa feel" to it to help the patient's feel that [the money spent here is worthwhile]. (Fieldnotes March 6, 2009)

Reflecting on this reference to the clinic still looking "ghetto," it appears as though the staff member may be drawing a contrast between the IMPC in the suburban Waterview and the urban and poorer city of Detroit.

Additionally, some of the political economic issues related to patients living in the Detroit metropolitan area indicate how this particular cultural context influences the accessibility and perhaps too the effectiveness of an IM approach to pain management. For example, Robin talked about how living in an unsafe neighborhood in Detroit limits her abilities to exercise, and she cited the very real possibility of not being able to continue with her comprehensive care at the IMPC if she lost her insurance coverage.

Julia was limited in this regard too as she self-described herself as poor and therefore unable to fully engage with the clinic's approach. Christina described her struggles coping financially in the shaky Detroit area economy and her worries over her husband losing his job in the automotive industry. She was currently finding a way to afford her care, but her precarious financial position had the potential of impacting her ability to continue some aspects of her treatment at the IMPC.

As these above-mentioned examples show, these issues continue to remain a defining feature of this region's history, and hint at why race and social class issues could be a very interesting topic for further exploration. Future in-depth analysis would involve taking a closer look at race and class issues in the making of the IMPC setting, including how these issues may emerge in staff relationships. Race and class were never directly evident in my observations or talked about in my interviews with the IMPC staff. But given some of the implicit ways these issues arose in certain parts of my data, it merits further future exploration regarding how these issues may emerge in the clinic's culture. Additionally, as I indicated in chapter 5, given Detroit's reputation as an "unhealthy" place to live (Michigan Department of Community Health 2005), one has to wonder if the clinic's more relaxed approach to patient responsibility is related to this "unhealthy" reputation. Perhaps the staff believes that patients need a more supportive rather than authoritative environment to foster the incorporation of health and wellness advice into their lives.

In addition to race and class issues, the results from this dissertation can also be interpreted through a gendered theoretical lens. The majority of the patients profiled in this study were female, and issues of gender and disempowerment are often evident when studying women's experiences of chronic pain health-seeking (Greenhalgh 2001; Skuladottir and Halldorsdottir 2008; Werner, et al. 2004; Werner and Malterud 2003). Pondering these issues, future investigation would pose the following questions: in what ways do the issues of gender and disempowerment appear in the illness narratives collected from the IMPC's patients? How does gender play a role in patients' relationships with the IMPC staff? For example, how do the female patients interact with Dr. Bennett as a male physician? While Greenhalgh (2001) had a more contentious relationship with her male doctor, the IMPC's female patients had a good rapport and bond with Dr. Bennett, with Linda even characterizing him like a "friend." Hence, how can these gendered experiences be studied and understood when looking at the IMPC's form of relationship-based care?

Additionally, the IMPC has a largely female staff with Dr. Bennett as a male physician and lead authority figure in this setting. The only other male staff member is Michael, the clinic's physical therapist who was not a full-time member of the staff. This mostly female to male staff ratio in this particular clinic setting warrants future analysis of their gendered relations with one another. Much like the issues of race and class, there were implicit references to gender that appeared in my data as indicated in the fieldnote below:

Today, I found out about a practical joke that "the girls" played on the MD [i.e. Dr. Bennett]. Roxy was taking out the trash, and she popped her head into the MD's office and I overheard her comment on something that was taped to the wall in the MD's office. I mouthed to her asking what it was and she said I had to come take a look. I stuck my head in the MD's office while he was sitting at his desk. There was a picture hanging off of one of his Obama framed pictures in his office. I wasn't able to get a thorough look, but there was what looked to be a magazine clipping of a man's body in possibly a swim suit with the MD's head pasted on the body...his head had a surgical mask on! The MD had spent the past 8 days in the Dominican Republic when the H1N1 (Swine Flu) epidemic

began in Mexico and quickly spread to other countries. Many in Mexico used surgical masks to prevent the spread of the virus. I asked the medical assistant [i.e. Joan] and the office manager [i.e. Pamela] about the practical joke. The medical assistant said "the girls" had done this before he got back. The office manager said that they play practical jokes on him and tease him...that he wouldn't know what to do with himself if they didn't joke around with him! (Fieldnotes May 4, 2009)

One can glean from this instance how fruitful it would be to further explore the role gender played in the staffs' relations with one another. Although Dr. Bennett was a male and lead authority figure at the IMPC, the female staff whom referred to themselves as "the girls" felt a sense of ease around Dr. Bennett, evident in their teasing behavior and the practical jokes they played on him.

# CONCLUDING THOUGHTS

Prior to embarking on this dissertation research on chronic pain, I naively thought I had a better "understanding" of this type of condition. I had read about patients' chronic pain experiences in the ethnographic literature. I witnessed firsthand in my own family how the sheer intensity of chronic pain defies words and can only be expressed through tears. Yet when I entered the field and started to hear about the suffering these patients went through, saw the raw emotions that accompanied their powerful words, and watched patients wipe away the tears they shed during interviews, I experienced "culture shock" much like I first participated in anthropological field schools out of the country. I was blindsided and quickly realized I knew very little about living with chronic pain. The IMPC staff and patients became my teachers and helped me begin to "understand" the countless ways this insidious and often unseen condition can affect a person's life. As a result, I not only changed as a researcher who studies chronic pain, but also as a person who lives with a chronic pain patient. My mother has been a fibromyalgia patient for many years and one day, when I was partway through my research, I admitted to her how I never truly realized just how life-altering her condition is. I never considered what it must have been like for her to have her pain invalidated by others, to search endlessly for relief, and give up so much in order to accommodate her condition that consumes both her body and mind, and has significantly changed her life. This "understanding" of chronic pain was one of the greatest insights the IMPC's staff and patients gave me because, as Julia notes, much of the chronic pain experience is "a fight to get somebody to understand you." As an anthropologist being trained to think about how voices of people marginalized in different ways come to be heard and understood, conducting this dissertation research in an integrative medicine pain clinic has been a very insightful process that has strengthened my desire to continue to extend my research program in this area.

# APPENDIX A

# TABLE OF MEASURES

Specific Aim	Methods	Data
1) To identify and describe	Participant-	Clinic organization
the history of this IM clinic,	observation	Clinic culture
including the development		Clinic outreach
of its IM approach generally		IM treatment approach
and for pain treatment		Conceptualizations of pain
specifically		
2) To identify and describe	Participant-	Practitioner and staff daily
the roles of clinic's		activities, roles
practitioners and staff, as		Training, education
well as their education,	Informal interviews	IM treatment approach
training, treatment		Conceptualizations of pain
approaches and		
professional experiences		
3) To document and	Life history interviews	Pain as a life disruption
describe patients'	Illness narratives	Treatment history
experiences with integrative		Treatment experiences
medicine and pain		
treatment through the		
collection of life histories		
and illness narratives		
4) To ethnographically	Direct observation	IM treatment approach
document the co-created		Conceptualizations of pain
integrative medicine clinical		Pain as a life disruption
encounter and examine		Perceived efficacy
how pain treatment		
approaches are enacted		
and perceived		

# **APPENDIX B**

# **STAFF INTERVIEW PROTOCOL**

# Career Choice Narrative

Tell me your job title and what your job involves. What training and education did you get to work in this field?

Were there any significant events or motivations in your life that led you to your chosen occupation? What were those events/motivations? Why are they significant to you?

Why did you decide to work at this particular clinic?

# **Specific Topics:**

How would you describe the kind of care/services offered at this clinic?

Tell me how this clinic got started. What was your vision to start this clinic? What funding and/or logistical issues were involved? How did you conceptualize the care offered here? What about the growth and future directions of the clinic?

How do you market the clinic and its services? Why? Do you find the public receptive of your vision?

How did you decide what complementary and conventional practices to offer here?

Why did you decide to set up the clinic in this way? Describe the layout of the building and why you chose the literature available in the waiting room.

Please describe what it's like working in this setting specifically. What is the working environment like? What is your role in the day-to-day operations?

How have you set up your treatment/exam room(s)? Why did you set them up in that way? What is the benefit to the patient to have the room(s) set up this way?

How do you develop your treatment strategies?

How would you describe your role in this treatment process? What do you believe is the patient's role?

In your experience, how is pain a disruption to the lives of the patients who come here? Please describe any particular cases that come to mind.

What do you see as the role of integrative medicine for pain in helping patient's return to a full life? Do any particular cases come to mind?

What is integrative medicine to you? How do you conceptualize it? Why do you conceptualize integrative medicine in this way?

I am interested in knowing how integrative medicine relates to other aspects of the health care system. In your opinion, how does IM relate to complementary medicine, alternative medicine, biomedicine, holistic medicine?

What do you see as the future of integrative medicine overall? What do you see as the future of integrative medicine for pain management specifically?

# APPENDIX C

# PATIENT INTERVIEW PROTOCOL-INTERVIEW #1

# Demographic Questions:

I'd like to begin our interview with some general questions about you. How old are you?

Gender [male] [female]

What is your marital status [single, married, divorced, widowed]?

What is the highest educational level you have attained [high school, college (undergraduate), graduate school]?

How would you describe your socioeconomic status? (optional)

How would you describe your race or ethnicity? (optional)

# Self-Rated Health (Idler and Benyamini 1997; Idler, et al. 1999):

I would now like to ask you some questions about your health in general:

In general, would you say your health is: excellent, very good, good, fair, or poor? Could you tell me what goes through your mind when you say that?

Compared to other people your age would you say that your general health is: excellent, very good, good, fair, or poor? Could you tell me what goes through your mind when you say that?

# Life History Narrative (STN Method-Luborsky, 1987; 1990; 1993)

Now that we have talked for a few minutes I'd like to know more about you and your life. Would you describe your life for me, whatever comes to mind about it? Start where you like, take as much time as you need.

If you were to describe your life as a book, what chapters would there be? What would you title those chapters? What would you title the whole book?

If you were to describe your life as a mural, what scenes would there be? What would you title those scenes? What would you title the whole mural?

# APPENDIX D

# PATIENT INTERVIEW PROTOCOL—INTERVIEW #2

# Illness Narrative:

I'd like to know more about you and your pain. Would you describe your pain for me, whatever comes to mind about it? Start where you like, take as much time as you need. (STN Method-adapted from Luborsky, 1987; 1990; 1993)

If you wanted to describe your pain to someone (e.g. a song, picture, etc.), how would you communicate what your experience is like? Why would you chose to communicate your pain in this way?

[Prompt] If you were to describe your pain as a book, what chapters would there be? What would you title those chapters? What would you title the whole book?

[Prompt] If you were to describe your pain as a mural, what scenes would there be? What would you title those scenes? What would you title the whole mural?

In what ways is your pain a disruption to your life?

What role does pain play in your expectations for the future?

# **Specific Topic Questions:**

Can you describe why you chose to come to this clinic for your pain? What were your expectations in coming here?

What has your experience at this clinic been like? Can you provide specific examples?

How have you felt since coming here? Have you experienced any relief from your pain?

What types of conventional (e.g. medication) and complementary (e.g. massage, acupuncture) treatments do you receive here? Why are these treatment recommended?

Are there any obstacles or challenges to getting the care you need? [Probe: finances, costs, insurance]

What is your role in the treatment process? What have you been told to do to help with managing your pain? What do you think of their advice? Are there other things that you think you should do? What and why?

Is there anything you would do differently regarding your treatment? What would that be and why?

If there was one thing that you could tell the staff at this clinic about how to improve care, what would it be and why?

What have others (e.g. family, friends) thought of your decision to come to this clinic for treatment? What was your response? Why?

Have you gone to any other medical clinics to receive conventional and/or complementary treatments for your pain? Why?

# **APPENDIX E**

# THE IMPC'S TREATMENT OPTIONS

Treatments	Practitioner	Description
Medical Acupuncture	Medical Doctor	"Acupuncture is a method of encouraging the body to promote natural healing and to improve functioning. This is done by inserting needles and applying heat or electrical stimulation at very precise acupuncture pointsMedical acupuncture is the term used to describe acupuncture performed by a doctor trained and licensed in Western medicine who has also had thorough training in acupuncture as a specialty practice" (American Academy of Medical Acupuncture N.d.)
Intramuscular Stimulation (IMS)	Medical Doctor	"IMS involves the use of acupuncture type needles [being inserted] into the body where muscles have shortened or contracted, or at points where muscles meet nerves. It is at these points where the long term pain originates. The knotted muscle will 'grab' the needle and after a while 'let go' and then carry on relaxing after the needle has been removed" (IMPC website). "Although IMS uses implements adapted from traditional acupuncture, it is based on scientific neurophysiological principles" (IMPC "What is IMS? A New Understanding of Chronic Pain" Pamphlet) <sup>51</sup>
Pain Relieving Injections	Medical Doctor	<b>Trigger Point Injections:</b> Injection of a solution containing Lidocaine ® and the all natural plant- based Sarapin® directly into the trigger point (i.e. a muscle knot). All the injections I observed used this natural alternative with the Lidocaine ®. The injections help with pain relief and help "to break up the scar tissue present" in the patient's muscle <sup>52</sup> (IMPC website)

<sup>&</sup>lt;sup>51</sup> Due to issues of confidentiality, the IMPC "What is IMS?" pamphlet will not be formally cited <sup>52</sup> While the procedure can also be performed with the option of steroids in place of the Sarapin (IMPC website), Dr. Bennett explained to me how he prefers Sarapin in place of the steroids to avoid damage to the muscle tissue. An additional option involves no liquid solution; only "a dry needle" is placed directly into the trigger point (IMPC website).

		<ul> <li>Prolotherapy: "The word prolotherapy is a combination of proliferant and therapy. The therapy results when proliferation occurs in the cells of the tendons and ligaments. Looseness or laxity of the ligaments and tendons cause pain. Proliferation of the cells forms new collagen and allows new growth and formation of ligament and tendon tissue in the areas where it has become weak. As the cells lay down new collagen, the body creates ligaments and tendons that are stronger, thicker, tighter, and bigger. Prolotherapy involves the use of natural substances, often as basic as a concentration of dextrose and Lidocaine®. These substances are injected into the area of pain, which then causes an inflammatory reaction. Proliferation of the cells results from the inflammation. As the body heals the inflammation, the ligaments and tendons tighten relieving the pain" (IMPC website)</li> <li>Nerve Block Injections: "Nerve block injections are performed on patients for a variety of conditions caused by inflammation of specific nerve roots" (IMPC website)</li> <li>Supartz®: "Supartz is a solution of highly purified sodium hyaluronate. Supartz is injected directly into the knee to restore the cushioning and lubricating properties of normal joint fluid. Supartz injections are approved for the treatment of osteoarthritis of the knee in those who have failed to respond to simple painkillers, exercise, or physical therapy" (IMPC website)</li> <li>Botox®: "Botulinum toxin Type A (Botox) is a protein that causes temporary weakness of the injected muscles." Botox injections help treat muscle spasms" (IMPC website)</li> </ul>
Aqua Massage	N/A	"The AQUA PT is a revolutionary new machine that provides a whole body water massage while the patient remains clothed and dryAqua PT is a (dry) water massager designed for musculoskeletal pain management. This 3 in 1 machine provides the benefits of dry hydrotherapy, dry heat, and massage therapy" (IMPC website)

Massage Therapy (Swedish, Trigger Point, relaxation, reflexology, etc.)	Massage Therapists	"Massage therapy promotes personal health and healing through the hands-on manipulation of soft tissue and muscles" (IMPC "Our Services" pamphlet <sup>53</sup> )
Physical Therapy	Physical Therapists	"Manual" and machine based physical therapy. "Modalities include weight and strength training, gait training, various exercises for strength, balance, and stretching, proper body mechanics, hot/cold packs, ultrasound, electrical stimulation, tractions and more" (IMPC website; IMPC "Our Services" pamphlet)
Additional Therapeutic Products	IMPC's Practitioners	Suggested to patients by the IMPC's practitioners and include gels to relieve pain, braces, nutritional supplements, TENS units, pillows, etc. that are available for purchase at the clinic (IMPC website)
Additional Complementary Medicine Services <sup>54</sup>	Contracted Practitioner	Examples include energy medicine (Reiki), guided imagery, medical hypnosis and lifestyle changes (life coaching, Nutritional Response Testing) (IMPC "Our Services" pamphlet; IMPC website)

<sup>&</sup>lt;sup>53</sup> Due to issues of confidentiality, the IMPC "Our Services" pamphlet will not be formally cited. <sup>54</sup> These non-insurance covered services were not frequently utilized by the IMPC's patients during my fieldwork.

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#### ABSTRACT

# "TREATING THE WHOLE PERSON:" AN ETHNOGRAPHIC STUDY OF AN INTEGRATIVE MEDICINE PAIN CLINIC

by

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Although chronic pain has been increasingly recognized as a critical health issue in the U.S., solely biomedical approaches to pain management are often less effective than comprehensive ones in addressing this condition (Crowley-Matoka, et al. 2009; Good 1994; Greenhalgh 2001; Institute of Medicine 2011; Kleinman 1988; National Center for Health Statistics-Centers for Disease Control and Prevention 2006). This ethnographic study describes in-depth how a Detroit metropolitan area multidisciplinary pain clinic specifically applies an integrative medicine (IM) approach to the treatment and management of chronic pain. The aims of this study included: 1) identifying the history of this IM clinic and the development of their treatment approach, 2) describing the roles of the clinic's practitioners and staff, 3) documenting patients' experiences with integrative medicine and pain treatment through the collection of narratives and 4) recording the co-created integrative medicine clinical encounter and examining how pain treatment approaches are enacted and perceived. This study took place between August 2008-August 2009, and utilized ethnographic methods that included participantobservation of the daily workings of the clinic, direct observation of the co-created

clinical encounters (N=40), and formal interviews with clinic staff (N=8) and patients (N=11). Findings describe a three part process that comprises the clinic's "treating the whole person" approach: 1) identifying the cause of the patient's pain, 2) developing the patient's integrative treatment plan, and 3) customizing this treatment plan to meet the patient's life circumstances. A series of eight narratives describe how the clinic's patients engaged with their approach. These narratives reveal how the real work of healing at this clinic resides not in the integration of treatment modalities, but in the social relationships that develop between practitioners and patients. While variability exists as to whether patients chose to embrace the clinic's approach either fully or in part, the patients concur that the clinic's approach appears to at least be doing something for their pain. By working with patients' current life circumstances, the clinic provides some hope that while patients' futures may not be completely pain-free, they can at least start working towards restoring some semblance of order to their lives.

## AUTOBIOGRAPHICAL STATEMENT

Lindsey Ann Martin is a Ph.D. Candidate in Anthropology at Wayne State University, Detroit, Michigan. She earned both her B.A. and M.A. in Anthropology at Wayne State. Specializing in medical anthropology, her research interests are in the study of chronic pain, integrative medicine (IM), practitioner-patient communication, aging and the life course, qualitative methods and public health. A publication from Lindsey's dissertation research, "Narrating Pain and Seeking Continuity: A Life-Course Approach to Chronic Pain Management," will appear in the forthcoming volume *Transitions and Transformations: Cultural Perspectives on the Life Course*, edited by Caitrin Lynch and Jason Danely (Berghahn Books 2012). Lindsey has presented research at both local and national conferences including the American Anthropological Association, the Gerontological Society of America, and the Society for Applied Anthropology.