BIOCULTURAL CORRELATES OF CHRONIC PELVIC PAIN IN WOMEN

By

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This work is dedicated to several individuals. First, Frank W. Ling, MD, FACOG, whose holistic approach to health care for women with chronic pelvic pain afforded me the opportunity to contribute to the science that seeks to explain this complex condition. Leslie Sue Lieberman, Chair of my doctoral committee deserves more than the usual acknowledgment for her role; her dedication is boundless and inspirational, this projected is dedicated to her and I am indebted to her forever. My family supported me in this effort in many ways and for many years, in what were often unconditional acts of love and faith. My cousin and colleague in social science, Michael Clemmers, PhD deserves a special dedication for pushing me to connect the dots between “will”, in all the connotations of the word, and completion of a dissertation. And finally, to the many women living with chronic pelvic pain for the privilege of serving them both as a physical therapist and an anthropologist; I am witness to the courage they exhibit as they negotiate the health care system in pursuit of relief and I am grateful for their willingness to share the details of their experience with me; they have profoundly effected my life and this work is dedicated to the hope that their suffering will end.
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BIOCULTURAL CORRELATES OF CHRONIC PELVIC PAIN IN WOMEN

By

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December 2008

Chair: Leslie Sue Lieberman
Major Department: Anthropology

Chronic pelvic pain (CPP) is a common health problem among women that responds poorly to biomedical intervention. Studies examining the implications of race/ethnicity on health care for women with CPP are scarce. This study utilizes a biocultural approach to examine social and clinical characteristics among a sample of ethnically diverse women seeking biomedical care for CPP. Interview data describe the impact of CPP on social roles and responsibilities, women’s explanations of the cause(s) of pelvic pain and their perceptions of biomedical treatment. Sixty-three women, 15 African Americans, one Hispanic, and 47 European Americans participated in the study. Despite the limitations of the small sample size, there was a statistically significant ethnic difference in level of pain intensity with sexual intercourse, \( M=8.43, \ SE=0.69 \) among African American women compared to \( M=6.18, \ SE=0.49 \) European American women. There were notable although not statistically significant ethnic differences in treatment response, ranking of CPP as a life problem and abuse history. Themes identified by analysis of interview data related to causality, sexuality, productivity, and fragmented health care corroborate findings in other studies and illustrate the relevance of conceptualizing CPP within a biocultural framework.
CHAPTER 1
CHRONIC PELVIC PAIN IN WOMEN: A BIOCULTURAL HEALTH PROBLEM

Introduction


This study is focused on African American and European American women residing in the southern United States, primarily in Tennessee, who live daily with chronic pelvic pain. For most women, pelvic pain is an intermittent physical discomfort expected to occur in association with the natural bodily functions of menstruation, pregnancy, childbirth, and menopause. Such “normal” intermittent pelvic pain may cause women to limit their physical and/or social activities for brief periods of time either by physical necessity, cultural custom or both. For other women, pelvic pain is extremely intense, evolving into an ongoing and debilitating condition known in biomedicine as chronic pelvic pain. (Grace 1995; Grace and Zondervan 2004; Howard 2000 a; Reiter 1990; Steege 1998; Ling 1993; Zondervan, Yudkin, Vessey, Dawes, Barlow, and Kennedy 2001)

Women with chronic pelvic pain (CPP) commonly consult with health care providers across a variety of medical specialty areas, often repeatedly seeking care for several years (Davies, Ganger, Drummond, Saunders and Beard 1992; Grace and Zondervan 2006; Howard...
1993; Latthe, Mignini, Gray, Hills, Khan 2006; McGowan, Clark-Carter, Pitts 1998; National Institutes of Health 2002; Ling 1993; Selfe, Matthews, Stones 1998; Stones, Selfe, Fransman and Horn 2000; Zondervan, Yudkin, Vessey, Dawes, Barlow, and Kennedy 1999; Zondervan, Yudkin, Vessey, Jenkinson, Dawes, Barlow and Kennedy 2001); however, population based studies indicate that many women experience chronic pelvic pain without seeking biomedical care. (Harlowe and Stewart 2003; Golding 1994; Golding 1996; Grace and Zondervan 2006; Randolph and Reddy 2006; Zondervan, Yudkin, Vessey, Dawes, Barlow and Kennedy 2001) All the women in this study actively pursued biomedical care for ongoing complaints of chronic pelvic pain. At the time of the study most of the women were under the care of biomedical clinicians specializing in the condition.

Women who seek biomedical care for CPP most often consult with gynecologists since the pain is located in the lower abdomen and/or genitalia and is frequently associated with sexual activity and/or the menstrual cycle. Gynecologic management traditionally focuses on the reproductive organs. Surgical interventions, including hysterectomy, are commonly conducted in attempts to eliminate pelvic pain. Symptoms often persist post-operatively and sterilization is often a result of treatment for pelvic pain, with or without resolution of the symptoms. (Reiter 1998; Reiter and Gambone 1991; Stovall, Ling and Crawford 1989; Yasmin, Bombieri, Hollingworth 2005) Despite the sincere efforts of biomedical practitioners to establish effective management strategies, health care seeking for women experiencing chronic pelvic pain is often met with unsatisfactory results, frustrating both the women who experience it and the practitioners involved in their care.(Grace 1995; Grace and Zondervan 2006; Howard 2000a; Latthe et al 2006; Ling 1993; McGowan, Clark-Carter, Pitts 1998; National Institutes of Health 2002; 2000; Reiter 1990) Women develop a variety of coping and self care strategies in order to
function when effective medical intervention is not obtained, many of which contribute to the invisibility of their condition to family members and co-workers. (Grace and Zondervan 2006; Zadinsky and Boyle 1996) The challenges this condition presents to biomedicine spawned the development of a multidisciplinary professional organization, the International Pelvic Pain Society (www.pelvicpain.org), and have been the subject of special conferences and research initiatives at the National Institutes of Health. (Abraham 2003; National Institute of Child Health and Human Development 2002)

Chronic pelvic pain (CPP) is characterized by severe emotional, social and physical suffering and encompasses a variety of pain patterns and related symptoms. Some women experience pain that intensifies with the menstrual cycle, others primarily have pelvic pain during intercourse and others live with on-going, unrelenting pain in various locations in the anatomic pelvis. Women with CPP all experience pain in the pelvis but in a variety of patterns. The pain is most often located in the lower abdomen (usually unilateral, meaning primarily on one side of the abdomen) but some women complain of pain throughout the abdomen and/or in the vagina, rectum, pelvic floor musculature and external genitalia. There are several variations in the temporal patterns associated with pelvic pain. Pelvic pain may be acute (lasting one month or less), recurrent (re-occurring in some type of pattern), or chronic (lasting three months or more by some definitions (Ling 1993; Howard 2000a) and six months or more by others (Grace and Zondervan 2006) Participants in this study include women with pelvic pain in any pattern as long as the pain is in the pelvic area. Recurrent pelvic pain may be either cyclic, as in the case painful menstrual periods (dysmenorrhea) or episodic as in the case of pain associated with sexual intercourse (dyspareunia). Specific activities or positions may also trigger recurrent pelvic pain such as sitting, standing, bending, or lifting; stress may also trigger an episode of pelvic
Many women experience pain that is both chronic and recurrent; these women describe constant, chronic pain that increases in intensity cyclically or episodically (either during menstruation, ovulation, intercourse, or other activities such as toileting, walking, or sitting). This study includes women with pelvic pain in any temporal pattern as long as a part of that pattern includes pelvic pain that lasted at least 3 months, hence classifying it as chronic.

Women with chronic pelvic pain are much more likely than other women to have been exposed to violence or abuse (physical or sexual and particularly childhood sexual abuse), to have a history of sexually transmitted diseases and to be diagnosed with depression and/or anxiety, including post-traumatic stress syndrome. (Champion et al 1995; Golding 1994; Golding 1996; Fry, Crisp, Beard and McGuigan 1993; Lampe et al 2000; Latthe et al 2006; Reiter, Shakerin and Gambone 1991; Rosenthal 1993; Turk 2002; Walker 1988) These complicating social and psychological characteristics appear to contribute, at least in part, to the resistance of the condition to biomedical management (Latthe et al 2006; Steege 1998) as well as to the ethnocentric perception among some practitioners that the condition is less than a “real” medical problem. (Grace 1995; 2000; Theve-Gibbons 2000) Table 1-1 provides a summary of social, psychological, biological and clinical characteristics with known correlations, both positive and negative, with CPP.

Although relatively few studies of CPP in women report racial or ethnic data, it is clear from available reports that CPP occurs among women from a broad range of racial and ethnic backgrounds. (Campbell et al 2002; Golding 1996; Haefner et al 2000; Haggerty et al 2005; Latthe et al 2006) With the exception of a stronger association between black race and/or African American ethnicity and menstrual related CPP (Latthe et al 2006), clear racial or ethnic epidemiological patterns are not depicted. A few studies attempt to explain reported relationships
between race/ethnicity and symptoms associated with CPP (Golding 1994; 1996; Haggerty 2005); however, there is a paucity of study providing ethnocultural, socio-cultural or biocultural perspectives on the condition and its racial/ethnic correlates. Although information is available that sheds light on the associations between race, ethnicity and CPP, the basic epidemiological facts are not yet clear and comparative ethnocultural information specific to chronic pelvic pain in women is not yet available.

**Purpose and Significance**

The purposes of this study are to evaluate relationships among selected ethno-cultural, psychosocial and biological variables in a sample of women seeking biomedical health care for chronic pelvic pain; to contribute to the body of knowledge that describes the relevance of social context to health care for women with chronic pelvic pain; and to contribute to the development of biocultural approaches to health care for women with chronic pelvic pain. The specific aims are to describe the social roles and responsibilities in which women with chronic pelvic pain are routinely engaged; to describe women’s perceptions of how pelvic pain influences their daily functioning; to provide an account of women’s explanations of the causes of their chronic pelvic pain; to investigate women’s perceptions of biomedical treatment for chronic pelvic pain; to determine if there is statistically significant racial and/or ethnic variation in selected clinical and social characteristics known to occur among women with chronic pelvic pain among the sample of women who participated in the study.

At this point in time there are not studies on record that were specifically designed to compare clinical characteristics and/or illness experiences among racially or ethnically diverse women with CPP. The importance of a comprehensive understanding of the social aspects of pelvic pain to efforts aimed at improving health care for the condition are acknowledged by biomedical practitioners and social scientists (Abraham 2003; Grace and Zondervan 2006;
National Institutes of Health 2002; Selfe et al 1998), signifying the relevance of anthropological perspectives to the development of the body of knowledge on CPP in women. The importance of increasing the attention of anthropologists to matters of race and ethnicity in health care was recently argued by Gravlee and Sweet (2008) who recommended, among other strategies, the advancement of biocultural approaches to the study of health and health care by anthropologists. The cross-cultural perspective of anthropologists facilitates more appropriate uses of the concepts of race and ethnicity in health care research contributing to a more extensive understanding of cultural differences and health disparities. (Gravlee and Sweet 2008; Oths 1999; Wardlaw 2003) Cross-cultural studies and critiques of biomedical approaches to pregnancy, menopause and menarche conducted by anthropologists and feminists, (Beyene1986; 1989; Chodrow 1999; Daly 1978; Davis -Floyd 1994; Davis-Floyd 2001; Douglas 1975; Martin 1988; 2001; Schepher-Hughes 1992; Schepher-Hughes and Lock 1987;Grace 1995; 1998; 2000; Lock 1994; 1998; 2002) and similar studies on chronic pain (Bates 1996; Bates and Edwards 1996; Good, Bodwin, Good, and Kleinman 1992) inform the current biocultural understanding of CPP in women; however, studies specifically focused on building the body of knowledge that describes the social context of CPP, including the relevance of race and ethnicity are needed. The complex array of biological and social factors associated with CPP makes it clear that biocultural perspectives are essential to the development of more effective approaches to health care for the condition. (Abraham 2003; Grace 1998; 2000; Grace and Zondervan 2006; Haefner et al 2000; Haggerty et al 2005)

The broad issue addressed by this study is the relevance of social context to health care for women with CPP. The specific aims are to gain an understanding of the women’s perspective on carrying out their social roles and responsibilities while living with pelvic pain; to understand
women’s beliefs about the causes of their pain; and to determine if there are racial or ethnic variations in those beliefs and experiences and/or in the clinical and diagnostics correlates of CPP among the women in the sample. An ethnographic account from the perspective of women in the study sample describes the effects of pelvic pain on their daily lives and their explanations of the cause(s) of pelvic pain. The current body of knowledge outside of this project that describes CPP from the point of view of women living with the condition includes interview based accounts of women’s experiences during medical encounters for pelvic pain (Grace 1995); narrative accounts of how women describe the pain they feel (Grace and MacBride-Stewart 2007b); a description of the physical activity limitations they experience both at work and at home because of CPP that was derived from a postal survey (Grace and Zondervan 2006), and an interview based report of women’s feelings of shame, stigma and loss of sexuality and femininity. (Theve-Gibbons 2000) Most of the research that investigates CPP from the perspectives of women with the condition was conducted in New Zealand (Grace 1995; Grace and Zondervan 2006); the women in those studies were predominately of European ethnicity, however, some native Maori women were included. Theve-Gibbons (2000) study included twelve women residing in the US and one living in the UK; twelve were white-non-Hispanic or Latina and one was Hispanic. This study adds an account of how black African American and white European American women, in the US describe the causes of CPP and the effects of the condition on their lives at home, at work and in the community to the current discourse on CPP in women; it also contributes an examination of racial and ethnic differences in the known diagnostic and social correlates of CPP to the relatively sparse literature that describes racial and/or ethnic correlates of the biomedical profile of the condition.
Sexual abuse/assault and pelvic inflammatory disease (PID) are the only two factors that demonstrated a positive association with all types of chronic pelvic pain (painful menstruation, painful intercourse, and non-cyclic/non-episodic pelvic pain) in a recent systematic analysis of the literature. (Latthe et al 2006) Studies indicate that compared to European American women and Latina women, African American women at greater risk for developing reproductive symptoms (which includes pelvic pain) when exposed to sexual assault (Golding 1996); are at greater risk for the development of sexually transmitted diseases, which are known to lead to PID (Champion et al 2005); and are at greater risk for cyclic pelvic pain or dysmenorrhea (Latthe et al 2006). To determine if ethnic correlates of characteristics of chronic pelvic pain reported in previous studies were consistent among the women in this study; and, to further explore the relationships between ethnicity and biomedical characteristics of pelvic pain, the following research questions were developed:

Are there ethnic differences in pain intensity, pain intensity with sexual intercourse and acceptable level of pain among a sample of women with chronic pelvic pain?

1. Are there ethnic differences in the review of systems or diagnostic profile for reproductive, urological, gastrointestinal, musculoskeletal, and psychological systems among a sample of women with chronic pelvic pain?

2. Are there ethnic differences in the perception of treatment effects among a sample of women with chronic pelvic pain?

3. Are there ethnic differences in perceptions of how chronic pelvic pain impacts life among sample of women with the condition.

4. Are there ethnic differences in history of sexual or physical abuse or assault among a sample of women with chronic pelvic pain?

Two additional research questions were developed to examine associations between sexual abuse/assault and biomedical characteristics of chronic pelvic pain as there is implication in the
literature that the presence of sexual abuse/assault may intensify symptoms and/or interfere with response to biomedical care. The additional questions addressed in this portion of the project are:

5. Are there significant differences in the perception of treatment effects between women with a history of abuse or assault and women without a history of abuse or assault among a sample of women with chronic pelvic pain?

6. Are there significant associations between pain variables and sex/physical abuse variables among a sample of women with chronic pelvic pain?

**Prevalence - An Unspoken, Common Problem**

Many women are reluctant to discuss sexual problems with health care practitioners much less friends and family members, creating a social silence about conditions such as pelvic pain and incontinence. (Grant 2005; Mitteness and Barker 1995; Porrett and Cox 2007) That lack of discourse negates opportunities for women to find professional and personal support and creates the impression that their condition is unique and uncommon. (Grace 1995; Theve-Gibbons 2000) The privacy and embarrassment with which women’s bodies, and sexual, reproductive and gastrointestinal functions, are viewed all likely contribute to the social silence that surrounds CPP. (Mitteness and Barker 1995; Porrett and Cox 2007; Theve-Gibbons 2000) The condition itself is difficult to describe and like many chronic pain conditions is essentially “invisible”. The social stigma or taboo of discussing sexual or pelvic problems can also impact choices women make about seeking health care and social support. (Theve-Gibbons 2000) When women do seek care for CPP, health care practitioners often ignore or minimally attend to concerns related to CPP when they are presented clinically, further marginalizing and silencing women with the condition as they often come to believe the pain that experience is not related to a viable medical problem, and a medical explanation is needed to validate their complaints. (Grace 1995; Theve-Gibbons 2000) Many women in this study expressed surprise to learn that I was studying pelvic pain as they did not realize that other women also experienced it. Similar viewpoints were
expressed by women in other studies of CPP. (Grace 1995; Theve-Gibbon 2000) One study participant in Memphis commented on the large number of files I had in the file box by my desk; I explained there was a separate file for each person who agreed to be interviewed, she replied:

This sounds weird but, do a lot of people have pelvic pain? It is weird that a lot of people are stricken with it.-M27

Other women interviewed commented on their perception that the condition was unique to them and, from their perspective, unheard of by most medical professionals:

Nobody has ever heard of anyone having butt pain. I just don’t understand that. I feel like a freak. –M51

People don’t know, but sometimes people have something that doctors never said or never acknowledged. –M52

Despite the social silence surrounding pelvic pain, and contrary to the perception of many women with the condition, chronic pelvic pain is, in fact, very common, accounting for at least 10-20% of all outpatient gynecology visits in the US. (Howard 1993; 2000a) As early as 1958 pelvic pain was reported the most common complaint presented by women to gynecologic physicians in the United Kingdom. (Morris and O’Neil 1958) Community based studies indicate that up to 40% of women experience pelvic pain without actively seeking medical care (Harlowe and Stewart 2003), implying that prevalence estimates based on medical utilization are likely low. (Harlowe & Stewart 2003; Jamieson and Steege 1996; Mathias et al 1996) In 1999 a clinically based study estimated the prevalence of chronic pelvic pain at 38/1000 for women aged 15-73 in the UK, a rate similar to that of more well known conditions such as low back pain and asthma. (Zondervan et al 1999) A follow up community based study in the UK (Zondervan, Yudkin, Vessey, Dawes, Barlow, and Kennedy 2001) indicated rates of CPP in the population of that country are most likely 24%. Other reports estimate 15% of women in the United Kingdom aged 18-50 experience CPP. (Stones, Selfe, Fransman and Horn 2000) The estimated prevalence
in New Zealand, based on a population study, is 25.4%. (Grace and Zondervan 2004) A Gallup poll was used to examine prevalence in the US finding 16% of women experienced pelvic pain; 11% of the women with CPP reported limiting time spent in home activities because of the pain, 4% reported missing at least one day of work per month, and 16% were currently taking medication to manage it. (Mathias et al 1996) Painful sexual intercourse is occurs in up to 41% of women with CPP. Collett (1998) compared complaints of painful intercourse in women with and without CPP, finding women with CPP much more likely to experience pain with intercourse; in addition to pain during sexual intercourse, women with CPP may also experience post-coital pain lasting hours or days. (Nickel et al 2007; Randolph and Reddy 2006; Zondervan, Yudkin, Vessey, Jenkinson, Barlow and Kennedy; Veri, Verit and Yeni 2006)

A recent US community based study on a particular urological subset of CPP, interstitial cystitis (IC) estimated IC was likely affecting 4% of women in the US; they based the estimate on their study results and the 2000 census. (Ibrahim, Ananiaas, Diokno, Killinger, Carrico and Peters 2007) A clinical study conducted in a primary care setting that used symptoms as well as physical screening procedures to identify cases of IC found 13.1% of those initially surveyed (357 of 2043) had findings consistent with IC and 14.3% were diagnosed with the condition after continuing work up. (Rosenberg, Page and Houssard 2007) The 13.1% included 17.5% of the women and 8.3% of the men in their study indicating a gender difference in IC prevalence, with a higher occurrence among women. Mirkin et al (2007) estimated the prevalence of endometriosis, the most common gynecological diagnosis associated with CPP, at 1.1% for women ages 30-39 and .7% for women 18-55 years of age in a US study that used medical coding in commercial insurance claims to determine prevalence. Irritable bowel syndrome (IBS), a gastrointestinal subset of CPP reportedly accounts for 12% of all primary care visits in
the US and is the most common diagnosis made by gastroenterologists. (Fisher 2002) IBS symptoms are reported by approximately 15% of adults in the US affecting about 3 times as many women as men. (Howard, Perry, Carter, El-Minawi 2000 p. 238) Reports indicate IBS occurs in 50-80% of women with CPP. (Longstreth, Preskill, Youkeles 1990; Walker, Katon, Jemelka et al 1991) In India it is reported that IBS occurs more frequently among men than women and that men and women are affected equally in Africa. (Fisher 2002) IBS is the most common diagnosis made by gastroenterologists and accounts for 12% of visits to primary care doctors in the US. (Fisher 2002) Studies on care seeking for IBS indicate individuals with IBS symptoms are most likely to seek health care if they have psychological disorders than individuals with IBS symptoms but no identified psychological distress. (Fisher 2002)

As previously mentioned, relatively few studies of CPP in women provide accounts of race or ethnicity. Latthe et al (2006) and colleagues extensively examined 110 articles to identify predisposing factors for CPP; although their analysis identified statistically significant associations between various socio-demographic characteristics, including race/ethnicity and CPP, relatively few of the articles in the study reported data on age, race, ethnicity, or SES. Pelvic inflammatory disease (PID) and childhood sexual abuse were both identified as risk factors for all types of pelvic pain (dysmenorrhea or painful menstruation; dyspareunia or painful intercourse; and non-cyclic/non-episodic pelvic pain) in their review and several other predisposing factors were also identified, however, only PID and childhood abuse were associated with all types of CPP. (Latthe et al 2006) Sexually transmitted diseases (STD), which are more common among minority women, are known to increase the risk for PID. (Champion 2005) Several studies support an increased risk among African American and other racial/ethnic minority women for all types of pelvic pain due to increased exposure to abuse, assault and
STD’s (Champion et al 2005; Golding 1994; Golding 1996). In contrast, Grace and Zondervan (2006) report statistically significant negative associations between non-European ethnicity and CPP in their population based study (postal survey) conducted in New Zealand, however, they also noted that non-European women (primarily Maori) were represented at a lower rate in the study population (10.3%) than in the population of New Zealand (14.2%). In a study of a largely minority urban population, Haggerty et al (2005) found non-black race predicted CPP. Other reports find vulvodynia and interstitial cystitis (IC), two diagnostic subsets of CPP, more occurring more commonly among non-Hispanic white women than African American women. (Arnold, Bachman, Kelly, Rosen and Rhoads 2006) The most recent study specifically undertaken to examine the prevalence of CPP in the US was telephone survey published in 1996 that reported no significant racial or ethnic differences in occurrence rates (Mathias et al 1996), a finding that is interesting since a variety of predisposing factors point toward an increased risk for minority women and girls (Campbell et al 2006; Champion et al 2005; Golding 1994; Golding 1996; Haggerty et al; Mahon, Temkit, Wang, Rosenman and Katz 2005) but may be supported by studies finding significance associations between ethnicity and pelvic pain symptoms disappear when SES (Portenoy, Ugarte, Fuller and Haas 2004) and/or other factors such as history of abuse and assault (Golding 1996) are controlled. Also of interest is the 10% difference in prevalence rates between the US and the UK and New Zealand which it has been suggested may be explained by cultural differences in willingness to report symptoms. (Grace and Zondervan 2006)

The majority of cases of CPP are reported during the reproductive years with the average age considered to be in the early 30’s (Howard 2000; Steege 1998), however, age differences are reported between the various subtypes of CPP. Endometriosis is the most commonly diagnosed
gynecologic cause of non-cyclical pelvic pain and is a condition that occurs primarily during reproductive years. (Howard 2000a; Rips and Martin 1993) Cyclic (menstrual) CPP was recently reported more common among younger women in a population based study in New Zealand (Grace and Zondervan 2006), consistent with the findings of Latthe et al (2006) that women under 30 years of age were more likely to experience cyclic CPP. Risk for pelvic pain with dysmenorrhea is increased by a history of sexual abuse, age less than 30, early menarche, thin body type (Body Mass Index (BMI) less than 20, irregular menstrual flow, history of premenstrual syndrome (PMS) or PID and high levels of stress. Risk for pelvic pain with dysmenorrhea is decreased by marriage, fish intake, physical exercise and higher parity. (Latthe et al 2006) Early menarche increases the risk for both pelvic pain and PMS. (Latthe et al 2006; Barnard, Frayne, Skinner and Sullivan 2003) Low BMI is associated with cyclic CPP (Latthe 2006) although higher BMI is reported with PMS. African American women are considered to be at increased risk for PMS and lesser risk for CPP than other women. Higher BMI is a known health concern among African American women associated with many other obesity related health conditions such as diabetes, heart disease and breast cancer. (Digham 2000) The prevalence of menstrual symptoms in a sample of women who used Veteran’s Administration (VA) ambulatory services was examined to assess the magnitude of difference in health status in women with these symptoms compared with those without. Data was collected using a self-administered questionnaire, which included the SF-36. The independent variable was menstrual symptoms. Using two independent sample t-tests, SF-36 scores were compared between women with and without menstrual symptoms. There was a surprisingly high prevalence of menstrual symptoms (67%). Sampling bias was suggested as an explanation due to the high prevalence of
co-morbidity, depression, and posttraumatic stress disorder known to occur in military populations. (Barnard et al 2003)

Although most cases of pelvic pain begin with or after menses, non-menstruating girls and adolescents are also affected as are post-menopausal women. (Gale, Ling, King, Myers and Muram 1990; Schroeder and Sanfilippo 2000) Early age onset of pelvic pain is associated with pelvic inflammatory disease (PID) as well as a history of menstrual “difficulties” (Champion 2005; Schroeder, B., Sanfilippo and Hertweek 2000) and childhood sexual abuse. (Champion et al 2005) As was already noted, minority adolescents have higher rates of sexually transmitted diseases which are considered causative in the development of PID, increasing the risk for CPP among young minority girls. (Champion et al 2005; Golding 1994; 1996; Haggerty et al 2005) Early maternal age also appears to increase the risk for PID in the post-partum year, which would also increase risk of developing CPP among younger women and girls. (Mahon et al 2005)

Material Consequences

Although the medical costs associated with CPP have not been examined extensively, the economic burden for the medical management of pelvic pain is considered to be high both individually and at a societal level. (Davies et al 1992; Gao, Outley Botteman, Spaulding, Simon, Pashos 2006; Mathias et al 1996; Mirkin et al 2007; Stones et al 2000; Zondervan et al 1999) Determining the medical costs of CPP is complicated by the variety of diagnoses, biomedical specialties and treatments involved as well as lack of information about utilization of alternative medical treatments for the condition. Estimates of medical costs often focus on one specialty area or one particular pelvic pain diagnostic group. The actual costs are likely much higher than estimated. Surgical costs for management of uterine fibroids alone, one particular condition often thought to cause pelvic pain (Rapkin 1986), was estimated at 1 billion per year for about 175,000
hysterectomies. (Perry 1998) In the 1990’s CPP accounted for over one third of all gynecologic laparoscopic procedures in the US. (Stovall, Elder and Ling1990; Howard 1993; Howard 2000a) According to the Royal College of Obstetricians and Gynecologists over 10,000 laparoscopies were performed for unexplained pelvic pain in the United Kingdom in 1978. (Fry, Crisp, Beard, McGuigan 1993) Howard (Howard 2000a) reports estimates of over two billion dollars per year for the direct and indirect costs of CPP in women in the United States. Economic impact estimates for CPP were reported over a decade ago in the amount of $274 million per year in the UK (Davies et al1992) and $881 million per year in the US. (Mathias et al 1996; Davies et al 1992; Mirkin et al (2007) examined commercial insurance claims for women between the ages of 18 and 55 in the years 1999-2003 to determine the prevalence and economic impact of endometriosis, the most common gynecological cause of CPP. They found that medical costs per patient per month (PPPM) were an astounding 63% higher for women diagnosed with endometriosis than age matched cohorts, largely related to higher hospitalization and surgery rates. Gao et al (2006) et al also attempted to estimate the medical costs of endometriosis, using review of published research reports and public databases such as the Healthcare Cost and Utilization Project and National Medical Ambulatory Care Survey/National Hospital Medical Ambulatory Care Survey. They commented on the scarcity of information related to the costs of endometriosis, particularly ambulatory services costs. They concluded that the costs of endometriosis were exceptionally high and primarily driven by the expenses of hospitalization and surgery; they also found that from 1993 to 2002 the length of hospitalizations for endometriosis progressively declined, however, the costs increased by 61% during that time. Although clear estimates of the costs of all types of CPP are not available, it is evident the medical costs associated with the condition are high. In addition to the medical costs, women’s
productivity is often negatively affected both in and out of the home by pelvic pain. (Grace and Zondervan 2006; Mathias et al 1996) Time off work, job loss and/or other occupational changes are all reported by women with pelvic pain as a consequence of the physical and mental changes associated with the condition. (Grace and Zondervan 2006) The time involved in acquiring medical care, recovery, and recuperation interferes with domestic responsibilities, recreation, leisure, family and social obligations. (Grace and Zondervan 2006; Mathias et al 1996)

**Social and Cultural Correlates**

The three domains of culture, social structure (social organization, social categories, kinship and interpersonal relationships), infrastructure (economic, technologic and material aspects of culture) and suprastructure (ideology, belief systems, cognitive models and symbols) are all relevant to understanding disease, illness and medical care. Anthropologists distinguish diseases as conditions identified by objective measure or observation of clinical signs and illnesses as conditions identified by an individual’s sense of not being well. (Brown, Barrett and Padilla in Brown 1998; Hahn 1995; Kleinman, Eisenberg and Good 1978) Perspectives from medical anthropology highlight the social context of health, clarifying relationships between social structure, cultural meanings, material culture as well as biological variation on health problems and medical care. Cultural approaches to medical anthropology emphasize understanding belief systems and ethnomedicine, the social construction of illness the social production of health and cross-cultural comparisons. Biocultural approaches emphasize how human adaptation to environments influences health and includes examination of evolutionary influences on health and disease, human biological variation, as well as the political and cultural ecology of health and medicine (medical ecology). (Brown, Barrett and Padilla 1998; Martin 1992; Margolis 1984; McElroy and Townsend 1996; Singer 1986) Understanding how biological and social variables interact to influence the health and illness experiences of women with
chronic pelvic pain facilitates our ability to reach valid and useful conclusions about the relevance of social facts and social context to health care for this condition.

**Ethnicity and Race**

Correlations between race/ethnicity and certain clinical characteristics of CPP are reported (Golding 1996; Haefner et al 2000; Harrop-Griffiths, Katon, Walker, Holm Russo and Hickok 1988; Latthe et al 2006; Wesselmann 2002) and culture specific practices such as female circumcision or female genital cutting are known to increase the risk for CPP. (Latthe et al 2006) Golding (1996) studied reproductive and sexual symptoms in an ethnically diverse group of women from two communities (North Carolina and Los Angeles) as a part of the Epidemiologic Catchment Area study. Data regarding sexual assault history, sexual symptoms and reproductive symptoms were collected from 3,419 randomly selected women, 362 of whom had a history of sexual assault. European American women comprised 51.7% of the study sample, 21.3% were African American, 22.5% were Latina and 4.5% were of other ethnic groups. Positive associations were identified between both reproductive symptoms (menstrual irregularities, menstrual pain, abnormal menstrual bleeding) and sexual symptoms (painful intercourse, sexual indifference, arousal disorders) and sexual assault history that was strongest for African American women. African American women were more likely to have experienced physical threats during sexual assault (89.3% of African American women who were assaulted were also physically threatened) than other women who were assaulted (65.2% of Latinas, 63.4% of European American women and 41.9% of women from other ethnic groups); when physical threat was controlled, the statistical effect of African American ethnicity on reproductive symptoms disappeared. (Golding 1996) One of the study conclusions was that risk for unexplained reproductive symptoms was related to a particular type of sexual assault, (assault associated with physical threat) and that the risk for that type of sexual assault was stronger for
African American women. In addition, reproductive health problems were found to be more common if women were assaulted by strangers and African American women reported more assault by strangers than other women in the study. (Golding 1996). Golding suggested that the stronger associations between assault and reproductive problems among African Americans may be associated with chronic stress of racism; however, the study was not designed to support that suggestion. Campbell, Licnyt, Sturza and Raja (2006) examined relationships between sexual assault and gynecologic problems among a predominately African American group of female veterans. Consistent with Golding’s (1996) study, they found significantly more gynecologic problems among women who were assaulted and they further identified symptoms more likely with increased physical threat during the assault. Different from Golding, they found more sexual symptoms associated with intimate partner assault than with stranger assault. Golding (1996) found development of sexual symptoms (painful intercourse, sexual indifference, arousal difficulties) were most strongly associated with multiple, nonviolent incidents of unwanted intercourse with a spouse (the report did not include reference to boyfriend or significant other assaults); multiple episodes of assault as well as assault accomplished by persuasion rather than physical threat was also associated with the development of sexual symptoms in the Golding study. Golding suggested assaults perceived as rape (stranger assaults) were more positively associated with reproductive symptoms and that non-stranger assaults (spouse or acquaintance) that were perhaps not perceived as rape were more positively associated with sexual symptoms.

Ethnic differences in the biological aspects of reproductive organ disease are described in the literature with more aggressive tissue pathology reported for African American women in both uterine and breast cancer. (Dignam 2000) Racial/ethnic differences in physiologic aspects of hypertension as well as treatment effects are reported for African American women. (Quan,
Kerlikowski, Gueyffier and Boissel 2005) Hypertension and conditions of the cardiovascular system may seem unrelated to the organic pathologies associated with CPP, however, at least one report connects systemic hypertension in black women with uterine leiomyomata. (Rubin and Ford (1974) Leiomyomata are benign neoplasms of smooth muscle fiber; the term is synonymous with fibroid, fibromyoma & myoma in gynecology, which are common diagnostic correlates of CPP. The uterine lining is a highly vascularized tissue and connections between vessel pressure and end-organ remodeling are physiologic processes affected by vascular pressure. Common perception among health professionals is that endometrioses is not as common among women of African origin as among white women, however; it is a common reason for gynecological surgery among African American women. (Kyama et al 2004) It is currently not clear if lack of endometriosis in indigenous African women is due to lifestyle differences or if disparities in health care technology and training create a situation where the condition is not readily recognized or treated. Racial/ethnic differences in obesity rates and body image attitudes might also influence the experience of CPP in women but variations in these characteristics have not been explored among diverse groups of women with CPP although body mass index (BMI) is correlated with and risk for dysmenorrhea. (Latthe et al 2006)

Although pain, menstruation, sexual intercourse, childbearing and menopause are experiences common to all women, the manners in which women respond and interpret these experiences are influenced by ethnocultural beliefs and attitudes. (Beyene 1989) Normal biological events for women, menses, pregnancy, childbirth and menopause are all associated with pain. The changes women’s bodies undergo are uncomfortable, physically challenging, and functionally and socially limiting but also are a part of normal, everyday life. The normally occurring pain may contribute to the tendency to normalize pelvic pain in women as something
that women “get” just as they “get” their period. (Grace and MacBride-Stewart 2006)

Differences in response may be related to social role or status changes associated with reproductive status, or, as Beyene (1989) suggested in her work comparing Greek and Mayan women’s reproductive lives, cultural specific differences in reproductive activity, such as birth patterns, may impact physiology as well as social interactions. Folk illness and folk remedies and can modify decisions to report symptoms as well as become barriers to effective communication between practitioners and patients. (Kleinman, Eisenberg and Good 1978) Intra-ethnic variation also occurs so that unique aspects of ethnic customs can vary by country, geographic region, or even neighborhood. Within ethnic groups, gender differences exist in roles, attitudes, beliefs and behaviors as well as biological that can impact health, particular health in a sex related condition such as CPP.

Few published reports on CPP in women consider the influence of ethnocultural attitudes, beliefs and behaviors on the pain and other symptoms women experience; however it is likely that differences in the psychological and cognitive characteristics associated with ethnicity as well as related health behaviors, sexual and reproductive practices influence the overall clinical picture and response to care. Studies that examine ethnocultural aspects of menopause (Beyene 1989; Leidy Seivert 2006), menstruation (Beyene 1989), child bearing (Davis-Floyd 1994; 2001; Scheper-Hughes 1992; Sargent 1989; 1991), genital operations (Scheper-Hughes 1991; Schell-Duncan 2003; Shell-Duncan and Hernlund 2001) and chronic pain (Bates 1996, Good, Bodin and Kleinman 1992) support the concept that ethnic variations relevant to health care likely exist among women with pelvic pain. The normal physiological changes in women’s bodies associated with reproductive process are painful to some degree for most women, however, it is well documented that variations in painful responses and attitudes toward the discomforts of
reproduction differ cross culturally. Increased attention to the discomforts of normal reproduction occurs in societies that embrace biomedicine has occurred with disease models applied to normal processes such as menopause, pregnancy and menstruation. (Davis-Floyd 1994; 2001; Martin 1992) Ethnic variations in symptoms associated with menopause are reported as are variations in and in attitudes and practices related to sexuality among perimenopausal women. (Avis, Stellato, Crawford, Bromberger, Ganz, Cain, and Kagawa-Singer 2001; Avis, Zhao, Johannes, Ory and Brockwell 2005) It seems reasonable to expect that variations in ethnomedical beliefs, attitudes and behaviors related to pain, sexuality and reproduction also exist in the clinical manifestation of symptoms, functional limitations and treatment responses in women with CPP. The incongruence of ethnocultural diversity in symptoms, practices and beliefs with the predominately Euro American perspectives of US and British biomedical practitioners likely contributes to the difficulties women are reported to experience in acquiring satisfactory health care for pelvic pain. (Grace 1998; 2000)

Cultural practices that induce pain can alter physiologic as well as behavioral responses to painful stimuli, particularly when the painful experiences occur in early life. (Ruda 2002) Studies on pre and postnatal pain experiences describe exaggerated pain behaviors and lowered pain thresholds later in life in children exposed to pain in infancy and early childhood. For example, circumcised males reportedly exhibit lower thresholds to pain and more exaggerated pain responses than non-circumcised males beginning in childhood and continuing through adulthood. (Ruda 2002) Studies that examine chronic pain from cultural and biocultural approaches (Bates 1996; Bates and Edwards 1992; Good et al 1992) inform our understanding of the lives of women with chronic pelvic pain, however, a focused examination of the contribution of ethnicity
and other social attributes to the experiences of women with CPP are needed to support more
efficacious medical management of this particular condition.

Cultural differences in attitudes, beliefs and behaviors related to reproductive symptoms as
well as changes in reproductive status such as menarche, pregnancy and menopause can all
influence the interactions between women with CPP and health care. The most obvious barrier
created by cultural diversity and the easiest to address is language differences. Clinical service
providers in the United States are required to provide translation or interpreting services for
patients and clients who are not able to communicate in English. In addition to language, social
standards regarding appropriate communication for members of a particular gender vary, and can
vary again when the communication is related to health and again when directly related to
interacting with health care practitioners. Even when women share a cultural background with
their health care providers, social expectations, attitudes and beliefs can interfere with effective
communication. Culture bound perceptions of pelvic pain can impede patient-practitioner
interactions when women seek health care for a variety of conditions (Dressler 1998; Heurtin-
Roberts and Reisin 1998), likely including CPP, however, no studies to do have evaluated
clinical interactions focused on cultural differences between women with CPP and their health
care practitioners.

The health belief model (HBM) is a classic tool for identifying differences in the health
beliefs of patients and practitioners that can be used to foster effective, socially informed, clinical
communication. (Kleinman, Eisenberg and Good 1978) The HBM was utilized as the basis for
the guiding questions utilized in the interviews in the studies during inquiry regarding the causes
of CPP. (Appendix 1) Differences are expected in the health beliefs between diverse racial and
ethnic groups, but also between biomedical personnel and lay individuals in their care. Baer,
Weller, de Alba, Javier and Salcedo (2008), however, found more similarity than differences in lay and professional views on causes and treatments for the common cold in a recently reported cross-cultural study. Likewise, in Grace’s work in New Zealand (1995), most of the women patients shared a racial and ethnic background with their male practitioners and most expressed beliefs in a biomedical disease model of pelvic pain; both women and their practitioners were frustrated by the biomedical diagnostic process which did not produce an effective plan of care. (Grace 1995)

**Social Class**

Women across the social and economic spectrum are affected by chronic pelvic pain; there is, however, limited study on class and CPP. Selfe et al (1998) examined class in their study of 105 women seeking care for CPP in a British hospital gynecology outpatient clinic. They used the United Kingdom Registrar General’s classification system (an occupational based classification system) to operationalize class. The woman’s partner’s occupation was utilized for women not employed outside the home. (Selfe 1998) In the Selfe study, social class was not significantly related to outcomes to care; relationships between class and other variables were not reported in their study. The most detailed insight into the relationship of class to the pelvic pain experience in women is found in Golding’s (1996) examination of sexual assault and reproductive and sexual symptoms. Women with lower education and lower income were more likely to have reproductive symptoms after assault than women with higher levels of either income or education. (Golding 1996) They found that less educated women and women with less income who were physically or sexually assaulted were more likely to have reproductive and sexual symptoms than women with higher socioeconomic status who were also assaulted. Spouse assaults were more likely in lower educated and lower income women; specific reference to boyfriends or significant others was not made in their report although they differentiated
assaults committed by strangers. Income was unrelated to the occurrence of an assault or the specific circumstances of assault. Specific circumstances of assault referred to a comprehensive group of characteristics including age at time of the incident, number of incidents, type of pressure, physical threat, offender’s identity, degree of sexual contact, emotional reactions and ethnic associations. (Golding 1996) A population based survey of chronic pain (not specifically chronic pelvic pain) among racially/ethnically diverse Americans found that socioeconomic disadvantage was the most important predictor of disabling pain. (Soares and Jabolonska 2004) Approximately one third of each group in the sample (Hispanic, non-Hispanic African American and non-Hispanic white) reported chronic pain and although race/ethnicity did not predict pain intensity in their sample, minorities (African Americans and Hispanics) had more characteristics positively associated with disabling pain than whites. Factors positively associated with disabling pain were female gender, divorce, less than a high school education and income under $25,000 annually; after multivariate analysis, income and education remained significant.

**Education**

Arnold et al (2006) conducted a clinically based study in New Jersey aimed at identifying predictors of vulvodynia, a subtype of CPP, noting their sample was predominately white and predominately college educated, consistent with Haefner et al (2000) finding that patients in their Michigan clinical sample with vulvodynia were more highly educated than women with other types of pelvic pain and women with headaches. A study of 30 women with pelvic pain in Maine found a lower level of education was significantly correlated with higher incidence of surgical treatment for CPP. Carlson, Miller and Fowler (1994) Carlson et al found higher levels of education significantly correlated with more positive treatment outcomes to traditional gynecologic treatments. Addis and colleagues (Addis, Van Den Eeden, Wassel-Fyr, Vittinghoff, Brown, and Thom 2006) found sexual dysfunction was more likely among women with higher
educational levels in their population based study conducted from Kaiser Permante. Champion et al (2005) studied abuse and PID in minority adolescents and found an association between abuse and lower education among the girls in their study signifying a relationship between greater risk not only for CPP, but CPP complicated by the psychological and social ramifications of abuse. Sexual assault history was more strongly related to with sexual and reproductive symptoms among women with less income or education in Golding’s previously discussed study. (1996)

In Emily Martin’s work (1992; 2001) on women and reproduction, she suggests there is an element of social resistance among all women, no matter their social class, that comes to the surface as symptoms of premenstrual syndrome. She makes a case for this resistance as class resistance, although she conjectures women are as one class more than of different classes when expressing social resistance through their bodies. She discusses the monotony, repetition and tedious nature of housekeeping, self keeping and family keeping and women’s resistance to those tasks through the socially acceptable feminine functions of their bodies. In this study at least one woman relates her symptoms in manner that is consistent with Martin’s suggestion of social resistance through women’s bodies. This woman is in her mid fifties and works in an upper management position; a corporate change was about to change her daily responsibilities in a way that upset her. When asked about the onset of her pelvic pain, the exchange went as follows:

Was there an event associated with onset of your pain?

Yes, it was work; we were moving to a different office; I didn’t want to go…I retired (from work) due to the pain

As is discussed in Chapter 4, the majority of women in this study, across class lines, with the above noted exception and a very few others, verbally expressed emphatic resolve to continue to work more often than they expressed a resistance to the requirements of work, either domestic or occupational while living with pelvic pain. From the perspective of Martin, however,
the pain itself may be the manifest expression of their non-verbalized resistance to their social conditions and relations.

**Age**

Pelvic pain occurs throughout a women’s lifespan, closely related to the biological developmental landmarks of menarchy, childbearing and menopause. Cyclic pelvic pain directly related to menstruation is, of course, limited to years between menarche and menopause. Many adolescent girls experience cyclic pelvic pain from the onset of menses that eventually progresses to non-cyclic pain and/or dyspareunia (painful intercourse). Differences in age of parity and menarche noted cross-culturally could have relevance to CPP but have not been explored although early menarche is positively associated with dysmenorrhea. (Latthe et al 2006)

The social and cultural aspects of reproductive transitions influence and are influenced by the phenomena of pelvic pain for many women and girls, however, little is known about this condition from a biocultural perspective, more is known about correlations between a woman’s age and specific biological characteristics of CPP. Although age is often perceived as factor in diminishing libido due to waning female hormones, a sizeable study on sexuality and menopause Avis et al (2005) report sexual intercourse, desire, arousal, or physical or emotional satisfaction are not significantly associated with perimenopausal age although perimenopausal age was associated with painful intercourse among the women who participated in that study. Relationship issues, more than biological factors, appear to explain more of the variance in diminished desire as well as sexual pain among older women. (Addis et al 2005; Avis et al 2005)

**Gender**

Although this study is focused on chronic pelvic pain in women it is important to note that pelvic pain also occurs in men. It appears CPP is more common among women (Rosenberg, Page, and Hassard 2007; Unruh 1996), and prevalence studies find women are more likely to
experience a variety of chronic pain syndromes than men. (Portenoy, Ugarte, Fuller and Haas 2004; Unruh 1996) Although gender differences in prevalence, etiology and co-morbidities of CPP have not been examined extensively, they can be described from the currently available literature. Prevalence rates for men are estimated at 15% by some reports. (Antolak 2005; Antolak, Hough, Pawlina, Spinner 2002) Rosenberg, Page, and Hassard (2007) reported gender differences in the prevalence of IC in their primary care clinical study. They found 13.1% of the study sample presented with symptoms consistent with IC; the 13.1% represented 17.5% of the women in the study and 8.3% of the men.

Pain location is essentially the same for men and women with CPP, with the lower abdomen, rectum, bladder, reproductive organs and genitalia being the affected areas. As with pelvic pain in women, pelvic pain in men is generally assumed to be associated with the reproductive or urogenital systems by both practitioners and patients. Prostatitis is a commonly assumed etiology for male pelvic pain, however, pelvic pain in men is, directly related to actual prostatitis in less than 5% of cases. (Antolak 2005) Faulty diagnosis of prostatitis commonly occurs in up to 95% of cases due to lack of lab studies to support the presence of infection or inflammation. (Antolak 2005) Male pelvic pain is strongly associated with physical injuries related to sports and occupation with pudendal neuralgia apparently responsible much male pelvic pain initially assumed to be prostate related. (Antolak 2005) Pudendal neuralgia is also common in women immediately after vaginal delivery with recovery from the injury usually occurring within 3 months. (El-Minawi and Howard 2000) Only one comparative study pain characteristics between men and women with CPP was identified in this review. (Heinberg 2004) Heinberg compared 4 groups of patients, women with CPP, men with CPP, men with low back pain (LBP) and women with LBP. No differences by gender or pain site were found in their
sample. Pain severity and pain site explained more of the variance in depressive symptoms than did physical functioning, pain coping, and gender. They found low back pain patients, regardless of gender had more problems with pain related physical functioning than did the pelvic pain group. They also found the pain coping style of catastrophizing more common in LBP than CPP patients, regardless of gender.

As with women, impaired sexual function is experienced by men with pelvic pain, with erectile dysfunction and ejaculation disorders being primary complaints. Sexual and physical abuse and assault have strong associations with CPP (Golding 1996; Latthe et al 2006; Walker and Stenchever 1993) and are described by feminists as expressions of gendered power differences in social structures and associated gendered attitudes about sexuality. (Margolis 1984; Martin 1984; Martin 1992; Doyal 1995) The depression and anxiety associated with CPP likely impact both care seeking behaviors; gendered stereotypes associated with depressed and anxious behaviors may effect practitioner’s clinical decisions about the clinical symptoms. (Baker Miller 1986; Doyal 1987 ; Margolis; Martin 1988; Martin 1992) Early reports on pelvic pain in women attributed the condition to women being conflicted about traditional female gender roles in domestic and childrearing responsibilities as well as in sexual intimacy. (Gidro-Frank, Gordon and Taylor 1960; Walker, Katon, Harrop-Griffiths 1988) Chronic pelvic pain in women has also been considered a metaphorical expression associated with painful childhood memories acting as a coping mechanism that protects them from additional painful, intimate relationships, including sexual ones. (Walker, Katon, Harrop-Griffiths 1988; Rosenthal 1993)

The literature supports the contention that the psychological ramifications of childhood abuse may be greater for women than for men. (Schanchter, Stalker and Teram 1999) A study of gender differences among abuse victims that used self-report to assess physical and mental
health found that females were more likely than males to report poor physical health, anxiety and depression. (Sundaram, Helweg-Larsen, Laursen, Bjerregaard 2004) Gender differences in the experiences of violence as well as gender related differences in health perceptions were suggested as explanations for the differences in that study. Negative personality traits and disorders including narcissism and borderline personality disorder are reported associations with CPP in men. Men, however, seem protected from some of the psychological consequences to childhood trauma that is manifested by women based on evidence in a report examining psychological characteristics in a sample of men and women with a history of childhood abuse. (Sundaram, Helweg-Larsen, Bjerregaard 2004; Schanchter, Stalker and Teram 1999)

Gender differences in care seeking decisions for a subset diagnostic category of CPP, IBS were reported in a population based study that found that men with pelvic pain were more likely to seek care when they have fear of being disabled and if abdominal cramping is present. (Black, Kim, Andrews, Mangel, Buda, Cook in 2006) Women with IBS were motivated to seek health care when they had fear the symptoms were related to a serious illness and when frequency of bowel movements was decreased. Neither male nor female care seeking for IBS was explained by pain severity or mental health status in their population based study. Gender differences as well as sexism can influence the effectiveness and the interpretation of clinical communication between women and health care practitioners. (Castillo 1997; Lieberman, Stoller and Burg 1997; Grace 1995; Van Dulmen 1999; West 1984) and were previously discussed in the section on clinical encounters.

Marriage

Marital relationships are often affected by CPP due to the sexual limitations and interpersonal stress caused by long term pain, extensive medical care and in some cases limitations on the ability to conceive children. Martial status and martial relationship dynamics
have reported associations with clinical characteristics of CPP and with risk for specific types of pelvic pain. Vulvodynia was reported to occur more commonly among married and more highly educated women. (Arnold et al 2006) Married women are, however, at a statistically significant decrease in risk for cyclic or menstrual related pelvic pain. (Latthe et al 2006) Lucht, Schaub, Meyery, Hapke et al (2003) found risk for depression, a common co-morbidity of CPP, was increased for married women with children. In a study focused on predictors of pain severity in women with pelvic pain, Milburn and Reiter (1993) found spouse responses to CPP that were categorized as “solicitous” or “punishing” were associated with more severe levels of pain; spousal responses that were more supportive and non-blaming were associated with lower levels of pain. Marital status changes (divorce, separation) and other marital difficulties were not statistically significant predictors of higher pain levels among the women with CPP in the Milburn and Reiter study. (1993) Similar relationships between spousal responses and the development of post-partum depression are reported (Huang and Nigel 2002; Romito, Saurel-Cuizolles, Lellong 1999), highlighting the significance of relationship interactions in two distinct women’s health conditions. Disturbed relationships with husband or spouse are the most consistent predictor of PPD across cultures in current studies (Huang and Nigel 2002; Romito, Saurel-Cuizolles, Lellong 1999; Simons, Reynolds, Morison 2001). Golding (1996) studied reproductive and sexual symptoms, and found that women exposed to multiple, nonviolent incidents of unwanted intercourse with a spouse were more likely to develop sexual symptoms than women exposed to other types of assaults. Sexual symptoms were also more likely if the women experienced an assault accomplished by persuasion rather than physical threat or if a woman was exposed to multiple episodes of assault.
Sexuality and Sexual Function

Sexual functioning, attitudes towards sexual activity and a woman’s perception of herself as a sexual being can all be affected by CPP. (Collett 1998; Curtis 2007; Randolph and Reddy 1996; Theve-Gibbons 2000; Weijenborg 2002) Pain during sexual intercourse (dyspareunia), pain after intercourse lasting hours or days (post-coital pain), disinterest in sexual activity (sexual indifference or sexual hypoactive disorder), and diminished physical sexual response (reduced libido) are all associated with CPP. Up to 41% of women with pelvic pain report pain with intercourse (Curtis 2007; Randolph and Reddy 2006; Zondervan; Veri, Verit and Yeni 2006). Collett (1998) compared complaints of dyspareunia in women with and without CPP, finding women with CPP were much more likely to experience pain with intercourse. Randolph and Reddy (2006) found rates of female sexual dysfunction (FSD) of nearly 68% among women with CPP and at 31% among controls without CPP. Nearly 75% of the women with FSD and CPP had a sexual pain disorders; other disorders reported included female hypoactive sexual disorder, arousal disorder and orgasmic disorder. (Randolph and Reddy 1996) Overall quality of life can be negatively impacted by the discomforts and restrictions on sexual activity associated with CPP. (Nickel et al 2007; Theve-Gibbons 2000; Weijenborg 2002) In a study of women in the military and dysmenorrhea, women with menstrual pain were more likely to be dissatisfied with their sex lives and have significantly lower scores in all eight domains of the Short-Form Health Survey (SF-36) for women. (Barnard et al 2003)

There is a large body of literature on sexual symptoms and sexual functioning in menopausal women cross-culturally (Addis et al 2006; Avis et al 2005; Beyene 1989; Leidy Seivert 2006; Lock 1992; 1998; 2002) Sexual dysfunction was found less likely among African American than non-Hispanic White women and Asian women in 2006 population based study from Kaiser-Permante (Addis et al 2006). Sexual dysfunction was more likely for women with
higher educational levels, women who reported poorer overall health, women with urinary incontinence and women in significant relationships. Women in significant relationships were more likely to participate in regular sexual activity than women not in relationships and they found that African American women were more likely to be satisfied with the sexual relationships; their study included 2109 women of whom 47.6 % were White, 18.2 % were African American 16.4% were Asian, 16.6% were Hispanic and 1.3% were Native American/other. Lower body mass index (BMI) and as well as better mental health scores were also associated with increased sexual satisfaction in the Addis (2006) study. Avis and colleagues (2005) reported on a cohort of 3,167 non-Hispanic white, African American, Hispanic, Chinese, and Japanese women from the Study of Women’s Health across the Nation (SWAN) who were not using hormones. After controlling for a variety of variables, ethnic differences were significant for sexual arousal (P < 0.0001), pain (P = 0.03), desire (P < 0.0001), and frequency of sexual intercourse (P = 0.0003). African American women reported higher frequency of sexual intercourse than white women; Hispanic women reported lower physical pleasure and arousal. Chinese women reported more pain and less desire and arousal than the white women, as did the Japanese women, although the only significant difference was for arousal.

Women with CPP are more likely to have a history of sexually transmitted diseases (STD’s) than other women. (Latthe et al 2006) Pain from most of the common STD’s is for the most part acute and short lived if proper treatment ensues. History of an STD, particularly recurrent or untreated STD’s may be a precursor to CPP due to the role of STDs in the development of pelvic inflammatory disease (PID), a statistically significant correlate of all types of CPP (Latthe et al 2006) Testing for STDs is usually a routine component of the medical diagnostic process for pelvic pain (Carter and Howard et al 2000); however, biomedical texts on
the topic of CPP give little attention to the topic of STDs except as an etiological factor for pelvic inflammatory disease. (Howard, Perry, Carter and Minawi 2000; Steege, Metzger and Levy 1998) STD’s are most common in women under twenty-five years of age whereas CPP is most common among women approximately 10 years older on average. (Howard 2000) Multiple sexual partners, particularly in the last 30 days and not using condoms or other barriers predispose women to both STD’s and PID. (Carter and Howard 2000; Ness, Randall, Richter, Pieper, Montagno, Soper, Sweet, Nelson, Shubeck, Hendrix, Bass, Kip 2004) Champion et al (2005) report on a sample of Mexican American and African American adolescents seeking treatment for sexually transmitted diseases (STD) in which they found links between STD’s, abuse history and later development of pelvic inflammatory disease (PID). The mechanism suggested for the link between PID and pelvic pain is biologic, with the long term effects of PID damaging the reproductive system. Although increased health care utilization is characteristic of abused women, Champion et al (2005) reportedly delayed care seeking behavior among the abused minorities with STD’s and PID in their study. A degree of normalizing of pelvic pain by the long term exposure to pelvic pain and symptoms of STD’s and PID apparently occurred among the young women in their study who delayed care seeking well past the appearance of clinical levels of symptoms. (Champion et al 2005) Delayed care seeking increases the likelihood STDs will progress to PID and on to the next step, CPP.

Many women with CPP resist and resent (Theve-Gibbons 2000) the emphasis on screening for STD’s as a component of biomedical care for CPP. (Theve-Gibbons 2000) The social stigma attached to STD’s (Inhorn 1986; Grant 2005) and the implication of promiscuous behavior is embarrassing and humiliating to many women. Some women report damage to their intimate relationships due to the suspicion aroused by the medical suggestion of STDs and others report
ongoing stigma even after they are diagnostically cleared as their friends, family and partners continue to believe that there must be a hidden aberrant sexual behavior that is causing their pain, especially if no other clear diagnosis emerges. (Theve-Gibbons 2000)

Abuse and Assault

Prevalence of sexual and physical abuse among women in general is between 15% and 30%, higher for chronic pain populations (Toomey, Seville, Mann, Abashian, Grant 1995) and up to 50% among women with CPP. (Walker and Stenchever 1993) Women and girls are much more likely to experience violence and abuse of all types throughout the lifespan than are their male counterparts with 20-30% of girls and 15% of boys estimated to be sexually abused before age 18 in the US and Canada (Schachter, Stalker and Teram 1999) Women with CPP are significantly more likely to have experienced physical and sexual abuse than other women. (Drossman, Lerman, Nachman et al 1990; Harrop-Griffiths, Katon, Walker, Holm, Russo, Hickok 1988; Latthe et al 2006; Rapkin, Kames, Darke et al 1990; Reiter and Gambone 1990; Toomey, Hernandez, Gittelman 1994; Verit, Verit and Yeni 2006; Walker, Katon, Harrop-Griffiths et al 1988; Walker and Stenchaven 1993, Walker et al 1993; Walling, O’Hara, Reiter et al 1994) Jacob and DeNardis (1998) reviewed studies on the co-morbidity of childhood abuse and pelvic pain and reported prevalence ranges between 48% and 56% among women with CPP. Their review of clinical studies and retrospective surveys of adults put prevalence of child abuse (sexual and physical combined) between 16-27% of girls of 15% of boys (Jacob and DeNardis in Steege 1998). Others estimate the range of occurrence at much higher rates 20-50% (Bachmann Moeller, Bennett 1988) Sexual abuse was one of two factors (PID being the second factor) with a significant association with all types of CPP in Latthe’s statistical examination of the literature on CPP. (2006) That review excluded gastrointestinal related CPP; however, sexual abuse is reported to have a strong association with irritable bowel syndrome and other types of chronic
gastrointestinal disorder in other studies. (Jamieson and Steege 1997; Drossman 1995; Drossman et al 1995)

Studies of childhood sexual abuse and CPP in adult women provide the type of data that could support causality between sexual victimization and development of CPP due to the temporal relationship of the abuse and the pain onset. Some reports indicate that childhood abuse alone or childhood and adult abuse combined are more strongly correlated with the development of CPP than adult abuse alone. Girls are at greatest risk for sexual abuse between ages 7 and 13 with risk increasing at puberty. The risk at puberty conflicts with popular notions that as girls age they are less likely to be sexually abused due to their larger physical size and ability to articulate the events to others. Statistics indicate the sexual transition of puberty is not however, protective from sexual abuse. Girls and boys are both more frequently abused by heterosexual men in a position of power and trust in their lives. For girls, the perpetrator is more likely someone in the home or family; for boys, it is more likely someone in the community, for example, the revelations in recent years of the long term sexual abuse committed by pedophilic Catholic priests. (Dale and Albert 2007) Much childhood abuse goes unreported, with estimates as low as 20% of cases reported (Bachman, Moeller and Bennett 1988). Licensed health care workers were mandated reporters of childhood abuse in all US states by the Childhood Abuse Prevention Treatment and Adoption Act Amendments in 1996, however, approaches to screening for abuse vary and many cases are overlooked. (Purtillo and Haddad 2002)

Frayne, Skinner, Sullivan, Tripp, Hankin, Kressin and Miller (1999) write that in a sample of military women utilizing the Veteran’s Administration health services 23% reported a history of sexual assault while in the military service. In their national sample of over 3000 women, history of sexual assault was associated with medical and physical symptoms in every domain
they assessed including statistically significant associations with lost pregnancies (46%), irritable bowel syndrome (26%), frequent urinary tract infections (19%), endometriosis (12%), hypertension (32%), heart attack (20%) and obesity (38%). Due to the cross-sectional design of their study, they were not able to assert causality between sexual assault history and the associated medical problems. They did control for potentially confounding variables (age, race and education) without change in significance in the initial findings. Painful intercourse is often associated with history of sexual and physical trauma. (Golding 1996; Howard 2000b; Latthe et al 2006; Walker and Stenchever 1993) Women who experience increased levels of physical threat during sexual and physical assaults are more likely to experience intercourse pain than women than women with less threatening abusive experiences. (Golding 1996; Walker and Stenchever 1993) Women subjected to female genital operations experience lifelong pain with intercourse, bowel and bladder function. (Latthe et al 2006) By intention of the procedure, circumcised women have difficulty participating in sexual intercourse and sexual pleasure. Repeated operations are often preformed to allow childbirth and intercourse. The risk for infection, PID and HIV/AIDS is inherently high among women who endure these procedures.(Latthe et al 2006; Nour 2008; Obermeyer 2003; Schell-Duncan 2003; Yount and Abraham 2007)

Other ramifications of childhood physical, verbal and sexual abuse relevant to women with pelvic pain include depression (Handwerker 1999), drug abuse and addiction, eating disorders, low self-esteem, lower self-control (Toomey, Seville, Mann, Anashian, Grant 1995) sexual disorders, and gender identity disorders. (Bachman, Moeller, Bennett 1988; Fry et al 1993; Rosenthal 1993; Schachter, Stalker and Teram 1999; Talley et al 1994; Walker and Stenchaven1993) Some have attempted to explain CPP as psychogenic and physical expression
of the pain of abuse; others refute abuse as an etiological factor (Fry, Crisp Beard, McGuigan 1993) Depression is considered by others to be a consequence of the suffering and frustration associated with CPP. (Rosenthal 1993; Grace 1995) Psychological distress in women exposed to violence is conceptualized by others as maladaptive coping that occurs in response to the abuse rather than to the pelvic pain. (Badura, Reiter, Altmaier, Rhomberg, Elas 1997) Similarly, dissociation is interpreted by some as a defensive or adaptive response to abuse; for example, in a study of women with CPP and an abuse history as well as samples of women with other medical illness and abuse histories, Spinhoven et al (2006) found physical abuse as the only clear predictor of level of somatoform dissociation in women with CPP. Handwerker (1999) reported higher levels of depression among Alaskan natives who were exposed to verbal abuse of a racist nature in childhood. Handwerker (1999) suggests stress induced changes in neurotransmitter biochemistry as a partial explanation for the increased risk for later life depression after childhood trauma, illustrating the bio-cultural nature of both depression and abuse (Castillo 1997) Body shame and body image disturbance may also manifest as a consequence of childhood abuse, for example, body shame was shown to be associated verbal and humiliation in a study of that examined teasing among African American children and adolescents. (Young-Hyman et al 2003) Body image has not studied among women with CPP.

Physical conditions that are statistically increased in women with abuse histories include chronic fatigue, bladder disorders, headache, asthma, diabetes, heart problems and reproductive disorders, including CPP. (Golding 1996; Roman, Belaise, Martin, Morris, Raffi 2002) Golding’s (1996) study which identified robust relationships between sexual assault and reproductive and sexual symptoms community group of ethnically diverse women, was discussed earlier in this chapter in the section on race and ethnicity. Physical injuries to the
pelvis and/or pelvic infection can result from sexual and physical abuse and lead to immediate or later life pelvic pain. Touch and/or contact sensitivity, is common among victims of abuse and domestic violence, (Johnson 1997; Schachter, Stalker and Teram 1999; Valpy 2003; Walker et al 1988) and is often a problem for women with CPP. Touch or contact sensitivity is also common among women with CPP who are not abused, particularly those with diagnosis of vulvodynia, vulvar vestibulitis or herpes zoster (Shingles). Emotional and psychological changes resulting from episodes of abuse and physical violence are suggested as a psychogenic explanation for pelvic pain that allows women to avoid sexual or physical contact that reminds them of the trauma. (Gidro-Frank, Gordon and Taylor 1960; Harrop-Griffiths, Katon, Walker, Russo, Hickok 1988) Golding’s finding that level of physical threat is associated with later symptom development indicates a role for the cognitive, emotional, and/or psychological in the development of CPP. Women and girls exposed to repeat assaults more are also more likely to develop painful problem than are their counterparts who suffer an isolated incident of violence or abuse. (Golding 1996) The relationship of the perpetrator to the victim also appears to impact the risk for developing pelvic pain as well as the type of pelvic pain that manifests. (Golding 1996)

Self-Efficacy

Women, as well as adolescent girls (Chen, Lin, Heitkemper and Lu 2006) may rely on self-care when biomedical treatment is ineffective for menstrual and other types of pelvic pain, or, they may utilize self-care rather than seeking biomedical care. (Grace and Zondervan 2006; Zadinsky and Boyle 1996) Zadinsky and Boyle (1996) described self-care by women with CPP to include 3 fundamental strategies: 1) assessing the need for self-care 2) developing self-care practices and 3) sustaining self-care practices. (Zadinsky and Boyle 1996) Conversely, many women develop the belief that the problem is not real and/or that they are somehow at fault and responsible for their symptoms when a viable medical diagnosis does not emerge, rather than
actively engaging in agency to improve their condition. (Grace 1995) Class may play a role in decisions to engage in self-care particularly in the use of complementary and alternative medicine where out of pocket expenses can be significant barrier. (Baer et al 2008) Some women with CPP limit their self-care in order to continue with their caretaking roles, particularly when care taking roles serve as the primary source of self-identify. (Theve-Gibbons 2000) Biomedical strategies to promote adherence to self-care regimes often build on the caregiver role of women by framing the importance of self-care as the means to regaining the ability to care for others. Health care professionals are known to avoid discussing and/or minimize conditions related to urinary and fecal incontinence as well as other socially stigmatized conditions. (Mitteness and Barker 1995; Porrett and Cox 2008) Ageism and sexism contribute to the inattention such conditions receive from health care professionals who often perceive conditions such as pelvic pain and incontinence as “normal” for women and the elderly, limiting treatment options offered by health care professionals. (Mitteness and Barker 1995) Women with pelvic pain often adopt coping strategies that allow them to appear “normal” which for many involves caring for others rather than self. Such coping strategies contribute to the “invisibility” of their condition to family members and co-workers (Grace and Zondervan 2006; Theve-Gibbons 2000)

Instrumentality or competency (Parsons 2001; Unger and Crawford 1992) are feminist terms referring to a dimension of personality and ability that is stereotypically male which implies the ability to carry out life responsibilities actively, objectively, independently, directly and unemotionally. Gender variations in this trait appear to manifest for women and girls during periods of biological or sexual changes. Prior to puberty, instrumentality in girls is at levels similar to boys. (Parsons 2004; Unger and Crawford 1992) Instrumentality is essentially analogous with competency in a social sense that is instrumentality is associated with a person
who is capable of “effectively manipulating the world around them.” (Unger and Crawford 1992). Instrumentality is directly in opposition to the affective dimensions of personality and behavior stereotypically associated with female gender such as passivity, emotionality, dependence and indirectness, all characteristics thought to produce a less competent approach to interacting in the world. Women may or may not accept stereotypical views of themselves and other women’s, and may or may not fit the pattern. However, studies have long indicated that women who do not accept stereotypically views of their instrumentality are more likely to achieve socially and professionally despite disadvantaged backgrounds (Unger and Crawford 1992). During times of biological transition, women often feel out of control as they negotiate the changes in their bodies and the changes in social expectations. They may question their own instrumentality during difficult times, however, their ability to overcome lack of confidence in their ability may be effected by the degree to which they accept or refute stereotypical beliefs about the instrumentality of women. (Kleinman 1988a) In a classic study of working class women in England by Brown and Harris (1978) found that when a relative lack of social power was combined with absence of affective support, no job outside the home and parenting pressures in the home, there was a marked decrease in self-esteem and increased vulnerability to clinical depression. Kleinman (1988a) identified a similar pattern of vulnerability and provoking agents among Chinese. Similar patterns may exist among women with CPP, explaining the differentials in susceptibility to developing CPP.

Women with low beliefs in their own instrumentality are likely to have difficulty making necessary changes in home or work routines to accommodate time for exercise, relaxation and other aspects prescribed to address CPP. A women’s belief in her instrumentality can impact her successful implementation of lifestyle changes recommended by health care practitioners.
Women with limited views of their own instrumentality may have difficulty with tasks that require them to negotiate and manage their time, actions, interactions and resources. The hormone fluctuations associated with menses, pregnancy and menopause all may have consequences on emotions and concentration which can further lower a women’s belief in her instrumentality as these events support the stereotypes.

**Summary: Chronic Pelvic Pain as a Biocultural Health Problem**

Chronic pelvic pain is a severely painful and functionally limiting condition that is prevalent among women of all ages from diverse ethnic backgrounds and from varied geographic regions. A multitude of biological, psychological and social variables are associated with the condition; the individual affects of these variables is poorly understood and their interactions are understood to a lesser degree. Many women routinely experience intermittent, pelvic pain as a normal part of reproductive and sexual life that does not significantly interfere with their lives in an ongoing fashion. Despite its prevalence, many women apparently perceive pelvic pain as a unique individual problem and rarely share their experiences with other women or in other ways seek out social support. The association of pelvic pain with reproductive and sexual activity may deter some women from seeking either medical care or social support for the condition. Social support is normally a strong point for women’s health, however, embarrassment or social taboos on the topics of sex, reproduction, gastrointestinal and urological functions may all contribute to a phenomenon of “social silence” regarding pelvic pain. Community based studies of prevalence indicate that higher numbers of women experience chronic pelvic pain than seek biomedical care for it. The association of pelvic pain with sexual and reproductive functions may also deter women from health seeking care if they perceive their symptoms as a “normal” part of womanhood, perhaps contributing to the chronicity of the condition and limiting their access to both health care and social support.
Limited economic resources and exposure to social environments conducive to or characterized by physical threat and sexual assault appear to contribute to the development of CPP. (Golding 1994; 1996; Champion et al 2005; Haggerty et al 2005) Ethnically diverse women are affected by the condition and correlations between ethnicity and specific types of pelvic pain are reported with African American women appearing to be particularly at risk. (Latthe 2006; Golding 1994; 1996; Champion 2005; Haggerty 2005) Cultural and biocultural approaches to chronic pain (Bates 1996; Good, Bodin and Kleinman 1992) and as well as cross-cultural studies and feminist critiques of biomedical approaches to pregnancy, menopause and menarche (Beyene 1989; Davis Floyd 1994; 2001; 2007; Martin 1992; Meade 1965) inform our understanding of the relevance of social context to chronic pelvic pain, however, focused study that specifically examines the contribution of ethnicity and other social attributes to the experiences of women and men with chronic pelvic pain are needed to support more efficacious medical management of this particular condition and to shed light on the reasons some women are more susceptible to this condition than others.
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CHAPTER 2
BIOMEDICAL ASSUMPTIONS AND PRACTICES

Introduction

One aim of this portion of the project is to provide a critique, from the perspectives of culture and gender, of biomedical assumptions about chronic pelvic pain as a foundation for the advancement of a socially informed perspective on pelvic pain that is also relevant to biomedical practitioners. A summary of biomedical assumptions related to chronic pelvic pain in women was developed by searching the biomedical literature on the topic; reviewing biomedical text books that specifically address pelvic pain in women; (Howard, Perry, Carter, El-Minawi 2000; Ling 1993; Rosen; San Filippo; Steege, Metzger and Levy 1998) reviewing proceedings of meetings of the International Pelvic Pain Society (IPPS Proceedings) and the National Institutes of Health; (NIH 2002); and from drawing on my experiences as a physical therapist involved in the clinical treatment of women with CPP, reflecting on my observations and perceptions as well as discussing the same with colleagues in the field, soliciting their insights and opinions. I also attended several meetings of the IPPS as well as the 2003 NIH meeting on chronic pelvic pain. Anthropological and feminist scholarship that addresses biomedicine, women’s health, sexual and reproductive health, and chronic pain was utilized as the foundation of the critique.

Challenges to Biomedical Models of Health and Healthcare

Biomedical practitioners are challenged and often frustrated in their attempts to alleviate the pain and physical complaints expressed by women with chronic pelvic pain. The etiology of pelvic pain is commonly accepted in biomedical practice to be multi-factorial and holistic approaches to diagnoses and interventions are attempted by many and recommended by leading practitioners who specialize in the management of the condition. (Howard 2000; Ling 1993; Peters, van Dorst, Jellis, van Zuurin, Herman, Trimbos 1991; Rosenfeld 1996; Steege 1996)
Although biomedical clinicians are well aware of the condition’s complex and multifactorial etiology, the biocultural nature of the problem makes it difficult to establish clear cut approaches to intervention within a biomedical framework. (Reiter 1990; Peters et al 1991; Steege 1992; Steege1993; Steege 1991; Ling 1993; Howard 2000a; Latthe et al 2006) Multiple body systems contribute to the biological causes of CPP and psychological co-morbidities are also common. (Rosenthal 1993; Peters 1991; Jacob 1996) A psychiatric diagnosis often accompanies a biological diagnosis. (Rosenthal 1993) The social factors such as sexual and physical assault that occur at higher rates among women with CPP further complicate both their lives and the medical management of the condition. (Bachman, Moeller, Bennett 1988; Harrop-Griffiths et al 1988; Golding 1996; Romans, Belaise, Martin, Morris, Raffi 2000) Disentangling the interactions between the psychological, social and biological attributes that contribute to health, illness and disease can be challenging for researchers and practitioners in biomedicine who by virtue of their training often approach health care from a hierarchal, mechanistic and dualistic point of view that minimizes the relevance of social context. (Engel1977; Davis Floyd; Hahn 1995; Helman 1984; Helman 2007; Kleinman 1978)

The foundation of traditional biomedicine is a disease model of health based in science and technology. Mechanistic and hierarchal views of the body as well as Cartesian dualities of mind and body characterize the approach. The Cartesian model as it has evolved in capitalistic societies depicts the body as a biological machine that works to “produce” health in a hierarchal system where body dominates over mind with the body being “real” center of an individual’s health. Feminists criticize the system for sexist, paternalistic and patriarchal approaches to both health and health care that they argue limit and in some cases even harm women’s health. (Grace 1995; 1998; 2000; Martin 1992; Rosser 1994) Grace (2003) who describes women with CPP as
the embodiment of the limits of Cartesian approaches to health and illness; she explains the
difficulties of effectively diagnosing and treating CPP within the dualistic framework of
biomedicine by examining the contradictions between collaborative and integrative feminist
approaches and traditional biomedicine. Biomedicine is characterized by hierarchal patterns of
organization of all aspects of health and health care including information, practitioners, diseases
and patients. Social structures dominated by hierarchy are considered masculine while
collaborative structures are considered feminine. Hierarchal structure influences in social
interactions including discourse patterns as well as information interpretation in science and
health care (Rosser 1988; 1994; Martin 1987; Martin 1992) and appear to influence the clinical
encounters of women seeking care for CPP. (Grace 1995; 1998; 2000) The appropriateness of
management of personal and intimate experiences like chronic pelvic pain within a medical
system (biomedical) that only marginally values the subjective femininity (Laurence and
Weinhouse 1994) is questionable from the feminist perspective. The chronicity of pelvic pain
may in many cases actually be caused by this incongruent relationship is a theory that finds some
support in my interpretation of the literature on this topic. (Grace 1995; Grace 2007)
Ethnocentric bias is also a problem as racial profiling is demonstrated to effect treatment
decisions across a variety of biomedical specialties creating a double bind for minority women
seeking healthcare.

CPP does not fit within a health care framework based on a Cartesian mind-body split;
many women who seek biomedical care are being told there is nothing wrong with them when
organic pathology is not identified. (Grace 1995) Singular vision by clinical specialists as well
as separation of the social and psychological from physical conditions are characteristics of
biomedicine emphasized by feminists as well as anthropologists as problematic in women’s
health care, (Grace 2000; Martin 1987; Martin 1992; Rosser 1988; Rosser 1994) and are particularly limiting in the care of women with a condition as complex as CPP. (Wesselmann 2002) Despite the criticisms of the biomedical system, feminist social scientists have acknowledged the significant benefits of advanced technology to women seeking care within biomedicine (Scheper–Hughes 1987). The efficacious technological approaches that maximize the biomedical clinicians’ abilities in physical diagnosis and intervention also contribute to a cultural climate that minimizes attention to psychological and social attributes. (Davis-Floyd 1994; 1997) Limitations of the biomedical model have long been recognized by social scientists, including medical practitioners with dual training in anthropology such as Art Kleinman (Kleinman 1980; Kleinman, Eisenberg and Good 1978) and were outlined by Engel. (Engel 1977; Engel 1980) In his call for a new model in medical practice and recommendation for a “biopsychosocial” approach to health care, Engle (1977) particularly noted the limitations of biomedicine to fully explain sickness, an issue addressed at length by anthropologists. (Hahn 1995; Hahn and Kleinman 1983; Helman 1984; Helman 2007; McElroy and Townsend 1996)

Over the three decades since the initial work of Kleinman, Eisenberg and Good (1978) and Engle (1977), bio-psychosocial models, bio-psychosocial-spiritual models have emerged in biomedicine; those models as well as the growth of the field of psychoimmunology, the convergence of complementary medicine and biomedicine and the recent changes in the World Health Organization’s International Classification of Function all mark a paradigm shift in biomedicine to a broader view of health and health care moving beyond it’s dichotomous, hierarchal Cartesian mind and body and foundations. Although mainstream medicine is moving from a dichotomous mind versus body view to a more holistic concept of health, traditional biomedical attitudes, values and beliefs that were prevalent in past decades (Baer 1987; Brown,
Barrett and Padilla 1998; Hahn 1987; Hahn and Gaines 1987; Harwood 1981; Helman 1984) are noted to continue to influence both practitioners and patients. (Grace 1998; Grace 2000)

Convergence of holistic and integrated perspective into biomedical culture to the point that application of these concepts is routine in the daily practice of medicine is a gradual process influenced by many factors, in the United States not the least of which is the consumer model of health care. The majority of women with CPP first seek care from their local primary care or gynecologic physician whose training and continuing medical education may or may not include exposure to the concepts of integrated care for CPP.

Leading biomedical practitioners in gynecology and family practice (Steege 1998; Howard 2000a; Ling 1993; Peters et al 1991; Rosenfeld 1996) have critically examined the failure of biomedicine to adequately diagnose and effectively treat pelvic pain in women. In a call for holistic approaches to CPP, Ling challenged gynecologic physicians to expand their approach to pelvic pain beyond “gynevision”, referring to medical treatment focused on reproductive organ etiologies. (Ling 1993) Steege (1996) and Peters et al (1991) suggest “integrated” approaches that involve the simultaneous consideration of biological, social and psychological conditions at the initiation of the diagnostic process. Peters et al (1991) conducted a randomized clinical trial that compared clinical outcomes in women with pelvic pain treated with an integrated approach treatment using a traditional gynecologic approach. They reported statistically significant results supporting the integrated approach to care which involved assessment by all members of an interdisciplinary team at the outset of the episode of care. The integrated models described by Steege and Peters differs from the traditional mind-body dualist approach of biomedicine in that biologic is not separate from but interactive with the biologic, consistent with a biocultural approach but different from integrated medicine concept that focus on the inclusion of
complementary and alternative medicine in combination with biomedical treatment regimes. (Baer 2008; Davis 2004)

**Clinical Encounters**

Biomedical clinical encounters for CPP in women were studied to examine the effectiveness of health care delivery models by Peters et al (1991) in the Netherlands, Selfe in the UK (1998), and Steege in the US (1993); those studies are discussed further in Chapter 2 (Peters 1991 and Steege 1993) and at later point in this section (Selfe et al 1998). Women’s perspectives on biomedical clinical encounters for CPP were studied by Grace (1995) in New Zealand. Grace provided an interview based account that revealed most women with CPP were frustrated over their inability to obtain a medical explanation for their symptoms. They were also distressed by the apparent lack of interest demonstrated by practitioners in hearing the story of how the pain had developed as was affecting their lives. Lexicology was used to develop a metadiscourse from a sample of 36 women who had undergone medical treatment for pelvic pain. The essence of the message from these women as provided by Grace’s work is: “They want to KNOW what causes their pain; they want to understand it as it relates to each woman’s INDIVIDUAL life and idiosyncratic set of symptoms, AND they want to KNOW what can be done about it.” (Grace 1995) The women in Grace’s study did not find out what caused their pain during the medical encounters. They did not perceive any validation for their symptoms or acknowledgement of the disruption of their lives that was ongoing because of CPP. They reportedly were left depressed, confused and often doubting their own mental stability.

Consistent with Grace’s findings, several women in this study expressed frustration about the quality of their clinical encounters for pelvic pain, both the communication style and the diagnostic and physical examinations they received. Some discussed medical consultations they
perceived as inadequate and/or inappropriate. One woman shared the following as a complement to the physician she had just seen at the Memphis clinic as a new patient:

“He was very impressive. He was like ‘you’ve been to all these doctors and not one of them have asked you exactly where it hurts for you to point it out?’ Well you know only two of them have seen me without all my clothes on.”

Another shared the following about her family practice doctor and pelvic pain:

He knows about it but I haven’t seen him about it. He knows about all my problems and he tells me I’m a problem person who stays with the doctors.

One young woman shared this about being treated for depression her physician:

He says as I was (depressed) but I said I wasn’t. He put me on medicine.

A lengthy account of an encounter came from an African American woman in Memphis:

He said I can’t find anything wrong with you. People don’t usually have pain there. I’m like people don’t have pain there, my goodness. He says I’ll tell you what I’ll just do an exam…. he made me so mad I wanted to forget him… He sent me across the street to get a CAT scan and that didn’t show anything. After that he told me that I was too big you know, nothing wrong but I was too fat so I got on the phone and called my doctor and I told him what the doctor told me and he gave me an appointment to see him. …I was telling the lady about my pain and she said I don’t see anything wrong with you. I told everybody where my pain is so she said there isn’t anything there.

A variety of issues create barriers to effective communication with women seeking health care in biomedical systems. Gender based differences in communication styles, the personal and sexual nature of many women's health care problems as well as cultural diversity all complicate communication during health care encounters related to women's health care. Some women in this study commented on the benefits of interacting with women during their clinical encounters for pelvic pain.

“I do feel much better that you are a female than a male. It’s a little I don’t know, embarrassing…he’s (the physician) a very nice looking gentleman.”

At the end of the interview session another woman commented:

“I’m more relaxed now (that I’ve had) a chance to talk about it a get it out; it helps to have a woman to talk about it to; helps to get it out”
The paternalistic style of clinical communication added to the frustration of the women seeking care for CPP in Grace’s (1995) study where in the physicians dealing with women with chronic pelvic pain, particularly males, minimized time interviewing and focused their dialogue on laboratory and other diagnostic tests, however, they women with minimal information about their exam results, diagnosis, treatment plan and/or prognosis. Self-doubt as well as frustration was a reported outcome to such clinical encounters for CPP by the New Zealander women in Grace’s study. (1995) Frustration, self-doubt as well as general dissatisfaction with and poor outcomes to health care are all reported associations with gender based communication style conflict (Castillo 1997; Lieberman et al 1997; Grace 1995; Van Dulmen 1999) consistent with the findings from Grace’s work with women with CPP as well as a report from interviews with women in the US. (Theve-Gibbon 2000) Women expect physicians to listen to their description of the experience of illness and disease rather than to just inquire about signs and symptoms. (West 1984) Women also expect to receive clear and comprehensive answers regarding the cause of their conditions and the treatment plan. Studies show that male physicians interrupt patients more often than do their female colleagues. Reports indicate that female physicians are interrupted more often by patients than are males, (West 1984) It appears gender may have primacy over professional status where women physicians are concerned (West 1984); for example, women patients provide more information with fewer triggers to female gynecologists than to males. Studies also find that more time is spent in gynecological consultation when the woman’s partner was present, when the woman disagreed with the physician more often, when the visit was related to pregnancy supervision, and when the gynecologist provided more medical information and asked more psychosocial questions. (Van Dulmen 1999) The gender and professional status of the gynecologists were not linked to length of visit in the Van Dulmen
(1999) report. Women physicians, across specialties, typically spend more time in conversation with their patients and patients report higher levels of satisfaction with their communication during encounters with women physicians.

Selfe, Matthews and Stones (1998) studied outcomes to medical care for 121 British women referred to gynecologists by primary care physicians for pelvic pain. The aim of their study was to identify factors associated with better treatment outcomes; treatment outcome was operationalized as changes in the score on pain intensity scales. Several sociodemographic factors of both patients and practitioners, as well as clinical, diagnostic and treatment variables were analyzed. The only factor associated with more positive treatment outcomes was the specific physician who did the initial consultation. Controlling for physician age, gender and training did not alter the significance of the associations between specific practitioners and better outcomes to care; neither did controlling for the type of treatment rendered; high scores on hostility were noted among the women in their study, however, high levels of patient hostility did not alter the relationship between specific practitioners and better pain outcomes. The recommendation from this work is for increased attention to the more “subtle, attitudinal, personality and behavioral factors” that influence patients’ experiences in care seeking for pelvic pain. (Selfe et al 1998)

**Epidemiology and Social Factors: Etiology versus Context**

In biomedical studies, ethnicity is most often considered from the perspective of epidemiology rather than from the contextual illness perspective emphasized by medical anthropology. (Hahn 1995; Helman 2007; Kleinman 1978; Kleinman 1998; McElroy and Townsend 1996) Ethnicity or, more likely, race, may be reported in prevalence studies that seek to understand race/ethnicity as a factor predictive of or protective from a particular health condition, in this case pelvic pain. The dynamic, responsive nature of culture is generally not
represented in biomedical studies that include reference to race, ethnicity and/or culture. (Wardlaw2002) Epidemiology identifies association, but the explanations for those associations arise from examination of epidemiological facts from the perspective of social context. Ethnic categories, however, represent much more than the artificial phenotypic expressions associated with popular ideas about racial and ethnic differences. Effective health care strategies for pelvic pain will include attention to social, cultural as well as biological and psychological variables; close scrutiny of the social context within which the known variables interact is need to develop such strategies.

**Disability**

Although specific reports on worker’s compensation in the CPP population were not identified in this review, leading clinicians in the field note that it is uncommon for women with CPP to be recommended for worker’s compensation disability and practitioners describe reluctance to pursue disability for patients with this condition. (Steege 1998) This is interesting since many women with CPP are employed and report difficulty with attendance and job requirements, often modifying their approach to work if not missing work because of pelvic pain, however. (Grace and Zondervan 2006; Mathias et al1996) Gender differences exist in worker’s compensation and disability in the chronic pain population, with men more likely to be on workers compensation disability than women. (Weir, Browne, Tunks, Gafni, Roberts 1996) Reluctance by medical professionals to suggest or support a women’s inquiry about disability due to limitations associated with CPP is discussed very briefly in the biomedical literature (Steege 1998) and was observed anecdotally during this writer’s clinical encounters. (King 1985-2007) The reluctance of biomedical and insurance personnel to accept reproductive related pain as an adequate reason for worker’s compensation and disability has been discussed by several feminist writers. (Doyal 1995; Grace 2007; Martin 2001; Margolis 1984) Practitioners who
hesitate to support disability applications for women with CPP reporting their hesitation related to concerns that labeling a woman with CPP as disabled may serve to worsen her condition and support the “sick’ role. (Steege 1998) Currently, there are not reports in the literature that provide a clear picture of the relationship of CPP to work status including numbers of women with the condition who are assigned temporary or permanent worker’s compensation and/or disability.

Gender differences in mental health related to work status and disability are reported. Unemployment was shown to increase the risk of depression for men but not for women in a German study (Lucht, Schaub, Meyer, Hapke, Rumpf, Bartels, von Houwald, Barnow, Freyberger, Dilling, John 2003) Studies on worker’s compensation note increase in health services utilization by women in the disability system are related to psychological distress as well as women’s perception of their ability to handle the problem. Increases in expenditures for health services are reportedly more likely to occur for men who negative attitudes about the condition in terms of its harmfulness its potential to create loss or threaten their security. (Weir, Browne, Tunks, Garni, Roberts, 1996) The review conducted for this project did not identify any studies specifically examining relationships between disability and/or worker’s compensation and CPP.

According to a report from a community based study of women in the US, most of the functional limitations reported by women with pelvic pain were related to home activities. (Mathias 1996) (Arnold 2006; Grace 2006; (Beard; Grace 1995; Rosenthal 1993; Reed, Haefner, Punch, Roth, Gorenflo, Gillispie 2000; Stones et al 2000) Weir et al (1996) note that there is no worker’s compensation board for the domestic work women carry out in the home. Women in this study reported difficulties carrying out domestic responsibilities; however, for the most part
they expressed strong resolve to continue roles despite interference from pain. Difficulties with sexual activities are one of the primary complaints related to interpersonal relationships at home related by women to medical practitioners.

**Pain: Women’s Descriptions and Biomedical Interpretations**

Women use a wide range of terms and phrases to give a verbal account of the pain they experience (Grace 1995; Grace 2007b; Haefner, Khoshnevisan, Bachman, Flowe-Valencia, Green, Reed 2000); the breadth of descriptors used for pelvic pain is a function of the complex biologic nature of the condition, the social ramifications of the limitations it causes and of the interpretive frameworks women use to explain the pain as well as those used by clinicians to inquire about pain. (Grace 1995; Grace 2007b; Loeser 2005) Biomedical interpretation of pain is focused on the character and intensity of pain which are in turn interpreted in the diagnostic process to direct attention to specific organs or tissues and to assist in determining the state of any inflammatory or infectious processes that might be present. (Boissonnault 2005; Magee 2002) Clinicians often provide a list of sensory and affective descriptors from which women can chose to describe their pain, such as the McGill Pain Questionnaire or MPQ (Melzack 1975); studies such as those conducted in the development of the McGill Pain Questionnaire (MPQ) (Melzack 1975) support associations between unique pain character descriptors and a specific physical pathology. A short form of the MPQ is included in clinical assessment tool recommended by the International Pelvic Pain Society.

Women’s sometimes use descriptors to explain their pelvic pain that imply the presence of chronic visceral disorders. (Wesselman 1993; 1997; 2001) Visceral pain is often accompanied by nausea, vomiting as well as fever. (Boissonnault 2005) One woman in this study described her pelvic pain as “Very extremely painful dysmenorrhea to the point of vomiting with nausea, fever, every month bad fever”-M40
Vague, aching pain is indicative of ligament, joint, and muscle problems. (Melzack 1975) Shooting, stabbing and cramping pain can be associated with myofascial trigger points and with nerve impingements. (Melzack 1975) Neurological conditions often have a “pins and needles” or “electric shock” or “sharp” nature to the sensation as well. (Melzack 1975) Pain that crescendos in intensity are often associated with visceral organ pathology or vascular congestion. (Boissonnault 2005) This description is common with pain from intestinal conditions such colitis and other inflammatory bowel disorders. Cramping is usually associated with menstrual pain, irritable bowel syndrome, or other intestinal pathologies; however, cramping pain that radiates along a nerve distribution can also occur with intervertebral disc pathology. Throbbing, pulsating pain is associated with vascular conditions and may be described by women with pelvic varicosities. Boring or drilling pain is associated with bone pathology. (Melzack 1975) Pain accompanied by nausea and/or vomiting is a flag for systemic illness or infection; pain that changes with bowel movements indicates involvement of the intestines or rectum. (Boissonnault 2005)

Women with pelvic pain from vulvodynia, interstitial cystitis, herpes zoster (shingles), and/or peripheral nerve entrapments all complain of burning, tingling, itching and skin sensitivity. In a study that compared pain descriptions between women with non-vulva pelvic pain, women with headaches and women with vulvar pain, women with non-vulvar pain were found to have lower total MPQ scores (indicating less severe pain intensity) as well as lower scores in all four of the subset indexes (affective, sensory, cognitive and miscellaneous) of the MPQ. (Haefner, Khoshnevisan, Bachman, Flowe-Valencia, Green, Reed 2000) Burning pain with urination or intercourse often occurs with CPP which implies infection or pelvic inflammatory disease (PID), but is also common with vulvodynia and vestibulitis in the absence
of infection. A feeling of pressure or of “falling out” in the pelvis is associated with organ prolapse and pelvic floor muscle weakness. Pressure may also be described with bladder infections, interstitial cystitis (IC), and cystitis and with tumors.

Pain descriptors used by abused and non-abused women with chronic pain (CP), but not specifically chronic pelvic pain were compared in 1995 finding no differences in pain descriptors between the abused and non-abused groups. (Toomey, Seville, Mann, Abashian, Grant 1995) A study of unilateral chronic pain, (not specifically chronic pelvic pain) that compared right sided and left-side chronic pain indicated that the contra lateral side of the brain is stimulated by unilateral pain resulting in emotional and behavioral changes consistent with the functions of side of the brain stimulated. (Gagliese, Schiff, Taylor 1995) Studies were not identified in this review that examined the relationship between unilateral pelvic pain and physiologically induced emotional or behavioral changes.

The tissues and organs of the reproductive, urogenital, gastrointestinal and musculoskeletal systems associated with CPP share innervations from the same spinal nerve roots, principally the thoracic and sacral spinal levels as well as from the same autonomic nerve plexuses, which complicates the clinical interpretation of pain patterns. (Baker 1993, 1998; Berkeley 2005; Berkeley 2002; Wessleman 1993; 2001; Wesselman and Lai 1997) The neurophysiologic connections between the key systems involved in CPP hamper medical approaches that narrowly examine one body system from the outset. (Berkely 2002; Berkley 2005; Rapkin and Mayer 1993; Wesselmann 1993; Wesselmann and Lai 1997) The fundamental neurophysiologic mechanisms of pain include the activation of peripheral nociceptors (receptor cells that respond to noxious stimuli) and the transmission of the pain stimulus through the nervous system to the point of stimulus perception in the cerebral cortex. (Abraham 2003) A complex pattern of
convergence at the central nervous system (CNS) coordinates the functions of the pelvic body systems and the transmission of painful stimuli. (Berkley 2002; Berkley 2005) Normally, bladder and bowel emptying (micurtation and defecation) inhibit each other and both are inhibited during intercourse. The positive functions of central convergence are easy to appreciate in those examples but for women with CPP the visceral-somatic convergence contributes to and complicates their symptomatology. Mechanisms of referred pain and convergence appear to contribute to the involvement of multiple organs, body systems and/or tissues in CPP. (Berkley 2005; Berkley 2002; Wesselmann 1993; 2001; Wesselmann and Lai 1997) Trophic or nutritional changes can occur in somatic areas of referred pain including changes in blood flow, tissue texture, structure of skin and subcutaneous tissue, and atrophy of muscular tissue. (Wesselman and Lai 1997) The influence of convergence on CPP is even more profound considering recent evidence that the variations in the patterns of pain and tissue change vary with the menstrual cycle and other alterations in reproductive status. (Bradshaw and Berkley 2000)

Through the process of neurophysiologic convergence, signals from each separate body system involved in CPP can alter function and pain perception in tissues and structures in the other systems. (Berkley 2002; Berkley 2005; Wesselman and Lai 1997) The afferent nerve fibers that supply the reproductive, urologic and gastrointestinal organs are very specific to the tissue they innervate, however, the source of pain in the pelvis is difficult to distinguish as the innervation patterns from these afferents is one that overlaps and converges prior to cerebral interpretation. Overlapping segmental innervation sets up the potential for referred pain, that is pain perceived in areas without pathology because of painful stimuli traveling to the spinal segmental level that innervates a variety of structures.
The pelvic organs derive their segmental innervation largely from the lower thoracic, upper lumbar and sacral nerve root levels. Referred back pain and thigh pain are common patterns that emerge with pelvic organ pathology. Afferent or sensory information traveling from pelvic organs converges with afferents from other structures such as skin and myofascia at the level of the spinal cord. The result is that very specific neurons and nuclei in the spinal cord respond to stimulation from pelvic organs and from skin and other structures. Studies demonstrate that neurons in the thoracic or lumbar spine respond both to manual contact to the skin and myofascia in that spinal region, but also to stimulation of the organs innervated at those same segmental levels. (Berkley 2002; Berkley 2005; Rapkin and Mayer 1993;) In other words, sensory information from the pelvic organs gets blurred at the level of the CNS; the sensory information is not only blurred or merged with that from other organs, but from somatic tissues that share segmental, peripheral and/or autonomic innervation as well. This process of central convergence of neurophysiologic information from visceral organs and musculoskeletal tissues is referred to as “viscero-visceral-somatic convergence”. The shared innervation of visceral and peripheral bodily structures renders traditional dualistic biomedical assumptions regarding the separation of visceral and somatic inadequate to explain common patterns of pelvic pain. Emerging studies in pain research also challenge the dualistic biomedical assumptions that separate central from peripheral and body from mind, as well as the hierarchal perceptions about the controlling role of the CNS. Research indicates that normal normally non-painful stimuli may activate the cortical pain system suggesting that CPP may result from both direct and indirect pain mechanisms. Recent data on the neurological aspects of pelvic pain challenges has leading gynecologist acknowledging that the primary physiological alterations cause CPP are more likely neurological than gynecologic or urologic and that a full understanding of pelvic pain is more likely to arise
from understanding changes in neurologic systems, not in reproductive end organs themselves. (Steege 2008)

Loeser (2005) suggests four components of the pain experience, nociception, pain, suffering and pain behavior that must all be understood to sufficiently describe a pain experience. Grace and MacBride-Stewart (2007) found that when women with CPP were given the opportunity to describe pelvic pain in a narrative form rather than using a word list from a clinical assessment tool, they most often described the pain in terms of how it restricted their life more often than they used sensory adjectives such as “sharp” or “hot” to describe the nature of their pain. In other words, when given the opportunity to freely describe their pain, women with pelvic pain tended to describe their suffering rather than the sensory experience of the pain; Loeser (2005) argues that it is the suffering, not the pain motivates individuals to seek health care, concept consistent with Kleinman’s (1992; 1997) suggestion that pain is an “idiom of distress”, a way to communicate a variety of social meanings and often means of expressing social resistance. Acknowledgment of the role of social distress in activating the neurological mechanisms that lead chronic pain and depression is not yet state of the art in the biomedical approach to CPP; social and psychological processes continue to be fall into the category of “unreal” problems for by most biomedical interpretations, in a variety of settings. (Kleinman 1997; Trnka 2007)

**Biomedical Diagnostic Correlates**

Establishing a definitive diagnosis and plan of care for complaints of chronic pelvic pain is difficult for biomedical practitioners and some argue does not necessarily support the acquisition of positive outcomes. (Selfe et al1998) However, by tradition and routine diagnostic process, medical care for women with pelvic pain is characterized in large part by diagnostic procedures and a sometimes unending search for a cause and a cure. Fragmented body systems approaches
are the usual approach to diagnosis and biomedical treatment for this condition, consistent with biomedical specialty practice. (Apgar 2002; Rosenfeld 1996) Fragmented approaches to care may delay acquisition of adequate care while the condition and its social and psychological ramifications worsen as well as add to the material and social consequences of the condition. Although conducting a review of systems (ROS) is a standard part of biomedical examination, the detailed attention to screening systems outside ones specialty that is put forward by the International Pelvic Pain Society on its Pelvic Pain Assessment Form is not necessarily routine in most practice environments. The likely exception would be practitioners with a very specialized practice niche focused on CPP. The medical care seeking experience most often described by women with CPP is one of exhausting the treatments from one specialty before being referred to another (Steege 2002) with many women resorting to self-care or perhaps carrying on with no care.

Most medical diagnoses related to problems with sexual function provide a descriptive label of the symptoms women describe as the “diagnosis” rather than usual etiology based diagnosis. Common diagnostic categories related to sexual problems are considered both reproductive (ICD9) and psychiatric disorders. (American Psychiatric Association 1994) The DSMIV (American Psychiatric Association 1994) lists dyspareunia, vaginisimus, hypoactive sexual desire disorder, orgasmic disorder, sexual aversion disorder and female orgasmic disorder in the category “sexual dysfunctions”. All these diagnoses are common among women with CPP and all have overlapping biological and psychological explanations. (Castillo 1997) In all these conditions, the diagnostic label essentially relays what the woman states is bothering her. Similarly, the diagnosis dysmenorrhea simply means “abnormally painful menses”. Biomedical diagnoses such as these that are symptom based rather than etiology based usually emerge when
the condition is ill suited for reductionist biological explanations. Fibromyalgia (painful myofascia) is another example of such a condition. The medicalization of problems that don’t fit well within the biomedical diagnostic framework can result in the development of beneficial treatment strategies, but the path to success is rarely clear, simple, or linear and is usually frustrating for patients and practitioners.

**Dyspareunia.** Women who complain of painful intercourse are diagnosed with dyspareunia which can be caused by a variety of biologic conditions of the vagina, external genitalia, reproductive organs, urologic systems as well as by musculoskeletal problems of the back, hips and pelvis. Vaginismus, a common cause of dyspareunia, is thought to affect 1% of all women. (Howard, Perry, Carter, El-Minawi 2000) Vulvodynia can also interfere with intercourse; it is a condition characterized by severe pain in the external genitalia, aggravated even by the light touch of clothing and often rendering sexual activity out of the question for many women because of the severe pain associated with genital contact. Dyspareunia can be related to particular intercourse positions, situations, and partners or to the timing during the menstrual cycle when intercourse occurs. Symptom investigation questioning includes determining if dyspareunia is “deep” or “superficial”; deep dyspareunia refers to pain during deep vaginal penetration; entrance dyspareunia is pain with initial penetration. (Howard, 2000 b; Steege and Ling 1993; Webster 1993)

Dyspareunia is more common in perimenopausal women than women in other age groups and is usually attributed to the biological changes of menopause by biomedical practitioners who have traditionally considered menopause a disease representing the failure of ovarian function, a perspective criticized by anthropologists and feminists (Inhorn 2006; Lock 1998; 2002; Martin 1992; Rosser 1994) Many physicians routinely prescribe hormonal medications and/or anti-
depressants for the symptoms associated with menopause, including dyspareunia. Contrary to the common biomedical viewpoint, perimenopausal dyspareunia is more often associated with social factors than the physical changes of menopause (Avis et al 2005) Sexual activity, attitudes, function and dysfunction among perimenopausal and menopausal women are influenced more by ethnicity, relationship factors, abuse history (Golding 1996; Walker and Stenchever 1993), however, biomedical approaches emphasize biological explanations. (King 2006)

**Sexual desire disorders.** Hypoactive Sexual Desire Disorder refers to the absence of desire for sexual activity accompanied by emotional distress. Women who are not distressed by the lack of sexual desire do not technically fit into this diagnosis. Medical explanations for hypoactive sexual desire vary; it is considered a common consequence of hysterectomy due to hormonal changes. Loss of libido also occurs among women with CPP without a surgical cause. Some women are disturbed by diminished libido, others are not. Many women with CPP express attitudes of sexual indifference with the trait reported significantly more frequent among Latina women in Golding’s study of sexual assault history painful sexual and reproductive problems. (Golding 1996) they may be seeking care for pain relief without concern about restoration of sexual desire. Ethnocentric and sexist assumptions can affect biomedical practitioner’s diagnostic and treatment for CPP. A young woman in Theve-Gibbons (2000) interviews described her frustration with physicians who believed the intercourse pain she experienced was because she was afraid of sex, despite her insistence that she was not afraid and wanted to participate in sex with her husband. Hypoactive sexual desire is medically explained by both biological and psychological factors; limited lubrication, difficulty relaxing pelvic muscles. Sexual Aversion Disorder is similar, but characterized by active avoidance of genital contact; the aversion is to the genitalia of partners more than to sexual activity. Anxiety reactions usually
accompany this disorder considered to be most frequently caused by sexual trauma such as childhood sexual abuse; sexual activity is often accomplished by the using psychoactive substances to alter consciousness. Female Sexual Arousal Disorder (FSAD) refers to a woman’s inability to maintain sexual arousal during coitus; without sexual pleasure, women often lose interest in sexual activity. Biological problems associated with arousal disorders include limited blood flow to the genitalia and reproductive organs. Lower body mass index (BMI) was associated with increased sexual satisfaction in a study of middle aged and older women (Addis et al 2006) study.

**Body Systems and Biological Correlates**

Biological correlates of CPP are organized by body system during the review of systems (ROS) component of the medical diagnostic process. Biomedical clinical specialty areas are also organized by body systems (for example: reproductive system-obstetrics and gynecology or women’s health physical therapy; as well as by lifespan patient population (pediatrics and geriatrics in medicine and physical therapy) and clinical setting or condition specific (sports medicine; sports physical therapy; oncology). (American Board of Physical Therapy Specialties; Boissonnault 2005) During the screening component of patient examination, body systems checklists are utilized to determine if further examination by a specialist in a particular specialty area and/or specific diagnostic screening tests are warranted. (Boissonnault 2005) Relevant body systems to biomedical examination of women with CPP are the reproductive system associated with obstetrics and gynecology, urogenital system, associated with urology and uro-gynecology, gastrointestinal system, associated with gastroenterology, and the musculoskeletal system associated with orthopaedic and/or women’s health physical therapists.
Reproductive System

A variety of reproductive system diagnoses are associated with CPP including endometriosis, leiomyomas, dysmenorrhea, dyspareunia, pelvic inflammatory disease (PID), uterine fibroids, pelvic adhesions, uterine prolapse, ovarian cysts and pelvic varicosities/pelvic congestion, vulvodynia, and pelvic floor relaxation, among others. Although diagnostic laparoscopy is commonly used in gynecology to investigate pelvic pain, results of procedure often do not reveal the discovery of any organic pathology. Pelvic pain is the reason for up to 40% of all laparoscopic procedures in gynecology and for at least 12% of all hysterectomies. Many of the laparoscopic procedures and vaginal hysterectomies are aimed at pelvic pain address adhesions and scarring from previous surgeries. (Howard et al 2000; Steege and Stout 1991) Howard (1993) reviewed the literature on diagnostic laparoscopy and CPP to evaluate at which organic (biologic) pathology was identified via this gynecology procedure; the reported rates varied between 28% for all age groups and 78% for adolescents who underwent laparoscopy for pelvic pain. Howard warned against reliance on laparoscopy as a first line diagnostic procedure for CPP. (Howard 1993) In eleven research reports covering 3,084 women with CPP who underwent diagnostic laparoscopy, 34% of the cases presented with a normal pelvis. (King et al 1991) At least one third of women treated for CPP are estimated to remain symptomatic despite the traditional interventions from gynecology, including hysterectomy. (Howard 2000a; Stovall, Ling and Crawford 1990)

Pelvic Inflammatory Disease (PID), which has the strongest positive association with CPP of all biological conditions (Latthe et al 2006), refers to a spectrum of inflammatory disorders of the female genital tract including endometritis, salpingitis, abscess of the ovaries and peritonitis. In their 2006 review of CPP studies, Latthe et al (2006) found PID significantly associated with all three types of pelvic pain, cyclic (menstrual cycle), dyspareunia (sexual intercourse pain) and
non-cyclic. PID risk is increased in women with sexually transmitted diseases (STD’s) and to a lesser degree in younger women during the post-partum year. (Mahon et al 2005) It is not known if the slight increased risk in younger women after childbirth might also be associated with STD’s. As discussed in Chapter 1, minority women are at increased risk for STD’s, PID as well as HIV/AIDS, subsequently increasing their risk for developing CPP. (Champion et al 2005; Golding 1996)

Excessive, irregular and/or prolonged menstrual bleeding commonly occurs with CPP. (Bergant and Wicschwendter 1998; El-Minawi and Howard 2000; Smith 1993) Dysmenorrhea is the medical diagnostic category for abnormally painful menstruation; pain is a normal part of menstruation for most women. Chronic dysmenorrhea (abnormal menstrual pain) with duration of 6 months or more is considered CPP as long as the additional diagnostic criteria of causing functional disability and requiring medical or surgical treatment are met. (Barnard, Frayne, Skinner, Sullivan 2003) Cyclic or menstrual pain is a well known common subset of chronic pelvic pain. (Latto et al 2006; Smith 1993) The intensity of pelvic pain, whatever its location, often varies with a woman’s menstrual cycle, usually worsening during the premenstrual (luteal) phase of the cycle and/or during menses. (El-Minawi and Howard 2000; Smith 1993) During the luteal (the days immediately preceding onset of menstrual bleeding) and menses (menstrual bleeding) phases of the menstrual cycle, hormonal changes occur that are similar to levels acquired during pregnancy; these changes are known to facilitate an increased laxity in ligaments and other musculoskeletal structures. (Eaves, Key, Rai and Shepherd 2006) Such laxity is hypothesized to increase risk for joint injury and inflammation and to exacerbate pre-existing musculoskeletal disorders and/or impairments (Bertram and Thompson 2005; Romani et al 2003) The hormonal influence on musculoskeletal structure could explain the cyclic nature to CPP that
responds to musculoskeletal treatment rather than gynecologic (Baker 1993). The ovarian cycle also influences bladder function with recent research revealing cycling changes in bladder reflexes in response to the ovarian cycle.(Johnson and Berkley 2002) Intensity of pain associated with ureter stones has also been shown to increase with ovarian cycle changes (Giamberardion, deLaurentis, Affaifati, Ierla, Lapenna, Vecchiet 2001) and kidney stones, which refer pain into the upper and lower abdominal quadrants in conjunction with flank (lateral low back) pain, are considered in differential diagnosis for both episodic and non-cyclic pelvic pain. (Howard et al 2000)

Endometriosis, considered the most common gynecologic cause of pelvic pain, occurs in 0-25% of infertile women. Uterine pathology associated with CPP includes leiomyomas (benign tumors of smooth muscle—also known as fibroids, fibromyoma or myoma), abnormal uterine bleeding, uterine prolapse and uterine fibroids, among other less commonly occurring conditions. Cancers of the reproductive, urologic and gastrointestinal organs are also considered in differential diagnosis. (Howard et al 2000)Vaginal conditions include vaginal prolapse and vaginismus (vaginal tension and constriction). Ovarian cysts, ovarian remnant syndrome, as well as varicosities of ovarian blood vessels (Pelvic Congestion Syndrome) are all common among women with CPP. (Howard et al 2000; Ling 1993; Steege 1998) As previously mentioned, laparoscopy is commonly used for both diagnosis and surgical intervention for reproductive organ conditions associated with CPP and many women undergo hysterectomy, partial or complete, to relieve symptoms of CPP. Results to both these surgeries are often unfavorable. (Howard 1993; Reiter 1998; Reiter and Gambone 1991; Stovall, Ling and Crawford 1990)

CPP may occur during pregnancy; however, it is most frequently reported outside of pregnancy. Previous miscarriage and Caesarean-section are statistically significant risk factors
for non-cyclic pelvic pain (Latthe et al 2006), however, there appears to be no increased risk for pelvic pain related to number of pregnancies (gravidity), number of births (parity), or number of elective abortions. (Reiter and Gambone 1990) Pregnancy related pelvic pain is often due to changes in pelvic musculoskeletal systems associated with pregnancy such as sacroiliac and pubic symphysis laxities and osteitis pubis, which may continue into the post-partum period if adequate care does not occur during pregnancy. (Boissonnault 2002; Ostgaard, Zetherstrom, Roos-Hansson and Svanberg 1994) Some musculoskeletal pelvic pain in pregnancy may be exacerbated by the physical strain of labor and delivery; some pregnancy related pelvic pain may not begin until labor and delivery. (Boissonnault 2002; Ostgaard et al 1994; Sturesson, Uden, and Uden 1997) Coccydynia, coccyx fracture, pelvic floor muscle tears, pelvic separation, pudendal nerve injuries are among several conditions that may have their etiology in labor injuries. (Boissonnault 2002) In addition to the physical injuries that can occur during labor and delivery, quality of and access to health care has the potential to impact pregnancy outcomes.

Pelvic pain associated with pregnancy is more likely to be acute rather than chronic due to its association with the short term anatomic and physiologic changes of pregnancy. Acute onset severe pelvic pain in pregnancy may be associated with ectopic pregnancy, dangerous condition that requires immediate medical intervention or mortality of the mother may result. Risk for PID (PID is a risk factor for CPP), after pregnancy has only recently been examined (Mahon et al 2005) and appears to be increased in the immediate post-partum period, with that risk further increased with young maternal age. Young maternal age and PID are both more common among minority women, would appear to increase the risk for CPP among young mothers form ethnic minority groups.
Urogenital System

A variety of urologic and urogenital conditions are associated with CPP including interstitial cystitis, cystitis, urethral syndrome, urethral diverticulum, vulvodynia, vestibulitis, urinary incontinence, chronic urinary tract infections (UTI), cystitis, and cystocele (prolapse of the bladder). (Summitt 1993; Summitt and Ling 1990; Howard, Perry, Carter, El-Minawi 2000) Stress or urge urinary incontinence and/or urinary frequency are often co-morbidities with IC and other urologic diagnoses. Vulvodynia and vulvar vestibulitis are painful conditions of the external genitalia and vaginal introitus that are managed by both gynecologic and urologic practitioners, and by medical specialists who combine the two fields, urogynecologists. Women with vulvodynia have difficulty wearing tight clothing and some are unable to wear slacks at all without unbearable discomfort due to contact sensitivity. Vaginal dryness, genital itching, swelling and redness are also reported. (Walker and Stenchever 1993) Touch and/or contact sensitivity, which is common among victims of abuse and domestic violence, (Johnson 1997; Schachter, Stalker and Teram 1999; Valpy 2003; Walker et al 1988) is often a complaint of women with CPP. Touch or contact sensitivity is also common among women with CPP who are not abused, particularly those with diagnosis of vulvodynia, vulvar vestibulitis or herpes zoster (Shingles). Pain with tampon use, gynecologic exams and intercourse is common in women with vulvodynia, vulvar vestibulitis and vaginismus. (Arnold et al 2006; Wesselman 2002)

Epidemiologic data on the co-occurrence of urinary and/or fecal incontinence with pelvic pain was not uncovered in the review conducted for this study, however, Addis et al (2006) reported daily or weekly urinary incontinence was associated with greater sexual dysfunction in their study sample although they chose not to present the incontinence data in that report. Neurogenic triggers from pathology in other body systems, musculoskeletal, gynecological and
gastrointestinal being the most notable, are known to lead to changes in bladder function and bladder pain. (Berkley 2005; Weiss 2001) Treatments in other anatomic areas such as the musculature of the pelvic floor are known to decrease central nervous system sensitivity associated with urological pain and to alleviate pain from dysfunctional muscles and the bladder. (Weiss 2001)

**Gastrointestinal System**

Gastrointestinal (GI) common among women with CPP include abdominal bloating, diarrhea, constipation. (Carter 2000; Rapkin and Mayer 1993) Bowel disorders, particularly inflammatory bowel conditions can refer pain and alter function in the bladder and reproductive organs (Berkley 2005) as well as cause abdominal pain and pain associated with bowel function. The GI diagnosis most commonly associated with CPP is Irritable Bowel Disease (Irritable Bowel Syndrome), although constipation, fecal incontinence, intestinal adhesions, inflammatory bowel disease (including Crohn’s disease and ulcerative colitis), chronic intermittent bowel obstruction, colitis, rectal prolapse and hemorrhoids may also contribute to the CPP symptoms. (Howard, Perry, Carter and El-Minawi 2000) IBS is thought to arise from functional impairments of the colon that cause abdominal pain, diarrhea, bloating, food intolerance and less frequently, constipation. IBS is associated with sexual abuse, depression and anxiety as is CPP in general. (Drossman 1995; Drossman et al 1990; Fisher 2002) IBS is more strongly associated with childhood than adulthood abuse and is more likely to occur in abused females than in abused males. (Talley et al 1998) In fact in the Talley study the relationship between childhood abuse and IBS disappeared when age, gender and psychological co-morbidity were controlled. Higher levels of neuroticism as well as scales of psychological morbidity were associated with IBS as was female gender and age of abuse in their study. The operational model they utilized
proposed that IBS was an expression of neuroticism and that childhood abuse was a cofactor leading to that expression. (Talley et al 1998)

**Musculoskeletal System**

Musculoskeletal diagnoses associated with CPP include abdominal and pelvic hernias, (Carter 2000b) myofascial trigger points (Baker 1993; King et al 1991; Slocomb 1984; Weiss 2001), pelvic floor muscle tension (Sinaki, Merritt and Stillwell 1977; Lukban, Whitmore, Kellog-Spadt, Bologna, Lesher, Fletcher 2001; King Baker 1993), pelvic floor muscle wasting, pelvic floor muscle strain (Hunter and Zihlman 1970), peripheral nerve entrapments(Howard, Perry, Carter, El-Minawi 2000; Steege 1998), sacroiliac dysfunction, levator ani syndrome and coccydynia among others (Baker 1993; 1998). Stiffness in the hips or pelvis or accompanying low back pain may be described by women with musculoskeletal factors contributing to CPP. (Baker 1993; 1998) A typical pattern of faulty posture associated with CPP labeled typical pelvic pain posture (TPPP) was identified by physical therapists including this writer using the work of Kendall and McCreary (1983) as a standard for postural examination. Interventions directed toward correction of muscle and joint impairments in the hips, pelvis, abdomen and low back associated with TPPP were successful in the clinical management of CPP in our studies and in others that followed. (King, Ling, Rosenthal, Bryant 1986; King et al 1991; Schroder, Sanfilippo and Hertweek 2000; Fisher 2007; Lukban et al 2001) The primary musculoskeletal impairments associated with TPPP, included shortened length of the hip flexor muscle groups (Appendix a), weakness of the abdominal muscles (Appendix a) reduced mobility (stiffness) in the hips joints in a capsular pattern (Appendix a) and limited flexibility in active lumbar mobility Functional problems associated with the posture included diminished standing balance and an upper chest or restricted breathing pattern as well as difficulties with household, occupational and sexual activities the women associated with CPP. The work of Kendall and McCreary (1983) was
utilized to correlate musculoskeletal impairments and faulty postural patterns. We utilized the human adaptability approach (Moran 1984) to explain the development of TPPP and the associated musculoskeletal impairments as responses to culturally dictated postural constraints (the increased time sitting and predominantly sedentary lifestyles) in technology based societies such as in the current day US. (King 1985; Myers, King, Rosenthal, Rosenthal 1990)

Our retrospective report on 132 women with CPP referred for physical therapy from a university based gynecology included the initial 75 women referred in the first one year period that physical therapy consultation was added to the gynecologic pelvic pain clinic. The initial group of women had unexplained CPP that was unresponsive to a combination of gynecologic and psychological treatment. The additional 57 women were referred over a one year period 2 years later. A typical pattern of posture was identified in the initial group, occurring in 75% of all the women referred to physical therapy that year and in 90% of those successfully treated by physical therapy. TPPP was identified at a similar rate in the second group of women by different physical therapists from those involved in the initial studies with similar outcomes to care. (King et al 1991) Overall in both groups, 70% of the women treated for musculoskeletal impairments had successful outcomes to care for CPP. The Fisher’s Exact test was utilized to examine the symptomatic improvement seen in the ‘Typical’ and ‘Atypical’ groups. The results were significant to p<0.0058. TPPP was characterized in the sagittal or side view by an increase to the normal lumbar lordotic curve, and increase in the normal anterior tilt of the pelvis as well as habitual unilateral standing habits. Other more discreet alterations in optimal posture as described by Kendall and McCreary (1983) were also noted. In an unpublished review of records, difference was noted in the sagittal view of the thoracic spinal curve with an increase in the normal kyphotic curve occurring more frequently in white women and a decreased or
flattened appearance to thoracic spinal curve among African American women. Follow up to further evaluate ethnic differences in physical characteristics of women with CPP were not conducted with that sample of women.

The results of our first year experience with physical therapy and musculoskeletal management of CPP were reported at the 1986 meeting of the American College of Obstetrics and Gynecologists (King, Ling, Rosenthal, Bryant 1986) and later published in the *International Journal of Psychosomatic Obstetrics and Gynaecology* (King et al 1991) To date no studies of musculoskeletal treatment for CPP have sought to confirm the occurrence of the TPPP pattern identified in our early study, although the other studies cited here that examined the results of physical therapy treatment were directed at the types of musculoskeletal impairments we found associated with that particular faulty postural pattern. In this study, a physical examination form is utilized to screen for the presence of selected musculoskeletal impairments associated with TPPP considered to be of key importance in the physical therapy treatment of women with CPP. The impairments included are passive range of motion (PROM) of hip internal and external rotation, abdominal muscle strength, hip flexor muscle length, functional pelvic stability in standing. In addition, two measures of lumbar posture at the lumbo-sacral angle and thoracolumbar angle are included in the physical examination component of this study.

Successful multi-disciplinary treatment of CPP in adolescents that included physical therapy to address musculoskeletal factors was reported in 1990. (Gale et al 1990) In 2000 Schroeder, Sanfilippo, and Hertweek reported similar success utilizing physical therapists to treat adolescents with unexplained pelvic pain that had been unresponsive to gynecologic interventions. In their study approximately 50% of the adolescent girls had a final diagnosis of musculoskeletal pain (31 out of 63). The age range in was nine to 23 with a mean age of fifteen.
Physical therapy also resolved CPP symptoms of musculoskeletal pain in a retrospective study of 52 patients with diagnosis of IC or urinary urgency-frequency syndrome. (Weiss 2001) Myofascial trigger points in the pelvic and hip muscles were identified as the primary pathology in that group that responded to manual therapy techniques with 83% of the patients with urgency-frequency responding favorable to treatment and a 70% favorable outcome in the IC group. (Weiss 2001) The success of pelvic floor physical therapy in that study was attributed to the arrest of neurogenic triggers in the musculature that led to bladder changes, decreases central nervous system sensitivity as well as direct pain from the dysfunctional muscles.

Peripheral nerve entrapments of pelvic and spinal nerves are another musculoskeletal source of CPP. Peripheral nerves can be entrapped by neighboring muscles, ligaments, and joint and by scar tissue and adhesion. Compression on peripheral nerves can also be the result of tumors, tight clothing, or occupational positions. (Koppel and Thompson 1976) Peripheral nerve entrapments usually result in burning or tingling pain as well as sensory changes, either hypersensitivity or hyposensitivity in the area supplied by the nerve. If the nerve has a motor component, weakness in the muscles supplied can occur as well. Nerve entrapments associated with CPP include the ilioinguinal nerve, iliohypogastric nerve, genitofemoral nerve, femoral nerve, lateral femoral cutaneous nerve obturator and pudendal nerves. Physical therapy can often relieve nerve entrapments related to myofascial tension and faulty posture; surgical release is required in some cases. Pudendal neuralgia has received a lot of attention as an etiology in CPP in recent years with injections and surgeries directed at that nerve becoming more common in the treatment of CPP. (Antolak et al 2002; El-Minawi and Howard 2000)

**Psychological Diagnostic Correlates**

Psychological co-morbidities, particularly depression, anxiety and somatization, are a common part of the biomedical profile of women with CPP (Harrop-Griffiths et al 1988; Latthe
et al 2006; Fry et al 1993; Rosenthal 1993; Slocumb, Kellner, Rosenfeld and Pathad 1989) as they are in all chronic pain populations. (Bates 1996) The Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision (DSM-IV-TR) is in the biomedicine for diagnoses of psychological disorders. The DSM IV-TR uses a disease centered model to categorize psychosocial disorders. (Castillo 1997) that also includes a listing of sexual dysfunctions; sexual diagnoses common among women with CPP were discussed at the beginning of the section on diagnosis earlier in this chapter.

**Disease Model of Mental Health**

Disease centered psychiatry is the paradigm of biomedical treatment of mental health conditions. The disease approach to psychiatry conceptualizes the cause of mental disorders to be “brain diseases”, primarily “chemical imbalances”. Despite the widespread acceptance of the disease model of mental health in biomedicine, research does not support a singular biological explanation for mental health conditions, and in fact psychiatric medications frequently address symptoms rather than diseases. (Castillo 1997; Guttmacher 1994) Cognition which contributes to the development of both the behavioral and biological symptoms of anxiety and depression (Castillo 1997; Handwerker 1999; Schwartz et al 1996) is influenced by cultural context as well as individual perceptions. Cognitive explanations can determine the mental health outcomes to stressful life experiences. Cognitive approaches to the management of psychological conditions are an option in biomedicine, but are far less frequently utilized than the first line of defense, pharmacological approaches.

An understanding of cultural influences on cognitive explanations is necessary for therapeutic approaches aimed at modifying thinking patterns to meet with success. Consideration of cultural influences on symptoms of mental disorders is addressed in the DSMIV-TR (American Psychiatric Association 1994), a topic not included in previous versions of the
manual. Cultural considerations are not, however, integrated into the diagnostic classifications or
descriptions of the diagnostic process, but included as reference information for clinicians with
interest in culturally diverse clients. Considering the lack of integration of cultural
considerations, including cultural aspects of cognition, in the diagnostic process outlined in the
DSMIV, the guidelines in that manual provide biomedical practitioners a diagnostic tool that is
quite reliable, but of questionable validity. (Castillo 1997) Many women with CPP carry
psychological diagnostic labels based on the DSMIV, adding a component to their illness
experience that from a culturally informed perspective may or may not be a valid representation
of their mental condition and may or may not result in prescription of more effective therapies.

The difficulty in acquiring successful medical care is thought to increase the risk for
mental health co-morbidities among women. (Grace1995), however, causality between CPP and
psychosocial co-morbidities is not considered clear cut in the biomedical literature. (Heim,
Ehlert, Hanker, Hellhammer1999; Latthe et al 2006; Rosenthal 1993) The search for a diagnosis
as well as for effective treatment is often fruitless for women with CPP, putting them in a
situation characterized by hopelessness, helplessness, and anger, traits associated with
depression. As their health as well as their social conditions worsens, many women with the
condition become fearful and anxious about the uncertainty of their health and their future due to
the chronicity of the symptoms. (Grace 1995)

Latthe et al (2006) evaluated over 60 risk factors in 122 studies on CPP and found strong
and consistent associations between CPP and coexistent psychological morbidity (presence of a
diagnosable psychological condition), history of abuse and as well as organic pelvic pathology.
(Table 1.1) They concluded that depression and anxiety are both statistically significant risk
factors for dyspareunia and non-cyclic pelvic pain, but not for cyclic pelvic pain. Somatization
(the expression of emotional distress in bodily symptoms) was significantly associated with CPP in their review but only pelvic pain in non-cyclic patterns. (Latthe et al 2006) Sexual abuse was significantly associated with all types of CPP in the Latthe review. CPP associated with GI conditions was excluded in the Latthe review, however, associations between GI related CPP and sexual abuse are found in other reports. (Drossman 1995; Drossman et al 1990; Talley 1998) Psychological morbidity appears to play a mediating role in the expression of physical and functional symptoms associated with IBS (Talley 1998) and is suggested to mediate the development of sexual dysfunction among women with pelvic pain (Randolph and Reddy 2006).

The most common psychological conditions associated with CPP are depression and anxiety. Studies indicate the co-occurrence of these conditions with pelvic pain are likely associated with social variables associated with CPP such as abuse or assault history and/or as a consequence of rather than cause of chronic pain. (Champion et al 2005; Golding 1996) Higher than average correlations of sexual and physical violence and abuse occur among women with CPP with 30-50% of women with CPP are identified as victims of sexual or physical violence or abuse. (Latthe et al 2006; Walker and Stenchever 1993). From an epidemiological standpoint, currently available data on CPP and abuse history is not sufficient to confirm a cause and effect relationship as the timelines of onset for each condition are not clearly delineated available reports, many of which are retrospective. (Golding 1996; Romans et al 2002) The interaction between psychological distress, abuse history and pelvic pain continue to be explored with depression appearing to play an important mediating role between pain and function. (Randolph and Reddy 2006) A direct biological causality from abuse to CPP is suggested by Champion et al (2005) in their report on risk of PID in a sample of abused minority adolescents. Others suggest that relationships between abuse and development of chronic pain syndromes may be related to
the emergence of maladaptive coping skills in response to abuse. (Toomey, Seville, Mann, Abashian, Grant 1995)

**Mood Disorders**

Mood disorders, as implied by the name, are characterized by a disturbance in mood, usually either excessive elation or sadness. Mood has considerable impact on an individual’s motivation and ability to function. Depression is the most common of the mood disorders followed by bipolar disorder in which mood fluctuates between depressed and elated moods (mania). Individuals may experience changes in mood in response to the onset of a short- or long-term physical disability. The reverse may also occur as mood can be affected by changes in ability to function due to physical impairments.

**Depression**

Depressive disorders are well known to be more common among women than men. (Cohen 2003; Depression Guideline Panel, Agency for Health Care Policy and Research; Lucht et al 2003; Weir et al 1996) The prevalence of depression is increased in all chronic pain populations and it is more common among women with CPP than other women. (Walker et al 1988; Waller and Shaw 1995) Depression is reported to diminish clinical responsiveness to medical intervention for CPP (Rosenthal 1993; Steege1993) and is well known to negatively impact function and quality of life in chronic pain populations. (Carter and Kinback 2000; Rosenthal 1993) Depression is a statistically significant risk factor for non-cyclic pelvic pain with and dyspareunia as reported by Latthe et al (2006) but was not significant for menstrual-related CPP. Sexual and physical abuse or assault is however significantly associated with all types of CPP and depression in turn is a known correlate of abuse and assault. (Bachman Moeller Bennett 1988; Schachter, Stalker and Teram 1999) High levels of trait hostility are found among women with CPP which can be associated with depression as well as history of abuse or assault.
(Fry, Crisp, Beard, McGuigan 1993; Selfe et al 1998) Negative emotions such as hostility are associated with lower socioeconomic status, social stigma and with poorer health. (Castillo 1997; Fry et al 1993; Handwerker 1999; Gallo and Matthews 2003)

Changes in reproductive status associated with CPP may contribute to the development of depression. (Carter and Kinback 2000; Rosenthal 1993) as grief over loss of childbearing status after hysterectomy can encompass women emotionally and psychologically in addition the emotional changes that may accompany the hormonal changes that result from the surgery. Loss of libido is an expected outcome of hysterectomy that can impact personal relationships negatively and relate to the development of depression post-hysterectomy, complicating the recovery from surgery for CPP. (Rosenthal 1993) Sexual hypoactive disorder accompanies CPP for many women with or without hysterectomy; loss of libido may strain interpersonal relationships, reducing overall quality of life and increasing the risk for depression.

Anti-depressants have been a commonly used therapy for women with CPP for many years principally to address co-morbid depression (Bashford 1998; Walker, Sullivan and Stenchever 1993). Side effects of anti-depressants can be problematic for women with sexual problems associated with CPP as arousal; vaginal lubrication and orgasmic response are all diminished with their use. (Bachman and Phillips 1996) Constipation is another side effect of tri-cyclic anti-depressants that can add to the problems women experience with CPP, however, that particular side effect can be helpful to women with irritable bowel symptoms as a part of the condition. (Bachman and Phillips 1996) Anti-depressants appear to be most effectively utilized for CPP as part of an integrated or multi-modal approach to care (Bashford 1998; Howard 2000a) Anti-depressant therapy for chronic pelvic pain has not, however, been studied extensively; the primary benefits of their use to patients found in studies of other types of chronic pain conditions
include improved pain tolerance, restoration of sleep patterns and reduction in depressive symptoms. (Howard 2000a) Some reduction in pain intensity with anti-use of tricyclic antidepressants was reported in a sample of women with CPP and normal laparoscopies, however, the sample size was very small (14 women) (Walker, Sullivan and Stenchever 1993) Recommendations for use of anti-depressants for CPP are primarily directed towards management of accompanying depression. (Howard 2000a) In this study, responses to selected questions on the IPPS assessment form regarding treatment for depression and depressive symptoms were utilized to determine if depression as biomedically defined was a characteristic of study participants.

**Anxiety**

Anxiety disorders are characterized by future-oriented fear, differing from ordinary fear, which is related to the perception of a present or current danger. (Bonder 1995; American Psychiatric Association 1994) The future-oriented fear experienced by individuals with anxiety disorders is described as uncontrollable, maladaptive and accompanied by feelings of helplessness. (Badura et al 1997; Bonder 1995) Anxiety, particularly post-traumatic stress disorder (PTSD), is associated with CPP (Heim, Ehlert, Hanker, Hellhammer 1998) and is also more common among victims of violence and abuse (Herman 1992; Cole and Putnam 1992;; Resnick 1993; Woods and Campbell 1993). Posttraumatic stress disorder (PTSD) is a behavioral disorder with significant medical implications PTSD increases risk for sudden and fatal cardiac events among men and women and is also known to increase suicide risk. (Bruce 2003) PTSD has characteristics consistent with both anxiety and dissociative disorders.(Bonder 1995; Castillo 1997) Dissociative disorders are characterized by a division of consciousness or a lack of integration of mental faculties or functions (Castillo 1997) and are noted to occur among abused women as well as women with CPP. (Badura et al 1997) Dissociative disorders
commonly occur in the form of culture bound illnesses as a response to the social stress of oppression and/or stigma. In his description of a holistic paradigm for mental health, Castillo utilizes the example of spirit possession as a means of socially acceptable escape for newlywed Indian women to escape an abusive family as an illustration a culture bound dissociative disorder.

In this study, information is collected regarding behaviors consistent with biomedically defined anxiety disorders on the Pelvic Pain Assessment Form. Individuals with combination of anxiety and depressive disorders usually suffer both more chronically and more severely (Bonder 1995; Gaynes et al 1999), are more at risk for suicide (Bruce et al 2003) and also have overall poorer health as well as poorer outcomes to health care. (Bruce 2003) Recovery is less likely from when anxiety disorders have an onset early in life. (Bruce et al 2003) The difference between the manifestations of attributes consistent with either anxiety or depression seems to be primarily based in an individual’s cognitive approach to a problem or traumatic event; that is how the individual explains problematic conditions and experiences in their lives to themselves may determine the appearance of behaviors consistent with the medical diagnostic categories of anxiety or depression.

**Substance Abuse and Addiction**

Substance abuse is a diagnostic category in the DSMIV. Substance abuse among women with CPP has been minimally examined although there is some report of correlation between the two. (Rosenthal 1993) The risk for substance abuse is increased among victims of violence and abuse as well as for individuals with chronic pain or illness, putting women with CPP at increased risk for substance abuse. (Chander and McCaul 2003; Bashford 1996) Substance abuse also increases with increasing levels of stress and distress (Chander and McCaul 2003; Bashford 1998), again implying an increase risk for women with CPP. Women with a history of
abuse or who are addicted to alcohol or drugs also commonly have co-morbidities of depression or anxiety; women with CPP are at greater risk for all these conditions than other women in the population. (Latthe et al 2006) Evidence indicates a role for anxiety, which is a problem for women with CPP, in the development of substance abuse and dependence. (Castillo 1997) PTSD, in particular, appears to be a factor in alcohol and drug dependence in women with a history of abuse, further increasing the likelihood of it’s occurrence among women with CPP due to the increases likelihood they have a history of abuse or assault. (Chander and McCaul 2003) Information about substance abuse and addiction history was collected in this study during the interview using the validated questionnaire included on the IPPS assessment form.

**Fragmentation and Holistic Biomedical Care**

Biomedical practitioners attempt to manage pelvic pain from a holistic perspective, however, holistic biomedical approaches are characterized by a disease model of health care that limits attention to the illness experience and determines the relevance of known social and psychological correlates of the condition through an ethnocentric lens. Women’s experiences within the biomedical system are often characterized by a lack of answers regarding causality, limited attention to the individual illness experience and gendered, paternalistic communication. (Grace 1995; 1998; 2000) Encounters with biomedicine are similar for women with Fibromyalgia and other chronic illnesses and disabilities (Burckhardt 1999; Wendell 1996) which are also better suited to socially informed biocultural approaches to health care than to holistic biomedical care.

Although there is wealth of biological data related to CPP, it has largely been captured by studies conducted by clinical specialists who design research framed around the perspective of their particular specialty area. So reports from gynecology primarily describe reproductive system variables, reports from urology primarily describe urogenital system variables, reports
from gastroenterology primarily describe gastrointestinal system variables and reports from physical therapists primarily describe musculoskeletal variables. The resultant views of the biological aspects of CPP as well as clinical treatments for the condition are often fragmented along the lines of medical specialties. (Apgar 2007; Beard, Reginad, Pearce 1988; Grace 2000; Ling 1993; Peters et al 1991; Rosenfeld 1996; Steege 1998) Leading biomedical practitioners recognize that attention to a broad range of biological condition as well as to social and psychological factors is necessary for effective management of CPP, however, establishing and implementing clinical strategies that encompass those intentions that are practical for physicians and accepted by patients is not easily accomplished. Studies that examine outcomes to medical care for CPP are of inconsistent quality adding to the difficulty biomedical practitioners face in establishing efficacious clinical decision models for women with this complaint. (McGuire and Hawton 2005; Proctor, Hing, Johnson, Murphy 2005; Stones, Cheong, Howard 2005; Young and Jewell 2005) The best outcomes appear to be associated with integrated, holistic or interdisciplinary approaches to care (Collett 2005; King, Ling, Rosenthal 1991; Milburn, Reiter, Rhomberg 1993; Peters et al 1991; Reiter and Gambone 1990; Steege 1998); however, holism in biomedicine often translates in clinical practice to an attempt to consider all medical specialties, which in essence equates to a consideration of all body systems, rather than a true equal weighing of biological, social and psychological. Holism from a biocultural perspective includes attention to the political, ecological, and economic as well as biological and psychological that goes well beyond epidemiological style of reporting social categories such as ethnicity, race, age and gender. (Hahn and Gaines 1985; It may be that holistic health care as defined and delivered within a medical system that is fundamentally disease based remains inadequate to fully address the dynamic interactions between the many dimensions of a biocultural health problem such as
chronic pelvic pain in women. The most holistic care in biomedicine for CPP most likely occurs in clinical settings staffed by practitioners with special interest in the condition, such as those described by Peters et al (1991) and were operated at the University of Tennessee, Memphis in the 1980’s and 1990’s (Myers et al 1991).
CHAPTER 3
DESIGN AND METHODS

Introduction

There are three aspects to this dissertation project, first a critical summary of current biomedical practices and assumptions about chronic pelvic pain in women (Chapter 2); second a prospective descriptive correlational examination of relationships between selected ethnocultural and biomedical profile variables in the sample of women with chronic pelvic pain who participated in this study; third an ethnographic exploration of how the women with CPP in the study sample describe the social roles and responsibilities in which they are routinely engaged and their perceptions of how pelvic pain influences their daily functioning in those roles; of their explanations of the causes of their chronic pelvic pain; and of their perceptions of biomedical treatment for chronic pelvic pain.

This project was approved by the Institutional Review Board (IRB) at the University of Florida. (Protocol #2003-U-523). Written and verbal explanations of the study were provided at all study sites by the principal investigator, even if the informed consent was already signed by the participant and witnessed by clinic staff prior to our initial meeting. HIPPA regulations were followed in all correspondence, conversation and record management. All participants’ received identification numbers (ID) numbers; all materials were kept in a locked, fireproof portable filing cabinet during the PI’s field visits to clinical sites. Only the PI and the faculty supervisor have access to records that identify participants. A paid typist was utilized to transcribe some of the tape recordings. Only the ID number used to identify participants on the recordings.

Study Population and Sampling

The target population of this study is ethnically diverse women with chronic pelvic pain who seek biomedical care for the condition. Purposive sampling was utilized to locate women
with chronic pelvic pain for recruitment to the study. Women seeking biomedical health care
services for chronic pelvic pain were recruited at selected clinical sites that were known to
provide specialized services for pelvic pain. English speaking women age 18 years or older were
accepted in the study, otherwise there were no exclusionary demographic criterria, however, an
ethnically diverse sample of women with pelvic pain was sought, with the specific intention of
including equal numbers of African American and non-Hispanic white (European American)
women. Women with a biomedical diagnosis of chronic pelvic pain, a related subset diagnosis,
or current complaints consistent with a diagnosis of chronic pelvic, were included in the study.
Women with more specific pelvic pain diagnoses such as endometriosis, vulvodynia,
dyspareunia, vestibulitis, irritable bowel syndrome, interstitial cystitis, among the many other
possibilities, were accepted into the study as long they reported experiencing pelvic pain for
longer than 3 months. Chronic pelvic pain was defined according to the biomedical standard of
pain of 3 or more months’ duration localized in the anatomic pelvis considered severe enough by
the woman experiencing it to require medical or surgical consultation and/or to limit normal
functioning. (Howard et al 2000; Steege 1998)

Clinical sites (privately owned physician offices and physical therapy clinics) known to
offer health care for women with chronic pelvic pain were identified as potential locations for
participant recruitment and data collection. Patient or client ethnicity was considered in the
selection of sites for data collection as well as the clinical services offered there for pelvic pain.
The initial intention was to include clinical sites that served African American, non-Hispanic
whites and Latina women in both Tennessee and Virginia. After identifying potential sites, an
initial phone and/or email contact was made with clinical directors followed by meetings on site
to discuss the details of the project. Study sites were ultimately selected in the Tennessee cities
of Knoxville, Nashville and Memphis; a viable clinical site for ongoing participant recruitment and data collection was not identified in Virginia, although one participant was recruited there.

Mountain Spirit Physical Therapy is a privately owned physical therapy practice located just outside Knoxville, Tennessee in the city of Maryville, Tennessee. The proprietor and sole practitioner, Donna Edwards, is a board certified clinical specialist in orthopaedic physical therapy (American Board of Physical Therapy Examiners) whose practice is focused on chronic pelvic pain and related pelvic problems such as urinary and fecal incontinence. Donna is recognized in the medical and physical therapy community in Eastern Tennessee as a source for specialized physical therapy care for the unique health problems associated with the pelvic floor musculature. The clinic usually schedules 40 appointments each week, 8 appointments per day. The majority of the clients are women with pelvic related complaints, although some men were treated at the clinic as well. Most patients/clients are referred to Mountain Spirit Physical Therapy by gynecologists, urogynecologists, urologists and colorectal surgeons from Knoxville, Tennessee. At the time of the study Mountain Spirit Physical Therapy had been in operation less than 1 year in the city of Maryville; previously, Ms. Edwards was an employee of private physical therapy practice in Knoxville, Tennessee, opening her own practice largely based on her success in building a clientele in the specialized area of pelvic health. When Ms. Edwards opened her own office, she was required to locate outside the Knoxville city limits according to the requirements of a non-compete clause in her previous employment contract. Consequently, many of her clients, and many of the women from her clinic who participated in the study, drove from Knoxville to Maryville (miles) for physical therapy appointments and to participate in this study.
Knoxville is the largest city in Eastern Tennessee and is the third largest city in the state of Tennessee (Memphis and Nashville are larger). Geographically Knoxville is located in the valley between the Great Smoky Mountains and the Cumberland Mountains. The city of Knoxville has a population of approximately 200,000 with a city and county combined population of just over 700,000. The population is predominately white non-Hispanic (87.9%). African Americans make up approximately 9% of the population of Knoxville, less than the national average and the Tennessee average (16.9%). In Blount County, where Maryville is located, the percent of African Americans is much lower at 3% of the population with non-Hispanic whites comprising 94.6%. (www.fedstats.gov) Knoxville is home to the main campus of the University of Tennessee as well as several other local and state supported smaller colleges. The percent of the population in Knox County with bachelor’s degrees or higher is 29%, higher than the Tennessee average of 19.6%. (www.fedstats.gov)

The clinical setting in Memphis was Women’s Health Specialists, LLC, a private medical practice owned by four physician partners, obstetrician/gynecologists and urogynecologists. Women’s Health Specialists is well known as a center for pelvic pain treatment among biomedical practitioners, gynecologists in particular, both regionally and nationally. The partners are actively engaged in clinical research as well as practice and were my colleagues in previous research projects on utilization of physical therapy in the care of women with pelvic pain (King et al 1991) and socio-cultural aspects of chronic pelvic pain. (Myers et al 1990) Memphis is located in the southwestern corner of the state of Tennessee on the eastern bank of the Memphis River. The city limits of the city of Memphis roughly coincide with Tennessee’s borders with Mississippi to the south and Arkansas (via the Mississippi River) to the west. The population of Memphis numbers approximately 650,000. Roughly 62% of the Memphis population is African
American and 35% is non-Hispanic white. (http://memphis.areaconnect.com/statistics.htm) The percentage of African Americans in Memphis is higher than the national average as well as the Tennessee average (16.9%) Women’s Health Specialists was identified as a potential site for the study in part due to the access to African American women Memphis affords as well as the reputation of Women’s Health Specialists as a center for care of women with pelvic pain.

The Nashville Alliance for Sexual Health (NASH) is an interdisciplinary organization of health care providers and patient advocates focused on improving health care for women and men with pelvic health issues that affect sexuality and sexual health. NASH was established in 2004; just before data collection commenced in this study, and was utilized to recruit study participants in Nashville, Tennessee. NASH is a relatively small organization comprised of close to two dozen individuals with a core membership that routinely attends meetings of approximately a dozen individuals. Members of NASH include sex therapists, physical therapists, physicians, medical social workers, nurse practitioners, psychologists, patients and patient advocates. The group conducts monthly meetings at various clinical sites in the Nashville area. I made a presentation on the this project at a NASH meeting that was attended by the president of the Nashville area Interstitial Cystitis Association (ICA) who invited me to recruit participants at an upcoming meeting of that organization. Nashville, the capitol of Tennessee, is located in the middle or central portion of the state. Geographically it is located on the Cumberland River situated in the basin surrounded by the Cumberland Plateau. Music, government and health care are the primary industries in the Nashville area. The African American population in Tennessee is 14.8% percent of the total population (http://www.eeoc.gov/stats/census/variables) in Nashville, African Americans comprise 26.8% of the population; white non-Hispanics are 64% of the total Nashville Davidson County
population. Several universities are located in Nashville including Tennessee State University, a historically black university (HBCU). Approximately 30% of the population of people over age 25 in Nashville hold a bachelor’s degree or higher. (www.citydata.com)

In an attempt to assure the inclusion of white Hispanics in the study population, a free health clinic in Winchester, Virginia that served migrant farm workers was approached regarding participation in the project. The nurse practitioner in charge of the clinic agreed to a meeting to discuss participation in the project but during that meeting declined to allow participant recruitment at that site stating that pelvic pain was not a problem for the women seen at that clinic. When she was probed during the conversation to elaborate on gynecological symptoms expressed by women who sought care at the clinic, she recalled noticing that many Latino women complained of abdominal bloating but stated she did not believe there was pain associated with that complaint. She did wonder if perhaps the condition I was mentioning (pelvic pain) was somehow related to the bloating complaints, however, she was unwilling to cooperate with the project due to perceptions about the absence of pelvic pain in her patient population. She indicated it would not be worth the time required to initiate the project in that clinic as there was not a significant problem with pelvic pain among the women seeking care there.

In addition to the free clinic, local physical therapy practices and massage therapy clinics in Winchester were approached about serving as a study site; however a suitable site with willing proprietors was not identified. In the course of recruiting sites, however, one of the health care practitioners approached by the PI volunteered that she had a long history of chronic pelvic pain and asked to participate as a subject in the study. Winchester is located Fredrick County, Virginia about 50 miles west of the Washington, DC metropolitan area in the Shenandoah Valley. Agriculture work, primarily in apple orchards, attracts a large population of migrant
farm workers. Shenandoah University, a small liberal arts college is located in Winchester. Local service industries, education and manufacturing are the other primary employers.

Data was collected over a 14 month period of time, with participant recruitment initiated by clinical staff several weeks before the initial interviews were conducted. In Memphis, many participants were recruited by staff while interviews with other women were underway on site. At the Knoxville site, the clinic director set a schedule in advance of my visits for interviews with study participant. In Knoxville, interviews were conducted in one treatment room while routine clinical appointments occurred as usual in the clinic’s second treatment room.

Once study sites were in place, written announcements about the project were posted in visible locations in waiting areas of the clinics in Memphis, Knoxville and Nashville; some participants read the announcements and initiated a discussion about the study with a member of the clinic staff. In some cases, women with appointments were verbally informed of the study by clinic staff members who asked if they were interested in participating and supplied them a copy of the announcement and the informed consent if they indicated an interest. In Nashville a presentations were at a meeting of NASH and at a meeting of the local Interstitial Cystitis Association in attempts to recruit participants. All participants received a copy of the Patient Education Booklet published by the International Pelvic Pain Society (IPPS) and a gift of a one-year Patient Membership in IPPS (patient membership dues were $35.00 per year). Additional patient appropriate education materials from various health care organizations such as Section on Women’s Health, American Physical Therapy Association were available for participants to review with several publications available for participants to take home if they desired. An expected financial benefit of participation was the physical therapy examination conducted as a part of the study; the cost of a physical therapy examination for chronic pelvic pain would
usually be billed at a cost of between $100- $200 per session. Participants were also expected to gain information about their own physical condition as it relates to pelvic pain from that examination. Women who participated were provided the results of their strength, mobility and posture measures and received professional advice regarding the use of therapeutic exercise, therapeutic activities and physical agents such as heat and cold modalities to address the impairments identified in during the assessments. Women who had to travel to the study site at a time outside of regularly scheduled clinic visits in order to participate in the study were reimbursed for travel expenses incurred such as taxi/bus fare and/or mileage up to a maximum amount of $10.00 per visit.

Participants were informed that psychological stress might occur when they were are asked to address the pain and their illness experiences during the interview process. Previous interview research with women with pelvic pain indicates that lack of opportunity to discuss the details of the pain experience is a common source of frustration for women with this condition; discussing the pain experience is reportedly considered desirable and beneficial by many women with chronic pelvic pain. (Grace 1995) It was anticipated that most women would welcome the opportunity to discuss their experiences with chronic pelvic pain rather than be distressed by it. Some of the questions covered in the interviews address potentially stressful or embarrassing experiences for the participants including questions about drug and alcohol use, sexual activity, and abusive encounters. During the interviews it was stressed that there are no right or wrong answers and that all information was confidential. The risk of embarrassment during the physical measurements was mitigated by the privacy of the environment (private clinic offices and/or treatment rooms were utilized for the interviews and physical measurements), the use of the participants own clothing and/or hospital gowns (participant’s choice) and by the professional
demeanor of the investigator. None of the women in the study expressed distress from participating in the study; many expressed that it was beneficial to speak in depth about the experience, particularly to another woman.

**Materials and Measurements**

**Measurement Instruments**

Standardized and non-standardized clinical screening questionnaires, standardized physical measurements as well as structured and semi-structured interviews were utilized to collect data from and about the women who participated in the study. Ethnicity data was collected by self-report from study participants. Their responses were documented on a form modeled after the Ethnicity and Pain Survey utilized by Maryann Bates in her studies on chronic pain. (Bates 1996) A copy of the form utilized in this study titled Ethnicity Survey appears in Appendix a. The Pelvic Pain Assessment Form (Appendix A) is a medical history and physical form developed by the Research Committee of the International Pelvic Pain Society. The majority of the demographic, diagnostic, pain and other clinical data collected from the study participants were documented on the Pelvic Pain Assessment Form which also served as the guide for the structured portion of the interview. The study ID number was substituted for Chart Number (see Appendix A) on page one of the form.

Physical examination conducted as a part of this study was focused on findings associated with musculoskeletal origins of CPP commonly addressed in a physical therapy examination as the PI is a physical therapist with a current license to practice in the states of Virginia, Tennessee, Mississippi and Florida at the time of the study. Selected physical impairments were measured using non-invasive procedures that are routine components of physical therapy examinations for muscle length, muscle strength, joint mobility and posture. Impairments and measurements were selected based on previous findings on the musculoskeletal status of women
with chronic pelvic pain. (Baker 1993; King et al 199) that identified a commonly occurring postural pattern among women with pelvic pain labeled Typical Pelvic Pain Posture (TPPP). The impairments measured are based on Kendall and McCreary (1983) and Kendall, McCreary, Provence, Geise, Rodgers, Romani 2005) describing the physical impairments associated with specific faulty postural patterns as well as the findings of the previous studies on women with pelvic pain. (King et al 1991) The specific physical impairments measured were hip flexor muscle length, abdominal muscle strength, and passive hip rotation range of motion, low back posture and pelvic girdle stability.

Structured interviews followed the questions on the PPAF. In some cases, the form was read in its entirety to participants and their answers documented by the PI. In other cases, women completed some of the PPAF themselves, which was then reviewed and discussed with the participant during the interview. Information collected during the PPAF portion of the interview included causality, pain intensity, pain character, health and medical history, social support, functional limitations and abuse history. Once the PPAF was completed, participants were asked to respond to questionnaire used to rate the traits heritage consistency (HC) and locus of control (LOC). The questions used to measure HC and LOC were based on the items from Bates (1996) Ethnicity and Pain questionnaire which she used to measure those traits among other traits, among others, in a multi-ethnic chronic pain population. Bates selected items from Rotter’s (1966) locus of control scale to measure internal and external LOC; five items were internally worded and five items were externally worded. Bates reverse scored internal items and heritage consistency. In this study, separate scores were calculated for internal locus of control (ILOC) and external locus of control (ELOC), with a high score of 5 possible for each. Bates used items related to family and community connections to measure degree of heritage
consistency (ties to ethnic heritage); the items she used were based on the work of Estes and Zitzow (1980) and Spector (1985). Five items based on Bates questionnaire were used in this study to measure HC. All items in this portion of the questionnaire were based on a Likert-type scale, using (0) not applicable (1) somewhat disagree (2) disagree strongly (3) agree somewhat (4) agree strongly.

Semi-structured interviews were used to gather narrative information about the lifestyle of participants beyond the specific questions on the Pelvic Pain Assessment form. Social roles and responsibilities, social and material resources, health beliefs and behaviors related to pelvic pain as well as the impact pelvic pain on their lives were described by participants. The primary purpose of the interviews was to explore the social context of the lives of the women in the study as well as the social consequences of living with chronic pelvic pain. Study participants’ perspectives on the cause of their pain and on the effectiveness of biomedical treatment were also solicited during the interviews. Guiding questions utilized in the interview found in Appendix a.

**Variables**

Ethnicity was operationalized by self-report with responses noted on the Ethnicity Survey (Appendix a). Participants were given the option of selecting from a list of ethnic categories (suggested categories were based on the US Census) or writing in their own response to both primary and secondary ethnicity. The Ethnicity Survey also asked about language(s) spoken at home and the name of their birth country of origin, based on Bates (1996). Age was operationalized as the age in years on date the Informed Consent was signed using the birthdates reported by participants and documented on the PPAF.

Pain intensity was recorded on the Pelvic Pain Assessment Form (International Pelvic Pain Society) which includes two body diagrams (front and back poses) that provide women a place
to draw in the location of their pain. Near the beginning of each interview, participants in the study were asked to draw on the body diagram (using an X to mark the area of most intense pain and shading in the other areas of pain). The numeric rating scale for pain intensity located on page one of the Pelvic Pain Assessment Form (PPAF) was utilized to determine level of pain intensity. Participants completed the entire questionnaire, however, only most severe current pain intensity, pain intensity with sexual intercourse and acceptable level of pain were coded for analysis in this project. Numeric scales for rating pain intensity from 0=no pain to 10=worst pain imaginable on 15 types of pain associated with pelvic pain are included on the PPAF. Three of the 15 choices refer to pain with sexual activity (Deep pain with intercourse; Pelvic pain lasting hours or days after intercourse; Burning vaginal pain with sex). Participants were considered to have pain with sex if they responded above 0 on any of those three items; the number recorded for pain with sex was the highest intensity rating they chose on a pain with sex item. Several women added numbers above 10 on the form when rating their pain; in those cases, pain intensity was recorded as 10. The highest number reported for any of the pain categories that related to pelvic pain was documented as the level of overall pain, a category designed to capture the severity of the pain women in the study were experiencing. Excluded from consideration for most severe pain were the categories of migraine and backache.

Abuse/Assault was identified from the response to the screening questions for abuse that are found on page 8 of the PPAF. The coding procedure utilized in the initial codes for this variable were as follows: 0=no history of emotional, physical or sexual abuse as child or adult; 1=sexual abuse as child/adolescent; 2=sexual abuse or assault as adult (over age 18); 3=physical abuse as child; 4=physical abuse as adult; 5=sexual & physical as child; 6=sexual & physical as adult; 7=emotional abuse; 8=emotional & sexual child; 9=emotional & sexual adult; 10=EPS.
child;11=EPS adult;12=Emotional & physical child13=emotional & physical adult; 99=missing data. These categories were later collapsed into 3 categories, sex, other, and no abuse in the recode when data was entered into SPSS.

The last question on page two of the PPAF states “Of all the problems or stresses in your life, how does your pain compare in importance?” Response choices are either 1) important problem or 2) just one of several/many problems. This was recorded as the Life Problem Rank. Participants were asked at the end of the interviews if they were getting better, getting worse or staying the same. Their answers were recorded on the semi-structured interview form.

A body systems approach was used to establish a biomedical profile for each woman in the study. The profile was determined based on the presence or absence of either a documented medical diagnoses or a positive response to screening questions on the Pelvic Pain Assessment Form for medical problems known to be associated with chronic pelvic pain as previously described in this chapter. The diagnoses identified were coded by body system; some women had several diagnoses under one body system, others might have one diagnosis under a particular body system. The presence of any diagnosis associated with CPP in that body system was considered a positive finding and resulted in a code for that system. The body systems involved were the reproductive, urogenital, gastrointestinal, musculoskeletal, and psychological.

The Pelvic Pain Assessment Form guides the interviewer, or as it is intended, the clinician, through a detailed medical screening process that uses a combination of validated clinical screening tools and original questions to review the body systems known to contribute to pelvic pain in order to identify potential pathology. Validated tools for screening for gastrointestinal causes of pelvic pain (Drossman 1994), sexual abuse, Leserman and Drossman 1995, alcohol abuse (CAGE), and functional changes are found on pages 2-8 of the form. Information
documented on these sections of the form were utilized to develop a biomedical profile of the women in the study using the review of body systems approach common to the biomedical diagnostic process. The coding procedures utilized for this section were as follows:

**Gynecologic (GYN).** was the code for Gynecological Signs or Symptoms. Documentation of 1=Yes, reports Gynecological signs or symptoms associated with problem either currently or in past; or 2=No, Gynecological Signs or Symptoms not reported. This item was coded “yes” or “1” if reported pain with orgasm, ovarian pain, positive response to pain with periods (during before or after-non cramping), diagnosis of endometriosis, dysmenorrheal, ovarian cyst, uterine during the interview or if the medical record revealed that information.

**Urological (URO).** Urological system screening questions were found on pages 1 and page 3 of the Pelvic Pain Assessment Form. Coding for Urological System (URO) was as follows: 1=yes, reports Urological Signs or Symptoms; 2=No, does not report Urological signs or Symptoms. The results were recorded on Pelvic Pain Assessment form page 1 (pain with full bladder) and page 3—reported as yes if answered in positive to questions regarding stress urinary incontinence (SUI), urinary frequency, urinary urgency, and/or or nocturia.

**Gastrointestinal (GI).** Gastrointestinal Signs or Symptoms from Drossman’s Bowel Disorders questionnaire appear on page 3 of the PPAF form; participants with positive responses to the items on this questionnaire recorded as positive for GI system (coded as 1 on the initial file); a designation of 2=No, does not report Gastrointestinal Signs or Symptoms was recorded if there were not positive responses to this section of the PPAF. Information regarding other gastrointestinal disorders or symptoms was recorded, but not coded or analyzed for this report.

**Psychological (PSY).** The question related to treatment for depression was utilized to operationalize a psychological profile in this study. According to the code book, the initial codes
were such that a 1=Yes, reports current or previous treatment for depression (page 7 PPAF) and
2=No, reports no current or previous treatment for depression

**Musculoskeletal (MSK).** was coded as either 1=participant fits the Musculoskeletal CPP
Pattern or 2=Participant does not fit pattern in 2 or more findings. To fit the pattern at least 2
positive findings on physical examination of the following: hip flexor length via the Thomas
Test; Hip Rotation Restriction-Passive Range of Motion of Hip Internal Rotation, measured in
Lying; an increased Lumbar lordosis (12> at L5-S1); Abdominal muscle strength measured via
manual muscle testing at 3/5 or less)

Hip flexor length was measured with the Modified Thomas Test (Kendall et al 2005;
Magee 2002); manual muscle testing was used to measure abdominal muscle strength,
specifically the modified sit-up and a leg-lowering tests as described by Kendall et al (2005);
Hip rotation range of motion was measured by use of an International Standard of Orthopaedic
Measurement (ISOM) standard hand held goniometer (Magee 2002); low back posture by use of
an inclinometer to measure degrees of lumbar spine curvature in standing (Magee 2002); pelvic
stability was assessed with the Trendelenberg’s Test (Evans 2002 and Magee 2002).
Participants wore swim wear, underwear, shorts and halters, or hospital gowns as per personal
preference during the measurements. Physical measurements were documented on the Physical
Assessment form (Appendix a) that was developed for this study

Prior to the physical measurements, participants were shown photographs and diagrams
(Appendix a) of each procedure and also shown the examination tools that would be utilized;
demonstrations were also used if needed to be certain participants understood the procedures and
the purpose of the various exam tools.
Analysis

Transcription and Coding

The Interviews were tape recorded and transcribed. Transcription services were provided by Melissa Graham, MSHS, and Medical Transcription Services, 151 South Cory Drive, Edgewater, Florida. Case numbers were assigned from #001-063 in chronological order of signed Informed consent beginning with participants from Memphis, followed by Nashville, Winchester and Knoxville (1-63). The coding procedures and operationalize for demographic, biomedical, ethno-cultural, and treatment variables utilized in the study appear in Appendix d. Coded data was initially loaded into an Excel database and later moved to SPSS. (Statistical Package for Social Sciences) Transcribed interview data were coded and triangulated with the PI’s written notes and written questionnaire data. Narrative data were examined for the presence of themes that were reported in other studies on women with pelvic pain including the need to know the cause of the pain (Grace 1995), invisibility and stigma, (Theve-Gibbons 2000) and fragmented approaches to biomedical health care for the condition. (Grace 1995; Grace 1998; Rosenfeld 1996; Steege 1998; Ling 1993) The narrative questions specifically asked participants to address their social roles. In addition to examining for the presence of previously described themes, the narrative data were examined for patterns in women’s descriptions of their roles and responsibilities as well as their descriptions of how they negotiated those roles while experiencing chronic pelvic pain. Word files were created for each theme and quotations consistent with specific themes were saved to analogous file. Examples of these files appear in Appendix d. As unplanned themes emerged, the same process was followed.

Statistical Analysis

First, descriptive statistics were used to summarize the characteristics of the study participants. More specifically, age, ethnicity, education level, marital status, head of household
and work status. In addition to using descriptive statistics to present the characteristics of the participants, a series of bi-variate and multi-variate analyses were conducted to address the research questions. To address research question one, a series of bi-variate analyses were first conducted to examine if there were any significant ethnic differences in pain-related variables. More specifically, a series of independent t-tests were conducted. If the results from the bi-variate analysis are not significant at the significance level of .05, it would be concluded that no ethnic differences. If, however, the results from any of the bi-variate analyses are significant at the significance level of .05, follow-up multi-variate (OLS regression) analyses was conducted to further explore if the observed ethnic/ racial differences remain after controlling for additional variables. The set of socio-demographic (age, education level, work status and marital status) variables and psycho-social (heritage consistency and locus of control) variables would be introduced into the regression models sequentially, and these two sets of variables were intended to account for the potential racial differences. If the coefficient on the dummy variable of ethnicity in the multivariate regression analysis becomes insignificant (not significantly different from zero), it would be concluded that the observed racial differences in the bivariate analysis could be explained with inclusion of the additional variables. If, however, the coefficient on the dummy variable of race in the multi-variate regression analysis remains significantly different from zero, it would be concluded that racial differences exist even after controlling for those additional variables and therefore, other explanatory mechanisms and variables are needed in order to assess how racial differences affect the pain-related variables. Miller, Campbell, Davis, Furner, Giachello, Prohaska, Kaufman, Perez, 1996; Kenagy & Hsieh, 2005a; Kenagy & Hsieh, 2005b)
The same analytical approach was used to address research question two. That is, a series of bi-variate analyses were first conducted to examine if there were any significant racial/ethnic differences in variables on review of systems profile. More specifically, a series of chi-square analyses were conducted. If the results from the bi-variate analysis are not significant at the significance level of .05, it would be concluded that no racial/ethnic differences. If, however, the results from any of the bi-variate analyses are significant at the significance level of .05, follow-up multi-variate (logit regression) analyses would be conducted to further explore if the observed ethnic differences remain after controlling for additional variables. The set of socio-demographic (age, education level, work status and marital status) variables and psycho-social (heritage consistency and locus of control) variables would be introduced into the regression models sequentially, and these two sets of variables were intended to account for the potential racial differences. If the coefficient on the dummy variable of race/ethnicity in the multi-variate regression analysis becomes insignificant (not significantly different from zero), it would be concluded that the observed racial differences in the bi-variate analysis could be explained with inclusion of the additional variables. If, however, the coefficient on the dummy variable of race/ethnicity in the multi-variate regression analysis remains significantly different from zero, it would be concluded that ethnic differences exist even after controlling for those additional variables and therefore, other explanatory mechanisms and variables are needed in order to assess how ethnic differences affect the variables on review of systems profile.

Research question three was addressed, based on the same analytical approach used to address research questions one and two. First, a bi-variate (chi-square) analysis was conducted to examine if there were any significant racial/ethnic differences in the perception of treatment effects. If the results from the chi-square analysis are not significant at the significance level of
.05, it would be concluded that no racial/ethnic differences. If, however, the results from chi-square analysis are significant at the significance level of .05, follow-up multi-variate (multinomial logit regression) analyses would be conducted to further explore if the observed ethnic differences remain after controlling for additional variables. The set of socio-demographic (age, education level, work status and marital status) variables and psycho-social variables would be introduced into the regression models sequentially, and these two sets of variables were intended to account for the potential racial/ethnic differences. If the coefficient on the dummy variable of race/ethnicity in the multi-variate regression analysis becomes insignificant (not significantly different from zero), it would be concluded that the observed ethnic differences in the bi-variate analysis could be explained with inclusion of the additional variables. If, however, the coefficient on the dummy variable of ethnicity in the multi-variate regression analysis remains significantly different from zero, it would be concluded that racial/ethnic differences exist even after controlling for those additional variables and therefore, other explanatory mechanisms and variables are needed in order to assess how ethnic differences affect the perception of treatment effects.

The analytical approach used to address research questions one, two and three reflects the following assumptions: (1) Ethnicity is a variable that is assumed to represent many complex social and psychological processes and therefore, it was first introduced alone to determine its global effect on the pain-related variables, variables on review of systems profile and the perception of treatment effects. (2) Socio-demographic characteristics, such as age, education, work status and marital status may be associated with pain-related variables, variables on review of systems profile and the perception of treatment effects. This block of variables was therefore entered next. (3) Psycho-social variables, such as heritage consistency and locus of control, may
affect respondents’ perception of pain-related variables, review of systems profile, and respondents’ perception of treatment effects. These two variables are also known to vary by ethnic groups and could explain any noted ethnic differences. By introducing this block of variables, the ways in which these factors account for the impact of ethnicity on pain-related variables, variables on review of systems profile and the perception of treatment effects could be examined. It should be noted that given the cross-sectional nature of the data, this study does not intend to make any causal inferences through the sequential inclusion of these variables. Rather, the hierarchical order is seen as suggestive only. A similar analytical approach has been used to explore racial/ethnic differences in the use of community long-term care services (Miller et al., 1996) and gender differences in social service needs (Kenagy & Hsieh, 2005a) and HIV risks (Kenagy & Hsieh, 2005b).

Biographical Profiles

Using the example of Martin (1992), a biographical profile was developed for each participant that briefly describes ethnicity, age group, occupation, family ties and household circumstances. Participant’s identity is protected by the use of pseudonyms and by generalized descriptions of occupations. More complete case summaries are presented for selected participants that illustrate the themes that emerged.

Text Analysis

Transcripts of the interviews were reviewed; quotes were coded within each case transcript and later organized thematically. Themes used for the initially coding were selected from previous related work (Grace 1995; Grace and Zondervan 2006; Martin 1992; 2001; Theve-Gibbons 2000) The decision to include the selected themes was based on the recurrence of the theme in the CPP literature and/or the anthropological literature related to chronic pain, chronic illness and/or women’s sexual, reproductive and/or mental health and my impressions from
clinical experiences with women with CPP about their experiences and perspectives. Causality, Sexuality, Invisibility, Stigma, Resistance, Fragmentation/ Alienation, Mechanical Metaphors, Multiple Role Strain (Spurlock 1995), were themes initially used to organize the data. Categories were modified as additional themes were identified and interpreted. Four themes were included in the final presentation of the data: Causality, Sexuality, Productivity and Fragmentation. (Appendix C)
CHAPTER 4
RESULTS

Sample Characteristics

Eighty-one women ranging in age from 19 to 79 years old agreed to participate in this study. The total included 59 women in Memphis, 18 in Knoxville, 1 in Winchester and in 3 in Nashville. All participants completed the Informed Consent and were entered into the study database by name and coded identifier. Of the 59 women who agreed to participate in Memphis, 15 did not complete the process, one withdrew stating the questions were too personal; the remaining 13 did not return for follow up meetings; several attempts were made to follow up, and some participants agreed to follow up appointments but for various reasons, some never known to the principal investigator (PI), did not return. In Knoxville, two women canceled their interviews; one decided to withdraw from the study and the other had a scheduling conflict. The sample size after attrition was 63, which included fifteen African American women, thirteen in Memphis and 2 in Nashville. Given the vast majority of the respondents (95%) self-reported their ethnicity as either European American or African American, this study focused on exploring the ethnic differences between the European American and African American respondents. The three respondents (out of the total sample of 62) who were in a race/ethnicity category other than European American or African American were excluded from statistical analyses; however, data from those three participants was utilized in the narrative component of the analysis.

Race/Ethnicity. In Memphis, 16 of the initial participants identified their ethnicity as African American, one as Mexican-American, all others were European American. In the Knoxville group several women indicated a secondary ethnicity; responses included Lebanese, Russian, Polish-German, British, American Indian, Cherokee, and Irish Cherokee. Secondary
ethnicity was not coded or further analyzed for this report. Many of the women in both Memphis and Knoxville wrote in their primary ethnicity using choices outside the official US census selections; examples include “Southern”, “Cajun”, “American”, “All American”, “American Mutt”, and “East Tennessean”. One woman said “I guess Southern would be what I consider my ethnicity, but I wear shoes; they think we don’t but we do.” One woman in Memphis referred to herself as “PING” for Polish- Irish-Native American-German and another expressed hers as British American. All of these women were coded as European American. Three participants, two in Memphis and one in Knoxville indicated Jewish as a secondary ethnicity. In Nashville, two of the participants were African American and one was European American; the African American women both met with the PI one completed the study process, the other did not complete all the questionnaire data due to time constraints. The white Euro-American participant in Nashville did not participate further in the study after the informed consent was completed due to scheduling difficulties.

**Age.** The mean age of the women in the study was 40.7; 39.07 for the African Americans (n=14) and 40.39 for the White non-Hispanic women (n=45); the Mexican woman was 29 years old. (Table 4-1)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>39.07</td>
</tr>
<tr>
<td>European American</td>
<td>40.39</td>
</tr>
</tbody>
</table>

**Education.** All but one of the study participants had completed high school, and that participant, the youngest in the sample, was enrolled in high school at the time of the study. The distribution of highest level of education completed was 45% high school graduates, 30% college graduates, 12% some college and 13% some graduate education. (Table 4-2)
Table 4-2 Education and Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Less than 12 years</th>
<th>High school graduate</th>
<th>Some college or technical school</th>
<th>Bachelor's degree</th>
<th>Graduate education</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>0</td>
<td>11</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Euro-American</td>
<td>1</td>
<td>16</td>
<td>11</td>
<td>10</td>
<td>6</td>
<td>1</td>
<td>45</td>
</tr>
<tr>
<td>Totals</td>
<td>1</td>
<td>27</td>
<td>12</td>
<td>10</td>
<td>8</td>
<td>1</td>
<td>59</td>
</tr>
</tbody>
</table>

**Marriage and Household.** The majority (60%) of the women in the study were married. Of those unmarried, 10% (n=6) were engaged or in a committed relationship; 10% (n=6) were divorced; and 1 was widowed. The mean number of people living in the household for all women in the study was 2.6. The mean number of children was 1.3 with 50% difference in the mean number of children between African American \( (M=2.1) \) and White women \( (M=1.09) \). (Tables 4-3 and 4-4)

Table 4-3 Marital Status and Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Married</th>
<th>Single</th>
<th>Divorced</th>
<th>Committed Relationship</th>
<th>Widowed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>8</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Euro-American</td>
<td>29</td>
<td>8</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>45</td>
</tr>
<tr>
<td>Total</td>
<td>37</td>
<td>9</td>
<td>6</td>
<td>6</td>
<td>1</td>
<td>59</td>
</tr>
</tbody>
</table>

Table 4-4 Household Size and Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Household Size</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>Mean 2.93</td>
<td>2.14</td>
</tr>
<tr>
<td></td>
<td>N 14</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 1.639</td>
<td>1.610</td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>Mean 2.56</td>
<td>1.09</td>
</tr>
<tr>
<td></td>
<td>N 45</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 1.099</td>
<td>1.104</td>
</tr>
<tr>
<td>Total</td>
<td>Mean 2.64</td>
<td>1.34</td>
</tr>
<tr>
<td></td>
<td>N 59</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 1.242</td>
<td>1.308</td>
</tr>
</tbody>
</table>

**Employment.** The majority of the women in the study were employed outside the home, approximately 50% full time and 5% part-time; 10% of the study participants described their occupation as homemaker; 10% were students not otherwise employed; approximately 15%
reported they were not working because of their health; and 2 women described themselves as retired. Detailed data is displayed in Table 4-5.

### Table 4-5 Ethnicity and Work Status

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>F Full-Time</th>
<th>P Part-time</th>
<th>Not Working Health</th>
<th>Not Working Other</th>
<th>Disability</th>
<th>Student</th>
<th>Retired</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Euro-American</td>
<td>21</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>45</td>
</tr>
<tr>
<td>Totals</td>
<td>31</td>
<td>3</td>
<td>6</td>
<td>6</td>
<td>10</td>
<td>2</td>
<td>1</td>
<td>59</td>
</tr>
</tbody>
</table>

**Abuse/Assault.** Abuse/assault occurrence was high among the women in the sample; 60% reported history of either sexual, physical or combined sexual and physical abuse and/or assault. (Table 4-6) Physical and sexual abuse were combined for this analysis as the literature supports strong associations between sexual assault and physical threat or physical harm and the development of pelvic pain. (Golding 1996; Latthe et al 2006) Among black/African American women 69.2% reported a history of sexual abuse (none of the African American women reported a history of physical abuse alone) compared to 72.7% of the white-non Hispanic women. Four of the white-non-Hispanic women included in this group reported physical abuse as a child; 20 of the 24 with a positive response for sexual and/or physical abuse reported sexual abuse or assault. Four women refused to respond to the questions regarding abuse; other records with missing abuse data were incomplete for reasons other than refusal to respond. Records of 55 African American and white-non-Hispanic women had complete data on abuse/assault history. (Table 4-6)
6) The one white-Hispanic woman in the study was excluded; however, her history was positive for sexual abuse.

**Clinical and Social Correlates**

Research questions were established that called for examination of correlations between selected socio-cultural and biomedical variables; variable selection was explained in Chapter 3, and was based on clinical relevance as established in the literature review on biomedical and ethno-cultural correlates of chronic pelvic pain.

Research question one is: Are there racial/ethnic differences in pain intensity, pain intensity with sexual intercourse and acceptable level of pain among a sample of women with chronic pelvic pain? Using the analytical approach described in Chapter 3, results of the analyses on exploring the potential racial/ethnic differences in pain intensity, pain intensity with sexual intercourse and acceptable level of pain are as follows:

**Pain intensity.** Results from the t-test show that on average, there was a higher mean level of pain intensity \(M = 9.07, SE = 0.47\) among the African American study participants, compared to that \(M = 8.31, SE = 0.25\) of the white study participants. However, the difference was not statistically significant \(t(57) = 1.48, p > .05\). Given that the results of the t-test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Pain intensity with sexual intercourse.** Results from the t-test show that on average, there was a higher mean level of pain intensity with sexual intercourse \(M = 8.43, SE = 0.69\) among the African American study participants, compared to that \(M = 6.18, SE = 0.49\) of the white study participants, and the difference was statistically significant \(t(27.85) = 2.66, p < .05\). Given the significant results of the t-test, OLS multiple regression analysis was conducted to further explore the potential racial differences in pain intensity with sexual intercourse and the results are presented in Table 4-7. Model 1 in Table 4-7 shows the regression results of a model with
pain intensity with sexual intercourse as the dependent variable and race as the independent variable. The coefficient on race is significantly different from zero, which confirms the t-test results in the bi-variate analysis. Model 2 in Table 4-7 shows the regression results of a model with pain intensity with sexual intercourse as the dependent variable and ethnicity/race and a block of socio-demographic variables (age, education level, work status and marital status) as the independent variables. With the inclusion of the set of socio-demographic variables, the coefficient on race/ethnicity (as shown in model 2) is no longer significant. According to the analytical approach outlined in Chapter 3, no further analysis would be needed.

Table 4-7 Regression Analysis on Pain Intensity with Sexual Intercourse (N = 57)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Model 1</th>
<th></th>
<th></th>
<th>Model 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>β</td>
<td>B</td>
<td>SE B</td>
<td>β</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White/non-Hispanic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>2.31</td>
<td>0.98</td>
<td>0.30*</td>
<td>1.95</td>
<td>1.08</td>
<td>0.26</td>
</tr>
<tr>
<td>Age</td>
<td>-0.08</td>
<td>0.04</td>
<td>-0.30*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[High school or less]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College</td>
<td>-1.10</td>
<td>1.19</td>
<td>-0.14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>1.02</td>
<td>1.21</td>
<td>0.12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate education</td>
<td>-1.87</td>
<td>1.32</td>
<td>-0.19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working outside of home</td>
<td>0.78</td>
<td>0.86</td>
<td>0.11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or in a committed</td>
<td>0.95</td>
<td>0.96</td>
<td>-0.13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>6.12</td>
<td>0.48</td>
<td></td>
<td>9.88</td>
<td>1.91</td>
<td></td>
</tr>
<tr>
<td>R²</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.26</td>
</tr>
</tbody>
</table>

* p<0.05  Note: " Reference categories are shown in brackets.

**Acceptable level of pain.** Results from the t-test show that on average, there was a higher mean level of acceptable level of pain (\( M = 2.68, SE = 0.25 \)) among the white study participants, compared to that (\( M = 2.54, SE = 0.63 \)) of the African American study participants. However, the difference was not statistically significant \( t(16.02) = 0.21, p > .05 \). Given that the results of the t-
Research question two is: Are there racial/ethnic differences in the biomedical profile among this sample of women with chronic pelvic pain based on a review of systems (ROS) screening approach for reproductive, urological, gastrointestinal, musculoskeletal, and psychological systems symptoms or diagnoses? Using the analytical approach described in Chapter 3, results of the analyses on exploring the potential racial/ethnic differences in the screening for reproductive, urological, gastrointestinal, musculoskeletal, and psychological systems are as follows:

**Reproductive system profile.** Among the study sample, 93% of the African American respondents and 89% of the white respondents had a positive response to the screening questions for reproductive system symptoms or diagnoses. Results from the chi-square test show no significant racial/ethnic differences in the review profile for the reproductive system, $\chi^2(1) = 0.2$, $p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Urological system profile.** Among the study sample, all (100%) of the African American women and 78% of the white women responded positively to the items indicating urological system related symptoms or diagnoses. Results from the chi-square test show no significant racial/ethnic differences in the profile on the urological system, $\chi^2(1) = 3.75$, $p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Gastrointestinal system profile.** Among the study sample, all (100%) of the African American women and 88% of the white women responded positively to the items indicating
gastrointestinal system related symptoms or diagnoses. Results from the chi-square test show no significant racial/ethnic differences in the profile on the gastrointestinal system, $\chi^2(1) = 1.78$, $p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Musculoskeletal system profile.** Among the study sample, all (100%) of the African American respondents and all (100%) of the white participants had positive findings for the typical pelvic pain musculoskeletal impairment pattern. Given that there is no observed racial/ethnic difference, no further statistical analysis was conducted. Although there were no statistically significant ethnic differences noted, the findings on the measures of hip internal rotation passive range of motion (PROM) were of interest because of the high frequency (52 women had restricted PROM in hip rotation) and severity of the impairments.

**Psychological profile.** Among the study sample, 71% of the African American women and 76% of the white women responded positively to the items related to psychological diagnosis of depression. Results from the chi-square test show no significant race/ethnic differences in this category, $\chi^2(1) = 0.1$, $p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

Research question three is: Are there ethnic differences in the perception of treatment effects among a sample of women with chronic pelvic pain? Following the analytical approach described in Chapter 3, a chi-square test was first conducted to explore the potential racial/ethnic differences in the perception of treatment effects. Among the study sample, 25% of the African American respondents and 56% of the white respondents reported positive treatment effects, 58% of the African American respondents and 39% of the white respondents reported no positive treatment effects, and 17% of the African American respondents and 5% of the white
respondents reported being unsure about treatment effects. The results from the chi-square test show no significant racial/ethnic differences in the perception of treatment effects, $\chi^2(2) = 4.34, p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

Research question four is: Are there ethnic differences in perceptions of how chronic pelvic pain impacts life among this sample of women with chronic pelvic pain? Following the analytical approach described in Chapter 3, a chi-square test was first conducted to explore the potential ethnic differences in the perception of how chronic pelvic pain impacts life. Among the study sample, 64% of the African American respondents and 51% of the white respondents perceived chronic pelvic pain to be the most important problem they face in life. (Table 9) The results from the chi-square test show no significant ethnic differences in the perception of how chronic pelvic pain impacts life in response to the question posed about it, $\chi^2(1) = 0.73, p > .05$. Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

<table>
<thead>
<tr>
<th>Problem Rank</th>
<th>African American</th>
<th>European American</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Most Important</td>
<td>5</td>
<td>21</td>
<td>26</td>
</tr>
<tr>
<td>Yes Most Important</td>
<td>9</td>
<td>22</td>
<td>31</td>
</tr>
</tbody>
</table>

Research question five is: Are there ethnic differences in history of sexual or physical abuse or assault among this sample of women with chronic pelvic pain? Following the analytical approach described in Chapter 3, a chi-square test was first conducted to explore the potential ethnic differences in history of sexual or physical abuse or assault. Among the study sample,
57.1% of the white respondents had a history of sexual or physical abuse or assault and 69.2% of the African American respondents had a history of sexual abuse (none of the African American women reported physical abuse). The results from the chi-square test show no significant ethnic differences in the history of sexual or physical abuse or assault, \( \chi^2(1) = 0.60, p > .05 \). Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

Research question six is: Are there significant differences in the perception of treatment effects between women with a history of sexual or physical abuse or assault and women without a history of sexual or physical abuse or assault among this sample of women with chronic pelvic pain? Following the analytical approach described in Chapter 3, a chi-square test was first conducted to explore the potential differences between women with and without a history of sexual or physical abuse or assault in the perception of treatment effects. Among the study sample, 46% of those with and 59% of those without a history of sexual or physical abuse or assault reported positive treatment effects, 43% of those with and 36% of those without a history of sexual or physical abuse or assault reported no positive treatment effects, and 11% of those with and 5% of those without a history of sexual or physical abuse or assault reported unsure about treatment effects. The results from the chi-square test show no significant differences between women with and without a history of sexual or physical abuse or assault in the perception of treatment effects, \( \chi^2(2) = 1.10, p > .05 \). Given that the results of the chi-square test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

Research question seven is: Are there significant associations in pain intensity, pain intensity with sexual intercourse and acceptable level of pain between women with a history of sexual or physical abuse or assault and women without a history of sexual or physical abuse or assault?
assault among this sample of women with chronic pelvic pain? Using the analytical approach described in Chapter 3, results of the analyses on exploring the potential differences between women with and without a history of sexual or physical abuse or assault in pain intensity, pain intensity with sexual intercourse and acceptable level of pain are as follows:

**Pain intensity.** Results from the t-test show that on average, there was a slightly higher mean level of pain intensity ($M = 8.50$, $SE = 0.40$) among those study participants without a history of sexual or physical abuse or assault, compared to that ($M = 8.45$, $SE = 0.28$) of those study participants with a history of sexual or physical abuse or assault. However, the difference was not statistically significant $t(53) = 0.10, p > .05$. Given that the results of the t-test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Pain intensity with sexual intercourse.** Results from the t-test show that on average, there was a higher mean level of pain intensity with sexual intercourse ($M = 7.03$, $SE = 0.51$) among those study participants with a history of sexual or physical abuse or assault, compared to that ($M = 6.32$, $SE = 0.78$) of those study participants without a history of sexual or physical abuse or assault. However, the difference was not statistically significant $t(53) = 0.80, p > .05$. Given that the results of the t-test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Acceptable level of pain.** Results from the t-test show that on average, there was a slightly higher mean level of acceptable level of pain ($M = 1.90$, $SE = 0.45$) among those study participants without a history of sexual or physical abuse or assault, compared to that ($M = 1.57$, $SE = 0.28$) of those study participants with a history of sexual or physical abuse or assault. However, the difference was not statistically significant $t(48) = 1.06, p > .05$. Given that the
results of the t-test are not statistically significant at the .05 level; no further (multi-variate) analysis was conducted.

**Biographical Profiles**

Pseudonyms were used in biographies of participants and specifics of occupation were described generally enough to protect the participants anonymity. Selected cases are summarized here to provide a brief, descriptive depiction of the social context and illness experiences lived by the women in the study. Summaries are organized to include a demographic account, each woman’s description of the pain she experiences, her views on causality, her response to biomedical treatments, her report on exposure to abuse or violence, and her explanation as to how pelvic pain has affected her at home, at work, and socially. Names and demographics are modified slightly in these summaries to protect anonymity. Five African American and six European American women were selected for presentation in the case summaries. Since the majority of women in the study were married, two women in each group are married women, two are divorced and one single, never married. Decisions about which women were chosen for the case summaries were based, in part, on the thoroughness of our interviews. Some women met with me one time for as little as an hour and a half; some women’s interview sessions lasted three or four hours. Some women met one time only, others met with me several times over periods of time that varied from one month to one year. Variation in the amount of time spent with each woman largely depended on her schedule, but also on her verbosity as well as her interest in sharing her story and/or following up with medical care. Many of the women in Memphis met with me several times during follow up visits to the clinic; follow up meetings did not occur in the Knoxville clinic where I met with each woman one time for a minimum of 2 hours. All of the African American women presented here were interviewed at the Memphis clinic.
Sharon Long. Sharon is an African American woman in her early 50’s. She is divorced, with grown children and grandchildren. She lives alone in Memphis. She is a high school graduate trained for both tailoring and secretarial work; she is now on disability as a result of her health. She started her menstrual period at age thirteen and experienced lifelong heavy, painful periods. She has experienced non-cyclic, right lower abdominal pelvic pain for over thirteen years. Sharon has severe pain with intercourse, she says “The pain makes me not want to have sex; pelvic pain stopped me from being able to take care of my husband.” She rates her pain with intercourse as 8/10. She thinks her pelvic pain was caused by colon resection surgery and scar tissue from hernia surgery; her current pain worsened after a hysterectomy. Sharon was raped when she was in her late 20’s. She can’t recall her exact age at the time. She also describes exposure to emotional abuse and humiliation by an ex-husband. Regarding the effect of pelvic pain on her social life, Sharon says “I have no social life because of the pain except for church. I attend church and sit with my grandkids. Other relationships don’t get much attention. My mom would like me to visit more.” Treatment response she is unsure about, telling me ‘I’m not sure if I’m getting better; I’m on medicine all the time; it seems like if I was better I wouldn’t need to take medicine all the time.”

Lauren Dobson. Lauren is a 42 year old African American woman who is married but lives alone; she states “I live alone. I like living alone.” She has no children. She has one year of college and says she is trained in mechanics and electronics but can’t do that type of job because of her health; she has two jobs, working as a dispatcher and a restaurant hostess. She is also a minister and takes on leadership activities in her neighborhood. She has had pelvic pain in her left lower abdomen for 24 years; she has been in the care of Dr. Ling for it for 19 years, moving as his patient from the university pelvic pain clinic to his private practice last year.
pelvic pain is present most of the time but increases with intercourse. She describes painful intercourse at level of 8/10. Although she is not living with her husband she remains sexually active. She states “I’m not living with my husband now but we spend time together and make love.” As for what causes her pain, Lauren says, “I did think it was because of the rape; it started after I was raped when I was 18 years old. I bled for two days after I was raped. I’ve been told it is because of ovarian cysts and scar tissue.” In addition to the rape, Lauren describes exposure to emotional abuse as both a child and as an adult. When we talked about how pelvic pain has affected her life, she says “I have learned to accept limitations; I tend to have high expectations and that’s what gets me down the most-I can’t accept limits. I think I tend to push.” Despite her limitations, she continues to work and relates the impact of pelvic pain on working life as follows: “I have a poor work record because of the pain; timeliness and attendance are not good. I work two jobs now, as a dispatcher and as a hostess; I am also a minister. I am able to work now, in the past I wasn’t able to work.” As for her social life, she says, “I spend a lot of time alone; I prefer being alone because of the pain; I don’t want to talk about it.” Overall she says that because of the pelvic pain: “All things are limited, especially my ministry. Pelvic pain affects every other aspect of my life.” She also told me there have been some positive outcomes to having pelvic pain for many years. She says “It has helped me become more compassionate and understanding of other people’. As for the effectiveness of treatment, Lauren told me, “I’m better recently since I started the vaginal valium.”

**Pamela Ryder.** Pamela is 36 year old African American woman who is divorced and lives with her two daughters (teenagers). She has a high school education and on the job training with various government agencies including and past experience in the military. She is currently working in the shipping industry but wants to go to school to be a funeral director. She is
considering applying for disability because of the pain she is experiencing at work. She was repeatedly sexually abused as a child between the time she was six and eight years old. She also reports emotional and physical abuse including life-threatening physical abuse. She has pain in her lower abdomen and vagina with sexual intercourse and with lifting and other physical activities. She describes pain that is 10/10 with intercourse 9/10 with lifting that has been a problem for thirteen years. She had a lot to say about her pain experience; our first meeting lasted four hours, and we had several follow up meetings over the next 6 months. Sharon recalls the specific time her pelvic pain started. She tells me: “It started with a ‘pop’ in my abdomen after sneezing. My husband thinks the doctors are too blame that it was from problems with 2nd C-section; during the 2nd pregnancy I was humiliated by physician and five residents in front of my husband the decision for the C-section made by the doctor and my husband, I did not want it; I did not want pregnancy or the C-section due to pain from 1st c-section; I was already upset to be pregnant 4 months after the first Caesarean Section (C-section)...Now that I’ve had a hysterectomy I think the pain is mostly muscular.”

Pam provided a detailed account of the effect of pelvic pain on her sex life. She tells me “My husband thought I had been with another man when I experienced a spell of not being able to grip his penis or feel it; it started when I sneezed before intercourse and felt a “pop” in my abdomen. He wouldn’t believe me (that I hadn’t had sex with someone else.” Pam says that “Pelvic pain caused my divorce; my biggest thing now is the reason why he claims he left me is because I was not fulfilling him sexually and I explained to him why don’t you come to some of my doctor appointments with me. I have and new doctor and she can explain to you what it is that I am going through because he was there with me with both Cesareans and he was there when they cut.” She now lives with her two daughters and says that “My daughters (young
teenagers) do whatever they can to help me; they think the problem is their being born and stuff. I said it’s just from what I had to go through to bring you into this world but it is not your fault.” The pain is an ongoing consideration in relationships with men she tells me that “…it’s easier to not have a relationship than to explain the problem to a man. Sometimes a man will understand, sometimes a man doesn’t. Sometimes I don’t’ want to go through explaining it to him. I just have close friends, no sex, maybe an occasional movie or come to the house and sit down and my best friend, Matt will come over and cook for me. He’s a good friend. He is in love with he told me. I said I just can’t return it what it is. He understands the feelings and respects that. Whenever he needs me if he’s in a rut or if he needs somebody to talk to because we’re both divorced I’m there for him too. It (sex) was more comfortable when it was spontaneous.”

Pam says that an acceptable level of pain would be 5/10. “If I could get it down to a five I would probably be happy with that. I have been living with this for a long time and my mom was telling me just go ahead and accept it and change this phase of your life around this and possibly the fact that you may not be able to get into another relationship without explaining it.” She also says that “Walking takes my mind off the pain; but I can’t walk like I used to because of the pain…I can’t even go to the mall without pain.” Sharon described the impact of pelvic pain on her working life as follows: “I was in the military during my pregnancies. I was injured during my second pregnancy, with back pain, and then was put on VA disability. I work now for the post office; I live in extreme fear of losing my job cause of the pain—I have to try to keep my absences down and I can’t do a lot of the lifting required on the job…I would like to get into school to change jobs; my current job is tedious, the standing and lifting increases the pain.” In terms of responding to biomedical care, she says “I am some better with pain medication, using
Mary Johnson. Mary is a 37 year old African American woman married with three children. She lives with her husband, children and her father-in-law. She is a high school graduate working full time in a clerical position. Mary’s pain is primarily located in the lower abdominal area, and the sacrum, both sides. She also hurts in arms and wrists and back of thighs from Fibromyalgia. Pain with intercourse is 10/10 that lasts for days afterwards. She describes it as a “sharp cutting pain in the vagina.” She had a hysterectomy last year for heavy menstrual bleeding and ovarian cysts; her current diagnosis is “chronic abdominal wall pain.” She says “It started after I was injured in a car accident fourteen years ago; I was mainly hurt on my left side—arms and legs. She discusses abuse as a child saying [I was sexually abused as a child and an adult by family members. I finally told my mom about it—it helped. It’s like it broke the cycle. I’ve dealt with it; I’m Ok.] She made a comment implying the abuse she experienced may be a “normal” situation saying “I think most black women were tampered with as kids.” In addition to sexual abuse, she reported exposure to humiliation and emotional abuse saying “I’ve also been teased a lot because of a scar on my arm from a burn.”

Mary describes coping with the pain in this manner: “I pray, worry, try to walk it out; I take pain medication, I tell myself it doesn’t hurt.” She says her husband’s coping with her pain is “terrible…He tries to pretend I’m not in pain”. She says “My husband gets angry because it interferes with our sexual relationship.” In terms of her response to the interference with intercourse she says “I don’t miss sex at all…Sex is the most stressful thing in my life; I sometimes pick an argument with my husband to avoid it. I am non-interactive during it.” Although Mary and her husband are currently married, she noted that “We’ve been divorced and
remarried because of this. Sexual activity is important in a marriage” As for other aspects of her home life, Mary shared that ‘I’m the sole caregiver for my father-in-law. My kids take care of their rooms. They don’t really know what’s going on with me, but they are concerned about me.’ And that “I’d like to have a corner of time to myself to relax and garden uninterrupted.” As for the impact of pelvic pain on her working life, Mary says that “I still work despite it. I’d stay at work even if I have to stay in a wheelchair.” Socially, she says “I do less.” She is involved in church, saying that “I carry on but I’m anxious and depressed while I’m doing things (at the church) and more easily frustrated.” She says “My whole life revolves around this.” She also says “I am not getting better. Medicine that knocks me out is all that helps the pain. I am hoping that some type of injection (trigger point injection) might help the pain.” At the end of our first interview she said “This has really helped; I talked about a lot of things I hadn’t talked about that I realize I needed to talk about.”

**Melanie Anderson.** Melanie is a 42 year old African American, high school graduate. She is single and has never been married. She lives with a relative who is seldom home because of her work schedule. Melanie has lived in the same home for about twelve years. She works at a local hospital. She is a non-smoker, no drinking; attends church regularly—raised Baptist, now Pentecostal. She denies sexual abuse but does describe occasional physical abuse as child; she say no to experiences of emotional abuse/humiliation, however, she has battled overweight most of life and makes some remarks about comments often made to overweight people during our interviews. She comes from large family and describes close connections with frequent visits to extended family. She likes to exercise but talks about limits on her ability to exercise by the pain. She had surgery for painful uterine fibroids several years ago and was better for years. Over the last year she began experiencing pain in the vagina, right lower abdomen and groin. “This is the
worst pain I’ve ever experienced; it’s the worst. Because of it you can’t lie down, sit up, walk or have sex… I feel great when I’m not hurting…I was hurting very bad.” Regarding the cause of the pain she tells me “I don’t know what is causing my pain. Dr. Ling says it is my muscles… It’s not normal to have pain there.” She tells me that “I pray to God it won’t last long” and that “I worry all the time about whether it will end.”

As for the effects at work, she says “I have to climb stars at work, I do it, but it hurts a lot.” I was working at the school cafeteria—lifting and walking; I resigned in 2002 because I had to stop lifting because of the pain.” As for social roles she says” My pain didn’t stop me from doing anything, (related to social roles) I just hurt-until this year when the vagina started. I was walking and doing strengthening exercises; I had to stop because of the pain…”The things I like to do with my leisure time are TV and walking; I like to watch soap operas; the pain has changed my walking—if I have it (the pain) I won’t (walk).” She is not currently in a relationship with a man, but says “I would like to have sex again; I want something stable—also a little afraid of the pain.”(She notes that the last time she had intercourse was three months prior to the interview; she experienced pain intensity of 10/10 with intercourse that lasted several hours afterwards) In spite of the pain, she tells me that “The most stressful thing in my life is being overweight; I want to lose weight; I’ve never been this big; I want to lose it! ...In 2002 I started walking real good, lots of dieting, then I took a fall and stopped it all” She says that vaginal valium, recently added to her treatment, is helping the pain.

**Debbie Taylor.** Debbie a woman in her early thirties; she describes her ethnicity as “Southern American”. She is single, never married, and is currently not working because of pelvic pain. She is a college graduate, trained in ministry (Presbyterian) and was working in that field until recently. She lives alone part of the year, another part of the year one of her siblings
lives with her while attending college in the Knoxville area. When asked about a history of sexual abuse or assault, she described an episode of sexual harassment in the fourth grade that was ongoing by boys in her age group but sanctioned by adults including a policeman. She described being groped and sexually teased on a regular basis while walking to school. She reflects that the police, parents and teachers who were aware of the behavior “should have been looking out for us.”

She has experienced painful periods since age eleven and had chronic pelvic pain for many years. The pain is in her lower abdomen, worse on the right and including the right buttock. She believes the cause of her pain is endometriosis, interstitial cystitis and muscle tension in the pelvic floor. She has been treated extensively, and recently had three laparoscopy procedures in a ten month period of time. She has also had a hysterectomy. Debbie has a lengthy history of treatment for irritable bowel disorder and other gastrointestinal symptoms. She expresses a great deal of frustration about the medical treatment for pelvic pain saying she has had to work hard to get good care and find out a lot on her own. Debbie also expressed frustration about not being able to work and about the attitude her supervisor took toward her illness. She talked about the change in her working conditions beginning to change her sense of herself. She described it this way:

I don’t want my life to be all about this and for the past two years my life has been going to doctors, therapists, hospitals, having tests and I want to be able to work again and participate in society and life and not just sit in doctor waiting rooms and know which ones have the best magazines. The pain clinic has terrible magazines…I can tell people who has the best magazines and which ones look dirty, who is going to make you wait an hour and a half, who will see you on time. I don’t want to know that. I want to be, I worked really hard to get my education and to pursue a certain career path and right now I can’t do that.

She discussed the toll the condition has taken on her energy level which she says altered her social life as well as her working life. The following is an excerpt about the impact on her social life:
It’s hard to make plans in advance because I don’t know if I feel like doing. I’ll make plans and have to cancel. I have friends that understand and they know what I’ve been going through and they are supportive and fine with that. I have other people that couldn’t deal with that so I don’t really have contact with them anymore because they just, I find myself a lot of times saying I’ll have to get closer to the date to let you know. When I was talking about I hate having instead of being a person who happens to have these conditions, it’s like the conditions are controlling and that’s been really hard too, I feel like they’re winning. I want to be somebody that people can count on and I don’t feel like I’ve been that. I don’t do as many social type things as I used to or they are much more last minute types of things.

Sue Davis. Sue is in her early thirties; she is married, she has 3 children, and describes her ethnicity as “American.” She is white, non-Hispanic; she has family members who grew up in the Middle East but does not identify with any ethnicity other than “American”. She lives with her husband and two of her children, one of her children lives with their father, who is not her husband. She says the one child living with the father is a situation a “judge decided.” She was raised Catholic, but reports she is no longer a practicing Catholic. She graduated from a community college with a computer and business degree, but had to quit her job as a bookkeeper because of the pain. She says “I can’t work 40 hours a week because of the pain; I am incapacitated by the pain.” Her pelvic pain started after tubal ligation surgery instigated by a premature birth and gynecological problems. She says she was advised by the doctors to have her tubes tied because the premature births were “going to happen every time I had kids”. She was in her early twenties at the time of the birth and surgery. Since that time she has experienced cramping, throbbing, stinging, hot pain in the primarily in the right lower quadrant of her abdomen that is at its worst during menses (8/10 pain intensity) but also causes deep intercourse pain (7/10). Sue says that 3/10 would be an acceptable level of pain. She is currently avoiding intercourse because of the pain. She says however she manages all the housework and household responsibilities except for yard work which her husband does, because she says “I like things done my way.” In addition to pelvic pain, Sue’s has had “kidney problems” and two episodes she calls kidney failure. She tells
me “I want a hysterectomy but the doctor won’t do it.” Sue has an extensive history of childhood sexual abuse that started when she was eight years old. She tells me in a matter of fact manner, “...that is why I quit eating in sixth and seventh grade.” Sue has never been in counseling or psychotherapy. Sue says she is getting better since she started physical therapy a few weeks ago; she says she can tell she’s better because she’s taking fewer pain medications. She identifies pelvic pain as the most important problem in her life. She is diagnosed with endometriosis and interstitial cystitis; she says she believes her pain is caused by endometriosis, but she also says that she thinks she is to blame for her pain because “I had my children.”

**Janie Young** Janie is a divorced woman in her mid-forties. She lives with her son, and occasionally with her ex-husband. She was raised protestant and describes her ethnicity as “American”. She works part-time as a travel agent; she says she did work full-time, but had to change her status because of pelvic pain. She says the change in her work status created financial hardship and that her ex-husband has helped her substantially since that time despite their divorce. She began having vaginal and low back pain five years ago that suddenly progressed to included severe rectal “spasms” that felt hot, throbbing and like “I was sitting on a rock” three years ago. The rectal pain extended to the labia where she has a burning sensation and was worsened by sitting, which was a significant reason for moving to part-time work. The pain is also worse with intercourse. She is diagnosed with a pudendal nerve entrapment and has had a surgical nerve release which she says improved the labia pain, but that all the pain continues at a level of 7/10. She says an acceptable level of pain would be 2/10. She has also been diagnosed with IBS, levator ani syndrome and constipation. Janie says she believes her pain is from the pudendal nerve entrapment; she says her family thinks it is because she is “overstressed” and that she has been told it is “in your head” and that “it can’t be that bad.” She describes her en-
husbands reactions to her pain as “he takes care of me” and “he gets angry.” She says there has been a “tremendous change” in her home life because of pelvic pain; she says “I had company, I cooked, I did a lot of socializing in my home as well with a bridge group, all of that has changed.” She says she used to travel, but “no more” because of the problems with sitting. Janie says she is getting better since the surgery and with the continuing treatment with medication and physical therapy. She says that pelvic pain is the most important problem in her life. She is hopeful she will continue to get better. Janie denies any history of abuse-emotional, physical or sexual at any age.

Betty Arnold. Betty is in her mid-forties; she lives outside of Memphis in a small town where she and her family own a business. She describes her ethnicity as “American” and her religion as Baptist. She is married, lives with her husband of many years and near her grown children and grandchildren. Betty is a high school graduate who worked in the family business for several years now works as “housewife and grandma”. She has pelvic pain in her right lower abdomen that has been there for about six months. She had a similar pain about a year and half ago that was better after a gynecologic surgery to remove “scar tissue” and she says she expects the same thing is causing her pain now. She describes the intensity of her pain as 5/10 with intercourse and 3/10 when her bladder is full but it bothers her most all of the time. She says the pain has made her “slow down” in her household responsibilities and in her interactions with family and friends. She say she is not as close to people as she was and that being afraid of being in pain keeps her home much of the time as she just doesn’t “feel like” going places. Her husband is very concerned about her condition and accompanies her to the clinic due to the length of the drive to Memphis and her level of pain. Betty says pelvic pain is the most important problem in her life and that 2/10 would be an acceptable level of pain. Betty says she
was “molested as a child” between the ages of six and twelve by a family member. She says she
told her mother, but that nothing was done. Betty has been treated for depression with
medication but has not had counseling or psychotherapy for any of her problems. When asked if
the pain is getting better, she says definitely not, that the pain is continuing to get “heavier”.

**Lisa Sanders.** Lisa is in her early thirties; describes her ethnicity as “American”. She says
she was raised Baptist but is now Methodist. Lisa is married and lives with her husband and two
young sons. She works fulltime as a child care center director; she has a high school education
and technical training in practical nursing and emergency medicine. She has had pelvic pain for
about a year and for “six months bad”. She has pain with intercourse at the level of 5/10 that
increases to 8/10 after intercourse and lasts for several days. She also experiences some burning
vaginal pain after sex that she rates at 6/10 and says the pain interferes with her sleep every
night. She says that pelvic pain is the most important problem in her life and that a pain intensity
of 3/10 would be acceptable. Lisa says she has never experienced any type of abuse, emotional,
sexual or physical. Lisa often works long hours while in significant amounts of pain. Her
youngest child is two years old and in addition to pelvic pain she has had thyroid surgery and a
hysterectomy since that childbirth. She says she copes with pain during her busy days of work,
wife and mother responsibilities by taking deep breaths (“I learned that from Oprah”) and
prescribed muscle relaxants. Lisa says she does all the housework, but that her husband helps
with laundry and she helps him with yard, although she says “I cannot push the lawnmower, that
is out of the question...I help bag the grass and mulch the flower beds”. She says pelvic pain has
not changed her work hours but her work activities; she cannot pick up kids or be as active as she
would like. She says she often feels ‘helpless” at work because of those limitations. Lisa says “I
still go to church and ballgames but I hurt all the time.” She and her husband have intercourse
less often because of the pain and that her husband feels helpless and frustrated by her condition. He told her once “...we’ve got to get you fixed...” She says that her pain is not getting better and she is “clueless” as to what might help. She says that pelvic pain is the most important problem in her life and that 3/10 would be an acceptable level of pain.

**Narrative Themes**

**Causality**

Women’s descriptions of causality fell into the categories Don’t Know/Not Sure; Medical Diagnosis (Gynecologic, Urologic, Gastrointestinal, Musculoskeletal, or Psychological), Medical Procedure, Accident/Injury, Abuse/Assault, Childbirth and Life Stress. (Table 4-9) Examples from the narratives that highlight women’s accounts of each category of causes are presented in Appendix c. The most frequently articulated perceived cause of pelvic pain was “Unknown” which was reported 19 times. (Table 4-9) Some women articulated more than one cause; however, women who reported not to know the cause did not report other categories. Of the 19 reports of “Unknown” 18 were from the Memphis sample. Neither the importance of knowing the cause nor impact of not knowing the cause were specifically explored in the interviews, however, some women brought it up with prompting. One Memphis woman put it this way:

**M34**: … I’ve dealt with it (pelvic pain) for over a year and a half… waiting for answers and this and that and it gets worse and worse.

**PK**: Anything else you want to say about this whole process before we look at your body?

**M34**: No, just waiting.

A woman in Knoxville spoke about the importance to her of knowing the cause:

**K10**: You do think ‘what is this horrible pain?’ I still want an answer about this swelling. I want to know why.

And in response to my question about what was the worst part of the experience of chronic pelvic pain, one of the Memphis participants said:
Not knowing; and the interrupted sleep-M37

Table 4-9 Perceived Cause of CPP by Self-Reported Ethnicity and Geographic Location

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Medical Diagnosis</th>
<th>Medical Procedure</th>
<th>Childbirth</th>
<th>Pelvic Musculoskeletal</th>
<th>Abuse/Assault</th>
<th>Injury/Accident</th>
<th>Life Stress</th>
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<td>5</td>
<td>12</td>
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</table>

A specific medical diagnosis was the second most frequent causality; it was reported 18 times. Commonly reported medical diagnoses include endometriosis, interstitial cystitis and adhesions; also reported but less frequently were ovarian cysts and bladder infections among others. Many women listed more than one biomedical diagnosis and included problems from more than one body system, consistent with their medical histories.

Some women related the onset of their pain to an event (examples include accidents, surgery, childbirth, and rape) but did not perceive the event as the “cause”. For example, one woman in Memphis said:

The pain started at age 14 when I was raped…What do I think is the cause of the pain? I have no idea.-M2
Others perceived the event as the “cause”. A woman in Memphis explained how she thought the pain was caused by a rape, but that she had been told it was something else:

I did think it was because of the rape; it started after I was raped when I was 18 years old. I bled for 2 days after I was raped. I’ve been told it is because of ovarian cysts and scar tissue.-M4

Of events related as the cause of pain, medical procedures were the most frequently reported (reported 8 times); childbirth was the next most frequent being reported 5 times; abuse/assault was reported 3 times and accidents or other injuries reported twice.

Three women, all in their fifties, and all white, related the cause as life stressors. Two of the three completed college, all three had worked or were working as either professionals or in management positions. Two of the women were from Memphis, both of whom described very specific work and family stressors and related specific parts of their pain to specific stressful events. The woman without a college education was on health related disability; she related the onset of her pain to stress at work, and recent symptoms to family stress. The following is an excerpt from our conversation:

PKB: What do you think is causing your pain?

M25: Life—my husband’s disability, my kids. I internalize a lot.

PKB: Was there an event associated with onset of your pain?

M25: Yes, it was work; we were moved to a different office; I didn’t want to go

The other woman from Memphis who related the cause of her symptoms related this scenario:

Maybe it’s stress; I’ve had a lot. My brother committed suicide; my husband lost his job; There were changes at work that have made work environment miserable for the last 4 years but I’m now the primary breadwinner at home so I have to put up with it; our children are having problems that are costing us money…it goes on. The last episode of increased pain did start while I was at work a few months ago…-M19
I met with this woman several times over a course of a few weeks. During one of our last meetings she shared that she had initiated procedures to apply for disability due to the effect her job was having on the pain. The other woman in this category was not working full time when we interviewed, but was in school for a career change and working part time. She had experienced pelvic pain for many years and related the following about the start of the pain:

I thought it was either irritable bowel or I had a tumor in my stomach or cancer. I thought I had some cancers internally because there was constant pain. I thought I had something seriously wrong with me. I think now, that what was going on, considering what was going on with me at that time was, I think it was most likely stress...-W1

**Productivity**

A resolve to carry out roles and responsibilities at work and at home, including sexual roles and responsibilities, even while in pain, emerged as a common theme among women in the study. The importance of productivity and a determination to continue to work as well as to carry out family obligations was clearly articulated by many women in the study. Although many women described isolating themselves from social activities outside the home, most of them related a strong desire to continue to work outside the home and to continue to uphold their household obligations to their families, including their sexual obligations to their husbands or partners. Most women described changes in the amount or the ways they were able to carry out work related and household responsibilities, as well as changes in the frequency and quality of sexual intimacy with their partners. They also described modifications to the time or responsibilities on their jobs; many described continuing to carry on responsibilities at work, at home and in bed while simultaneously enduring very high levels of pain.

The importance of productivity and/or work was expressed in extreme terms by some women. For example, one of the African American women in Memphis stated that:

I still work despite it; I go to work no matter; I’d stay at work even if I had to stay in a wheelchair. –M6
One of the European American women in Memphis actually described going to work in a wheelchair because of the pain:

So the week before I actually got married they had to wheel me into the office (because of pain).-M16

One of the women from Knoxville described not being able to work as the most stressful thing in her life:

PKB: the most stressful thing in your life on an average day?

K4: Probably not working is the thing I feel like I cannot control; I used to be…I’m not as busy.

Another of the women Knoxville simply stated the following:

The biggest way pelvic pain has affected my life is my productivity.

Two African American women in Memphis described working while in pain:

I have to climb stairs at work, I do it, but it hurts a lot (but I do it).-M22

I don’t just dwell on it. It hurts and I continue to do things. It’s alright one way or the other…I just keep going.-M48

A woman in Knoxville described how she went to work in pain until her husband intervened:

I then packed myself in ice to be able to go to work the next day and that’s when he (ex-husband) said “You got to quit it. You are suffering far too much.”-K1

Many women discuss no longer being able to work or taking a different type of job that is more accommodating to the modifications they need to make to their schedules or physical activities because of the condition, however, most express frustration with the changes and limitations imposed by the illness indicating a strong desire to be able to participate fully at work as well as at home. Some women expressed acceptance with less frustration, noting that adhering to limits lessens the pain, but for most women, the pain of limited productivity was as apparent as the physical pain in their pelvis in much of their dialogue. For example:
**M34:** I’ve had to miss several meetings just because of the pain. I’ve had to put a lot of things off on my vice president. My kids have had to go to my parents’ house a lot because of it.

**PK:** And then you missed some work too.

**M34:** I missed a lot of work.

**PK:** Did that put your job in jeopardy at all?

**M34:** It did not put it in jeopardy but it made me feel worse and worse just because I did not want to miss.

Some comments provided insight as to why women chose to work both outside and inside the home despite pain follow:

The fear of losing this house was greater than the pain I was going through. It was like *work was the only value I had*… Maybe that’s all I know… I mean my sister and I have been working all our lives; I was 10 and she was 12 when my dad opened a store up so that is all we know. …My dad owned a restaurant…we would alternate days, we worked every other day with my father from the time we would get out of school to like 9 or 10o’clock at night. So we’ve been working, you know… from the age of 10.-M7

Many women spoke about continuing do what needed to be done at home but noted that it took longer to do most things because of the pain. As one woman put it;

It limits what I can do—like washing a sink full of dishes or standing will cause a problems; I have to put it off or not do it or modify what I’m doing; it takes more time to do everything.-M21

Others talked about household responsibilities their husbands or other members of the household took over from them or assisted with because of their pain, however, despite modification, most of the women described a lot of physical activity at home while in pain. A Memphis woman (white), who works full time as a paraprofessional explained her attitude about continuing her household responsibilities while in pain this way:

I can either take medicine or get it fixed or I can just shut up and go on. I’m like every other woman you know. I get up at 4:45 and start exercising. I get my house cleaning done before I come to work. I do all those things so I have to get up in the morning so that’s why I think I’m so tired at night….Literally if I finish the kitchen at 8 o’clock and sit down in the recliner to watch TV I’m asleep at 8:05 and then I’ll get up at 10 and go get in the
bed and sleep to maybe until 12 or 1 then I wake up and not get up to go to the bathroom or anything just wake up and toss and turn for a few minutes then go back to sleep. I’m usually back up about 2:30 or 3:00 then my alarm goes off at 4:30. –M18

A retired woman (European American) in Memphis talked about fulfilling her obligations at home while in pain saying:

I still do everything I always did, doing it all just means I’ll have less ease; exercising is the only thing I had to stop because it hurt too badly. –M24

The same woman who is 70 years old, and retired went on to say:

M24: I rode my riding lawnmower yesterday for 5 hours yesterday.

PKB: Do you feel that pain while you are riding or is that afterwards?

M24: Well, yesterday it was when I was riding, then it went away, its’ not something that’s going to kill me, it just hurts.

Another tells me that her husband now takes about half the responsibilities at home, but gives this account of her activity level, carried out while experiencing severe pelvic pain:

I cook dinner when we are home at night and we can’t eat out, I do the cooking and I will clean the kitchen and the housework and he always helps me with the laundry and my boys do too…I cannot push the lawn mower, that’s just out of the question. But I do help like bag the grass. I did mulch my flower beds last week and I should have never done that. You know I do try, I would say I think that to a halfway point…-M10

Another describes getting help from young children when she is in pain:

It seems to be the hardest thing is the house cleaning. My little boy helps me you know. If I’m really bad or don’t feel like, come and pull these out and bring them in here and I’ll fold them up. He helps me -K1

Some explanations for why they continue to work in the home despite pain include the following:

It helps to keep myself going; I get panic attacks and if I keep going it is better. –M17

I like to clean house. I like to put things in order. I like things in order. –M37

I don’t want to be (limited in what I can do). I’m the kind of person that will push myself to do what I want to do even if it means I’m going to pay for it later. I don’t like being inactive. I like contributing. My boyfriend lives with me and we have a household.–M38
She went on to say:

…cleaning up and doing things, that are my way of coping and that’s one of my outlets because it makes me feel productive. I can go at my own pace. If I’m hurting I can rest. It doesn’t require a lot of heavy strenuous exertion…It’s cathartic for me to take care of the home and also as a woman I know about the women’s lib stuff and I’m all for it except I really need a bra because my boobs are too big to not have one but I like it’s that nurturing side of me.-M38

One woman expressed her motivation to keep going despite pain to be based on a family example she was trying to avoid:

I’m not going to put my life on hold because I’m in pain. I watched my mother do that I think and I’m not going to do that. There is too much living to do then just waddle around, that’s how I feel anyway... I just have mountains I want to climb. –M43

Others shared the following:

I’m recently back at work; I’m doing it (working) now because I need the income and it makes me feel worthwhile.-M38

It helps me if I keep myself going; I get panic attacks; if I keep going it is better.-M17

I’m currently not working because of it; I used to work 10-15 hours a day. I’ve never not worked since I was 15; I didn’t realize until I was off that you can’t get well when you are so busy…“It’s like my body says ‘stop’-you take care of yourself.-M19

This was the first time in my entire life that I haven’t worked. I haven’t worked, not because I didn’t want to, but because I couldn’t walk. I couldn’t sit. It was horrible. I’m recently back at work; I’m doing it (working) now because I need the income and it makes me feel worthwhile. –M38

I worked in the law library as a librarian. I had to walk five floors quickly like you. I had to move fast, get there, I had to have patrons. I had to have a sharp mind and I had to know what I was doing because I was dealing with the law. I was dealing with cases when the attorneys called and they needed things it had to be precise. I had to have a sharp mind and I had to be able to move around. I got to the point where I couldn’t do those things anymore. I would get to work and didn’t remember how I got there. I would do my day’s work and wouldn’t remember what I did. … I would read over things and it’d be like oh girl you were really sharp in the mind. It just came out automatically but I wouldn’t remember. I would read my work and it was like it was someone else’s’. –M40

Sexuality

Women’s descriptions of their sexual behaviors, attitudes and beliefs were categorized under the theme of sexuality. Sexual intercourse was reported to be painful by most of the
women in the study, some chose to abstain because of the pain; others described continuing to engage in intercourse despite the pain, usually out of a desire to satisfy their partner. Some women reported desire to resume pain free intercourse both for the relationship and for their own pleasure, others reported indifference to sexual activity except for its role in maintaining a relationship with significant others. Beliefs about sexuality and sexual activity were not investigated in depth, however, the perception that it was normal to be sexually abused as child and that it was normal for women to be less interested in sex than men were both commonly reported.

Sexual Behavior-Endure Pain or Abstain?

It was funny because I have an ex-cousin, it was my first husband’s cousin who was gynecologist, and he was one of those people that I knew well enough that I could talk to about you know sexual problems or whatever. He said what you have is called dyspareunia and he said the only thing you can do is have your husband come in and we’ll whack it off and you’ll be fine. There’s a joke among doctors that it’s better to have dyspareunia than have no pareunia at all.-M55

Apparently not all women find dyspareunia is better than no pareunia, although many women continued sex even if it hurt, others take the opposite approach to not participate in sex without losing their marriages. One woman in Knoxville described pain during intercourse that as “…almost bad enough you don’t want to keep on…”

However, she apparently was keeping on. She shared the following details:

The intercourse pain is not better yet, just the arousal pain. The arousal pain is probably about a 9 (out of 10). It’s almost bad enough where you don’t want to keep on. It’s very bothersome. The pain during intercourse, it kind of eases off... Once I get past that initial arousal pain it kind of goes to about a 6. The pain afterwards I just feel really I guess sore. The level 6 kind of stays afterwards….K14

Another woman from the Knoxville clinic shared this:

… I have cramping after intercourse. Sometimes I have cramping during but that’s just like if that happens it’s just stopped. Mainly I get more easily than I used to. I’m just sore. It’s like a 3 or 4 on the 10 point scale afterwards; it’s nothing compared to the other pain I have
but I wouldn’t have sex again you know for maybe a day or two because of the soreness. During intercourse I can go to a 7 before I have to stop. –K8

The reasons given for continuing to have sex despite pain largely focused on meeting the partners’ needs. A desire to be close to the partner emotionally was also expressed as was a fear for the relationship if the sexual aspects of it did not continue. One woman reported losing a boyfriend when she explained that sex hurt and so she didn’t like to do it very frequently. Others described marriages that ended because of it. As one Memphis woman told me:

I’m fearful of not being able to pleasure him during sex…-M17

Some women described avoidance strategies to deter the frequency of painful intercourse:

Sex is the most stressful thing (in my life); I will pick an argument with my husband to avoid it; I’m non-involved during sex because it hurts more if I move; if we go slowly with music it helps me relax- M6

One woman described giving up intercourse with little impact on her relationship with her husband telling me:

At home my husband is very understanding; it (pelvic pain) limited our physical intimacy 100%.-M39

Another relates changes in her relationship with her husband because of the lack of sex:

We never have intercourse a lot, not as much as we should but …it’s not been a real issue… but I think my husband and I would be a lot closer if we could have more relations…-K64

Another initially gave the impression that lack of sex is not a problem in her marital relationship saying her husband is an “angel” about the situation, but as we talked further, their mutual distress over the situation was related. The exchange went as follows;

K10: My husband is wonderful. He’s an angel. We haven’t had sex for two years.

PK: How does he handle that?

K10: Horribly… The last time I had sex it stayed at a 10 for two or three days. I want to be able to have sex with my husband again…?
Attitudes-Sex and Intimacy

Very few women expressed a desire to resume sexual activity because they personally enjoyed it and wished to resume it for their own pleasure or mutual pleasure. The following exchanges illustrate some of the common attitudes expressed by women in the study.

M40: Now it is much better. I don’t go to bed with a yearning and a desire…

PK: Despite the fact it hurts to have intercourse you’ve always desired it? The pain never affected your interest?

M40: No, I never liked intercourse.

PK: You said you were going to bed with this yearning and desire.

M40: Because I wanted my husband’s affection; I didn’t want intercourse, I wanted his affection.

M21: Being a wife is the most stressful thing in my life because my husband hates the pain and then trying to be that wife that’s fantastic and cuddle and all that stuff that affects (me) because I don’t want him touching me… but I try… bit I hate it (sex). With pain I hate it more…I wish if I didn’t have the pain. I would be able to do it enough just to please him but I wouldn’t care if I didn’t do it...The pain makes me not want to have sex; pelvic pain stopped me from being able to take care of my husband.

Attitudes-Abuse and Pain are Normal?

I thought all girls were messed with, weren’t you?-M8

Although none of the women with a history of abuse or assault reacted neutral to it, they all had negative responses, and expressed a variety of negative emotions and reactions. However, many described it as a relatively “normal” part of life, in some cases, a normal part of being a child. Abuse and assault perpetrated by authority figures (family or community) as well as abuse or assault that was repeated or continual or that they also witnessed others experience contributed to some perceptions of normalcy.

...That whole atmosphere was sexual, part of it I think is normal curiosity that starts around that time but it went beyond that. (Discussing experiences at ten years old) Your daughter better tell you if the boys are bothering her. It is something I just thought about recently because I was watching just the other day on a show they were talking about kids who had been bullied and harassed and stuff and about how if these were actions that were taking

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place when we were adults they would be harassment. I thought this kid that came up and
was always putting his hands on me, grabbing me from behind, saying things. I’m like you
know, because we were in the fourth grade it was kids being kids... –K6

When I was a kid there was some pervert who would flash us on the way to school and the
policemen knew him and knew where it happened and all this; I forgot about him. We had
all kinds of names for him. There were five of us and we all walked to school at the same
time - K13

When I was in high school I guess I was developed pretty well so I had old men all the
time try to get me to go out to dinner with them, try to get me to spend the night in a hotel.
This was in a farming community in the Mid-West... It happened probably about 20 times
during the time I was in high school that I was kind of like what am I doing wrong. I think
it was I’d run a lot of errands for my mom and so I’d be out by myself instead of with
somebody so I think that may have been. That’s the closest I’ve come to being scared.
One time some man put his hand on his arm to try to lead me somewhere and I jerked it
and said do not ever do that again and walked off. I was kind of shaken. Other than that
fortunately it didn’t go any further. –K16

...Not rapes, just forcing sexual act; this guy got kicked off campus actually. It was my
freshman year. He was harassing me afterwards like stalking me kind of and my RA, I just
turned 18, RA figured out what was going on and took me through the whole process. I
never had to see him again. Years later I found out that all of this one group of people this
guy was with them and everyone there knew-K8

I was molested as a child. I think the first time it happened I was about five that I recall. It
was actually by my older brother. He’s three years older than I am. It started out as like a
playing doctor type of a thing and it kind of progressed to you know; it’s come out in later
years that he himself might have been raped. He told his first wife that he was actually
raped by an uncle who we know is a pedophile. To make a long story short he would play
games... As soon as I got a little bit older, I think I was about nine I would say no I’m not
going to do that anymore. He left me alone but then he went after my younger sister who
is five years younger and we found out that she had been very molested and maybe even
raped for ten years by him but she would never tell. -M51

My dad was pretty abusive, physically and just always him always feeling us and stuff; I
was seven, eight, nine, probably to twelve years old then I lived with my grandparents. My
mom didn’t know what he was doing he was abusive to her.-K15

I think most black women were tampered with as kids.-M6

**Fragmentation**

Fragmentation was a theme expected to be reflected in descriptions of health care that also
extended into descriptions of fragmented selves. Many women described alienation from their
bodies, their emotions as well as from their friends and families and in some cases even from
their sense of self as a result of or part of the illness experience with chronic pelvic pain.

Fragmented health care was reflected in stories of complex treatment regimes and consultations with a wide array of practitioners that encompassed numerous medical diagnoses and multiple medical procedures, in many cases, over several years time. Extensive medical care that was fragmented along the lines of medical specialties was described by most women in the study.

One woman even discussed her observation of the mind-body split informing the health care she received. She complained about the inability of the practitioners she had seen to connect the trauma of abuse to her physical pain saying:

They (health care professionals) did not understand (the relationship between abuse and my pain). They were saying that it was in my mind—that my illness was psychosomatic. They were saying depression I had was borderline manic depressive and all these things. When I realized that it wasn’t my fault that I didn’t do anything to make that happen to me then I didn’t have those problems anymore.-M40

Other stories of fragmented care were more about lengthy experiences with a variety of specialized practitioners than about mind-body disconnections. For example:

Well it certainly helped me since I’ve seen the new doctor the past three years. He ended up doing two surgeries which after the first one well that was actually my second one helped me and then I got worse and then he found some more endometriosis in there and took it out. That has certainly helped seeing him and learning things that help make it better like swimming and Pilates and noninvasive types of things...within that time I had like four cystoscopies on my bladder. Then I had gallbladder removal and three weeks later I had an ovary remnant and they put me back in and that was a four hour surgery. They had to remove some of my colon as a part of the ovary remnant. That was in November, a couple days before Thanksgiving. I’ve had about ten to eleven procedures since January 15 of last year.-M32

Comments from women describing the supportive nature of their health care encounters, including participation in the study include the following:

I’m more relaxed now (that I’ve had) a chance to talk about it a get it out; it helps to have a woman to talk about it to; helps to get it out –M7

This has really helped; I talked about a lot of things I hadn’t talked about that I realize I needed to talk about.-M6

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My social world pretty much consists of my coming to the doctor’s office. When I leave the doctor’s office because I’m out I’ll go by my mom’s or one friend’s. The reason that I do that because when I sit down I may go to sleep and sleep four hours and I can’t go to other people’s houses and do that so I was not going anywhere. Of course I just started driving myself in these last few months.-M40

I feel better seeing you. I have felt so hopeless and even sometimes not exactly suicidal but to the point where if I have to be like this the rest of my life it would be okay if I just don’t wake up. I have my daughter and I think well I’ve just got to go on. My mammogram is a year and a half late and I don’t even care. My cholesterol is very high and she gave me medication and I won’t take it. The last time I took the Lipitor it nearly killed me. It put me in an ulcerative colitis bout that lasted three months. I was literally home bound on steroids and I couldn’t leave the bathroom. I’m terrified that another drug will do the same thing. I think I’ve got enough going on right now to have to deal with I’m surprised I haven’t had a flare up with all the Motrin and stuff I’ve been on. My colonoscopy is overdue. I just can’t think about it. I don’t care about it. This just consumes me.-M51

Although the narrative accounts described health care that was often complex and carried out by a variety of practitioners in several different locations, when the women told of the experiences, they told them as one story; one very long and complex story. Underlying the description of fragmented health care delivery was the story of one person who received that very complicated care, perceiving all of the appointments and procedures as one combined experience rather than as many separate experiences, which was the mode of their delivery.

One of the difficulties or pitfalls of providing health care for pelvic pain by a team of providers in various clinics is establishing and maintaining effective communication between practitioners; clarity, frequency and completeness of communication between providers can be challenging to attain and maintain those situations. In addition to the complications of effective communication across the health care team, patient practitioner communication is also frequently imperfect For example it was obvious in several conversations that participants in the study often did not share all their symptoms with the providers they were seeing for pelvic pain. One exchange that illustrates that went as follows:

M32: Yesterday I just took a bite of a wheat sandwich with cheese on it and got severely nauseous. I’ve been nauseous really bad for two days now.
**PKB**: You’ve actually had vomiting too.

**M32**: Oh yeah.

**PKB**: Does Dr. Ling know about that? (The doctor now treating her for endometriosis)

**M32**: I’m not sure. The vomiting is not as frequent as the nausea and diarrhea. That is more predominant. It can be occasionally on the vomiting I would say it’s every month. The Zofran they got me on has helped as far as the vomiting. The nausea I took three yesterday, not at the same time but I had three Zofran yesterday and it still didn’t do much.

In that example, the practitioner is receiving a fragmented rather than a complete view of the woman’s symptoms.

Fragmentation was also reflected in women’s description of their relationship to their pain and their bodies. Many women describe the pain as something outside themselves, for example:

- It’s not there all the time like it used to be like every day, all day. When it does come every often I can hardly move. Lately it is though but not before I guess. I started not trying to take anything. That’s why I like it not to be there.-M27

- It’s like my body says ‘stop’-you take care of yourself.-M19

- It (the pain) does whatever it wants to!-M23

Fragmentation also appeared in coping strategies described by many women, for example, the following comments were made while discussing having painful intercourse for 17 years of marriage and painful urination since a childhood bladder infection:

- Being still and closing my eyes and trying to mediate, trying to do mind over matter before I resort to medication…Cause I hate feeling like I’m a walking drugstore-M21

- I might have ignored it more than I should have. –M27

In many cases social isolation and alienation from friends and family were described.

- I find like I don’t want to go out to the movies as much to be with people, I’m kind of right now not hibernating but kind of recharging myself. I do that as kind of a safe retreat. If I can just relax and be okay then, I guess I’m finding myself doing less of that now. I’m working on it; it’s not like I won’t go but if my husband says do you want to do something tonight? I’m like no. I just like want to stay home tonight. He’s like sure and we do. If he really wants to go somewhere I’ll go with him. –K16

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I thought I was going to die, and I was really ready, not afraid, and just ready. It was in the beginning when I was in the house and nobody understood. I was in the dark. My husband would come home and I couldn’t make him understand. They dilated my eyes and I couldn’t see and can’t stand light. I couldn’t read and watch TV. I couldn’t work.-K10

In some cases it appears the women become separated from themselves as well as lack of social wholeness becomes the standard state for daily functioning. Separation from emotions is one example:

I’m not a crier so for me to cry it’s a big deal, like today; but it did feel better. –K10

Fragmented self as a strategy for self-care was related in the following manner by one of the women from Knoxville:

To me taking care of myself is getting up in the morning and making myself look good. I have an attitude where if I make myself look good then y’all think I feel good. That to me is taking care of myself, going in my room, closing my door, doing stuff by myself that kind of thing K14
CHAPTER 5
DISCUSSION

Social and Demographic Characteristics

Ethnicity. Many more African American women were expected to participate in this study than were recruited; this was particularly true for the Memphis clinic. This expectation was based in part on the demographics of Memphis, as well as on the perceptions of the Memphis clinic staff regarding the number of African American women in their care for chronic pelvic pain (CPP). The expectation was that at least 50% of the women recruited in Memphis would be African American rather than the 20% who were actually recruited.

The clinic that served as the study site in Memphis was a newly established private medical office located in suburban East Memphis. Although the practice site was newly established, it was operated by physicians with over twenty years of practice and research experience in Memphis with women with chronic pelvic pain. (King et al 1986; King et al 1991; Myers et al 1991; Ling 1993) Until a few weeks prior to data collection for this study, the physicians practiced through university based clinics in both the eastern suburban part of the city where the study site was located as well in the medical center in downtown Memphis. At the time of the study they no longer had a clinical office in downtown Memphis. The lack of access to downtown Memphis likely contributed to the relatively low numbers of African American encountered during the study timetable compared to expectations from the previous patient population served by those particular physicians. The residential population in East Memphis is predominantly middle to upper income as well as predominately white, whereas the residential areas surrounding downtown are predominately lower income and black and/or African American. The clinical records kept in Memphis do not include racial or ethnic information, so the expectations of the clinic staff that larger numbers of African American women would seek
care during the study timetable were not statistically based, but rather on the perceptions of the clinicians and staff about the racial mix of the patient population, which calls into question the realistic nature of those projections.

In Nashville, two African American women were recruited; however, other African American women who were approached in Nashville declined to participate. The two primary attempts to recruit participants in Nashville occurred in group settings where a presentation was made on pelvic pain followed by invitation to participate in the study; both of those sessions were attended by several African American women. During one of the meetings in Nashville, questions were raised by one woman as to why there was a specific interest in recruiting African Americans to the study. She was skeptical about the motivation to consider race and ethnicity when studying women with pelvic pain. Mistrust of biomedicine is common among African Americans. (Belgrave 1992; Davis 1981; Dula 1994; hooks 1989; Jazieh and Buncher 2002; Kilgus, Pumariega and Cuffe 1995)

In contrast to the recruitment experience in Nashville, all the African American women in Memphis who were approached about the study agreed to participate. The nature of the relationship the African American women in Memphis had with their physician likely reconciled any concerns, fostering a positive attitude toward the project. Study participants often articulated trust and confidence in the practitioners operating the clinical sites in Memphis and Knoxville. Comments such as the following were common:

Recruiting participants from clinical sites in the downtown area of Memphis would likely not only have increased the percentage of African American women encountered, but also the percentage of women who had not completed high school and/or were not employed. Although it was unintentional, the study sample was biased away from recruiting women of the lowest SES
at all sites. A clinical presence in the downtown area of Memphis could have alleviated this as well as a clinical presence in Nashville at locations known to serve lower income women such as those at Meharry University’s medical school and those at Nashville General Hospital both of which are located in residential areas predominately populated by lower income African Americans. The church that was utilized for recruitment in Nashville is located in that area of Nashville, however, as previously mentioned, the recruitment method was a one shot attempt and relationships, well known in anthropological research for their importance attaining participants, were not established with the women encountered there (Agar 1980; Bernard 1994). Working through churches makes sense as a strategy for recruiting both more African American women and lower income women to future studies that could be utilized in all geographic areas. The church community is often utilized as an access point for health and research initiatives aimed at African Americans and church attendance is often associated with better health; for example, in a study of church attendance and health practice related to breast health screenings, Aaron (2003) found church attendance was not only associated with increased likelihood of positive health care practices, including health care seeking, but that it was particularly linked to better health practice, especially an increase in the number of doctor visits, for the less healthy and the uninsured. Establishing relationships within a church community could not only facilitate recruitment of a non-clinical sample, but would also provide a means of recruiting both men and women with CPP who may or may not seek health care for their condition.

Transportation, clinic schedules and locations are all well known barriers to accessing health care for lower income and minority women. (Lieberman, Stoller, Burg 1997) During the course of this study only one African American woman was interviewed who previously made appointments with the Memphis physicians at the downtown clinic and followed him to his new
practice. She was employed and owned a car. Financial assistance for transportation was offered to study participants to cover cost of travel to appointments for interviews. Only one participant, one of the African American women in Memphis, requested assistance.

In addition to the issues of local demographics and clinic access, differences in care seeking behaviors may partly explain the smaller percentage of African American women. (Aaron, Levin, Burstin 2003; Belgrave 1992; Dignam 2000; Miller et al 1996; Mitchell 2002; Pikler and Winterowd 2003). African American women are known to be less likely to ask for help, perceiving themselves as strong and capable of enduring pain and physical hardship. (Banks and Malone 2005; Davis 1981; Lieberman, Probart, Schoenberg 2003; Pikler and Winterword 2003) The experiences of slavery and ongoing racial discrimination contribute to attitudes of self-reliance, mistrust and possibly an increased desire for control of one’s body as well as to disparities in physical health and health care. (Collins, David, Handler, Wall and Andes 2004; Davis 1981; hooks 1989; Lackland et al 2004; Lieberman, Probart, Schoenberg 2003)

**Abuse and Ethnicity.** The ethnic variation in abuse rates was not statistically significant; however, the difference was notable, (69.2% among African Americans compared to 57.1% of European American women), which combined with the strength of associations between African American ethnicity and risk factors for abuse support further examination of racial/ethnic variation in abuse/assault history in larger samples of women with CPP. Explanations for the statistically significant ethnic variation in pain intensity with sex found in this study could be related to differences in the characteristics of sexual assault such as those reported by Golding (1996), however, with the exception of noting whether the age at the time of abuse/assault was thirteen or earlier or fourteen or older, data regarding the circumstances of sexual abuse/ assault
were not collected in consistent detail in this study. Many women who participated in this study provided lengthy and detailed accounts of abusive or assaultive experiences; others chose not to discuss it at all. I did not attempt to retrieve comparative data on circumstances of assault due to the variations in both the quantity and quality of information on the topic acquired during the interviews. Future work that provides more focused ethnographic exploration of differences in pelvic pain variables, sexual behaviors and attitudes as well as experiences of abuse and assault among ethnically diverse women are needed to clarify the relevance of these interrelated social characteristics and experiences to the development and treatment of CPP. African American women historically experienced more sexual objectification than their white counterparts (hooks 1989); bell hooks states that black women with a history of physical abuse frequently have a lack of interest in sex, which she explains as based in a lack of trust. She discusses the development of attitudes of self-reliance and enduring in order to cope as a child with racism and abuse, but goes on to note that “What may have worked well as a child doesn’t work so well as an adult” referring to African American women’s difficulty in developing a positive attitude towards sex. African American women are more likely to have experienced abuse and may have more intense need for body control than do white women, influencing both their attitudes toward sexuality and to medical intervention.

Age. The mean age of the women in the study sample (40.7 years) is consistent with other reports that CPP peaks at midlife. (Howard 2000a; Latthe et al 2006; Steege 1998) The mean age for women in the study who were on health related work disability was of interest, being slightly below the study mean age at 37.1. Only three women in the study sample related the cause their pelvic pain to be “life stresses” and all three of those women, notably, were in their 50’s. In addition, all three were also either in the process of changing their work conditions or
had already made a change to their work conditions because of pain and stress. It appears that women past mid-life may recognize the role of stress in CPP when they reflect back on the experience, whereas, in the earlier years while actively engaged in diagnosis and cure seeking, the role of life stress may not be clear. The one woman in the study from Virginia, who was one of the women who identified life stress as a cause of CPP explained it this way:

...I thought it was either irritable bowel or some cancers internally because there was constant pain. I thought I had something seriously wrong with me. I think now, what with what was going on (in my life) at that time, I think it was most likely stress.-W1

Whereas many women in the study emphasized the importance of working and described enduring severe pain while working long hours outside the home, these older women were choosing to limit the time spent at work. Maturity, the greater self-confidence that often comes with age for women as well as higher levels of personal economic resources accumulated from earlier work could all factor into the change in attitude toward work noted in this group of women who were now over 50 years old.

African American were slightly younger (mean age 39.07) than the European American women (mean age 40.39), a difference that was not statistically significant but of interest nonetheless. Considered the small size of the sample, it may be this difference would emerge with a higher level of significance in a large sample. The younger age of African American women could possibly be explained by the fact that cyclic (menstrual cycle) pelvic pain is more common among both younger women (age less than 30 years) and African American women.(Latthe et al 2006) Many women in this study had dysmenorrhea and non-cyclic pelvic pain as well as episodic dyspareunia (intercourse pain); relationships between the subtypes of CPP and racial, ethnic and sociodemographic variables were not a focus of this study, however, a
research design that facilitates that type of analysis could provide insightful information from future studies.

Younger women from minority groups, including African Americans, are more likely to experience both sexual and physical assault, which increases their risk of developing pelvic inflammatory disease (PID) a risk factor for all types of CPP. Exposure to abuse and assault as a precursor to PID increases the likelihood of minority women developing CPP at earlier ages (Champion et al 2005; Golding 1996; Walker et al 1998). Early age exposure to violence has been related to changes in blood pressure in minority teens (Ewart, Jorgensen, Schroder, Suchday, and Sherwood 2004); systemic hypertension was identified as a correlate of uterine fibroids in black women many years ago (Rubin and Ford 1974). Uterine fibroids, or leiomyomata, are somatic pathologic conditions commonly occurring in women with CPP; hypertension affects the highly vascularized uterine lining, resulting in end-organ remodeling that manifests as fibroids and possibly as endometriosis. This study by design addressed only adult women over 18 years of age; considering the implications from the literature that the precursors of CPP begin at earlier ages, the inclusion of adolescents and younger girls in future studies, particularly those aimed at promoting prevention and/or or understanding the developmental course of CPP and susceptibility to the condition seems warranted.

Marital Status. Marital or relationship strife, particularly over sex, was described by many of the women interviewed. Many women expressed distress that their family members (spouse, and/or children) had to take on more domestic responsibilities because of the limits on their function from CPP. Those who were divorced often cited the pain experience, and particularly sexual problems related to the pain, as contributing factors to the break up of the marriage. African American women were more likely to be divorced than their white counterparts, with 4
of the 14 African American women (just under 30%) were divorced; whereas only two of the 45 Euro women (less than 5%) were divorced. It appears that among women in this study sample, African American women who were married were more likely to divorce during the experience of CPP than were the European American women. More detailed exploration of marital relationships than was carried out in this study is needed to clarify and explain the influences between marriage, divorce and CPP in women from multi-ethnic background.

Being married was inversely related to health related disability among women in this study, with seven of the ten women on disability being married; one of the women on disability was divorced and two identified their marital status as single. It may be that the financial security associated with marriage increases the likelihood a woman will pursue disability status; or it could be that pelvic pain is complicated by the marital relationship, exacerbating the effects of the condition. Some studies indicate marriage increases the risk for CPP with lack of a supportive spouse (which in many cases may in fact be an oppressive spouse) being a significant variable in sexual dysfunction (Randolph and Reddy 2006) as well as in depression in women. (Baker Miller 1986; Doyal 1995; Ussher 1991; 2001) According to Engels, monogamous marriage transformed the nuclear family into the basic economic unit of society with women and children dependent on an individual man, facilitating the social oppression of women (Humphries 1987; Leacock 1972). From that perspective, the only way for women to be liberated is to participate in social production, which further deteriorates the position of women by moving domestic work to a private service assigned to women of lower class (Marx 1906). Marital relationships during the pelvic pain experience need further exploration; perhaps beginning by examining dialogue from women with CPP about the nature of their marital relationships and how they see those relationships effecting and being effected by their pain.
CPP as a Life Problem. Although not statistically significant, there was a notable difference in the percent of African American women (64.3%) compared to European American women (51.2%) who ranked CPP as the number one problem in their life. (Table 4-9) Structured follow up questioning aimed at understanding how women decide on the rank of their life problems among ethnically diverse women with CPP could shed light on the reasons for this variation as well as any relevance it may have to either susceptibility to the condition or recovery from it.

Work and Productivity

Work was the only value I had--M7

The majority of the women in the study (34 of 59) were employed (31 full time and three part-time); approximately 60% of both African American and European American women were working full time. None of the African American women who worked held part-time jobs, which may be related to SES and household need for income. Ten women were on health related disability eight of whom are white Euro-Americans and two are African American. The women on disability represented just fewer than 20% of all white women in the study and approximately 12% of the African American women. Seven of the women on disability were married; two were single, both white; and the one divorced woman is African American. The mean age for the women on disability was 37.1, slightly below the study sample mean age. The conversations in this study made it clear that most women with CPP strongly desire to continue to work and do so. The reasons why they work and the influence of marital and family relationships, SES, on the decisions about working are pertinent for further study. Asking a sample of women from a range of with CPP about their reasons for working pertinent to the continued study of CPP in women.

Most women in this study insist that pelvic pain will not stop them from working, especially not working outside the home. Women talked, sometimes at length and often
passionately, about the importance of being able to work; they spoke of their willingness to
tolerate pain on the job in order to keep working. The stereotypical perspective biomedical
practitioners have of patients with chronic pain syndromes is that they do not want to work and
are seeking care in part to seek a way out of work. In opposition to that expectation, women in
this study expressed a commitment to maintain their status in the work force was extreme in
some cases, and the majority of them were in fact working. Although the motivation not to give
up or give in can be interpreted as a positive coping strategy, it may in fact be detrimental to
health and recovery as was pointed out by one of the study participants. The question is raised as
to why women with CPP are willing to work so hard while in so much pain? What does staying
productive, either outside or inside the home, provide that women are willing to physically
suffer to maintain it? A Mexican woman in the study noted that throughout her life “work was
the only value I had”; she described a variety of social difficulties, and an almost equal number
of somatic complaints all of which limited her in her domestic responsibilities.

Emily Martin (1992) suggests from that the pain associated with premenstrual syndrome is
women’s embodied resistance to sexist oppression, emphasizing the oppressed position of
women and domestic work in the process of social production. Women in this study also spoke
of oppression with similar commentary on the monotony of domestic work and of sexist
workplace practices and attitudes. While describing her around the clock schedule of housework
and work outside the home one woman in Memphis said “I’m like every woman you know”
(M19) However, the women of this study spoke less about boring and monotonous jobs and
more about personal violence, assault, and physical and/or emotional harm. Many of them lived
the horrific realities of sexual abuse and violence, some more cognizant of the ongoing influence
of those experiences on their mental and physical health than others. One African American
woman in Memphis said, “The doctors don’t understand that all my problems are related to the rape…” Women often expressed resolve to establish and maintain their status as valued workers. For some, it seemed the value gained from working was worth enduring pain. Perhaps the most telling insight came from the Mexican-American woman in her twenties who as previously noted commented that “…work was the only value I had”. The need to continue to feel “normal” is suggested as an explanation for women with CPP to maintain high levels of function. (Grace and Zondervan 2006) Women with CPP clearly do not feel “normal” although pelvic pain is one sense normalized as something that women “get” (Grace and MacBride-Stewart 2007); the normalcy of the condition, particularly in the absence of a clear cut, organic or “real” medical diagnosis could contribute to woman’s need to continue to appear “normal.”

The determination expressed by many women in this study to continue to work and their ability to do so despite severe pain, not only raises questions about why they want to work despite pain, but also about how they do it. Continuing to function while in pain is difficult at best. It seems that staying productive, especially outside the home, as well fulfilling sexual obligations to spouses and significant others provides women with a social or emotional return so valuable that they are willing to physically suffer to maintain it. One possible explanation lies within the psychological profile of victims of abuse and violence. Trait dissociation, common among abuse victims (Hall 2003) and considered maladaptive in biomedicine. (Castillo 1997) Perhaps dissociation contributes to the ability of women with CPP to remain highly functioning despite extreme pain.

I approached this study with the expectation that work would factor significantly into women’s experiences with CPP. I expected that women would describe multiple social roles (Spurlock 1995) that they desired relief from in order to relax and heal. In fact, I framed the
initial questions to lead to discussions about overlapping and burdensome daily routines. I expected to hear themes of resistance to the many social obligations and perhaps see pain as a means for some women to escape the least desirable of those obligations. In some cases, that theme did emerge. Most notably in two mid-life women who clearly stated their desire to leave unhappy work situations drawing clear connections between the onsets or worsening of pain and the work related problems. The majority of women, however, clearly related a strong desire to stay on the job both at home and at work, despite pain.

When participants described the effects of CPP on their ability to carry out their daily responsibilities, most were much more likely to describe modifying their work at home than modifying their work outside the home. That aspect of the productivity theme, continuing to function at work outside the home, is consistent with other reports on work and women with CPP. (Grace and Zondervan 2006) Women may be more limited in their ability to negotiate changes in roles and responsibilities outside the home than in the home. Although variations certainly exist between family units, women may be more willing to express their social distress in the home, however, the reasons women with CPP continue to work and how they decide not to work are topics pertinent for continued study of women with CPP. The division of labor (DOL) typical of patriarch societies is such that women typically have less access and control over financial resources than men (Burn 2000; Chodrow 1999; Leacock 1972; Margolis 1984). When access to wealth is limited, perceptions of lack of power, control as well as a real and perceived lack of independence and value result (Burn 2000; Durkheim 1984; Leacock 1972; Margolis 1984; Marx 1906). Capitalistic societies place values on people based on their ability to produce wealth. People whose work is primarily domestic and not directly wealth-producing are considered low on the social value and power scale (Burn 2000; Castillo 2997; Martin 2001;
Margolis 1984; Marx 1906). Domestic work is most often carried out by women and girls across cultures and so by association with domesticity, women and girls often find themselves in a place of low social value. A particularly low value is placed on women directly involved in domestic occupations, and this low value can be associated with even lower status if the female domestic worker is also a member of a minority ethnic group. Low social value is reflected in the low wages and minimal benefits, such as lack of health insurance as a benefit for domestic workers. The same type of value system is often applied in the home when members of a family consciously or unconsciously evaluate each other’s contributions, usually giving heavier weight to the contributions that produce economic wealth than to those associated with domestic functions. (Doyal 995) It is likely that women who contribute substantially to the household income are less likely to modify their work schedules than women who produce discretionary income for the household. Other social and psychological factors likely factor in as well; further contextual examination of the decisions women with CPP make about work are needed to fully understand the meaning and clinical relevance of their productivity in and out of the home.

**Sex and Sexuality**

The slightly higher mean level of pain intensity among women without a history of sexual or physical abuse or assault, compared to that of women with a history of sexual or physical abuse or assault found was not statistically significant, however, the weight of the statistical analysis was limited due to the small sample size, in particular the small number of African American participants. Further examination of ethnic differences in pain variables among women with CPP in studies that include larger numbers of ethnically diverse women is warranted. The non significant differences in pain variables between abused and non-abused women in the study also warrant further study as the relationship between abuse and clinical manifestation of pelvic pain is not yet well understood. Comparing pain intensity with sex between women who are
premenopausal and those who are post-menopausal is another logical next step with this data set or in future studies as painful intercourse is known to be more common among post-menopausal women with CPP; however, pain intensity was not examined between those groups for this report. Further examination of associations between pain intensity and characteristics of abuse/assault among the participants in this study compared with women without an abuse history and in future studies may shed light on relationships between abuse/assault and the clinical course and presentation of CPP.

**Sexual abuse.** The majority of the women in the study had a history of sexual abuse (60%). The positive association between sexual abuse and CPP is well established, and plausible theories exist to support the etiologic nature of abuse for CPP. A biological causality from abuse to CPP is suggested by Champion et al (2005) in their report on risk of PID in a sample of abused minority adolescents. Others suggest that relationships between abuse and development of chronic pain syndromes may be related to the emergence of maladaptive coping skills in response to abuse. (Toomey et al 1995) From the perspective of anthropology and feminist science, CPP is likely an expression of social distress, the embodiment of pain caused by abusive experiences (Kleinman 1988a; 1988b; Kleinman 1992; Kleinman, Das and Locke 1997). The stories shared by the women in this study reveal distress about past traumatic, abusive, and/or threatening experiences. Comparative examination of the social and psychological aspects of CPP from the perspective of the abused women who “get” it (Grace and MacBride-Stewart 2007a) would help to enhance our understanding of susceptibility to CPP as well as the links between its clinical course and the various factors that contribute to it. Further explorations of the belief that sexual abuse and sexual and reproductive pain are “normal” may provide insight into care seeking behavior, sexual behavior, coping strategies and self-care strategies used by women
and girls with CPP. Early intervention for pelvic pain that targets abused and assaulted women as well as those already diagnosed with an STD or PID could prevent the development of CPP; understanding women’s thinking about their symptoms would be key to the development of effective prevention program.

**Causality and Diagnosis**

What do I think causes it? …it’s a little bit of a mystery…to me and the doctors... K2

One woman described the process of health care seeking for CPP as “waiting to know” acquiring an explanation for the pain is important in the biomedical process to determine the course of treatment, since treatment is diagnosis-driven for the most part. Many women indicated that knowing what is causing the problem would have a therapeutic benefit, and for some, it seemed to be the most they hoped for at this point as resolution of the symptoms did not seem possible. When asked to define an acceptable level of pain is, many women gave values above zero. Similar to the New Zealander women with CPP (Grace 1995; Grace and MacBride-Stewart 2007) both black African American and white-Hispanic and white-non-Hispanic women in this study were focused on gaining a clear, singular biological explanation their pain. The disease model of “catching” pelvic pain as you might catch a cold was verbalized by one participant as she tried to make sense of the diagnostic information she had been given. Using biocultural models to direct the development of both patient and clinician education programs and materials in a manner that is accurate and meaningful will be challenging, but has the potential for improving both diagnostic processes as well as understanding of pelvic pain as both an illness and a medical condition.

Biomedical diagnostic profile of the study participants revealed complex histories, with the review of systems (ROS) positive in almost all body systems on almost all participates. The majority of participants had multiple diagnoses across many body systems; some of the women
were beginning to question the medial diagnostic labels similar to the women in Martin’s (1992) study of childbirth who began to question information they were provided, however, all the women in this study were continuing to seek the cause as well as effective treatment. Selfe et al (1998) questions the relevance of a specific biomedical diagnoses based on their research using clinical samples in Britain; similar recommendations are suggested by others, however, the standard approaches of system by system examination to establish a diagnosis continues to be the most common approach for most women with the condition. Most of the women in the study have symptoms consistent with a diagnosis from each of the possible contributing systems—reproductive, urogenital, gastrointestinal, musculoskeletal and psychological. Although most of the women described signs and systems indicative of multi-system problems, most are receiving body system specific health care. The finding that multiple systems are involved could, from a reductionist perspective, support the suggestion from Selfe et al (1998) that diagnosis is not helpful in this population. Although the fact that that these women have symptoms of so many different body systems points out the inadequacy of a singular diagnosis, promotion of an interdisciplinary diagnosis seems more appropriate than completely condemning the concept of a somatic diagnosis for women with CPP. Effective diagnostic approaches to CPP would seem to be ones that views body systems in a collaborative rather than a hierarchal model. The psychological and social value of having a ‘name for the pain’ repeated by women in this study and others (Grace 1995) illustrates the importance of diagnostic labels to the women suffering with CPP. For women with CPP the diagnostic label provides validation of their pain to colleagues, friends, and family and legitimizes their symptoms to themselves as well; self-doubt related to “not knowing” what is wrong was commonly articulated by women in this study. In more practical terms, the diagnosis, and the related medical code, is the primary determinant of
payment for health care services from both private and government agencies. One recommendation from this study would be for the development of interdisciplinary clinics for CPP and/or increased attention to CPP in primary care with a primary care practitioner serving as the case manager for women with CPP. Increased involvement of primary care physicians in the management of CPP has been suggested in the past (Rosenfeld 1996) and is an approach that may or may not fit well within health care payment guidelines. Clearly attention to diagnostic categories appropriate for CPP care in the primary clinic may need to be developed, with recommendations for needed modifications in payment plan closely following.

The specialist and consulting center nature of the clinical practices where the study data was collected could possibly have contributed to the broad range of diagnostic variables found so consistently across the study population. The clinical sites in Memphis and Knoxville, where the majority of the women were located, specialize in chronic pelvic pain and so provide services to many women referred by other clinicians after failed courses of treatment. It seems likely that women with more complicated social and medical histories are less likely to respond to traditional biomedical care and so are more likely to find their way through professional or self-referral to specialty clinics such as those used in the study. The possibility exists that the complicated medical care could be iatrogenic for some of the multi-system involved, for example, chronic pain medication and antibiotic use, both common among women with CPP, could have ramifications in the gastrointestinal system. At this point in time, multi-system problems among women with CPP have not been approached from that perspective.

**Fragmentation**

The division of labor within the biomedical system is problematic for women seeking care for pelvic pain. The American women in this study, consistent with the New Zealander women in previous studies (Grace 1995; 2000; 2007) reveal experiences with health care for CPP that
leave them frustrated, doubting themselves and continuing to look for the answer to the primary question that brought them to health care—what is causing this pelvic pain and what can be done about it? The system is set out so that all body systems are not thoroughly addressed without consulting across clinical specialty areas, which for women with CPP means multiple clinic appointments, in multiple locations and often with multiple and many times conflicting directives on how to manage the condition. Although integrated and interdisciplinary approaches to CPP are the recommended approach to biomedical management, establishing a diagnosis is a reductionist process aimed at identifying a singular etiology responsible for a patient’s symptoms that is often prolonged, perhaps contributing to the chronicity of the condition (Grace 1995; Grace 2007)

Although integrated approaches are recommended and supported by this study as they have been in others, including a randomized clinical trial (Peters et al 1991), it appears that reductionist diagnostic approaches to CPP prevailed in the experiences of many of women in this study as they sought medical care for CPP. It appears that “Gynevision” (Ling 1993) continues to survive to some degree. Bates (1996) discussed the shortcomings of a fragmented approach to chronic pain management (i.e. health care providers choosing to address either physical or psychosocial aspects of pain) in her biocultural study of chronic pain patients. She emphasized the importance of practitioner’s placing both psychological and physical findings in the context of socio-cultural roles and beliefs for effective management of chronic pain. In practice, it appears that a biomedical holistic approach is conducted in a fragmented fashion as the division of labor in biomedicine is such that each body system has its one specialized practitioner with a separate office and separate approach. Holistic biomedical care turns out to add variables rather than pull them together as women are moved through various medical specialties, being
examined and treated one body system at a time. Women in this study, as in others, described how their senses of self as well as their understanding of the problem both become increasingly fragmented during the course of treatment. Many women presented a fragmented perception of the problem as well as of their medical care. The extensive and complex medical history of many of the women in this study bears witness to the phenomena of fragmentation of both self and health care common for women with CPP.

Several women in this study described the character of their health care encounters as supportive, many times emphasizing their appreciation for the care they were currently receiving. The frequent medical appointments, which I expected to be described as problematic, were viewed by many women in the study as a positive attribute of their care as the continual interaction with health care professionals provided not only needed interventions, but also support. Biomedical caregivers may need to be convinced that enhancing the function as a support mechanism is effective and appropriate role. Although trained to be compassionate and “patient centered”, biomedical practitioners are instructed to weigh most heavily the physical realities of a patient’s condition, keeping involvement with social aspects of the problem to a minimum (primarily consist of making appropriator referral) and keeping their own emotions separate from their practice.

**Conclusions and Future Work**

For women with CPP, biocultural perspectives on the causes of their suffering and their responses to treatment have the potential to contribute meaningful information about their health and the rehabilitation process. This study provides an account of how African American and European American women with CPP view the causes of their pain, the effects of pelvic pain on their lives at home, at work and in the community and their perceptions of the effectiveness of treatments that gives direction to future contextual studies. This study also contributes an
examination of racial and ethnic differences in the known diagnostic and social correlates of CPP to the relatively sparse literature that describes racial and/or ethnic correlates of the biomedical profile of the condition. Despite the limitations of the sample size, the study findings corroborate findings in previous studies and support further examination of ethnic differences in the clinical and social characteristics of women with CPP as well as more focused study on the relationships between sexual and physical abuse and women’s experiences with pelvic pain. The findings support further study aimed at explaining why some women exposed to abuse do and others do not develop CPP, and as well as why women without an abuse history are also susceptible. In addition, further study is warranted to clarify what role, ethnic background contributes to the development of CPP among women. Susceptibility to developing CPP, the developmental course of the condition from simple and acute to chronic and complex, and the responsiveness of symptoms to treatment are all important issues on the future research agenda for CPP in women that will be best addressed from a biocultural perspective. Cross-cultural studies as well as cultural and feminist critiques that examine ethno-cultural and socio-demographic characteristics among women with CPP with larger sample sizes that encompass both clinical and non-clinical samples of women with CPP will be helpful to gaining a better understanding of this problem and to alleviating the suffering associated with it.

**Health Care for Women with Chronic Pelvic Pain Through a Biocultural Lens**

The diagnostic profiles of the women in this study support an interdisciplinary, integrated bioculturally informed approach to CPP management. A biocultural approach to health care for women with CPP would ultimately be characterized by changes in delivery models to a more patient centered, comprehensive/interdisciplinary clinical examination and treatment than most women are currently experiencing. Clarifying causality would also be a priority as women in this study, consistent with the New Zealander women interviewed by Grace (1995), indicated that
they want to understand the cause of their pain almost as much as they want it to be alleviated. Considering this, a biocultural approach to CPP would emphasize explanatory models that clarify for women how both the biological and the cultural aspects of their lives interact to contribute to their pain and to their recovery from it. Cognitive and behavioral therapies would also be central to a biocultural approach to health care for CPP. Behavioral conditions associated with CPP such as depression, anxiety and post-traumatic stress disorder (PTSD) are routinely treated with medication designed to alter the biochemistry that drives the behavior. The recognition of the interaction between biochemistry and psychological pathology is consistent with an integrated approach that recognizes psychological and biological factors and their interaction. Physiological intervention is, however, the more customary first line approach to the clinical management of psychological, social and emotional issues. Family and individual counseling was infrequently a component of treatment for women in this study with less than 10% reporting referrals to counseling services but the majority reporting treatment with antidepressants and some point in their course of care for CPP.

Testing and expanding biocultural models in clinical situations will facilitate the continued acquisition of information about the social context of CPP and enhance the ability of biomedical practitioners to provide health care that better meets the needs of the many women affected by this condition. Changed approaches to biomedical practice would also in practical terms, need to be supported in the curricula of medical and other health professions schools addressing ethnocultural as well as psychological and biological aspects of CPP. Biocultural studies such as this one will help inform such broadened training and practice.
Guiding Questions: Explanatory Models-Cause of Pelvic Pain

1. What do you think causes your pelvic pain?
2. What do you think is causing the symptoms/changes you are experiencing during sexual activity?
3. Why do you think it started when it did?
4. What does pelvic pain do to you? How does it work on your body?
5. How long do you think it will last?
6. How have you treated it so far?
7. Are there other treatments you would like to have or that you think would help?
8. What are the main problems that pelvic pain has caused you?
9. What do you fear most about your pelvic pain problem?
10. I know very little about your culture, is there something that’s been suggested for to treat your pelvic pain that does not fit with your beliefs about pelvic pain or how to treat it?
Ethnicity Survey

1. Do you consider yourself to be a member of any of the ethnic group? If you have more than one ethnic affiliation, which is primary and which is secondary?

African American

Hispanic

Irish

Polish

Italian

French Canadian

American Indian/Native American

Other group?

Did you grow up in a country other than the US? Your parents or grandparents?

2. If you are currently religiously active, what affiliation? Is it different from your childhood/

Participant ID:

Biocultural Correlates of Chronic Pelvic Pain in Women: Patricia M. King Baker
Semi-structured Interview-Social Roles, Responsibilities & Resources (SRRR)
Interview Guide

Part I. Introduction to this part of the interview

Introductory statement:

“This is the part of the interview where we will talk about your daily routine. I’ll be asking you questions about the jobs you do each day---not just paying jobs, but other things like, for example, your responsibilities at home, with your friends and family and in your neighborhood, in your church. I have the idea that the number of things people have to do each day and the amount of time they have to do their jobs and to take care of themselves might have some affect pain and other illnesses. Just like with the other parts of the interview, you don’t have to answer any question you don’t want to answer. There are no right or wrong answers to any question. I will ask you some questions about your income and other resources that are available to you to do the things you want and need to do each day. And again, you don’t have to answer any question you don’t wish to answer. All of your answers will be kept strictly confidential, as is all the information from today’s session.

A. Social Roles

How many people in your home? Kinship or other relationship to people in home?

Family, friends and groups (regular contact)

Occupational roles and responsibilities

Household roles and responsibilities

Community roles and responsibilities

Other?

B. How Roles are altered by Pelvic Pain?

Any changes in how roles altered for better or worse with treatment?

Average day: types of thing do for other and time spent?
Average day: types of things do for self and time spent?

Average day: types of things others do for you and time spent?

II. Health Behaviors
A. Free List

What types of things do you do on a regular basis to take care of your health?

Has pelvic pain changed those things?

B. Sleep

Do you sleep well at night?

How many hours a night would say you sleep each night?

Has sleep been altered by pelvic pain?

What time do you go to bed? Get up/

B. Exercise

How much time do you exercise each week?

Type of exercise

Has exercise been altered by pelvic pain?

C. Health Care

How often do you see a doctor or other health care practitioner?

Has pelvic pain altered the frequency of doctor visits?

C. Stress

How would you describe your stress level?

What’s the most stressful thing on an average day?

How to you respond?
III. Lifestyle

How has pelvic pain changed your life:
   At work?

   At home?

   Socially? In the Community?

   Other Ways

IV. Treatment Response

Are you better? What’s helping if anything? What do you think will help?

**Bio-Cultural Correlates of Chronic Pelvic Pain in Women Study**

**Physical Assessment Form**

Participant ID: _______________

Date : _______________ Examiner Initials: ____________

**Group A. Lumbar Posture Assessment**

Inclination Angles

L5-S1 ____________ Degrees   T12-L1 ____________ Degrees
Group B: Hip Mobility-Flexibility and Range of Motion Assessments

Hip Passive ROM Test Position: ________ Sitting ________ Supine

_______ ° Internal Rotation (Right) _________ ° External Rotation (Right)

_______ ° Internal Rotation (Left) _________ ° External Rotation (Left)

Thomas Test

_______ ° Hip Flexion (Right) _________ ° Hip Flexion (Left)

Group C: Muscle Performance Assessments

1. Kendall Abdominal Test I

N (5)_______ G (4) _________ F+ (3)_______ F (2)_______ P or below (1)_______

Kendall Abdominal Test II

N (5)_______ G (4) _________ F+ (3)_______ F (2)_______ P or below (1)_______

Trendelenberg’s Test

Right Gluteus Medius: _______(0) Negative _________(1) Positive

Left Gluteus Medius: _______(0) Negative _________(1) Positive

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(205) 877-2950 www.pelvicpain.org (800) 624-9676 (if in the U.S.)
**Pelvic Pain Assessment Form**

**Physician:**

**Initial History and Physical Exam Date:**

**Contact Information**

Name:  
Birth Date:  
Chart Number: 
Phone:  
Work:  
Home: 

Is there an alternate contact if we cannot reach you?  
Alternate contact phone number:

**Information About Your Pain**

Please describe your pain problem:

What do you think is causing your pain?

What does your family think is causing your pain?

Do you think anyone is to blame for your pain?  
Yes  
No If so, who?

Do you think surgery will be necessary?  
Yes  
No

Is there an event that you associate with the onset of pain?  
Yes  
No If so, what?

How long have you had this pain?  
< 6 months  
6 months – 1 year  
1 – 2 years  
> 2 years

For each of the symptoms listed below, please “bubble in” your level of pain over the last month using a 10-point scale:

0 – no pain  
10 – the worst pain imaginable

How would you rate your present pain?  

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
<th>8</th>
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<tr>
<td>Pain at ovulation (mid-cycle)</td>
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<td>Pain level just before period</td>
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<td>Pain (not cramps) with period</td>
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<td>Deep pain with intercourse</td>
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<td>Pain in groin when lifting</td>
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<td>Pelvic pain lasting hours or days after intercourse</td>
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<td>Pain when bladder is full</td>
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<td>Muscle/joint pain</td>
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<td>Ovarian pain</td>
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<td>Level of cramps with period</td>
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<td>Pain after period is over</td>
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<td>Burning vaginal pain with sex</td>
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<td>Pain with urination</td>
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<td>Backache</td>
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<td>Migraine headache</td>
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<td>What would be an acceptable level of pain?</td>
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What is the worst type of pain?  
Kidney stone  
Bowel obstruction  
Migraine headache  
Labor & delivery  
Current pelvic pain  
Backache  
Broken bone  
Surgery  
Other

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Demographic Information

Are you (check all that apply):
- Married
- Widowed
- Separated
- Committed Relationship
- Single
- Remarried
- Divorced

Who do you live with?

Education:
- Less than 12 years
- High School graduate
- Bachelor’s degree
- Postgraduate degree

What kind of work are you trained for?

What type of work are you doing?

Health Habits

Do you get regular exercise?  Yes  No  Type:

What is your diet like?

What is your caffeine intake (number per day, include coffee, tea, soft drinks, etc.)?  0  1–3  4–6  >6

How many cigarettes do you smoke per day?  How many years?

Have you ever felt the need to cut down on your drinking?  Yes  No

Have you ever felt annoyed by criticism of your drinking?  Yes  No

Have you ever felt guilty about your drinking, or about something you said or did while you were drinking?  Yes  No

Have you ever taken a morning “eye-opener” drink?  Yes  No

What is your use of recreational drugs?  Never used  Used in past, but not now  Presently using  Choose not to answer
- Heroin
- Amphetamines
- Marijuana
- Barbiturates
- Cocaine
- Other

Have you ever received treatment for substance abuse?  Yes  No

Coping Mechanisms

Who are the people you talk to concerning your pain, or during stressful times?
- Spouse/Partner
- Relative
- Support Group
- Clergy
- Friend
- Doctor/Nurse
- Mental Health Professional
- I take care of myself

How does your partner deal with your pain?
- Doesn’t notice when I’m in pain
- Takes care of me
- Not applicable
- Withdraws
- Feels helpless
- Distracts me with activities
- Gets angry

What helps your pain?
- Meditation
- Relaxation
- Lying down
- Music
- Massage
- Ice
- Heating pad
- Hot bath
- Pain medication
- Laxatives/enema
- Injection
- TENS unit
- Bowel movement
- Emptying bladder
- Nothing
- Other

What makes your pain worse?
- Intercourse
- Orgasm
- Stress
- Full meal
- Bowel movement
- Full bladder
- Urination
- Standing
- Walking
- Exercise
- Time of day
- Weather
- Contact with clothing
- Coughing/sneezing
- Not related to anything
- Other

Of all of the problems or stresses in your life, how does your pain compare in importance?
- The most important problem
- Just one of several/many problems
**Menses**

How old were you when your menses started?
Are you still having menstrual periods? Yes  No
Answer the following only if you are still having menstrual periods:
Periods are: Light  Moderate  Heavy  Bleed through protection
How many days between your periods?
How many days of menstrual flow?
Date of last menses?
Do you have any pain with your periods? Yes  No
Does pain start the day flow starts? Yes  No
Starts days before flow starts: Yes  No
Are periods regular? Yes  No
Do you pass any clots in menstrual flow? Yes  No

**Bladder**

Do you experience any of the following:
Loss of urine when coughing, sneezing, or laughing? Yes  No
Frequent urination? Yes  No
Need to urinate with little warning? Yes  No
Difficulty passing urine? Yes  No
Frequent bladder infections? Yes  No
Frequency of nighttime urination: 0–1  2 or more Volume: Small  Medium  Large
Frequency of daytime urination: 8 or less  9–15  >16 Volume: Small  Medium  Large
Do you still feel full after urination? Yes  No

**Bowel**

Is there discomfort or pain associated with a change in the consistency of the stool (i.e., softer or harder)? Yes  No
Would you say that at least one-fourth (_) of the occasions or days in the last 3 months you have had any of the following
(Check all that apply)
- Fewer than three bowel movements a week (0–2 bowel movements)
- More than three bowel movements a day (4 or more bowel movements)
- Hard or lumpy stools
- Loose or watery stools
- Straining during a bowel movement
- Urgency – having to rush to the bathroom for a bowel movement
- Feeling of incomplete emptying after a bowel movement
- Passing mucus (white material) during a bowel movement
- Abdominal fullness, bloating, or swelling


**Gastrointestinal/Eating**

Do you have nausea? No  With pain  Taking medications
With eating  Other
Do you have vomiting? No  With pain  Taking medications
With eating  Other
Have you ever had an eating disorder such as anorexia or bulimia? Yes  No

© 1999, The International Pelvic Pain Society Page 7
Have you ever been hospitalized for anything besides surgery or childbirth?  Yes  No If yes, explain:
Have you had major accidents such as falls or back injury?  Yes  No
Have you ever been treated for depression?  Yes  No Treatments:
- Medication
- Hospitalization
- Psychotherapy
Birth control method:  Nothing  Pill  Vasectomy  Hysterectomy
- IUD  Rhythm  Diaphragm  Tubal Ligation
- Condom  Other:
Is future fertility desired?  Yes  No
How many pregnancies have you had?
Resulting in (#): Full 9 month Premature Abortions (miscarriage) # living children
Any complications during pregnancy, labor, delivery, or post partum period?
- Episiotomy  C-section  Post-partum hemorrhaging
- Vaginal lacerations  Forceps  Medication for bleeding
- Other:
Has anyone in your family ever had:
- Fibromyalgia
- Chronic pelvic pain
- Scleroderma
- Endometriosis
- Lupus
- Interstitial cystitis
- Cancer
- Depression
- Irritable Bowel Syndrome
- Recurrent Urinary Tract Infections
Place an “X” at the point of your most intense pain.
Shade in all other painful areas.

Dear Healthcare Professional:

The Research Committee, headed by Deborah Metzger, M.D., Ph.D., along with the Board of Directors of The International Pelvic Pain Society are proud to present this Pelvic Pain Assessment Form for use in the medical community. This form has been developed by clinicians who treat chronic pelvic pain on a daily basis, and is the culmination of two year’s effort. We hope that you find it useful. The Pelvic Pain Assessment Form is designed to be printed front and back to yield a total of 10 pages on 5 sheets, for your convenience.

It is our desire that this form become a standard in your intake procedures. We solicit your constructive comments. It is only by open communication from the clinician who uses this form consistently that we will improve it. You can phone your comments to the number shown on the form, or e-mail us at pelvicpain@aol.com.

Sincerely,

C. Paul Perry, M.D., Deborah Metzger, M.D., Ph.D.
Chairman of the Board of Directors Chairperson, Research Committee
Please type or word process the following information.

UFIRB #_2003-U-523___
PRINCIPAL INVESTIGATOR__Patricia M. ing_____________________________

PROTOCOL TITLE_Bio-Cultural Correlates of Chronic Pelvic Pain in Women: Examining Relationships Among Ethnicity, Social Roles, Pain Character, Physical Impairments and Level of Function_____________________________________

Continuing Review/Study Closure Report

To help us keep our records current, please complete the following and return it to the UFIRB Office, PO Box 112250, Gainesville, FL 32611-2250.

If you have any questions, please call 392-0433. (This form is also available at http://www.ortge.ufl.edu/irb/irb02.)

Check all items that apply to your protocol and provide requested information. (You may attach additional sheets if necessary.)

1. On what date did data collection begin? ___will begin 5/10/04_____

2. Please indicate the statement that best describes the status of this protocol:
   ____ a) I have completed work on this protocol. I will answer the remaining questions on this form to enable the IRB office to officially close the protocol.
   ____ b) I have not begun data collection. I plan to start on _____
   _X_ c) Human participants are currently being recruited.

I have attached 3 clean copies of the current informed consent. Upon approval, the IRB will stamp an expiration date on them, and return one copy for me to duplicate.

   ____ d) No further recruiting will occur after the expiration date. However, the data collected during the research shall be analyzed.
   ____ e) No further recruiting of participants will occur, but data collection will continue on at least one participant.
   ____ f) No further recruiting will occur. All interventions are completed on all participants, but follow-up is being conducted as described in the informed consent. These follow-up activities are described as follows:
3. If there have been any additions or deletions to the list of researchers involved with this protocol, I have described the reason for each change below and have updated the informed consent form to include only the current researcher(s):

N/A

4. If the protocol is externally funded, and the information about sponsorship is not correct in the protocol, the revised IRB form identifies the following sponsor(s):

Self-funded by PI: no changes

5. Please indicate the following:
   _____ a) The total number of participants recruited during the past year:_________
   _____ b) The total number of participants to be recruited during the next year:_________
   _____ c) I have recruited, or plan to recruit, more participants than originally estimated because:
   ___X___ d) I have recruited no participants because: I relocated from Virginia to Tennessee after the study protocol was approved. I put the study on hold during the transition period when I had teaching responsibilities in both locations. I am now settled in the new location in Tennessee and have established new contacts here for participant recruitment and will begin data collection in Tennessee in May. A small number of participants (less than 20) are expected from the Virginia location. Data collection in Virginia is scheduled for May 25- June 4, 2004.

6. Was written informed consent required by the IRB and obtained from each participant?
   ___Yes___No

   N/A

If the answer is YES, attach to this form a photocopy of the last signed consent that you obtained.

If the answer is NO, please explain the circumstances under which written informed consent was not obtained:
7. Were any changes, however minor, made to your protocol last year? __X_ Yes __No

One change is included in this report. Local support groups for women with chronic pelvic pain will be utilized to recruit study participants in addition to clinical sites where women are seeking care. Written and verbal explanations of the study will be provided to support group members during meetings with the prior approval of support group leaders.

If YES, were those changes reviewed and approved by the IRB prior to their implementation? ___Yes___No

If changes were made to the protocol that were not submitted to and approved by the IRB, please describe the revision and explain why it was not sent to the IRB for review:

N/A

8. Did any unanticipated outcomes or adverse events occur the past year? __Yes __No

If YES, please indicate which ones were previously reported to the IRB:

9. Did any participant withdraw from this research project during the past year? __Yes __No

If YES, please indicate the reason for EACH participant's withdrawal:

10. The research participants in this protocol include the following that are checked:

___ Infants ___ Children ___ Adolescents

__X_ Adults ___ Prisoners ___X_ Pregnant women

___Mentally or emotionally challenged individuals

Participants in the above categories will be recruited for this protocol.

11. The IRB, the University of Florida, and the Federal regulatory agencies consider continuing reviews to be extremely important. Research studies are approved based on an estimated ratio of potential benefits to possible risks.

• Comment on how your participants responded to the study and tolerated your interventions. (This item may be omitted only if no data were collected on research participants in the last year.)

N/A

• Give your opinion about any changes in the risk-benefit ratio. Is there any new information (e.g. alternative procedures, new information published in the literature) that might affect the risk benefit ratio?
I plan to add additional compensation for travel to the study site for participants who make a special trip to the sites outside their regularly scheduled clinic visits. Otherwise, there is no new information to report regarding the risk benefit ratio.

- If data from your study have been reported, attached one copy of each published report.

Principal Investigator: __________________________ Date __________________

Supervisor (of student PI)________________________ Date __________________

Department Chair________________________ Date __________________

Thank you for completing this information. Please return this form to the UFIRB Office, PO Box 112250, Gainesville, FL 32611-2250. If you have any questions, please call 392-0433.
APPENDIX C
CODING AND TEXT ANALYSIS

Code Book
Chronic Pelvic Pain Data- Excel File: CPPdataKingBaker07
Trish King Baker, Biological Correlates of CPP in Women

A=Case #001-063
In chronological order of signed Informed consent beginning with participants from Memphis, followed by Nashville, Winchester and Knoxville (1-63)

B=Ethnicity
1=African American 2= White non-Hispanic 3=Other
Self-report

C=Age
Age in years on date Informed consent was signed

D=Marital status
1=Married 2=Single 3=Divorced 4=Committed Relationship 5=widowed 6=separated

E=Head of Household (HOH)
Adult with sole financial responsibility for household
1=Yes, participant is HOH
2=No, not HOH

F=Work Status (WrkStat)
1=Full time employed 2=Part-time employed 3=Homemaker 4= student, not working 5=not working due to health 6=retired 7=not working not due to retirement/health

G=Education
1=less than 12 years 2=High School Graduate 3=some college or technical school after high school 4=BS degree 5=graduate school

H=Musculoskeletal Pattern (MSKPtrn)
1=participant fits the Musculoskeletal CPP Pattern (at least 2 positive findings on physical exam-+Thomas Test, +Hip Rotation Restriction, +increased Lumbar lordosis (12> at L5-S1), Abdominal strength 3/5 or less)
2=Participant does not fit pattern in 2 or more findings

I=Pain Intensity (P!Intensity)
0-10 scale
(0=no pain, 10 worst imaginable, need to be seen in hospital) Overall worst level of pain associated with CPP
J=Pain with intercourse (Sex!P!)
0-10 scale
Highest # selected on scale for either deep pain with intercourse, pelvic pain lasting after intercourse or burning pain with intercourse from page 1 IPPS form

K=Pain Location (P!Location)
1= abdominal-midline or both sides
2=right abdominal is predominant
3=left abdominal is predominant
4=pelvic floor, vaginal or rectal pain is predominant
From pain drawing IPPS form, description of problem page 1 IPPS

L=Acceptable level of pain (Acceptp!)
0-10
Participant rating of an acceptable level of pain on 0-10 scale (page 1 IPPS)
99=Missing data

M=Gynecological Signs or Symptoms
1=Yes, reports Gynecological signs or symptoms associated with problem either currently or in past
2=No, Gynecological Signs or Symptoms not reported
Coded Yes if reports pain with orgasm, ovarian pain, positive response to pain with periods (during before or after-non cramping), diagnosis of endometriosis, dysmenorrheal, ovarian cyst, uterine fibroid, gynecological adhesions, history of hysterectomy to resolve CPP)

N=Urological Signs or Symptoms
1=yes, reports Urological Signs or Symptoms
2=No, does not report Urological signs or Symptoms
Reported on IPPS form page 1 (pain with full bladder) and page 3-reported as yes if answered in positive to questions re: SUI, frequency, urgency, nocturia

0=Gastrointestinal Symptoms
1=Yes, reports Gastrointestinal Signs or Symptoms on Drossman’s Bowel Disorders questionnaire page 3 IPPS form
2=No, does not report Gastrointestinal Signs or Symptoms

P=Exercise Regularly
1=Yes, reports participates in exercise regularly (page 2 IPPS)
2=No, reports does not participant in exercise regularly

Q=Depression Treatment
1=Yes, reports current or previous treatment for depression (page 7 IPPS)
2=No, reports no current or previous treatment for depression
R=Problem Rank
1=CPP is the most important problem in the woman’s life
2=CPP is on of many problems/stresses in the woman’s life (page 2 IPPS)
99=Missing

S=Treatment Response—are you getting better (Better?)
1=Yes, Participant reports CPP is getting better (final question, semi-structured interview)
2=No, reports not getting better
3=Better only when taking medication
4=Reports unsure if better or not
99=Missing

T=Number of Pregnancies (Preg#)
0-10 number of pregnancies
99=missing

U=Low Back Pain as co-morbidity? (LBP)
1=Yes, LBP reported as co-morbidity either on page 1 IPPS, on pain drawing or during interview
2=No, LBP not reported

V=Abuse History (AbuseHx)
0=no history of emotional, physical or sexual abuse as child or adult
1=sexual abuse as child/adolescent
2=sexual abuse or assault as adult (over age 18)
3=physical abuse as child
4=physical abuse as adult
5=sexual & physical as child
6=sexual & physical as adult
7=emotional abuse
8=emotional & sexual child
9=emotional & sexual adult
10=EPS child
11=EPS adult
12=Emotional & physical child
13=emotional & physical adult
99=missing

W=Clinic Location (Clinic)
1=Memphis
2=Knoxville
3=Nashville
4=Winchester
NARRATIVE THEME:
CAUSALITY

Cause Unknown
   African American Women
M2: The pain started at age 14 when I was raped. **What do I think is the cause of the pain? I have no idea.**

M21: I don’t know what causes it; I’m on the go all the time; my mom thinks it’s because I don’t get enough rest

M22: I don’t know what is causing my pain. Dr. Ling says it is my muscles… It’s not normal to have pain there.

PK: What do you think is causing it?
M36: I don’t know.
PK: Sometimes even though they haven’t told you but you might have something in your mind that kind of seems like it is but nothing like that, no clue?
M36: No clue

PK: Did they do the hysterectomy because of the pain or for some other reason?
M36: The pain and also he said I had a lot of scar tissue.
PK: What was the scar tissue from?
M36: I don’t know.
PK: Did you feel better for a while in terms of the pain after the hysterectomy?
M36: Yes.
PK: Is the pain you have now the same as before the hysterectomy?
M36: Yes it was.
PK: It got a little better but for the last 10 years you still have it?
M36: Yes. It never really went away. I thought it was maybe from the scar tissue because he went in and he never did get anything out because I started bleeding real bad so he had to close me up. Ever since then it never stopped.
White American Women-Memphis

M9: I do not have a clue what is causing the pain

M17: Pelvic? Trying to understand (me and my family)

PK: In terms of an event that started it initially when it first started was there anything you had related having this pain?
M32: When I was young.
PK: Has it been constant since then?
M32: Yes. Since I was 13 or 14 and I went to a doctor, a gynecologist, when I was about 15 and he said I was too young to have this, to have problems like this and he kept putting me on the pill which my body reacts very negatively to. I get violently ill and ended up in the hospital a few times. Anything that increases my hormone levels just sends my body in more pain.

M32: There has never been any rhyme or reason to any of it. Ever since I was 13 or 14 I had a really bad one then I wouldn’t for months. It’s been that way. It’s never changed as far as the roller coaster. It’s not the same every month. Some months I feel great.

M34: At times I just feel like I need to start my period and you know of course I haven’t had one going on seven years so I’ll just get in a ball and try.

M37: I don’t know. I thought adhesions since I’ve had so many surgeries and Dr. Ling has ruled that out with a CAT scan
PKB: What’s the worst part of this experience?
M37: Not knowing; and the sleep (interrupted sleep) When it’s going on (pain) often it is in the middle of the night
PKB: Cause of your pain, you have a question mark.
M43: I don’t know.
PK: You just don’t really have any idea?
M43: I’ve had every test and I’m sure there’s more out there but I’ve had a lot of tests and it’s not showing anything.
PK: Sometimes we will have an idea in our mind like it seems to me like it’s this or that?
M43: I have said from the beginning of it I thought it had something to do with the screen that he put in to repair the hernia only because it started after that surgery but it doesn’t feel like anything else I’ve had before.

PK: Okay. And in terms of what you think is causing the pain, endometriosis is it?
M52: I have no idea.
PK: You really feel like you have no idea?
M52: I really don’t; since I’ve had so many surgeries and it just doesn’t seem to help and I’ve tried every hormone drug available and you know, anti-inflammatory and everything and it doesn’t seem to help that you just kind of think it could be something else, you know what is it
M52: People don’t know but sometimes people have just like something that doctors never said it or doctors never acknowledged it but it just feels like if this would just happen or that would just happen it might get better.

M52: On the cause and what might help: “That’s just a big question mark.”

White American-Knoxville

K1: Concentrating on staying on ice, going to the doctor, trying to find out what was wrong, staying on ice, getting in the bed, doing a load of clothes then getting back in the bed, get on heat, alternate, alternate to be able to get up and go back to work. Work on ice all day, why can’t I see it, nobody has a reason you know. It was just a continuation of that until I started doing this (physical therapy) on my own.

K2: Well, the physical therapist thought all along that I had two lumbar issues and I do have, but she doesn’t think that’s what’s causing my problem. I think it’s a little bit of a mystery to her too.

K9: Interstitial cystitis causes the bladder pain. It just came out of the blue as far as I can tell. I used to drink a lot of coffee and I’m sure that I ate, of course I ate all those other things, acidic things that were irritating. It just hit me like a bolt out of the blue--knocked me off my feet. I have burning pain in my vagina; I don’t know what causes that

K10: You do think ‘what is this horrible pain?’ I still want an answer about this swelling. I want to know why

K14: I don’t feel like there’s an actual explanation. Even when they did the surgery for the endometriosis he was expecting to go in and find a whole bunch and that would explain and they even cut the nerves that connect to my uterus and ovaries and apparently it didn’t work because I still feel all the pain. He won’t tell me that he’s run out of options. He keeps telling me we’ll try different things. He sent me here. He sent me to the IC clinic.

Childbirth

African American

White American-Memphis

M23: Cause: Giving birth and placenta not coming out. Children are 2 years old and 6 years old, pain related to having children; no pain with periods, no intercourse pain.

M39 Actually it’s been seven years, it started after my second child, he’ll turn seven in August. The pain got to the point where I couldn’t walk, I couldn’t function any more and that started at five years ago. One year after having him I went to an OB/GYN and she said oh that’s just normal for two kids and she just kind of sent me away.

K3: This last doctor I went to said that it could be a scar from childbirth
M5: “My daughters do whatever they can to help me; they think the problem is their being born and stuff. I said it’s just from what I had to go through to bring you into this world but it is not your fault.”

M5: My husband thinks the doctors are too blame that it was from problems with 2nd c-section; during the 2nd pregnancy I was humiliated by physician and 5 residents in front of my husband the decision for the C-section made by the doctor and my husband, I did not want it; I did not want pregnancy or the C-section due to pain from 1st c-section; I was already upset to be pregnant 4 months after the first Caesarean Section (C-section)... Now that I’ve had a hysterectomy I think the pain is mostly muscular.

Abuse/Assault
African American
M2: The pain started at age 14 when I was raped. What do I think is the cause of the pain? “I have no idea.”

M4 I did think it was because of the rape; it started after I was raped when I was 18 years old. I bled for 2 days after I was raped. I’ve been told it is because of ovarian cysts and scar tissue.

M40: My daddy kicked my mom in the behind when she was pregnant with me, kicked a hernia in my stomach so I was born with a hernia needing hernia surgery and they couldn’t wait any longer. I had it at two but they couldn’t wait any longer. I was wounded before I was born.
PK: Do you have memories that far back?
M40: I remember hurting in my thighs. That’s all I remember.

White American Knoxville

Life
White American Memphis
PKB: What do you think is causing your pain?
M25: Life—my husband’s disability, my kids. I internalize a lot.
PKB: Was there an event associated with onset of your pain?
M25: Yes, it was work; we were moved to a different office; I didn’t want to go.

W1: I thought it was either irritable bowel or I had a tumor in my stomach or cancer. I thought I had some cancers internally because there was constant pain. I thought I had something seriously wrong with me. I think now, what it that was going on there at that time was, I think it was most likely stress. There was something else that was going on.

M19: Maybe it’s stress; I’ve had a lot. My brother committed suicide; my husband lost his job; There were changes at work that have made work environment miserable for the last 4 years but I’m now the primary breadwinner at home so I have to put up with it; our children are having problems that are costing us money...it goes on. The last episode of increased pain did start while I was at work a few months ago...
Injury/Accident
African American

M6: It started after I was injuries in a car accident 14 years ago; I was mainly hurt on my left side—arms and legs

White American Memphis

White American Knoxville

K7: My mother and I were talking about this last weekend. I was working tables in a restaurant in college. I had an episode in my lower back and who knows that’s when this could have all started. I was leaning over a table and wiping it. I just stopped. It was to the point where I got down on the floor and couldn’t get back up kind of thing. I went to a chiropractor at that time. That kind of worked out. I had episodes that had gone through my mind that were what I called lower back and diagnosed many times with lower back problems.

Medical Diagnosis
African American

M1: I mean I’ve read a lot about it (endometriosis) so I mean that’s basically my only question is the endometriosis and then what actually is the pelvic floor pain, I mean I know what they are but, and the muscle spasms, how des that actually, if its’ not caused from the endometriosis, how is another way that I could have got this?

White American Memphis

M28: I know that a lot of it is period related and my guy (doctor) said that’s definitely the worst time and my pain is the worst then.

M32: Pt: I think I’ve read every book on endometriosis and women’s disorder and I just wanted to be sure you didn’t have anything else that I could do.

PK: When you had the gallbladder surgery it didn’t make it any better, right?

M34: Right. My main thing is adhesions that the surgeries they tried to do laparoscopies and they get in there and can’t see because I’m so balled up with adhesions and this and that. I feel that’s the main factor

White American Knoxville

K5: That’s what I think it is the endometriosis causing my pain; most of the doctors and my therapist agree I think, one may be a little more one way and one may be a little less another way but all around about my doctors thinks I have interstitial cystitis as well as he’s the one that said I had the chronic pelvic pain. You know I was associating it with my periods and the fact that this all seemed to get at its worst point when I got, when I did tubal ligation…a lot of times I just honestly feel like if I could just cut those bands off this pain would end.
**PKB:** What do you think is causing your pain?

**K8:** Endo and IC

**PK:** You are pretty comfortable those are the answers? You don’t have an idea it was something else out there they haven’t figured out yet?

**K8:** I have such good doctors. I just can’t go through life like what if I have this, what if I have that. I look at the Internet. Before I had interstitial cystitis my dad would look up a bunch of stuff and I was like don’t tell me anything. I don’t want to know unless I have it. If I have it we’ll look at it but I don’t want to know

**K9:** Interstitial cystitis causes the bladder pain. It just came out of the blue as far as I can tell. I used to drink a lot of coffee and I’m sure that I ate; of course I ate all those other things, acidic things that were irritating. It just hit me like a bolt out of the blue--knocked me off my feet. I have burning pain in my vagina; I don’t know what causes that

**K15:** I’m thinking maybe its arthritis, I don’t know. My mother had osteoarthritis. She had a hard time with that. it didn’t start happening until after my surgery but I was thinking because I’m not on any hormone replacement that it could be from that.

**Medical Procedure**

**African American**

**M3:** I think it start after the colon resection surgery and from scar tissue from hernia surgery; the pain I have now got worse after the hysterectomy

**PK:** That was a hysterectomy?

**M48:** No, they went in and tried to stop the flow of the blood going to the fibroid tumors and they went in through the main artery on the right side

**M48:** Nobody knew what was the problem that is why I came to Dr. Ling. One doctor thought it was appendicitis but they didn’t take it out; they said it was okay. They ruled that out. One doctor said irregular bowel syndrome because it causes so much pain in that area. One time they said it was muscles…They put me on medication…that didn’t help.

**PKB:** You think the problem does come from the surgery you had?

**M48:** I kind of think so, it may not be but I kind of think so. I started having the day I had the procedure done.

**White American Memphis**

**M35:** I used to blame God for a while. I worked that out. Now I blame birth control. I was on birth control pills when I was about 14-years-old. I really think that maybe it played a part. I started my periods just before my 10th birthday.

**PKB:** How old were you when the hysterectomy was done?

**M35:** Just after my 22nd birthday.

**PKB:** You don’t think it is endometriosis?
M35: Not anymore…
PK: Just really feel like you don’t know?
M35: My personal opinion it might be from eight surgeries. You cut into somebody eight times you’re going to cut nerves and you’re going to cut muscles and eventually things can’t form back the way they are supposed to be you know no matter how much scar tissue tries to develop. I don’t have to be a doctor to know that. It’s kind of like embroidery. You stitch and stitch and eventually you remove stitches and the fabric never goes back to the way it was originally.

PKB: Cause of your pain, you have a question mark.
M43: I don’t know.
PK: You just don’t really have any idea?
M43: I’ve had every test and I’m sure there’s more out there but I’ve had a lot of tests and it’s not showing anything.
PK: Sometimes we will have an idea in our mind like it seems to me like it’s this or that?
M43: I have said from the beginning of it I thought it had something to do with the screen that he put in to repair the hernia only because it started after that surgery but it doesn’t feel like anything else I’ve had before.

White American-Knoxville
K2: I have a chiropractor in town and that’s when the problem really started; it started with the chiropractor… I was having a mid back (bra strap level) adjustment but it was not a problem… I had a herniated disc in my thoracic spine… In fact I had MRI because of the problem I was having. But I was with the chiropractor and he was doing some mid back adjustments and during that time I went in one day and my tail bone was bothering me. Well I had been sitting hours at the computer and I could find a reason for my tailbone to be bothering me. I said to him that day I said my tailbone is bothering me. He said we can take care of that. He took films and said you tailbone is out of line so he adjusted it and after that, well… And so that was on a Wednesday and by Saturday I felt like something, like I said in the beginning, was sticking in me and I called him and he told me to come back in and he tried adjusting me several more times and finally said that what he was doing was not helping and suggested at that time that I have an MRI. He said he could get it adjusted but it was holding and that’s where I associated with the problem starting but if he had anything to do with it I don’t know. I’m not trying to put blame on him

K5: That’s what I think it is the endometriosis causing my pain; most of the doctors and my therapist agree I think, one may be a little more one way and one may be a little less another way but all around about my doctors thinks I have interstitial cystitis as well as he’s the one that said I had the chronic pelvic pain. You know I was associating it with my periods and the fact that this all seemed to get at its worst point when I got, when I did tubal ligation… a lot of times I just honestly feel like if I could just cut those bands off this pain would end.
FRAGMENTATION

Fragmented Health Care

K8: I always think I’m going to feel better after surgery. You feel happy when you go in there and think you’ll wake up and be fine.

African American

M22: …They said we’re going to have to send you to have surgery to have your ovary removed. We’re going to send you to Memphis to this doctor named Dr. Something and blah, blah, okay. I got up there, he didn’t take no kind of x-rays or anything, he’s just going by what they told him so he said he would inspect me and told me that it is small and not a big cyst and all that stuff. He said I really don’t see no reason to operate …so he put me on some birth control pills to shrink it. He still never took no tests or ultrasound on me. I started having real bad again so I called him and I told him I can hardly, I said this pain has gotten worse. I said it is even hurting in my vagina. I said something can be done. I know I’m in pain. I said something is going on and I don’t know what it is …but the last thing he told me was well I’ll tell you what, I know coming here hasn’t helped you out but there is such a lot in pelvic pain so he sent me here.

M40: They (health care professionals) did not understand (the relationship between abuse and my pain). They were saying that it was in my mind—that my illness was psychosomatic. The depression I had was borderline manic depressive and all these things. When I realized that it wasn’t my fault that I didn’t do anything to make that happen to me then I didn’t have those problems anymore.

M40: I have a doctor’s appointment every week. Either with Dr. Ling, who is my pelvic pain specialist, I also have a gynecologist. Dr. Ling is not my gynecologist. I stopped seeing my rheumatologist. He wants to put me on a medication that I don’t want to take.

M48: Nobody knew what was the problem that is why I came to Dr. Ling. One doctor thought it was appendicitis but they didn’t take it out; they said it was okay. They ruled that out. One doctor said irregular bowel syndrome because it causes so much pain in that area. One time they said it was muscles…They put me on medication…that didn’t help.

White American Memphis

PKB: You have had pelvic pain for over five years.

M17: They kept diagnosing me well I told you the last time they thought it was gallstones at the time but they kept telling me I had pelvic inflammation. They never diagnosed me as pelvic disease until I got with Dr. Ling about five years ago, four years maybe.

PKB: When did the gallstone thing start?

M17: I was 22-years-old.

PKB: Did they take them out?

M17: Yes ma’am. I had my gallbladder out. I kept having a lot of that pain stuff going on where my pelvic area, now that I’m understanding it, another doctor, Dr. Show he couldn’t decide if there was endometriosis. He just didn’t know what to do. When I got pregnant I went through
UT because I was a specific case, apparently this one doctor I don’t even like him, it was a blessing in disguise because I now have the appropriate care that I need.

PK: You do have irritable bowel symptoms.
M32: I do. I’ve had the upper and lower GI and even had a colonoscopy. I have had all three of those. They didn’t necessarily diagnose me with IBS more than you are saying you have these other symptoms and I know it’s a factor with endometriosis that you can get that. That’s basically what it’s been.
PKB: Nausea is with eating and with pain.
M32: For instance yesterday I just took a bite of a wheat sandwich with cheese on it and got severely nauseous. I’ve been nauseous really bad for two days now.
PKB: You’ve actually had vomiting too.
M32: Oh yeah.
PKB: Does Dr. Ling know about that? (the doctor now treating her for endometriosis)
M32: I’m not sure. The vomiting is not as frequent as the nausea and diarrhea. That is more predominant. It can be occasionally on the vomiting I would say it’s every month. The Zofran they got me on has helped as far as the vomiting. The nausea I took three yesterday, not at the same time but I had three Zofran yesterday and it still didn’t do much

White American Knoxville

K2: I started that with an orthopedic doctor and he wanted to give me a steroid epidural but he thought first that I should GYN check that….So I went to my GYN and he didn’t find anything and so he sent me to a colorectal doctor; he did a colonoscopy-that came back all right-I had polyp. So he took it out, but I don’t think he thought that was what the problem was, so he ordered an MRI and sent me to a neurosurgeon and when I went to the neurosurgeon I went with my MRI pictures in hand and he looked at them and said it was not coming from my lumbar and really didn’t offer anything. His (neurosurgeon) suggestion was the pain clinic and my doctor at that time didn’t, want to throw me to the wolves (he didn’t want me to go that route). So we tried several things; I went on Neurontin for a while and later saw a specialist. I’ve been through all of that. I’ve had an EMG, nothing showed up. I had the body scan and nothing showed up. Finally someone on the internet, I kept getting posts from people or females saying you need to look at potential nerve entrapment. I actually haven’t been diagnosed with it but I went on the web site and read some information that they have there and for a long time and from what I read from the other people on the site and their symptoms were much than mine it felt like. So one girl had sent me some e-mail and went back to getting the coccyx adjusted and she said you need to try to find somebody that deals, a physical therapist that deals in women’s health or pelvic pain—that was two years ago this past April. I had already had two rounds of physical therapy in and they didn’t know much to help my problem. They did ultrasound and electrical stimulation and massage and would stretch me and that’s it. So when this girl told me this, I thought, and I knew the chiropractor she went to did internal work so I began to search myself and I found Donna and I went to Donna for about six months and I did get a little better at that time, in fact there was one point during that I felt like maybe that feeling that I was having right there at the rectum was going away but there was some little part that just stayed there, you know. Then when Donna went and opened practice for herself I came back to her and we didn’t make much progress with my symptoms. I just recently went to a GYN and he did the nerve block and it
didn’t make any difference. He gave it vaginally right there at the ligament where there is a nerve there is and Donna and I were just talking about all though I was numb all over I could still feel that, it was like somebody was taking a little marble and just bust it right there at your rectum

K6: He (doctor) had given me my prescriptions to take. My other doctor is saying don’t take them. What am I supposed to do? He says I’m supposed to have this particular bacterium. She says that my levels are too high. I’m going to trust her because she’s the woman who stuck with me through all this, not him who keeps telling me there’s nothing wrong. He asked me if I had diarrhea and I said no I haven’t but if you look at the list of medications I’m on about all of them cause constipation. It could be that. If I was on them I could have diarrhea.

K6: I’m mad that I’ve had to fight so hard to get good treatment. I mean you’re feeling at your worst and you don’t have the energy to fight but you have to… Doctors care but at the end of the day they don’t go home with me so I’m just amazed there are people who call themselves health care providers. I’m very angry at the unwillingness of physicians to treat pain. This fear that they are going to get somebody hooked on drugs. There is a huge fear of that and so they do under treat pain and that does not help you get better. I feel like this is taking my life away from me.

K7: This physical therapy is different in that one thing she said the other places think that you’re thigh stops here and so Donna you know who has gone up into the muscles that there’s a muscle running from here to here underneath the, around the bottom of, right there, that’s probably the culprit of all this for me and I complained of it the whole time but nobody She did some internal massage on that muscle… more hands on than anybody else. Most of the other places they’d take a look to see if you needed adjusting in terms of was something out of whack and then about 15 minutes of some sort of soft tissue massage. Usually you were on the hip and down the side here and like I say occasionally right in here but no further up probably than right there. I had exercises to do.

**Fragmented Bodies**

**White American Knoxville**

K9: Interstitial cystitis causes the bladder pain. It just came out of the blue as far as I can tell. I used to drink a lot of coffee and I’m sure that I ate all those other things, acidic things that were irritating (to the bladder). It just hit me like a bolt out of the blue--knocked me off my feet. I have burning pain in my vagina; I don’t know what causes that.

K8: (Regarding pain descriptors) It depends on when, you know what I mean. Throbbing I would say that’s mild. That happens after the shooting pain. The IC flare is Sharp, no other word to describe it. Cramping obviously is severe. Gnawing is mild. Aching is constant, all the day all the time. I’m pretty tender most of the time. It does make me throw up sometimes too.

K10: Well my urethra was really inflamed. She does work on that. It has a tendency to want to stay inflamed. Mine I feel like it is more my urethra than it is my bladder. When you try to catch yourself, it just doesn’t want to go through it
White American-Memphis

M39: We now know the reason was my uterus was hitting continuously my intestines. They did the gallbladder surgery for it...My bile duct was blocked...The pain was worse. Nine days after that surgery I was bedridden.

M43: I had an ovarian cyst that had gotten so big it had pushed my ovary back into my kidney. The doctor went in there to take my ovaries out I was all filled up with adhesions. She told my husband she wouldn’t be able to do surgery on me. I asked her what it was like and she said it was like someone had thrown a can of latex paint in there.

African American-Memphis

M40: scar was stationary. It wouldn’t move. Everything from here was just stuck. That’s where Deanne came in. We pulled and stretched and then she did the electrical stimulation therapy and the apparatus on the inside which is a cross and everything. We got things to moving in there because I felt like something was stuck. I always told Dr. Ling I think my bladder is stuck inside. It feels like something is stuck. We moved things around and everything, pulling, stretching and exercising and all that.

M40: Sitting on chairs with no pad causes extreme pain and I think that has to do with the osteoarthritis pubis. Sitting on a chair and that makes the vaginal pain worse. It’s a separate pain but because it’s a very hard pain they kind of mesh. Does that make any sense?

Fragmented Self / Alienation from Self and Others

Pain

Mexican American-Memphis

M7: …I try to (appear happy and upbeat) at work. I try really hard…Almost too hard sometimes…

White American-Memphis

M19: It’s like my body says ‘stop’-you take care of yourself.

M23: It (the pain) does whatever it wants to!

African American-Memphis

M27: I might have ignored it more than I should have. (While discussing have painful intercourse for 17 years of marriage and painful urination since a bladder infection at age 13)
M27: Pain is crucial sometimes. I’m painful sometimes. I just don’t want to be bothered
PKB: You just don’t want to be bothered. I’m having a hard time imaging you saying just don’t bother me. **Do you ever actually do that?**
M27: I think it.
PKB: So you feel it in your mind but you giggle and keep going, right?!
M27: Oh my gosh, I just leave it alone I guess. I don’t really know. I guess it’s hard for me to sit down and not do it. I’m scared if I don’t do it, it won’t get done. I guess I kind of push it back. I’ve learned that.

White American-Knoxville

K8: There are two different parts of my life, there is a part where I can be in pain every day and I feel kind of you know when I talk to somebody I’m limited and then when there is a lot of pain when I’m flared up, that’s the word I’m going to use when I have an episode of having pains and that just seems to be like more and more frequent recently. It’s really taking up a significant part, like I feel like I lost yesterday. Yesterday I didn’t do anything. I can’t even read because I feel loopy. It just sucks. I wish today was Wednesday but so I mean as far as that’s like if I’m in a lot of pain I won’t be able to climb any stairs or do anything.

K8: In some ways I feel like I control my pain like I can take medicine to make it feel better when it gets really bad and I can try to do all my exercises so that’s controlling it but this morning I still feel like it controls me

*Emotions*

White American-Memphis

M17: I pull together; I have to be the strong one… my mother testified for her father in her mother’s murder… she is never strong; I get tired of always being the strong one; I only had my father to be the strong one. “I act like I’m some tough girl and I’d really like to just lay down maybe for 2 weeks”

M32: I kind of separate depression and emotional. They are separate. I have always pretty much been a happy person but I say the only time I get really emotional is when I’m just not feeling right and I know I’m not. I was like that about three weeks ago and I totally went off on one of my friends and I’m not the type of person who does that. I’ve had what my mother calls communist moments. When I was 17 maybe I came home and she had cleaned up my room…

PK: You called your mother a communist when you were upset once.
M32: It’s like an out of body experience that I have no control over. That’s when they finally diagnosed me with PMDD along with the endometriosis and everything else and they put me on the combination of Prozac and Wellbutrin to kind of calm things down.

M35:… Emotions, I can take it, I can do that thing where you step outside and say you shouldn’t feel this way, you should understand this… That’s why I write, my writing is cathartic. I do
write. I have actually managed in the last three months to write two poems about it which actually my husband says he refuses to read them because he says it is something sad and my poetry is very heart felt and it is very emotional and it’s obvious to anybody who reads it that it is very emotional but he (my husband) refuses to read it which makes me mad.

White American-Knoxville

K10: I’m not a crier so for me to cry it’s a big deal, like today…but it did feel better.

Fragmenting to Cope

White American-Winchester

W1: : I try to get my mind off of it, that’s what I’ve found works the best is to either, often times I don’t do the right thing though. I will just keep doing like, I should relax but I don’t. I try to just work through it. If I can distract myself that works best, get my mind off of it. But really sometimes that’s not very smart., because if it’s really getting bad, I just need to stop what I’m doing and rest. It’s like sitting at the computer, I will sit there longer by putting it out of mind, but I should stop and get up.

White American-Knoxville

K14: One of therapists I saw for the depression did a good job to help with relaxation, breathing techniques, stuff like that. Especially at night when I’m able to lay down and relax and get ready to go to sleep I can do most of that. It still hurts me during the day; just try to get your mind off of it. You don’t have a lot of time to sit there and count to 100 or stuff like that.

K14: To me taking care of myself is getting up in the morning and making myself look good. I have an attitude where if I make myself look good then y’all think I feel good. That to me is taking care of myself, going in my room, closing my door, doing stuff by myself that kind of thing

K7: I smoked off and on since I was in college when I was in the master’s program. Probably three years off and on. I was a social smoker and my sisters smoke. We went on sisters trips which we did a lot. When I retired I decided that I was thinking more about it and didn’t like it so I just quit. Once I decided, it’s just a matter of time for me. Being in a certain category I figure I didn’t do heroin, I didn’t do other stuff and it’s around so I allow myself other pleasures. I let myself feel free to breathe or do things. Part of what I liked too is just having that time to myself. Most of the time if I was over my sisters I did do it myself, not around my husband. It was giving myself the liberty to do. I hid it-I did it for relaxation; I would normally consider it frivolous.

K4: The pain is probably more intense but to me I can tolerate the pain pretty well. I think the worst pain I had was when I lost the baby and that was just a lot of pain. ..I’m kind of, I don’t know, just to me pain is not real severe…I don’t like to think about it…I grew up with a mom that was a pain sharer and to me I thought she was a hypochondriac so I try not to focus on
things….She had a lot of things going on with her. She died of ovarian cancer…She had diabetes and a lot of other stuff that was going on and that’s all you heard was pain all your life and I think it just kind of overwhelmed us cause that was a majority of our life. I try not to focus on that because I know there are more important things to do… No I try to just ignore it.. I know a lot of people focus on their pain and it probably is worse than what I think it is I just try not to focus on it and I don’t know if its because of my background

**White American-Memphis.**

**M32:** I’d rather not be around people when I get in that state and I just had a really bad moment two weeks ago with my friend, Brian. I just totally went off on him. Most of my friends and family know, they can tell I’m really in that state because I’m not really a person that complains or gets upset or anything like that. I’m pretty even keel so when I’m like that they know. They say you need to be alone

**African American-Memphis**

**M21:** Being still and closing my eyes and trying to mediate, trying to do mind over matter before I resort to medication…Cause I hate feeling like I’m a walking drugstore

**Social Alienation**

**African American-Memphis**

**PK:** What about your family, do they have any idea what causes it?
**M36:** My mom and grandma I don’t discuss it with them.
**PK:** What about your kids, do they know you have trouble?
**M36:** No.

**White American-Memphis**

**M39:** I think the most frustrating thing does not know how to verbalize it because it was so internal.

**M38:** It’s been frustrating and it’s been a learning experience and it’s made me more thorough in my health and my care and my knowledge of me I guess. I have a lot of time on my hands. I have a lot of times to explore myself and really think and get to know myself on a more intimate level which is definitely part of the at a better place than a year ago

**White American-Knoxville**

**K6:** When I was trying to just get diagnoses I was never there, I was always at the doctor trying to find out what was going on, wasn’t available to people. There’s a whole spiritual side that my faith has stayed pretty strong through all this but there is the whole spiritual side of excuse me God you know what’s going on and why am I not getting better. How do you counsel somebody that comes in to your office when you feel like you don’t have control of yourself? It’s really interfered with all of that.
K6: I feel (socially) undependable, unreliable and that is not me. That’s one of the most frustrating things… I want to be somebody that people can count on and I don’t feel like I’ve been that. I don’t do as many social type things as I used to or they are much more last minute types of things.

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K8: I just feel like I’ve always been a really social person. I think social connections and emotional connections are really, really important. Even though my family and my friends are really great, I feel like totally alone. No one can possibly understand. Not that they don’t understand, like it makes me feel selfish to say this but I just feel like blocked off and limited from everybody. Like I put up a wall and I can’t explain how I’m feeling and I don’t want to because it makes me weak. I don’t feel as connected to anybody.

K8: I loved being an only child. The one thing I would like want to warn your daughter about is when you do ever get sick, you tend to isolate yourself. I’m good at being by myself. It wasn’t necessarily the best thing for me. I stopped calling all my friends. It doesn’t seem abnormal to be alone. No one from college knows I’m sick except for one person. People in my graduate program know because my stepsister told them and that made me really mad. I didn’t want anybody to know. I was missing a lot of school obviously. I had surgery right in the middle of the semester. A couple people knew just having surgery but I just like always blew it off, no biggy. My stepsister told them everything and it made me mad

K6: Oh yeah I pray a lot. I don’t know that it has helped…My prayer lately has been God are you still there?

K10: I thought I was going to die, and I was really ready, not afraid, and just ready. It was in the beginning when I was in the house and nobody understood. I was in the dark. My husband would come home and I couldn’t make him understand. They dilated my eyes and I couldn’t see and can’t stand light. I couldn’t read and watch TV. I couldn’t work

K6: I’ve just learned that, I’m the one who has to live with this body… Doctors care but at the end of the day they don’t go home with me

K16: I find like I don’t want to go out to the movies as much to be with people, I’m kind of right now not hibernating but kind of recharging myself. I do that as kind of a safe retreat. If I can just relax and be okay then, I guess I’m finding myself doing less of that now. I’m working on it.; It’s not like I won’t go but if my husband says do you want to do something tonight? I’m like no. I just like want to stay home tonight. He’s like sure and we do. If he really wants to go somewhere I’ll go with him.
PRODUCTIVITY OVER PAIN
Why and how do they work so hard while in so much pain?

Is it resistance as described by Martin, resistance embodied or is it resolve to establish and maintain their worth in the only socially acceptable ways they know—staying productive at home and at work and fulfilling their sexual obligations. Psychological trait of dissociation, considered maladaptive, may contribute to ability to remain high functioning despite extreme pain

Work outside the Home –

Mexican American
M7: Yes. The fear of losing this house was greater than the pain I was going through. Work was the only value I had…. Maybe that’s all I know. I mean my sister and I have been working, I was 10 and she was 12. My dad opened a store up so that is all we known. ..My dad owned a restaurant…So we would alternate days, we worked every other day with my father from the time we would get out of school to like 9 or 10o'clock at night. So we’ve been working, you know... from the age of 10.

M7: …it seems like at night because I just don’t have busy-ness going around me it feels like everything kind of settles and it hurts a lot more and then on the weekend because I’m not as active as I am during the week. So it seems like on the weekend or when I’m at home it seems to be much worse... You know during the weekend I rest all night. And during the week you know at least I have something to take up my time which is work

African American women
M6: I still work despite it; I go to work no matter; I’d stay at work even if I had to stay in a wheelchair.

M22: I have to climb stairs at work, I do it, but it hurts a lot.

PK: How would you say pelvic pain, has changed your life at home, at work or out socializing?
M36: It hasn’t.

M48: I don’t just dwell on it. It hurts and I continue to do things. It’s alright one way or the other…I just keep going.

White American-Memphis
M10: At work, it’s really changed it because I can’t pick up the kids as much as I would like and I feel like I am neglecting my job. I’m there every day but I still feel like I’m neglecting.

M10: I’m not able to sleep at night because of the pain…the assistant director is off again (at work) and I have been trying to open and close and I think that may be another reason I am
hurting more…then not being able to sleep at night makes it worse and then having two boys with ballgames and everything else, you know, it is tough at night.

**M10:** But my husband is like, we got to get you fixed because you’re just irritable and all this stuff. You’re working so much.

**M16:** So the week before I actually got married they had to wheel me into the office (because of pain).

**M34:** I’ve had to miss several meetings just because of the pain. I’ve had to put a lot of things off on my vice president. My kids have had to go to my parents’ house a lot because of it.

**PK:** And then you missed some work too.

**M34:** I missed a lot of work.

**PK:** Did that put your job in jeopardy at all?

**Pt:** It did not put it in jeopardy but it made me feel worse and worse just because I did not want to miss.

**M19:** I’m currently not working because of it; I used to work 10-15 hours a day. I’ve never not worked since I was 15; I didn’t realize until I was off that you can’t get well when you are so busy…It’s like my body says ‘stop’-you take care of yourself.

**M38:** This was the first time in my entire life that I haven’t worked. I haven’t worked, not because I didn’t want to, but because I couldn’t walk. I couldn’t sit. It was horrible. I’m recently back at work; I’m doing it (working) now because I need the income and it makes me feel worthwhile.

**White American-Knoxville**

**K1:** I then packed myself in ice to be able to go to work the next day and that’s when he (ex-husband) said you got to quit it. You are suffering far too much.

**PKB:** the most stressful thing in your life on an average day?

**K4:** Probably not working probably is the thing I feel like I cannot control like I used to be, I’m not as busy. I always thought I’d want to be home, but not full time…My time management is not as good as it used to be.

**K5:** Because of the pelvic problems. I’ve lost many jobs. I got part-time jobs in between for a little extra money and I lost them and its been due to the periods, to the pain, to just overall wellness and then because during that time I’m getting my period I’m not capable of doing much of anything and it may not be a whole nine days, it may just be the first three days or the first four days or the first two days, just depending on the period but I mean it literally you don’t know, you don’t know. I’ve had to call them saying I’m not coming in today, I’m not coming in today…I am frustrated…I want to be able to do part-time. I’m going out for substitute teacher in August. I thought that was something that I could, something that would work because you have the capability of saying well when I’m having that kind of period to say no I can’t do that.
K6: I don’t want my life to be all about this and for the past two years my life has been going to doctors, therapists, hospitals, having tests and I want to be able to work again and participate in society and life and not just sit in doctor waiting rooms and know which ones have the best magazines. The pain clinic has terrible magazines…I can tell people who has the best magazines and which ones look dirty, who is going to make you wait an hour and a half, who will see you on time. I don’t want to know that. I want to be, I worked really hard to get my education and to pursue a certain career path and right now I can’t do that.

K8...I would push myself to the limit then I’d be in excruciating pain for two days then I’d be depressed. I felt like I failed or something

K10: went from A++ personality. I could do everything I ever thought I wanted to do I would do it and could do it and did do it. I went from running a business that I owned and I started to have to pay people to do it all and that’s where I am still today. I don’t do any of the physical work. It’s all my brain because I can’t sit at the computer. I can’t sit long periods of time. I can’t physically go out and see my stores. They don’t see me. They have to trust my voice on the phone. It had changed my family as I told you before. There is nothing the same about me except who my inner core is and that’s a positive researching, I will still try to do it with the acceptance I know I can’t. I have enormous limitations.

**Work at Home- Keeping the home fires burning- while it hurts**

“I’m like every other woman you know.”

White American-Memphis

M18: I can either take medicine or get it fixed or I can just shut up and go on. I’m like every other woman you know. I get up at 4:45 and start exercising. I get my house cleaning done before I come to work. I do all those things so I have to get up in the morning so that’s why I think I’m so tired at night….. Literally if I finish the kitchen at 8 o’clock and sit down in the recliner to watch TV I’m asleep at 8:05 and then I’ll get up at 10 and go get in the bed and sleep to maybe until 12 or 1 then I wake up and not get up to go to the bathroom or anything just wake up and toss and turn for a few minutes then go back to sleep. I’m usually backed up about 2:30 or 3:00 then 4:30.

M10: I cook dinner when we are home at night and we can’t eat out, I do the cooking and I will clean the kitchen and the housework and he always helps me with the laundry and my boys do too…I cannot push the lawn mow, that’s just out of the question. But I do help like bag the grass. I did mulch my flower beds last week and I should have never done that. You know I do try, I would say I think that to a halfway point…

M17: It helps me if I keep myself going; I get panic attacks and if I keep going it is better.

M23: I keep it going; the pain hasn’t changed my lifestyle except for doctor appointments and some limits to playing with my kids.

M24: I still do everything I always did, doing it all just means I’ll have less ease; exercising is the only thing I had to stop because it hurt too badly. (gave up cardio training on a glider)
M24: I rode my riding lawnmower yesterday for 5 hours yesterday. (This woman is 71 years old, retired)
PKB: Do you feel that pain while you are riding or is that afterwards?
M24: Well, yesterday it was when I was riding, then it went away, its’ not something that’s going to kill me, it just hurts.

M37: I like to clean house. I like to put things in order. I like things in order

M38: I don’t want to be (limited in what I can do). I’m the kind of person that will push myself to do what I want to do even if it means I’m going to pay for it later. I don’t like being inactive. I like contributing. My boyfriend lives with me and we have a household.

PKB: You have not been feeling good and still had all the responsibilities for your home?
M38: It is still okay because he buys the groceries and it is a way for me, like cleaning up and doing things, that are my way of coping and that’s one of my outlets because it makes me feel productive. I can go at my own pace. If I’m hurting I can rest. It doesn’t require a lot of heavy strenuous exertion…It’s cathartic for me to take care of the home and also as a woman I know about the women’s lib stuff and I’m all for it except I really need a bra because my boobs are too big to not have one but I like it’s that nurturing side of me. I like doing the taking care of (the home) as most women do but not to the extent where my needs get excluded and that is sometimes a point of contention. (In our relationship)

M43: I’m not going to put my life on hold because I’m in pain. I watched my mother do that I think and I’m not going to do that. There is too much living to do then just waddle around, that’s how I feel anyway.. I just have mountains I want to climb.

M? : I’ve been really lucky. My husband has been very supportive. My daughter is very helpful.
PKB: She’s 14?
M?; She’s 14. She never says to me or you know never gets angry that I can’t go to the movies with her or that we’d all love to eat out and maybe those two will go. Like tomorrow for instance they’re going to Graceland and I won’t go because I don’t want to be a burden to them. I want them to go and have fun and not have to deal with can mom sit here or can mom sit there, oh her back hurts.
PKB: How much fun would that be for you?

Mexican American-Memphis

M7: I feel like a burden (to my family/socially) because of the pain.
African American

M21: It limits what I can do—like washing a sink full of dishes or standing will cause a problems; I have to put it off or not do it or modify what I’m doing; it takes more time to do everything

White American-Knoxville

K1: It seems to be the hardest thing is the house cleaning. My little boy helps me you know. If I’m really bad or don’t feel like, come and pull these out and bring them in here and I’ll fold them up. He helps me.

K4: If I could change anything about my daily responsibilities it would
Be to keep my house up more with more organization… one of my former employers said one time that that would be my downfall because I was too organized

K13:… it’s funny though you think that when the kids are gone and stuff like that I mean you think that you would do something to play and all that, are you kidding I’m like let’s go home, let’s get this house cleaned while they are not here, it’s so much easier to do. That’s just the way my brain operates. It’s very rare that I just do something I won’t say frivolous because it’s not frivolous but just something you know.

K11: I pay much more attention to getting more sleep and I’m trying to eat healthy. I’m trying to do things that are fun like sometimes I pull out a box of crayons, having fun, just doing those things I’m giving myself permission to do things that are fun. A lot of what I do right now is not fun. I’m trying to make sure it’s okay to have fun. I had fun as a kid; I played. I think that somewhere though I lost permission to do that. I’m not sure if it was pressure I put on myself, I don’t know how that happened but became more serious…I think that if we would all sit down and do some of those things like finger paint or play with Play-Doh or whatever every once in a while it would be a better world because we tend to make everything very serious. I’m not trying to make light of things that are really serious but I just think we can calm down

Sexual Relationships-Doing it when it hurts
“It’s almost bad enough where you don’t want to keep on.”

African American

M22: I would like to have sex again; I want something stable—also a little afraid of the pain.(last intercourse was three months prior to the interview; she experienced pain intensity of 10/10 with intercourse that lasted several hours afterwards

PKB: It’s worse with intercourse, worse with your period. It lasts for a while after your period is over and it goes up to a 10/10.

M27: Yes ma’am. I can take something and kind of keep pushing. I try to go on and pretend it’s not there... I have vaginal pain but not burning anymore, that is better.

White American-Memphis
M17: I’m fearful of not being able to pleasure him during sex…

M55: It was funny because I have an ex-cousin because it was my first husband’s cousin who was gynecologist and he was one of those people that I knew well enough that I could talk about you know sexual problems or whatever. He said what you have is called dyspareunia and he said the only thing you can do is have your husband come in and we’ll whack it off and you’ll be fine. There’s a joke among doctors that it’s better to have dyspareunia than have no pareunia at all.

M28: Intercourse is complicated.
PKB: Has that gotten any better?
M28: No.
PKB: That hasn’t changed at all with any of this.
M28: It’s more painful sometimes. I don’t want to because it’s painful.
PKB: How is that going?
M28: Dr. Ling prescribed Tylenol with codeine to take afterwards.
PKB: Do you feel really tense at the start like it’s hard to even get started because of pain?
M28: Yes ma’am. Is that normal?
PKB: It happens a lot but it is not normal. I mean it’s not what we want you to be going through normally. A lot of women experience that. Previously you didn’t have a problem right? There were times in your life that it didn’t hurt.
PKB: It just wasn’t as bad as it is now.

PK: I understand you are still having pain with intercourse, and you are still having intercourse. After intercourse how long does the pain last, hours or days?
M34: At least one to two days burning, hurting.
M35: There’s no burning pain with intercourse at all. The real pain is after intercourse.

55: I had a lot of problems before I had my hysterectomy, it hurt to have sex, not to have sex…After the hysterectomy, it didn’t hurt to have sex anymore but yet I still occasionally would get that particular pain.

White American-Knoxville

K1: When I have intercourse that builds my pain level, I have a little burning and it gets better but there’s nothing really in it for me, why do it you know. Then after then the next day the next day it’s worse and the next day burning, this was before surgery, I knew I’d be in the bed like a 7, but now I don’t have sex so I don’t have that pain; the physical therapist said not to do that (sex) right now

K7: In terms of sexual activities, I think every time we set about to it I think my husband i in the back of his mind is thinking You don’t want to hurt her. So it has changed little bit, not for the best
K14: I was having pain with sexual arousal that seems to be muscle pain. It’s amazing what she’s (the physical therapist) been doing. I didn’t realize that I was having that much pain from that. It has helped a lot the dull pain. The intercourse pain is not better yet, just the arousal pain. The arousal pain is probably about a 9. It’s almost bad enough where you don’t want to keep on. It’s very bothersome. The pain during intercourse, it kind of eases off. Once I get past that initial arousal pain it kind of goes to about a 6. The pain afterwards I just feel really I guess sore. The level 6 kind of stays afterwards.

K15: …the sex we couldn’t have without it being very painful. We had it but it was uncomfortable. I think when you have a healthy sexual relationship with your husband I think that in and of itself that’s been relaxing, enjoyable, stress relieving activity that if that happened and everything is right with that then the stress, even if you have stress at work, is not as severe. If you have stress somewhere else it’s not as severe because there’s that release when you have been all that other stuff you’re working on I think. It’s not that everything revolves around that because my husband and I talk about that. That’s not what our relationship is based on but I also know that in a healthy relationship like that and like we’ve had up until that it wasn’t tense or tight.

Avoiding Sex-Pain and Indifference

African American

M21: He (my husband) gets irritated but he tries to act concerned
PKB: You think it is an act?
M21: Yes, I really do but everyday he’s like ‘I just worry about you’…I think he is actually angry, especially because I do not want to have sex because it’s painful. He gets really angry with me…He gets on my nerves

M21: Being a wife is the most stressful thing in my life because my husband hates the pain and then trying to be that wife that’s fantastic and cuddle and all that stuff, that affects (me) because I don’t want him touching me… but I try… bit I hate it (sex). With pain I hate it more. (said with emphasis) I wish if I didn’t have the pain. I would be able to do it enough just to please him but I wouldn’t care if I didn’t do it…The pain makes me not want to have sex; pelvic pain stopped me from being able to take care of my husband.

M6: Sex is the most stressful thing (in my life); I will pick an argument with my husband to avoid it; I’m non-involved during sex; if we go slowly with music it helps me relax’

M40: I never liked sex. It always hurt. I was never comfortable because it was wrong. I’d think this is dreadfully wrong.
PKB: Were you taught that or you think it was a feeling from these experiences?
M40: Both.
PK: Of course if you were taught that it was wrong, then have to hide it, I was just wondering if there was someone in yourself freeing you up?
M40: A Christian auntie, old school Church of God in Christ Christian so she said this is wrong, that is wrong, so I lost my boyfriends a lot because when they asked me for sexual favors I quit them. A couple of boys that I really liked one of them raped me.
PK: How old were you with that?
M40: 15
M40: In ’76 I learned that it (Marijuana) was helpful and with sleeping with my husband it made it less painful. So my girlfriend showed me how to do it and everything so then I’d come home and I wouldn’t bleed or any of that; usually if I had intercourse with my husband. I would just tighten up and he couldn’t get in or I’d tighten up and he couldn’t get out.
PK: So you would use marijuana to relax?
M40: Yeah. It would make me less, I’m not ashamed of it because this is something that we’ve talked about for years. I am so glad we can have intercourse now and I don’t have to go to bed with that yearning desire.
PK: Despite the fact it hurts to have intercourse, and you never liked it, you’ve always desired it?
M40: No I never liked intercourse.
PK: You said “going to bed with this yearning and desire.”
M40: Because I wanted my husband’s affection.

White American-Memphis

M39: At home my husband is very understanding; it limited our physical intimacy 100%.

M48: It has changed with my husband. We don’t do things. I can’t stand nobody to lay on this side or that side. This side here is limited to just me putting my leg over, it’s just irritable. You can’t put any kind of pressure to this side.

White American-Knoxville

K10: My husband is wonderful. He’s an angel. We haven’t had sex for two years.
PK: How does he handle that?
K10: Horribly
K10: The last time I had sex it stayed at a 10 for two or three days. I want to be able to have sex with my husband again… Will you help me with my sex problem?

K4: We never have intercourse a lot, not as much as we should but …its not been a real issue… I think my husband and I would be a lot closer if we could have more relations

K10: I’m not the same, intercourse wise and it’s an issue they (doctors) cannot deal with. They choke up on it. This is any kind of doctor. The physical therapist I’m seeing now is the first person to address it.

SELF-CARE-NON-PRODUCTIVE TIME
“Me? No, I take care of other people, I’d rather do that”

PK: Do you feel like you spend much time taking care of yourself each day?
M39: Me? No, I take care of other people. I’d rather do that. The walking I’ve done every morning except the last three because I was on a deadline. My mother-in-law her husband died and she’s a widow so I’m her honey do list person.

M52: Pt: Um, doing things for myself pretty much I am just sitting down and watching a movie or something because I’m hurting…Otherwise I’m running errands. We have five dogs and six cats and that’s a nice load, working for my mom and stuff like that. My best friend is always busy. My boyfriend didn’t even get me a birthday card this year. He was in the dog house for one week.

PKB: What kind of things do you do for yourself?
K4: Um.

PK: So zero time spent on self.
K4: Probably not, yeah maybe 30 minutes at night taking a bath.
PK: And the reason for this is?
K4: I don’t know, I just get doing other things.
PK: Okay and the type of things that other people do for you on an average day.
K4: My husband does the laundry and he’ll help do dishes and stuff like that and he helps with things like the vacuum.

PK: Do you do things for yourself on a regular basis?
M37: No. It sounds like you’re not doing anything… I have tried to do more for myself. I’ve been very uncomfortable with it. I’ve been trying to read

M19: I’m currently not working because of it; I used to work 10-15 hours a day. I’ve never not worked since I was 15; I didn’t realize until I was off that you can’t get well when you are so busy…It’s like my body says ‘stop’-you take care of yourself.

K8: Sometimes I feel selfish. I feel selfish or guilty. I think guilt is something that definitely plays into my stress level. I feel guilty because my dad has to take me to treatment every week and that he’s going to have to take a couple days off for my surgery.

Sexuality, Sexual Attitudes and Behaviors

Sex, Abuse and Assault…Is…Normal?

M8: I thought all girls were messed with growing up; weren’t you? (white woman)

M6: I think most black women were tampered with as kids.

M1: Something happened to me when I was three-years old, what I don’t know. All I know is it was my mom’s friend and all she told me that sexually abused me….She won’t tell me what it is. She won’t tell me who, I mean I know who it is but it’s all I know.

Grandmother: I’m Christian, if I’d have known that I’d have killed him. He really kept that quiet
M1: It was…that guy she dated right after dad and her got a divorce…Actually my mom didn’t know that I knew nothing about it. Actually I heard my mom telling to my grandma about it, my
other grandma...I brought it up to her one day and she just, she don’t want me to know about it right now because of everything that’s going on.

Grand mom: But you need to know so that they can help you.

M1: I mean it don’t bother me. I don’t remember it. ‘

Grandmom: But deep seeded into your brain, don’t it happen?

M32: Pt: My biological father was abusive emotionally and sometimes physically and my mom divorced him when I was very young. She was married to him for 12 years. She experienced that as well.
PK: She divorced him when you were 12?
M32: They were married for 12 years. I haven’t had a relationship with him and even when I was younger I had to legally go see him for years but I haven’t seen him since I was 17 or 18 maybe.
PKB: Was he the one who did the sexual abuse too?
M32: No that was one of his family members. That’s really something that I dealt with at quite a young age because I’ve seen women that go through, I mean one out of three women are abused. I’ve seen a lot of women go through this and I’ve seen how they allow it to affect their lives. I don’t believe it’s something that I ever wanted to affect my life because it wasn’t my fault. It was nothing that I did. I dealt with the esteem issues and all that.

PK: Okay so some history of abuse.
M37: From what I hear it’s from my uncle, from other people. Supposedly I dealt with it.
PK: Did you have therapy?
M37: No.
PK: Just dealt with it on your own?
M37: Yes.
PK: How old were you?
M37: I don’t know how old. I know what house I lived in which means I was less than 10-years-old.
PK: OK.
M37: My cousin was the source and I didn’t like him for a lot of years but
PK: One time or multiple?
M37: Twice. Once he exposed himself and once touching.
PK: It happens too often.
M37: My dad somewhat had a temper and he kicked me one time and that really has bothered me off and on a lot...The issue is that I have a flash temper and I don’t want to be like him...And my brother has a flash temper and my cousin and my uncle and my dad. **It’s a family history of this temper** and that I get anxious when I get that way. I don’t get that way often...I have had some counseling with my children and how I dealt with them because I also had a flash temper when they were young but I think I got over that too, I thought I did. My biggest problem now is just students when they push me sometimes I have to go outside and leave, my administrator got mad at me last year and I jumped all over him and embarrassed myself like that. So maybe I should (get more counseling) I don’t know.

M40: Yes. I found out it had a lot to do with all the molestation and the rapes.
PK: So you’ve done quite a bit of therapy to deal with that?
M40: Yes, I had to. I didn’t know what was wrong with me.
P K: At what point in your life did you do that?
M40: I had a nervous breakdown. My baby was months and I went into the baby blues. My grandmother died the same day. I went into the baby blues. I didn’t know what was wrong with me.
P K: How old is your baby now?
M40: That baby is 3, I was 23,
P K: This was quite a while ago?
M40: Yes. I’ve been institutionalized three times not knowing that it was the molestation and the rapes that was keeping me depressed all the time and unable to function and not feel good about myself, low self-esteem. Not knowing that this was the source of the problem.

I noticed that whenever I did anything and I had my classes I made very good grades, it’s just that I would stop because I didn’t have the confidence in myself. My teachers did so in the middle of study they recommended me for the jobs anyway all the jobs that I received. I did very well with the jobs. It was just that I didn’t have the confidence.

PK: You had these things bothering you.
M40: Yes. I thought it was something I did, it had to be to make this happen to me. there were three uncles, they were all uncles,
P K: That did it to you?
M40: Yeah.
P K: They all had sex with you?
M40: Yes. We were children. We had the full beds so that meant that I was maybe third grade, fourth grade something like that. We then went to the bunkbeds then I had to be pretty young. I don’t remember what age.
P K: You were very young. Eight to nine.
M40: Eight, nine and ten is when my uncle was molesting me so I was younger than that.
P K: It came first?
M40: Yes. The two-year-old thing came first because I was wearing yellow training pants. That was my mother’s brother. He’s dead now. He died. His girlfriend shot him because she said he molested her daughter. He went away with a smile on his face actually because he was relieved that she did that.
P K: You remember that?
M40: I kept having the dream that somebody was putting their hands under my panties and I had the dream and I would always wake up sweating and I would always wake up scared. Then one time during the dream I saw the face and after I saw the face I didn’t have the dream anymore. I just remember laying on the sofa with no top on, yellow training panties, I remember they were yellow, and I was laying on the sofa in the living room. That’s all I remember.
P KB: So you were two or three?
M40: I had to be. I was in training pants. I wet the bed until I was eight…
It was pretty rough. I know why a lot of my life was stopped and I couldn’t continue on in a lot of things because I never felt good about myself
M40:…That’s when it was really bad. That’s when he actually penetrated. I was 11 or 12. I never had a chance to be a virgin. That bothered me. I still had a hymen because when I had my first consensual scared to death sexual experience barely penetrated I bled all over the bed so
after I got older and I read that was still having a hymen. I never liked sex. It always hurt. I was never comfortable because it was wrong. I’d think this is dreadfully wrong.

M40: Pt: I’m being honest. When I was married before my husband stopped sleeping with me, he had a girlfriend. He is a pretty faithful guy so he was faithful to her. After I had the 25-year-old he came in one day and he just tore my clothes off and he raped me. The day before I had gone to my friend’s who is now my husband and asked him if he would do me a favor. So we got in the room and I couldn’t do it but we had petted heavily but I couldn’t have intercourse, I just couldn’t do it.

M51: I was molested as a child. I think the first time it happened I was about five that I recall. It was actually by my older brother. He’s three years older than I am. It started out as like a playing doctor type of a thing and it kind of progressed to you know; it’s come out in later years that he himself might have been raped. He told his first wife that he was actually raped by an uncle who we know is a pedophile. To make a long story short he would play games… As soon as I got a little bit older, I think I was about nine I would say no I’m not going to do that anymore. He left me alone but then he went after my younger sister who is five years younger and we found out that she had been very molested and maybe even raped for 10 years by him but she would never tell.

K6: It (emotional abuse) is one of those things that I endured from my parents. You know when you’re little you think that’s normal and what everybody is like. Later on my job a relationship became very abusive toward the end of the position and I got out of there. I did allow it to go on because I had hoped there was potential for it to get better so, I stayed, but I finally stopped it.

K6: I look back now at these two boys in the fourth grade that were allowed to harass all of us (all the girls). Now I can very much say that they sexually harassed us. They stuff like coming up, fourth and fifth grade girls were starting to wear bras, they would pop our bra straps. They would come up and grab girls from behind and do different things. At the time it was really frustrating when that was going on and I learned some self defense moves and got one of them pretty good. He came up from behind me and he got me and I took my elbow like that and I took my head like that back into his face. They would grab us, any part of our bodies. That was in 1980, 1981 something, I don’t know. People didn’t talk about sexual harassment of fourth graders then and I see shows like Oprah and stuff and I’m going you know that’s exactly what they did. My parents knew it was going on and the teachers knew it was going on. I complained. I found out later that the teacher told my mom that she knew I could take care of myself; which I did but I had to resort to violence to get this kid to leave me alone. Now there’s a name for it and now I couldn’t say what it was but at the time it just wasn’t an issue you talked about. Now I know that he was really out of line and my teachers should have stood up for me; my parents too. That whole atmosphere was sexual, part of it I think is normal curiosity that starts around that time but it went beyond that. Your daughter better tell you if the boys are bothering her. It is something I just thought about recently because I was watching just the other day on a show they were talking about kids who had been bullied and harassed and stuff and about how if these were actions that were taking place when we were adults they would be harassment. I thought this kid that came up and was always putting his hands on me, grabbing me from behind, saying things. I’m like you know, because we were in the fourth grade it was kids being kids.
K8: Not rapes, just forcing sexual act; this guy got kicked off campus actually. It was my freshman year. He was harassing me afterwards like stalking me kind of and my RA, I just turned 18, RA figured out what was going on and took me through the whole process. I never had to see him again. Years later I found out that all of this one group of people this guy was with them and everyone there knew. Also, I have vague memories of a doctor that I think was like inappropriate and I found out later; when I became a camp counselor at the Jewish Community Center my other friends used to call him Dr. Lust Chester because everyone felt the same way about him. He was my pediatrician. My step mom worked with him so she just didn’t want to hear it. I don’t have memories of it being bad I just have memories of being very uncomfortable. I don’t have memories of being touched or anything like that. I do remember him looking at my privates when I had the flu or something and I was just like its not necessary buddy. That’s never really been a big deal, I know it sounds weird but it really hasn’t. A lot of my friends had the same experience. I’d like to see him shut down. He lives across the street from my parents. I told my stepmother about and I stopped going to him pretty quickly.

K10: Somebody showed me their body at UT when I was about 20. A telephone man and I just went oh. I was a student. There was a telephone guy, he was asking for directions and stupid me kept saying what, what and getting closer then I saw it. He was in his truck.

K13: When I was a kid there was some pervert who would flash us on the way to school and the policemen knew him and knew where it happened and all this; I forgot about him. We had all kinds of names for him. There were five of us and we all walked to school at the same time.

K15: My dad was pretty abusive, physically and just always him always feeling us and stuff; I was 7, 8, 9, probably to 12 years old then I lived with my grandparents. My mom didn’t know what he was doing he was abusive to her.

K16: When I was in high school I guess I was developed pretty well so I had old men all the time try to get me to go out to dinner with them, try to get me to spend the night in a hotel. This was in a farming community in the Mid-West. It happened probably about 20 times during the time I was in high school that I was kind of like what am I doing wrong. I think it was I’d run a lot of errands for my mom and so I’d be out by myself instead of with somebody so I think that may have been. That’s the closest I’ve come to being scared. One time some man put his hand on his arm to try to lead me somewhere and I jerked it and said do not ever do that again and walked off. I was kind of shaken. Other than that fortunately it didn’t go any further.

Sex: Doing It When It Hurts
It’s almost bad enough where you don’t want to keep on- K14

-“Intercourse is complicated”-M28

M55: It was funny because I have an ex-cousin because it was my first husband’s cousin who was gynecologist and he was one of those people that I knew well enough that I could talk about you know sexual problems or whatever. He said what you have is called dyspareunia and
he said the only thing you can do is have your husband come in and we’ll whack it off and you’ll be fine. There’s a joke among doctors that it’s better to have dyspareunia than have no pareja at all. Something like that. At least he actually put a name on what the problem was. Every time I would have sex it didn’t actually hurt that much during but afterwards my side would hurt so badly.

**M21:** Being a wife is the most stressful thing in my life because my husband hates the pain and then trying to be that wife that’s fantastic and cuddle and all that stuff, that affects (me) because I don’t want him touching me… I try… **but I hate it (sex).** **With pain I hate it more.** (said with emphasis) **I wish if I didn’t have the pain. I would be able to do it enough just to please him but I wouldn’t care if I didn’t do it…** The pain makes me not want to have sex; pelvic pain stopped me from being able to take care of my husband.

**M6:** Sex is the most stressful thing (in my life); I will pick an argument with my husband to avoid it; I’m non-involved during sex (because of the pain); if we go slowly with music it helps me relax’

**M17:** I’m fearful of not being able to pleasure him during sex…

**M22:** I would like to have sex again; I want something stable—also a little afraid of the pain. (note: last intercourse was three months prior to the interview; she experienced pain intensity of 10/10 with intercourse that lasted several hours afterwards)

**M28:** Intercourse is complicated.

**PKB:** Has that gotten any better?

**M28:** No.

**PKB:** That hasn’t changed at all with any of this.

**M28:** It’s more painful sometimes. I don’t want to because it’s painful.

**PKB:** How is that going?

**M28:** Dr. Ling prescribed Tylenol with codeine to take afterwards.

**PKB:** Do you feel really tense at the start like it’s hard to even get started because of pain?

**M28:** Yes ma’am. Is that normal?

**PKB:** It happens a lot but it is not normal. I mean it’s not what we want you to be going through normally. A lot of women experience that. Previously you didn’t have a problem right? There were times in your life that it didn’t hurt.

**PKB:** It just wasn’t as bad as it is now.

**PK:** You are having pain with intercourse still, that’s no good, and when you lift. After intercourse how long does the pain last, hours or days?

**M34:** At least one to two days burning, hurting.

**PK:** And you’ve done the Valium vaginally right and that gave you relief?

**M35:** That has helped. It’s completely nixed my sex life.

**PK:** The Valium or the pain?

**M35:** The Valium and the pain
M35: There’s no burning pain with intercourse at all. There’s really during intercourse no real pain it’s after intercourse.

M39: At home my husband is very understanding. It limited our physical intimacy 100%.

M40: I never liked sex. It always hurt. I was never comfortable because it was wrong. I’d think this is dreadfully wrong.

PKB: Were you taught that or you think it was a feeling from these experiences?

M40: Both.

PK: Of course if you were taught that it was wrong, then have to hide it, I was just wondering if there was someone in yourself freeing you up?

M40: A Christian auntie, old school Church of God in Christ Christian so she said this is wrong, that is wrong, so I lost my boyfriends a lot because when they asked me for sexual favors I quit them. A couple of boys that I really liked one of them raped me.

PK: How old were you with that?

M40: 15

M40: In ’76 I learned that it (Marijuana) was helpful and with sleeping with my husband it made it less painful. So my girlfriend showed me how to do it and everything so then I’d come home and I wouldn’t bleed or any of that; usually if I had intercourse with my husband. I would just tighten up and he couldn’t get in or I’d tighten up and he couldn’t get out.

PK: So you would use marijuana to relax?

M40: Yeah. It would make me less, I’m not ashamed of it because this is something that we’ve talked about for years. After my hysterectomy in ’89 my husband stopped sleeping with me so we didn’t have intercourse for 15, this will be the 16th year. We just started again.

M40: Three years it was just great then after the hysterectomy he (husband) stopped sleeping with me. Dr. Ling even called him in and told him do I need to write you a prescription to sleep with your wife. She needs you. She’s got a lot of surgeries and she needs to have things moved around in there and nobody can do it but you. If you could just move things around in there so they won’t go back together. Dr. Hamby was seeing the same thing that he needed to intercourse me so that or palpitate it or something because I had surgeries that were inside and things needed to be moved around. My scar was stationary. It wouldn’t move. Everything from here was just stuck. That’s where Deanne came in. we pulled and stretched and then she did the electrical stim shock and the apparatus on the inside which is a cross and everything. We got things to moving in there because I felt like something was stuck. I always told Dr. Ling I think my bladder is stuck inside. It feels like something is stuck. We moved things around and everything, pulling, stretching and exercising and all that. At that time I couldn’t go up and down stairs either because of the multiple surgeries. He didn’t intercourse you.

Now it is much better because we’re talking and I don’t have to worry about those things. I don’t go to bed with a yearning and a desire and wake up the next day the same then day after day after day the same thing with no explanation so that makes it less.

PK: Despite the fact it hurts to have intercourse you’ve always desired it, that never affected your interest?

M40: No I never liked intercourse.
PK: You said going to bed with this yearning and desire.
M40: Because I wanted my husband’s affection.

M48: It has changed with my husband. We don’t do things. I can’t stand nobody to lay on this side or that side. This side here is limited to just me putting my leg over, it’s just irritable. You can’t put any kind of pressure to this side.

55: I had a lot of problems before I had my hysterectomy, it hurt to have sex, not to have sex…After the hysterectomy, it didn’t hurt to have sex anymore but yet I still occasionally would get that particular pain.

K1: When I have intercourse that builds my pain level, I have a little burning and it gets better but there’s nothing really in it for me, why do it you know. Then after then the next day the next day it’s worse and the next day burning, this was before surgery, I knew I’d be in the bed like a 7, but now I don’t have sex so I don’t have that pain; the physical therapist said not to do that (sex) right now

K4: We never have intercourse a lot, not as much as we should but …its not been a real issue… I think my husband and I would be a lot closer if we could have more relations

K7: In terms of sexual activities, I think every time we set about to it I think my husband i in the back of his mind is thinking “You don’t want to hurt her.” So it has changed little bit, not for the best.

K8: Sometimes I have cramping after intercourse. Sometimes I have cramping during but that’s just like if that happens it’s just stopped. Mainly I get more easily than I used to. I’m just sore. It’s like a 3 or 4 on the 10 point scale afterwards; it’s nothing compared to the other pain I have but I wouldn’t have sex again you know for maybe a day or two because of the soreness. During intercourse I can go to a 7 before I have to stop.

K10: I’m not the same, intercourse wise and it’s an issue they (doctors) cannot deal with. They choke up on it. This is any kind of doctor. The physical therapist I’m seeing now is the first person to address it.

K10: My husband is wonderful. He’s an angel. We haven’t had sex for two years. PK: How does he handle that?
K10: Horribly
K10: The last time I had sex it stayed at a 10 for two or three days. I want to be able to have sex with my husband again… Will you help me with my sex problem?

K14: I was having pain with sexual arousal that seems to be muscle pain. It’s amazing what she’s (the physical therapist) been doing. I didn’t realize that I was having that much pain from that. It has helped a lot the dull pain. The intercourse pain is not better yet, just the arousal pain. The arousal pain is probably about a 9. It’s almost bad enough where you don’t want to keep on. It’s very bothersome. The pain during intercourse ,it kind of eases off. Once I get past that
initial arousal pain it kind of goes to about a 6. The pain afterwards I just feel really I guess sore. The level 6 kind of stays afterwards.

**K14:** I had a boyfriend and explained the whole issue about sex is not pleasurable, it’s not something I want to do on a daily basis. He was okay with it for a little bit and now he’s not very nice he moved on.

**K15:** …the sex we couldn’t have without it being very painful. We had but it was uncomfortable. I think when you have a healthy sexual relationship with your husband I think that in and of itself that’s been relaxing, enjoyable, stress relieving activity that if that happened and everything is right with that then the stress, even if you have stress at work, is not as severe. If you have stress somewhere else it’s not as severe because there’s that release when you have been all that other stuff you’re working on I think. It’s not that everything revolves around that because my husband and I talk about that. That’s not what our relationship is based on but I also know that in a healthy relationship like that and like we’ve had up until that it wasn’t tense or tight.
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