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LES LIVING WITH CHRONIC PELVIC PAIN

I INTERPRETIVE PHENOMENOLOGICAL STUDY

by

NCES STRZEMPKO BUTT

DISSERTATION

faction of the requirements for the degree of

TOR OF PHILOSOPHY

in

NURSING

in the

ADUATE DIVISION

of the

CALIFORNIA, SAN FRANCISCO

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Chisla RN DNSc

R.N. Ph.D.

PhD

RN, PhD Committee in Charge

ary, University of California, San Francisco

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ABSTRACT

'ERIENCE OF COUPLES LIVING WITH CHRONIC PELVIC PAIN FROM ENDOMETRIOSIS: AN INTERPRETIVE PHENOMENOLOGICAL STUDY

Frances Strzempko Butt

)elvic pain (CPP) is a disabling condition affecting 10-15% of U.S. ductive age. Endometriosis, one of the most common causes of ed with symptoms of pelvic pain, painful sexual intercourse and rpose of this study was to articulate the woman's and her partner's ding, symptom experience, and relationship responses to living

was a mixed-method design, with qualitative methodology as e interviews were conducted individually and jointly. A distress, the Symptom Checklist-90-R (SCL-90-R) was used as tative method. Thirteen English speaking women in a partnered ship, who had received a diagnosis of endometriosis, and c pain for at least six months, and their partners, comprised the

's illness experiences were categorized into themes including ing answers, getting a diagnosis, and finding relief of pain. experienced as ambiguous. Making sense of symptoms and ght with uncertainty and contradiction. Living with CPP life as well as areas of intimate relatedness. Five relational

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ng with endometriosis are described that vary on degree of
sponsibilities are enacted, how conjoined the couples are
d how overtaken their lives are with the disease. A broad
ibilities were evident. These patterns articulate couples'
well as daily management of illness.

subscale scores for this sample of women with CPP were
published norms for women from non-clinical settings
parallel high rates of depression found in other chronic
esearch sheds light on how depression may evolve while
all of the women described feeling desperate at points in
cause of the lack of effective treatments and perpetual
out the future. Implications for health care are included.

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NSc, FAAN
Family Health Care Nursing

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CHAPTER ONE

INTRODUCTION AND THEORETICAL BACKGROUND

ıic pelvic pain (CPP) is an ambiguous and disabling condition affecting .S. women of reproductive age. Endometriosis, a condition for which ffective treatment, is one of the most common diagnoses of CPP. mptoms of endometriosis include pelvic pain and dyspareunia, or al intercourse. Relationship and role disruptions due to CPP are the woman, her partner, and the couple's symptom experiences and ave not been documented. The purpose of this study is to articulate and her partner's illness understanding, symptom experience, and ship responses to living with CPP. The larger aim is to develop support holistic care for such women with CPP so we may provide nd effective nursing interventions for women and their partners.

Background and Significance

nd endometriosis are complex, ambiguous, and disabling PP affects 10-15% of U.S. women of reproductive age (Mathias, Liberman, Lipschutz, & Steege, 1996). There is no generally ıition of CPP, although in many gynecologic publications many used duration of 6 or more months as the major criterion of elvic pain" refers to pain that is localized to the pelvis, anterior l at or below the umbilicus, the lumbosacral back, or the buttocks . Symptoms associated with CPP and endometriosis are pelvic xual intercourse, and infertility. CPP is a frustrating and complex

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clinical problem in obstetrics and gynecology. It accounts for 10% of outpatient consultations, 10-12% of hysterectomies (Reiter & Gambone, 1990), and more than 40% of all laparoscopies performed in the U.S. (Howard, 2000). Etiologies of CPP include endometriosis, pelvic inflammatory disease, adhesions, bowel-related pain, bladder-related pain, musculoskeletal pain and nerve related pain (Moore & Kennedy, 2000). Depression and a history of sexual abuse are associated with CPP (McGowan, Clark-Carter, & Pitts, 1998).

The total estimated annual direct costs for physician visits for CPP is $1.5 million and an estimated out-of-pocket cost of $1.9 billion for the U.S. population (Mathias et al., 1996), however, it is difficult to make meaningful comparisons between CPP and other chronic diseases. For example, when cures of economic burden of CPP are compared to the $98 billion spent on diabetes in the United States (Berg & Wadhwa, 2002) or the $61 billion in direct medical costs for cancer (Chang et al., 2004), one must consider that CPP is gender specific. In addition, compared to diseases that occur frequently across lifespan, CPP is most frequently diagnosed in women of reproductive age (Price & Kao, 2004).

Women with CPP hope for a simple cure, but unfortunately, there is rarely a straightforward approach to alleviate CPP (Steege, 1998). Various treatment approaches include oral analgesics, psychotropic medications, drug therapy for motility disorders, musculoskeletal pain, ovarian cycle suppression, antibiotics, and cognitive and behavioral therapy. Pharmacological agents are invasive and associated with harmful, unpleasant side effects including

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eversible voice changes and possible increased risk of malignancy
lumenfeld, 2004; Pattie, Murdoch, Theodoros, & Forbes, 1998). Surgical
erapies, such as laparoscopy and hysterectomy are invasive, and associated
h serious complications. Evaluative efforts of these treatments are incomplete,
d often conflicting (Hughes, Fedorkow, Collins, & Vandekerckhove, 2003;
obson, Barlow, Garry, & Koninckx, 2001; Yap, Furness, & Farquhar, 2004).

Endometriosis is the most common diagnosis of CPP (Zondervan &
ow, 2000). Little is known about its true prevalence, etiology, or risk factors
enazi & Warner, 1997). Retrograde menstruation, in which tiny fragments of
nal endometrium implant into the peritoneal cavity, is the most widely
pted theory of cause. It is argued that this theory does not explain the full
trum of the disease, since endometriosis implants are found in other places,
as the lung (Wellbery, 1999). The role of genetics, environmental factors,
ne immune system are being examined to provide insights into the
physiology of endometriosis and associated pain (Giudice & Kao, 2004).

Since endometriosis is found in asymptomatic women, there is question if
netriosis could be a naturally occurring phenomenon (Hill, 1997). Although
ous risk factors have been explored, only childbearing age correlates with
sis (Eskenazi & Warner, 1997). Although prevalence estimates are
to obtain, a recent comprehensive review of the endometriosis science
ed that endometriosis was diagnosed in approximately 25% of women
ping laparoscopy for pelvic pain, 20% of women who presented with

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/mptomatic women presenting for sterilization

').

ıtionships has been documented that include

Denny, 2004) as well as difficulties with sexual

ard, 1991). There is a strong association between

. Approximately 50% (Harrop-Griffiths, 1988) to 75%

Jagger, 1998; S. A. Selfe, Matthews, & Stones, 1998)

ence dyspareunia. Almost half of women with CPP

ters et al., 1991; Richter, Holley, Chandraiah, &

an a quarter (Peters et al., 1991) to half (Collett et al.,

xperience post-coital pain. Forty percent (Collett et

smus and more than a half (Collett et al., 1998)

sexual activity.

udy is to articulate the woman's and her partner's

om experience, and their relationship responses to

the link between CPP and sexual activity and

der pelvic pain in a socio-cultural context, taking

ul personal and psychosocial implications of such a

e multi-theoretical approach presented in the

es the complexity of taking up an ambiguous

bio-psycho-social context.

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Theoretical Framework

been described as one of the most frustrating and complex
s in obstetrics and gynecology (Kennedy, 2000). The Cartesian
ced much of the existing research and clinical practice of CPP.
n CPP has been guided by a Cartesian view of the self and
ed to the biomedical understanding or treatment of the disorder.
ounts are needed to begin to articulate the woman's experience
eyond her symptom experience. Symptom patterns over time,
esponses to the illness and particularly the joint responses of the
ntimate partner are explored. To not examine first-person
s ignores a body of knowledge that could supplement our
ding of CPP. This project drew on several theoretical
elped to extend the understanding of CPP, weaving together
s shedding light on the lived experience of CPP, with the goal
re enriched understanding of the phenomena of CPP from the
artners' experiences. In particular, the lived experience was
olistic, biopsychosocial, and embodied perspective. Strengths
arious theoretical frameworks that augment our understanding
ed.

alifornia San Francisco (UCSF) Symptom Management Model

chool of Nursing Symptom Management Model was one
rk used to understand CPP from a holistic nursing
mptom Management Model was developed and tested by

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d students at the UCSF School of Nursing Center for Symptom
ent. It is a model that augments the understanding of CPP, in
for its broad holistic approach in understanding the symptom
e from a biopsychosocial perspective (Dodd et al., 2001). The
Management Model consists of three related dimensions: (a)
Experience, (b) Symptom Management Strategies, and (c) Symptom
The emphasis of this study is on the Symptom Experience dimension
el, which consists of the individual's perception of a symptom,
of the meaning of a symptom, and response to a symptom. The
anagement model was an interpretive guide in the following two main

Symptom Management Model served as a theoretical guide from a
rspective. The authors of the Symptom Management Model (Dodd et
gue symptom perception becomes more complex when viewed in the
ltiple perceivers. The proponents of the model suggest that when
ceptions are congruent then symptom management approaches will
n contrast, when perception between multiple perceivers are not
mptom management approaches will become more difficult.
omen with CPP, these difficulties and incongruencies of symptom
ave been documented. Findings from Grace's study (1995b)
whether or not pathology was found, women struggled with other's
pain was psychological not physiological in origin. Findings from
yle's (1996) qualitative study suggest when pain made it difficult

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P to engage in sexual intercourse, some of the women
mplied the pain was an excuse to limit sexual activity.
eptions of CPP have not been documented and
es of symptom perception between women with CPP
rs is a gap in the literature.
nagement Model has served as a guide to understand
ms, evaluation of symptoms, and response to
the women's perspectives, but also from the intimate
he authors of the model argue that variables such as
ocial support network influence the perception of a
e influenced by the symptom. Specific areas
included how couples individually and together
system and how couples identified and negotiated
disease. One goal of the investigation was to uncover
differences of perception of symptoms may influence
ategies and responses to symptoms.
gement Model also served as a guiding framework to
tus of one partner may impact the health status of the
comprehensive in nature, incorporating the
al, cultural), the person (demographic, psychological,
aspects), and health and illness (risk factors, health
Dodd et al., 2001). Within the encompassing scope
ptions, as well as distinctions and similarities

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an's and her partner's perception of symptoms, evaluation of
sponse to symptoms were explored.

ggests that chronic pain, in general, can have significant
er's emotional and physical health (Habbema et al., 2004;
ck, Sandelowski, Harris, & Belyea, 1995; Rowat & Knafl,
later, 1991; A. G. Taylor, Lorentzen, & Blank, 1990).
(1995) found a phenomenon of "symptom attunement"
ertile couples showing similar amounts of general types of
rtile couples' responses were positively correlated within the
symptom category. While evidence strongly supports a
lness, there is not a clear theoretical understanding of this
vis et al. (1995) suggest the similarity between the infertile
may reflect the high investment that infertile couples have in
ey also suggest symptom attunement might serve to
elative estrangement that husbands and wives experience
nent. Infertility has been found to decrease marital and
pecially after the second year of treatment.

Management Model served as background to
ships between the woman with CPP and her intimate
perience. Specific areas under investigation include how
ay-to-day living with chronic pain, how couples
ptoms and symptom distress, and an exploration of
ctices.

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ation of the symptom management model is that there is a lack of
out positive possibilities that symptoms may open up for the
l/or couple. In the revised model, the outcomes dimension focuses
rs including functional status, self-care, costs, quality of life,
co-morbidity, mortality, and emotional status (Dodd et al., 2001).
on to the original Symptom Management Model was a study by
, Mitchell & Lentz (1992) of perimenstrual symptoms that
ite women having moderately or extremely distressing
symptoms, positive effects of menstruation were identified.
as an important contribution, overall, little emphasis has been
positive possibilities that may arise as a result of the symptom
h as increased intimacy between a couple.
imitation of the Symptom Management Model is that it remains
the biomedical model. The symptom experience, as a dynamic
een the patient's perception of a symptom, evaluation of
ymptom, and responses to a symptom, is a prominent
e original Symptom Management Model (The University of
. The updated and revised model, includes under "new insights"
eption (Dodd et al., 2001), exciting possibilities of accessing
ion through technological advances such as brain imaging and
nce imaging. However, the authors do not consider the patient's
nces of symptom perception (Dodd et al., 2001). An interpretive
l framework will guide this research, and an extensive

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ulation of Interpretive Phenomenological Theory will be taken up in the
wing chapter.

nman's Chronic Illness Model

Kleinman's Illness Model also offered significant contributions to the
rstanding of the lived experience of CPP from a chronic illness perspective.
arkably little is known about the lived experience of CPP. Women's lived
iences as they are reported in their own voices are absent (Tiefer, 1994).
derstand the lived experience of illness, one must gain "entrée into the
of the sick person" (Kleinman, 1988a, p. 233).

Whereas disease is the alteration in biological structure or functioning,
is the human experience of symptoms and suffering. Kleinman argues the
health care system "does just about everything to drive the practitioner's
n away from the illness experience" (Kleinman, 1988, p. xiv). This is
in the CPP literature, as very few investigations are approached from the
ctive (Cox, Henderson, Anderson, Cagliarini, & Ski, 2003; Denny, 2004;
1995b; Zadinsky, 1996) of the woman experiencing the disorder.
n (1988) lists three components of the illness experience: (a) illness
rs, (b) illness problems, and (c) illness "complaints." Illness behavior
an individual initiating treatment for their illness. Examples of illness
s may include changing one's diet, taking over-the-counter medication,
eciding when to seek care from health care professionals. Illness
are the day-to-day difficulties created by symptoms of the disease.
mplaints are what individuals communicate to the health care provider.

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t only impact the individual, but also family
ıman, 1988a). Illness behaviors, illness complaints,
ıay include relational issues, may be similar or
ıan and her intimate partner. An understanding,
d differences of these components of the illness
embers was a gap in the existing knowledge of

Kleinman's Illness Model is that it supports a
ɔm an acute illness model, toward a chronic illness
of "chronic" pelvic pain, the discourse in the
CPP as an acute condition. There are plausible
n primarily viewed from an acute illness
e that historically, CPP has been treated from a
& Ling, 1991). Gynecologist physicians who are
for an extended period of time after surgery.
are accustomed to providing well-women care
ble operating within a chronic illness model.
arch has been directed toward understanding
versus nonorganic pathology. This focus has not
ffects of chronicity on day-to-day life, or the
nd medical, which were the focus of this

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Research Aims

l approach presented acknowledges the complexity of
us chronic pain condition within a biopsychosocial
theoretical approaches this research aimed to

nd differences across couples of the lived experience
ve CPP with a medical diagnosis of endometriosis,

erience from the perspective of the woman and her
ype, pattern and severity of symptoms and response
uding personal function (daily activities and sexual
terpersonal relationships.

differences elicited from dyads' joint construction of
mpared to individual constructions.

ilarities of illness disruptions between the women
partners.

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CHAPTER TWO

NIC PELVIC PAIN FROM ENDOMETRIOSIS

onic Pelvic Pain: An Ambiguous Condition

hedical and psychiatric literature about chronic pelvic pain
past two decades begin with the observation that CPP is
The "difficulty" or "challenge" pertains to the elusive
ective treatments (Grace, 2000; Harrop-Griffiths, 1988).
y, from the perspectives of both the patient and the health
en described (Grace, 1995b; S. A. Selfe, Van Vugt, M.,

ain" is a label that covers a wide range of conditions.
al conditions can cause CPP and include endometriosis,
inal adhesions, and pelvic inflammatory disease (PID).
n urogenital syndromes such as vulvodynia, a pain
by vulvar pain, and interstitial cystitis (IC). IC is an
ndition characterized by chronic suprapubic or perineal
rinary urgency (Sand, 2004). Causes of CPP not
causes have also been identified and include bowel-
eletal pain, nerve-related pain, and psychogenic pain
).

he most common diagnosis associated with CPP
00). Difficulty and controversy exist around the process
dometriosis is considered one of the gynecological

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Cordle, & Stewart, 2000; Nothnick & D'Hooghes, 2003) for
ariations in the appearance of endometriosis make
diagnosis difficult and subjective. Red raspberries, purple
sicles, blebs, blueberries, black puckered spots, and
ust a few of the many possible appearances of
rd, 1993). Furthermore endometriosis is paradoxical in its
e women with significant pathology are asymptomatic, while
omen with minimal anatomical appearances of
en an irrefutable diagnosis. Conversely, women with
laparoscopic findings are not given a diagnosis (Collett et
e ambiguities and controversies are not a focus of my
te important contextual conditions that frame the lives of
their intimate partners.

dometriosis as a Disease Classification

00) argue that once a diagnosis is made, the patient and
e locked into a "treatment = cure" expectation. The more
greater expectation of a cure. Wegman, Woods, & Bailar
f critically examining how disease categories, such as
accepted and understood, and explicate the
stic criteria as a social process, reflecting consensus not
essionals, but also among the lay public. As people seek
symptomatology, they also seek an explanation that their
s something within known categories in their culture.

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attempt to classify each set of symptoms, or
framework or taxonomy of professional construction
assification of Diseases (ICD) (1989) or the
anual of Mental Disorders (American Psychiatric
n, Woods, & Bailar (1997) suggest this social
ymptoms is influenced by multiple social forces
prevalent in the culture/society about the
tionships (who has the power to declare a
bnormal condition); (c) consequences of the
e, social ostracization); (d) dominant frames of
iagnosis, and; (e) who benefits from the diagnosis
t paid, patient does or does not have access to
analysis, it is crucial to continuously shift lenses
tient, the clinician, and society, and to keep these
when trying to understand the evolution of the

etriosis

ergone dramatic transformations since its initial
Sanmiguel (2000) argues the changes in
nce of endometriosis must be understood
eb of interests, practices, and policies that have
sease. The following will trace some major

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pact the current context of the construction of

g with the current state of the science.

ecame classified and named a uterine disorder in 1921

. Sampson, at that time, proposed the retrograde

sease, which is still prevalent today. Although

dition associated with a variety of symptoms, primary

he most significant effect of the disease. Occurring

oing anxieties about race suicide that framed

g problem of infertility. President Theodore Roosevelt

e of contraceptives in 1905, heightening public concerns

ulation of native-born Americans. There was a sense

mmunity around declining birth rates among educated,

. Dr. Joe Vincent Meigs, a prominent professor of

as a chief proponent of what we would call today a

who argued endometriosis was caused by

rcles. Meigs proposed that endometriosis was caused

childbearing and the use of contraceptives.

uggested young girls to marry earlier and have

ment of the times was captured in a 1948 *New York*

m Dr. Meigs that read, "Social Ill is Laid to

ilment Restricting the Propagation of the Intelligent

80).

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occurring within the women's movement during this time
women's equal rights in the labor force, and women's
n. The numbers of women in the paid labor force were
Comstock Law passed by congress in the late 1800's,
raception was considered "obscene material" and mail was
s shut down if they published such information. Margaret
onent of the birth control movement, opened the first U.S.
w York in 1916, however, it was shut down ten days later
mprisoned. Eventually Sanger organized the American
hich evolved into the Planned Parenthood Federation in
ed in a long and arduous fight as the pill was not
til 1960 and approved for marketing in the US until 1961.
men's Health Book Collective published the self-help
selves: A Book By and For Women, incorporating
personal experiences. This represented the emergence
movement that encouraged women to engage in self-
authority of the medical establishment (Sanmiguel,

e were many changes within the field of endometriosis.
aracterized as a "career woman's" disease, considered
ass disorder. In the 1970's, laparoscopy became the
or the definitive diagnosis of endometriosis.
arity at a time during trends of consolidation and

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health care, dramatically affecting the practice of medicine.
endometriosis focused on personality and psychological
women. In 1976, a pivotal article was published by Dr. Donald
can American gynecologist from the University of Chicago
Medicine (Chatman, 1976), reporting that 21% of his African
exhibited the disease, and many had been incorrectly
lvic inflammatory disease. Prior to Chatman's publication,
understood as a concern for primarily Caucasian "upper
mmiguel, 2000, p. 145).
s there was another major shift. Research in biomedical
during the 1980's and 1990's, focusing extensively on the
genesis of the disease. In the 1990's, new findings suggested
etween endometriosis and immune system dysfunction with
of the possible impacts of environmental toxins on the
uctive systems. This focus challenged the "career women"
lometriosis, suggesting endometriosis is not a product of
f a particular personality profile, but a product of hormonal
uel, 2000).
hifting understanding of endometriosis from a career
a disease of environmental toxins, a certain amount of
ility was still placed on the woman with endometriosis by
e medical community, whether for postponing childbirth or
ated water. In 1991, women with endometriosis

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billion market targeted by a growing number of
ialty clinics focused solely on the care of endometriosis.
nor medical therapies, nor holistic approaches offered
endometriosis (Sanmiguel, 2000, p. 262).
ay organizations, such as the Endometriosis Association
ometriosis has been documented (Whitney, M.L, 1998).
ng and social support provided through support groups,
ation about the disease have been found to offer
nen's resources in dealing with the disease.
ndent self-help organization founded in Milwaukee,
Lou Ballweg and Carolyn Keith, and has grown into a
anization with chapters, groups, sponsors, and
roughout the world. Operating as a non-profit
stablished funds to support investigations into the
d is associated with research at Dartmouth Medical
lt University School of Medicine. The EA has funded
throughout the world (Endometriosis Association,

es information about symptoms, theories of cause,
ndometriosis in 28 languages. Other services
pport groups worldwide, "informal" crisis call help,
scription discount program, and a program specific
sis (Endometriosis Association, 2005).

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historical analysis of endometriosis illuminates some of the
cultural and political factors at play with the diagnosis of
It is crucial to understand the history of endometriosis within the
y and the women's health movement, in order to understand
dividual woman and her partner's lived experiences. While the
stic labeling and social/cultural understanding of endometriosis
al focus of my research, they provide important conditions for
e lived experience and relational responses to living with CPP.

atment of Endometriosis

ears of biomedical research, "clinical confusion" surrounds
arry, 2004, p. 760) and is widely recognized as a complex and
d condition (Blumenfeld, 2004; Lemaire, 2004). There is
s in the medical community that endometriosis is a common,
dent, chronic gynecological disorder that is associated with
ertility, and is characterized by the presence of endometrial
c peritoneum, the ovaries, and in the rectovaginal septum.
s are less commonly found on the pericardium, pleura, and the
ao, 2004).

dely accepted theory of pathogenesis of endometriosis was
20's, and suggests the condition originates from retrograde
dometrial tissue that passes through patent fallopian tubes
avity. Endometriosis has been more recently considered as

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luenced by multiple factors including genetics,
immune system function (Giudice & Kao, 2004).
or endometriosis include both surgical and medical
:an be performed with diagnostic surgery and may
ndometriotic tissue (ablation), division of adhesions
l of endometriotic cysts (Yap et al., 2004).
r intractable pain associated with endometriosis is
y and bilateral salpingo-oophorectomy (Kramer &
pies for systemic hormonal suppression of
ol (a synthetic testosterone hormone derivative),
one (GnRH) agonists, progestins, gestrinone and
ecurrence of endometriosis symptom and disease is
of medical therapy (Yap et al., 2004).
nt treatment options for endometriosis are scant.
e often recommended for endometriosis-related
etin states that only one clinical trial suggested that
were comparable to a GnRH agonist in relieving
cal trial evaluating the use of monophasic
after surgical resection of endometriomas showed
t significantly affect the long-term recurrence of
dress the use of cyclic versus noncyclic combined
04).

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ochrane Review (Hughes et al., 2003) examined ovulation
n in general, including GnRH agonists, progestins, danazol, and
ral contraceptives, and concluded that while ovulation suppression
o be useful for the management of endometriosis related pain, the
sts must be taken into consideration. For example, GnRH agonists
k of accelerating bone loss as much as 1% per month. Vaginal
t flashes, headaches, and nasal congestion are also common
Danazol may increase LDL cholesterol, cause weight gain and oily
stins may also cause weight gain, as well as depressing mood and
dose combined birth control pills increase thromboembolic risk. The
t also must be considered as patients using GnRH agonists and
expend several hundred dollars per month for treatment (Hughes et

rch supporting the efficacy of surgical treatments is limited.
nors of a Cochrane Review (Jacobson et al., 2001) examining the
aroscopic surgery in the treatment of pelvic pain associated with
, conclude that the combined approach of laparoscopic laser
siolysis, and uterine nerve ablation is likely to be a beneficial
elvic pain associated with mild to moderate endometriosis, the
st that these findings should be interpreted with caution as only
l was included in the analysis (Jacobson et al., 2001). It is
CPP is the preoperative indication for 10-12% of hysterectomies.
ctice Bulletin concludes based on observational studies, that at

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f women who have a hysterectomy for CPP thought to be caused by disease, which would include endometriosis, experience pain relief of follow-up (ACOG, 2004).

Symptom Experience

esearch conducted to understand the phenomena of CPP and s, has been conducted from a biomedical perspective, which has d by feminist scholars (Clarke & Oleson, 1999) as routinely silencing ne woman in both the provision and receipt of health care, as well olicy. We must consider what role Cartesianism plays in the omen's voices in the scientific literature. Within the medical culture, archy of signs of knowledge in which certain signs (i.e., objective e privileged and considered more valid than others (i.e., patient's vidence of such knowledge hierarchies are found in the CPP ere are many investigations exploring laparoscopic findings in (Baker, 1992; Vercellini et al., 1991; Vercellini et al., 1996), but women's experiences (Grace, 1995b; Zadinsky, 1996). ies have documented experiences of women living with nd/or CPP. Two qualitative studies utilized focus groups to experiences of women living with endometriosis. Grace (1995b) cus groups in New Zealand to understand women's experiences services for CPP. All of the women in three of the focus groups nosis of endometriosis or suspected they had endometriosis. In cus groups, pelvic pain was undiagnosed or women had

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r in addition to endometriosis. Although different groups

, no differences were noted in the findings. Rather,

using a method of discourse analysis called lexicology.

identification of key words and associated fields of

building a picture that is common to the whole. The

in a metadiscourse, which represents a cohesive

nd each individual narrative. The following is an excerpt

the women's health-seeking experiences. Words and

d highlighted as presented in the original metadiscourse

ructure.

has pain; she believes there is *something wrong*,
rong, and seeks *help* from the medical profession. Her
is to ***know***, to *understand* what is wrong; the question
treatment then follows. But the first thing is to ***know***.

unter with the doctor (a general practitioner or
t) she tries to communicate in words her experience of
e tries to ***tell*** the doctor the story of *her pain* – when it
w long it lasts, what it feels like, and how it changes.
pain has been so *intense* and has gone *on and on* for
e is a lot of emotion associated with the *telling*. She
the doctor about her pain so that he or she will
. This is very personal; the doctor needs to ***listen***.

countering someone who listens and enters into a
woman experiences a somewhat *patronizing*
ring which she might even be called ***"my dear"*** – as if
ative and understanding are somehow not a central
the process. There is the woman's *body* and the
rtise... (Grace, 1995b, p. 513)

derson, Cagliarini, & Ski (2003) also utilized focus

riences of women living with endometriosis. Five

ed with 61 Australian women diagnosed with

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though the research focus was to understand the informational
ndergoing laparoscopy for treatment, the majority of the
ocused on the experience of living with endometriosis more
of the women had been living with symptoms for many years.
n shared the "trauma, distress and anger" (Cox et al., 2003, p.
n seriously by providers. Pain was explained and interpreted
particularly if there was a family history of pain with
ral practitioners had a general widespread attitude that
l having kids" (Cox et al., 2003, p. 6) would solve women's
ems. Even though some of the participants had experienced
hey were too embarrassed to discuss such personal issues.
also reported relational difficulties and even break-ups that
mpact of the illness on partners over time. Some of the
eling suicidal, and feelings of depression and worthlessness
ole factors including workplace discrimination, being judged
by family and friends, marital disruptions, and a
mptoms (Cox et al., 2003).

yle (1996) conducted an ethnographic study in a CPP clinic
nterviews, participant observation and a pain diary, to
with CPP develop self-care strategies to allow them to
ally and socially prescribed roles. The women reported that
merous painful physical examinations, diagnostic tests,
nd surgeries, the women still had pain that their physicians

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lered disproportionate to the identified pathology. Some women reported being without pain and experienced other symptoms such as physical and l fatigue, periods of depression, episodes of crying and difficulty sleeping at Even during pain free episodes, the anticipation of recurring pain made it for the women to plan their daily lives. Some women experienced inty and a feeling of loss of control over their lives.

The women in Zadinsky & Boyle's (1996) study found it difficult to fulfill f-expectations in their relationships with husbands or boyfriends. The s pain often limited their ability to participate in social activities with their ls and sometimes made it difficult for them to engage in sexual rse. Women reported that some men implied the pain was an excuse to ual activities. Due to numerous sick days, many women found it difficult ge full-time employment or develop their careers because of the pain. In to the many disruptive changes in their lives and the inability of their to offer a cure, women developed their own self-care practices. All of n took over-the-counter pain medications on their own initiative. At e medications provided only temporary relief. Home remedies were ne women such as drinking Epsom salts, drinking wine with the belief it n the pain out of the body. Hot compresses, heating pad, and were used. Taking breaks and resting throughout the day was helpful, straction techniques, such as watching TV and interaction with children & Boyle, 1996).

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(2004) conducted a qualitative study utilizing interviews with 15
ad been diagnosed with endometriosis and thematically analyzed
ucing eight themes: (a) delay in diagnosis, (b) pain, (c)
d) treatment, (e) work, (f) social relationships, (g) the workplace,
re. Women differentiated the pain of endometriosis from "normal"
its longer duration, and its inability to be managed with over-the-
edication. Women were told by their providers that they were "just
y, 2004, p. 644) when they presented in pain, and described not
able "volunteering" information about their symptom of
s they considered it very personal information and few providers
nen about it. Some women learned to accommodate dyspareunia
tioning, while others experienced strain on their intimate
sulting in breakups. Women had a range of responses regarding
ips as some women found friends and family to be a source of
ractical support, while others found their social lives constricted
shed their ability to attend social events. Additionally, women
ant concerns about the future, worrying that symptoms would
their ability to cope over the long-term.

litative studies have focused on the lived experience of women
is, encompassing multiple symptoms, the relational impact of
difficulties with the provider relationship. The following section
ific symptoms related to the broader category of CPP.

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evalent symptom of endometriosis and CPP, which
e in seven U.S. women (Mathias et al., 1996). Pelvic
comprehensively assessing unidimensional and
of pain through a variety of tools including investigator-
visual analog scales (VAS), somatization scales, pain
uations of pain, and multidimensional pain instruments,
Questionnaire (MPQ).

dometriosis Association (EA) member survey (EA
women reported pain, 95% experienced menstrual
ulation pain, and 75% reported pain at other times.
uring or after sexual intercourse. A commonly
ition, pain in the lower abdominal region lasting at
location and duration of pelvic pain. However, it does
pain and overlapping symptom experiences. Findings
st women experience qualitative distinctions between
arch has also examined CPP, dyspareunia, irritable
burinary symptoms, demonstrating a substantial
other abdominal symptoms (Burkman, 2004; Williams
n et al., 2001).

hat women have pain symptoms for years prior to
Miller, & Fowler, 1994; Peveler, Edwards, Daddow,
, Van Vugt, M., Stones, W., 1998; Stones, Selfe,

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T. Zondervan et al., 2001). The duration of pain for
ment ranges from two and a half years (Reiter,
(Reed et al., 2000), depending on the study.
with CPP experience moderate levels of pain
e the MPQ (Peters et al., 1991; Reed et al., 2000)
Vugt, M., Stones, W., 1998; K. T. Zondervan et al.,
und that women's rating of pelvic pain severity on
was 5.0 (SD 2.3) on a scale of 0-10, with 0 being
s bad as it could be." A majority (82%) indicated
enced in the past month was typical for them.
without pathology (CPPWOP) are compared to
ology, there is no significant difference in duration
e in pain severity between the two groups (Richter
nic pathology describe significantly more severe
er persistence of pain than women with CPPWOP

en with another gynecological pain disorder,
PP experience significantly more severe pain (as
ain severity and suffering in response to the
tially more days from work in the previous two
vith vulvodynia (Reed et al., 2000). When
to groups of women with other pain disorders,
es, researchers found that on the total score of

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IPQ, women with vulvodynia scored significantly lower than women with
or headaches, however, they did not control for duration of pain in the three
s (Haefner et al., 2000).

When women with CPP are compared to other illness groups, based on
al functioning subscales, including physical functioning and bodily pain,
n with CPP do better than patients with noninsulin dependent diabetes,
ension, and cardiac failure. However the burden of CPP is illustrated when
tribution of scores in the emotional, social, energy, and psychological
les are compared. Only patients with clinical depression scored
ently lower than women with CPP on all subscales (physical functioning,
sical, bodily pain, general health, vitality, social functioning, role
al, mental health) except bodily pain (Stones et al., 2000).

summary, the qualitative distinctions in the pain experience of women
identified as having endometriosis are not well understood. There is
nted lag in help seeking behavior by women who experience
riosis and CPP (Reed et al., 2000). One possible factor contributing to
lty with diagnosis of CPP may be its polysymptomatic nature.

mptoms

vestigations have focused on the polysymptomatic nature of CPP.
n et al. (2001) found in a large community sample that approximately
women with CPP had at least one additional symptom beside pelvic
he most common were symptoms related to irritable bowel syndrome
%). Selfe et al. (1998) examined clinical characteristics of women

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primary care physicians for investigation of CPP to a university
ecology outpatient clinic. Fifteen percent of the women with CPP also
ve for symptoms of irritable bowel syndrome, 71% experienced
, and almost half experienced sleep disturbance from the pain.
rt of a randomized clinical trial comparing two treatment approaches
ith CPP, Peters et al. (1991) used an investigator designed
e to assess the presence of associated symptoms. The most
ptom was backache (86%), followed by malaise (80%), headache
a (53.5%), insomnia (42.5%), vertigo (39%), and diarrhea (14.5%).
ently, there has been attention in the literature to bladder-related
sociated with CPP (Burkman, 2004; Mishell, 2004; Parsons, 2004).
bel of "CPP" and the focus of the pelvic region in both the diagnosis
of the condition, research suggests a polysymptomatic nature of

on Daily Function

ercent of women with CPP experience a level of distress that
daily functioning (Mathias et al., 1996; Peters et al., 1991) and
ce from work as a result of the pain (Reed et al., 2000; S. A. Selfe
ore than a third take daily analgesic to control their pain, and
xperience impaired family activities (S. A. Selfe et al., 1998) due
cial functioning, mental health difficulties and reduced energy
et al., 1996; Stones et al., 2000).

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een suggested that gender impacts the way women take up living
ous conditions (Clarke, 1999; Finkler, 1994; Yunus, 2001).
PP may not allow their pain to interfere with culturally constructed
tions, and they tend to place the needs of others ahead of their
al., 2000). Zadinsky & Boyle (1996) found that while women with
to provide physical care for their children, they were unable to
en's emotional and developmental needs consistently.
colleagues (1999) found that as women described the problems
heir sex life, they focused on their inability to meet the
heir partner rather than addressing their own sexual needs.
sequences of these unspoken social expectations on women
examined, the effects are potentially profound (Meleis &

Pain and Relationships

hip Quality/Satisfaction

ch suggestion of relational difficulties and CPP, few studies
stigated relationship quality or satisfaction and there is gap in
d to the separation and divorce rates of women with CPP.
used the Dyadic Adjustment Scale to compare women with
nd control group women and found no significant difference in
quality between the three groups. Mathias et al. (1996) in a
munity survey, found a small but statistically significant
status between women who did and did not report CPP.

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en who were separated, divorced, or widowed had an increased likelihood orting CPP compared with single women ($p<.05$). The authors suggested elvic pain may co-evolve with marital dysfunction, but how this occurs is not Indeed, research on pelvic pain and marital status is somewhat dictory. Haefner et al. (2000) compared women with CPP with two other roups, women with vulvar pain, and headache pain. Patients with vulvar ere more likely to be married than the women in the other two pain groups). Yet, Collett and associates (1998) found significantly fewer married in a pain-free group compared to women with CPP or women with pain in site (p value not reported).

Satisfaction

ittle is also known about the sexual satisfaction of women with CPP. al. (2000) compared perception of sexual impairment in women with vodynia, and a control group. All three groups rated the quality and of their sexual activities similarly for the time prior to the onset of chronic wo years before the present for controls). However, women with a and those with pelvic pain rated the current quality and quantity of al activities as significantly more impaired as compared to control nd to their own premorbid activities.

roup of researchers (Fry et al., 1991) applied a modification of s Illness Model approach in a qualitative study of study of sixty-four h CPP. The goal of the study was to understand the nature of the of the illness process and to understand the woman's personal

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pts of the illness. Their findings suggest that rather
cts of pain on day-to-day life were seen as most
The largest problem reported by the majority of
y 62% of the sample.

he CPP literature in relation to sexual activity
l functioning or dysfunction such as lack of
al., 1994), lack of interest (Carlson et al., 1994;
riffiths, 1988; Reed et al., 2000; Richter et al., 1998),
riffiths, 1988), feelings about self as woman or
, 1994; Reed et al., 2000), dyspareunia (Collett et
9; Harrop-Griffiths, 1988; Mathias et al., 1996;
e et al., 1998; K. T. Zondervan et al., 2001), post-
; Mathias et al., 1996; Peters et al., 1991; S. A.
W., 1998), inhibited orgasm (Harrop-Griffiths, 1988),
01; Richter et al., 1998), and details about sexual
ding orgasm, fallatio, and cunnilingus (Reed et al.,
ts a strong association between sexual difficulties
(Harrop-Griffiths, 1988) to 75% (Collett et al.,
of women with CPP experience dyspareunia.
conducted by Mathias et al. (1996), of the
exually active and of this group, 88% reported
course "some most or all of the time in the past

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n." Research also indicates that almost half of women with CPP experience
asmia (Peters et al., 1991; Richter et al., 1998), and more than a quarter
s et al., 1991) to half (Collett et al., 1998) of women with CPP, experience
oital pain. Additionally, 40% (Collett et al., 1998) experience vaginismus
ore than a half (Collett et al., 1998) experience loss of interest in sexual
.

Zondervan et al. (2001) found that while 50% of women with CPP in their
experienced moderate to severe dyspareunia, only 30% reported a
se in frequency of sexual intercourse because of pain. When subgroups
en with CPP and overlapping symptoms were examined, the proportion
orted having sexual intercourse less frequently because of pain varied
ntly, from 22% with women with CPP only, to 52% among women with
nitourinary symptoms, and symptoms of irritable bowel syndrome.
search also demonstrates that although a large proportion of women with
erience sexual difficulties, those in partnered relationships continue to
ual relations as frequently as women without CPP and were as likely to
e in sexual activities with their partners as asymptomatic women,
intercourse, having orgasms, and giving and receiving oral sex.
lly, when women with CPP were compared to women with vulvodynia,
trol group of asymptomatic women, no significant difference in feelings
as a sexual person were found (Reed et al., 2000).
summary, we do not have a complete understanding of the sexual lives
with CPP. Although sexual dysfunction and dyparuenia have been

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earch also suggests that partnered women with CPP continue to
ons as frequently as women without CPP (Reed, 2000).
of women's health have been proposed (Ruzek, Clarke, &
Taylor & Woods, 2001) which radically differ from narrow
that only acknowledge prevention, detection, and treatment of

) cautions that the current focus of women's sexuality, as it
omedical framework reflects an individualistic perspective,
res the relationship context but also the larger political and
ork. Tiefer argues that the biomedical frame "privatizes" sexual
hem the result of some malfunction of a "natural" or "normal"
ributing to shame (Tiefer, 1994, p. 155). She also argues
absent in the way that their sexual complaints are reported

Ambiguous Health Conditions and Relationships
ences of women with other ambiguous conditions, such as
ne (FMS), irritable bowel syndrome (IBS), headaches, and
ome (CFS) are compared to CPP, a startling number of
are evident. The first notable theme is that these ambiguous
common in women than in men (Yunus, 2001). Other
s the studies of individuals with ambiguous conditions
rustration for patient and provider when no etiology can be
others not believing the pain is real, communication

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s with the health care provider, and a decrease in the quantity and
f work produced inside and outside the home (Draucker, 1991;
on et al., 1999; Zadinsky, 1996).

n overlapping theme that is of primary interest to this investigation is the
disruption in the lives of women suffering from ambiguous conditions.
l disruptions include family members and friends not accepting and
nding the pain, and questioning if the pain is real. Communication
close down and there is a reduction in the amount of time spent with
ding to social isolation (Schweitzer, Kelly, Foran, Terry, & Whiting,
oster, 1997). Some women experience divorce (Schweitzer et al.,
breakup of relationships as a result of the pain (Draucker, 1991).
d Narvanen (2002) reported a number of relational strategies
by the women to avoid stigmatization, such as withdrawing socially,
distance from others, and concealing the illness by maintaining a
ade. Women controlled information about the illness, to gain
e in various situations.

kasalo (1998) qualitatively studied chronic pain as a lived, embodied,
lered experience with Finnish women. The findings shed light on how
nce of chronic pain can shape spatiality and relatedness, as pain
not only space and time but also relations to other people. While
s experienced with pain, individuals were able to emerge from the
the use of their imagination, and with the help of other people. In
vement and motility often decreased with the experience of pain, and

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y were often limited to, for example, going back and forth to
ily member's home.

ficulties related to ambiguous conditions (Johansson et al.,
997; Zadinsky, 1996) have also been reported. Webster (1997)
al and sexual experiences of women with interstitial cystitis
lf-care strategy used to prevent or manage symptoms of IC
course. The women described the effects of partially or totally
se on their relationships with intimate partners. One woman
ner would get upset when she interrupted intercourse to go to
s data is consistent with Zadinsky & Boyle's (1996)
in which women reported that their partners believed their
e to limit sexual activity.

archies in which women's voices and experiences are
een documented (Clarke & Oleson, 1999; Malterud, 1999).
greater risk for women with ambiguous, difficult-to-diagnose
e of the western separation of mind *and* body, women with
nd themselves caught between a narrow *biomedical*
s their physical view of their symptoms and a *psychological*
matizing. Arguments have been made for *a paradigm shift*
tanding of the *illness experience* and *personal meanings* of
cknowledging a chronic *illness* as opposed to an acute *illness*
& Carson, 2001).

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Conclusion

a disease classification, is the most common cause of
ex women's health problem affecting approximately 15% of
age in the U.S. (Mathias et al., 1996). Despite its
rrently known about the phenomenon of CPP. The
f CPP has been studied extensively. Particularly, the pain
udied comprehensively using investigator-designed
omatization scales, and multidimensional pain
women have pain for years prior to seeking treatment and
f pain that interferes with daily functioning. CPP is a
on. More than half of women experience dyspareunia.
n endometriosis and CPP have been primarily disease-
erstanding of the contextual factors that impact the ways
their condition and the impact of illness on daily life.
es not adequately illuminate our understanding of the
and endometriosis from a relationship perspective.
s helpful and illuminates variables related to women's
ve little insight into the lived sexual experiences of
ir intimate partners.

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CHAPTER THREE

H: UNDERSTANDING COUPLES' EXPERIENCES

INTERPRETIVE PHENOMENOLOGY

Introduction

between suffering that occurs in a hospital and

camp. The difference is between suffering that has its

ng that is left in its own uselessness (Frank, 1995,

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early 15% of women of reproductive age in the U.S.

in (CPP) (Mathias et al., 1996). CPP is a complex

at has been described as "one of the most frustrating

ns in obstetrics and gynecology" (Kennedy, 2000, p.

ng of CPP is limited and numerous questions have

is known about the etiology of the condition, and

te medical intervention (Price, 1999). A large

PP experience significant amounts of disability as a

sturbance of daily activities, inability to work, and

ddition, it is estimated that half to three-quarters of

dyspareunia, or painful sexual intercourse. There

indirect economic costs of CPP (Mathias et al.,

f literature that documents the severe impact of

n's voices are virtually absent from the scientific

ge of Arthur Frank (1995), the "cries" of women with
ttended to.

d profound effects on the study of CPP. The study of
ease-focused, placing little emphasis on the meaning
t of the woman's life. Considering the
ex roles of women's lives, little is known about how
n the woman's perspective. In studies of CPP,
have predominated and have emphasized
with CPP as well as diagnosis and treatment
nese investigations, the experience of CPP has
zed by assessing the symptom experience
atric distress (Reed et al., 2000), and comorbidity
veness of various treatment modalities (Peters et
ant conceptualizations, empirical studies have
een women with CPP and factors including
nce, childhood events, particularly sexual abuse,
fficulties (Savidge & Slade, 1997). By focusing on
ever, these investigations have ignored what the
an, as well as to the people around her, including
994).

hat the meaning one attaches to a particular
of illness, exacerbating, reinforcing, or
ations based on meanings can also take place at

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s level, making changes in daily health practices, such as
ysical activity, dietary intake, and medications (Cassell, 2001).
001) suggests that because of statistical methods inherent in
lical research, individual variations, and qualitative distinctions
participants are lost. Supported are alternative methods that
"to see the fabric of the person as seamless with all its threads
ell, 2001, p. 380). Cassell (2001) points out that a barrier to
tesian conceptualizations may be the modern-day ease with
to control pain. Because of the safety and efficacy of
ain, there is a tendency to move pain that is not so easily
categories by emphasizing, for example, the psychological
ent's problem. This leads to the troublesome dichotomy, in
pain is considered either physical or psychological. It is
cannot explain a symptom physiologically, then it must be
s paradigm of inquiry sheds light on the plethora of literature
chological characteristics of women with CPP (Waller, 1995).
mple of the effects of Cartesianism on the study of CPP can
women with CPP are labeled. An examination of the medical
terature from 1980 to the present suggests women with CPP
subgroups and labeled as women with pelvic congestion vs.
, women with pelvic pain vs. women with normal pelvises,
py positive women vs. negative laparoscopy women. These
functional in the design of various investigations,

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listance the researcher from the woman, as a living, breathing
g within a world. A sense of the woman with CPP as a human
ystematically diminished by the Cartesian model of the
(Leder, 1992). Such truncation is illustrated in the disease
ndometriosis), diagnostic techniques (i.e., video laparoscopy)
rocedures (i.e., hysterectomy and laser surgery) associated

this discussion is not to devalue contributions of the Cartesian
onsible for numerous therapeutic and life-saving techniques in
ose of this discussion, however, is to briefly illustrate how the
its influence has shaped the existing theory and practice of
e a reasonable philosophical alternative.

Interpretive Phenomenological Theory

ological orientation offers an alternative to the Cartesian view
most existing research and clinical practice of CPP from
aim of approaching CPP phenomenologically is not to
understandings of the problem and its treatment, but to enrich
f CPP. The aim is to address questions of how CPP is
erpreted in the engaged and habitual practices of everyday
ur understanding about the taken-for-granted meanings,
in the daily lives of women with CPP and their intimate
e phenomenology uncovers the implicit self-understandings
le to direct questioning about attitudes, impressions, and the

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rpretive phenomenology is designed to access these non-explicit,
d meanings in human activity.

n interpretive phenomenological study provides an account that
es the participants' world (Benner, 1994b). Interpretive phenomenology
n the philosophical works of Kierkegaard, Heidegger, Merleau-Ponty,
tein, Dreyfus, and Taylor (Benner, 1994a). Interpretive phenomenology
on the understanding that human beings are situated within their world,
aningful activities, relationships, commitments and involvements that
th possibilities and constraints for living. Four areas of focus in
nological study include: the way of being in the world, meanings and
the person as self-interpreting, and the person as embodied (Leonard,

e World

om a phenomenological viewpoint, the first essential facet of a person
the relationship of the person to the world" (Leonard, 1994, p. 46).
is context, has a different meaning from our common understanding
environment. World, as a phenomenological term, represents "the
set of relationships, practices, and language that we have, by virtue
rn into a culture" (Leonard, 1994, p. 46).
term "throwness" is a term used by Heidegger, to express his view of
as always already situated, as being in the world (Leonard, 1994).
ed means we have a lived understanding of who we are.
ngs are transmitted in the daily habits and practices of those around

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hese common understandings are the bases on which we understand one
er in everyday life. Cultural meanings and practices constitute individuals
ouples living with CPP. Rather than understanding the woman, the partner,
couple as a collection of traits that are chosen, changed or transformed,
re understood as being grounded in the cultural possibilities available at
me (Chesla, 1995).

ngs and Concerns

Human beings are also engaged in their world by what matters to them.
standing individual and couple's concerns is essential because it is for the
f these things that humans act (Benner, 1994a; Dreyfus, 1991). Another
gerian term, "for-the-sake-of-which," describes "the way in which our
is directed in a transparent, taken-for-granted, nonmental way towards
re..." (Leonard, 1994, p. 49). A hermeneutic researcher tries to
and things which have significance and value in individual's and couple's
hin a context of language, culture, and individual situations.
enological researchers must enter the context of everyday lives of
living with CPP, including taking up what may be the uncontrolled,
ed, disorganized reality of couple's lives (Chesla, 1995).

rpreting

the Heideggerian view of person, humans are self-interpreting and are
n a world with shared meanings. Humans, rather than being self-
ng in a theoretical or cognitive way, are self-interpreting in relation to
ground and culture. The many hidden skills and practices of daily life,

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sive, go unnoticed, yet make the world intelligible and either
down possibilities (Leonard, 1994).

so live in the world in embodied ways. The Cartesian sense of
ifferent from the phenomenological notion of the body, as
ed. In a phenomenological perspective of embodiment, we live
ather than possessing a body (Leonard, 1994). It is through
are able to engage in concrete action in the world, and it is
that we are able to move with intention and meaning in the
being as embodied is particularly suited for exploring issues of
en with CPP and their intimate partners. Researchers with a
ve have identified characteristics of women with CPP and
disease, but have not been successful in explaining how the
whole, relates to others.
this particular project, is how women and their intimate
ng with CPP in the context of their everyday lives. Heidegger
s of engagement in relation to being involved with
hand, unready to hand, and present at hand (Dreyfus,
and mode of engagement refers to when individuals are
y activities, and the equipment they use functions smoothly
s mostly unnoticed. If there is a breakdown in the smooth
uipment, the mode of engagement turns into unready-at-
t becomes conspicuous and in the foreground where

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iously it went unnoticed. Finally, present-at-hand refers to engagement of an erver who stands back and reflects on the situation, for instance, on the erties of the equipment (Dreyfus, 1991). Narrative accounts will be used to tate disclosure of participants' and couples' experiences of the everyday, ng at the ready to hand mode of engagement in their day-to-day lives.

This theoretical framework will be used to understand, in a new way, the lex phenomenon of CPP. New ways to understand CPP are needed since nt models have not provided much success in moving towards effective gement or treatment of CPP. The goal was to illuminate concerns and iences from the woman and her partner's perspectives in order to provide ve dyadic nursing interventions, especially related to the relational impacts illness.

Preunderstandings

Human beings are engaged in their worlds by what matters to them. rns, or those things that matter, set up how we enter a situation, what we do not see and how we act (Benner & Wrubel, 1989; Dreyfus, 1991). neutics makes several assumptions based on the Heidegerrian nenological view of person. It is assumed, based on common background gs of the culture and language, that the researcher has a preliminary anding of the human action being studied (Chesla, 1995). We bring rstandings, or as Heidegger called it, a forestructure of understanding to earch project. This forestructure of preunderstanding has three aspects: having, fore-sight, and fore-conception.

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Fore-having refers to the taken-for granted background, the familiar world
m which we approach a project that makes interpretation possible. We
proach a phenomenon with a sense of what constitutes this phenomenon. The
e-sight is a preliminary sense of what counts as a question and what would
nt as an answer (Plager, 1994). It is my background experiences that frame
perspective from which I view the data. It is through my collective
eriences as a woman, an intimate partner, a patient, and a nurse, that set up
research questions for this project. Also, the completion of a pilot project with
nen with CPP and their intimate partners has provided preliminary data for
dissertation project. An interpretive phenomenological study, "How Couples
re the Pain of Endometriosis (2000-2001)" was conducted using individual in-
h interviews with three couples.

Fore-conception refers to the point of view, the perspective of a particular
pretive lens that orients us globally toward the phenomenon in a particular
and is therefore critically important to the study (Plager, 1994). The literature
w in Chapter Two outlines other theoretical frameworks from which the data
understood, and lays out my current, most up-to-date understanding of
related to endometriosis.

Research Design

The aim of interpretive phenomenology is to take into account the context
ch human beings live, and their history and to illuminate common or distinct
ns of meaning and action in the lives of those studied. Rather than trying to
terize a modal or group response, this research provides detailed

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varied patterns of human understanding and action (Chesla,
n, 1990). The study was a mixed-method design, with qualitative
the primary method, guiding the conduct of the study. Select
distress and affective response was used as an adjunct
nod. A prospective interpretive design (Cohen, Kahn, & Steeves,
ucted with repeat interviews with both members of the couple in
nd conjoint interview contexts.

clusion Criteria

English speaking women in a partnered or marital relationship,
d a diagnosis of endometriosis and experienced pelvic pain for
, and their partners, comprised the sample. Additional inclusion
eing at least 18 years of age, and living with a partner for at
olland, 1994). Diagnostic status of endometriosis was based on

om a Committee on Human Research was obtained for the
6597-17875-05). The study was initially explained to
he telephone, and again, before the interview, at which time the
read and signed by the participant(s) (See Appendices A and
consented together, unless individual interviews were
rent days. Both partners were given an informational sheet
al health referral services specializing in women's health and
rapy in the San Francisco Bay Area, as well as mental health

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ers (See Appendix C). It was explained that while it was
cipation in the study would create a need for counseling,
d as a potential resource for the future. The difficulty in
ersonal health experiences was acknowledged. A copy
given to participants. Once the participant had
ed interview of up to two hours was conducted. A
nducted approximately three weeks after initial
ayment of $40.00 per couple was given after the
r time and inconvenience. Four couples (30%) refused
ne payment be donated to an endometriosis cause.
llars was donated to the San Francisco Endometriosis
terviews were tape-recorded and transcribed verbatim
ith the use of codes instead of names.

dy was to recruit couples from a variety of sites, in
ally diverse sample. It was noted fairly early on in the
diverse in terms of ethnicity, but the sample was
were being recruited from endometriosis related
support groups. Permission was obtained from the
jects to widen recruitment sites to include an online
www.craigslist.com), and the Endometriosis Resource
center.org).

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diversification efforts, all of the couples were recruited from
elated recruitment sites including support groups, endometriosis
site, and a clinic specializing in endometriosis treatment. One
icipated in earlier pilot work, but had been recruited through an
upport group at that time.

tion was made in the inclusion criteria for one couple. Although
teria included having experienced pelvic pain for at least 6
ticipant expressed recently having a hysterectomy after suffering
ic pain for many years. Although she was still having post-
covery pain, her pelvic pain had been significantly improved.
s made to allow entrée into the study, hoping this case might fill
rstanding of the lived experience of CPP and perhaps be a

Sample Description

ouples participated in the study. All of the intimate partners
eported by the women, the length of time that couples had lived
rom one to 23 years, with a mean of 6 years, and a median of 4
ipants were childless except for two couples, in which each
hild. The study sample characteristics are presented in Table 1.

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mple Characteristics (n=26)

eristic	***Woman***	***Partner***
ize *(N)*	13	13
ars		
	34.90 (7.56)	38.14 (9.06)
n	33.65	36.66
	23-48	24-50
g together		
	6.65 (5.99)	7.65 (6.28)
	4.0	4.0
	1-23	2-24.50
for pay	92%	84%
l Income *(N)*		
-$10,000	0	1
0-$20,000	0	2
0-$40,000	1	0
0-$50,000	1	0
0-$75,000	2	1
0-$100,000	3	3
00 and above	6	6
ade of education *(N)*		
Grade	0	1
de/Graduated	2	0
College	2	3
/Graduated	5	6
aining/Grad. Degree	4	3
)		
uropean-American	9	8
	0	2
	1	1
slander	0	1
al	1	1
	2	0
	4	4
	0	1
nt	3	3
	6	5
ian	2	1
filiation or No Religion	2	3
response or N/A	2	1

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Data Collection and Measurement

Interviews

All interviews, except for two individual interviews, were conducted in the participants' homes. Two individual interviews (of the same couple) were conducted in the researcher's home, because scheduling conflicts and other factors made interviewing at their home impossible. Each couple was interviewed three times, once each individually, and once together. All of the couples except for three had their individual interviews conducted on the same day. Because of scheduling conflicts, three couples had their individual interviews on different days, ranging from 1 to 7 days from their partner's interview. The length of time between individual interviews and couple interviews (calculated from latter individual interview if conducted on different days) ranged from 2 weeks to 7 weeks, with an average of 4 weeks.

All interviews were audio-recorded. Individual interviews focused on illness understandings, symptom experience, and narratives about the person's perspective on living with endometriosis. Couple interviews focused on eliciting the couple's joint perspective on the illness, symptoms and narratives of living with endometriosis. Interviews were conducted in an open-ended, minimally structured format, encouraging the respondents to articulate their own experiences.

Individual interviews. Individual interviews included questions about the informant's illness understanding, symptom experience, and narratives of living

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s. Illness understandings were elicited using Kleinman's
s including the informant's perception of the cause, nature,
ıent needed. Symptom experience was assessed using the
ment Model of symptom perception, using specific questions
ke's qualitative study which was conducted to compare the
n and women with chronic fatigue syndrome, focusing on
erceived illness experience and relationship with medical
e, 1999). Sexual functioning questions were adapted from
al. (1996) study of sexual functioning of women with vulvar
r partners. Questions are included regarding symptoms
and significance), reactions of significant others, diagnostic
of causes of disease, and impact on symptoms on day-to-day

counts have been used repeatedly and successfully to
al phenomena, such as transition to teenage mothering
caring practices with a schizophrenic offspring (Chesla,
f partners with AIDS (Wrubel & Folkman, 1997), and
eriences of sexuality (Tolman & Szalacha, 1999).
f everyday experience, reveal the participant's situated
ized by the social world they inhabit. In prospective
e aim is to elicit the informant's current experience and
erience. Narrative questions that invite the informant to
ience include, "Please tell me about something that has

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relation to your endometriosis that was difficult for you or just tell me the story as it happened." Probes were used to it's complete narration of the experience. Additional ed, about an incident with the opposite emotional valence, ay (Cohen et al., 2000) (See Appendices D and E).

iews. Joint interviews have been used to elicit shared or at occur beyond the bounds of the individual (Chesla, 1995) nergism generated by the relationship of the couple avens, 2000) (See Appendix F). Couples were asked to spects of their illness understanding where they agree and ked to narrate in the presence of their partner additional mptom experience, with particular probes about the various symptoms. Narratives about shared couple metriosis and its effects on the couple's lives were elicited. tained to describe interaction patterns of each couple as nunication with each other and with the interviewer (Racher

study, to examine sensitive and intimate relational issues, ne consent process. This investigator understood the of these questions and used clinical expertise as a e specialist to conduct the interviews in an appropriate As with all interpretive interview procedures, couples and to refuse to answer any question. Efforts were made to

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te a trusting relationship with participants. Many participants expressed
n pain and sadness in the telling of their experiences. Comfort strategies
as listening with empathic silence, and use of body language to convey
rstanding were used (Morse, Deluca Havens, & Wilson, 1997). Because
ipants were asked to speak about areas of their lives that perhaps hadn't
previously articulated fully, great care and respect were utilized to follow the
ipants' lead, and to introduce new questions at a pace that allowed the
opment of trust and that allowed participants to reflect as they constructed
esponses. Rather than collecting socioeconomic data at the beginning of
erview, demographic data were collected, after a relationship had been
ished, at the end of the first interview (See Appendices G and H) (Tolman
acha, 1999). At that time, individuals also completed the Symptom
list-90-Revised (SCL-90-R).

ological Distress and Depression

The SCL-90-R was administered to the woman and her partner (See
dix I) after the first interview. Chronic pelvic pain has been associated with
sion and psychological distress (McGowan et al., 1998). The SCL-90-R, a
multidimensional, self-report symptom inventory has been designed to
e psychological distress and normed on large samples of women and
clinical and non-clinical settings (Derogatis, 1982, 1994; Derogatis &
1977). Research on depression suggests the SCL-90-R is very sensitive
esence and alteration of depressive disorders (Derogatis, 1982).

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SCL-90-R is rated from 0 (not at all) to 4 (extreme)
e over the past six months. Factor scores range from 0 to
cores ranging from 0 to 1.0). The results of three factors
included in this study: depression, anxiety, hostility, and
ss (GSI).

symptoms of the Depression dimension reflect a
he manifestations of clinical depression. Symptoms of
ct are represented as are signs of withdrawal of life
n, and loss of vital energy. In addition, feelings of
of suicide, and other cognitive and somatic correlates of
(Derogatis, 1994).

signs of anxiety such as nervousness, tension, and
the definition as are panic attacks and feelings of terror,
Some somatic correlates of anxiety are also included
nts (Derogatis, 1994).

tility dimension reflects thoughts, feelings, or actions
ne negative affect state of anger. The selection of
ch as aggression, irritability, rage, and resentment

ex. The Global Severity Index is the best single
el or depth of distress. It combines information
symptoms reported with the intensity of perceived

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used in most instances where a single distress
or (Derogatis, 1994).
own high levels of internal consistency reliability
s: total distress = .90-.95; subscale coefficients:
n α = .90-.94 and hostility α = .85-.88). The SCL-
he shorter 53-item BSI version due to the high
ble subscale scores (Derogatis, 1994).

Data Analysis

r and the pair reporting as a unit, were two sources
interviews, eliciting joint construction of illness,
onstructions. The relationship between the woman
perience was examined.

logy aims at gaining a deeper understanding of
iences, not previously reflected upon or
Interpretive phenomenology embraces and
nilies such as shared meanings and a family's way
995). In studying the lifeworld, the goal of
alities and differences of narratives, as opposed to
nderstandings. The ongoing process of
ata collection and continues throughout the final

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e process involved three strategies: identification of exemplars, and thematic analysis, all of which were used as s (Benner, 1994c). Interpretation began with the close (e.g. all of the interviews and field notes from one couple). A d as a way to enter the text, and illustrates participants' rough daily habits and practices. A case may be chosen ne researcher thinks they understand well, or they may hey find puzzling or unsettling. This is a process of s for everyday skills of perception and understanding to of the paradigm case. First, the whole interview text of one n overall understanding of the story. Then topics, issues, lected for more detailed analysis. A systematic moving iew back to the whole allows the interpreter to check for and repeated concerns. It is not expected that the the meaning of the text. The goal is to present the text as fying incongruities and mysteries (Benner, 1994c). The was repeated with the text of the other partner within the repeated, with the goal of examining the couple as a unit. cher has identified a pattern of meaning, common xperience, exemplars may be extracted from the text to ity or difference. Exemplars illustrate aspects of a atic analysis. A range of exemplars allows for the ability to

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ditional clinical boundaries and add nuances and qualitative
o the understanding of the phenomenon (Benner, 1994c).
natic analysis was done across cases to clarify distinctions and
he interpreter moved back and forth between portions of the text
of the analysis, which allowed for new interpretive questions. During
researcher struggles to understand the text, but the struggle must
king the practical world more rational, coherent or consistent than it
ner, 1994b).
oject generated a considerable amount of data. The software
AS-ti, was utilized to mark and organize the text to manage the
a. Also, it was discovered that a method was needed to track
ss and symptom histories. A comprehensive table was created for
nalysis (couple) which served to provide clarity in understanding the
iences over time. The *x* axis of the table tracked time starting with
ate of birth, and ended with the date of the interviews. The *y* axis
luded the following categories: a) the age and type of pain onset;
) significant life events; d) treatment course; e) symptom
ain descriptors/use of metaphor; g) understanding of disease; h)
interruptions; i) relational issues; and j) disclosure/nondisclosure.
arrated about their illness and symptom experience over time,
y years, therefore the table was a helpful tool in ordering their
ronologically, to get a clearer picture of their lived experiences.

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ently throughout this project, analysis was conducted in
h other doctoral students and faculty. Through small group
minars, as well as one on one interaction, the reiterative process
portunity to challenge each other's blind spots and
s regarding interpretations of data.

k List-90-R (SCL-90-R)

-90-R was used as a screening measure for general distress in
and the partners. Analysis of the SCL-90-R included the
general distress (GSI) and depression/anxiety/hostility scores of
iagnosis of endometriosis and their partners, with nonpatient and
atient normative scores of the same gender (Derogatis, 1994).
ans were tested against the normative data with one sample *t*-
scores were also compared with women with severe
ndrome (PMS) (Taylor, 1999). Since normative distress and
es are available, as well as scores from other groups such as
onic conditions, the SCL-90-R was used as an adjunct, to provide
t the psychological impact of living with CPP. The Statistical
Social Sciences (SPSS™, version 12.5), was used to organize
quantitative data.

s of three factors and global distress are reported here:
ty, hostility, and general symptom distress.

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Table 2

Descriptive Statistics and One-Sample t-tests for Women's General and Emotional Distress (SCL-90-R General Symptom Distress and Selected Subscale Scores)

	Women's Scores M (SD)	Norms: Nonpatient Women M (SD)	Norms: Psych Outpatient Women M (SD)	Norms: Women with PMS M (SD)
Global Severity Index (GSI)	.97 (.55)	.36 ** (.35)	1.35 * (.69)	1.2 (.53)
Depression	1.43 (.82)	.46 *** (.52)	1.94 * (.93)	1.8 (.76)
Anxiety	.76 (.56)	.37 * (.43)	1.59 *** (.90)	1.2 * (.67)
Hostility	.76 .68	.33 * (.42)	1.17 * (.95)	1.6 *** (.98)

Note. *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$.

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Table 3

Descriptive Statistics and One-Sample t-tests for Partners' General and Emotional Distress (SCL-90-R General Symptom Distress and Selected Subscale Scores)

	Partner's Scores M (SD)	***Norms: Nonpatient Males M (SD)***	***Norms: Psych Outpatient Males M (SD)***
Global Severity Index (GSI)	***.51 (.55)***	***.25 (.24)***	***1.14**** ***(.64)***
Depression	***.63 (.84)***	***.28 (.31)***	***1.59**** ***(.92)***
Anxiety	***.54 (.75)***	***.22 (.27)***	***1.30**** ***(.83)***
Hostility	***.29 (.26)***	***.29 (.37)***	***1.00**** ***(.89)***

Note. *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$.

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Women's study participant GSI mean scores were significantly higher than npatient means and significantly lower than the means of psychiatric tpatients. When study participants' GSI scores were compared with women's ores with severe PMS, no significant difference was found. A similar pattern s found when depression scores were compared. Study participants had nificantly higher mean depressive symptom scores than nonpatient women l significant lower mean scores than psychiatric outpatients. However, when dy participants' depressive symptom scores were compared to scores of nen with severe PMS, no significant differences were found. When the iety and hostility scores of the study participants were compared to normative , the study participants' means were significantly higher than nonpatient ns and significantly lower than both the psychiatric outpatient mean and the n for women with PMS.

The mean scores of the partners on all three factors including global ess show no significant differences when compared to normative data of atient males. However, the partner's mean scores were significantly lower psychiatric outpatient males on all three factors, as well as on the GSI .

An application of the SCL-90-R involves its use as screening measure for iatric disorders in a variety of nonpsychiatric populations (Derogatis, 1994). amental to screening is an operational definition of "caseness," the score on reening measure that serves to define a positive case. The operational r "caseness" states that if the participant has a GSI score greater than or

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ore of 63 (on the nonpatient normative scoring sheet), or if any two
sion scores were greater than or equal to a *t*-score of 63, then the
nsidered a positive risk or a "case."

men (62%) in the present sample were a positive risk, or a "case."
31%) were a case. In two couples (15%) both partners were a
n ten couples (76%), at least one partner was a case.

Triangulation

ose of the mixed-method design is complementarity, as
ndelowski (2000), to explain or to offer more fully, a description
Blending or merging of the data occurred by adhering to the rules
s inherent to each method. Each analysis was conducted
The quantitative measure of general distress and
ety/hostility scores were used to strengthen the description of the
partners, to get a better understanding of their lived experience

Evaluation

ural science research, the quality of an interpretive account
a fixed set of criteria such as reliability, validity, objectivity or
lizability, and repeatability. Discussions in the social sciences
ound questions such as, "How do you know? Which methods
to use? What criteria should be applied?" (Bochner, 2000, p.
been much written to warn against using the same terms and
tative and quantitative methods are derived from different

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er (2000) cautions qualitative researchers, that a
criteria based on quantitative methods, may result in a lack of
sight of more important questions, such as if the research is
r meaningful – and to whom" (Bochner, 2000, p. 267).
been many methodological discussions in which numerous
sted guidelines and criteria for evaluating qualitative
nd Guba (1985) have developed four criteria to assess
research, which include "credibility," "confirmability,"
"dependability" (Lincoln & Guba, 1985). These four criteria
an ongoing evaluative process throughout the investigation.
nes postmodern issues of validity and offers a radical
lity Checklist", "where the test of validity is whether the
existing ways of knowing, rather than corresponding to
att & Hodkinson, 1998, p. 518).
also discusses issues of validity and outlines validity as
mmunication," and "action." According to Kvale (1995)
n the quality of craftsmanship, involving continually
tically interpreting the findings. Craftsmanship of research
so based on the quality of work the researcher has
. Communicative validity involves testing the validity of
e. Those who validate an interpretation through dialogue,
ts of an investigation, the general public, or the scientific
criteria used by Kvale (1995), involves pragmatic validity, in

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evance of the interpretation to create change, or

kes up a much more aesthetic and artful perspective
arch and distinguishes between the substantive,
nantic aspect of the text, how the text speaks or
He suggests four criteria for evaluating qualitative
which is the way in which the lived experience is
so we can phenomenologically reflect on it. The
nich is the attention paid to giving "key words their
enomenological meaning become strongly
anen, 1997, p. 355). The third is "tone," which is
aks to the reader in an affective, noncognitive way
h is "epiphany" which is the way in which a text has
nly providing an understanding or intuitive grasp of
an Manen (1997) acknowledges that in thoughtful
istinction between poetic and narrative is not

ggests qualitative research needs to be evaluated
ence and art, and offers five criteria as a guide. The
," which poses the question if the piece
g of social-life. The second is "aesthetic merit,"
s aesthetically, and is satisfying, complex and not
and poses the question about how the author

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he fourth is "impact" which addresses issues of impact of
The fifth and final criterion is that it "expresses a reality,"
ied sense of the lived-experience.

any diverse opinions about the validity of qualitative
single, unchallenged paradigm has been established for
ises valid and significant knowledge (Bochner, 2000), we
ltiple perspectives in the historical and current
n of qualitative research.

project was undertaken from the discipline of nursing
the personal, first-hand experiences of women with CPP
rs. Evaluative criteria for such a project would pay
the "scientific" and "literary" aspect of the research
rsing, as an applied science, requires that rigorous
place, such as those proposed by Lincoln and Guba
Yet, equally important, are evaluative methods that
spects, such as the aesthetic, and artful qualities of the
posed by van Manen (1997) and Richardson
se evaluative criteria are especially appropriate
this project were to give voice to a previously silenced
insights that supplement and enrich an understanding
vn from biomedical research.

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Limitations

recruitment strategies were in place to ensure diversity, such as
ent sites that offered services to a broad range of ethnic and
groups, the sample was homogeneous in several ways. First, the
nogeneous in its constitution of women who were involved in
lated activities. All of the couples were recruited from
lated recruitment sites including support groups, endometriosis
ite, and a clinic specializing in endometriosis treatment. One
cipated in earlier pilot work, but had been recruited through an
pport group at that time.

ne sample did not meet targeted ethnic diversity. The city of San
rnia, with a population of approximately 800,000, is ethnically
d of approximately 48% ethnic and minority groups and
prise 52% of the total population (San Francisco, 1999).
nent efforts targeted demographics to approximate those of the
the sample comprised of nine Caucasian women (69%) and
asian partners.

sample was homogenous in terms of income and education
women (75%) and nine of the partners (75%) had completed
n. Nearly half of the couples (46%) had household incomes
0,000 per year.

was also homogeneous in terms of severity of disease.
common gynecological condition with a range of symptoms

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dysmenorrhea, pelvic pain, and infertility. However,
y also be asymptomatic (Yap et al., 2004). As a whole, this
sentative of women who experienced significant distress from
etriosis. The relationship between severity of symptoms and
dometriosis-related support groups and activities is unknown,
h to understand the lived experience of women who experience
etriosis not involved in endometriosis-related groups would be a
existing literature. Future research efforts can target women
as opposed to medical sites, through the use of newspaper
nd community bulletin boards.
limitation points to management and interpretation of
hat involved complex past medical histories and illness
ed by all of the women during the individual interviews.
past medical histories were not a central focus of this
ative questions focused on informants' current experiences,
ecounting the past for the women was a significant finding of

ative data analysis, it was extremely difficult to tease out from
hat was often a number of different types of surgeries, as
nd various treatments over time. Rather than collecting
ch as number and type of surgeries in a survey, it may be
e a historical timeline as a tool to be utilized during the
ompleted as a collaborative process between the interviewer

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and interviewee. This process would have two particular goals. One goal would be to use the information to aid in data analysis, while another goal would be to stimulate useful probes during the interview process.

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CHAPTER FOUR

AMBIGUITY

elvic pain (CPP) from endometriosis is experienced as an
body that is simultaneously distressing and puzzling. The label
ain" is misleading as the pain is usually intermittent, sporadic,
e in nature. A more accurate label of this phenomenon is
nic pelvic pain" acknowledging the unpredictable and recurring
. With CPP, everyday taken for granted activities are

er describes the ambiguity of the woman's lived experience of
etriosis. The first section describes the onset of pain, the
odied sense of something gone wrong in her body early in the
. The second section articulates the complex and arduous
g to get answers from health care providers. The third section
rience of receiving a diagnosis of endometriosis, and in
gs associated with the diagnosis. The fourth section illuminates
women's treatment experiences in seeking relief of pain. The
timate partners are introduced by their first names only, which
identifying information has been changed to protect
fidentiality.

Pelvic Pain: A Bodily Interruption

ight be able to see a blister on the toe from a new shoe, or
d from a bee sting, the causes of pelvic pain are not visible to

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as the interiors of the pelvic cavity are hidden and out of view.
ı body is functioning normally and smoothly, it is seldom in
eder (1990) has pointed out, our bodies are normally absent to
actions and lived activity of the body are taken-for-granted. For
er in front of the classroom does not notice her own body as
ass through a lesson plan. It is in situations of breakdown, that
suddenly in view.

es heightened awareness to sensations of the body, as women
and make sense of what is happening. Having their bodies
was a common indicator for all of the women that something
women had an acute awareness to changes in their bodies
et of pelvic pain, ambiguity and uncertainty were enhanced by
e a cause of the pain. While all women experienced the
ng into view, women experienced that process in different
ences ranged from gradual bodily changes to more sudden
ir daily lives.

anges

ely half of the women experienced their bodies coming into
sometimes cyclic, bodily changes that indicated to them
ng. Worsening menstrual cramps, sometimes in combination
mptoms were indications of changes in their bodies. As their
ew, women questioned if these experiences were "normal."

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ese gradual bodily changes were strongly associated with the
cycle.

nen, as opposed to men, experience pain as a part of normal
e life (Stones, 2000), therefore, it was difficult for the women to know
ld be concerned about the pain. Women closely monitored changes
odies, thoughtfully piecing together clues, as if solving a bodily

of womanhood. Sociocultural understandings influenced both the
her health care provider's interpretation and response to symptoms
endometriosis. Two women who had watched their own mothers
nenstrual pain described understanding their own pelvic pain as
xpected because of their mothers' experiences. Others were told
nale elders and/or health care providers that pelvic pain was a
of womanhood. As a result, paying attention to bodily sensations in
e out if something was wrong became clouded with doubt and

arted menstruating at a very young age. She was only eight years
e of her first menses, and was experiencing severe menstrual
e age of ten. Her pubescent body came into view with monthly
She missed school frequently as a result of her pain and recalled a
e eventually had to go to the hospital, because she could no longer
in.

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When she talked to her mother about her pain, she was assured that it ould go away when she got married, and if not then, surely when she had a aby. During her childhood and adolescence doctors assured Lani the pain presented normal menstrual cramps and treated her with increasingly stronger ainkillers, which were not effective in taking away the pain. As a youth, she shed her childhood to be over, to be relieved of her pain. As an adult, she peatedly sought medical treatments as she was sure something was wrong.

> Lani: ... I went to several ob/gyns. They didn't tell me that I had endometriosis. They didn't tell me anything. They just gave me painkillers so I always thought, "Okay, I'm maybe fine, just normal people just have to live with it." (011: 0348-0354)

Menstruation is considered in western society as an affirmation of manhood (Bramwell, 2001). The manner in which her care was managed by alth care providers, might have falsely reassured Lani that pain with her nses was normal. Simultaneously, however, it reinforced a sense of elessness and fear that she would "just have to live with it." She had always ed, based on her mother's suggestion, that when she got married the pain ld go away. When it didn't, she continued to hope that having a baby would her. While pregnancy may seem like an odd treatment or cure, pain with struation, or dysmenorrhea, has been documented to improve after a full pregnancy (Sundell, Milsom, & Amderscj, B., 1990).

Meanwhile, Lani continued to search for answers.

> Lani: I looked for help. I went to many doctors and I kept asking the doctors, "Hey, I think I have endometriosis". .. The doctor said, "Well, I don't think so. It's not that serious." I said, "But I have menstrual cramps." He said menstrual cramps, "Oh, lots of women have menstrual cramps." (011: 0559-0569)

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r health care providers took into consideration the severity

and unsatisfied with her care, Lani was medically

diagnosed with a large ovarian cyst. During the surgical

ni was diagnosed with endometriosis.

er I came back after the surgery a month later, I went to
rs in the San Francisco Bay Area and then they all said,
u have endo (endometriosis)" after looking at my
, and from looking at the doctors' letters. And I'm just
wonder how come no doctor told me about it or knew
at me. They just ignored endo. The other doctor actually
me with endo and gave me advice on "Hey, you need to
." (011: 0686-0699)

he United States could later recognize the diagnosis of

alizing the endometrial lesions on her surgical videotape,

agnosis on formal documentation of her procedures, yet

jective experience of pain. While the basic

the women was that a certain amount of pain was

t was unclear. When gradual, cyclical pain interfered

omen were moved to action.

hen she first started experiencing pelvic pain. Whereas

st known as a disease of womanhood, affecting women

nias et al., 1996), Lani's history demonstrates that

isease of "girlhood." Almost a third of the sample

encing pelvic pain before the age of sixteen.

nree years old, diagnosed with endometriosis a year

d has had pain since her very first menstrual periods as

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She was told from a young age that her pain was a part of being a

June: Well, I've always had really heavy periods and always had a lot of pain, but my mom always just pulled me aside and said, "That's part being a woman. You are going to have pain. You have to just suck it up." So growing up I was kind of like "Hmm. All right, well, I guess this is just part of it." And my parents are very religious, so they'd tell me about Eve and blah, blah, blah, ate the apple.

Int: What did they tell you about Eve?

June: Well, Eve ate the apple and persuaded Adam to eat it and that's part of the reason why it's so hard for me to have periods, a period where they're painful.

Int: So it's a punishment kind of thing?

June: Right. Exactly.

Int: So meanwhile you're how old when you started getting bad cramps?

June: I had my first period when I was 15 or 16 and my first real period was a heavy period. It wasn't like a light period. It started off with being a heavy, painful period. And I'd go to the doctor and he'd give me Motrin. He'd pretty much say the same thing, "That's part of being a woman." (121: 0041-0043)

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enstrual cramps may be associated with normal ovulatory cycles,

of menstruation related to myometrial contractions (Speroff, Glass,

), the response June received from the significant and trusted

life was inadequate. While she was offered Motrin for her pain from

e provider, the explanation was not useful in helping June make

was happening in her body. June's parents were very religious

ible that if perhaps June doubted the religious explanation, it may

reinforced when a health care provider also advised that her pain was
nd expected part of womanhood.

evaluation could have been reassuring, serving as positive news that
s "seriously" wrong or life threatening. June, however, was given little
obtaining relief of her suffering. June eventually got a diagnosis of
sis, however at the time of the interviews, she still had not found
elief of her pain. The biomedical explanation in combination with the
cramps were punishment offered her no relief.

ain cultural beliefs and ideologies may influence both the woman and
care provider's response to symptoms of pelvic pain from
sis. According to Helman (1995), many chronic diseases, and their
involve major changes in body image. Helman describes a three
l map including an individual map, a medical map, and a cultural map.
l map is a view of the body shared by members of a particular culture.
bility to distinguish between "normal" versus "abnormal" levels of
was complicated by the cultural understanding that pain is a "normal"
struation.

struation: A hidden bodily function. Pain from endometriosis was not
erience that shifted the body into awareness, as characteristics of
caused a disruption of engaged activities and practices. Nearly all
n described worsening pain related to the menstrual cycle. A couple
mmented on characteristics of their menstrual flow as being "heavy"
, which prompted alarm.

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y believed strongly that characteristics of her menstrual cycle had

n "normal." She started her menses at the age of eighteen, much later

ends.

> Molly: ...I have never had a normal period. It's never been normal. I've had one that would last for three months. I would bleed. I got anemic. Then I would have clots so bad. Then I would have pain so bad. And from the very beginning, it's never been normal, from the very beginning. I never had anything to compare it to. I always just assumed because my mom had always complained about cramps. So I always said, it's just like mom and I never really talked in depth with her about it. (081: 0025-0033)

ough she had an embodied sense that the characteristics of her

ren't "normal," Molly initially accepted it. Molly shared a narrative of a

school field trip where her fun was interrupted. She could no longer

ights around her or enjoy the companionship of her peers because

n was shifted to her bodily disruption, but in this case it was not pain

focus to the body.

> Molly: The first time I remember it being so bad I was on a school bus trip... And we went to Chicago and we had to come home on a bus. I was in choir. And I remember my grandmother had made us these ugly blazers made out of corduroy and she had made me a burgundy colored one. And I remember I started bleeding on the bus. When we got about halfway home, I remember tying the (blazer), I didn't want my friends to see. I was very shy anyways in school, which I'm not now. But in school I was really introverted.
>
> So I took the blazer and I remember tying it around my waist. It's the wintertime. It's the middle of January, it's freezing, and we're on the bus so we're warm. I tied it around my waist and I remember I sat in the seat praying that it wouldn't leak onto the seat and I bled all the way home. When I got off the bus my dad picked me up and it was dark. And I remember going and sitting in the truck thinking I don't want my dad to know either. And when I got up to my room, pulling the blazer off it was completely like welded with blood. It was saturated hugely. And I was sitting and I'm thinking, thank God the blazer was cranberry colored. Thank God nobody knows.

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at's when I knew okay, something's really, really wrong, that I'm eeding that quantity of blood. (081: 0024-0072)

had previously experienced severe pain, it was the volume of shifted Molly's attention from her engagement in sightseeing to ɔdy. Large amounts of blood that saturated her clothing alarmed d her and made her certain something was wrong with her body. way we learn about other techniques of self-care such as h or tending to a scraped knee, most aspects of menstruation, dling of it, remain hidden. In her first quote, Molly clustered characteristics of her menses, such as the volume, duration, es. Because her mother had a history of having pain with possibility Molly believed that she was prone to other cteristics of her menses as well.

92) acknowledges the unspoken and hidden aspects of ur society. The general cultural view is that menstruation is sle" and according to prescribed cultural norms, the challenge is s" absolutely private, making sure it doesn't show in public, such niture, or on the floor. Martin comments on the incompatibility ation and the world outside the home, as it is not an easy task tion hidden, especially in situations of school and work. uation are asked to do the impossible, "conceal and control their Martin, 1992, pp. 93-96).

o Martin (1992), Molly acted according to prescribed cultural n though she was soaked in her own menstrual blood, she told

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ıer burgundy colored blazer to cover herself, and sat
›me to clean herself privately. She did what she
show" (p. 93).

uting to the private and hidden nature of menstrual
Menstrual blood is a bodily fluid unique to women
a. The vagina is considered to be a "sexual" body
e private nature of the vagina and its excrement may
ıent of openly discussing menstruation. Whereas
:ulty in asking her father for help if she had skinned
ıer menstrual bleeding was kept private and
). This unspoken and hidden cultural stance toward
and directly impact care as it relates to symptoms
s.

erpretations of pain. Despite pain from
d "part of womanhood," women did not describe
upportive in the process of seeking appropriate care
escribed being aware of and witnessing their
pain when they were children and two women
ng hysterectomies. Despite the trans-generational
women in the study did not articulate physical
ed from mother or female elder, to daughter in
lometriosis. There was a sense of isolation as
gure out matters of their menstruating bodies.

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One possible explanation for this lack of trans-generational support may be that there was very little knowledge of CPP and endometriosis to pass on. This may be due to technological advances such as the laparoscopy which became the diagnostic gold standard for the diagnosis of endometriosis in the 1970's, and the advancement of biomedical sciences which increased during the 1980's and 1990's focusing on the etiology and pathogenesis of the disease (Sanmiguel, 2000). Another possibility is that perhaps disclosure regarding menstrual events, even between mothers and daughters, remained private and unspoken.

Felicia recounted that as a child her mother had an acute pain attack that resulted in a hysterectomy. As a teenager, Felicia suffered silently for two years from pelvic pain, until she finally got the courage to talk to her mother about it. At that time, her mother did not make a connection between her daughter's pelvic pain and her own. It was only after Felicia's diagnosis of endometriosis, that her mother began to gain awareness and decipher her own bodily experience retrospectively.

> Felicia: ...then my mom became more interested because then it explained a lot more about her health problems. She now realizes she really did have it (endometriosis) back then but she just kind of thought it was normal. (051: 0365-0370)

Felicia and her mother's story illustrate the possibilities for misunderstanding complex and varied presentations of onset of CPP from endometriosis. Felicia's onset was more gradual, and her mother never made the connection between this and her own history of sudden, acute pain.

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into view was a common indicator for all of the women

rent, or there was a problem with their health.

women experienced gradual bodily changes related to

aden with ambiguity and uncertainty. The other half

CPP that sharply disrupted their lives.

Approximately half of the participants experienced a

dden and acute in nature, often requiring immediate

of women, taken-for-granted activities were interrupted

ctivity at hand to be modified to attend to the

of the body. This type of pain was not always

tion.

mobilized them and caught women completely off

e pain) started around the late '80s, '88 or '89. It
t work and I got these huge, sharp, just sharp pain in
domen not related to my period, just weird things. And
Medical Center (an outpatient health care facility) and
ey didn't know what it was. They gave me a great shot
aughing), some kind of muscle relaxant and gave me
ant pills. Those really helped...

rom the pain I was sitting on the ground because I
up in a chair so I was kind of like laying, half lying on
I couldn't stay. I mean, it was just so intense pain.
050)

activity, such as sitting in a chair, became impossible.

y unable to function in its prior capacity. An ordinary

ecame impossible with pelvic pain. While the incident

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Mary to seek medical attention, she did not get an explanation for the did get short-term relief of the pain with both pain medication and axant pills. Pain medication allowed most of the women, in a limited esume life again.

reas sudden pain may have prompted one group of respondents to al treatment, others tolerated the pain without seeking medical

> Carolyn: ...before I had my first period I had cramps. I will never forget it. I actually was on vacation with my mom and my aunt and my brother in Cancun, Mexico and I was, I guess, about 10 years old or something. I woke up in the middle of the night and I was just in so much pain in my abdomen, but it wasn't a flu. I had never experienced that pain before and I was describing it to my mom. She said, "It sounds like menstrual cramps." But I hadn't had a period yet and so we thought it was strange. I was in the fetal position and she was rubbing my back. And that experience sticks out because that was kind of the first introduction to pain related to endo... (091: 0037-0046)

ough her pain at the time was normalized, this experience was a olyn that something was seriously wrong. Her holiday was s the pain shifted her awareness to matters of her body.

n, ten years old at the time, relied understandably on her mother's ationalize and make sense of the sensations she experienced in her lanation of menstrual cramps might have served to normalize the nd comfort both Carolyn and her mother. Carolyn did not get tion in Mexico, but she received comfort and loving support from She did start her menses within the year, but continued as a ave severe disruptions of daily life. She was prescribed Vicodin for

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evere menstrual pain, and missed so much school every month that she
ventually home-schooled.

Celeste also had a sudden onset of pain in the night. She described being
n by an unfamiliar sensation, which made the possibility of falling back to
mpossible. The pain pummeled her, transforming her previously pain-free
arent body, into focused awareness.

> Celeste: ...it felt like somebody had shot me in my stomach or in my pelvic area. I don't think I've ever felt pain like that in my life. And I couldn't move. I was just on the floor. I just, I could not move. And, Frank said "I'm calling an ambulance because, you know, we don't know what this is." And I said "okay." And so the ambulance came, I went to the hospital, and they put me on tons of morphine, so I could at least talk or something. And nobody could figure out what it was at the time. (041: 0078-0100)

ne unexplained pain in the middle of the night, woke Celeste, and
ed her partner, Frank. Severe pain that arises without prior warning in
ence of a known malady creates a sense of vulnerability and fear for the
and her partner. Immediate action is directed toward relief of the pain,
ore long term efforts are required to investigate its source.

ain with sexual intercourse. Dyspareunia, pain with sexual intercourse,
mptom that nearly all of the women had experienced (12 women) in the
f their illness. For two participants, pain with sexual intercourse was the
ator that something was wrong in their bodies. Because their sexual
had been unproblematic, the new sensation of pain with intercourse
ne previously absent body into awareness.

> Susan: Yeah, sex was painful with Steven and that's not a nice way (laughing) to find it out. We're like "Okay, something's wrong here." And so that was my primary complaint to my gynecologist as

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kind of a diffuse pelvic pain that I couldn't really pin down.
ng uncomfortable all the time and hitting some threshold
'Okay, got to do something about this." (111: 0100-0108)

usan had experienced a more generalized "diffuse" pain for

ion in bodily experience during sexual intercourse was the

vinced her that something was wrong in her body, and

edical attention. The pain during sexual intercourse created

y for the couple as they describe during their couple's

I would call that the discovery symptom of it
triosis).

Mmm.

And I hadn't known you that long. And so that's hard,
at early on in a relationship. That's hard. That's really
x hurts, that's really frustrating. This guy is so hot
to husband and laughing).

Did you tell him that it was hurting you?

Yeah.

It was so obvious.

Yeah, it was like, "My God."

Yeah. I remember her all doubling up pretty much a few

And crying.

Yeah.

Oh, that's really awful. That's really awful. Yeah.

What did you think was wrong?

(Pause) I don't know if I knew at that point what it was.

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Int: Were you scared, concerned? (asking Steven)

Susan: Oh, yeah, he turned, he got all white.

Steven: Really?

Susan: Yeah. (111/112: 1563-1604)

A previously noted "diffuse" pain had been largely ignored by this
ant, and had not been acted upon. Even at the time of the interviews,
he acknowledged that the diffuse general pain was part of the
etriosis, it was the intense and shared experience of pain during
urse that was presented as her "discovery" symptom. Pain that
tely immobilized the woman or interrupted an activity could not be
ked.

Whether the onset of pelvic pain, was chronic or acute, women had an
wareness to changes in their bodies. Through rich description, metaphor
ratives, women articulated clearly and concisely their bodily experiences
The ambiguity rather, was embedded in their interpretations of pain.
ltural understandings of "normal" characteristics of menses, and religious
al beliefs, led to a delay in formal health seeking.

his section examined various ways women came to know something was
their bodies. Whether women came to understand there was something
their bodies from sudden or more gradual pain, the experience was
with uncertainty as it was difficult to get answers regarding cause or
ain. Women utilized various techniques to try to understand, decipher,
evaluate their pain. Complicating the process was the shared cultural

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ng that pelvic pain was "normal." Also complicating matters was the losive" spaces (Benner, 2004) about menstruation and the "private" ealth within the medical system as well as within our Western

The Experience of Seeking Answers

en demonstrated much perseverance, resilience, and skilled n their quest for answers regarding changes in their bodies, yet the f seeking help from health care providers was a complicated and ess. Most described a frustrating system of going from doctor to times from specialty to specialty. Some chose to seek providers ir insurance health care coverage to get answers.

e point, most women were told by health care providers either ertly, that there was nothing wrong with them. Many were h other pelvic/abdominal conditions such as lactose intolerance, syndrome (IBS), and/or bladder infections. Usually the women oubted these alternative diagnoses as the prescribed treatment was Most women were told that what they were experiencing was e at the same time being prescribed pain medication that made o function in their daily lives.

Self

e women over time became strong advocates for themselves in formal health seeking. Women began to change their ideas about nal" through embodied knowledge about their own bodies and

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acquired from lay sources such as family members, friends, and

such as books and the internet.

y, the woman who experienced the large volume of menstrual

n her class field trip, suspected that characteristics of her menstrual

ever been "normal," and although she was experiencing pelvic pain,

eking treatment for six years. When the pain reached a level she

nger tolerate, she finally sought treatment from a health care provider.

> Molly: I went to a doctor that said he dealt with endometriosis. I got to his office...and he told me I had a pelvic infection, I needed to be on tetracycline. I said "Why? I didn't understand." Well, maybe my husband had been messing around.
>
> It made me burst into tears and I said to him, "You have to believe your patients. I don't have an infection. I know Thom. I know this is not right." And he said, "All right, I'll make a deal with you. Go take this blood test. If your white count is up or whatever we'll know you have an infection. If it's not, if it's normal then don't take the antibiotics. I'll call you by 7 or 8 tonight."
>
> He called me at 7 o'clock and he said I don't know where this pain is coming from but you have no infection and there's a huge amount of pain. He said I couldn't even touch you to do an exam, you were in so much pain. He said we need to schedule a laparoscopic surgery. So they did a laparoscopic surgery and told me at the time that they removed endo and that I was full of it. Apparently later I found out they didn't remove any of it, but that's when I got, that's when I first heard the word endometriosis, when he told me, "You have endometriosis." (081: 0104-0121)

ears of delay, Molly finally decided to seek treatment, only to have

s misdiagnosed as an acute infection. It was only through her

ection of the physician's diagnosis that further tests were ordered

metriosis was formally diagnosed. Molly advocated strongly for

ne can only wonder what the physical, emotional, and relational

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ces might have been if she had not. Embodied knowledge, combined
h her husband, prevented her from accepting the doctor's erroneous
n.

e first experienced a sudden onset of very sharp pelvic pain when she
down the freeway two years prior to the interview. She sought help at
ncy room and was told there was nothing wrong with her. Unsatisfied,
ught answers from her general practitioner who "ran tests" and
ner with IBS and depression. She was prescribed Metamucil for her
s told to get "mental help." It took approximately one year to get these
which she believed were inadequate. She tried to convince her
was something else.

> Julie: ...I kept going, "You know what, it's not my stomach." I kept going over and over "It's not my stomach, it's not my stomach," and he wouldn't believe me. I had to have a barium enema. I had a CT scan with contrast. I can't even remember all the tests that I've had.
>
> Int: But you somehow knew it wasn't the right thing.
>
> Julie: I kept telling him and I was like "Should you send me to a gynecologist?" He's like "No." And then he's like "Lots of women," he's like "I just went to a conference on depression and many women have unexplained abdominal pain and it's often caused by depression. I think you're depressed." So I was like, "Okay, well, I'd agree that I might be depressed but I think it's because of the pain because I can't do anything." (061: 0044-0071)

with unexplained pelvic pain, the physician settled on an answer
pursuing other diagnostic options, in spite of Julie's request for a
l consult. During a trip to visit her grandmother, Julie was teased
a young woman who took Metamucil.

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: ...my grandma's like "What are you doing? I don't even take
mucil." (Laughing) I'm like "Oh, my God, I'm an old lady." But
was down there and I was telling my grandma and my aunt
t having all this pelvic pain and they said, "Well, you know your
in has endometriosis and maybe you should look in to see if
ndometriosis." And then Nate and I started reading up on
metriosis and we were like "I have endometriosis."

inally got a new doctor who would listen to me because this
. was the one that wouldn't listen to me and told me that it was
omach. So I switched doctors and I got a new doctor and she
diately sent me to a gynecologist who said, "You might have
metriosis." Then I had a laparoscopy in August of this year
es, indeed, I had endometriosis. (061: 0143-0156)

embodied knowledge, persistence, and the help of her

became an advocate for herself as she switched doctors and

who would listen to her. All along she did not believe IBS was

ctal pain. It is possible that her close attention to the pain,

rstand that her rectal pain was pelvic, as opposed to bowel

gled with steadfast determination and assertiveness to obtain

lieved was appropriate. Her behavior is particularly striking

ssion combined with her pain, was limiting her ability to

en may not have had the energy to fight, and may have just

to suspect something was wrong when she began having

ual intercourse, as well as a more "diffuse" pain that she had

Before seeking help from a physician, she began to do some

.

I read *Our Bodies, Ourselves* and that had a page in it and
"Hmm, that looks pretty close." I was like "ding, ding, ding,
So I went to this new gynecologist and I said "Blah-blah-

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> blah, I think I have endo." He's like "You're too young." And I was actually older than the median age but he was out of date with information like most "gynies" are. So I really had to arm wrestle him to do a laparoscopy. So he went in, and saw that I had it. He wasn't expecting me to have it because he didn't think I had it, so he didn't book O.R. (operating room) time or prep me properly or anything. So he came out and said, "Yep, you've got it." So I decided that was time to switch to somebody else because there were a lot of bad signals there but it was nice to have a diagnosis. But to have to fight against so much misinformation at the time when you're not knowing. But you're in a lot of pain, that's not a nice place to be in. (011: 0116-0132)

Susan was prepared with information before even consulting with her new ctor. She was an informed consumer and although her health care provider ially resisted, he did take her advice and agreed to do a laparoscopy. Having ormation about endometriosis readied Susan for a dialogue with her necologist about plans for treatment, and influenced her health care outcome.

Each of these three cases demonstrates the importance of knowledge and severance in obtaining a diagnosis of endometriosis. All of these women were uired to advocate for themselves actually working to change the provider's al conception of their symptoms in order to obtain appropriate diagnostic s. In two of these instances, the process broke trust in the provider's capacity n the women sought alternative care. This process resulted in the women g forced to take somewhat of an adversarial stance towards providers, as struggled to get adequate explanations for their pain.

The Experience of Diagnosis

Getting a diagnosis of endometriosis offered all of the women an initial e of relief. A diagnosis provided validation and a name to what had been a ce of tremendous distress. Using Helman's (1995) conceptual theory of body

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d perceptions of self in chronic illness, a diagnosis
n to understand the anatomical and physiological
. The medical diagnosis provided an authoritative and
th understand and talk about their experience. Relief
ever, because most of the women continued to
e, requiring further diagnostic workup, and opening
fertility and living with a debilitating chronic illness.
metriosis, which was sometimes accompanied by
ometrial growths and lesions, reassured the women
xperiencing was real, and offered a glimmer of hope
ent and relief. While all of the women were relieved to
ey had various reactions based on their individual

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en experienced great relief in the biomedical
is. Maryann had a history of what she describes as
years with her menstrual cycle. When a health care
stic laparoscopy when she was in her mid-twenties
t to have surgery at that time, and chose to treat her
e was eventually diagnosed with endometriosis after
t her into the emergency room. Exploratory surgery

like great, wonderful. No wonder. No wonder I hurt
me, it was, I knew it wasn't my imagination because

some people are like, "Oh, it's just cramps, it's just bad cramps, that's all." It's like "Well, no, you don't understand. This really hurts." People don't believe you or you feel like it must be all in my head. I've got to be making this up but to find that there was actually a reason why, it's like oh, this is good. This is good. (131: 0347-0354)

While health care providers suspected endometriosis years ago, Maryann efused surgery. There is a sense that she chose the ambiguity of not knowing ver a diagnosis early on. Yet, there came a turning point when her pain crossed threshold into something that was no longer tolerable or acceptable.

Like so many women, she began to wonder if the pain was somehow in er head. An acute pain attack warranted an exploratory surgery in which ndometriosis was found, and offered her, in a sense, relief after so many years. aryann's reaction was similar to most of the women in the study, relieved to ally have an explanation that her pain was real.

Lucinda's story is a unique case related to the experience of diagnosis. cinda felt relief after learning she had endometriosis, because it wasn't a agnosis of cancer. After suffering from severe pain for approximately two years, alth care providers suspected Lucinda had bladder cancer.

Lucinda: ...basically I'd sit down and I'd, you know, I'd get pain certain times of the month. That would throb with certain things I ate. My bladder was causing me problems. I felt like someone was stabbing me in, I don't know if it's okay to be graphic.

Int: Oh, yes.

Lucinda: In the vagina when I had my period. And then there was like a hot line, it was this burning line and then it would just be burning. I'd have my period and my bladder, my whatever, urethra, whatever, would just be burning and I'd be laying on the bed and I've just never, I was just so, it was so painful...It started being worse before the period and after the period, so basically I had

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about three, almost a whole month where I was in pain. I would have been able to deal with the pain, but when I found out that my bladder was invaded it started becoming more serious.

They first thought it was cancer. One doctor said, a urologist, I finally saw a urologist, because I was crying in pain. They did a preliminary biopsy and found out it was endometriosis. Found out the source was the uterus...(071: 0437-0474)

ucinda, a diagnosis of endometriosis had become even more

ecause it wasn't cancer, but she did not embrace a diagnosis of

is, either. She had hoped the outcome of treatment would be to no

endometriosis.

Lucinda: And basically they did the same surgery that they do for cervical cancer and I don't know if cervical cancer invades the bladder or not... But they basically removed the uterus, removed the ovaries, removed the masses and separated the uterus and the bladder because they were cemented together. Then they cut the endometriosis, I think it was like 5 centimeters, so they cut the dome of the bladder off and then they sewed it back together.

And they went beyond the margins of the endometriosis so that no cells would grow. Because basically mine was dangerous because it was there...And they reconstructed a little bit. They padded the area between the rectum and the vagina because unfortunately those places are very close, as you probably know. And, and then I had a little stitch here (pointing to her abdomen). Luckily it (the endometriosis) hadn't gone through the colon and the cecum, that's very common. And so they just took that stitch out and sewed it back together. So that wasn't bad...(071: 0485-0517)

t immediately after learning she had endometriosis; Lucinda had

move it. She optimistically believed surgeons had been able to

remove all of the endometriosis, and no longer believed she had

s. In spite of this, even after surgery, Lucinda continued to identify

metriosis community, and attended endometriosis support groups

he time of the interviews, her pain had returned and she was in the

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consulting with the surgeon once again to get an explanation for her
loped pain.

of Endometriosis

ly all of the women found comfort in the diagnostic label of
sis. In addition to giving them an explanation for their pain, a
abel offered entrée into a specialized community. Most of the women
y involved with endometriosis support groups. One young woman
n an on-line endometriosis support group that was specific to women
ving a label "normalized" them within a group of other women with
gnosis and similar experiences.

tory of Celeste is a contrasting case to the majority of women who
rt in having a diagnosis and knowing the reason for their pain.
ally found more comfort in the ambiguity of her disease. While she
d endometriosis, she also understood that there could have been
logical or structural anomalies causing her pelvic pain, so she didn't
endometriosis as the cause.

Celeste: I mean I know for sure that I (have endometriosis), I've had a couple of surgeries now so I know that they've found pretty severe endometriosis. They've found endometriomas and scarring and, you know, things like that. So I know that's happened in the past. However, I feel that since you don't really, you can't really see anything on the outside, I feel that sometimes even if I have pain, sometimes I don't know if it's scar tissue, or if it's some kind of chronic pain with weakened muscles, or if it's endometriosis, if it's cysts, if it's just another pain, that they can't explain. So sometimes I feel, since I don't know for sure, that I don't always want to say, yes, hi, I'm Celeste with endometriosis. Because when I label myself as, you know, for sure, it gets ingrained in my head. It's most likely that I do, because I have some pain. But I'm not 100%

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sure. So I don't want to go around saying that I have it. (041: 0227-0255)

Whereas other women struggled with the ambiguity of the disease, , in contrast, found safety in its ambiguity. In order to protect her identity, not want to totally identify with the diagnosis. She did not want to wear el" of endometriosis. She felt comfort in the understanding that her pain e caused by something, other than endometriosis. Perhaps the idea of th the chronic debilitating disease of endometriosis, was too threatening ne had so many unrealized dreams, such as finishing college and g her career, which had been put on hold because of the pain.

s Believing

some cases, a diagnosis came with photographs of endometrial tissue ring surgery. Nearly all of the participants, who talked about their ce of visualizing photographs of their interior pelvic cavity, described it ve or beneficial. Three women showed their surgical photographs during rch interview, although they could not articulate what they were looking dition to providing validation, the pictures also provided a more concise nding to the relationship between their endometrial pathology and their experience.

icia and Charles watched portions of her surgery on video-tape during -up visit with the surgeon.

Felicia: When I was in his office and we were looking at the video and I was like it looks like the thin film off a chicken, you know, like a chicken breast kind of a thing. And it's just everywhere and he was cutting and cutting and cutting and burning and burning. And I was like, "Is that what adhesions are?" And he was like, "Yeah,

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those are all adhesions." He's like, "Look at that. That ovary had all those adhesions attached to your bowel and that was attached to your bladder and that was attached to here with all these adhesions."

And I'm thinking no wonder why I couldn't even bend over without getting pinched, feeling pinched everywhere. And that was what was amazing when we were both watching the video. We were like my God, look at all those adhesions. We just could not get over the amount of adhesions. So it was really, it was just a whole other experience getting to watch that video. It was quite something. Even as I talk about it I can like totally picture it in my head. (051/052: 2374-2405)

In Felicia's case, the graphic images assisted her, and possibly her band, to understand and acknowledge in a new way, not only how the ctures of her inner body had influenced her pain, but also how it had been ted. Seeing the pathology might have had even more significance because of lengthy history of lack of adequate answers and support from health care iders. Endometriosis presents with a variety of appearances via laparoscopy ding varied colored lesions, scar tissue, vesicles, cysts and adhesions ard, 2000). Peritoneal adhesions have been linked to pain associated with ching movements (Moore & Kennedy, 2000). The visualized excessive nt of adhesions proved there was really something wrong with her, and the on was taking action to help her get relief from the pain.

Steven, who was recently married to Susan, explained that a positive ence related to endometriosis involved going to an endometriosis meeting cluded a formal lecture and a surgical video of endometriosis.

Steven: Seeing the videos and hearing the talk, and I think there were some pamphlets around as well, were really good because they were very emphatic in the way that they were describing the disease and its effects, which I hadn't got from you (speaking to

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Susan)... Because I know if someone says you're in pain, they're in pain, it doesn't mean anything.

Susan: Yeah, it's very, right.

Steven: It's like they could have a hangnail or they could have chopped their finger off.

Susan: Uh-huh.

Int: But somehow seeing the pamphlet, getting the information, seeing the endometriosis on the screen.

Steven: Yeah.

Susan: It made it more real, right?

Steven: Exactly. (111/112: 0885-0962)

Steven suggested that the tangible information such as the pamphlets, eing the videos of live endometrial tissue growing in the pelvic cavity, gave understanding that was more "real" and absolute than the understanding gotten from his wife, Susan. He also brought to light the subjective of the word "pain," acknowledging its ambiguity. It can be interpreted that ast, when Susan had stated she was in pain, he didn't truly understand erity of the pain, or the significance of the disease.

lot all participants found it helpful to visualize the interior of the pelvic One woman, Julie, admitted the photos offered little meaning to her.

Julie: Yeah. I was in the recovery room and she (the doctor) came in with pictures and I'm like still like "Oooh, I've been on anesthesia, oooh." And she's like "Look, these are the pictures of your uterus, you have endometriosis." I'm like, "They're blurry pink circles. What am I looking at? I can't see right now... Go tell my parents or my boyfriend. Go tell one of them." Yeah, I was like half out of it. I was drugged when she told me so.

Int: So those pictures didn't mean very much at that point?

at point. No, I saw them later and they still didn't
ch. I still have pain even after the surgery now. Even
copy and it's been, since August and it's December
ll in pain and it's not going away.

ere (to the physician's office) the other day, "So, did
the cervix? Did you look here? Did you look
ke "Did you do your job right?" I'm not necessarily
she did. (061: 0425-0465)

f her pain and effective treatment over validation of

eatment did not give her the pain relief she had hoped

ns of her endometrial lesions had little significance,

erstanding of the pervasiveness of the disease, and

ng the surgeon's success in ridding her of the

een associated with infertility (Garry, 2004) and for

lity was a concern in relation to their diagnosis.

ongst participants depending on the age of the

out parenthood within the couple, the developmental

onship, and the stage of diagnosis and treatment of

e women issues of fertility were in the foreground,

fertility were more recessed, but still present.

concern to some partners. A couple of women

s of their fertility after having the surgical treatment

s contemplated their reproductive future as it related

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Carolyn was diagnosed with endometriosis at the age of sixteen. When
eceived her diagnosis of endometriosis she also remembered hearing the
'infertility."

> Carolyn: So it (infertility) was a huge struggle...just the whole issue of fertility has been like the monster in the room for me for years.
>
> Int: Now, would you say, even at sixteen, you began to worry that it might be an issue?
>
> Carolyn: Yeah. Well, because I remember hearing, the first thing, "You've got endometriosis, infertility." It's the very first thing you learn about it. Before you even understand what that means. (091: 1144-1161)

It is unclear what information was provided to Carolyn when she received
gnosis of endometriosis in relationship to her future reproductive health. It is
lt to know with the passage of time, what was actually communicated about
lity. She recalled the two conditions as associated and perhaps infertility as
able to her diagnosis of endometriosis. While Carolyn had successfully
ated a career as an advertising executive and was married, it is not known
sychological, emotional, or relational consequences this information may
ad, especially during adolescence, a formative developmental stage.

Another woman, Maryann, got a diagnosis of endometriosis just six
s before her wedding day.

> Maryann: When they went in to do the surgery on the surgery consent, they had possible oophorectomy, possible hysterectomy and I'm sobbing. I'm like, "My God, no, I'm getting married, I want to have kids, you've got to preserve that fertility." And I was really scared.
>
> Then after he said it was endometriosis, like, okay, I'm not really surprised because we thought it but I didn't know how bad it was. And I asked, "Well, could I have kids?" (131: 0331-0338)

voman who initially chose the ambiguity of not knowing
ner than a definitive diagnosis early on. It is unknown if
as associated with infertility may have played a role in
nd Tim did eventually have a daughter together.
nterviews, Julie and Nate were busily and excitedly
wedding. While issues of fertility were not in the
couple, Julie did acknowledge her concern about the
meday.

them evil pregnant ladies.

gnant ladies like walking down the street?

regnant ladies are evil. I've told the nurses several
gyn's office, I said, "There needs to be a room"
ere's so many pregnant ladies at the gynecologist's
n't want to see all these pregnant ladies. So I told them
ne unhealthy vagina office and the healthy vagina office
should never mix. I don't want to see all these damn
dies, okay, when there's a very high possibility that I
kids.

thers you?

Yeah. My cousin had endometriosis so severely she
a hysterectomy at 26.

ne cousin that helped you get diagnosed because your
about it?

At 26 she had to have a hysterectomy and she had to
reconstruction because of the endometriosis. Now
y case of endometriosis is considerably milder, unless
ln't find everything which I wouldn't be surprised.
102)

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ars old, a year younger than the age of her cousin when

y and vaginal reconstruction surgery as a result of pain

hile Julie and Nate were joyfully solidifying their

ther, issues of fertility loomed in the background for her.

geries and infertility were very real for her, considering

e her physical concerns may have been attended to in the

r emotional concerns were ignored. Pregnant women

ul reminder of her perceived health status.

common symptom of endometriosis and was

ll of the women in the study (12 out of 13 women). The

xual dysfunction" and reproduction has been

ecessary that women reach orgasm or be aroused during

n, but a lack of desire or aversion to sexual activity may

king conception unlikely (Morokoff & Calderone, 1994).

n were newlyweds and although they were not

e near future, Susan described their dilemma.

> can't have sex because it's too painful... Oh, it's just you go to the doctor's office and they're like well, you nancy is a cure. You're like you're not hearing what I'm nnot have sex comfortably, I'm not going to try and get s a cure right now. (Laughing) It's wacky... (111/112:

e women were prescribed the very thing for which they

s women were told by health care providers that having

in associated with endometriosis, they were prescribed

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egnancy as a curative treatment, when painful intercourse was a symptom of e disease.

The dilemma for these women was that they felt that their pain was scounted, or ignored in the process of prescribing a cure. Health care oviders could acknowledge the extent and severity of the pain, while offering sistance with sexual approaches and positions that might ease the pain. In so ing, they could support, assist, and "join" the couples in their suffering. None the women interviewed in this study acknowledged such care.

The experience of diagnosis was one that generally offered initial relief but s problematic because women, with time, came to understand that the gnosis addressed what was going on in their bodies, but provided no easy utions. Rather, many women experienced a sense of uncertainty in terms of r future especially in relation to concerns of fertility and living a life with a onic condition.

Finding Relief of Pain: Range of Treatment Experiences

The experience of seeking treatment for relief of pain surfaced as a stantial element in all of the interviews of women's experiences of living with ometriosis. A treatment spiral emerged in which initial pain led to a plicated and arduous search for a diagnosis, which led to a treatment, which ally was effective in providing pain relief only for a period of time. Then ately, for all of the women, the pain returned, cycling them back to needing ner explanation for either the same pain, or a different pain. While there are tions in the spiral for individual women, the common experiences included

uncertainty about ever getting permanent relief of pain. The emotional
ed to this treatment cycle was fear. Even after diagnosis and treatment,
if pain-relief was achieved temporarily, women still lived with concern
ain would return.

arly all of the women utilized numerous treatments over time in the
their treatment spiral, and experienced much variation of effectiveness.
f the following section is to present the range of the treatment
e of endometriosis according to types of treatment including surgical,
and the use of pain medication. While the varied effectiveness of
within each category will be highlighted, it is not the focus of the
Rather, emphasis will be placed on participants' concerns, as well as
lities each treatment opened up and closed down for women and their

eatments

rall, the women in the study had undergone a myriad of surgical
from "routine laparoscopies" to more complicated surgeries which
involved organ removal. The common understanding of the goal of
c surgery was to visualize endometriosis for diagnostic purposes and
t" the endometriosis in hopes of relieving the pain. Sometimes
it" the endometriosis meant removal of bodily organs. Whereas the
oval of endometriosis is the focus of this section, other types of
edures and their effects are also highlighted.

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an it out. The most common surgical treatment was the "routine"
by, done for the purpose of initially diagnosing endometriosis and also
as a treatment to reduce or eliminate endometriosis. The methods of
ncluded excision, burning and cauterizing the endometriosis.
efits of laparoscopy over laparotomy, a more invasive surgery, include
ospital stay, smaller incisions, less scarring and a shorter recovery
arly all of the women reported that a recovery from laparoscopy was
they expected. One woman described her difficulty in relying on her
r care during her recovery period after her second laparoscopic

> Celeste: When I had my second surgery, he had to take, he took two weeks off and that was the only vacation he got, and he took it off because he needed to take care of me, because I couldn't do anything. I couldn't get out of bed. I couldn't move. I couldn't go to the bathroom. I couldn't do anything. So for him to, you know, sacrifice that, and it's different if you're just, it's a pretty light surgery and it's just a little bit of help, but, when it's so intense, pretty much doing everything all the time.
>
> It's like, in the middle of the night, you know, I have to go to the bathroom. He has to get up, go around, you know, the other side of the bed, kind of lift me up, help me, you know, when I sit down on the toilet, you know all, all those things. And that went on for a while, because it was pretty extreme at that time. And so, I think that was, I mean of course it was extremely hard for me, but I think it was really hard on him, too. (041: 0453-0477)

ough surgery was often described as a "routine" laparoscopy,
ated significant interruptions in the women's lives involving pain and
siderable care.
t a third (4 women) of the women's mothers came to stay with them
to provide assistance with hands-on care. Mothers may have been

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etter prepared to provide extensive hands-on care. Also, mothers

relied upon so that partners didn't miss significant amounts of

e couples, intimate partners took up actions of care giving.

r take the role of care giver was one relationship pattern in living

sis and will be discussed in the following chapter.

he interruption of daily life from "routine" laparoscopy, the surgical

ed women hope of relief of pain. Maryann, who lived with pain

sis for most of her adult life, described a routine laparoscopy as

technique.

ryann: My treatment basically consists of pain control and
iodic surgeries to go in and clean it out, sort of like a Roto-
oter job, because the hormonal treatment which is the treatment
choice just doesn't work. (131: 0440-0444)

netaphor of Roto-Rooter was unique, it spoke precisely to the

ed about routine "maintenance" laparoscopy. The goal of the

iminate endometriosis, and a secondary benefit was to

had two surgeries since her initial diagnosis in the five years

ews. She believed that her surgeries were a successful

still having pain.

an: Surgeries have been great. I had one in the summer that
oved adhesions and I was like "I can move again." That was
llent. (111: 0257-0258)

concern among the women was the pervasive and ubiquitous

ase. Women understood that even in the most optimal situation

ompletely remove the endometriosis during surgery.

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he pain relief after surgery could be temporary, as endometriosis
ially grow back.

case of Molly illustrates that even after a complete hysterectomy and
ny as a treatment for endometriosis, a woman may continue to have
gh Molly had undergone a complete hysterectomy a year and a half
ks prior to the interview, she had undergone a "clean-up"
, which she described as an effective treatment for her pelvic pain
rned after her hysterectomy.

> Molly: I have the pictures I could show you if you're interested. He showed me the pictures of the spots. I had new endo growth, minimal, and old endo that was left in there from last surgery and lots of scar tissue that he removed. And I haven't had any pain. I was limping when I went into his office. I haven't had any pain since the surgery. Yeah, just post-surgery, I had a lot of post-surgery pain. He's very thorough but he poked everything in there apparently. I was really sore. Somebody warned me, too. They said with Dr. D. after your surgery you're going to be really sore but once you heal the pain will be gone. And as soon as I healed the pain's gone. (081: 0412-0425)

s life had been profoundly affected by her treatments for
s. For many years she self-medicated with over the counter pain
and with the use of alcohol. She had undergone a round of Lupron
lucing her body into a pseudo-menopause. She also had multiple
luding a complete hysterectomy to treat her endometriosis.
er most recent surgery, she describes her pain "pretty much zero"
n pain scale. Yet, she understood that even after so many
d a complete hysterectomy that her pain would most likely return.
nt: Do you still consider yourself as having endometriosis?

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y: Oh, yeah, I'll always have endo. I just have to have

Even though it's all surgically removed?

y: I still have endo. I'll always have to maintain it. It's always a ıce it's going to grow back, especially with estrogen therapy. I no doubt that it'll grow back. I have no doubt that in five or six s I'm going to need a laparoscopic cleanup to remove it. I've it so aggressively and it's grown back each surgery worse than revious one. I have no doubt in a couple of years I'll probably him to go in and clean it up again. (081: 1796-1808)

ndometriosis was an incurable disease. Despite undergoing idered radical and extreme treatments, she continued to live out her future. For Molly, maintenance of endometriosis surgical intervention. Surgery opened up possibilities for a life st temporarily.

of the interview, Molly and Thom were planning a trip to Hawaii nt meaning for them as a couple. For as long as she could ations from work were scheduled to accommodate surgeries. different as it was solely for leisure, and even more s not in pain. The couple was excitedly preparing, buying new g, as they anticipated their upcoming vacation.

I couldn't plan things before and now we planned the Hawaii nd I'm thinking, I had so much fun getting ready for the trip and g a new dress and just

I noticed that.

Being out of pain and feeling good that I'm like "All right, I o go see my friend in San Diego. He's been up here the last imes. He's driven here with his kids, five of them, a long and he's driven here the last three times. We definitely owe rip. So I call him the other day and I go "How about we down for the 4th of July weekend?" He's like "All right, I'll plan

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e time off work." And I go "Oh, that'll be great. We'll stay at a with a pool and the kids can play. A year ago I wouldn't have ed anything like that. I couldn't commit to a trip that far ahead now that I'd be okay. Now I can.

: Me too.

See. He (Thom) was always ready to go. But I couldn't do efore. And now it's nice to go "Okay, let's go down to the or let's go." Now I want to do all this stuff because the pain e... The pain's so damn debilitating that I couldn't do ing. Yeah. I could write it on the calendar but I'd never know how up. Or I'd go "Yeah, we better not." Every time he would e, "What about coming up next month?" And I would say, let's see how I feel." It was never "Yeah, let's get tickets." It Let's see how I feel" because I just knew. (081/082: 1640-

urgery benefited Molly in several ways. First, not being in pain to think about things like buying a dress for an upcoming g plans to go visit a friend. Second, it gave her hope for the ited about being able to make plans and be spontaneous ing" nature of endometriosis also had an effect on Thom as able to plan and do things together because of the pain. te also opened up possibilities that enabled her to live in her to enjoy life again, including sexually.

The first time we had sex after the surgery and it didn't hurt I nto tears. He said, "What's wrong?" I'm like "It didn't hurt." I happy that it didn't hurt (laughing). And he goes "What'd I at'd I do?" I was like "Nothing, it didn't hurt." (081/082: 3882-

s after intercourse might have had a significantly different lly and Thom. Thom shared in Molly's excitement as he

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cribed her as "The woman I first met fifteen years ago." (101/102: 0141-4)

In a couple of cases, laparoscopic "clean up" was done to relieve pain with condary motive of increasing the chances for pregnancy. Felicia and Charles been trying for over six years to get pregnant without success.

> Felicia: Prior to this surgery, for this last year, it's just kind of been ahhh forget it... And now that we've had this surgery (laughing), things are clean so to speak and everything's in its right place. So he (Charles) got a phone call the other day for something on the twenty-eighth of this month and I went are you going out of town or are you staying home (laughing)? And we both started laughing because it was funny because that's the way it always used to be. It was like well, you can't be out of town at that time ...I need some sperm.... So we are a little bit back in this phase again now after surgery. We spent all this money now on surgery. Statistically I know I still have probably less than a 10% chance of conceiving. (051: 2479-2513)

Surgery not only "cleaned" out her reproductive system but also rekindled for conceiving a child. The laparoscopy opened new relational possibilities een the couple. While the surgery offered hope of pain relief, it also allowed uple to share hope once again of conceiving a child together.

Sometimes "cleaning it out" resulted in removal of bodily organs; four n had hysterectomies as a surgical treatment for endometriosis. All of the n who had undergone hysterectomy believed they had no other viable ent at that point, other than to relinquish their uterus. The hope was al of the uterus would eliminate endometrial growth and ultimately the pain ated with it.

Mary had lived with severe pain from endometriosis for over ten years, ntensified right before her decision to have a hysterectomy. After the

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and her husband were greatly relieved that the surgery

ng her severe pelvic pain. Still, her outcome was not

sult of the endo, you ended up losing your uterus. I'm
if you can talk as a couple how that was for you.

ne, fairly minimal just because it felt so good afterwards.
ou can take off my right arm if it stops the pain. The
t off his arm when it was caught underneath a boulder, I
. There gets to be a point, and you say okay, it's gone
ne, type of thing. It is a little weird. I think that for me
t first, sex was a little weird because it's kind of like I'm
hollow feeling...The removal of the uterus itself was, I
lready knew that we weren't going to get pregnant
the normal way. That was not going to happen so I
hat that was, it may have been the final period at the
entence, but the sentence had been written. For me,
sterectomy) was just a minimal part of what I had gone
hat about for you?

k it was lesser than you, but I mean it was the same. I
me point you get to the point where this is cut and run
our damages before they overwhelm you. Get out. Get
s too late kind of a thing. But if I had lost my sex
rt of my sex organ, I would be kind of disappointed,
essed. So I'm surprised it doesn't, but I can empathize,
erstand why you wanted it out of there at that point.
id to me

out!

out of me! It's killing me kind of a thing so...for like a
e or a normal woman, I think their uterus would
extremely valuable to them, generally, but at some
nes a liability and something you want to get rid of.
a good analogy, the guy who cut off his hand to get
er the boulder. The hand at that point was not
31/032: 0971-1046)

eriences of pain, and possibly infertility, her uterus,

lity" for the couple. Even though Mary and Scott had

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esperately to have children, and had undergone infertility treatment,
luating the situation as a whole, they chose a hysterectomy because of
sing pain and damage to other organs from endometrial disease.
s a sense of urgency and fear in their response to the situation. The
of cutting off one's arm in order to survive was a powerful one that
ner understanding of the need at the time to relinquish her uterus in
rvive.

y's pain was significantly improved after the hysterectomy, yet the
urgery were not unproblematic for both her and her husband. There
expected adjustment period that involved becoming familiar with
ects of her post-surgical body.

Mary: My only lingering symptoms which I think, I'm hoping, are healing. My bowels and I are getting to know each other again because they're different now because I had a chunk removed. So I've had to potty train myself and learn what-signals-mean-what. My body's had to learn what signals to make and that's coming along. I have some back pain which we're hoping is just the bowels healing. I do have a compromised kidney from the endo but it was very minor. The fluid retention was very minor so I'm hoping that also will heal with time. And I'm having things that have happened that are new that I'm hoping also will eventually go away like the hot flashes. But I have my phytoestrogens and stuff for that. I have a buzzing in my ear that I've had for six months and I'm going to the ear, nose and throat people about next month to see what's going on because that's been since the surgery. So weird sequelae from the surgery, you don't know why. Coincidence, who knows? But that we'll slowly take care of. As far as endo pain, I mean, it's hard to tell what's endo pain and what's not endo pain. So my things right now are still getting better so I don't classify it as endo pain. I classify them as surgery-healing at this point. So other than that, yeah, I think I pretty much am pain-free. Threw away all my pile of drugs in there (pointing to her bathroom and laughing).

Int: Did you really?

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Mary: My whole bag of drugs. Not just painkillers and stuff, but I just went through the house… I'm just looking at stuff and saying, "Oh my God, I had so much stuff."

Int: About your illness?

Mary: Oh, yeah! Bottles and bottles. I mean, I had stool softeners, I had pain pills of like three different kinds. I had just all these different things and so

Int: How was it to throw them away?

Mary: Well, they're still sitting there, but (laughing) we still have the bag. But the best thing was I gave away all my sanitary napkins because I'd always worn pads…I gave my sister all my pads (laughing). A care package. Here's a whole bag. You won't have to shop for weeks, months, years. It gave a whole new room in my cabinet in my bathroom. It's like almost empty now because now I don't have to buy huge, huge stocks of pads. That's very, very, yeah, it's like I'll never ever have another period. That is the most joyous phrase…Even though it's, in a way it's depressing, to me my period was never my identity. It was never my femaleness. It was a pain in the butt literally and figuratively so getting rid of it is good. (031: 2324-2418)

gical treatment of hysterectomy opened up and closed down certain

or Mary. While it closed down the possibilities of having biological

ened up a new life that does not require numerous medications and

r optimism about the future allowed a celebratory, yet bittersweet

never having another menstrual cycle.

Mary may have been prepared for certain aspects of life post-

, such as cessation of menses, infertility, or symptoms of

she did not understand or anticipate an impact on her sexual

Mary: Having sex for the first time was really funny (laughing) after the surgery…it was a crackup. He didn't bug me and "whenever you're ready." There wasn't any ounce of pressure or anything and

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because he knew that they had removed part of my
d had stitched me up. So he didn't want to break
I didn't want him to break anything so we're being
ınd everything, and as soon as he penetrated, he
is erection. And I mean, it's not the first time it's
m and it's not like a huge deal to us, but it was just
ıd he said something. He said (whispering), "It's like
there."

s that psychological or physical or both? I didn't
s talking to my female friends about it and one of
the first time that people have sex after birth, if it's
soon, a man has described it as throwing a hot dog
' (laughing). Isn't that good? And I thought the
ust like, whoa!

of what he had been describing so I asked him
"So we were like throwing a hot dog down the
ıing) and he said "Okay." ...

ocused on just relaxing everything that I think
s decreased and they had done some major stuff...
come out (after the hysterectomy) and said well, "I
part of the vaginal canal, but I've banded
d no idea what that meant...he had reconstructed
cally the whole canal and banded it with muscle to
pport. So I thought well, it can't really be that bad.

on presented many challenges, some of which were

viders and others that were quite surprising for the

well, I need to tone that whole area so I started
d it was really weird because the first time I tried it I
done them much anyway. The first time I just tried
g, to test that stop-the-peeing-muscle type thing
e I can't. I'm going as tight as I can and I'm still
ty good and I'm thinking, that's really lost its tone.
doing them more and more and I found that it
hat it helped my bowel control and I basically need
much everyday or I pay for it as far with the
I don't do it for a few days, it's kind of like it tends

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Int: But did you figure that out on your own?

Mary: I figured that out on my own.

Int: No one really helped you figure that out?

Mary: No. That's one thing that I thought was very sorely lacking even though I think my surgeon is wonderful and women in his office are fabulous. No one really told me what to expect. (031:1396-1429)

Mary and her husband were operating in a field of unknowns after her erectomy regarding the timing, and risks of resuming intercourse. It may be women encountered health care professionals who simply didn't know the yday symptoms and sexual aftermath of vaginal reconstruction associated hysterectomy. However, she and her husband relied on humor, advice and ult of friends to learn more about the normalcy of her experience. They also tively explored her body. Despite this adjustment period, the hysterectomy a success because it relieved her severe pelvic pain, and opened up bilities for them as a couple to begin procedures to adopt a child.

Lucinda experienced a similar sense of limited treatment options, prior to ysterectomy one year ago. Because of her severe pain and urinary toms, her doctors did a biopsy suspecting cancer.

Lucinda: She sat me down, she talked to me and she said, "Lucinda, you have severe invasive endometriosis. It's stage four and it's not like the typical endometriosis." She goes, "I have the same. It grows and it's fueled by estrogen. And no matter what you do, it's going to grow unless you eradicate it." And she said, "That's the bottom line." She said, "We can try to save the uterus but, I don't know." (071: 2351-2542)

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cinda had a surgery that resulted in a hysterectomy, and a bladder

n.

> Lucinda: I think the biggest adjustment is having this empty feeling here (putting her hand on her lower abdomen) and having your lower digestive system kind of drop a little bit and you have more space in there. (071: 0972-0976)

though children were never in the plans for Lucinda and her boyfriend,

ed a story after the formal interview, once the recorder had been turned

ollowing is an excerpt from a field note memo.

> Lucinda recounted a time after her hysterectomy when she was having some discomfort and she put a warm heat pack on her belly. The bulge reminded her of what it might feel like to have a baby in her belly. She said it made her wish that she would have a baby someday, and be able to know what that would feel like. She expressed having feelings sometimes that her cat was her baby. Alan, her boyfriend who was lingering around, implied these feelings were a bit odd. As a woman, I could relate to her feelings and I told her so. (071/072: 1/6/04-FNM)

Lucinda adjusted to her body on a physical level, she also dealt with

f never being able to have children. Lucinda's pain was much improved

erectomy, yet at the time of the interview her pelvic pain had returned

ad an upcoming appointment with her surgeon. Lucinda thought

er returning pain may have been caused by scar tissue or constipation,

believe the pain was a result of endometriosis.

> Lucinda: Yeah. I feel kind of arrogant. I'm like I don't have endometriosis and my friends say you never know and that kind of bugs me because it's kind of like saying you'll have this disease all our life. I don't feel like it. For me I feel like it was kind of like cancer. It's like I had a situation and it was anatomical and I had to get it fixed and now it's fixed. So I have a different view. It's like I feel like maybe a cancer survivor. (071: 1980-1991)

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arly all of the other women, Lucinda had a unique
sease. Lucinda believed the endometriosis was isolated
, which may have contributed to her identity as "survivor"
ıg herself, as a woman still living with endometriosis.
s. While women were hopeful about the effects of
ıence somewhat prepared for the changes of the body
side the pelvic cavity, they were possibly less prepared
ıt were more visible. After surgical treatment of
en described the experience of being discharged home
ıanating from their bodies. The women themselves were
s of surgery, so they relied on the help of others to deal
chanical extensions of themselves. Boyfriends and
xperience in such matters.
s emanating from more than one orifice, from her
a. The tubes from her abdomen were Jackson-Pratt
inside the body and is connected to clear plastic tubing
ubing connects to a bulb reservoir and when the bulb
in, it pulls fluid out of the body. She also had a urinary
lastic tube that was inserted into the bladder to drain
catheter was attached to a drainage bag to collect the
, described the pressure of wanting to take care of her,
v.

during the day she had to be alone because I had to
as trying to keep a job. It was really daunting for me

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first of all, that they booted her from the hospital with drainage tubes. I mean it was just, I, I had no idea how to deal with that. I just did it, but it was, a catheter, and it was, it was pretty harsh....I'd have to drain the tubes.

Int: Cook for her, and drain the tubes?

Alan: Yeah, oh, yeah. Well, because she, she couldn't do it. (072: 1668-1684)

is powerful experience left an everlasting impression on Alan. When he ed to describe something positive that has come from the experience of triosis, he recalled that, in general, the experience of endometriosis has ed their level of intimacy with one another; caring for her after surgery im realize the seriousness of her condition in a new way.

Alan: I think it (the endometriosis) brought us a little closer. I mean (pause) it made us a little more able to talk to each other about stuff.... Right after her surgery, she told me that she could tell that the endo pain was gone even though she could feel her surgery wounds. That was a relief to me. And I don't even know if that's really positive, but with all the tubes hanging out of her and a big red bag of urine, and I was more concerned about, "Wow, this is pretty serious stuff here." (072:1272-1293)

Tubes and drains served as markers of Lucinda's vulnerability, and a sense of seriousness of her condition that may have otherwise been ked. The partner joined her in a new way, illustrating increased levels of ility and intimacy achieved through care giving practices shared between when dealing with endometriosis. Observing this vulnerability, her felt greater intimacy and connectedness with her via his care.

urgical outcomes made women doubt their general attractiveness and o their partners. Molly relied on her partner in a similar way after

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he wondered how the experience may have influenced her husband's

of her, especially sexually.

Molly: I don't know how he can even want to have sex anymore after having so many tubes down there. It's like, God! The poor guy has stood outside the shower with a garbage bag, with the shower running, me completely naked, and he stood there holding a garbage bag so that he could help me clip the end of the catheter and get it out...because that's the easiest way to get it out. And then he's standing there and I hand him the catheter bag and, unbelievable.

Int: So this is a catheter from the drainage from your incisions?

Molly: No, from my bladder catheter.

Int: Oh from your bladder.

Molly: Yes. Because I had a nick to my bladder, I came home from the hospital with a leg bag on...The guy (her husband, Thom) woke up every few hours and dumped it. I could hear him take the thing off, dump the urine in the thing and then I could hear him take it to the sink and go, "ooh (making a wretching, vomiting noise) because it smells really yucky. And he'd dump it and then I'd feel him put my leg back under the covers and put the covers over it. And then he'd lie back down, because I was barely conscious I was so tired from the surgery and the loss of blood. And then I could feel him again, move the blankets, take my leg back out, drag the leg over the bed, I could hear him do it all.

And so I have this memory of him doing it every few hours. Plus he got up to work. And then when he'd get up to work in the morning then I would stay awake all day so that I could drain it while he was at work....I don't know how he did it, but he did it and that thing never backed up, because he knew he had to take care of it. (081: 1284-1329)

was both impressed and discomforted by Thom's ability to move into

ction. She may have felt out of control as a result of the effects of

perhaps even repulsed by her body. She expressed a sense of

ıame, in being disclosed to her partner in such a way. Molly

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rience as a detached witness or observer, suggesting some
body post-operatively. Although the tubes and drains were
nts of the recovery process of surgery, the experience
ant event in the lives of these women and their partners.
pain device. A surgical treatment unique to one woman was
evice. After living with CPP from endometriosis for
n years, and after numerous surgeries, including a
resorted to an implanted pain device to cope with her

ad difficulty keeping track of the numerous surgeries related
had had over time. The combination of the number of
of treatment made Joan's case remarkable. After a
ars prior to the interview, she continued to have pain. It was
surgery three years later that her ovaries were removed. In
had problems with her bowels from the effects of narcotic
lting in another surgery.

had a double bowel resection. And my intestines, they're
ted now. The transverse colon is prolapsed and dilated,
n my pelvic floor...basically it was all being caused by
s that I was taking for pelvic pain. Now that I'm off the
s, things are starting to go back to normal. (021: 1015-

escribe the effects of living with an inert bowel from

as having to clean myself out digitally.

u're kidding.

Joan: No. No. It was so bad.

Int: Oh, my God.

Joan: I went 18 days without a bowel movement…I've been through gastric studies to try and figure out that my bowel motility is basically eight times longer than normal. Food stays in my gut, in my stomach six times longer than it should. They tracked it. I ate radioactive isotopes or something. It's a mess. It was basically inert. Nothing would move through it, nothing.

Int: But you kept eating I would imagine?

Joan: I had chronic nausea, though, and I was vomiting with the bowel movements when I did have one. We were doing injections of Phenergen here in the pelvis. He (Marcus, her husband) learned how to do that. It's been a nightmare and it just started out with one thing and it spiraled way down to something much worse. (021: 1044-1091)

elieve continued pain after a complete hysterectomy, Joan relied on

The narcotics she was using, however, were simultaneously causing

o her gastrointestinal system. She eventually sought treatment from a

agement specialist.

Joan: …none of the treatments, the conventional treatments have been helping me. So it led me to see a pain management specialist and he tried some other things, noninvasive treatment and that didn't work. So I ended up having a stimulator, a spinal cord stimulator implanted to help with some of the pelvic pain that's residual with IC (interstitial cystitis) and a pump for a pain pump for the nerve pain that's like an epidural thing. And right now, I don't have any pain.

Int: So you've got a permanent pain pump?

Joan: Uh-huh. I have two devices implanted.

Int: And where are they? May I ask?

Joan: Yeah, I have the stimulator here and the pump here on my stomach (pointing to places on her abdomen).

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So on the left and right side of your abdomen.

: Exactly.

Interesting. So by looking at you when you're naked, can
ee them?

: Yeah. The pump is the biggest of both of the two of them,
f you look at my profile when I'm standing naked, I have a
here (pointing to her abdomen). And one's higher than the
. It's not that noticeable, but you can definitely see it. It sticks

And so how do you feel about that?

I'm really thrilled because it helped so much.

Because you're not in pain anymore.

Exactly.

I mean, it's so interesting that they've actually implanted this
e to make you feel better.

And one of them, it's interesting that the pain, I still have the
ut my brain doesn't perceive the signals. With the stimulator,
all it's doing. (021: 0942-0997)

erous surgeries, including a complete hysterectomy, Joan

ain that was intolerable. Complicating matters was the effect

ications on her bowels. Her latest treatment involved an

e, which not only gave her pain relief, but also the hope that

resume a normal life again.

feel a lot more like a normal person. I feel like I can, I'm
g my life again. Remember when we drove to the Napa
untry a few weeks ago?

When you laid down two days afterwards?

o. That's not what I was going to say. On the way home, I crying.

Yeah.

started crying. And he says, "What's wrong?" I'm just so, ying my life again and I was happy. Oh. He said, "Okay, so happy go ahead and cry. I just wanted to make sure there ning wrong."

No, we had a blast. Walked around the vineyards and and had lunch.

was the first time I'd been out just doing something fun in, It felt really good. I paid for it for a couple days afterwards, keep telling him I have to enjoy the good days. I can't know, let them pass by.

now is that as a result of your stimulator? Was that since

eah. (021/022: 1426-1466)

aid for" her increased activity for a couple of days

ted pain device gave her the ability to resume previously

ese precious new pain-free episodes took on heightened

mensely valuable, in contrast to her prior life that was

She may have valued them even more because she began

er pain relief would not last.

ght now my biggest fear is having an allergic reaction to g they put in me, implanted. Because I have so many and I live in fear that that's going to happen and they'll vay from me.

s anybody posed that to you? Is that a possibility?

mm. I didn't ask a lot of questions before. I did do some online about it. The doctor did not really tell me you could re could be, and he knows my history of allergies. And e been a few things that happened and everybody's

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starting to say, "Hmm, you've got to keep an eye on that." I left his office a week ago in tears because I thought they're going to take it away. (021: 1834-1855)

e of her history of numerous allergies, she was concerned she may

llergy to her pain-relieving device.

Joan: I've been having almost constant itching in some of the places. And I'm on a pretty strong antihistamine for it and it's helping. But there's still something going on and I have a little spot of where it's inflamed and it, the skin just always looks pink. And so what Dr. F., X. Company, the people who make the stimulator, they actually have a test kit for allergies so obviously there are patients who have had the problem. So he's ordered the test kit so we can test me for allergic response to any of the things that are touching tissue. He had told me today he's just waiting for them to get it to him because he did order it. So he said if we test and we find out there is an allergic response

Int: Then what?

Joan: He's going to get me involved with an allergist to try and figure out a way to desensitize me. Because what they start looking for is if you're rejecting it your skin starts breaking down and it will work its way out of your body, which is so bizarre. (021/022: 1344-1372)

finally having a surgical treatment that was successful in reducing

n continued to live with a considerable amount of uncertainty about

g of her body and her future. Despite having a diagnosis and an

ment, there were still things going on in her body for which she

nation. Her history, as well as recent symptoms, was impetus for

e answers regarding a potential allergic reaction to the implanted

ralized sense of uncertainty about the future in regards to pain was

arly all the women, even during pain-free periods. Also common

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se of worry that even if pain relief was achieved, it might be only
. The women had legitimate reasons for concern, as this was
the case.

women with mechanical extensions or implants as described in the
ection, paralleled the description of a cyborg body as described by
(1991). A cyborg is a "cybernetic organism, a hybrid of machine and
." (Haraway, 1991, p. 149). Women with implanted pain devices or
tubes and drains did not perceive their bodies in any sort of unusual,
remarkable way. Rather, the women accepted graciously the new
l elements as parts of themselves, as a goal to ultimately get relief of

Treatments

rly all of the women had undergone hormonal treatment during their
of living with endometriosis. The two most common hormonal
used by the women to treat endometriosis included the use of oral
ves and gonadotropin-releasing hormone (GnRH) agonists. Women
understood that hormonal treatments were not curative, but were used
new growth of endometriosis. The following section will highlight the
periences of the various medical treatments.

control pills. Oral contraceptives were prescribed to these women to
ate of pseudopregnancy, which is believed to produce shrinkage of
tissue (Olive, 1995). Side effects of birth control pills include fluid
usea, thromboembolic disorders, and abnormal vaginal bleeding.

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e the physiological concept of pseudopregnancy to treat endometriosis, is a edical one, women did not use this understanding as they described their experience.

Nearly half of the participants (6 women) described using birth control pills me point during their illness trajectory. For nearly all of the women who them, birth control pills were an effective treatment in reducing pain, and ew side effects. The women oftentimes stayed on the birth control pill for years. While, the use of the birth control pill may have decreased omatology, it was not without problems.

Lani's story illustrates how the use of the birth control pill may open up ilities for pain relief but close down reproductive possibilities. Although she diagnosed with endometriosis until the age of thirty, she had suffered from pain since the age of ten and was put on the birth control pill at the age of en. She had been on the birth control pill and off since the age of eighteen tment of pelvic pain. In addition to reducing her pain levels, she also ed the birth control pill as having a therapeutic effect on decreasing the of menstrual flow.

> Lani: ...they gave me birth control pills and it works great. No more pain and very minimum on the period. The period time is from like 8, 10, 12 days down to like 7 days and it controls the blood volume and I feel good about it. Sometimes I don't even recognize that I am having a period. It's so easy. So my life was getting much better. (011: 0273-0286)

er being diagnosed with endometriosis two years ago she was d Lupron, a GnRH agonist, for the pain. After the Lupron treatment, her rned and doctors recommended she go back on the birth control pill.

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treatment had been effective in achieving pain relief in the past, but now
licted with her changing desires for motherhood. As her relational status
ged, the birth control pill became problematic.

> Lani: Most of the doctors say hey, you have the pain, it works for you, I'll give you the solution. Go back on birth control pills. Then the problem will go away but I say I am getting married.
>
> Int: Earlier you mentioned wanting to have kids.
>
> Lani: Exactly. So I told my doctor that I am getting married and we want to have kids and so I say I'm going off the birth control pills and all the problems came back and not even came back, but worse and worse, like four times more than before. (011: 1073-1100)

Lani needed a new "solution" to her pain that while also kept open the
ibilities for motherhood. Without much support from health care providers,
chose to give up effective pain treatment so that she and Matt could try to
a family together. Lani's story was not unique, as other women described a
ar dilemma in which potential fertility was chosen over pain reduction.

A contrasting case illustrating a negative experience with the birth control
s well as relational concerns, is the story of Celeste and Frank. Although
ste and Frank were not ready to have children, they both acknowledged a
e to have children in the future. Celeste had two laparoscopic surgeries
ut lasting relief of pain and understood there was not a cure for
metriosis. Despite learning to organize her life around taking care of
lf, utilizing alternative healing modalities such as Traditional Chinese
ine, Pilates, meditation, visualization techniques, and others, she still lived
PP which had a profound impact on her life.

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Celeste: You can get endo in so many places. On your intestines so your intestines are failing, on your bladder, so you can't have kids or you're in constant and extreme pain all the time. You can't have sex, you can't have a job. You can't live, basically. And so I mean, that's pretty bad. I mean, I don't know. Might not in some ways be as bad as dying, but I almost think it's worse. Really...And you can't do anything about it a lot of times, you know? I mean, you can but there's not a cure. (041/042: 1192-1212)

rs repeatedly suggested to Celeste that she take birth control pills as

or endometriosis, but a negative prior experience with birth control

er resistant. She wondered if the birth control pills she took as a

re a trigger for her condition. Frank, her partner, explained:

Frank: I think she was early 18, 19 years old, got on birth control and it threw her system out of whack, made her feel crazy. She started, she came off it and ever since then, she started getting cramps like really bad, severe cramps and so she is convinced that there was something with the birth control that triggered all this. That has been one of the reasons why she has not gotten on birth control even though every doctor we've gone through and after every surgery, it's the first thing they say. This is the only thing that we can really do to combat this. It will never go away, but we can at least stop it until you're ready to have children. (042: 0137-0154)

e of her negative experience with birth control pills, Celeste,

not want to take them again, even when potential benefits of

re explained. Frank understood a triple purpose of the birth control

he effect on "combating" the disease while preserving Celeste's

ney were ready to have children, while also relieving her pain.

supported Celeste during crises of severe pain attacks, surgeries,

e day to day management of the disease. Yet, he believed Celeste

dealing with her pain.

Frank: That's part of the disease that it just feels like you're so alone and we constantly go over that you're-not-alone thing. You

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might feel like it, but you're not. But in some ways she is. Because she's dealing with this, she's the one feeling the pain. She's the one who can't sleep at night. She's the one. (042: 1446-1451)

eas, perhaps Frank perceived Celeste's pain as an experience that

er own, he took up a different stance in relation to her fertility as he

wledging that her reproductive issues were also his reproductive

nk was alarmed because in addition to her symptoms of CPP and

ual intercourse, she had recently experienced a new symptom, rectal

believed this could be a signal that her condition was worsening.

a sense of urgency on his part to take birth control pills, because of

perceived as her worsening health status.

Frank: She's never been on birth control and they say that

Celeste: Well, I have but just

Frank: Well, not on this

Celeste: No. It seems like I can't tolerate it very well so now the next stuff is to explore different ones that might work.

Frank: Right. Because they say that it'll never cure it but it'll stop it from growing until you're ready to have children, you come off of it. And if you need another surgery they do it then and then you've got a good chance of getting pregnant after that.

Celeste: You never know. Of course you never really know anyway, even if you don't have endo.

Frank: Right.

Celeste: But at the same time, there's so much, there's just so much stuff going on and scar tissue and it just, you just hope that it's not going to be in the wrong place and you hope that your, basically, that your tubes and your ovaries are going to work and that they have been spared somehow. (041/042: 2492-2525)

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n regards to fertility, Celeste was aware of the damaging effects
ietriosis may have already had on her reproductive organs, but she was
peful. Despite her prior resistance to the birth control pill, she expressed
st in considering it as a treatment option.

Frank was excited and hopeful that Celeste might consider the birth
l pill. They had gotten significant support with a new doctor who was
sing to assist them in trying different types of birth control pills until they
one that worked best for her.

> Frank: The doctor is probably one of the best doctors we've had. You can just feel the bedside manner and you're talking to somebody who really cares versus some of the other ones that have just been yeah, well, we'll do this, we'll assign these meds and blah, blah, blah. And she has Celeste's ear and Celeste is now for the first time considering well, maybe I should get on birth control and we all know including her, that there are many, many different types. Her body has changed so many times since she was 19 years old. So the way things would affect you then, could be different now. And I have two sisters and they've both told me the same thing, that oh, yeah, there's one (birth control pill) that made me crazy, one made me break out until I found after two or three tries, I found the right one. This new doctor has vowed, has promised that we will find the right one for you. There's one for everybody and some people ultimately can't handle it, but if you can handle it, we'll find one that can. (042: 0220-0250)

o even consider taking birth control pills to keep the endometriosis "at bay"
numental for Celeste. It contrasted with the more holistic and natural
s that framed her health beliefs. With each partner's candidness and
tness about their individual desires and concerns, a meaningful action
ght. As Frank actively engaged in the process of finding a health care

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vider that would assist them, Celeste was able to move toward an action that
t both of their needs.

It was evident that Frank was experiencing increased tension and possible
r about what he perceived to be the worsening of her disease. What makes
s case unique is that concerns about fertility were coming into the foreground
the partner, Frank.

> Frank: That's my biggest fear is her not being able to have kids because I know how hard it's going to be on her. But it could have been prevented... And if the birth control thing works out which I have a feeling it's going to, maybe not on the first try or the second, but I think the third one and we have a doctor that has vowed to help us find one and if not, she'll tell us that yeah, you're just one of those people that can't handle it. But at least we'll know and we've tried it and we didn't say oh, well, we could have but just never really got around to it or kept blowing it off and I had a bad experience. I think especially if it's the only known thing to kind of keep it at bay, what are we waiting for? (042: 3087-3107)

nk was experiencing increased pressure to be proactive in suppressing, or
ping her disease "at bay." He felt confident that there would be a birth
trol pill that Celeste could tolerate.

Lupron and Synarel. Gonadotropin-releasing hormone (GnRH) agonists
e also common hormonal treatments used by more than half of the women
%) in the study. Two common brand names of GnRH agonists are Lupron
Synarel, but the mechanism of action is the same. A desensitization of the
tary produces a hypogonadotropic state creating a "pseudomenopause" in
en. Side effects of the medication include hot flashes, headaches,
nnia, decreased sex drive, depression, emotional lability, fatigue, painful
, and dizziness. Long term consequences of the hypoestrogenic state on

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um metabolism and bone are of concern. Treatment with GnRH agonists, as Lupron, is generally limited to six months because of the undesired cts of prolonged hypoestrogenism, such as osteoporosis. An "add-back apy," consisting of estrogen and progestin, has been suggested to overcome nptoms associated with hypoestrogenism (Surrey & Judd, 1992). Although it enerally accepted that with one year of GnRH agonist treatment add-back rapy is needed, there is no overall consensus among specialists about the imal add-back therapy (Zupi et al., 2004).

Women in the study were prescribed GnRH agonists at various stages of ir treatment, and for various lengths of time. Most commonly it was prescribed mediately after a laparoscopic surgery or when pain continued after a surgical moval of endometriosis. Women found side effects such as hot flashes and anges in their sleep patterns most troublesome. Women tolerated the side ects in hopes of getting relief of pain. Pain relief varied during treatment and in of the cases the pain returned after a round of a GnRH agonist was complete.

Felicia was still having pain after two surgeries and numerous treatment tegies including a round of Lupron, which was effective, at least temporarily.

> Felicia: My pain came back pretty quick after that first surgery, like within two months. I mean, I was pretty, having a lot of big-time pain. She (the doctor) was wanting to put me back on the pill. I did that on and off and then that wasn't really helping. Then I finally did Lupron for six months which was pretty devastating when I decided to do it, but I needed a break. I was at the point where I just couldn't take it.
>
> I became a Lupron junkie because (laughing) I'd go in for that shot and the first month was pretty bad. I went through what I think maybe is a typical chemo person. I was violently ill the first two weeks after I had the first shot, losing clumps of hair out of my

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head. I probably dropped about 20 pounds that first month so it was a great diet (laughing). But I had no pain, no pelvic pain whatsoever. And so that second month, I thought all right, let's give it another shot and then I didn't have any of the other side effects. The only side effect I had after that first three weeks was hot flashes which was totally workable after all the pain. I had no pain and it was the first time since I was about 15 years old that I had no pain and it was the most wonderful five and a half months of my life (laughing). The thing was two or three days before I needed another shot, I could start feeling it. I would start getting pain and in my lower back and on my right side and I'd be like God, I need my shot. So we joked that I became this like (laughing) Lupron junkie because I would be on the phone again and they were like well, yeah, you're scheduled to come in because they had to wait like it was 31 days apart or something like that. And man, that 30 or 31st day, I was in her office as her first appointment bending over saying give me that shot and they'd give me the shot and within 12-24 hours, I was fine again. (051: 0802-0852)

upron provided a window of time where Felicia was able to resume

s life. Although Lupron provided huge benefits in terms of Felicia's

ement, it was temporary and not without problems. Her husband,

membered her time on Lupron fondly in his individual interview, as he

ow wonderful it was to be able to have their "old" lives back.

Charles: That (Lupron) was kind of her miracle drug that really subsided everything, but you can only go on it for six months at a time. And then you have to be off of it for a while. And plus, now they're finding out all the side effects and everything and how bad it really is for you. I mean, it may have not been the best thing for her but during that six-month period when she was receiving those injections, she was probably, I would say, in my eyes I would say 85 to 95% better. You know, the pain kind of stopped and went away and we were able to go out and do things, and go for bike rides. She was more up for going out and doing things during that period. But then after that stopped, then it was kind of back to the same old...(052: 0620-0641)

elicia was asked what she hoped for the future of her illness, she

ping to feel like she did when she was on the Lupron.

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Felicia: I hope that I could feel like I felt when I was on the Lupron. You wake up every day and you have energy and you don't have pain and life can go on....I really need to get to a point where I'm physically feeling better all the time. (051: 2823-2833)

xperience of living with endometriosis Felicia had coped with many

ding infertility. Yet, she was less certain how to continue living a life

ntrasting case to Felicia's was the story of June, a physical trainer.

ffered from severe pelvic pain with her periods since the age of 15. At

2, after years of taking Motrin for her pain, she was diagnosed with

sis. After her laparoscopy, her doctor recommended Lupron as a

She initially refused because it didn't "feel natural for her body."

June: Right after my surgery (diagnostic laparoscopy) I had just gone back to work. I'd taken three weeks off and up until this point I was in denial. "Oh, they're crazy." I'll do whatever they say but I don't have that whatever that is (endometriosis). And it started off, I woke up and I put my running shoes on and I was ready to go. I couldn't run after my surgery. They told me I couldn't run for 6 weeks, and I'm all, "Screw that. That's too long. This is ridiculous. It's the summertime, it's beautiful." So three weeks after (the surgery) I put my running shoes on and I started running around the block and I get to the end of the block and I'm running 15 miles, no problem. And I get to the end of the block and there's blood running down my leg.

And I come home and I'm devastated because all I wanted to do is go, and forget that I have to deal with all this (crying). And I come home and I take a shower and I'm like I don't want to live like this. I cannot live like this, ridiculous. I, I just felt overwhelmed by it all and I did not want, this is before I'd taken the Lupron.

With the side effects, I didn't want to take it (the Lupron). I didn't feel it was natural for my body to be doing something like that. So I got in my car, I packed a couple clothes for maybe a couple days and I just called into work and told them I would not be in ever, that I'm quitting and I'm going to be, just said I'd go to stay with my friend in Los Angeles and didn't even call and tell her, just packed all my stuff and left....

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Int: Leaving for good?

June: For good, that I wasn't coming back and I didn't want to deal with any of it (crying). I didn't want to deal with not being able to run and ...have the things that you love to do not being able to do. It was just I couldn't deal with it...I was just feeling so overwhelmed with it and not knowing how to deal with it. (121: 1245-1283)

June was overwhelmed by her diagnosis and its effect on her life. As an lete and physical trainer, running was an activity that she had relied upon as a nstant in her life. Not being able to run after surgery was a great appointment and represented losing a major part of herself as a consequence the illness. Not being able to run more than a block was a significant eakdown that seemed to alert her to the seriousness of her condition. esponding to her crisis, her family and her boyfriend rallied around her.

June resumed life, and even got her job back. She began to face the alities of her illness. Trusting her doctor's advice, she eventually was treated h Lupron.

June: When I agreed to it, I didn't really know. I had gotten a little pamphlet from the people that make Lupron and they say like oh, some people get hot sweats, some people get headaches, some people are really nauseated. It sounds really blasé. Just like normal drugs, like some people get allergic and

Int: Like that 1% who have an adverse reaction.

June: Yeah, whereas Lupron, I think everyone gets all those things. And going into it, I think just going into it I didn't know. I just trusted that my doctor knew what he was talking about, and did it. (121: 0431-0444)

June's case was unique because she did not get what she considered to ufficient pain relief, even temporarily, to outweigh the side effects. Rather,

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nulative effects of her medications were causing a serious interruption in . June had been on Lupron for eight months at the time of the interview. In addition to continued pain, she had hot flashes that interrupted sleep. as a young woman who had to learn to manage menopausal hot flashes ssing in layers. Consistent with the side effects of Lupron, she also bed the effects on her sexual life. The Lupron had caused her to ence decreased vaginal lubrication, difficulty achieving orgasm, and an ll decrease in her sex drive. Also troublesome were the cognitive and al changes. Because she was having considerable amounts of pain, she ed significant doses of pain medication. The cumulative effects of the cations were making it difficult for her to function at work and home.

Her life with endometriosis on Lupron hardly resembled her old self. use of Lupron's possible degenerative effects on bone, June was advised run while taking Lupron. Overall, June was beginning to feel a sense of eration and hopelessness, and began to question if her current treatment e, most specifically the Lupron, was helping her.

> June: I'm kind of having a conflict with my doctor right now, too, because I'm feeling that Lupron's not the answer for me. I don't think that taking multitudes of drugs is solving anything because I'm still having the pain and it's not where it's crippling as it was before, but I'm kind of curious. I'm wondering well, I can't do the things I used to do and it's affecting me negatively. I'm just not doing the things I want to do...(121: 0354-0361)

With unsatisfactory results from numerous treatment efforts, June was in a t" with her provider. She had gotten to a point of considering taking her in her own hands by stopping all medications. This juncture marked a

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e considered the pain as being more tolerable than the

hink that some people have taken Lupron and it works
ally for them and I think some people, it does not work for
ersonally I'm kind of leaning towards a more naturalistic. I
t if I eat right and I'm able to exercise and I think that I
ust know that I'm going to have times where it's going to
nd the pain's going to be bad and I just accept that those
going to suck, and hopefully in between those times I can
iods where I'm pain free or almost pain free and able to
ull life. (121: 0474-0482)

ghlights, in particular, the fragility of trust in the relationship
e treatment of endometriosis. While June initially resisted,
ed her provider's treatment advice and started on Lupron.
s on Lupron, June began to reconceptualize her goals of
ered if having more predictable pain at certain times of the
n her current situation. While she experienced significant
bout the effects of treatment, and its impact on her life,
be a clearing or space to be able to share these concerns
rovider. Like so many other women, June was, in a sense,
mplications from the illness as well as the adverse affects

ear that her provider offered personalized care, taking into
e was an active woman. For example, because of the
se in June's life, a discussion about running in moderation
nefit June's health outcomes, as well as improved the
nship.

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June was very much on her own in her treatment decision-

y of Carolyn and Nicholas illustrates the case of a partner's

atment decisions. At the age of ten, two years prior to onset of

n had severe pelvic pain. By the age of thirteen, she was on birth

ch "regulated" and "stabilized" her symptoms, and by the age of

s prescribed Synarel for six months, which induced

use.

arolyn: He right away (after laparoscopic surgery) put me on
ynarel for six months so that put my body into the simulated
enopausal state and so my pain was gone. Of course, you've got
ll the side effects associated with the Synarel. I'm 17 years old,
aving hot flashes, and I gained a ton of weight and I don't
emember what else, and mood swings and stuff. But the pain was
reat and, in fact, after that I went years being relatively pain free.
fter the Synarel I went back on birth control pills continuously
ithout the break to get a period and did that for years. (091:
172-0179)

nth course of Synarel followed by continuous birth control pills

r Carolyn in terms of relieving her pain for approximately ten

ime she got into a serious relationship with Nicholas. When

cholas got engaged three years ago, she went off birth control

at was going happen."

pping the birth control pill, her pain, over the course of a year,

ned and intensified around her menstrual cycle. Approximately

topping the birth control pill, she experienced pain with sexual

he first time. With this new symptom of dyspareunia and

she sought treatment.

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Carolyn: I went up to U. Medical Center and saw this doctor. I wanted to find out what my options were since it's clear that yes, I still have endometriosis. I hadn't had the surgery since I was 16 and then I did the Synarel right after that but then I had just been doing the pill as a treatment. And I hadn't maintained my relationship with the Endometriosis Association or done any of my homework. I didn't know any of the new stuff. So I went to this doctor... And he was very, very nice, really good doctor, great bedside manner, listened to me, he validated me, but he really didn't know that much about endometriosis. But he stopped and that very morning, consulted with his colleagues, who's more of the expert in reproductive health I guess.

And that doctor suggested Lupron. And so I spent another, I don't know, probably 45 minutes talking to this other doctor about what that was all about and what that meant and the side effects and everything like that. And I actually walked out of there with a prescription. And I called Nicholas from the car in the parking lot and explained it to him and his immediate instinct was like, "No, I don't want you to do this."

Nicholas: No, hell with that.

Carolyn: But I was feeling like maybe I should take this chance and get the prescription...So part of me was just like maybe I should just do it, thinking about preserving my fertility. And the doctor actually said something that was really powerful for me. He said if it was my wife I'd want her to do it. And knowing that my number one goal was to try to be able to get pregnant he thought that this was the way to do that. So I left with that prescription, was almost going to do it, and Nicholas really said, "I really don't want you to."

Int: What were your concerns? (to Nicholas)

Nicholas: I just didn't like any of the side effects and I said you know what? You're not his wife. You're not his wife. I know enough about pharmaceuticals to know there's politics involved in giving out prescriptions even if you're not benefiting from it.

Carolyn: I think that's where he was coming from.

Nicholas: Her pain, well we knew that if she went back on the pill that it would alleviate it and she'd

Int: So you knew that you had another option.

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Nicholas: Yeah. There are plenty of other options that we hadn't tried.

Carolyn: My fear was the fertility. And if this is going to help me in any way have better chances to get pregnant then I'll do it.

Int: Then it was worth it.

Nicholas: Yeah. But Lupron is not going to make you more fertile. It doesn't make you more of anything. It doesn't give you better health.

Int: If anything, it's counter-intuitive because it puts you into premature menopause.

Nicholas: Exactly…

Carolyn: But it stops the growth.

Int: It stops the growth of the endometriosis.

Carolyn: Uh-huh.

Nicholas: Yeah. It stops a lot of things, you know. (091/092: 1109-1218)

yn did not, at any time during her interviews, make a connection prior treatment of Synarel and the proposed Lupron, which are both sts. Perhaps the different brand names confused her, but it does not rior history impacted her decision making process. She called to and's advice, and he drew on his training as a physical therapist to against the Lupron. He was protective and skeptical of the physician the pharmaceutical industry, in general. She decided not to take nd chose to follow her husband's suggestion, illuminating the role of influence in treatment choices.

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ominantly, this case illustrates the complexity of decision making with

and all that is at stake. While the pain is a critical part of the

arolyn also wanted to do all in her power to "preserve her fertility."

> Carolyn: I'm happy with her (the new doctor) and she says that she doesn't recommend, because she's felt around and things move and so it doesn't feel like there's so much growth that things aren't moving around in there. And I've explained to her everything that's happened. I came with my own medical records and stuff so her recommendation is that I just stay on the birth control pill continuously and not do another laparoscopy. She doesn't think that that's helpful at this time. She's all "We know you have endo." The best thing is just to minimize any chance of that, the growth. And of course, I want to get pregnant and that's a big part of her recommendation. So I want to get pregnant in about a year, I want to start trying. So she's like getting pregnant is, trying to get pregnant is a good thing so let's just try and keep things calm (laughing). And since I've been back on the birth control pills continually, continuously, I haven't really had any problems. There are certain times where I'll get a little bit of cramping but because I'm not having a period it's not a big deal and it just kind of passes. But the painful sex thing is still an issue. (091: 0299-0319)

olyn resumed taking the birth control pill, with the goal keeping "things

e hopes of trying to get pregnant in the near future. Her pelvic pain

ed to minimal amounts of cramping, but the problem of dyspareunia

en resolved.

use of hormonal treatments varied in effectiveness and the benefit of

was weighed with numerous side effects. When pain relief was

t was usually temporary. The use of hormonal treatments created

about menopausal side effects, and the relief lasted only so long as

ere taken. Lupron and Synarel also offered hope that would women

ee of pain, and be able to resume their "old" lives again.

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Pain Medication

te surgical and hormonal treatment, the majority of women
a level of pain that interrupted daily functioning. The use of
ither prescription and/or over-the-counter analgesics, assisted
managing" their pain, and made it possible for them to function in their
ives. The use of pain medications created a paradox of mobility; the
was used to enable functioning, but often created new immobilizing

nal of painkillers. Pelvic pain was predictable in that it worsened for
en around the time of their menstrual cycle. At the same time, the
quality that was sudden and incalculable. Women living with CPP
metriosis lived with uncertainty regarding the timing and severity of
ain episode. Nearly all of the women had learned to live with a level
dness to "manage" the pain.

an, who in the past five years had undergone Lupron treatment and
es, described the effectiveness of her various treatments.

> Susan: For me, the continuous birth control have always worked fairly well. It really feels like it's just kind of quieting everything down and locking it down. Surgeries have been great. I had one in the summer that removed adhesions and I was like "I can move again." That was excellent. What else?... I guess also symptom management like having a decent pain med arsenal with you all time so people are like "Oh, I have a headache." I'm like "Well, I have this" (laughing) I'm like this traveling little mini-pharmacy. (0255-0264)

adequately prepared with a "mini pharmacy" was a common
sed by the women.

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ere are different ones (pain medications) that I've tried
tter. And so I always carry that with me everywhere I
now if I should say this, but, actually, when I had
time I got some Morphine pills. And, and so sometimes
those. Because I don't know if something can happen
know how painful …

security, almost?

ah, Yeah. The step below that would be like Vicodin or
something like that. The low stuff would be just regular
take quite often. (041: 1048-1070)

ed in the middle of the night with severe pain that she

omeone had shot her in the stomach or pelvic area. It

n fear, never knowing when and if a similar pain would

fety in protecting herself by having various types of

ing Morphine. The need for an arsenal of pain

aps, the worry and chronicity that permeated the

ne carried Morphine pills which had been prescribed

posed to chronic pain. This practice was not

described using medication acquired from family

was prescribed for other ailments to treat their pain.

g alcohol to treat, or numb themselves from the pain.

. The use of pain medications presented a paradox

used to resume levels of functioning, often had

n were acutely aware of the side effects of various

ere described by some as the most troubling aspect

ometriosis.

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Mary: Feeling like IT'S (with emphasis) controlling your life, not you....Being told that it's normal, pain is normal during your period and you're popping Advil like they're Skittles and they're telling you pain is normal during your period. Having to take huge pain medicine that makes you. I mean, Advil makes me groggy and I'm taking Darvocet and Vicodin for my pain so I'm like totally out of it. I almost O.D.'d on Darvocet because I was taking it per their recommendations which was too much for my body and I was like God, oh, my gosh, I've taken too much. (031: 0514-0532)

Women were acutely aware of the side effects of various pain medications, ncluding troublesome cognitive and physical effects. No one type of medication merged as the most common or effective medication to treat pelvic pain across ll of the women. However, all worked to balance pain relief with an ability to unction.

Many women also perfected the skill of medication titration. Maryann escribed a process, in which she would bite off the least amount of medication ecessary in order to treat her pain.

Maryann: Starting around 5:30, 6:00 o'clock every night, the pain just gets really intense and I'm having to take like a half a Vicodin, a third of a Vicodin. I try to not take a whole one.

Int: So you literally kind of break them?

Maryann: I bite off, I bite off. If I drive somewhere, if I have to go somewhere and have to drive, I take a quarter and it doesn't really affect me but it does take the edge off the pain. If it's a little more, I take a third, but if it's really bad, I take a half.

Int: And would a whole one just make you too groggy to function?

Maryann: No, actually it would probably not but I wouldn't feel comfortable driving. If I was staying home and I was in really bad pain, I mean I have taken a half of one and then waited 20 minutes. It usually starts working within 20 minutes. And if it isn't working say 45 minutes later, I'm still having a lot of pain, I take the other half so then it's like a whole one. It doesn't really make me, some people it knocks them out. It doesn't do that to me. If I took two I

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suppose it would, but it doesn't really do that. But it just, it takes the edge off and helps me get through that. And then after a few hours it subsides and it'll go away. (131: 0040-0063)

en used their own embodied knowledge to adjust the prescribed pain

dose so that it worked best for their bodies. While the prescribed

ave taken into account the quantity of medication necessary to

in most women, it did not take into account individual differences in

odies nor women's need to drive, to go to work, and to be able to think

, a kindergarten teacher, took Motrin, as opposed to something

r her pain at work because it did not interfere with mental clarity.

pain, she would go to sleep every night with Motrin and water at her

Molly: I would lay there in bed. Get up, take 800 milligrams of Motrin and lay there until I could put my feet on the floor. As soon as it kicked in I could put my feet on the floor I could get up and get into the shower. I can remember days just standing in the shower.

Int: So the Motrin helped?

Molly: It would take the edge off so I could function.

Int: But then you must have been relying on this medication throughout the day?

Molly: Oh, I was taking it for ten years. I would never take any narcotic based medication with the children during the day because I knew I had to drive and I was responsible for them. So I would rather just take enough Motrin to take the edge off of the pain and then in the evening when I got home it was like oh, thank God, now I can take something heavier for the pain. (081: 0813-0829)

had integrated a self-care practice into her life which mobilized her

. Her choice of medication was influenced by her responsibilities

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o be cognitively and mentally alert during the time she was

young children.

Molly: Working with kids is really hard if you're in pain. You have o be really, really patient and be centered and be kind and be atient with them and when you're in pain, you have this chronic, ngering ouch going on all day long, it makes you a little short-empered. It makes you a little crankier, a little more on edge. And I on't ever want to be that way with them. So I'm really, I maintain it eally well now so that I'm not ever like that with them. That's my ggest concern is having that affect my teaching. (081: 2285-292)

ay with Motrin to balance, or "maintain" the pain so she could

taking the edge off the pain."

rtainty of pain and how to treat it created concerns for women in

lives. Nearly all (92%) of the women were employed for pay

me at the time of the interviews. In order to function at work,

h a level of preparedness that most likely created extra stress

acy: It was hard when it would happen at work, because then, do ive to work? What do I do? I ended up deciding I always had to e all kinds of medicines in my work bag with me, because I didn't ow what was going to work and not work. I had to take the ating pad with me depending on how long I'd be out. I had to ve it somewhere, whether it be in the car or my work bag or atever. And then I'd come home, like if it was a bad day at work n a lot of pain, then I just would come home and just completely e it easy. (101: 0899-0908)

to pain medicine, Stacy's pain arsenal also consisted of a

a physician, she was very conscientious about the importance

her mental status while caring for patients. She utilized

o pain medication that assisted her to get through a work

hen you're having this intense pain, what would you do?
u continue to work, could you continue to go through your

Vell, a lot of times I would continue to work. I would try to,
hen I would have the pain, I would take Advil, like a
on dose of Advil and I would put heat. I don't know if heat
r not, but I always use it for cramps and health.

d you, did you have heat at work?

eah, I ended up having to take this little thing that I could
e microwave. I ended up having to carry it with me all the
rk, because I never knew when it was going to happen,
don't really have, all they have is moist heat at work, and I
know, with moist, with having to work. So I would just
ills right away, and I would start using the heat, and just
e that I was having trouble. And at that time I had a
that would help see patients if I needed a little downtime.

w would you do the heat at work though?

ll, it's just a little fabric bag with these popcorn

u could put it right in your clothes, and nobody would

ah, I would heat it and I would just put it on, yeah.

nd that helped?

uld just put it, hold it there. I mean, and people would
that I was having problems.

ple saw. People saw that you had something on your

I'd sit in my chair and just kind of hold it there.
could lay back in my chair a little bit or put my legs up
n or something.

s not sound fun.

Stacy: I didn't want to miss work. Oh, it was horrible. And sometimes it was better when it happened at home because I could lie on the couch. But when you're out, like when I was back in Boston visiting them (her family), I didn't even have any heat. I just had to just take deep breaths and I meditate, so I try to do those kinds of activities, that whole focusing on the thing, and knowing it'll get better. So, yeah, it was a real pain. You just pray it doesn't happen somewhere that you can't deal with it in some way. And then when it got to the point where the Advil wouldn't help, then people said, "Oh, try Tylenol." And then I would do both, and it got to the point, that nothing really, I just have to, had to, just wait it out. (101: 0433-0491)

lthough Stacy's job involved caring for others, her condition occasionally ded that she simultaneously provide care for herself so she could get h the work day. Stacy had significant support from coworkers and tanding from her patients. However, it is likely her self-care techniques ely impacted her role as a provider. The patient-provider relationship sets sibilities for patients to disclose their concerns, fears, and problems r, 2004). If the provider is visibly attending to her own physical needs, the disclosure on the part of the patient will most likely be compromised. Stacy was cautious in using pain medication that did not interfere with e function, but it also did not offer adequate pain relief. This exemplar s the difficulties of balancing effective pain management and maintaining to work. A technique such as "waiting it out" was effective at home, but lways possible at work.

cording to Helman (1995), individuals with chronic illness attempt to hysical and psychological experiences of bodily changes with body aid in conceptualization of both internal and external spaces of the

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nd video from laparoscopic surgery may influence
t is going on inside their bodies. Maps of external
explore women and work. Helman points to
at extend beyond the physical body. These varied
are "symbolic skins" (Helman, 1995, p. 170) that help
intimate distances, which may be appropriate between
tances, where no personal interaction may take place.
ysical boundaries or structures, such as one's home,
idual's layer of "symbolic skin."
work, was a place of solace and comfort where
end to the needs of their unpredictable illness. For
y was a particular room, in which they could literally
ge while in pain. Within the protection of their home,
r guard down, medicate themselves if necessary,
e pain until it passed. In contrast, going to work was
ed women to relinquish the safety and protection of
arly all of the women experienced problems related
%) changed careers or jobs to be able to work from

scribed that pain medication did not eliminate the

ainkiller for over 10 years, it didn't work. I mean, it
ntrol the pain, but it's not that the pain went away. It
So a painkiller doesn't work, really work, you know.
to manage the pain.

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nt: It helps you to get by?

ani: Not even get by. I mean, it just helps you with the degrees f pain, lowers the degrees of pain.

nt: Okay, so it never even makes it go away.

ani: Oh, no, no. Never. (011: 0812-0830)

s pain medication was used to "manage the pain," "lower the " or "take the edge off," it was not effective in relieving the pain addition, women were faced with the effects of narcotic pain physical and cognitive functioning.

described a general ease in obtaining pain medications to treat ere was an overall sense of dissatisfaction with the treatment was a general understanding that pain medications were treating were not, however, treating the underlying problem causing the n women treated their pain with pain medication, interruption of as often unavoidable.

Conclusion

ll experience of living with CPP from endometriosis was ing sense of symptoms, and appropriate care and treatment uncertainty, and puzzling contradictions. This chapter ts of the lived experience of CPP from endometriosis including king answers, getting a diagnosis, and finding relief of pain. was puzzling for most women. The cause for the pain could nd a certain amount of pelvic pain was considered to be

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" Women questioned if their pain signaled a condition requiring concern
ıe women wondered if their pain was "real." Women in the study were
ırticulate a decisive point when they first began to understand something
ng in their bodies and responses were categorized as either a sudden or
ɔnset. The area between these two extremes, however, is murky as
nay have experienced CPP, but did not perceive it as problematic.
hile pelvic pain and dyspareunia were common symptoms of
riosis, the illness experience in terms of symptom onset, progression of
and treatment experiences was unique for each woman. Nearly all of
en had difficulty getting answers regarding the cause of their pain, and
s explanations were frequently offered. Advocating for themselves to
ıre they perceived as helpful, fostered skepticism by the women. Self-
often led to an adversarial relationship with health care providers.
nen got a diagnosis of endometriosis, the relief was often fleeting as a
not provide adequate solutions for the pain. Nearly all of the women
to live with levels of pain that were disabling despite treatment.
a diagnosis of endometriosis represented an interminable chronic
d a future of perpetual uncertainty.

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CHAPTER FIVE

RELATIONSHIPS: HOW COUPLES TAKE UP LIVING WITH CHRONIC PELVIC PAIN FROM ENDOMETRIOSIS

Introduction

en demonstrated in the Ambiguity Chapter that living with an be a physically and emotionally painful experience. dometriosis, including CPP (chronic pelvic pain), disrupt day to s areas of intimate relatedness. In the following chapter I will ıples' stories and attempt to understand how the couples take up ıetriosis together.

atterns of relating include (a) Together but Alone, (b) Battling ogether, (c) Conjoined through Disability, (d) Totalized by Care alanced Care Giving. The first pattern "Together but Alone" s within relationship that disrupt possibilities for mutual hesiveness, and connection, and how illness may accentuate ifferences between couples. The second pattern "Battling gether" illustrated the relevance of congruent symptom nd illness understandings, as mutual interpretations of pened up possibilities for actions to achieve resolve. The third by Care Giving" illustrated a range of care giving, in which the ized care giving, over all else, even care of self. The fourth Care Giving" highlighted possibilities of care giving that e prior pattern, in which flexibility of care and reciprocity of care

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were observed. Finally, "Conjoined through Disability" stood for a pattern of elating characterized by mutual disability. A unique characteristic of this pattern f relating was each individual's bodily limitations opened up greater possibilities or patience and understanding of the other. The patterns of relating as they are resented are not meant to be exclusive, as other patterns may exist amongst ouples. Nor are the patterns presented as rigid or static, as the ability to shift atterns over time was demonstrated. The first paradigm case illustrates patterns ithin the couple's relationship that disrupt possibilities for mutual understanding, hesiveness, and connection. The remaining four patterns illustrate ranges of lationships that foster connectedness through the illness experience.

The five patterns of relationships illuminate commonalities and differences nong couples, as well as a spectrum of possibilities. For example, while care ing was a common action amongst partners, the relational pattern of being talized by Care Giving" was unusual. Emphasis is placed not only on the tterns of relationship, but also on factors that opened up and closed down ssibilities for each form of relating. Rather than presenting the stories as ndensed and one-dimensional, the stories have been retold as they were derstood, with the goal of shedding light on the complexity of the couples' world. Often times contradictions, and puzzles are embedded in the couples' eriences. The quotations presented have been selected from individual or t interviews as indicated in parentheses, and the couples' names and ntifying information have been altered.

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Together but Alone

This section presents the paradigm case of Lani and Matt, a couple
n because their story illustrated one range of relationship in living with
etriosis, living together as a unit, but each partner living alone in their
ate lifeworld. The patterns of relations within this couple's relationship
possibilities for mutual understanding, cohesiveness, and connection.
Three areas of their mutual lives have been chosen to illuminate their
ual lifeworlds including: a) daily health practices, b) their sexual
nship, and c) creating a meaningful life. These areas were chosen because
rominently showed up in the foreground of this couple's narratives of their
-day lives.

round

Lani and Matt were a married couple who had been in an intimate
nship for several years. They were both in their thirties, and lived in a
minium that was on serene waterfront property with beautiful bay and
in views. A kayak was visible on their patio which faced the ocean.
Lani has had a diagnosis of endometriosis for two years, but her life had
rofoundly affected by her pelvic pain for approximately twenty years.
rted menstruating before all her friends, at the age of eight. By the age of
started experiencing severe menstrual cramps. Her pain was episodic
ed to her menstrual cycle, and it wasn't uncommon for her to miss school
of the pain. She recalled a time in particular that the pain was so bad
to go to the hospital because she could not tolerate the pain any longer.

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weating, dizzy, and eventually fainted. This was the turning point she
en she knew something was wrong with her health.

ing that time there were not many people Lani could talk to about her
pain because it was a topic that was not openly discussed. Her friends
nates couldn't relate to her experience because they had not reached
When she talked to her mother about it, she assured her the pain
way when she got married, and if not then, surely when she had a

ng her childhood and adolescence, doctors assured Lani the pain
d normal menstrual cramps and treated her with increasingly stronger
which were not effective in taking away the pain. As a youth, she
childhood to be over, to get relief from her pain. At the age of 18, she
he birth control pill which reduced the duration of her menstrual cycle
d the pain considerably. At times, while on the birth control pill, she
ief from the pain that she didn't even realize she was having a period.
ing such good results, she went on and off the birth control pill for
ly eight years with few complaints.

ationship with Matt began at a time when she was on the pill and her
nimal. They had the same goals of succeeding professionally and
tart a family. Qualities that Lani admired about Matt were that he
g, and very active, and enjoyed exercise and outdoor activities.
courtship, Lani was inspired to take good care of her health because
o be able to keep up with him biking, hiking, and kayaking.

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unexpectedly, her symptoms of sweating, dizziness and severe
ps, returned. She had just eaten spicy food and thought perhaps,
from her meal. An friend, aware of her symptoms, told her it
e had endometriosis. When the pain continued, she went to
cal/gynecological physicians but she wasn't able to get a
kept prescribing painkillers to treat the pain, and she was
use they kept telling her everything was fine. She eventually got
sult of continued pain medications. She also sought help from a
without any relief.
and Lani were married, Lani's symptoms worsened. She had
lyspareunia, painful sexual intercourse. On a trip abroad, she
er pain. An ovarian cyst was found and surgical removal
he surgery, two years prior to the interview, they found
d she was finally was given a diagnosis.
ing section lays out how Lani and Matt have taken up daily
elated to endometriosis. It also illuminates and contrasts their
es of health, which sets up a chasm between them. Lani and
nowledged the struggles and tensions in their patterns of
r Lani and Matt were able to lay out their individual
the other, but each had difficulty understanding the other's
n to practices of health. Together they experienced a pattern
ng and disconnection.

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Competing ideologies of health practices. Both Lani and Matt valued health
aily practices which support healthy living. They each, however, had
nt ideologies framing daily health practices. Matt believed the
nsibility of health belongs to the individual and one must have an inner
o achieve such results. This is contrasted with Lani's view which prioritized
nships as a vehicle to wellbeing, and healthy habits.

Matt recalled a childhood event that influenced his strong beliefs. In the
ng text, he was talking to Lani about his personal experience with pain as a

> Matt: I know. I know. I know how it is. I mean I have pain. I have had sickness before. I know. Remember, I told you this one time that I was sick and my dad was sitting right next to me when I was a little kid. He was sitting there the whole night. And then I realized one thing. I realized, and that's maybe the day that I realized you have to take care of your body yourself. No matter how caring my dad was, he was sitting by my side the whole night. I was having a fever or something. It was a pretty painful fever where your joints are hurting. He was there and I could see how loving he was. And I realized no matter how loving you, your, your, your, your, the people that are close to you care about you, but they can't do anything about your body. He was there and I was still in pain and there was nothing that he could do. Nothing was working. He tried everything. There's nothing. (011/012: 1396-1424)

Matt was aware as a child there was nothing his father could do to take
s physical pain. In this realization, Matt under-attended to the relational
otional aspects of his father's care. The story encapsulates his ideology
ily pain or functioning are private, individual physical events untouched
l or psychological support. The story that Matt told of being a child in
dly contrasted with a story that Lani told of care she received from her
when she was a child in pain:

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Lani: I remember when I was a little kid, when I was sick, when I was in the hospital, my mother, who actually when I grew up told me that she was really worried, too. But when I was in the hospital she was totally calm and she just told me, "Oh, you will be fine. Don't worry. You'll be just like normal," and it made me think that I am a normal person and the pain will go away. And that really helped because when you're in pain, when you are sick, you are really worried and you are really scared. But if somebody can tell you that "Oh, no, it's not that bad," and "It will feel better. You will feel better soon." It calms, it really helps you, makes you feel better. The pain, yes, it doesn't go away right away, you know. But at least it's kind of a relief a little bit. So I think that I was looking for, hoping I can have, some support. (011/012: 2160-2184)

These childhood stories illustrate the incommensurability between Matt and Lani's health understanding and ideologies. Mat defined one's control over health in a way that was autonomous, and in control, something devoid of relations and emotion. He did not believe in the therapeutic value of relationship, whereas Lani did.

Matt held a mind over matter philosophy. He believed if one has control over a healthy regime of habits and practices, there is an ability to have a direct impact on outcomes of health. Matt believed strongly that healthy eating and regular exercise are such ways to master health. One of the ways Matt took up caring for Lani was by reminding her of the importance of living a healthy lifestyle. He was aware, however, that his approach had not been successful in the past, and he was aware, in fact, that it had hurt her. Prior to her diagnosis of endometriosis, he believed her poor diet and lack of regular exercise might have been responsible for the pain.

Matt: ...I blamed her before and I know there must be a scar in her heart because I did that, right? Then it reflects in the way that she asks for help. It reflects in the way that she talks about things... On one side I'm not strong enough to handle it or to be strong myself...

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all of a sudden, you are separating even more. (011/012: 1921-1931)

He acknowledged how difficult the situation was. He felt bad about blaming for her pain, and was aware his behavior impacted the way in which she losed her illness experience. While he considered himself the healthy one in elationship, there were times when he wondered if he could handle all that disease presented to them. He was aware of the chasm between them. Matt elieve, despite a having diagnosis of endometriosis, that Lani could improve ealth and reduce her pain, by certain lifestyle choices.

Regular exercise was also something Matt valued. He believed in having a routine and sticking to it no matter what. Lani believed exercise was rtant, but she also valued companionship and emotional support. She dly described a time in her life when she went to the gym regularly with a rker when she was working at a company. Lani considered the buddy-nique successful even though it meant that when the coworker didn't go to ym, neither did she.

In the following text, Matt described the conflict within the couple regarding ay they take up exercising in their daily lives:

> Matt: I guess we never worked out the issue of this major difference between us. I don't know. I'm a very, in a way, would you call it independent? I think things you want, if you want to change your life, it has to come from within. Because I'm a very stubborn person on one side. But then I also, I do a lot of self-discovery that looks at my own self. If you don't, if it does not come within yourself, you don't have that drive to do it. You're tagging along. You will never, never, never achieve it. ...I cannot understand the concept why she would think that way. Because in my whole life, my path, my life experience I learned things that you have to do it from within... So I keep telling her if there's something

> that you want to get rid of, you have to work. And we never communicate that well and we never have an agreement on the same level....it's like a big chasm between us. She always feels that I'm trying to drive her away and then she'll say, "Well, ... why don't you help me, why don't you do things together with me?" (011/012: 0768-0804)

This quote illuminated their incommensurate stances on health and tionship. Matt devalued her preference for companionship during exercise understood it as an unhealthy dependence on the presence of another which lead to eventual failure. Matt believed by "tagging along," one will never ieve the desired goal, which in this case referred to Lani achieving optimal lth.

For Lani, taking care of her health extended beyond diet and exercise. i valued listening to her body and taking up activities like laying down to rest n she needed to because of fatigue or pain from endometriosis. Lani's ability xercise regularly was curtailed by high pain levels. Lani quit her job at the pany to be able to work at home with more flexibility.

Lani acknowledged physical activity wasn't something that came naturally er. This was one of the qualities she admired in Matt when they were dating. had hoped she would be able to become more active in order to "keep up him." Lani and Matt did not share stories about taking up an active lifestyle ther in their day-to-day lives. While Lani wished they could walk together to up groceries at the local market, or kayak together off their back deck, they did.

One activity they both enjoyed was yoga. Lani brought Matt to a yoga but unfortunately, Matt couldn't handle the advanced class. They joked

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ne had severe abdominal pain from class and couldn't stand up for days.
both continued to go to yoga, but separately, attending different classes.
went to yoga when she felt like she could. Matt went more regularly and was
to fit it in to his schedule.

On the surface, it seemed likely that if they valued Lani's health ideology,
could step up or step down to a level that the other could attend. Yet, if they
hoose to attend yoga class together, it would undermine Matt's ideology and
ose in attending the class. Lani and Matt did not attend yoga class together,
ather each alone in their experience.

Relating as means to health. While Matt cared for Lani by coaching her in
she could and could not eat, Lani perceived his efforts as parenting. Lani
ed to make healthy choices around food, especially when she was having a
attack. When in pain, she would get angry with herself and tell herself she
eat healthier. Yet, when she was feeling well and feeling "normal," she
ed to eat "normal" by eating what she wanted including eating the same
s that Matt was eating.

> Lani: I especially love chocolate and now I have to quit it. So once in a while he has to really, really follow me and hide it and that kind of thing. And I think that's really helpful and I thank him for doing that. But sometimes I just don't like being parented, treating me like a little kid. "Oh, you cannot have that." And then it's just like parenting. That's worse because I feel that I'm not that little kid. You don't talk to me that way. But he likes to do that.
>
> Matt: Because you ask for it.
>
> Lani: No I didn't ask for it. I asked for your help.
>
> Matt: When you say, "Next time..."

Lani: No, I say, yes, every time when I was in pain I say, "Well, next time if I have chocolate or whatever's spicy..."

Matt: "Stop me. Do anything you can to stop me."

Lani: You have to help me and stop me. But there are so many ways you can help me, right? You can hide it or you can nicely say, "No, you can't have any." Or you just basically remind me and say, "Hey, you told me to help you not to give it to you." That will feel much better instead of like a parent that says, "No you can't have that," every time when you are in pain. That is not easy to accept. I don't think it's helpful because like when you have that temptation, when you're well, you think that, "Okay." When I am not in pain and it's a normal day, I think I am like the normal person. I can eat anything I want like any other people, right? So when he is eating, of course, I want to eat it too, right. And I forgot that I have that pain that I have to deal with it, right? So I have to fight myself really hard, every time to control myself. "Okay, try to remember how painful it was." Then not to eat it. It's hard. It's not easy. (011/012: 0568-0619)

ani wanted Matt to help her but she lived with internal contradictions. On de, she struggled to be disciplined by avoiding certain foods, such as ate and spicy foods, which made her pain worse. Yet, on the other hand, he was feeling well, she wanted to enjoy simple pleasures such as ate. In this dilemma, she wanted Matt's help but sometimes his help felt enting.

Matt's "parenting" behaviors were motivated by how much he cared about le hated to see her in pain. It made him feel frustrated, helpless and from her.

Matt: Whenever she has pain she becomes inactive. She would lay there struggling and she would be in a bad mood. I understand... because she wants to deal with the pain. She concentrates most of her energy just trying to deal with the pain. And that's the part that bothers me the most. Not just the sex part. The worst part is when she's in pain she becomes very inactive and

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she doesn't even communicate. It almost feels like she want to just put me aside and that bothers me the most. (012: 0634-0655)

t's description, Lani's world closed down when she was in pain, and

nced the separation as painful. Matt telling Lani what to eat and how

se she needed was his concrete way of helping her and trying to

m that isolating world of pain.

blem for Lani was she felt like she could never exercise enough or

enough to please her husband. She used the metaphor of a child

on a report card.

Lani: ...I think that I'm not being encouraged because I'm already changing but maybe not the way he wants. Like a student. Okay. Just like a kid who got a B. The kid tried really really hard to get a B. But the parents say, "Oh, no, you got a B, you are supposed to get an A." And the kid says, "Oh, I tried my best, very best," and he's still getting a B. But the parents don't see that. "No, you didn't try your best." ...If you try your best you should get an A." This is the message that I am getting. It's the same. He keeps telling me that I am not working hard enough. I am not working hard. And I know that. Okay. I still have a lot of room to grow. I still need to improve. I know I can get an A but I don't know how!

Matt: No, but you do. My problem is, I guess, a lot of times, is there a desire to get an A? Is there a desire to get an A...Because that's the coming from within, that's the fundamental change. In my life I feel just so different. It's just, if you see the person who has a desire to do something from being a person being forced to do something. It's two different people approaching things...An A is given to her if she has the drive.

If she would say..."I have set myself a schedule. I'm going to walk no matter if you're walking with me or you are not." She brought me to yoga but it doesn't matter now whether she goes with me on Monday morning at 7:00 o'clock. She never wakes up. She goes at 8:00 o'clock. I go (at 7 am) because I have my own desire to go. I enjoy doing that. Not because someone else is there with me, because you may enjoy the company. Then you're not enjoying the exercise. What attracts you to do the exercise is not the exercise,

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not getting healthy. It's a by-product because you enjoy the company. (011/012: 2194-2286)

Matt viewed social connectedness as a weakness, or as a vice to be avoided. He defined social commerce and exercise as competing claims. Lani viewed companionship and social support as not only enriching the experience, but valuable to her health. The above quote illustrated Matt's extreme self reliance and cognitive control. He had very little acceptance of vulnerability or illness.

Matt's acute illness beliefs and the meanings he assigned to her symptoms of endometriosis suggested that the right foods and enough exercise would eliminate her symptoms of disease. Lani viewed endometriosis as a chronic disease. She lived with worry and fear that the pain from endometriosis was something she was going to have to live with for a long time. Lani agreed that eating healthy and exercise were a part of a healthy lifestyle, but she also valued the emotional support of others. She was disappointed in not having the emotional support around her that she needed, and she was becoming aware of the toll this disease was taking on her.

In regards to a healthy lifestyle, they both wanted Lani to be healthy and pain-free. They both believed diet and exercise had a beneficial effect on her symptom experience. They each experienced a sense of rigidity that created an inability to understand the other's lifeworld. Matt was independent, wanting her to have the necessary inner drive which would possibly cure her endometriosis. She did have an inner drive, but it was for emotional support and companionship.

his couple's first interview took place just a few days after their first intra-
nsemination (IUI) procedure for infertility. Coincidentally, the second
, approximately one month later, took place the day after she had
ramps from her period, signifying an unsuccessful procedure. Despite
ommunication regarding other private and sensitive areas of their lives,
es during the interview, Lani and Matt did not address the recent
ntment. My interpretation was that the repetitive hope/disappointment
y have been so painful that they could not address it. Once again,
they were probably both experiencing pain and disappointment, the
reated a chasm between them.

iscontent with Sexual Relations

is section lays out Lani and Matt's sexual relationship which was very
ne foreground of both of their lives. They both experienced difficulty
tisfaction in this area of their relationship. The tensions and
ies of their sexual relationship will be articulated.

ni and Matt had an active sexual relationship, but Lani experienced pain
al intercourse, a common symptom of endometriosis. Although she
ne symptom to a health care provider, lubrication was prescribed
provement. A helpful strategy for her during intercourse was to close
nd pretend to enjoy it. She took up this behavior out of sense of
and a desire to please her husband. Together they had developed
to make sex more comfortable such as incorporating positions during
that give her more physical control.

Lani also experienced a lack of desire for sex which incited feelings of

She felt she was not "normal" because she didn't enjoy nor desire

ourse. Lani understood intercourse as something for his enjoyment, not

In the following quote she explained the pain involved with intercourse as

s her need to hide it:

> Lani: I always felt pain during intercourse and to a certain degree, it does affect our relationship. I feel all the guilt because I cannot provide what I should to him. And he always thought that I don't like him or I don't love him because I don't want to have sex with him. And I keep explaining to him that I don't feel comfortable. It always hurts...I spoke with one of my girlfriend, close girlfriends and I said I just have to fake that I enjoy it. It was really, really painful that I did not enjoy it but I have to because I don't want to damage our relationship. That's what's tough. (011: 0398-0416)

Although she tried to "fake" it, Matt was acutely aware of her discomfort

intercourse. He lived with self-doubt that perhaps his technique was

g her pain. When they did have sex, he was very tense because he did not

trigger more pain. He also felt guilty and was concerned about their

g libidos.

> Matt: It's not just sex. It's making love, right? I want her to want to have it, and participate as much as I want to. I don't feel like it's a one-person thing. When she's having pain, sometimes it makes me feel like I'm becoming this animal now. She's not enjoying it. She's just, sometimes it feels like she's doing it just for me and I feel guilty and I don't want that, because I don't want to be an animal. And so that affects me. And then her desire is less than mine so a lot of times we're out of sync in that and I have to hold myself back. So that's how it affects us. The worst thing is it feels like we're doing this because of me, we're not doing this because both of us want it.
>
> Int: So there's something about it that feels like it's for you, it's kind of like out of obligation.
>
> Matt: Yes. She's doing it for obligation.

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Int: To meet your needs or something.

Matt: Yeah. Uh-huh. And I don't want that. That turns me off a lot of times. (012: 1684-1715)

Matt dwelled in an emotional realm related to their sexual relationship. He uilty about his desires and wanted her to share in an enjoyable sexual rience as he wanted sexual intercourse to be an expression of their love ther. Because of their difficulties, Lani worried that Matt would get his sexual s met from another woman. Matt told a story of Lani being suspicious when ent out with friends.

Lani wondered that if she knew about such behavior, if she would disclose n, as she felt guilty for not providing, what she felt, was adequate sex in the onship. Lani believed it was her responsibility to provide her husband with nd even considered and legitimized the possibility of her husband having an to meet his needs. Her statements demonstrated little consideration of her ghts to a satisfying, non-painful sexual relationship. They struggled as a e with her guilt and his disappointment around sex.

Lani: I can see disappointment on your face. I feel guilty and I'm disappointing you. You are not feeling happy...

Matt: Yeah, but you don't need to feel THAT (with emphasis) guilty. Of course, you dangle a candy, let the kid lick halfway and pull it out, the kid will cry a little bit but

Lani: No, but the thing is I don't even know.

Matt: Just don't feel too guilty about it. ...I'm saying it's natural for me to feel, to show disappointment. It's only natural. It's okay for me to feel disappointed. Don't feel too guilty because I'm disappointed. It's only natural for me to be disappointed a little bit.

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'ell, maybe, when I was feeling guilty, when I was feeling
/ about the whole thing, I wish he would comfort me and
ney, it's okay. We can do it next time," and how we can
it. I mean he's just a normal human being, right, normal.
t disappointed. Then I feel so bad. And then we would just
ach other.

at's like another bar, okay, I haven't reach that level yet.

now, I know, I'm not blaming you.

ah, I know

just saying that you, if he can do that. I would feel better.
: 3655-3717)

sexual relationship, they both experienced tremendous

r not providing her husband with a satisfying sexual

felt guilty for having sexual needs; he began to feel

s. Help was sought from a health care provider for this

was as if there was no one to help them with their

al intercourse and mismatched libidos.

ed to remedy the situation, was to put his energy into

ani would go to bed early at night, he watched TV, read

games until really late hours. He waited until he got to a

would be able to get into bed and fall asleep right

essened his time in bed with Lani, decreasing the

Meaningful Life

n lays out what constituted a meaningful life for Lani

desired children, they each had separate ideas about

ed a meaningful life. This section will present the complexities of
nd familial relations, reproduction, and health were intricately and
twined.

d Matt were actively pursuing parenthood together. When they
d, Lani went off the birth control pill so they could have a family.
unsuccessful in their attempts to get pregnant thus far on their
ndergone infertility treatment during the past year. Matt told the
ent experience in the doctor's office:

Matt: That morning, I went to the office with her. I was by her side
hen they did the procedure. It's pretty simple. They just wash
our sperm, they wash your, you know, and they extract the sperms
ut of it and put it into the uterus. It's pretty simple. It took less
an an hour to perform. And so it's a simple procedure. I think it's
orth it to go through it couple times. It's not guaranteed that one
me it'll work and most people go through it a couple times... It's
teresting that supposedly we're so advanced with health, you
ow, medicines and technology, but there's still a lot of things that
ey can't explain, they don't even have control of, especially like
ildbirth and all these things. (012: 2149-2178)

ribed their recent attempt at conception in the doctor's office as
l event. He did not dwell in an emotional domain, as he did in
onship. Matt used the word "simple" multiple times denoting the
cated, somewhat mechanical nature of his experience. While
the lack of control over reproductive processes, he hadn't
a baby. He knew that after IUI there was another level of
fertilization (IVF). Matt also hoped that pregnancy and having
Lani.

'm still hoping, I think we're leaning a lot of hopes that once
ve a baby that will cure her. So that's one hope that we have.

One

family with

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T

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Having a child would help her. But the hard part is having that child... So, I'm prepping her for one possibility that we don't have kids for life. (012: 2009-2029)

e of the reasons Lani married Matt was because of her desire to have a
him. Lani wanted to be a mother and could not envision herself
One of the realities of endometriosis, however, was it had made
s for childbearing uncertain. Although she had not been able to
produce children, Lani considered adoption a viable option. She felt
be meaningless without children in her life. Matt, however, was not
onsider adoption. Rather, he tried to convince Lani that life could be
without children in their life.
fertility issue was complicated by not only pressure from Matt to
child, but from his extended family as well. Lani was growing tired of
responsibility of his family's happiness in her ability to produce a
following quote she talked about freeing herself from this burden:

Lani: ...my chance to get pregnant is not even fifty percent so it really bothers us. We're getting pressure from the in-laws... Pressure, great pressure and I actually have been thinking about if I cannot pregnant...I could not stand the pressure from his family. I told him about it. I told him that my bottom line...is if I'm getting pressure, if I can't be a happy person myself. I don't want to be fake all the time that I am happy with you. And I say I'll walk away by next year if I'm not getting pregnant. I mean, it hurts our relationship. It hurts myself, too, by saying that. It hurts him.

nt: What does he say?

ani: I think if I remember clearly he didn't say anything. That really urt me. I think it's last year he didn't say anything...deep inside y heart I knew that if we could not have a baby and if he's not oen for adoption, and we are getting the pressure from the family, hould leave. Not by what he told me. He didn't tell me, but by e pressure that we are getting, so he has a chance to (pause)

Int: Reproduce?

Lani: Reproduce. (011: 1195-1244)

ani did not want to live with a sense of failure of obligation to her husband ended family. In addition, she wondered who would be there to take care especially around her disappointment if she was not able to get pregnant.

> Lani: We were going through the infertility treatment. I was on the daily drugs and we're trying IUI, not even IVF yet. And I told him again, I told him hey, if I cannot have baby, I think I should walk, I should go away. I know that I cannot make your life happy. I know that your life will not be complete. It is not because I don't love you, it's because, several things. I cannot handle the guilt. Second, I cannot make you happy completely. I want to have a kid, too, but who is going to take care of me, and who will say, "Hey, it's okay." Nobody tells me this. Not even my husband. (011: 1315-1332)

tt agreed they were getting pressure from his parents, but he ged Lani to ignore their comments. Matt believed, and tried to convince a meaningful life was possible with or without children, although Matt iving up hope for a biological child. Even if they were not able to pregnancy, Matt was sure they could have a meaningful life without

e context of their couple's interview they shared a story about a that was nesting on top of their doorway of their home. Lani identified nerable nesting bird, and had requested that Matt use another door ered their home. In this story, Lani laid out metaphorically exactly s looking for in her relationship: she longed for protection and safety led with a painful chronic illness and infertility. In the story of the

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nesting bird, Lani was able to articulate in a visceral way, her unmet needs for nurturing in their relationship as a necessary condition of having a baby together.

Lani was told as a child in pain that when she got married and had children, her pain would go away. It is not known what influence this information may have had on her marital expectations and/or her health beliefs. Lani had many hopes in her life end in disappointment. One hope in particular was that when she got married and had an active sexual relationship, her pain would go away. Instead, at the time of the interviews, she experienced additional pain from sexual intercourse.

Lani had hoped for uneventful childbearing and a large extended family.

> Lani: I never thought that I would not have kids. I always pictured myself with a full house and enjoying family. I grew up in a big family... I always told people before I got married, "It will be so easy (laughing) to have a baby," and now I'm facing all these problems and it's really depressing. (011: 2030-2043)

In addition to disappointment about having a child, her dreams of a large, intimate extended family were unraveling. Her mother-in-law was initially someone she trusted and confided in about her illness. There had been a shift in relationship, as Lani came to understand the conflict between her personal need for empathy from her mother-in law, and her mother-in-law's need for a child.

> Lani: I still have high hopes that I would have baby...I don't want to have a baby because they want to have a grandchild. I don't want to have a kid because my husband wants me to have child. I told myself I want to have a child because we love each other so much that we want to create a child that belongs to us that we both can pass along, bring out good from each other, to the baby. And if that's not the case, I don't want to have kid to hold my marriage or to maintain my relationship. (011: 1374-1405)

lerstood a relational obligation to not only her husband, but in a
to her in-laws as well. While she could cover up other aspects of
ch as being in pain, she could not conceal her inability to
ear a child. Lani lived with what she was beginning to consider an
unt of familial pressure to have children from her husband and his

h Lani and Matt were experiencing infertility, she perceived the
own. More specifically, she viewed herself as the problem as she
e left the relationship, it would give him the opportunity to
e they were each going through a range of emotions regarding
ere divided on the issue of adoption, which separated them.
Lani's health ideology placed value on relationship and
e familial disappointments provided a lens of clarity for her as
e future. The isolation and lack of social support were wearing
t her illness and infertility were issues were alone for her to
ne acknowledged that they talked openly about it, she did not
erstood the complexity of her situation.

feel that I always deal with the problems myself. I have to
one that is more mature to guide him to, to be patient, to wait
to grow up, to understand me... We are physically going
it together. We are mentally trying very hard to go through
er. But deep inside my heart, I don't have the same feeling.
We talk. We openly talk. That's good. Some couples
lk. We are really open. We talk. I don't know how openly
t each other's feelings. That's another point. We say it
ut is that really registering to him what I have been going
nd dealing with? I don't think so. (011: 2056-2084)

The physical expression of talking openly about what divided them was
ough for Lani. Lani's ideological beliefs were based on connection and
nal support. As she looked realistically into her future, she had concerns
who would take care of her. Her picture of health and well-being included a
loving, supportive, and accepting environment, but she was unclear about
ailability of this environment in her life.

Matt believed their communication was better than ever and dealing with
dometriosis had given the two of them an opportunity to develop their
nication skills with one another. In addition, he admitted it had even
heir relationship grow stronger.

> Matt: I felt that going through this, it actually helped our relationship to grow stronger. I don't think I say that to her a lot but it actually does. We've found ways to communicate…it helps us to communicate with problems. (012: 0837-0846)

When Matt looked into the future it was filled with hope. He longingly
her symptoms would be alleviated from the right amount of exercise and
iet. He looked forward to having a baby together in which a secondary
uld be curing her endometriosis. Even without children, he optimistically
d a meaningful life together. While Matt looked forward with many
nd desires of the future, he did not dwell in a future of living with
d pain and suffering from endometriosis.

this couple was living together in their daily lives, they were moving
ne developmental stages of early couple-hood such as creating a home
y together. They yearned for the same things out of life such as a
estyle, a fulfilling sexual relationship, and a meaningful life. Yet, in

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y were two individuals living in separate lifeworlds. While taking
style, sharing sexual intimacy and creating a baby together were
could have potentially fostered an opportunity for intimacy and/or
married couple, Lani and Matt experienced a pattern of
g and rupture in their relationship.

dual lifeworlds of this couple have been presented in order to
which both Lani and Matt took up living in the world. While they
goals, needs and desires, the pattern of their relationship
ity to recognize the similarities of their shared worlds. The
own's individual's way of being in the world, fostered an
dity, which set up a way in which both Matt and Lani were living
lifeworlds.

Battling Endometriosis Together

ving section I will describe another couple's story. I argue this
ing with endometriosis with patterns that suggest they are
sis together. This metaphor will be the organizing framework
uple's interpretation and includes: a) their mutual enemy, b) an
fight; c) a winning strategy; and d) mutual healing.

lott were married and had been together for several years.
y home in a trendy urban neighborhood, with numerous
staurants within walking distance. When I arrived to conduct
s, Mary was working in the yard wearing work gloves hauling

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s that had been recently cut. During the couple's interview she set a
when to move the sprinklers that were watering blossoming flower
small section of lawn.

nd Scott considered themselves lucky. They had been through
n considered a particularly "scary" and potentially life-threatening
the last five years. They shared graphic accounts of their
d were both relieved that Mary was having significantly less pain
rectomy six months ago.

ife had been profoundly affected by endometriosis, even before
In her late teens, she was prescribed birth control pills which
ers" for her menstrual pain. In her early twenties, she had a
e of sharp pelvic pain at work. She recalled this acute pain as the
nen she realized there was something wrong with her body. At
she sought medical treatment, she did not get an explanation for
e received a muscle relaxant which relieved her discomfort at the
rs following that episode, she suffered from "GI stuff" with
arrhea, constipation, and flatulence. She was diagnosed with
nce.

Scott had only been married a few years when her symptoms
r they married, she stopped taking birth control pills with hopes of
After two years of trying to conceive without success, she
ttention. It was during a visit for infertility that the health care
ed endometriosis as a result of Mary's severe pain during a

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pelvic exam and a nodule that was found. A diagnostic laparoscopy shortly thereafter confirmed endometriosis.

Their Mutual Enemy

Scott described the first three years of their marriage as remarkable because Mary was "herself." This was in marked contrast to the last five in which he watched Mary suffer the debilitating effects of endometriosis. In the previous five years, Mary's general health had been progressively worsening. After her initial diagnostic laparoscopy, she had another surgery, in which the goal was to increase her chances of pregnancy, and to "take care of some of the symptomatology." It wasn't as effective as they had hoped because her symptoms only worsened.

One of Mary's primary complaints was an overall decreased energy level. She was "borderline" anemic from heavy blood loss during her menstrual cycle.

> Mary: I ended up in the ER once and could have gone a few other times from just bleeding through pads in 15 minutes. Blood through pads, underwear, jeans, onto the chair at work type of thing (laughing). It's like this is really gross. I mean especially during the periods it's totally disruptive during the periods. I took time off work. I usually couldn't work during my period. I went down to part-time after the first major surgery which was good because then really I was only working half of the days of the month. So chances were I'd be off during my really bad days and wouldn't have to call in sick. In my job, it's hard to call in sick because everyone else has to scramble and take up the slack. It doesn't just sit there and wait for you to come in the next day so
>
> Int: Someone has to do it.
>
> Mary: It's there. Yeah. It's got to be done. So that took off some stress. (031: 0431-0457)

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result, Mary made employment changes to accommodate her illness.
ss gave her more flexibility to be able to adjust to personal needs
menstrual cycle. Also, by decreasing her employment status, she had
ind that she was not burdening coworkers by her lack of dependability
sulting from her declining health status.

also experienced severe gastrointestinal symptoms which were
problematic. She likened her bowel-related pelvic pain to childbirth.

> Mary: The two most prevalent (types of pain) were the one during bowel movements which to me was I could feel the peristaltic waves and it was kind of like when you have a burn and you rub it and afterwards and the nerves kind of wake up. That's the kind of pain to me. It was very raw. Very, very raw.
>
> The other was the cramping, the bowel cramping which did not usually lead to a bowel movement but was just, I mean, it was like having food poisoning, that kind, when you have that. You know it's coming, but with me it didn't really come.
>
> Int: You're waiting.
>
> Mary: You're waiting and you rush in the bathroom and you go uh, okay, maybe not this day, type of thing. And that would go on pretty much with the peristalsis and it would be every, it would depend. It was like okay, I've done my childbirth, it's just that my childbirth was bowel movements. I've had the huge waves every few minutes, every two minutes, here comes another wave.
>
> Int: Right, like labor.
>
> Mary: Yeah, it was just like going through labor every month. Nothing really to show for it. Pretty depressing. It's bad. It's like I have no sympathy for my friends who have given birth. It's like that ain't nothing. I'm sorry. (031: 1889-1930)

lated symptoms also impacted their sex life.

> Mary: It affected sex. I mean, I never was too keen on sex during my period, but it became impossible. It became impossible several

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days before and several days afterwards because the pain would build and then it would linger. So it kind of elongated that time.

Int: So there was more and more time that you really couldn't have sex because of the pain?

Mary: Right, right. Yeah, or just didn't feel like it. I mean, it hurt down there. You don't even want to go in there, it just hurt. It's not comfortable so it's not going to be a good experience. (031: 0407-0423)

e endometriosis was slowly and insidiously beginning to impact

ful areas of her life. Mary was currently working as an accountant in a

ounting firm. Reducing her status from full-time was a difficult decision,

she felt was imperative as a result of her changing capabilities.

addition, her sexual relationship with her husband was impaired, at a

n she was trying to get pregnant. The illness seemed to be changing, in

way, her sense of identity. Whereas she had considered herself

y an active, healthy, and productive woman, she was beginning to see

s someone whose body was disrupted and whose capabilities were

the bodily changes.

Mary: My body always felt like I had to have a bowel movement. It was just cramping kind of almost constant....I'm thinking we pretty much already got to the point where yes, we're going to adopt, but I can't imagine then having a child and being on the toilet as much as I was. I thought that's not functioning. I mentioned that to my primary care and ...she said something like "Well, other people raise children with problems. No one's perfect."

But I'm like, so? How does that relate to me? I want to be healthy. Is that a bad thing to want? (031: 1172-1195)

ary and Scott had begun to consider adopting a child, she couldn't

renting in her current state. She wanted her old life back and simply

ted to be healthy again. She was not willing to accept her health care vider's argument which urged complacency in the face of symptoms. Mary ted action and resolve.

They mutually acknowledged that prior to her illness Mary had been the taker in the relationship.

> Scott: I think she is just one of these people who is just caring of other people. Not like me you know (laughing). I mean, I might care about other people, but I'm not, I'm not empathic or she's just always worried about other people and what, what they're going through. That's the other thing that sort of suffered...She's, she's like a caretaker. She's a caretaker for her friends. She's sort of like the core, the glue that keeps her friends together...she's always helping people. (032: 2132-2153)

Mary described, however, that as her pain increased and capabilities ased there was a shift in roles. Her declining health made her increasingly cupied with issues related to her illness and less available to friends and . In a marked contrast rather, she found herself relying on Scott for onal support, which she acknowledged to be a difficult transition. They sed their shifting roles in the joint interview.

> Mary: For the woman, it's like you're kind of wrapped up in all your things and the guy, just kind of, is the bystander for most...
>
> Scott: But it is your responsibility at least to do whatever little you can and just be there.
>
> Mary: Right.
>
> Scott: So I know you wanted me to be there just to be going to the doctor's office with you and just being there.
>
> Mary: Well, it did shift the responsibilities because I am a pretty independent person. Even though he couldn't do anything, I still wanted him there for moral support and that was more than I usually need him for that. (031/032: 0290-0313)

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Prior to this point, Mary considered herself to be an independent person. This new sense of needing Scott for "moral support" represented a shift in their relationship as she became more vulnerable, both emotionally and physically.

> Mary: I think that a lot of it is that I'm not good at being sick or needing help. I'm usually the helper so having to rely on someone else for emotional and physical help is new and different for me. I mean, I've been sick in the past, but Mommy was there, that's different (laughing). So it's different with an intimate relationship so I think that that changed. I think it really it was good in that it got us to a different level and a different communication level. A better one, having to go through that kind of thing. Especially the infertility aspects I think really opened up a lot of communication. (031: 0485-0500)

There is a sense that the increased vulnerability produced by the dometriosis opened up possibilities for trust and intimacy that had not been esent before. Mary struggled with changes in relationships in response to her wly identified sense of frailty as she distinguished between parental care ing, which was more comfortable and familiar to her, versus care giving from husband.

While Mary's life had obviously been affected by endometriosis, there was ense that at least initially, she employed tactics to protect her husband from disruptive effects of endometriosis. She didn't want him to worry so she itted "hiding it" at times, by not letting him know the extreme levels of pain was in. This tactic was not successful as he perceived her pain levels ugh nonverbal communication, including physical characteristics such as gait allor, and emotional changes in her overall mood.

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ner most significantly symptoms were bowel-related, Mary didn't
ily details of her symptom experience to Scott as she acknowledged
reserve some mystery" in their marriage. Rationale for
e, rather than being exclusionary, was driven more from a sense of
despite her own personal suffering, a desire to preserve their

was a sense of increased danger with Mary's worsening health
admitted a strategy that involved trying to overlook all that was
n her life. She described a personal internal process that helped her
e pain.

> Mary: Hiding it (the pain) from myself...You get to this point of you close off everything because that's how you manage pain is you retreat to a different part of your brain or you do something where you don't let yourself feel it...it's just all or none so when it gets past the barrier, it just explodes. I think that kind of thing. But yeah, I mean there were times when he (Scott) would ask or I would say something. Probably on the whole, I don't think I told him as much because I don't think I was letting myself know very much. It's just kind of like if you stay really still, then maybe it won't hurt so much type of thing. (031/032: 1879-1900)

ter went on to describe this process as a type of "denial." By not
er symptom experience served another purpose in which she could
st temporarily, the seriousness of her condition. She described a
; however, when she realized she had to come to terms with the
hat was happening.

> Mary: Took a lot of drugs, but I don't like drugs because they make me sleepy so it was when I started really realizing that I was in that much pain, was when I was taking the prescription medicine and I was taking the maximum amount I could take which was giving me over dosage symptoms and the pain was not changed. And that's

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kind of when I kind of had to face the truth that this was more than I could deal with. (031/032: 1900-1910)

She was able to recognize the amount of pain medication she was taking, as its decreased effectiveness. This was a turning point which made her she needed to "face the truth" of her situation. To face what lie ahead was ularly difficult, as she knew one possible treatment was hysterectomy, yet nd Scott wanted so desperately to have a biological child together.

While a goal of her latest surgery had been to decrease symptomatology, er goal was to increase chances of pregnancy. After six months of trying ut success, the couple started IVF. They had success after their first round F, but unfortunately, the pregnancy ended in miscarriage.

Despite Mary's protective efforts during this time, Scott's world was being pted by the illness. He tried to make sense of what was happening as he e comparisons between the woman he married eight years ago, to the an Mary had become with endometriosis.

Scott: She was just this take-charge, confident smart person and I'm not saying that as a bragging thing... You go back in her history, she was sharp as a tack. She was getting awards. She's one of these high-powered, potentially high-powered people... she's just one of these people that's a go-getter and then she couldn't do that. She lost all that stuff and

Int: And how was that for you to watch that?

Scott: You could see the depression. It was (deep sigh) just horrible. Part of you is in denial because you don't want to, and in some ways you can, you can sort of fool yourself because like some days she, she could, she could do it. She could keep functioning and all that stuff. So it's not like the person looks really horrible. It was changing her personality, changing what she could do because she was healthier earlier on in our relationship so I

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know what her capabilities are and I know what was gradually happening.

Then the panic that she, it's almost like she was losing control of her life and then you could see that's what you could really see. You could see her panicking saying, "What's going to happen to me?" All you could do is just sort of say well, "It's going to be okay. We're going, we're going to get the best doctor. We're going to get, we're going to keep going," and that kind of stuff. But not being in that position, if you try to put yourself in the position of someone who's really, really sick and, and it's not getting better, I try to put myself in that position. I don't think I could have functioned as well as she was functioning. I think I would just immediately go into a very deep depression. Personally, I mean, because I don't like being sick even for like a week (laughing). I start whining and moaning. (032: 0172-0240)

Mary also acknowledged this period as one in which her emotions

subdued. With humor, she joked that her bowels were responsible for her

ing personality.

Mary: ...since that (the bowel) was the main reason for not doing things and the reason for bitchiness on my part or irritability. Irritable bowel, irritable person, same thing (laughing). (031: 1873-1977)

Mary acknowledged the chronicity of the illness was wearing her down.

she found most troubling about her situation of a sense of a loss of control.

Mary: Well, just the whole thing of not being able to make plans, not being able to do things, not being able to pull your weight at work so to speak. Just kind of feeling like IT'S (with emphasis) controlling your life, not you. (031: 0510-0515)

Scott also experienced a sense of loss and fear as he watched

etriosis slowly transform the energetic woman he married into a

tely different person. While he also admitted it would have been easier to

k the situation acknowledging she oftentimes didn't "look" any different,

dn't ignore the fact that her previous capabilities were no longer present.

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r diseases may disfigure or ravage physical bodies in ways that are
parent to loved ones, it was her "personality" and capabilities that
oly changed for her partner.
osed to positionalities that might have created distance in their
such as being angry, or overwhelmed into a state of helplessness,
Mary with a compassionate stance of empathic relatedness. He
perpetual process of working to gain an understanding of her
By understanding her plight, he gained considerable respect and
r her strength and conviction to keep going despite her pain and
apabilities.

> Scott: Well, she was just a soldier. She kept working, but her friends (from work) would come to me, because I would just talk with them on the phone sometimes. They would say, "Well, we're worried about her. She doesn't have the energy that she had to work eight hours."
>
> Int: So it sounds like her productivity was decreased.
>
> Scott: Yes, and once she got home from work, we could do nothing. She would just crawl into a fetal position and just, she would just have to recover. And then she would go back to work. I mean (laughing) she would recover and go back to work and, and, and some days would be a little better, some days would be worse and depending on all that biological cycle stuff. That would, that would go on. (032: 0123-0160)

scription of her as a soldier suggests that he perceived her to be a
ook on the symptoms with a sense of strength and bravery. He
fight to keep going at work, but understood she suffered the
s at home and made allowances for that. Scott was not alone in
physical decline as Mary's coworkers also shared concern. Scott

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ıd comfort and support in others recognizing her decline, and at the

ıay have increased his worry because it validated his concerns.

ı Mary's strength and conviction to keep going, Scott worried that

ıd chronicity of her situation might eventually overcome her.

Scott: I was worried that she was really going to just give up and stop living sort of. If not, maybe not suicide although that did cross my mind. I mean, the fact that she was just so, so down and so depressed over it and trying to imagine myself being in ill health and not being myself. When I get sick or something, I get really, really depressed and then I tried to say well, what if I had this, I was sick with some flu or something and I just had to live with it forever. What if you had the flu forever so and so that's the way I sort of, well, I would probably feel really hopeless at some point. It would just break me down eventually after a month or two. She'd already been living with this for years.

Int: So did you see signs, though, that she was giving up hope? Did you see evidence of that in her?

Scott: I felt it, yeah.

Int: How?

Scott: Oh, gosh, I guess just the gradual change, sort of just she was just I could just tell from the first time that we were, from the time we were married and the time we were going together before, her energy levels and her outlook and her confidence and optimism seemed gone at times.

Int: Had she ever verbalized the thought of just ending it or wishing she was dead? Or anything like that?

Scott: I think, yeah, sort of. Like sometimes, "I don't know if I'm going to be able to go on," or something like that. I think she said that a couple times. And that sort of triggered it in me saying uh-oh. That's scary. Yeah, when somebody starts saying things like that it does go through your mind that they're really not having a good time of it. Then you start worrying about things like that because then your mind starts trying to imagine how you would feel if you were in that situation. (031/032: 0537-0596; This section of interview was done privately with Scott.)

The endometriosis was a powerful force that, in addition to the physical
cts of her illness, was also eating away at her optimism and positive outlook
fe. Though she was fighting it with treatments and life adjustments, the
ometriosis had taken on considerable power, as there was a compelling tone
ar, desperation, and even panic about her worsening condition and what it
nt for their future.

For Mary, a series of consecutive health related events began to erode
ense of confidence she may have had in her body's normal functioning.
strong sense of diminished trust in her body caused an increased worry
her future health status as evidenced in narratives in her interview. In
on, she expressed a desire in simply wanting to resume normal bodily
ons such as having regular and pain-free bowel movements. As a result of
dometriosis on her diaphragm, even her breathing, a bodily function so
atic that it usually goes unnoticed, was affected. The endometriosis had
lous power as it was not only impacting physical functioning, but its
ad begun to seep into vital aspects of her life.

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ry and Scott perceived endometriosis as having increased control over
They perceived that the disease was literally invading her body. Their
rstanding was initially shaped during Mary's diagnosis of
is when her surgeon "got in" and realized the endometriosis had
npantly, there was nothing he could do.

Mary: He (the surgeon) got in and he basically took lots of pictures and backed out and said you need to go to someone else because it was just, it was too

Int: He thought you needed a specialist?

Mary: Yeah, he thought it was going to be that little nodule and maybe a couple other

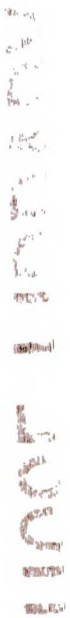
Int: That he could maybe take it out?

Mary: Yeah, clean it up. And I'd be on my merry way. But he got in there and went "uuuuuhgg." (031: 0222-0237)

In addition to her physical symptoms, the sense of endometriosis taking
er her body may have created a sense of hopelessness because even the
rgeon couldn't handle it.

Mary was losing an inherent trust in her body's capabilities as she began
iew herself as an anomaly. She gave numerous examples in her interview
t highlighted a theme of her body as malfunctioning, or aberrant. An example
ides a lengthy narrative she shared about a barium enema procedure to
ss constriction of the colon that might have been a source of her pain. The
s of the procedure suggested, upon initial evaluation, cancer.

Mary: They put the air in it and they expand your colon...then the guy called. It turned out that he called one of my doctors. He goes, I'm really worried about her, it looks like she has thousands of polyps. And the doctor goes she just had a clean colonoscopy like two weeks ago. Well, now my x-rays are now at T. University in the learning file for false positives. It was that I was not cleaned out enough so it was pieces of fecal matter stuck to the inside of my intestine that looked like polyps. So that's what he was all freaked out about....So I was like okay, yeah, leave it to my body to be totally whacked out and confuse everyone...I could not, I could not, it got to the point where I could not remember my last normal bowel movement, it was not in my memory. (031: 1085-1128)



Her X-rays were so atypical that they have been kept for teaching purposes at a large teaching institution. Another example was a narrative during the time of her infertility treatments when her body did not respond appropriately to the infertility hormones. She described her ovaries "not waking up" to the normal dose of hormones as expected. A more general example that was woven throughout her interviews was her disappointment and sense of failure in not being able to get pregnant. When she did finally achieve pregnancy with the assistance of IVF, the pregnancy ended in miscarriage as a result of a genetic disorder. Even when she was able to finally get pregnant, there was something severely wrong.

This belief of her body as anomaly was possibly heightened by her belief here was something growing out of control inside her body.

> Mary: The inside of my pelvic cavity, there was not a surface that did not have endo on it whether that be female organs, bowel diaphragm, other organs, ureters, I mean, just coated, just thick, huge, thick adhesions and stuff. (031/032: 0877-0833)

In addition to her pelvic cavity not being normal, it was beyond repair by the al surgeon. Her belief may have been further perpetuated during a sequent surgery.

> Mary: They couldn't find my appendix. They had to call in another surgeon to scrub in to find my appendix to make sure that was it before they removed it because they weren't sure. It was not an appendix anymore. It was endo. It was thoroughly and completely destroyed and the path report came out endo.
>
> Int: Oh, my God.
>
> Mary: It had taken over, so that's the invasiveness that it had done to me. (031/032: 0939-0953)

Despite having an experienced surgeon for this surgery, there was still a d to call in another expert to identify her appendix. She was also beginning ear that if endometriosis could do that to her appendix, it most likely had the er to destroy other parts of her body. After this second surgery, when her ptoms worsened, she began to worry about whether the endometriosis could ethal.

> Mary: They don't know how much damage is doing, not just to your reproductive organs because to me that's kind of secondary. But to other organs that can, I mean, it can potentially kill you. (031/032: 0331-0336)

Endometriosis threatened her fertility, but in Mary's perception, it also tened her life. The information gleaned from the surgeries created a shift in ties in which her desire to have a baby became secondary to saving her life. As Scott obtained information and data from her surgical photographs, the et, and from other women with endometriosis, he shared a similar standing and concern about what was happening in her body.

> Scott: It (endometriosis) is like a growth and it's just spreading and yeah, you've visualized, you've seen the pictures so you visualize all these chocolate things and these sticky lesions and gluing stuff together and it's just, it's …
>
> Int: So to actually see it was pretty powerful it sounds like.
>
> Scott: Well, part of it is well, you don't really know what you're looking at …then over time you learn more and you visit websites and you see other pictures and, and you go to the meetings and stuff and you see all these, you start picking up the terminology and, and then in your mind you go wow, no wonder you need such a great surgeon to deal with this disease because it's all just stuck. It's all intermixing itself with healthy tissue and it's ruining things and it's just growing. It's growing through bowel walls and it's just spreading and it's on your, it's spreading throughout your whole torso and it's on your diaphragm and it's just …(032: 1402-1454)

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Scott was thoroughly engaged with his wife and her condition. As they to understand the seriousness of the condition, and its ubiquitous nature, ook up wholeheartedly and passionately the attack against endometriosis.

ed Fight

Mary and Scott fought their "endo crisis" together. As Mary's health was in , Scott found meaningful ways to remain connected to her and to support ough what they both perceived to be a complex and dangerous time. engagement in the relationship is the primary focus of this section. Although Mary was going through a very difficult time in relation to her there was a striking sense that Scott shared a similar lifeworld of pain and g.

> *Scott:* Well, the experiences have been negative in the most sort of obvious ways (laughing). I'm trying to think, on the positive side, there's not much positive really. You want to say something like oh, well, whatever doesn't kill you makes you stronger or something, some platitude like that, but it just doesn't ring true (laughing). It's really really just a suck ass, awful, rotten thing, you know, to, to, to watch someone who you love go through. And I, I, I don't know how to sugar-coat it at all. And the other thing is it's just, it's so insidious, too, because you know, at some points things are better, right? And then they're worse, but there's this gradual decline and, and just sort of, just loss of joy, loss of just that person's energy level and that loss, the loss of the, their self. And you're sitting there, and yeah, with time, you're just sitting there sort of looking at it and watching it. And it's like it's so shocking because nobody seems to be able to do anything about it. And with Mary, Mary's just this dynamic person's who's very take charge and just she's not a passive person waiting for something to hit her like some people are. I mean she's just constantly fighting this battle on all fronts, nutritionally, you name it. Everything, emotionally, all those, all these things, and gradually it's, it's just beating her down. (032: 0012-0062)

as sharing Mary's world as he experienced the ups and downs of
felt helpless as he witnessed a woman, previously so full of life,
ned and transformed by the illness and by ineffective treatments.
ied by the fact that her strength, a trait that he had so much
eing drained by this disease.

knowledged that while it may have been easier to trivialize his
ose rather to be frank and honest, as painful as it may have been,
metriosis and its impact on their lives. This suggests that even in
is engaged in a fully emotional way. While he presented Mary as
e on all fronts, his interview makes clear that he was fighting too.
nted to understand Mary's illness experience. To have a sense of
oing through was a concern and priority for him. For example,
aking large amounts of pain medications, the effects, according to
out her personality." Rather than having a negative or selfish
e of its effects, which most likely affected their ability to engage
the experience rather helped him understand how much she
needed the medication. As Scott observed Mary's increased
pain medication, he was alerted to the severity of her pain and
on.

continually empathic towards Mary and to the needs the illness
there was a qualitative distinction in Scott's engagement that
ng empathic. Scott moved relationally closer to Mary, to join her
as created by the illness.

ook on a new role of caretaker in the time of Mary's continued

ther, with humor and a sense of mutual affection, they jointly

w Scott would routinely wait patiently for hours outside the bathroom

/ to emerge.

Scott: She would disappear into the bathroom for hours and you wouldn't see her and you'd be looking around for her (laughing).

Mary: He would knock on the door, "You okay in there?" Yeah, go away (laughing).

Scott: Go away, exactly (laughing)...

Scott: The bowel thing when it gets involved is just horrendous. It just sucks your time away and you can't move. You just can't move and so you're just tethered to her so you're just kind of

Mary: Because I couldn't go anywhere. (pause) And I couldn't make plans to go on trips. I couldn't

Int: Because of the pain or because of needing to be near the bathroom?

Mary: Both. Both. The pain I could medicate to a certain extent, a good portion of it, but yeah. (031/032: 2079-2107)

ok up caretaking in a way that was emotionally supportive, but did

irect and hands-on care. After Mary's surgeries, for example, her

d with the couple and provided such assistance to Mary. Other

artners were more directly involved in hands-on care such as

ary catheters or helping their partners with daily tasks such as

ed when in pain.

actions fit onto a continuum of care giving actions that were

other partners ranging from time-limited and/or symptom specific

mbedded in everyday practices. Scott was directly engaged in

ng emotionally supportive care for Mary. Her immobility and

atically affected Scott. His concern was exhibited by this

king on her periodically from outside the bathroom door to make

ight.

ott: For all I know, she could've been in a fetal position on the
or, but there was that and just she was so pale. I mean, when,
en it was really bad, she was just like white as a sheet. (032:
41-2049)

dous pain, copious amounts of menstrual bleeding, and pallor,

was making sure she was conscious and medically stable. Even

e separated by a closed door, Scott's attentiveness created

gave Mary the privacy she wanted around her bowel symptoms,

lly remaining connected to her. For Mary, the bathroom was the

ir home where she could retreat when in pain.

: I'm interested in how when you weren't feeling well and had
in how would you tell your husband? (Pause) Or would you tell
m?

ary: I think it was pretty obvious. I tend to wear my emotions on
sleeve most of the time. I think I hid a lot as much as I could,
t I don't think I was very successful.

: Did you try to keep it inside?

ary: Sometimes I'm sure I did. But I mean, he would know. He'd
eck on me if I were in the bathroom for a long time. I'm okay, I'm
ve, I'm just going to be here a while.

Banging on the door.

ry: You okay? (Laughing) I'm fine, give me another two hours,
be just chipper. He would check on me.

So what are some ways you think that he knew (about the
n)?

Mary: Well, that. I mean, I disappeared in the bathroom for hours at a time. (031: 2072-2101)

her efforts to "hide" her symptom experience from Scott, the very

ng into the bathroom was an indicator of her distress. Scott's

ss, attentiveness and concern were appreciated by Mary. His role

lemonstrated efforts to join Mary and stay connected to her,

action limited his abilities as he was "tethered" to the bathroom door.

er example illustrating a relational movement to join Mary was

complicated effects the illness had on their sexual relationship.

Scott: During the points where she was having trouble, I mean, there would be long periods where we just wouldn't do it.

Int: No sex?

Scott: No sex, yes. Our frequency went down. Early in our relationship we were probably doing it three times a week I would say or something like that, two times a week. Which you know, that's not a lot, but that's pretty frequent. We would do it when she felt well. But then we would have to go for like a month or so between times when she felt well, so and then that's a long time. And then gradually you get used to that and then even as she gets worse and worse, the frequency goes down further. Then you, I, I don't know, I sort of started losing it, too. I mean, after you don't do it for a long, long time (laughing) you sort of shut yourself down. (Pause) And again, that sort of affects you, too, because then it's not just sort of an easy thing anymore. When you actually do do it, then you're actually thinking about it and you're doing all that stuff, so it affects it in that way. (032: 1246-1283)

ticulated that as a result of going for long periods without sexual

prior sexual drive and activity decreased resulting in a pattern that

ic with Mary's sexual needs and abilities at the time. It is not

gine other possibilities that a husband might employ in a similar

situation

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ster even a greater sense of physical and emotional

uple relationship. On the contrary, Scott's pattern of

" sexually, mirrored her sexual libido, may have been a

with, and possibly more connected to Mary.

ncrete practices in the fight against endometriosis, which

ntrol," was important to Scott. He worked to ensure that

sicians available. Scott described going to informational

ups, and searching on the internet to gather information

ans and about forms of treatment for her pain.

of finances was raised in relation to accessing the "best"

gly that money was not an issue.

ne was worried about the money and I was, I was "Phhh, I
e about the money (laughing). We have the money and
ur health and whatever you want."

use I would imagine for some couples that might put a
their relationship.

nagine if I was a, a, I guess a stingy kind of (laughing)
bout money. I mean, but it seemed like she was more
bout the money than I was. She was constantly asking
the money, and I, I don't really care about the money.

s worth it to you.

s. It didn't matter to me one way or the other and I
ink of a better way to spend money than that. (032: 0667-

of such concern to Scott that he was willing to pay even

re out of pocket. Scott recalled that a single round of IVF

fifteen to twenty thousand dollars. The total cost of her

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ıust have been extraordinary. It is likely his generosity fostered an

nment of acceptance of Mary's illness and implied a willingness to fight

ıetriosis at literally any cost. In addition, Scott suggested that finding and

for the best care was an element of dealing with the illness that he could

l, and as a result, made him feel better.

Another practice Scott took part in was accompanying Mary to her doctor's

tments.

> Scott: It's scary being in hospitals and having people poke at you and all this other stuff. Just being there in the room and they let you go into the room which is nice and you just sit there and you can hold her hand and it's, it's some, some small measure of control. (032: 2969-2975)

cott described being shocked that many women were sitting in waiting

alone. He believed accompanying Mary to her appointments was so

al, it was the piece of advice he gave to all partners.

> Scott: When you think that you have a valuable relationship and you're going to try to do everything you can to, to help that and so the converse of that would be is, I guess, if you didn't have a strong relationship, it would tend to fall apart very quickly under this kind of stress. I would think....
>
> Int: I would think so. I would think that it might be easy to walk away.
>
> Scott: Walk away, yeah. But I guess you learn and you grow, too. I mean, you learn a lot about medical things and (laughing) reproduction so it's, it's a learning experience, too.
>
> Int: You get dragged into all that.
>
> Scott: Yes, (laughing) dragged in, dragged in kicking and screaming, yes. Going to the doctor's offices, sitting there. That's really important, though. I mean, just, just being there for her seemed like that was one of the best things I could do for her. Just to go with her to the appointments. Yeah. That would be my

> advice to anyone who's going through this is suck it up and just show up. Just sit there in the waiting rooms and be there. (032: 2913-2952)

Scott realized he had grown as a result of Mary's illness. For example, he described how his experiences of being a proactive consumer in the health care system with endometriosis had influenced the way he took up matters when a family member was ill with a chronic illness.

Scott valued his relationship with Mary and despite their difficulties and adverse circumstances, he still believed they "fit well together" as a couple. He appreciated their bond and experienced reminders of how special it was.

> Scott: Even being in hospital rooms and listening to other husbands and wives through the curtain. I go wow. We're a lot better off than them (laughing) because they're sitting there fighting, they're fighting each other. (032: 2791-2797)

While Mary and Scott fought against endometriosis together, the couple did not fight against each other. Even during what may have been considered a particularly difficult time for this couple, they did not describe conflict around everyday responsibilities. Rather, there was a sense that all of their energy was energistically and efficiently targeted toward fighting the endometriosis. They agreed that when Mary was too weak to do her usual share of responsibilities around the house, Scott picked up the slack and did her share without any complaints or resentments. As Scott consistently spoke of his response in control terms, cooking dinner and vacuuming may have been a concrete way that he was able to exert some control over a very overwhelming and frightening situation.

dmitted his professional training as an architect influenced his

nt style and thinking processes as he described an inclination to

ix and solve things.

> Scott: I guess what I learned personally is that you really do need to get in there and fight on the things that you can have an effect on, right? If you're the spouse and you're trying to support somebody through something like this, I think you need to do that, right?
>
> Int: Can you describe ways that you did that?
>
> Scott: Well, when she would get really angry or sad or, or mad you know, my first instinct as a man and as an architect who trouble-shoots a lot with clients and contractors, is to solve a problem. But you can't really do that and so what you have to do is back off, I think, and just sort of let that come out and let her just use you as a sounding board or listen. And then sometimes logic is not (laughing), just because there is a logical position, when you're dealing with someone in extreme pain and just at, at, at wit's end. Logic isn't going to help much. So but on the other hand, since you're the one who's thinking more clearly, you have to play that role, too. So at times you have to put your foot down and several times I did put my foot down and say well, we're going to have to do this and we're going to have to do that and that hurts, too. (032: 0386-0430)

h more comfortable with being an active partner in the relationship,

l that at times, a more passive role on his part, was best for Mary.

dged the importance of simply listening and giving her room to

xtreme range of emotions. He also acknowledged that although his

ould be to "solve" the problem, the nature of endometriosis

s straight forward approach. At times he needed to be supportive,

l. Over time he came to appreciate the moments when he needed

here" for Mary and those when he needed to take charge and map

n, which she could not construct, given her level of pain. His

attunement to and respect for Mary is evident in his acknowledgement that even the taking charge "hurts too" because it marked Mary's level of disability.

The incident in which he put his "foot down" was a pivotal decision that Mary and Scott made together: for Mary to have a hysterectomy. The decision was a painful one for Scott as well, as he knew it meant it would be the end of his hope of having a biological child with Mary. Despite his loss, he kept Mary's best interest in mind as they mutually agreed they couldn't fight any more, and needed a strategy to win this battle once and for all.

A Winning Strategy

Things were starting to feel out of control for both Mary and Scott. There was an uncertainty about the future that was infused with panic and fear. There was also a sense of confusion and ambiguity during this time. The couple was actively undergoing IVF which included complicated and precisely timed medical treatment and interventions.

Because of increasing pain during this time, she also sought care from her primary care provider who treated the endometriosis "medically" and prescribed continuous birth control pills for a period of three months. Mary started the prescribed treatment but because of continuous spotting and no pain relief, she stopped taking the birth control pills. She sought a second opinion from a gynecologist who looked at all of her medical records and suggested surgery. The gynecologist referred her to the surgeon who had done her previous surgery.

This situation is complex as it does not seem her care was carefully managed. While Mary and Scott worked diligently to be assured they had the

health care providers, Mary lacked a single provider to oversee her entire picture. Her care was fragmented, with each provider having different and little communication between them. At this point, Mary and Scott, felt ate, and went to see the surgeon.

> Scott: At some point you get to the point where this is cut and run time. Cut your damages before they overwhelm you, get out, get out before it's too late (laughing) kind of a thing...I sort of understand why you wanted it out of there at that point. You even said to me
>
> Mary: Get it out.
>
> Scott: Get it out of me (laughing), it's killing me kind of a thing so
>
> Mary: It's like it wants to come out, it feels like it's trying to get out so just take it out so I think it just gets to that point. (031/032: 1012-1031)

lary and Scott knew hysterectomy was a possible solution. The visit with eon was a pivotal experience for the couple and Scott described being ased and satisfied that he was in the room with Mary to be able to share cision making process.

> Scott: I can, I can remember being in the doctor's office and going through examinations and I could see that she was worried about what I was thinking. And when we were deciding to do the hysterectomy, then it's my position to just say well there, there's always doubt and there's always this, but you say well, we have to do this. Somebody has to take charge and say we, we must get the hysterectomy. Don't worry about the in vitro anymore, don't. Look at this now from a cold thing of, of we have to do this, we have to go forward with this. We can't, we can't waste anymore time. So there are points like that where you're sitting there and you, you have to come to terms with it yourself and then
>
> Int: But how was that for you considering you wanted to have a baby?
>
> Scott: It's a hard thing to give up. (032: 0434-0463)

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While fertility was an issue for Mary initially related to her decision to have sterectomy, she reached a point or threshold, where fertility became ndary to her wellbeing and survival. She described this pivotal decision that nade at the doctor's office with Scott by her side.

> Mary: We went to him (the surgeon) and he was giving me an exam. And it was painful and he was talking, telling his nurse what his plans were for the surgery and stuff. I said, "Dr. H., fertility's no longer an issue." He goes, "Oh, okay." I said, "Yeah, I don't want to see you again. Nothing personal, but I don't want to be here again." So he goes, "Okay." That's when he started talking about taking as much as he could. I said if you can leave me any ovarian tissue that would be great because I'd love to have my own hormones, but if they're so messed up that it's not worth it, take them. So he took them. I just said get rid of it, whatever's bad that in there, just get rid of it. (031: 1230-1250)

The decision about a hysterectomy as treatment was solely dependent on choices around her fertility. Mary's official announcement of fertility "no being an issue" opened up new possibilities for treatment that could not een previously considered and a new strategy was implemented.

Although having children was not always a priority for Scott, he described into the idea. As they went through IVF, and shared a short pregnancy, carriage which ended the pregnancy, devastated him. In that experience, zed how much he wanted to be a father.

> Scott: When I got married I was never that driven. Like I have friends of mine who are really driven by that. They really wanted a family and they really wanted kids and that stuff. I was never that way so in the beginning, it was less with me, less important. But when we actually started going through all this in vitro stuff and she really wanted the child, well, that's good. I went along with it, sort of, right? And then as we got more and more into it, I started getting more and more excited about it and so I started getting more and more onboard with it (laughing) so I sort of got sucked

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into this whole thing. That was why when it got to the point where we could see that it wasn't working I had to do sort of a 90 degree or a turnaround and say okay, well, okay, calm down about this. Remember, to begin with you weren't that, it wasn't that important to you.

Mary: Go back in time. Go back in time. (laughing)

Scott: (laughing) Yeah, it wasn't that important to me to begin with so why am I all hyped up about it now. So you sort of have to let go of that then. So I sort of started out not a big deal, then I started getting into it and it became a bigger deal and a bigger deal and then she got really, really sick and in trouble and it was really a liability and it wasn't really that important finally. I got back to my original mindset. Right, and plus we knew we could adopt. (031/032: 1052-1092)

use of her progressively worsening condition and increasing pain, they

to view Mary's uterus as a "liability". Although Scott had grown into

wanting a child, when evaluating the entire situation, he realized

lth and well-being were ultimately more important to him.

Scott: It's a hard thing to give up....but at some point, she's a lot more valuable to you than a, than a, than having the baby. (032: 0467-0479)

ling

nonths after having a complete hysterectomy, Mary was still healing

n invasive surgery.

Mary: I just said get rid of it, whatever is bad in there. Just get rid of it. And so it was very long, very intensive surgery (crying). Ovaries, tubes, uterus, cervix, vaginal wall, part of the vaginal wall and the colon. (031: 1248-1254)

tion to healing physically, both Mary and Scott were adjusting to life

gery. Overall, they both perceived the effects of surgery as positive

pain was gone. While she still had a few minor symptoms, and was

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o regulate hormonal shifts in her body, and contemplating hormone

ent, they both agreed, her old self had returned.

though, the pain was gone, they both understood there was a possibility

and the endometriosis may return.

> Mary: Well, I hope it doesn't come back. I know it can. One of my doctors wants to put me on estrogen. I'm very hesitant. One, I think I need to give my body more time to figure out where it's at. And two, I just I'm hesitant because he really would have to watch the endo because it could come back. And that scares the living daylights out of me. So I hope it's a cure, I kind of feel like I'm in remission and I hope it lasts. (031: 2220-2230)

lthough they both believed the surgeon who reported successfully

g all of the endometriosis, the worry of endometriosis continued to enter

mind.

> Scott: We hope (that endometriosis is gone permanently). That's the other thing that it's always in the back of your mind.
>
> Int: Right, because it can
>
> Scott: It can come back, yes. She's been a lot better. She's just leaps and bounds getting better and better and it's like wow, it's working. Dr. J. did a great thing. He got all of it. You hope it might be really, it might be gone for good. (032: 1342-1374)

th Scott and Mary lived with optimism that they had won the fight against

triosis.

ile the battle against endometriosis may have been won, as a couple

ggled with consequences of the surgery for which they were not

l. Mary's vagina had been reconstructed resulting in difficulties in sexual

ng. While both partners stated separately in their individual interviews

was not the foundation of their relationship, it was an aspect of their

relationsl

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health c

ıey both valued. Complicating their situation around their sexual

'as a sense that they were on their own with little support from

roviders.

Mary: It is a long healing process. The doctor told me that for a year or more you'll be feeling different, be healing. So that's part of it and I really find that it's very shameful the way it's not addressed by physicians whether it be during the whole endo thing or whether it be now with the hysterectomy. They just don't address the aftermath or the side issues and even just like trying to find books, it's difficult. A lot of the books on hysterectomies, searching Amazon.com or whatever, a lot of them are very "don't have the hysterectomy." And I go okay, too late for that. Then they're done. It's a little bit disappointing that you can't find how-to books that are geared towards people, towards young women, relatively young women with no hormones and with surgery, reconstructed vaginal canals and stuff. I mean, I know it's not a huge number of those out there, but I would think it's a substantial number. I mean, it's not huge, but it's substantial and it's significant....

So I'm feeling very bitter about that and very angry that it's, that women's health. Because it affects everyone. I mean, it affects society, but women's health whether it be sexual or just bone health or heart health or whatever is so much not really dealt with.

(Beeping sound reminding Mary to go move the sprinkler)

Int: Is it time for you to water again?

Mary: No, I've got a few minutes. That's all right. It (the sprinkler) can sit there for a minute. So I think not having help in those regards. I mean, I talk to some of my friends who have some similar issues, but I'm finding that I get a lot more help from Scott because most of my friends, the ones in relationships, are in relationships that are not, where the man is very demanding sexually and also the woman is not really getting much of a chance to figure it out and so I'm not really being able to learn much from them unfortunately. (031/032: 1747-1816)

ruggled with lack of support from the medical establishment in

xual issues post-hysterectomy. When she turned to friends who

ıe a similar experience, she was surprised to discover that because

elationships with very different patterns of relatedness, they were

esource.

t the help of health care providers or friends, Mary and Scott

ether, as they learned how to have sex again.

Mary: He was scared because he knew that they had removed part of my vaginal wall and had stitched me up. Okay? So he doesn't want to break anything. And I didn't want him to break anything so we're being very tentative and everything. As soon as he penetrated, he went flat, lost his erection. (laughing) and I mean, it's not the first time it's happened to him and it's not like a huge deal to us, but it was just kind of funny and he said something. He said it's like there's nothing there (whispering). And I thought is that psychological or physical or both? I didn't know. And that's really interesting, so I was talking to my female friends about it and one of them (laughing) said that after birth, the first time that people have sex after birth, if it's really relatively soon, a man has described it as throwing a hot dog down a hallway. (Laughing) Isn't that good? And I thought the visual there is just like whoa.

And that's kind of what he had been describing so I asked him about it. I said so we were like throwing a hot dog down the hallway (laughing) and he said okay…It was probably at least two and a half months after the surgery before we tried or maybe three, I don't know and I was so for all those months, I had been SO (with emphasis) focused on just relaxing everything that I think muscle tone was decreased and they had done some major stuff. (031: 1323-1368)

cott's perspective, he agreed that indeed things were changed

Scott: It's still a worry because the surgery was only six months ago, right? And things are, it definitely changes your whole sexual life. And, and and it's still changing it.

Int: The endo or the hysterectomy?

Scott: The endo and the hysterectomy. The hysterectomy, I mean, she's rearranged physically, right? So the parts don't work like they used to work anymore (laughing).

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Int: Can you say more about that because I'm not exactly sure what you mean.

Scott: Okay. Well she doesn't have the muscle control that she used to have so it's not as pleasurable.

Int: So it feels differently?

Scott: It's like you know, it's like pushing against air. So actually I think she's started trying to work those exercises, those Kegel exercises, to try to make it better for me.

Int: So were you guys able to talk about that? It sounds like you were.

Scott: Well, sort of, yeah. It's, it's hard to talk about things like that (laughing) but we raised it. I mean, because I wasn't functioning as I would just sort of we would go for a while and then I then would lose the erection and, and I would, that's part, part of just sort of me getting older, I guess, but also it's part, you do need something there. You need some friction to, to push against otherwise it just doesn't work mechanically.

Int: Yeah, exactly. From a mechanical perspective.

Scott: So you sort of have to admit that (laughing)

Int: Once again, you've got to face it.

Scott: Face it. It's hard, though....The hysterectomy really did, they had to cut part of her vagina out and all of that and it did change a lot of things. We have to use this lubricant now. We never had to do that before. It's not natural like it used to be. It's not. It's sort of more forced and we have to think about things and that's the enemy. At least to me it is. I mean, the less I have to think, the better and now I have to think a lot and worry a lot and, and, and so it's definitely changed. I don't know if it'll ever get back to what it was. But we're still going to hang in there and keep trying (laughing). (032: 0958-1052)

While this situation may seem daunting, this couple was mutually excited that they were simply having a sexual relationship again. It was evident they

were ve

their se

eager to start exploring more regularly, and in essence, reestablish

al relationship with one another.

Scott: I think we're trying to learn how to do, we're trying to learn how to adjust to that (the physical changes after the hysterectomy), I guess. But then we don't do it that often. I think, we're starting to get back, though. We're trying to get like back to once a week or so, at least (laughing).

Mary: So we'll work up to that. It's kind of

Scott: We enjoy our, we still enjoy it, though.

Mary: We enjoy it no matter what happens.

Scott: No matter what happens, we still like it so. That's a good sign to me anyway.

Mary: Yeah, I think the physical closeness is a lot more important than the actual completion of the act or anything.

Scott: Well, that's important, too, but (laughing).

Mary: Well, yeah, but yeah, I think it's important to keep that.

Scott: It's just a nice thing to be able to do it again (laughing) because months and months and months could go by in the worst periods where we just couldn't do it because of surgeries or whatever. You were just in extreme pain and stuff. I think we're adjusting still.

Int: So you're in an adjusting mode?

Scott: We're confident that eventually we'll get there. (031/032: 1647-1689)

er the couple found intimacy and pleasure in resuming a sexual

In addition to being hopeful about their sex life, there was a sense of

easure or enjoyment in their day to day lives. They had developed

tual of once a week walking to their neighborhood ice cream parlor

to share

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hot fudge sundae. With the pain gone, Mary was able to resume
ke yard work.

y's optimistic self had returned. She was able to see the silver lining in
ience together.

> Mary: I never worried about us. (Pause) I think that if anything, going through the whole endo and then the infertility and the surgeries and all that kind of stuff showed me that I didn't really need to be worried about us as a couple because we seemed to weather those. I mean, those are hardships that a lot of people never go through and we weathered them quite well, I thought, and got closer and more intertwined in our emotional lives. So it's actually a good thing. There's one silver lining.
>
> Scott: I think so. (031/032: 2171-2185)

and Scott both agree they have "weathered" the experience with
sis quite successfully with the added benefit of a stronger marriage as
addition, they are making room in their lives to adopt a child. The
oceedings required a home inspection. Mary went through the
the checklist in hand, baby proofing their home. As Mary was going
home, excitedly preparing for a new phase in her life, she stumbled
e reminders of her life with endometriosis. As she no longer needed
medications or pads for her heavy periods, it was a bittersweet
though she described being "joyous" about never having another
was a sense her sentiments were bittersweet, as these objects
emories of a very difficult time in her life, and of parts of herself that
t.

Totalized by Care Giving

rtners as care givers were a common relational pattern in nearly all of
es. This section presents the paradigm case of Julie and Nate, a
osen because their story illustrated, based on daily habits and
, how a partner's life, as well as a relationship, were affected by
iosis. This type of care giving, characterized by care giving in the
, was more chronic and routine in nature, when contrasted with other
g patterns that were more time-limited and symptom or event specific.
mptom experience, as well as the couple's illness understanding is
d to provide a sociocultural context from which to understand the care
tterns.

und

lie and Nate were both in their twenties and at the time of the interviews
lergoing exciting transitions in their lives. They shared the news of their
gagement and their plans to marry. While it was, on the surface, a
ne, the couple was living with severe life disruptions from endometriosis.
as not known whose decision it was to marry, Julie clarified in a joking
at their upcoming marriage was not because she was pregnant, as
y wasn't a possibility on her latest endometriosis treatment, Lupron.
addition to the wedding planning, they were also busy with ongoing
s of their home which was located in a small agricultural community of
California. Visible from their home were beautiful views of large open
d gentle rolling hills. It was a particularly special time for the couple

ause owning a home was a lifetime dream they both had shared. Nate's
st project was painting the kitchen walls and cabinets. They were also
ectors of antique furniture. Julie gave a tour and explained a few of their
sured pieces that were displayed throughout their home. They
nowledged acting older than their respective ages, and enjoyed "being
nebodies together."

While they had been in an intimate relationship for three and a half years,
y had been living together for three. According to both Julie and Nate, her
nptoms worsened about the time they moved in together. The past few years
d been stressful as they struggled with getting an accurate diagnosis and
ective relief for Julie's pelvic pain. Initially, Julie was diagnosed with IBS and
ated with Metamucil, which was not effective in relieving her pain. After Julie
rned from her grandmother that her twenty-six year old cousin had had similar
nptoms which resulted in a hysterectomy from endometriosis, she changed
alth care providers. She searched for a doctor who, according to Julie, took
pelvic pain seriously, and suspected endometriosis. A diagnostic
aroscopy confirmed the disease approximately one year ago.

Disabled Body

Julie's symptoms interfered with various levels of functioning. At the time
he interviews, Julie was living with two chronic conditions, CPP and
ression. There was a time, however, when Julie's symptoms were more
te in nature. Her first episode of pelvic pain occurred while driving down the
way.

ust had really, really sharp pains and it got so bad I had to
e emergency room...Of course, they said, "Nothing's wrong
." (061: 0019-0025)

ıtil her next acute episode of pain.

here was probably about a six-month lapse where
as no pain at all and then one day I went out running...I had
one of those really sharp pains and I was just like "Nope,
doing that again, no more running," because the pain was
ɔad. And ever since that point the pain has been chronic.
)82-0094)

ain episodes shed light on a time when she experienced a

ɔning that included "working out" regularly. These acute pain

te the immobilizing and disabling quality of the pain, as both

ed to stop what she was doing to attend to the pain.

f pain that occurred while running also has had long term

.

fear working out now...I asked the doctor, I said I want to
ıt and I'm afraid and, they gave me a thing (a referral) to go
ysical therapist... The first thing she told me was hire a
l trainer. And I go okay, well, I'm not rich... So she gave me
al to see a physical therapist but I couldn't even afford to
physical therapist. And she's like join a gym. And I go
ɔt the point. I said it's not that I can't work out, I'm afraid to
t. I don't know what will, what my body can do. I want
ɔdy to guide me through, like okay, this won't hurt you. I
be able to do stuff that won't hurt me. (061/062: 4027-4101)

ced a level of fear that was immobilizing; she had lost faith

er body. Movement, such as working out, came to be

precipitator of pain, and thus was avoided. While there

ssionals to help Julie with various instructional techniques

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and mobility, it was more difficult to find someone who could

h her newly developed fear.

diagnosis approximately one year prior to the interviews, Julie's

e more consistent in nature.

e: I have painful bowel movements. I didn't start pain with sex
il probably within the last six months ...I had constant pain on
left side and as the time grew on, I spent about a year with
L. trying to figure out what it was. The pain was moving from
left side into my right side so it was on both sides now.

And it wasn't related to your menstrual cycle?

ie: I wasn't keeping a pain journal at the time, or even now,
fortunately. I should be but (pause) but, no, it wasn't related to
menstrual cycles. The main thing was the pain would be really,
lly severe in the mornings and in the evenings. In the middle of
day I usually felt like good, okay. But it was worse, I think,
ring my menstrual cycle and I think the worst that it ever
s, was probably when I was ovulating. But it was throughout the
cle, the entire cycle, like every day of the week, basically. (061:
82-0213)

most notably fluctuated according to the time of day, as

es of the menstrual cycle, and although she experienced pain

in was worse during menstruation and ovulation. A relatively

Julie, which had only started in the past six months, was

ain with sexual intercourse. Julie had a fairly systematic pattern

erfered significantly in her daily functioning. With pain being

e mornings and evenings, activities during those times were

ed what symptoms affected her relationship with Nate the most,

r depression. Despite a family history of depression, both Julie

and Nate were convinced there was a link between her depressive symptoms and her pelvic pain. As Julie's symptoms worsened, her depression and hopelessness about the situation grew. Although she had sought appropriate psychiatric treatment, she had not found assistance that she considered to be helpful.

> Julie: I stopped going to the psychologist too. He was not very, I don't know, he just didn't talk back. He just sat there and stared at me for an hour and I'm like "Okay, that's fine. Great. Thanks." And then claimed I was depressed and gave me the medicine. There's been some other issues financially that are kind of not here or there but I quit seeing him. I had just accidentally missed an appointment and never bothered rescheduling because I didn't, I don't know. Maybe with somebody else I'd feel better but that guy wasn't really working. I did talk to my regular doctor the other day about two weeks ago. She asked me "Are you depressed?" Because I had told her I had been on the Lexipro and I'd quit it and quit my seeing the doctor and so she asked if I was depressed and I said, "Yeah, I might want to think about taking another happy pill." (Laughing) And so she prescribed Selexa for me, which I have the prescription still sitting in my purse and I haven't filled it yet.
>
> Int: Did you tell your doctor about some of your feelings about wanting to kill yourself?
>
> Julie: Well, she asked "Why do you think you're depressed?" And I said, "Well, I think about killing myself." And she quit there and just wrote the prescription. (061: 3248-3284)

Julie was feeling hopeless about her pain, because despite numerous treatments, it had persisted. She was experiencing significant disability in her life, missing work at least one day per week because of pelvic pain related to endometriosis. Julie had begun to consider suicide as an option.

> Julie: Just the other day I had stayed home from work and I was pretty stressed out about staying home from work...I was really, really stressed out about it and I was like "Well, I have a lot of pills in there. I could take all of those and, everybody says suicide is answer to a temporary problem, a permanent solution to a

temporary problem and I've been dissecting that and I'm like but wait a second. This isn't a temporary problem, this is almost a permanent problem. This isn't going away.

Int: Which problem?

Julie: Endometriosis. The endometriosis isn't going away. So

Int: So does killing yourself seem like a cure or a solution to the problem? It would make the pain go away?

Julie: It would make the pain go away maybe. I'm not sure. One would surely hope but, I haven't, I think about it but, I don't, I, I, I say "Oh, I want to kill myself," or "I feel like killing myself" but I, I don't think about how I would actually do it and it wasn't only until like two nights ago that I was like "Pills, I have lots of pills." (061: 3178-3223)

Vhen the health care provider heard Julie's feelings of desperation she ibed antidepressants as a solution, never exploring in depth Julie's ality or plan. The option of antidepressants had been offered by both her ologist and general practitioner, but Julie was resistant to be treated for the ssion. She did not fill the most recent prescription for the antidepressant ation because it was "too expensive" and "wasn't covered" by her nce plan. Financial strain may have made resources limited for the couple e would not expend these resources for her health.

Another possibility may have been that both Julie and Nate understood pression to be a consequence of her pelvic pain.

Int: So how do you think the depression is related, if at all, to the endometriosis?

Julie: Well the pain really, really depresses me because it's kind of like a

Nate: It makes her too tired to cope.

IISE LIBRARY

: Yeah, it's fairly cyclical. Because what happens is like the makes me not be able to go to work and then I totally stress bout not going to work. And then the stress, I get depressed it just keeps, it's just this little cycle that I can't break. I know if ld just get in like two straight weeks at work without missing a or without having to stay home and work from home, that I d feel better about it. That I could probably break it. But lly there's at least one day out of the week where I'm having to k from home, or stay home sick.

e: The pain usually, when she gets depressed, it's not essarily the pain that's keeping her that way but it's definitely l k just kind of her defenses are down from coping with the pain then it starts the cycle. Something that wouldn't bother her mally does or it bothers her more than it should and it just als down, like she said.

Into the depression?

te: Yeah.

ie: Yeah, and then I can't get rid of the depression and then I n't go to work and then I get stressed out about not going to work d it just continues on and on. (061/062: 0714-0760)

ain that interrupted Julie's ability to go to work was of particular

uple described a fairly predictable pattern in which pelvic pain

ycle that resulted in a depressive episode. It is possible that

ad hoped that finding adequate treatment of her pelvic pain

ntly result in successful treatment of her depression.

ossibility may have been that it was more comforting for Julie

erstand depression as a result of the pelvic pain, rather than a

ulie understood the stigmatizing effect of mental illness because

ed from "clinical depression" since Julie was four years old. Julie

pression as distinctly different from the depression her father

IRSE LIBRARY

Julie: I worry that it's like oh, it runs in the family. You're destined to be clinically depressed, kind of stuff. But my dad and I, I believe we have different types of depression. When he gets depressed, he gets very angry. When I get depressed I get very

Nate: You get angry too sometimes.

Julie: Yeah, but mainly I just get like

Nate: You get angry too sometimes.

Julie: Sometimes but usually when I'm depressed it's not that I get angry as much as

Nate: Despondent.

Julie: Yeah. Yeah. I just want to be alone and I don't want anybody to be near me. (061/062: 0905-0928)

e perceived that her depressive symptoms of despondence and isolation
d her from a family history of depression. While Julie also had a family
f endometriosis, there may have been less shame associated with this
cal condition. Julie may have had held more hope for treatment for
triosis than depression given that she had witnessed her father's
ng depressive symptomotology after taking antidepressants for numerous

lie had hope in biomedical treatments for endometriosis. In the past
had undergone a myriad of unsuccessful treatments for endometriosis
a laparoscopic surgery, continuous birth control pills, and Lupron. At the
e interview, Julie was beginning to understand endometriosis as a
nt problem. Her desperation also led her to consider a hysterectomy as
e solution.

Julie: The only thing I haven't done is Danazol, I think as far as everything they give you. And then, of course, there's hysterectomy and total hysterectomy and so forth. And have I considered a hysterectomy? Yes.

Int: You have?

Julie: Yeah. I'm thinking about it. Because I mean, I don't know, I got to get the pain to go away.

Int: So it sounds like you're feeling pretty desperate.

Julie: Yeah.

Int: To make it go away.

Julie: Yeah, I want it to go away. I barely think I'm functioning. (061: 2299-2320)

e was concerned about her decreasing ability to function, and viewed

sterectomy as a possible hopeful solution, especially related to work.

Julie: The pain is really, really bad and I just, I can't put up with it that much longer. I'm trying all these medications. The Lupron's not working. Where is there to go after this? There's Danazol. If Danazol doesn't work, where is there to go after that? There's nothing. The only thing left is a hysterectomy. And so I feel like to work I'm going to have to have a hysterectomy, to continue working. (061/062: 3962-3974)

Julie was desperate to find a solution for her pain, depression, and

ulting disability. Her cousin had achieved pain relief from hysterectomy as a

ult of endometriosis, and thus this seemed a hopeful solution for Julie.

nazol, a derivative of the male hormone testosterone, like Lupron, produces a

dical state similar to menopause and can relieve the symptoms of

ometriosis. Remaining treatments that hadn't been tried generated continued

e for Julie, leaving a space for optimism in her outlook.

closedness of the Condition

Nate had become Julie's primary confidante and support system, as Julie d few other relationships in which she could be vulnerable and show her pain. ring her illness Julie had come to rely enormously on Nate. She did not have lose relationship with either of her parents, and although she had a best end, Julie was acutely aware of the responses her pain elicited.

> Julie: My best friend knows and she doesn't handle me being in pain real well. She doesn't know what to do. She kind of sits here and then she kind of, she'll sit here for about an hour and then I'm like "I'm sorry, I can't entertain you and go out right now." And then she'll just go, "Okay, well, I got to go do my laundry," and so she leaves. She's not real good at handling it so, which is understandable. I'm okay with it. (061: 2933-2944)

Julie was empathic to her friend's reaction, but there was a hint of sappointment. Julie was in a difficult predicament; she could sense her ndition made others uncomfortable. After a story about a doctor's visit when e did not communicate her intense and severe pain to the doctor, she plained her rationale for nondisclosure.

> Julie: I don't try to hide it from the doctor. I mean I don't, it's not that I'm purposely trying to hide it from the doctor. It's just kind of like I'm used to hiding it out in public, trying to look like I'm okay.
>
> Int: And why? Why do you want to do that?
>
> Julie: Because I don't think anybody likes to see people in pain. I mean it's kind of like when you see like a homeless person on the street people look away. And when you see somebody in pain that you don't know or you're not really familiar with you look away so
>
> Int: So you want to try to be normal and
>
> Julie: Yeah, I want to be normal. (061: 1744-1764)

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In addition to preventing the discontent of others, there may have been other concerns related to disclosure. Julie had experienced multiple disappointments from revealing her vulnerability related to the illness. For example, Nate's mother expressed concern to Julie about their upcoming marriage.

> Julie: I feel like his mother discredits me because I'm in pain. Like we're getting married and she just said to me the other day, she goes, "Well, I worry about Nate marrying you because, you're in pain"...And she said, "You being sick all the time." She didn't say the pain, she said "you being sick all the time," which bothers me. But she goes, "But we believe in love, so it's like okay. Well you guys love each other..."
>
> Int: So she actually said that to you...So do you feel, it sounds like you feel maybe, well, ostracized isn't the right word but, I don't know, what's the word? Because of the endo?
>
> Nate: Not accepted.
>
> Julie: Yeah.
>
> Int: Not accepted.
>
> Julie: Yeah, exactly...One of the things that really, really, really bugs me is, especially in the case of his mother, is that she used the endo and me being sick as a weapon against me. It's not something that I did to myself. I didn't go off and like jump off a cliff and try to dive into some lake or something like that and like break my back or something that was completely my fault. I had nothing to do with this, but yet I feel like she's using it as like this is your fault, so... Any time anybody uses me being sick as a weapon against me, it really, really upsets me a lot. (061/062: 3196-3289)

Divulging details of her illness experience may have initially created a sense of closeness and intimacy, but Julie had learned that one possible outcome was being judged negatively because of her condition. Julie developed techniques to hide her pain.

Julie: I try really hard to hide it....I don't often wear makeup. I only wear makeup on my days that I'm feeling my worst. I basically never wear makeup. I grew up not wearing makeup...So I'm pretty used to not wearing makeup. I do own some, of course, so only on the days that I'm feeling really, really bad and I know that you can see it in my face, I put on makeup to hide any of the pain. (061: 2331-2347)

e was particularly sensitive about her co-workers seeing her in pain.

Julie: Well, I told basically everybody at work that I have endometriosis. I've told them it does cause me pain but in a very kind of like clinical kind of aspect. I don't really want them seeing me in pain. I want them to think that I can do my job and not really be affected even though everybody knows that I'm missing four days of the week out of the month. Obviously, it is affecting me but I do try to hide it as much as possible at work. (061: 2920-2930)

work when she was in pain, she would rest by placing her head down

ng her computer wrist rest as a pillow. She would close her office doors

coworkers would not see this behavior.

These examples highlight, in contrast, the sense of trust and acceptance

with Nate. In addition to accepting her in pain, he felt he was able to

vhen she was in pain. Nate described a visit to the doctor's office, when

s in severe pain, but she didn't let it show.

Nate: There was one particular point where I went in with her and she was in really bad pain and I could tell because I could see, just kind of the signs. But even if she's hurting and she's talking to somebody other than me, she puts on a happy face and tries to make herself look more presentable or more sociable. But I could tell that she was in a lot of pain.

Int: How could you tell?

Nate: Just like she was, in particular she was holding her back and I could see it in her face when she's not talking to somebody. I can tell, just by her general demeanor I could tell that she's in pain. And also I've had been speaking with her before we got into the

appointment and she was in pain then. But like she was sitting there and she said, "It feels like somebody's sticking a knife into my side." And the doctor said, "Well, you don't look like somebody's sticking a knife in your side." And what do you say to that? Yeah, I can't, I don't look like that because I always have that pain. I can't walk around 24/7 looking like somebody's sticking a knife in my side. It just doesn't work that way. And I just don't think the doctor could kind of process that. (062: 0505-0540)

e agreed that Nate had the ability to know when she was in pain. There nse from both of them that Nate was privileged with access to her inner ces, in a way that was unique. While Nate validated Julie's experience ysician's office, he did not articulate his concerns to the provider. It is ising a health care provider might miss the cues that Nate so astutely . If Nate actively engaged and shared his knowledge as an expert in o day provision of care, the provider may have better understood her f pain, as well as its impact on their mutual lives. By limiting disclosure alth care provider, opportunities for empathic action were closed down. ie and Nate shared numerous examples that illustrated their frustration pointment with care received from health care providers. For example, e found a doctor who took her pelvic pain seriously and suspected osis, rather than experiencing a sense of relief, Julie was concerned provider's plan of treatment, and was forced to take an adversarial

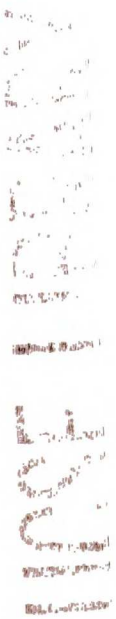
Julie: My doctor wanted to put me on Lupron to begin with to see if I had endometriosis. She said, "If you have endometriosis and we put you on Lupron the pain will go away and we'll know for a fact that you have it, or on Synarel. We'll know for a fact that you have endometriosis and then we don't have to do to the laparoscopy." And I said, "Look, I'm not going into menopause to figure out that I have endometriosis. Because when you figure out

> that I have endometriosis you're still going to want to go in there and do a laparoscopy anyways. So just do the laparoscopy and let's get it over with." (061: 2270-2286)

The idea of being pharmaceutically induced into menopause without a definitive diagnosis was not a treatment plan that Julie felt comfortable with. At a time when she may have been particularly vulnerable from worsening CPP and episodes of depression, she was put in the position of negotiating her own treatment plan.

Laparoscopy is generally understood as the gold standard in diagnosing endometriosis. While advantages of laparoscopy include reassurance to the patient, ruling out malignant disease, as well as increased accuracy of diagnosis, there are drawbacks, as well. For example, endometriosis presents with a variety of appearances, which may make laparoscopic diagnosis inaccurate in some cases. Laparoscopic evaluation allows for diagnosis and assessment of the severity of endometriosis, but does not prove that endometriosis is the cause of the pelvic pain (Howard, 2000). Recent discussions in the endometriosis literature acknowledge the "clinical confusion" regarding evidence as to whether to treat or not treat endometriosis in the absence of a clinical diagnosis. Discussions include weighing the benefits and risks of treating without an indication versus sanctioning the use of early laparoscopy that is also not without risk and significant cost implications (Garry, 2004).

Julie may have gotten the information regarding standards of practice for diagnosis of endometriosis from the internet, books, and/or family members.



Regardless, being treated with a medication that would induce her body into pseudo-menopause without a clinical diagnosis was unacceptable.

When the laparoscopy confirmed a diagnosis of endometriosis, Julie was treated with continuous birth control pills. She had hoped results from the laparoscopy combined with birth control pills would bring her relief, but the pain returned just a couple of weeks after the surgery.

> Julie: What happened was after surgery I went back a couple weeks later and I said, "I'm still in pain." And she goes, "Well, when you're ready to try Lupron give me a call." And I called the office and I told the nurse and the nurse got the authorization and I haven't seen my doctor since but I've been getting the Lupron shots. And so I said, "Well, should we talk about add back therapy?" And they're like "Well, you'll have to make a scheduled appointment for November." That was like back two or three months ago that they're like "You'll have to schedule for November to talk to her." It's like "Okay, well, I have a Pap smear coming up, I'll talk to her then." So it's impossible to see her.
>
> Int: So how is that for you?
>
> Julie: Horrible. Actually tomorrow I'm going to, I finally got my regular doctor to give me a referral to a different gynecologist so I'm going to go interview him (laughing) to see if he's even willing to spend time talking to me because not being able to get in to see her when I have such pain, if I had a healthy vagina it would be just fine but since I don't. (061: 0799-0834)

The experience of not being able to get her questions answered about her Lupron treatment was another example of Julie's disappointment in the patient-provider relationship. The care that Julie received neglected her needs in several ways. Treatment with gonadotropin-releasing hormone (GnRH) agonists, such as Lupron, is generally limited to six months because of the undesired effects of prolonged hypoestrogenism, such as osteoporosis. An "add-back therapy," consisting of estrogen and progestin, has been suggested to overcome

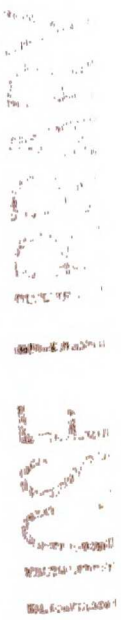
ssociated with hypoestrogenism (Surrey & Judd, 1992). Although it
accepted that with one year of GnRH agonist treatment add-back
eeded, there is no overall consensus among specialists to the optimal
rapy (Zupi et al., 2004).

rding pharmaceutical management, she may have been put at risk
appropriate doses of hormone replacement therapy while on the
dd-back therapy has been associated with reduced mineral density
ntrol of pain symptoms and better patient quality of life when
th GnRH agonist alone (Zupi et al., 2004). Second, from a
perspective, Julie's emotional and informational needs were
This situation moved her to action to search for yet a third provider,
of finding one who was committed to a mutually communicative

escribed that in general, her encounters with providers were

> Julie: My doctor comes in, talks to me, starts her stopwatch (laughing), not really but it feels like she's in there for like five minutes. At minute four she's looking at the door. She's on her way out. I bring in a list and I like go through them like an auctioneer trying to ask her questions. Because she's so fast trying to get out of there, I don't always think of everything. I'll tell her something and she doesn't ask about it, she just goes, "Oh, okay, that's good to know. Great, thanks for sharing." (061: 0388-0401)

as aware and attentive to the response of the health care provider.
essed concern that he didn't believe her suffering was attended to
appropriately. He shared a story that suggested the primary care
spicious of Julie's need for pain medications.



ate: Any time we've ever talked to her about any kind of pain
edicine, whatsoever, she just shot it down. I mean, it wasn't like
ne said, "Okay, well there's these options that you could take that
re non habit-forming" or whatever. She just went, "no." She
aid, "We don't want to start that."

t: So she didn't give her any pain medicine?

ate: No, her primary care physician didn't. And I could tell that
ne was just, she thought that we were just asking for pills,
ecause of the way she shot it down. She didn't even
ntertain the option of, well you could try taking a Tylenol regimen
something like that. (062: 0542-0561)

sked what treatments were needed or appropriate for

Nate stated effective pain management was important, and

lie had received care from one acupuncturist in particular, that

fortunately, the out of pocket expense disallowed continued

ate: She was taking acupuncture and that was helping her and
so the acupuncturist was the only doctor that she's ever felt
ctually cared about her pain and her well being. So I think, I think
e acupuncturist

t: Of all her doctors?

ate: Yeah. Out of everybody. The acupuncturist is the only one
at she's ever really liked even.

: Do you know why?

te: Well, personally I think that just between western medicine
d eastern medicine is that in western medicine there's really a
sh towards finding out what's wrong and fixing it. Where in
stern medicine it's just there's something wrong, fix what's
ong. You know, it doesn't matter what's causing the problem,
u just fix it. And I think none of her doctors have ever got past
finding out what's wrong part to actually fixing it.

d then of course with endometriosis they don't know how to fix it
he doctors are just like, "Well, did you take your medicine?"

> Where the acupuncturist at least sticks her with needles and causes her to have either pain or not pain. So I think that at least something is being done…and we wanted to continue it but when we bought the house we couldn't afford it anymore, because it was $40 a visit before we moved here and that was like twice a week. If we got a referral from her primary care physician, then it went to $20 a week, which at this point she wants to do, but still it'd be really hard for us to swing that. (062: 0279-0338)

Nate concluded that the acupuncturist was helpful for a couple of reasons. The first was that despite the ambiguity of endometriosis, the acupuncturist was able to do "something," which in addition to providing hope, at least occasionally reduced her pain. The second was a sense that the acupuncturist cared for Julie in a way that was different from the other providers. The acupuncturist's holistic concern "about her pain and wellbeing" may have been very different from the focused but compartmentalized care of a psychiatrist, a gynecologist, and a general practitioner. The acupuncturist's care relieved Nate because it directly addressed Julie's pain; he lived day to day with an insider's view of the effect of the pain on her life and experienced the disruptions it created in their joint life. Having another person care for Julie, may have eased his personal burden and responsibility.

Nate was aware of the lack of straightforward treatments and his knowledge of computers as a video game programmer helped him to appreciate the complexity of Julie's situation, while also fueling his doubt in the medical profession.

> Nate: I can understand from a doctor's point of view how it can be hard to diagnose it and why you'd be reluctant to diagnose it, just because it, I detect, I feel that doctors are basically tech support for your body…I just kind of recognize…you get a kind of a mental rubric of how to go through, start at the top of the checklist and you

work down the checklist. And like after I started doing that and then I went to a doctor a couple of times and then I just kind of listened to the questions, I could just see it in their head. Like the exact same process that was going on in my head trying to fix the computer, just going on in their head. And I kind of lost a little faith in medicine from that.

Int: But it works for computers.

Nate: Sort of. It doesn't always work, you know. And the thing that scares me is half the time when I fix a computer it's not because I actually diagnosed the problem and fixed it. It's because I hit the restart button or it just magically started working again. And I know that that's not a common thing. That's not just magic to me…I'm sure that happens to doctors too, where they come in and it works. And I think it's also more problematic because you're not necessarily fixing the computer. If the computer's working and there's a problem it doesn't matter. But if there's a problem with a person then it's

Int: You can always get a new computer.

Nate: Yeah, exactly. (062: 2334-2419)

Nate, from his experience with Julie, became aware of the fallibility of medicine. He understood the possibility that physicians they dealt with did not have the answers to her physical ailments and may not have a "fix" for Julie.

Care Giving Practices

Nate demonstrated patterns of systematic care giving that were in sharp contrast to Julie's numerous relational disappointments around her illness. At times during the interviews, Nate's care giving practices were surprising and unfamiliar, which may be apparent in the interviewer's responses. Nate's primary role in the relationship was as a care giver. His everyday care giving patterns were embedded into the routines of their daily lives and had the qualities of vigilance, attention, and utmost concern for Julie's needs. These qualities will be

illustrated in three patterns of care which include: a) care as a spark to life and movement; b) care as protection; and c) care as extending abilities of the disabled body.

Care as a spark to life and movement. Julie's depression and pelvic pain were immobilizing at times. Mornings and evenings were most difficult for Julie as it was the time of day when her pain was the most severe. Nate, provided hands-on care giving, to do what he could to mobilize Julie. Julie allowed herself to be vulnerable during the interviews as she shared the extent of her disability and Nate's care giving practices.

> Julie: He helps me a lot. Usually in the morning I need him. He has to help me out of bed because I'm in pain.
>
> Int: Really?
>
> Julie: Yeah. So
>
> Int: Because you can't stand up?
>
> Julie: I, I do occasionally. I do manage to stand up but I'm usually kind of balled over so, and then he comes to me, he grabs me and
>
> Int: So can you describe to me the last time that happened?
>
> Julie: Two days ago.
>
> Int: And so what happened? Can you describe to it to me, the incident?
>
> Julie: I mean, I, what happens is I go, okay, I'm in pain, I know this so, and I'm "Yeah, but I'm strong enough." Mental, mental thoughts. And so I get up and I get around the bed and then I'm kind of like "Oooh, oooh," on the side of the bed and then he goes "Are you feeling okay? Do you need my help?" And I go "Yeah, come help me." So he helps me and he walks me into the bathroom and he gives me his arm so that I can sit down on the toilet and then he picks me back up and so

Int: And then what?

Julie: And then he walks me out to the shower or he has me come and sit on the couch until the pain subsides or usually what happens is he comes and he sits me out on the couch and he goes "Okay, time for your Bextra." And so he gives me a Bextra. Then our morning time, usually it should only take you an hour to get dressed in the morning, it takes us two. Yeah. Because I have to sit here on the couch for so long just so I'm feeling better to start moving again...(061: 1119-1179)

While mornings were distressing for Julie, the CPP and resulting immobility also created considerable distress for Nate. However he did not believe there were any other relational possibilities. Nate acknowledged that although his work schedule was flexible, the quantity of time missed from work as a result of caring for Julie was substantial. Finances were limited, and he was concerned about the amount of money lost in this process of caring for her in the morning.

Nate: I leave work at five, regardless of what time I get in, basically.

Int: You do?

Nate: Yeah. Where she tries to at least, if she gets in late she'll stay later, and try to make up for lost time. I don't always have that option, because my bosses leave. And also I just get tired. I can't stay that late. So that's one thing where I think, it's lost income. Like if I could go in earlier, yes, I would probably make more money. Then also just lost time, lost productivity. (062: 0620-0640)

Nate noted that his care for Julie had begun to infringe on other activities in his life like painting their kitchen, and spending time with his brother. Nate described needing to ration his energy to complete tasks. Despite these

concern

unwave

concerns, his commitment to provide care for Julie in the mornings was unwavering.

> Nate: One of the biggest, one of our biggest problems is when we have to get up in the morning and there's certain kind of roadblocks that we hit. Either it's like, if she's in pain when she wakes up, it's getting out of bed. That's the first obstacle…Usually it's just I kind of try to get her to move, or do something…usually it's just, it's just questions to try to get her to move.
>
> Int: To get going, to start the day kind of thing?
>
> Nate: Yeah. And then it's, I'll ask, "Do you want me to help you into the shower? "Do you want to eat something?"
>
> Int: Okay. But doesn't this get tiring for you? I'm kind of getting tired listening to it.
>
> Nate: Yes.
>
> Int: Like if I knew every morning that I was going to have to go through this getting up
>
> Nate: Yeah.
>
> Int: I mean, it's hard enough for me to get up. I mean, I would imagine, don't you get tired?
>
> Nate: Yes.
>
> Int: And so how do you deal with it?
>
> Nate: I just do.
>
> Int: You just do it.
>
> Nate: Yeah….there's no other option. (062: 0998-1073)

Nate's role was to spark and support Julie into action each morning. Being aware of her symptomotology, he may have anticipated that her pain would decrease in severity by mid-day, so the task at hand was to assist her through the difficult morning time. While her pain was also severe in the evenings, it

created much less disruption for the couple, because Julie was home and able to rest.

Providing care as a spark to life and movement was noted at other times as well in the routine of their day to day lives. For example, Julie may have preferred to stay home when she was experiencing pain, but Nate encouraged her to keep going, to keep moving, and not to quit.

> Int: Did you ever have to cancel out on any parties or anything because of the pain?
>
> Nate: Not that I can recall. I can recall situations where she was having pain beforehand and having trouble ready to go and she just goes, "I don't want to go" and I don't let her do that. I say, "That's silly. You're not in so much pain where you can't go because I can tell that you're not in that much pain. You're just in pain and you're having trouble so you're frustrated so you just want to quit." And I don't let her quit. (062: 1836-1851)

The couple's interdependence functioned to motivate Julie into action. At times her pain was so severe that Julie lost her ability to communicate effectively.

> Nate: If she's in a whole lot of pain, then she kind of loses the ability to communicate specific kinds of pain to me. Like she'll get to the point where she's unable to communicate anything, basically, including, it hurts here.
>
> Int: Right. So if it gets too bad she just can't talk at all.
>
> Nate: Yeah, basically. I mean, she can talk but she can't
>
> Int: Communicate.
>
> Nate: Communicate.
>
> Int: And so what does she look like at that point? Is she usually
>
> Nate: She usually just kind of has a vacant, vacant look, or a pained look but she won't, one of the things that I try to do is get her to look at me and make eye contact with me and that's hard for her.

Int: When she's in pain?

Nate: Yeah, when she's in the most pain she can't just kind of, like one of the things I try to do is look at her and say, "Here, just look at me and focus on my face and kind of slow down and just look at me," and she can't do that. She can't stop and just kind of focus and make eye contact. (061/062: 1600-1638)

Nate described periods where Julie's pain was so severe that she was completely engrossed in her pain and would disconnect from the outside world. For Nate, this was most likely difficult for several reasons. First, his fear may have led him to coach her to gain control over the pain. Second, he may have experienced such severe effects of pain as a reflection of himself as a failure related to his care giver role. Third, while Julie's response to pain most likely frightened him, he may have felt the responsibility to be appear stoic and in control of the situation to be available to comfort Julie.

Nate: (Demonstrating with loud fast breathing) I say, "Breathe with me (taking a deep breath). Hold the breath in. Hold it in. Take the next breath," and she'll try to do it. (Making sharp gasping sounds), and she can't, she can't. The pain is so much on top of the, I'm sure the stress from trying to get dressed exacerbates the pain, but it's beyond anything that she can deal with and she just kind of checks out. She's not there anymore. (062: 2040-2052)

Despite a situation which may have been frightening and alarming to Nate in the narrative, his feelings were not apparent, as he remained calm and purposeful in the role of care giver. Nate's role of providing care as spark to life and movement was demonstrated as he literally used his connection with Julie as a link that prevented her from "checking out" as a result of the pain.

Care as protector. Julie received assistance from Nate with some of her most basic human needs. For example, it was Nate's responsibility to do most of

the cooking in the relationship because Julie did not know how to cook. Also because of her pain, he would help her get dressed in the morning.

These caring practices were consistent with the couple's mutual understanding that a certain amount of responsibility fell onto Nate to "protect" Julie and to make their situation better in ways that he was able.

> Nate: I just feel like there's not a lot of medical support for it, for her.
>
> Julie: Yeah, that's frustrating. That frustrates me a lot, is the lack of
>
> Nate: And the fact that I can't do anything to help her and that she really wants me to.
>
> Julie: Yeah. He, he's at one point said "I'm going to go into medicine so I can fix you," kind of like standard male response, like I'm going to fix the situation, by his involvement.
>
> Int: It sounds like you are helping her (to Nate).
>
> Nate: Well, yeah, I know I am and I'm doing the best I can but I'm not, I can't.
>
> Julie: He wants to medically solve it.
>
> Nate: She wants me to fix her and I can't do that and I tell her I can't fix it.
>
> Julie: I've kind of accepted that more now though.
>
> Nate: Yeah, you're much better at that now.
>
> Int: Did you used to want him to fix it?
>
> Julie: I used to ask him to fix it. I mean, I knew he couldn't but I was just kind of like, make it go away. Make it go away.
>
> Nate: Well, she wants me to make it better.
>
> Julie: Right. Well, besides that, you're like my protector. We live in this house together and if something bad were to happen, more

than likely you would be protecting me and not the other way around … So in that sense, I wanted you to protect me, I wanted you to make it go away. (061/062: 3513-3563)

To understand their motivations and concerns is complex. Julie hoped that, in a chivalrous sense, Nate would be her "protector," and rescue her from her pain. This expectation may have served to comfort her, as it possibly diminished her personal responsibility over her own health. While Julie did expend large amounts of time, energy and money on medical treatments, there was little evidence of daily habits and practices that fostered a sense of control or mastery over her own body. For example, whereas many other women altered their diets as a strategy to control their pain, Julie did not.

Int: Do you notice that your diet affects your health at all or your energy or your pain?

Julie: Um (pause). I,I haven't, I think on purpose I've been avoiding paying attention to seeing if certain foods affect if I'm in pain.

Int: And why do you think you're kind of staying away from that?

Julie: Because I'm sure they're like my favorite foods.

Int: Oh.

Julie: I said, "So are there any foods I should be definitely, definitely avoiding?" And she (her physician) was like "Greasy, fatty foods." I'm like, "So everything that I eat, okay." And she's just like "Anything with, don't eat sugar. Don't eat greasy foods. Don't eat things with fat." And I'm like "Okay." But you can't eliminate all of life. And so the day she told me that I went to a Mexican restaurant. I had enchiladas. (061: 1954-1991)

While other women made dietary changes in hopes of pain relief, Julie was not willing to follow the physician's dietary suggestions. Even at home, Julie relinquished responsibility for her diet to Nate who did most of the cooking.

Another way that Julie may have taken more responsibility for her body was to have a pain management plan in place. Rather, Julie relied on Nate.

> Nate: I don't think she had really strong pain management skills to begin with and she doesn't like taking painkillers. Like oftentimes when she's in really bad pain I'll be like take some medicine. Take, do you want a Vicodin? Do you want some Aleve? And she just says, "Maybe." And so it doesn't help me because I know she wants to not be in pain but she doesn't want to take the medicine. (062: 0269-0279)

Nate's role of protector was demonstrated across numerous aspects of their lives together. In this example, he made attempts to protect her from unnecessary pain, by suggesting pain medication. He admitted that his life with Julie was "stressful" because he lived with perpetual pressure of being a protector.

> Nate: I'm probably generally stressed by her pain. Not stressed in the same way where I'm like up nights worrying about it but it doesn't, if she's in pain I have to do something about it. I can't ignore it.
>
> Int: So what do you usually do?
>
> Nate: Whatever I can.
>
> Int: Give me another example. Yesterday, or the day before, if she was in pain, what did you do?
>
> Nate: Start asking her questions. "Can I do something for you?"
>
> Int: Okay, so you try to help.
>
> Nate: Yeah. If she doesn't respond to "Can I do something for you?" it's "can I get you something?" Then I start making suggestions. Do you want a drink of water? Do you want to drink some iced tea?...Or can I bring you a blanket? Are you in pain? Can I, do you need to move? What can I do? Something basically. (062: 0928-0966)

Nate demonstrated a way of being in the world in which his primary concern was protecting her and being attentive to her needs at all times.

> Nate: I always know that there's times when she's going to be in pain. Like it's usually going to be difficult getting up in the morning. When she gets home from work, I usually expect her to be in pain from when she gets home from work, so I'm kind of expecting it. I'm kind of prepared to mitigate the situation, try to get her to sit down, help her, do things to get her to slow down and kind of take it easy. And so those times it's, it's not really like I saw something and went oh, okay. Basically, if she walks in the door and she's smiling, I can tell how well she's feeling. If she's smiling then it's situation-normal. If she's not, then I kind of jump-into-action. (062: 1705-1724)

Nate lived in a constant state of "preparedness to mitigate" any problems on the horizon, to rescue or lessen her pain. His "jump-into-action" mode characterized his role as protector.

He also protected Julie by going to work with her on days she was in severe pain. Going to work in pain was particularly difficult for Julie for a couple of reasons. First, the act of getting out of bed and dressed was arduous. Second, being productive in an environment where she did not want her coworkers to be aware of her condition was an addition strain.

> Int: You go with her to work?
>
> Nate: I just, I
>
> Julie: He tags along.
>
> Nate: Yeah, I call in sick and I just
>
> Int: You go with her to work, like you go with her?
>
> Nate: Yeah.
>
> Julie: Yeah.

Nate: I ride in the car with her and

Int: And go with her into work?

Nate: Yeah. And I just

Int: And now what do you do at work again?

Julie: I'm a magazine layout editor, so usually what he does

Nate: I'll just sit in her office.

Julie: Yeah....if I just feel really, I just get out what I need to get out, and we take off.

Int: So you have your own office?

Julie: Yeah.

Int: So he just kind of hangs out with you.

Julie: Yeah, I have my own office.

Nate: And they know who I am at work.

Julie: Yeah...

Int: And so what are some benefits of him being there with you at work on bad days?

Julie: I just, I feel more comfortable driving when he's there...if I'm having a really bad time. So I feel like when he's there I can leave early if I'm in pain. Like otherwise I feel like I'm obligated to stay there and finish out the day even if I'm in a severe amount of pain, if I'm there on my own. So it helps me to feel like I can leave.

Int: Does he help you decide that? Like, "Come on, honey, you've been working really hard."

Julie: Well, just the presence, just the fact that his presence is there...I'm just wasting your time. We should go where I'm more comfortable.

Nate: And you also feel more relaxed when I'm there or something, not as stressed. I don't know what it is.

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Julie: Yeah.

Int: And how is that for you to go to work with her?

Nate: I don't care. I mean, if

Julie: I always feel like he's bored to tears.

Nate: It bothers me if I really did need to go to work. If I let my work know ahead of time, it doesn't bother me at all.

Int: Uh-huh. So as long as you're absolved from your work responsibilities, you're fine being there.

Nate: Yeah, yeah. As long as I let her (his boss) know ahead of time and I didn't have anything really important to do that day, then I just call in.

Int: Okay, but what about your absenteeism at work? Like do you think at some point they're like, okay, he's been out too many times this month. Has that ever happened?

Nate: Sort of. I've been working with my bosses a long time. It's a small business so we know each other pretty well and they know what's going on with her, so they kind of accept the situation and are aware of what's going on. And there's been a couple times where I actually went in and said, "I'm sorry, you know, Julie is not feeling very well. Is there anything I can take care of just real quick and then get out of here?" And they say, "Oh, just go."

Int: So it sounds like your work allows you to have some flexibility in order to take care of things.

Nate: Yeah, it's very flexible in that way. (061/062: 0452-0583)

Nate's presence gave Julie perceived permission to leave early if her pain dictated. She did not want to disclose her pain to coworkers, but in these instances she had to explain Nate's presence at the office. It may have been more acceptable for Julie to give the impression that she was leaving work to accommodate her partner's needs, as opposed to her own. Flexibility of work was very important in the lives of women because of the unpredictable nature of

the illness. In this case, a level of flexibility in the job of the partner was required to accommodate her illness, as well. In going to work with Julie, Nate demonstrated prioritizing Julie's work over his own.

Considering the level of disruption in their lives, the couple did not explore in the interviews what the future might bring for their relationship given Julie's chronic debilitating illness. Julie had received a written warning regarding her absenteeism and was concerned about their financial situation because of her missed work. Serious considerations about Nate's roles and responsibilities related to work were not discussed in the interview. The couple also did not discuss a future that may have included needs for care that extended beyond Nate's capabilities. Rather, Nate held on to the hope that Julie's pain would "go away" and they would "live happily ever after."

Nate did acknowledge the value of "time lost" caring for Julie. Most specifically he regretted that he had less time to spend doing his favorite activities, like going to baseball and football games and spending time with his friends. He was troubled by the hourly wages lost from being late to work, but was more concerned with Julie's health and well being. Caught in an awareness of the fallibility of medicine, Nick tried to be a chivalrous partner who held uncertainty and unease at bay for Julie. He attempted to care for Julie in a manner that addressed her many needs, in part response to her unsolved pain.

Care as extending abilities of the disabled body. As a result of her pelvic pain, Julie was not able to stand for longer than two hours without severe pain

and it also affected her ability to bend down. Nate provided care with patience and commitment that compensated for her body's inability.

> Julie: He does do a lot of like caretaking kind of things. He has to help me out of bed a lot of times, probably about half of the time. I think it's been a little bit less lately but about half the time. And recently he's had to like stand there like this with his arms out to make sure I don't fall while I'm getting dressed. So he's like "Okay, well, if you're going to fall, fall towards me." I'm like "Okay, sure." if you say so. (061: 1643-1654)

Julie and Nate developed rituals for her everyday care.

> Julie: It hurts too much to bend over...Bending over is never a good thing....He has to sit there on the toilet and wait. I have to have him pick up the shampoo and stuff for me because it's one of those tiny showers that doesn't have any lips for shampoo or anything. So often he'll have to pick that stuff up for me because it's so painful for me to bend over so... bending over is painful. Yeah. He dries my legs when I get out of the shower so that I don't have to bend over and dry them. (061: 2547-2582)

Nate used his able body to compensate for Julie's disability. While the couple may have explored other possibilities to aid Julie, such as installing a suction cup shampoo holder, or allowing her legs to air dry after the shower, Nate demonstrated care by literally using his able body to compensate for hers.

Julie shared a narrative which illustrated in a profound way her growing dependence on Nate.

> Julie: My parents want us to get married...They want us to separate (and not live together)...and then get married...But they do not realize that if Nate wasn't here I couldn't do it on my own. I couldn't get up. (061: 2590-2613)

The profound disruptions within the lives of this couple seemed to ienerate little notice or alarm on the part of health care providers who managed r care. While health care providers had been alerted to Julie's physical pain

tional suffering, it is doubtful that they were aware of the disruption

eir day to day lives. Julie's parents also seemed unaware of the couple's

endence. Their concern that they be married and live apart prior to the

y was impractical given her current dependence on Nate for physical

l Possibilities of Totalized Care Giving

te's patterns of care giving in the everyday opened up certain relational

es for the couple. Julie was able to develop a strong attachment to

a sense of vulnerability which may have been a new experience for

dition, Nate's patterns of care may have allowed her to maintain a level

ning that may have not been possible without his assistance.

e's valiant efforts, in addition to awarding him the status of "protector"

ationship, also gave him a sense of meaning and purpose in his life.

Nate: It takes a lot of energy. It takes a lot of energy but it's not like I'm using it to do anything else so. I'm not like going to go out and climb a mountain instead. I mean, if I wasn't using it to do that, then I wouldn't be using it to do anything, so...

nt: Right. So you feel like it's a good investment, like you're pending it on

te: I don't feel like it's wasted energy. I don't feel like, I mean, if vasn't for that, I mean, if we were single and I didn't have to deal this, I wouldn't be, I don't think I'd be using that energy to do ething like monumentally different. I do feel like I'd have more gy to do just kind of things, personal things like building my nal life. Like I've been trying to build a website for myself for and just have never got around to it. And I know if we t together I'd have to deal with anything, not just her pain but ng together. If I didn't have that commitment then I'd be spend more time on it but I can't say that I'd be finished. I'm good at ever finishing projects. I like to start projects I always finish them.

Int: They're kind of ongoing.

Nate: Yeah. So I mean, probably some of my energy that could have gone to that goes to helping her, but I don't feel like it's wasted energy or anything like that. (062: 1856-1896)

Nate acknowledged difficulty with "finishing projects" in other areas of his life, but his commitment to Julie was unwavering. When Nate was asked in the couple's interview to talk about his decision to move forward in their relationship despite their struggles, he emphasized the positive rewards of the relationship.

Nate: Well, it's having companionship, having somebody to talk to, having somebody who's there by your side no matter what. I mean, I know because she sometimes says "Why do you stay with me?", the same question, "Why are you still with me?" And I say, "Well, if the situations were reversed would it be any different?" I mean, because I feel that she would have done the same thing. (061/062: 0804-0814)

He acknowledged the energy his care giving required, and yet consistently emphasized the positive rewards of his care giving. Despite a relationship that was totalized by care giving, Nate was moving forward in their relationship by formally committing to a life with Julie.

The care giving patterns within their relationship, make some possibilities available, and close down others. For example, Nate's primary role as care giver in the relationship, shifted the majority of responsibility of "maintaining" Julie's wellbeing to Nate.

Nate: She's mainly worried about not being able to have kids, but that doesn't affect me nearly as much as she's in pain and she's just in pain a lot and it affects everything about her. She doesn't have the ability to do as much as she could and she takes more maintenance. (062: 1497-1504)

Julie's dependence on Nate contrasted significantly from other women in the study who took more proactive and independent approaches of managing their health. One woman who also suffered from immobilizing pain in the morning, learned to expect pain, and therefore, be prepared for it. This shift in illness understanding prevented her from being surprised or caught off guard by the pain's immobilizing effects. Rather, she developed an effective pain management ritual that involved keeping a supply of pain medication and water at her bedside table, in which she self-medicated immediately upon waking. She would set an alarm and go back to sleep until the medication took effect. This daily routine prevented her from being immobilized by the pain.

Other women in the study implemented a strategy of carrying with them an "arsenal of pain medicines" to treat pain, which was quite different than how Julie managed her condition. Rather, Nate would "intuit" her pain and offer her an array of comforting strategies, such as pain medicine, a drink, or a blanket to alleviate her suffering. This dynamic of relying on Nate to care for her when in pain, closed down possibilities of Julie acting autonomously and independently in managing that pain. Hence, she could seldom function separately from Nate in the world.

Another relational possibility that was perhaps closed down by Nate's role as care giver was his inability to express a wide range of emotions. In addition to direct care, Nate may have carried the responsibility of keeping the uncertainty of endometriosis at bay, to be the "strong" one or the "rock" in the relationship. To

live in a vulnerable emotional realm may have threatened his ability to "jump-into-action" to care for Julie when necessary. Nate's stoic stance troubled Julie.

> Int: What would make you feel supported?
>
> Julie: That's a really good question because Nate tries to ask the same question because a lot of times I accuse him of not caring or not being supportive, which offends him a lot, a lot, a lot. And he goes "Well, how should I support you?" And I go "Well, you always seem so strong. You never seem like any of this affects you. I want to see that me being in pain besides you just helping me and taking care of me actually affects you emotionally." I said, "So if I'm crying because I'm upset or worried, I'm not going to be able to have kids or something like that, one of the more emotional aspects besides just the pain aspect," I said, "Cry with me. Or if I'm depressed, you don't have to be a rock." It's hard to hug a rock. (061: 3007-3028)

Julie interpreted Nate's lack of emotional expression as a lack of caring, even though his actions strongly suggested otherwise. An ability to be vulnerable may have been closed down by his care giving role.

Another possibility that may have been closed down for the couple was a flexibility and adaptable of action within their relationship. With Nate being so thoroughly the caregiver, certain expectations for action were formed. For example, Nate expressed how difficult it was for him when he was the one who got "sick" recently.

> Nate: Sometimes if there's anything wrong with me then it's harder (caring for her).
>
> Int: Yeah, then what happens? What if you're having a bad day or you're in pain or you're sick?
>
> Nate: I just, I drop out basically. Like if I'm sick I just say I can't, I'm sick. I'll just stay asleep.
>
> Int: You say "I can't help you"?

Nate: Yeah.

Int: And then what will she do?

Nate: Up until, actually last week I had a cold. I'm still kind of getting over it. And it was the first time like I was, I got sick on Thursday night. I'd been sick like the whole week before. Well, it hit me in my stomach first and it was just a really bad cold and so I wasn't feeling well the whole week. And I'd been telling her, "I'm not feeling that well," and she kind of laid off pressing me on doing other stuff because we wanted to get the kitchen painted. Before that it'd been like "You've got to work on the kitchen, you've got to work on the kitchen." So I started saying, "Okay, I'm not feeling that well, I'm kind of tired." I'd just come home and sit on the couch and not press myself. Then she wasn't pressing, she was kind of backing off, which in previous times, I felt like if I've ever said I'm sick it didn't, it just kind of bounced off, it didn't

Int: It didn't quite register?

Nate: Yeah. And just this last week I really felt like she listened to me and when I was, like Friday and Saturday I was flat, and she didn't push me to do other stuff. But one thing she did on Friday. I was in bed, I was asleep, and she went out to mow the lawn and this is only the second time in her life that she's ever mowed a lawn. So she was starting to have trouble and again pushing herself to the point where she couldn't, she was starting to get to that point where she's like stopping functioning basically and she called me and so I had to go out there and finish mowing the lawn. I'm just like "ooohh." But afterwards she said, "I'm sorry I did that. I didn't mean to." I went right back in and fell asleep and she didn't push it any further. And Saturday she didn't make me do anything, so. (062: 1074-1140)

This narrative illustrates several points. First, Nate was astutely aware of the shift in action when he was unable to function as care giver. There was not a range of care taking possibilities available for Nate that may have involved caring for Julie in a less demanding way. Rather, Nate was forced to "drop out" of his care giving role. Second, Nate did not have any expectations of reciprocated care. Instead, he was most grateful for the reprieve in his role of care giver. It

was possible that Julie's attempt to mow the lawn was a care giving gesture as she saw it as his responsibility and she took it on, but when her attempt failed, they both seemed to assume than finishing the lawn took precedence over Nate's need for rest. Third, his self-depiction in the text such as "she laid off pressing me" and "if I've ever said I'm sick it... just kind of bounced off" suggested hierarchical positions within their relationship in which he was being disregarded and unattended to as a partner.

Another relational possibility that may have been closed down for the couple was receptivity to support from others. Support and assistance coming from outside their relationship may have threatened the balance they had established; Nate's role and identity as protector and her entrenched role as recipient of care and attention may have been threatened by external support.

> Int: You guys are going through a lot and I guess I just wonder who the heck do you talk to about it or share some of your struggles with?
>
> Nate: Each other.
>
> Julie: Each other.
>
> Int: Each other. So you guys are, it sounds like, a really strong support for each other.
>
> Julie: Yeah. I mean, it might not be the best thing that we don't talk with anyone else. Probably not. But we're like a little self-contained cell. I mean, it's like I think it's like, it works and it doesn't work. It's functional and dysfunctional all at the same time.
>
> Nate: It probably wouldn't hurt us to talk to other people.
>
> Julie: Yeah, probably not.
>
> Nate: But we find our support in each other.

Julie: Yeah. Yeah, even if I did talk to other people, I still feel better when I talk to him about stuff.

Int: And it sounds like, because he understands in a way that maybe other people can't. Would you say that that's true?

Julie: Yeah, definitely, because he's here all the time. I mean, even my parents, when I tell them, they don't get it.

Nate: The only other people that could really understand are other people with endometriosis. (061/062: 3837-3880)

Julie may have understood the paradoxical effect of their relationship, that while it offered many benefits, it also posed limitations. Although Julie had an acquaintance who was someone she had met at an endometriosis support group who had recently undergone surgery, this friend was not someone who offered assistance in day to day life. It is a possibility that those who could truly "understand" may have been so overwhelmed and consumed by their own illness experience that they were not physically or emotionally available to offer needed assistance.

Another limitation created from the care taking patterns within their relationship was the opportunity for a pleasurable life that was not totalized by lness. Other than their new home, the couple shared few aspects of life that vere not related to the illness or care giving. Nate acknowledged that Julie was is first girlfriend, and he did not express any desire or curiosity about dating, or esire for a different kind of life.

Nate: Julie's really my only girlfriend that I've ever had and we were only together like a year or so before she had it.

Int: So you guys were together a year and

Nate: Basically as soon as we moved in together is when she started presenting symptoms so. When we moved in together that was like, it just kind of came with it. So it was like, I mean, I don't really have anything to compare it to, to say this is how it would be if I was with somebody who didn't

Int: Right. Like this is all you know.

Nate: Yeah, this is what I know. (062: 0013-0032)

The couple did share pleasure in eating together, yet food and food preparation were also tied to Nate's care giving role since he cooked for the couple. They both acknowledged Julie only cooked simple dishes on occasion. As a couple, they shared the task of provisioning. They had a ritual of going on an extensive shopping trip together once a month to stock up with necessary ingredients.

Because Julie's pain worsened in the evening, Nate made efforts to make sure she would eat dinner. He would cook her foods that she liked, believing eating was important for her health. In addition, "eating" was one of a few activities that gave Nate pleasure.

Nate: I enjoy eating. I enjoy food a lot. And I wouldn't say that's where I derive my joy from but I like it a lot. And so if it's there, yes, I'll probably eat it and even when I was eating better, if it was something that I really liked I would oh, I'd eat more or whatever because, for whatever reason. But I know that my normal, for me to exist normally, I need a very little amount of food and don't need it on a regular basis and I feel fine. I feel I feel better because I lose weight and just everything gets better because I'm not as heavy.

Julie: I don't press you to eat breakfast. I try to eat breakfast.

Nate: Yeah. And I try to help you to eat breakfast too. (061/062: 3001-3022)

While food may have given him pleasure as well as being a way to care for Julie, the tangible effects were evident. Nate had gained over 50 pounds over the past couple of years and simultaneously, Julie had also gained a large amount of weight.

> Julie: When we first started having sex I knew that I could lean backwards, like way backwards...like after a while I started leaning backwards and I'm like wait, what am I feeling? And I'm like oh, my God, those are rolls of fat on my back! I can feel the fat on my back and it used to be that my back was bone and just like the skinniest layer of skin, like the thinnest layer of skin. I used to be, since the endo came I've gained 35 pounds. (061/062: 2670-2683)

The couple's mutual weight gain may have been a consequence of numerous factors, including decreased exercise and increased stress levels. Another possibility may have been eating together was one of few pleasurable activities they shared.

Whereas in the past, their sexual relationship had been a pleasurable part of their lives, Julie and Nate's sexual relationship had become problematic, particularly for Julie.

> Int: Has anything changed in your relationship since the endo or because of the endo?
>
> Nate: I don't know. It's hard to tell.
>
> Julie: I'm not as happy as I used to be, for sure.
>
> Nate: But that's not really with each other.
>
> Julie: Well that's true. (Long pause)
>
> Int: Maybe that affects your relationship? (Long pause)
>
> Julie: I don't know. He's more of a, it sometimes feels like he falls into more of a caretaker role than like my lover role. So I think that would probably be the biggest thing is that I'd prefer him not

to have to be in that position. I'd prefer to be independent enough to do it on my own. (061/062: 2232-2257)

In Julie's view, Nate's absorption in care giving disrupted her attraction to him as a lover. One aspect of the disruption may have been her own dependency, which made her fell less attractive as a sexual partner and reciprocally less attracted to him as a lover. However, another aspect of the rift appeared to be his capacity and willingness to care which may have cancelled out his attractiveness as a sexual partner.

Their current sexual relations were contrasted by Julie with their previous relationship, prior to the endometriosis. Earlier, both had prioritized their sexual relationship, made time for intimacy, and by their accounts, had a lot of fun as sexual partners. They contributed the decreasing frequency of their sexual relations to complex factors including dyspareunia, and Nate's libido.

Julie excitedly got up from the interview to share a recent purchase of some new lingerie. While this gesture symbolized excitement and hope on Julie's part about their sexual relationship for her, Nate's role of care giver competed with his role as lover.

Nate: I think part of it is just that we've both kind of had a decreased sex drive. I don't think with relation to the endometriosis just kind of, we had a lot of sex in the beginning and it's just kind of trailed off as we've been together.... (062: 2841-2847)

Int: So I guess I just want to explore that a little bit more, about the change. So can you think of anything else that might have attributed to that, other than your length of time together.

Nate: More tired, more just, with working and just more tired.

Int: It might be that energy thing.

Nate: It could be.

Nate: That probably is part of it. She's always had, at least at the beginning of our relationship and through most of it up until basically now she's always had a higher sex drive than me. I never had a really high sex drive to begin with. Like after the first say four or five months together it was, I was not performing enough.

Int: And she let you know?

Nate: Yes. And then there was kind of a period where we, she kind of trailed, like came down to my level of sex drive and then, but especially over the past like say nine months, both of our sex drives, I think we both feel that we'd like it a little bit higher, but we just

Int: You both would? You both would like it a little higher.

Nate: Yeah. (062: 2937-2973)

There are several reasons Nate may have been less interested in sexual relations. His laborious daily routine and responsibilities may have made him to too tired. Julie and Nate may both have been struggling with shifting relations, including their work against traditional gender expectations (Okin, 1989) and shifting hierarchies within their relationship.

It is striking that at this time of apparent unhappiness with at least some aspects of their relationship, they were planning a wedding for the near future. To the external observer life may have seemed exciting and bright for this couple, but their narratives illuminate a relationship that is totalized by care giving. It is possible that getting married, and buying and renovating their home were desperate gestures toward a "normal" life.

Balanced Care Giving

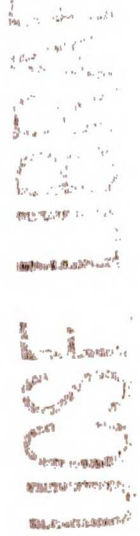
This section presents the paradigm case of Celeste and Frank, a couple chosen because their story illustrated in numerous ways balanced care giving, which contrasts the previous case. While Frank did take on a care giving role, it was not his primary action in their relationship. Together the couple took up creating a meaningful life together accommodating the day to day needs of endometriosis. Their relationship, as evidenced through the actions in their day to day lives, was infused with sensitivity and mutual concern for the other. Most notable was a coupled relationship that demonstrated flexibility and reciprocity of care.

Background

Celeste and Frank had been living together for approximately four years. Celeste had been diagnosed with endometriosis approximately three years prior to the interviews. She was a clothing designer, and worked part-time in an upscale woman's clothing boutique. Her creative abilities were evident in the ornate window coverings she had sewn for their home. Frank was the owner of a large restaurant and had been working long hours for the past couple of years.

Celeste and Frank had been living together one year before Celeste experienced her first pelvic pain episode.

> Frank: She woke me up at four o'clock in the morning for me to make something to eat and I went and made something. She ate it, fell back to sleep, half hour later, she was complaining, just like couldn't move like a belly wound, like a bullet wound in the belly. She couldn't move, couldn't do anything and I said, "Oh, my God, what should I do?" "Do you want me call 911?" She said, "Call 911." So I called them, they came and first thing, they came and asked if we had been doing drugs like because they found her in the



> bathroom curled up on the floor and it looks like O.D. (overdose) or a drug thing. Fifteen firemen and paramedics came in and went through the whole thing, kept asking me, "Are you sure you haven't done any drugs? You've done any drugs?" And we just said, "She's been taking Acidophilus, everything's right there on the counter." They went through everything, loaded her in the ambulance, took her to the hospital and at O. Hospital and they couldn't find anything wrong with her. They said they found a little bit of fluid but other than that they thought it was possibly in her head. And that's where this whole thing started. (042: 0085-0117)

This experience was frightening to Frank as evidenced by the tone of his narrative. As a partner, he most likely wanted to help but not knowing the cause of her pain, he may have felt helpless and uncertain as to how to help. The professional care they received that night may have provided temporary relief for Celeste, and comfort to Frank, but the couple was also distressed by the care they received. First, there was a sense of violation and intrusion as firemen and paramedics repetitively questioned Frank and "went through" their home looking for clues of an overdose or other plausible explanations of her severe pain. Second, the couple perceived that health care providers suggested the pain was "in her head". This undoubtedly added confusion and uncertainty to an already disturbing situation. In both cases, with the paramedics and subsequently with the physicians, there was an intimation of blame in the explanation for her pain. It is not known how Celeste's age and gender may have influenced these initial assumptions about the cause of her pain.

When Celeste was discharged from the hospital, she continued to experience disabling levels of pain.

> Celeste: When I was at the hospital...everybody looked at me, GI doctors, gynecologists, I mean I don't know, probably like seven, eight doctors. When I was in the hospital they couldn't figure out

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what it was. So nobody gave me the diagnosis. And then I did follow ups with gynecologists actually at T. Hospital. They said ... "Well, just go home and if this doesn't get better in a few months come back." I was like, I can't function. You know? And so, I said something has to be wrong with me. This can't be okay or normal. I can't just take Motrin and be in bed for months. And so, I kept looking for doctors to be able to help me, because I still hadn't gotten a diagnosis. And then eventually, I think it was like in April, I found a doctor and he said, "You probably have something that is called endometriosis. I can't say, I'm about ninety to ninety-five percent sure that you have this. And, we need to do a laparoscopy." And so that's when I had my first surgery. (041: 0153-0195)

eleste's surgery which confirmed a diagnosis of endometriosis, she

live with CPP.

Celeste: I pretty much have chronic pain everyday. Sometimes the pain is really bad, depending on what's going on. Sometimes it's very low, like it could be down to, at times it can even be a one or a two, mostly like it never goes down to a one, but like a two. So it's you can actually have, I feel like I can deal with it. I don't have to think about it all the time, but when it goes up to like 4, 5, 6, it gets harder not to think about it. Then you have to start using more pain relievers and things like that. When you have pain all the time, it wears on you. You get very tired. Not only emotionally, because it reminds you all the time, but physically. I think it's just you get tired of your body having to feel the pain all the time. And sometimes, actually a lot of times, you can't do everything that you want to do. Like you can't go out running or I have to think about a lot of things all the time. Diet is a big part of me so it plays a role. Sometimes I can't sleep on one side because it hurts. So, it effects me all the time, and, and I try to kind of flow with it more than trying to let it consume me. When things are pretty good, it's easier to be optimistic and positive and strong, like, "Yeah, I feel pretty good now," when things are going well. And then when things are not so good, and you're laying in bed and you're in mega-pain and you just feel like you want to hide, then it's emotionally very hard, too. So, then, it's easier that it does consume me. So, I don't think that there's, it goes back and forth. But I try to live my life as much as I can when I feel good. And, yeah, kind of do other things in my life that are positive so I don't have this on my mind all the time so it does consume me. So, the balance there sometimes is hard but I try as much as possible, because it's going to be a richer life for me and for Frank too. (041: 0320-0374)

Throughout the interviews, both Celeste and Frank used numeric scales to describe her pain and functioning levels. With lower levels of pain, Celeste had the ability to function in other meaningful areas of her life, and was able to maintain an outlook that was "positive" and "optimistic." Celeste was cognizant of the disabling effects of her pain, and was concerned about the effects it may have on her relationship with Frank. Although Celeste experienced pain nearly every day, some days were much worse than others. Severe pain triggered feelings of hopelessness, which was in sharp contrast to the way Celeste wanted to live her life. Celeste's primary concern was her health and doing what she could to decrease her pain levels, as she understood what was at stake when her pain reached debilitating levels.

Creating a Meaningful Life with Endometriosis

Celeste believed endometriosis was caused by an imbalance of her body, possibly related to her immune system. "Healing" represented returning her body to a "balanced" state. Frank agreed and consistently witnessed that her symptoms worsened if she ignored basic needs such as adequate sleep and good nutrition. Despite her chronic and debilitating levels of pain, Celeste did not take "heavy hormone" treatments such as Lupron. Rather, Celeste sought treatments that were consistent with realigning "balance" in her body.

Celeste went to psychotherapy, and *chi-gong* and Pilates classes. She believed in meditation and structuring her thoughts in a therapeutic way.

> Celeste: I think, the way you can, kind of structure your thoughts, too, that the way you think about things can effect how you handle pain and how you handle your day and how you handle your life

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> really. And how when you, yeah, I think you're, you're, the power that you have in your mind can be, it's a very powerful tool. And I think you can also use that with visualization with, I mean I have no proof that this is, that this is helping me, but, I, I feel better when I do it. And I do, sometimes I put my hands on my, on my abdomen, or my pelvis, sometimes I put one hand on my heart, and just kind of, you know, give that area attention. And transfer love from my heart to my abdomen, just to, to show that I know this part of my body is going through a hard time and just to put more awareness on that area … and, instead of just trying to, which I did a lot of in the beginning, was looking at it as if what's wrong with you. I don't have time for this. Stop. And so forth. So I was, now I'm starting to be more gentle, and being more helping towards myself, than, rather than trying to shut it part, you know, just living in my head and separate myself from that. So I'm kind of unified more. (041: 1288-1319)

Celeste described a shift that went from trying to ignore or "separate" herself from the needs of her body, to being more accepting of the new requirements of her illness. Rather than embodying negative feelings about certain parts of her body, this shift allowed her to integrate a more "unified" and affirmative perception of self.

In addition to self-care strategies, Celeste sought treatment from an acupuncturist and took Chinese herbs. As a couple, they engaged in numerous daily habits and practices that were "patterned" around the needs of Celeste's illness. For example, the couple had moved from their previous home because noise from neighbors interrupted Celeste's pattern of sleep.

> Frank: Once she starts sleeping through the night, then the pain thing starts to go down and then, so it truly is a cycle that we have to recover from. It's like someone having an asthma attack. You've got to talk them back down and get the inhaler and get them to come back down to a stable ground and it's very, very much like that. No rest or too much stress or too much pushing yourself, by not having enough sleep and working twelve hour days, boom that guarantees that she'll come home the next day and say I don't feel good or I've been "hurty" all day and so that's why I've really been

[illegible]

> pushing her to put yourself first. Really, really, really do that. (042: 1196-1213)

"Hurty" was a term the couple had coined to describe the period of time when Celeste was in severe, as opposed to lower levels, of pain. The audible noises heard through the walls, kept Celeste awake at night. The couple initially remedied the situation by moving their bedroom into their living room. As the situation grew more problematic, the couple searched together, and found a new home that met Celeste's sleep requirements.

At the time of the couple's interview, Celeste and Frank were settling into their lovely new home which was protected by large eucalyptus trees in a quiet rural neighborhood. Mutual awareness and prioritization of Celeste's health allowed them to collectively find a home that was extraordinary, while also meeting their personal needs.

While adequate rest had become important to keep Celeste's health in balance, "eating right" was also crucial.

> Frank: The responsibilities have just been more like really defining this whole rest pattern and because again, I know, I know when she goes too much or we're not eating right or we eat out three nights in a row because we're so busy, that's when everything flares up again. (042: 1238-1245)

Together, Celeste and Frank took on the "responsibility" of creating new "patterns" in their lives, to avoid exacerbating the pain. They made an effort to eat "health-conscious" meals and ate an organic and hormone-free diet. When asked if their responsibilities of daily life had changed because of the illness Frank replied:

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> Frank: When we eat at home, we'll have two types of vegetables and a piece of fish or chicken and maybe even a salad so it's very, a very health-conscious type meal. We don't fry a lot of food and most of the stuff is organic or no hormones. So when we go out and have a burrito or something, we're not eating vegetables, I even see a pattern in that where she will not feel good so that's why we have made adjustments that we don't eat out three times unless we absolutely have to and if we do, let's try to go someplace like sushi where we can get a salad and fish and soup and that type of thing versus going for fast food. I mean, we don't eat that stuff anyway, but that has been a responsibility. Also another thing that I have noticed that eating at different times sets it off as well. So it's really we need to kind of get into a manageable routine. Let's try to eat by six o'clock. Let's try to eat in as many times as we can and let's plan and so in the last couple of years to combat all this, we've really kind of figured out a structure that has even kind of turned into a routine that we shop on Saturdays, we buy enough stuff to get us dinner Saturday, Sunday, Monday, Tuesday and then we'll pull something out of the freezer for Thursday and maybe eat out Friday or something. So that has been a responsibility to keep that going ...I really have noticed that it does affect the pain levels...running too hard too fast and not resting and not eating right that is just a recipe for her to be uncomfortable. (042: 1255-1300)

The aim of this question was to understand possible shifts in responsibility of household tasks since the illness but Frank's response was quite illuminating. From his perspective, rather than transferring responsibilities from one partner to the other, the new "responsibility" was to jointly construct a structure and routine that kept her symptoms at bay. It's striking how joined he perceived them to be in this process as is evident in the repetitive reference to "we" taking action. The only time he referred to himself in singular form is when he was observing her symptoms. Otherwise, all action was presented as conjoined and directed to prioritize Celeste's health and wellbeing.

Celeste shared the belief that optimal daily patterns were correlated with less pain, but more in the foreground for her, were issues related to work. As a

[illegible]

result of her CPP, Celeste was forced to quit numerous jobs. She maintained a hope that improved health and a decrease in her CPP, would allow her to pursue her career again full force.

> Celeste: You kind of have to accept, I mean, it's hard for me sometimes but you kind of have to take a little bit of just a more easy going approach than I would if I didn't have endo, because I feel like oh, I want to do this and that and yeah, I can figure this out, and finish this project.
>
> Frank: And then you pay for it.
>
> Celeste: And all that. And I can't do as much as I could before I dealt with this and I know that. But sometimes it's hard to balance, but yeah. I mean, I can't be, I know that right now I can't be a career woman that is working from six in the morning to ten at night. There's just like absolutely no way. It couldn't happen. (041/042: 2217-2235)

While Celeste had the drive and incentive to be more productive at work, both she and Frank agreed that if she worked too hard, or too long at the boutique, she would "pay for it" by subsequent sleeping difficulties and exacerbated pain. Celeste had accepted, at least temporarily, that she had to make lifestyle changes, including changes related to work, that would accommodate her illness as a result of her physically limited capabilities.

Celeste's part-time job at the clothing boutique was a gesture toward a balanced life as it opened up numerous possibilities. One possibility may have been that her position at a successful and trendy boutique was a connection to the fashion world. It may have also created a sense of purpose in her life, as she took much pride in her responsibilities. From a financial perspective, just as Frank had been working hard to develop his thriving business and was reaping

the economic rewards, it was possible that Celeste also wanted to contribute financially to their relationship.

One benefit of Celeste's job was its tremendous flexibility, which allowed her to expend energy relative to her physical capabilities at any given time. For example, if Celeste was feeling particularly well, she had opportunities to work extra hours. Celeste had missed work because of pelvic pain related to endometriosis and during her post-operative recovery periods. Her unique work related disability was having limited reserves of energy. If she expended more energy than she had, pain would follow. Celeste lived her life, including at work, needing to ration her energy reserves.

> Celeste: If you have a project that kind of needs to be done you think okay, well, I'll just instead of putting a five, you say okay, well I'll go to six but then maybe that's compromising a little bit too much of yourself. And where's the boundary there?...It's like if you want a little bit of both it's really hard.... (041/042: 0288-0299)

> I don't have the energy to do as much as I used to. Or maybe other people maybe have energy to work a whole day, make dinner and then go out. I can't do that. I can only do, work all day, come home and eat. You know what I mean? So, it's very limiting in that way that I have to think about how much can I do without wearing myself down too much. So sometimes, I even, I even push at it a little bit too much because I just feel like, okay, I just need to finish this, or something like that, when I know that it might go a little bit too far. But so, it does affect me, because, affect the relationship in the way that, you know, I come home. Frank has had like a long day at work. He doesn't, he's too tired to make dinner. I'm too tired to make dinner. So, if, if I wouldn't have to deal with physical issues, I maybe would have had the energy to go, oh, I'll make dinner. Or, I'll, you know, so, maybe if I pick something up at the store I just go, here, you know. Really, it's really like that. So, that's what I mean, it affects us everyday.

> Int: Right. So who makes dinner then? Who would make dinner, if you're too tired and he's too tired?

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Celeste: Well, either, you know, we pick something up on the way. We go out somewhere where we feel like, okay, well let's go out, and ...

Int: So you guys buy dinner?

Celeste: Yeah. Or, you know, pickup, you know, like something at, you know, or make something really easy....so, that's another way of adjusting. But I think that affects our relationship because I can't do as much as I would like to. Like, if I, if I, I kind of have to pick what I need to do. And sometimes I think Frank feels like, oh, you know, he feels like, he's got to do a lot of things. He does enjoy making dinner, a lot, because he likes making food, but, I, I, I would like it to be balanced as much as possible, and sometimes I feel like should I think about myself? What I need to do? Or should I compromise that and help him? Because otherwise I'm compromising what he needs from me. So it's, it's very hard. That's I think the day-to-day basis for how we deal with things in the relationship, that way. And usually it functions pretty well. (041: 2112-2198)

Celeste struggled with balancing a sense of accomplishment and taking care of herself. At times, this created conflict within the couple, as it was hard for Frank to understand Celeste's decision to choose work over her health needs.

Frank: I've noticed one thing again, with this pattern that when Celeste lets her batteries get down is when it gets worse. When she doesn't take care of herself or is like putting work in front of her health which it's really easy to do especially when you get in the workforce. I've got to work, I've got to go there. You don't feel so great but I got to go. I can't call in sick, so-and-so is gone, I'm covering for her. I've got to go do it. Well, when she doesn't get good sleep or she works too much, too many days in a row, that's when you see she doesn't feel good. She comes home, "I feel terrible, I hurt and my pain's at a six," and those types of things... So you are letting your batteries get way down so trying to get her to say forget work, tell Carrie (her boss) to forget it or whatever, you can't do it. You need to put yourself first because this is the type of thing that can affect the rest of your life. And to put a ten dollar, fifteen, or twenty dollar per hour job or whatever she makes there, to me is not worth it. It's not worth it. We'll get by. You could quit that job tomorrow, we'll figure it out. I guarantee you we'll figure it out. But that's how I know and once the pain thing starts happening, then it's kind of like the domino effect. Now she doesn't

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> sleep very well because she's in pain and so then she'll take Advils or whatever and it takes a couple days of that just to get her back to where now she can sleep through the night and then once she starts sleeping through the night, then the pain thing starts to go down. So it truly is a cycle that we have to recover from. (042: 1158-1199)

Celeste believed so much of her life had been put on hold as a result of the illness.

> Celeste: Everything has been kind of on hold for me, because of this and I feel like, I still have things I want to do for myself. Traveling and I want to focus more on my career. I want to just go dancing or, or, at night or be a little bit more irresponsible. Get a lot of that out. I feel that, because I've had times where I spend so, I haven't been able to do that. It just kind of feels like it puts you in, in, in a box. (041: 2839-2835)

Celeste may have felt blamed by Frank or responsible when she experienced worsening pain episodes. The feeling of living "in a box" may have been due to an inability to push herself or go beyond her safe "boundaries" because she feared personal and relational repercussions of pain. She feared that increased pain and subsequent demands of care may have disrupted the delicate balance they had integrated into their lives.

Frank had a sense that work was important to Celeste yet he did not worry because he believed in her talent and capabilities.

> Frank: We're not 19 years old…with the career thing we know what we're going to do. I know what I'm doing and it might not be forever, but I know what I'm doing now. And Celeste doesn't really think she knows but I know. She's a designer and she will be doing design stuff no matter what it is. I don't know whether it's fashion design.
>
> Int: She'll be doing design.

> Frank: She'll be doing some medium whether she'll work in a boutique or creating her own line of clothing or accessories, it's going to be something like that. (042: 0383-0399)

Since Frank was not concerned about her future career success, the money gained from a twenty dollar per hour job was not worth the permanent cost it may have had on her health. However, Celeste struggled with the much larger issue of deciding how much of her life she was going to give up, or put "on hold" because of the endometriosis. She struggled with personal ambitions that had nothing to do with money. Frank's encouragement for Celeste to call in sick when she was in pain or if "her batteries were low" was clearly considered a thoughtful and generous gesture, but for Celeste it may also have been a reminder of her continued disability. Despite their mutual efforts, her ability to work was a reminder of what she had already lost because of the illness.

Despite this running conflict, Celeste and Frank's relationship embodied a quality of freshness and sense of vibrancy. As they made new discoveries together, they adjusted their lives in meaningful ways. They patterned their lives around the needs of Celeste's illness, but also preserved space and time in their lives for other things, cultivating a meaningful life with endometriosis together. Actions of care giving within their relationship were demonstrated in their flexibility and reciprocity of care.

Flexibility of care. Both Celeste and Frank agreed that Celeste inherently was an "independent" person. Her independence was apparent throughout the interviews as Celeste consistently took charge of her health care. She

autonomously sought care from various practitioners and integrated self-care strategies into her day to day routine.

> Celeste: There's a, a Chinese herb called Moxha. Which is a, I don't exactly know how to explain it. But you light it and it, it, it, you have, you, how should I explain this. You, you, make, it's kind of glowing. So it's not burning, but it's, it's, and then you, you keep it about an inch or so above your, your skin. I do it on my, my abdomen a lot. So it increases the circulation and the blood flow a lot. And it, it penetrates a little bit deeper than if you would just put heat on. It's, it's, an Asian herb that's supposed to be very, very healing and, and, so, sometimes I do that everyday for like half an hour and sometimes even an hour. And it really does, just, makes everything, like the circulation instead of having that stagnant feeling, it moves things better. (041: 0928-0947)

Celeste was referring to concepts of Chinese medicine, and her intention was to move "stagnant" energy, also known as *chi*, which decreased her pain. She also demonstrated self-sufficiency by being prepared for pain at all times.

> Int: It sounds like it would be really hard to live that way, not knowing if pain is right around the corner.
>
> Celeste: Yeah, it's very hard. Yup. That's why I go around sometimes having little pills with me, because I just feel like, if something happens, I just know that if I can take something so I don't have to be in, that it will help it until I get to the hospital or something. So, it changes your, your thinking… ((041: 2759-2771)
>
> I don't know if I should say this, but, actually, when I had surgery last time I got some morphine pills and, and, and so sometimes I even carry those. Because I don't know if something can happen anywhere. I know how painful…
>
> Int: It's like security, almost.
>
> Celeste: Yeah, Yeah. (041: 1051-1057)

In addition to Celeste's self-reliance, she also demonstrated tremendous foresight and self-determination in caring for herself. For example, at times when

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her pain was more tolerable, she made efforts to put together a useful and constructive support system.

> Celeste: There are things you can do on the physical level. I think there are things you can do on the emotional level, like trying to be in a supportive environment. I think that becomes very important that you have people that can help you. That when things get a little bit tough that you have a supportive partner, that you have friends, family, support groups, doctors, so you have like a network. So you set that up before things start going downhill, because it's easier to, to do that when you're feeling well. (041: 1267-1280)

While having a supportive partner was important to Celeste, she did not rely exclusively on him. Assembling a group of people to offer support in times of need may have been particularly important for Celeste considering Frank worked long hours during the day.

Being independent came naturally for Celeste but she found it more difficult to rely on Frank in times of need. In the couple's interview, when she was asked what symptoms affected their relationship, she pointed to times when her pain impeded her independence.

> Int: Which symptoms would you say affect your relationship?
>
> Celeste: Because if I'm not feeling good and I start going on, having a lot of pain, then I'm really worried and have a lot of fear, then I might not be so calm anymore. And then it definitely affects us because then I need more from you.
>
> Frank: Right.
>
> Celeste: And I'm not maybe, I'm much more sensitive emotionally and physically and mentally probably, and I just, I just need more care and patience and, yeah, support from you.
>
> Frank: Right.
>
> Celeste: And then, it's more on Frank. So that definitely affects it. And then I'm not, it's not like I go around laughing. I mean, then I

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> feel pretty bummed out. So then it might not be the same kind of, "Oh, let's go out and have fun." It's more like, "Let's stay home and put a heating bag on and possibly take some pain relievers and possibly watch a movie at best." So that does affect it in those ways. And then we can't do certain things. If it gets bad enough, we might not be able to do things that we want to do or that we planned. So it affects it I think all the time.
>
> Frank: That doesn't happen that often though.
>
> Celeste: Not right now but it does affect it in a way of that, we might not push it as hard. If there's been a really stressful day, we might tone it down and take it easy because it's just too much to go out and do something. (041/042: 1734-1783)

Celeste was acutely aware of the shift that occurred in their relationship when she "needed" to rely on Frank for emotional support and physical hands-on care. Depending on him may have incited feelings of vulnerability and weakness. Although Frank reassured her by minimizing the number of occurrences in which she had relied on him, the issue remained one of great concern for her. With reoccurring pain, and having a new type of pain in a new site, there was a possibility that Celeste may have been uncertain about her future health and its impact on their relationship.

Frank clarified that the times when Celeste depended on him were few. One such time was the night of Celeste's initial pain episode when Frank called the ambulance for help. Another episode was after her second laparoscopic surgery when Frank took two weeks off from his busy work schedule to care for Celeste around the clock. Being the owner of the restaurant where he worked, gave Frank the ability to miss days without the risk of losing employment; however, the act was still considered a significant "sacrifice" to the couple.

Celeste: In some ways, I know it's been really hard...I know that at times, for example, when I had my second surgery, he had to take, he took two weeks off and that was the only vacation he got. He took it off because he needed to take care of me, because I, I couldn't do anything. I couldn't get out of bed. I couldn't move. I couldn't go to the bathroom. I couldn't do anything. So, so for him to sacrifice that, and it's different if it's a pretty light surgery and it's just a little bit of help. But when it's so intense, pretty much doing everything all the time. In the middle of the night I have to go to the bathroom. He has to get up, go around to the other side of the bed, kind of lift me up, help me. When I sit down on the toilet, all, all those things. And, and, that went on for a while, because it was pretty extreme at that time. And so, I think that was, I mean of course it was extremely hard for me, but I think it was really hard on him, too. I really feel like instead of us going away for a vacation for two weeks, he was at home and it was exhausting for him. And then go back to work. So, things like that I think, has been hard. (041: 0449-0486)

Frank provided hands-on post-surgical care that included ambulating and toileting Celeste. The couple shared during their couple's interview how this experience had left an indelible mark on their relationship.

Celeste: In a way I think it brought us closer but I also think that it was pretty, pretty hard on our relationship too, don't you think?

Frank: Well, I don't remember a whole lot of it but I know it was never to the point where I said, "I'm throwing in the towel. I can't do this." It was never that bad. Nothing like that. But yeah, I think there were a lot of things you had to do to make way for it and

Celeste: Yeah, a lot of work. I mean, there wasn't room for any, I mean, I didn't have a lot to give to Frank. He was the one (long pause)

Int: Yeah, taking care of your most basic needs, it sounds like.

Frank: But imagine being on the other end of that, having to have somebody take care of you. That can't feel super great either. Everyone's so independent and to be dependent on somebody, so

Int: I would imagine that would be very difficult.

Frank: Right. And someone who's as independent as Celeste, because she's independent, even trying to get her to sit still and things like that is sometimes, you need duct tape (long pause).

Celeste: Yeah.

Frank: Am I right?

Celeste: Yeah.

Frank: Yeah, it's all over with. It can still hurt though, huh?

(Celeste was crying. There was a long silence.)

Int: Can I ask what the tears are about?

Celeste: Oh, I think it's just remembering how it felt and remembering how extremely vulnerable you are. It's like you need help with everything and it's almost like you, it's like Frank said, it's very hard, especially, you're dependent. You're so dependent on everybody because you can't do it yourself. And that just makes it really hard. It's like you're, it's not like your self-worth but it's your life, it just feels like

Int: It reminds me of being an infant again.

Celeste: Yeah, yeah.

Int: And just needing to be completely taken care of.

Celeste: Yeah, you're so dependent on everybody else and what they do for you and things like that. And I think then also, thinking about it, of course I feel scared that things are going to happen again and things like that. But it's not something I go around and think about all the time. But when I think about how hard that was to go through that, I think about that. I really hope I don't have to go through that again.

Frank: Right. I think we both do. (041/042: 0776-0861)

While the experience, according to Celeste, had made their relationship stronger, she was profoundly aware of her level of dependence on Frank post-surgery. Frank had difficulty remembering the experience, but nonetheless, their

mutual concern for the other was apparent in their dialogue. At a time when Celeste was physically incapacitated from post-surgical pain, she was sensitized to the demands the situation placed on Frank, as well as her inability "to give to Frank." She realized he was taking a much needed "vacation" to care for her which may have been particularly meaningful for Celeste, sensitized as she was to the physical need for rest. In response, Frank empathically acknowledged how difficult this situation must have been for her. A level of intimacy and vulnerability was apparent from this intense caring giving episode.

As Celeste resumed mobility and the ability to care for herself, Frank stepped back from active care giving and resumed his responsibilities at work. Frank demonstrated the capacity to flexibly adapt the degree of care he provided to Celeste's changing needs. From their history, it appears that even in the most intense phase of physical care post-surgery, he handled care giving responsibilities with relative ease. Frank, having experience in food preparation and motivated by their interest in "health-conscious" eating, would surprise Celeste by baking special cookies for her.

> Frank: Dietary things like sugars can make this worse and yeast and bread, certain breads can make it worse. So we try to do treats. Like we've figured out, we've made a recipe of a wheatless, sugarless peanut butter cookie that we'll make a big batch and then we throw them in the freezer. Then if she doesn't feel good or something, I'll sneak a batch and kind of make cookies for her. But those types of things, making her feel that you're okay, you're not alone, I'm right here, I'm trying to do the best I can for what I got. (042: 1737-1750)

Using his special skills, Frank discovered a unique and creative way to show his continued support for Celeste, while also honoring the dietary requirements of the disease.

Frank acknowledged that his busy work schedule at times competed with his ability to care for Celeste.

> Frank: And for the most part, at least once during the day, I try to make an effort to call her and see how she's doing and I'm not the best at it, but it's on my mind that I want to call and see how she's feeling and see how the pain thing is. And again, it's all part of a support model that I'm trying to do and trying to fit in. (042: 1424-1432)
>
> Being that I run a large restaurant, I'm constantly working and I work from seven o'clock in the morning to eight o'clock at night almost every day. Sometimes I get so busy that she'll call and I'm just, "I'm going to have to call you back or I'm in the middle of a crisis." (042: 1641-1644)

Although his demanding work schedule made it difficult at times to provide what he believed were adequate amounts of support, he demonstrated a fluidity and flexibility of care.

Frank also shifted into actions of care giving during "lovemaking." Celeste experienced severe pain with "deeper intercourse" and had come to rely on Frank's sensitivity and understanding about their situation.

> Celeste: It's just when deeper intercourse. So it's just, when it hits certain places, I, I feel like I see stars, I mean. So it makes it very, very hard to relax with intercourse. And then it makes it extremely important that your partner is very careful and, and sometimes it's like, okay, so if, if, sometimes, I, he has to kind of take the responsible role and not get too excited, that he doesn't think. It's not, sometimes I feel like it's very unfair to have to live like that. But somehow it's working. It's like, I can have intercourse, it's just that we have to be careful. And if we're not careful, it's like, the worst pain ever. I mean it's, it's so sharp, it's, it's, it's awful. I mean it's like, it's hard also to be excited when you have to, you kind of

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tense up, and you know that it could happen. It could happen. So it's like

Int: You have to be careful.

Celeste: How do you couple that with being really excited? Yeah, so that's, that's hard. But I feel like Frank is very understanding and very supportive and he does think about that. He kind of, he, he like, he tells me okay, it's okay, you can relax. I'll be alright. And so it kind of puts me like in a state where I can relax more. (041: 1556-1593)

Together the couple had found a way to make their sexual relationship mutually satisfying. In this process, Frank demonstrated the ability to maintain the action of care giver and lover simultaneously.

Frank: It's more focused on Celeste and making sure that she's comfortable and relaxed and in the beginning after the first surgery, yeah, it did affect us, but again, it wasn't like the full-blown pain type of affecting. It was more of she couldn't relax because she was afraid it was going to hurt so it got to the point where we figured out warmth was a key to that. So maybe give her a bath first and get her relaxed and even to the point where we had gotten a warm towel and put a warm towel on her stomach and below her belly button. Kind of warm her up a little bit and relax her. It's okay. That is something that, again, we just kind of figured out like this is, hey, I've noticed and what if we tried this and it helps and then she would say yeah. Again, through communication that yeah, the bath helps and for the longest time, if she was uptight or feeling like she can't relax, of course she's never going to orgasm. She'll never get there because she's too worried about it hurting or something. So again, another positive by-product from this, from the endo has taught me to be a better communicator through lovemaking and being more connected to what the partner needs and what the requirements are and to really get as much out of it as we can. It's not just about jumping in and humping each other. It's a lot different than that. And that's something that I've learned through this, endo has taught me that and taught us both that. I bet she would say the same thing. That she's learned that through that and we might not have ever gotten to that level if endo had never been introduced. (042: 2910-2953)

Frank pointed to numerous "positives" that were "by-products" of their process of working through their challenges with their sexual relationship. First, by being perceptive and understanding to Celeste's anxiety, he was able to "figure out" an effective therapeutic strategy. Second, working through such a sensitive aspect of their lives together, most likely proved to be very challenging and possibly honed their communication skills with one another, in a way that was new to them.

Reciprocity of care. Also demonstrated in their relational patterns was reciprocity of care. Throughout the interviews it was clear that when Celeste could have been preoccupied by her pain experience, she was continually sensitive to the needs of Frank. For example, when Frank provided hands-on care after her laparoscopic surgery, she was not only aware of how much he was "sacrificing" but she also regretted that her pain disabled her ability to "give" to him. She appreciated his efforts especially because she understood what he was giving up.

Reciprocity of care was also demonstrated in an incident that occurred around scheduling the interviews for participation in the study. Because of their busy schedules, the couple's individual interviews were scheduled on different evenings. Celeste's interview was originally scheduled to take place at their home. On the day of her interview, she called to request the interview be conducted in an alternative location because Frank had had a particularly long and exhausting day at work and she wanted to respect his need for privacy and rest. This demonstrated that his health and wellbeing were also a priority in their

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relationship. The illness experience of endometriosis may have created an increased awareness to self-care for both partners. In addition, Frank's need for rest did not close down the opportunity to participate in the study, rather, Celeste's request for another meeting place, demonstrated the flexibility in which they lived their lives.

Relational Possibilities of Balanced Care

Patterns of balanced care opened up certain relational possibilities. One such possibility was increased intimacy and closeness that resulted from weathering the crises of endometriosis together.

> Frank: This has been in many ways a positive thing for me as an adult to see a whole other side of life and how things like this can easily put distance in between you and your partner but can also bring you much closer together. It's like people that have been in an earthquake together or a car accident together, there's some type of bond there. And I believe that even though there have been some surgeries and medical bills, we have by far come to a better place than a worse place in this and that's why we're very fortunate in this. I don't think that we're done with it either. I think we're coming into a new phase of this. And again, it's just from an educated guess of being three and a half, four years into this whole, once endometriosis came into both Celeste's and my life. (042: 0061-0080)

> I feel that we have, I think we've hit levels that some people that have been married for twenty-five years don't have the understanding and the closeness that we have because of this. Because we've been able to learn to be better communicators and be honest. And so many couples are so good at not being completely honest or omitting things just by, "Oh, let's not talk about it." Or she'll never know kind of thing, or he'll never know. This has really been one of those things that has brought us to an understanding because we communicate about all this stuff. (042: 2394-2409)

While Celeste agreed that they had become "closer," she deeply struggled with feelings of vulnerability the illness presented.

> Celeste: I think that because it's been going on so many years, I think it's a little bit heavy, because it's there all the time. And, I feel like that when things are not going so well, I get pretty needy. Like I need his support…So, a lot of it gets put on him, which he knows, and he feels, he feels that that's okay. But I can still tell sometimes, it's a little bit much for him. Because he has so much going on with him, and then it's almost like, he's got to help me, too. So, so it's, so it's definitely both. But it has brought us closer with things. (041: 0531-0546)

Frank's ability to move in and out of care giving actions opened up certain relational possibilities. While Frank exclusively took responsibility for Celeste's post-surgical care, he was able to move back as Celeste regained the ability to care for herself. Subsequently, Frank demonstrated a re-prioritization of his own work. Relational flexibility created opportunities for variability in care giving within the relationship, rather than rigid and prescribed actions.

Reciprocity of care also opened up certain relational possibilities. Celeste was aware of the effects of her illness on Frank and made careful choices about how much she would disclose on a daily basis about her pain.

> Celeste: Sometimes you feel guilty too because you feel like well, should I just, I mean, you can't complain or maybe I shouldn't say complain, but share or like voice exactly everything that's going on all the time because there's so much that I feel like, okay, if my pain is like two or three I usually don't say much. But if it goes beyond that I do say something. So even if I have some pain a lot of times I don't say anything because it's just going to be, I don't know, it's going to be too much.
>
> Int: So why don't you say something?
>
> Celeste: Because I feel like there's just more to, there are just so many other things going on too. I mean, if I feel like it's getting worse, I want Frank to know because maybe I need extra support or maybe I need, maybe something needs to happen, like I need medication or pain relievers or go to the doctor, ultrasound or something.

> Int: So maybe you feel like you can manage it on your own, more alone?
>
> Celeste: Yeah. And I also don't want to be, like sometimes it's hard but I try I think to have other things going on in my life, have other things that we talk about than that. Because otherwise it's so much that, that it becomes everything. (041/042: 0515-0550)

Celeste made conscious efforts to protect their relationship from being "consumed" by endometriosis. On days when she was in severe pain, she would recommend "getting a movie," which simultaneously met her need for rest while also taking into consideration Frank's needs for entertainment and pleasure.

Celeste and Frank made space and time in their lives for activities, other than the illness. One of Celeste's favorite activities was rollerblading. Rollerblading had been the only type of exercise she could still do without exacerbating the pain.

The couple cherished their weekends together. The couple looked forward to relaxing, having fun, and going on picnics which allowed them to share delicious and "health-conscious" food. A problem for the couple was that these activities were only possible on days that were not "consumed" by the pain.

The pattern of balanced care giving also closed down certain relational possibilities. Possibilities for spontaneity in day to day life, as well as the ability to actively pursue life goals were diminished. The balance which served to create equilibrium in their relationship related to the illness, also closed down opportunities for action outside their established patterns.

Celeste felt closed in and limited by the illness. She wanted to be free of the confines imposed on her, and actively pursue her work. Celeste felt "boxed" in because of all the things she wanted to do with her life, and couldn't.

Frank also felt limited by the illness because he wanted a family. This created a conflict within the couple, as Celeste was not "ready" to have a child. She had hoped her health would improve enough to re-open possibilities for travel and work, and perceived a child as posing additional limitations. Frank had strong concerns about Celeste's health and age in relation to her fertility.

> Frank: This new doctor was saying you might really want to think about it, think about if you're going to have children. You might want to think about it sooner than later. And so now the seed is kind of planted in my head and I think it's even starting to be planted in Celeste's head as well and that's why I think even considering to go on birth control is a step in that right direction that it will save us now to wherever you are now. At least it will hold us at bay until we're ready. And the fertility doctor even said yes, even if it's bad, it will stop the growth and then when you're ready to have children we will do another surgery and get your right there and then we'll get you pregnant...
>
> Int: Because I was going to say it's interesting. It sounds like they're giving you parallel advice. If you want to have kids, you might want to start thinking about it, but at the same time maybe start birth control. But it sounds like you can do the birth control now and then when you're ready.
>
> Frank: Right. The birth control is just buying us time. (042: 0402-0434)

Although Celeste, preferred methods of treatment that were more natural, she considered a hormonal treatment to suppress the growth of the endometriosis.

> Frank: The doctor is probably one of the best doctors we've had. You can just feel the bedside manner and you're talking to somebody who really cares versus some of the other ones

that have just been, "Yeah, well, we'll do this, we'll assign these meds and blah, blah, blah." And she has Celeste's ear and Celeste is now for the first time considering well, maybe I should get on birth control and we all know including her that there are many, many different types…

Int: Right, like a perfect combination that works for you.

Frank: Right, and this new doctor has vowed, has promised that we will find the right one for you. There's one for everybody and some people ultimately can't handle it, but if you can handle it, we'll find one that can. (042: 0220-0250)

The decision to take birth control pills to keep the endometriosis "at bay" was monumental for Celeste as it contrasted with the belief that framed the patterns of her life. Yet, this was another example of balanced care and actions toward a meaningful life together. With each partner's candidness about their individual desires and concerns, a meaningful action was sought. Frank actively engaged in the process of finding a health care provider that would assist them, and Celeste was able to consider birth control, that met both of their needs.

Despite patterns of balanced care giving, both Celeste and Frank shared concerns about future.

Frank: I worry it's going to come back and it's going to be harder to deal with. And you hear her talk about it and now she has, sometimes she has pain in the rectum, and that to me, ughhh, you think oh, man, what else is it going to be? Chances are now it's spreading back there and we're going to have to deal with that. And it's more of just her having to go through this again. And it's not as much as we would have to deal with it. It's more Celeste's going to have it, and another surgery, and another round of this. The whole package is very taxing on everything, and again everything we touch base on, from the money, to the being intimate, to the family, to work, to all those things get tied in. Everything is involved in that if another surgery has to happen or if it flares up and it comes back worse. I think that's something that I worry about. (041/042: 2466-2491)

Frank acknowledged the post-surgical hands-on care giving experience was "taxing" on their lives together, and he lived with an uncertainty about the future. He comforted Celeste during the interview by reinforcing that he was not to a point of "throwing in the towel." At the same time he worried about illness progression and increasing demands from her suffering on his care requirements. It's clear that they have successfully worked out a balance of care in the context of intermittent severe pain. Substantial changes in Celeste's illness experience might strain this balance or require different responses for the couple.

For Celeste, it was fears about the future that troubled her most about living with endometriosis.

> Int: What issues of pelvic pain, endometriosis do you find most troubling? …
>
> Celeste: …One is the suffering from pain, like, living with the pain all the time. The suffering from that and also the fear of having to do it in the future. Like not knowing that you're going to have a life where you can enjoy like doing the things you want. You, you don't know if it's going to get worse and worse. (041: 2779-2796)

While the future may have created uncertainty for the couple, they made efforts together to live consciously and thoughtfully "in the moment."

> Celeste: I think it's just you plan as well as you can. You can say well, how can you have a job? How can you do all these things? But I think it's good now or it's good enough now. So let's just keep on trying to take care of myself which is hard to balance sometimes. But you go on and not push too hard but push enough so you feel like something's happening in your life.
>
> Frank: Right.

> Celeste: And then if things are good then embrace that, and try to feel like okay, well, today's good and okay. So it's more of living in the moment now than before. (041/042: 0201-0219)

The couple made many adjustments in their day to day lives to accommodate the needs of the illness. The couple represented balanced care giving as their paradigm case illustrated flexibility and reciprocity of care infused with sensitivity and mutual concern for the other. Celeste and Frank made space in their lives for the illness in a fresh and creative way. They equally protected non-illness aspects in their lives together, which constituted a meaningful life for the couple.

Conjoined through Disability

This section presents the paradigm case of Maryann and Tim, who illustrate a relational pattern of being conjoined through disability. Both Maryann and Tim lived with what they considered to be a physical disability. The couple demonstrated the challenge of living between two worlds, a social world where they were called upon to function in their bodies with ease and stamina, and a private world that they created together that acknowledged and made room for their bodily realities. While they had hoped a cure might put an end to each of their suffering, they ultimately hoped to maintain their levels of functioning. Despite numerous struggles and disappointments, the couple shared a unique camaraderie and partnership that was infused with laughter and joy. Each individual's bodily limitations opened up greater possibilities for patience and understanding of the other.

Background

Maryann and Tim have been married for ten years and have a daughter named, Lucy. Mary and Tim were participants in the pilot study for this dissertation project in 2000. Maryann lived with severe debilitating CPP and was diagnosed with endometriosis just a few months before they were married. Over the course of her illness, Maryann has undergone multiple treatments without permanent relief of pain, including numerous surgeries. Maryann has also been diagnosed with interstitial cystitis (IC), and according to her gynecologist, Maryann's case of IC was the worst she had ever seen, with "wall-to-wall-ulcers" in the bladder.

Maryann experienced multiple types of pelvic pain. One type of pain was related to her period which was "cramping," and "a deeper, more widespread" type of pain. Another type, which had been more bothersome to her recently, was bladder related pain.

> Maryann: It feels like I'm either sitting on a double-edged dagger or sometimes when I have to go to the bathroom, it's just the urge to have to go is so intense and I can't pee. It won't work. It won't open. The sphincter stops working because it's so much pain, it's in spasm. And when I finally do push and push my brains out practically to try to force urine out, it feels like I'm peeing razor blades. It's like trying to pee razor blades. That's what I take a Vicodin for, when it's like that. When that pain is like okay, I've got daggers or burning. (131: 0250-0258)

When asked to describe her pain in her own words, she distinguished between the different types of pain.

> Maryann: It depends on the pain. Sometimes it feels like I have got a shovelful of burning hot charcoals that have been placed in my pelvis and are just sort of burning a hole in the pelvic area.

> Sometimes it feels like, as I mentioned, sitting on a dagger or having a knife impaling me in the original sense of the word which is like straight up through the pelvic bone. Sometimes it just feels like a heavy pressure or just like I've been socked in the stomach or like way down in the abdomen. It's mostly the knife but sometimes the coals and then sometimes just the general (deep sighs), yeah, it's really heavy, heavy like a heavy pressure. (131: 0897-0906)

Maryann could vividly articulate her pain, because although severe pain was intermittent and cyclical, pain had become chronic in her day to day life. She was hopeful about a new medication she started two months ago for bladder related pain. Approximately eight years ago she switched careers from selling real estate to owning her own business that she operated from home. Working from home offered flexibility to accommodate the numerous demands of her illness. She was also a musician, and played the flute in a community orchestra, which served as her most effective stress reliever.

Maryann had informed me over the phone before meeting again in 2004 that Tim had been diagnosed with Multiple Sclerosis (MS). The significant decline in his general health in the time between interviews was apparent. Tim's speech and gait were slow, and he shuffled his feet when he walked, which was markedly different from three years before. In addition to a diagnosis of MS, Tim was also having increased anxiety, which he believed was a symptom of the MS.

There was another notable difference in the lapse of time between interviews. When we first met three years ago, the couple proudly gave me a tour of their meticulously kept home. Three years later, their home was in disarray. There were papers, mail, and magazines cluttering the kitchen counter, the window sills, and the table where we sat and talked. Their daughter's papers,

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books and toys were strewn on the floor. Their home, in which they had previously taken such pride, looked neglected and uncared for.

Immobile Bodies

Maryann and Tim both experienced decreased mobility, as a result of their respective medical conditions. Maryann experienced disabling unpredictable pelvic pain. Her bladder symptoms of urinary frequency and pain required that she be near a bathroom at all times. This particular symptom was demonstrated during the interviews as she was unable to sit through her two hour interview. Twice during her interview, she literally jumped up from her chair, politely excused herself, and ran to the bathroom. She explained her urgent need to empty her bladder in order to eliminate building pressure and pain.

Over the past year, Tim had experienced worsening symptoms of MS which included general weakness, "shakiness" of muscles, and anxiety. Tim demonstrated his physical limitations during the interview process, as well. Approximately forty-five minutes into Tim's two hour interview, his discomfort was apparent; he grimaced, groaned, and stood to stretch his legs. Approximately one half hour later, he took another break to stand up, and shuffled to the kitchen to take his medications. Sitting for long periods of time was not possible for Tim, as he needed to move in order to eliminate stiffness and discomfort. When he did get up, ambulation had become difficult.

The couple each had handicap placards to accommodate their health related conditions and subsequent disabilities. Maryann had gotten her handicap placard a few years ago. The idea came from a friend in an

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endometriosis support group, who had also gotten a placard for pelvic pain. When Maryann was in pain, the placard offered convenience by shortening her walking distances.

> Maryann: I got a placard. I got one of those placards, the handicapped placard just so I'm close to a bathroom or if I'm in a lot of pain and can't walk or it's hard to walk. (131: 0210-0212)

Maryann found the handicap placard particularly useful because of the debilitating nature of her pain. Most troublesome was the uncertainty of knowing when she would have pain. When she did, it required an emergent escape to find a rest room, or to get home quickly. Tim appreciated the "fringe benefits," and the "money" and "effort" he saved with a placard.

Straddling Two Worlds

Despite living with debilitating medical conditions, Maryann and Tim demonstrated throughout their interviews straddling two worlds. The first was a world that they had created together, that acknowledged and made room for their bodily realities. The second was a world where they were called upon to function with strength and stamina performing tasks of daily living. Throughout the interviews, the couple described their experiences in these two very distinct worlds, usually with frustration that the social world did not recognize and accommodate their bodily requirements.

Tim had experienced recent limitations, as a result of MS, that had been difficult to accommodate. As a sports cars enthusiast, driving was an activity that Tim particularly enjoyed. It was while he was driving approximately two years ago, that Tim first began to notice the symptoms of MS. As a result of leg

[illegible]

weakness and "shakiness" associated with MS, his sports car with a "heavy clutch" had become too difficult to drive.

Tim: "One of the reasons I sold the car because I couldn't, my left lower leg shakes.

Maryann: Yeah, he couldn't

Tim: And I first noticed it when I was driving that car I used to own. I'd shake on the clutch and I, I used to think it was heavy clutch

Maryann: It was a heavy clutch.

Tim: It really was heavy but that wasn't the only reason.

Maryann: One of these fancy cars.

Int: So it was difficult?

Maryann: It was James Bond

Tim: It was fast, it wasn't that fancy.

Int: What kind of car was it?

Maryann: A Ferrari.

Tim: A Ferrari.

Int: Oh, a Ferrari.

Maryann: A 335. Nice black, sleek, big, heavy, heavy car, hard to drive, scary

Int: It got too hard for you?

Maryann: Noisy.

Int: You couldn't maneuver?

Tim: No, it wasn't too hard to maneuver. It was I couldn't

Maryann: The clutch

> Tim: If it would have been an automatic I'd probably still have it. (131/132: 1063-1103)

There was a pile of sports car magazines and catalogs on the kitchen table where the interview was being conducted. During the interview, Tim opened up one of magazines, pointing to the car he was describing. When his sports car became too difficult to drive, he sold it, and was currently driving a vehicle with an automatic transmission. With time, even his new vehicle had become difficult to maneuver.

> Tim: And he (the doctor) noticed that the MS affects my right side much more than my left side which is kind of annoying because ... it's the side I use mostly to drive. It's kind of hard since you get weaker with MS ...So now I drive sort of with both feet.
>
> Int: I see.
>
> Tim: Which is kind of hard sometimes. (132: 0203-0214)

At the time of the interviews, Tim drove in a very limited capacity. He did not drive at night and did not drive more than a couple of miles from home. Although Tim had always been the "driver" in the family, with worsening of symptoms, Maryann had taken on the primary responsibility of driving in their family. His decreasing ability to drive was stripping him of previous levels of independence and autonomy.

His decreasing ability to drive was particularly difficult for a few reasons. Driving was an activity that allowed him to engage with the larger world. To go shopping, to go to the bank, and to go to work, driving was a necessity. Maryann's ability to drive preserved Tim's mobility in a sense, but it was problematic, as Maryann struggled with her own health related problems that

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made driving difficult. It is a possibility that selling his sports car was a concrete sign of his decreasing ability to function in his prior capacity.

Going to work was also becoming problematic. Although he was still able to drive to the commuter train, his increased anxiety was becoming immobilizing.

> Int: You drive to work?
>
> Tim: I drive to the train station...(laughing).
>
> Int: You drive to the train station.
>
> Tim: It takes me 5 minutes to get there. And actually I find that probably taking, going to work is probably the most stressful thing I do.
>
> Int: Really?
>
> Tim: Yeah. Because it, when I go on the train, I try to go when it's not crowded, but it is, so I have to stand. And it's really hard on the legs and the balance. And (pause) I think that's actually why I take the Xanax is to go to work. (132: 0838-0852)

It is likely that his worsening anxiety was related to a commute that was becoming less physically possible over time. It may have been that going to work was a reminder of a world that operated on a different set of expectations than the ones he shared with Maryann. While his handicap placard offered him allowances while driving, he did not make his disability known on the commuter train. For Tim, struggling to stand on a crowded moving train, may have been more desirable that the social stigma or social recognition of disability. This experience can be distinguished from his use of a handicap placard; anonymity may have been preserved inside an automobile.

This particular commuter train did offer "accessibility features" for passengers who used a wheelchair or had "limited mobility." Access included

accessible elevator service to all levels, level boarding from the platform to all trains, and space to accommodate wheelchair users. These "accessibility features" put Tim in a difficult predicament, however, as he did not use a wheelchair, and although his symptoms of "shakiness" and "shuffling" were noticeable at times, they could have been easily overlooked by passengers on a hurried morning commute. While there was a special space for wheelchair users, persons with "limited mobility" would have to disclose their disability to be assured a seat. The complexity of getting his special needs accommodated may have been the root of his increasing anxiety.

Tim may have also been concerned about his decreasing capabilities at work. Tim spent many hours conducting business on a computer. When he asked if MS was impacting work he described:

> Tim: It doesn't seem to really affect it most of the time at work. (Pause) Except I think the medicine which is sort of short-term memory loss. Well, not short-term memory loss but I tend, I tend to forget to do things which I didn't used to do. I eventually remember (laughing). I can't do six things at once anymore like I used to be able to. And I don't know if that's the MS, the medicine or just getting older.
>
> Int: Right, right, right. The multi-tasking isn't working for you.
>
> Tim: Yeah. And but it's actually, I think it's actually arthritis because my fingers don't move as fast...So I tend to type this way now (demonstrating one finger at a time). If I don't have to type, it's fine (pause). I could still do everything else. And my boss, they all know I have it so. And my co-workers make accommodations if necessary, which isn't too much. (132: 0219-0235)

Tim had noted changes in his ability to perform at work, yet minimized them. His coworkers, up until this point, had made necessary "accommodations." A concern may have been that while Maryann had

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demonstrated flexibility of action by taking on more responsibility within their relationship, it is unlikely that his coworkers would do so. The uncertainty related to his future of work may have also been a root to his anxiety.

Tim "had no choice" but to continue working because his family's security and wellbeing were at stake.

> Maryann: He knows if he doesn't work, we don't eat. If he doesn't work, we lose this house. If he doesn't work, we have no medical insurance and we're both up shit creek without a paddle because no one will insure us. Not with what he has. Not with what I have. We cannot get insurance. Not without paying outrageous prices which if we didn't have the house or anything else, we wouldn't afford it anyway. I think just he has no other choice and he just goes (to work) and I pray for him. Yeah. I don't know, I don't know what keeps him. I think God's just sustaining him but he doesn't know that or he just, he just keeps going because he has no choice. (131: 0735-0745)

Because of the family's reliance on his salary and benefits gained from his employment, they did not perceive any other options than for Tim to keep working until he was eligible for retirement in several years.

Maryann understood Tim's struggle because she had also experienced significant difficulties with work given her symptoms of endometriosis. Her condition was an impetus for her to start her own business and work from home. The unpredictability of her pain made working as a real estate agent with strict time lines impossible. Running her own business from home enabled her to rest and self-medicate when her pain dictated. Their home was the place in which she was most prepared to deal with her pain, by having pain medication, a bathroom, and a place to rest available. If immobilized by a pain episode, she would make herself as comfortable as possible, and wait for her pain to pass.

> Maryann: If I take the Vicodin, it's usually alleviated, not completely gone but to a bearable level where I can get up and walk around again, usually alleviated within 20 minutes to an hour...If I don't take anything and I just try to lay down and rest, it might take an hour to two hours and then it'll subside and then it'll be fine. It's really weird. It's like a light switch. It's like well, I couldn't move an hour ago and now I'm okay. (131: 0937-0945)

At times, her work situation continued to be problematic.

> Int: Do you talk to people about what you're dealing with, with the endometriosis and the IC and day-to-day life? Or do you pretty much just keep it to yourselves?
>
> Tim: I don't think she gets much sympathy.
>
> Maryann: I don't. (Pause) Like Sophie (a colleague), the other day. I was over there and I hadn't had anything to drink for a couple hours and I went to the bathroom. Big mistake. I stepped out and it was like "Oh, my God," I felt it starting. And she was trying to keep me there for some reason, trying to talk to me and she wanted me to stay around and I wanted to leave right away, right away. I have to go now. And I was like leaning on her desk. I'm like (heavy breathing). She's like "What's wrong with you?" I said, "I am having a pain attack." She doesn't get it. She doesn't get it. So I get no sympathy from her. (131/132: 2346-2361)

Although Maryann had created a flexible work environment for herself that made room for her illness demands the majority of time, running her business required interactions with clients and colleagues. Maryann also struggled with expectations of a world that was organized around strong, healthy, and reliable bodies in a similar way that Tim had experienced.

Maryann shared numerous other examples throughout the interviews that illustrated a contrast between her two worlds. One such example was when she was unable to get her daughter to school on time because of her pain.

> Maryann: A couple times, like last year I had to take Lucy to school. It doesn't hit in the morning very often. I mean usually not. But I've had a couple hit in the morning and one where I couldn't

drive her to school. I had to wait like ten minutes before I was able to have the pain level drop enough where I could drive safely. And it created like a big stink because she was considered tardy. And I'm like "This is a medical emergency." "Well, "You ought to have a note from a doctor." That's bullshit. I was really mad because she'd had perfect attendance.

Tim: They get little awards for that.

Maryann: Yeah, they get little awards for that so

Int: So did it mess up her record?

Maryann: Yeah, it did. But I mean she's only like five minutes tardy but I couldn't help it. I couldn't help it.

Int: You couldn't help it. You couldn't drive?

Maryann: I could not help it...it just, it just happens so sudden. I mean literally you turn around and boom. (131/132: 1840-1865)

Maryann's severe pain shifted attention to her body, prioritizing relief of pain and driving safety, over her daughter's need to get to school on time. Maryann had grown accustomed to a more flexible world that made room for bodily disruptions, and was angered when the school administrator did not make such accommodations. This narrative also points to the "competitive structure" (Wendell, 1996) of western society that values perfection and performance.

The inability for her daughter to get the perfect attendance award because of Maryann's inability to drive may have triggered shame and self-blame, and may have served as a reminder of her condition and its subsequent disability. This narrative also illuminates a way her bodily reality was not acknowledged. It is likely that if she had sought treatment in the emergency room for her pain, and had gotten a "note from a doctor," a medical authority, her daughter's tardiness would have been excused. Because Maryann had severe pain related to a

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chronic condition, and had successfully learned to manage such episodes on her own, no exception was made.

Other narratives illuminated, in a profound sense, how her incapability in a world of non-symptomatic and reliable bodies made her feel not "normal." For example, she could not sit through a three hour movie, like other people could. Even going to church was problematic for two reasons. The first was she had to arrive early to be assured a seat in the back and at the end of the aisle so she could get up unobtrusively to use the bathroom during the service. The second was related to the physical requirements involved.

> Maryann: Yeah, well, it's like last month when I was on my period, I was at church…and had to stand up, sit down, stand up, sit down…I can't do that when I am hurting really badly. (131: 0172-0176)

She couldn't have lunch with her daughter at fast food restaurants, like so many other moms.

> Maryann: We can't go out and just eat fast food… The only thing at A. Restaurant is a fish sandwich and maybe a milk shake. B. Restaurant has a chicken sandwich but they put a lot of sodium in it and I always have to make sure that there's no tomatoes, no mayonnaise, no this, no that. It's just I can't. We can't go out to eat because restaurants put weird, they always put lemon and stuff. I have to be very specific.
>
> Int: So you have to monitor your intake very carefully.
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> Maryann: I have to watch everything. When I go to a restaurant, I have to go over every ingredient that goes into that food and waiters, they just I don't know. I think they think I'm being ultra-picky, but if I crump over 20 minutes after eating their food and I can't walk because I'm in so much pain, I'm not going to eat there again. But it makes dining out a really frightful proposition. But just making my own food fresh, I don't have a choice. You can't, like TV dinners, can't do that. Most prefab fish fries, prefabricated food and the trend nowadays, I don't know if you've noticed in the grocery

> store, it's all prefab set food. In the meat department, you've got your meat that's already seasoned, you just put it in the oven. Bingo. How stupid, I can't do any of those. (131: 1513-1534)

The latest "trends" to maximize convenience for busy families were not a possibility for Maryann.

When Tim was asked which of her symptoms interfered with their relationship the most, he pointed to the fear of potential problems, including the consequences of eating something that might "awaken the pain."

> Tim: The IC pain and the fear of creating an awakening of the pain....there's probably always the fear. It has to do with things like going out to dinner because she can't eat things in a restaurant because we, I think the last time we went to some place and got something in the food, she realized after she ate some that it had. What the hell did it have in it? Onions or cinnamon or something. Something or nutmeg. Nutmeg sets it off. So it had nutmeg in it so didn't realize it until afterwards and then it caused a lot of problems. So you can't do. You can't easily do things like go out to dinner. When we went over to our friends' house last Sunday, we had tacos. She brought her own food because she just couldn't deal with cayenne pepper and stuff like that. So it's, you don't do certain things because you don't want to create the possibility. (132: 1502-1520)

When Tim recalled a particular incident, he only had a vague understanding of the precipitating food. Tim, with his own medical condition to manage, did not take on the role of a care giver, but he did understand in a more general sense the inconvenience it caused them as a family. Perhaps Tim missed a relaxed, social act of sharing food with loved ones, which had become problematic in their family. Perhaps Tim was also pointing to the lack of predictability of her medical condition, which contrasted from his own.

Eating out was a potentially dangerous action for Maryann, and her pain had repercussions on the entire family. In response, Maryann made careful

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choices around food as a strategy of self-care, such as bringing her own food to a social gatherings and cooking at home. Maryann's sensitivities to food forced her to be scrupulous and on-guard.

Maryann's medical condition was different from Tim's in that it was invisible. While Tim shuffled when he walked, and had shaky hands that might be noticeable to people, Maryann had no visible external signs. This at times, was frustrating, as people could not make allowances for her in public settings.

> Maryann: Two weeks ago I was at a concert, and after the performance I went to sit down with a friend of mine and the seat I was sitting on happened to have somebody else's purse under it. The lady next to me goes, "Excuse me, but that's my daughter's chair." There was a chair on the other side, and my friend said, "Well, what if we just move over one?" I stood up and I was hurting. And the girl was like, "Oh, no, never mind," and I sat down and the lady said "No, that's her chair, you have to move." And I stood up and finally I turned her and I said make up your mind. I mean I was hurting so bad from going up and down and she's like "Well, you don't have to be rude about it."
>
> I was hurting really bad and the sit down, stand up, sit down, she didn't understand. But she took me for being really rude. And I was like no, make up your mind. I'm sorry, I can't do this again, I don't want to sit down again. You don't get it, I'm disabled. Okay? I got a placard. I got one of those placards, the handicapped placard just so I'm close to a bathroom or if I'm in a lot of pain and can't walk or it's hard to walk. (131: 0193-0212)

This narrative illustrates the experience of living with a physical disability that is not visible to strangers. While people close to Maryann were prepared for the unpredictable and severe nature of her pain, and were "used to" making allowances for her pain, interactions in public were more problematic. The hidden nature of her disability closed down possibilities for understanding from others. It is likely that the women who asked Maryann to change her seat had no

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idea of the pain it caused her. While having a handicap placard on her car, may have made an invisible condition visible while she was driving, and served the purpose of opening up possibilities for allowances for her disability, there was no such symbol with a universal meaning that she carried on her person in the everyday.

"Cure" as a Possible Way Out

Maryann and Tim shared the complex task of negotiating two distinct worlds, as well as having something else in common. They each had a major chronic disease for which there was, at the time, no medical cure. While the future presented much uncertainty for the couple, and their family, they both expressed hope for a cure.

> Maryann: Well, yeah, I'm thinking that they'll actually within the next five years find some sort of more permanent cure for either MS or endometriosis or IC. For them to do the genetic studies and for Congress to quit futzing around and getting upset about fetal cell or the stem cell, well, about the Korean stem cell guy.
>
> Tim: Yeah, I know what you're talking about.
>
> Maryann: That one. The one stem cell that was not made by a fertilized egg. They had done it without the fertilization but they had stem cells. I'd like to see that. I'm hoping that Congress would allow that. I mean no human being was killed for that but have the treatments found to cure these diseases. That's my hope for the future and the hope that we just continue or that we can keep on a steady level.
>
> Int: How about you? (To Tim)
>
> Tim: Well.
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> Int: You had said that the medicine works.
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> Tim: Well, I mean they seem to be most of the time. Yeah, that's true. ...

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Tim: If there is a cure of any of them that it's available in the United States, which is not always the case. My cousin knows a neurologist in England and they have treatments available that they're not available in the United States for whatever reason.

Maryann: Are they effective?

Tim: Yeah, some of them.

Maryann: Road trip. (laughing) ...

Int: So it leaves you, with more hope it sounds like because maybe we'll get those treatments over here. (131/132: 2685-2743)

Burgeoning science and prayer opened possibilities for a cure.

Maryann: A cure. I want a cure. I want to be healed. All I wanted for Christmas, all I wanted for Christmas was to have either Tim or myself healed of one of five things. And that's either MS, endometriosis or IC. That's my hope for the future is that somehow they'll find a cure. I think by that time I'll already be through menopause and it won't matter anyway but the ultimate hope and I keep praying is for healing from one of those three. Because it would make living with the other two very easy or easier I guess. Just for healing. (131: 1634-1642)

Maryann and Tim had hoped that if a cure was not found for endometriosis, menopause might bring lasting relief, since the symptoms were hormonally influenced.

Tim: (Sigh) I hope it (endometriosis) goes away. I would imagine it will lessen itself if not disappear when she reaches menopause just because of the nature of what it is. I could be wrong. I don't know. I don't think they're going to find a cure for it. I think they're probably closer to finding things for my disease than hers. (132: 1704-1708)

While Maryann's menopause opened up possibilities for a decrease in her pain symptoms, the idea of endometriosis being a hormone-related disease also posed great concern for the couple. They calculated that their daughter Lucy

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would be entering puberty at approximately the same time Maryann would be entering menopause.

Maryann: When I start to go through menopause, Lucy hits puberty (laughing)

Tim: (laughing)

Int: It's too scary for you, huh?

Maryann: He's like "I will just go hide."

Tim: Well, no. But I know what she's like (referring to Maryann)...And I have this great fear that Lucy will have more or less the same problem.

Int: Oh.

Maryann: Yeah, I pray for her.

Int: Do you really? So can you tell me about that?

Tim: Well, I mean it's

Maryann: It runs in families.

Tim: It's hereditary to a certain degree. Unfortunately, (laughing and pointing to Maryann) she's the one of her five sisters that has it.

Int: Right.

Maryann: I'm the one out of all of us who have it.

Int: So you fear that she (Lucy) might get endometriosis and all this stuff?

Tim: Well, I also fear just that she'll inherit the sort of, you used to have bad periods all the time, and she'll inherit that.

Int: So puberty is ooh, a scary time to think about for Lucy.

Maryann: And then the hormonal things because I get really big huge mood swings.

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Tim: And Lucy already has big mood swings as it is. ((131/132: 1352-1402)

The couple looked into the future hoping menopause might bring Maryann relief, but their emotions were combined with feelings of concern about their daughter. Situated as they were within illness conditions, the unstated concern was how they would be able to care for a daughter in pain.

Discussions of "cure" also sparked a dialogue between the couple that highlighted perceived differences between their conditions. For example, Tim pointed to the lack of societal awareness and research for endometriosis as compared to MS.

Tim: We are a celebrity disease (laughing)...

Int: You make the comparison that there's a lot more resources for MS?

Tim: Well, they're a lot more obvious. There are several associations and there's (pause) a lot more. I would guess a lot more research. (132: 1464-1483)

Tim noted another distinction between their conditions.

Tim: It's sort of an obvious disease. People shake and people shuffle and you don't like to see your father or your brother doing that. As opposed to endometriosis which is sort of internalized and you don't see it. It doesn't have really sort of external continuous manifestations. That's the sort of disease that doesn't get looked at much. (132: 1733-1740)

Tim's disease was visible and "obvious" when compared to Maryann's "internalized" condition. While Tim framed his observation in a positive light, suggesting MS received more recognition and possibly more research dollars, Tim also expressed the vulnerability that accompanies an obvious disease. He uses the familial relational example of "father," possibly underlining his emotions

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in regards to having to "shake" and "shuffle" in front of his seven year old daughter.

Both members of the couple believed in science, but Maryann also had great religious faith. The following dialogue ensued when they were asked what they each hoped for the future:

> Tim: That whatever diseases we had wouldn't progress and were just sort of, I mean it'd be nice to get better but I know that's not going to happen so it would be nice not to get worse.
>
> Maryann: Yeah. Yeah, it's nice not to get worse. Getting better would be good. Not getting worse would be better.
>
> Int: Just kind of keep it where you guys are at. It would be okay.
>
> Tim: But I mean I think that's probably, that's, that's a reasonable or realistic, well, I don't know if it's realistic. But it's a reasonable hope without anything else. (131/132: 2706-2718)

While they each held places in their minds and hearts for a cure, ultimately they both had hoped their conditions would stabilize, which would allow them to maintain their current levels of functioning.

Attachment via Disability

The two had created a conjoined life together that made room for and respected the other's disabilities. Within their relationship, there was a profound acceptance of the other, despite physical limitations and disappointments. Camaraderie around their respective illnesses had been formed and a delicate balance of responsibilities had been achieved in their relationship. Together, the couple demonstrated remarkable courage and engagement with life.

It is likely, however, that the worsening of either's condition would upset the balance they had created, but together, they hung on, trying to maintain the

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equilibrium they had achieved as a family unit. The following sections will illuminate how the couples' lives were conjoined through "dis-ability."

Prioritizing physical safety. Maryann and Tim held together, shifting priorities of their lives, to meet the needs of their family. Tim had the responsibility of making sure he got to work everyday to protect their livelihood and shelter. Maryann was doing her part by working around the clock at home when needed. Maryann mentioned the difficulty in squeezing in time for the research interviews.

There was a joined and united effort in the couple's attempt to preserve their lives together. On a concrete level, they prioritized their own physical safety; Tim limited the distance he drove and Maryann controlled her diet very carefully. Physical safety around their home had also become a priority for the couple.

> Maryann: It's like when are we going get carpet on the stairs? We've been living here ten years and we still don't have carpet on the stairs and
>
> Int: Okay. So you're not that interested in it?
>
> Tim: No I'd like to finish the stairs but I'm thinking if I have carpet on the stairs I might fall down the stairs.
>
> Maryann: It's slippery.
>
> Tim: Carpet's slippery.
>
> Int: Right. Okay. So you have some concerns...it sounds like you have some worry about your health and safety...
>
> Tim: Yeah. I mean we first put the gate up for Lucy and now the gate is actually up there for us.
>
> Maryann: Yeah.

Int: Right. Right.

Maryann: Because I'm afraid of falling in the middle of the night. I'm stumbling around, my balance, actually, my balance isn't good when I first get up because my joints are stiff...so I'm trying to get to the door and let the stupid dog out because he's been whining for the past half hour and, yeah, I'm afraid of falling down the stairs. And I'm afraid of him falling down the stairs. So that (the gate) stays.

Tim: It'd be nice if it were nicer, which is something I want to get done but

Maryann: Yeah, we've got this like "To Do" list.

Int: You mean nicer in terms of the weather?

Maryann: No, nicer as in like

Tim: The nicer gate.

Maryann: A nicer gate.

Int: Oh, oh, a nicer gate. I see.

Maryann: Something a little more permanent, something, instead of like strapped on bungee cords.

(The conversation is about a child's gate that is attached with bungee cords on the top of their stairway going downstairs from the main living area of their home.)

Int: I see. Something that was built-in.

Maryann: Actually, to paint the posts around the stairway, which were supposed to be painted, they were primed. That was ten years ago. They've never been finished. So a lot of unfinished things.

Int: So it's a work in progress.

Maryann: Oh, yeah, I mean we're not making any, that's the problem.

Int: I see. I see.

> Maryann: We're just not making any progress. (131/132: 0415-0500)

This was in stark contrast to a few years ago when the décor and appearance of their home was a priority. Their shifting priorities resulted in household tasks just not getting done.

> Maryann: Things just don't get done. I vacuumed and I mopped the floor yesterday for the first time in like three weeks. I vacuumed a week before, but I used to vacuum and mop the floor every day but I'm also busy working. I'm working upstairs. I'm trying to get work done. I don't do it, it won't get done. Now he does the dishes, he pays the bills, he does the finances. He'll do the laundry if I don't get to it. He'll clean the toilets. That's nice, I hate cleaning toilets. But he doesn't have energy for much else. I am tired a lot of the time or hurting or just plain busy so things just get dropped. (131: 0754-0765)

As each individual partner struggled to complete necessary obligations, tasks such as cleaning the house "got dropped."

With each partner having a physical disability, flexibility of action may have been limited. Up until this point, the couple had managed tasks of daily life quite successfully. However, it was a likely that at some point in the future, the couple would need some outside help. The couple sought help on one occasion from a relationship counselor for dealing with the MS, however, continued treatment was not possible because of their already taxed schedules. Rather than counseling in a more traditional sense, the counselor offered Maryann concrete assistance with business related tasks.

Sharing joy through laughter and competence. Within their delicately balanced world of responsibilities, Maryann and Tim had created quite an extraordinary life together, that included a beautiful daughter. Their mutual

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commitment to co-parenting was demonstrated in they way they accommodated their special needs by enjoying "sedentary" activities together as a family. Rather than being negative or angry about their circumstances, the couple used laughter as a way to tolerate painful moments together, and despite physical complications, they prioritized their sexual relationship in their lives. They shared an engagement with life that was unique that involved making room for joyful and pleasurable activities.

> Tim: We tend to watch, we watch a lot of movies because it's (laughing) sedentary…it's sort of stress-relieving and whatever so that's what we do. That's sort of a typical day. (132: 0500-0503)

In addition to watching movies together, their passion for reading was apparent in the numerous piles of books and magazines piled around their home. Their mutual physical abilities also influenced the activities they took up as parents.

> Tim: Basically our activity is mostly intellectual. She keeps
>
> Int: She's very smart.
>
> Tim: (Laughing) Yeah. And her schoolwork where she goes to school, they're very challenging so we sort of have to keep up with that.
>
> Int: So you had mentioned she did really well on her report card and is learning
>
> Tim: Yeah, I mean
>
> Int: Very advanced things for her age. You were surprised so
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> Tim: Yeah.
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> Int: She's kind of an intellectual kid it sounds like.

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Tim: Well, I mean the school she goes to is very. They're very interested in that and the kids are very motivated and all that kind of stuff. And she's smart anyway. I mean I came up one Sunday and she was reading a book and I said, "When did they teach you that?" Because she was reading it silently. I remember when I was at school, they taught us how to do that. She just said, "Oh, I just started doing it." I said, "Okay." That's nice (laughing) so she reads. She takes after what we do. I mean I read a lot so she, I mean those are her books on that couch. She's read most of those and those are her magazines, and her books, so she

Int: So is that her way of having together time with you? You guys can sit and read together?

Tim: No, we actually read to her and we watch the movies together and I don't play with her so much anymore because she wants to play on the floor and I have trouble getting down and getting up (laughing). And I'm not as imaginative as Maryann is unfortunately. But we do other things together like she started making models. We made that little car over there (pointing to a brightly painted car model). She painted it. I helped her put it together and she's got a butterfly model. She loves insects. So we have a giant grasshopper model that we're going to finish. (132: 1651-1690)

In addition, Lucy played the guitar. At the time of the interviews, Lucy let me pick a song from her song book, and played "Twinkle Twinkle Little Star." Within the constraints of their physical abilities, the couple provided wonderfully rich opportunities for their child.

About a year ago the couple built a rabbit cage together in their large backyard.

Maryann: It's like the last big project I think we really tackled is probably building the rabbit cage, yeah.

Tim: Yeah.

Maryann: Where we, he was out there with, we were working together building the cage. Now that was a big project. It's a nice cage. It's a very nice cage. (131/132: 0379-0386)

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At the time of Tim's interview, Maryann came upstairs into the kitchen with Lucy carrying one of the rabbits. She sold the rabbits, and the money earned went towards their feed.

Initially it was curious with all that was going on in their lives, how Maryann raised rabbits in her back yard. Yet, with a greater understanding of this couple and their relationship, it is a possibility the rabbit cage represented something very special between the couple. Activities associated with the rabbits accommodated Maryann's love for nature, and was an activity she could share with her daughter that also kept her close to home. The rabbit cage may have held sentimental value, and been a marker in their lives, because it was the last "big project" the couple had completed together.

Also during the interviews, Maryann was in the kitchen, listing the ingredients she needed to buy to make dinner that evening.

> Maryann: The ingredients. I have to watch my diet. very, very carefully. I can't do additives and MSG and they put all, they put like onion powder. I can't do onions so store bought sausage has a lot of additives. A lot of really funky multodextron and so I make my own. A lot of stuff I make I have to make fresh.
>
> Int: I mean that's pretty, I mean that's probably day to day to you, but to me that's pretty remarkable. Do you know what I'm saying?
>
> Maryann: Yeah.
>
> Int: Once again you probably see that as normal.
>
> Maryann: Yeah. It's normal for me.
>
> Int: And it's normal for you. But that's pretty remarkable that you're doing that.
>
> Maryann: Because we can't go out and just eat fast food. (131: 1491-1513)

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Thinking this act was fairly remarkable; I wondered how she had the energy and time to make sausages from scratch. However, making her own sausages served multiple purposes for Maryann. It was a way she provided care for herself and her family, while also meeting the needs of her illness by monitoring her intake and staying close to home.

The couple shared a mutual sense of humor that exhibited a profound sense of relational intimacy. Throughout the interviews, they poked fun at the other in a loving and tender way. They laughed good-humoredly about rituals they shared as a result of their medical conditions.

> Maryann: "I've got to find a bathroom. Got to find a bathroom. There's no bathroom here." I start worrying about (whispering) is there a bathroom around here?
>
> Int: Right.
>
> Tim: Every pancake house knows her between here and Los Angeles.
>
> Maryann: Yeah, they are used to seeing her come running in. Usually I'm on my way to a concert and I'm all dressed up. I always stop at the same pancake house. It's like "Dang, if I've got a concert I'm going to stop at the pancake house." They'll say, "Look, there she is again…It's like "Oh, God, she's not buying any coffee, don't worry, she's just going to the bathroom." (Laughing)
>
> Int: But at least you can laugh about it. That's pretty good.
>
> Maryann: Yeah.
>
> Int: I mean you guys are laughing about it.
>
> Maryann: Yeah. It's
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> Tim: It's amusing.

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Maryann: I have expected them to charge me or say, "I'm sorry, no, you can't do that." (131/132: 1876-1903)

They found a way to make fun out of their difficult situation.

Maryann: And he's right. It's like we'll be out shopping somewhere and it's like "We got to go home. I got to rest. I got to lay down. I want to go home. I want to go home. I want to go home."

Tim: We should go shopping in stores that always have testing beds or something. "I want to go lay down on the bed."

Maryann: I could go lay down on the mattress. (131/132: 1865-1872)

They joked with each other in a reciprocal manner.

Maryann: One day, he was really mad and he was swearing and I really don't like to hear, I don't really like, I mean I will say it but I don't like to hear the f-word, and especially in the house, if Lucy's in the house. It's like, "Shut up. Shut up." And one day he was getting really mad and swearing at the computer. I said, "Honey, look, you have MS, you do not have Tourette's," and he just

Tim: (laughing)

Maryann: I mean we

Tim: (laughing)

Tim: We've been making jokes pretty much as long as we've known each other about our various disabilities. (131/132: 2478-2492)

Their sense of humor was evident even when discussing the most difficult and sensitive topics.

Maryann: ...the humor.

Int: It's important it sounds like.

Maryann: Humor is really, really important.

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Int: Yeah. You guys are laughing. That's good. Okay, so the last question I want to know is, what do you both most fear about the future.

Maryann: (Sigh) Incapaci - the -inc – (laughing and stumbling with her words)

Tim: It's already started, hasn't it?

Maryann: (In sarcastic voice) Incapacitation, being totally disabled. (laughing). (In normal voice) Being totally disabled, I think. Isn't that it? Not being able to work.

Tim: Yeah.

Int: Yeah.

Maryann: Not being able

Int: Would you say that's the same for both of you

Maryann: Yeah. Well, actually, it's cancer and dying in an airplane but I mean just having the pain be so excruciating that I can't do things, that I can't function, can't going out. Or for him having the MS I think just makes him, I mean my fear for him is having it make him totally, completely and utterly useless and disabled. And I don't think I could, I don't, I don't how I'd deal with that.

Int: Hmm. What do you most fear? (To Tim)

Tim: Probably the same thing. Actually, what I most fear is an earthquake when I'm taking a shower because I'll fall over and really hurt myself on the bathtub.

Int: Seriously?

Tim: (Laughing) Because…I'm not too steady (laughing). I'm not as steady as I used to be. Now I lean on a shower chair, I didn't used to do that. (Laughing) I mean that's really sort of a (laughter) strange kind of fear but

Maryann: Earthquake in the shower (laughing). (131/132: 2583-2628)

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Maryann and Tim acknowledged their humor was a technique they used to "diffuse" various difficult situations. In their laughter they found ways to tolerate painful moments together. Maryann shed light on having an awareness of their possible future. She stumbled with her words as she explored possibilities of each of their worsening conditions. Tim's jokes about falling in the shower also expressed a serious concern. He struggled to maintain his balance every morning on the train, and perhaps taking a shower was becoming more troublesome. Using the "shower chair" for stability was another example of the couple creating physical safety within their home to accommodate his illness and to promote competence.

In terms of a meaningful life together, the couple also prioritized their sexual relationship together. They shared a lengthy history of difficulties in their sexual relationship, mostly related to their mutual disabilities, as well as Maryann's fear of getting pregnant. They both experienced discomfort during sexual relations, as a result of their respective medical conditions.

> Maryann: In terms of actually having intercourse, it generally doesn't hurt. I mean even if it does hurt, it stops hurting. (Laughter) I don't know why. It generally doesn't hurt. It's just hard sometimes because our positions are so limited because of his pain or his ability to move. My knees start really hurting if I'm on top of him and it's like after a while it's like okay, honey, I was fine, we had a good time. Five minutes is up, I can't move my legs. Okay? Now we're done, okay? (Laughter) He's like okay. It's just kind of hard to find positions that one or the other of us aren't in a lot of pain or getting cramped muscles or really sore. It's just the pain is the only thing that would really inhibit it. That and fertility. (131: 1139-1149)

The effects of pain and neuromuscular disorders, including muscle weakness, fatigue, and decreased flexibility, have been described as being a

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deterrent to sexual activity (Dalton, 1990). Despite the problems associated with the physical activity of sexual relations, the couple had successfully worked out a system which balanced their mutual needs. Tim would write Maryann a note to express his interest in sex and Maryann would respond if it was an "okay" time in her menstrual cycle.

> Maryann: He wrote me a note. And I'd been thinking about it for a couple of days like I really need to, I'm okay in my cycle, I won't get pregnant. And so I took Vicodin even before the pain, when I first felt the first start of it, I was like I'm taking Vicodin now so that later in the evening, okay, honey, I'm hurting, but it's okay, I've got medicine onboard, let's go do this. (131: 1131-1137)

Tim shared a lengthy story describing an unusual burst of energy he had the prior weekend when he put together his daughter's elaborate swing set in the back yard. He was animated and visibly excited in retelling the process. Maryann pointed out that this extraordinary burst of energy came the day after the couple had shared a particularly pleasurable sexual experience together. Together, with perseverance, despite all that was going on their lives together, the couple prioritized their sexual relationship.

Maryann and Tim demonstrate a couple conjoined through their respective physical disabilities. It was through their own bodily limitations, that one had greater understanding and patience for the other. The couple successfully demonstrated navigating a life that straddled two worlds, a social world whose expectations were organized around reliable and able bodies, and a private world that acknowledged and made room for their bodily realities. They sought safety and comfort in their private world which focused more on their abilities than

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disabilities. Despite numerous struggles and disappointments, the couple worked to protect their meaningful life together.

Conclusion

The first couple's story "Together but Alone" illustrated patterns within relationship that disrupt possibilities for mutual understanding, cohesiveness, and connection. When the couple embarked upon a life together, they shared mutual goals of starting a family and achieving financial success together, and each perceived endometriosis as impeding their common goals. This couple illustrated how illness may accentuate already existing differences and heighten tensions within couples. It was mutually understood that upon coming together in partnership, each had a way of engaging in the world that was uniquely different from the other. The ill partner even acknowledged it was these very differences that initially attracted her to her husband. Yet, in the face of illness, the rift grew as their competing ideologies, particularly in relation to health and what constitutes a meaningful life, created a bigger divide. This couple illustrated that the action of talking and communicating was not enough to bridge the gap that divided them. Each partner demonstrated open and candid communication. They wanted desperately to be understood by the other, yet, neither could truly get inside the other's lifeworld. This relational pattern also highlighted the difficulty of a well partner bearing witness to incurable human suffering. A focus on fixing and remedying distress may have eased his discomfort but enlarged the chasm between them.

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The second couple illustrated the relevance of congruent symptom understandings in "Battling Endometriosis Together." The symptom experience includes the perception of a symptom, evaluation of the meaning of a symptom, and response to a symptom (Dodd et al., 2001). This couple demonstrated that a possibility of active engagement in the ill partner's health over time was to be in-tune with and hence, alert to a drastic shift. When the ill partner's condition began to steadily decline, both partners experienced fear, panic, and uncertainty as evidenced by the corresponding tone of their interviews. They both interpreted her worsening pain as an indicator that the endometriosis had become potentially a life threatening disease. They were able to focus their actions to attempt to resolve the disease. This relationship was characterized by mutual understanding and empathy for the other. The well partner valued his relationship with his partner above all else, and perpetually made conscious attempts to shift perspectives to understand life through her eyes. This move allowed him to transcend his own desires to open up new relational possibilities.

The third case illustrated a partnered relationship totalized by care giving, in which the well partner prioritized care giving, over all else, even care of self. This pattern of care giving in totality involved numerous legitimizing practices such as an array of comfort strategies, as well as more ritualized types of care embedded in practices of daily life. This level of care required a keen sensitivity to the ill partner's symptom experience, and located responsibility of care on the well partner. There was an insular quality to the relationship as both partners

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The fourth couple's story, "Balanced Care Giving," highlighted possibilities of care giving that contrasted with the prior case. Although the ill partner had a debilitating and chronic condition, a bi-directionality of care was demonstrated. Each partner held commensurate feelings of empathy and understanding toward the other. This pattern of relating demonstrated prioritization of self-care as opposed to dependence on care. This pattern of relatedness also sheds light on coupled efforts to "protect" their relationship from the ravaging effects of illness.

The fifth couple demonstrates a pattern of relating characterized by mutual disability. A unique characteristic of this pattern of relating was each individual's bodily limitations opened up greater possibilities for patience and understanding of the other. The increased sensitivities and relatedness created space for building a meaningful and vital relationship and family life together. Together, with their corresponding disabilities, they tackled life united as a team. As a result, the couples' lives hung in a delicate balance that relied upon each other's capabilities.

CHAPTER SIX

IMPLICATIONS OF RESEARCH

Introduction

This phenomenological investigation of the lived experience of women with chronic pelvic pain (CPP) and their intimate partners offered a view of a person that was profoundly different from more traditional Cartesian conceptualizations. It offered the opportunity for understanding the rich and complex world of women with CPP and their partners taking into account the sociocultural aspects of the condition. This study provided important insights into lived bodily disruptions and treatment experiences of CPP, as well as possibilities for relatedness within the couple relationship. Such insights have practical applications in clinical practice, as well as public health arenas. Proposed implications for clinical practice, public health, and future research will be described in this chapter.

Implications in Clinical Practice of Women with Chronic Pelvic Pain

Attending to Grief

The grief endured by women with CPP in this sample was profound. In general, women with CPP from endometriosis experienced major losses of familiar worlds and familiar embodied capacities (Benner, 2000). Whether women grieved the loss of a sexual relationship they had previously shared with a partner, or the loss of a sexual relationship they had always hoped for, the grief was legitimate and deeply felt. With surgeries that resulted in loss of body organs or treatments that provided inadequate relief of pain, women grieved the

loss of their previous selves. Some women experienced the heartbreaking grief of infertility. A common experience among all the women was ruptured dreams of goals and plans for the future. A goal of providers should be to attend to the grief and emotional pain associated with CPP from endometriosis.

Relational and physical space. Of the estimated 15% of women of reproductive age in the U.S., the percentage of women actually seeking treatment for CPP is not known. Mathias, Kuppermann, Liberman, Lipschutz, & Steege (1996) conducted a community-wide investigation of CPP with a telephone survey of over 5000 women in the U.S. aged 18-50. Of the 16% of the women who reported CPP, 75% of the women had not used any health care resource at all in the last 3 months. There are reasons women may not choose to seek treatment.

Grace's study (1995a) as well as findings from this study suggest women with CPP experience many problems related to communication with their providers, as well as difficulty with diagnosis and treatment. The quality of relations between women with CPP and their health care providers remains a central concern in their care. Clinical skills of providers should include "good relational ethics" (Benner, 2004, p. 349) and "skillful comportment" (Benner, 2004, p. 349). Relational ethics and skillful comportment take into consideration the use of the human relationship between provider and patient as fundamental in the provision of therapeutic and effective care. The use of such skill opens up clinical possibilities including a "disclosive" space. Disclosive space fosters the emotional safety necessary for the expression of vulnerability. For example, a

noticeably rushed provider may create a constricted disclosive space. In contrast, a provider that is attuned to a patient, taking the time to listen or provide a comforting measure, may in contrast, open up disclosive space.

The goal of creating disclosive space in the patient provider relationship should be a priority in the provision of health care related to CPP. This is especially so because so many aspects of the condition are "private" in nature. Because a disclosive space allows for patients' concerns to be heard and attended to, it sets up possibilities for providers to attend to concerns of the illness in an empathic and comforting way. In addition to the increased awareness of social space between provider and patient, the physical environment of care settings should be considered as well.

Helman (1995) points out that in many cases of disabling illness, individuals may experience a "phantom body image" (Helman, 1995, p. 173) which can be compared to the "phantom limb" phenomenon after amputation. The phantom body image of the woman with CPP emanates from personal memories of a previously healthy and/or functioning body, as well as comparisons to the ideal cultural image of how a healthy body should look, move, behave and function. Findings from this study suggest that women with CPP are faced daily with reminders of a body that no longer functions the way it used to. Subsequently, women integrate numerous health practices and adjustments of daily routine to adjust to their changing bodies.

Findings from this study suggest that women with CPP experience unnecessary confrontations in the delivery of health care. Women's experiences

of visits to the obstetrician/gynecologist (ob/gyn) were particularly concerning. Some women perceived the ob/gyn provider as more interested in issues related to future fertility, as opposed to providing adequate pain relief, and tending to quality of life issues related to pain. Also, women found it difficult to share the office space with women who were obviously pregnant. We must consider, as providers, if we are doing harm to patients by placing them in close proximity to the life option that has been closed down to them by infertility. We must consider if the structure of health care practices deserve consideration, especially if they do harm by exacerbating grief in women with CPP. Just as gynecology split from obstetrics as a medical specialty, perhaps the patients would be better served if care giving settings were split as well. One solution would be for providers to block off appointment times, and schedule patients according to specialty. These changes may be less convenient for the health care system at large, but take into consideration the special needs of women whose chronic illnesses result in sexual difficulties, chronic pain, or infertility.

Making room for the history. The findings of this research as well as findings from other work (Cox et al., 2003) highlight the significance of the past medical history in the experience of living with endometriosis. In this study, women were not asked directly about past treatment experiences. However, nearly all of the women extensively described troubled relationships with providers and difficult processes of seeking care. Treatment experiences were fraught with confusion and ambiguity, and patient-provider relations were frequently ruptured when women advocated for themselves to get the care they

believed to be adequate. These findings are corroborated by qualitative research (Cox et al., 2003) which identified "a long struggle" and "the doctor trail" as significant themes in focus group research with women with endometriosis. Women experienced "damage" and "trauma" as a result of providers not listening, not taking their symptoms seriously, and trivializing their symptom experiences.

We must consider how past conflict-laden and problematic health seeking experiences impact women's current understanding of the illness, as well as current relations with providers. A proposal is made to implement care that acknowledges and makes room for the patient's entire illness experience including the past medical history. Findings from this research shed light on the chronicity of endometriosis, and such care practices would simultaneously attend to grief and loss by acknowledging prior levels of functioning and capabilities.

Ideas for such an intervention include a patient-maintained data base, an extension of a "focused pain diary" (Zadinsky & Boyle, 1996, p. 225) developed to enable research participants to provide a more complete description of pain experiences and management strategies. The proposed data base, however, would be a project conducted over time, in which women would record interactions with providers, as well as dates and effectiveness of surgeries and therapies. Women may be interested in keeping photographs of their surgeries, as well as monitoring symptom and relational experiences. The data base could be either computerized or hand written so that women could conveniently bring it to provider appointments.

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There are several goals to keeping such a data base. First, this practice would bring to the forefront greater contextual awareness of the past, preventing it from being forgotten or ignored. Openly acknowledging trauma related to past care experiences would be a step toward healing and promoting trust with current providers to create disclosive clinical spaces (Benner, 2004). A second goal would be to document the impact of the condition on day to day life, and to mark changes over time. The documentation of such details, such as the inability to go to work five days out of the past month because of incapacitating pain, for example, might increase the chances that a provider would take serious notice. A third aim would be to use such a documentation system as a road map for the future, encouraging women to set goals for a meaningful life. Two qualitative studies demonstrate the potential importance of the proposed data base. Cox et al. (2003) showed that women with endometriosis live with great concern about their future related to the unreliability of symptomatology and their ability to cope over time. Denny (2004) identified the importance of goal setting for the future regarding adequate treatments and pain relief. Documenting goals for the future in the proposed data base would assist women with staying on track regarding their treatment goals and open up possibilities for optimism and hope for the future. Finally, from a relational perspective, the partner can get involved as well, documenting observations or experiences related to health or illness that they find meaningful, as well as recording mutual goals for the future, such as plans for pregnancy and/or adoption. A risk, however, of keeping such a

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data base is the medicalization (Reissman, 1983) of daily life that may result from an orientation and preoccupation with recording details of bodily function.

Attending to Pain

Findings from this study suggest CPP from endometriosis is most commonly treated in outpatient settings. While women seek medical treatment, including surgery, the time spent receiving such care is minimal when compared to the time spent with living with chronic pain in the community setting. Although the assessment of pain in inpatient settings has become a health care priority and described as "the fifth vital sign" (Douglas, 1999, p. 285), similar policies and measures need to be in place to provide adequate pain relief in outpatient community settings related to CPP. The literature suggests an awareness of the need to manage outpatient pain in other populations such as those with cancer (Davis & Walsh, 2004) and HIV (Kutzen & Bennett, 2000). However, there is a clear need to modify clinical protocols for effective management of pain related to CPP (AWHONN, 2003; Woods, Mitchell & Taylor, 1999). The range of effectiveness in pain management for CPP suggests that clear clinical guidelines are either underdeveloped or poorly implemented.

Attending to Immobility

Findings from this investigation suggest that CPP significantly impacts mobility. The health benefits of an active lifestyle have been well documented (van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Taylor's (1999) intervention study utilizing a package of nonpharmacological strategies including exercise, was effective in reducing premenstrual syndrome (PMS)

severity by 75%, premenstrual depression and general distress by 30-54%, as well as increasing well-being and self-esteem in women experiencing severe PMS. Exercise is an important aspect of health promotion that should not be overlooked in the care of women with CPP.

For women in this study pelvic pain and associated symptoms from endometriosis interfered directly with physical activity. Many of the women reported an inability to exercise because of pain or fear of precipitating pain. Many women reported gaining weight as a result of limited mobility in the course of their illness experience. Physical activity has been identified as one of ten high-priority public health issues in the United States (Healthy People 2010, n.d.). Providers must take into consideration the impact of CPP as well as women's individual physical limitations, while supporting patients to find ways to be physically active with the goal of reducing the risk of secondary health problems (van der Ploeg et al., 2004).

Interventions at the primary care level should include educating patients about the importance of physical activity on health, as well as working with women to help them regain faith in their bodies. For some women with CPP, exercises that involve less physical impact such as yoga, swimming, or dancing may be more achievable.

Attending to Depression

Depression is extremely prevalent among women with CPP (McGowan et al., 1998). Much of the scientific literature on CPP has focused on differences between psychological characteristics, such as anxiety and depression, between

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those with and without organic pathology. McGowan et al. (1998) conducted a meta-analysis and concluded that searching for differences in levels of anxiety and depression between women with laparoscopically identified pathology and those with no pathology was not useful. However, women with CPP (with or without pathology) exhibit significantly more depression, anxiety, neuroticism and psychopathology than women who are pain free, but show no differences when compared to women living with other forms of pain. The authors suggest that differences in levels of psychological morbidity may be due to the presence of chronic pain, rather than being specifically related to pelvic pain (McGowan et al., 1998).

The findings from this investigation support and illuminate McGowan's meta-analysis. The Symptom Checklist-90-Revised (SCL-90-R) was used as a screening measure for general distress in both the women and the partners of this sample. The depression subscale scores for this sample of women with CPP were significantly higher than published norms for women from nonclinical settings ($p \leq .001$). Sixty-one percent of the women's scores were high enough to be considered a positive risk, or "case" of a psychiatric disorder, demonstrating the extent of the psychological distress in this sample. However, this research also sheds light on how depression may evolve from living with CPP. Most of the women described feeling desperate and exasperated at points of their illness trajectory related to the lack of effective treatments for CPP, which was compounded by perpetual uncertainty about their future. A proposal is made for providers in primary care settings to assess women with CPP routinely for

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depression. Because CPP is considered a chronic condition, assessment and treatment considerations for depression need to be ongoing.

Although partners' subscale SCL-90-R scores of depression were not significantly different from normed outpatient males, four partners (31%) were identified as a positive risk, or a case for a psychiatric disorder. This finding supports other research that has demonstrated that chronic pain experienced by one member of a dyad, can have a significant impact on the partner's emotional and physical health (Holditch-Davis et al., 1995; Rowat & Knafl, 1985; Schwartz & Slater, 1991; A. G. Taylor et al., 1990). Therefore, providers in primary care are encouraged to broaden assessment of care of women with CPP to include at least a screening of their partners for health or mental health difficulties.

Implications in Clinical Practice for Women with CPP and their Partners

Broadening Assessment to a Relational Focus

A limitation of the biomedical model, which focuses on biological variables as the primary cause of disease, is that it may overlook other significant social and psychological factors. The provider who cares for individuals within a narrow biomedical frame may miss the impact of other factors, such as the person, the provider-patient interaction, and/or the family (McDaniel, Campbell, & Seaburn, 1990), and how these psychosocial variables may impact the illness experience and decision making around the illness.

Because CPP is linked to sexual activity and fertility, the condition is laden with powerful personal, psychological, and cultural meanings (Stones, 2000). In addition, findings from this study suggest numerous relational disruptions from

CPP. Therefore, it is essential to provide encompassing health care that extends beyond the traditional biomedical model to include a relational focus of care.

Inviting partners into care is proposed in order to broaden assessment to a relational focus. The findings from this research suggest numerous benefits from partners' active engagement in the health care process. Attending health-related appointments kept the partner informed and apprised of the woman's condition, which sometimes included a new understanding of the graveness of her condition, and treatment options. Being informed allowed the partner to take more of an active role in treatment decisions that kept in mind the couples' mutual goals. Another benefit to partners' engagement in care was that it served as a care giving action which benefited both partners. Women felt supported and cared for, while partners felt relieved that they were able to take on an active role and do "something." The experience of being more engaged was more desirable as it contrasted with the general experience of not knowing how to help and feeling fearful and helpless. Of course, not all couples will equally benefit from care directed to the family or couple. Some women prefer to manage their care independently and share information about changes in health status in their own way. The recommendation for relationally focused CPP care is that it be made readily available to patients.

Partners do not need to be present for providers to engage in relationally focused care. A relationally focused biopsychosocial approach is care that acknowledges that psychosocial factors are as important in health and illness as biological factors (McDaniel et al., 1990). The practice of relationally focused

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care involves providers constantly viewing the patient within the larger system of the family, taking into consideration, for example, that family is often the primary source of health beliefs and behaviors. Family health can also appreciate that chronic illness creates stress and impacts a family (McDaniel et al., 1990).

Various levels of provider involvement with relationally focused care have been described (McDaniel et al., 1990) ranging from Level One which involves minimal emphasis on the family, to Level Five which involves family therapy and addresses more deeply rooted family patterns of dysfunction. Based on the findings of this research, a level of care described as Level Three is recommended (McDaniel et al., 1990). The provider with the skills to function at this level not only gathers information about the patient and the family, but also addresses family stress and feelings by actively eliciting family feelings in a supportive way (McDaniel et al., 1990). Unfortunately, because current health care structures are so geared toward cost-efficiency and the individual, these suggestions may be a huge shift in thinking.

Couples' patterns can serve as discourses that can be drawn upon to address relational issues as well as daily management of illness. It is proposed that the patterns presented in Chapter Five be used by health care providers to assist couples in identifying their own relational patterns and to understand other possibilities of relatedness when living with CPP.

"Together but Alone" illustrates a dyad, in which each individual has a strong sense of self, as well as separate ideas and practices about day to day life, which leads to isolation between both partners. Relationally, the ill-partner,

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is driven by a lack of acceptance, and tries to act as if she is not ill. As a result she is alone and isolated in her suffering. While the ill partner integrates and accepts the illness into day to day life, as well as considers a future living with chronic illness, the well partner continues to pattern life in such a way that supports an acute illness model. By not mutually accepting and integrating the illness into their lives, a chasm develops between them. Such a relational pattern lacks sustainability as the isolation and separateness within the dyad would continue to grow.

"Battling Endometriosis Together" illustrates combined efforts within a dyad that allows for fighting illness in an undivided manner. Each partner embraces the other, and focuses his or her energy on ridding life of the illness, which is mutually perceived as a separate entity, as an "it" or as an alien thing. Efforts to eliminate this foreign "invader," take over day to day life in an exhausting, frightening and consuming way that would be difficult to sustain over time. Respite that comes with "winning the battle," opens up possibilities for comfort, and difficulties open up greater relational closeness.

"Totalized by Care Giving" is a relational pattern characterized as a "chivalrous" one, in which the well-partner's actions prioritize care giving over all else, even care of self. While the care giving actions may be considered altruistic, honorable, and compassionate, this pattern illustrates confused boundaries and loss of personhood within a dyad. This pattern of relating also illustrates in a profound way how the partner's experience of bearing witness to suffering on a daily basis, is taken up and dispersed throughout the relationship.

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This relationship pattern may be sustainable in the short run, but is dependent on the well partner's ability to maintain required levels of care which may not be possible or realistic.

"Balanced Care Giving" is a relational pattern that illustrates mutual acceptance of the other, as well as mutual acceptance and integration of the illness into daily life. Conjointly, the couple takes up a daily routine that supports the health of the ill-partner. From an egalitarian perspective, this relationship pattern may be considered "just" and "fair" as described by Okin (1989). It is not defined by traditional gender roles, but rather by each partner contributing to and being responsible for wage work and domestic life. The couple's flexibility and reciprocity open up possibilities for sustaining this relationship over time.

"Conjoined through Disabilities" is also characterized by mutual contribution to the relationship, however with this relational pattern, there is even more of an emphasis on each individual's capabilities as opposed to disabilities. This pattern relies on tremendous flexibility of action to adapt to each partner's respective illness needs and symptom experiences. It is possible, that with time, this relational pattern practiced in isolation, may no longer be sustainable by the couple, and may require the assistance of outside help or care givers.

It is proposed that providers initiate dialogue with couples about the impact of chronic illness on the family using the language of strengths, strains, and sustainability. The five patterns presented may serve as exemplars to open up discussions with couples, and to illuminate alternative relational possibilities.

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Attending to sexual health. Findings from this study suggest couples were on their own in a field of unknowns when dealing with issues of sexuality related to CPP related to endometriosis. Even when participants sought help from providers, they recommended interventions that were generally not found to be helpful. Findings suggest a disclosive space was not available in the medical encounter to discuss issues of sexuality.

Tiefer (1994) cautions against locating women's sexuality in the realm of health issues for several reasons. First, the medical model is based on a normative structure which would assume "healthy" versus "nonhealthy" sexuality. Second, with an individual focus of care in medicine, focusing on women's sexuality within the biomedical framework not only ignores the relational context, but also ignores the larger political and ideological framework. Third, locating women's sexuality within the domain of health inevitably places focus on the biology of sexuality; inquiry shaped by biological reductionism might dominate research of sociocultural aspects of sexuality.

In spite of these concerns, providers who fail to address issues of sexuality related to CPP as part of an overall assessment of women's health are negligent. Warner et al. (1999) have documented barriers, or contributing factors to the lack of adequate sexual assessment in health care. First, inadequate assessment may be related to providers' perceptions of relevance; providers may not perceive the sexual history as being related to the reason the patient is seeking care. The second factor is inadequate education and training of

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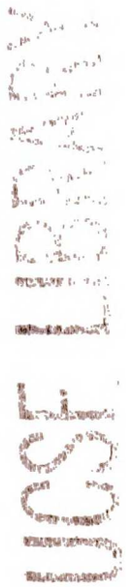
Findings from this investigation suggest issues of sexuality were of primary concern to the couples and health care visits were often linked to issues of sexuality, even if concerns went unstated. Limited time during primary care visits, as well as numerous other concerns to be addressed meant that issues of sexuality were rarely addressed appropriately. Based on the reactions from participants when issues of sexuality were addressed in the conduct of the study, women with CPP and their partners would be relieved and feel supported if issues were addressed within the medical environment.

Assessment of sexual problems depends on the initiative of the provider (McDaniel et al., 1990). The causes of sexual problems can vary widely from marital tension, to the side effects of medications, to organic problems such as endometriosis. Interventions proposed include an orientation of practice that takes up a couple's sexual issues within a relational context. In addition, providing information to women and their intimate partners about sexually related side effects or bodily changes related to treatments should be discussed with patients, and routinely included as part of informed consent before the initiation of a particular medical or surgical treatment.

Implications for Public Health

Women, through the use of metaphor and illness narratives, suggest an acute awareness to changes in their bodies related to pelvic pain. There was much ambiguity, however, embedded in the interpretation of the pain with



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seeking treatment and getting a diagnosis of endometriosis. Findings suggest sociocultural understandings influence both the woman and her health care provider's response to symptoms of CPP from endometriosis. Factors such as (mis) interpretation of "normal" characteristics of menses, religious and moral beliefs, and suffering in relation to the state of womanhood were identified in women's narratives and led to delay in formal health seeking, delays in formal medical work-ups for endometriosis, and repeated prescription of treatments by health care providers that were marginally or completely ineffective at relieving pain symptoms.

"Break the Silence" of Pelvic Pain

The health care profession has an obligation to promote menstrual education (Speroff et al., 1999) as well as appropriate care for pain related to menstruation, including other female conditions such as CPP. A public health initiative that widens the discourse of menstruation and CPP is proposed. Similar campaigns have popularized discourse about other sensitive topics in our culture including the "Break the Silence" campaigns around colorectal cancer (Division of Cancer Prevention and Control, 1999), and domestic violence (Mary Kay Ash Charitable Foundation, n.d.). The goal of popularizing discourse in our society about menstruation is to clarify (mis) interpretations and alleviate unnecessary suffering of women. Although targeted efforts need to be implemented across the lifespan with the inclusion of both genders, special efforts should be aimed at preadolescent school age children as the median age of menarche in U.S. girls is 12 years of age (Speroff et al., 1999).

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It is important for both women and providers to understand and take seriously symptoms of pelvic pain to assist with adequate pain relief, as well as to prevent associated disease. Although ovarian cancer has often been called the "silent killer," several retrospective studies have indicated the majority of patients with ovarian cancer do have symptoms, including pelvic pain (Goff, Mandel, Melancon, & Muntz, 2004). In addition, women with endometriosis are at increased risk of malignant tumors of the pelvis, including ovarian cancer (Giudice & Kao, 2004). Strict practice policies and guidelines need to be in place in order to diagnose endometriosis, as well as other health related conditions, in a timely manner.

Implications for Research

The public health implications of widening the public discourse of menstruation also have implications for future research. The experience of menstruation has been widely studied qualitatively and has focused on particular populations of women, such as African American women (Hawthorne, 2002) and young Western women (Beausang & Razor, 2000). There has also been a focus on menstruation specific to health related conditions such as learning disabilities (Ditchfield & Burns, 2004), polycystic ovarian syndrome (Varcoe, 2003), and Parkinson's Disease (Tolson, Fleming, & Schartau, 2002). A contribution to the existing literature, however, would be to interpretively explore how the general population views menstrual health and women's cycles with a focus on pain, taking into consideration cultural and developmental variability. This line of inquiry is particularly timely as safe suppression of menses has been proposed

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via continuous oral contraceptive use (Thomas & Ellertson, 2000). Additionally, future interpretive research to understand women's beliefs about menstrual suppression and desires to suppress menstruation for pain relief could open up new questions for menstrual cycle research.

The aim of this study was to collect current narratives and lived experience, and was not longitudinal in design. Therefore, this study did not capture the illness experience of CPP from endometriosis over time. It may be helpful to clinicians and researchers if future research could explore how couple's relatedness, in regards to their ranges of relationship, change over time.

Another possibility for future research includes qualitative inquiry to examine the lived experience of women with endometriosis with less severe symptomatology. There is a wide range of symptoms associated with endometriosis that may include dysmenorrhea, pelvic pain, infertility, and some women have no symptoms whatsoever (Yap et al., 2004). As a whole, this sample was representative of women who experienced significant distress from CPP from endometriosis. Also, future research to understand the lived experience of women who experience CPP from endometriosis but are not involved in endometriosis-related groups would be a contribution to the existing literature. Future research efforts can target women in the community, as opposed to medical sites, through the use of newspaper advertisements, and community bulletin boards.

The disability of endometriosis has been captured in this and other research (Mathias et al., 1996; Peters et al., 1991) yet there is little discourse

specifically addressing the needs of women with CPP who experience significant disability from the condition. The Americans with Disabilities Act (ADA) of 1990 recognizes and protects the civil rights of people with disabilities and covers a wide range of disability, from physical conditions affecting mobility, stamina, sight, hearing, and speech to conditions such as emotional illness and learning disorders. The ADA addresses access to many public services and public spaces, as well as access to the workplace. A line of inquiry that specifically examines CPP in relation to aspects of disability would be a contribution to the literature. Findings from this study suggest women's work is affected from CPP and adequate legal protection is not perceived as being in place. Further investigation into the needs of women with CPP as they relate to the ADA is recommended.

Another contribution to the literature would be to understand how religious teachings and beliefs may influence not only interpretations of pain, but also how religious faith may affect the way women take up living with endometriosis. For example, one participant was told by her mother that her pain was a punishment for Eve's sins. The implications of endometriosis for women who observe Jewish law *(Halakha)* have been described (Chertok, Zimmerman, Taragin, Silverman, & Hallak, 2005) but not examined empirically. Because Jewish law forbids all physical contact, including intercourse, between a married couple during the time when the wife has uterine bleeding not related to injury (*niddah),* bleeding may have little clinical significance, but much emotional significance for couples due to periods of physical separation between the couple. The most common cause

of *niddah* is menstruation, but also includes side effects of hormonal treatments for endometriosis, and bleeding between menstruation that some women experience as a symptom of endometriosis.

Conclusion

CPP is a complex women's health problem. Understandings of CPP have changed over time, and certain diagnostic categories such as symptomatic retrodisplacement (malposition of the uterus), pelvic congestion, and peritoneal defects (lacerations of the pelvic peritoneum), are used less frequently because their link with CPP have not been clearly established (Stenchever, 1990). Sufficient evidence strongly suggests a causal relationship between endometriosis and CPP (ACOG, 2004). Despite a plethora of research on both CPP and endometriosis, much confusion and ambiguity exists in the understanding of these conditions.

The goal of this study, a mixed-method design with qualitative methodology as the primary method, was to articulate the woman and her partner's illness understanding, symptom experience, and relationship responses to living with an ambiguous and disabling condition such as CPP. The larger aim was to develop knowledge to support the holistic care for women with CPP, so we may provide humanistic and effective nursing interventions for women and their partners. Based on these goals, numerous implications for clinical practice, public health, and research were offered.

The findings from this research study need to be considered within a sociocultural and temporal context. While the findings illuminate the experiences

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of 13 couples living in the San Francisco Bay Area between the years 2003 and 2004, there are limitations to applying these findings to other couples. Couples living in a different geographic area or within a different culture may experience different possibilities. In addition, availability to technology and treatments, may also greatly impact the lived experience of CPP from endometriosis.

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REFERENCES

ACOG, B. (2004). Chronic pelvic pain. *ACOG Practice Bulletin No. 51: Clinical Management Guidelines for Obstetrician-Gynecologists, 103*(3), 589-605.

Association of Women's Health, Obstetric & Neonatal Nurses (AWHONN). (2003). *Evidence-Based Clinical Practice Guideline: Nursing Management for Cyclic Perimenstrual Pain and Discomfort*. Washington, DC: Association of Women's Health, Obstetric & Neonatal Nurses.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders*. (Fourth edition). Washington, D.C.

Asbring, P., & Narvanen, A. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research, 12*(2), 148-160.

Baker, P. N., Symonds, E.M. (1992). The resolution of chronic pelvic pain after normal laparoscopy findings. *American Journal of Obstetrics & Gynecology, March*.

Beausang, C. C., & Razor, A. G. (2000). Young western women's experiences of menarche and menstruation. *Health Care for Women International, 21*(6), 517-528.

Benner, P. (1994a). *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*. Thousand Oaks, CA: SAGE.

Benner, P. (1994b). Introduction. In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment Caring, and Ethics in Health and Illness* (pp. xiii-xxvii). Thousand Oaks: Sage.

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Benner, P. (2000). The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy, 1*, 5-19.

Benner, P. (2004). Relational ethics of comfort, touch, and solace: Endangered arts? *American Journal of Critical Care, 13*(4), 346-349.

Benner, P., & Wrubel, J. (1989). *The Primacy of Caring: Stress and Coping in Health and Illness*. Menlo Park, CA: Addson-Wesley.

Berg, G. D., & Wadhwa, S. (2002). Diabetes disease management in a community-based setting. *Managed Care, June 11*(6), 45-50.

Blumenfeld, Z. (2004). Hormonal suppressive therapy for endometriosis may not improve patient health. *Fertility and Sterility, 81*(3), 487-492.

Bochner, A. P. (2000). Criteria against ourselves. *Qualitative Inquiry, 6*(2), 266-272.

Bramwell, R. (2001). Blood and milk: Constructions of female bodily fluids in Western society. *Women & Health, 34*(4), 85-96.

Burkman, R. T. (2004). Chronic pelvic pain of bladder origin. *Journal of Reproductive Medicine, 49*, 225-229.

Carlson, K. J., Miller, B. A., & Fowler, F. J. (1994). The Maine women's health study: II. Outcomes of nonsurgical management of leiomyomas,

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abnormal bleeding, and chronic pelvic pain. *Obstetrics & Gynecology, 83*(4), 567-572.

Cassell, E. (2001). The phenomenon of suffering and its relationship to pain. In S. K. Toombs (Ed.), *Handbook of Phenomenology and Medicine* (Vol. 68, pp. 371-390). Boston, MA: Kluwer Academic Publishers.

Chang, S., Long, S. R., Kutikova, L., Bowman, L., Finley, D., Crown, W. H., et al. (2004). Estimating the cost of cancer: Results on the basis of claims data analysis for cancer patients diagnosed with seven types of cancer during 1999 to 2000. *Journal of Clinical Oncology, 22*(17), 3524-3530.

Chatman, D. L. (1976). Endometriosis in the black woman. *American Journal of Obstetrics and Gynecology, 125*, 987-989.

Chertok, I. R., Zimmerman, D. R., Taragin, S., Silverman, Z., & Hallak, M. (2005). Implications of endometriosis for women who observe Jewish Law *(Halakha). Israel Medical Association Journal, 7*, 71-74.

Chesla, C. A. (1994). Parents' caring practices with schizophrenic offspring. In *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (pp. 167-184). Thousand Oaks, CA: SAGE Publications, Inc.

Chesla, C. A. (1995). Hermeneutic phenomenology: An approach to understanding families. *Journal of Family Nursing, 1*(1), 63-78.

Clarke, A. E., & Oleson, V. L. (1999). Revising, diffracting, acting. In A. E. Clarke & V. L. Oleson (Eds.), *Revisioning Women, Health, and Healing: Feminist, Cultural, and Technoscience Perspectives* (pp. 3-48). New York: Routledge.

Clarke, J. N. (19
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Clarke, J. N. (1999). Chronic fatigue syndrome: Gender differences in the search for legitimacy. *Australian and New Zealand Journal of Mental Health Nursing, 8*, 123-133.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic Phenomenological Research.* Thousand Oaks, CA: Sage Publications, Inc.

Collett, B. J., Cordle, C., & Stewart, C. (2000). Setting up a multidisciplinary clinic. *Bailliere's Clinical Obstetrics and Gynecology, 14*(3), 541-556.

Collett, B. J., Cordle, C. J., Stewart, C. R., & Jagger, C. (1998). A comparative study of women with chronic pelvic pain, chronic pelvic pain and those with no history of pain attending general practitioners. *British Journal of Obstetrics and Gynecology, 105*, 87-92.

Cox, H., Henderson, L., Anderson, N., Cagliarini, G., & Ski, C. (2003). Focus group study of endometriosis: Struggle, loss and the medical merry-go-round. *International Journal of Nursing Practice, 9*, 2-9.

Dalton, J. (1990). Chronic musculoskeletal symptoms and sexuality. In L. Lauver (Ed.), *Sexual Health Promotion*, (pp. 325-336). Philadelphia: W.B. Saunders Company.

Davis, M. P., & Walsh, D. (2004). Cancer pain: How to measure the fifth vital sign. *Cleveland Clinic Journal of Medicine, 71*(8), 625-632.

Denny, E. (2004). Women's experience of endometriosis. *Journal of Advanced Nursing, 46*(6), 641-648.

Derogatis, L. (19

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Derogatis, L. (1982). Self-report measures of stress. In L. Goldberger & B. Shlomo (Eds.), *Handbook of Stress: Theoretical and Clinical Aspects* (pp. 270-294). London: Free Press.

Derogatis, L. (1994). *The SCL-90-R manual (revised).* Baltimore, MD: Johns Hopkins University, School of Medicine.

Derogatis, L., & Cleary, P. (1977). Confirmation of the dimensional structure of the SCL-90R: A study in construct validation. *Journal of Clinical Psychology, 33*, 981-989.

Ditchfield, H., & Burns, J. (2004). Understanding our bodies, understanding ourselves: The menstrual cycle, mental health and women with learning disabilities. *Tizard Learning Disability Review, 9*(4), 24-32.

Division of Cancer Prevention and Control. (1999). Colorectal Cancer: Let's Break the Silence. Atlanta, GA: Centers for Disease Control and Prevention.

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*(5), 668-676.

Douglas, M. (1999). Pain as the fifth vital sign: Will cultural variations be considered? *Journal of Transcultural Nursing, 10*(4), 285.

Draucker, C. B. (1991). Coping with a difficult-to-diagnose illness: The example of interstitial cystitis. *Health Care for Women International, 12*, 191-198.

Dreyfus, H. L. (1991). *Being-in-the-world, A Commentary on Heidegger's Being and Time,* Cambridge, MA: MIT Press.

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EA (Endometriosis Association) Newsletter. (1998). North American Membership Survey.

Endometriosis Association. (2005). The Endometriosis Association: Who We Are. Retrieved June 7, 2005 from http://www.endometriosisassn.org/press3.html

Eskenazi, B., & Warner, M. (1997). Epidemiology of endometriosis. *Obstetrics and Gynecology Clinics of North America, 24*(2), 235-258.

Ferrell, B. R., Dean, G. (1995). The meaning of cancer pain. *Seminars in Oncology Nursing, 11*(1), 17-22.

Finkler, K. (1994). *Women in Pain: Gender and Morbidity in Mexico.* Philadelphia: University of Pennsylvania Press.

Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics.* Chicago, IL: The University of Chicago Press.

Fry, R. P. W., Crisp, A. H., & Beard, R. W. (1991). Patients' illness models in chronic pelvic pain. *Psychotherapy Psychosomatics, 55*, 158-163.

Garratt, D., & Hodkinson, P. (1998). Can there be criteria for selecting research criteria? A hermeneutical analysis of an inescapable dilemma. *Qualitative Inquiry, 4*(4), 515-539.

Garry, R. (2004). The endometriosis syndromes: A clinical classification in the presence of aetiological confusion and therapeutic anarchy. *Human Reproduction, 19*(4), 760-768.

Giudice, L. C., & Kao, L. C. (2004). Endometriosis. *Lancet, 364*, 1789-1799.

Goff, B. A., Mandel, L. S., Melancon, C. H., & Muntz, H. G. (2004). Frequency of symptoms of ovarian cancer in women presenting to primary care clinics. *JAMA, 291*(22), 2705-2712.

Grace, V. M. (1995a). Problems of communication, diagnosis, and treatment experienced by women using the New Zealand health services for chronic pelvic pain: A quantitative analysis. *Health Care for Women International, 16*, 521-535.

Grace, V. M. (1995b). Problems women patients experience in the medical encounter for chronic pelvic pain: A New Zealand study. *Health Care for Women International, 16*, 509-519.

Grace, V. M. (2000). Pitfalls of the medical paradigm in chronic pelvic pain. *Bailliere's Clinical Obstetrics and Gynecology, 14*(3), 525-539.

Gurel, H., & Gurel, S. A. (1999). Dyspareunia, back pain and chronic pelvic pain: The importance of this pain complex in gynecological practice and its relation with grandmultiparity and pelvic relaxation. *Gynecologic and Obstetric Investigation, 48*, 119-122.

Habbema, J. D., Collins, J., Leridon, H., Evers, J. L., Lunenfeld, B., & teVelde, E. R. (2004). Towards less confusing terminology in reproductive medicine: A proposal. *Human Reproduction, 19*(7), 1497-1501.

Haefner, H. K., Khoshnevisan, M. H., Dent, D. P., Bachman, J. E., Flowe-Valencia, H. D., Green, C. R., et al. (2000). Use of Mcgill Pain Questionnaire to compare women with vulvar pain, pelvic pain, and headaches. *Journal of Reproductive Medicine, 45*(8), 665-671.

Haraway, D. J.
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Haraway, D. J. (1991). A cyborg manifesto: Science, technology, and socialist-feminism in the late twentieth century. In *Simians, cyborgs, and women* (pp. 149-181). NewYork: Routledge.

Harrop-Griffiths, J., Katon, W., Walker, E., Holm, L., Russo, J., Hickok, L. (1988). The association between chronic pelvic pain, psychiatric diagnoses, and childhood sexual abuse. *Obstetrics & Gynecology, 71*(4), 589-594.

Hawthorne, D. J. (2002). Symbols of menarche identified by African American females. *Western Journal of Nursing Research, 24*(5), 484-501.

Healthy People 2010. (no date). Leading health indicators: Priorities for action. Retrieved March 22, 2005 from http://www.healthypeople.gov/LHI/Priorities.html

Helman, C. G. (1995). The body image in health and disease: Exploring patients' maps of body and self. *Patient Education and Counseling, 26*, 169-175.

Hill, J. A. (1997). Immunology and endometriosis. *Obstetrics and Gynecology, 2*, 291-306.

Hodgkiss, A. D., Watson, J.P. (1994). Psychiatric morbidity and illness behaviour in women with chronic pelvic pain. *Journal of Psychosomatic Research, 38*(1), 3-9.

Holditch-Davis, D., Black, B. P., Sandelowski, M., Harris, B. G., & Belyea, M. (1995). Fertility status and symptoms in childbearing couples. *Research in Nursing & Health, 18*, 417-426.

Honkasalo, J. (1998). Space and embodied experience: Rethinking the body in pain. *Body & Society, 4*(2), 35-57.

Howard, F. M. (2
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Howard, F. M. (2000). The role of laparoscopy as a diagnostic tool in chronic pelvic pain. *Bailliere's Clinical Obstetrics and Gynaecology, 14*(3), 467-494.

Hughes, E., Fedorkow, D., Collins, J., & Vandekerckhove, P. (2003). Ovulation suppression for endometriosis (review). *The Cochrane Database of Systematic Reviews* (3. Art. No.: CD000155. DOI: 10.1002/14651858.CD000155.).

Jacobson, T. Z., Barlow, D. H., Garry, R., & Koninckx, P. (2001). Laparoscopic surgery for pelvic pain associated with endometriosis. *The Cochrane Database of Systematic Reviews* (4. Art. No.: CD001300. DOI:10.1002/14651858.CD001300.).

Johansson, E. E., Hamberg, K., Westman, G., & Lindgren, G. (1999). The meanings of pain: An exploration of women's descriptions of symptoms. *Social Science & Medicine, 48*, 1791-1802.

Kennedy, S. (2000). Preface. *Bailliere's Clinical Obstetrics and Gynaecology, 14*(3), vii-viii.

Kleinman, A. (1988a). *The Illness Narratives: Suffering, Healing, and the Human Condition*. USA: BasicBooks, Inc.

Kleinman, A. (1988b). The personal and social meanings of illness. In *The Illness Narratives: Suffering, Healing, and the Human Condition* (pp. 31-55). USA: Basic Books, Inc.

Kramer, M. G., & Reiter, R. C. (1997). Hysterectomy: Indications, alternatives and predictors. *American Family Physician, 55*(3), 827-834.

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Kutzen, H., & Bennett, M. (2000). Clinicians are encouraged to use HIV patients' pain as a fifth vital sign. *HIV Clinics, Winter 12*(1), 1-5.

Kvale, S. (1995). The social construction of validity. *Qualitative Inquiry, 1*(1).

Lather, P. (1993). Fertile obsession: Validity after poststructuralism. *The Sociological Quarterly, 34*(4), 673-693.

Leder, D. (1990). *The Absent Body*. Chicago: The University of Chicago Press.

Lemaire, G. S. (2004). More than just menstrual cramps: Symptoms and uncertainty among women with endometriosis. *JOGGN, 33*(1), 71-78.

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P.Benner (Ed.), *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*. Thousand Oaks, CA: SAGE.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.

Malterud, K. (1999). The gendered construction of diagnosis interpretation of medical signs in women patients. *Theoretical Medicine and Bioethics, June 20*(3), 275-286.

Martin, E. (1992). Menstruation, work, and class. In *The Woman in the Body: A Cultural Analysis of Reproduction* (pp. 92-93). Boston: Beacon Press.

Mary Kay Ash Charitable Foundation. (no date). A Legacy of Love. *Turning Belief into Action* Retrieved March 21, 2005 from http://www.mkacf.org/BreakTheSilence.html

Mathias, S. D
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Mathias, S. D., Kuppermann, M., Liberman, R. C., Lipschutz, R. C., & Steege, J. F. (1996). Chronic pelvic pain: Prevalence, health-related quality of life, and economic correlates. *Obstetrics & Gynecology, 87*(3), 321-327.

McDaniel, S., Campbell, T., & Seaburn, D. (1990). Basic premises of family-oriented primary care. In *Family-oriented primary care* (pp. 3-15). New York: Springer-Verlag.

McGowan, L., Clark-Carter, D., & Pitts, M. K. (1998). Chronic pelvic pain: A meta-analytic review. *Psychology and Health, 13*, 937-951.

Meleis, A., & Lindgren, T. (2001). Show me a woman who does not work! *Journal of Nursing Scholarship, 33*(3), 209-210.

Mishell, D. R. (2004). Chronic pelvic pain in women: Focus on the bladder. *The Journal of Reproductive Medicine, 49,*3 (Supplement), 223-224.

Moore, J., & Kennedy, S. (2000). Causes of chronic pelvic pain. *Bailliere's Clinical Obstetrical and Gynaecology, 14*(3), 389-402.

Morokoff, P. J., & Calderone, K. L. (1994). Sexuality and infertility. In V. J. Adesso, D. M. Reddy & R. Fleming (Eds.), *Psychological Perspectives on Women's Health* (pp. 251-284). Washington, DC: Taylor & Francis.

Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40*(2), 120-123.

Morse, J. M., Deluca Havens, G. A., & Wilson, S. (1997). The comforting interaction: Developing a model of nurse-patient relationship. *Scholarly Inquiry for Nursing Practice: An International Journal, 11*(4), 321-347.

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Nothnick, W. B., & D'Hooghes, T. M. (2003). Medical management of endometriosis: Novel targets and approaches towards the development of future treatment regimens. *Gynecologic and Obstetric Investigation, 55*, 189-198.

Olive, D. L. (1995). Medical treatment for endometriosis: Overview and alternative options. In M. L. Ballweg & E. Association (Eds.), *The Endometriosis Sourcebook* (pp. 153-180). Chicago: Contemporary Books.

Parsons, C. L. (2004). Diagnosing chronic pelvic pain of bladder origin. *The Journal of Reproductive Medicine, 49*, 235-242.

Pattie, M. A., Murdoch, B. E., Theodoros, D., & Forbes, K. (1998). Voice changes in women treated for endometriosis and related conditions: The need for comprehensive vocal assessment. *Journal of Voice, 12*(3), 366-371.

Peters, A. A., van Dorst, E., Jellis, B., vanZuuren, E., Hermans, J., & Trimbos, J. B. (1991). A randomized clinical trial to compare two different approaches in women with chronic pelvic pain. *Obstetrics & Gynecology, 77*(5), 740-744.

Peveler, R., Edwards, J., Daddow, J., & Thomas, E. (1996). Psychosocial factors and chronic pelvic pain: A comparison of women with endometriosis and with unexplained pain. *Journal of Psychosomatic Research, 40*(3), 305-315.

Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.),

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Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness (pp. 65-84). Thousand Oaks, CA: Sage.

Price, J., Blake, F. (1999). Chronic pelvic pain: The assessment as therapy. *Journal of Psychosomatic Research, 46*(1), 7-14.

Racher, F. E., Kaufert, J. M., & Havens, B. (2000). Conjoint research interviews with frail, elderly couples: Methodologic implications. *Journal of Family Nursing, 6*(4), 367-379.

Reed, B. D., Haefner, H. K., Punch, M. R., Roth, R. S., Gorenflo, D. W., & Gillespie, B. W. (2000). Psychosocial and sexual functioning in women with vulvodynia and chronic pelvic pain. *The Journal of Reproductive Medicine, 45*, 624-632.

Reissman, C.K. (1983). Women and medicalization: A new perspective. *Social Policy*, pp. 3-18.

Reiter, R. C. (1990). A profile of women with chronic pelvic pain. *Clinical Obstetrics and Gynecology, 33*(1), 130-136.

Reiter, R. C., & Gambone, J. C. (1990). Demographic and historic variables in women with ideopathic chronic pelvic pain. *Obstetrics & Gynecology, 75*(3), 428-432.

Richardson, L. (2000a). Evaluating ethnography. *Qualitative Inquiry, 6*(2), 253-255.

Richardson, L. (2000b). Introduction - Assessing alternative modes of qualitative and ethnographic research: How do we judge? Who judges? *Qualitative Inquiry, 6*(2), 251-252.

Richter, H. E.,
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Richter, H. E., Holley, R. L., Chandraiah, S. C., & Varner, R. E. (1998). Laparoscopic and psychologic evaluation of women with chronic pelvic pain. *International Journal of Psychiatry in Medicine, 28*(2), 243-253.

Rolland, J.S. (1994). Families, illness, & disability. New York: BasicBooks

Rowat, K. M., & Knafl, K. A. (1985). Living with chronic pain: The spouse's perspective. *Pain, 23*, 259-271.

Ruzek, S. B., Clarke, A. E., & Oleson, V. L. (1997). Social, biomedical, and feminist models of women's health. In S. Burt (Ed.), *Women's Health: Complexities and Differences* (pp. 11-28). Columbus, Ohio: Ohio State University Press.

San Francisco. (1999). *Citizen Survey*. City of San Francisco.

Sand, P. K. (2004). Chronic pain syndromes of gynecologic origin. *Journal of Reproductive Medicine, 49*, 230-234.

Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing and Health, 23*, 246-255.

Sanmiguel, L. M. (2000). *From "career woman's" disease to "an epidemic ignored": Endometriosis in U.S. Culture since 1948.* Unpublished Doctoral Dissertation, University of Illinois at Urbana-Champaign, Urbana, Illinois.

Savidge, C. J., & Slade, P. (1997). Psychological aspects of chronic pelvic pain. *Journal of Psychosomatic Research, 42*(5), 433-444.

Schwartz, L., & Slater, M. A. (1991). The impact of chronic pain on the spouse: Research and clinical implications. *Holistic Nursing Practice, 6*(1), 9-17.

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Selfe, S. A., Matthews, Z., & Stones, R. W. (1998). Factors influencing outcome in consultations for chronic pelvic pain. *Journal of Women's Health, 7*(8), 1041-1048.

Selfe, S. A., Van Vugt, M., Stones, W. (1998). Chronic gynaecological pain: An exploration of medical attitudes. *Pain, 77*, 215-225.

Sharpe, M., & Carson, A. (2001). "Unexplained" somatic symptoms, functional syndromes, and somatization: Do we need a paradigm shift? *Annals of Internal Medicine, 134*, 926-930.

Smith, R. P., & Ling, F. W. (1991). Gynevision. *Obstetrics and Gynecology, 78*(4), 708-709.

SmithBattle, L. (1994). Beyond normalizing: The role of narrative in understanding teenage mothers' transition to mothering. In *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (pp. 141-166). Thousand Oaks, CA: SAGE Publishers, Inc.

Speroff, L., Glass, R. H., & Kase, N. G. (1999). Menstrual disorders. In C. Mitchell (Ed.), *Clinical Gynecologic Endocrinology and Infertility* (pp. 557-573). Maryland: Lippincott Williams & Wilkins.

Steege, J. F. (1998). General principles of pain management. In J.F.Steege, D. A.Metzger & B.S.Levy (Eds.), *Chronic Pelvic Pain: An Integrated Approach* (pp. 282-297). Philadelphia: W.B. Saunders Co.

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Stenchever, M. A. (1990). Symptomatic retrodisplacement, pelvic congestion, universal joint, and peritoneal defects: Fact or fiction? *Clinical Obstetrics and Gynecology, 33*(1), 161-167.

Stones, R. W. (2000). Female genital pain. In R. B. Fillingim (Ed.), *Sex, Gender, and Pain: Progress in Pain Research and Management* (Vol. 17, pp. 355-369). Seattle: IASP Press.

Stones, R. W., Selfe, S. A., Fransman, S., & Horn, S. A. (2000). Psychosocial and economic impact of chronic pelvic pain. *Bailliere's Clinical Obstetrics and Gynaecology, 14*(3), 415-431.

Sundell, G., Milsom, I., & Amderscj, B. (1990). Factors influencing the prevalence and severity of dysmenorrhea in young women. *British Journal Obstetrics & Gynaecology*.

Surrey, E. S., & Judd, H. L. (1992). Reduction of vasomotor symptoms and bone mineral density loss with combined norethindrone and long-acting gonadotropin-releasing hormone agonist therapy of symptomatic endometriosis: A prospective randomized trial. *Journal of Clinical Endocrinology and Metabolism, 72*, 558-563.

Taylor, A. G., Lorentzen, M. A., & Blank, M. B. (1990). Psychologic distress of chronic pain sufferers and their spouses. *Journal of Pain and Symptom Management, 5*(1), 6-10.

Taylor, D. (1999). Effectiveness of professional-peer group treatment: Symptom management for women with PMS. *Research in Nursing & Health, 22*(6), 496-511.

Taylor, D., &
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Taylor, D., & Woods, N. (2001). What we know and how we know it: Contributions from nursing to women's health research and scholarship. In J. Fitzpatrick, D. Taylor & N. F. Woods (Eds.), *Annual Review of Nursing Research* (pp. 3-28). New York, NY: Springer Publishing Company, Inc.

The University of California San Francisco School of Nursing Symptom Management Faculty Group (1994). A model for symptom management. *Image: Journal of Nursing Scholarship, 26*(4), 272-276.

Thomas, S. L., & Ellertson, C. (2000). Nuisance or natural and healthy: Should monthly menstruation be optional for women? *Lancet, 355*, 922-924.

Tiefer, L. (1994). Women's sexuality: Not a matter of health. In *Reframing Women's Health: Multidisciplinary Research and Practice* (pp. 151-162). Thousand Oaks, CA: Sage Publications, Inc.

Tiefer, L. (2004). *Sex is Not a Natural Act & Other Essays*. Boulder, CO: Westview Press.

Tolman, D. L., & Szalacha, L. A. (1999). Dimensions of desire: Bridging qualitative and quantitative methods in a study of female adolescent sexuality. *Psychology of Women Quarterly, 23*, 7-39.

Tolson, D., Fleming, V., & Schartau, E. (2002). Coping with menstruation: Understanding the needs of women with parkinson's disease. *Journal of Advanced Nursing, 40*(5), 513-521.

van der Ploeg, H. P., van der Beek, A. J., van der Woude, L. H., & van Mechelen, W. (2004). Physical activity for people with a disability: A conceptual model. *Sports Medicine, 34*(10), 639-649.

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van Manen, M. (1990). *Researching Lived Experience*. London, Ontario, Canada: SUNY.

van Manen, M. (1997). From meaning to method. *Qualitative Health Research, 7*(3), 345-369.

Varcoe, C. (2003). Women with polycystic ovarian syndrome had excess hair, irregular or absent menstruation, and infertility and felt freakish, abnormal, and not proper women. *Evidence-Based Nursing, 6*(1), 30.

Vercellini, P., Bocciolone, L., Vendola, N., Colombo, A., Rognoni, M. T., & Fedele, L. (1991). Peritoneal endometriosis. Morphologic appearance in women with chronic pelvic pain. *Journal of Reproductive Medicine, 36*(7), 533-536.

Vercellini, P., Trespidi, L., DeGiorgi, O., Cortesi, I., Parazzini, F., & Crosignani, P. G. (1996). Endometriosis and pelvic pain: Relation to disease stage and localization. *Fertility and Sterility, 65*(2), 299-304.

Warner, P. H., Rowe, T.R., Whipple, B. (1999). Shedding light on the sexual history. *American Journal of Nursing, 99*(6), 34-41.

Webster, D. C. (1997). Recontextualizing sexuality in chronic illness: Women and interstitial cystitis. *Health Care for Women International, 18*, 575-589.

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Wellbery, C. (1999). Diagnosis and treatment of endometriosis. *American Academy of Family Physicians, 60*, 1753-1768.

Wendell, S. (1996). The flight from the rejected body. In *The rejected body: Feminist philosophical reflections on disability* (pp. 85). New York, NY: Routledge.

Whitney, M.L. (1998). Importance of lay organizations for coping with endometriosis. *The Journal of Reproductive Medicine*, *43*(3), 331-334.

Williams, R. E., Hartmann, K. E., Sandler, R. S., Miller, W. C., Savitz, L. S., & Steege, J. F. (2005). Recognition and treatment of irritable bowel syndrome among women with chronic pelvic pain. *American Journal of Obstetrics and Gynecology, 192*, 761-767.

Woods, N.F., Mitchell, E.S., & Taylor, D. (1999). From menarche to menopause: Contributions from nursing research and recommendations for practice. In A.S. Hinshaw, S.L. Feetham & J.L. Shaver (Eds.), *Handbook of Clinical Nursing Research* (pp. 485-507). Thousand Oaks, CA: Sage Publications.

Woods, N. F., Taylor, D., Mitchell, E. S., & Lentz, M. J. (1992). Perimenstrual symptoms and health-seeking behavior. *Western Journal of Nursing Research, 14*(4), 418-443.

Wrubel, J., & Folkman, S. (1997). What informed caregivers actually do: The caregiving skills of partners of men with aids. *AIDS Care, 9*(6), 691-706.

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Yap, C., Furness, S., & Farquhar, C. (2004). Pre and post operative medical therapy for endometriosis surgery. *The Cochrane Database of Systematic Reviews* (Art.No. CD003678. DOI: 10.1002/14651858.CD003678.pub2.).

Yunus, M. B. (2001). The role of gender in fibromyalgia syndrome. *Current Rheumatology Reports, 3*(2), 128-134.

Zadinsky, J. K., Boyle, J.S. (1996). Experiences of women with chronic pelvic pain. *Health Care for Women International, 17*, 223-232.

Zondervan, K., & Barlow, D. H. (2000). Epidemiology of chronic pelvic pain. *Bailliere's Clinical Obstetrics and Gynaecology, 14*(3), 403-414.

Zondervan, K. T., Yudkin, P. L., Vessey, M. P., Jenkinson, C. P., Dawes, M. G., Barlow, D. H., et al. (2001). Chronic pelvic pain in the community: Symptoms, investigations and diagnoses. *American Journal of Obstetrics and Gynecology, 184*(6), 1149-1155.

Zupi, E., Marconi, D., Sbracia, M., Zullo, F., DeVivo, B., Exacustos, C., et al. (2004). Add-back therapy in the treatment of endometriosis-associated pain. *Fertility and Sterility, 82*(5), 1303-1308.

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APPENDICES

Appendix A: Informed Consent Woman

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

CONSENT FOR THE WOMAN

Understanding How Couples Share the Pain of Endometriosis

Researchers: Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc, Associate Professor
Department of Family Health Care Nursing,
University of California, San Francisco

A. PURPOSE AND BACKGROUND

Fran Strzempko, RN, PhD(c), and Catherine Chesla, RN, DNSc, of the School of Nursing are conducting a study to learn about how your life has been affected from your diagnosis of endometriosis and pelvic pain. We want to learn, from your perspective, how you feel you and your partner's relationship has been affected by the pain. You are being asked to participate in this study because you are a woman who has had chronic pelvic pain for at least six months, has received a medical diagnosis of endometriosis, and you have been living with your partner for at least one year.

B. PROCEDURES

If you agree to participate in this study, the following will happen:

The study will be explained to you and your partner, then each of you will sign a consent form. You will talk with Fran individually for approximately 2 hours about your experience of living with pelvic pain and how you feel it affects relationships in your life. At the end of the first interview, you will complete the Symptom Checklist 90 Revised Questionnaire and a demographics questionnaire. Approximately three weeks later, you and your partner will be interviewed together by Fran for approximately 2 hours about aspects of your symptom experience, and aspects of the illness in which you agree and disagree. Fran may contact you for a second individual interview which may be conducted in phone or in person, if required, to clarify information from the prior two interviews.

Sensitive questions will be asked during the interview about sexual activity. Issues of comfort and confidentiality will be of utmost priority. The interviews will take place at a time and place that is convenient for you, taking your comfort and

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confidentiality into consideration. The conversations will be tape-recorded. The amount of time required to complete this study is 5-7 hours.

C. RISKS/DISCOMFORTS

Due to the sensitivity of the topic, some of the questions may cause you emotional discomfort. You can refuse to answer any question. You may discontinue the interview at any time. Some people may have a delayed emotional response to talking about their experiences of chronic pelvic pain. During the study, you may contact Fran Strzempko, RN, PhD(c) at (415)518-7897 or contact the Crisis Center telephone numbers that are in your study packet.

Confidentiality: Participation in research may involve a loss of privacy, but strict procedures will be carried out at all times to protect the information you give. Care will be taken to maintain confidentiality by protecting individual interviewees from being overheard by the other partner. The interviews will be conducted in a private place, the tapes of the interviews will be transcribed to written form using a code number instead of your name, and the audiotapes will be destroyed when the project is complete. During the study, the tapes and written transcriptions will be kept in a locked file cabinet. All identifying information will be concealed in reports that are produced from this project.

D. BENEFITS

There are no other direct benefits to you from participation in this study. You may find that talking about your experiences of pelvic pain with the interviewer may be helpful. However, it is hoped that the information gained from this study will help physicians and nurses better understand the lived experience of the woman with pelvic pain and endometriosis, and her partner.

E. COSTS

There are no costs to you for participating in this study.

F. PAYMENT

Each partner will receive $20.00 at the completion of the second interview. If an additional follow-up individual interview is required, an additional $10 will paid. If the final interview is via phone, the $10 will be mailed to you.

G. QUESTIONS

This study has been explained to you by Fran Strzempko and your questions were answered. If you have any other questions about the study, you may call Dr. Chesla at (415) 476-4439 or Fran Strzempko at (415) 518-7897.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason, you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California San Francisco, San Francisco, CA 94143.

H. CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study.

If you wish to participate, you should sign below.

_____

Date Participant's Signature

_____

Date Person Obtaining Consent

Appendix B: Informed Consent Partner

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

CONSENT FOR THE PARTNER

Understanding How Couples Share the Pain of Endometriosis

Researchers: Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc, Associate Professor
Department of Family Health Care Nursing,
University of California, San Francisco

A. PURPOSE AND BACKGROUND

Fran Strzempko, RN, PhD(c), and Catherine Chesla, RN, DNSc, of the School of Nursing are conducting a study to learn about how your life has been affected by your partner's diagnosis of endometriosis and pelvic pain. We want to learn, from your perspective, how you feel you and your partner's relationship has been affected by the pain. You are being asked to participate in this study because you are the partner of a woman who has had pelvic pain for at least 6 months and has been given a diagnosis of endometriosis, and you have been living with your partner for at least one year.

B. PROCEDURES

If you agree to participate in this study, the following will happen:

The study will be explained to you and your partner, then each of you will sign a consent form. You will talk with Fran individually for approximately 2 hours about your perspective of being the partner of a woman with pelvic pain and how you feel it affects your personal relationship. At the end of the first interview, you will complete the Symptom Checklist 90 Revised Questionnaire and a demographics questionnaire. Approximately three weeks later, you and your partner will be interviewed together by Fran for approximately 2 hours about aspects of your symptom experience, and aspects of the illness experience in which you agree and disagree. Fran may contact you for a second individual interview which may be conducted in phone or in person, if required, to clarify information from the prior two interviews.

Sensitive questions will be asked during the interview about sexual activity. The interviews will take place at a time and place that is convenient for you, taking your comfort and confidentiality into consideration. The conversations will be tape-recorded. The amount of time required to complete this study is 5-7 hours.

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C. RISKS/DISCOMFORTS

Due to the sensitivity of the topic, some of the questions may cause you emotional discomfort. You can refuse to answer any question. You may discontinue the interview at any time. Some people may have a delayed emotional response to talking about their experiences of living with someone with chronic pelvic pain. During the study, you may contact Fran Strzempko, RN, PhD(c) at (415)518-7897 or contact the Crisis Center telephone numbers that are in your study packet.

Confidentiality: Participation in research may involve a loss of privacy, but strict procedures will be carried out at all times to protect the information you give. Care will be taken to maintain confidentiality by protecting individual interviewees from being overheard by the other partner. The interviews will be conducted in a private place, the tapes of the interviews will be transcribed to written form using a code number instead of your name, and the audiotapes will be destroyed when the project is complete. During the study, the tapes and written transcriptions will be kept in a locked file cabinet. All identifying information will be concealed in reports that are produced from this project.

D. BENEFITS

There are no other direct benefits to you from participation in this study. You may find that talking about your experiences of being the partner to someone who is living with pelvic pain, may be helpful. However, it is hoped that the information gained from this study will help physicians and nurses better understand the lived experience of the woman with pelvic pain and endometriosis, and the needs and experiences of her partner.

E. COSTS

There are no costs to you for participating in this study.

F. PAYMENT

Each partner will receive $20.00 at the completion of the second interview. If an additional follow-up individual interview is required, an additional $10 will paid. If the final interview is via phone, the $10 will be mailed to you.

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G. QUESTIONS

This study has been explained to you by Fran Strzempko and your questions were answered. If you have any other questions about the study, you may call Dr. Chesla at (415) 476-4439 or Fran Strzempko at (415) 518-7897.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason, you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California San Francisco, San Francisco, CA 94143.

H. CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study.

If you wish to participate, you should sign below.

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Date Participant's Signature

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Date Person Obtaining Consent

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Appendix C: Mental Health Referral

UCSF

Department of Family Health Care Nursing
San Francisco, CA 94143

Thank you for your participation in the study, "Understanding How Couples Share the Pain of Endometriosis." Sometimes talking about personal health experiences may be difficult. If you, or your partner, wish to discuss how study participation is affecting you, you may contact Fran Strzempko, RN, PhD(c) at 415-518-7897. If you experience psychological or relationship distress during or after the study, you may contact the following referral center and local crisis treatment centers. I do not anticipate that participation in the study will create a need for counseling, but offer these contacts as a potential resource for the future.

Mental health referral services:	
The University of California San Francisco Adult Psychiatric Services	415-476-7500
The University of California San Francisco WomenCare Mental Health	415-476-7500
The San Francisco Medical Society	415-561-0853
For mental health emergencies call:	
The San Francisco Mobile Crisis Treatment Team	415-255-3610
San Francisco General Hospital Psychiatric Emergency Services	415-206-8125

The following is a partial list of mental health providers that was compiled by WomenCare Mental Health Clinic at UCSF.

Name/Address	***Phone Number***	***Insurance***	***Specialty***
PSYCHIATRY			
Robin Cooper, MD 3841 24th Street San Francisco, CA 94110	415-642-0144	Insurance	General mental health for adults
Karin Hastik, MD 999 Sutter, Suit 1 San Francisco, CA 94109	415-441-1273	Insurance	Women's mental health, mood disorders, hormone disorders, relationship issues, couples therapy, gay and lesbian issues

Kathryn Lee, M
2305 Ashby Av
Berkeley, CA 9

Theresa
McGuinness, M
350 Parnassu
Suite 303
San Francisc
94117

Bruce Milin, M
1939 Divisad
San Francisc
94115

Nan Orman,
851 Fremen
Suite 98
Los Altos, C

Elizabeth S
350 Parnas
Suite 309
San Franci
94117

Lynn Schr
3323 Sacr
St.
San Franc
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PSYCHO
LCSW/M

Meryl Bo
1721 Sc
San Fra
94115

Jonatha
Ph.D.
2340 Cl
Floor
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Elizabe
MFCC
315 Sa
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Kathryn Lee, MD 2305 Ashby Ave. Berkeley, CA 94705	510-841-3623	Self Pay	Women's issues, anxiety, panic disorders
Theresa McGuinness, MD 350 Parnassus, Suite 303 San Francisco, CA 94117	415-681-3408	Self Pay	Women's mental health, mood disorders, psychopharmacology, psychotherapy
Bruce Milin, MD 1939 Divisadero St San Francisco, CA 94115	415-346-7316	Insurance	Mood disorders, anxiety disorders
Nan Orman, MD 851 Frement Ave, Suite 98 Los Altos, CA 94024	650-941-5539	Self Pay	Women's health, mood disorders
Elizabeth Schiff, MD 350 Parnassus, Suite 309 San Francisco, CA 94117	415-681-8112	No HMO Insurance	Adult outpatient psychotherapy and psychopharmacology, mood disorders, depression anxiety, eating disorders, women's health issues
Lynn Schroeder, MD 3323 Sacramento St. San Francisco, CA 94118	415-346-9566	Self Pay	Women's issues, depression
PSYCHOLOGISTS/ LCSW/MFCC			
Meryl Botkin, Ph.D. 1721 Scott St. San Francisco, CA 94115	415-664-4060	Insurance	Couples therapy, children, general mental health
Jonathan Cannick, Ph.D. 2340 Clay St., 7th Floor San Francisco, CA	415-567-2184	Insurance	Clinical and neuropsychology, individuals and couples psychotherapy
Elizabeth Cotton, MFCC 315 Sanchez San Francisco, CA 94114	415-552-9552	No HMO Insurance	Women's reproductive health concerns, couples therapy, long-term psychotherapy

Mary Diazo-Ru
LCSW
2127 Ashby Av
Berkeley, CA 9

Linda Sue Edw
MFCC
1736 Divisade
San Francisc
94115

Karen Erlichm
LCSW
945 Irving St
San Francisc
94122

Fran Goldie-
LCSW
859 Diablo A
Suite C
Novato, CA
94947fun

Ellen Resni
LCSW
1117 Clem
Suite 2
San Franc
94118

Joanell Se
MFCC
214 West
Ave
Larkspur,

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Mary Diazo-Rudy, LCSW 2127 Ashby Ave Berkeley, CA 94705	510-540-6678	Self pay	General psychotherapy, children, adults
Linda Sue Edwards, MFCC 1736 Divisadero St. San Francisco, CA 94115	415-931-1928	Insurance	Relationships, depression and anxiety
Karen Erlichman, LCSW 945 Irving St, Suite 3 San Francisco, CA 94122	415-566-2183	PTO Insurance	Pregnancy, miscarriage, women's health issues, depression, eating disorders
Fran Goldie-Marcus, LCSW 859 Diablo Ave, Suite C Novato, CA 94947fun	415-892-4310	Insurance	Mood and anxiety disorders, post-traumatic stress disorder, new mothers, parenting issues
Ellen Resnick, LCSW 1117 Clement St, Suite 2 San Francisco 94118	415-454-7155	No HMO Insurance	Mood and anxiety disorders, relationship issues, couples therapy, individual therapy
Joanell Serra, MFCC 214 West Baltimore Ave Larkspur, CA 94939	415-945-0215	Insurance Sliding Scale	Women and infertility, miscarriage, menopause, postpartum, parenting issues, adolescents

UCSF Institutional Review Board Approval Number H6597-17875-03

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Appendix D: Woman's Individual Interview Guide

Project Title:
Understanding How Couples Share the Pain of Endometriosis

Researchers:
Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc
Department of Family Health Care Nursing
University of California, San Francisco

Interview Schedule for the Woman

*In all of the following the informant's language for her condition, elicited in the first question will be used in subsequent questions.

Could you tell me about the first time you suspected there was something different or that there was a problem with your health? What did you call this problem *?
Could we spend a few minutes talking about your experiences of being a woman with endometriosis? What has it been like for you?
Could you describe the particular event that made you realize what was happening wasn't "normal"?
Tell me about the first time you learned you had *endometriosis/chronic pelvic pain? Who told you? How did you react?
Could you describe a recent experience, for example, something that happened yesterday, that made you aware of the *endometriosis?
What do you think *endometriosis/ chronic pelvic pain is? How does it work in your body?
Can you describe an experience that was particularly difficult for you in dealing with *endometriosis? Tell me the story of what happened. You know like a movie. With a beginning, a middle, and an end.
What treatments are needed/appropriate for *endometriosis? Could you tell me a story about a time when you believe you received a treatment for * endometriosis that was particularly effective? Ineffective?
Have your responsibilities of daily life changed? Can you think back to a specific time when there was a change in responsibilities and how you responded and tell me about that time. Like a story. With a beginning, a middle, and an end.
Has anything changed in your relationship with your partner? Can you describe a recent time that was particularly difficult/or positive, to help me understand? (specific rituals of daily life: bedtime, diet, food preparation, travel)
Could you tell me a story about when *endometriosis created a complication in your life? Are there other issues that come up in your life that I should be aware of?
Could you tell me about a memorable or positive time related to *endometriosis?

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I have learned people are paying a lot for this disease. Would you be willing to talk with me in a general sense what you've expended financially for this disease?
What issues of *endometriosis do you find most troubling? Could you tell me about a time when you felt this way?
Can you tell me about a difficult experience you had with your partner that was strongly influenced by the *endometriosis?
Do you feel like you get enough support around handling the *endometriosis? In terms of support, what has been most helpful for you? (either from the health care family/ friends/partner) Is there any support you wish you were getting that you are not?
What do you hope for the future of your illness? (Ask last in interview.)
Being as descriptive as possible, using your own words, what does your pain feel like?
I'm also interested in symptoms your partner might experience. Which symptoms are most common for him? Can you tell me a story about a time he experienced this symptom?
Think about your pelvic pain in the past 3 months. Then using a 0 to 10 scale with "0" representing NO PAIN, "5" representing MODERATE PAIN, and "10" representing THE WORST PAIN IMAGINABLE, a. Choose a number that best describes the AVERAGE amount of pain you felt____ b. Using the same 0 to 10 scale, choose a number that best describes how you felt when your pain was at its WORST_____ c. Again, using the 0 to 10 scale, choose a number that best describes how you felt when your pain bothered you LEAST ____ d. Has this pain severity been consistent over the past 6 to 12 months? e. What is the duration of your pain? How long does it usually last?
Who do you usually tell about *endometriosis?
Who, if anyone, do you avoid telling about * your symptoms?
Who does (partner's name) talk to about his experiences of *endometriosis?
Of the symptoms you have mentioned, which interferes with your daily life the most? Which symptom(s) interfere with your relationship the most? Which symptom(s) interfere with your partner/husband/boyfriend the most? Can you tell me about a time when you felt the *endometriosis was interfering with your relationship?
Painful sexual intercourse is a common symptom of endometriosis for many women. Do you have sexual intercourse that is painful? Do you have any symptoms that affect your sexual well-being? Specific areas will be explored such as anxiety, lubrication, orgasm, genital pain, negative emotions, fear of pain. If applicable, could you tell me about a time recently when this was a problem for you?
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Appendix E: Partner's Individual Interview Guide

Project Title:
Understanding How Couples Share the Pain of Endometriosis

Researchers:
Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc
Department of Family Health Care Nursing
University of California, San Francisco

Interview Schedule for the Partner

*The informant's language for the partner's condition will be used.

Could we spend a few minutes talking about your experiences of being the partner of a woman with *endometriosis? What has it been like for you?
Could you tell me about the first time you learned your partner had *endometriosis? Who told you? How did you react?
Can you describe an experience that was particularly difficult for you in dealing with *endometriosis? Tell me the story of what happened. You know like a movie. With a beginning, a middle, and an end.
What do you think *endometriosis/ chronic pelvic pain is? How does it work in her body?
What do you think is happening to her body when she has pain/symptoms?
What treatments are needed/appropriate for *endometriosis? Could you tell me a story about a time when you believe she received a treatment for * endometriosis that was particularly effective? Ineffective?
I'm interested in how *endometriosis may affect your everyday life. Could you tell me about a time recently when you were aware of your partner's illness? (get examples of day to day living)
Could you describe a recent experience, for example, something that happened yesterday, that made you aware of the *endometriosis?
Which of her symptoms do you think affect her the most? Which of her symptoms affect you the most? Which symptoms interfere with your relationship the most? Could you tell me about a time when you felt the *endometriosis was interfering with your relationship?
Could you tell me a story about when *endometriosis created a complication in your life? Are there other issues that come up in your life that I should be aware of?
Has the responsibility of daily tasks within your relationship changed? Can you think back to a specific time when there was a change in responsibilities and how you responded? And tell me about that time. Like a story. With a beginning, a middle, and an end.
Has anything changed in your relationship with your partner?

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Can you describe a recent time that was particularly difficult/or positive, to help me understand? (specific rituals of daily life: bedtime, diet, food preparation, travel)
What issues of *endometriosis do you find most troubling? Could you tell me about a time when you felt this way?
Could you tell me about a memorable or positive time related to *endometriosis?
Can you tell me about a difficult experience you had with your partner that was strongly influenced by the *endometriosis?
I have learned people are paying a lot for this disease. Would you be willing to talk with me in a general sense what you've expended financially for this disease?
Who does your partner talk to about her experiences of *endometriosis?
Who, if anyone, does she avoid telling about her experiences of *endometriosis?
Who do you talk to about your experiences of *endometriosis?
Do you each feel like you give/get enough support around the *endometriosis? What has been most helpful for you? (either from the health care system or family/friends/partner) Is there any support you wish you were getting that you are not?
What do you hope for the future of her illness? What do you hope for your future? (Ask last in interview.)
Being as descriptive as possible using your own words, can you describe what your partner's symptoms feel like?
Think about your partner's pelvic pain in the past 3 months. Then using a 0 to 10 scale with "0" representing NO PAIN, "5" representing MODERATE PAIN, and "10" representing THE WORST PAIN IMAGINABLE, a. Choose a number that best describes her AVERAGE amount of pain ____ b. Using the same 0 to 10 scale, choose a number that best describes her pain at its WORST_____ c. Again, using the 0 to 10 scale, choose a number that best describes her pain when it bothered her the LEAST ____ d. Has this pain severity been consistent over the past 6 to 12 months? e. What is the duration of her pain? How long does it usually last?
When your partner is having symptoms, how do you know? How are her symptoms/pain communicated to you? How does this vary at different times? Can you recall a recent experience when you knew she was having symptoms and tell me what happened?
Are you aware of any effective symptom strategies to relieve her symptoms? Please describe. Do you take part in any of the symptom relief strategies? Please tell me the story of a specific time to help me understand how you helped her.
I am also interested in symptoms that partners might be experiencing. In your everyday life, like today for example, which symptoms are most common for you? (If applicable) Can you tell me about the time when you first started experiencing these symptoms?

Painful
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Painful sexual intercourse is a common symptom of endometriosis for many women. Does your partner experience symptoms that may affect her sexual well-being? Do you have symptoms that affect your sexual well-being? Specific areas will be explored such as anxiety, lubrication, orgasm, genital pain, negative emotions, and fear of pain. If applicable, could you tell me about a time recently when this was a problem for you?
(If she has dysparuenia) Are there strategies that you have learned that help you deal with the pain?

[illegible]

Appendix F: Joint Interview Guide

Project Title:
Understanding How Couples Share the Pain of Endometriosis

Researchers:
Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc
Department of Family Health Care Nursing
University of California, San Francisco

Joint Interview Questions

*Informants' language will be used.

In our last interview, I asked you both many questions about how *endometriosis affects you in your everyday life. Do you have anything to add that you thought about since we last talked?
Could we spend a few minutes talking about your experiences of being a couple living with *endometriosis. What has it been like for you?
How has the last month been for you as a couple related to the *endometriosis?
We talked about this individually, but as a couple, can you talk about how the responsibilities of daily life may have changed? (specific rituals of daily life: bedtime, diet, food preparation, travel) Can you think back to a specific time when there was a change in responsibilities and how you responded and tell me about that time. Like a story. With a beginning, a middle, and an end.
Has anything changed in your relationship? If yes, can you describe a situation, that was particular difficult/positive to help me understand? (specific rituals of daily life: bedtime, diet, food preparation, travel)
Can you describe a recent experience, for example, something that happened yesterday, that made you aware as a couple, of the *endometriosis? Can you tell me the story about what happened.
Please think of a specific time where you had some difficulty as a couple with the *endometriosis. Please tell me the story of what happened.
Living with *endometriosis sounds like it might be difficult. Who, if anyone, do you talk to about all of this? Is there anyone you avoid telling? Do you each feel like you get enough support around handling the *endometriosis? What has been most helpful for you? (either from the health care system/family/friends/partner) Is there any support you wish you were getting that you are not?
Can you tell me about a memorable or positive time related to *endometriosis?
Could you tell me a story about when *endometriosis created a complication in your life? Are there other issues that come up in your life that I should be

aware of?
I have lea talk with m disease?
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Can you (addressi
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Which of Which of Which sy partners Can you with you
We talke function either of areas w negative with sex If appli you? (If she that he
(Addre you kn Can yo knew,
As a c in her/
What Could treatm
(Addr relieve sympt under

aware of?
I have learned people are paying a lot for this disease. Would you be willing to talk with me in a general sense what you've expended financially for this disease?
What issues of *endometriosis do you find most troubling? Can you tell me about a time when you felt this way?
As a couple, what do you fear when you consider the future? What do you most hope for? (Ask last in interview.)
Can you describe, as clearly, as possible, your symptoms in the past month (addressing both partners)?
Are there times of the day/month/week when you experience more symptoms than others (addressing both partners)?
Which of the symptoms of * affect you the most (address the woman)? Which of the symptoms of * affect you the most (address the partner)? Which symptoms interfere with your relationship the most (address both partners)? Can you tell me about a time when you felt the *endometriosis was interfering with your relationship?
We talked individually about symptoms related to sexual intercourse and sexual functioning. I would like to explore this further with you both as a couple. Do either of you experience symptoms that affect your sexual well-being? Specific areas will be explored such as anxiety, lubrication, orgasm, genital pain, negative emotions, fear of pain. If you do experience symptoms that interfere with sexual well-being, how do you handle this as a couple? If applicable, can you tell me about a time recently when this was a problem for you? (If she has dysparuenia) Are there strategies that you have learned as a couple that help you deal with the pain?
(Addressing partner) When she is not feeling well/having pain/symptoms, do you know? Can you describe a time recently when she was having symptoms and you knew, and tell me the story of what happened.
As a couple, what is your understanding of *endometriosis? How does it work in her/your body? What is happening when there is pain?
What treatments are needed/appropriate for *endometriosis? Could you tell me a story about a time when you believe you received a treatment for * endometriosis that was particularly effective? Ineffective?
(Addressing partner) Are you aware of any effective symptom strategies to relieve her symptoms? Please describe. Do you take part in any of the symptom relief strategies? Please tell me the story of a specific time to help me understand what happened.

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Appendix G: Woman's Demographics

ID# _____

Project Title:
Understanding How Couples Share the Pain of Endometriosis

Researchers:
Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc
Department of Family Health Care Nursing
University of California, San Francisco

In order to describe who you are as a group when reporting the findings from this study, the following information will be helpful.

1. What is your date of birth? _____

2. How long have you been in an intimate relationship with your current partner? _____ years

3. How long have you been living with your current partner? _____ years

4. What year were you diagnosed with endometriosis? _____

5. How long did you suffer from pelvic pain prior to being given a diagnosis?
_____

6. How would you describe your ethnic identity?

____ Black/African-American	____ Native American/Alaskan Native
____ White/European-American	____ Pacific Islander
____ Hispanic/Latina	____ Multiracial
____ Asian	____ Other:_____

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7. What is your religion?

____	Catholic	____	Jewish
____	Protestant	____	Other:_____

8. What is the highest grade or type of education you reached in school?

____	No School	____	12th Grade/Graduated
____	1st to 6th Grade	____	Partial College
____	7th to 9th Grade	____	College (Graduated)
____	10th to 11th Grade	____	Professional Training (Graduate Degree)

9. Do you have children? ____ No ____Yes
If Yes, please list:

Sex of child	Age
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

10. Are you currently employed for pay? ____ No ____Yes

11. Which of the following best estimates income for your household in the last tax year, not just from wages, but from all sources before taxes and other deductions? (check the appropriate range)

____	Less than $5,000	____	$41,000 - $50,000
____	$5,000 - $10,000	____	$51,000 - $75,000
____	$11,000 - $20,000	____	$76,000 - $100,000
____	$21,000 - $30,000	____	$100,000 and above
____	$31,000 - $40,000		

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12. Have you missed work because of any health-related reason/condition and/or treatment? _____ No _____Yes

If yes, please describe

_____
_____
_____

13. How is your medical care paid for?

_____ Out of pocket, fee for service, (no insurance)
_____ MediCal, Medicare
_____ Patient paid or employer paid
If YES:
Is that:
_____ Kaiser
_____ Managed Care, like Healthnet
_____ Preferred Provider, like BlueCross
_____ Indemnity Plan – go anywhere, all paid

14. Other than a diagnosis of endometriosis, do you have any other medical diagnoses or health conditions? _____ No _____Yes

If yes, please specify

_____
_____

15. Are you currently taking any medications, either prescription or non-prescription? _____ No _____Yes

What Type	Reason	Dosage
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

16. What medication are you taking – either prescription or over- the-counter for your pelvic pain?

_____
_____
_____

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Appendix H: Partner's Demographics

ID # _____

Project Title:
Understanding How Couples Share the Pain of Endometriosis

Researchers:
Fran Strzempko, RN, PhD(c)
Catherine Chesla, RN, DNSc
Department of Family Health Care Nursing
University of California, San Francisco

In order to describe who you are as a group when reporting the findings from this study, the following information will be helpful.

1. What is your date of birth? _____

2. How long have you been in an intimate relationship with your current partner? _____ years

3. How long have you been living with your current partner? _____ years

4. Can you recall the year that your partner was diagnosed with endometriosis? _____

5. Do you know the length of time your partner had pelvic pain prior to being given a diagnosis? _____

6. How would you describe your ethnic identity?

_____ Black/African-American
_____ White/European-American
_____ Hispanic/Latina
_____ Asian
_____ Native American/Alaskan Native
_____ Pacific Islander
_____ Multiracial
_____ Other:_____

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7. What is your religion?

_____ Catholic
_____ Protestant
_____ Jewish
_____ Other:_____

8. What is the highest grade or type of education you reached in school?

_____ No School
_____ 1st to 6th Grade
_____ 7th to 9th Grade
_____ 10th to 11th Grade
_____ 12th Grade/Graduated
_____ Partial College
_____ College (Graduated)
_____ Professional Training(Graduate Degree)

9. Do you have children? _____ No _____Yes
If Yes, please list:

Sex of child	Age
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

10. Are you currently employed for pay? _____ No _____Yes

11. Which of the following best estimates income for your household in the last tax year, not just from wages, but from all sources before taxes and other deductions? (check the appropriate range)

_____ Less than $5,000
_____ $5,000 - $10,000
_____ $11,000 - $20,000
_____ $21,000 - $30,000
_____ $31,000 - $40,000
_____ $41,000 - $50,000
_____ $51,000 - $75,000
_____ $76,000 - $100,000
_____ $100,000 and above

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12. Have you missed work because of any health-related reason/condition and/or treatment? _____ No _____Yes

If yes, please describe

_____
_____
_____

13. How is your medical care paid for?

_____ Out of pocket, fee for service, (no insurance)
_____ MediCal, Medicare
_____ Patient paid or employer paid
If YES:
Is that:
_____ Kaiser
_____ Managed Care, like Healthnet
_____ Preferred Provider, like BlueCross
_____ Indemnity Plan – go anywhere, all paid

14. Do you have any medical diagnoses or health conditions?
_____ No _____Yes

If yes, please specify

_____
_____

15. Are you currently taking any medications, either prescription or non-prescription? _____ No _____Yes

What Type	Reason	Dosage
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

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Appendix I: Symptom Checklist-90-Revised (SCL-90-R)

SCL—90—R®

SIDE 1

INSTRUCTIONS:

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask about them.

SEX

MALE ○

FEMALE ○

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR.__ SEP.__ DIV.__ WID.__ SING.__

DATE			ID. NUMBER	AGE
MO	DAY	YEAR		

VISIT NUMBER: _____

EXAMPLE HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	0	1	2	(3)	4

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Headaches	1	0	1	2	3	4
2. Nervousness or shakiness inside	2	0	1	2	3	4
3. Repeated unpleasant thoughts that won't leave your mind	3	0	1	2	3	4
4. Faintness or dizziness	4	0	1	2	3	4
5. Loss of sexual interest or pleasure	5	0	1	2	3	4
6. Feeling critical of others	6	0	1	2	3	4
7. The idea that someone else can control your thoughts	7	0	1	2	3	4
8. Feeling others are to blame for most of your troubles	8	0	1	2	3	4
9. Trouble remembering things	9	0	1	2	3	4
10. Worried about sloppiness or carelessness	10	0	1	2	3	4
11. Feeling easily annoyed or irritated	11	0	1	2	3	4
12. Pains in heart or chest	12	0	1	2	3	4
13. Feeling afraid in open spaces or on the streets	13	0	1	2	3	4
14. Feeling low in energy or slowed down	14	0	1	2	3	4
15. Thoughts of ending your life	15	0	1	2	3	4
16. Hearing voices that other people do not hear	16	0	1	2	3	4
17. Trembling	17	0	1	2	3	4
18. Feeling that most people cannot be trusted	18	0	1	2	3	4
19. Poor appetite	19	0	1	2	3	4
20. Crying easily	20	0	1	2	3	4
21. Feeling shy or uneasy with the opposite sex	21	0	1	2	3	4
22. Feelings of being trapped or caught	22	0	1	2	3	4
23. Suddenly scared for no reason	23	0	1	2	3	4
24. Temper outbursts that you could not control	24	0	1	2	3	4
25. Feeling afraid to go out of your house alone	25	0	1	2	3	4
26. Blaming yourself for things	26	0	1	2	3	4
27. Pains in lower back	27	0	1	2	3	4
28. Feeling blocked in getting things done	28	0	1	2	3	4
29. Feeling lonely	29	0	1	2	3	4
30. Feeling blue	30	0	1	2	3	4
31. Worrying too much about things	31	0	1	2	3	4
32. Feeling no interest in things	32	0	1	2	3	4
33. Feeling fearful	33	0	1	2	3	4
34. Your feelings being easily hurt	34	0	1	2	3	4
35. Other people being aware of your private thoughts	35	0	1	2	3	4

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Please continue on the following page ▶

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SCL—90—R®

SIDE 2

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Feeling others do not understand you or are unsympathetic	36	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	37	0	1	2	3	4
38. Having to do things very slowly to insure correctness	38	0	1	2	3	4
39. Heart pounding or racing	39	0	1	2	3	4
40. Nausea or upset stomach	40	0	1	2	3	4
41. Feeling inferior to others	41	0	1	2	3	4
42. Soreness of your muscles	42	0	1	2	3	4
43. Feeling that you are watched or talked about by others	43	0	1	2	3	4
44. Trouble falling asleep	44	0	1	2	3	4
45. Having to check and double-check what you do	45	0	1	2	3	4
46. Difficulty making decisions	46	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	47	0	1	2	3	4
48. Trouble getting your breath	48	0	1	2	3	4
49. Hot or cold spells	49	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	50	0	1	2	3	4
51. Your mind going blank	51	0	1	2	3	4
52. Numbness or tingling in parts of your body	52	0	1	2	3	4
53. A lump in your throat	53	0	1	2	3	4
54. Feeling hopeless about the future	54	0	1	2	3	4
55. Trouble concentrating	55	0	1	2	3	4
56. Feeling weak in parts of your body	56	0	1	2	3	4
57. Feeling tense or keyed up	57	0	1	2	3	4
58. Heavy feelings in your arms or legs	58	0	1	2	3	4
59. Thoughts of death or dying	59	0	1	2	3	4
60. Overeating	60	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	61	0	1	2	3	4
62. Having thoughts that are not your own	62	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	63	0	1	2	3	4
64. Awakening in the early morning	64	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	65	0	1	2	3	4
66. Sleep that is restless or disturbed	66	0	1	2	3	4
67. Having urges to break or smash things	67	0	1	2	3	4
68. Having ideas or beliefs that others do not share	68	0	1	2	3	4
69. Feeling very self-conscious with others	69	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	70	0	1	2	3	4
71. Feeling everything is an effort	71	0	1	2	3	4
72. Spells of terror or panic	72	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	73	0	1	2	3	4
74. Getting into frequent arguments	74	0	1	2	3	4
75. Feeling nervous when you are left alone	75	0	1	2	3	4
76. Others not giving you proper credit for your achievements	76	0	1	2	3	4
77. Feeling lonely even when you are with people	77	0	1	2	3	4
78. Feeling so restless you couldn't sit still	78	0	1	2	3	4
79. Feelings of worthlessness	79	0	1	2	3	4
80. The feeling that something bad is going to happen to you	80	0	1	2	3	4
81. Shouting or throwing things	81	0	1	2	3	4
82. Feeling afraid you will faint in public	82	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	83	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	84	0	1	2	3	4
85. The idea that you should be punished for your sins	85	0	1	2	3	4
86. Thoughts and images of a frightening nature	86	0	1	2	3	4
87. The idea that something serious is wrong with your body	87	0	1	2	3	4
88. Never feeling close to another person	88	0	1	2	3	4
89. Feelings of guilt	89	0	1	2	3	4
90. The idea that something is wrong with your mind	90	0	1	2	3	4

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