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An Exploration of Positive Identity Development in Women Living with Chronic Pain

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We explored the concept of living positively with chronic pain using a mixed-methods design that relied primarily on hermeneutic phenomenology. Ten women described their experiences of developing a positive identity while contending with chronic pain. Throughout their journeys, the women interviewed experienced a number of key themes including: the sense of being separate from their bodies, the failure of the biomedical system, and the creation of support networks. Three major categories emerged from the data: (a) Before Diagnosis, (b) Redefinition of Self, and (c) Moving Forward. The implications for healthcare providers and the limitations of this study are discussed. *Keywords: Coping, Hermeneutic Phenomenology, Chronic Pain, Women's Health, Identity*

Chronic pain is a widespread phenomenon in North America. In Canada, persistent pain is estimated to affect approximately 15% of the population (Van Den Kerkhof, Hopman, Towheed, Anastassiades, & Goldstein, 2003). Due to the debilitating nature of chronic pain and the staggering economic costs associated with it there has been a proliferation of research surrounding chronic pain in recent years (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

One of the primary tasks that individuals living with chronic pain or illness must contend with is identity reconstruction (Eccleston & Crombez, 1999; Frank, 1993; Wilson, Whitehead, & Burrell, 2011). Patients with persistent pain are faced with a litany of life changes and negative emotions that accompany these. The limitations imposed by pain and illness often necessitate changes in what constitutes a valued sense of self and the incorporation of new coping strategies that facilitate identity management (Charmaz, 1983; Wilson et al.).

Research on coping has predominantely focused on behaviors and cognitions that lead to negative consequences (Geisser, Robinson, & Riley, 1999; Park & Sonty, 2010). Only recently has there been a shift in the literature towards a focus on positive behaviors and beliefs that lead to the creation of a positive sense of self for those living with chronic pain (e.g., Evers, Kraaimaat, van Lankveld, Jongen, Jacobs, & Bijlsma, 2001). This article explores the concept of living positively with chronic pain, drawing on the experiences of 10 women with diverse chronic pain conditions. The common themes that emerged in this study serve to highlight both the process of identity management for women in chronic pain and the implications of their experiences for other pain patients and those who seek to help them.

Women and Chronic Pain

The biological underpinnings of most long-term pain conditions remain largely unknown (Gatchel & Okifugi, 2006). This is one of the greatest challenges to both patients and healthcare providers because of the psychological, social, and environmental factors that act to sustain the pain cycle (Hanson & Gerber, 1990; Keefe, Rumble, Scipio, Giordano, &

Perri, 2004). Chronic pain can interfere with all aspects of an individual's life. It has been associated with limitations on work, household chores, leisure activities, fatigue, depression, and difficulty fulfilling social roles (Hitchcock, Ferrel, & McCaffery, 1994; Kroenke et al., 2011). Chronic pain can result in a reduced quality of life and psychological functioning for individual sufferers and also presents high costs to private industry and healthcare systems (Gaskin & Richard, 2012; Meana, Cho, & DesMeules, 2004).

Research has shown that men and women differ in their responses to pain and in their access to healthcare. For instance, women have generally been found to report greater pain intensity and frequency than men (Fillingim, King, Ribeiro-Dasilva, Rahim-Williams, & Riley, 2009; Unruh, 1996). Women are also more likely than men to experience feelings of despair and helplessness when confronted with pain (Keogh, McCracken, & Eccleston, 2005). The reasons for these findings are unclear; however, many investigators are willing to draw the conclusion that women are more sensitive to painful stimuli than men and conclude that this discrepancy likely stems from biological differences (Aloisi & Sorda, 2011; Berkley, 1995).

Although biological differences between men and women offer one explanation for their differing experiences of pain, cultural and social factors can also play a role. The social changes of the last 50 years have blurred the boundaries between the roles available to men and women both at home and at work. Women still perform the majority of household work and child-rearing within the family, but they are also working more outside the home (Borman, 1993; Patton & Johns, 2012). This dual responsibility can leave women at risk for stress-related disorders, including chronic pain (Borman). The socialization of men and women can also lead to differences in pain reporting because women are more likely than men to voice their pain and discomfort and are more likely to seek out medical treatment (Derbyshire, 1997; Fillingim et al., 2009).

Despite the fact that women seek healthcare for pain at a higher rate than men, they are more likely to be under-treated for their pain (Bernardes, Keogh, & Lima, 2008). There are numerous studies that indicate that this might be due, in part, to commonly held attitudes within the healthcare community that view women as more tolerant to pain or, conversely, assume that women's pain is imagined (Hoffmann & Tarzian, 2001). In one such study, it was found that female patients experiencing pain were more likely than their male counterparts to be diagnosed with attention-seeking behavior, histrionic disorder, or excessive emotionality (Fishbain, Goldberg, Meagher, Steel, & Rosomoff, 1986). Another study, regarding physician perceptions of female patients with pain, found that physicians perceived attractive patients as experiencing less pain than those deemed unattractive, evidencing a *healthy is beautiful* stereotype (Hadjistavropoulos, McMurtry, & Craig, 1996).

Sadly, such gender stereotypes and negative patient experiences are frequently reported in the literature (e.g., Asbring & Narvanen, 2002; Bernardes et al., 2008; Ostlund, Cedersund, Alexanderson, & Hensing, 2001; Werner & Malterud, 2003). The largely invisible nature of chronic pain can lead to others questioning the credibility of the pain experience, and this is particularly true in the case of women (Richardson, 2005; Ballweg, Drury, Cowley, McCleary, & Veasley, 2011). These attitudes present women with barriers in accessing healthcare and also in validating their pain (Institute of Medicine, 2011), which plays a key role in determining whether or not a woman with chronic pain is able to progress toward positive coping mechanisms that lead to greater health and well-being (Howell, 1994; Skuladottir, 2011).

Identity Management and Chronic Pain

Individuals who suffer from long-term pain conditions must contend with the potential loss of a valued identity or sense of self (Eccleston & Crombez, 1999; Wilson et al., 2011). How this process unfolds has been a growing area of interest within recent years; however, there are multiple and often contradictory theories that have muddied the waters in this regard. What has been established thus far is that constructing and maintaining a positive identity while living with chronic pain is the exception rather than the rule (Risdon, Eccleston, Crombez, & McCracken, 2003).

The concept of the self is shaped by the amalgamation of cultural, societal, familial, and individual values. Identity refers not only to the individual aspect of the self that defines the separateness of each person, but also speaks to a social process or how we relate to others (Golden, 1987). The basis of identity is multifaceted and includes aspects of gender, socioeconomic class, ethnicity, race, religious or spiritual beliefs, and age (Collins, 2010). The experience of living with chronic pain can also shape identity development. Feelings of confusion, depression, and loss of control often accompany the experience of searching for a sense of self while living with chronic pain.

Identity management is a process that is mediated by a diversity of life experiences and transitions. Given the systemic barriers that women face in dealing with chronic pain, the establishment of a valued sense of self is a difficult task (Reynolds & Vivat, 2010; Richardson, 2005). One's identity as a mother, partner, student, employee, or member of a non-dominant cultural group can influence the experience of integrating a chronic pain diagnosis into an overall sense of self. The complexity of women's lives makes it essential that their identity development be explored from within a research paradigm that supports attention to these multiple and intersecting aspects of identity.

Researchers

The primary researcher, Hillary, has lived with a chronic pain condition for the past 10 years. This research project was undertaken during her master's program and stemmed from her curiosity surrounding the experiences of other women living with chronic pain. Hillary had struggled to articulate her own transformation over the course of her experiences with chronic pain and she found that the process of living positively with persistent pain was rarely explored in the literature. Her intentions in conducting this research were to add to research literature and also further her own understanding of how to live positively with chronic pain. The other authors of this paper, Kevin and Sandra, served as supervisors and mentors throughout the research process.

Methodology

The primary methodology used in this study was based on Max van Manen's (2002) conceptualization of hermeneutic phenomenology. According to van Manen (1997), hermeneutic phenomenology can be broken down into component disciplines: phenomenology, which is the study of lived experience, and hermeneutics, which is the interpretation of language. Yet the two aspects together create a new discipline. Hermeneutic phenomenology is, therefore, both descriptive (phenomenological) and interpretive (hermeneutic) in nature. van Manen describes the aim of hermeneutic phenomenology as "to explicate the meanings as we live them in our everyday existence, our lifeworld" (van Manen, 1990, p. 11) and to describe this in a text in such a manner that the research "re-awakens" the lived quality of the phenomenon being researched (van Manen, 1990, p. 13).

One of the central tenets of hermeneutic phenomenology is the existence of multiple truths based on subjective realities that are influenced by temporal, spatial, and cultural factors. Although a mixed methods model was used in the overall study (i.e., quantitative measures of pain were included), only the qualitative data collection and analysis are reported in this article.

The Research Question

The main research question was, "What is the experience of women who construct and maintain positive identities while living with chronic pain?" Secondary questions included: (a) how do women living with chronic pain construct and maintain positive identities, (b) what challenges do these women face, and (c) what does a positive identity mean for these women?

Participants

The 10 women who participated were between ages 25 and 54. Each participant self-identified as having a positive identity and a diagnosed chronic pain condition (such conditions included fibromyalgia, rheumatoid arthritis, and polycystic ovary syndrome). Upon approval from the Research Ethics Board at the University of Calgary, participants were recruited via (a) posters placed in coffee shops, health food stores, libraries, and medical offices; (b) notices placed on the webpage of a Canadian chronic pain organization and a women's community service organization; and (c) snowball sampling.

Biographical Questionnaire

The biographical questionnaire, developed by the first author, provided information on what it means to live positively with chronic pain, including sections regarding participants' general background, chronic pain condition and identity, emotional health, and spiritual beliefs. Participants were asked to write their own definition of what it means to live positively with chronic pain and the extent to which they believe they have attained this (as measured on a 5-point Likert scale).

Procedure

Participants completed an informed consent form, a biographical questionnaire, and provided a pseudonym. Each interview began with the prompt: "I want to understand the journey you embarked upon to feel good about yourself as a woman living with chronic pain. In other words, tell me the story of how you came to adopt a positive identity or sense of self." After the participants told their stories, the first author reviewed a list of 18 formal interview questions to ensure key topics or issues had not been missed. Participants were invited to add additional detail at the end.

Interviews were tape recorded and ranged from 50 to 90 minutes. The tapes were transcribed within one month of the completed interview. No additional participants were interviewed after saturation of themes occurred.

Participants were sent a themes questionnaire between six to eight months after their interviews to provide feedback on the preliminary results to triangulate the results. This questionnaire included the categories and themes that emerged during data analysis

Data Analysis

In hermeneutic phenomenology, data collection and analysis are processes that occur together rather than sequentially. Each transcript and biographical questionnaire was read and reread by the first author one at a time. During the initial reading, the overarching meaning or essence of the text was sought. Notes were made during the second reading, looking for details regarding content, issues, and themes. Content refers to key words or phrases, issues pertain to broader conceptualizations, and themes refer to yet broader commonalities within and between the texts. This process was undertaken with each of the transcripts until common themes began to emerge.

Each resulting theme and sub-theme was recorded and organized along van Manen's (1990) suggested dimensions of lived space, lived time, lived body, and lived relations. Themes were re-organized and condensed to reach the core or essence of the theme. Once a coherent organization of the themes was reached, the transcripts were reread to ensure that the organization and themes fit within the broader experiences. The product was then verified with participants using the themes questionnaire.

Trustworthiness

The measures taken to enhance trustworthiness included the following suggestions based on the work of Beck (1993), Morse, Barrett, Mayan, Olson, and Spiers (2002), and Whitehead (2004): (a) a comprehensive literature search was undertaken focused on qualitative and quantitative research, as well as a variety of other sources such as newspaper and magazine articles, government reports, and anecdotal accounts (Beck; Whitehead); (b) the first author maintained in-depth field notes regarding pre-understandings and a journal reflecting on experiences and behavior (Beck; Morse et al.; Whitehead); (c) during data collection and analysis, an openness to differing interpretations and understandings was maintained (Beck; Morse et al.; Whitehead), (d) a detailed description of the entirety of the research process was kept, including an audit trail (Beck; Whitehead), and (e) the final work includes participants' own words and references wherever possible (Beck; Whitehead).

Findings

The data derived from the interviews were organized into three major categories: (a) *Before Diagnosis*, (b) *Redefinition of Self*, and (c) *Moving Forward*. Each category represents a phase of living positively with chronic pain. The Before Diagnosis category is marked by inner turmoil because of the presence of the undiagnosed pain condition. In this phase, the women were more likely to experience feelings of hopelessness, frustration, confusion, anger, and depression. Movement into the next phase, Redefinition of Self, was typically facilitated by a medically-validated diagnosis of the pain. This was the most common turning point that allowed the participants to contend with the task of making sense of who they were after the diagnosis. During this process the women experienced a shift in their sense of self, which allowed them to begin to learn how to live positively with their pain. The final category, Moving Forward, encompasses the continued development of a positive sense of self and the re-establishment of healthy relationships with others.

Within each of these phases, there are two minor categories: *Inner World* and *Outer World*. Inner World refers to how the participants negotiated their changing relationship with themselves: their feelings, thoughts, behaviors, and sense of self. Outer World refers to relationships that the participants negotiated with others. As the women began to shift their understanding of themselves and their pain conditions, their relationships with others or their "outer world" also evolved. Within the phases described, 47 themes or sub-themes were found that represent the journey of living positively with chronic pain. While this is a relatively high number of themes in qualitative research, each represents an important dimension or aspect that was relevant in the participants' stories. A selection of themes was chosen by the authors for presentation here as we feel that they provide key insights for helping professionals and represent the evolving nature of living positively with chronic pain.

Thirteen of the themes will be discussed in the following sections, which outline the journey through the three phases: (a) *Before Diagnosis*, (b) *Redefinition of Self,* and (c) *Moving Forward*. Within these phases, themes are further grouped according to Inner World and Outer World. Pseudonyms are used to protect the women's identities.

Figure 1. The Journey of Living Positively with Chronic Pain

BEFORE DIAGNOSIS

Inner World	*Outer World*
-Pain as Defining Feature of Self -Time as Fixed -Negative Emotions Related to Pain -Striving for Perfection -Separation of Self and Body -Lost Sense of Self -Hitting Rock Bottom -Fear of Addiction to Pain Medication	-Lack of Understanding from Important Others -Failure of the Biomedical System

REDEFINITION OF SELF

Inner World	*Outer World*
-Turning Points -Pain as One Part of Whole Self -Time as Flexible -Inward Focus -Physical Activity -Allowing for Experience of Negative Feelings -Choosing a Positive Attitude -Gaining Control Through Letting Go -Re-evaluation of Capabilities -Striving for Self-acceptance -Reintegration of Self and Body -Alternative Treatments -Learning About the Pain -Positive Self-talk/Visualization -Pushing Through the Pain	-Connecting with Similar Others -Learning from Negative/Positive Role Models -Self Advocacy -Navigating the Biomedical System

MOVING FORWARD

Inner World	*Outer World*
-Focus on Abilities -Planning for the Future -Reclaiming of Previously Lost Aspects of the Self -Balancing Momentum -Living in the Moment -Choosing to Maintain a Positive Attitude -Spirituality -Drawing Strength from Past Trials and Tribulations -Maintaining a Healthy Lifestyle -Escapism -Developing/Maintaining a Sense of Humour	-Stoicism Towards Intolerant Others -Outward Focus -Creating and Maintaining A Support System -Importance of Physical Touch -Living For/Through Others -Loving a Pet -Comparison of Self to Less Fortunate Others

Before Diagnosis: Inner World

Pain as defining feature of self. At the beginning of each of their journeys, the effect of unexplained and pervasive pain eroded the women's sense of self until the pain became a single focal point in their lives. The process involved a gradual shift as the experience of pain took up more space within the women's lives and began to permeate their very sense of being, overshadowing other aspects of identity. All of the women interviewed identified this theme within their own stories. Sasha and Lynn explained how this unfolded:

> It was like I couldn't see anything else but the pain, it was just . . . all of me. It was all I could think about. I guess cause when I hated that, the pain I mean, that's such a big part of me that I was, I guess just starting to hate existing (Sasha).

> I couldn't fulfill my job. I couldn't be happy. I couldn't be myself because of the pain. One day I just woke up and I thought I can't be myself, I don't even know who myself is. I just feel pain all the time, is that all there is to me? I cried that day . . . (Lynn)

Separation of self and body. Seven of the women described a sense of the body and the self as two distinct and often opposed entities. The body in pain became associated with a loss of control and often a betrayal of the self. To preserve a cohesive and valuable sense of self, the pain and therefore the body were relegated to the realm of outside the self. Beth stated: "Instead of changing who I am I tried to just stay who I am and allow my body to change as it decides to." Sasha spoke about hating both the pain and her body during a particularly difficult time. In response to the interviewer question, "So how did you perceive your body when you say you were kind of hating it?" She replied: "I guess just like it had sort of broke down and it kind of betrayed me, you know, what was wrong with me?"

Hitting rock bottom. Nine of the participants also spoke about a time in their journeys when they were consumed by despair. The primary thoughts and feelings associated with this time were depression, hopelessness, and, in some cases, suicidal ideation. This point was typically the culmination of a number of months or years living with unexplained pain and was often precipitated by a particularly stressful life event. Marie described such a period in her life:

> Two years ago, when I was studying for my RN exam and also had my basement flood, I had the worst bout ever and I was in the hospital on and off for about a week or so. And that was just pretty unbearable, and I think it was just, the pain, everybody kept telling me that maybe it was cause I was under stress . . . I just remember laying on the couch crying and just going in the hospital, and they were quick to dismiss it because I wasn't having any other symptoms. It was very subjective and there was nothing to be like, look there's something wrong here . . . I think that was really actually one of the worst times in my life. I couldn't cope with it, I was crying a lot, I felt like, I kept saying to people, "I'd rather just be taken out to the backyard and shot." Because that's how bad the pain was. And that was one point in the chronic pain thing that I just like, I was ready to give up because I just couldn't handle it and I didn't know if it was going away (Marie).

Lynn also experienced a period of despair in which she considered ending her life: "There was a time when I would have killed myself if something hadn't happened, cause I said to my doctor, 'I can't live like this, I just can't do it.' It's either stay at home in bed, which I won't do, or do that" (Lynn).

The pain and accompanying feelings were compounded by the unknown nature of the pain and the possibility that it would become a life-long ordeal for the women. They were left questioning whether their symptoms were real or imagined. Astrid stated: "Before I was diagnosed I didn't know what was wrong and to be honest you just think you're losing your mind."

Before Diagnosis: Outer World

Failure of the biomedical system. Chronic pain is a daunting problem within the healthcare system. Due to a number of social and cultural determinants of health, women face specific barriers in accessing adequate treatment for chronic pain conditions. The intimidating and frustrating task of finding a medically-validated diagnosis for pain often takes years and requires great perseverance. All of the women interviewed spoke at length about their negative experiences within the biomedical system.

> It's been frustrating as hell. I think honestly that's been the most frustrating part of this whole journey, has been going to doctors . . . . And you know they ask all these questions and just look at you like there's something wrong with your head . . . . They were just really unreliable and I just felt like I was never, ever listened to. They would just look at me like I had three heads . . . my experience with medical doctors has been so impersonal and so degrading (Beth).

> I've found that doctors are really reluctant to acknowledge chronic pain, like they don't want to say, "Yeah this is forever and you're stuck with it." Because

> it makes them, it kinda takes them off that expert podium, you know? They want to say, "I have a magic pill for this" and when they don't have a magic pill they don't want to say anything (Esmerelda).
>
> It was frustrating. I think probably the biggest thing was frustration. And so many people disbelieved me. In fact I had a physiotherapist tell me, "There's no reason for your arm to be hurting." Like, it's all in your head (Ann).

Nine of the women interviewed expressed feelings of being degraded and ignored by medical professionals and an overall sense that their concerns were not valid. Three of the women used the term "all in your head" to describe how they were made to feel that their pain was not real or that they were actually causing it. Yet, despite this, all of the women continued onwards in the hopes that they would find answers and relief from their pain.

Redefinition of Self: Inner World

Turning points. Nine of the women noted a specific turning point during this phase, which signified a period of inner growth and renewal. One of the key elements for most of the women was attaining a diagnosis or an answer to why they were in pain. This opened up a number of doors for them in terms of receiving treatment, gaining support, validating their symptoms, and moving forward. Being able to name the pain signified a degree of control over it. Other turning points included the realization that negative thought patterns were worsening the pain and a connection with a long-lost family member, which helped one woman realize that she was not alone.

In the following excerpt Isabel outlined how receiving a diagnosis allowed her to create a protocol for taking care of herself and led to her connecting with others with similar conditions. She was responding to the question: "What happened for you in order to build a positive identity regarding your chronic pain?"

> I think it was definitely the proper diagnosis and also the sort of I guess medical, medically-valid diagnosis, that I was then able to come up with a protocol for taking care of myself… it meant that I wasn't alone with this problem, and that other people have it, and there are ways to deal with it. And also that I could do a lot of reading and talking with other people and figure out that the prognosis for it isn't necessarily complete deterioration and disability and that kind of stuff. It was just very reassuring to find out that kind of stuff . . . I think the most important thing for becoming more positive about it was the diagnosis (Isabel).

Beth spoke about the justification for her pain that a diagnosis brought her:

> When I found out why I was having these feelings it was so relieving because you don't feel like it's in your head anymore, you feel like you can justify what you're feeling . . . I mean I was kind of glad to find out what was causing this. It was kind of a relief and it gives you a starting point to figure out, like, okay well what do we do now? What does the future look like? (Beth)

Pain as one part of whole self. During an earlier chapter of the women's stories, they spoke about being consumed by the pain, as if it overshadowed everything about them. Once the nature of the pain was illuminated, it was slowly relegated to one part of the whole self, rather than the defining feature of the self. This was marked by an acceptance of the pain as the women strove to incorporate it within their self-schemas. All of the participants experienced this theme.

> I guess for me the pain is a part of me and it's not going anywhere so I have to be the one to choose how I'm going to live with it, so I try and be who I am. I have pain; I'm not Sarah the pain anymore. You just don't let it become you and you'll be fine (Sarah).
>
> I don't want to like just sit back and let it control my life. Like it'll be a part of my life, but I don't want it to determine everything I do or interfere with everything I do (Beth).

In responding to the question, "So what does having a positive identity regarding your chronic pain mean for you at this time in your life?" Esmeralda said:

> Honestly, it means that my identity is not built around my condition. I'm a person, and I have a messy apartment and a grumpy boyfriend and thighs I would like to be a little bit thinner, and this and that, oh, and I have chronic pain. It shouldn't be the defining characteristic in your life or what that hell are you living for? (Esmeralda)

Gaining control through letting go. With the acceptance of the pain, the women were able to learn new techniques to control their symptoms. One of these techniques was the practice of consciously letting go of the desire to control the pain to overcome it. The women who practiced this technique indicated that by letting go they were able to relax and in some cases lessen the physical and emotional experience of the pain. Eight of the women spoke about the practice of letting go. Alex stated: "I've really learned that sometimes you just need to go with the pain. Let it all go and just be swept along." Esmerelda provided the following descriptions:

> Have you ever ridden a rollercoaster? And then have you ever driven a really hot car really fast? You're going just as fast as a rollercoaster, you're just as out of control, but you're driving, and that's what makes all the difference. And I find that when pain gets really intense if you're willing to let go of it you can actually roll with it. It's kind of like going with the beat of music in a club. You know first the music is way too loud and you can't cope with it, and then you sit back and relax, and then you're going in that rhythm and you're working with it . . . you have to accept I can't stop this so let's try and work with it (Esmerelda).

Reintegration of self and body. This theme is marked by a need to reconnect with the body and respect it. By accepting the pain as one aspect of self, the women were once again able to see their bodies as belonging to themselves instead of the outside world. The process of turning inwards created a space for bodily sensations and emotions to be explored at a deeper level, which aided in the discovery of new pain management techniques. Eight participants identified this theme within their accounts. In the following excerpt Sasha explained how she learned to work with her body instead of fighting against it. She was responding to the interviewer question: "And how about now, how do you perceive your body now?"

> I think better because I can, I feel like I've got that edge over the pain sometimes. So I kind of feel like there's hope because some part of my body is able to take over that little bit. It's hard to explain, but it's not like everything's bad, there's this one little part that gets the headaches…. working with what my body does, instead of working against it and letting everything sort of shut down. You just have to be quiet and listen to your body sometimes, and that can help you, just trusting your body to know what to do, instead of mistrusting it (Sasha).

When Marie was asked what advice she would give to other women living with chronic pain, she also drew on the concept of listening to her body:

> I think that they need to learn about their body, I think that's the one thing that's got me through this the most, which is hard to do. Maybe if they don't feel like they could do that on their own, maybe take a class, kind of like, maybe like a meditation class . . . (Marie).

To hear the messages of the body, the women had to create a quiet and meditative place within themselves. The very act of listening seemed to lessen pain and aided in the creation and maintenance of coping skills such as journaling, getting enough sleep, taking time for pleasurable activities, and trying new treatments.

Redefinition of Self: Outer World

Self advocacy. Learning to advocate for themselves was an essential step for nine of the women who shared their stories. This encompassed advocating for special needs such as extra time to complete projects at work, the implementation of assistive devices in public areas, and advocating for services and treatments provided through the medical system. For most of the women who experienced this theme, it required practice and courage in revealing the often invisible pain condition to others. Once the women began advocating for their needs and receiving support and validation from others, their level of confidence and perceived control over their condition increased.

> Even having to deal with a very difficult supervisor has helped. Those weren't fun things, but they helped me. And realizing that I'm the only one who can advocate for myself and set my boundaries… There's probably people who don't even know I have it, but in a lot of cases I find it necessary to inform them so that they don't have expectations that I'll be able to do something I can't do. Like I'm looking for a place right now so I need to tell potential landlords that I cannot do yard work; I cannot do snow shoveling. The doctor has restricted me from doing that (Ann).
>
> I try to be as upfront as possible. Like I find that people respond, like if you were my instructor I would say, "Look I'm scheduled for a surgery this semester. I might not be able to be here for a month, you're not gonna fail me, I'm gonna catch up on my work, and you know I might be here in a week, I might not, this is what I need from you" (Esmerelda).

Moving Forward: Inner World

Choosing to maintain a positive attitude. The choice to maintain a positive attitude toward life is one that the women had to make again and again throughout their stories. The option of giving up and falling into despair and depression was always present, and the women continually had to fight to live positively with their pain. Nine of the participants expressed this theme within their stories, and, for most, the decision to maintain a positive attitude was one that they made everyday.

> Well, I guess for me the pain is a part of me and it's not going anywhere so I have to be the one to choose how I'm going to live with it . . . I've experienced the positive living, I've experienced the negative living and so what's better, what's funner, what makes a more, like what would I rather live in? I would rather live in the positive, which can be hard sometimes (Sarah).

> I need to have a positive outlook on life and move forward so therefore I need a positive identity. For me a positive identity is just being able to take what I'm given, take the pain and move on… so it's just like what are you gonna do? You have to move forwards and I think that's something that I use for a lot of my life, like I just move forward despite things that are going on. You gotta choose that all the time (Marie).

Spirituality. Of the ten women who participated in this research, nine identified a sense of spirituality as integral to the maintenance of a positive sense of self. Spirituality refers to the sense of peace, purpose, and connection to the self and others that stems from contemplation of the transcendent, sacred, or divine (Russell & Yarhouse, 2006). Spirituality and religion are related, but separate terms, meaning that one can exist without the other. For the women in this study who participated in a certain religion, spirituality was the common thread between the various faiths. In the following excerpt, Esmerelda explains how Aboriginal spiritual beliefs helped her to see her pain as a gift. She was responding to the question: "What events, experiences, personal changes, or other factors have contributed to you coming to the point where you are today?"

> Well part of it was learning about aboriginal spirituality, that was a huge part of it for me… I spoke with a woman who is Cree. And she told me that it's a Cree legend that people who have cleft lip and palettes have actually been chosen, and they've been marked by the spirit of the bear, which means that you're strong and you've got these abilities and stuff like that. And in the white world it's a defect, a birth defect. It makes you feel defective. It makes you feel crappy, like you're a broken vacuum cleaner. And talking to her really made me internalize the thought that maybe there is a reason, maybe this is, like maybe I've actually been given a gift that other people don't have and it sounds a little nuts, but it helps me get through the bad days (Esmerelda).

Viewing the pain as a gift was a sentiment also expressed by Isabel:

> Around Thanksgiving I was at the church and, of course, the sermon was about gifts we should be thankful for and I was thinking about some of the things I have been given. I came to the conclusion that pain is a gift and I tried to think of positive reasons for being given such a gift. One is that it is a reminder to

> take care of my health. Another is that some of my health issues (especially my sensitive stomach) make it impossible for me to damage my health with bad food or drink (Isabel, from an email response).

Moving Forward: Outer World

Stoicism toward intolerant others. Strangers and even important others in the women's lives could not see their pain, partly because the conditions that the women suffered from did not manifest in outward physical signs and partly because hiding pain can be easier than explaining it. To maintain a positive sense of self, eight of the women had to learn how to ignore intolerant others and not let insensitive comments or rude stares lessen their sense of self worth. Esmerelda stated: "There's no reason for me to be ashamed of this, this is my life, this is the only life I get and if other people can't deal with it, the hell with them." Others provided the following descriptions:

> I guess I've just kinda gotten used to the discomfort and the pain and everything. And I usually don't notice how bad my writing is or how long it takes me to write something until somebody points it out, or makes fun of my chicken scratch, which was really hard to deal with at first cause I used to have really beautiful writing, and everyone used to compliment me on how nice it was. And now it seems like everyone comments on, "What the heck's wrong with you? Why can't you write faster?" You just have to shrug it off (Beth).

> I've had to learn to become more thick-skinned. You know not let what people say bother me so much, not take it so personally all the time, which I very much tend to do, it's my personality type . . . you know I work on it, like not being shy to use disability aids such as elevators, power doors, because people look at you funny cause it doesn't look like there's anything wrong. So, so this is the wheelchair door, why are you using it? Well it's because I can't open the door. You just kind of have to get over that, wanting to look like everything's okay cause everything's not okay, and take advantage of those aids that are put there, don't try to be the hero all the time. That's probably the biggest thing is forgetting that shyness over using them (Ann).

Creating and maintaining a support system. The support of friends and family can act as a protective factor against feelings of depression, despair, and isolation. By educating and informing family and friends about their chronic pain condition, eight of the women were able to gain greater acceptance, validation, and understanding from important others. For some of the women, their focus was on maintaining the support system that they already had, and for others a support system was an integral part of their journey that they were still working toward. Maintaining supportive friends and family required taking the time to connect with them on a regular basis, keeping them informed about the progression of the chronic pain condition, and making life choices such as moving closer to friends and family.

> And now that I'm older and not in high school in a teeny weeny little town I can pick my friends. My friends are wonderful, like the friends I have now are amazing. They put up with a lot, like one of my friends, when my boob was herniated I had to rub my boob day and night for about four weeks, so my friends would laugh and tease me a little and show me that it was okay to be a little bit weird and that acceptance is huge (Esmerelda).

> Right now I don't have a lot of friends, they've all gone and moved on, but I'm trying to make some new friends right now. It's nice to talk about with people, but it's hard to make friends. It's so important to keep going though, to have understanding friends (Alex).

Discussion

In this study we provide an understanding of how women live positively with chronic pain through the use of a qualitative approach, primarily focused on hermeneutic phenomenology. Three main phases were found: (a) Before Diagnosis, (b) Redefinition of Self, and (c) Moving Forward. The minor categories of Inner World and Outer World define these phases by dividing the themes into experiences pertaining to internal processes, such as thoughts and feelings, and external contacts, such as relationships with others.

During the Before Diagnosis phase, the women experienced a range of negative feelings because of the presence of pain and the uncertainty that surrounded it. A turning point, usually as a diagnosis, facilitated movement into the next phase, Redefinition of Self. The issues and themes encountered in this phase helped the women in coming to terms with their pain condition and allowed them to begin constructing a new sense of self. The continued development of this positive identity and the re-establishment of healthy relationships with others occurred during the third phase, Moving Forward.

Comparisons and Contrasts of Findings with the Literature

The overall structure of the categories, subcategories, and themes present a temporal framework wherein the women moved between the various phases in the construction and maintenance of a positive identity. This framework is similar to a number of other theories and models that examine how the construct of identity is influenced by chronic pain. For instance, in the *Shifting Perspectives Model* (Paterson, 2001), the *Temporal Dimensions of the Self Model* (Hellstrom, 2001), the *Schema-Enmeshment Model* (Pincus & Morley, 2001), and Kralik's (2002) model of identity transition, the mutable nature of identity is emphasized, and there is no determined endpoint in terms of identity evolution. Although the participants in these studies seemed to become stuck in a dysfunctional pattern of living with chronic pain, the authors do not foreclose the possibility of change and positive adaptation to chronic pain and illness.

In the present study, there is a fluidity in which the women moved between the phases, and there is no conclusion to identity development. Instead, this is a process that occurs throughout the lifespan. This evolving identity is supported by data gathered in the biographical questionnaire, which asked participants the degree to which they thought they had attained a positive identity on a scale from 1 (not at all) to 6 (completely). The ten participants' answers ranged from a 4 to a 5, indicating that although all of the women identified as living positively with chronic pain, there was still room for growth. As in the other models discussed, the framework presented here is nonlinear. While the participants initially moved through the three phases in a sequential manner, the trajectory of the chronic pain condition and other life events necessarily lead to a revisiting of earlier phases. It can be speculated that the more positively one is able to contend with pain and the more external factors or individuals support a positive identity formation, the more time is spent in the third phase of the process, Moving Forward.

Within the chronic pain and illness literature the onset of pain is usually accompanied by a state of chaos in which the individual is confronted with the uncertainty of living with pain of an unknown origin (Monsivais, 2005). In the present study, the women interviewed also encountered this uncertainty during the Before Diagnosis phase. The majority of women in the present study also described the theme Hitting Rock Bottom in which the physical and mental pain became too much to bear, and some of the participants experienced suicidal thoughts during this time. A similar experience was cited in a study that examined the illness experiences of 20 Swedish women with undefined musculoskeletal pain using a grounded theory approach (Johansson, Hamberg, Westman, & Lindgren, 1999). The authors termed this experience the final straw, and it was usually precipitated by a stressful life event, much like the experiences of the women in my study.

In the Swedish study, the participants experienced a lack of control over their conditions and hence their bodies, which led to feelings of being detached from the body. This sense of detachment was described by the women in the current study in the theme Separation of Self and Body and has been described in other studies of chronic pain patients as well (Miles, Curran, Pearce, & Allan, 2005; Shariff, Carter, Dow, Polley, Salinas, & Ridge, 2009).

During the Redefinition of Self phase, the women reached a turning point that allowed them to begin re-conceptualizing who they were. The most common turning point discussed was a medical diagnosis that was assigned to their pain. This allowed the women a degree of control over their pain and the validation that it was not all in their heads; the very act of naming the pain seemed to bring with it a renewed focus on the future. The desire to explain the presence of chronic pain using a medically-validated diagnosis is cited in the literature as integral in the experience of many chronic pain patients (Asbring, 2001; Bullington, Nordemar, Nordemar, & Sjostrom-Flanagan, 2003; Harding, Parsons, Rahman, & Underwood, 2005; Hellstrom, 2001; Kralik, 2002; Shariff et al., 2009). Once a diagnosis was achieved, the women in the current study were able to slowly accept that the pain would most likely be a constant companion, and they began integrating it into their self-schemas.

The theme of Spirituality was found within the last phase of the journey, Moving Forward. The women indicated that spirituality helped them in finding meaning in their lives and a deeper connection to themselves and the world. The literature supports the conclusion that many people who live with chronic pain turn to spirituality as a way to cope with their suffering (McCracken, 1998; Rippentrop, 2005). However, the effects of spirituality are not as well documented, and some research indicates both positive and negative consequences of spirituality in chronic pain samples (Glover-Graf, Marini, Baker, & Buck, 2007; Rippentrop, Altmaier, Chen, Found, & Keffala, 2005). Among the positive effects of spirituality cited were increased meaning, connection, and hopefulness (Glover-Graf et al., 2007) and increased positive affect (Rippentrop, 2005). The women in the current study cited these positive effects and did not highlight any negative effects of spirituality.

Answering the Research Questions

In addressing the experience of women living positively with chronic pain, we sought to answer the following questions: (a) how do women living with chronic pain construct and maintain positive identities, (b) what challenges do these women face and (c) what does a positive identity mean for these women?

The first question pertains to the processes involved in constructing and maintaining a positive identity. Based on the rich accounts given by the participants, the journey can be understood as movement through and between three primary phases spanning both the inner and outer worlds of the women. This journey was found to be a continuous one in which individual themes and processes were revisited, resulting in further growth and development of a positive identity.

The challenges that the women faced along their journeys were numerous and included a lost sense of self, the failure of the biomedical system, a lack of understanding from friends and family, and the negative emotions that stemmed from these challenges. While the participants dealt with obstacles throughout the three phases, many occurred during the initial phase before a diagnosis had been reached.

In addressing the third question we sought to understand the essence of a positive identity and what meaning this held for the participants. The understanding that we reached encompasses both the losses and gains associated with living with chronic pain. The women who let us glimpse into their lives described a process of transformation in which they lost aspects of themselves, fought to hold onto others, and learned how to incorporate new values, beliefs, attitudes, and capabilities into a whole new conceptualization of the self. Along the way, the women cultivated strength, courage, empathy, understanding, wisdom, confidence, acceptance, and a sense of empowerment. These attributes are the essence of a positive identity.

Much of the literature surrounding the experiences of chronic pain is focused on the losses and negative consequences of living with pain. This necessarily limits the exploration of the strengths and capabilities that may arise. This research has focused on a unique subset of women who have overcome many obstacles in their quest to live their lives positively with chronic pain. Given the large percentage of individuals who suffer from chronic pain, and the fact that living positively appears to be the exception in the large majority of cases, there is a great need for further research into the nature and processes of developing a positive identity while living with pain.

Implications for Healthcare Providers

The stories of the women suggest that they were forced to construct positive identities within a cultural context that promotes the invisibility of chronic pain and the silencing of their voices. For the most part, this attitude was felt predominately within medical settings from the very people who were supposed to be helping the women. The importance of receiving validation from medical professionals, such as doctors and nurses, cannot be overstated. Patients need to tell their stories in an atmosphere of care and concern; they need to be listened to. Teaching healthcare professionals how to do this is an integral part of creating an atmosphere of healing and legitimization. Training programs, practica, and continuing education opportunities for healthcare professionals should strive to incorporate these teaching objectives.

Despite the fact that the women in this study faced a lack of validation from the healthcare community, they continued to seek a diagnosis and treatment for their pain; a process that for most took a number years. During this difficult time before a diagnosis was assigned, the women faced a myriad of negative feelings, which for some culminated in deep depression and suicidal ideation. Suicidal thoughts and behaviors can occur at any point during the chronic pain experience, but this is especially prevalent when there is no known cause for the pain (Stenager & Stenager, 1998). Being cognizant of this and watching closely for warning signs of suicidal behaviors in patients who live with pain is a crucial part of working with this population. Communicating that this is an experience that other people with chronic pain have contended with might help patients in feeling that they are not alone. Helping patients connect with a support group or a therapist may also be beneficial during these times.

Finding a reason for the pain was an often-cited Turning Point for the women. Although a medical diagnosis was the most common catalyst for acceptance of chronic pain, other strategies might be available. For instance, working with mental health professionals such as counsellors and psychologists can facilitate acceptance of undiagnosed chronic pain, which allows for the shift necessary to begin reconceptualizing a new sense of self. This process necessitates deep reflection on various components of identity including values, beliefs, roles, and relationships. Relegating the pain to one part of the whole self, rather than the defining feature of the self, can also be achieved through work with mental healthcare professionals.

The theme Gaining Control Through Letting Go describes the concept of consciously letting go of the desire to control pain to lessen the intensity of the physical and emotional experience. Healthcare providers can aid women who suffer from chronic pain by exploring techniques such as meditation and relaxation training, which can lead to greater acceptance of pain and a decrease in emotional distress and physical symptoms (Baird & Sands, 2004; Jensen, Turner, Romano, & Karoly, 1991; Kabat-Zinn, 1982).

Although defining a new sense of self is the primary component of living positively with chronic pain, medical treatment is often necessary to control pain levels and associated symptoms such as fatigue. Because of the difficulty inherent in navigating the biodmedical system, women who suffer from chronic pain might need help in advocating their needs. This can be accomplished through connecting with patient advocates within the healthcare system or teaching self-advocacy skills such as assertive communication.

Creating and maintaining a support system is another important aspect of living positively with chronic pain. Support groups for women with chronic pain offer an avenue for gaining these important connections. There are a number of support groups available for those with diagnosed chronic pain conditions, however support groups for individuals with undiagnosed pain are lacking. Counseling agencies, clinics, and hospitals can act to change this by offering group therapy to patients suffering from pain of an unknown origin. Having the support of others who are also experiencing this can validate patients' feelings, provide them with coping resources, and allow them to seek out positive role models.

Finally, the spiritual aspect of living with chronic pain must not be ignored by healthcare professionals. The women in this study experienced spirituality as a coping resource that allowed them to find meaning in their lives and connect more deeply to themselves and the world. Although exploring spirituality with patients might fall outside of the realm of a typical appointment for most doctors and nurses, a referral to a spiritual advisor such as priest or rabbi can aid in this process. Likewise, helping professionals should also strive to explore spirituality with patients living with chronic pain, either directly or through helping patients connect with spiritual advisors or resources (Wong, 2004).

The results of this study have also highlighted the need for greater integration of services pertaining to health and wellness. The physical, emotional, and spiritual aspects of living with chronic pain are interrelated, yet services pertaining to these areas are often separate. Combining such services under one roof can create more holistic support for those who suffer from chronic pain.

Possible Limitations of this Study

Many of the values and strengths associated with hermeneutic phenomenology have also been cited by some to be limitations. Morse (2006, p. 1) stated that "qualitative research has developed in the shadow of quantitative inquiry," thus the principles that are used to judge the trustworthiness of qualitative research are often discrepant. The term validity as applied to traditional quantitative research refers to something that is repeatable, but the reproduction of results does not imply validity in qualitative work (Lincoln & Guba, 1985). Instead, the truth value of qualitative research is found in the rhetoric that is used to construct a new understanding of the truth. The strength of hermeneutic phenomenology in exploring a certain phenomenon at a certain moment in time, within a certain population, is also its weakness, because of the restrictions this necessarily places on the scope of inquiry. A potential limitation of this study is the homogeneity of participants. Most of the women interviewed were middle-class, educated at a post-secondary level, living in an urban setting, and Caucasian. The development of a positive identity while living with chronic pain might be a vastly different experience for a person from a visible non-dominant group or for someone living in another geographic area. Another potential limitation is the possibility of experimenter bias, which occurs when a researcher's preconceived notion of what he or she expects to find influences the results. In this study, the first author, who conducted the interviews, did not have hypothesized results, and she attempted to explicate her own pre-understandings and experiences to focus on a deeper understanding of the women's stories. Bias can also be introduced to a study when participants attempt to tailor their responses to what they believe the researcher wants to hear. The first author tried to minimize this by keeping questions open-ended, establishing a good rapport with participants, creating an atmosphere of curiosity and acceptance, and by using summarizing statements and questions to clarify participants' meanings.

Concluding Comments

The experience of living with chronic pain is one that is different for each person, yet the themes discovered in this study point to a number of commonalities experienced by women who have learned to live positively with chronic pain. The journey that the participants embarked on was fraught with self-doubt and moments of despair, yet they continued striving forward in search of a new sense of self and understanding of their pain. This process was one that began as a solitary journey for most of the women; the inner resources that they learned to rely on developed through introspection, trial and error, and the burgeoning belief that by choosing to continue onwards, transformation was possible. The women began reaching out to others, listening to their bodies, and speaking up for their needs. They became new women, no longer defined by their pain. Their experiences can guide other women who struggle with chronic pain and light a path for the healthcare professionals who work them.

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