



Although situated in hermeneutic phenomenology, this study's theoretical perspective is informed by a feminist perspective and is thus not necessarily reflective of human experience generally on the issue of chronic pain and its link to further learning. Moreover, it should be considered that it is a very real probability that men with similar chronic pain as the women focused upon in the article are also similarly affected when it comes to entering the realm of further learning. [Editor's note]

Chronic Pain and Returning to Learning: Exploring the Lived Experiences of Three Women

by **Anita Sinner**

An in-depth analysis of the post-secondary learning experiences of three women revealed that their decisions to participate in college and university courses in Canada were interconnected with lived experiences of chronic pain. A causal link between chronic pain and returning to learning was an unexpected outcome of a study focusing on women's learning experiences in post-secondary institutions. Each woman in this study learned to cope with and adapt to her chronic pain, and over time, returned to learning to undertake new areas of study to accommodate a redefinition of self based on chronic pain. Eventually chronic pain became a conduit to more positive experiences of learning and reflection. The role and meaning of chronic pain in the learning equation represents a blind spot in the existing educational literature and it is through such in-depth, descriptive stories of participants that we learn how this invisible barrier may influence the learning decisions of women.

Introduction

An in-depth analysis of the post-secondary learning experiences of three women - Christina, Tina, and Giustina - revealed that their decisions to participate in college and university courses in Canada were interconnected with lived experiences of chronic pain. A causal link between chronic pain and returning to learning was an unexpected outcome of a study focusing on women's perceptions of learning and the processes of change experienced when entering a post-secondary institution. In the context of this study, learning takes place formally and informally as "a process by which behaviour

changes as a result of experiences" (Merriam & Caffarella, 1999, p. 250). Further, a "return to learning" is defined as formally participating in college or university courses at a public post-secondary institution (Mohney & Anderson, 1988; Wilson, 1997). While each woman's pain experience was unique, they shared the key commonality that chronic pain was at the core of their decision to return to learning. The emergence of chronic pain in the lived-learning experiences of all three women, who are unknown to each other, in different geographic regions, of different ages and from different

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cultures, education levels and lifestyles, I believe, warrants further discussion.

In this study, chronic pain is defined as a multidimensional experience; a distinct form of pain because of the persistence of continuous pain over time that is accompanied by emotional responses, but which may or may not be the result of autonomic reflexes (Ahmed, 2002; Daly, 1999; Peolsson, Hyden & Larsson, 2000; Price, 2000; Whalley & Oakley, 2003). Chronic pain thus embodies elements of physical effects and/or psycho-spiritual affects upon the self. The term “self” describes an individual’s experience and reflective understanding of “being” that is articulated as the way each individual’s mind and body “exist[s], act[s], or [is] involved in the world” (van Manen, 1997, p. 175). In an analysis of these narratives, the chronic pain experiences of Christina, Tina and Giustina describe how each woman coped with and adapted to her chronic pain, and over time, returned to learning to undertake new areas of study to accommodate a redefinition of self based on chronic pain experiences. Eventually chronic pain became a conduit to more positive experiences of learning and living. The role and meaning of chronic pain in the process of learning for women has not been explored in educational literature and represents a blind spot in the existing academic discussions. This article serves as an entry-point so that we may begin to discover how such an invisible barrier may influence the learning decisions of women.

Research Methods

In the field of education, hermeneutic phenomenology as a research methodology is based on a pedagogic concept that everyday lived experiences are starting points that attempt “to unfold meanings” and offer insights into how individuals actively shape their relationships of self in the world (Laverty, 2003, p. 4; van Manen, 1997). In the words of van Manen:

It is a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena. The implied contradiction may be resolved if one acknowledges that the (phenomenological) “facts” of lived experience are always already meaningfully (hermeneutically) experienced. Moreover, even the “facts” of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process (1997, p. 180-181).

Van Manen’s “alternative phenomenological approach ... combines aspects of both Husserl’s and Heidegger’s philosophies” (with reference to Plager 1994, in Miller, 2003, p. 3), even though the Husserlian and Heideggerian schools of thought are fundamentally different in orientation (Conroy, 2003; Laverty, 2003; Priest, 2002; Rockmore, 2003). This subjective approach “begins with a sense of wondering about what some thing, phenomenon, or experience is like” (Fitzpatrick & Watkinson, 2003, p. 3). As van Manen’s hermeneutic phenomenology is “quite amenable to feminine forms of knowing, inquiring and writing,” it is within this theoretical framework of hermeneutic phenomenology that I situate this study (van Manen, 1997, p. xvii). Engaging in research from a position that knowledge is rooted in the essence of day-to-day experiences, hermeneutic phenomenology opens a discussion of personal life histories and perceptions, offering a “multiplicity of voices, perspectives and roles” to educational inquiry (Gough, 1993, p. 561).

Hermeneutic phenomenology “requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience ... [so that we can] ... best understand human beings from the experiential reality of their life worlds” (van Manen, 1997, p. xi). In this project, the “first-

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person accounts of experience ... [serve as the] ... primary source of information” (Riessman, 1993, p. 25). Because this approach is supported within feminist perspectives, I blend aspects of “nurturing our own voices” in the body of this article by including participant narratives (Richardson, 1994, p. 518).

By sharing our experiences we are “revealing truths,” and in the process, the telling of our stories gives meaning and interpretation to experience, to ourselves, and to the world around us (Riessman, 1993, p. 22). According to Reinhartz, “women’s oral history is a feminist encounter because it creates new materials about women, validates women’s experiences, enhances communication among women, discovers women’s roots, and develops a previously denied sense of continuity” (1992, p. 126). These narratives are structures of experience that give “control and order to our research and writing” (van Manen, 1997, p. 79). Narratives are critical to the purpose of this study as the lived experiences of others encourage personal reflection and provide the basis for the generation of theoretical implications.

Given this theoretical framework, I engaged in interviews that provided “access to people’s ideas, thoughts and memories” (Reinhartz, 1992, p. 19). Although interviews followed a loosely defined question and answer format, significant portions of the interviews took the form of oral histories. These life-story segues were rich in depth and scope. These stories display “the data rather than analyze them ... [and the text is] ... used demonstrably, performatively” (Lather, 1992, p. 96).

Hermeneutic phenomenology draws our attention to aspects that are often taken for granted in the world. This methodological approach does not rely on generalizations. It allows that which might seem insignificant to gain prominence. For this study, participants were selected because they “have lived the experience, [were] willing to

talk about their experience, and ... [were] diverse enough from one another to enhance possibilities of rich and unique stories of the particular experience” (Lavery, 2003, p. 18; Polkinghorne 1989).

While participants in this study were not asked specific questions relating to pain in the course of interviews, all questions were “generally very open in nature,” encouraging more holistic reflections (Lavery, 2003, p. 19). By attending to “what is said between the lines,” it became evident that descriptions of chronic pain were intricately braided into their experiences of the lived-learning environment (Kvale 1996 in Lavery, 2003, p. 19). Peolsson *et al.* describe this as “presenting pain in relation to social contexts, activities, events and aspects of the physical world” (2000, p. 118). It is through this process of telling that we begin to give experience meaning and interpretation (Riessman, 1993, p. 22).

Revealing the unexpected: The lived experience of participants

My goal is to bring forth the voices of Christina, Tina and Giustina, and include as much of each participant’s dialogue as possible to describe defining events and circumstances in their learning experiences. The following textual portraits highlight the significant role of chronic pain in women’s lives and the influence of chronic pain in their return to learning and their enrolment in post-secondary courses.

1. CHRISTINA

As a professional singer, Christina is steeped in the traditional milieu of operatic art and culture. At 34, her career is taking shape with numerous solo roles across Canada and the United States. When she reflected upon her lived experience, she followed a timeline that is strongly defined by key life shifts due to chronic pain, with returning to learning as a means of managing pain in her life.

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After my third year of college I transferred to university. The new world of university was nerve-racking. Let's say there was something about the word 'university' that rang in my ears. Like everyone, I had a plan which I think was pretty realistic. I had no intention of being a performer. I wanted to complete my undergraduate degree in general music, in clarinet, take language training in Europe, then do a teaching degree, and eventually get a job teaching music and French in the public schools. Every plan I had made fell apart because of physical reasons. In my final term, I developed tendonitis in both arms. I was able to play my final exam and graduate, but after that I stopped playing clarinet. I then developed chronic pain throughout my body, and the only diagnosis I received was fibro-myalgia. I worked for the next year to save money to go to Europe and learn French, and ultimately to return to school. My physical condition deteriorated during that year so I had to cancel the flight I had booked as well as quit my job. It was a terrible year. I couldn't go back to school in the fall. I could not do any fine motor skills. I could not play. I could not write. I couldn't sit for long periods of time because of the pain. To read or study was simply out of the question.

Becoming a singer was by default. I was in chronic pain for five years. I tried everything and after a few years had some relief through Japanese medicine. One of the only highlights of those years was that I discovered singing. A good friend hooked me up with a voice teacher and I began to take lessons. I had sung in choirs since high school, but I was not a solo singer. My health was improving, and I still wanted to go to Europe to learn languages, so I saved money again and booked a flight. It was then my five-year relationship began to dissolve and I thought going away would help me sort out my life. Europe had always been my dream. I knew I had to go. Later I learned two women [I knew] in the chorus were going to Italy, to Siena, to do master classes, and they invited me along. And so I went to Italy.

I think being in a warm climate was profound for me. It was the first time in years when I wasn't in pain all the time. When I arrived I didn't even know if the

school received my application. There were a hundred-and-something people at the audition so I didn't feel I had a chance. Well, the next day, we stopped at the school and I saw my name on the short-list of fourteen people. In the end I didn't get in, but something struck me about that experience. Out of this many people, they heard something special. I was still invited to go to the classes and observe, but as it turned out, it was completely in Italian. I would have been dumbfounded if I had been a full participant in the course. In addition to observing the master classes, I took a language course. Just being there for six weeks, meeting singers mostly from Europe, I realized they were normal people who were singers. And so I thought, well, why not? I never thought of myself as a singer, but when some friends were auditioning in Toronto, I thought, 'Oh, I'll go too,' and somehow I sang a really good audition. Within six months, I was moving to Toronto, and two years later, I completed a Diploma of Operatic Performance.

Singing is connected to my music training, yet singing is very different from playing clarinet. When I started singing, I felt less pain because of the way the body is used. The tendonitis never stopped. I still have it. I've just altered what I do. So, in a lot of ways being an opera singer made sense. It is very physical, but not fine motor physical. I am capable of dealing with it and I am much stronger now.

2. TINA

Formerly an art coordinator for a prominent magazine and now managing her artist/husband full time, Tina, 47, in her own right, is an artist with a discerning eye for colour and design, which she expresses in the spontaneity of her fabric and glass artworks. Looking back on her life, Tina offered insight into the process of returning to learning while suffering with lifelong chronic pain.

The doctor missed my congenital hip dislocation when I was born and by the time they realized something was

wrong, it was too late. I've lived with this my whole life. I was having surgeries in and out of school so I missed almost all of Grade 8, but I managed to go forward into Grade 9. I was academic and they thought I'd be fine. I missed a lot of Grade 11, but they told me I could be with my friends in Grade 12. In the end, I was told I couldn't graduate because I was missing Guidance. Guidance!

When I quit school in 1971, I just wanted to get a job and get out of the house. I married young too. I worked for seventeen years, mostly with the magazine, and then physically dropped-out. When I went to stand up at work, my hip would dislocate. I finally had to quit. I'd gone through the separation and divorce and I was a single mom and all that. When I quit working I really went down physically. It was worse. I went on a disability pension, but I never felt right being on it because my mind was fine. I'm talented, but the pain was too much. There were times, maybe three weeks, when I had a reasonable level of pain and I could work, and one week when I couldn't. But during those three weeks I could be productive, out of my home, doing various things.

The conflict with the pain level and what I could do as a job was very apparent to me, so that is when I decided, well, I'm going to get my Grade 12. And I went back to high school. I met my second husband during that time. We were both recently divorced, had young children, and within three years, we were married. I was struggling at that time with my health, a new relationship and marriage, the family situation, blending our homes, and then my education.

I graduated with my diploma and started a Business Administration program at the college the following fall. I was looking for a change of occupation that would support me with my condition. I was experienced in business so I thought I could enhance that aspect and that would be my fastest, easiest way to retrain myself for another career. If I could get a job that paid twice as much, but only worked half as much, then that would be the way I could use my academics to overcome my hip problems. That was

the logic behind it. I had to retrain myself to earn a living in a capacity that I could fulfill. I knew I was an intelligent person and I could learn and do more. What I didn't realize was that pain is a very, very strong factor. I didn't acknowledge pain, but it drained me. I thought if I became an accountant, I could earn a really good wage and not have to work as much, but accounting didn't fit me. I didn't have the drive and passion to pursue that amongst everything else. It didn't match my lifestyle or my needs and wants.

The courses I took along the way have helped me immensely. I took Marketing and learned computer skills, and I enjoyed the accounting. I always got along well with the instructors, perhaps because I was a mature student, sometimes they relate to you on a different level. It was hard, balancing family, learning and a disability. It was so stressful. It would be much easier to be a single person without family obligations. A lot of my family couldn't understand why I was doing it, and I didn't get a lot of support as a disabled person. I thought, maybe they didn't think I'm a disabled person because I'm not in a wheelchair.

I was in my mid-thirties and all of these things were happening at once. There was this raising of family and maintaining a relationship and marriage. And to me, being a maternal person, I always put people ahead of myself. It is easier just to give over than to struggle and do something for myself. I realized that maybe my path of learning in this life is not through a structured institution and a degree, maybe it is the road, and the people you meet, and courses here and there, and things you pick up. Eventually I gave in and let it go, I felt my place was with my family. I brought a person into this world, and to me, he was a priority. I made that choice and I couldn't say, you're not important and school is more important than you are. The only frustrating part is that I started a program of schooling in my life and I didn't finish.

I still had a bad hip and during the next summer, I made the decision, it was time to have a hip replacement. They didn't want to give me a replacement because they said I was too young. I

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went back to my doctor and he finally said he'd do it. I had the operation. It was the first of three.

My first hip replacement was painful. I knew it was coming loose. My doctor told me it would be fine, and made me keep it for two years. He kept telling me that basically it was me. Finally, they realized it was coming loose and then they did another hip replacement. They said, "OK, this is it, twenty-five years, it will be fine. We'll take that one out and glue this one in, and you'll be fine". I wasn't fine, I wasn't fine, I wasn't fine. I had to have that one for another four years and then it came loose too. I'm bordering on insanity. The pain was incredible. And they're saying, "There's nothing wrong with this, it's you," and I'm saying, "No one tries any harder than I do!"

I wanted to be Tina first, and disabled second. I should have embraced my disability and accepted it, and life could have been easier for me, but I always felt I had to prove that I belonged. I was on crutches for almost two years, and by the time the doctor realized that there was something wrong with the second replacement, I guess the prosthesis had rubbed the bone so thin, it was so close, if I had walked on it, I would have shattered it. I went onto the Internet and I started diagnosing my X-rays. On the Internet I found a doctor who had pioneered a procedure that was a total reconstruction. It is called "Fillet of Femur." So I decided I'd have it done. And it was brutal. It was brutal. I was there for hours, wondering, yes, it was pretty wicked.

But all those years of pain, from my teens right through to about a year or two ago, off and on, constantly, now it is behind me. There have been problems from the reconstruction, a leg-length discrepancy, and once in a while, my body goes out, and my neck and my shoulders, and I get numbness in my hands. It is like a domino effect. It was such a nightmare, to think back, and it is such a dream to think it is all gone now.

I'm learning to let go of more. I'm caring less physically and more emotionally for people. People will aspire to their own goals in their own time. I'm caring for myself. I'm

enjoying more of the simpler things in life. I am independent and strong-willed, understanding and caring, hard working, and innovative and creative. Now in my life, I want to just experience everything and try all of it. There was a wicker chair course offered somewhere, and I thought, 'Hm, why not?' Maybe I'll take a watercolour course. There is a one-week woodworking course, and I thought, that would be pretty good. I'd like to take welding. I'd love to sandblast. I want to try all these things. And I need a place that is mine. I need my space so I can go into my little room and create. I need light. I need skylights, and I need heat. I need to be warm and bright. Then I can create. I know I'm very capable. I can handle whatever comes my way. If I want to take a course in colour, I'll do that. I'm pursuing my dreams now, let's put it that way. I didn't have a lot of dreams when I was younger. There were other priorities in my life, but I'm really touching base with my dreams now.

3. Giustina

Giustina, 55, is a deeply spiritual person for whom family is central and the betterment of the community is an ongoing concern. As a learner, Giustina prefers to learn by doing, relying on her intuitiveness to steer her in the right direction. Chronic pain was critical in her decision to return to learning, and this resulted in her participating in a variety of learning situations that she would not have, had chronic pain not become part of her everyday living.

When I talk to myself (don't think I am crazy), I always say, "You are a beautiful soul, you are so good." It wasn't easy to get to this point in my life, but I still believe each day is a new experience. We learn from each other, from all the people we encounter, and from those experiences, some good and some bad, I've become who I am today.

My troubles began in my life with the loss of my parents, and my sister and niece. Then you see life differently. I became quite sick a few years ago. I couldn't run my restaurant because I

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injured my knee. I had my own business for five years and it was long enough to aggravate my situation. I was running like crazy, from six o'clock in the morning to about eleven o'clock at night. Go, go, go. I think there is a reason for everything, looking back now, I'm sure the good Lord said, "OK, now I have to stop you, you can't stop by yourself." If he hadn't stopped me, I wouldn't be here today. I developed an ulcer on my leg that opened up and started leaking. My leg really swelled up. The doctors thought I was going to lose my leg, so they said, 'That's it. You can't do that job anymore.' I stayed home for a little while. Then I went to work for somebody else and had a terrible fall with all my weight, and I really injured myself, really, really badly, both knees. I kept saying, "Please Lord, let me be better so I can go back to work." Now I say, "Thank you Lord for not answering that prayer!" God knows better what we need or not in our lives.

From then the doctors insisted I had to take it easy. There were all sorts of tests and they discovered I had no circulation from my knee down. It was very serious and very painful. I came home and I cried and felt sorry for myself, and then I thought, well, that's what the doctor says, but I know somebody who can make me better. And so I had a little talk with somebody above. Then I took charge of myself, [had the operation] and so, here I am.

I can't stand for too long so I needed to retrain myself for a job where I have a bit of movement and can sit down. Of course, there's not a job available without having some kind of schooling. So I decided, well, maybe I better go back to school to see if I can find something where I can meet a lot of people. I've always helped people so I thought I would train for some work like that. I still have health problems, but I'm young and I still need to make money. When you have a family, you need to go out there. I can't see myself sitting at home.

I'd never been to a Canadian school until three years ago, almost forty years after I went to school in Italy. I didn't know correct English. I learned on my own. It is still extremely hard because I think in my [home] language. Even

now, I have to think what does this mean and turn it around, so I do double the work. On my first day of school I felt very scared. My heart was beating fast and my legs were shaking. I didn't know what to expect. I walked into the classroom, of course I was the oldest one there, but there were many people from other countries, like Japan, China, the Philippines, from all over the world. This was English as a Second Language so when we talked to each other it was very hard to understand because we all had different accents, so really, it was a challenge. It was nice to meet all these different people. I always get along with everybody. I never have any problems. From there, I went to learn about employment strategies and of course, office administration was zero, but working with people was up there! Accounting was in the middle because I like numbers. Some of the math I enjoy, but I have to learn everything again. The way they do it here is different from what I learned, so there again, I have to retrain myself. It wasn't easy but I pulled myself through. Then I went to ABE for English and now I've finished my Business Administration program. My kids are really proud, and my grandchildren always say, "Way to go Nona." I want to show them that it is never too late to learn. It doesn't matter how old you are, if you really want to do something, you do it. Now they say, "If my Nona can do it, I can do it." If I didn't have the determination, I wouldn't have made it. It is very rewarding for me that I accomplished this learning, I'm really proud of myself.

It was tough for me. I kept asking myself, 'Can I make this? Can I do this?' I've grown a lot, learned a lot, and I've experienced a lot. Even if I talk to somebody, I hope I make the difference, maybe not today, maybe not even tomorrow, but at some point they might remember what I said. We need to have love. We need to have faith. If you don't have love, you don't have anything. You have to have it in your heart. The rewards for me are inside, and they are enough. Whatever I give comes back to me more than a hundred times. What I need to do now is make myself strong and healthy so I can do even more. And I've got to be around for my grandchildren. My granddaughter drew a picture of me,

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and the picture took the whole page, but she drew the heart bigger than the body. When we asked her why she did this, she said, "Because my Nona has a big heart." So they can see at a young age. If I go on with my schooling, I will need to take more English. Since I was small, it was a dream of mine to be a counsellor. They say you always need to have a dream because when you stop dreaming, there is no sense to live. So maybe I'll stop here, who knows, maybe I'll go back to school for more, I don't know if I can. We'll see.

Engaging in the research

While I recognize that "different readers might discern different fundamental meanings ... [and one interpretation is not] ... necessarily more true than another," I believe that the richness of each participant's story conveys how the experience of chronic pain was interconnected with their return to learning (van Manen, 1997, p. 94). In this study, chronic pain emerged in what I describe as a third space, in the social context of learning, where each woman's way of thinking about the self-body-world relationship was profoundly transformed. Clinical frames of medicine or psychology do not strictly bind the experiences of chronic pain described in this study; instead, chronic pain was "a subjective, complex phenomenon of inseparable physical, mental, spiritual and social processes" (Howell, 1994, p. 94).

The chronic pain experiences of these women emerged through their narratives of returning to learning. Voicing pain through such narratives is of critical importance since, as Greenhalgh argues, this is "a means to political awareness" and "women's pain must be politicized" (2001, pp. 324 & 327). Greenhalgh states:

Narrativizing their pain is a way to give meaning to suffering ... to learn what one's own voice sounds like, perhaps for the very first time. On a communal level, when we tell stories we create communities, groups of people who are tied together by common accountings of human experience. Whether narrated

orally, written down, or simply enacted in daily life, by telling our stories we also make resources available for others (2001, p. 323).

Peolsson *et al.* reiterate Greenhalgh's perspective regarding such intimate stories as enabling women "to place the pain in a context ... pain is described as being connected with what the [women] do in their daily life, the conditions to which they are subject, how they arrange their everyday life" (2000, p. 117). It is through such narratives that the connectivity of the self-body-world relationship with chronic pain is revealed (Ahmed, 2002). According to Ahmed, "pain has to be read ... with the kinds of attachments and feeling that surface in our everyday lives" (2002, p. 27).

Participants established the self-body relationship early in the interviews, describing their sites of chronic pain. Christina developed "tendonitis in both arms ... then developed chronic pain throughout my body." Tina's chronic pain remained located in her hips, "the doctor missed my congenital hip dislocation when I was born and by the time they realized something was wrong, it was too late. I've lived with this my whole life." Giustina's chronic pain experience was localized to her lower leg. "I developed an ulcer on my leg which opened up and started leaking. My leg really swelled up. The doctors thought I was going to lose my leg ... I had no circulation from my knee down."

Each woman revealed a complex relationship to her pain experience, describing the pain as a constant "companion" that affects engagement in the world (Peolsson, 2000, p. 119). Each highlighted "incidents of the physical environment ... which would otherwise ascribe little if any significance in other contexts." Taken for granted activities of the body reveal how the lives of participants were disrupted in unexpected ways. Christina described, "I couldn't sit for long periods of time ... To read or study was simply out of the question." Tina

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stated, "If I had walked on it [her hip], I would have shattered it ... When I went to stand up at work, my hip would dislocate." And Giustina said, "I can't stand for too long." As Peolsson *et al.* state, "the surrounding world is seen in a different way by a patient suffering from chronic pain compared with a person not in pain," and in the case of this study, each participant described the physical environment in terms of social expectations of physical activities (2000, p. 120).

The participants expressed how their own initiatives helped them develop strategies of living with chronic pain while maintaining a sense of control of their body. Christina stated:

I tried everything and after a few years had some relief through Japanese medicine. One of the only highlights of those years was that I discovered singing ... My health was improving, and I still wanted to go to Europe ... And so I went to Italy. I think being in a warm climate was profound for me. It was the first time in years when I wasn't in pain all the time.

Unable to find an adequate medical response to her situation, Tina's initiative finally led to the resolution of life-long chronic pain. As she described:

I went onto the Internet and I started diagnosing my X-rays. On the Internet I found a doctor who had pioneered a procedure that was a total reconstruction. It is called "Fillet of Femur." So I decided I'd have it done. And it was brutal. It was brutal. I was there for hours, wondering, yes, it was pretty wicked ... But all those years of pain, from my teens right through to about a year or two ago, off and on, constantly, now it is behind me.

Giustina's religious faith guided her during the onset of illness and defined her approach to chronic pain management:

God knows better what we need or not in our lives ... and then I thought, well, that's what the doctor says, but I know somebody who can make me better. And so I had a little talk with somebody above. Then I took charge of myself, [had the operation] and so, here I am. I still have health problems, but I'm young and I still need to make money. When you have a family, you need to go out there. I can't see myself sitting home.

All participants expressed a sense of frustration and a lack of progress when they sought support within the medical system. This suggests "notions of dignity and autonomy" are fundamental in the chronic pain experience (Pullman, 2002, p. 80). The absence of a medical response left each woman with a "disjunction between the person and the body ... the body [became] an other" (Peolsson *et al.*, 2000, p. 114). This disembodiment of the self-body-world resulted in each woman finding an alternative means of constructing a solution to her situation. I would not describe any of the participants as passively being under the care of a doctor. Rather, all women oscillated in and out of treatment as required, and only engaged in the medical system once they deemed they had found the best solution. This independence of action and thought is consistent with and parallels participant's self-determination within the educational system.

For each participant, chronic pain was clearly interconnected with their return to learning and their participation in college and university courses. Christina charted a lengthy transitional path, as she developed pain during the completion of one educational program, and after several years of chronic pain, began another program that accommodated her physical state.

I wanted to complete my undergraduate degree in general music, in clarinet, take language training in Europe, then do a teaching degree, and eventually get a job teaching music and French in the public schools. Every plan I had made fell apart because of physical

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reasons. In my final term I developed tendonitis in both arms. I was able to play my final exam and graduate, but after that I stopped playing clarinet ... It was a terrible year. I couldn't go back to school in the fall. I could not do any fine motor skills ... [But] when I started singing, I felt less pain because of the way the body is used.

For Tina chronic pain clearly resulted in her return to learning. As she stated:

There were times, maybe three weeks, when I had a reasonable level of pain and I could work, and one week when I couldn't. But during those three weeks I could be productive, out of my home, doing various things ... There was a conflict with the pain level and what I could do ... that is when I decided, well, I'm going to get my Grade 12 ... I could use my academics to overcome my hip problems ... I had to retrain myself to earn a living in a capacity that I could fulfill.

Giustina recognized that she “needed to retrain ... for a job” where she could “have a bit of movement and can sit down. Of course there’s not a job available without having some kind of schooling ... so I decided, well, maybe I better go back to school.” Peolsson (2000) suggests such activity breaks imply “a sort of apprenticeship” through which women with chronic pain learn “how to maintain a balance among their physical resources, situational demands and the demands of the world around them (p. 118).

As participants spoke about their choices and actions, it became clear that chronic pain was causal in their return to learning. Once they had returned, secondary, more traditional factors of adult education emerged as part of their learning experience (Mohney & Anderson, 1988; Wilson, 1997). For example, embedded in their accounts of returning to learning are elements of “seeking an increase in competency” and being “motivated by the need for security” in terms of career development (Mohney & Anderson, 1988, p.

272). This suggests that the decision-making process is complex and multifaceted, and may be connected to a range of values and outcomes extending beyond chronic pain. But in this study, reasons for returning to learning were unquestionably interconnected with chronic pain.

At the same time, the experiences of chronic pain and returning to learning are somewhat paradoxical. The learning narratives of participants reflect dichotomous themes of “burdensome-cherished, connecting-separating, engaging-distancing”, and “choices-will be” (Pilkington, 2000, 7). Based on their descriptions of returning to learning, it may be argued that the participants in this study were “inventing unique ways of living” with chronic pain and therefore shaping personal “self-emergence” at the same time (Pilkington, 2000, p. 7). For the women of this study, chronic pain eventually became the conduit to more positive experiences of learning and reflection, with outcomes that extended beyond the initial desire to address chronic pain. As Christina states:

When I started singing, I felt less pain because of the way the body is used. The tendonitis never stopped. I still have it. I've just altered what I do. So, in a lot of ways being an opera singer made sense ... I am capable of dealing with it and I am much stronger now.

Tina described her present state as “Now in my life, I want to just experience everything and try all of it ... I’m pursuing my dreams now ... I didn’t have a lot of dreams when I was younger.” And Giustina too focuses on her future possibilities, not chronic pain:

Since I was small, it was a dream of mine to be a counsellor. They say you always need to have a dream because when you stop dreaming, there is no sense to live. So maybe I'll stop here, who knows, maybe I'll go back to school for more, I don't know if I can. We'll see.

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It is most important to note that each woman returned to learning while experiencing chronic pain. Chronic pain “is a form of communication” that can be expressed in a variety of ways, yet none of the participants reported articulating their experiences of chronic pain in the classroom environment (Montes-Sandoval, 1999, p. 938). Indeed, the “lack of verbal transmission or expression does not imply that there is no pain” (Montes-Sandoval, 1999, p. 940). For Christina, Tina and Giustina, the meaning of chronic pain is intimately reflected in every aspect of their self-body-world relationships. In all cases, their lives were profoundly impacted by chronic pain, yet they continued to function within this invisible barrier, eventually making chronic pain a conduit to more positive experiences of learning and reflection.

Insights into chronic pain and returning to learning

I believe the potential implications of chronic pain and returning to learning are extraordinary, and like Peolsson *et al.*, I also believe “this kind of [research] is important in constituting a structure of relations between a suffering person, pain and context” (2000, p. 114). Yet, situating chronic pain experiences in the broader educational literature has proved challenging. I have not located literature that addresses the meaning of chronic pain and returning to learning.

As an entry-point, this study may prompt questions within the field of education, encouraging further research in a framework that explores the relationship of women’s chronic pain and learning activities. Questions guiding such research may include:

- Does the self-body-world relationship improve or worsen, and why, once women with chronic pain return to learning?

- As a relational experience, how can women’s chronic pain experiences inform theories of curriculum?
- Is there a body-in-curriculum experience for women in chronic pain?
- In the application and delivery of learning, how can women in chronic pain best be supported to achieve their potential?
- In terms of curriculum, in what broader learning theories, assumptions, and philosophical frameworks can questions of chronic pain, women and learning best be situated?

Based on this study, I wonder if women generally accept chronic pain in a manner that is uniquely female and if unconscious manifestations of degrees of pain are part of women’s ways of being. Is it possible then that women’s chronic pain has not been part of the discourse of learning because pain is viewed as a natural occurrence in maternal life? Women are born of pain, and pain remains a fact of the physical lifecycle, as pain is associated with menstruation, sexuality, childbirth, breast and ovarian cancer, hysterectomy, as well as the pain resulting from women-oriented work performed in our society.

Citing numerous studies, Sullivan *et al.* observe “there is a growing literature suggesting that gender is an important determinant of pain experience” (Lautenbacher & Rollman 1993; Levine & De Simone 1991; Unrub 1996, in Sullivan *et al.* 2000, p. 121), and “the findings of several clinical and experimental investigations suggest that women experience more frequent and more intense pain than men” (Crook, Rideout & Browne 1984; Lautenbacher & Rollman 1993; Taylor & Curran 1985, in Sullivan *et al.*, 2000, p. 121). Based on the experiences of chronic pain shared by the women in this study, I wonder if such pain exists under the veneer of many

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women's public self, for "women differ from men in their behavioural responses to pain" (Sullivan *et al.*, 2000, p. 122).

While pain takes many forms, I can only speculate that chronic pain has not emerged in the discourse of learning for a multitude of reasons, which may include:

Women accept chronic pain and do not identify pain as noteworthy in their learning experiences because of social expectations of women.

Social science researchers do not ask women about their lived experiences with chronic pain.

Women do not have language to articulate the experience of chronic pain in their learning (DeVault, 1987).

Although an interconnection of chronic pain and curriculum does not appear explicitly in the literature, Bauer and Shea (1999) engage in a discussion of inclusive learning for learners who are physically and learning disabled, but this discussion does not extend to learners experiencing chronic pain and who function without direct assistance. Even an understanding of the physical learning environment – the physicality of time and length of classes, classroom equipment, curriculum delivery, and workloads – for learners with chronic pain is absent in educational literature. I located several studies of women's lived experiences with pain that are based on narratives and phenomenological interviewing, but these studies are unrelated to learning environments (Kelley & Clifford, 1997; Schlesinger, 1996). As Howell states, "a gender-sensitive theory based on the understanding of the relationships among these processes has not been formulated" (1994, p. 94).

From the lived experiences of women, we may learn a great deal about chronic pain and how such pain influences what women learn and why.

This begs the question, where does pain fit into curricular discourse and curriculum delivery?

Chronic pain as a new voice on the learning landscape

This study helps to place women's chronic pain experiences within a larger landscape of meaning, purpose, learning, and self-determination. Voicing experience as women brings important insights to the field of education, for such knowledge serves as the basis of theory generation and potentially, curriculum development. One of the most significant contributions Christina, Tina and Giustina make to research is in teaching us about chronic pain, and the role chronic pain has in defining every aspect of their lives and their learning.

As Peolsson *et al.* state "learning to live with pain includes a process where one learns to develop different routines in everyday life and knowledge in terms of awareness" (2000, p. 122). The lived experiences shared by these participants give rare insights into the challenges some women face day-to-day. Based on this study, I believe Christina, Tina and Giustina are truly "agents of knowledge" (Harding, 1987, p. 4).

Like Christina, Tina and Giustina, the individual voices of other women must come to the fore to address the gap in the existing educational literature. I believe a theory about women's chronic pain and returning to learning can only result from further in-depth research. A much larger participant study may generate greater understandings and implications for such a theory which would be woven into the stories of women and their experiences of time, space, body and relationships with others (van Manen, 1997, p. 172). There are many opportunities to explore questions of chronic pain and learning. For example: Are the experiences described in this study unique to these three women? Do women in chronic pain experience more than one form of pain? Are there general patterns and

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understandings of chronic pain and learning shared by women cross-culturally?

This study demonstrates how applying a methodology like hermeneutic phenomenology can generate unexpected results and bring forward findings about lived experiences previously ignored. While the sample size of this study limits the generalizability of the findings, awareness that chronic pain can be causal in returning to learning warrants further research into the lived-learning experiences of women with chronic pain.

Christina, Tina and Giustina offer another view of the world from their perspectives of chronic pain, and the dialectic of pain offers a new lens onto learning, moving beyond the current boundaries of educational thought. We need to learn more about the concept and meaning of chronic pain in women's lives, "to shed light on how [women] actively explore their pain in their everyday life, its relationships to their actions and to factors in the physical world around them"

(Peolsson *et al.*, 2000, p. 115). I believe the interconnections of chronic pain and returning to learning constitutes an emergent area of research in the field of education. Chronic pain brings a new voice to the learning landscape, and it is within the lived experiences of chronic pain that our dialogue may begin to develop curricula that are sensitive and aware for all.

About the Author

Anita Sinner is a PhD student in Curriculum Studies at the University of British Columbia, Canada. Her interests include arts-based research, women's lived experiences, and the social construction of identity and place. Anita teaches art in the Teacher Education programme and she is also an exhibiting photographic artist. Anita has participated in local, regional, national, and international exhibitions, and her images have appeared in commercial and promotional publications.

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