The Experience of Living with Chronic Joint Pain

Patient Engagement Research Study Report

Marlyn Gill, Mary Sheridan,

Nancy Marlett and Svetlana Shklarov

Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis Care in Alberta

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The Experience of Living with Chronic Joint Pain

Introduction

This qualitative study has been undertaken to fulfill the requirements of an internship in the *Patients Matter* Project[1] and is one of three studies completed at the request of the Bone and Joint Strategic Clinical Network. *Patients Matter* is an innovative research project where patients are taught to engage in qualitative research with other patients. At each step of the way students are advised and closely supervised by two University of Calgary instructors – professor Nancy Marlett who conceptualized the project, along with Svetlana Shklarov, and mentored by Mary Sheridan, who has previous experience of the innovative methodology through her work with the *Grey Matters* Project (Marlett & Emes, 2010). Each student or student group had choice in the specific topic to be researched, although all had to be related to osteoarthritis. The first author (Marlyn Gill) joined the project after experiencing a glitch in her clinical pathway toward surgery, deciding to become part of the solution rather than simply registering her complaint. She has a 35-year history of osteoarthritis (OA) in multiple joints, experiencing increasing pain and decreasing mobility. Since starting the study she has had a hip and a knee replaced. Mary who joined Marlyn in the research is in the early stages of osteoarthritis.

Initial discussions in the *Patients Matter* group revealed that there were many people with a long history of increasing joint pain and that most did not appear to meet the criteria usually cited to explain chronic joint pain. Old age, wear and tear, excessive weight, over-exercise, injury, or other factors did not seem to be wholly responsible and, as the conversation expanded, it became apparent that people in the group believed that chronic joint pain, whether undiagnosed or diagnosed as OA, was not seen as a disease, and that the pain and disability they endured were often dismissed. We became curious about these perceptions and decided that the focus of our study would be the experience of chronic

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[1] The *Patients Matter* Project has been completed in partnership between Alberta Health Services and the University of Calgary (Community Rehabilitation and Disability Studies and the Institute for Public Health). The project was funded through a two-year grant from the Canadian Foundation for Healthcare Improvement (CFHI).

joint pain. We wanted to shed light on the experience of patients living with a disease for which there was no cure and to bring the reality of living with OA to the attention of both the medical and general populations.

It should be noted that, as participants began telling their stories in the first focus group, they chose to relate their experience of chronic joint pain from onset to the present time. In our proposal we had set out to study early untreated joint pain. It became obvious that to focus on such a narrow time frame cut off participants from sharing the depth of their experience. They wanted to share the entirety of their lives with the researchers and we decided, in consultation with our academic advisors, to expand the study to include experience from onset to the present time.

Background and Literature Review

This study explored the experience of people living with chronic joint pain. It is a qualitative study as befits research into an uncharted area since there is "no a priori theory or hypothesis" (Lincoln & Guba, 1985. p. 43) on which to base a quantitative study. It also facilitates an understanding of the participant's social construction of their lives (Glesne & Peshkin, 1992).

Previous quantitative research has focused on joint injury, fatigue and psychological issues such as depression and anxiety associated with joint pain (Hawker et al., 2008a; Ratzlaff & Liang, 2010), and Canadian research on osteoarthritis has used a biomedical model to study OA in communities (Hawker et al., 2008b). Little, if any research has focused on the experience of the whole person living and coping with chronic joint pain. There is evidence that these experiences are widespread, because many people with joint pain do not seek early medical intervention and, if they do, their condition is often misdiagnosed or inappropriately treated (Marra et al., 2007). As noted in the introduction, we became interested in this area after multiple discussions with fellow students in the Patients Matter Group as well as comments by participants during practice focus groups and interviews. We heard that medical response was often unhelpful and hat chronic joint pain was often attributed to aging, wear and tear, or over-exercising, Research conducted by Hawker et al.

(2008a) and Marra et al. confirmed the existence of that trend, but did not explore the breadth and depth of patients' experiences or the complexities of interactions encountered by individuals living with chronic joint pain. We hope to uncover the richness of these experiences and interactions. Lohmander (2000) suggested that not only patients living with OA need information, but also the medical community equally needs information about the experiences of people living with OA.

As students in the *Patients Matter* Project we used the Patient Engagement Research (PER) methodology (Marlett & Emes, 2010) integrated with a phenomenological perspective as outlined by Patton (1990), Bogdan and Taylor (1975), Lincoln and Guba (1986), Kirk and Miller (1986), and Berg (1989). Since we engaged in a qualitative exploratory study the exact number of participants was unknown (Mason, 2010) and, as noted below, we chose to go beyond the theoretical saturation (Glaser & Strauss, 1967) point in the interests of depth and richness.

Engagement Methods

This is one of three studies that are breaking new ground in the qualitative research field. For the first time, as far as we have been able to discover from a literature search, patients with a particular disease (osteoarthritis) have been intensively trained to engage in research with fellow patients. Please note the language, which is intentional, as the level of engagement we were able to reach was remarkable. Comments such as "I'm excited to know they are actually doing something apart from surgery and I am pleased to see they are studying what it's like. I get pooh poohed – everyone has arthritis (I am told). I like I can share with you, you understand" (251),[2] were repeated time after time by the participants. What we came to realize was that there was a different quality to the research; we were treated like comrades in arms and allowed into a private world that few researchers could have accessed. Participants' responses, "It is really exciting to talk to someone who gets it. I'm young to have severe arthritis and I don't talk to someone who gets it like you do" (371), and "It has been validating talking with you. Sometimes I feel I'm just whining and I

[2] Numbers after each quote indicate the line number in each participant's interview transcript. Because of the ethical requirements, we preserved the anonymity of participants' quotes.

don't feel that with you" (253) exemplify the comments we received and the beliefs that the participants held. Peer-to-peer research opened doors into their lives that few had entered. We moved from being interested researchers into an almost charmed space where peers were sharing their experience of lives changed by severe joint pain. Whether we met our participants in their homes, a Tim Hortons, or any of the other multiple coffee shops or restaurants we used, there was a sense, once we had got over the necessary preliminaries, of being two people enclosed in an intimate capsule, oblivious of their surroundings sharing the difficulties and joys of their lives. This was a new experience of research. One always strives to engage with participants but we reached a new level of disclosure and understanding.

We also came to realize, as we listened to our participants, that we were being invited into their world to hear and understand their reality. Not only were we engaged in peer-to-peer research, we were embarking on journeys, hearing stories with a phenomenological perspective, a perspective that asks "what is the structure and essence of experience of this phenomenon for these people" (Patton, 1990, p. 69). Because of our shared phenomenon, we were privileged with information few others would be given. This could have caused problems with keeping bias out of the research had we not been rigorously trained to be alert for this possibility.

The research study's design followed the SET COLLECT REFLECT structure outlined in the *Grey Matters* book (Marlett & Emes, 2010), using engagement techniques only possible in peer-to-peer research. As noted we used a phenomenological perspective in the data collection. The realities of the participants were explored within the SET COLLECT REFLECT structure, explained in this section, using the guiding questions produced by the SET focus group (see below). We used these questions at cognitive and emotional levels to gain an understanding of the experience of living with OA, to uncover basic elements that may or may not be common and to establish any patterns that were evident (Bogdan & Taylor, 1975; Patton 1990). One may assume that there are "essences to shared experience ... core meanings mutually understood through a phenomenon commonly experienced" (Patton, p. 70).

In our proposal we had posited the use of the Sense of Coherence Scale (Antonovsky, 1987) to give us more information about the participants. We received a special permission for the use of the scale from the Center on Salutogenesis, Trollhättan, Sweden. We applied the scale with all participants of the study. However, it quickly became obvious when we approached our analysis of the data that the information gained was not amenable to the methodology outlined in this report. We intend, at a later date, to analyze the data and publish the findings in a separate report.

We have protected the confidentiality of the participants by assigning them code numbers (see Table 1). All identifying data such as consent forms, demographic information and SOC scores are stored separately from all the raw data and analysis.

We used the PER method of SET COLLECT REFLECT outlined in *Grey Matters* (Marlett & Emes, 2010). We had 46 participants in the study, all self identified as having experienced joint pain (the main selection criterion). Participants came forward in response to an e-blast from the Arthritis Society, an advertisement at Living Well programme sites, advertisements in the Calgary Herald and community newsletters, a request for participants in an apartment complex for residents over 55, and word of mouth from participants. The age of the participants ranged from 28 to 82 and the age of onset of joint pain ranged from 12 to 76. There were 10 male participants and 36 female participants.

Table 1
Study Participants

Code #	Gender	Age	Age at Onset	Education	Diagnosis	Ethnic Origin	SOC Score
F1	Female	52	35	College Diploma	OA	Caucasian	68
F2	Female	47	35	University Degree	OA	Caucasian	69
F3	Female	64	35	High School	Arthritis	Caucasian	53

F4	Male	64	30s	High School	Arthritis	Caucasian	51
F5	Female	50	early 30s	University Degree	OA	Caucasian	77
F6	Female	68	50	University Degree	OA	Caucasian	81
F7	Female	64	40	College Diploma	OA	Caucasian	60
F8	Male	79	45	Post Graduate	OA	Caucasian	66
S1	Female	30	27	University Degree	PA	Caucasian	50
S2	Male	63	50	High School	Arthritis	Caucasian	62
S3	Female	75	59	University Degree	OA	Caucasian	62
S4	Female	55	12	Some University	OA	Caucasian	51
S5	Female	58	50	Some University	None	Caucasian	71
S6	Female	71	60	College Diploma	None	Caucasian	76
S7	Female	53	50	University Degree	Possible Arthritis	Caucasian	38
S8	Female	55	30	Post Graduate	RA	East Indian	46
S9	Female	39	32	Post Secondary	None	Caucasian	74
S10	Female	50	23	College Diploma	Arthritis	Caucasian	49
S11	Female	77	60	Post Graduate	OA	Caucasian	68
S12	Female	63	early 20s	University Courses	OA	Caucasian	75
S13	Female	72	39	Grade10	RA	Caucasian	78
S14	Female	68	20	PhD	OA	Caucasian	85
S15	Female	74	70	College Diploma	None	Caucasian	78
S16	Female	81	20s	College Diploma	None	Caucasian	67
S17	Female	82	46	University Degree	OA	Caucasian	75
S18	Female	65	38	University Degree	OA	Caucasian	75
S19	Female	74	54	College Diploma	OA	Caucasian	68
S20	Female	41	30	University Degree	None	Caucasian	63
S21	Male	49	48	College Diploma	RA	Caucasian	75

S22	Male	70	55	Trade College	OA	Caucasian	59
S23	Female	68	40	Business College	OA	Caucasian	77
S24	Male	72	63	Grade 8	Arthritis	Caucasian	65
S25	Male	70	62	College Diploma	OA	Caucasian	80
S26	Female	48	33	Post Graduate	RA/ Fibromyalgia	East Indian	74
S27	Female	80	72	College Diploma	OA	Caucasian	73
S28	Female	60	56	University Degree	OA	Caucasian	72
S29	Male	78	76	High School	OA	Caucasian	78
S30	Female	70	40	College	OA	Caucasian	69
S31	Male	65	55	Post Graduate	OA	Caucasian	67
S32	Female	75	65	College Diploma	OA	Caucasian	87
S33	Female	63	mid 30s	University Degree	OA	Caucasian	66
S34	Female	55	20	University Degree	OA	Chinese	61
S35	Female	72	27	College	OA	Caucasian	71
S36	Male	49	44	Trade College	OA	Caucasian	71
S37	Female	61	34	SAIT Dip	None	Caucasian	64
S38	Male	43	22	University Degree	None	Caucasian	68

Note. In the first column, *F* indicates focus group participant, and *S* indicates survey interviewee. Abbreviations: RA – rheumatoid arthritis; PA – psoriatic arthritis.

The SET focus group component had eight participants who were asked two guiding questions: 1) What did you experience when you first realized you had joint pain (where was pain, what were you thinking about the pain, did you notice any emotions around the pain)? 2) Did you seek help or advice about the joint pain (whom did you ask, how helpful was advice, what help do you think you needed)? All responses were recorded and process notes taken.

It important to acknowledge that during the SET focus group the peer-to-peer nature of the research allowed an openness among 12 strangers (8 participants and 4 researchers) that was astounding. We heard of broken lives, shattered dreams, and fears around employment, as well as the day-to-day difficulty of living with joint pain.

The COLLECT portion consisted of 38 individual taped interviews lasting approximately 45 minutes each with five guiding questions derived from the SET data. Each participant in this section was interviewed once.

Guiding Questions:

1. What is the overall impact of joint pain on your life?
2. One of the findings from the SET focus group was that participants felt they had to hide their pain. Has this been your experience? Please explain.
3. Who and what has helped?
4. Who and what has not helped?
5. What insights will you take away from this interview?

The interviewer allowed the participants to outline their experiences of joint pain, using probes to clarify their stories. The open-ended format ensured richness of data as the participants were not merely responding to structured questions, but were describing their lives (Berg, 1989). Each interview was broken up into pieces of information, as in the strategy of "phenomenological reduction" (Patton 1990, p. 408), and all the pieces were numbered and examined for distinct elements or categories that make up the phenomenon, that is we coded the data (Patton). In our proposal we had estimated that we would need to interview 60 people. In fact, to our surprise, we reached theoretical saturation, meaning "that no additional data are being found whereby the researcher can develop properties of that category ... as he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated" (Glaser & Strauss, 1999. p. 61), at 15 interviews; we were finding no new emerging themes. We decided, in consultation with our academic advisors and mentor, to continue interviewing to ensure and augment the richness and depth of our findings. The data and emerging themes were reviewed by Nancy Marlett, one of our academic advisors, and our mentor, Mary Sheridan, to eliminate bias.

We employed several strategies to raise the credibility and trustworthiness of the study. The Patient Engagement Research methodology, in which patients are interviewing patients, means that the researcher is the instrument in the study. It becomes very important that any biases are noted (Bogdan & Taylor, 1975; Kirk & Miller, 1986; Patton, 1990). The interviewing and analysis were undertaken by Marlyn Gill and Mary Sheridan. Mary, unlike Marlyn, has early OA rather than advanced, severe OA, and had a different set of biases to contend with. Mary's bias was that arthritis and the pain are simply part of life and growing old. She balanced this with a healthy sense of curiosity about the phenomenon of chronic point pain. Marlyn balanced her potential bias of favouring those experiences similar to her own with healthy skepticism and an openness to rival experiences. We ensured that before identifying an experience as a theme, we had at least three sources (Lincoln & Guba, 1986). It became essential that we kept track of our responses to the emerging data to ensure the analysis was "clean."

The second strategy to raise trustworthiness and credibility is an integral requirement of patient engagement research. PER is a natural method to combine with a phenomenological perspective. As noted above, patient engagement researchers are in a unique position to engage with participants. In Marlyn's case, as she is visibly disabled by OA, engagement centered around the participants' recognition of a shared experience eliciting such comments as "if you don't have arthritis you don't understand. You have understood everything I have said. Your body has told me that as we talk" (191), "it's really exciting to talk to someone who gets it. I'm young to have severe arthritis and I don't talk to anyone who gets it like you do" (254), and "good to talk to someone who understands, I really don't have that in my life and I see that it makes a difference" (390). Mary had been diagnosed with early arthritis and shared this information with the participants. She brought her earlier experience of health an resilience research (Marlett & Emes, 2010) to this chronic joint pain study. She listened carefully to patient responses and worked closely with Marlyn observing her day-to-day struggle with OA and her experience of two related surgeries. Mary came to understand that the patients were her teachers. Learning from patients how to live with chronic joint pain allowed her to access the depth and richness that Marlyn was able to access.

Research colleagues examined the coding of the interviews to eliminate researcher bias and to increase confirmability of the results (Lincoln & Guba, 1986). We also kept returning to the tapes and transcripts to see if "the constructs categories, explanations and interpretations made sense and really reflected the nature of the phenomenon" (Patton, 1990, p. 462). We looked at the data from different perspectives to uncover the essence of the experience, and questioned the possibility of rival hypothesis (Berg, 1989). Since the PER structure calls for a REFLECT focus group, we were able to check that we had asked the correct questions and that the emerging themes were "recognizable as adequate representations of their own ... realities" (Lincoln & Guba, 1985, p. 314).

The REFLECT section of the study involved recalling the original focus group members and presenting them with the information gained from the COLLECT portion. As noted above, this is done to check that the researchers have asked the correct questions and that the findings reflect the focus group participants' experience. Four members of the original focus group were unable to attend, so we invited four survey interview participants to the REFLECT focus group. This worked well as we had enough of the original core group to make sure we had stayed true to the realities of the SET focus group and a representation from the individual interviewees to confirm the data presented. The group was asked to consider and give feedback on how we set up the COLLECT section of the study using the flip chart and process recording notes; what we had drawn from the SET focus group; how we got to the interview questions and what had surprised us. We then presented the data and themes and asked each member of the group to choose the five emerging themes that they believed were the most important explaining their choices.

The REFLECT focus group engaged in lively discussion around the data presented. Once more there was an openness we found quite humbling as group members used their lives to illustrate why the thought one theme was more important than the other. While the discussion remained civil there was a great deal of passion expressed as participants wrestled over the emerging themes and their components.

We believe that the methodology of Patient Engagement Research, which seeks to reflect the experience and reality of the participants by engaging them at a deep level to tell their

stories, melds well with the utilization of a phenomenological perspective. Each methodology supports the other. We combined an innovative methodology (PER) with an older more established phenomenological perspective. The difference in this study from a more traditional phenomenological approach is firstly, the potential to reach the depth and richness of the phenomenon, and secondly and more importantly, the questions asked all come directly from the sample of patients. The researchers, themselves patients, decide on an area to be researched, the SET focus group direct the next step of the study by showing the researchers which topics are of greatest interest. The researchers take this information and ask questions in the COLLECT phase around the identified topics. The REFLECT focus group decides a) if the researchers have followed the direction indicated by the SET focus group and b) if the emerging themes and their components accurately reflect the experience of living with chronic joint pain.

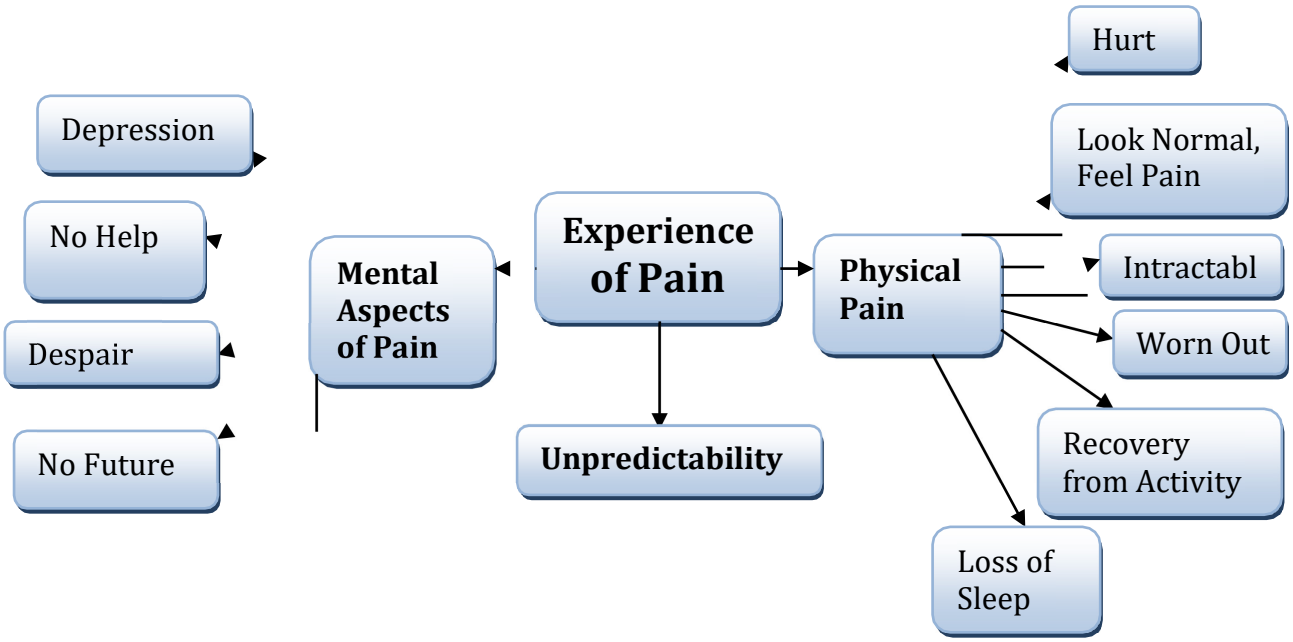
Articulating Experience (Findings)

We found five major categories or themes emerging from the data with 16 component sub themes variously attached to the major categories. Each major theme will be presented and discussed using verbatim data to allow readers to experience the breadth and depth of the reality that the participants are living. Each section will start with a diagram of the component parts of each major category.

The Experience of Pain

In this section we identified quotes that included references to pain and looked for the ways that people spoke about their pain and what they include in their descriptions (Figure 1). People seldom spoke of pain in isolation and we have separated it into the experience of the unpredictability of pain, the experience of depression that is related to pain and the despair that builds from the incessant, never ending pain with no future hope or help. The pain never seems to go away with a resulting loss of energy, loss of sleep and need for recovery time after any exertion.

Figure 1. Experiences of Pain.



The Hurt Itself

There are very few words for the pain. We heard, "everything just hurts" (20); "pain in my feet will strike" (300); "you just have to sit in pain and wait" (1227), and "pain in the lower back is pervasive" (702). While there are few actual descriptors of the pain, which is profound, people suffer doubly from the fact that people with OA look normal. There is no recognition of the hurt being endured. "You can look perfectly fine and feel like shit, inside you are dying" (220), "people just don't see a difference – you look like everyone else when you sit in a chair" (45). It is very irritating and dismissive "when you tell people you have arthritis and they say – I know, I've got this sore knee" (394). "People just don't understand you look normal but you're not" (458), clearly showing that "they don't understand the pain" (552), which is profound and pervasive. The pain is chronic and episodic and always alive in reality, memory, or as an expectation, so that some days "all I do is fight negative thought" (211), and "my God draining all of the time, it's so frustrating" (345). An unexpected aspect of the pain that appears to be a common occurrence is that during a

flare up there is increased colour in the face and a slight puffiness that decreases wrinkles, causing increased frustration, as "people tell me I look good when I have more pain" (446); "I hate it when people say I look so good. It means I'm having a flare up" (397), and a marked increase in pain is dismissed by others.

Pain prevents or disrupts sleep, increasing the loss of energy. "It can often be difficult to go to sleep because of the pain" (304), and "the pain affects my sleep so that there are times when I'm just not getting enough and my energy is lower" (1342) are common comments. Participants describe a constant nagging pain which is accompanied by intense episodic pain caused by a flare up that can be apparently without reason or as a result of increased activity. Recovery from an intense flare up caused by excessive activity results in "suffering a month for a day's enjoyment" (93) and the reality "that if I am active one day I will be in pain the next. I wish I didn't know this, but I do" (1252).

Despair

Despite an overwhelming intention to "continue with their lives" outlined below in the Standing up to Pain category, the experience of living with the pain of arthritis clearly engendered feelings of despair. The following quotes speak to the despair of loss of hope, rejection, the anticipation of a downhill degeneration. "There is really not much hope for the future" (1023). "I know it's going to get worse. It starts off with one knuckle ten years ago and then everything blows apart" (1206). The language used by participants, "I'm screwed" (1119), "it appears to be downhill from here" (1297), "if I didn't try to have a positive attitude I would just slit my throat" (1396), shows the depth of feeling in response to OA, a chronic disease that, as yet, has no cure. There is no "magic bullet."

Unpredictability

Especially in the early experience of arthritis pain, the unpredictability of when and where the pain will strike and intensify creates a major challenge, sometimes stimulating optimism and always confusion: "I hate the unpredictability. One thing will settle down then another part of your body will bounce up" (252); "the most horrific thing about this

disease is the unpredictability and it moves around. You wake up and you don't know what it's going to be like" (450); "Some days you almost think you got hit by a truck or something" (1033). All the quotes exemplify the difficulty patients have dealing with "pain that is unpredictable" (920), pain that "you never know when it will strike" (299).

Depression

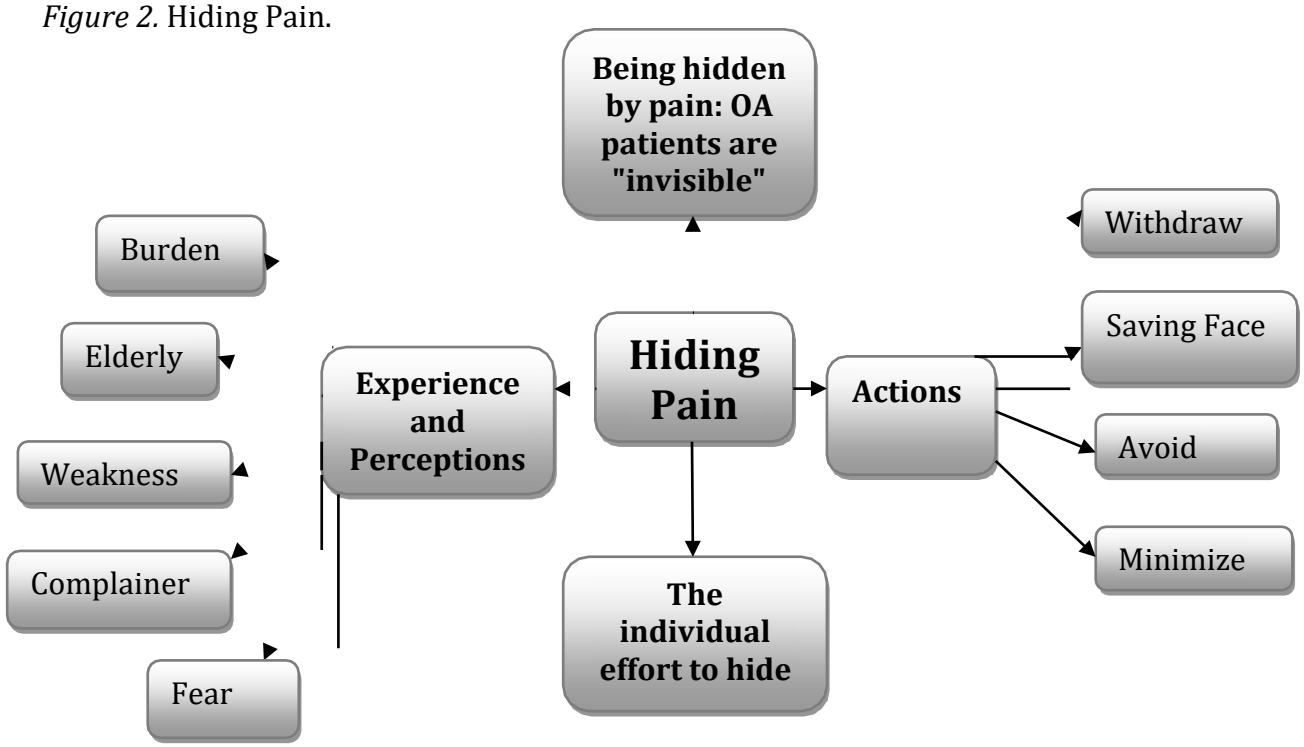
Pain and depression are companions, and depression seems to be an expected outcome of dealing with the reality of intractable pain. While we noted that comments about pain and depression generally go together, it was interesting to see that the pain itself was not seen as the main cause of depression except in the early stages: "I felt very depressed earlier in life. The depression came from the pain" (668). The depression seemed linked more to the feeling of futility, lack of hope and the unpredictability outlined above. In listening to the tapes and reading the transcripts, one is left with the impression that depression is partly due to the lack of recognition that the pain is real, "I hate going to my family doctor. I think she is tired of the same pain problem. Maybe she thinks it's all in my head " (1473), and that it is not real because it is not predictable, treatable, acknowledged or manageable. Those who have taken up the challenge to defy the common assumptions seem more able to "handle the depression." This huge task and how people do this is outlined in the Standing up to Pain section.

Hiding Pain and Being Hidden by Pain

Two themes emerged from the interviews in the responses to the question concerning hiding pain (Figure 2). The experience of hiding of the pain itself is a highly individual, unpredictable and fearful experience, and the experience of being hidden by the pain involves self-concealment or cloaking of the individual's social, psychological and emotional needs. The effort of hiding pain is a daily and debilitating task in itself for many patients who experience early joint pain. Being hidden by pain means patients remain cloaked to the world around them, including friends and family and work relationships, and even relationships with medical personnel. This cloaking can grow to the extent that

some patients become isolated in their pain. As one patient says, "No-one knows. No-one can see I have arthritis. I just don't tell them" (309).

Figure 2. Hiding Pain.



The hiding of pain can take place over long periods of time, in some cases for many years. The exhausting daily effort to hide the pain is seen by many patients as necessary so that they can hold onto jobs and/or maintain family and social relationships. Hiding the pain can mean that the patient's level of trust in self and in relationships with others is compromised and that information about the illness related to the pain is not shared. One patient reveals, "I've never told the kids or grandchildren" (101).

Fear of Being or Becoming a Burden

Some patients hide their pain out of the fear that they will be reduced to complete dependence on others, often family, because of their constant osteoarthritis pain. They fight a daily battle to keep from revealing their pain even to loved ones: "I won't let my children know how much pain I'm in" (224) and "I hide how havingto rely on others affects

me emotionally" (383). Patients find the experience of pain can prevent open and honest relationships with family members: "I try to keep my pain from my daughter because she gets upset and then starts to say you should do this or that" (1324).

Occasionally patients meet someone who is able to pull back the curtain of fear about being a burden. That person is able to convey her own struggle with pain, and the shared experience of hiding pain is revealed through body language alone: "You have understood everything I have said. Your body has told me that as we talk" (191).

Fear of Aging and Pain as a Sign of Weakness

One patient reveals herself as living in constant fear when she speaks of hiding the pain, "so I wouldn't look like a weak person" (605). Fear is palpable in the patient who reveals: "I don't want to appear sick and don't want to focus on the pain. It saddens me" (547). Fear can overtake the patient altogether and prevent any chance for improvement or recovery from pain: "I'm not going to tell anyone that one of knees is getting much worse. I can't cope with any more surgery. When my knee fails I guess I'll live in my wheel chair" (225).

Some patients experience fear of the pain as a sign of being and becoming elderly. "I never volunteer information about my arthritis. I don't want to be one of those whiney old people" (1122). Some young and middle-aged patients name the pain as the hallmark of aging: "Of course you hide the pain because you associate arthritis with elderly people" (219).

Fearing pain as a character flaw or a weakness has an impact for many patients as they try to continue to work and build a career: one patient speaks of hiding the pain at work "because you seem weak. You are trying to get a career going. Illness is perceived as weakness, as if they can't count on you" (222). Another took the attitude that she could not show any pain for fear of being seen as incompetent: "...in retail I couldn't show pain." To show pain might mean she could lose her position as manager, so she "had to grin and bear it" (608.) The fear of pain can also have a negative effect if you are seeking work: "If I were trying to get a job I might hide it" (480).

Many patients told of hiding the pain at work for years. One patient spoke of hiding in her office "shaking hoping no-one sees you because you can't write" (43). One spoke of being a truck driver and his elbows and wrists being "on fire" (1086) and another patient spoke of hiding the pain at school until "it just became too bad to do that" (980). Another tells of hiding pain "by standing at all day meetings ... until [her] knees froze" (603).

Fear of Being Labeled as a Complainer

Some patients emphasize that if you show that you have pain and talk about the pain, you risk being viewed as a complainer. "I don't let my customers know how bad it is. I don't want to be seen as just a bloody paranoid complainer" (1046). Complaining is seen as an anti-social behaviour which will deter others from wanting to have a social relationship: "I don't ever talk about it like at a party because you don't want to become that person whom people don't want to invite because all she talks about is her aching bones" (1255). One patient takes a stoic stance about her pain that invites another layer and kind of pain into her experience: "I'm not going to complain about it even when it is killing me" (1256).

Withdrawing, Saving Face, Avoiding and Minimizing

Many patients withdraw from social contact rather than explain the source of or reasons for their pain. One patient says, "I almost shy away from people" (148), while another tells of withdrawing completely from doing anything: "it's easier than explaining" (102). A sad participant tells of withdrawing from the meaningful volunteer work because of her pain: "I was a member of the Daughters of Jesus and involved in conferences and things and while it makes no sense, it's almost like airing dirty linen talking about it, and so I resigned because I can't count on it to be able to do it" (162).

Others try to ignore the pain, in some cases trying to save face, seeming to be deeply shamed by the experience of pain. One patient speaks of hiding her pain from her family: "My family knows I have joint pain but they are not really interested so we just ignore it" (275), while another tells of ignoring her pain by not limping: "I just focus on better days" (310).

Avoidance of activity or contact with others is common: "I avoid things that I know are going to create problems" (88) and "I stay away from people because they come up to you and say you look so good" (159). Others try hiding the pain from themselves and others by drinking. "When I first had problems working as an executive chef in the nineties, I tried to cover the problems. I think I drank to cope with the pain I was having in my back and feet" (978). Another says, "I keep stress inside and that makes it harder to talk about it" (512), while the comment "I almost shy away from people" (148) is a common tactic.

Some patients avoid discussing the pain with anyone because of the perceptions and judgments of others. One patient speaks of being overweight but being unable to speak about doing anything about this. Being unable to communicate can prevent a patient from ever finding relief from pain. "I don't tell them because part of you feels you're being judged because you're overweight" (38). Minimizing the pain is second nature to most patients: "I minimize because it's so frequent that I don't want to keep dwelling on it" (104).

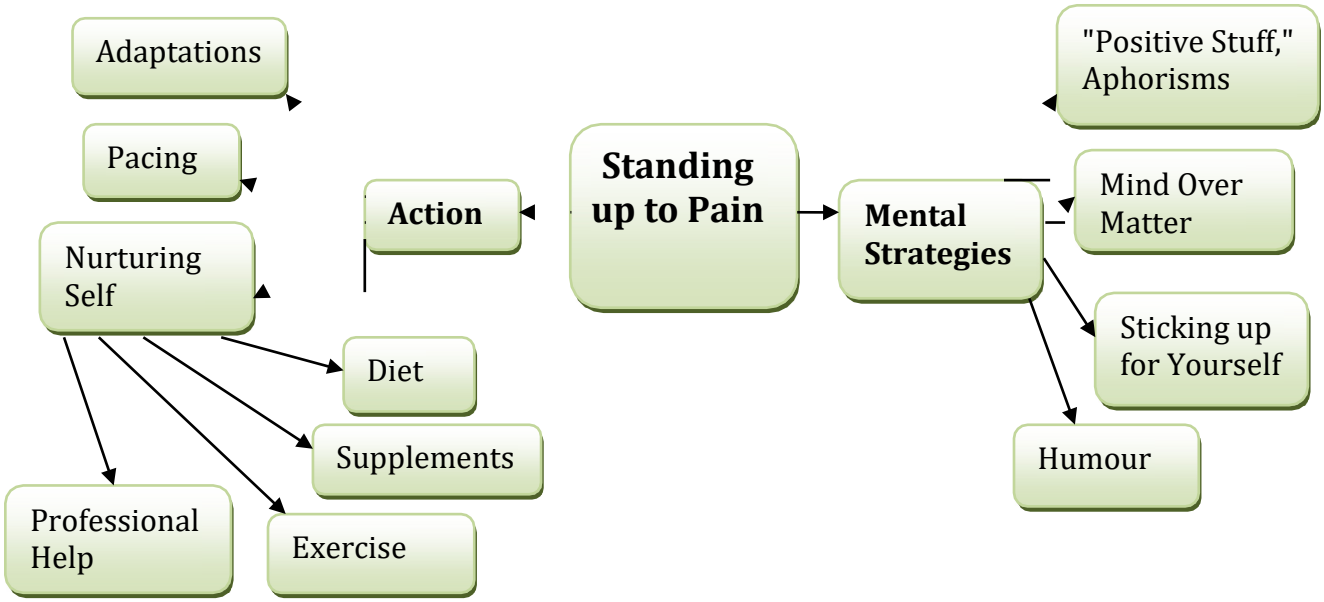
Being Hidden by Pain

Being hidden or feeling cut off from others because of the experience of living with constant pain is a parallel experience for many people who experience chronic joint pain. "Let's face it. You can't explain it. You have no diagnosis" (417). "People look at you differently when you have joint pain" (1286). Loneliness and social isolation is the cost of being hidden by pain. This isolation means patients are unable to communicate and have meaningful relationships with others: "For the first 7-8 years no-one would listen to me" (1193); "Some of my friends and relatives don't want to hear how much it is affecting me" (368). Patients being hidden by their pain sometimes feel invisible and even abandoned: "Being on a wait list to be seen, you haven't even made it to being in limbo" (370). Patients are cloaked from others in their pain because the symptoms are invisible to onlookers: "Unless you're with me every day you just don't know" (42). "It's not helpful that you don't look sick or ill. You're just in pain and no-one can see it" (369) are emblematic of the cut off arthritis patients experience. As one participant succinctly put it, "arthritis is just a run-around – symptoms but no proof" (75).

Standing Up to Pain

In this section we found examples of how the participants manage or cope with the physical pain so that they can lead their lives to fullest extent possible (Figure 3). We have separated these strategies into two sections: 1) the changes in thinking or mental attitude and 2) the actions they have taken to make positive changes in their lives to accommodate the increasing pain and decreasing mobility.

Figure 3. Standing up to Pain.



Mental Strategies

The mental aspects of change include what we term “positive stuff” i.e. aphorisms, the use of mind over matter to move forward and the importance of a sense of humour.

Aphorisms. These “positive messages” to the self seem to anchor the participants’ approach to dealing with the physical pain. Phrases such as you "keep smiling because you can’t beat it" (483) and "learn to accept and forge ahead anyhow" (536), as well as beliefs like "you are not ever going to beat this disease like you might with cancer but you can live

with it" (374), "pain will not hold me back" (838), and "you can't just give up – try to have a good attitude" (1461) appear to form a cornerstone and an almost tangible approach to living with OA. There is also the intangible spiritual aspect where we have been told "my faith keeps me going" (1175).

Mind Over Matter. Using the mind to overcome the pain and disability is a popular strategy. We heard it described as ignoring, rejecting ("I rejected the pain rather than hiding it," 835), overcoming, bearing ("I just tried to suck it (pain) up. I didn't want to make a mountain out of a molehill," 879), moving through, submerging ("I submerge pain. Going to damn well do what I want to do," 822), and getting acclimated to a certain level of pain ("I call it discomfort rather than pain. It's just you, you don't complain about it you deal with it and bear it," 1362). For multiple reasons, but mostly to remain even semi-active and independent, there is a strong belief that you can "think your way" out of the worst of your pain, at least temporarily. It also seems that people are prepared to carry on despite the pain and the knowledge that activity will probably result in increased pain once the activity is over: "I sometimes push myself to get things done. If you don't push yourself you don't get anywhere, but you pay for it" (237). "I don't let the pain get in the way of my volunteering" (308) aptly describes the determination to live as normal a life as possible.

Humour. There is a need to try to find humour, no matter how black, to deal with painful situations. This may be a defense against the perception that arthritis is not commonly perceived as a painful chronic disease or simply a belief that if you don't laugh you cry. The 39 year old woman who quips that she wants to tell people who say she looks good when she is having a flare up and her face becomes a little flushed and puffy, "get arthritis and you won't need botox" (435), and the sixty-two-year-old newly retired man who jokes to friends, "It's not the golden years, it's the rusty years" (99) are trying to make the best of their disease by inviting others as well as themselves to laugh at their situation.

Actions Taken

Joint pain as a result of arthritis forces people to make changes in how they live their lives. They adapt their former activities, they change the pace of their lives, they adopt new self-

nurturing techniques, they may become more self assertive in getting what they need and often engage in research of their disease to try to find answers that are not readily available. Most people found the internet sites and the advertisements for supplement confusing as they often seem to contradict each other.

Adaptation. Adapting to life with joint pain and the resulting lack of mobility and flexibility covers several aspects of the participants' lives. Their physical activity, lifestyle, safety, work-lives, and prospective futures are all affected. They have attempted to find alternates or adjusted what they were doing before the onset of joint pain rather than give in to the restrictions.

"It's mostly physical. I can't do aerobics, cycling etc. and I've had to move to swimming, yoga and walking" (392), and "I can't aquacize any more so I walk and walk. I walk for 45 minutes or an hour every day. It hurts but I walk" (1445) typify the determination to keep as active as possible. Walking, with or without aids, appears to be the most popular, as it seems to help loosen up the body: "In the morning to be able to function during the day I have to get a good hour's walk on flat ground. That gets me loosened up. My day is very painful if I don't do this" (1053). Even those who were not particularly active prior to the onset of OA "have learned to do exercises since diagnosis" (673) and have made changes by learning new posture habits (871).

Many participants have found ways to continue with their previous physical activities and day to movement: "you don't give stuff up – you just try to be a bit easier when you do it. I have to curl with a stick now and I skip so I don't need to sweep" (1039), or they have simply accepted that they cannot engage in exercise at their previous intensity be it bike riding, "I've had to adjust bike riding for shorter periods" (595) or hiking, "I hiked a lot, but I'm not doing such big inclines because of the knees and hips" (1238). "I've had to alter the way I do things" (1246). Simple things like going up and down stairs sideways, wearing orthotics or having "canes everywhere in house, one on each level, bought 3 small vacuum cleaners, one for each level of house" (733) are all adaptive strategies that make life easier.

Safety, mainly avoiding falls, is often something OA patients have now to factor into their lives. Adjusting to the use of "safety rails and a raised toilet seat" (235), "using ice grippers" (594), walkers (734) and generally learning "to adjust things so I am not injuring myself" (588) become familiar tasks that increase as mobility decreases. Use of aids and learning to make adjustments and "not put huge pressure on the self" (1174) appears to be difficult for many patients and is often dismissed as unnecessary until they are forced by disability "give in." This aspect is addressed in more detail under the Hiding category.

Those patients who work often have to adapt either what they do or how they do it. As we noted in the Pain section, depleted energy is often an issue. Many, such as the woman who told us "I had to quit the corporate work and I now have a home-based business" (461), or the man who "had to cut down working to three days a week" (464) face huge adjustments in working conditions and in pay. Many others try to work from home as much as possible. Some change their work routines, like the schoolteacher who "had to modify teaching behaviour. I used to get up and down on the floor, lots of bending and crouching. I began to sit on a stool and used big cushions whenever I sat" (874).

Finally, many try to think through the adjustments they will have to make when their OA becomes much worse. Plans to reluctantly move house, "probably get a Stairmaster" (144) and look ahead "at what changes we will have to make to stay in our own home – make it wheelchair accessible – move our bedroom downstairs" (1281) are especially common in those patients who have experience of the disease in their families.

Pacing. OA patients, as we alluded to earlier have very limited energy and learn to pace their lives. They know that if they expend a large amount of energy on any given day they will have to allow some catch up time. "Weekends are dead days as I'm trying to get my energy back. If I go out with friends I need time to recover, if I do something extra – I need time to recover" (1143) recounted a woman who lives alone and generally works five days a week. Others pace, themselves by doing little pieces and resting in between bursts of activity. "I have to bring my groceries in a few pieces at a time because it's too heavy" (1420), lamented one participant who explained she brought in the frozen food first and

often left the non perishables till the next day to bring in. Shopping had exhausted her and so she took her time unloading and putting her groceries away.

Nurturing Self. Most OA patients are aware that there is no cure for their disease and turn to self-nurturing strategies to help ameliorate pain. The two most popular ways are accessing professional help from chiropractors, physiotherapists, massage therapists, acupuncturists, naturopaths, and other practitioners and becoming involved in exercise programmes such as Tai Chi, yoga, swimming and aquasize. Unfortunately, while patients attest to the helpfulness of their chosen support, they also find using these services very expensive. Few patients can utilize professionals as much as they would like and some exercise programmes are also very expensive or difficult to access. "Using a chiropractor and physio is useful but it's very expensive. We don't have good plans so there's an impact on our budget and it will only get worse" (272) and "physiotherapy has helped, I would do more but it costs too much" (762) are typical comments from those using such services. More disturbing is the large number of patients who don't even try because of limited funds: "I've thought about a physiotherapist but it costs too much. Really nothing and nobody has been helpful with the pain" (318) is a refrain heard all too often.

Indeed, with respect to self-nurturing through professional help and exercise programmes, we found only one participant who believed he had been highly successful. This man was a proficient researcher and was financially secure enough to be able, as he said, to "go to a physio and get exercises and then I did a lot of research and added this and that. I got into yoga and I use the stretches. I joined a class for a while but now I do things on my own. I have a treadmill, rowing machine – a little mini gym downstairs" (1368). This participant added that if he feels he is not doing something correctly he goes along to the appropriate professional to make any necessary adjustments.

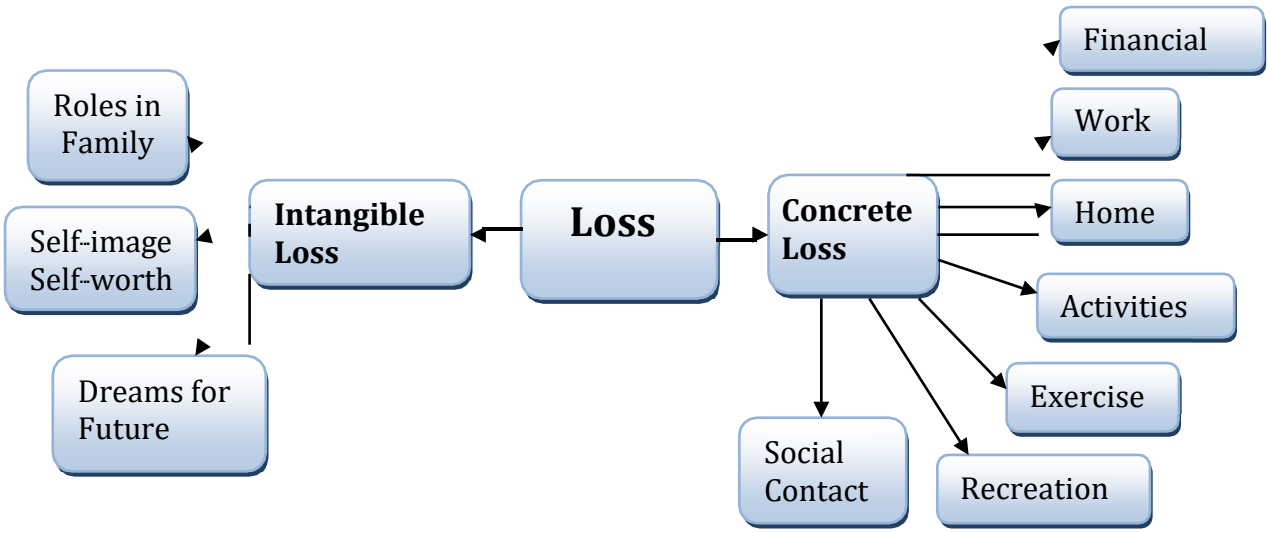
Less popular, and sometimes costly, is the use of supplements and dietary adjustments. Vitamins, fish oil and glucosamine are among the most used, while others aver that "losing weight is important, on Weightwatchers diet I lost 16 lbs with focus on fruits and veggies and keeping record of calories" (731) and that "diet matters, I stay away from the nightshade vegetables like tomatoes, peppers, potatoes and mushrooms" (949).

Sticking up for Yourself. In light of the difficulties faced by OA patients outlined in other sections, the ability to be vocally proactive and try to get what you needed was seen as an enormous bonus and an important self-nurturing skill. We were told how important it was "to be able to go to bat for [one]self" (577), "to learn to speak up and question the doctor" (578), and "to learn to insist on answers and express [one's] opinions" (579).

Loss

In this section we are looking at the differences in life people experience with the onset of joint pain (Figure 4). The predominant theme is loss: "there hasn't been an area in my life that hasn't been touched negatively by joint pain" (196), "there is no piece of life that is not affected" (1080) and "I really did not understand at a conscious level the differences and losses in my life arthritis has caused" (192) accurately reflect the wide ranging losses OA patients live through. Not only are there the concrete losses involving work, home, financial security, familiar life-long activities, recreation and social contact, there are also the less well-defined but important losses in self image. Roles, dreams for the future, how people define themselves are all subject to loss. All of these losses often bring depression and anxiety in their wake.

Figure 4. Loss.



Concrete Losses

Concrete losses tend to start small and grow over time as the pain and mobility issues become more severe. People note that "over time [they] have had to limit activities" (826), often with extremely negative results. As we noted in the Pain Section, there is no end to arthritis; you don't die from the disease, it can just keep progressing and piling up losses. "The key with OA is it's not going to go away and it's not going to get better" (572).

Losses at Work. Patients find that work becomes increasingly difficult as the disease progresses, with losses varying from being on disability, "at 53 went on disability but had pain before 40" (654), choosing early retirement, "I had reduced energy at work and so I retired early" (81) to those who simply find the work becoming difficult and less enjoyable, "I work two days a week and I'm more tired than I should be I have to lift stuff and I have problems getting back up" (410). As noted in the Hiding Section, participants tend to conceal their OA from employers as long as possible and some of the experiences seem to ratify the sense of that decision. Two participants variously noted that there was a "possibility of being fired – I'm costing them money" (23) and that her employers are not treating me well any more – "I think they moved me to force me to quit or fire me" (71), while a third cited problems with an "insurance company [which] was downright nasty. You are at your weakest point and they prey on that and lay games with you" (249). Additionally, a self-employed man noted, "when I was laid up I got people to do the work for my customers and a lot of them have not come back. My biggest customer did not come back" (1043).

Participants who were able to keep working, as noted in the Standing up to Pain section, had often to adjust both how they work and the hours they work: "I have had to alter my hours at work and how I do my work. I can't do demonstrations in class any more so I get one of the kids to it" (968). Some find it difficult to get to work, "I have to walk 5 blocks to work and some days it hurts and I'm exhausted by the time I get there" (270), while others choose to focus their whole life on doing their job: "I can do a full time job but that is all. I go home and crash and weekends are dead days as I'm trying to get my energy back" (1142). Work is often one of the cornerstones in a person's life and patients with OA

encounter losses at differing levels in this aspect of their lives: "I've had to give up my stained glass and I loved it – I am a creative person and it was wonderful. I worked 5 days a week – I just try to find other things to do – I gave that up 15 years ago" (1386).

Financial Loss. Joint pain has resulted in financial loss no matter whether employers were sympathetic and helpful or, as seen above less than helpful. "There is a financial loss as I can't work the hours any more, but at least they kept me" (975) and "I lost a lot of money both not working and on my pension" (149) are examples of participants' experiences and there is a recognition among those who retired early that they have probably lost pension money. Opting to start a home business does not necessarily lead to financial success as we are told, "this has been financially very difficult I have no RRSP's left. Yep I'm done. I will have to work for the rest of my life now" (466). On the other end of the spectrum there is the hopelessness engendered by the 30 year old who laments, "I had a great career and now it's at a standstill" (8). Fear of poverty lurks in the background as we hear, "I don't want to live on cat food when I am retired or have to sell my home. I hide how difficult it is for me to type some days. That could be the end of my job and I need to build my pension up" (223). Looking at the average and median age of onset of joint pain, it becomes obvious that loss of earnings and pension money are major concerns especially among the younger joint pain sufferers.

Loss of Home. Participants with moderate to severe joint pain, especially those who know they are experiencing worsening of the disease in their legs and feet, are concerned that they may have to move out of a much loved home. Two of the younger participants have had to move because of location; one from an acreage back to the city close to parents, the other moved "downtown closer to work so it costs more to live here" (1146). Bungalows and single level condominiums are the popular choices as there are no stairs. However, moving is not without difficulties. "I live in a four level split and we need to move to a bungalow. We're not keen to move as we've been in our house for 32 years and it's going to cost me $15,000 to sell the house. We don't want to leave this area. Our friends are here, our doctors are here, we know the stores and they know us" (1058). This would be a major relocation for the couple who have been married for over 50 years and whose children live

close. Across the board there is a disinclination to move for multiple reasons: "I love my house but one day I might have to think about moving" (1314) and "my husband and I are thinking about a condo, even though we don't like it, but we don't have any choice" (1347) are typical statements.

Loss of Familiar Leisure Activities. Joint pain, which can strike at any joint in the body, severely curtails people's leisure activities. Patients can no longer enjoy hobbies, sports or attending events and venues that have previously filled their time with enjoyment.

Hobbies. We were told, "many things in my leisure time [have been] affected" (514) and that the "result is depression and giving up hobbies that meant a lot to me" (137). Joint pain meant that people could no longer spend their relaxation time in life-long fulfilling pursuits, but had to give up on simple pleasures like baking ("loved baking but could overdo this so I stopped," 658), cooking, sewing and knitting ("I used to do a lot of crafts, knitted, sewed, macramé, I can no longer manage that," 1383). Creative pastimes such as sketching ("very hard to give up sketching," 666), stained glass ("can't cut things up – it just kills me," 2181), even doll making, a life long passion evidenced by the display in her home ("I made dolls right from scratch – I can't do that now," 138) become off limits, while dancing ("I was dancing a lot and then I just couldn't," 329), gardening ("I've had to give up gardening," 84), and camping ("I will have to give up camping," 476) become pleasures of the past.

Sports and Exercise. The most obvious recreational losses occur in the sport and exercise area. People in the study variously discussed being forced to give up running, jogging, skiing, playing ball, hiking, mountain climbing, biking, swimming, waterskiing, badminton, cricket, aerobics, basketball, golf, squash, and even walking creating sentiments like "will I ever be able to get back to what I love to do? " (32). Unfortunately, these people not only lose an activity which they enjoy, they become more sedentary and encounter problems such as "I don't exercise any more because it's tough when you have joint pain and if you don't exercise you gain weight, it's just a circle" (288) and "I miss going to exercise class. You don't put as much effort in when you are alone as you can't see what everyone else is doing. You don't try to keep up with the other people. You just say oh I'm tired now"

(1309). For most OA patients painless exercise is an impossibility. As one man put it "I know people say exercise is good for arthritis, but that's someone who does not have it speaking" (121) and the sentiment "mobility is the biggest thing just feeling free to get up go for a walk a bike ride or a hike. Knowing something is going to hurt is kind of a deterrent to doing it" (78) is a common theme.

Attending Events and Venues. Going to the theatre and concerts, Flames and Stampede games, or even going for a stroll at the zoo become difficult for many patients. Some even have to give up shopping in malls, "I don't have the stamina to go shopping in a mall – my upper thigh just starts burning and I really can't move" (1002).

Loss of Social Contact. Patients did not realize how much of their leisure and recreation time was spent with friends who had similar interests so it came as a surprise that the less they did, the smaller their circle of friends became. There is a "huge impact on [one's] social life – people just don't understand. You look normal but you're not" (457), "I regret that my social activities are reduced. My circle is getting smaller " (862) and "I lost huge social contact as all my socializing was around dancing. I'm out of the circle now. Everyone I used to dance with has gotten a lot better. I won't go just to watch" (336/7) are typical comments from arthritis patients. Even those who try to go out find it difficult to fit in, for example, "my husband tries to understand why I don't want to go out in the evenings and we often leave early" (427) and "we go to a lot of family reunions and I can't play horseshoes or lawn bowling and you feel a bit left out" (1083). Vacations are severely affected as we are told, "I couldn't ski so we haven't gone on another ski holiday with friends" (415), "I don't go on vacation with those old friends from climbing as I can't do the things they want to do and I don't want to hold them back, so that's kind of out of the picture" (1305) and "I can't go on those golfing trips where you play five rounds in three days – I don't see those guys" (1365).

Intangible Losses

Loss of Self-Image. The disabilities caused by arthritis appear to have a negative influence on how people perceive themselves. There are significant perceptual losses in the areas of

roles with respect to family, their faith, self-mage and future dreams. People's lives become more constrained and they often lose their sense of self worth.

Loss of Role in Family. The resulting pain and loss of mobility caused by OA can cause losses in spousal relationships. Both men and women noted that they lost companionship: "my wife is very active, she runs marathons. I tell her I don't want to drag you back and I can't go as fast as you like so it does affect our relationship" (96), "I can't walk with husband any more . He walks too fast and leaves me behind" (266), "I can't keep up with my wife when we are biking, especially on the hills" (1115) are all examples of losses in mutual activities and, as some noted this can cause problems in the relationship. Others observed that their partners are sometimes unhappy with their inability to "carry on as normal" in that "he looks at you like what's your problem – he doesn't get it" (57), or "my husband teases me about keeping the chiropractor in business" (293). It seems that in spousal relationships, especially if only one partner has joint pain, the OA patient appears to believe they are somehow "letting their partner down" by not managing their pain.

Being a mother with joint pain, especially when there are young children seems to be particularly difficult. One mother asked us "how do you help your kids when you can't help yourself" (29), while others told us, "It's hard being a mum with three young kids. When my youngest was a baby I had problems picking her up. I can't pick any of my kids up and the youngest one is just four" (399-402), and "I'm a single mom and my children are dependent on me" (455). The distress caused by the loss of ability to mother their children is palpable.

Grandparents too are negatively affected by their inability interact with their grandchildren in the way they want. "I can't do what I want to with my grandchildren. I can't lift and carry my great grandchild. You love your kids and it really affects you" (1064) and "I can't throw a baseball with the kids" (90) are comments we heard from the participants.

Loss of Connection to Faith. For some participants the inability to be able to continue following their lifelong religious pursuits causes sorrow and they see themselves as not being connected to an important part of their lives. We were told, "I have lost the

community in pastoral care that surrounded me" (147) and "my religion is around giving to the community it hurts that I cannot do this properly" (385).

Loss of Self Worth. As has been noted above, the loss of ability to be a “good” mother, grandparent or spouse has negatively affected patients’ feelings of self worth. When people can no longer perform as they used to, or as they want to, they start to see themselves as less than or lacking in some important way. "I am no longer part of 'the club’ [of half marathon runners]. I’m walking on the pathway and runners don’t acknowledge me like they used to when I was running. I’m sad about that. I miss the camaraderie and pathway etiquette of runners. I no longer have bragging rights to the marathons and half marathons. I no longer have an accomplishment I can be proud of" (1108-13). This participant not only lost the ability to run, he lost an important part of his self identity. He not only lost the "endorphin high" (1104), he lost belonging to a group that, in his mind, defined him. Whether it be as a volunteer, skier, mountain climber, cook, or any of the multiple losses outlined previously, every participant has lost part of how they lived their lives and defined themselves.

Loss of Dreams. Last but not least is the loss of dreams for the future. "Life might have been very different if I hadn’t been in pain, might have gotten more involved in things" (611) and "life is just not what you were expecting" (17) reflect sentiments expressed by the participants. The feeling of grief for a lost future was expressed, for example, by one of the participants who lost her future as a bank manager; another had to abandon her plans to pursue her interest in dancing when her child left for university, while traveling with her old rock-climbing friends became impossible for yet another participant as she could not keep up with them no matter the activity. Sadly, many "have just withdrawn from doing things rather than explaining" (101) or finding alternates.

Gaps in Service Perceived by Patients

"Do you know why I did this study, and I looked into it carefully, as I have never entered any others, I saw the words 'untreated joint pain.' For thirty years I have been going to doctors and am still untreated" (1475). This woman’s experience is replicated by the vast

majority of the participants who had either been diagnosed with OA or who remained undiagnosed. The only bright light was provided by two of the participants who had RA: "I have a great doctor and get everything I need from conversations, from physios, to meds and lifestyle courses. I get almost an hour with the rheumatologist if I need it" (986). The two quotations cited highlight the differences in treatment received by RA and OA patients. OA patients know there is no curative, or ameliorative treatment for their disease, but they also believe their physicians could be more helpful and involved in their disease. The comment "I got much better support for my cancer than I did for my OA and OA is painful, depressing and debilitating" (1407) sums up the belief that "doctors are not really interested in my joint pain" (317), and since there is no cure don't give "any advice about how to keep it from getting worse and what things to avoid doing. I think lack of advice has led me to do things that have made the arthritis worse" (1429). It is interesting to note that, while eight OA patients were more positive about their medical experiences, their comments were somewhat restrained, for example, "My doctor was helpful in that I got a diagnosis" (1371). Only two of the eight could report "doctor and I worked together to get medication that works for me" (177).

Patients are generally told to take Tylenol Arthritis, and when they say it does not help they have variations of this experience, "my doctor told me there was nothing he could do and that I would just have to suffer for the rest of my life" (1465). Most patients give up on medical help and turn, if they can afford it, to the professionals outlined in the Standing up to Pain Section. Most also believe that some of the services like physiotherapy, massage, chiropractic services and dietary advice, which appear to be helpful, should be available for OA patients and that family physicians could and should be referring patients to these services. "There is a need for a multidisciplinary team including physiotherapy, massage, etc." (778).

The overwhelming experience of OA patients in this study is "there has been no emotional support, no physical support, and no support for the future" (442). Patients report disinterest, feeling rushed and dismissed, being disbelieved, being refused pain medication and antidepressants and cite the need for "someone one can talk to on a continuing basis about your arthritis. It's sad when there is no follow up" (1409).

Summary

The findings of this study suggest that patients with chronic joint pain, which is attributable to osteoarthritis, are not well served either by the medical profession or the community at large. For the first time a forgotten and hidden section of the population allowed themselves to be accessible and shared their lives. We believe that the methodology used in the peer-to-peer research was an important key to unlocking beliefs, emotions, physical pain and its sequelae, as well as revealing the reality of the immense impact chronic joint pain has in all areas of the participants' lives. As we noted in the methodology section, a common bond of experience allowed the researchers to engage at a deep and meaningful level. Participants thanked us for undertaking this research and expressed relief at being able, most for the first time, to talk openly and frankly about their lives. For the first time they perceived that they were not being judged or dismissed.

The participants and the researchers hope that this study will lead to further patient engagement focus in research on patient satisfaction, quality of life studies, and patient reported outcomes measures. We also hope that it will result in a movement to educate medical personnel, alternate and support professionals, exercise programmers, and the community at large about the reality of living with chronic joint pain. This study has turned a small spotlight onto the plight of people living with arthritis, and it is our hope that it is only the beginning.

The Journey

Since this study is one of the first to utilize patient engagement research, it is important that we try to record the experience so that those who follow, new patient engagement researchers (PERs) and those who might wish to use PERs to obtain in-depth information about patient experience have an understanding of the process.

When it became apparent at the end of the teaching section of the internship that Marlyn Gill was the only student in her group who wished to move forward with the study, Mary Sheridan, the mentor, stepped forward as her partner in the research. This greatly

increased Mary's time commitment to the *Patients Matter* project but she quickly became fascinated by, and embroiled in the research process. Together they wrote the proposal, planned and ran the SET focus group, analyzed the focus group to decide on the guiding questions for the COLLECT interview section, interviewed the participants, analyzed the data emerging from the COLLECT section, planned and ran the REFLECT focus group to get input on the emerging themes, and finally decided on the five themes with their component parts. Throughout this process Nancy Marlett and Svetlana Shklarov were working in the background as advisors, being available for consultation and advice to move the study forward. This was truly a team effort with much discussion, a little dissention, and a lot of excitement as the study progressed.

In this report Mary and Marlyn are presenting their perspective of their personal journeys. Both hope that Nancy and Svetlana will find the time to record their own journeys as they worked with the three original studies and two from the second cohort of students.

Mary's Journey

The role of mentor with this project emerged over fifteen months as one of being a generalist across many spheres: recorder for learning sessions, teaching assistant with individuals and during whole group sessions, writing assistant, problem solving with learners and lead investigators and managing petty cash to pay for the costs incurred during the actual research phase of each of the five studies.

There had been no expectation of the mentor becoming a researcher at the outset of the project but engagement as a learner walking side-by-side with patients drew me into the research process. Successful data collection and completion of the early joint pain study called for engagement in early joint pain research to be added to the mentoring role. This was an exciting addition which offered a remarkable learning opportunity: not having been a patient struggling with an illness I quickly learned what it meant to be an OA patient. Not only did I learn first hand from Marlyn what it meant to undergo two surgeries within a year but also I learned from the dozens of patients who were interviewed what life means when you have no choice but to live with chronic pain.

Mentoring, I had thought at the outset, would mean assisting the lead researchers to guide the patient researchers and interns along the pathway to completion of each study. Engagement with Marlyn as a co-reseacher and an intern learning about the experience of patient reversed this role and showed me that I had much to learn about what it means to live with OA. Marlyn and all the patients living with OA became mentors to me as I came to understand the individual patient experience of living with OA.

Learning about Self-Care. During the coursework in gerontology I found a short article by Carolyn Rosenthal, *Caring for Myself to the End: A Sacred Enterprise*; to this article I have now returned since it resonates with what I have experienced while doing this research. Though Rosenthal is writing about aging her words are relevant to the experiences of patients living with OA. At age 76 this writer becomes aware of "the absolute miracle of how the body works, of *my* body's functioning in a blessedly stalwart way all these years" (Rosenthal, 2000, p. 25-26).

Rosenthal tells of receiving a new knee and driving to the rehab hospital pool for whole body exercises, of walking and swimming to resist further erosion by osteoporosis and arthritis, of grumbling about taking medicine at exactly the right time and swallowing too many supplements. Still she is able to sing about her own strength. Her words echo the many brave voices of those patients we interviewed for this chronic joint pain research study. Rosenthal ends her article with "chanting" a May Sarton's poem *Friend or Enemy* (Sarton, 1994):

> I can look
> At my body
> As an old friend
> Who needs my help,
> Or an enemy
> Who frustrates me
> In every way
> With its frailty
> And inability to cope.
> Old friend,
> I shall try
> To be of comfort to you
> To the end. (p. 26)

Being engaged with Marlyn and all the patients struggling with chronic joint pain has thrown the light of experience onto the words of this poem. They are not just words now; they capture in a fleeting moment of sound and rhythm and image the experience of a patient living with the chronic pain of osteoarthritis. I came to know fear on this journey – fear that I too might become disabled, become a burden, continue to hide my pain as it increased. Learning with Marlyn and the participants about chronic joint pain, I am better prepared for what may lie ahead if my OA becomes severe.

Marlyn's Journey

The journey, oh the journey. Little did I know when I enquired whether I was too late to join the Patients Matter Project the huge impact such a seemingly little step would have on my life. For almost a year and a half this project has dominated my life. It became the focal point and guiding force that allowed me to sail through two joint replacements within six months and continue to manage my other joint pain. It gave me back a measure of self-respect because I felt useful despite having a useless body. As one participant put it my "life (with OA) had kind of got in the way of taking care of myself" (637). Another participant made me realize that I could still be useful and contribute when she told me, "[when] I saw you at the Arthritis Society I saw how feisty you were and it gave me hope. You are still contributing and so I will be able to as well" (370). Patient engagement research has given purpose to my life and I believe will give purpose to many other patients' lives, whether they be researchers or participants in the research.

During the six-month formal academic training I struggled with accommodating the new methodology and philosophy with my previous training. I had been trained in qualitative phenomenological research and had been a family therapist for almost twenty years. I had to relearn how to ask questions and probe, as well as "get my head" around the philosophy. It was not until I started the actual study that things really started to fall into place and I became confident in what I had been taught in class.

Then came the proposal. At the beginning of this stage I thought my group was solidly set at three members. However, the other two decided to leave the project and I was left alone,

yet not alone. Mary Sheridan, the mentor, stepped forward and took up the slack while Nancy and Svetlana were in solid support in the background so we got the proposal completed. While we were waiting for approval I had hip surgery and by the time we were ready to start the study I was fit and well. This is an aspect of being a PER that most researchers do not have to contend with, that is becoming sick, having bad flare up days, or having surgery. The study got underway in the last week of January and we finished interviewing people by the middle of May. One more surgery at the end of May, then it was right back into the analysis and result writing.

Throughout the process I have been learning about myself and my disease. The most surprising finding was how people hid or did not talk about their arthritis, the pain or the disability. After hearing this articulated in the SET focus group I began to realize I had, fairly successfully, hidden my arthritis for over 30 years. Even when my femur would shift in my hip socket, shooting a pain down my leg as I was putting on the golf course, I did not disclose the problem till I was unable to walk off a plane; I had more connectedness with the participants than I had initially believed. At first this connectedness was difficult to accept as it meant I had to fully accept my own disease; a huge milestone for me.

This connectedness grew exponentially as I interviewed more and more people. I had lived their highs and their lows and they recognized it. Time and time again I was hugged, thanked, and told how wonderful it was to talk to someone who understood. I was told "how good it was to talk to someone who really gets what is going on for me" (1020) and "just knowing you share the same pain and you ask the right questions let's me know that what I say is important. I realize how good it is to talk to someone that can make sense of what my life is really like" (1099). Slowly but surely I was coming to understand the power of patient engagement research and its unique ability to reach into the kernel of patients lives. I was able to accept that I could share and research at one and the same time. The two are not mutually exclusive if care is taken to keep bias out of the picture. I was sharing simply by my presence as an identifiable OA patient so I could use my experience to probe deeply into areas of concern for the participants.

One concern arising for me from the wonderful and almost immediate engagement I experienced with the participants is around the transferability of engagement across diseases. Would my engagement be as easy or as profound with people experiencing cancer or heart problems or is the connection disease specific? This is a question that can only be answered by further research using patient engagement researchers.

Our hope, echoed by all the participants in the study is that patient engagement research is taken seriously by government, professionals, programmers, and the community at large. We have taken great care to engage in this innovative research with an eye to the validity and reliability of the material we produce. As the following quote attests we have accessed information previously uncovered: "This is the first time I have had this depth of conversation with what I have been dealing with. Nice to be able to talk and many of the things I have said I have never vocalized before" (1371/72). We are the new guys on the block and we have something to offer when there is a serious attempt to understand patient needs.

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