

PaCER REPORTS

**Understanding Low Back Pain Patients' Experience with Family Physicians
and Diagnostic Imaging**

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For Choosing Wisely Canada (Alberta)

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Introduction

This qualitative study is the patient component of the Choosing Wisely Canada (Alberta) Low Back Pain Quality Improvement Project: Physician and Patient Perspectives. It is estimated that just over 20% of adult Canadians experience low pain lasting more than six months (Bath, Trask et al., 2014) and low back pain has been cited as the third most prevalent reason patients consult their primary physicians (St. Sauver, Warner et al., 2013). There has been much discussion about the usefulness of diagnostic imaging for low back pain when there are no “red flag” symptoms and this has been chosen as a priority topic by Choosing Wisely Canada (CWC) in Alberta. This study investigates low back pain patients' perspective on the treatment they received from their primary physicians, whether or not they were referred for diagnostic imaging, with a view to designing interventions that would improve the quality of care for such patients.

In an effort to understand the negative and positive experiences of patients with low back pain, as they try to find solutions and management options, patient and community engagement researchers – team members of the PaCER Program were asked to undertake this research. All of the researchers in this study were low back pain patients allowing the participants to acknowledge that they felt comfortable and understood. We encouraged all participants to talk about what really worked for them, what they found difficult and frustrating and what would make it easier for them to be confident they and their family physicians were managing their low back pain as well as possible.

Background and Context

Low back pain is one of the most common reasons patients consult with their primary physicians (Hoffman, Del Mar et al. 2013; Sauver, Warner et al. 2013; Balague, Manion et al., 2012), and is also a conditions with a wide disparity between patient expectations and outcomes (Haanstra, Hanson, et al., 2013; Hoffman, Del Mar et al., 2013; Tulder, Koes, Metsemakers, Bouter, 1998; Cherkin & MacCornack, 1989). Several reasons for this gap have been put forward and include: the unproven efficacy of most interventions (Tulder et al., 1998; Ferreira, Manuela et al., 2013); providers' lack of recognition that LBP patients need open patient-centred communication (Farin, Gramm & Schmit, 2013); and patient perceptions that they are not believed (Dima, Lewith et al., 2013). Diagnostic imaging education for low back patients with dual emphasis on usefulness and danger of radiation exposure was seen as necessary and should be undertaken by the primary physicians when choosing not to refer the patient for diagnostic imaging. This has the benefit of engaging patients in a discussion and allows for shared decision-making. (Tapp, McWilliams & Dulin, 2014)

Engaging low back patients in their own recovery process is seen as an important factor in improving their pain and mobility (Rheumatology Editorial, 2002; Ferriera, Manuela et al., 2013) and matching patient beliefs about the efficacy of the differing holistic and alternative treatments is believed to be central to successful referral to such providers (Dima, Lewith et al., 2015) The therapeutic relationship between the primary physician is of great importance, with stress on “met or matched” expectations as an indicator of a successful consult (Georgy et al., 2013). Toye and Barker (2012) believe that adherence to a biomedical model creates tensions between the primary physician and the patient with low back pain that could be resolved if there were a shift to a biopsychosocial model (Engel, 1977). There is evidence that a biopsychosocial multidisciplinary clinic approach may yield moderately better results for low back pain patients than a biomedical model (Kamper, Apeldoorn et al., 2014).

Methods

PaCER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (Marlett & Emes, 2010) For this study we chose grounded theory (Glaser & Strauss, 1967) as we wanted to understand the patient experiences and beliefs in the hope of developing some theory on which to base any interventions to improve care.

Recruitment and Inclusion Criteria

We had originally planned to seek our participants through three Alberta Patient Care Networks (PCNs) with an adequate regional spread throughout Alberta whose management had agreed to help us recruit. We sent information to all 3 PCNs including posters and release for contact forms. Unfortunately, few family physicians were able to help us recruit although we did gain three participants who had seen the poster in their doctor’s office. We decided to change our recruitment strategy and, with ethical approval and the co-operation of a specialized back clinic, were able to recruit enough participants to reach saturation. The back clinic posted the study information on their web site and gave non red flag patients FAQ sheets about the study. We had two participants referred by primary physicians and 13 were self-selected.

Potential participants had to have visited their family physician about their low back pain within the last 12 months, be over 18, and speak enough English to participate in a focus group. The participants from the clinic were asked only about their experience prior to attending the clinic. Each prospective participant was interviewed by telephone by the research team lead to ensure that they fitted the criteria and understood the parameters of the study.

Participants

We recruited 15 participants; three from Northern Alberta, two from Southern Alberta and nine from the Calgary area. There were six men and nine women aged between 30 and 76. We facilitated one Set focus group (2 participants), three Collect groups (3, 3, and 5 participants respectively) and conducted two narrative interviews. Our Reflect group had four returning participants. All of the participants had experienced low back pain and had consulted with their primary physicians at least once in the last 12 months. All had non red flag LBP symptoms lasting more than 3 months, some for many years.

Data Collection and Analysis

We collected data using the PaCER framework, which consists of three phases: SET, COLLECT and REFLECT.

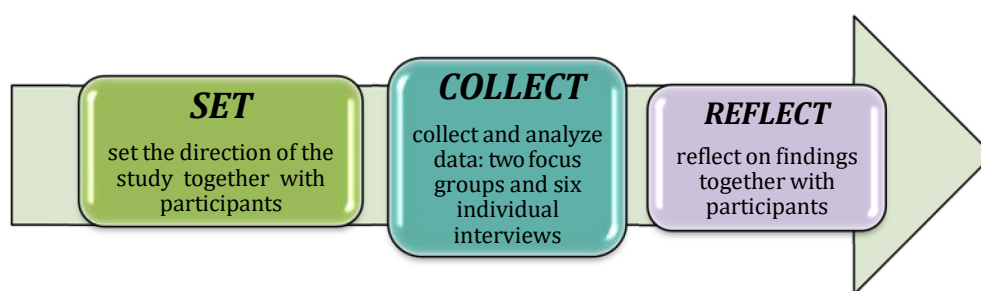


Figure 1. PaCER Research Method

Our patient engagement research process is iterative and amenable to changes in direction depending on the information received from any group (Marlett, Shklarov et al., 2014). The Set group is used to indicate what topics are of the highest importance to the patient participants and directs the guiding questions for the first Collect group. Information from each subsequent Collect group or interview is used to inform the guiding questions for the next group or interview. However, each group or interview participant was asked the same initial question: *Please tell us what happened when you went to your family physician about your low back pain.* This opened the door for participants to describe their experiences. We encouraged discussion among the participants and only used short prompt questions to deepen the information being given. PaCER uses 3 facilitators; one to facilitate the discussion, one to take flip chart notes and one to do a process recording. All groups and interviews are audio recorded and later transcribed. All three recording methods are used in the analysis.

Set Group

Our Set group had two participants, one from Lethbridge and one from Calgary; both of whom had been recruited to the study by their primary physician. Despite the small number, the group lasted for the full five hours as both participants discussed their experiences. In keeping with PaCER protocol we used the flip chart notes to develop the guiding questions for the first Collect group. The flip chart

notes were posted on the walls and both participants were asked to check the veracity of the notes and were invited to give additional comments on all of the noted topics as well as identifying any omissions. Transcribed tapes of the Set group are only used if the overall participant recruitment is low. In this study, with 15 participants, we used the Set transcription in our analysis.

Topics of major importance to our participants used to formulate guiding question for the first Collect group were:

- A trusting relationship with your primary physician
- A lack of understanding of diagnostic imaging and reasons for referral or non referral
- Discrepancy of wait times for DI depending on referring agency
- Cost of alternative treatments for low back pain
- The opinion that patients are not always believed and/or listened to by their primary physicians.
- Power of primary physicians to adequately refer within the health care system.

Collect Groups

We held three Collect groups, one in Northern Alberta, and two in Calgary. The first Collect group consisted of three patients who had seen the study poster in their doctor's office. None of them had consulted either their physician or office staff and all three presented as being very frustrated and angry with their ongoing low back pain problems. The overarching topic of most importance to this group was a lack of a clear diagnosis and treatment/management plan. We added this to our list of guiding questions. Collect groups two (3 participants) and three (5 participants) consisted of patients who had either consulted the back clinic's web site or had been given FAQ sheets by clinic staff. We reached saturation of information after Collect 2, but ran another group and two interviews as our numbers were low. Collect 3 and the two interviews confirmed that we had reached saturation.

Reflect Group

We had four returning participants for the Reflect group. Seventeen sub themes, identified using grounded theory analysis, were posted randomly on the walls. Explanations of the sub theme and supporting participant quotes were shown. Participants were given clipboards with comment sheets and asked to go round all of the posters making notes on as many as they liked. They could disagree, agree with the information as well as add comments and experiences within the subtheme. They were also asked to identify any topic we had missed. Participants were asked to fix a stickie note to the poster if they had made a comment, allowing us to see which sub themes were most popular and therefore most important to our participants. We then had a discussion about their findings and asked if they could group the sub themes into larger groups. This was to explore the framework we had used for the data. Based on the

findings outlined in the posters, participants were then asked for recommendations or interventions they thought might improve the service they received for their LBP.

Research Credibility and Trustworthiness

We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient or family member researchers facilitating the groups, interviewing patients and family members and analyzing the data are the instruments in the study and each had to understand, reflect on, and state his/her biases (Bogdan & Tylor, 1975; Kirk & Muller, 1975; Patton, 1990) (2) As patients we had a familiarity with the experiences of the participants (Shenton, 2004). (3) We used research colleagues, academic supervisors from PaCER, and peers to review and discuss the emerging data, coding, and themes (Lincoln & Guba, 1986, Shenton, 2004). (4) We used member checks (Reflect group) to ensure the accuracy of our analysis. (5) We employed iterative questioning, triangulation (e.g., using a combination of two methods – grounded theory and content analysis, and two different data collection techniques), and thick description of low back pain patient experiences Lincoln & Guba, 1986, pattone, 1990). (6) We completed a literature review to assess the congruence of our findings with previous research (Berg, 1989; Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004)

Results

We identified five major themes and 16 sub themes emerging from the data gained from patient experience when consulting their primary physicians about low back pain. Included in this is their experience with diagnostic imaging. The five major themes are:

1. Patient perspectives on the health care system as it relates the their primary physician.
2. Patients' perceived needs from their primary physicians when they consult with low back pain (LBP)
3. Patients' responsibilities when they consult their primary physicians with LBP.
4. Patient perceptions around diagnostic imaging
5. Patients need for healthcare professionals to understand the impact of LBP on patients' lives.

Each sub theme, sited within the main themes, will be explained in detail and exemplar quotes supporting that sub theme will be provided.

Major Theme 1: Patients Perspectives on The Healthcare System as it Relates to their Primary Physicians

This theme has seven sub themes outlined in figure 1.

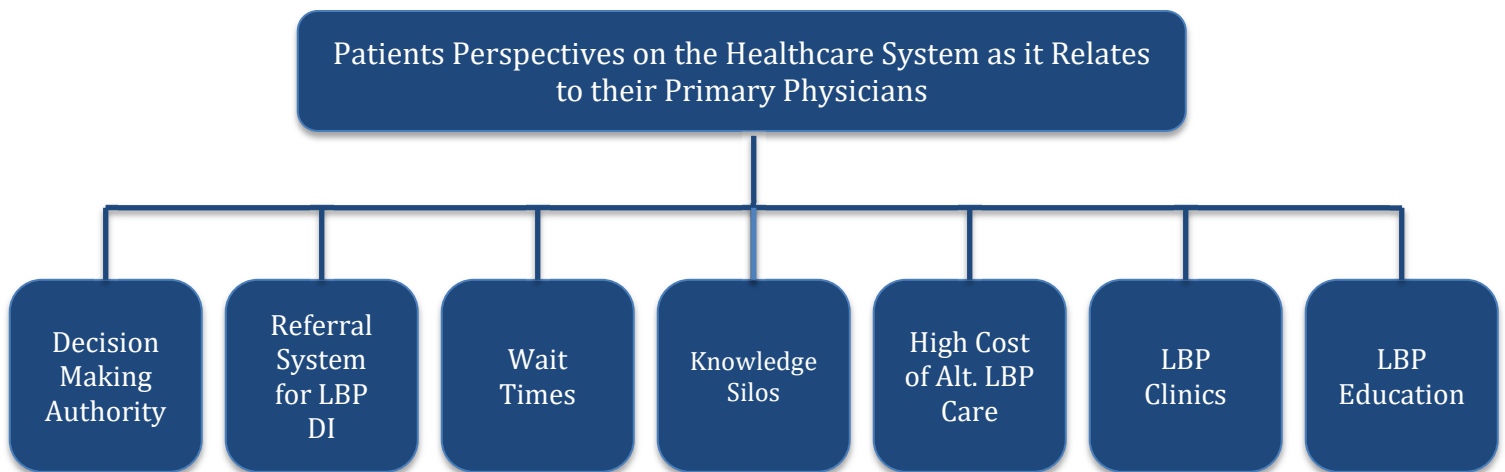


Figure 1, Major Theme 1

I. Decision Making Authority

Patients with low back pain noted that they were unsure if their primary physicians had the decision-making power and necessary authority to make the referrals they wanted for diagnostic imaging and specialist care for low back pain. Our participants appeared to believe that their primary physicians were low in the health care hierarchy and that it was difficult for them to make referrals with any certainty of being heard. Patients perceived that little notice was taken by specialists of any gradation of concern for the patients' severity of condition expressed and noted by the referring primary physicians.

Table 1

Sub Theme	Exemplar Quotes
Confused about decision making authority	<p>1) <i>G.P tries hard to accommodate but I think it's a system issue. G.P. has not enough power for decisions</i></p> <p>14) <i>My G.P does not have a voice,</i></p> <p>39) <i>Yes, you know his (G.P.) hands are tied.</i></p> <p>3) <i>G.P. is discounted in future discussions about patient. He holds the door for patient to go through.</i></p> <p>R3 <i>Even though my GP determined that I needed an MRI because of my genetic disorder, my appointment was 9 months away. If the GP does not have a voice they become frustrated with the system and can't deliver the type of care they aspire to.</i></p> <p>R5 <i>GPs do not have the power as one would think. They seem to be a "go between" between patients and specialists</i></p>

II. Referral System for LBP Diagnostic Imaging

Many patients were confused about the differences in wait times for diagnostic imaging that appeared to be dependent on the referring agency. While the primary physician did the actual referral, it seemed that there was a difference if a surgeon, Workers Compensation, the patient willing to pay, was triggering the referral. More than one patient pointed out that if they told their physician they had injured their back at work, they got a fast and successful referral to DI.

Table 2

Sub Theme	Exemplar Quotes
Referral System for LBP Diagnostic Imaging	<p>87) <i>So what is the G.P.'s power if his criteria for an MRI takes months and a WCB job injury triggers an MRI in two weeks? Does WCB pay more? Why so fast if the same injury (non job related) takes months?</i></p> <p>19) <i>I was seeing a chiropractor, which did not help much. She told me to tell my doctor I had slipped on ice at work and I got an MRI right away. Non-work related injury 8 months WCB related 2 weeks.</i></p> <p>1345) <i>I was fortunate that I could pay for it. It took me three days to get my MRI when I paid my own money out. What is it in the system that all those poor people that have to wait,... how come I can get it that quick?</i></p> <p>1380) <i>What about the criteria for them to request an MRI? I think they do triage and unfortunately low back pain is the last thing... if the doctors put the request in and the triage people look at it and then it's that group that determine...they're making that decision about us while we wait in excruciating pain in the interim.</i></p> <p>85) <i>Before, a while ago, I waited 10 months to have an MRI and they said it wasn't bad enough. Then when I told my doctor I had had a work related injury and it went through WCB, I got an MRI appointment in 2 weeks and was referred to the Caleo clinic for triage. I guess this is good for the employer as it gets the worker back to work faster.</i></p>

III. Wait Times

Our participants, while unhappy with the wait times for LBP diagnostic imaging and / or referral to a specialist, did not believe there was much their primary physicians could do to speed things up. They did however, as will be noted in another sub theme below, believe that they should not be left in limbo as they waited for their appointments. They perceived that low back pain symptoms were generally not seen by the medical profession as a condition meriting speedy referral.

Table 3

Sub Theme	Exemplar Quotes
<i>Wait Times</i>	<p>93) <i>I have been referred for surgery but I have been told it will be 18 to 28 months before I will get a consultation with a surgeon with no guarantee he will operate. Meantime, I am in pain, I try not to bother my G.P. as there is nothing he can do.</i></p> <p>1115) <i>Just recently ended up having severe back pain and went to the family doctor in January who requested an MRI but my appointment wasn't until September. So I paid for my own because there is no way that was going to help me. I wouldn't be walking in September so I paid for my own (MRI) and got the results from that and they were very helpful. I'm glad I didn't have to wait for September.</i></p> <p>1288) <i>The pain clinic on Richmond Road has 2,000 people on their wait list...it took me two years just to get in and now it takes 6 months to get started and then 18 months to see a doctor...</i></p> <p>SI108 <i>It is really difficult with this waiting game...it would be nice if there was a system that I could see that my referral has been received...because I now have this fear of referral not being received...that would give me peace of mind...</i></p> <p>R10 <i>Long wait times impact the sense of empowerment (in patients) and the validation of the complaint. Even if GP has initially validated your complaint, the long wait times remove that belief.</i></p>

IV. *Knowledge Silo*

Participants noted that there was sometimes a block in communication among all the health care professionals who were treating their LBP. Most of the patients who were using alternative care to treat their LBP symptoms noted that they had to carry reports with them if they wanted all of their professional help, including their primary physician, to be aware of all the various treatments and outcomes. They also noted that many professionals were uninterested in the other treatments they were having.

Table 4

Sub Theme	Exemplar Quotes
	<p>3) <i>G.P. is discounted in future discussions about patient. He holds the door for patient to go through</i></p> <p>739) <i>There were silos in places but that is getting better. My physio would know what my doctor was recommending.</i></p> <p>32) <i>You know I never had a report from that first MRI</i></p>

	<p>1375) I was going to my own physio...I would get my report...the doc would look at it...I managed to get a team...</p> <p>1454) Doctors are often in silos and don't talk to each other.</p> <p>R12 There is little or no communication between health care providers. If communication was better LBP patients would not be as confused and stressed by differing opinions and/or treatments.</p>
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V. High Cost of Alternative LBP Care

There was unanimous agreement among our participants that alternative care for low back pain, often recommended by the primary physician, was extremely expensive. While many patients had insurance that would cover some alternative care, this appeared to be insufficient to cover the ongoing care supplied by physiotherapists, chiropractors, acupuncturists, massage therapists etc. Those without insurance coverage usually stated that they were unable to access such services because they could not afford the care. Most participants were advised by their primary physicians to seek alternative care and were unable to give alternatives when the cost was out of the patients' reach. This is a major problem for patients with low back pain who are unable to access the recommended treatment either immediately or on a long-term basis. Many stated they had to fall back on pain medication, which they knew was not going to improve their condition.

Table 5

Sub Theme	Exemplar Quotes
	<p>70) I go to acupuncture and it releases for one week. For one week your muscles feel okay. But it's really expensive</p> <p>686) There was a lady in the clinic yesterday she's been on the list for almost 2 years for the ablation surgery. I told her if she wants to get in, pay for it.</p> <p>34) The doctor prescribed Tramacet but Blue Cross will not pay for it ... he takes the Tramacet when we can afford it.</p> <p>1120) When I had insurance I could keep the pain under control by going for physio and acupuncture. IMS worked pretty well for me... My husband lost his job in oil and gas so we haven't had coverage for a year now so I don't go as often for treatment. It (LBP) seems to be getting worse.</p> <p>1516) Wouldn't it be nice if the doctor had a physiotherapist on staff so that everybody coming in could get looked at?</p> <p>1396) ...Lack of coverage for appropriate treatment plans...the thing that is bizarre is I can go and see my family doctor any time I need for any other issue and it is covered by AHS but I can't go and get treatments for my back.</p> <p>R16 I believe this plays a huge role in how we approach back pain. For me I am fortunate that cost is not an issue but for</p>

	<i>my son who is a young adult he starts out on the journey with LBP knowing he will not be able to cover costs of long term physio/ massage etc.</i>
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VI. Low back Pain Clinics

Many of the participants believed that specialized low back pain clinics would be a much more efficient and effective way to deal with LBP patients. They perceived these as being multi-disciplinary with a triage team who could make sure patients were directed to right kind of treatment for their unique condition. This, they said, could save money, time and energy for both professionals and patients. The entrance to the clinic could be either by referral from the primary physician or on a walk in basis. A few stated a hope that the development of PCNs might encourage doctors to provide multidisciplinary care at a strategically placed location.

Table 6

Sub Themes	Exemplar Quotes
Low Back Pain Clinics	<p>891) <i>I researched and found a clinic in Edmonton, a back institute, the only one in western Canada No one would send me there so I had to pay my own way.</i></p> <p>1083) <i>The model here (Caleo clinic) to me is the way that things should be going</i></p> <p>1291) <i>The doctor could refer to a clinic, or you could refer yourself or do a walk in... they have people good for an assessment... you go a million times to a doctor...think of all that money that's wasted...</i></p> <p>1302) <i>I would definitely by pass all my doctors...and go straight to a place like Caleo....having everybody under the same roof is phenomenal.</i></p> <p>1414) <i>a multidisciplinary clinic is great...but we have to come up with something that is workable.</i></p> <p>1443) <i>Why is there no structure (pathway) for your back when it (LBP) is so common?</i></p> <p>R21 <i>If there were access to specialized clinics or PCNs I believe that the burden of LBP on the health care system would be lifted and the medical community would not be so resentful (of returning LBP patients).</i></p>

VII. Low Back Pain Education

There were two avenues for education identified by our participants. They wanted to have more explanation from their primary physicians about the reasons for their LBP. They wanted to understand what had gone wrong so that they could make changes in lifestyle that could

ameliorate their LBP. Additionally, our participants were unequivocal about the need for education for the general community in caring for their backs. While they acknowledged that there are pamphlets, web sites and literature about caring for backs and low back pain they believed education has to become more widespread and be embedded within community daily life. They voiced the concern that people pay no attention to their backs until there is a problem. They perceived that prevention education, especially since people are living longer, should be part of the primary physicians' role in keeping their patients healthy. They also believed schools and organized sports could play a major role in prevention education. Prevention education, they believed could save health care dollars in the long run.

Table 7

Low Back Pain	Exemplar Quotes
	<p>1276) <i>If somebody explains to you, it's going back to education...the chiropractor showed me the issue and we're dealing with it. I'm fine with it.</i></p> <p>1410) <i>We're living longer so if we were more proactive in health care then as we get older we can maybe keep our backs healthy.</i></p> <p>1416)...<i>Taking responsibility for your own care...so with my physio it wasn't just come in for a treatment...it was this is what you have to do every day to maintain your health which reflects patient education... if we had known ABC we would have been doing it...the lack of patient education on back care and back health even in a general sense of how we move...and how it affects things, what we do...</i></p> <p>1419) <i>(We need)</i> <i>A lot more. (education) You hear about our heart and how we're supposed to eat...so what about our back and how we're supposed to stand and walk as part of your overall health from the family physician?</i></p> <p>1425) <i>how we move...as a prevention...if you had a really strong core strength in the first place it may have an impact for some people...that trip may not totally kill you back... prevention would cost less... where do you inject that training into the education system?</i></p> <p>R23 <i>patient education for backs should start as soon as we are born, when mothers take their kids to be immunized and continue on. Doctors should check for that at least once a year.</i></p> <p>R26 <i>How to avoid back pain training should start in elementary school and continue through life.</i></p>

Major Theme 2: Patients Perceived Needs When They Consult Their Primary Physician About Low Back Pain.

This major theme has four sub themes outlined in figure 2. All of our participants verbalized the important part their primary physician played in their pursuit for help with their low back pain. As noted above, many patients seemed to believe that their primary physicians were not valued highly enough by their peers in the medical profession. They observed that the relationship with their family physician was the fundamental base they relied on to remain healthy and find solutions for their LBP problems.

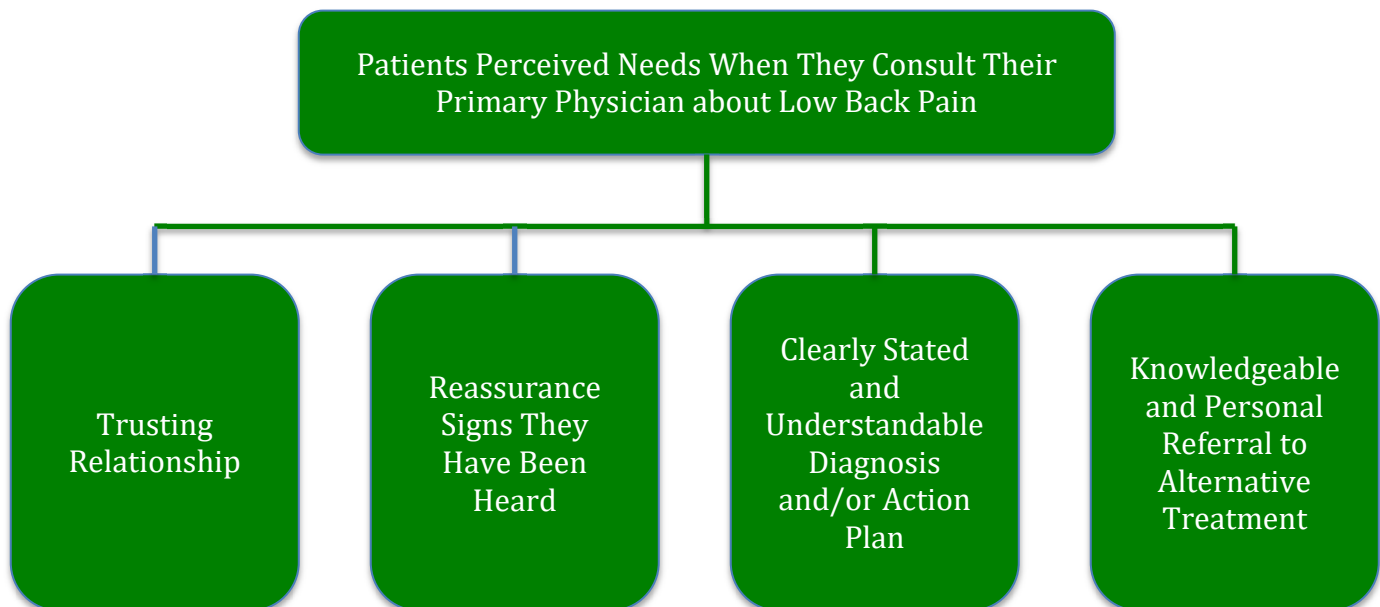


Figure 2

I. *Trusting Relationship*

All of our participants noted the importance of having a trusting relationship with their primary physician. They saw this as the cornerstone in their ability to seek help with their low back pain. Unfortunately, many of our participants appeared to have lost trust in their primary physicians because they were unsatisfied with their LBP care. Some noted that they noticed a deterioration of the existing relationship when they consulted about LBP, as they believed their physician had not dealt as seriously or assiduously with this condition as he/she had with all of their previous health concerns. As noted below they did not “feel believed” about the severity of their pain and the resulting anxiety.

Table 8

Sub Theme	Exemplar Quotes
Trusting Relationship	<p>69) <i>I think the most important thing in my relationship with my GP is trust, trust I will be heard.</i></p> <p>163) <i>What I can say is that I was so dissatisfied and still am that I told him I have lost all my faith in you</i></p> <p>1220) <i>This (LBP) has definitely changed our relationship when I go to see him...I feel like I'm annoying him or being a nuisance.</i></p> <p>1460) <i>When I went for my (annual) physical I wanted to discuss my back...he said that I had to make another appointment because that way I can do a better assessment. I said that you are supposed to check me from head to toe...that didn't make sense...</i></p> <p>S1146 <i>he told me he was going to fire me if I went to a naturopath...I decided to see a new physician...</i></p> <p>1006) <i>Honestly, I was impressed with the last time that I went to her when she actually said the advice that she gave me before was not going to be helpful. I've learned something in the meantime. I think that you should do this other thing.</i></p> <p>R28 <i>I believe a trusting relationship is very important. It gives me a sense of empowerment (as a patient)</i></p>

II. *Reassurance, Signs they Have Been “Heard”*

There was general agreement among participants about the importance of being “heard” or validated when they consulted their primary physicians about their LBP. Some felt their physicians did not believe them, while others perceived a distinct lack of interest in their symptoms. Most were surprised that there had been no physical examination and that their physician appeared to dismiss what they saw as a painful, debilitating condition. While they understood that LBP was not life threatening, they believed that they were being dismissed as “whiners” rather than patients who have lost the ability to function adequately in their daily lives. Patients found this distressing and frustrating remarking that it added to the stress and anxiety they were experiencing.

Table 9

Sub Theme	Exemplar Quote
Reassurance, Signs They Have Been “Heard”	<p>90) <i>The only one who knows everything is the patient and they don't really listen to me.</i></p> <p>43) <i>They are not looking at the patient as a whole. The focus is on symptoms in a part of you and they are not</i></p>

	<p><i>looking at you being functional.</i></p> <p><i>174) Not being listened to. Pooh-poohed. What we think, what we feel...</i></p> <p><i>185) Yes, you go in with symptoms – do you think they listen to you? We go in a number of times, the two of us have been with the doctor since and it is not an examination, just talk. No one puts a hand on you.</i></p> <p><i>1169) One of the things that bothered me is that he didn't do any physical examination or anything to tell me what I had...I wanted an answer... Anything else when you go to a primary physician...</i></p> <p><i>1217) With other issues, I had abdominal surgery in January, he was great to help me with that stuff...he was really helpful...you should be up and do this, yeah that works....as soon as I complained about back pain...he was oh just take some pills...it was like something that he heard all the time and didn't care to deal with it...</i></p> <p><i>1320) to be in that much pain when they wouldn't listen, it was almost degrading... I didn't know who I was anymore...</i></p> <p><i>1473) I think with back pain again for some reason doctors don't think it is as big a deal as with pain somewhere else...you're not fast tracked through the system... they don't look at the overall, (effects of back pain) they're not looking at the mental health component of the back pain...</i></p> <p><i>R30 Knowing I have been heard, that my complaints have been validated gives me a sense of empowerment (I can manage)</i></p>
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III. *Clearly Stated and Understandable Diagnosis and/or Action Plan*

All of the participants in this study had returned to consult their physician multiple times as they had experienced no improvement in, or a worsening of their LBP and were unclear what was causing their pain. Most understood that surgery was probably not an option, but they wanted some sense that they were moving forward or had a plan to manage their condition. Long-term pain medication was not seen as a viable single option as they believed there was something they could do to manage better. They expressed that mentally they felt better when there was a plan and they could work toward improvement.

Table 10

Sub Theme	Exemplar Quotes
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<p>Clearly Stated Diagnosis and/or Action Plan</p>	<p>75) <i>People get hooked on pain medications. Too much of “take this”, but it’s not really helping. It solves the symptoms but does nothing to help the cause.</i></p> <p>172) <i>I just had the x ray when I was told I had degenerative discs and I was too fat to have surgery. That was the only answer.</i></p> <p>48) <i>I wanted a full report to know what was happening but my G.P. did not give me that. He said everything was all right. I don’t feel all right.</i></p> <p>1184) <i>when I did get the results from the MRI it was the nurse who called to give me the results. That is where the doctor dropped off and left it for the nurse to explain things to me and left it to me to where I was going to go from there.</i></p> <p>1275) <i>I told my doctor too. I want to know what I have and then I’ll deal with it. That makes a difference. If somebody explains to you, it’s going back to education...the chiropractor showed me the issue and we’re dealing with it. I’m fine with it. It’s not as scary is it? When you have extreme pain and you’re terrified and your back is affecting your mobility then you are lost in that dark hole like you said. When you find out and it looks like it is fixable, it changes your mindset and that changes how you approach it. We can work at it instead of sitting on a wheel. It’s a big game changer, your mindset and what you are determined to do to make yourself better.</i></p> <p>1442) <i>with most other illnesses the protocol is specific but again with your back it isn’t and it’s up to the physician to decide....physio, chiro....it seems to be all over the place.</i></p> <p>1480) <i>they have an attitude...oh, it’s only back pain... Could it be that they are afraid of what we’re dealing with it? It’s not like when you go in with a cold and they write you a prescription for an antibiotic and then you’re done, I’m gone.</i></p>
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IV. Knowledgeable and Personal Referral to Alternative Treatment

As noted above our participants were very aware that LBP is often best aided by some form of alternative treatment such as physiotherapy, chiropractic intervention, acupuncture etc. One of the difficulties they encountered is choosing an alternative therapist who is well versed in LBP treatment. Since these practitioners are costly, they believe their primary physicians could be helpful in guiding them to a competent alternative therapist. The few patients whose physicians have been able to do this were happy with the outcomes and stated that they felt they were being treated by a team

rather than separate health care practitioners. All patients liked the concept of a team, multidisciplinary approach to LBP care.

Table 11

Sub Themes	Exemplar Quotes
<p>Knowledgeable and Personal Referral to Alternative Treatment</p>	<p>848) <i>like I've been to I don't know ten physio people but pretty well none of them get it that I can't do three sets of ten on a rep of this or rep of that. I'm lucky if I can get through the first ten and you want me to do thirty? I'll stomp you to death on your back and you try to do it.</i></p> <p>853) <i>It's a crap shoot. Nobody has the answers. You can't just blanket that any activity is a good idea.</i></p> <p>1182) <i>She (physio) is different in her delivery. How she explains to you about how you take control of your core strength...pull your Kegels in when you roll over, there was no pain... My family physician recommended her saying that she was really good and very engaging especially with people that are very active...otherwise I would have been hit and miss.</i></p> <p>1192) <i>The doctors here don't had a good network of referrals...They're not trained on where to refer you to. They should be more oriented on where to send you...</i></p> <p>1198) <i>The family doctors are trying and they know about the alternatives but they don't know who is good or not good...</i></p> <p>R50 <i>GP knowing which alternative treatments to refer you to would get better results and you get better faster</i></p> <p>R51 <i>Alt treatment is very expensive so patients should be referred to where you will get results... having to pay for ineffective treatments causes financial stress</i></p>

Major Theme 3: Patients' Responsibilities When They Consult Their Primary Physicians with LBP.

This major theme, while it has no sub themes, was seen as very important to most patients in the study. Those who were less likely to see they had responsibilities as a patient were those who came to the group feeling very angry and frustrated at their lack of progress in solving or managing their LBP. It was unclear whether they had given up on trying to do something different or whether this was their normal perspective and they just wanted “fixed”. The vast majority of our participants believed that there were important responsibilities such as consulting the physician in a timely manner, clarity in stating symptoms, asking good questions, listening to advice and following through even if it involved difficult physical exercise. These patients were aware there is no “magic bullet cure” for most LBP problems and that hard work was involved in obtaining a successful outcome.

Table 12

Theme	Exemplar Quotes
Patients' Responsibilities	<p>704) <i>I can manage it just with exercise. I swim, I do Pilates. I was doing yoga but that aggravated it. I do some core stuff.</i></p> <p>793) <i>I mean like I say, I should have gone back to the doctor a long time before this. That was 7 years in between the time I felt that first searing pain to when I finally went back to the doctor just last year.</i></p> <p>988) <i>The doc is not a scanning machine. You have to clearly identify where the issues are as best you can and for people that feel uncomfortable talking about their bodies, well they get what they earn on that one. It's not the physician's 100% responsibility to identify your issues.</i></p> <p>1279) <i>It's a big game changer, your mindset and what you are determined to do to make yourself better.</i></p> <p>R38 <i>Patients need to be up front with all the symptoms, be strong in explaining what is going on with them. Be her/his own advocate. Where possible try to have someone with them to hear, listen and if necessary speak up on their (patients' behalf</i></p> <p>810) <i>I think the purpose (of physio) is for me to get a better understanding of what I can do to try and fix my problem.</i></p> <p>833) <i>I'm doing it (going to a multidisciplinary clinic) because I'll try all the pieces and see if anything they recommend will make a difference.</i></p>

Major Theme 4: Patients Perceptions About Diagnostic Imaging

There were two sub themes within this theme. Some of the concerns about diagnostic imaging have been described in the systemic healthcare themes above. The following are the concerns that patients believed could be addressed by their primary physician.

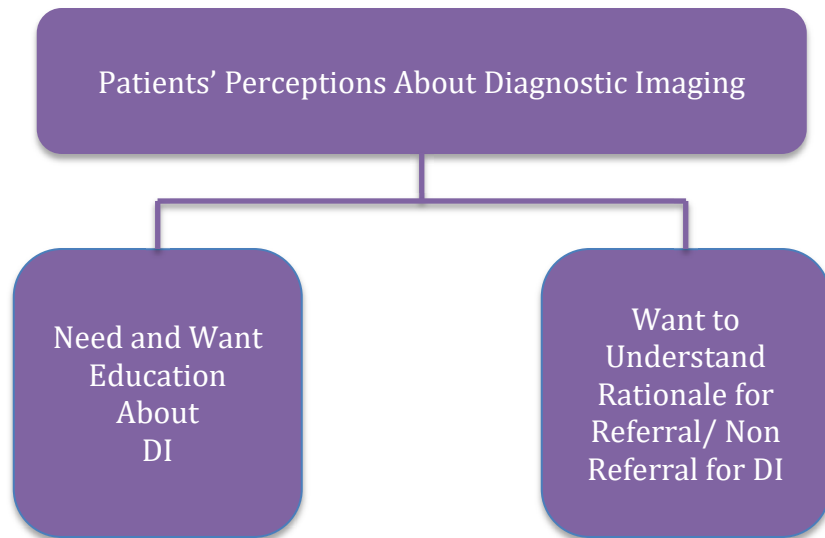


Figure 4

I. *Need and Want Education about Diagnostic Imaging*

Throughout this study it became obvious to the research team that few patients had any knowledge of the differences among the various diagnostic imaging procedures that are now available for patients. Such lack of knowledge may be one reason that MRI is seen as the “gold standard” by most patients who, not surprisingly, demand this procedure without understanding that it may not, and probably is not, indicated by their symptoms. In discussions they started to believe that it would be important for them to understand more about the different procedures that their primary physician could order for them as well as the possible risks of unnecessary radiation. It seemed that increased knowledge of such procedures and the possible risks, explained by their primary physician, would be beneficial in decreasing the demand by patients not only for an MRI but any diagnostic imaging.

Table 13

Sub Theme	Exemplar Quote
Patients need and want education about DI	<p>51) <i>The reports I have seen (when I paid for MRI) are Greek to me. Doctors have to explain everything to you so you can understand what is happening in your body. It is my body I want to know.</i></p> <p>45) <i>Why don't they give you a full body examination when they are using the machine. Let's do a whole picture – everything that is going on. If you are having an MRI why not a full scan?</i></p> <p>46) <i>the Caleo Triage surgeon explained everything to me. I had never seen or heard any of the other reports for all the tests or X-rays I had had.</i></p> <p>1525) <i>Is there argument in the medical field about the diagnostic tool for back pain?</i></p> <p>1068) <i>What is the difference between a CT and an MRI? I got</i></p>

	<p><i>sent for the CT after the MRI to get more info and I asked “Why didn’t you just send me for the CT first?” The thing is that the MRI was supposed to show more but I ended up going for the CT.</i></p> <p><i>1070) I hate going for stuff I don’t know what I’m going in for. When I look at a new machine and I’ve got to get in there...I’m not real comfortable with it...</i></p> <p><i>1071) I think the CT from what I’ve read is more detailed. So that is a good point, why go for the MRI?</i></p> <p><i>R39 Cat scan patients should be advised about the radiation exposure.</i></p> <p><i>R40 We need an info pamphlet explaining the procedures in layman’s terms</i></p>
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II. Want to Understand Rationale for Referral / Non Referral for Diagnostic Imaging

This sub theme, although closely allied to the previous sub theme indicates the need for the primary physician to explain to the patient the reasons why they either need or do not need any particular diagnostic imaging procedure. Patients expressed frustration when their physician indicated they did not need a DI procedure and failed to explain why it was unnecessary. This omission led to the belief that they were not being taken seriously or that they were not believed. Those few patients who received an explanation were less likely to demand a DI examination during future visits for their LBP.

Table 14

Sub Theme	Exemplar Quote
<i>Rationale for Referral/non Referral for DI</i>	<p><i>1508) Do I have to be paralyzed before I get an MRI? You can’t do that...I don’t want to get there...</i></p> <p><i>147) Well I think I should have had x rays anyways to see if it is arthritis. If it is arthritis you got to treat it accordingly. I don’t think it’s anything different. Just the burning that bothers me but it does bother me mentally.</i></p> <p><i>1524) but if an MRI does everything why not have it done and find out what it is and be able to get treated faster, even though MRIs are expensive maybe it would be cheaper in the long run?</i></p> <p><i>1535)...when I first went to my physio...she said you really should go for an MRI because you’re not responding the way I expected you to... why would a doctor would outright say no when the physio says that you need it and they’re the experts...</i></p> <p><i>1334) The sad part of not being able to get the MRI when you</i></p>

	<p><i>should have and kind of the alternative is going to the emergency room...you're sitting there and tying up another system...all they're doing is diverting you to another system instead of getting to it...</i></p> <p><i>1380) What about the criteria for them to request an MRI? I think they do triage and unfortunately low back pain is the last thing...</i></p> <p><i>R44 I believe each patient would be better equipped to go through the process (DI) if they knew why the decisions are made the way they are.</i></p> <p><i>R46 It's often heard from GPs that we don't need DI and that it's expensive. We need to know why we don't need DI</i></p>
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Major Theme 5: Patients Need Physicians to Understand The Impact of LBP on Their Lives

This major theme has three sub themes. It is included in this study because our participants held a deep belief that their primary physicians did not understand how their lives were impacted by LBP. Few patients, when asked by researchers ever talked about this aspect of their LBP with their primary physicians. When asked why, they stated that they did not wish to appear lazy, a wimp, or a whiner. All of these patients knew they were not mortally ill, but they believed that their primary physicians had little, if any recognition, of the major negative impact LBP had on their lives.

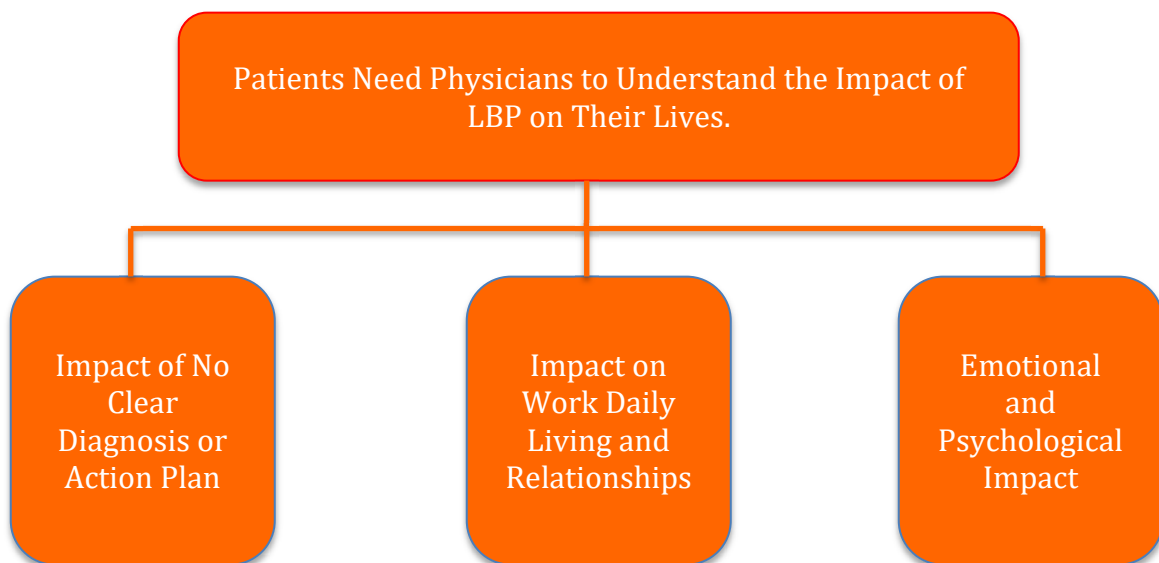


Figure 5

I. Impact of No Clear Diagnosis or Action Plan

Participants saw that one of the biggest challenges in dealing with their LBP was the feeling that nothing was being done, that they were helpless and constantly seeking some way of relieving their pain and managing their lives. They believed that if their primary physicians were aware of their despair they would be more inclined to spend time helping them come up with an action plan. Patients said that just being told to go to a physiotherapist or chiropractor was not enough help to set them in the direction of managing. This is why they kept returning to their primary physician and in some cases changing physicians.

Table 15

Sub Theme	Exemplar Quotes
Impact of No Clear Diagnosis or Action Plan	<p>22) <i>All this time I was in pain and you can't do the simple things because of your pain. How long do you put up with that?</i></p> <p>95) <i>You wait with no idea what is happening and your pain gets worse and so does the rest of your body.</i></p> <p>855a) <i>From my point of view anyways there isn't anything that you can do for low back pain. (sigh -It's depressing)</i></p> <p>1384) <i>For them (doctors) it's clinical for us it's real life.</i></p> <p>SI38 <i>I feel like my life is on hold...</i></p> <p>SI63 <i>It's scary I'm only 30 and that I might have to do this for the rest of my life or that it might get worse and how do you manage that trying to do some long term planning?</i></p> <p>SI66 <i>The unknown is terrifying...it would be lovely to get a diagnosis...I</i></p> <p>R41 <i>No action plan takes away the sense of hope for the patient. The sense of empowerment in their ability to improve their own condition.</i></p> <p>R43 <i>This is a big problem (for me). There is no clear plan and differing opinions of what's wrong and what to do about it effect me a lot – lack of sleep, affect on relationships, work and my view of life.</i></p> <p>1466) <i>It changes your life...You go from being a happy person to a terrible person.</i></p>

II. Impact on Work, Daily Living, and Relationships

Patients described the changes in their lives, the reality that they can't work, the effect of their condition on family life and relationships with spouses and children as they are no longer able to fully participate. Once more there a general belief that

LBP, especially if surgery is not an option, is viewed as a minor inconvenience not the “game changer” most described.

Table 16

Sub Themes	Exemplar Quotes
Impact on Work, Daily Living and Relationships	<p>28) <i>It's (LBP) is a game changer for your relationships. Your family should not have to change their lives because you feel like crap</i></p> <p>36) <i>If I want to do this or that, how many days will I be in pain? It's all a trade off.</i></p> <p>1129) <i>I can't work because I can't sit for long periods of time. I can't take a job where I have to stand for a long time either.</i></p> <p>1468) <i>You become grumpy and take it out on people that have nothing to do with it.</i></p> <p>SI68 <i>right now it is so hard to work because I'm so tired and dealing with pain and the pain medications make you tired. I work most of the week and on the weekends I need to sleep so I don't have much of a social life because I'm trying to manage my energy to work and that's really hard to deal with.</i></p> <p>1471) <i>You turn into a different person...it affects your relationships and family matters...</i></p> <p>E190: <i>It was surprising how dependent I was from other people... Someone to get you out of the chair and someone to help me go to the bathroom I couldn't sit on the toilet...I have never knew a sneeze could be so painful...</i></p> <p>SI77 <i>if you have a cancer diagnosis you have all these supports but when you don't know where to turn...you feel like your life is in limbo</i></p> <p>SI85 <i>I feel like I'm hanging on by my fingernails to keep working so I will do whatever I can to keep my job. I enjoy my work and it gives me a lot of meaning...hopefully I can get a bit of my social life back...it's really hard to explain with people that have never been through this process before...I'm really young too and there's not a lot of people that have witnessed what it's like...it can be very isolating effect when you have to keep cancelling out of things.</i></p>

III. Emotional and Psychological Impact

Most of the participants in this study stated that they believed they were depressed and anxious, however few were receiving any treatment for these conditions. They saw the depression and anxiety as simply part of their LBP experience and were reluctant to discuss these issues with their primary physician. Once more the fear of

being stigmatized as lazy, complainer or whiner appeared to be a stumbling block. A few participants related that they had tried to explain to their primary physician about their depression related to their LBP but had chosen not to go forward when they were told it was a separate issue and they had to make a separate appointment to discuss it.

Table 16

Sub Theme	Exemplar Quote
Emotional and Psychological Impact	<p>25) <i>It's depressing to watch the family struggle because you can't do things with them.</i></p> <p>62) <i>The moment you are injured you are treated differently</i></p> <p>71) <i>when you are younger, you complain but you say in your mind it really doesn't exist. When a bit older you start to get depressed. It (pain) doesn't go away.</i></p> <p>1461) <i>When I first got the pain all over my body it was terrifying...no one knew what it was and I had to deal with this...if I'd known what it was it wouldn't have had as much stress...</i></p> <p>S171 <i>sometimes it's this feeling of abandonment</i></p> <p>S192 <i>it's really hard because there are times when it feels terrifying...but I try to think about what I do have control of and what can I do to help me get through this.</i></p> <p>R55 <i>The emotional impact is huge. It is the white elephant in the room – it is what wimps, complainers and whiners have and is not a valid issue.</i></p> <p>R56 <i>There is very little validity to this complaint and typically the end result is depression and low self esteem.</i></p> <p>R57 <i>Because it is an invisible condition, you are looked at as a complainer and lazy etc. You feel alone and useless.</i></p>

Discussion

Many of our research findings conform to themes identified in previous research including: a trusting relationship with the primary physician (Georgy et al., 2011; Dima et al., 2013; Ferriera et al., 2012); reassurance patient has been heard (Toye & Barker, 2012; Cherkin & MacCornack, 1989; Amirdelfan, McRoberts & Deer, 2014); LBP patients' need for clarity and a diagnosis (Dima et al., 2015; Farin, Gramm & Schmit, 2013); diagnostic education for patients (Tapp, 2014; Deyo, 2013); patient responsibility (Dima, 2013); and multidisciplinary LBP clinics (Kamper et al., 2014; Toye & Barker, 2012; Engel, 1977). This study covers multiple aspects of low back pain as it affects patients and gives a complete picture of their experience.

As noted in our methods section PaCER used a Reflect focus group, not only to

check on the findings, but also to allow patient participants to discuss the findings and allow theory to be formed. As our participants went through making notes and discussing the five major themes and sixteen sub themes we had identified, it became clear that the theory developing around their experiences grew into “Into the Frenzy Without a Clue”. Participants acknowledged that some patients (those with red flag symptoms) consulted with their primary physicians and were guided onto an established clinical pathway that included diagnostic imaging and referral to a surgeon. Our patient participants, who had no red flag symptoms, consulted with their primary physician, received no diagnosis or action plan and were sent out, sometimes with pain medication, into the confusing and unpredictable world of alternative treatment. They were given little, if any guidance, about whom to consult be it chiropractor, physiotherapist, acupuncturist, massage therapist etc. and there was no indication which route would be most beneficial or which alternative therapists were competent specialists in low back pain. Many of our participants tried multiple therapists, spending large sums of their own money, to no avail. Each time there was a failure they went back with decreasing confidence and increasing frustration to their primary physician who had no choice but to send them back out into the frenzy. Few of our participants found satisfactory alternative treatment and their low back pain moved into a chronic condition.

The majority of our participants wanted to be partners in their recovery, and were willing to work hard, but felt there was no support or direction for them to do so. Their self esteem and belief in their ability to cope decreased each time they returned to their primary physician with no progress. This is when they tended to start demanding medical tests and interventions, which are of low value in resolving non red flag low back pain. Thus tension between primary physicians and low back pain patients developed, with some patients changing primary physicians while others perceived their physicians had no power to help them. Development of an alternate care clinical pathway would ameliorate this situation for non red flag low back pain patients, would stop the primary physicians’ revolving door and potentially save health dollars and the high economic impact of low back pain. Taking a salutogenic approach (Antonovsky, 1979) to low back pain where the stressors of low back pain (mobility issues, pain, depression, anxiety, inability to work or function in daily life etc.) were recognized and addressed could open the door for low back pain patients taking more responsibility for their recovery and wellbeing.

Based on our findings and Reflect discussion, it might be beneficial as we move forward to improve low back pain care, to investigate the literature relating to the discussion about the benefits of using a biopsychosocial model of care for low back patients rather than the existing biomedical model.

Strengths and Limitations

This study was conducted through all phases of the research by patients with low back pain who, as noted above, were continuously reviewing and discussing their

biases. Recognition by participants that the researchers shared their experience of living with low back pain may have allowed participants to openly share their lived experience at a deeper level than would have been possible with “traditional” health care researchers. There was no perceived power imbalance and both researchers and participants were focused solely on patient concerns and perspectives (Gillard, Simons et al., 2012; Berger, 2015). The direction of the research was driven by the patient participants and they were an integral part of the analysis process (Marlett, Shklarov et al., 2014). Despite the relatively small number of participants, the data is authentic, thick and rich and saturation was reached prior to the two semi-structured interviews.

We did have some representation from the north and south of Alberta but results would benefit from a wider spread of participant experience. Transferability of the findings may be limited as the participants were all from the same large healthcare system (Alberta Health Services) so there may be differences in service delivery within other systems. Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended.

Further Work

This study was initiated and the report developed to inform interventions for improving low back pain patients’ service experiences within the province of Alberta. Using the information, in collaboration with the parallel physicians perspective study, we hope to work with patients and primary physicians to develop interventions that will be of benefit to both patients and primary physicians.

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