

The physical and psychological impact of neurogenic claudication: the patients' perspectives

Carlo Ammendolia, DC, PhD¹

Michael Schneider, DC, PhD²

Kelly Williams, MPH³

Susan Zickmund, PhD⁴

Megan Hamm, PhD⁵

Kent Stuber, DC, MSc⁶

Christy Tomkins-Lane, PhD⁷

Y Raja Rampersaud, MD⁸

Background: The patient perspective regarding the impact of neurogenic claudication (NC) has not been well studied. The objectives of this study were to determine what is most bothersome among patients with NC and how it impacts their lives and expectations with surgical and non-surgical treatment.

Methods: Semi-structured telephone interviews were

Contexte : Le point de vue du patient concernant l'effet de la claudication neurogène (CN) n'a pas fait l'objet d'études poussées. Les objectifs de cette étude étaient de déterminer ce qui gêne le plus les patients atteints de CN, ainsi que les répercussions sur leur vie et leurs attentes vis-à-vis des traitements chirurgicaux et non chirurgicaux.

Méthodologie : Entrevues téléphoniques semi-

¹ University of Toronto, Institute for Health Policy, Management and Evaluation, Faculty of Medicine

² University of Pittsburgh, Department of Physical Therapy and Clinical and Translational Science Institute

³ University of Pittsburgh, Department of Behavioral and Community Health Sciences, Graduate School of Public Health

⁴ Informatics, Decision-Enhancement and Analytic Sciences Center (IDEAS 2.0), Health Services Research and Development Center of Innovation, 2C21 Building 2, Salt Lake City VA, Salt Lake City, UT

⁵ University of Pittsburgh, Department of Medicine, Center for Research on Health Care

⁶ Canadian Memorial Chiropractic College, Division of Graduate Education & Research,

⁷ Mount Royal University, Department of Health and Physical Education

⁸ University of Toronto, Division of Orthopaedic Surgery, University Health Network-Arthritis Program

Corresponding author:

Carlo Ammendolia

Mount Sinai Hospital, 60 Murray Street Suite L2-225 Box 7, Toronto Ontario, Canada

Phone: 416 586-4800 ext. 6759

E-mail: Cammendolia@mtsinai.on.ca

© JCCA 2017

The authors' report no related conflict of interest. The following organizations have provided funding for this research: The Canadian Chiropractic Research Foundation (Ammendolia), NCMIC Foundation (Ammendolia and Schneider) and the Veterans Administration Health Services Research and Development Program, award number 5150HX001240 (Zickmund) and The Toronto General and Western Hospital Foundation (Rampersaud).

conducted, audio recorded and transcribed verbatim. A thematic analysis categorized key findings based on relative importance and impact on participants.

Results: Twenty-eight individuals participated in this study. Participants were most bothered by the pain of NC, which dramatically impacted their lives. Inability to walk was the dominant functional limitation and this impacted the ability to engage in recreational and social activities. The most surprising finding was how frequently participants reported significant emotional effects of NC.

Conclusions: From a patients' perspective NC has a significant multidimensional effects with pain, limited walking ability and emotional effects being most impactful to their lives.

(JCCA. 2017;61(1):18-31)

KEY WORDS: chiropractic, spinal stenosis, neurogenic claudication, outcome measurement, qualitative research

Introduction

Neurogenic claudication (NC) is the clinical syndrome associated with symptomatic lumbar spinal stenosis (LSS). It is characterized by bilateral or unilateral buttock, thigh or calf discomfort, pain, numbness or weakness precipitated by walking or prolonged standing and relieved by sitting and lumbar flexion.^{1,2} Low back pain may or may not be present in individuals with NC. The pathophysiology is thought to be compression and/or ischemia of the lumbosacral nerve roots due to narrowing of the lateral and central vertebral canals, usually as a consequence of degenerative osteoarthritic changes in the lumbar spine.^{1,3} Neurogenic claudication due to LSS is one of the most common causes of disability and loss of independence in older adults⁴ and the most common reason for spine surgery in this population⁵.

New cases of NC due to LSS are expected to rise

structurées avec enregistrement audio et transcription textuelle. Une analyse thématique a permis de catégoriser les principales conclusions selon l'importance relative et les répercussions sur les participants.

Résultats : Vingt-huit personnes ont participé à l'étude. Les participants étaient surtout gênés par la douleur de la CN, qui a d'énormes répercussions sur leur vie. L'incapacité à marcher constituait la limitation fonctionnelle dominante qui avait des conséquences sur la capacité à réaliser des activités récréatives et sociales. La conclusion la plus surprenante était la fréquence à laquelle les participants ont déclaré d'importantes séquelles émotionnelles associées à la CN.

Conclusions : Du point de vue des patients, la CN présente d'importants effets multidimensionnels avec la douleur, la capacité de locomotion limitée et les séquelles émotionnelles comme répercussions les plus considérables sur la vie des patients.

(JCCA. 2017;61(1):18-31)

MOTS CLÉS : chiropratique, sténose rachidienne, claudication neurogène, mesure des résultats, recherche qualitative

dramatically over the next 20 years when an estimated 25% of the population in both the U.S. and Canada will be over the age of 65.⁶ Studies evaluating the effectiveness of both operative and non-operative treatments for NC have used a wide variety of primary and secondary outcome measures.⁷⁻¹⁰ These outcome measures assess various constructs including bodily pain, bodily function, low back pain disability, back and leg pain, other leg symptoms, walking capacity (distance and time), walking performance, global improvement, quality of life, ranges of motion, treatment satisfaction and medication use.

In most studies the outcome measures used are reflective of the bias of the investigator(s) and is often inferred as the desired outcome of the patient. However, rarely has the perspective of the patient regarding the most important outcome been considered. For example, limitation in walking is felt to be the hallmark of NC and is used as a

primary outcome measure in clinical trials.^{7,11,12,28} However, previous systematic reviews by this group^{7,11,12} have demonstrated that many interventions for NC did not significantly improve walking performance or capacity. Despite this, several interventions were still associated with good patient satisfaction and/or pain relief.

Given the burden of NC, a lack of understanding of what outcomes are most important to those afflicted with NC represents a significant gap in both clinical and academic knowledge. Clinicians need to know what is most important to a patient in order to recommend effective intervention(s) that address the patient's concerns. Researchers need to know what to measure in order to assess the most relevant patient outcome for a given intervention. Moreover, to make valid comparisons across studies and enable the pooling of data, a standardized set of outcome measures unique to this population and most relevant to patients is essential. In addition, there may be other constructs beyond those currently measured that may help to explain how this condition impacts people in different ways, and how these other factors can affect the patients experience and outcomes of NC.

The objectives of this study were to determine what outcomes matter most among individuals with NC due to LSS and to assess patients' expectations and their experiences with surgical and non-surgical treatment.

Methods

Participant population and setting

We recruited a purposeful sample¹³ of participants from two university-affiliated hospital surgical and non-surgical spine clinics both located in Toronto, Canada. To be eligible to participate, patients had to experience NC with axial imaging-confirmed LSS, and be able to communicate in English. To gain maximum variation of patient perspectives regarding their condition and success with treatment an attempt was made to select participants along the continuum of care. Specifically, we recruited participants scheduled for non-surgical (early, less severe symptoms) or surgical care (late, more severe symptoms), as well as those who had received surgical and non-surgical treatment. We included individuals of varying ages (50-90 years), gender, intensity and type of symptoms, as well as duration of symptoms (months to years).

All participants provided written informed consent.

Research Ethics Board (REB) approval was received from the Mount Sinai Hospital REB Registration Number 13-0184-E and University Health Network REB Registration Number 13-6914-BE, as well as the Institutional Review Board (IRB) at the University of Pittsburgh (PRO13090531).

Semi-structured interviews

Research assistants, trained by a qualitative research expert (SZ), conducted semi-structured telephone interviews lasting between 40 and 60 minutes. Interviews were audio recorded, and transcribed verbatim. Interviewers followed a standardized set of open-ended questions asking participants about their condition, focusing on what bothered them most and expectations regarding treatment. Figure 1 outlines a sample list of open-ended questions that were used.

Quantitative measures questionnaire

A questionnaire was administered by telephone directly following the completion of the semi-structured inter-

1. What things bother you most about your lumbar stenosis (condition)? Degree of pain in your back or legs? Functional ability? Walking ability (distance), independence? Getting up from chair? Posture? Balance? Falls? Medication used? Overall health?
2. If you had to pick one important thing that bothers you most what would that be? How has your condition changed over time? What would be the least thing that bothers you about your lumbar stenosis?
3. What aspects of your condition would you like your treatment to address?
4. What type of treatment did your specialist recommend? What treatments have you received? How effective have the treatments been?
5. How would you measure the success of your treatment?
6. What would you consider the smallest improvement that would be worthwhile following your treatment... for each of the important outcomes you mentioned?
7. How much do you expect that things that bother you the most will change with your treatment?

Figure 1.

Sample questions for the semi-structured interviews.

view. The aim of the questionnaire was to characterize the participant sample with respect to demographics, duration of symptoms, pain intensity and functional status and to compare surgical and non-surgical participants. Box 1 below lists the measures included in the questionnaire.

Analysis

Descriptive statistics were used to analyze the questionnaires. We compared pain, function and symptom outcomes among and between participants recruited from surgical and non-surgical clinics.

For the semi-structured interviews the frequency and types of responses were determined using the Crabtree and Miller “editing” approach to qualitative data.¹⁸ Coding categories were developed through an open, iterative process that involved reading the interviews with a focus that included physical and emotional effects of NC. From this process, a master code list of categories was developed. These codes were refined with inclusion and exclusion criteria, and then applied to the transcribed interviews. Two analysts [KW and MH], the qualitative expert [SZ], and the study team discussed the coding categories (e.g. coping) and worked to integrate the codes into the larger analysis.

Primary coding was completed on all transcripts, and secondary coding was completed on 25% of the transcripts. Cohen’s Kappa statistics¹⁹ were then calculated

Box 1.

Quantitative questionnaire measures

Socio-demographic characteristics
Dominant pain location (back or leg)
Duration of symptoms
Numerical rating scale for back pain with and without activity ¹⁴
Numerical rating scale for leg pain with and without activity ¹⁴
Zurich Claudication Questionnaire ¹⁵
Oswestry Disability index ¹⁶
Modified Patient Centered Outcome Questionnaire ¹⁷

Table 1.
Characteristics of study participants

Characteristics	Summary (N= 28) n= count (%) unless otherwise specified
<i>Age Range (y)</i>	
50-59	1 (3.6)
60-69	13 (46.4)
70-79	10 (35.7)
80-89	3 (10.7)
90-99	1 (3.6)
Female	15 (53.6)
Married or living with other	16 (67.9)
<i>*Education (N=27)</i>	
< Grade 8	1 (3.7)
> Grade 8 but did not graduate from high school	1 (3.7)
High school graduate	3 (11.1)
Post-Secondary school	10 (37.0)
Technical graduate	1 (3.7)
University graduate	11 (40.7)
<i>*Employment</i>	
Full Time	4 (14.3)
Part-time	2 (7.1)
Retired	20 (67.9)
Disability Leave	2 (7.1)
Other	1 (3.6)
<i>Dominant Pain</i>	
Legs	16 (57.1)
Back,	3 (10.7)
Back & Legs	9 (32.1)
<i>Duration of symptoms impacting standing/walking (years)</i>	
0-1	4 (14.3)
1-	11 (39.3)
5+	13 (46.4)
Usual Mean Numeric Pain Score (SD) (N=26)	5.1 (2.9)
<i>Walking duration before symptoms (minutes)</i>	
0-5	6 (22.2)
5-10	6 (22.2)
10-30	9 (33.4)
30-60	4 (14.8)
60+	2 (7.4)
Spinal Stenosis Score (symptoms) (sd)	2.8 (0.7)
Spinal Stenosis Score (function) (sd)	2.1 (0.7)
Oswestry Disability Index (sd)	40.2 (16.8)
Oswestry Disability Index Walk Score (range 0-5) (sd)	2.9 (1.8)
<i>Source of Participants (N=27)</i>	
Non-surgical clinic: receiving treatment	5 (18.5)
Non-surgical clinic: completed treatment	10 (37.0)
Surgical clinic – had surgery	7 (25.9)
Surgical clinic – scheduled for surgery	2 (7.4)
Surgical clinic – not scheduled for surgery	3 (11)

Legend:
SD= standard deviation. Variable number of responses due to missing data
*characteristics with categories that are not mutually exclusive

Table 2.
Comparison of non-surgical and surgical clinic participants

Mean (SD)	Mean Usual overall NPS (0-10)	Mean SSS Symptoms (1-5)	Mean SSS Function (1-4)	Mean ODI (0-100)	Mean ODI Walk (1-5)	Mean Usual Interference with activity (0-10)	Duration of symptoms impacting walk/stand Years n, %
Non-surgical clinic n=16	5.2 (2.8)	2.9 (0.6)	2.0 (0.7)	37.6 (14.8)	2.8 (1.8)	4.6 (4.1)	0-1 2, 12.5% 1-5 8, 50.0% 5+ 6, 37.5%
Surgical clinic n=12	4.9 (3.1)	2.7 (0.8)	2.3 (0.8)	43.7 (19.3)	3.0 (2.0)	5.1 (3.9)	0-1 2, 16.7% 1-5 3, 25.0% 5+ 7, 58.3%
All participants n= 28	26	28	28	28	28	26	28
p-value (from T-test or Chi-square)	0.82	0.33	0.25	0.36	0.79	0.78	0.40

Legend:

NPS= numeric pain scale (higher score worse pain), SSS= Spinal Stenosis Score (higher score worst symptoms/function), ODI= Oswestry Disability Index (higher score worst disability/walk ability), SD= Standard Deviation

on each code to determine inter-coder reliability. A mean Kappa score of 0.71 was obtained, indicating substantial agreement.¹⁹ Discrepancies in coding between the analysts were resolved via discussion and then recorded in a final dataset for use in the analysis. Coded passages were then examined to better understand patients' views and perspectives. The software program *Atlas.ti* (Scientific Software, Berlin, Germany) was used to assist in data organization and management. Quotations were chosen based on representativeness and their capacity to convey common participant views and themes.

Results

Participant characteristics

A total of 28 participants agreed to participate in a phone interview and complete a questionnaire. Table 1 describes the characteristics of the participants. Sixteen were recruited from a non-surgical clinic and 12 from a surgical clinic. The majority of participants (82%) were between 60 and 79 years of age, 54% were female, 68% were retired and over 80% received post-secondary education. Most participants reported that their dominant symptoms involved chiefly the leg(s) (57%) or their back and leg(s) equally (32%). Almost half of the participants had symptoms for more than five years and over 75% ex-

perienced symptoms within 30 minutes of commencing walking. Participants from the surgical clinic appeared to have greater functional limitations and longer duration of symptoms compared to participants from the non-surgical clinic (see Table 2).

Major themes from interviews: Participants' experiences with LSS (see Quotes Table 3)

1. Physical effects:

The most commonly reported symptoms were pain and discomfort; mentioned by each of the 28 participants. The location of the pain varied but included lower back pain and leg pain. Other reported discomforts included: tingling, leg and knee failure (i.e. sudden inability to stand, sit or walk, including falling), burning, a sensation of something crawling just under the skin (i.e. paresthesia), and a sensation of fullness or heaviness in the legs (Table 3: Theme 1 Quotes A.1-3). Problems with fatigue centred on the legs or other body parts tiring quickly such that walking for long distances or, in the case of a school teacher, standing at work all day became impossible (Table 3: 1 A.4-5).

While a few participants did not describe their pain from stenosis as particularly intense, most regarded their pain as debilitating. One described it as "pure hell." For some participants the pain had always been intense, whereas for

Table 3.
Example quotes from participant interviews

Theme	Example Quotes from Participant Interviews
<p>1. <i>Physical Effects</i></p>	<p>A. Symptoms of Pain, Discomfort:</p> <ol style="list-style-type: none"> 1. "It's the pain in my leg and also there is times that when I have to go to the washroom; excuse me; that I have to sit. It's my knees; like sometimes I can hardly sit down on the toilet and sometimes it's hard for me to get up. Let's say, if I sit down on the chair, I'm fine, but then when I have to stand up, I cannot stand up or when I start walking, it's hard to walk. When I feel better it's when I'm lying down or sitting down, but then when I'm sitting down and then stand up and starting walking that's the worse part." 2. "A burning feeling say from the top of the leg to the knee. A feeling that there was something crawling, as if they were bugs just underneath the surface of the skin crawling up and down and you know, it was pretty disconcerting." 3. "Like I said it started in 2010 and I had often a lot of back pain, lower back pain. It went down into my left leg, but it was also accompanied by numbness in both legs, so severe at times that I would lose the feeling in both my legs and I would fall and go down." 4. "Not being able to walk as far as I would like to without having to stop and experience the tingling in the front of my leg and the numbness in my foot and the pain associated with it." 5. "When I first started the clinic here, I could not walk for than a minute and a half and I had to stop. My legs would swell. My feet would hurt that the sciatic nerve in my back would almost pull me down that it would cripple me. Even to walk, I work at [Name of Location] and to walk here I got to stop 6 or 7 times and this is me, I'm use... to running that distance." 6. "It started I suspect 5 years ago, as a minor back pain. One usually would think it is just a strain, but over the years it has gradually progressed to the point where now it is very debilitating." 7. "Now I've had that for very many years, but it's always been bearable. The stenosis has really affected my daily life and it makes me sad at times, such I have to contend with it. At the same time, I must honestly admit that I am grateful for the health I've had. I realized that I have been very lucky. So, I can't have it always, but at the same time its human nature to resent it that I get such pain all the time."
<p>2. <i>Activity Effects</i></p>	<p>A. Limitations on Walking/Standing/Sitting:</p> <ol style="list-style-type: none"> 1. So I really, I can walk may be 4 or 5 minutes. It's really tough on my lifestyle. I used to love to walk. Me and my wife used to walk for miles... and now I cannot walk a block." 2. "Like I say everything depends on my legs because I walk and I'm one of them simple people; I don't do anything. I don't travel. I have no interest in that." 3. "Well it affected my ability to get around and walk... It affected my exercising, which is walking. I do quite a bit of walking for exercising and I just love to walk. I get out and I walk all over the place... Now, I go around in the car... I take the dog. Instead of walking about three blocks to take my dog out to run, I take the car there to let her run." <p>B. Limitations on Recreational Activities:</p> <ol style="list-style-type: none"> 1. "Usually each weekend in the summer I'm outside... in the canoe or with backpack you know, but now I am sitting at home." 2. "When it first started what it did curve is my physical activities such as curling and walking long distances and so on, and eventually it curved all activities that even stairs were very difficult to manage." 3. "...we were in a wedding and I was dancing. It was a slow dance and it seemed that my legs were giving up on me. I was shocked and I didn't know what was happening. I had to go and sit down." 4. "Because I wasn't able to, say, walk any distance, so that pretty well inhibited, so you were sort of left with sedentary hobbies like reading and crocheting that sort of thing because you've found that you've gravitated towards that than avoiding the physical."

Theme	Example Quotes from Participant Interviews
<p>2. <i>Activity Effects</i> (continued)</p>	<p>C. Limitations on Social and Household/Daily Activities:</p> <ol style="list-style-type: none"> 1. "It changed my lifestyle because you know, as I said before I was very cheerful. I like friends. I like being among people. I am [a] social person. I'm a socializing person and all this pain and weakness, like, it stopped me from being among people." 2. "One of the major and also major things that really bothered me a lot; my granddaughter had a child, two and half years ago and also I'm crazy about babies. I found that profoundly sad that I couldn't hold the baby. I cannot even lift him of course...I cannot lift him." 3. "Well, it affected me to the point where I couldn't go walking with my wife for more than a block and a half and standing around talking or when we go to parties, I would stand talking then I would have to sit down because I just couldn't stand up anymore after a while." 4. "Well, I love to garden. I kind of filled in my flower beds with rocks because that's just another thing I can't do." 5. "I couldn't do my usual home activities like cooking. I depended on my husband to assist me with the cooking and housework and things like that." 6. "Eventually it got to the point where I couldn't even rinse off three cups, three bowls, and put them into the dishwasher. I couldn't stand up long enough with that pain." 7. "Or go shopping, I used to go by myself for the shopping and now I got to go with my husband or my son because I realized that I cannot take shopping bags or heavy things. I used to do my grocery shopping and now I got to go with my husband. Why? Because I cannot lift anything." 8. "I think on a daily basis is that I cannot shower, dry my hair, and put on my makeup without sitting down and that kind of happened in the last few months. I have to take a break, you know sit down for 5 or 10 minutes. We put a stool in the bathroom, so that I can sit and do my makeup and stuff like that."
<p>3. <i>Emotional Effects</i></p>	<p>A. Depression/Social Isolation:</p> <ol style="list-style-type: none"> 1. "Really, it's a miserable life, miserable. I don't wish this to no one... The worst thing is... how people see you in the outside; your face, they think you're not sick; you're not suffering, but inside you are suffering. I have a life, but it's not life because you cannot do what you want to do... I was a very active woman and which right now I feel inside of me, I feel 90 years old. I feel terrible, like inside because I want to do things with eyes and with my mind, but then when I start doing things it stops me from doing them." 2. "My life is not the best, you know. Sometimes if I want to go out or let's say go to parties or if I am invited to parties, sometimes I avoid it. I don't feel like do nothing. I rather stay home and do whatever I can." 3. "I can't take part in my church activities in the same way that I did. I tend to give money instead of labour and I know you have to give what you can, but that's all I can give, but it grieves me. I rather be in there with all the other women doing things. It upsets me very much." 4. "Well, I have hard times walking and I feel a little out of place when I can't go that fast anymore. I have to stop or I have to sit down or I have to do something like that. It sort of puts me in a different area than the friends that I'm with who can do all this stuff." <p>B. Anxiety:</p> <ol style="list-style-type: none"> 1. "Well, I guess there is an underlying stress all the time that you know, I'm waiting for an operation and it may not be and it's probably not going to be 100% successful, so it is a gradual accommodation to the fact that this is who I am now." 2. "Well, it's yes, but not that fine. Before it was the walking, I felt like I was going to be kind of paraplegic that I wouldn't be able to do things myself and I would have to sit in one of those electronic chair things." <p>C. Frustration:</p> <ol style="list-style-type: none"> 1. "The first time I had it I thought it was a condition that I was fighting that I would get rid of it, which I did and it would go away, but it has been there all the time. The lack of information I had at that time was, I would get free of this, but eventually I knew that I got this for life. This is something you inherit for life. It is threatening and it is very debilitating." 2. "You had to this, this and this and I thought quite naively that if I did the regimen while I was taking physiotherapy then when we were finish we were finish and that was good... I would be cured. I <u>did not realize</u> that this was an ongoing thing that just got worse when I stopped doing it."

Theme	Example Quotes from Participant Interviews
<p>3. <i>Emotional Effects</i> (continued)</p>	<p>D. Hurt Pride</p> <ol style="list-style-type: none"> 1. "It affects in so many ways, it's the whole quality of life, the whole thing. Your wife is dependent on you, your kids and grandkids are dependent on you for doing these things. Now all of a sudden this person who used to run with me and play with me and can't even walk down the end of the street with me and it takes a lot of your pride, well at least me it takes a lot of my pride. Even to think of someone having to take care of me, to me it's just unacceptable." 2. "I walk kind of awkwardly. I cannot wear heel shoes either, but that really does not bother me that much. All my days of heel shoes are really behind me, so that would be in anyway an older woman wouldn't be wearing fancy shoe anymore. I am the same as the other old ladies. You know it is awful giving up your autonomy and moving into a different phase. This is one of the reasons why I lie about my age all the time. People tend to put you in category of nature. If you are a certain age, you are just kind of put aside."
<p>4. <i>Coping Strategies</i></p>	<p>A. Coping Mechanisms for Physical Effects:</p> <ol style="list-style-type: none"> 1. "I have to... generally stand a few seconds or so before my husband is ready, maybe while he is doing the cheque... I stand right there waiting for him because if I get up there is no way I can start walking again because of the pain in my thighs. The front of my thighs is screamingly painful. I just stand for a minute or two and get my act together... I do walk strangely to begin with when I've been sitting down." 2. "My condition, you know the pain in my legs increased. I get tingling in my legs, sometimes pain, but I learned not to take painkillers. I don't take nothing. When I get like this, I just lay down, I rest for a bit and after rest I feel a little bit better."
<p>5. <i>Treatment Effects</i></p>	<p>A. Partial Relief from treatments:</p> <ol style="list-style-type: none"> 1. "It just involves may be 2 hours a day of specific exercise and walking and if you don't do it, you know you can't miss 2 days in a row because your symptoms all come back." 2. "...now having done the physiotherapy it's been a miracle. It is just wonderful. It's so much better. It will never go away, but at least I can do things that can help the pain and you know alleviate the different symptoms that occur." 3. "They helped, but it's not like they changed my life, either." <p>B. Complete Relief from Treatments:</p> <ol style="list-style-type: none"> 1. "I don't have this excruciating pain. I can walk up the stairs. I can run up the stairs. I can run down the stairs... since I had the surgery, this surgery, I have improved considerably and I am almost back to normal like a normal person."
<p>6. <i>Expectations from Treatment</i></p>	<p>A. Pain Relief/Decreased Pain</p> <ol style="list-style-type: none"> 1. "I try to keep an open mind that the treatment will alleviate the pain. If that happens, so much the better, but I am not counting on it to eliminate the pain. I will continue with the process and do the exercises and just hope for the best, but I haven't set a high level of expectations that this is going to cure me." 2. "I would like to think in doing the treatment that the pain level will be not necessarily gone, but certainly tolerable and not be something that I thought would stop me from doing what I wanted to do." <p>B. Pain Elimination</p> <ol style="list-style-type: none"> 1. "Based on my own experience, I would expect it to eliminate the problem. It did the first time and I would assume that it would the second time." 2. "Well, I would say significantly. It wouldn't make much sense to have an operation if it was not going to have much effect on the pain [in reference to surgery]." <p>C. Increased Physical Activity</p> <ol style="list-style-type: none"> 1. "That I can walk better. Walk with more distance and that I can stand on my own feet and do at least my housework. Taking care of my family properly. Instead of being in pain, when I'm standing or walking I'm in pain, but pain goes away. To relieve me from pain and suffering." 2. "Run around with the grandkids a little bit maybe, you know, maybe be able to do some things and not feel like I have to stop because of the pain in my leg" 3. "...consciously plan my route when I wanted to do an activity that I wouldn't have to very, very specifically, what is it that I need to do to accomplish today and how am I going to do it and not have my back stop me from doing it" 4. "Just to be able to stand around more without the pain and be able to walk farther without stopping because of the pain in my leg."

others it had gradually increased to the point of causing debilitation (Table 3: 1 A.6). In addition to concerns about the severity of their pain, participants described the emotional impact of the wearing, grinding nature of having to endure ongoing pain, including feelings of resentment (Table 3: 1 A.7).

2. Activity effects:

Participants mentioned a wide range of activities that their NC interfered with including: walking, recreational activities (such as sports and exercise), standing, social activities, household activities, controlling comorbid health conditions, working, sleeping and lifting.

Each participant mentioned that their NC interfered with their ability to walk. Interference with walking was most frequently mentioned as the “most bothersome” aspect of the condition, identified as such by 17 of the 28 participants. For some participants this was a minor concern or one that had affected them profoundly in the past but with successful treatment was no longer an issue. For many however, the walking limitations caused major disruptions in their lives, from being unable to walk or run for exercise, to being unable to do basic social and daily activities such as grocery shopping, holiday shopping, going to the mall with family and friends, or even visiting neighbors (Table 3: 2 A.1-3). Related to walking, many participants described being unable to participate in recreational activities. Recreational activities mentioned included walking itself or hiking, various sports (football, cricket, soccer, golf, badminton, curling, snowshoeing, cross-country skiing, squash), travel (due to the walking that travel entails), dancing, bicycling, and aerobics (Table 3: 2 B. 1-3). Many participants described themselves as active, outdoorsy people who, as a result of their NC, had become sedentary and were unable to participate in what had been previously seasonal outdoor activities (Table 3: 2 B.4). Inability to participate in recreational activities was mentioned as the “most bothersome” aspect of having LSS by 11 of the 28 participants.

Interference with social activities was mentioned fairly often, and was linked to participants' difficulties with walking, standing, or doing recreational activities. Many described limiting time with family and friends, difficulties standing while socializing or being unable to play with grandchildren in the way that they wanted (Table 3: 2 C.1-3). Often the inability to stand or pain upon standing was linked with an inability to do household/daily ac-

tivities, such as cleaning or other chores, in the way that the participants were used to doing. For many there was difficulty with transitioning between positions or activities, describing not being able to walk immediately after standing for example, or having extreme difficulty sitting and standing back up. This difficulty in transitioning made a wide range of activities difficult or impossible, from social events to using the toilet.

For some participants, the amount of pain experienced while standing meant that they could not wait in lines, go shopping without physical support such as a shopping cart or another person, clean their households, cook, or even stand in the bathroom to do their hair or makeup in the morning (Table 3: 2 C.4-8). This directly impacted individuals' sense of independence, and for some, eliminated activities that they had previously found enjoyable, such as cooking or gardening (Table 3: 2 C.4).

3. Emotional effects:

In addition to their physical symptoms, participants reported an array of emotional responses to their condition. Twenty-two of the 28 participants reported emotional impacts that were associated with their NC. The most frequent of these was depressed mood, although not always specified by name. Instead they described their feelings as sadness, loss of interest in activities, or hopelessness (Table 3: 3 A.1). These participants were likely to mention deep feelings of sadness, discouragement, social isolation or loss, as their NC prevented them from doing activities that they enjoyed (i.e., walking or other outdoor activities) or from which they derived meaning (i.e., work, volunteer work, being independent, socializing, lifting and holding grandchildren) (Table 3: 3 A.2-4). Additionally, for some of these participants, the perceived incurable/untreatable nature of NC was described as “depressing” in and of itself.

Eight of the participants mentioned anxiety, expressing deep worries that family members would have to take care of them, or that their condition would worsen significantly (Table 3: 3 B.1-2). Seven participants expressed feelings of frustration with their NC (Table 3: 3 C.1-2). For some, this was focused on the physical limitations imposed on them by NC, such as only being able to walk for short distances or the ongoing relationship between exercise and pain relief.

Lastly, six of the participants described NC as having hurt their pride. Most of these participants mentioned in

passing feeling embarrassed at having to rest frequently, or lamented the loss of complete independence (Table 3: 3 D.1). One participant had concerns about loss of independence that were so severe that he spoke favourably of assisted suicide. Similarly, another participant spoke of the embarrassment of dealing with NC in social situations, describing the limitations that always having to sit at parties imposed on her, and describing NC as having pushed her into an older, different phase of life (Table 3: 3 D.2).

4. Treatment effects, non-surgical:

Participants had experienced a wide array of treatments for their NC. The most common treatments were manual therapy and supervised exercise (rehab therapy), and pain medication (see Table 2). Of the two, rehab therapy was spoken of more favourably. Rehab therapy was described as significantly to relieving pain and increasing mobility. For some participants, it provided complete relief, although that relief was contingent upon continuing the therapy. Some participants noted that the frequency with which one had to do the therapeutic exercises was sometimes frustrating (Table 3: 5 A.1). For others, however, while rehab therapy did not provide complete relief, it reduced pain or discomfort in ways that were meaningful, such as allowing them to sleep at night, or increasing the distance they could walk at one time from under 100 metres to one kilometre. Others mentioned that rehab therapy could provide temporary relief, interspersed with some relapses (Table 3: 5 A.2). More participants found it efficacious than those who did not, and some found that it completely relieved their symptoms.

5. Treatment effects, surgical:

Seven participants had undergone surgery for their NC, four of whom directly praised the surgery as effective (Table 3: 5 B.1). Two participants found that their surgeries were initially successful but that over time, their symptoms were beginning to return. Another two participants found their surgeries to be helpful, but had them so recently that they weren't sure what level of function they would ultimately achieve in the longer term.

6. Expectations from treatments

When it came to the relief that participants expected from their treatment, the most frequently mentioned expectations were decreased/eliminated pain and increased physical abilities. Overall, the majority of participants (n=20/28) felt that treatment would have to improve

(rather than simply maintain) their condition in order to be worthwhile.

(i) Pain relief.

Many participants expected and accepted that they would live with some level of chronic pain. Those who expected to live in pain frequently indicated that simply being in less pain would be adequate for them, and that any amount by which it could be lessened would be beneficial. They described themselves as going through life by just dealing with it (Table 3: 6 A.1). For example, one participant called her desire to be without pain "greedy," and described pain as her "partner in life." Two others indicated that if 10 were the worst pain possible, they would be willing to live at a constant two. Another participant indicated that a five out of 10 would be acceptable. These participants seemed aware and accepting of the fact that they would never be completely pain free (Table 3: 6 A.2)

Rarely, participants expected complete and total relief of their symptoms, and expressed a desire to have no pain whatsoever (Table 3: 6 B.1). It seemed that participants expected more in terms of absolute pain relief from surgery than they did from other interventions, such as rehab therapy, although relatively few participants spoke about this issue (Table 3: 6 B.2).

(ii) Physical abilities.

Relief from pain overwhelmingly appeared to be the single most important thing that could be done for these NC sufferers. However given that decreased pain should lead to increased physical ability, these two outcomes generally go hand-in-hand.

When participants spoke about increased mobility, they generally did not expect 100% recovery but rather would set an individual benchmark, which generally meant being able to do "more" than they currently could do. Benchmarks included: being able to walk a greater distance, being able to handle household chores alone, being able to transition from sitting to standing without pain, being able to perform activities like playing with grandchildren, or being able to "get out of vehicles" (Table 3: 6 C.1-3). Echoing the data discussed earlier about activities impacted by LSS, the most commonly mentioned activity in this area was walking: participants strongly want to be able to walk without pain (Table 3: 6 C.4).

Discussion

In this study we interviewed 28 individuals with NC due

to LSS with the goals of better understanding how this condition impacts their lives and what they expected from non-surgical and surgical treatments. This study uniquely confirms that from the perspectives of patients, NC has a multidimensional impact on individuals with pain, limited walking ability, and depressed mood arising as the most common and significant symptoms. Most participants had undergone multiple treatments for their NC, many of which they found to be ineffective. The most effective treatments were rehab therapy/exercise and surgery. Pain medication was also frequently used but participants generally indicated that they wanted to reduce or eliminate use of medications. Patients felt that treatment would have to improve (rather than simply maintain) their condition in order to be worthwhile. Finally, a consistent theme arose amongst participants suggesting that pain, physical abilities, emotional state, and their expectations of treatment are strongly inter-related and at times inseparable.

By far our participants were most bothered by the pain associated with NC. Described pain ranged from somewhat mild and well controlled to absolutely crippling and debilitating. For most participants, the pain from their NC had dramatically impacted their lives; the impact of which cannot be overstated. Beyond the experience of pain itself, participants regularly expressed the desire to re-engage in their regular day-to-day, recreational and social activities. The activity most frequently mentioned, and the source of the most frustration, was the inability to walk and/or stand. In a study using focus groups to assess important outcomes among 33 older patients receiving epidural injections for NC, Edward *et al.*²⁰ had similar findings. In their study the highest rated problem areas were “experiencing pain/discomfort” (88% of participants), “problems with physical function” (85%), “difficulty exercising” (73%), “difficulty participating in hobbies and leisure activities” (55%), and “problems with weakness” (52%)²⁰.

In a recent qualitative study by Lyle *et al.*²¹ assessing 15 patients undergoing physiotherapy for NC, pain and the threat of pain was the most prominent feature leading to a loss of engagement in meaningful activities and sense of self. Similarly in our study the majority of patients perceived pain as the central cause of their other symptoms, with relief from pain overwhelmingly being the single most important thing that could be done for them. This finding was also prominent in the study by Lyle *et al.*²¹,

where most participants wished to get rid of the pain completely as they felt that was key to getting back to their normal activities. While others implied complete relief was unlikely and they would be happy if they could get relief of some of the pain. In our study participants hoped for their pain levels to decrease and walking to return to the levels that they were capable of prior to their symptoms arising. However, the majority of participants were willing to accept any achievable improvement over their current symptoms.

Perhaps the most surprising finding was how frequently participants reported various emotional effects that resulted from living with NC. The most common was an expression of depressed mood. In addition to depressed mood, participants mentioned experiencing anxiety (i.e., fear that it would become worse or that they would be debilitated), frustration and hurt pride (i.e., hurt pride at having to be taken care of or being viewed as disabled or unattractive) as a result of their NC. In the study by Lyle *et al.*²¹, the authors noted fluctuating and unpredictable symptoms resulted in anxiety and uncertainty, however, they did not report depressed mood as a prevalent theme. Although we did not specifically ask about treatment for psychological illness in our interviews, it is worth noting that patients did not report receiving treatment for their mood alteration. The apparent emotional (psychosocial) impact of NC on patients suggests that these factors should be considered during assessment and management not unlike patients who suffer from chronic pain. Current diagnostic criteria for neurogenic claudication due to degenerative lumbar spinal stenosis do not include psychosocial factors^{2,29}.

Our findings strongly suggest that the emotional aspects of NC, particularly given the high prevalence of depressed mood, need to be considered and that treatment for depression and/or anxiety is possibly an unmet need in this population. Specifically, the emotional effects of NC may be important mediators of pain intensity, and/or related to limitations in walking and standing ability, and recreational activity. Emotional effects may also explain why there is a lack of correlation between decreased pain or disability scores and improved walking ability.¹² It is also possible that the emotional effects may explain why patients' symptoms and functional status are variable, as noted in the Lyle *et al.*²¹ study and concurs with recent clinical trial data (Ammendolia *et al.* and Schneider *et al.*,

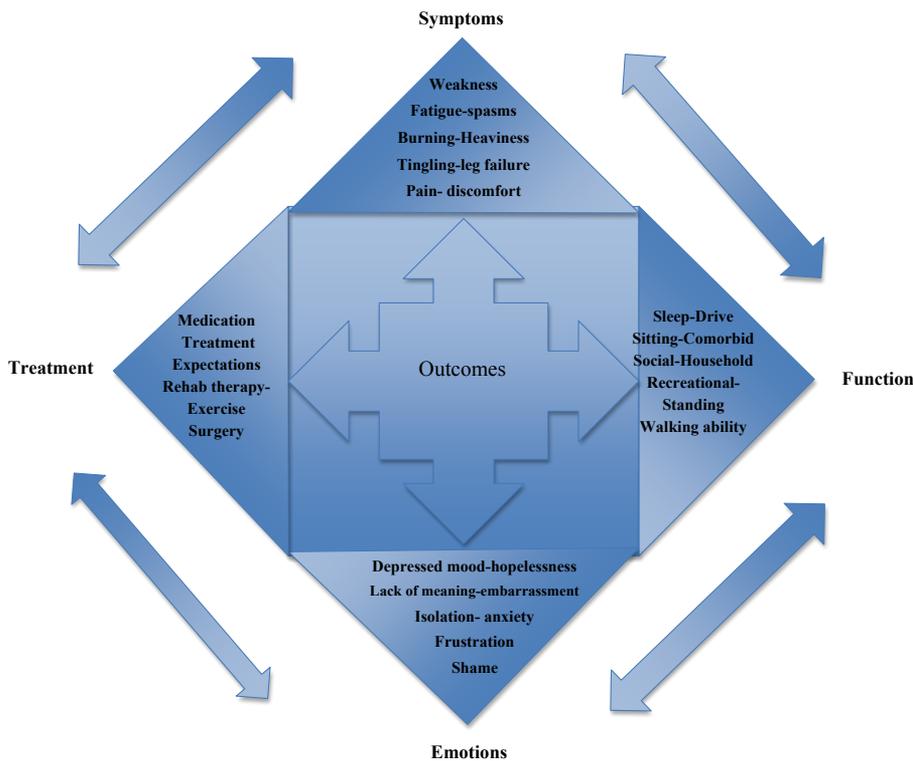


Figure 2. Conceptual Model of potential interrelationships of factors impacting patient outcomes in neurogenic claudication. Items are ranked with the most important items being in the centre, and least important items being at the periphery.

unpublished data). These results are consistent with the literature on psychosocial impacts of NC. Studies have shown that high levels of depression and hopelessness may have a compounding effect on walking ability and recreational activity in individuals with NC, as well as surgical outcomes.²² A systematic review of prognostic factors in NC showed that pre-operative depression is likely a prognostic factor for post-operative NC related symptom severity and disability. However, the prognostic value of depression on the outcome of pain and walking capacity was less clear.²² Therefore, interventions directed at addressing psychosocial issues associated with NC might improve pain levels and functional activity through better coping mechanisms.^{22,23}

For the most part participants' expectations for treatment seemed realistic, likely in part because most received education on what they could expect from treatment by their practitioners (CA, RR). Patient expectations are known to impact outcomes^{24,25} and the ability to mitigate unrealistic expectations prior to treatment would likely reduce the risk of disappointment and despair, as well as facilitate the acceptance of some degree of pain and

physical limitation. In this study, patient expectations for improvement appeared higher for surgery than non-surgical treatment. This suggests that the minimally clinically important difference (MCID) may be different between patients in these two groups. This has been demonstrated in quantitative studies evaluating the MCID for the Spinal Stenosis Survey and Oswestry Disability Index.^{26,27} This may have implications in clinical trials when comparing the proportion of participants achieving MCID among subjects receiving surgery and those receiving non-surgical treatment for NC.

Based on our patient-centred findings, we propose that both clinicians and researchers need to address NC as a multidimensional entity when considering management options and designing or evaluating specific intervention(s). We have proposed a theoretical framework to illustrate the potential inter-relationships of factors that impacts patient outcomes in NC (Figure 2). In this framework we ranked, based on our participants' experiences, the most bothersome symptoms, functional limitations, emotional aspects and treatment successes and hypothesized how these factors potentially interact. Patients who

are depressed are not likely good surgical candidates, and this is an example of how psychosocial factors can impact treatment decisions. Treatment outcomes can change the direction of future treatment is another potential interaction. This framework can provide a guide to clinicians to establish how NC individually affects their patients and to inquire about their treatment expectations. This can allow for a more stratified approach to management ranging from rehabilitation therapy, psychosocial support and /or surgery that may lead to better individual patient outcomes. Future research is needed to validate and quantify these proposed interactions between pain, physical ability, emotional state and treatment expectations in NC.

Future studies should address and measure priority areas including pain, walking and standing ability, recreational and social activity and emotional well being. In a Cochrane review examining non-operative interventions to improve outcomes in symptomatic LSS, none of the 21 studies reviewed directly assessed recreational activity, while only seven of 21 studies assessed psychosocial status, and 12 of 21 studies used an objective walking measure.¹² This paper provides valuable insight from a patient's perspective and this information can influence how we treat LSS patients in future and how we select outcomes for research.

Study limitations

Our study is not without limitations. Our qualitative approach is not designed to be generalizable, but instead to provide depth and insight into patients' lived experience. For that reason we sought to achieve thematic saturation per group, which can be achieved with 10-12 interviews per group. We were able to recruit additional subjects per group and in our thematic coding we noted saturation, which occurs when key themes such as physical limitations are present for all participants. However, it is still possible that if more patients were interviewed different themes may have emerged.

Another potential limitation is that our purposeful sample focused on a Canadian sample in a hospital setting. Variations in health care system characteristics and related factors such as access to treatment may impact patients' outcomes and expectations. Recruiting from a hospital setting may result in participants with more severe symptoms and physical limitations. Although an attempt was made to recruit a representative sample of patients

with NC due to LSS, it may be that the participating sample was not a true general reflection of this population. This selection bias may also be reflected in our conceptual model of factors that impact patient outcomes and their potential interactions. These hypothesized interactions should be determined quantitatively using a random representative sample.

Conclusions

The results of this qualitative study show that NC should be considered as multidimensional in its impact on patients. We found that pain, and limited walking and standing ability were the most bothersome aspects of NC that significantly impacted important activities of daily living, as well as meaningful recreational and social activities. Additionally, this study is the first to qualitatively identify the significant emotional impact of NC. This is a finding that should not be overlooked in clinical practice and future research. A holistic understanding of how psychosocial and other factors impact outcomes in this population is needed. We present a conceptual model of potential interactions between important outcomes in LSS as a framework for future study.

Acknowledgements

The following organizations have provided funding for this research: The Canadian Chiropractic Research Foundation (Ammendolia), NCMIC Foundation (Ammendolia and Schneider) and The Toronto General and Western Hospital Foundation (Rampersaud). Dr. Zickmund is supported by the VA Salt Lake City Medical Center and the Health Services Research & Development IDEAS 2.0 Center (Award number ISOHX001240).

References

1. Katz JN, Harris MB. Clinical practice. Lumbar spinal stenosis. *N Engl J Med*. 2008;358: 818-825.
2. Suri P, Rainville J, Kalichman L, Katz JN. Does this older adult with lower extremity pain have the clinical syndrome of lumbar spinal stenosis? *JAMA*. 2010; 304: 2628-2636.
3. Comer CM, Redmond AC, Bird HA, Conaghan PG. Assessment and management of neurogenic claudication associated with lumbar spinal stenosis in a UK primary care musculoskeletal service: a survey of current practice among physiotherapists. *BMC Musculoskelet Disord*. 2009;10: 121.
4. Kalichman L, Cole R, Kim DH, Li L, Suri P, Guermazi A, et al. Spinal stenosis prevalence and association with

- symptoms: the Framingham Study. *Spine J.* 2009; 9:545-550.
5. Deyo RA. Treatment of lumbar spinal stenosis: a balancing act. *Spine J.* 2010;10:625-627.
 6. Government of Canada. Statistics Canada. Statistics Canada . 6-11-2006. Government of Canada, accessed November 2, 2008 at: www.statcan.gc.ca/bsolc/olc-cel/olc-cel?lang=eng&catno=11-008-X
 7. Ammendolia C, Stuber K, de Bruin LK, Furlan AD, Kennedy CA, Rampersaud YR, Steenstra IA, Pennick V. Non-operative treatment for lumbar spinal stenosis with neurogenic claudication: a systematic review. *Spine.* 2012; 37: E609-616.
 8. Kovacs FM, Urrútia G, Alarcón JD. Surgery versus conservative treatment for symptomatic lumbar spinal stenosis: a systematic review of randomized controlled trials. *Spine* 2011;36: E1335-1351.
 9. Moojen WA, Arts MP, Bartels RH, Jacobs WC, Peul WC. Effectiveness of interspinous implant surgery in patients with intermittent neurogenic claudication: a systematic review and meta-analysis. *Eur Spine J.* 2011;20(10): 1596-1606.
 10. Zaina F, Tomkins-Lane C, Carragee E, Negrini S. Surgical versus nonsurgical treatment for lumbar spinal stenosis. *Spine.* 2016;41: E857-868.
 11. Ammendolia C, Stuber KJ, Rok E, Rampersaud R, Kennedy CA, Pennick V, Steenstra IA, de Bruin LK, Furlan AD. Nonoperative treatment for lumbar spinal stenosis with neurogenic claudication. *Cochrane Database Syst Rev.* 2013;8: CD010712.
 12. Ammendolia C, Stuber K, Tomkins-Lane C, Schneider M, Rampersaud YR, Furlan AD, Kennedy CA. What interventions improve walking ability in neurogenic claudication with lumbar spinal stenosis? A systematic review. *Eur Spine J.* 2014;23: 1282-1301.
 13. Coyne Imelda T. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Advanc Nurs.* 1997;26: 623-630.
 14. Jensen MP, Karoly P, Braver S. The measurement of clinical pain intensity: a comparison of six methods. *Pain.* 1986;27: 117-126.
 15. Stucki G, Daltroy L, Liang MH, Lipson SJ, Fossel AH, Katz JN. Measurement properties of a self-administered outcome measure in lumbar spinal stenosis. *Spine.* 1996;21: 796-803.
 16. Fairbank JC, Couper J, Davies JB, O'Brien JP. The Oswestry low back pain disability questionnaire. *Physiother.* 1980;66: 271-273.
 17. Ruta DA, Garratt AM, Russell IT. Patient centred assessment of quality of life for patients with four common conditions. *Qual Health Care.* 1999;8(1):22-29.
 18. Crabtree BF, Miller WL (1992). *Doing Qualitative Research: Multiple Strategies.* Thousand Oaks: Sage Publications.
 19. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics.* 1997; 33:159-174.
 20. Edwards TC, Lavalley DC, Bauer Z, Comstock BA, Jarvik JG, Patrick DL, Makris UE, Friedly JL. Problem areas identified as important to older adults with lumbar spinal stenosis. *Spine J.* 2015;15:1636-1644.
 21. Lyle S, Williamson E, Darton F, Griffiths F, Lamb SE. A qualitative study of older people's experience of living with neurogenic claudication to inform the development of a physiotherapy intervention. *Disabil Rehabil.* 2016; 23:1-9.
 22. McKillop AB, Carroll LJ, Battié MC. Depression as a prognostic factor of lumbar spinal stenosis: a systematic review. *Spine J.* 2014;14: 837-846.
 23. Tomkins-Lane CC, Lafave LM, Parnell JA, Rempel J, Moriarty S, Andreas Y, Wilson PM, Hepler C, Ray HA, Hu R. The spinal stenosis pedometer and nutrition lifestyle intervention (SSPANLI): development and pilot. *Spine J.* 2015;15: 577-586.
 24. Saban KL, Penckofer SM. Patient expectations of quality of life following lumbar spinal surgery. *J Neurosci Nurs.* 2007;39: 180-189.
 25. Gepstein R, Arinzon Z, Adunsky A, Folman Y. Decompression surgery for lumbar spinal stenosis in the elderly: preoperative expectations and postoperative satisfaction. *Spinal Cord.* 2006;44: 427-431.
 26. Copay AG, Glassman SD, Subach BR, Berven S, Schuler TC, Carreon LY. Minimum clinically important difference in lumbar spine surgery patients: a choice of methods using the Oswestry Disability Index, Medical Outcomes Study questionnaire Short Form 36, and pain scales. *Spine J.* 2008;8: 968-974.
 27. Cleland JA, Whitman JM, Houser JL, Wainner RS, Childs JD. Psychometric properties of selected tests in patients with lumbar spinal stenosis. *Spine J.* 2012;12: 921-931.
 28. Conway J, Tomkins C, Haig A. Walking assessment in people with lumbar spinal stenosis: capacity, performance, and self-report measures. *Spine J.* 2011; 11(9): 816-823.
 29. Tomkins-Lane C, Melloh M, Lurie J, Smuck M, Battié MC, Freeman B, Samartzis D, Hu R, Barz T, Stuber K, Schneider M, Haig A, Schizas C, Cheung JP, Mannion AF, Staub L, Comer C, Macedo L, Ahn SH, Takahashi K, Sandella D. ISSLS Prize Winner: Consensus on the Clinical Diagnosis of Lumbar Spinal Stenosis: Results of an International Delphi Study. *Spine.* 2016;41(15):1239-1246.