Patients' Perceptions of Carpal Tunnel and Ulnar Nerve Decompression Surgery

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ABSTRACT: Background: Carpal tunnel syndrome and ulnar nerve entrapment at the elbow are the most common entrapment neuropathies seen in adults. Surgery for nerve decompression is a safe and effective treatment option, and is usually performed under local anesthesia and as an outpatient procedure. This study aimed to explore patients' satisfaction and other aspects of the overall experience with this type of surgery. Methods: Qualitative research methodology was used. Semi-structured, open-ended interviews were conducted with 30 adult patients who had undergone carpal tunnel release or ulnar nerve decompression at the elbow 6-24 months prior. Interviews were digitally audio recorded and transcribed, and the data subjected to thematic analysis. Results: Four overarching themes emerged from the data: (1) most patients did not perceive their condition to be serious; (2) patients were satisfied with the overall surgical experience; (3) the outcome was more important to patients than the process; and (4) majority of patients had a realistic expectation of outcomes. Conclusions: Patients had a positive experience with carpal tunnel and ulnar nerve decompression surgery, although their level of satisfaction was dependent on the surgical outcome. Areas requiring improvement, specifically information about post-operative care and expectations of recovery, will be implemented in the future care of patients.

RÉSUMÉ: Les perceptions des patients concernant la chirurgie de décompression du canal carpien et du nerf cubital. Contexte: Le syndrome du canal carpien et le syndrome de compression du nerf cubital au niveau du coude sont les neuropathies de compression les plus fréquentes chez les adultes. La chirurgie de décompression nerveuse est une option de traitement sûre et efficace, habituellement effectuée sous anesthésie locale en externe. Le but de cette étude était d'explorer la satisfaction des patients ainsi que d'autres aspects de l'expérience globale concernant cette chirurgie. Méthode: Nous avons utilisé une méthode de recherche qualitative. Nous avons procédé à des entrevues semi-structurées, non limitées dans le temps, chez 30 patients adultes qui avaient subi une chirurgie du canal carpien ou une décompression du nerf cubital au niveau du coude, de 6 à 24 mois auparavant. Nous avons effectué un enregistrement audio digital des entrevues qui ont ensuite été transcrites et les données ont été soumises à une analyse thématique. Résultats: Quatre thèmes principaux sont ressortis des données: 1) la plupart des patients ne pensaient pas que leur problème de santé était grave; 2) les patients étaient satisfaits de l'expérience chirurgicale en général; 3) le résultat était plus important pour les patients que le processus et 4) la majorité d'entre eux avaient des attentes réalistes concernant les résultats. Conclusions: L'expérience des patients qui avaient subi une chirurgie de décompression du canal carpien ou du nerf cubital était positive, bien que leur niveau de satisfaction dépendait du résultat chirurgical. Ce qui devrait être amélioré à l'avenir, ce sont les informations fournies aux patients concernant les soins postopératoires et le processus de guérison.

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Carpal tunnel syndrome (CTS) and ulnar nerve entrapment at the elbow are two of the most common entrapment neuropathies seen in the adult population. These conditions are initially treated by conservative management but some patients eventually require surgery consisting of appropriate nerve decompression. Since these procedures are fast and safe, they are usually performed under local anesthesia and on an outpatient basis, with minimal morbidity. However, very few studies¹⁻³ have been done to explore patients' thoughts and feelings about their condition, the surgical procedure itself, and the post-operative results, including level of satisfaction and perceived disability. This study aimed to discover patients' perceptions about carpal tunnel and ulnar nerve decompression surgery by utilizing qualitative research methodology in the form of interviews with patients.

Prior studies^{4,5} have shown that there may be dissociation in the assessment of the severity of disease and functional outcome

between physicians and patients, underlining the need for clinicians to be aware of patients' perspectives in order to improve patient care. As a treatment option for nerve entrapment, nerve decompression surgery has been found to be safe and effective from the medical standpoint, but it is also important to ascertain the patients' thoughts and insights

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RECEIVED JULY 29, 2010. FINAL REVISIONS SUBMITTED SEPTEMBER 27, 2010. Correspondence to: Rajiv Midha, Division of Neurosurgery, 1195-Foothills Medical Centre, 1403 29 St. NW, Calgary, Alberta, T2N 2T9, Canada. regarding these procedures. Specifically, a positive response from patients would help validate the use of these procedures, and the feedback would help identify aspects that require improvement.

METHODOLOGY

Study Design

This was a prospective qualitative research study using interviews with patients who had undergone carpal tunnel and ulnar nerve decompression surgery.

Setting and Participants

Participants were ambulatory patients who were recruited from the practice of one neurosurgeon specializing in peripheral nerve surgery (RM) in a tertiary referral hospital. The inclusion criteria were as follows: (1) patients who underwent carpal tunnel release or ulnar nerve *in situ* decompression surgery within the last six to twenty-four months, (2) patients who were 18 years-old and above, (3) patients who spoke and understood English well, and (4) patients who did not have any cognitive deficits.

Sample Size

Thirty patients were recruited to participate in the study, 8 of whom underwent carpal tunnel release and 22, ulnar nerve decompression. This number was selected because most qualitative studies reach "saturation" levels at approximately 25-30 interviews. Saturation describes the situation wherein no new concepts arise during analysis of successive interviews, beyond those that have already emerged.

Data Collection

One semi-structured, open-ended, face-to-face interview was conducted on each patient by a single investigator (KJK). The interview was semi-structured in the sense that it followed an interview guide (Appendix), but themes were explored as they arose. The techniques and general approach used were similar to what we have employed previously.^{6,8,9} All interviews were digitally audio recorded and transcribed. Demographic data such as age, sex, education, occupation, and handedness were collected, as well as clinical data such as the type of procedure and date of surgery.

Data Analysis

The data were examined using a modified thematic analysis employed by a specific type of qualitative research methodology called "grounded theory." This was a process of generating theories based on the evidence seen and heard, and analyzed using a systematic procedure called "coding." The first step was open coding, wherein data were broken down into discrete parts, classified according to their similarities or differences, and placed into categories. They were then subjected to axial coding, which was the technique of reassembling data that were fragmented during open coding and establishing the relationships between them. The end result of the coding process was a theme, a central idea that appeared frequently and repeatedly in the data. The transcripts were analyzed by all the

investigators using the coding technique, after which dominant themes were culled from the interview material. The two groups (CTS and ulnar neuropathy patients) were analyzed separately but the analysis yielded the same themes, thus the results will be presented together.

Research Ethics

Participation was entirely voluntary, and informed consent was obtained from all participants. Confidentiality was ensured, and audiotapes and anonymized transcripts were kept in a secure location. The study was approved by the Conjoint Health Research Ethics Board of the University of Calgary.

RESULTS

Patient Information

Thirty patients were interviewed over a six-month period between January to June 2010. Forty-five patients fulfilled the inclusion criteria, 34 were approached, none declined, but four could not be interviewed due to logistic reasons. The demographic and clinical data for the 30 patients who participated in the study are shown in the Table.

Table: Demographic and clinical data of the study participants

Age (years)	Range Mean	33-80 56.8
Sex	Male Female	17 13
Handedness	Right Left	28 2
Education	Secondary Post-secondary	16 14
Occupation	Tradesman/laborer Administrative Retired Service industry Homemaker Artist	9 9 4 3 3 2
Diagnosis	Ulnar nerve entrapment at the elbow Carpal tunnel syndrome	22 8
Side of surgery	Right Left Bilateral	14 15 1
Months post-op	Range Mean	6-24 8.6

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Thematic Analysis

Four overarching themes emerged from the analysis of the interviews. These are briefly described and illustrated using verbatim quotes from participant interviews, as is the norm when reporting qualitative research. Presenting the participants' own words adds transparency and accountability to the themes generated.¹

1. Most patients did not perceive their condition to be serious

Patients presented with the typical symptoms of numbness and tingling of the fingers in the respective nerve distribution, as well as some weakness and loss of dexterity for the ones with ulnar neuropathy. Several patients also complained of nocturnal symptoms, particularly those with carpal tunnel syndrome. Hand pain and coldness were also present in some.

"My basic symptom was at night time: my hands would fall asleep, right up to my elbows. So I'd be awake... probably almost every half hour."

"I had weakness in my left hand. I couldn't open doorknobs, squeeze toothpaste, or anything that requires putting my fingers together. I also had numbness in my little finger and the next finger, and numbness in my palm... sometimes I would pinch it or burn it and I wouldn't feel it."

They had difficulty with tasks that required fine motor movements of the hand. Consequently, their home, work, and leisure activities were affected in various ways.

"Doing housework, like peeling potatoes.... holding anything tight in it. Lifting things, opening things...Yeah, and I couldn't do any more handicrafts. I used to do a lot of crocheting and knitting, and I couldn't do that anymore..."

"Clumsiness with my left hand... like when I use my knife and fork. I thought maybe I had changed my cutlery. The fork didn't fit, but it was me, not the fork."

"I was not able to carry things for a long time because my hands would lose feeling and become painful. If I use my hands frequently, it becomes numb, so I have to stop and rest and wait for the feeling to come back, then start again."

A few patients, especially those with more advanced disease resulting in muscle atrophy or clawing of the hand, had issues with their body image.

"I hide my hand a lot, put it in my pocket or whatever, when I'm meeting people. It makes me feel weird, 'cause it doesn't close, right? So, yeah, I guess it does change my perception that way."

Patients developed different ways of adapting to their functional impairment. They modified their activities and found ways to adjust.

"Everything was slower and you learn to be a bit more careful how you were doing it and not doing anything really quick..."

"I kind of overcome it by using my right hand. It hindered my work but not to the point that I couldn't work. I just had to be careful with my hand when I work, so I don't pinch it."

"I had symptoms gradually happening over two or three years. I'm not sure that, as they started happening... if I developed ways of dealing with it."

Presumably, the chronicity of the disease and the fact that the patients remained functional contributed to their relative lack of concern about their condition. When asked, they stated that they

were still able to go about their work and home activities by doing minor adjustments and that they did not require assistance from others. They did not consider themselves disabled and only started to worry once their condition had worsened. They were able to tolerate their symptoms for a long time, ranging from several months to years, before seeking medical attention.

"No, I didn't need help. I just waited till I shook them [my hands] out. I did everything myself, once the feeling comes back."

"No, I wasn't depressed or anxious. I knew it was curable or treatable. And I knew it wasn't permanent... well, I hoped it wasn't permanent."

"I first got the CTS when I was pregnant with my last child, so that would have been 20 years ago, and it never really went away after that."

"I think it was just a question of me wanting to deal with it. I mean, I could have gone on like that for a long time, but I just wanted to get it done, get it addressed."

Patients decided to have surgery because of the persistence or progression of symptoms.

"I had the tingliness and pain for ten years... it was a progressive situation so I decided to see somebody about it."

"I had enough of the pain. It was taking over my life... I couldn't do things I wanted to do."

"Well, it wasn't getting any better. And, uh, it almost seemed to be getting worse!"

2. Patients were satisfied with the overall surgical experience

The nerve decompression procedures were performed under local anesthesia augmented with intravenous sedation, and were booked as outpatient surgery cases, which meant that the patients were discharged a few hours after the operation. The patients were pleased with the overall experience. They were quite comfortable during the surgery, and approximately one third were amnestic for the operative event. Those who did recall the surgery remembered the surgeon speaking with them or with other operating room personnel, as well as the sensation of the arm or hand being worked upon.

"I could feel the tugging, like when they're working on your teeth... I could feel the tugging but no actual pain."

"I had the feeling of people around me, and I could hear voices, that type of thing... but what they were doing, I don't know. They were working on my arm... I couldn't believe how little pain there was!"

"He asked me if there was any discomfort... and I'm sure normal questions. He was making sure I was okay."

Patients were also happy about having their surgery as an outpatient. The reasons they cited for preferring outpatient surgery include greater comfort in their own home, a general dislike of hospitals, and a social conscience that makes it unacceptable for them to occupy hospital beds for something relatively trivial.

"It's just that I feel patients recover faster at home, because he's in a familiar place, with the comforts of being at home rather than in the hospital. It's more the environment is better."

"Oh, who wants to stay here? I'm all for that!"

"It's good! I guess you could say it doesn't tie up any beds..."

Majority of patients had a smooth and uneventful postoperative course. One patient developed a wound infection and

a few had incisional pain which lasted for a few days. Most of them went back to work within a week.

3. The outcome was more important to patients than the process Most of the patients were satisfied because they had a good outcome in terms of symptom relief.

"Yeah, my symptoms improved. The main ones that I wanted to get rid of are the tingling, the asleep feeling...so when all that went away, it made me able to sleep and made everything a little easier."

"I'd say it's 99% back to normal. I expected my strength to get better but I didn't think I would get this much better and as quickly. And my pinkie is not sticking out as much!"

"There's no pain, there's no numbness. I can use my hand again, and the hand is a lot stronger."

However, the few patients who did not experience improvement declared themselves unsatisfied with the surgery.

"The experience was fine, the doctors were fine, the recovery was fine. It's just the fact that it didn't solve anything... so I'm not satisfied with the result."

4. Majority of patients had a realistic expectation of outcomes

Most of the patients were aware that the surgery would decrease the degree and frequency of sensory alteration, but would only halt the progression of motor symptoms instead of reversing them.

"The symptoms would go away, or for the most part be resolved, right? I mean, I don't expect 100%..."

"Uh, I expected it to get better... partially. I felt as long as I didn't have the pain, I could handle the numbness."

"Um, I know it would take time...for it to...for the nerve to come back. Like it didn't come overnight so it's not gonna go away overnight."

This awareness reflected the amount and quality of information that patients received from their doctor(s) preoperatively, which most patients believed was adequate in helping them make the decision for surgery and preparing them for the operation.

"The doctors explained what they were gonna do, how they were gonna do it, and everything. And what I didn't understand, I asked them, they told me. Yeah, I was quite comfortable with it."

"What was explained to me prior to surgery, is exactly what I got. In other words, everything he said would go away did."

DISCUSSION

Qualitative research methodology was employed to explore patients' perceptions and feelings regarding CTS and ulnar nerve entrapment outpatient decompression surgery. Despite the utilization of patient-oriented outcome measures such as the Boston carpal tunnel questionnaire, ¹⁰ the Michigan hand questionnaire, ¹¹ and the Disabilities of the Arm, Shoulder, and Hand (DASH) ¹² for CTS and the Ulnar Neuropathy at the Elbow Questionnaire (UNEQ) ¹³ and the DASH ¹² for ulnar neuropathy, the closed-ended nature of these assessment tools may not capture every outcome deemed important by patients or allow prioritization of these outcomes. ¹ In addition, these techniques would not be sufficient to explore the totality of patient experience, from the initial symptomatology to the operative

experience and the recovery process. This is best achieved by qualitative research methods, as employed in the present study. Although qualitative research is unfamiliar to most quantitatively oriented physicians, it is an effective means of gaining insight into patient perspectives and answering questions that cannot be explored by quantitative research methodology.

There have been very few qualitative research studies dealing with CTS or ulnar neuropathy. Jerosch-Herold et al1 utilized interviews to determine the impact of CTS on patients' lives, as well as the patients' expectations from surgery. They identified relief of symptoms, specifically tingling, numbness, and sleep disturbance, as well as resumption of important activities, as patients' most important criteria for judging the success of the surgery.¹ Martin² examined the health beliefs of patients and sought to determine why there was a delay in seeking medical attention among patients with CTS. McCormick et al³ studied patients with advanced ulnar neuropathy and concluded that this condition not only had a tremendous impact on activities of daily living, but also caused patients to avoid social situations where their hand deformity would be noticed. To date, there have been no qualitative studies focusing on patients' surgical experiences and recovery process with these conditions.

Twenty-two patients with ulnar nerve entrapment and eight patients with CTS were recruited for this study. These two disease entities share several clinical characteristics: they both affect the hand, present with similar symptomatology, and cause some degree of discomfort and functional impairment. Subgroup analysis yielded the same themes, which, together with the similar characteristics shared by these two conditions, made it reasonable to combine the results of the two groups during the presentation of the thematic analysis.

The most common symptoms reported were numbness, tingling, and slight weakness, and the symptom that bothered patients the most is numbness and tingling. Because of the hand symptoms, virtually every aspect of a patient's life is affected, from activities of daily living to work to recreational pursuits. However, because of the chronic and gradually progressive nature of entrapment neuropathies, patients' lives were not greatly affected at the outset and they developed adaptive behavior to work around this problem. They were not very worried or anxious about their condition, and majority did not consider themselves disabled since they were still independent and functional. It was only when their condition has worsened that their work, leisure, and home activities were compromised, requiring them to give up certain activities or ask help from their co-workers or family members. This was also the time when patients actively sought medical attention.

Patients were satisfied with the surgical experience as a whole. The awake component was comfortable for them and was not traumatic or scary. Most of the recollection involved conversations between the surgeon and the patient or with the other members of the surgical team. Patients also recalled a tugging or pulling sensation as the surgeon worked on their tissues, and hearing the scraping sound made by an instrument. Surprisingly, only two patients complained of pain which was relieved by giving more local anesthetic. With regard to the outpatient experience, patients were happy to go home after the procedure because they felt more comfortable at home, surrounded by their loved ones. They also felt that outpatient surgery was less disruptive to their lives in general.

The most important part of the surgical experience was the result. Regardless of how pleased patients were over the conduct of the operation, their satisfaction rating about the whole procedure was heavily dependent on the outcome. This was consistent with other studies wherein patient satisfaction after lower limb surgery was determined by clinical and functional recovery rather than by the type of injury or treatment. ¹⁴ Another group of researchers found that subjective variables of symptom and function, such as pain, functional difficulty, and work disability, have the most robust associations with patient satisfaction following rotator cuff¹⁵ and anterior cruciate ligament surgery.16 In our study, most of the patients were satisfied with the result of the operation because it gave them varying degrees of symptom relief. None of the patients had total relief of symptoms, however, although they had been ameliorated to a satisfactory extent. The symptom relief that gave the most satisfaction included numbness and nocturnal symptoms, the latter enabling them to have a good night's sleep. When asked, majority of patients had no regrets about undergoing surgery, and they would do it again if they had to. However, patients who did not experience symptomatic relief were not satisfied with the surgery and expressed regret about their decision.

CONCLUSIONS

What are the practical lessons learned from this? The patients were quite satisfied with the pre-operative and intra-operative conduct of events, but some felt that improvements could still be made in the post-operative phase, particularly in terms of information. This seems to be a recurring theme in qualitative research studies in surgery and should encourage surgeons to strive to do a better job at information dissemination, particularly after surgery for benign conditions.9 Even though patients received verbal discharge instructions from the surgeon and a printed instruction sheet before they go home, a lot of them did not remember what was said or misplaced the paper. This problem can be addressed by giving the patients written discharge instructions even prior to the surgery date, to allow them time to digest this information and ask additional questions should they have any. As a result, we have constructed and are now providing a one-page information sheet to patients at the time of their surgical booking, regarding important aspects of their post-operative course.

Another aspect of peri-operative information that patients commented on was expectations about recovery. Patients wanted to know which symptoms will improve, to what degree, and the time line for any such improvement. This information had already been provided as part of the informed consent, but perhaps these points need to be stressed to make sure that the patients understand completely. These concerns may seem trivial in the general scheme of things, but since they are important to patients, they need to be addressed in order to improve patient care.

(See Appendix on following page)

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APPENDIX

PATIENTS' PERCEPTIONS OF CARPAL TUNNEL AND ULNAR NERVE DECOMPRESSION QUESTIONNAIRE

PREAMBLE:

This interview is intended to explore your perceptions about your carpal tunnel syndrome/ ulnar nerve compression and discuss your experience with the surgery you had for it. Your input is important to us and will help us do a better job.

INTERVIEW PROPER

- 1. What were your symptoms prior to surgery? Among them, which bothered you the most? What tasks did you have the most difficulty with? Did it interfere with your work? Your activities of daily living? Did you require assistance at home? Did you perceive yourself as disabled? Did you suffer from anxiety or depression because of your condition? (For patients who had a deformity such as claw hand or muscle atrophy: Did it alter your body image?) Tell me more about it.
- 2. Was surgery recommended to you immediately? If not, what was the duration between diagnosis and surgery? Did you undergo conservative treatment during that period? What made you decide to have surgery? Tell me more about it.
- 3. What were your expectations from surgery? Tell me more.
- 4. What were your fears and concerns regarding surgery? What did you think was the worst thing that could happen? Tell me more.
- 5. Your surgery was done while you were awake/ under light sedation. What do you remember from the surgery? Did you feel any pain or discomfort?
- 6. Your surgery was done as an outpatient procedure. That means you come in for the surgery then you go home after a few hours. What do you think about that? Does it make your surgery seem less "major" if you can go home on the same day? Do you expect to make a faster recovery if you go home immediately? Or would you prefer staying overnight at the hospital? Tell me more.
- 7. Did you have any problems at home during the first few days after your surgery? Did you require somebody to look after you?
- 8. Are you satisfied with the result of the operation? Did your symptoms improve? Which symptom relief gave you the most satisfaction? Have your expectations been met? Do you have any regrets about going through this operation? If we can turn back time, would you still agree to have this operation? Tell me more.
- 9. (For those who symptoms did not improve) What is/are the symptom/s that is/are still bothering you? What tasks do you have the most difficulty with?
- 10. What can you say about the amount of information you received before your surgery? Was it adequate in preparing you for the operation? What about after the surgery? Was the information adequate regarding home care and expectations during the recovery period? Did you encounter any surprises? Tell me more.
- 11. Do you have any suggestions as to how we can improve the whole surgical experience for the patient?
- 12. Is there anything else you'd like to add?

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