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## Original Research

# "Pill Pushers and CBD Oil"—A Thematic Analysis of Social Media Interactions About Pain After Traumatic Brachial Plexus Injury



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Key words: Brachial plexus injury Facebook support groups Gabapentin Opioid Opioid epidemic Qualitative thematic analysis *Purpose*: Brachial plexus injury (BPI) patients use on-line groups for peer support, often seeking information from Facebook groups devoted to BPI. We hypothesized that a qualitative thematic analysis of posts from BPI Facebook groups would demonstrate the areas in which patients were seeking information regarding treatment of BPI and reveal potential sources of misinformation that patients may encounter.

Methods: We identified the 2 most popular public Facebook groups for BPI by searching key words "traumatic brachial plexus injury." We selected posts containing comments regarding BPI from November 1, 2018 through October 31, 2019. We excluded posts regarding brachial plexus birth injury. We used iterative inductive and deductive thematic analysis for the qualitative data to identify recurring topics, knowledge gaps, potential roles of patient educational interventions, and patient interaction dynamics. Two investigators independently coded all posts and resolved discrepancies by discussion. Results: A total of 7,694 posts from 2 leading Facebook support groups were analyzed. Three themes emerged: (1) When discussing pain management, there was recurring anti-opioid sentiment. Posters who currently used opioids or supported those who did discussed perceived effects of the opioid epidemic on their treatment, on their relationships with care providers, and on availability of the medication. (2) Posters advocated for alternatives to traditional approaches to pain management, referring to prescribers as pill pushers and touting cannabinoids as a safer and more effective replacement. (3) There was strong anti-gabapentinoid sentiment owing to reported adverse effects and a perceived lack of efficacy, despite its role as a first-line treatment for neuropathic pain.

Conclusions: Examination of posts from Facebook support groups for BPI revealed recurring themes, questions, misinformation, and opinions from posters with regard to treatment of neuropathic pain. These findings can help clinicians who care for BPI patients identify areas to focus on during patient encounters to address neuropathic pain that commonly occurs with BPI.

Clinical relevance: Brachial plexus injury surgeons should be aware of information, misinformation, and opinions on social media, because these may influence patient—surgeon interactions.

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Traumatic brachial plexus injuries (BPIs) are often devastating injuries with far-reaching physical,  $^1$  mental,  $^{2-4}$  social,  $^5$  and financial  $^{6,7}$  effects.  $^{8,9}$  Surgical reconstruction after BPI is effective at restoring some function,  $^{10}$  but current treatment strategies cannot restore all lost function or completely alleviate pain after BPI. The latter is a major concern to many patients  $^{1.5,8,9,11,12}$  and can be severe, persistent, and resistant to pharmacologic, psychological, and surgical treatment.  $^{13-15}$  Gabapentinoids,

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serotonin-noradrenaline reuptake inhibitors, and tricyclic antidepressants all have shown effectiveness in treating neuropathic pain, <sup>16,17</sup> but may be poorly tolerated owing to side effects <sup>17</sup> and have the potential for misuse and abuse. <sup>18</sup> Nearly one-third of BPI patients had prolonged opioid prescriptions after surgical reconstruction, <sup>19</sup> although opioids are considered a third-line pharmacologic treatment for neuropathic pain. <sup>16</sup> The challenge of treating neuropathic pain is compounded by the current epidemic of opioid overdose deaths and addictions, which has led both physicians and patients to be more judicious in the prescription and use of opioids. <sup>20,21</sup>

Persistent neuropathic pain, functional loss, and isolation associated with BPI often leave patients desiring more information about treatment options and in need of social support. 4,5,9 Social media provide a space for patients and their families to share their experience and knowledge and to seek information regarding the diagnosis and treatment with others who share similar experiences. These health-related social media support pages are unique in that they are usually not monitored by health care providers; patients often share perspectives that they would not normally share with doctors, nurses, and therapists in a formal care environment (De Choudhury et al, presented at the 2016 SIGCHI Conference on Human Factors in Computing Systems). For this reason, clinicians caring for BPI patients should be aware of what patients and families are reading and sharing, because the content on social media support group pages can identify common knowledge gaps and potential misinformation patients may encounter, and can provide an opportunity for patient education. The purpose of this study was to examine posts from Facebook support groups for BPI patients using thematic analysis to identify common themes regarding the patient experience and treatment of neuropathic pain after BPI.

# **Materials and Methods**

After receiving approval from our institutional review board, we evaluated content from Facebook BPI groups. After searching for key words "traumatic brachial plexus injury," we selected 2 private groups with open membership and substantially more posts, reactions, and overall engagement for inclusion: United Brachial Plexus Network Support Group and the Brachial Plexus Injury Awareness Group (BPIA).

Posts and post responses dated from November 1, 2018 to October 31, 2019 were collected and documented in chronological order. Posts were not collected or stored for analysis if they met exclusion criteria: posts that were strictly social in nature (babies in Halloween costumes, for example) and generated no included content in the responses; posts or responses that were not written in English; posts or responses that merely repeated or reiterated previous posts while adding no new content (for example, posts or responses that consisted solely of "This," "Same," "I know, right?"); and posts and responses that were clearly and exclusively focused on birth BPI/ Erb's palsy, with no relevant content regarding traumatic BPI. Data collected consisted of the text of the post itself, a written description of posted pictures or videos in place of those media, the date of the post, and the user ID of the poster. All posters were assigned anonymous ID numbers and all posts were deidentified before analysis, with some exceptions. Posts that clearly named someone in a business context, such as the name

of a successful baker with a BPI or solicitations for a business that included an individual's name in the business name, were documented verbatim. The study team did not pursue or attempt to document details about the demographics of deidentified posters, such as age or sex, in the interest of preserving the anonymity of individuals. Posts were written by persons with a BPI and friends or family members of BPI patients; a small number of posts were made by businesses and sales representatives.

The deidentified posts were then uploaded into NVivo 12 (OSR International, Melbourne, Australia), a program used for qualitative data analysis. A collaborative iterative approach was used to conduct a thematic analysis of the data using a grounded theory approach, an accepted qualitative research approach.<sup>22</sup> In this process, 3 study team members (L.R., E.Z., and E.T.S.) individually reviewed 2 months' worth of posts from each Facebook group to identify potential recurring themes in the data. This review entailed the use of inductive and deductive qualitative coding strategies when identifying themes. The a priori deductive hypothesis was that patients would express frustration with pain control after BPI. After completing the individual reviews and study team discussion, a draft codebook was developed that contained a mutually agreed-upon table detailing the themes or codes as identified and defined during the meeting. This codebook draft was then tested by having the 3 study team members code 2 months' worth of posts. After this test coding, revisions were made to the codebook. The second version of the codebook was then tested using the same process and subsequently adopted as the final version of the codebook, because no new gaps, unclear definitions, or suggestions arose during the second round of testing. All posts were then coded by 2 study team members (L.R. [a full-time qualitative research associate] and E.T.S. or E.Z., both of whom received detailed hands-on training in coding techniques from the senior author, who had completed formal graduate-level coursework in qualitative research). Any discrepancies regarding the code(s) selected for a particular post were resolved through discussion among the coders involved. In accordance with standard qualitative research methods, <sup>22</sup> codes of similar nature were organized into themes (phrases that capture meaning of the corresponding codes) during subsequent group discussion. Analysis was conducted until data saturation had been achieved (ie, no new themes emerged from the data). This report focuses on themes related to peer-to-peer interactions, opioid and gabapentinoid experiences, and perceptions of pain management. The content and interpretations of these codes were confirmed by cross-checking the data against other codes.

## Results

A total of 7,694 posts from 2 Facebook support groups for BPI patients, Brachial Plexus Nerve Injury and Erb's Palsy Support Group: UBPN (UBPN) and BPIA, were analyzed. Of these, 5,504 posts came from the BPIA Facebook support group (71.5%) and 2,190 from the UBPN Facebook support group (28.5%). The average number of posts per individual was 8.3 (SD, 20.4); median number of posts per individual was 3. Of those who posted to either UBPN or BPIA, 329 individuals posted once, 406 individuals posted 2 to 5 times, 279 individuals posted 6 to 20 times, 62 individuals posted 21 to 50 times, 25 individuals posted 51 to 100 times, and 9 individuals posted more than 100 times.

Some BPI patients express anti-opioid sentiment when discussing pain management

There were 313 posts regarding opioid use. Many group members described negative attitudes toward opioid use and negative sentiment about other group members using opioids to treat BPI neuropathic pain. Some group members discussed the potential risks and dangers associated with using opioids and warned others: "Aim to get off the oxy as your goal. Take it only when you cannot bear it. ... Too many people developing dependence or addiction to opioids" (Table 1). Many posters denounced opioids either because of its perceived ineffectiveness at treating BPI neuropathic pain ("I quit all my pain meds after 20 plus years ... I can't believe I have a lot less pain and helluva lot more energy. Pain meds are not the answer") or because of adverse side effects ("You have to quit Tramadol if you want to have a healthy liver. ... Tramadol is pure poison with a lot of side effects"). Some posts were written in ways that shamed or judged other members for using opioids, and many times they referred to other posters' comments to support and verify their negative judgments regarding opioid use ("Opioid ... How about you don't"). However, many posters also commented on the negative impact of the current opioid epidemic, their relationship with their provider, and their decreased ability to obtain the pain medicine they needed ("My GP sucks and refuses to prescribe me any pain meds for fear of abuse. ... It's hard when your GP doesn't care").

Some BPI patients expressed a preference for alternative options to treat BPI neuropathic pain

When discussing pain management, many group members touted a preference for alternative pain management (320 total posts) rather than prescription medicine. Most times, this focus on alternative treatment emerged out of anti-opioid sentiment and the perceived negative aspects of opioid use, including ineffectiveness, adverse side effects, and the risks or dangers associated with opioid use and the opioid epidemic. Posters often promoted the use of cannabinoids (cannabidiol [CBD] oil and/or cannabis; there were 313 posts regarding cannabinoids) as a preferred alternative pain management to pain medication ("I have had a lot of pain over the years but now I have finally got a license for medical marijuana and it actually helps really good with the spasticity/tensions. ... I'm happy to get rid of all the opioids I have been taking before"). Other times, posters suggested that instead of using pain medication to treat BPI neuropathic pain, using a stronger or more positive mindset and having the ability to distract oneself was a preferred and successful alternative, regardless of the time since injury or the differences in the degree of injury among posters ("I found that, over time, rather than taking meds etc., endure the pain and eventually it goes away!").

Some BPI patients express anti-gabapentinoid sentiment when discussing pain management

There were 312 posts regarding the pain medications traditionally used for neuropathic pain. Some posters had negative sentiments toward gabapentinoids to treat BPI neuropathic pain, just as they did toward opioids. Many posters did not view gabapentinoids favorably either, because of their perceived lack of efficacy ("I [tried gabapentin] and it didn't help at all. My specialist kept increasing the dosage but still no good. After reading all the side effects I decided to come off it"), but more often, patients denounced gabapentinoids because of the adverse side effects they experienced ("I was put on gabapentin after a BPI caused by posterior dislocation and break in my shoulder. After 9 months on it I

decided to come off due to how it was making me feel — I felt like I was swimming in a pit of despair and physically it made me have crazy twitches and all manner of oddities. ... It took me 3 months to wean off it and I experienced severe withdrawals, it did help with the pain in the early days but in the end the relief wasn't worth the side effects for me"). Some posts often misclassified gabapentinoids as opioids.

## Discussion

In this thematic analysis of BPI Facebook support groups, we encountered charged opinions regarding the management of pain after BPI. The most common posts were related to anti-opioid sentiment and the preference for alternative options to treat pain after BPI. Although some posts supported opioid use and effectiveness for pain after BPI, most denounced opioid use because of its perceived ineffectiveness or adverse side effects, or as a result of the perceived risk and danger of opioid use. This may be because patients perceive the negative aspects of opioids to outweigh any pain relief provided. In addition, these sentiments toward opioid use reflect the social impact of the social environment involving the opioid epidemic and the public's evolving understanding of the potential harm of long-term opioid use. Similar to our findings, when discussing pain management, many patients who presented to the emergency department described hesitancy when receiving medication, especially for pain management.<sup>23</sup> This sentiment largely stemmed from an awareness of opioid dependence and a fear of developing long-term opioid dependence or addiction.<sup>23</sup> Furthermore, many patients expressed that much of their understanding about opioids came from popular media exposure or other unofficial channels that they consulted as sources of information about opioids.<sup>23</sup> In our thematic analysis, although some participants limited their posts to describing their own experiences with opioids, others advised and occasionally denounced group members who currently used opioids and called those who prescribed opioids pill pushers. However, other participants discussed the difficulty of obtaining opioids and their doctor's hesitation to prescribe more medicine; some participants thought that the provider's desire to prescribe less opioids reflected a lack of caring or misunderstanding about the severity of pain. During the current opioid epidemic, many physicians are confronted with the challenge of treating patient pain in an appropriate and adequate manner simultaneously balancing the potential risks associated with opioids, such as opioid dependence and addiction.<sup>24</sup> These contrasting opinions regarding opioids are an example of evolving social opinions toward balancing the current national opioid epidemic with the desire to treat patients who are in severe pain. The current analysis provides further examples of patients' sentiments toward opioid use and provides new perspectives from BPI patients regarding the use of opioids for treating pain. It presents an opportunity for physicians and patients to discuss individual goals, preferences, and concerns more openly regarding pain management, including what patients see as intolerable side effects.

Our analysis demonstrated that BPI Facebook group participants had strong opinions about gabapentinoid use for pain. Although there were some positive posts, most about gabapentinoids were negative. However, despite the cited effectiveness and place of gabapentinoids as a first-line treatment for pain after BPI, 16,17 we found that many participants denounced their use for pain. Gabapentinoids were not viewed favorably owing to their perceived adverse side effects and their perceived ineffectiveness for treating neuropathic pain. These medications are known to have side effects of dizziness and somnolence, 17 and they have the potential for misuse and overprescription 18,25; many posts cited the

**Table 1**Themes and Example Quotations From BPI Facebook Support Group Posts

#### Theme Illustrative Quotations

#### Against opioid medications

- "Aim to get off the oxy as your goal. Take it only when you cannot bear it. ... Find cannabis as a substitute. Too many people developing dependence or addiction to opioids."
- "I quit all my pain meds after 20 plus years. ... I can't believe I have a lot less pain and [a] lot more energy. Pain meds are not the answer."
- "You have to quit tramadol if you want to have a healthy liver. ... Tramadol is pure poison with a lot of side effects."
- "... Try and kick [OxyContin] when you can."
- "I promise [it] gets better. All I can say is that meds ain't the solution."

go back up or anything. I'm in so much pain [I don't know] what to do."

- "I don't take pain meds (they [don't] work anyway)."
- "My son was 22 a college senior when he had BPI ... he went to therapy and did grueling workouts without pain meds for fear of addiction for two weeks." "I'm in the same situation but instead of increasing my doctor decreased my pain medication because of the 'opioid crisis' and the CDC guidelines. ... He refuses to
- "My pain should be between my doctor and I, not what the government says my doctor can do."
- "I told my doctor about it and he insist I should not be taking opiates and should try to avoid them as much as I can ... is it safe to take Tylenol in high doses? Doctor says yes but I think he has a personal vendetta against opiates especially because of the opiate epidemic."
- "Just to me [a] pain management doctor is a pill pusher."
- "I have no idea but a pain management doctor seems the type to hand out pain meds [whether] you need them or not."
- "My GP sucks and refuses to prescribe me any pain meds for fear of abuse. ... It's hard when your GP doesn't care."

#### Against gabapentinoid medications

- "Gabapentin is a wicked drug! My suggestion is to ask whoever prescribed it for you to help you off it."
- "I know and everyone else knows how gabapentin is a drug no one likes. At least the ones who comment."
- "No medication has ever helped with the pain apart for pregabalin. This worked for a while, but over a number of weeks I had progressed on to the maximum dosage and got no pain relief from taking it."
- "I think my gabapentin is causing my liver numbers to increase."
- "I [tried gabapentin] and pregabalin. It made me hallucinate badly so I didn't sleep well at all. I don't remember it doing much for the pain either."
- "I was put on gabapentin after a BPI caused by posterior dislocation and [a] break in my shoulder. After 9 months on it I decided to come off due to how it was making me feel I felt like I was swimming in a pit of despair and physically it made me have crazy twitches and all manner of oddities. ... It took me 3 months to wean off it and I experienced severe withdrawals, it did help with the pain in the early days but in the end the relief wasn't worth the side effects for me."
- "I [tried gabapentin] and it didn't help at all. My specialist kept increasing the dosage but [it was] still no good. After reading all the side effects I decided to come off it."
- "They prescribed my gabapentin but I've heard a lot of bad side effects come with it."
- "[Gabapentin] worked for a bit but it stopped helping after a few years. The more they upped the dosage the more side effects I had. Lyrica landed me in the hospital unable to feel a single thing in my body (couldn't even feel my legs to walk)."
- "I use CBD so I'm not falling asleep from the side effects of Lyrica and such."
- "He mostly used gabapentin, for about 9 months after his accident, but ultimately went off of it since he didn't like the side effects including spaciness and irritability."
- "[Gabapentin] made him nauseous and he said it made him very emotional and sad. When the doctor heard this, he weaned him down and took him off it."
  "I take gabapentin as well as [Roxicodone]. ... I'm not thrilled that I take an opiate."

## Alternative pain management

- "Daily exercise. Drop all pain meds. Keep your mind occupied on things other than the pain. The more you think about the pain, the more pain you'll be in."
  "I choose to not take meds and to use the pain to my advantage. Pain isn't a negative, it's the body's way of telling you that something is wrong, something's different, but I've chosen to turn it into a good thing."
- "Not sure if marijuana is legal where you are but it has changed our lives in terms of [a BPI patient's] pain management."
- "I have had a lot of pain over the years but now I have finally got a license for medical marijuana and it actually helps really good with the spasticity/tension. ... I'm happy to get rid of all the opioids I have been taking before."
- "Opioid ... How bout ya don't ... Try CBD oil."
- "I found that, over time, rather than taking meds etc., endure the pain and eventually it goes away!"
- "I use marijuana after 15 years of opiate use. I just couldn't live like that anymore."

decision to stop using these medications because the participants believed that the negative side effects outweighed the potential pain relief. The current literature on gabapentinoid use for neuropathic pain treatment mainly discusses the biological mechanism of action, the efficacy and analgesic effect of gabapentinoids for reducing neuropathic pain, recommendations for pharmacologic management, and trends of increased gabapentinoid prescribing over the past decade. Patient attitudes toward gabapentinoids are poorly understood and represent an area for future investigation. Our findings regarding patient attitudes toward gabapentinoids are similar to what we have anecdotally noted in practice. Given the need for effective management of pain after BPI, our findings provide a helpful starting point for physicians to address patient misinformation and begin conversations about pain management in a way that is tailored to patients' concerns and interests.

One sequela of the anti-opioid sentiment in the BPI Facebook groups is an emphasis on using alternative treatments for neuropathic pain among patients. Participants who expressed strong anti-

opioid sentiment touted CBD oil and/or cannabis as safer and more effective treatments for neuropathic pain. Patients with safety concerns regarding opioids and gabapentinoids may be best suited for interdisciplinary care from a pain psychologist, with an emphasis on self-management tools. In addition to emphasizing CBD oil and/or cannabis as a more effective and safer for pain management, many posters also cited having a stronger mindset, positive thoughts, and the ability to distract themselves as alternatives to opioids for pain management. These posts could be interpreted by social media participants as shaming or judging other BPI patients for using opioids to treat pain. Some posts referred to other participants' anti-opioid comments to verify their judgments of those who used opioids, creating the impression of an echo chamber environment. Such an environment may perpetuate information inconsistent with messaging provided by health care professionals, adding to confusion for patients. Del Vicario et al<sup>26</sup> reported that echo chamber environments on Facebook are common, leading to confirmation bias and the formation of polarized groups. Our research demonstrates problems inherent in echo chamber environments on social media and the impact that misinformation can have on patient care and

patient outcomes. Given these findings, physicians treating BPI patients should be aware of the information that patients may be learning through social media, so that patient preferences can be discussed potential misinformation about neuropathic pain treatment can be addressed.

In contrast to the opinions expressed by posters in these 2 Facebook support groups, current literature suggests gabapentinoids as an effective first-line treatment and opioids as a second-line treatment for neuropathic pain. <sup>16,17</sup> However, as noted, despite these findings in the literature and their widespread use as treatment for patients with neuropathic pain, both gabapentinoids and opioids may be poorly tolerated owing to side effects, <sup>17</sup> and they have the potential for misuse and abuse. <sup>18</sup> Based on our results, many patients also perceived gabapentinoids and opioids to be ineffective at treating pain and denounced opioid use on the basis of its perceived danger.

There were limitations to this study. First, we looked at only 2 of the larger Facebook support groups. We recognize that this may not be representative of the general population and the posters may not be representative of the general population. Investigating some of the smaller support groups, Facebook support groups that are not public, and other social media platforms may provide even more insight into patients' experience with BPI and discussions about pain management. Moreover, the support groups used, UBPN and BPIA, were found to be the largest and most active public Facebook support groups for BPI, with 3,960 and 3,659 members in the UBPN and BPIA Facebook groups, respectively. Furthermore, the limited time frame used may not be representative of all patient discussions about pain management. A longer or shorter window of data collection used in the methodology might have resulted in different or new types of discussions among posters. However, we believe that the time frame used was able to capture a sufficient number of posts to reach data saturation and allowed for a full range of themes to emerge. In addition, we recognize that results may have been influenced by observer bias in quantitative thematic analysis. We attempted to mitigate our own bias by having multiple study team members assign codes, and we resolved any coding disagreement through discussion. Finally, analysis of other social media platforms (such as Twitter, Instagram, and Snapchat) might have yielded different themes. We analyzed Facebook support groups because of the substantially larger presence of BPI patient advocacy groups on that site.

People living with BPI actively engage in peer-to-peer teaching through the Internet and other social media platforms. Our thematic analysis of posts from 2 Facebook support groups identified strong sentiments regarding the use of opioids and gabapentinoids, preferences for alternative pain management treatments such as cannabinoids and mindfulness, and a desire for more effective treatment of neuropathic pain. These findings can help clinicians caring for BPI patients identify areas on which to focus during patient encounters to address neuropathic pain that commonly occurs with BPI.

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