

A Thematic Analysis of Online Discussion Boards for Brachial Plexus Injury

Marie T. Morris, MD,* Aaron Daluiski, MD,† Christopher J. Dy, MD, MPH*‡

Purpose Patients with brachial plexus injury (BPI) and their family members contribute to Internet discussion groups dedicated to BPI. We hypothesized that a thematic analysis of posts from BPI Internet discussion groups would reveal common themes related to the BPI patient experience, providing topics for patient education and counseling.

Methods Internet discussion boards were identified using the search term “brachial plexus injury support group” in Google, Bing, and Yahoo! search engines. Two discussion boards had substantially more posts than other Web sites and were chosen for analyses. Posts from January 1, 2015, through January 1, 2016, were examined. Using an iterative and established process, 2 investigators (M.T.M. and C.J.D.) independently analyzed each post using thematic analysis in 3 steps (open coding, axial coding, and selective coding) to determine common themes. In this process, each post was reviewed 3 times.

Results A total of 328 posts from the 2 leading discussion boards were analyzed. Investigators reached a consensus on themes for all posts. One central theme focused on emotional aspects of BPI. Four other central themes regarding information support were identified: BPI disease, BPI treatment, recovery after BPI treatment, and process of seeking care for BPI.

Conclusions Examination of posts on Internet support groups for BPI revealed recurring concerns, questions, and opinions of patients and their family members. The most common themes related to disease information, treatment, recovery, and the emotional element of BPI.

Clinical relevance These findings provide a helpful starting point in refining topics for patient education and support that are targeted on patients’ interests and concerns. (*J Hand Surg Am.* 2016;41(8):813–818. Copyright © 2016 by the American Society for Surgery of the Hand. All rights reserved.)

Key words Brachial plexus injury, online discussion groups, online support group, qualitative, thematic analysis.



From the *Department of Orthopaedic Surgery, Division of Hand and Upper Extremity Surgery; the †Department of Surgery, Division of Public Health Sciences, Washington University School of Medicine, St. Louis, MO; and the ‡Department of Orthopaedic Surgery, Division of Hand and Upper Extremity Surgery, Hospital for Special Surgery, New York, NY.

Received for publication March 8, 2016; accepted in revised form May 16, 2016.

No benefits in any form have been received or will be received related directly or indirectly to the subject of this article.

Corresponding author: Christopher J. Dy, MD, MPH, Department of Orthopaedic Surgery, Division of Hand and Upper Extremity Surgery, Washington University School of Medicine, 660 S. Euclid Ave., Campus Box 8233, St. Louis, MO; e-mail: dyc@wudosis.wustl.edu.

0363-5023/16/4108-0001\$36.00/0
<http://dx.doi.org/10.1016/j.jhssa.2016.05.007>

THE INTERNET HAS BECOME A MAJOR source of health information for patients. Patients seek information regarding the diagnosis and treatment of disease, and many of them use this information for decision making.^{1–4} Internet discussion groups, in particular, make up a special component of the online resources for patients suffering from chronic illnesses, including brachial plexus injury (BPI). These sites are generally not monitored by health care providers and provide a forum for patients to share their experiences coping with disease and for seeking advice about treatment. They also search for

emotional support from fellow users who share in their disease experience. Examination of the content of these Internet discussion groups can provide health care professionals with information on the patient experience and allow identification of specific information that is sought by patients.⁵

The existing literature on Internet discussion groups has primarily focused on their role for patients with chronic illnesses including breast cancer, prostate cancer, human immunodeficiency virus/acquired immunodeficiency syndrome, eating disorders, and others.^{6–9} A better understanding of common concerns and questions of patients with BPI would be useful in targeting patient education efforts both in the clinic and in the development of other patient education resources. The purpose of this study was to examine posts on Internet discussion groups dedicated to BPI and identify common ideas through thematic analysis.

MATERIALS AND METHODS

Online discussion boards were identified via an Internet search using the search term “brachial plexus injury support group” in Google, Bing, and Yahoo! search engines. Two discussion boards (United Brachial Plexus Network [<http://www.ubpn.org/>] and Traumatic Brachial Plexus Group—UK [<http://www.tbpi-group.org/>]) had substantially more posts than other Web sites and were chosen for analysis.

Posts were taken from conversation threads and grouped into 3 main categories based on content: personal experiences with disease, treatment, and management. Conversation threads with titles relating to logistics of the online discussion board or not directly related to the disease experience were not included. Posts from January 1, 2015, through January 1, 2016, were examined. In discussion threads started prior to January 1, 2015, only the posts after this date were analyzed. Data extracted included the name of the conversation thread, the text of the post itself, the poster’s username, and the date and time of the post. Posts could relate to either birth or traumatic BPI, and posts could be written by persons affected by BPI or their caregivers/family members. We originally intended to separately analyze posts relating to adult traumatic BPI and brachial plexus birth palsy. However, early in our experience reviewing the online posts, we found that many of the individuals contributed to both adult and pediatric conversation threads to share their experiences. This made it impossible to differentiate the posts and associated codes/themes in a reliable way. Following established qualitative

research methodology, 2 investigators (M.T.M. and C.J.D., blinded) independently analyzed each post using thematic analysis in 3 steps: open coding, axial coding, and selective coding.^{6,7} In the first stage of analysis (open coding), each post was assigned qualitative themes that captured the specific thoughts and ideas of each post. More than 1 code could be assigned to each post regardless of its length. The posts were then reviewed in the second stage of analysis (axial coding). In this step, broader themes were assigned to posts that consolidated the open codes. In the third and final stage of analysis, selective codes were identified that portrayed central messages. For example, the selective code of “Process of Seeking Care for BPI” encapsulated central messages that included the importance of advocating for your own care and dissatisfaction with physicians who seemed to lack knowledge regarding treatment options for BPI (Table 1). The axial codes and selective codes were agreed upon by the 2 evaluators. After evaluating all posts that were collected, the final group of axial and selective codes appeared to capture the range of users’ ideas and concerns, and we agreed that no new data were forthcoming from the posts—in other words, data saturation had been reached. Our institution’s human subjects’ research review board granted an exemption of this study from further review.

RESULTS

Of the 336 posts identified from the 2 leading discussion boards (United Brachial Plexus Network and Traumatic Brachial Plexus Group—UK), 328 were analyzed. Five posts were duplicates either within a single thread or between the 2 discussion boards and were excluded so the text was analyzed only once. Among the United Brachial Plexus Network posts, there were 50 individuals who posted (27 posted once, 19 posted between 2 and 5 times, and 4 posted > 5 times). Among the Traumatic Brachial Plexus Group—UK posts, there were 38 individuals who posted (17 posted once, 12 posted between 2 and 5 times, and 9 posted > 5 times). Investigators reached an agreement on themes for all posts. Thirty axial codes and 5 selective codes were created and are shown in Table 1. Representative quotations for each theme are shown in Table 2. The 5 selective codes could be grouped into either emotional or informational support. The codes are described in detail later.

Emotional aspects of BPI

Several posts emphasized the importance of sharing in the disease experience with other similarly affected individuals in an online community. Users expressed

TABLE 1. Selective and Axial Codes Created From Posts

Selective	Emotional Aspects of BPI
Axial	<ul style="list-style-type: none"> • Emphasizing the importance of sharing with others via online community • Expressing gratitude for support of family and friends • Expressing a desire to “move on” after the injury • Recognizing that “things could have been worse” • Recognizing the long-term nature of recovery after BPI • Expressing the desire to function independently • Psychological and emotional impact of BPI (posttraumatic stress disorder, depression, anxiety/fear for the future, substance use, self-esteem, emotional guards)
Selective	Information Support: BPI Disease
Axial	<ul style="list-style-type: none"> • Discussing mechanisms of injury and details of injuries • Seeking or providing information about BPI symptoms • Providing information about BPI pathoanatomy
Selective	Information Support: BPI Treatment
Axial	<ul style="list-style-type: none"> • Personal experiences with nonsurgical treatment (including observation and alternative medicine) and surgical treatment • Discussing role of amputation • Management of associated BPI symptoms (eg, edema, stiffness, atrophy) • Discussing adjunct treatments for BPI (eg, muscle stimulation) • Recognizing the challenges associated with neuropathic pain • Discussing different types of neuropathic pain management • Diagnostic tests for BPI (electromyography, magnetic resonance imaging, other)
Selective	Information Support: Recovery After BPI Treatment
Axial	<ul style="list-style-type: none"> • Timeline of nerve recovery, signs, and ways to expedite recovery (with or without surgery) • Personal experiences with rehabilitation • Discussing slings and orthotics for BPI • Sharing information or hopes for advances in technology • Discussing importance of a healthy lifestyle • Personal experience with compensatory ways to accomplish activities of daily living and high-level activities • BPI impact on career (employment, disability applications, financial problems)
Selective	Information Support: Process of Seeking Care for BPI
Axial	<ul style="list-style-type: none"> • Emphasizing the importance of being your own advocate • Dissatisfaction with treating physicians (lack of knowledge of nonspecialists, inadequate patient education, wrong diagnosis, delays in treatment, differing plans, poor attitude) • Satisfaction with, and importance of, BPI specialist care (surgeons, therapists) • Frustration with obtaining referral to BPI specialists • Inadequacy of information about BPI online • Sharing information on specific BPI specialists

gratitude for the existence of online discussion groups dedicated to BPI and for the advice and support they received from fellow users. Others discussed the niche of an online community where they could “offload and tell [their] story or vent [...] frustrations and fears,” but also “offer assistance [for] brothers and sisters in the experience.” In coping with BPI, users often discussed their desire to “move on” from the injury and to function independently without burdening family and friends. The psychological and emotional impact of BPI was evident in many posts, as users discussed their struggles with posttraumatic stress disorder, depression, anxiety, fear for the future, substance use, issues with self-esteem, and relating to others outside the BPI community.

Information support: BPI disease

Users largely began their posts sharing the mechanism and details of their injuries to provide background or to share in others’ similar stories. Users often had been seen by health care providers for their BPI and included specific details about the pathoanatomy of their injuries such as the nerve roots or named nerves and muscles that were affected. Owing to the nature of the Internet, we were unable to verify the accuracy or reliability of the self-reported case histories. The online discussion boards served as a way for users to ask for information about their BPI symptoms, provide others with their symptomatology, and answer questions about the

TABLE 2. Representative Quotations for Selective Codes**Emotional Aspects of BPI**

- “Sometimes we just need to offload and tell our stories or vent our frustrations and fears. Other times we need our space or just need to hide away. Also maybe as we recover it’s part of the moving on process.”
- “I suggest get back doing ‘life’ again as quickly as possible [...] Don’t wait till you are ‘recovered’ to do life again.”
- “[...] many of my concerns are related to short-term issues or inconveniences that have to be put in perspective relative to the long-term benefits.”
- “I’m only 6 months into this and I am sick and tired of people asking me if I’m alright. After a while it makes you wonder if there is something wrong with you!”

Information Support: BPI Disease

- “What if I told you that the pain is all in your brain? Chronic pain has been neuroplastically wired into our brains because our brains don’t know what to do with the jumbled signals coming from our BPI arm.”

Information Support: BPI Treatment

- “Is it worth it to go through this complicated surgical procedure then wait, wait, wait (we’re told it can take 2 years) to see if he’s able to bend his elbow and support 2 lb or less. Is elbow flexion with minimal biceps strength worth it?”
- “The idea of a nerve transfer is kind of freaking me out. I know that I can function just fine as I am and I don’t want to find that rewiring me so that shrugging my shoulders results in raising my arm was a horrible mistake that I can’t get used to!”
- “I understand it can take months or years for results to appear, but what can I expect the month directly after the operation?”
- “I went for amputation after 3 years of putting up with my dead arm. It instantly improved my life. I had to push the doctors a bit to get it done.”

Information Support: Recovery After BPI Treatment

- “What signs am I looking out for to tell if the nerves have taken and feeling coming back?”
- “If there is someone anywhere in the world who could tell us how long do we have to wait until seeing any improvements?”
- “What I cannot understand is why the muscle doesn’t show not even a little sign of contracture or flickers when he is trying to flex the elbow. He says he is giving the signal from brain and wants to bend the elbow but the muscle doesn’t respond at all.”

Information Support: Process of Seeking Care for BPI

- “The best advocate is us trying when doctors offer no help”
- “When I was told that I had “BPI and would never use my arm again and would never be rid of the pain, sorry, but here’s a surgeon who knows about this stuff, go see him” ... I headed straight for the Internet to find out information.”
- “Little did I know how inept the doctors were about this injury until I was released and started doing research on my own.”
- “I appreciate any advice I can get. I am truly at my wits’ end with this but refuse to give up. I feel as though my doctors have written me off.”
- “I have since left a message for my doctor to call me back (twice) in order to get a referral to a BPI specialist. I haven’t heard back in 2 days. I will continue to pester them until I get results!”

pathoanatomy of the condition using their own research or personal experience.

Information support: BPI treatment

Users both sought and provided information regarding personal experiences with various treatments for BPI including surgical and nonsurgical options. Surgical options discussed included nerve transfers, nerve grafts, muscle and tendon transfers, joint fusion, and limb amputation. When discussing operations that had been offered by surgeons, users asked about the relative advantages (eg, possibility of regaining some function) and disadvantages (eg, the long wait time to recovery and uncertainty of outcomes) of surgery, the outcomes of surgery from “a patient’s perspective,” and whether surgery was “worth it.” Multiple users asked about the logistics of recovery such as length of hospital stay, duration of immobilization, and

postoperative pain management. Topics mentioned by users who had undergone surgery included postoperative improvements in function and overall satisfaction or dissatisfaction with the results. Patients also showed interest in nonsurgical treatments for their BPI. Users shared their stories about regaining a personally acceptable level of function nonsurgically and with rehabilitation. Patients often posted about adjunctive treatments for BPI, such as nerve and muscle stimulation devices. Some of the most recurrent themes were the challenges of neuropathic pain and its various options for management.

Information support: recovery after BPI treatment

A common concern among postoperative users was the time from surgery to the first sign of nerve recovery or a successful outcome. Often users would ask about the personal experience of others and when

they first experienced the “little twinges,” “muscle twitch[es],” or “flickers.” These users often stated that, although they understood that nerve recovery generally takes several months, they sought reassurance that their courses were normal. Users also discussed strategies for rehabilitation including general activity and exercise, range of motion exercises, massage, and hydrotherapy. Users discussed their adaptations to performing their activities of daily living and efforts to return to high-level activities, including playing musical instruments and recreational activities. They also discussed the negative impact of their injury on their careers. In addition, users were eager to share links to articles discussing new technologies for diagnosis and treatment of BPI.

Information support: process of seeking care for BPI

Users discussed the various aspects of seeking treatment for their BPI including the importance of being one’s own advocate with their doctors, especially with obtaining referrals to BPI specialists and making decisions about surgery. Many users expressed frustration with their treating physicians, namely with the lack of knowledge of nonspecialists, receiving inadequate education about their disease, receiving a wrong diagnosis, delays in treatment, conflicting treatment plans, and poor bedside manner. Users who were satisfied with their experience made note in their posts and often emphasized the importance of receiving BPI specialist care. Many expressed their desire to research more about BPI but were dissatisfied with the lack of information online about treatment options, postoperative courses, and patients’ testimonies. They did, however, feel that the online discussion groups helped address that void.

DISCUSSION

Thematic analysis of posts from online discussion boards dedicated to BPI demonstrates common and recurring themes regarding social and informational support. Users valued the unique opportunity to share in the disease experience with similarly affected individuals online. They also used the discussion boards as an informational guide for BPI diagnosis, treatment, recovery, and seeking care for BPI. These findings are consistent with those of previous studies examining Internet discussion boards dedicated to cancer, in which informational and emotional support were also the overarching themes.^{6,7}

The emotional and informational support that online discussion boards provide is distinct from that given by health care providers or patients’ families and caregivers. This outlet is a readily available

resource for users to find others who are experiencing similar struggles. Based on our analysis, it appears that the Internet discussion boards fill the need for a “patient’s perspective,” which is missing from educational content produced by health care providers. The information gathered by patients from Internet discussion boards would then ideally be complemented through discussion with health care providers. Interestingly, the users who offered advice were well-educated in BPI, and rarely did we find misinformation relative to the current knowledge base for BPI (as judged by a fellowship-trained hand surgeon (C.J.D.) with a clinical interest in BPI). Our findings suggest that the overarching themes that we identified can complement physician-to-patient education. Reaching mutually agreed upon expectations for short-term and long-term recovery is critical to optimizing the chances of patient satisfaction, particularly for BPI.¹⁰ Pain management strategies outside the traditional recommendations of physicians were a common topic in online posts, indicating the importance of this topic to patients.

Users’ frustration with seeking care for BPI and with the lack of BPI information online highlights possible areas for improvement in the treatment of these patients. An overarching impression in posts was that BPI specialists were integral to optimal recovery. However, prompt treatment and referral to a BPI specialist was a recurring problem reported by users, and multiple users felt unsupported by their general practitioners when they wished to see a BPI specialist. These reports are substantiated by findings from interviews with BPI patients,¹¹ who also expressed frustration in trying to find information about BPI from their doctors or on the Internet. Because the option of surgery in BPI is often time-sensitive, this finding suggests the need for health care centers to address patients’ BPI at the time of injury and to set up the proper follow-up care after discharge.

There were limitations to this study. First, the nature of the primary source data did not allow us to reliably separate posts that related to adult traumatic BPI and brachial plexus birth palsy. We recognize that these are very different experiences for both patient and caregiver and that our combined analysis obscures these differences. Second, our analysis was based on a sample of posts from 1 year and examined only the 2 leading online discussion boards. We analyzed a relatively small amount of posts; however, we felt data saturation had been reached and a full range of themes was found in our selected posts. Furthermore, the thematic analysis process relies on a subjective analysis of the online posts, and the themes that emerged

during our analysis could potentially fail to capture more subtle ideas or feelings of users. However, the independent analysis by 2 investigators (M.T.M. and C.J.D.) and iterative review process served to ensure that appropriate themes were identified. In addition, our findings are consistent with existing research regarding themes present in online discussion boards for other diseases (information exchange/support regarding diagnosis and treatment as well as emotional support for those experiencing disease or those caring for patients with the disease).^{6–9} These consistencies suggest that our analysis was sufficiently comprehensive and accurate. Lastly, we did not include analysis of social media sites such as Facebook and Twitter. Although the popularity of these social media sites may increase the volume of posts regarding BPI, our experience from this analysis does not suggest that these posts would be fundamentally different from those on the online discussion boards.

Through our thematic analysis of online posts about BPI, we characterized the role of online discussion boards for patients with BPI. Our analysis provides a starting point for the development of education resources that are tailored to what patients want to know. Addressing these knowledge gaps will be an important step toward improving the patient experience for those affected by BPI.

REFERENCES

1. Trotter MI, Morgan DW. Patients' use of the Internet for health related matters: a study of Internet usage in 2000 and 2006. *Health Informatics J*. 2008;14(3):175–181.
2. Rahmqvist M, Bara AC. Patients retrieving additional information via the internet: a trend analysis in a Swedish population, 2000–05. *Scand J Public Health*. 2007;35(5):533–539.
3. Gupte CM, Hassan AN, McDermott ID, Thomas RD. The internet—friend or foe? A questionnaire study of orthopaedic out-patients. *Ann R Coll Surg Engl*. 2002;84(3):187–192.
4. Shah A, Kuo A, Zurakowski D, Waters PM. Use and satisfaction of the internet in obtaining information on brachial plexus birth palsies and its influence on decision-making. *J Pediatr Orthop*. 2006;26(6):781–784.
5. Conrad P, Bandini J, Vasquez A. Illness and the Internet: from private to public experience. *Health*. 2016;20(1):22–32.
6. Gooden RJ, Winefield HR. Breast and prostate cancer online discussion boards: a thematic analysis of gender differences and similarities. *J Health Psychol*. 2007;12(1):103–114.
7. Sullivan CF. Gendered cybersupport: a thematic analysis of two online cancer support groups. *J Health Psychol*. 2003;8(1):83–103.
8. Kendal S, Kirk S, Elvey R, Catchpole R, Pryjmachuk S. How a moderated online discussion forum facilitates support for young people with eating disorders. *Health Expect*. 2016 Jan 3. Epub ahead of print.
9. Mo PK, Coulson NS. Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *Int J Nurs Stud*. 2014;51(7):983–993.
10. Franzblau LE, Shauver MJ, Chung KC. Patient satisfaction and self-reported outcomes after complete brachial plexus avulsion injury. *J Hand Surg Am*. 2014;39(5):948–955.
11. Franzblau LE, Maynard M, Chung KC, Yang LJ. Medical treatment decision making after total avulsion brachial plexus injury: a qualitative study. *J Neurosurg*. 2015;122(6):1413–1420.