

Failed Spinal Cord Stimulation Therapy: The Perspective of Facebook Support Groups

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Failed back surgery syndrome (FBSS) is actually a group of conditions describing persistent low back pain, with or without leg pain following one or more spine surgeries [1,2]. It is known that the failure rate of lumbar spinal surgery lies between 10% and 46%. Although > 50% of primary spinal surgeries are successful, no more than 30%, 15%, and 5% of the patients experience a successful outcome after the 2nd, 3rd and 4th surgeries, respectively [3]. The FBSS patients experience greater levels of pain, lower quality of life, and a higher rate of unemployment compared with other chronic pain syndromes [2,4].

Spinal cord stimulation (SCS) has been shown to be a cost-effective treatment option not only for these patients, but also for patients with complex regional pain syndrome (CRPS), peripheral vascular disease, and angina pectoris [5]. However, as with all procedures, complications cannot be ruled out. These could be biologic (hematoma, infection, cerebrospinal fluid leak), technical (lead breakage or migration, battery failure, hardware malfunction) or other (pocket pain, skin erosion, allergic reaction, overstimulation) [6]. Although these problems occur rarely, they do occur and many dissatisfied patients express their disappointment on various social media (SM).

Social media can be defined as a world of human interactions driven by content and supported by the use of technology [7]. Nowadays, patients are informed (80% of internet users have searched for health information online) [8], engaged (27% of patients comment or post status updates based on health-related experiences) [8], social (29% of patients viewing health information through SM are viewing other patients' experiences with their disease) [8] and decision makers (77% of patients use search engines prior to making an appointment and 41% of patients reported that information found on SM would affect their choice of a specific doctor, hospital, or medical facility) [9,10].

According to global mobile application rankings, Facebook (FB) is the most popular app [11]. More precisely, it encompasses 2.41 billion monthly active users, 71% of American adults use it, and 1.4 billion people join FB Groups [12]. Such groups have been created by FBSS patients who have received a SCS system and are not satisfied with it. The main topics of interest in these groups (with corresponding original posts/examples) are the following.

Information gathering before an SCS-implantation or explantation:

- “Can anyone plz tell me how painful it was after having your stimulator install surgery?”

- “Please please ask your surgeon to do a allergy test prior to permanent implantation!!! Had placement in June allergy tested started yesterday today HIGHLY ALLERGIC!!! I have to have the surgery AGAIN to have everything removed!!!”
- “Still searching for others who had a successful removal of a device that had paddles. I have 2, and they were amazing for 2-3 years then my neck unit started pulling tight, the cords at the surface and I’m in unbearable pain 24/7. I’ve spoken to quite a few who have had theirs removed but only one who had paddles and theirs wasn’t in long. Mines been in since 2015. I can no longer bend my neck down, it’s yanking my vertebrae to where I have a 3 inch divot in my spine. I can’t go on like this but also have very little confidence I’ll find an orthopedic surgeon willing to touch it!”

Post-implantation or post-explantation problems:

- **Infection:**
 - “Well it is not keloid it is another infection starting antibiotics today this time close to my spine. And this happened 6 weeks post op of the removal. Please everyone keep an eye on your incision sites”.
 - “Those of you who have had infections, how were they treated? My first stimulator was infected with staph and I was on many rounds of oral antibiotics for about 3 months. This time, the infection is MRSA and I was given an oral antibiotic for only a week. Does this sound right?”.
- **Hematoma:**
 - “I also have a hematoma. I’m in so much pain now, more than after my initial SCS surgery. Anyone had a hematoma and what was the result?”.
 - “After your removal anyone else have huge hematoma with no bruising?”.
- **Pocket pain:**
 - “Hi again - so now my non-functioning Scs has a NEW problem - the battery has apparently come out of the pocket and is no longer secured in place and is now “flopping around” (my drs words) - causing me more and more pain and swelling every day”.
 - “Additionally, about a month ago, the battery of my Scs came out of the pocket it had been placed into and is “flopping around” causing me a whole new and different constant pain. I’m on the waiting list to have it removed, but there are only two drs that will touch another surgeons’ work”.
- **Paralysis:**
 - “Paralyzed in September 2017 during lead implant for a one week trial of a SCS. Walked into the clinic w low back pain, flown out via life flight helicopter. I will never stand or walk again. The pain management doctor recommended the SCS to get me off of opiates. Still have low back pain, still on opiates but now a paraplegic as well”.
- **Overstimulation:**
 - “Has anyone else had electric shocks through your body, strong tingles and numbness and extreme pain due to your spinal cord stimulator?”.

- “I had burning shocks so bad during the trial that caused me to lose all ability to use the arm. My GOOD ARM is now 100 times worse than the bad arm it was supposed to help, I now need carers every day to help with even basic personal care”.
- **MRI:**
 - “Long story short, I need to get a MRI and turns out I’m not able to get a MRI with this thing in me, even though they said I could when I got it”.
 - “Then on top of that, I need a MRI on my brain and I can’t have a MRI (wasn’t told no MRI’s until after surgery) do to the battery being right along my spine and no MRI setting. UGH!!”.

Legal issues:

- “Now the problem is he is outside my insurance plan. Of course he is, just what I needed to hear. Now I have to figure how to navigate the minefield of insurance nightmares. I feel that my age and the number of surgeries, as well as the cost are against me”.
- “Does anyone have any information about any lawsuits/class actions against any of the manufacturers etc?”

Comments about reps:

- “Apparently shocking is normal so says my Rep. My lead has moved and pocket where battery is isn’t healing. She suggested more reprogramming and to call her in 10 days. Listened to nothing I had to say”.
- “The rep n service is horrible n now I just had x-ray last week cause I’d been having trouble n seems like the lead wasn’t rt. So they took x-ray n the rt lead has fallen down several inches. I had 2 MRI’s Thursday n they also show this. Rep suppose to been there on Thursday never showed up. Even after calling me n verified time in place”.

The above mentioned posts underline the importance of further reducing the frequency of complications, even though the complication rates for this minimally invasive procedure are low. In this context, an improved implantation technique based on practical guidelines and on the available literature is imperative. Satisfied patients and their relatives could then serve as FB-ambassadors to raise awareness of the role of neuromodulation in treating chronic pain. Social media are a great tool to disseminate knowledge and by doing so, even more patients could benefit from this opioid-free treatment option.

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