

Getting in Sync: Health and Digital Literacy in Patient Deep Brain Stimulation Device Use

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Abstract

With the growing number of mobile health devices, a description of the factors that lead to adoption and use of these personal health devices is needed. We observed and recorded 11 routine deep brain stimulation (DBS) programming appointments. We found an overall lack of health literacy surrounding DBS as well as a lack of digital literacy in patients' ability to use their DBS Patient Programmer to modify their DBS settings. These two factors led to patient disuse of their programming device outside of the clinical setting. This paper's contribution is to present this relationship and suggest ways we can better facilitate patients in gaining both health and digital literacy.

Introduction

A turn towards a patient-centered care model has prompted an interest in providing patients with devices to monitor their health, adjust treatments accordingly, and share this data with their clinicians. In essence, putting power in the patient's hand to give them agency over their own care. However, the context around device usage could be a significant factor in evaluating the efficacy of these devices in actually achieving patient engagement or empowerment. Most significant in this regard is the importance of health literacy and numeracy in understanding one's disease and the relationship between symptoms and treatments [1]. In addition, as further technologically advanced devices are developed, a patient's ability to understand and use the technology plays a greater role in patient engagement [2].

In the following study, we describe the particular case of deep brain stimulation (DBS) in Parkinson's disease (PD) symptom management. In this instance, patients are provided with a device to modify the brain stimulation parameters to better address symptoms throughout the day. As we show in our findings, low health literacy and digital literacy often limit and occasionally altogether deter patients from modifying their stimulation device parameters outside of the clinical setting. This presents a real challenge in (1) presenting patients with health devices to maintain control over their own quality of life and (2) engaging patients in guiding clinicians in making further treatment changes that provide therapeutic benefit. Our findings lead us to make design recommendations for the development of visualizations to explicate the relationship between DBS adjustments and symptomatic outcomes in order to facilitate patient engagement through increased health literacy and digital literacy.

Background

There has been a shift from the traditional clinical care model, where clinicians are solely in charge of the care of the patient, to a patient-centered care model that is more focused on patients being engaged in their own medical decision-making and treatment [3]. Patient engagement has been associated with a decreased number of annual visits for specialty care and fewer hospitalizations and diagnostic tests [4].

Prior work has shown that health literacy is important for patient engagement as patients can then better manage their health, make more informed decisions, and increase communication with their doctors [1]. Health literacy allows chronically and progressively ill patients to better "obtain, process, and understand" their health conditions and assists them in making more informed decisions surrounding their care [5]. With low health literacy, patients often lack the skills to effectively communicate important information, such as symptoms or other health concerns, to their doctors, and they frequently feel that their physicians fail to explain health related information in a manner that they can understand [6]. This, in turn, can lead to poor compliance when it comes to taking medications or following a treatment plan, and as a result, worse health outcomes [6].

Likewise, digital literacy, the ability to appropriately use digital tools to access and manage digital resources [7], has also been shown to be a fundamental factor in patient engagement primarily with regards to searching for online health information [2]. For instance, in a 2013 study examining the relationship between functional health literacy, self-efficacy, social support, and empowerment in individuals living with Parkinson's, nearly 50% of patients indicated that the Internet was the most common source they used to find health information relating to their disease [8].

As wearable sensors and mobile digital devices for health tracking become ubiquitous, knowing how to use and integrate the knowledge from these devices into one's care plan is essential.

From our own understanding of the literature, the interplay between these two factors has not been addressed with regards to patient engagement. In particular, the importance of both health literacy and digital literacy on the use of at-home health device usage has not been described. In this paper, we show the impact of low health literacy and digital literacy on PD patients' use of a DBS patient programmer that should provide patients with a modicum of power and engagement in their healthcare, but instead is a source of confusion and further disempowerment.

Fieldwork Domain of Deep Brain Stimulation Surgery Assessment and Programming

DBS is a procedure that uses electrodes to target specific areas of the brain, to help regulate some of the worst symptoms of Parkinson's disease, including tremors, rigidity, bradykinesia, dyskinesia and gait problems. DBS has been shown to have a significant impact on improving the quality of life for many patients, and reducing the amount of medication they need on a daily basis [9].

There are a number of DBS parameters that can be adjusted including the number of leads activated and the frequency, voltage, and pulse width being received by the leads. These various parameters can affect different symptoms and are able to be adjusted during the programming sessions with the clinician or outside of the clinic by the patient or caregiver. Each patient will respond differently and the symptoms of Parkinson's disease are highly variant throughout the day or from week to week, which is part of what makes the customizable aspect of the DBS program so effective for Parkinson patients. Through the DBS Patient Programmer (Figure 1), the clinician can provide each patient with a limited ability to adjust his or her DBS unit at home. The patients have the ability to turn their devices on and off, and can also adjust their stimulation settings within a limited set of "clicks" up or down whenever they feel it necessary with regards to their symptoms. As patients are seen one month after DBS surgery and subsequently every four to six months in order to adjust the programming device to their optimal settings it is important for a clinician to find the right setting for each patient and to provide the right level of control for the patient to use at home.



Figure 1. DBS Patient Programmer (image: Medtronic)

Methods

After obtaining IRB approval, we conducted a field study at an outpatient clinic of a hospital. Participants were consented at the beginning of their routine post DBS surgery clinical appointments. We observed and video recorded a total of eleven (11) individual patient appointments, each approximately 45 minutes. Each appointment included a registered nurse and an attending neurologist. The patients also had informal caregivers present (e.g. spouse) for most of the observed sessions. Additionally, open-ended interviews were conducted with the clinicians before and after the appointments to gain further insights. From the data collected we focused our attention on the programming sessions that took place with both the RN and attending neurologist as well as discussion of the DBS device. The authors reviewed their field notes, transcribed their observations, and video recordings then iteratively open coded and found common themes across patient recounts, the researchers then compared their themes for internal consistency. The following findings are the relationships between the DBS Patient Programmer disuse and reasons for confusion or concern leading to that disuse.

Findings

Although, patients were provided with a DBS Patient Programmer along with the 136-page Medtronic manual, clinic devised simplified instruction sheet, and were frequently instructed by the RN or neurologist on the modifications they were able to control at home, all of the patients we observed indicated their disuse or minimal use of the DBS Patient Programmer when at home. This is troubling, as the DBS Patient Programmer has been developed to provide the patient with a level of control and customization for the patient's particular symptoms. The optimum efficacy of the DBS treatment is through modifications just as one may modify their medication intake, e.g. taking a lower dose mid-day or taking the next dose sooner because the prior one is wearing off too soon. The revelation that patients were not modifying at home was oftentimes surprising to the clinicians themselves and this admission would often prompt the clinician to engage in another round of explanations as to how the patient can and should make modifications to their DBS device.

Patient 9: (6 Years Post-Surgery)

Neurologist (MD): [to the nurse] How much patient control does she have?

Registered Nurse (RN): I gave her 2 up and 4 down. I actually took her up 3/10 of a volt on her right electrode because she had increased rigidity and bradykinesia in her left arm, now she matches.

MD: [to the patient] Did you notice anything?

Patient (PT): Not really, but I think I will notice it later on.

MD: Have you ever used the patient control?

PT: No, I have never needed it.

MD: No, I am just saying during the down times, you have never kicked it up during the down times.

PT: No, I am relying on the medicine.

MD: I am just saying, one of the things if there are down times you could always try...

Patient 4: (2 Years Post Surgery)

RN: "Now you have two programs. Do you ever switch to the B program?"

PT: "I don't ever mess with that. Well, I turned it off once and that was enough for me."

RN: "Oh."

PT: "I just did that in case it does get turned off."

Having the ability to adjust the DBS patient controller should empower both the patient and caregiver to take initiative when they feel the programming should be modified to better address symptoms; however, we observed that it is very rare for patients to adjust their DBS patient controller unless under instances where it was required, such as turning it off during an MRI and then turning it back on to the same settings.

There are two reasons that emerged from our observations of conversations between patients and their clinical caregivers leading to this disuse. First, we found that there are low-levels of health literacy for both patients and caregivers concerning how deep brain stimulation can assist with Parkinson's symptoms.

Patient 11: (6 Years Post-Surgery)

PT: "Previously, I've only changed it when I felt dystonia [involuntary spasms and posturing] in my feet...you know cramping or big tremor or really off, but...it shouldn't help the balance a lot, should it?"

RN: "The way it helps balance is it keeps your two sides pretty equal."

PT: "Oh"

RN: "Because with Parkinson's disease usually one side is worse than the other. That's the big thing."

PT: "Huh. Well maybe I do need to get it in sync."

This low-level of health literacy also affected the patient's ability to understand how the DBS programming adjustments made in-clinic by their clinical caregiver affected their symptoms, thereby making it difficult for the patients to accurately understand how the adjustments made related to the symptoms they were experiencing.

Patient 6: (5 Years Post-Surgery)

RN: "So, if I could make you better today, what could I do for you?"

PT: "Um, Less rigidity."

RN: "Well, you still have the carpal tunnel and I can't do anything about that"

PT: "Well, you asked"

Patients often had an overall lack of understanding on how their DBS system assisted them with their Parkinson's symptoms and had to ask for clarification from their clinicians. They would ask to have a symptom fixed that is not fixable by the DBS. This lack of understanding presents a gap with the patient's health literacy with both Parkinson's symptoms and the DBS system.

The second reason for patients not using their DBS device to modify their stimulation settings outside of the clinic was due to digital literacy. Many of the patients were intimidated by the technology itself and were afraid they would make a mistake or even hurt themselves. Some patients showed that they did not understand how each of the buttons worked on the device itself and so, even if they were motivated to make a change, could not take action.

Patient 1: (6 Years Post Surgery)

PT: "I wanted to tell you too, last time I was here we had me good but by the time I got home I could hardly walk, it was crazy, and but then like it took a couple days for me to get used to it, it was so frustrating but I thought I would remember to tell you that too."

RN: "That does not surprise me, and that's why when ever I do something I give you the right to undo it because sometimes if I take you up a click or two it works, you go home and it's not working, you can go back down and then go up one click and then go up that second click."

PT: "I've never used the programmer. I'm afraid of it."

RN: "You can't hurt yourself."

PT: "My old one I loved, I loved the old one, I used to turn myself off for the nurses at my dad's hospital because it's a small town hospital and they wanted to see how cool it was, this is a digital one and it makes me nervous."

RN: "It's easier than the old one."

PT: "I know it is, I thought about bringing it but I thought I will bring it next time"

Patient 3: (7 Years Post-Surgery)

CG: "Can I get the classroom exercise? Now I'm raising my hand, teach." [laughs]

RN: "Ok let me...ok you can go up or down two on each side. I'm ok with that."

CG: "Up or down two on each side?"

RN: "Ok."

CG: "We're not leaving this room until I get a lesson."

RN: "Ok go ahead."

CG: [gesturing to patient control device] "These two buttons?" [stands up and walks over to his wife] "I need to figure out instructions. I need to take notes."

RN: "I will give you...I will give you written instructions when you go home, too. Ok, basically...basically...small white button"

CG: "I hate that little white button."

Patients and caregivers often felt confused and overwhelmed when shown how to use the devices, despite being given a tutorial in a safe setting. This discomfort with the technology prevents the patients from integrating the device and the information it provides (i.e. the current and adjusted settings) into their daily care plan. This in turn prevents them from sharing this information with the clinicians and thus further engaging with their care. Thus, there is a gap with both health and digital literacy that DBS patients must be able to bridge in order to be empowered to make adjustments outside of the clinical environment. However, current methods of explanations, demonstrations, manuals, and information sheets are currently unable to bridge that gap.

Conclusion

This study showed that DBS patients and caregivers have a general lack of health literacy surrounding DBS programming, as well as how the adjustments affect the body. We found that due to this lack in knowledge the patients are disempowered to make adjustments at home and are instead relying solely on their clinicians and their medication. In addition, low digital literacy with regards to digital, mobile devices hinders their ability to make the modifications without the guidance of their clinician. We suggest that health literacy and digital literacy can be enhanced by facilitating patients' understanding of the adjustments that are occurring in the clinic and the result they have on their body's response to the DBS device. From this understanding, they could take that knowledge home with them to further adjust their settings when needed.

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