Living with Brain Data: Collaboration and Equity in Data-Intensive Brain Implants

JUN ZHU, Michigan State University, United States
MEGH MARATHE, Simon Fraser University, Canada

This paper examines the lived experience of implanted medical devices through the case of brain implants for epilepsy. These data-driven devices record brain signals to detect and interrupt seizures, introducing new forms of technology-mediated care. Drawing on interviews with 17 patients and caregivers, we examine how data-intensive implants reshape medical interactions and everyday life. Participants reported shifts in doctor-patient collaboration, including the integration of a new expert—an engineer responsible for device-related concerns—into clinical visits. The preparatory and ongoing work of data transfer posed challenges for participants who were low-income, aging, traveling, or busy. Participants expressed a strong desire to access implant data to better understand and manage their condition. They were satisfied with the device unless their medications and/or seizures increased. We discuss emerging considerations for collaborative care and design justice introduced by medical implants that, unlike wearables, deliver treatment and cannot be easily set aside.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; **Empirical studies in HCI**; • **Applied computing** → Health care information systems; • **Social and professional topics** → *People with disabilities.*

Additional Key Words and Phrases: medical implants, data work, technology-mediated collaboration, design justice, collaborative care, patient experience, epilepsy

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1 Introduction

In recent years, brain implants have drawn hundreds of millions of dollars in investment by technology industry leaders [3, 34, 46, 56]. Brain implants are devices that directly connect to a person's brain for treatment or assistive purposes. CSCW and HCI research has long examined how data-intensive technologies such as consumer-facing wearables shape collaboration in healthcare. Implants present a new set of considerations that provide a long-term and embodied perspective on care collaboration and design justice. Consumer wearables are usually peripheral to care delivery, whereas implants are the mechanism through which medical treatment is delivered. Further, wearables can be easily set aside, whereas implants are a long-term commitment, being surgically embedded into the patient's body. Finally, implant data is physician-facing and integrated into clinical records and decision-making processes, raising distinct design considerations in comparison to patient-facing data from wearables. These characteristics position brain implants as an ideal site to examine collaboration and equity considerations in relation to data-intensive health technologies.

Authors' Contact Information: Jun Zhu, Department of Media and Information, Michigan State University, East Lansing, Michigan, United States, zhujun@msu.edu; Megh Marathe, Simon Fraser University, Burnaby, British Columbia, Canada, megh_marathe@sfu.ca.

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In this paper, we focus on therapeutic brain implants used to treat chronic conditions such as epilepsy and Parkinson's disease [7, 31, 68]. These data-driven devices are seen as the future of care for neurological conditions and are increasingly common in medical practice. For example, over 160,000 people had received deep brain stimulation implants as of 2019, with about 12,000 new procedures per year [14]. CSCW/HCI research on therapeutic implants has focused on cardiac devices [2, 19, 20, 71]. Mentis and colleagues present the only studies of brain implants, examining how Parkinson's patients, caregivers, and clinicians collaborate to adjust device settings [52, 53].

We add to this nascent body of work by examining patient and caregiver perspectives on brain implants for epilepsy. Epilepsy is a chronic illness and disability characterized by recurrent and unpredictable seizures. Implants are used to treat patients whose seizures do not respond to medication [69]. Based on a qualitative study consisting of interviews with 17 participants, we found that brain implants impacted people's medical interactions and daily lives in several ways.

Participants reported shifts in doctor-patient collaboration, including the involvement of a new expert—an engineer responsible for device-related concerns—and an emphasis on implant data in clinic visits. Further, participants who were low-income, old, aging, traveling, or busy found it difficult to transfer and upload implant data on an ongoing basis as required to sustain data-intensive care. They also expressed a strong desire to access recorded data to better understand and manage their condition. Most participants were satisfied with their device unless their medication and/or seizures increased. These findings show how data-intensive medical devices shape people's experiences across clinical and everyday settings, responding to calls to study healthcare and technology in the wild [10, 15, 43, 74]. Undoing the distinction between home and clinic and examining real-world challenges remain crucial propositions that need consideration in the ongoing program of CSCW research focused on healthcare. We discuss emerging sociotechnical considerations for research on technology-mediated care collaboration and design justice introduced by data-intensive medical implants that, unlike wearables, deliver treatment and cannot be easily set aside.

Our novel contributions include the following:

- We present the first empirical investigation of the patient experience of brain implants in CSCW/HCI, detailing the lived experience of embodied technologies that deliver treatment, rely on data, and cannot be easily set aside.
- We describe how implants reshape doctor-patient collaboration by introducing a technical expert and novel forms of data into clinical decision-making, thus contributing to CSCW/HCI understandings of how expertise is negotiated and perceived in care infrastructures.
- We surface critical design justice implications in relation to non-optional and treatment-delivering technologies by showing how the design of data-intensive implants poses challenges for low-income, aging, and non-white patients.
- We extend CSCW/HCI understandings of data work by examining the preparatory and ongoing labor required to manage data-intensive implants, highlighting how this work is shaped by socioeconomic and lifestyle factors.
- We show that patient definitions of device satisfaction may differ from definitions used in clinical studies, thus adding to CSCW/HCI literature on technology-mediated collaboration.

2 Background

2.1 Epilepsy

Epilepsy is a chronic neurological condition characterized by recurrent and unpredictable seizures. Seizures are brief episodic events during which people lose control of bodily function. Generalized tonic-clonic seizures cause convulsions throughout the entire body, often accompanied by falling and loss of consciousness. Between 36% and 65% of people with epilepsy experience seizures with symptoms such as nausea, language dysfunction, and localized muscle spasms [27, 37, 38]. Seizures are unpredictable, difficult to experience, and stigmatized in mainstream society [4].

Over 2.2 million people in the U.S. and approximately 50 million people worldwide have epilepsy, making it one of the most prevalent neurological conditions [1, 80]. Epilepsy cannot be cured but it can be managed with medication and other forms of treatment. Approximately 30% of people with epilepsy continue to experience seizures despite treatment [6, 80]. In such cases, therapeutic brain implants may be recommended as a potential option to manage seizures [69].

2.2 Brain Implants

Brain implants are recognized as an important way to address treatment-resistant seizures originating from specific areas of the brain [68]. Currently, three types of implants are used to treat epilepsy (see Figure 1): vagal nerve stimulation (VNS), responsive neurostimulation (RNS), and deep brain stimulation (DBS). This paper focuses on RNS and VNS.

RNS. Responsive neurostimulation is the first commercial closed-loop implant for epilepsy [22, 68, 69]. RNS implants are battery-operated devices inserted underneath the patient's skull. These devices are connected to wires positioned in the brain region where the patient's seizures originate. The implant continuously monitors brain activity, detects seizures, and delivers stimulation to stop them [73]. The RNS system continuously records data about brain and stimulation activity [35, 64]. Figure 2 shows an example snippet of data recorded by the RNS device. After implantation, this data can be accessed using an online portal. During follow-up appointments, an engineer from the manufacturer works with doctors to interpret data and adjust settings to optimize device performance. Patients can also reach out to engineers about device issues without an appointment. The RNS system was approved by the U.S. Food and Drug Administration (FDA) in 2013 [75].

VNS. Vagus nerve stimulation applies pre-programmed, repetitive electrical pulses to a specific target site without using real-time feedback to adjust the therapy [23, 68, 69]. The VNS stimulator is inserted in the chest area under the skin and connected to a thin wire that wraps around the vagus nerve in the neck [23, 68, 69]. After implantation, patients receive a magnet that can be swiped over the VNS to deliver an extra pulse that may help stop the seizure, shorten its duration, or reduce its intensity [23]. The VNS system was approved by the FDA in 1997 [76].

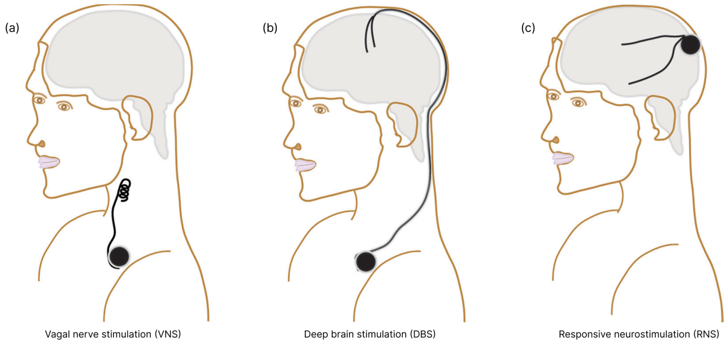

Fig. 1. Three implant types used to treat epilepsy: vagus nerve stimulation (VNS), responsive neurostimulation (RNS), and deep brain stimulation. VNS and RNS are common in medical practice. Image taken from [68].

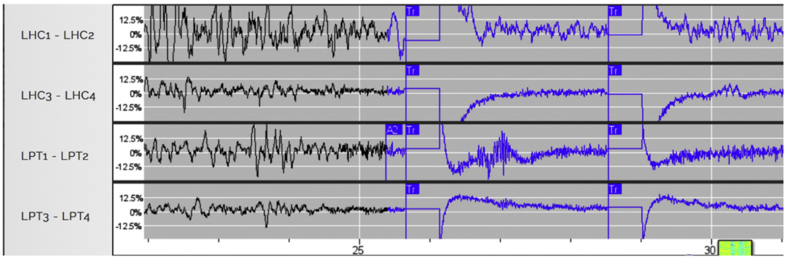

Fig. 2. Snippet of RNS data showing the start of a seizure at the first white vertical line and its detection one second later. Blue vertical lines indicate stimulation delivered to stop seizures. Image taken from [31].

3 Related Work

This section reviews prior research on technology-mediated collaboration, data work, and implanted medical devices in social computing and the social sciences.

3.1 Technology-Mediated Collaboration and Data Work in Healthcare

HCI/CSCW researchers have extensively investigated how technologies mediate collaboration in healthcare by influencing communication, interpretation, and shared decision-making processes between a variety of stakeholders including patients, clinicians, and caregivers [28, 40, 63]. With the rise of wearables capable of recording health data, researchers have studied how patient-generated data (PGD) could support chronic condition management, enhance collaboration between patients and clinicians, and enable personalized care [13, 51, 54, 57, 66, 72].

Researchers have examined considerations around supporting the use of PGD in clinical settings. Schroeder et al. studied how patients and providers interpret interactive visualizations based on PGD in the context of irritable bowel syndrome [66]. They found that the work of reviewing visualizations together helped patients and providers better understand PGD and develop mutual trust. Additionally, patients and providers both expressed a desire to use such visualizations outside the clinic, particularly to prepare for appointments and manage their condition on an ongoing basis. Evans et al. explored how sensor-based PGD could support PTSD therapy in everyday contexts [24]. They prototyped a homework review system that visualized PGD such as heart rate and phone use along with therapy-related homework. They found that while some clinicians believed that reviewing PGD in advance would help patients be better prepared for appointments, others worried that allowing patients to independently access PGD could lead to misinterpretation and distraction. This finding emphasizes the need to consider when and how PGD is accessible to patients and design tools to support people in making sense of PGD in a chronic care context.

The work that people perform to interpret and use PGD in practice is called *data work*. Kaziunas et al. conducted an ethnographic study to investigate how parents used the Nightscout application to remotely monitor their children's blood glucose levels to manage Type 1 diabetes [42]. They found that PGD reshaped care and collaboration in complex ways. While continuous data access enhanced parents' understanding of their child's health status, it also created additional data work. Further, the ability to access data from afar produced tensions around autonomy and privacy between parents and children. Kaziunas et al. developed the notion of "caring through data" to describe these impacts, suggesting that data work can facilitate the delivery and experience of care.

Data work can also help third parties, such as caregivers, contribute to care delivery. Foong et al. developed and evaluated a system that allows caregivers to manage and share data about patients' home environments to facilitate remote home safety assessments by occupational therapists [28].

They found that caregivers played an important role in supporting patient-clinician collaboration by contributing contextual knowledge based on daily interactions with patients and an understanding of their needs and desires. With experience, caregivers became experts in home care and advocated on behalf of patients with healthcare professionals. Thus, data work is a mechanism through which caregivers can support doctor-patient collaboration.

Most studies in this area focus on consumer health data that patients can access independently using consumer-oriented wearables, mobile apps, and symptom diaries. Our study extends this body of research to the realm of medical-grade PGD, that is, data recorded by medical devices that is part of the medical record and accessible primarily via medical systems and providers. We investigate how medical-grade PGD shapes collaboration and data work in therapeutic brain implants.

3.2 Therapeutic Implants in HCI/CSCW

HCI/CSCW researchers have conducted a small number of studies on therapeutic implants, largely seeking to understand patient experience and data privacy concerns. These studies have found that patients worried about receiving fewer opportunities to interact with clinicians and successfully transfer data, whereas clinicians prioritized quick and continuous data access to aid decision-making. Little attention has been paid to the long-term and embodied perspectives on collaboration and data work that implants can provide, with a notable exception.

Mentis and colleagues conducted field observations and a design study with 11 patients with DBS implants for Parkinson's disease, focusing on how clinicians collaborated with patients and caregivers to reprogram device settings [52, 53]. Mentis and colleagues found that assessing the patient's movement abilities requires doctors, nurses, patients, and caregivers to participate in a collaborative process that they call co-interpretation. They designed patient-centric visualizations to enable patients and caregivers to make sense of implant data, finding that these alternative visualizations helped give patients a voice in device adjustment discussions [52]. We draw inspiration from this work and extend it outside the clinic to examine how brain implants shape patient experiences and doctor-patient collaboration in RNS and VNS implants for epilepsy.

Other than Mentis and colleagues, CSCW research has focused on cardiac implants that support remote monitoring, broadly finding that patients received fewer opportunities to interact with clinicians and expressed anxiety about data transmission and device functioning [2, 71]. Cardiac implants such as implantable cardioverter defibrillators (ICDs) and insertable cardiac monitors (ICMs) are devices that detect and stop irregular heart rhythms associated with chronic heart conditions. Based on a diary study and interviews with 19 ICD patients and their spouses, Skov and colleagues found that participants were dissatisfied with ICDs because they reduced opportunities for interaction with clinicians [71]. While participants appreciated the safety ICDs provided, they felt anxious due to the lack of feedback regarding whether the device was operational and whether data transmissions were successful. Andersen and colleagues conducted a field deployment and interviews with ICM patients to evaluate a mobile app prototype intended to facilitate remote asynchronous communication between patients and clinicians [2]. They found that participants were anxious about the additional work imposed by the ICMs, such as regular data transmission and carrying the external monitoring system with them whenever they left the house. Participants also became anxious when the device detected symptoms that the patient did not experience and reached out to ask clinicians using the mobile app. Participants were dissatisfied when clinicians could not provide detailed responses due to limited time and resources.

Implants record and transmit sensitive health data from a person's body to servers maintained by device manufacturers. Denning and colleagues examined privacy and security concerns associated with ICDs [19, 20]. In one study, they investigated the priorities of medical experts regarding data generated by ICDs. They found that experts' highest priority was prompt and uninterrupted access to data, followed by simplicity to avoid additional device training for providers who were not cardiologists [20]. In a second study, Denning and colleagues interviewed ICD patients to understand their perspectives on data safety. They found that although participants were cautious about digital privacy and security writ large, they did not express similar concerns for ICD data because they believed that ICDs could not be accessed by unauthorized users [19].

Two other studies examined *assistive* implants that enable activities of daily living such as communication and movement. Faltaous et al. developed a prototype system to support social interaction for people with locked-in syndrome [25]. Combining a brain implant with augmented reality glasses, a camera, and a communication interface, the system sought to help patients perceive and respond to their environment. The authors found that while the system had the potential to support communication and interaction, caregivers might be concerned about their privacy and patients might face challenges due to communication delays. Similarly, Jochumsen et al. examined how implant-based rehabilitation training for stroke patients could be made more engaging [41]. They tested three techniques to make rehabilitation training less frustrating: providing extra positive feedback, softening failure, and automatically turning failures into successes. They found that all techniques fostered an enhanced sense of control for patients who struggled with the system and a decreased sense of control in those who had mastered the system. This finding suggests that researchers should expect variation in how patients respond to implanted interventions.

We build on and extend this nascent body of literature to examine the impact of brain implants on care collaboration and digital inequity from a long-term perspective.

3.3 Therapeutic Implants in the Humanistic Social Sciences

We review research from science & technology studies, sociology, anthropology, and ethics to supplement HCI/CSCW studies of medical implants. Humanistic social science researchers have examined what patients and providers expect from therapeutic implants and whether they are satisfied with them. Broadly, these studies have found that patient and clinician expectations differ and patients may feel dissatisfied when an implant's side-effects are worse than its benefits.

Gisquet found that patients with Parkinson's disease were disappointed with DBS implants because although they experienced a marked improvement in motor ability and reduced dependence on medication, their lives were deeply affected by unanticipated impacts such as fatigue, weakness, loss of balance, pain, and mood changes [32]. Participants also worried about device failure due to interference from external sources such as airport security scanners. Dalibert studied the intimate relationship between bodies and implants in spinal cord stimulation [18]. She found that patients may have divergent and even contrasting perspectives on device satisfaction. While patients whose quality of life improved were happy with their device, other patients felt dissatisfied when unanticipated impacts outweighed therapeutic impacts. For example, one patient was deeply unhappy because she could see and feel the device under her skin. Dalibert critiqued clinical research for focusing on technical outcomes without examining impacts on people's daily lives.

Gardner and colleagues proposed that patient disappointment may arise from unrealistic expectations fostered by overly positive and simplistic portrayals of DBS implants in mainstream media [29, 30]. Based on a content analysis of popular DBS videos on YouTube, they found that patients played a role in perpetuating unrealistic expectations: most amateur-created videos were positive in tone and tended to oversimplify the realities of living with implants and Parkinson's, reinforcing implant benefits without drawing attention to negative impacts [30]. In contrast to and perhaps in response to unrealistic expectations perpetuated by popular media, Gardner and colleagues found that clinicians engaged in considerable collaborative goal-setting work with patients and caregivers to prevent dissatisfaction [29]. Based on an ethnographic study, they found that clinicians engaged in recalibration work to prepare patients and caregivers to expect realistic outcomes by eliciting specific goals from patients and recalibrating them to more achievable goals.

Mauldin explored differences in perceptions of device success and failure between patients and practitioners through interviews and observations with deaf children with cochlear implants and their caregivers [50]. She found that for clinicians, device success was tied to the device's ability to function (that is, deliver stimulation as expected) and help patients produce speech. In contrast, patients and caregivers cared more about integrating the child into society by communicating via sign language and facilitating social interaction with peers and family members. Thus, for patients and caregivers, device satisfaction was a social phenomenon that exceeded technical outcomes.

Modern closed loop implants use automated techniques to detect and stop symptoms. The rise of closed loop systems has led to analyses of the ethical implications of using artificial intelligence (AI) techniques in people's bodies. Maris et al. found that ICD patients saw potential in using AI to compensate for human error, but they were concerned that the introduction of AI would reduce opportunities for meaningful interaction with clinicians [48]. Kellmeyer et al. found that while closed loop AI systems can help restore communication and motor control for patients with severe neurologic conditions, they also shift decision-making capacity to devices [45]. This shift raises concerns about who should be held accountable in case of device malfunction or misuse.

We bring a social computing perspective to this research by describing how data-intensive implants bring new modes of collaboration to the clinic and amplify digital inequities in daily life.

4 Methods

We conducted semi-structured interviews with 17 participants to examine the impact of brain implants on the lives of people with epilepsy. The research was approved by our institutional ethics review board (IRB). All names are anonymized. Quotes are lightly edited for readability.

4.1 Participant Recruitment

We recruited 14 participants with brain implants to treat epilepsy and 3 caregivers. People with epilepsy can be difficult for researchers to access due to the invisibility and stigma associated with the condition. We recruited participants through outreach via local neurology clinics (n=9), epilepsy-focused nonprofit organizations (n=6), and snowball sampling (n=2) in metropolitan areas in the Midwestern and Southwestern United States [59]. Three caregivers were included at the behest of participants who suggested that their caregivers would be better at recalling information during our interview (epilepsy can impact people's memory function). Table 1 provides details on participant demographics. Since access to social and financial resources impacted patient experiences, we report socioeconomic data about participants to contextualize these differences. Participants reported their gender as woman (n=12) and man (n=5). Participants identified as White or Caucasian (n=9), Mexican American (n=6), Black or African American (n=1), and Arab American (n=1). Participants were between 22 and 68 years old (median age = 44, mean age = 45). All patient participants had an RNS and/or VNS implant. While it is challenging to obtain precise demographic information about people with brain implants due to their relative novelty, a recent study suggests that the demographic breakdown of epilepsy patients with implants is 51.1% female and 48.9% male; 67% White, 13.3% Hispanic, 9% Other/Unknown, 8.5% Black, and 2.1% Asian/Pacific Islander [77]. Our sample includes a higher proportion of women (70.6%) and Hispanic people (35.3%).

4.2 Interview Process

We conducted semi-structured interviews to understand people's everyday experiences with brain implants, with a particular focus on their interactions with clinical practitioners, their data practices, and the benefits and challenges they experienced after implantation. We asked participants to

Table 1. Participants' self-reported demographic information.

Pseudonym	Age	Gender	Ethnicity	Implant	Annual Income
Franco	30	Man	White / Caucasian	RNS	$75-99k
Amanda	50	Woman	White / Caucasian	VNS	>$150k
Lucy	22	Woman	White / Caucasian	VNS	>$150k
Margaret	64	Woman	White / Caucasian	VNS	$75-99k
Tyler	36	Man	White / Caucasian	RNS	<$25k
Sean	44	Man	White / Caucasian	RNS	Declined
Coco	37	Woman	White / Caucasian	RNS	$50-75k
Danah	40	Woman	White / Caucasian	RNS	$50-75k
Louise	68	Woman	White / Caucasian	RNS	$25-34k
Jorge	61	Man	Mexican American	RNS	$25-34k
Inez (caregiver)	57	Woman	Mexican American	RNS	$25-34k
Marcela (caregiver)	58	Woman	Mexican American	RNS	$50-75k
Renata	36	Woman	Mexican American	RNS	<$25k
Rafael	38	Man	Mexican American	RNS	<$25k
Sofia (caregiver)	46	Woman	Mexican American	VNS, RNS	Declined
Gwen	50	Woman	Black / African American	RNS	$35-49k
Zainab	32	Woman	Arab American	VNS	<$25k

describe how they decided to get an implant and their symptoms before and after implantation. Further, we asked participants about their perception of implant effectiveness, practices related to the device and its data, and reasons they liked or disliked their implant. We also asked participants to describe their interactions with their doctor before and after implantation.

The average interview duration was 73 minutes. Interviews were conducted based on participant preference via phone or Zoom (n=13) or at a location of their choice (n=4). We audio-recorded and transcribed each interview. We had multiple conversations with some participants to seek clarification. Participants received $25 in recognition of their time and expertise.

4.3 Data Analysis

We used a two-cycle bottom-up inductive process to analyze interview data. We used this approach because our study focuses on experiences that involve complex, interconnected narratives. This method allowed broad insights to emerge first before refining them into specific codes, ensuring that our analysis remained grounded in participants' experiences without imposing a predefined structure. In the first cycle, we used descriptive codes [65] to identify topics that emerged from the interviews. In total, we identified four descriptive codes: 1) doctor-patient interactions, 2) device data and maintenance practices, 3) patient and caregiver expectations, and 4) patient and caregiver perceptions of whether the device works. In the second cycle of coding, we grouped data in the four codes into several sub-codes using an inductive approach. For instance, the data under the code doctor-patient interactions was further categorized into the following codes: 1) changes in interactions after implantation, 2) presence of the device representative, 3) reshaping of medical expertise, and 4) implant-related decision-making. Overall, we developed thirteen new codes in the second cycle of coding. We explicate the four codes and thirteen sub-codes in the findings.

4.4 Positionality

We are two social computing researchers with over nine years of combined experience working with people with epilepsy in the US. We grew up in non-US international locations and identify as middle class due to our socioeconomic status and education. The second author identifies as disabled and has personal experience with epilepsy. Our positionalities influenced how we framed and conducted this study. The second author's experience with epilepsy informed our interview protocol, especially in terms of developing questions that invited participants to describe both clinical and everyday experiences of living with implants. It also helped us attend to brief comments during which participants described personal and logistical burdens of living with implants. Our non-US upbringing and the second author's research experience in Global South settings sensitized us to issues of internet access and resource access. Our backgrounds in computer science and engineering led us to focus on the role of data, digital technologies, and infrastructures in participants' experiences with brain implants. Participant discussions about the role played by an engineer in a clinical setting caught our interest since we previously worked as engineers.

5 Findings

Participants reported several changes to clinic appointments, challenges and needs around implant-recorded data, and considerations around device satisfaction.

5.1 Changes to Clinic Visits

Participants reported several changes to their clinic appointments, most prominently an increased focus on data and the presence of an engineer from the device manufacturer.

5.1.1 Patients must engage in data work daily. Before implantation, appointments were primarily oriented around meeting the doctor. After arriving at the clinic, participants would be greeted by a nurse or technician who led them to a consultation room. Once the doctor arrived, the discussion focused on how the patient had been since their last appointment including the number and severity of seizures. Patients with recent epilepsy diagnoses or frequent seizures were asked to maintain a record of the date, time, and duration of each seizure and associated circumstances (such as what they were doing and stress levels) using paper diaries or digital tracking applications such as My Seizure Diary. Doctors used this *seizure log* to understand how the patient was doing, ask them about circumstances that may have precipitated changes in seizure activity, and adjust medications.

After implantation, patients had to transfer data from their implant to a laptop everyday. The preparatory and ongoing work of transferring data is time-consuming and resource-intensive. We delve into this data work in Section 5.2. In addition to this data work, patients were asked to continue manually logging seizures using diaries or tracking applications. Patients also had to upload data from the laptop to the manufacturer's online portal regularly, as Franco described: *"on a nightly basis, you download the data to a laptop. Then you take an internet cord up to your router and upload it to the portal. I upload to their server once every other week."*. Patients whose seizures became less concerning over time could upload data to the portal less frequently: for example, Coco uploaded data before each appointment (*"I upload the night before my next appointment."*). Implanted patients are asked to bring their seizure log and laptop to every appointment.

5.1.2 Doctors compare self-tracked and implant data. Patients are greeted by an engineer (a representative from the device manufacturer) who makes sure that the laptop has the latest data and transfers data from the laptop to the manufacturer's portal. The doctor walks in during or after this process, after which the discussion focuses on data recorded by the device.

Continuous data about the patient's brain activity and the device's detection and stimulation behavior is a key new source of data for doctors. Working as a team, the doctor and engineer begin by comparing implant-recorded seizures with the patient's manual seizure log, as several participants including Franco noted:

> *"We go back and compare our data. [Usually,] I'm off because it picks up some [seizures] while I'm sleeping. I may have 15 seizures and they got 19. I say, 'I got one on this day at that time.' They say, 'okay, that one wasn't a seizure. What happened there?' I say, 'I dunno, I was dizzy.' Afterwards, we find out why I've had an increase. They ask, 'have you not been sleeping?' I spill stuff: 'no, the kid's been waking us up at night."'*

Doctors will often lead patients through implant-recorded data using a specialized tablet connected to the online portal, pointing out any seizures that were detected by the device. Coco described: *"[the doctor] reviews with me significant events that are definite [seizures]. He'll pull them up, watch the recorded waveforms, and point out to me where the seizure starts. Then, he will think about what he's going to do with programming."* Thus, after a detailed investigation of data recorded by the implant and patient, doctors proceed to the next step of device programming.

5.1.3 Doctor and engineer reprogram the implant. A specialized tablet gives doctors and engineers access to programmed settings that modulate the implant's detection and stimulation algorithms. Detection settings specify waveform characteristics used to automatically detect seizures and stimulation settings specify the duration and amplitude of electrical pulses used to stop seizures. While doctors are skilled at interpreting data recorded by implants, they do not have the engineering expertise needed to adjust device settings because RNS implants are relatively new to medical practice. Hence, the engineer serves in a collaborative and advisory role during device programming (see Figure 3 for an example scene from the clinic).

The engineer provides the doctor with suggestions on modifying settings to maximize the likelihood of detecting and stopping seizures and minimize the possibility of unnecessary stimulation. The doctor usually accepts the engineer's suggestion and the engineer inputs the new settings into the tablet. Franco described this process of device programming: *"they're looking for the seizure, so they can say, 'okay, we can turn stimulation on five seconds before that.' They're also looking at other patterns. So if there's a spike right before every seizure, they're gonna say, 'we're going to target that spike in [channels] B and C.' Then, I sit with the wand up to my head and they change the parameters."* After collaborative review and discussion, the engineer reprograms the device using a wand (a specialized magnetic device). In older implants without recording capabilities, participants reported that doctors adjusted device parameters by themselves.

Zainab said that VNS programming was closer to decision-making around medication management: *"with the VNS, the doctor adjusts the settings up until what they think would be the good dose for you, just like with medications."*

The device's battery status is checked at each visit. Implants contain batteries that need to be replaced every few years (between 2 to 10 years depending on model and settings). Louise described: *"each time I go in, [the engineer] tests the battery and lets me know how much is left."* Amanda, a VNS patient, described a similar process: *"they have this tool that they wave over and they can see the life of your battery. So, you can kind of predict with your doctor when you want to have it replaced."*

Participants reported that after reprogramming their device and checking battery status, doctors usually discussed medication changes, gave patients and caregivers an opportunity to ask questions, and concluded the visit. Participants also reported that doctors tended to hold a single clinic day with appointments for all RNS patients in their practice to ensure the engineer's availability.

5.1.4 A new expert in the room. Traditionally, epilepsy appointments consist of patients, caregivers, and doctors. With implants, appointments included a new expert – an engineer from the device manufacturer. As described earlier, the engineer collaborated with the doctor to review recorded data, moved into an advisory role during device programming, took the lead in adjusting device settings, and worked with patients and caregivers to transfer data and check battery status.

Fig. 3. A recreation of the device programming part of clinic appointments. The doctor and engineer use a specialized tablet to view and adjust implant settings. The tablet is connected to a magnetic device called a wand. The patient holds the wand next to the implantation site during programming.

Further, the engineer assisted newly implanted patients with questions outside the clinic. Tyler, who had obtained his implant a month earlier, expressed strong appreciation for the engineer:

> *"He's a very nice guy. I feel like I can call him 24/7 and ask about the activity on my [implant]. After my surgery, he advised me on whether it was safe to shower and go out by myself. The RNS wouldn't be as impactful on my life without him."*

This feeling of reassurance was echoed by other participants who appreciated the engineer's availability to support them outside the context of appointments.

The engineer's presence in each appointment also meant that participants got a first-hand view into the doctor and engineer's collaboration. Some participants were happy to have access to an additional expert to help them with treatment and device maintenance. For example, Inez appreciated the engineer's description of how her husband was doing from month to month, *"[the engineer] is very kind and very alert. He explains to us that this month is like this and next month was like that."* Other participants appreciated the collaboration because it meant that more experts were invested in helping them. Sofia found it reassuring to have them working together to care for her son: *"the doctor has known my son's case for a long time. Isn't it better if they are working together for the good of my son?"* Some participants likened this collaboration to a distribution of expertise, where the doctor made medical decisions while the engineer led technical decisions. As Gwen explained: *"the engineer and doctor both have parts to play. During physical exams, the doctor doesn't allow the engineer in the room. [The engineer] deals with the technicalities of the computer and data."*

For some patients, the engineer became the central figure in the appointment with the doctor playing a secondary supportive role. Renata saw her doctor as a good resource to have on hand to answer the engineer's questions given her memory problems. She explained: *"sometimes with my memory, the doctor can remember things that the [engineer] asks me. Every couple of weeks, I call [the clinic] and give them notes that I have written down. So, if I forget my notes, it's on file."* The subtle shift in Renata's perception was magnified by Tyler. Tyler started on a positive note, saying that he liked knowing that the doctor, engineer, and patient were on the same page, but later noted that he felt uncomfortable about the engineer's advisory role: *"I like that [the engineer] is there because we are all on the same page. ... [The doctor] needs to catch up with how the RNS works instead of having a* *co-pilot guiding them. It makes me ask, does my doctor know what they're doing? It would be better if they could do this on their own."* Tyler found it disturbing that his doctor took directions from another person. The doctor-engineer collaboration raised questions about his doctor's expertise.

Thus, participants had varied feelings about the engineer's presence in each clinic appointment. Participants' reactions ranged from gratitude at having an additional expert participate in their care to doubt about their doctor's ability to care for them. These varied perspectives suggest that patients may have mixed feelings about collaboration between medical and device experts.

5.2 Needs and Constraints Around Data Work

Implants with recording capabilities required patients to engage in data work on an ongoing basis. Participants reported challenges with transferring and uploading data and expressed a desire to access data on their own to help in self-tracking and collaborative health management.

5.2.1 Data transfers are cumbersome. Participants found data transfers challenging for several reasons. Currently, implants do not automatically transmit recorded data. Instead, patients must manually transmit data from the implant to an online portal so that doctors can review it and assess therapeutic performance during appointments. This data work involves two steps. First, patients must hold a specialized wand at their implantation site to transfer data from the implant to a special-purpose laptop provided by the device manufacturer. Patients are asked to transfer data to the laptop on a daily basis so that the data does not get overwritten due to the device's limited storage capacity. Then, they must use an Ethernet cable to upload data from the laptop to the portal once a week or before appointments, depending on the severity of the patient's condition.

The biggest challenge participants faced was the need to use a wired connection instead of wireless protocols such as WiFi or Bluetooth. This requirement created extral logistical work and made routine data transfers more difficult. Internet routers were usually located in shared spaces in the home. Router placement created logistical and social challenges for participants who shared their homes with others. Renata, a low-income woman, could not afford to live on her own and shared an apartment with roommates. She found it difficult to sit in the common area to upload data: *"it is inconvenient and stressful to have to sit with my computer in the common area when I upload data. My roommates fight a lot. To come out and hear it causes more anxiety for me. That's why this morning when they went to work I came out and did the transfer."* Renata has to time her transfers to avoid running into roommates since stress can aggravate seizures. Participants who could afford private housing also found wired connections restrictive. Having made a nightly routine of transferring data to the laptop, Franco did not like the idea of having his laptop seen by visitors in the living room: *"They want you to hook it up with an Ethernet cable. I'm not going to leave my RNS computer out in my living room with my router so that it's all connected up. I'm gonna leave it next to my bed until I remember to download my head."* The requirement to sit in a different room next to the router reduced the time he could spend with his wife and newborn.

Manual data transfers also conflicted with demanding schedules. Gwen, a recording artist and mother of three, noted that manual data transfers added extra work to her busy schedule: *"honestly, I'm still not able to set it up. I don't always [transfer data] actually. In this busy world, it's one more thing that I have to do."* Coco, a housing insurer and mother of two, added that this extra work felt futile because her data did not contribute to treatment for a long time: *"I don't like it. It's so annoying to get the laptop out. For the first year and a half, it was every night uploading data. ... [The doctor] was getting a lot of junk data that ended up not being relevant to my treatment."* Participants found it frustrating that the data they worked hard to steward each day did not contribute to care. Finally, older adults struggled to remember to transfer data. For instance, Marcela's sister forgot despite reminders: *"it's supposed to be happen daily. But even if I remind her, she will forget."*

Broadly, participants expressed a desire for an less demanding data transfer process.

5.2.2 Stable internet is not always an option. Participants' ability to upload data depended on reliable internet access, creating an additional layer of complexity. Most participants regularly transferred data to their laptop, but had trouble uploading data due to internet access problems.

Older and low-income participants rarely had wired internet at home. Inez said: *"I don't have the connection. We only save the information. Every time we see [the doctor], we take the computer. They transfer the information there."* Jorge did not have his own internet connection and relied on WiFi access borrowed from his neighbor, but he did not have the wired internet access needed to upload implant data: *"we used to receive the internet via a low-income [scheme], but in this apartment we don't have it. The neighbor gave the WiFi, but I don't have the [wired] connection."* Renata did not have internet at home and obtained an internet connection for the sole purpose of data uploads: *"old people don't have internet. I was using my friend's internet that lives in [closest city]. I got the internet here now just so I could transfer my data."*

Participants also faced problems when traveling. In addition to traveling with a bulky laptop, participants had to obtain access to a wired internet connection. Coco said, *"it's already [carrying] the medications and the laptop. If it's more than a week, I need to have access to the internet."* She said that wired internet is difficult to find in most houses and hotels including those with WiFi access.

Participants were much more likely to have access to mobile internet on their phones. Renata said it would be great to upload data using her phone: *"it would be awesome: just place my cell phone next to the RNS, and then it automatically transfers the data."* Rafael echoed this idea: *"if we were able to scan our head with our phone or maybe put the information from the laptop on my phone. Then I can send it through my phone instead of having to plug my laptop into the WiFi router."* Participants were much happier using their phones instead of a specialized laptop and wired internet.

5.2.3 Patients and caregivers desire access to data. Prior research has found that implanted devices can produce data privacy and security concerns due to the sensitive nature of health data [19, 20]. Our participants did not express privacy or security concerns. In fact, participants appreciated that the device made their brain data available for doctors to monitor and review. Coco noted: *"I actually like knowing that the seizures are being recorded and can be seen."* Rafael liked that his device tracked seizures and reduced the burden of manual tracking: *"it collects information if I am having a seizure. So, I just have my computer and scan my head. My mother doesn't have to take notes with a pen and a notepad all the time."* Continuous recording made Tyler feel safe: *"[by recording] 24 hours a day, the RNS makes me feel more safe because I know I'm not having seizures without [someone] noticing them."* Indeed, Tyler went so far as to say that he would be okay with other sensitive data being tracked as well, if it helped improve his health: *"I don't have concerns about the data. [The device] is in my head. You could put a GPS-tracking system in it. You either trust the company or you don't. If I didn't trust them, it wouldn't be in my head."* Participants trusted implants recommended by doctors with whom they had long-term relationships as their only remaining treatment option.

At the same time, participants were unhappy that they could not access their data and had to wait until two to four months until their next appointment to learn about their health status. Several participants questioned this state of affairs: *"why don't patients have access to their data?"* (Sean), and strongly disliked the lack of access: *"I can't see any of the data until I go the [the doctor]'s office. I actually hate that part of it"* (Coco).

Participants understood that the manufacturer may not want to share data with patients to avoid panic (*"I understand that some people panic,"* said Tyler) and ensure safe operation (*"possibly, somebody would do something wrong with it. But at the same time, it's mine,"* said Sean). Nevertheless, participants expressed a strong desire to access their own data, arguing that their role in managing the device, including data transfer and uploads, justified their right to access data about their own bodies: *"the doctor has access to that information. I think I should too. It's absolutely nonsensical. They should be giving me as much information as possible. Isn't it very valuable for me to know if I have a seizure? Why wouldn't my RNS tell me?"* (Tyler). Participants found it frustrating that they could not access data generated by their own body.

5.2.4 Access to understandable and actionable data would help patients with sensemaking. Epilepsy is a lifelong condition that requires patients and caregivers to track seizures and take preventive measures to reduce the likelihood of seizures such as avoiding alcohol, reducing stress, exercising regularly, and sleeping well on a daily basis. Participants felt that having access to actionable insights and alerts based on implant-recorded data could help manage their chronic condition by providing insight into their current health status and the impact of lifestyle changes.

Participants expressed a strong desire to have access to a user interface that provided patient-understandable data and actionable insights. Some desired daily or weekly updates on seizure frequency. Sean suggested, *"if there is a computer program that will let me know, 'hey, this week is great,' or 'this week, no good, man.' It will give me a more analytical way to think about myself."* Tyler tended to lose consciousness during his seizures. He expressed interest in an interface that would help him understand that he had a seizure and whether it was stopped by his implant: *"if it gave me some kind of patient interface for if I had a seizure. I don't always know when I have seizures. So just, 'hey, you're having seizures.' 'Hey, you're not.' My doctor told me the device has gone off 500 times to prevent seizures."* With such an interface, Tyler would not have to wait long periods to find out about his seizure activity. Sean reinforced this point, saying that it would enable regular self-monitoring: *"it would be nice to have access to my information because then I wouldn't have to wait on [my doctor]. ... If I am in charge of my [data], I can be looking at it and alert my doctor if there's a problem. Also, it could alert me: 'hey, man, you're in danger zone'."*

Rafael expressed curiosity about implant data and desired detailed information about his seizures including the occurrence and type. People with epilepsy can have multiple types of seizures. Grand mal seizures (medically referred to as generalized tonic clonic seizures) involve whole body convulsions, falling, and loss of consciousness. Other seizures include symptoms such as zoning out or staring (medically referred to as absence seizures), impaired language, unexplained joy, nausea, and tensing of individual body parts. Rafael explained: *"it would be interesting to see whether I am having a seizure, and whether it's a small one or a grand mal. How would the brainwaves look? What's normal, what's not?"* A patient interface would help Rafael develop a more nuanced understanding of his seizure activity, brain data, and how doctors distinguish between seizures and other types of brain data. Similarly, Coco, a researcher by profession, was curious about the data being recorded by her implant and wanted to understand more about her seizures and the circumstances surrounding them: *"how long the seizures last. What kind of feelings I get with them. I have morbid curiosity. I'm not an epileptologist, but I still want to see what my brain is doing when I collect data, when I activate the implant."* Thus, part of the motivation includes getting better acquainted with the data that patients know is being recorded on an ongoing basis.

Epilepsy can demand significant involvement from caregivers. Caregivers expressed a similar desire for data access to understand their loved one's health status and learn about the utility and effectiveness of their actions. For example, Marcela wanted to know whether data work was useful in practice: *"I would like to see how it actually works. I would like to know the data, just to understand how it actually functions and in a way to help my sister better. Is it necessary for her to [transfer data] daily? If [they] are not getting good information, there is no need for them to do it daily."*

Thus, patients and caregivers held that access to implant data and actionable insights would enable them to monitor their health status and manage seizures. Without such access, they were limited in their ability to play an active role in managing their chronic condition.

5.3 Satisfaction with the Device

Participants' satisfaction with their implants was associated with perceived impacts on seizures and medications. Participants who experienced fewer seizures tended to be satisfied with their device. Participants who did not experience a reduction in seizures and medications tended to be dissatisfied with their device. Other unanticipated side-effects such as sensitivity near implantation site did not impact participants' satisfaction. Satisfaction could differ between patients and caregivers. Doctors have an important role to play in helping participants understand what to expect.

5.3.1 Many were satisfied with the device. Participants with fewer or less intense seizures after implantation were satisfied with the device. Franco was happy with the device because he had fewer and more manageable seizures: *"after the RNS, the severity and frequency of my seizures has gone down. In my book, it's a win. Earlier, I'd have a seizure and my day would be ruined. Now, they are just annoying. They put me out of commission for 10 minutes. I sit down, get my bearings back, and go on with my day."* Franco is better able to function due to the reduced severity of his condition.

Louise decided to get an implant because her medications became less effective after she developed an autoimmune condition. Her doctor recommended the device as the best approach to reduce her seizures. As predicted, Louise had fewer seizures after some months of device programming: *"since I got my autoimmune disease, the medications seemed to not be working well. The device definitely helped reduce seizures. It took time for the doctor to adjust it, but there's no doubt at all."*

Although some participants started by hoping for a cure, that is, hoping their implant would stop seizures completely, they were able to adjust their expectations along the way. Jorge was satisfied due to the reduced seizure frequency enabled by the device: *"[initially] I had too much expectation because I want to be free from the seizures, but overall I am happy because I am surprised I am having these [seizures] only once in three months."* Rafael also hoped that his device would stop his seizures completely, but he became satisfied after realizing that he was experiencing fewer seizures. Additionally, his seizures changed from grand mal seizures to absence seizures, which are easier to recover from and less noticeable to others: *"I thought it would stop them completely. But I'm getting absence seizures. I would rather get these types of seizures than a grand mal seizure. ... I would say the RNS definitely works."* Thus, participants who saw improvements in seizure symptoms and were able to adjust their expectations generally expressed satisfaction with the device.

5.3.2 Dissatisfaction is associated with increased medication, seizure frequency, and side effects. Several participants were dissatisfied when implants did not perform as expected.

Multiple participants wanted to reduce medications after implantation and this almost never happened, leading to disappointment and dissatisfaction. Marcela, a caregiver, wanted her sister to be able to take fewer medications. She was frustrated because in contrast to this desire, her sister's medications increased after implantation. They were unhappy because adding a new form of treatment (the implant) did not lead to a reduction in her existing treatment (medications). This made Marcela question whether the implant was doing anything: *"The goal was to reduce the medicine because my sister is sick of taking medicine. But actually, the medication has been increasing. That makes me wonder: does the RNS really help?"* Sean was similarly disappointed because he was unable to reduce medication, which was his primary goal for implantation. He noted: *"I knew that the RNS wasn't a cure. It was a hope that it could quiet down seizures and hopefully, stop medication. Three years later, that has not stopped. I'm very disappointed. Now they're even making additions to my medication. It's discouraging when it's the same thing over and over with no improvement in medication."* Thus, some participants were disappointed that implants did not lessen medication.

Other participants became dissatisfied when implants failed to decrease their seizure frequency or intensity. Coco's seizures intensified and became more frequent after implantation. Coco was unhappy with this outcome and unconvinced that the implant would achieve what she and her doctor had hoped for: *"[the doctor]'s goal was to slow seizures down, making them less intense or less frequent. The intensity went down, but the frequency went up by a large amount. I'm not convinced that the [RNS] has done what I had hoped. It worked to some extent, but the frequency scared me."* Coco was troubled that her seizures were much more frequent and intense despite the RNS. Similarly, Zainab's VNS implant failed to control her seizures: *"a few years after the VNS, the tonic-clonic seizures started again. With the RNS, I was like if VNS did not work, why will RNS work?"* Zainab's dissatisfaction with one device impacted her evaluation of future devices.

A minority of participants experienced severe side-effects after implantation. Lucy decided to have her VNS removed due to constant physical pain: *"Getting the VNS was probably the worst choice in my life. I know that VNS is very helpful for a lot of people, but I had pain every day. I really trucked through it and then at the year mark I was like, 'doc, I can't do it anymore.' I also didn't want to be on pain medication, so I decided it was time to take it out. It was a great decision."* Lucy's doctor supported her decision and continued to manage her seizures using medication.

Thus, patients felt let down when seizures and/or medications did not decrease, or severe side-effects cropped up, after implantation. Such dissatisfaction led to some patients having implants removed and negatively impacted their consideration of other implants going forward.

5.3.3 Patients can take unanticipated life impacts in their stride. Several participants reported device-related life impacts that they did not recall being told about by their doctors. Although participants found these impacts worrisome, they did not affect their satisfaction with the device.

One unanticipated impact was pain at the site where the implant was inserted. Some participants reported experiencing pain and sensitivity when combing their hair or getting a haircut. Gwen reported: *"even now [years after the surgery], when I want to do my hair, I don't go to just anybody. I have to tell them, 'you have to be careful. There was an incision there and it's not painful, but it has sensation.' It hurts to comb hair."* Rafael noted similar pain near his incision site during haircuts: *"it does hurt sometimes, but it only hurts really when I get a haircut. I tell her to be careful."* Inez explained that her husband had to educate his barber each time he got a haircut: *"he needs to explain to every new person. He doesn't have only one person to cut his hair. I told him, 'please let them know that you have that,' because they cut his hair short. The [barber] needs to be careful."*

Participants also had to carry a medical note and request permission to avoid metal detectors and security scanners at airports, government buildings, stadiums, schools, and even shopping malls. Metal detectors could mislabel brain implants as dangerous objects and security scanners could interfere with device operation. Inez did not like having her husband taken to separate place for screening during air travel: *"when we go to Mexico, we need to [let security agents know] what is inside his body so that they don't stop him. They take him to another place for screening and I need to be aware with that. I'm not happy."* Calling attention to oneself by approaching security personnel and requesting alternative forms of screening could be extra stressful for non-white participants.

Other participants reported side effects related to energy levels, memory, and mood. Sean said, *"I'm often more tired than I ever have been in my life. I didn't notice it but my kids say, 'dad, you're grumpy all the time.' Also, I'm having a lot of problem with my short-term memory."* Side effects impacted participants on an ongoing basis, but did not affect their satisfaction with the device.

5.3.4 Doctors have an important role to play. The lack of reduction in medications and/or seizures led to some participants being dissatisfied. This dissatisfaction could creep into the doctor-patient relationship instead of staying limited to the device. Sean was disappointed that his doctor failed to explain that he may need to stay on medication after implantation: *"I'm hoping the doctor would say, 'that's not a possibility.' But my doctor said, 'yeah, that's a possibility.' We were never able to attain this goal. When we first met, I said, 'I do not want to take medication for the rest of my life.' That's* *one of the main reasons I had brain surgery for the RNS. Otherwise, I would've just taken medication."* Sean clarified that he held his doctor responsible and not the device: *"I'm not disappointed in the RNS. I'm more disappointed in my doctor. My doctor is responsible for my RNS and not vice versa."*

Participants affirmed that their doctors communicated clearly with them that the implant would not cure their epilepsy. Many patients and caregivers reported that their doctors did a good job setting realistic expectations. Inez said: *"[the neurosurgeon] told us that [for] some people the seizures may stop, but in others maybe not. We need to know about that. My husband consider that and said, 'we're gonna try it.'"* Despite these efforts, we found several instances of patients hoping for very positive outcomes. Inez and her husband were initially discouraged because they did not see any improvement for a while after implantation. Their doctor counseled them and helped them realize that they need to give the device time to work: *"at first, we were really happy because we thought he would be free [from seizures]. After that, he saw that, 'oh, I had another seizure.' [We were] discouraged because we thought the device would stop them. But after [talking to the doctor], we realized we need to wait."* Thus, doctors helped participants understand that it may take time to see results.

Tyler noted that many people in online support groups tended to have unrealistic expectations and expressed disappointment when the implant did not cure their epilepsy: *"people online were upset that it didn't cure their epilepsy. [The doctor] sat me down and said, 'we're hoping that the RNS will help but it will not cure your epilepsy. [People online] had unreasonable expectations. Had they had proper expectations, they wouldn't have been upset with the outcome."*

Family members who were not involved in care held higher expectations than those of patients and caregivers who were closely involved. While patients and involved caregivers formed opinions about device satisfaction based on immediate experience, more distant relations sometimes had different perspectives. Franco and his wife were satisfied with the device because he had fewer and more manageable seizures. However, Franco's family members were frustrated because they expected the implant to stop his seizures completely: *"my family is annoyed that I'm still having seizures. They think that this device, plus the meds, and everything that we have been doing should have been a cure all. But where we're at now is a million times better than where we were three years ago. So my wife and I are looking at this as a win. My family, though, are scratching their head going, 'how come the thing isn't working?'"* Whereas relations with limited involvement hoped for a cure, patients and involved caregivers recognized improved seizure control as meaningful progress.

Thus, doctors have an important role to play in counseling patients and caregivers on a continuing basis. Doctors must directly address impacts on medications (and not just symptoms) during these conversations. Doing so may prevent dissatisfaction from transferring to the doctor-patient relationship, which is crucial to the management of chronic conditions such as epilepsy.

6 Discussion

We found that brain implants led to several changes in people's lives and clinical interactions. Participants reported changes in care collaboration dynamics and challenges in data transmission and access. We discuss implications for CSCW/HCI research on technology-mediated collaboration and digital inequity grounded in patient experiences of embodied data-intensive technologies.

6.1 Collaboration in Data-Intensive Medical Devices

Implants introduced new forms of expertise, expectations, and data to the care collaboration dynamic. Participants were both deeply appreciative of and somewhat concerned by these changes. We discuss these changes in relation to prior research and reflect on how CSCW/HCI researchers and designers should account for them to support "caring through data" [42] in the long term.

6.1.1 Expertise. Prior research has found that implants negatively impacted care collaboration by reducing opportunities for patients to interact with clinicians and other experts [2, 48, 71]. In contrast, we found that brain implants increased opportunities for interaction with experts. Participants had just as many follow-up appointments, they could call the clinic and leave messages, and they could also reach out to the device engineer. Thus, rather than limiting communication, the implant expanded patients' care network and provided them with access to an additional expert. Participants deeply valued this expanded access to expertise, especially appreciating the opportunity to seek advice outside clinic hours and get personalized support with device maintenance. At the same time, an expanded care team also created new dynamics in care collaboration. In particular, although the engineer's presence in the clinic largely supported collaboration by providing device expertise, it also risked negatively impacting patient perceptions of medical expertise. A few participants noted that the advisory role occupied by the engineer during device programming made them question their doctor's expertise. This finding differs from prior work on other types of brain implants likely because device programming was led by doctors in those studies [52, 53]. For example, while nurses were present during the DBS programming sessions described by Mentis and colleagues, they primarily assisted doctors and did not serve in an equal capacity. In contrast, our participants reported that doctors treated engineers as independent experts, accepted their suggested device settings, and had them lead device programming. This shift highlights how the introduction of technical expertise can change care collaboration dynamics and patient perceptions of expertise in the clinic. Our findings contribute to research on technology-mediated collaboration by showing how emerging expert roles, like engineers, may influence the doctor-patient relationship. Brain implants present an interesting case in which technical experts without clinical training become central to medical decision-making. Interdisciplinary and collaborative approaches to innovation are on the rise in medicine [11, 33, 39, 44], and we are likely to see more such instances of non-medical experts joining the doctor-patient collaboration as a third party.

Prior research has investigated the role of lay third parties, such as caregivers, in care collaboration [28, 36, 63]. Foong et al. found that family members played an important role in the care dynamic, advocating for patients and adjusting practitioner recommendations to meet patient desires [28]. Along similar lines, we found that engineers supported doctor-patient collaboration by attending to patients' needs around device maintenance issues such as battery replacement. At the same time, engineers served an advisory role, unlike the supporting role occupied by caregivers. This difference in roles is likely due to the different types of expertise the actors possess: while caregivers are lay experts who learn from daily interactions with patients, engineers are professional experts who specialize in brain implants, a technology that is relatively new in the clinic. While the engineer's advisory capacity led some patients to question their doctor's expertise, prior research does not show similar concerns around caregiver participation. Hence, we suggest that the complex impact we see may arise when third parties have an independent form of professional expertise outside the medical or biological realm. Future research should examine the role of such expert third parties in other care collaboration contexts and propose ways to better integrate other forms of expertise to support and enhance the doctor-patient relationship.

6.1.2 Device satisfaction. We found that device expectations and satisfaction played an important role in care collaboration. These are new dimensions for CSCW and HCI research on technology-mediated collaboration, which has mainly focused on consumer wearables and apps. Unlike wearables and apps, implants are central to care collaboration in that they are the mechanism through which medical treatment is delivered, evaluated, and adapted. Further, while wearables and apps can be abandoned, implants are a long-term commitment, being surgically embedded into the patient's body. Thus, studying implanted devices has the potential to provide a long-term and high-stakes perspective on how technology-related expectations and satisfaction mediate collaboration.

We found that patient expectations for therapeutic implants were quite different from clinical expectations. Clinical literature on brain implants tends to focus on their clinical efficacy, that is, how well they reduce the frequency and intensity of seizures, with little consideration for impacts on other treatment modalities [31, 70, 73]. In addition to these clinical priorities, our participants were concerned with the device's impact on their medication regimen. Epilepsy medication has a significant impact on patients because it is usually lifelong, taken daily, and comes with severe side effects such as nausea, depression, fatigue, and mood changes. Hence, participants hoped that adding an implant to their treatment regimen would lead to an associated reduction in medication. This finding is similar to social science research showing that the priorities of patients and caregivers tend to differ from those of clinicians in determining device success and failure [18, 50]. For example, in cochlear implants, Mauldin found that clinicians defined success as the deaf individual's ability to produce speech, whereas patients and caregivers defined success as integrating the deaf person into society [50]. Hence, we suggest that CSCW/HCI research should consider how patients and caregivers perceive device success and adopt a holistic perspective that goes beyond the symptoms being treated and incorporates aspects that patients value when measuring device efficacy [47].

Given the misalignment between patient and clinical expectations, prior social science research has found that doctors can help patients set realistic goals prior to receiving implants [2, 29, 30, 32]. We agree that doctors have an important role to play in setting expectations. Participants described that their doctors engaged in expectation-setting conversations mainly prior to implantation. We suggest that doctors must continue to manage expectations long after implantation. Brain implants require regular follow-up visits for reprogramming and maintenance for years after the initial surgery. Patient priorities may shift during this period. For example, medications may become more important once a person's seizures become less severe. Hence, it is important that doctors continue to engage patients in conversations around expectation setting in ways that account for the possibility of shifting priorities. We also found that caregiver expectations may differ from those of patients. For example, while Franco was happy with fewer seizures, his family expected the implant to completely stop seizures. Hence, we suggest that caregivers should also be included in the collaborative relationship to establish a shared understanding of goals and expectations. HCI/CSCW research should expand beyond system design to consider the socio-technical processes that shape people's expectations with medical technologies. One possible direction for future research is to explore how technology can support ongoing discussions between patients, clinicians, and caregivers to manage expectations and improve user experiences in the long-term.

Next, we found that there was a complex relationship between device satisfaction and the doctor-patient relationship. While participants' satisfaction was primarily based on a reduction in seizure symptoms, their dissatisfaction was usually associated with being unable to stabilize or reduce their medication. When these hopes were not fulfilled even years after implantation, participants expressed strong dissatisfaction with the device. For some participants, this dissatisfaction transferred to their relationship with their doctor. These participants noted that since doctors were responsible for their treatment, they held doctors (and not devices, engineers, or manufacturers) responsible for failing to achieve treatment goals such as medication reduction. In such cases, prolonged dissatisfaction with the device began seeping into the doctor-patient relationship. However, this was not always the case: other participants continued to work with and trust their doctors despite being unhappy with their devices. This included Lucy who experienced constant pain after implantation and had the device removed as well as participants with less severe impacts such as sensitivity while combing hair. In these cases, prolonged dissatisfaction with the device did not transfer to the doctor-patient alliance. This is a novel finding that calls for further investigation. Prior research has not uncovered such a relationship between device satisfaction and the doctor-patient dynamic, suggesting that it may differ based on the condition being studied, the type of implant, participant characteristics, and how benefits compare to side-effects. Future research should investigate when and under what conditions device-related challenges begin impacting the doctor-patient dynamic and design ways to prevent negative effects. Such investigations are likely to uncover useful insights for research on long-term technology-mediated collaboration. In chronic conditions like epilepsy, the doctor-patient relationship is a key determinant in the patient's quality of life and overall well-being. Future research should examine how designers could support doctors in addressing device concerns and satisfaction by facilitating ongoing collaborative conversations.

6.1.3 Data. Implants brought new forms of data and work to people's everyday lives and clinical interactions. At home, participants had to engage in additional data work, transferring implant data to a specialized laptop daily and regularly uploading data to an online portal, in line with prior research showing that implanted devices create additional responsibilities for patients [2, 58]. Prior research has suggested that patients feel anxious and stressed about data work [2]. In contrast, we found that participants were happy and reassured that their data work would contribute to medical decision-making. At the same time, the presence of implant data meant that doctors, patients, and engineers spent a good chunk of the appointment reviewing data recorded by the implant and comparing the patient's seizure log with implant data; in contrast to pre-implantation visits where the patient and their seizure logs were more at the center of the visit. Prior research has found that data-intensive technologies reshape care collaboration dynamics in both positive and negative ways: Kaziunas et al. reported that while continuous blood glucose data enhanced caregivers' understanding of Type 1 diabetes, it also produced concerns around autonomy and privacy for patients [42]. We found evidence of a similar tension: while continuous recording enhanced doctors' understanding of the patient's brain, it shifted the focus of appointments away from the patient. In line with Kaziunas et al., our participants believed that good care could be delivered through data, provided the broader implications of data-intensive care, such as the emotional complexity of engaging with health data and the ways data access may shift relationships between doctors, patients, and others, were accounted for. Future CSCW/HCI research should delve further into how data can support collaboration while addressing these broader implications.

6.2 Digital Inequity and Design Justice in Data-Intensive Medical Devices

We found that the design of data-intensive brain implants may reproduce and even amplify social inequities. Implants depended on stable access to resources that were not easily available to all participants. Participants also lacked access to the data that they helped steward on a daily basis. We discuss these findings in relation to prior research on digital inequities and design justice, suggesting that the designers must look beyond the user-technology relationship and account for infrastructural considerations and their interactions with wider social inequities.

Data transfers were disproportionately challenging for participants from low-income backgrounds, older adults, people living in shared housing, and those traveling away from home. Low-income, older, and traveling participants found it difficult to access stable wired internet since they rarely had it in their home. HCI research has found that designers may fail to account for socio-economic inequities and cultural factors that affect people's use of technology [5, 78, 81]. For instance, Wyche et al. found that youth in low and middle-income countries rarely use phone-based diabetes interventions due to limited internet access, highlighting a mismatch between the resources participants had access to and the design features prioritized in mobile health interventions [81]. We found similar challenges around internet access in the case of brain implants. Even though most participants lived in urban and peri-urban US settings, they had trouble accessing wired internet, which was required to upload implant data to the online portal. Participants were much more able to access the internet on their phones, but current protocols did not permit data uploading via phones, hotspots, or even WiFi networks. Further, participants who lived in shared housing or were away from home found it difficult to access private spaces for extended periods to transfer data to their laptop. Since implants have limited storage capacity, delays in data transfer may mean that data that is not transferred is lost, and unavailable to doctors. Thus, resource access issues may negatively impact clinical decision-making and patient health outcomes. Even in a part of the world that is considered developed, internet and resource access constraints shaped participants' ability to engage in the work needed to sustain data-intensive technologies.

Equity considerations surrounding data-intensive technologies are an often overlooked consideration in HCI research and practice. While researchers have focused on systemic and community-level issues [12, 17], limited attention has been paid to the experience of living with data-intensive technologies. Our study addresses this gap by showing how infrastructural inequalities manifest in routine interactions with embodied health technologies. We suggest that future research should investigate ways to make data work more responsive to people's real-world constraints. In the short term, researchers could work to reduce the connectivity demands of data-intensive technologies by drawing on work from the fields of HCI4D and ICTD that have investigated solutions for contexts with limited and intermittent connectivity (e.g., [21, 67, 79]). In the long term, we suggest that researchers, designers, and policymakers should work towards building equitable technologies and infrastructures, and improving and subsidizing internet infrastructures in areas with limited connectivity [81]. Designing with a diverse group of participants and attending to their everyday experiences as shaped by infrastructural constraints may shed light on inequities that need to be taken into account to design systems that work for diverse populations.

Participants expressed a strong desire to access data and insights derived from their implant. At the time of writing, patients and caregivers did not have access to data recorded by brain implants, as noted in prior work [52, 53]. They could only access data once every few months during appointments and at their doctor's discretion. In our experience, patients did not participate in interpreting implant data (beyond sharing their seizure log), partly because data was presented in the form of complicated waveforms that were difficult for laypeople to interpret. In effect, the data that participants underwent surgery, navigated infrastructural barriers, and stewarded on a daily basis remained out of their reach. This is a critical concern from a design justice standpoint [17]. While implant data is meaningfully used to inform treatment, participants raised reasonable concerns about their inability to access their own data. Since epilepsy patients require lifelong self-management even after receiving implants, providing patients with data access may help them in sensemaking and illness management, and give them a voice during device programming, as prior CSCW/HCI work has shown [16, 26, 52, 54, 63]. Social scientists have similarly advocated for helping patients develop situated knowledge about their condition [61]. At the same time, prior research has found that clinicians have concerns about how and when patients should be given access to medical data given its complex nature and the possibility of misinterpretation [24]. Unlike consumer health data, implant data is integrated into the patient's medical record, potentially necessitating clinician input and oversight in the data sharing process. Future research should use collaborative processes such as co-design workshops involving clinicians, device experts, patients, and caregivers to determine data access considerations.

While access remains a challenge, our findings also suggest that people should have *meaningful* access to data. That is, the data provided should be understandable and useful for lay users. Participants especially desired to know when seizures occurred, understand the type of seizures they had, explore potential triggers, and track changes in seizure frequency over time. Since current implant data interfaces are not designed for lay people, patients and caregivers are likely to find it difficult to engage with implant data, even if access is granted. We suggest drawing on CSCW and HCI research that seeks to support patients and caregivers in interpreting and acting on health data to design patient-facing interfaces [9, 16, 54, 55, 60, 66]. For example, narrative-driven interfaces have been found to improve patient engagement and decision-making with complex health data [62]. Future research should investigate how to design patient interfaces for therapeutic implants.

Finally, we suggest that researchers should examine how the curiosity that participants expressed around data and medical decision-making could be fostered and supported using technology. For example, Coco was curious about what her brain was doing when she collected data or activated the implant. Rafael wanted to know what seizure activity in the brain looked like, and how doctors differentiated between normal and abnormal activity. Designing to answer such questions may not immediately impact illness management, but it is likely to help patients and caregivers develop a better sense for how bodies, devices, and clinicians work, ultimately making data work more meaningful and encouraging greater participation at home and in the clinic.

6.3 Limitations

This paper focused on the experiences of a small number of people with brain implants for epilepsy in the United States. Patient experiences may differ based on how healthcare systems are set up across regions and countries [49]. Future research should compare our findings with studies conducted in contexts with differently structured healthcare systems. Our sample is relatively small and not representative of the population of people with brain implants, as is common in qualitative research [8]. Future work should use a representative sample to investigate the applicability of our findings to the broader population. Finally, this work focused on epilepsy. Given the widespread adoption of brain implants to treat conditions such as Parkinson's disease, dystonia, and depression, and the rise of experimental brain-computer interfaces for assistive purposes, future research should investigate user experiences with a wide range of implants and applications.

7 Conclusion

We conducted a qualitative study on the patient experience of implanted medical devices used to treat epilepsy. We found that the brain implants impacted people's lives in several ways. Implants led to changes in clinic appointments, including an increased focus on data and the involvement of a new expert during doctor-patient interactions. In addition, participants faced challenges related to data work, including cumbersome data transfers, unstable Internet access, and limited access to data recorded by the implant. Participants expressed a strong desire to actively engage with the data recorded by their implant. Finally, while participants were generally satisfied with their implants, increased medication and/or seizures led to dissatisfaction. We discussed how implanted devices impacted collaboration in the clinic, surfaced equity considerations related to data-intensive technologies, and described how patient definitions of satisfaction may differ from definitions used in clinical studies. This paper offered the first empirical investigation into the experiences of brain implant patients in CSCW/HCI research, highlighted opportunities to support patients adjusting to life with data-intensive devices, and discussed challenges and needs that need to be addressed to better support care collaboration in implanted medical devices.

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