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ORIGINAL PAPER

The "Wheels That Keep Me Goin'": Invisible Forms of Support for Brain Pioneers

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Abstract Research participants in long-term, first-in-human trials of implantable neural devices (i.e., brain pioneers) are critical to the success of the emerging field of neurotechnology. How these participants fare in studies can make or break a research program. Yet, their ability to enroll, participate, and seamlessly exit studies relies on both the support of family/caregivers and care from researchers that is often hidden from view. The present study offers an initial exploration of the different kinds of support that play a role in neural device trials from the perspectives of brain pioneers and their support partners (spouses, paid caregivers, parents, etc.). Using a mixed methods approach (semi-structured, open-ended interviews and a survey) with interpretive grounded theory, we present narratives from a study of six pioneers – four in brain-computer interface (BCI) trials, and two in deep brain stimulation (DBS) trials – and five support partners, about their experiences of being supported and supporting participants in implantable neural device studies. Our findings indicate the substantial amount of work involved on the part of pioneers – and some support partners – to make these studies successful. A central finding of the study is that non-logistical forms of support – social, emotional, and epistemic support – play a role, alongside more widely acknowledged forms of support, such as transportation and physical and clinical care. We argue that developing a better understanding of the kinds of support that enable neurotechnology studies to go well can help bridge the gap between abstract ethical principles of caring for subjects and on-the-ground practice.

Keywords Neurotechnology · BCI · DBS · Implantable · Care · Support · Qualitative · Brain pioneers

"Brain pioneers" [1] – research participants in long-term, first-in-human trials of implantable neural devices, like brain-computer interfaces (BCIs) and deep brain stimulation (DBS) – are a small but expanding, and often highly visible, group critical to the success of the emerging field of neural device development. Implantable BCIs, such as the one developed by Neuralink, aim to provide new ways of interacting with the world, such as allowing users to control a computer cursor solely through their neural activity associated with visual or motor imagery [2]. Implantable BCI studies typically require research

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participants to have a motor impairment, such as paraplegia or quadriplegia. Another kind of implantable neural device, a deep brain stimulator, has been used clinically to treat Parkinson's disease, and is currently being investigated as a potential treatment for other conditions, like treatment-resistant depression [3]. People who agree to participate in implantable neural device studies take on a variety of risks – of surgery, infection, device failure and more – in an effort to help science move forward. How these brain pioneers fare in studies can make or break a research program. When studies go well, researchers' successes are widely lauded as transformative, and brain pioneers appear in media reports that often glowingly describe their contributions to advancement in science [4]. If they do not go well, though – e.g., if pioneers feel unsupported, exploited, disrespected, or abandoned at the end of the project – there is risk of media coverage and public opinion turning against the very idea of neural technology [5]. The fate of the field rests in many respects on the effort and persistence from, and well-being of, brain pioneers.

Participants in these studies are "pioneers" in that they are among the first humans to be implanted with the experimental neural devices, and, in some cases, play an active role in learning how to operate such a device (i.e., "BCI pioneers" [6]). The label of "pioneer" typically applies to people who exhibit a variety of features, including bravery, dedication, and perseverance [7, 8] in the exploration of a risky new challenge. Following brain surgery to receive the neural implant, these studies often require intensive time and energy investments on the part of the research participant (e.g., attending lab sessions three or more times per week for hours at a time, often over the course of as many as three to five years). Given that, participants get to know researchers well, and develop close relationships with them [1]. Furthermore, because the implants are in the brain, understood as a central site of identity and agency, brain pioneers take on personal risks that go well beyond the surgical [9]. In return for their participation, they gain experience with cutting-edge technologies that offer novel ways of interacting with the world (e.g., BCI studies that allow people to "do things with thoughts" [10]) and/or treating conditions where standard therapies have failed (e.g., DBS for treatment-resistant depression). They are helping to chart new territory for humanity, and in this way they often see themselves as pioneers. As a participant in one recent study noted: "You were some kind of pioneer in this field and that was cool. No doubt, that was really cool. That was adrenaline, that was ego booster and so on.' (Rudi, participant)" [11].

Media depictions of brain pioneers laud their contributions to the new frontiers of science [12–14]. This picture of pioneers often has an individualistic frame around it, e.g., "trailblazers" who bravely lead the charge into the future [15]. What is less evident in most public and scientific discourse on brain pioneers is the significant support structure needed for them to participate and do *well*. Most brain pioneers are significantly dependent on others – family or other support partners and research teams – to make their research participation viable.

Our neuroethics research group has worked in close collaboration with neurotechnology researchers for over a decade [16, 17], emphasizing the importance of attending to the voices and values of disabled people who are typically the targeted end-users for the technologies. None of the authors were researchers in these device studies directly, and were not involved in designing nor conducting them. Nor do any of us have lived experiences with physical disability or using implantable neurotechnologies. Our group's previous interviews with brain pioneers focused on issues of identity, agency and privacy, but across studies many participants described ways in which their family members played a role in helping them participate in the study. Learning of the expansive scope of the nature of support in these studies moved us to develop a grant project (NIH grant R01 MH130457-01) aimed at studying that kind of often invisible support, and how it affects neurotechnology studies.

The present study offers an initial exploration of the different kinds of support that play a role in neural device trials from the perspectives of brain pioneers and their self-identified support partners (spouses, caregivers, parents, etc.). We present narratives from a study of six pioneers (four BCI, two DBS) and five support partners (two parents, one spouse, and two professional caregivers), who were interviewed about their experiences of being supported and supporting participants in implanted neural device studies.[1] Our findings indicate the substantial amount of work involved on the part of pioneers – and some support partners – to make these studies successful. A central finding of the study is that non-logistical forms of support – social, emotional, and epistemic support – play a role, alongside more widely acknowledged forms of support, such as transportation and physical and clinical care.[2]

Methodology

Our study utilizes a mixed methods approach that includes semi-structured, open-ended interviews and a survey. The aim of our interviews was to instigate conversations about the different kinds of support provided to brain pioneers to help them successfully participate in neural device trials. Our survey, on the other hand, aimed to provide us with a succinct picture of who these participants are (their demographics), their motivations for participating in a neurotechnology clinical trial, how they felt about the experience, and the nature of their relationship with their support partner(s). As such, the survey did not directly aim to answer our research questions, but was rather designed to supplement and contextualize our interview data and analysis by helping us better understand the people with whom we were speaking. Using a survey to accomplish this made our interviews more time efficient, as we did not have to ask participants questions that were already included in our survey.

Recruitment

Our brain pioneer interviewees participated in our previous neuroethics interview studies focused on identity, privacy, and agency. We recontacted them and invited them to participate in this study, and additionally used a snowball method (via a neuroethics colleague at a different institution) to expand our recruitment to include an additional pioneer we had not previously interviewed. One pioneer did not respond to our recruitment outreach. In total, we enrolled eleven participants: six brain pioneers and five support partners. Of the six pioneers, four were in implantable BCI device studies, and two were in DBS device studies for treatment of psychiatric conditions. BCI and DBS studies were conducted at four different institutions in the U.S. Both kinds of studies were experimental in nature, and offered no expectation of therapeutic benefit. In the BCI studies, surgery to explant the device was expected at the end of the study, because continued device use outside of the lab was often not feasible. In the DBS studies, users who experienced benefit were allowed to continue using the implanted device. The two DBS participants we interviewed had already exited their respective studies, but continued to use the devices for off-label treatment of their conditions (treatment resistant depression (TRD), and TRD combined with obsessive compulsive disorder for the other). Importantly, we received information about these studies directly from participants, not from researchers or from review of study protocols.

At enrollment we asked each pioneer to identify a "support partner" if possible. While we wanted to speak to "caregivers," we also wanted to explore additional forms of support offered by family members and friends who pioneers may not identify as their "caregiver," but identify as an important

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[1] There are key differences between BCI and DBS clinical trials. In many BCI studies, the devices are only activated during laboratory research sessions and do not provide any intended clinical benefit. DBS devices, in contrast, often remain active in the participant at all times, and sometimes provide clinical benefits (such as remission of depression). The significant differences between these two trial types shaped how participants chose to answer our interview questions. For example, DBS pioneers and their support partners emphasized the importance of relying on clinical care (psychiatrists or counsellors) for emotional support. In some cases, these clinical appointments were required during participation. Further, given that DBS pioneers are as much patients in neural device research as they are participants, they frequently receive clinical support in the form of meeting and interacting with their doctors for device adjustment and tuning. These are clinical support structures that BCI pioneers generally do not experience in the context of research. In our interviews with BCI pioneers, clinical support was scarcely brought up, and when it was, it almost always in the context of brain surgery and surgery aftercare.

[2] For reasons of brevity, we decided not to include an analysis of clinical forms of care in the scope of this paper. In turn, given that the support partners of the two DBS pioneers in our study (1SP and 3SP) mostly spoke about the importance of clinical care, they are less represented in the data we present here.

support nevertheless. To do this, we defined a "support partner" as someone "who was close to you and provided assistance during the time you were in the study (e.g., family member, spouse, aide, etc.)" (see [18] for a similar process). Every pioneer identified at least one support partner. One pioneer identified two support partners – a family member as well as a paid caregiver – and both were subsequently enrolled in the study. One support partner did not respond to our recruitment outreach, and another declined to be interviewed. In total, we enrolled two paid caregivers and one spouse from BCI studies, and two parents from a DBS study. In what follows, we identify pioneers using a number, i.e., '1' through '6,' and their respective support partner(s) using the same number followed by 'SP,' i.e., '1SP' through '4SPa' and '4SPb' (as this fourth pioneer identified two support partners).

Data Collection Interviews

Interviews were semi-structured and open-ended, and lasted approximately 60–90 min. Interviewees were compensated with a $100 gift card. We interviewed each participant separately, except for in one case where a pioneer's support partner unexpectedly joined and answered some of the questions, turning it into a "joint interview" [19]. Our rationale for interviewing participants and their support partners separately was to explore consistency and variety of responses to our questions rather than a more narrow focus on interpersonal dynamics of joint interviews.

Interview guides for pioneers and support partners were developed with the aim of instigating conversations about support. The interview guides went through several drafts over the course of three months. To help refine the guides, each author drew from their combined experiences of over ten years conducting interviews related to neurotechnology research (e.g., deep brain stimulation or brain computer interface devices for psychiatric illness, addiction, Parkinson disease, amyotrophic lateral sclerosis, spinal cord injury). Feedback from our broader neuroethics research group (ten individuals) was also incorporated into the final version of the guides. While we did not construct our interview guides around any specific theoretical framework, they were nevertheless guided by our theoretical sensitivities around the topic of care and support, given our research backgrounds and experiences with this topic. For instance, some of those sensitivities were beliefs about the demandingness of BCI research studies, the difficulties people with motor disabilities face in modern industrial societies, and differential power dynamics within biomedical research. Interview guides contained standardized question categories. Each interview question fell into one of the following five areas of interest: a) what support looks like for them; b) the social life / social dimensions of participating in the neural device study; c) practical suggestions to improve/assist participation in neural device studies; d) views about the role support partners had or could have in the neural device studies; and e) public-facing activities that pioneers participate in (such as giving talks at conferences). Our interview questions primarily focused on support provided by researchers and support partners, not on potential support from friends and other family members.

To prepare for each interview, the interviewer read transcripts, when available, from previous interviews conducted with participants by a previous member of the group (this practice was within the scope of the approved IRB (STUDY00011099)). When possible, the interviewer also made an effort in advance of the interview to become familiar with public-facing work of each pioneer, including published books, media interviews, and other online content. These practices allowed the interviewer to deliver interview questions in a personalized way. This method has proven effective in research studies that focus on interviewing people with public profiles, as a way of establishing effective rapport and building trust [20, 21]. In a few cases, this method also influenced the descriptive nature of the interview data that was collected.

For example, one BCI pioneer, prior to receiving the neural implant, completed a book she had been writing about her experience of being disabled in an unaccommodating world. While the book did not provide information on her experience participating in BCI research, it did describe many instances of supporting, and being supported by her spouse, family, friends, and students (she used to be a teacher). During the interview, a few of these examples of support that she described in her book were read to her as a way of broaching the topic of support in BCI research. One benefit of doing this is that it invites the pioneer to continue using her own language, phrases, and ideas to talk about what support looks like, now in the context of BCI research. For instance, one recurring theme in her book is how she prided herself on building supportive relationships with her students; after bringing this theme up during the interview, she made several comments about how one facet of her participatory role in BCI research was being a “teacher,” with young BCI research assistants being her “students” (see the section on social support below). Within the range of data we present in this paper, however, this was the only notable example of descriptive data being influenced by this method of reading public works of participants and incorporating them into the interviews.

Coding and Analysis

The scope of this study was to provide an initial empirical exploration of the different kinds of support provided to brain pioneers to help them successfully participate in neural device trials. As such, we wanted to avoid interpolating ideas or conclusions that were not explicitly stated by the interviewees, and for our interpretations to follow primarily from the data rather than preexisting theories or frameworks. To accomplish this, we used interpretive grounded theory [22, 23] to guide our coding and analysis of the data. Interpretive grounded theory is a methodology whereby data collection and theory formation go hand-in-hand [24]. This methodology was apt to the subject matter since, to our knowledge, there is no existing robust theory of support structures in the emerging technology context. Acknowledging that all interpretations of scientific research are theory-laden [25], we strengthened our grounded theory approach through team-based research [26]. We initially chose three transcripts for each of us individually to review and thematically code on our own. We then compared our codes with each other and made adjustments until we reached consensus on a standardized codebook. During this process, we reflected on our own, and each other’s personal and professional knowledge of and experience with the field of neurotechnology and theories and practices of care, and how these backgrounds influenced each of our coding decisions. We also discussed some of our coding decisions with our neuroethics group for additional perspectives. This was most notable in our process of using “theoretical coding” [27] to categorize and name the different kinds of support. The standardized codebook we developed was then used by the first author [AB] to code the remaining eight transcripts. We used ATLAS.ti qualitative software to facilitate the coding process [28].

Survey

In addition to interviewing pioneers and support partners, both groups filled out a 31-question survey after the interview. The survey collected demographic data and used truncated forms of the Measurement of Intergenerational Relations [29] and the Research Participation Reception survey [25]. We adapted the Research Participation Reception survey for support partner respondents. In total, we received ten responses (six pioneers and four support partners). One support partner we interviewed did not respond to our request to fill out the survey. Due to the small number of participants in our study, we present individual responses to individual survey items rather than group averages of summary scores.

Results

Survey Data

In this brief section, we review survey results in order to paint a succinct picture of who these pioneers are, the nature of their relationships with their support partner(s), their motivations for participating in DBS or BCI research, and how they felt about their experiences participating. The findings in this section are not meant to answer our research questions about the different kinds of support in implantable neurotechnology research, but rather to help contextualize the interview data presented below.

Demographics of participants are shown in Table 1. Responses to a set of questions we adapted from the Measurement of Intergenerational Relations suggest the relationships between pioneers and their support partners were highly satisfactory, regardless of whether the support partner was a spouse, parent, or paid caregiver (Table 2). Responses on the Research Participation Reception suggest the pioneers we interviewed were/are committed to neural device research (Table 3). Most of them never considered leaving the clinical trial, except for one due to unrelated work/family

Table 1 Demographic information*

	Pioneers (P) (n = 6)	Support partners (SP) (n = 4)
Age		
25–34	1	0
35–44	1	0
45–54	2	1
55–64	1	1
65–74	1	1
75 or older	0	1
Gender		
Male	3	3
Female	3	1
Race		
White	4	3
Black	1	0
Asian	0	1
Prefer no answer	1	0
Employment		
Employed (incl. self-emp)	4	2
Not employed (incl. retired)	2	2
Married		
Yes	3	3
No	3	1
Enrolled in a DBS or BCI trial?		
DBS	2	n/a
BCI	4	n/a
Currently enrolled		
Yes	3	2**
No	3 (3, 7, 9 years since exit)	2

*Not all response options are shown here, only those endorsed by participants

** Discrepancy in one P/SP pair with P endorsing current enrollment and SP endorsing past enrollment

issues, and all felt they were valued partners in the research. Support partners scored similarly on the same measures, including feeling valued as partners in the research process. Survey responses indicated that pioneers and support partners were also highly trusting of researchers. Overall, these results suggest that pioneers and their support partners perceived their participation in the neural device studies as successful.

Table 2 Measurement of Intergenerational Relations*

	Pioneers (P) (n = 6)	Support partners (SP) (n = 4)
Who is SP in relation to P?		
Spouse	n/a	1
Parent	n/a	2
Caregiver	n/a	2
P and SP relationship closeness		
Very close	5	4
Somewhat close	1	0
How well P and SP communicate		
Very well	3	3
Somewhat well	3	1
Similarity of P and SP life views		
Very similar	2	3
Somewhat similar	3	1
A little similar	1	0
How well P and SP get along		
Very well	3	3
Somewhat well	3	1

*Not all response options are shown here. The Table depicts those who endorsed very close and somewhat close (etc.) because these were all the options chosen by the people who took the survey

Responses related to motivations for research participation suggest that both pioneers and their support partners were personally invested in the research and had altruistic desires to help others (Fig. 1). The least commonly endorsed motives were to get free healthcare or to earn money.

Interview Data

In this section, we review the qualitative results related to various forms of support that allowed these pioneers to successfully participate. We begin by listing the kinds of support we identified based on our interview data. Following that, we present more detailed findings, providing representative quotes, of each kind of support. We start with more traditional, logistical forms of support (e.g., transportation), and then present the non-logistical forms of support (e.g., social, emotional, and epistemic support).

We identified six kinds of support from the interview data (see Table 4). Some forms of support

Table 3 Research participation reception: Research experience*

	Pioneers (P) (n = 6)	Support partners (SP) (n = 4)
Did you ever consider leaving the study early?		
Yes	1[i]	0
No	5	4
[i](due to family/work issues unrelated to the study)		
How much did the study demand of P (Simple, moderate, intense)?		
Moderate	3	1
Intense	3	3
Did the research team involve SP(s) as much as you wanted them to (yes, no, somewhat, mostly, completely)?		
Yes, completely	4	4
Yes, mostly	2	0
Did you feel you were a valued partner in the research process?		
Always	5	2
Usually	1	2
Did you have confidence and trust in the research doctor or investigator leading the study?		
Always	6	4
Usually	0	0
After the study was over, did you want to have more contact with the research team?		
Yes	4	3
No	0	1
N/A (e.g., still in study)	2	0
Did the research team involve your support partner(s)?		
Yes	2	4
No	4	0

*Not all survey questions or response options are shown here. Table depicts only those response options that were endorsed by participants

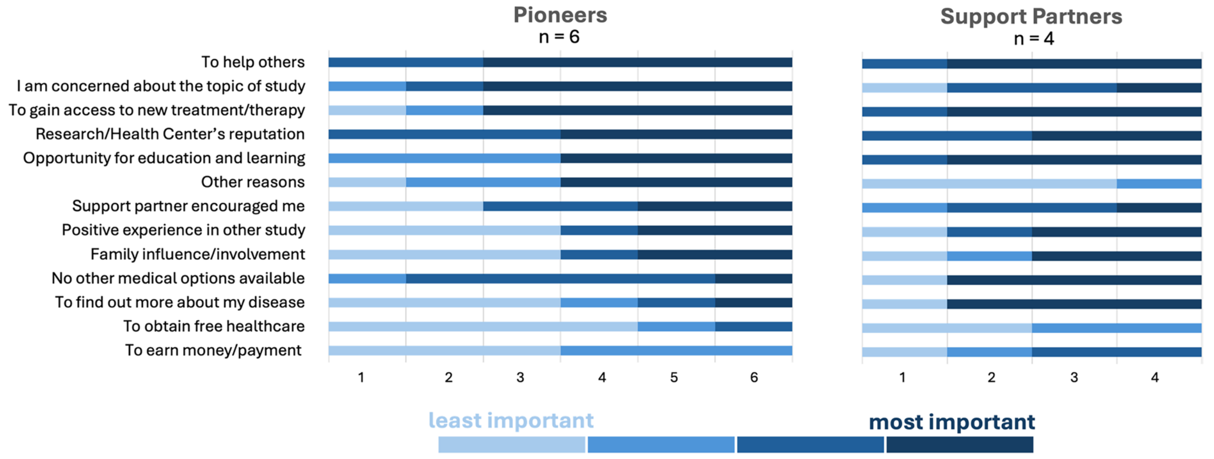

Fig. 1 Research participation reception: Motivations

Table 4 Kinds of support

	Definition/themes	*Representative quotes*
Logistical		
Transportation	Travel to and from the research sessions.	**"**[Pioneers] may have transportation issues, so if [the researchers] could provide that, [that would help with study success]." (4SPa)
Other logistical	Logistics related to study participation, such as physical care, scheduling, managing everyday tasks, and financing. (see Table 5)	"[My spouse is] an amazing person. She's the wheels that keep me goin'. […] She's very much the person behind the scene of things. I couldn't do [the study] if she wasn't involved." (6)
Non-logistical		
Social	Socializing or supporting pioneers' efforts to socialize with others. (see Table 6)	"When I was first getting my device tuned up, I was just in this room with these people that I didn't know very well. […] Just having my dad there as a guest [made me feel] more comfortable because he's my father. It's just easier to talk to him and stuff like that." (3)
Emotional	Showing one cares, uplifting morale, or being motivational. (see Table 7)	"[Researcher's] two children made me [posters] encouraging me and saying, 'Go, [pioneer]!' We put those on the wall." (2)
Epistemic	Support that relates to the transfer of knowledge. (see Table 8)	"[During the research sessions] sometimes [the researchers] couldn't immediately go back [on their computer] and see the results from like two trials ago. They'd [ask me], 'Oh, do you remember what happened X number of trials ago?' I'm like, 'Oh, yeah, this is what happened.'" (2SP)

discussed – the importance of transportation and physical and clinical care – are already widely acknowledged in clinical trial literature [30–32]. However, other forms of support also were discussed, including what we describe as emotional, social, and epistemic support. In most cases, participants did not explicitly use these terms. Instead, we categorized and defined these kinds of support based on examples the pioneers shared using our grounded theory approach. For example, our initial analysis yielded a seventh kind of support that we named "moral support," but after discussing our initial findings with our neuroethics group, we realized that "moral support" needed to be collapsed into "emotional support" to more accurately describe the data. More detailed thematic breakdowns and representative quotes of each kind of support can be found in supplementary Tables 5, 6, 7, 8.

Transportation, Caregiver Reliability Issues, and Other Forms of Logistical Support

Transportation is an essential form of support in most neural device studies. Pioneers must be able to travel to and from the research sessions in order to participate. In BCI studies, transportation can be complicated for people with bodies that the world is not structured for (e.g., wheelchair users). For instance, not all cabs or personal cars for hire (e.g., Lyft or Uber) are wheelchair accessible, and public transportation accessibility is often unreliable. While it is generally common for studies to provide reimbursement for travel expenses, and while study protocols differ, it is often required, as a matter of eligibility, that pioneers find their own transportation. This could include, as was the case for one pioneer we spoke to, hiring a part-time caregiver for the sole purpose of driving. Across our interviews, having steady transportation to and from the research sessions was identified as a key factor for study success. Not having transportation was often related to inconsistent or unreliable drivers. Even if studies covered the costs of getting to the experimental site, this covered transportation was not always reliable. Although all the pioneers we interviewed indicated that they were usually able to secure consistent transportation, some described cases where other pioneers in their cohort (whom we did not interview) had trouble with transportation:

> They're having to call for rides. I know that it's a big thing where rides just won't show up, or they'll cancel on you, or you just are waiting there forever for them to show up. [….] I was talking to [one of the researchers]. [They said that] the new participant's ride didn't show up. She [the researcher] actually took the bus to his house, so she could get him and take him on the bus back to the lab. (5)

Two pioneers we interviewed stated that technological advancements had allowed researchers to move the study to the pioneers' homes, thus obviating the transportation concerns. Even so, similar concerns over caregiver consistency and reliability remained.

Indeed, several of our participants indicated that reliable caregiving was important to their participation and that unreliability put their participation at risk. They also lamented that reliable paid caregivers are hard to find. When asked why, various answers were given, including poor wages. Most caregivers are hired out by agencies that take a significant cut of the pay; one pioneer stated that caregivers in his area only make $13/hour, approximately half of what is required (~ $26/hour) to support a basic standard of living without food and housing insecurity [33]. Other reasons given include caregivers prioritizing their full-time jobs over part-time caregiving work, lack of care about the work, incompetency, drug abuse, and poor language skills (some BCI pioneers, though none in the current study, can only use words to communicate, not hand gestures, so their caregivers must be able to speak their language fluently). One interviewee stated that if researchers could help participants find reliable caregivers that this would be a "real benefit for [the] study" (2SP).

Aside from transportation, interviewees described a variety of other supportive tasks that relate to the "logistics" of pioneers successfully participating in studies, including physical care, financial support, scheduling, and just helping to manage the mundane necessities of life. Given how time-consuming and intensive many of these studies are, pioneers often could not work while participating. In such cases, they had to be able to financially support themselves, or rely on financial support from others, in order to live and sustain themselves while participating. Other examples included handling the logistics of caregivers (hiring, training, and scheduling them) and building new accessibility devices (not related to the neural device study) or workarounds for the pioneer when at home (e.g., crafting mouthsticks, putting in wheelchair ramps, etc.) (see Table 5 for a more complete list of examples). When pioneers needed help with these tasks, they relied on support partners or family members for assistance.

Although participants described transportation and other logistical supports as necessary for their participation, they also discussed multiple kinds of *non-logistical* support as critical for their participation as well. These included social, emotional, and epistemic supports.

Social Support: Researchers as Coworkers and Friends

Social support was consistently noted as important for participation. In our analysis of interview data, we defined social support as efforts to socialize or support pioneers' efforts to socialize with others. This definition was derived from many descriptions and examples of what support was said to look like for pioneers. All pioneers (and in two cases, support partners) described feeling the *need* for social support, and were happy to find different versions of it within the neural device study. Some participants noted how being disabled can be isolating, and that the social dimensions of participating in a study were beneficial for their general well-being.

One avenue of social support that every pioneer experienced was the development of rich social relationships with at least some of the researchers, frequently described by participants as "coworkers" or "friends." These relationships, in most cases, were described in ways similar to friendships that can form in workplaces amongst coworkers who spend ample time together working on collaborative projects. For example:

> At that time, I didn't really have any friends to hang out with, so it was—that was my structure. People go to work every day, they meet colleagues, or people go to school, and they meet other people. That was my life. I would go to [the lab]. That was the only structure I had in

> my day. [The researchers] were there and that's how it happened [how the friendships developed]. (3)
>
> Every morning when they hooked me up, that took about 10 minutes, and we'd catch up with each other. "How was your night?" "How was your day?" "How was your weekend?" (2)

These relationships were bolstered by social functions put on by researchers or associated organizations:

> [The university] had some things that [the pioneer] was invited to – some meet-and-greets with different people and stuff. [Organization] had a couple things that she was invited to and things like that that we all – that all the people were there. Social functions. (4SPa)

Being around other people, communicating with them as a part of the work, having down time during the research sessions to talk about non-work topics, and attending social functions relating to the work are ways in which pioneers and researchers gradually developed mutual "friendships," sometimes "very close" ones:

> We met [researcher]'s family, his wife, and he just had a couple—two kids. We had 'em over a couple times in the summer. […] Yeah. We [all] became very close. (4SPa)
>
> Over the course of these years, I've had some core team members that are like family. (6)

In another case, a pioneer described her relationship with certain researchers as akin to a mother-son or teacher-student relationship, referring to how she helped many young researchers develop social skills, provided advice to them about childrearing, helped them obtain their PhDs, and more. For example:

> [One researcher] pretty much hid behind the computer screen rather than deal with me eye-to-eye. I'm like, well this has just gotta stop, because I'm a verbal person. […] You guys gotta work with me here a little bit. It took a while for him to crawl out from behind the monitor, and that became another good relationship as well. (4)

Many of these social supports – being around people, having "coworkers," and attending social functions – disappeared for participants after they exited the study, sometimes making them feel vulnerable:

> I don't have as much to say [now that the study is done], because I'm not doing much these days. [...] I don't have that much to contribute to a conversation. You know? [My friends] say, "What's new with you?" There's usually not much. (2)
>
> They explanted her so fast. That was tough for [pioneer]. It was tough for both of us, actually, 'cause it was like we went from being a part of the team to being done within about two weeks. (2SP)
>
> The only thing that I wanna say is just don't forget the group [the pioneers]. […] Don't forget them. I feel like, if you [pioneer] already give the information, they forgot about you [pioneer], but I wanted this group [to] continue, [to] be in touch with these people. (4SPb)

One method of slowing down, or possibly halting, the challenging effects of the loss of social connection gained in the lab was to keep pioneers involved in the lab's work in other ways, e.g., giving public talks about the science, and continuing to provide information to other interested parties:

> For about two years she gave talks to people all over the place about what she had done. [...] She even did a talk with kindergarteners one time… you know, "I'm in a wheelchair and I did this. Any questions?" They ask anything. Kindergarteners are amazing. [Giving public talks] really helped her come down from the study slowly. (2SP)

Researchers and family members were often described as helping to facilitate these public-facing activities for pioneers.

Emotional Support

While the pioneers we interviewed were all deeply committed to the neural device research and self-motivated to participate, our data suggest that many of them, and their support partners, recognize the importance of receiving emotional support from others to sustain them. Pioneers described many instances where something someone else did for them made them feel cared for, uplifted their morale, and/or helped them to stay motivated. We categorized all of these instances as examples of emotional support. For example:

> [My husband's] role was more emotionally supportive. […] He would ask every day how [the research] went and be encouraging. Usually, it was good news. Every day, "we achieved this. We achieved that. We tried this." Then he would just say, "Wow. That's great. Glad to hear it." (2)
>
> [Pioneer] had people coming in to visit her all the time in the lab. So-and-so would come in this day, and another person would come the next week, and another person would come in the week after, 'cause they wanted to see what she was doing. [The researchers] were like, "You have so many family." She's like, "I know." (2SP)

Emotional support might also involve empathy: e.g., providing a shoulder to cry on, being a good listener, and so on. Close family members, caregivers, friends, and clinicians (psychiatrists, therapists, etc.) were identified by participants as key emotional supports:

> My dad was the one that was closest to me throughout this whole time, and he's the one that was my support. I told him about everything—every time I was feeling miserable, I talked to him. (3)
>
> She doesn't really ask for a lot of support. There are times when she'll just—she'll be feeling down and she'll just cry, and you just have to kinda give her a hug and wipe her face and say, "It's okay." (2SP)

Emotional support was also offered relating to concerns over self-image. For instance, a support partner described having to reassure the brain pioneer that she should not worry too much about the "tubes in her head":

> After the first meeting [prior to surgery], she met with the doctors, the researchers, and then I was waiting for her. She came out and said, "Okay. I am gonna have a surgery, and they're gonna put the little buttons in my head. It's a haircut, it's nothing." [After the surgery] she sent me a picture from the hospital and said, "Look at me, how I look!" I replied, "Don't worry about it, about your hair. It's gonna grow so fast." [….] In the beginning, it was hard, like I said, for her to get used to it, to have those tubes in her head. (4SPb)

Researchers also provided emotional support to pioneers by incorporating methods that helped motivate pioneers to continue doing the work. Participating in neural device research was sometimes described as boring, or frustrating, especially on days where something does not work the way it was expected to work. This could include a pioneer not being able to complete a task that they were successful at during a previous session, for various reasons (computer malfunction, mental exhaustion, unknown variables, etc.). Researchers were described as offering helpful forms of emotional support during these scenarios:

> They encouraged me to look at the study as a marathon and not a sprint. If we couldn't do a certain task one day, that was okay. Maybe we get it the next day or the day after that. We didn't have to get every task on the first try every time. That made me a lot more comfortable if a task was taking a while to learn. (2)

While researchers tailored some study activities to the individual participants to achieve better research data, such as implementing differently themed video games that each pioneer might appreciate for data collection and device adjustment, pioneers and their support partners sometimes framed such tailoring as motivational:

> Right around the time [Pioneer] had to end the study, another pioneer started. [...] He was very different minded than [Pioneer] 'cause he had more of a video game mind. […] So when they started planning stuff for his study they went off a lot of gaming stuff for him because he thought that way. […] I know they changed up a bunch of stuff for him. (2SP)

In one case, a pioneer was provided with home equipment so that he could continue playing video games with his BCI device even when he was not in a research session; he described this as "cool" (5) for the researchers to do.

In addition to day-to-day encouragement in the lab, researchers sometimes provided important emotional support in the form of backup for the pioneers. For instance, in one case, researchers offered to call a DBS pioneer's parents (who were financially supporting the pioneer to live and sustain herself while participating) to help discuss options for her being able to continue in the study. To the pioneer, this demonstrated their investment in her and helped her trust them:

> When my parents were like, "Look, it's been a year. You need to get a fucking job," and I was like, "Hey, trial team, I think my parents are gonna yank me out." They were like, "Do you need [lead researcher] to call your dad, because [lead researcher] will call your dad." That idea that they were invested in me personally made all the difference in my ability to trust them. (1)

Epistemic Support: Desiring Peer Support and Treating Someone as a Team Member

Interviewees described many instances where a transfer of knowledge of some kind contributed to pioneers' successful participation – a type of support we categorized as "epistemic" [34]. This broad definition – support that is derived from the transfer of knowledge – can encompass a variety of heterogeneous cases (see Table 8). In this section, we describe two particularly notable cases of epistemic support in our data.

The first is the desire for epistemic support via peer supports, i.e., being able to learn from the experiential knowledge of other pioneers. Peer support amongst pioneers was often described in the sense of experienced pioneers providing information to new pioneers who reach out to them via online channels. In one case, a DBS pioneer described her and her cohort as forming a "gang" despite researchers' concerns:

> I think it would be so much more helpful [for researchers] to facilitate becoming friends with my cohort and talking to them about what they were going through. Because literally, nobody else on the planet knew what I was going through except them. Nobody else understood what we were feeling. […] Those relationships, we formed them extracurricularly. There was obviously some concern on our trial team's point of like, "We don't necessarily want you guys making a gang here." (1)

When asked how this "gang" formed, she replied:

> The psychologist and the psychiatrist… ran late every single week. We would all be sitting in this waiting room holding our manila pad, our manila folder that had our DBS number on it. We would be like, "When did you have your surgery? What's going on?" Yes, we would sit in that waiting room and we would talk. We would be like, "How are you doing? How's it going? You notice anything?" All those things. (1)

A second notable case of epistemic support is how researchers treat both pioneers and support partners as active members of the research team. For example, one pioneer described how her support partner attended "ninety percent" of the research sessions throughout the study, and provided epistemic support to the researchers:

> [The researchers] were taking notes themselves. But it would very much help to have [my support partner there], because sometimes they go back and say, "Now what was that number, the last time we did that test, what did it say?" Before they could look it up, [support partner] would say, "It took 12 attempts," or something like that. She'd be able to get the answers for them faster than they could. [The researchers] had to take such painstaking copious notes that very often when they would refer back to something, it would take them so long to find it, while [support partner] had it right at her fingertips. (2)

According to the support partner, this epistemic support she provided led researchers to invite her to co-author an academic paper with them:

> I was a part of the research team on the paper that they wrote, [and they] included me in that 'cause they did say that I kept notes and helped them with stuff. (2SP)

Discussion

Brain pioneers are critical to the success of the emerging field of neurotechnology, and how they fare in studies can make or break a research program. While motivations to participate as well as general trust in science and researchers are important factors for study success, so are the various forms of support pioneers receive throughout the duration of the study. It is well known that neural device clinical studies depend on forms of logistical support such as transportation and physical care [31]. But successful research participation depends on more than just logistical support. Our findings suggest that non-logistical support – social, emotional, and epistemic forms of support – are also integral to successful participation in neural device research.

When it comes to transportation in BCI studies, one topic that needs more exploration is the question of participant exclusion and driver reliability. Should prospective participants be excluded from enrolling in BCI studies if they do not have reliable access to a driver? Not every potential participant has family or friends, or a consistent, reliable caregiver, to drive them, or to assist them with the logistics of hiring, training, and scheduling drivers. If not having these supports excludes certain people from participating, this may contribute to a lack of diversity in participant pools. According to some of the pioneers we spoke to, reliable transportation is important for study success. This raises the question of how to find reliable drivers, and whether researchers can offer help with this. Whether such help would be in the form of researchers sending a wheelchair-accessible van with a qualified, licensed, and reliable driver to pick pioneers up for research sessions, or in the form of increased compensation to pioneers' drivers to incentivize them to be more consistent and reliable, is a point of discussion for future research.

Implantable neural device trials often require participants to engage with research teams intensely and over an extended period of time [35, 36]. The relationships that develop between researchers and participants can resemble co-workers in certain ways. The current study found that social support was an important kind of support provided to research participants, and one thing that co-workers can provide is social support. Many of the pioneers we spoke to describe their social world as having shrunk, in the case of DBS pioneers, after the onset of treatment-resistant depression, or in the case of BCI pioneers, after the onset of significant motor impairment, at least in part due to ableist structures and disability-related stigma in society. Feeling like one has a role in society – such as having a job or playing a key role in groups or organizations – is an important aspect of socialization in the contemporary world, even if just to have something to talk about with others [37]. Participants in the current study described one of the benefits of participating in neural device studies to be reclaiming a valued social role in society – feeling like one has a job, being excited to talk about it to others, and the pride of showing friends and family members how cool the work is. One key finding of the current study is that researchers provide social support by treating research participants as a kind of co-worker.

One notable difference between neural device research and most workplaces, however, is that pioneers enter these studies with various vulnerabilities that may make acculturation even more challenging. The conditions that make them eligible for the studies are often widely stigmatized, and common assumptions about disability may trigger stereotype threat [38]. They thus may have to learn to navigate the new, unfamiliar social milieu of working with a team of academic researchers from a position of significant vulnerability. Acknowledging the multiple roles of a study partner and encouraging pioneers to choose a trusted partner to accompany them can help to address some of these challenges.

In the broader world, workplace social support can push against boundaries, as co-workers try to be both co-workers and friends. This is made more complicated by different work roles, responsibilities, and power in the workplace. As we have argued elsewhere, moral entanglements can arise from the collegial environment of the research sessions in neural device trials, where pioneers feel included as team members [1]. These entanglements can generate new moral responsibilities, such as ensuring that research participants have access to continued device use or follow-up clinical care after the conclusion of a trial. The development of friendships between participants and researchers complicates these entanglements all the more. In our view, moral entanglements are not at all a reason to avoid or discourage friendships between researchers and participants – after all, friendships are a natural and valued benefit of working together for common ends, including research – but a reason to attend to, and strive to navigate, these complications and the power dynamics within them.

In our society, workplace social support generally does not extend past when someone leaves a job. If one retires or becomes unemployed, for example, they often lose much of the social support they received from the workplace. There are exceptions, as workplace connections may continue in some fashion, like having friends from an old job, or continuing to be part of an organization or community. In the case of neural device trials, some of the conditions or special features that led pioneers to participate in a study – namely, the desire to help progress neurotechnology research and play a role in the research – continue after the study ends. Pioneers we interviewed talked about how these special features of the research context made them want social support even after the study was over, when their work role ended. They described wanting to stay connected to the research in some fashion. Although researchers should not feel obligated to remain close or even keep in touch with pioneers after the study is over, or if the researcher moves away to a new city (as often happens with co-workers who leave the job), it is important to recognize that the formation of these relationships and interdependencies can create new vulnerabilities for pioneers after exiting the study. Such a moral entanglement means that researchers have an obligation to at least support them through this process [1].

These new vulnerabilities may be further exacerbated when the neural device is explanted from the pioneer upon exiting the study, as is the case in most BCI studies. The plan for explantation is discussed with BCI participants upon enrollment, as part of the consent process, but nevertheless the actuality of it can be a jarring experience, one that is hard for participants to fully grasp when they first enroll [39]. While clinical care is provided for post-explantation follow-up (checking for infections, etc.), researchers may consider additional ways to help pioneers manage this disorienting experience. One possible way to support pioneers is for researchers to assign a contact person who continues to be in touch with pioneers who have exited the study. This person could provide the pioneer with research updates from the team for a set period of time, and after that, could send periodic updates to the pioneer about how the field is advancing, or where various researchers are in their careers, as a way of helping pioneers continue to feel connected to the people they spent so much time working with. Providing pioneers with opportunities to present at conferences, offer peer support to new pioneers, and other educational outreach activities are ways that researchers can help pioneers adjust to post-trial life [40].

Previous research suggests that participating in clinical research can be emotionally taxing, and how important emotional supports are for clinical care [41–43]. Emotional supports are also vital for brain pioneers. Pioneers often describe participation as a “full-time job” (1). The work is intense, mentally taxing, and time consuming. Support partners provide emotional backup and identity “holding” that is crucial to surviving challenges of illness and/or transformation [44, 45], and this is no less true of transformations and vulnerabilities that arise from participating in a neural device study. Much of the emotional support described by participants in the current study related to explicit demonstrations of care, such as a willingness to care about what the pioneer is doing, what they are feeling, what could help them, and upholding and reinforcing their beliefs in what they can achieve for themselves, for science, and for humanity. While support partners were described as key emotional supports, friendships between researchers and pioneers, while social, can also be considered a form of emotional support in this regard.

Successful neural device research participation often involves pioneers being able to share information about the research with their friends and families. Participants develop expertise and also share their experiences by passing details on to others they care about. In some cases, this circulation of knowledge can help participants and their families or friends discuss important matters relating to the research, including decision-making, a kind of epistemic support. In neural device studies, support partners play an epistemic role in every phase of the study, from helping pioneers make the decision to enroll [46], to reporting psychosocial changes that the participant may be less aware of [34, 47]. In this sense, they epistemically support not only the research participants but also the research itself.

Researchers are another source of epistemic support for pioneers, helping them learn more about the science behind the research. Several pioneers described the importance of researchers being able to explain the science to them, so that they could keep up with the general picture of what was going on in the research. Not only did this help motivate pioneers, it also allowed some of them to carry that knowledge into public-facing activities, such as giving talks or providing peer support to others interested in BCIs or DBS. In one case, a DBS pioneer expressed gratitude for researchers helping her to understand *her* depression better (i.e., what made *her* depression treatment resistant, and why DBS worked when nothing else did).

Toward a New Paradigm of Support for Neural Device Trials

In a prior study, 104 BCI researchers' were surveyed about their views regarding potential ethical principles and guidelines for neurotechnology development [48]. One notable result was that the principle of Care for Subjects ("researchers are obligated to look out for the current and future well-being of research subjects") received the highest level of agreement (89%); a full 83% agreed that "researchers ought to ensure that subjects have appropriate care *even after* the completion of a study" [48]. Researchers and ethicists agree on the obligation and importance of providing care and protection for research participants. What is less clear is how to translate the high-level obligations into implementable plans for providing the needed support.

Looking to the clinical world is *somewhat* helpful for developing this new paradigm. For instance, in clinical practice, increasing attention has been given to the integral role of family members in navigating decision making (e.g., [49–51]). "Family-centered care" disrupts the traditional paradigm of patient as unilateral decisionmaker, replacing it with a model of families-as-partners. It understands families as "experts" and "collaborators" who contribute to the delivery of care [49, 52]. In a recent study of family and patient perspectives on ethical issues in clinical care, Cho et al. report that familial relationships emerged as a key theme; they call for more work to be done to "implement supportive, and respectful family centered care in clinical practice and clinical ethics consultation" and note that supporting families "is warranted not merely as a matter of fairness to them but also as an indirect source of support to patients" [53].

In sum, the literature regarding clinical medicine is beginning to appreciate the critical role of family support in achieving successful outcomes. We are beginning to see this shift in research domains as well, such as cancer clinical trials. As Paidipati et al. argue, researchers in cancer trials should seek to acknowledge "the presence of caregivers [in research and clinical settings] and dedicate a designed time and space to speak with caregivers" in order to, for instance, "inquire on what additional resources or supports they need" [18]. In dementia trials, study partners are sometimes a required part of the study structure [54]. But if the current paradigm of support in the field of neurotechnology remains limited to the logistics of transportation and physical care, implementing pragmatic approaches like these still risk overlooking or underappreciating the invisible forms of support that are also integral to study success. Developing a better understanding of the kinds of support that enable neurotechnology studies to go well can help the field move toward a new paradigm of support that bridges the gap between abstract principles of caring for pioneers and on-the-ground practice.

Limitations

Our present study primarily investigated what counts as good support and how research projects might encourage these good forms of support. Our Measurement of Intergenerational Relations survey indicated that relationships between the pioneers and their support partners in our study were highly satisfactory (Table 2). Given that our study only captured highly satisfactory relationships, our interview data are less helpful in identifying and understanding what kinds of support or family involvement should be avoided or how research projects can discourage insufficient practices of support.

Although the availability of caring support partners can be essential to successful participation, in some cases familial attitudes may be damaging or detrimental to the participant. Some neural device study participants have reported feeling "dehumanized" by how their family members responded to the reality that they could be "turned up" via their DBS hand-held programmers [34, 46]. Similarly, studies have found that increased burden on support partners may occur during neural device trials, which may lead to marital conflicts or poor valuation of the trial outcome [55]. Better access to education about the devices and potential relational difficulties through more robust inclusion of family members might help to avert some of these tensions. We don't pretend that all families – or paid caregivers – are loving and supportive, but most people rely on those who care for them to manage in times of illness or difficulty, and ensuring that some such support is available is an understandable requirement for most device trials.

Similarly, our Research Participation Reception survey indicated that pioneers and their support partners in our study felt that the research was going well (or had gone well; Table 3). The current study identified how different kinds of support can enable successful participation, but it did not fully explore insufficient practices of support. Future research is needed to explore whether participants in other neural device studies feel similarly supported, and if not, what could be done to ensure that they are better supported.

Future research design on this topic should also seek to incorporate community based participatory research (CBPR) approaches to improve data collection and analysis. Such an approach could be done in collaboration with organizations such as the BCI Pioneers Coalition, and could include holding workshops where multiple participants collectively reflect on their experiences together, and discuss what improvements to research design could potentially be implemented in future clinical studies. Drawing on the public works of pioneers (books, media interviews, public social media accounts, etc.) can also help guide interviews and workshops by building and expanding upon aspects of neurotechnology research participation that these pioneers are already calling attention to in their own venues.

Conclusion

The role of a support partner lacks a good model within most medical research. The guiding documents on protection of human subjects in research [56, 57] tend to focus almost exclusively on research participants as individuals. Typical studies rely on individuals who volunteer for relatively short studies (whether to assess safety or effectiveness) of medical interventions, or long-term cohort studies that are often designed to assess correlations between health conditions and other factors (behaviors, demographic characteristics, genetics, etc.) given a large sample size. In these studies, support partners might seem less needed, given the limited time frames and/or limited engagement with researchers.

But support partners do so much more in neural device research. Support partners are sometimes best or uniquely situated to give epistemic feedback on how neural devices affect brain pioneers in their day-to-day lives, offering assistance with data collection and settings adjustments, battery recharging, etc., and providing important social and emotional support for their friend or loved one to persevere through challenges.

Given the key role that brain pioneers play in neural device trials, and the ways in which their success is dependent on myriad forms of support from researchers and family alike, it is somewhat surprising how little work has been done to better acknowledge, understand, and secure these various forms of support. Caring for and supporting brain pioneers should be a priority for the entire field. Important neuroethics work has been done exploring ethical concerns related to these individuals, such as motivations for participating [58], experience of agency in using devices [59] and exit from studies [60]. Yet, the ability of this group of pioneers to enroll, participate, and seamlessly exit studies relies on both the support of family/caregivers and care from researchers that is often hidden from view yet critical to study success and participant safety.

Appendix 1

Table 5 Other types of logistical support

Types	*Specific tasks/activities mentioned by various pioneers and support partners*
Scheduling	Booking appointments; cancelling or rescheduling; handling the logistics of attending study-related conferences (hotels, vehicle rentals, booking flights, etc.); handling the logistics of moving to a new home in order to participate in a trial in a different city (finding an apartment, hiring movers, etc.); handling the logistics of other caregivers (hiring, training, and scheduling them)
Managing everyday necessities	Getting groceries and supplies for home; making and bringing a lunch for the pioneer to eat at the lab; bringing puzzles and magazines for the pioneer to entertain themselves during downtime in the sessions; waking up the pioneer early enough to get to sessions on time; building new accessibility devices (not related to the neural study) or workarounds for the pioneer when at home
Physical care	Feeding; dressing and undressing; using catheter for bowel and bladder movements; putting sling underneath body and using a Hoyer lift to help pioneer into and out of wheelchair; setting up ramp, positioning and locking wheelchair for vehicle transportation
Financial	Researchers covering costs of transportation and parking; family covering cost of living expenses for pioneers while in the study; family covering costs of specialist doctors or psychiatrists unrelated to the study

Table 6 Social support. Definition: socializing or supporting pioneers' efforts to socialize with others

Themes	Representative quotes
Recuperating a sense of purpose or participatory role in society	"The research] was very positive not only for her, but for me, 'cause it gave her some purpose, I guess you could say, after her accident […] it helped her mental state." (4SPa)
Helping pioneer transition to new social milieu of the research	"I remember when she started. The first week, I decided to stay with her because I wanted to make sure that she felt comfortable, because it's new faces, new people." (4SPb)
Attending work events with researchers	"Sometimes we'd go to have lunch after we're done in the program, and I say, "Okay, let's all regroup, and then let's go have some lunch in this place." I drive with [Pioneer] and then wait'til the group to get there. Sometimes they'd come to her house and then have a meeting, a little reunion, eating a little." (4SPb)
Getting to know researchers	"Just everybody that did work with me, I would get to know 'em a little bit more personally along the way." (4) "Yeah, they were just genuine people. […] [Researchers] would talk to each other having their own conversation, we'd all be in the conversation, rather than just everyone focused on me. It was like that majority of the time. It wasn't like people buttering up to me." (3)
Depth and intensity of friendships with researchers	"Over the course of these years, I've had some core team members that are like family. We go out, eat, meet each other's at different venues, and we look forward to spending time with each other just like you went any other friend or family member. […] It doesn't even involve the research project. They'll call and say, "Hey, [pioneer], what are you doin' today? Mind if we stop by?"" (6) "Sometimes we celebrate Christmas together [with the researchers]…. Yeah, everybody being a family, and that was very nice. Yeah, good times." (4SPb)
Social vulnerabilities after the study ends	"For [pioneer] [exiting the study] was really hard. I know she put a positive spin on it at the time, but I think it was a couple weeks later where she had a breakdown and was just super sad about it and cried for a while. That was hard." (2SP)

Table 7 Emotional support. Definition: showing one cares, uplifting morale, or being motivational

Themes	Representative quotes
Emotional support offered by support partner/family/friends:	
Related to enrollment/surgery	"When she got a room after the surgery they came into her room and decorated her whole room with signs of encouragement and poems and pictures and stuff like that. Her family was very much behind her and kinda gave her support when she needed it." (2SP)
Reminding pioneers of their commitments	"There were times when [pioneer] wouldn't be in the mood to go do the research. My support would be to encourage her, to say, 'you signed up for this, so you need to stay with it.'" (4SPa)
Self-image	"Sometimes she would say, 'I smell bad. These buttons smell bad.' I'd say, 'Okay, don't worry about it. I'm gonna clean around them.' Sometimes I'd call to ask, 'What can I do now? She's complaining about the smell.' I'd say to her, 'Don't worry about it,' or sometimes a button would be coming off. I'd say, 'What can I do? Don't worry about it.'" (4SPb)
Emotional support offered by researchers	"Every time I saw [researcher], he was just like, "I'm so grateful for you. Thank you so much." And just overwhelming flattering me with thank yous. It was good." (4) "If I said, "Oh, I didn't do that well" [the researchers] were always the first ones to say, "No. You did that fine, and you did that as well as you could…. They really helped me to come to terms with how I was performing…. If we couldn't do a certain task one day, that was okay. Maybe we get it the next day or the day after that." (2)
Reciprocal emotional support	"The researchers get more frustrated than I do, so I'm the one havin' to pat them on the shoulder and say, 'Hey, you know what? We'll get it. Don't even worry about it. I'm here for the ride.'" (6)

Table 8 Epistemic support. Definition: Support that relates to the transfer of knowledge

Themes	Representative quotes
Offered by researchers:	
Scientific translation	"[The researchers] didn't laugh about my need to question everything and to know the why behind everything. […] They were absolutely willing to have those conversations with me. […] Their willingness to include me [in those conversations] made it so much easier to trust them because I wasn't just a number." (1)
Offered by support partners:	
Helping pioneers think through decisions	"We talked about [the trial]. We talked it through—but I always said, "It's up to you." I gave her support. We talked it through, the good and the bad, positive and negatives, and then she ultimately made the decision." (4SPa)
Reminding pioneers of their progression	"In the beginning, you don't really notice yourself getting better, people around you will say, 'Oh, you look better today.'" (3)
Providing insights about the pioneer to researchers	"I just felt so depressed and so overwhelmed and so I needed someone close to me there [at the research session] and that was my dad. Just to get through this because I felt everything was on me and if people had questions about me—if I didn't answer questions and stuff they could just refer to my dad because my dad knows a lot about me." (3)
Scientific translation	"For me the science behind it was fascinating. A lot of times I was kind of like the translator between the team and [pioneer], explaining the science to her." (2SP)
As members of the research team	"They included both [pioneer] and I [as co-authors in the research paper]. We reviewed the paper when they first wrote it." (2SP)
Offered by pioneers:	
Peer epistemic support	"[Other pioneer]'s wife was really apprehensive of [other pioneer] having the surgery, so [pioneer] talked to both of them. Now he's, I think, getting implanted." (4SPa)
As members of the research team	"Monkeys can't say, 'I don't feel good today', or 'I don't feel like working for you today.' The monkeys can't say, you know, 'can you change that color?', 'can you make that a little bit bigger?' The monkeys couldn't say that, but I could." (4)

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Declarations

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