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Understanding Patients' Experiences with Borderline Personality Disorder: Qualitative Interviews

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Background: Patient perspectives of living with borderline personality disorder (BPD) are not traditionally captured in the literature. To overcome this gap, we explored participants' experiences with BPD to gain a better understanding of symptoms and impacts related to the condition.

Methods: Two experienced researchers conducted semistructured interviews with a subset of participants from a randomized controlled trial evaluating a BPD treatment. The interview study was independent from the trial. Interviews focused on participants' experiences with BPD prior to the trial, including the symptoms and impacts of BPD. Interview transcripts were analyzed to identify dominant trends and generate patterns in the way participants described their experiences with BPD.

Results: A total of 50 adults with BPD participated in the interview study. The mean age of the participants was 28.5 years (range, 18-53 years) and 72.0% were female. All participants described having difficulties with extreme emotional responses and interpersonal relationships, and most participants reported experiencing issues with self-image, impulsivity, suspiciousness/distrust, feelings of emptiness, and anger. The symptoms that were most bothersome to participants were extreme moods or emotional responses and a pattern of unstable personal relationships. All participants remarked that their BPD-related symptoms negatively impacted their interpersonal relationships, and nearly two-thirds of the sample reported that the impact of BPD on their relationships was the most bothersome. Additionally, more than half of the participants discussed impacts on work or school, memory or thinking, self-care, and financial and legal issues.

Conclusion: Participants reported that the most bothersome symptoms of BPD were those related to extreme moods or emotional responses and interpersonal relationships. Participants similarly described the impact of BPD on their interpersonal relationships as the most bothersome. Overall, participant perspectives from this study indicate that the burden of BPD is significant and new treatments tailored to patients' real-world needs are warranted.

Keywords: borderline personality disorder, patient experience, symptoms, impacts, patient perception

Introduction

Borderline personality disorder (BPD) is characterized by a pattern of instability in relationships, affect, self-image, and impulsivity.¹ The prevalence of BPD is approximately 1% of the general population and ranges from 12% to 22% of the population in psychiatric care settings.² Individuals with BPD face functional impairments and emotional dysregulation that can lead to difficulties with judgement, relationships, and employment, as well as legal entanglements.³⁻⁵ Additionally, the intense, volatile emotions and impulsive behaviors experienced by individuals with BPD can lead to self-harm and recurrent suicide threats or behavior.¹

Treatment for BPD consists primarily of psychotherapy, with pharmacotherapy available as an adjunctive treatment component.³ Psychotherapy may be beneficial for several outcomes, such as suicidal and self-harming behaviors, but its effectiveness varies across individuals.³ While outcomes of treatments for BPD are described in the literature, patients'

perceptions of their condition and its impacts on their daily lives are not traditionally captured. Notably, in a study exploring patients' perspectives of BPD treatment and recovery, patients expressed that current treatment approaches focused too narrowly on specific areas of functioning and that some of their personal recovery goals were not well-addressed.⁶

By exploring data on patients' subjective experiences with BPD, clinicians may be able to better empathize with their patients, leading to improvements in the treatment of BPD.⁷ To date, many qualitative interview studies in individuals with BPD have focused on understanding specific aspects of the disorder, such as chronic feelings of emptiness;⁸ relationships to self and others;⁹ perceptions of suffering;¹⁰ self-image;¹¹ and self-injury and overdosing.¹² However, there are few comprehensive qualitative studies in the current literature focusing on patients' perspectives of BPD. Furthermore, these studies typically have small sample sizes,^{13–15} limiting their generalizability to a broader patient population. A better understanding of the patient perspectives of BPD symptoms, impacts, and treatment outcomes is needed; such perspectives may support the development of effective treatments that are tailored to patients' real-world needs.¹⁶ Accordingly, the present study explored participants' experiences with BPD to gain a better understanding of symptoms and impacts related to the condition.

Methods

Study Design

In this qualitative, observational study, semistructured interviews were conducted with participants selected from a randomized controlled trial evaluating a treatment for BPD (ClinicalTrials.gov: NCT04100096).¹⁷ The interview study focused on participants' experiences with BPD prior to the trial; it was not part of NCT04100096 and no medical treatments were administered. To avoid selection bias, all English-speaking adults selected from 12 clinical sites in the United States participating in NCT04100096 were invited to be interviewed without regard to trial completion status or treatment assignment. To be eligible for inclusion, participants must have fulfilled the following criteria: (1) participated in NCT04100096; (2) been able to speak, read, and comprehend English with at least moderate to good conversational proficiency; and (3) been willing to provide written consent for audio recording and participation in a telephone interview. Clinical sites informed potential participants about the interview study and obtained written, informed consent from interested participants; consent was also confirmed verbally before proceeding with the interview. The study was approved by Advarra, a central institutional review board.

Semistructured Interviews

Interviews were conducted by 2 experienced qualitative researchers, including a clinical psychologist, using a semistructured interview guide. Interviews were approximately 60 minutes in duration, conducted over the phone, and audio recorded. The interview guide provided structure by maintaining a conversational flow with interviewees while ensuring data on participants' experiences with BPD were collected in a systematic way to meet the study objectives. The interviews began with open-ended questions about the participants' general experiences with BPD before transitioning to more-targeted, open-ended questions. These more-targeted questions were designed to gather information about the symptoms and impacts of BPD experienced by participants before their entry into the clinical trial, as well as the symptoms and impacts that were most bothersome to participants and the reason that these aspects of BPD bothered participants the most.

Analysis

Interview transcripts were analyzed using an iterative process to incorporate emerging themes as new concepts were identified.¹⁸ Specifically, dominant trends in each interview were identified and compared across interviews to describe the themes and the relative importance of concepts mentioned by participants. This process was used to generate patterns in the way participants described their experiences with BPD. Microsoft Excel and ATLAS.ti 7.5 software were used for analysis of the interview data, and participant characteristics were summarized with descriptive statistics. Anonymized participant quotes were used to illustrate the interview results and key concepts.

Results

Demographic and Clinical Characteristics

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A total of 50 adults with BPD participated in the study (Table 1). The mean age of the participants was 28.5 years (range, 18–53 years), and the majority of the interview sample was female (n = 36; 72.0%). Prior to participating in NCT04100096, many participants (n = 36; 72.0%) had received medication (eg, antidepressants; antipsychotics and other mood stabilizers; anxiolytics; stimulants) to manage 1 or more of their BPD-related symptoms. However, 15 participants (41.7%) said their previous medication did not help with their BPD-related symptoms or they did not notice much difference from the medication. Conversely, 5 participants reported that their previous medication helped with some of their BPD-related symptoms, and 13 participants reported they helped either with 1 symptom but no other symptom(s) or came with side effects.

Symptoms Related to Borderline Personality Disorder

The frequency of symptoms related to BPD and representative quotes of participants' experiences with these symptoms are presented in Figure 1A and Table 2, respectively. All 50 participants (100%) reported experiencing extreme moods or emotional responses (eg, quickly changing emotions, intense anger, anxiety, irritability). Additionally, all participants (100%) reported that they had intense or unstable relationships, such as frequent arguments or repeated breakups, significant fears of abandonment or being left alone, or being very close to someone and then being very disappointed in them.

Participants also reported experiencing a number of other BPD-related symptoms. Nearly all participants (n = 47; 94.0%) reported that they had an unstable self-image (eg, sudden and dramatic shifts in self-image) and had engaged in impulsive behaviors that were potentially dangerous or harmful (n = 45; 90.0%), including spending sprees, sexual activities, reckless driving, drug use, binge drinking, or self-injurious behaviors. Most participants (n = 44; 88.0%) reported that they experienced feelings of suspiciousness or distrust of others, that they had chronic feelings of emptiness (n = 43; 86.0%), or that they experienced intense anger or had difficulty controlling their anger (n = 42; 84.0%), including frequent displays of temper, constantly being angry, or recurrent physical fights. Participants also spontaneously reported experiencing other symptoms that they thought were related to BPD, including depression (n = 12; 24.0%), dissociative symptoms (n = 5; 10.0%), and having trouble focusing or concentrating (n = 3; 6.0%).

Characteristic	Total (N = 50)
Age (years)	
Mean ± SD	28.5 ± 7.3
Range	18–53
Sex, n (%)	
Male	14 (28.0)
Female	36 (72.0)
Time since BPD diagnosis (years), n (%)	
0	19 (38.0)
1	8 (16.0)
2–5	11 (22.0)
6–10	5 (10.0)
11–15	5 (10.0)
> 15	2 (4.0)
Past medications, n (%)	
Yes	36 (72.0)
No	14 (28.0)

 Table I Interview Participant Characteristics

 $\label{eq:abbreviations: BPD, borderline personality disorder; SD, standard deviation.$



Figure I Symptoms Related to Borderline Personality Disorder.

Notes: Frequency of symptoms (**A**) and most bothersome symptoms (**B**) of BPD reported by participants (N = 50). A few participants (n = 8) chose more than 1 most bothersome symptom. ^aSpontaneously reported by participants; not specifically probed.

Participants most often described extreme moods or emotional responses as the symptom they found the most bothersome (n = 19; 38.0%), followed by intense or unstable relationships (n = 10; 20.0%), intense anger or difficulty controlling anger (n = 8; 16.0%), unstable self-image (n = 7; 14.0%), feelings of suspiciousness or distrust of others (n = 6; 12.0%), and chronic feelings of emptiness (n = 6; 12.0%) (Figure 1B). Symptoms related to BPD less frequently reported as most bothersome to participants included impulsive behaviors (n = 3; 6.0%), lack of focus/concentration (n = 3; 6.0%), and suicidal ideations (n = 2; 4.0%).

Impacts Related to Borderline Personality Disorder

Participants reported having problems with their relationships, work/school, memory/thinking, self-care, and finances due to their BPD-related symptoms (Figure 2A). All participants (100%) reported that their BPD-related symptoms impacted their relationships, including repeated breakups and conflicts in romantic relationships or with family/friends. Almost all participants (n = 47; 94.0%) noted that their BPD-related symptoms affected their work/school, including their ability to

Table 2 Participant Quotes Describing Symptoms Related to Borderline Personality Disorder

Symptom	Participant Quotes
Extreme moods or emotional responses	 A lot of people say I am a very intense person as it is, and it's hard to calm that down. It can go from zero to 60 very quickly for me in any direction. It could be elation, to sadness, to anger. I feel them very deeply, and then it's just very strongly. (ID 1) not being able to control my emotions is just something that has always caused me a lot of grief because it's the rational part of meI do not want to feel so intensely about this situation because most times it's not proportionate to what is going on. But my brain chemistry cannot stop feeling that way. (ID 6) I have noticed that I do not really have a middle ground. Either I am really happy or really mad or really sad. It will just go from one to the other. (IDI 20) I noticed my mood changes to where I would be fine one minute and then just sad for absolutely no reason or angry for no reason. (ID 29) A lot of it was just a complete unregulation of my emotions. My emotions were in control of me rather than me in control of them. I'd get very overwhelmed and overstimulated very easily. (ID 39)
Intense/unstable relationships	 I am kind of reactive and will sometimes end up blowing up friendships. And then later on, like a week or a year, I will look back and just feel completely wrong. (ID 5) I would start a relationship, fall instantly in love, and the relationship would go bad on me. When I had longer lasting relationships, I had anger issues inside the relationships. (ID 9) I normally just, like, will really like someone and then just stop wanting to be friends with them. I have been in toxic relationships, romantic relationships, but mainly with my friends, I would just stop liking some of them. (ID 36) I guess some of the highlights isreally unstable relationships, had some really bad abandonment issues. Trying to keep people from abandoning memy entire self-worth being based on how many friends I have. (ID 48)
Unstable self-image	 There [are] definitely days where I feel really self-confident and good, and there's days where I cannot even look at myself in the mirror. (ID 8) Just feeling like I do not really know what I am here to do, not really feeling as though I have a stable consistent sense of self. I can go from really great, I can do anything, girl power, to, like, I am the worst and everybody hates me, and I will not accomplish anything in life. (ID 13) I feel like I view everything black and white all the time, like with my image. I either feel really good about myself, or I feel like I cannot even leave the house because I look so bad. (ID 33) I had a hard time kind of figuring out who I am, sometimes, during my normal routine, business, thinking that I could be more than one different person at a time. (ID 34)
Impulsive behaviors	 If I have an argument with somebody or something or there's a problem at work, I will immediately need to cope by drinking alcohol I will get a huge jug of vodka and just go with it because I feel worthless or not able to handle these emotions. (ID 1) There was the shopping where I was just spending a lot more than I could afford. I was maxing out all my cards. Impulsivity, just, like, acting before thinking. I feel like my body acts before my brain is finished thinking. I am just always jumping the gun. It's hard to control. (ID 4) I drive too fast, and I do spending sprees sometimes, and I have gotten into dangerous sexual practices. (ID 31) I do have an addiction to self-harm. Definitely much, much better than it was when I was younger, much more under control, but I do think it's worth mentioning. (ID 46)
Suspicious/ distrustful of others	 I do not like people, and I am always suspicious of them. (ID 25) Constantly wondering if people hate me or not or just unsure about people's intentions. (ID 37) I assumed that everybody was out to get me. I would not talk or say certain things because I was afraid it was going to get used against me. (ID 38)
Chronic feelings of emptiness	 I feel like there's a certain voidlike I cannot fill [it]. (ID 17) I have described [the emptiness] before to other people as kind of like being at the bottom of the ocean or in space. It's just like things are floating past you, and you cannot really do anything about them. (ID 35) I felt empty every day when I woke up. Just wanting to feel some type of motivation to get the things that I would have to get done. (ID 47) I think the one thing that bothered me was the feeling of emptiness. I felt like I was losing track of blocks of time because I would just zone out. But there was no excitement, there was no looking forward to things. (ID 49)

(Continued)

Table 2 (Continued).

Symptom	Participant Quotes	
Anger issues	 The anger [bothers me the most] because I anger a lot of people, said the wrong things, and sometimes not knowing when I am going to get set off. (IDI 9) I would lash out. I would slam doors and break things. It was pretty extreme. (ID 20) I would be very impulsive with my anger, the shouting, screaming, cursing, yelling, things like that. (ID 23) I just get extremely angry to the point where I just have to walk away because I know it's out of proportion. (ID 31) 	
Depression, anxiety, suicidal ideations	 I definitely have a lot of anxiety and depression, so I know a lot of those symptoms overlap. (ID 8) I did not have the drive, just low energy from the depression, but then exhausted from the anxiety. Suicidal attempts, suicidal ideation, and self-harmstuff like that. (ID 39) I felt like I was really depressed, and I just gave into alcohol and weed. (ID 47) 	
Dissociative symptoms	 If under a lot of stress, either financial, work, or anything like that, even if it's relatively small to a normal human being, it's a lot to this person [that] you can actually dissociate. (ID 1) I would have periods where I would [dissociate] just zone out, and I would not even be aware of how much time was passing. It just would not even occur to me, I would not even know I was doing it. (ID 18) 	
Lack of focus/ concentration	 I cannot concentrate on book learning and that means I cannot get a degree. (ID 2) I was organized at one point in time, now I cannot concentrate. Short-term memory is a little hard. (ID 4) 	

keep their job/stay in school; caused trouble with coworkers, employers, or teachers; and caused absences at work or school due to emotional concerns or hospitalizations. Additionally, 46 participants (92.0%) reported that BPD-related symptoms impacted their memory/thinking, which included having difficulty concentrating, focusing, planning, or organizing. Forty-three participants (86.0%) reported that their BPD-related symptoms negatively affected their self-care, including eating, showering, doing laundry, cleaning the house, exercising, or partaking in excessive smoking/ alcohol/drug use. Thirty participants (60.0%) discussed the financial impacts of BPD-related symptoms, including getting into debt and the inability to pay bills on time. Lastly, 11 participants (22.0%) reported that they experienced legal issues due to their BPD-related symptoms, particularly due to their impulsive behaviors, extreme moods or emotional responses/control, and anger. Table 3 presents representative quotes describing the impact of the participants' BPD-related symptoms.

Figure 2B presents the most bothersome impacts of BPD-related symptoms. Of the 49 participants who described the most bothersome impacts of BPD-related symptoms, nearly two-thirds of the sample (n = 31; 63.3%) reported that the impact of BPD on their relationships was the most bothersome, because these participants desired stable and healthy familial and nonfamilial relationships. Impacts related to BPD that were less frequently reported as most bothersome to participants included experiencing financial problems (n = 7; 14.3%), issues with work/school (n = 6; 12.2%), issues with memory/thinking (n = 6; 12.2%), legal complications (n = 3; 6.1%), and issues with self-care (n = 2; 4.1%).

Discussion

The present study characterized participants' experiences of BPD and provides a deeper understanding of BPD symptoms and the impact of these symptoms on the lives of individuals with BPD. All participants described having difficulties with extreme emotional responses and interpersonal relationships. Additionally, most participants reported experiencing issues with self-image, impulsivity, suspiciousness/distrust, feelings of emptiness, and anger. All participants remarked that their BPD-related symptoms negatively impacted their interpersonal relationships. Furthermore, more than half of the participants discussed other impacts related to their BPD symptoms, including impacts on work or school, memory or thinking, self-care, and financial and legal issues.

Given the paucity of qualitative research in this patient population, the current study provides valuable information on interview participants' perspectives of their BPD-related symptoms and impacts, including the aspects of BPD that bothered participants the most. The symptoms that were most bothersome to participants were extreme moods or



Figure 2 Impacts of Symptoms Related to Borderline Personality Disorder.

Notes: Frequency of impacts (**A**) and most bothersome impacts (**B**) of BPD-related symptoms reported by participants (N = 49). A few participants (n = 6) chose more than 1 most bothersome impact of BPD-related symptoms. One participant in the sample reported that extreme moods/emotional response was most bothersome in response to questions regarding most bothersome symptom and most bothersome impact related to BPD; thus, this response was not included in the current figure, as it was included in Figure 1.

emotional responses and a pattern of unstable personal relationships. The most bothersome impact experienced by participants was consistent with these most bothersome symptoms, with nearly two-thirds of the sample reporting that they were most bothered by the impact of BPD on their interpersonal relationships. In agreement with these findings, social relationships were a common theme identified in previous qualitative studies in individuals with BPD.^{13,14} In an interview study in 9 adults with BPD, 8 of whom were female, Black et al¹⁴ found predominant themes of self-harming behavior, suicidality, and BPD-related impacts on interactions with family and friends. Miller¹³ conducted qualitative interviews with 10 patients with BPD and identified common themes of estrangement, inadequacy, and despair. In an early phenomenological study about the experiences of 30 adult female participants living with BPD, Nehls¹⁹ similarly identified themes of living with a label and living with self-destructive behavior but did not emphasize social relationships among the key themes. Given the diversity of symptoms and impacts experienced by those with BPD, the

Table 3 Participant	Ouotes Describing	Impacts of Borderline	Personality Disorder
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Impact	Participant Quotes
Relationships	 I would have to say that the stormy relationships [is most bothersome] and feeling like there's always some type of distance between me and the other person [and] thatreally upsets me (IDI 2) I have definitely had some really bad breakups in the past. Just being super overreactive to everything. (ID 8) Probably the relationships with other people [bother me the most]. It's been something I have experienced for a very long time. With platonic friendships, I have lost a lot of friendsjust a constant shift of people in and out of my life. (IDI 16) I would have friendships that I valued, but I could not maintain them because I was just so hard to handle. There are people that I would be relying on as a support network that I would just totally ruin and it sucked. There was just nothing that I could do to control it even though I really wanted to. (ID 18) With family relationships, there's been a lot of rocky territory there. (ID 26)
Work/school	 it affects my job because I was super paranoid that people were talking about me and saying that I was doing a bad job. (ID 3) The suicidal ideations were very persistent and consistent throughout my day, so I found it really difficult to work. I kept having to reduce the amount of hours I was working. Eventually, I did have to stop working. (ID 21) I could not manage my emotions at my job. I ended up being hospitalized a few times in the middle of my job, even to the point where I had ended up self-harming myself, going into work, and then being taken out by police officers. (ID 34) when I went to collegeI almost got kicked out twice, I was put on suspension for a while, and it was just all day of manipulative behaviors and drug usewith most of that, it was just not showing up to class or stuff like that. (ID 39)
Self-care	 When you get really depressed, and you think about a lot of things, it becomes very easy to skip meals, to stop eating completely, stop drinking water, just chain smoke cigarettes because you are constantly anxious. (ID 1) I have a high BMII do not really exercise or eat welltaking care of myself does get more difficult when I was severely depressed. (ID 7) I was drinking excessively for a while there. I definitely attribute my drinking to my BPD. (ID 18) I am severely overweight and obese, and I try to fill my emotions with food, so I think that stops me from caring for myself in the best way, and I do have times where I do not want to get out of bed, or I do not want to shower. (ID 50)
Finances	 I definitely got into debt, and I missed credit card paymentsI fell into debt, I did not renegotiate my student loansit affected my credit score. (ID 3) Paying bills on time. I mean that's more of function of the disorganization and not being able to afford things. I was homeless up until very recently for the past 2 years. (ID 5) I kept quitting jobs for a whileI did not have any money and I had to rely on my mom. (IDI 17) It took years to pay off all the financial fees. The money irresponsibility went on for years past that, all of which is sort of bound up with the drugs and alcohol and self-medication. (ID 40)
Legal	 I think it was 5 years ago, but I did assault someoneI picked him up by the throat and really beat this person to shreds, and I was in court for it. (ID I) I did have a restraining order back in 2016 that was only for a year because I could not control my emotions with my partner at the time. (ID 34) I had a DUI, but I also had possession of a controlled substanceI was actually in jail for a night. (IDI 40)
Memory/thinking	 Not being able to focus because of the depression and the anxiety. (ID 9) There's a lack of focus, like not being able to get anything done because my mind is just overwhelmed with everythingit's frustrating. (ID 26) I do have a lot of problems keeping on task of what I am supposed to be doing or like remember things. My memory is shot. (ID 50)

qualitative data from the present study on a larger sample of adults, including both males and females, provides a more comprehensive picture of the symptoms and impacts that are most important to these individuals.

The results of this study align with the DSM-5¹ as well as with results from both qualitative and quantitative studies suggesting that individuals with BPD lack a sense of belonging and experience impairments in their social interactions.^{20–23} The participants in the present study desired stable, healthy relationships, which are understood as an essential component of the recovery process.^{24,25} Notably, individuals with personality disorders describe meaningful engagement in relationships and a sense of belonging and integration as important aspects of their personal recovery.^{6,15,22,26} For example, Fallon²⁶

conducted unstructured interviews with 7 patients with BPD and found that relationships were viewed as the most important supportive variable in patients' lives and that these relationships played a crucial role in patients' abilities to contain their distressing emotions. Furthermore, in a qualitative study by Ng et al,¹⁵ the authors recommended an increased focus on patients' relationships in the treatment of BPD. Taken together, these findings suggest that the development of therapies focused on relationship building may be important for individuals with BPD.

A limitation of this study is that the data obtained from clinical trial participants may not be representative of the larger, non–clinical trial population of individuals with BPD. However, the symptoms experienced by the interview participants closely align with the diagnostic criteria of the disorder,²⁷ which support that these qualitative findings are credible and trustworthy.^{28,29} Additionally, a strength of this study was the experienced qualitative interviewers, which included a clinical psychologist. Interviewing participants with a personality disorder about sensitive topics of a very personal nature can be challenging, and it is critical that qualitative interviews are conducted by experts to engage interviewees, maintain conversational flow, and augment concept elicitation.^{30,31} Finally, the present study's large sample size and focus on the most bothersome aspects of BPD provide an important contribution to the landscape of literature on this topic.

Conclusion

This study provides much-needed data on the patient perspective, including in-depth quotes representative of the participants' lived experiences with BPD. Interview participants reported that the most bothersome symptoms of BPD were those related to extreme moods or emotional responses and those related to interpersonal relationships. Participants similarly described the impact of BPD on their interpersonal relationships as the most bothersome impact of their BPD-related symptoms. Overall, results from this study indicate that the burden of BPD is significant and new treatments are warranted that target the BPD-related symptoms and impacts that matter most to individuals with BPD.

Data Sharing Statement

Data are primarily in the form of transcripts and field notes and cannot be made available in order to protect participant privacy in accordance with the principles of the Belmont Report.

Ethics Approval and Informed Consent

This study complies with the Declaration of Helsinki and was approved by Advarra, a central institutional review board (IRB Number Pro00046283). Participants provided written, informed consent prior to participation in the interview study as well as verbal consent prior to the start of each interview.

Consent for Publication

Participants provided consent for publication of anonymized study findings.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

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