

Factors Affecting Participant Recruitment and Retention in Borderline Personality Disorder Research: A Feasibility Study

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Abstract

Background

Previous studies have shown that stigma is a major barrier to participation in psychiatric research, and that individuals who participate in psychiatric research may differ clinically from non-participants. However, no previous study has explored research recruitment and retention challenges in the context of personality disorders.

Aim

To provide an analysis of the factors affecting participant recruitment and retention in a study of borderline personality disorder.

Methods

Adult inpatients in a tertiary psychiatric hospital were approached about participating in a cross-sectional study of borderline personality disorder. Recruitment rates, retention rates, and reasons for declining participation or withdrawing from the study were collected. Demographic characteristics were compared between participants and non-participants, and between patients who remained in the study and those who withdrew.

Results

A total of 70 participants were recruited into the study between January 2018 and February 2020. Recruitment and retention rates were 46% and 70%, respectively. Lack of interest was the most commonly cited reason for non-participation, followed by scheduling conflicts and concerns regarding mental/physical well-being. Age and sex were not predictors of study participation or retention.

Conclusions

More research is needed to explore patients' perspectives and attitudes towards borderline personality disorder diagnosis and research; determine effects of different recruitment strategies; and identify clinical predictors of recruitment and retention in personality disorder research.

Trial registration:

The study was not registered as it did not involve the provision of a health care intervention to human participants.

Key Messages Regarding Feasibility

1) What uncertainties existed regarding the feasibility?

There were uncertainties regarding the barriers to participant recruitment and retention in borderline personality disorder research, and strategies for improving recruitment and retention.

2) What are the key feasibility findings?

Lack of interest was the most commonly cited reason for non-participation, followed by scheduling conflicts and concerns regarding mental/physical well-being. Age and sex were not predictors of study participation or retention.

3) What are the implications of the feasibility findings for the design of the main study?

The lessons from the feasibility findings were applied to address the common barriers to participant recruitment and retention in the main study design. For instance, strategies were implemented to address the stigma surrounding borderline personality disorder, resolve scheduling issues, and make the study process less stressful and tiring for participants.

Background

Borderline personality disorder (BPD) is a common mental illness. According to a recent meta-analysis, BPD has a global prevalence rate of 1.8%. (1) BPD is found in 10–12% of psychiatric outpatients and 20–22% of inpatients. (2) BPD is also associated with a high burden of disease. About 75% of patients attempt suicide while 5–10% die from suicide (3, 4), making it one of the most lethal psychiatric diagnoses. Longitudinal studies also demonstrate severe and persistent social impairment. (4, 5)

Despite the high prevalence of BPD, it continues to be heavily stigmatized. (6, 7) Negative perceptions of and emotional responses to BPD are common among patients, public, and even healthcare workers. (6, 7) Stigma leads to significant discrimination in the healthcare system, poses a barrier to diagnosis and treatment seeking, disrupts the therapeutic alliance, and hinders treatment adherence and retention. (6–8) Although the effects of stigma on BPD treatment and function have been previously documented, its effects on research are less clear. Previous studies have shown that stigma is a major barrier to participating in research on mental illness in general. (9, 10) This poses a major issue in psychiatric research, as it can reduce external validity of research findings. In fact, psychiatric research samples do not tend to be representative of the overall patient population (11), and research participants differ significantly from non-participants in terms of illness severity and symptomatology. (12, 13) Although studies have explored this issue in other psychiatric conditions, no study has explored factors affecting study recruitment or retention in patients with BPD, or the representativeness of study samples in BPD research. Better understanding of these issues will help contextualize current research findings, improve recruitment and retention, and allow for more representative samples in future research.

We experienced this issue first-hand in our Transitional Objects in BPD (TOB) project, a study exploring the association between BPD and the use of transitional objects (also known as comfort objects, such as stuffed animals or blankets). During the recruitment phase of the study, investigators realized that recruitment and retention rates were lower than expected, and that many potential participants voiced reluctance about being associated with BPD in any way. Therefore, we decided to conduct a feasibility study analysing the factors affecting recruitment and retention in BPD research. Here, we compare recruitment and retention rates from the TOB sample to those of the previous literature and discuss the most commonly provided reasons for non-participation and attrition in the TOB study. We also provide strategies that were implemented to improve recruitment, retention, and external validity in the TOB project.

Methods

This study was approved by the Hamilton Integrated Research Ethics Board (#3786).

Participants

Participants were recruited from inpatient units of a tertiary psychiatric hospital in Canada. Inclusion criteria included: 18 years of age or older; ability to provide written informed consent; and psychiatric inpatient at time of recruitment. Participants were excluded if there were English language barriers or if they were about to be discharged from the hospital in the next few days. No restrictions were placed on the type of existing psychiatric diagnoses.

Study investigators approached hospital staff in various inpatient units to inquire about patients who may be suitable for the study. After obtaining permission from the patients, staff-recommended patients were approached by the investigators to discuss potential participation in the study. The study purpose, protocol, and potential benefits and harms were explained to potential participants. Written and verbal informed consent was obtained from each participant. Participants were not provided with any form of reimbursements (monetary or otherwise) for participation. After participants provided consent, they were scheduled to undergo a comprehensive assessment. During this assessment, trained interviewers administered various questionnaires and semi-structured interviews including the Structured Clinical Interview for DSM-IV (SCID), the Diagnostic Assessment Research Tool (DART), and the Borderline Symptom List 23 (BSL-23). This assessment usually took place within seven days following recruitment, and generally took about two hours.

Recruitment began in January 2018 and is ongoing. Here, we report on data collected until February 2020. Unfortunately, at the beginning of the study no record was kept of the number of individuals approached, the number of individuals who declined participation, and common reasons for declining. Anecdotally, the consensus felt amongst the study coordinators was that a significant number of approached patients were declining to participate. Having recognized the issues with recruitment, our team began to maintain a record of the number of individuals approached for the study in June of 2019.

Outcome measures

Demographic information was obtained through a self-report questionnaire at time of recruitment. Employment status, reason for hospitalization, and pre-existing psychiatric diagnoses were collected in a semi-structured interview based on the DART. Participants were screened for BPD using the BSL-23, a validated, self-report questionnaire. (14) An average score greater than two (on a scale from zero to four) was used as the cut-off value. (14) Lastly, the SCID Axis II Personality Disorders was used to determine whether patients met the diagnostic criteria for each personality disorder, including BPD. During recruitment, potential participants were asked to provide reasons for declining to participate in the study. Similarly, participants who withdrew consent from the study were asked to provide reasons for doing so.

The primary outcomes of interest were: 1) recruitment rate, 2) retention rate, and 3) common reasons for declining to participate in or withdrawing from the study. Recruitment rate was defined as the proportion of approached potential participants who consented to participate in the study. Retention rate was defined as the proportion of recruited participants who did not withdraw consent from the study.

As part of the secondary analysis, mean age and sex were compared between participants and non-participants, as well as between patients who remained in the study and those who withdrew. Two-tailed, independent samples t-test and Pearson χ^2 test were used for comparing age and gender, respectively. The Statistical Package for Social Sciences Version 21 was used. Statistical significance was set at $\alpha = 0.05$.

Results

Recruitment and retention rates

Between January 2018 and May 2019, 34 participants were recruited into the study. Between June 2019 and February 2020, 78 potential participants were approached regarding the study. 36 consented (46%) and 42 declined to participate (54%). In total, 70 participants were recruited into the study between January 2018 and February 2020. Of those, 21 (30%) withdrew consent and 49 (70%) remained in the study.

Table 1 compares demographic characteristics between participants and non-participants, as well as between patients who remained in the study and those who withdrew. There were no statistically significant differences in age or sex between groups. More detailed demographic and clinical characteristics of the recruited participants are shown in Table 2. 56 of the participants completed the BSL-23. Of those, 30 (54%) screened positive for BPD in the BSL-23. The overall prevalence of BPD based on the SCID in the study population was 30%.

Table 1
Demographic characteristics of participants

	Consented (N = 70)	Declined (N = 42)	Statistic
Mean age	40.5 ± 14.6	44.0 ± 13.0	t = 1.279, p = 0.204
Sex:			
Female	41 (59%)	28 (67%)	$\chi^2 = 0.727, p = 0.394$
Male	29 (41%)	14 (34%)	
	Remained in study (N = 49)	Withdrew from study (N = 21)	Statistic
Mean age	40.2 ± 15.0	36.1 ± 12.1	t = 1.106, p = 0.273
Sex:			
Female	30 (61%)	13 (62%)	$\chi^2 = 0.003, p = 0.957$
Male	19 (39%)	8 (38%)	

Table 2
Demographic and clinical characteristics of recruited participants

Characteristic	N
Ethnicity (N = 69):	
European	52 (75%)
Other/mixed	8 (12%)
East/South Asian	6 (9%)
African	3 (4%)
Reasons for admission (N = 51):	
Suicidal ideation/attempt	21 (41%)
Depression	14 (27%)
Unclear	6 (12%)
Other	6 (12%)
Mania/mixed	5 (10%)
Psychosis	3 (6%)
Pre-existing psychiatric diagnoses (N = 46):	
Depression	21 (46%)
Bipolar disorder	17 (37%)
Anxiety disorder	13 (28%)
Borderline personality disorder (BPD)	9 (20%)
Post-traumatic stress disorder	7 (15%)
None reported	5 (11%)
Schizophrenia	4 (9%)
Obsessive compulsive disorder	3 (7%)
Screens positive for BPD (N = 56) ^a	30 (54%)
Meets diagnostic criteria for BPD (N = 37) ^b	11 (30%)

^aAn average score greater than two (on a scale from zero to four) on the Borderline Symptom List 23.

^bBased on the Structured Clinical Interview for DSM-IV Axis II personality Disorders.

Factors affecting recruitment and retention

Tables 3 and 4 show the reasons provided for declining to participate in and withdrawing consent from the study, respectively. As shown in Table 3, “not interested” was the most common reason provided for non-participation (N = 24, 57%). When asked further about why they were not interested, the most common response was, “I do not have borderline”. One particular patient adamantly denied having any mental illness.

In addition, six individuals declined participation or withdrew because they found the interview process either too long or too emotionally exhausting. In particular, two participants found questions in the DART too triggering and thus asked to terminate the interview. Similarly, four individuals reported feeling too unwell to engage meaningfully in the study.

Another challenge encountered in the study was participants forgetting the date and time of their interview. There were also scheduling conflicts with other activities such as off-ward privileges, medical imaging, group sessions, or assessments with other healthcare providers. Every effort was made to reschedule the interview and to contact the participants again. However, at times the study personnel were unable to reach the participant on multiple occasions, and thus four patients were discharged before they could be seen. Among the nine participants who did not provide a reason for withdrawing consent, many of them had also failed to attend their scheduled interviews on multiple occasions prior to leaving the study.

Table 3:
Reasons for declining to participate in the study (N=42)

Reason for declining	N
“Not interested”	24 (57%)
Imminent discharge	11 (26%)
Already enrolled in study	3 (7%)
Too unwell to participate	2 (5%)
Interview process is too long	2 (5%)

Table 4
Reasons for withdrawing consent from the study (N = 21)

Reason for withdrawing	N
No reason provided	9 (43%)
Discharged from hospital	6 (29%)
Interview process too upsetting/ tiring	4 (19%)
Too unwell to continue	2 (10%)

Discussion

In our sample, 46% of psychiatric inpatients who were approached were recruited into the TOB study. On the other hand, a randomized controlled trial (RCT) of dialectical behavioural therapy on women with BPD in Netherlands reported a much higher recruitment rate of 70%. (15) In studies of other psychiatric illnesses, recruitment rates vary widely between 35% and 68%. (10, 13, 16) In terms of retention, 70% of the recruited participated remained in the TOB study. This is similar to findings from a meta-analysis of psychotherapy trials for BPD, which reported an overall retention rate of 71–75%. (17) Retention rates in trials involving other psychiatric illnesses tend to range between 40–75%. (10, 18)

Age and sex were not predictors of recruitment or retention. This is consistent with previous studies on and BPD that reported no significant association between retention and sociodemographic factors. (17) However, studies on psychotic disorders had found that younger patients are more likely to participate in research studies compared to older patients. (12, 13) In terms of clinical variables, a meta-analysis found that commitment to change, low impulsivity, and strong therapeutic relationship were predictive of retention among patients with BPD. (17) In studies of psychotic disorders, patients with higher illness severity, suicidality, longer length of hospitalization, and medical comorbidities were less likely to be approached about study participation (13) and more likely to decline participation when approached. (12)

Overall, “not interested” was the most common reason provided for declining to participate in the study. Although this is very broad explanation that can encompass many different reasons, it seemed to frequently stem from the stigma related to BPD. Potential participants frequently expressed discomfort about being associated with BPD, and were quick to emphasize that they do not have a diagnosis of BPD. This is consistent with previous findings that BPD is by far one of the most stigmatized psychiatric disorders, even within the mental health system itself. (6, 7) In fact, attitudes and behaviours of mental health workers towards BPD are even more negative than other illnesses such as schizophrenia and mood disorders. (19–21) Individuals with BPD are often perceived as “annoying” and “undeserving of sympathy” by the public. (6, 7) As a result, BPD patients experience greater levels of existential shame and self-stigma compared to those with other mental illnesses (22), and report significant discriminatory experiences. (23) Stigma is also a common barrier to participation in psychiatric studies in general. In a systematic review of this topic, Woodall et al. reported stigma and lack of acceptance of diagnosis as two of the most common barriers to research recruitment among patients with mental illness. (9) Similarly, disagreement with psychiatric diagnosis was the fourth most frequently cited barrier to recruitment, in a RCT of individuals with severe mental illness. (10)

Another potential reason behind the lack of interest in participation was that we were unable to provide participants with monetary or other forms of reimbursement for their time and effort. Similarly, the study process was quite long, and involved two hours of psychological interviewing and administration of several standardized questionnaires – a process that can feel intrusive and tiring for many patients.

In terms of study retention, there were some logistical challenges around scheduling. This issue is by no means specific to BPD or psychiatry, and is commonly encountered in all clinical trials. (9, 10, 24) In fact,

the inpatient setting often allows for easier scheduling and access to participants compared to outpatient clinics. Regardless, 29–72% of the participants withdrew from our study either directly or partially due to scheduling issues.

Another major factor in recruitment and retention was the well-being of the patients. Two patients were unable to participate meaningfully in the study due to the poor state of their physical or mental health. The fact that four participants withdrew consent because they found the study process too upsetting or tiring is perhaps unsurprising, given that the study involved lengthy interviews with highly personal questions. This may also reflect the fluctuating course of most mental illnesses. In fact, illness severity and fear of exacerbating illness were two of the largest themes that arose in the systematic review by Woodall et al. (9)

Having identified these challenges, throughout the TOB study we began to implement some strategies to improve recruitment and retention. To target the stigma surrounding BPD, best efforts were made to avoid the use of stigmatizing language in explaining the study to patients. As well, the need for controls in the study was emphasized; being part of the study did not necessarily mean that the participant had BPD, as the aim of the study was to explore BPD characteristics in a random sample of psychiatric inpatients. With regards to the scheduling challenges, the study investigators communicated more closely with inpatient unit staff to avoid any scheduling conflicts. Written and verbal reminders were also used. Lastly, to make the process less tiring for participants, we offered to perform the interview in multiple shorter segments. Participants were reminded that they could pause or leave the interview at any time.

As these strategies were gradually implemented over time and not in a structured manner, we were unable to determine their effects on recruitment and retention rates. Generally, it was felt that the strategies used to target stigma were not very effective. Although patients were reassured that participation in the study did not mean that they had BPD, patients still continued to express discomfort about being associated with BPD in any way. Considering the prevalent and deep-rooted nature of the stigma surrounding BPD, there is only so much that can be done in individual studies to address it. There is a need for more concerted, large-scale efforts to address the stigma surrounding BPD, such as public awareness campaigns and psychoeducation of diagnosed patients. (7)

A recent systematic review reported on various recruitment strategies used in psychiatric research such as: travel support; avoiding stigmatizing language; and better education about the purpose and nature of the investigation. (9) However, very few of these strategies have been formally evaluated and thus their relative efficacies are unclear. (9) For instance, simply not using the term “borderline personality disorder” may in fact add to the stigma in the long run, by avoiding the clinical term of a common and serious mental illness. On the other hand, in a more recent systematic review, Liu et al. found 11 studies on recruitment and two studies on retention strategies in mental health trials. (25) Recruitment by clinical research staff and non-web-based advertisements were found to be effective in improving recruitment, while the use of abridged questionnaires and regular reminders were helpful in retention. Financial incentives were effective in improving both. (25) Outside of psychiatry, stakeholders’ advisories,

personalized update letters, and educational materials have been reported as successful recruitment and retention strategies in clinical trials. (26, 27)

There are several limitations of the current study. Firstly, no data on recruitment rates were collected at the beginning of the study. We only began to collect this information after implementing several recruitment and retention strategies; thus, it's possible that recruitment and retention were even lower previously, and that the reported values are an underestimate of the study average. Secondly, the strategies were gradually implemented over time and thus their effects on recruitment and retention could not be evaluated. Thirdly, only brief descriptions were provided by participants regarding their reason for declining consent or withdrawing from the study. Fourth, limited data were available on individuals who declined to participate, making it challenging to examine clinical predictors of recruitment. Fifth, only patients who were deemed to be suitable candidates were approached by the recruiters, introducing sampling bias. The more severely ill and agitated patients were likely left out of the study, thus underestimating the true recruitment and retention rates in this population.

Conclusions

To the best of our knowledge, this feasibility study is the first to comment on factors affecting recruitment and retention in personality disorder research. We found that recruitment and retention rates were comparable to studies of other mental illnesses. Recruitment and retention were not associated with age or sex. Lack of interest, scheduling issues, and mental and physical well-being were the biggest barriers to participating and remaining in the study, consistent with findings from other psychiatric disorders. We hope that the findings of the current study will help ensure that future studies are better designed to address the barriers to BPD research participation.

The lessons learned from this feasibility study were applied to improve recruitment and retention in the TOB study. As mentioned previously, we were unable to determine the efficacy of these strategies in improving recruitment and retention rates. However, anecdotally it was felt the strategies were not very effective in addressing the deep-rooted stigmas surrounding BPD in a psychiatric population. In this regard, the objectives of the feasibility study were only partially met; while we were able to identify common barriers to recruitment and retention, we were unable to identify effective strategies for addressing them within our study context. The TOB study recruitment is still ongoing, and the findings from the main study will be presented and discussed elsewhere.

Going forward, qualitative studies would be beneficial in providing an in-depth look at the barriers and facilitators to participation in BPD research. In fact, systematic reviews of recruitment issues in psychiatric research did not identify any studies on personality disorders. (9, 25) Moreover, very few recruitment and retention strategies have been formally evaluated in psychiatric research, and none have been evaluated for personality disorders. Considering that personality disorders may be even more heavily stigmatized than other mental illnesses, it would be worthwhile to explore these issues in the context of personality disorders such as BPD. Lastly, studies have utilized clinical databases to compare

demographic and clinical characteristics between research participants and non-participants. (12, 13) Similar approaches could be used for BPD in the future. Doing so will help shed light on whether the current research on BPD is truly representative of the overall patient population, and identify potential strategies to improve external validity of BPD research going forward.

Abbreviations

BPD: borderline personality disorder. BSL-23: borderline symptom list 23. DART: diagnostic assessment research tool. RCT: randomized controlled trial. SCID: structured clinical interview for DSM-IV. TOB: transitional objects in borderline personality disorder.

Declarations

Ethics approval and consent to participate:

This study was approved by the Hamilton Integrated Research Ethics Board (reference number 3786).

Consent for publication:

Not applicable.

Availability of data and materials:

The datasets generated and analysed during the study are not publicly available to help protect the privacy of the participants. However, they may be available from the corresponding author on reasonable request.

Competing interests:

The authors declare that they have no competing interests.

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Authors' contributions:

HS and ZS designed the concept and methodology of the paper. AH, AA, SD, BP, and NS conducted participant recruitment. JW conducted data analysis and was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

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