

Studying the Relationship between Challenging Social Experiences and Engagement in Compassionate Acts among Individuals with Borderline Personality Disorder

We invite you to take part in a research study

- Before you decide, it is important for you to understand why we are conducting this research and what taking part will mean for you.
- We have provided this information for you to consider carefully before you make your decision.
- Taking part in this research study is voluntary.
- Please feel free to discuss it with others.
- If anything in this information sheet is unclear, or if you would like more information, please get in touch with a member of the research team.

Can I Take Part

We are looking for young adults aged 18-25 who have been diagnosed with Borderline Personality Disorder (BPD), Emotionally Unstable Personality Disorder (EUPD), or Personality Disorder (PD) with Borderline Pattern. This includes individuals who have received a formal diagnosis from a healthcare professional, as well as those who have a working or differential diagnosis of BPD or EUPD but have not yet been formally diagnosed. A working diagnosis means your healthcare professional thinks you might have a condition, but more monitoring or a referral to a specialist is needed to confirm it. A differential diagnosis is when other possible conditions are being considered alongside BPD, before being ruled out to better understand what's causing your symptoms. Your participation is valuable regardless of whether you have a received a formal diagnosis or not.

We aim to recruit 100 young adults to complete questionnaires and about 10 young adults to complete interviews. Your unique perspectives and lived experiences are essential in helping us understand how challenging social experiences affects compassionate behaviour in individuals with BPD or EUPD. By taking part, you will contribute to important research that seeks to improve support and interventions for individuals with this condition.

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If you would like to speak to someone about this research study, please contact Catrin (ces389@bham.ac.uk) or their primary academic supervisor, Dr. Jordan (g.jordan@bham.ac.uk), or the principle investigator, Prof. Broome (m.r.broome@bham.ac.uk)

Can I Take Part?

This research aims to understand how challenging social experiences impacts the ability of young adults diagnosed with Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD) to engage in acts of compassion. Compassion, which involves understanding and helping others in distress, is known to improve mental wellbeing. However, challenging social experiences, including stigma, social exclusion, emotional abuse, mindfulness, and quality of mental health care may create barriers for people with BPD/EUPD, potentially impacting how they engage with compassionate acts.

By exploring how challenging social experiences affects compassionate behaviour through interviews and surveys of young people with BPD/EUPD, the research hopes to provide valuable insights that could lead to better support and interventions for individuals with BPD/EUPD. Ultimately, the goal is to reduce social challenges and promote understanding of BPD/EUPD, helping to improve the lives of those affected by this condition.

What does Taking Part Involve?

If you choose to participate, you will be asked to complete questionnaires that explore topics such as stigma, exclusion, emotional abuse, mindfulness, and quality of care, BPD and compassionate acts. These questionnaires will provide valuable insights into your experiences and perspectives. Questionnaires will take around 1 hour 30mins - 1hour 45 mins in total, and do not have to be completed all at once.

Additionally, you will have the opportunity to participate in a one-on-one qualitative interview with the principal researcher. During this interview, which will last up to one and a half hours, you will be asked questions about your expectations and experiences related to social exclusion, stigma, emotional abuse, mindfulness, and quality of care, BPD, and compassionate acts. The interview can take place either in person at the University of Birmingham, in an accessible venue in the community, or over Zoom or Teams, depending on your preference. The 1:1 interview will also be audio-recorded and transcribed (put into a written format) to ensure accuracy, but your anonymity will be protected throughout.

After the interview, there will be dedicated time for you to debrief and discuss any concerns or questions you may have with a member of the research team.

Your participation in both the questionnaire and interview will greatly contribute to our understanding of how social challenges impacts compassionate behaviour in individuals with BPD.

Do I Have to Take Part?

No. Participation in this study is voluntary. If you do decide to take part, you will be asked to sign a consent form. If you give consent to take part, you will still be free to withdraw from this research study at any time without needing to give a reason, however data collected up until this point will be kept by the study team and may be used anonymously in the study. To withdraw from the study please contact the study team.

What are the Possible Benefits of Taking Part?

By participating in this research, you will play a vital role in advancing our understanding of how challenging social experiences affects individuals with BPD/EUPD. Your insights and experiences will contribute directly to efforts aimed at improving support and interventions for individuals with these conditions.

Additionally, your involvement in this research has the potential to influence healthcare policies and practices, leading to better outcomes for the BPD community. By sharing your perspectives, you can help shape future initiatives that aim to reduce stigma and promote greater understanding of BPD.

What are the Possible Risks of Taking Part?

There are some risks involved in taking part in this research. It is possible that sharing accounts of your lived experience or related topics may cause distress. Should you experience distress because of your participation in this study, you may speak with any member of the research team. If you become emotional or distressed during the interview, it can be paused at any time for you to take a break and resume when you feel like you can continue. The interview can also be stopped all together if you do not wish to continue at any point.

You will also receive an information sheet with contact information for relevant support services, in the event that you feel you need additional support. Should it be identified during the study that you are at risk of harm to yourself or others, local safeguarding procedures will be followed and confidentiality may be breached in order to inform a member of your direct healthcare team.

Will I be Reimbursed for my Time?

If you complete the questionnaires, you will be entered into a draw to receive one of 10 £25 vouchers, while participating in an interview grants you a £50 voucher. Travel costs for interviews held at the university can be covered.

What if something goes wrong?

If you have any concerns about the study you can speak to a member of the research team in the first instance, contact details are available within this information sheet. If you wish to make a complaint about how your information has been handled you can do so by contacting the University of Birmingham's Data Protection Officer via dataprotection@contacts.bham.ac.uk

Who Is Organising, Insuring & Funding the Research?

This research project is being conducted as part of a PhD study funded by the Hilary Green Studentship at the Institute for Mental Health, in the School of Psychology at the University of Birmingham.

The University of Birmingham, as the sponsor of this study, provides oversight and support for the research activities. The PhD student leading the research is supervised by experienced researchers from the University of Birmingham, who provide guidance and support throughout the study.

The University of Birmingham has in place Clinical Trials indemnity coverage for this trial which provides cover to the University for harm which comes about through the University's, or its staff's, negligence in relation to the design or management of the trial and may alternatively, and at the University's discretion provide cover for non-negligent harm to participants.

Who Has Reviewed the Study?

The North of Scotland (2) Research Ethics Committee has reviewed this study. University Study Number: ERN_2169-Feb2024 & The NHS Ethics Procedure, IRAS Number: 343478

How will my Information be Kept Secure?

The University of Birmingham is the sponsor for this study, and is responsible for looking after your information. All information collected for this study will adhere to the General Data Protection Regulation and Data Protection Act 2018. Personal data will be securely stored electronically on the University of Birmingham's encrypted network, accessible only through password-protected university computers. Paper copies of study documents will be kept in a locked filing cabinet within a secured room at the University of Birmingham, accessible solely to authorised research personnel.

To safeguard your privacy, any data that could identify you will be removed and replaced with a unique code. The research team will maintain a separate code key to link the data to you. Additionally, audio recordings will be promptly erased once transcripts are generated. During interviews, any personally identifying information will be removed from transcripts, and pseudonyms chosen by participants will be used instead of real names.

Demographic information (e.g., age, sex, ethnicity) will be summarised for the entire group to prevent individual identification. Data will be securely retained electronically for 10 years.

How will We Use Information About You?

We will need to use information from you and your Forward Thinking Birmingham healthcare professional for this research project.

This information will include:

- Your name
- Your contact details
- Your gender
- Your age
- Your ethnicity
- Your employment/education status
- Whether you have sought help for your mental health in the past
- Whether you are currently receiving support for your mental health
- Whether you have been given [a] mental health diagnosis/diagnoses
- Your mental health diagnosis/diagnoses

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

What are My Choices About How My Information is Used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

International Transfers

Your data will not be shared outside the UK

Where Can I Find Out More About How My Information is Used?

You can find out more about how we use your information by:

- asking one of the research team
- emailing the University of Birmingham's Data Protection Officer: dataprotection@contacts.bham.ac.uk
- contacting one of the research team, at m.r.broome@bham.ac.uk, or g.jordan@bham.ac.uk, or s.l.griffiths@bham.ac.uk, or ces389@bham.ac.uk

What Happens if New Information becomes Available?

If any new information becomes available which might affect your participation in this study, a member of the research team will discuss this with you.

What Happens at the End of the Study?

You will have contributed valuable insights and perspectives that will help advance understanding and support for individuals with Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD). Your participation will directly contribute to efforts aimed at improving healthcare policies, interventions, and societal attitudes towards mental health, benefiting the BPD community as a whole. Anonymised data may be shared for future ethically approved research.

Where can I get More Information?

If you would like to speak to someone about this research study, please contact Catrin Street-Mattox – ces389@bham.ac.uk, their academic supervisor Dr. Gerald Jordan – g.jordan@bham.ac.uk, or Matthew Broome, the Chief Investigator – m.r.broome@bham.ac.uk

Thank you for taking the time to read this information sheet
