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Not Just Right Experiences in OCD and Autism

Participant Information Sheet

Central University Research Ethics Committee Reference: [MS IDREC 2639137]

1. Introduction

My name is Clara Lee, and I am a Trainee Clinical Psychologist at the University of Oxford, working alongside Dr Sam French and Dr Eloise Stark, Clinical Psychologists. This information sheet provides information about our study exploring OCD and autism, to help you decide if you would like to take part.

Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve. Please take time to read this information sheet, and to discuss it with others if you wish to. If there is anything that is not clear, or if you have questions and would like more information, please email me on clara.lee@hmc.ox.ac.uk.

2. Why is this research being conducted?

For this study, we are interested in Obsessive Compulsive Disorder (OCD) and autism. OCD is a common mental health condition in which a person experiences obsessions (recurrent and persistent thoughts, urges, images, and doubts) and/or compulsions (repetitive behaviours or mental acts). OCD is often related to avoiding harm: people may carry out compulsions to prevent perceived harm being experienced by themselves or others.

However, not all compulsions are driven by fear of harm. Some are motivated by an urge to correct a feeling that something does not feel quite right or complete. These experiences are described as feelings of incompleteness, or 'Not Just Right Experiences' (NJREs). NJREs are typically associated with a feeling of discomfort or tension, rather than anxiety. They can arise through different sensory experiences, such as touch, sight, or sound.

NJREs can take many forms. One common example involves a need for symmetry or a sense that things should feel 'even'. For instance, if something touches a person's left arm, they may feel the urge to touch their right arm as well to 'even up'.

Autistic people often experience OCD, and it is suggested that NJREs could help us understand this overlap. This study therefore aims to explore how NJREs vary across autistic and allistic (not autistic) individuals, both with and without OCD.

Each member of this research team is autistic, and two of us have personal experience of OCD (including NJREs). We have used our personal experience to inform the development of this study.

3. Who can take part in this study?

We are looking for adults, 18 years and above, who fit into one of these four groups:
1. Identify as autistic and as having OCD
2. Identify as autistic and do not have OCD
3. Do not identify as autistic and have OCD
4. Do not identify as autistic and do not have OCD

4. Do I have to take part?

No, taking part is entirely voluntary. If you would like to ask any questions about the research before deciding whether to take part, you can email Clara Lee (clara.lee@hmc.ox.ac.uk) or Dr Sam French (sam.french@psy.ox.ac.uk).

If you choose to begin the study, you may stop at any point before submitting your responses. Stopping the study early will have no negative consequences and you do not need to give a reason. If you begin the study but do not submit your responses within 2 weeks, we will assume you have chosen to withdraw, and we will delete any data collected.

Because all data collected is anonymous, we will be unable to withdraw your data once you have completed the study.

5. What will happen if I take part in the research?

This research takes place entirely online. If you decide to take part, you will first be asked to provide your consent by ticking a box to confirm that you have read this information and agree to participate.

Next, you will answer some questions to help us determine whether you fit into one of the study groups. For example, we will ask whether you identify as autistic or as having OCD (you do not need a formal diagnosis of either). You will also be asked some general questions about yourself, including your age, level of education, gender identity, and whether this differs from the sex you were assigned at birth. We are collecting this information to help us better understand the diversity of participants taking part in the study and whether demographic differences may relate to the study findings.

After this, you will complete two questionnaires that help us check your eligibility for the study. The questionnaires are the Obsessive Compulsive Inventory Revised (OCI-R) and the Comprehensive Autistic Trait Inventory (CATI). If you are not eligible, this does not mean that you are not autistic or do not have OCD — it simply means that your experiences do not match the specific criteria we need for this study.

If you meet the eligibility criteria, you will then be asked to complete further questionnaires about your experiences, including aspects of mental health and sensory processing. If you are in the group for autistic individuals with OCD then you will also be asked two questions about your experience of NJREs that you will answer as free text.

The entire process should take approximately 30-45 minutes to complete. If you leave the survey before completing it, you will be able to return to it using the same link within one month from beginning the survey.

6. What are the possible disadvantages and risks in taking part?

All questionnaires are measures that are commonly used in psychological research. At times, some of the questions may feel difficult to think about and it is possible that you might find answering some questions upsetting. You can take a break from the study and return to it later or withdraw from the study completely at any point before submitting your responses. At the beginning and end of the study, you will be provided with contact details of services and third-party organisations that will be able to offer you further support and guidance if needed.

7. Are there any benefits in taking part?

We hope that your participation in this will help us understand experiences of NJREs in relation to OCD and autism. This might then contribute to the development and improvement of psychological support. However, there will be no direct or personal benefit to you from taking part in this research.

8. What information will be collected?

The information you provide during the study is the research data. This study is completely anonymous; we will not collect your name, email address, telephone number or IP address.

Research data obtained from questionnaires, such as responses regarding your mental health, will be stored securely by the University of Oxford for 3 years after publication or public release of the research results. This information will then be permanently deleted and destroyed from University storage.

The research team involved in this study will have access to the research data. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research. Using the research data, we hope to report our findings in academic journals and present them to relevant charities, and to other health professionals at conferences. The findings will also contribute to my doctoral research thesis. You will not be identified or identifiable in any reports or publications arising from the study.

9. Will the research be published?

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives researchers easy access to the full text of freely available theses, thereby increasing the likely impact and use of that research.

The research will be written up as part of my Doctorate in Clinical Psychology. On successful submission of the thesis, it will be deposited both online and in print in the University archives to facilitate its use in future research. The thesis will be openly accessible, and the research is also likely to be written up for publication in a peer-reviewed scientific journal. The research team also aims to disseminate findings to UK charities involved in supporting autistic people and/or those with OCD. You will not be identified or identifiable in any reports or publications arising from the study.

10. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University's Information Compliance website at https://compliance.admin.ox.ac.uk/individual-rights. This study uses Qualtrics to collect survey responses. Qualtrics has been approved for use by the University of Oxford's Information Security team. Data collected through Qualtrics may be transferred to or stored on servers located outside of the UK or EU. Any data collected will be handled securely and in accordance with University of Oxford data protection policies.

11. Who has reviewed this research?

This study has received favourable opinion through a subcommittee of the University of Oxford Central University Research Ethics Committee (Reference number: MS IDREC 2639137). Additionally, 3 experts by experience have reviewed the study materials and provided feedback.

12. Who do I contact if I have a concern about the research or I wish to complain?

Every care has been taken to ensure your safety during the course of this study. If you have a concern about any aspect of this study, please contact Clara Lee (clara.lee@hmc.ox.ac.uk) or Dr Sam French (sam.french@psy.ox.ac.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with.

If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on +44 (0)1865 616480.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Clara Lee
Trainee Clinical Psychologist
University of Oxford
Institute of Clinical Psychology Training and Research
Email: clara.lee@hmc.ox.ac.uk

You can also speak to the supervisor of the project about any questions or concerns using the details below:

Dr Sam French
Clinical Psychologist
University of Oxford
Institute of Clinical Psychology Training and Research
Email: sam.french@psy.ox.ac.uk

Address: Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
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