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Investigating the Experience of Severe and Enduring Anorexia Nervosa

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

This is an invitation to participate in a study by researchers at the University of Sydney. The purpose of the research is to investigate the experience of Severe and Enduring Anorexia Nervosa. The study will use a narrative inquiry approach with the method, Photovoice, in order to facilitate the collection of data.

(2) Who is running the study?

This study is being conducted by Catherine Broomfield, Associate Professor Paul Rhodes and Professor Stephen Touyz from the School of Psychology at the University of Sydney. This research is contributing towards the dissertation of the Doctor of Philosophy at the University of Sydney for the researcher, Catherine Broomfield.

(3) What does the study involve?

If you choose to participate, you will be asked for permission to measure your height and weight, as well as a series of demographic questions asked. You will be asked to photograph 10 pictures that relate to your experience with Severe and Enduring Anorexia Nervosa, and send these images to the primary researcher. Photographs may be taken either with your personal camera phone (please turn off geo-tagging for the purposes of increasing privacy and confidentiality), or a disposable camera provided by the researcher, which will need to be returned one week prior to the interview. You will be asked to keep journal entries for each image to record (1) what was in the photo, (2) what the photo meant, and (3) why the photo was taken, in order to facilitate the interview. A semi-structured interview will take place one week after the images are sent, which will take around two hours to complete. Member checking, which allows participants the opportunity to check the narrative created from the initial interview, will also take place, and believed to take one hour per session.

(4) How much of my time will the study take?

The time taken to capture images is personal and can take as long as the individual would like as it is done by the participant in their own time. The initial interview will take no more than two hours, and then any additional interview will only take up to one hour.

(5) Who can participate in this study?

The following criteria needs to be met in order to participate: (a) Age of 18 years and older, (b) Meet the DSM-V criteria for Anorexia Nervosa, and (c) Have experienced Anorexia Nervosa for a period of 7 years or more.

(6) Can I withdraw from the study?

Your involvement in the study is voluntary and you may withdraw your participation from the study at any time up until the data is published. There are no penalties for withdrawing from this study.

(7) Are there any risks or costs associated with being in the study?

Although there are no known risks for participating, discussion surrounding an eating disorder can be distressing for some people. In order to ensure participants are protected, you are free to skip any questions that you do not want to answer with the interview excluding any topics that you do not wish to discuss. If distress is experienced at anytime during the research, you will be referred onto the University of Sydney Counselling and Psychological services, as well as provided the Butterfly National Helpline details. You will not be identified through this study, as a pseudonym will be provided for each participant. Participation in this study will not cost you anything.

(8) Are there any benefits associated with being in the study?

Other research adopting the current study's method of photovoice, has reported a potential benefit for participants is the sense of power that can be felt through the telling of their story. This can help with the processing of the experience and has been reported to facilitate closure for the individual. This is a potential benefit from participating in the current study.

(9) What will happen to information about me that is collected during the study?

All aspects of the study, including results, will be strictly confidential as a pseudonym will be provided for each participant and only the researchers will have access to information on participants. A report of the study may be submitted for publication and a conference presentation, along with the results used towards the dissertation of the researcher, Catherine Broomfield. Individual participants, however, will not be identifiable in such a report given each participant will be provided with a pseudonym.

(10) Can I tell other people about the study?

Yes, you may tell others about the study and if they are interested in participating, please feel free to pass on the contact details of the primary researcher, Paul Rhodes, by email, p.rhodes@sydney.edu.au

(11) What if I require further information about the study or my involvement in it?

If you have any questions about the research, or would like a copy of the final paper, please contact Associate Professor Paul Rhodes, (email: p.rhodes@sydney.edu.au).

(12) What if I have a complaint or any concerns?

If you have any concerns or complaints about the research, please contact the Secretary of the University of Sydney Human Ethics Office at the Margaret Telfer Building (K07), University of Sydney, NSW 2006 on +61 29036 9161 (email: human.ethics@sydney.edu.au).

This information sheet is for you to keep