Illness narratives of young women: Impact of Inflammatory Bowel Disease on the Relationships, Intimacy and Sexuality

Participant Information Leaflet

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You are being invited to take part in a research study undertaken as part of a PhD project supervised by Professor Debra Jackson and Dr Helen Aveyard, and conducted by Simona Fourie. Before you decide whether or not to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. If you have any questions or would like further information about the study, please contact the researcher Simona Fourie via email 16009995@brookes.ac.uk or phone (07923081660).

What is the purpose of the study?

Inflammatory Bowel Disease affects the lives of those who have the condition in many ways. The existing evidence suggests that the symptoms have a great impact on peoples’ lives as they struggle with fatigue, abdominal pain and medication side effects whether they have a flare or not.

There are many studies that looked at treatment options or at what may cause the illness, but we know little about how people with the condition deal with their daily life. Nursing is a profession that aims to give holistic care to all patients, but for that a good knowledge on how peoples’ lives are affected by the illness, and what is important for those who are affected by IBD is needed.

There are studies that looked at how adults experience living with IBD but we’ve found very little evidence on how young adults aged 16-24 experience living with the condition. Adolescents and young adults with chronic conditions have a challenging time transitioning to adult life. You must make complex decisions about your health care with less involvement from your parents. At this time building relationships is very important. It is also the time when adolescents or young adults become romantically involved and intimacy and sexuality are important aspects of your life. But for young people with IBD this can be a challenging time as you could experience body image issues or difficulties in disclosing your condition. We are carrying out this study because we do not know how IBD is affecting the lives of young women, especially their relationships, intimacy and sexuality.

We would like to find out from those affected by IBD either face to face, or via Google Forms or instant messaging (WhatsApp). We would like to hear stories of how it is to live with this illness and what their experiences are. We are interested in this instance only in female participants.
This study will give us a better understanding of how the illness is affecting the relationships, intimacy and sexuality of young women with IBD. By gaining this knowledge we could help develop care pathways that are specifically designed with the patients in mind that include aspects of sexual health that are important to young women with IBD.

Why have I been invited to participate?

You have been invited to participate as you are a 16 to 24-year-old, female, have been diagnosed with IBD at least 18 months ago and have responded to our study advert on the Crohn’s and Colitis UK website.

What will happen to me if I take part?

You will have time to consider this participant information sheet and you are invited to contact the researchers should you have any questions.

If you decide to take part in the study you will be invited to write a detailed account (your story) on how your condition has affected your relationships, intimacy and sexuality (if applicable). A few details about you will be also required, such as the age you were diagnosed and if you have Crohn’s or Ulcerative colitis. You can do this at a time and place that is convenient to you. If you prefer to have a discussion with the researcher via WhatsApp you will need to send a text to agree with the researcher on a time that is convenient as the discussion may last for approximately one hour. If you choose to use WhatsApp we recommend you create an account that will not allow your identity to be seen by the researcher.

If you submit your story to the researcher via Google forms or request an interview with the researcher via WhatsApp we will consider this as implied consent.

What are the possible benefits of taking part?

There are no direct benefits of taking part in our study, however although there is evidence to suggest that people who openly discuss certain aspects of their life after being diagnosed with a chronic condition feel that the discussion can be therapeutic. However, interviewing during the study should not be seen as a substitute for counselling.

What are the possible disadvantages to take part?

You may feel distressed when talking about sensitive issues and how illness is affecting you. If you feel distressed or you may want to get further information about IBD and the charity, call Crohn’s and Colitis UK (CCUK) Helpline on 0300 222 5700. For emotional support the Support Line is available on 0121 737 9931. A list of external support groups can be found at the end of this leaflet. Also, there is a risk of others accessing your phone or PC and reading your story. We strongly recommend that you take all the necessary steps to ensure that your phone is well protected (access pin or 2 factor identification for Apple phones) and chats are deleted immediately to avoid any potential disclosure of sensitive information to those who may access your phone/PC. For those who wish to use WhatsApp we recommend
Will what I say in this study be kept confidential?

Your privacy will be kept at all times, during the study duration and after. Your personal details (email address) will not be visible to the researcher if you complete a Google Form. The contents of the forms or the instant chat will be kept strictly confidential, subject to legal limits. If you have not taken measures to use the WhatsApp version without your real phone number, this, alongside with your name, can be visible to the researcher. Although the chances of being identifiable to the researcher are very small, this would not be considered a fully anonymous interview. The data however will be kept strictly confidential.

Only the research team members will have access to the data. The forms will be stored in Google Drive, for which the University has a security agreement. Any data submitted via Google Forms or social media cannot be withdrawn. Paper documents (anonymised printout of WhatsApp chats) will be securely stored at Oxford Institute Nursing, Midwifery and Allied Health Research offices, in filing cabinets that are kept locked. Responsible members of the University may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Research data will be kept securely at all times, especially before being transferred back to Oxford Brookes University. An IPhone used strictly for the study purposes (WhatsApp) will be encrypted and 2 factor authentication will be enabled. Data generated by the study must be retained in accordance with the University's policy on Academic Integrity. Data generated in the course of the research must be kept securely in paper or electronic form for a period of ten years after the completion of a research project.

We may use quotes from your stories with your permission, but any publication as a result of this study will not make it possible for you to be identified.

What should I do if I want to take part?

If you wish to take part in this study please follow the link https://goo.gl/forms/TmITFYg9UsSypIKO2 to write your story on a Google Form. This will protect your anonymity and the form will be kept securely on Google Drive. Although you are required to log into Google, your email will not be visible to the researcher. If you prefer WhatsApp please send a message to the number 07923081660 and a suitable time to chat will be agreed. This contact number will be only used for the purpose of this study.

What will happen to the results of the research study?

The results from the study will be used for a PhD thesis with the aim to be published as journal articles or presented at conferences. The results will help in gaining a better understanding of the concerns and needs of young women with IBD. If you
wish to acquire a summary of the final results, please contact the researcher directly via email from July 2020.

Who is organising and funding the research?

The study is conducted as part of a student research project from OXINMAHR, Health and Social Sciences Faculty, Oxford Brookes University.

Who has reviewed the study?

The research has been approved by the Faculty of Health and Life Sciences Research Ethics Committee, Oxford Brookes University.

Contact for Further Information

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If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee on frec@brookes.ac.uk.

Thank you for taking the time to read this leaflet.

Organisations providing information and support

If you need further support for your emotional needs, you have unmet needs in your care or safeguarding issues, please find a list of external organisations available to offer information and help.

1. **Crohn’s and Colitis UK** offers information about IBD and charity on Helpline 0300 222 5700.
   - **Information Service** [https://www.crohnsandcolitis.org.uk/support/information-service](https://www.crohnsandcolitis.org.uk/support/information-service).
   - **CCUK Support line** is available for emotional support on 0121 737 9931. [https://www.crohnsandcolitis.org.uk/support/emotional-support](https://www.crohnsandcolitis.org.uk/support/emotional-support)
2. **Women's aid** - offer support for those who suffered domestic abuse
   

3. **Relate** offers counselling and psychosexual therapy to anyone who seeks help. Search for your local centre on [www.relate.org.uk](http://www.relate.org.uk)

4. **The Bladder and Bowel UK** is a National Confidential helpline managed by a team of Specialist Nurses and Continence Product Information staff, who can be contacted for advice on specialist services, product information and general advice on continence promotion on (0161 607 8219) or via email bladderandboweluk@disabledliving.co.uk