

LAY SUMMARY

Food is a very important part of people's lives. It can be a source of pleasure (eating tasty food), a method of coping (treating yourself after a difficult time), and it can communicate belonging to particular groups (eating foods from a particular country) and our relationships with family and friends (cooking for loved ones). Eating and drinking are also a means of social interaction (having a takeaway with friends, going for dinner on a date) and peer acceptance (going to the pub with friends).

These important psychosocial meanings and impacts of food may be dramatically altered in people with inflammatory bowel disease (IBD). For example, eating can result in painful or embarrassing symptoms, being undernourished can limit people's activities and diet can also be used to treat IBD. A report by NACC, and our own research, has found that many people with IBD experience problems with food and nutrition, such as impaired social activities and problems with eating "trigger foods". Unfortunately, this very important issue is rarely discussed during people's consultation with their doctor or other healthcare professional.

The major issues are that we do not know in detail about the meaning and impact of food in the lives of people with IBD, and we do not have a way of measuring it. If we were able to measure food-related quality of life, then this could be done during clinical consultations or as part of future research studies. Therefore, this research will investigate the psychosocial impacts of food in the lives of people with IBD, then develop an accurate way of measuring food-related quality of life and increase awareness of this issue among health professionals, in order that they can provide improved support for people with IBD.

Firstly, we will undertake in-depth interviews with 30-40 people with IBD regarding the meaning and impact of food in their lives. The range of people will be chosen so that they have many diverse features that are likely to influence psychosocial aspects of food. The interviews will be recorded and then analysed using standard qualitative methods. This will enable the description of the meanings and impacts of food in the lives of people with IBD. The results will be published in a journal for health professionals to read.

Secondly, based upon the themes that emerge from the interviews, we will design a questionnaire that measures food-related quality of life (QoL). This will be refined with the involvement of people with IBD to check that it is clear and relevant. We will then test whether the questionnaire is accurate (valid) at measuring food-related QoL by conducting a survey. In total, 300 people with IBD from a wide range of hospitals will be asked to complete the questionnaire. The questionnaire results will be compared between different groups of people to see if it is accurate at detecting differences between them (for example by comparing results from those with IBD and healthy controls). We will also test how consistent (reliable) the results are by asking 100 volunteers to complete the questionnaire again after 7-days. The results will be analysed to assess whether the questionnaire is accurate (valid) and consistent (reliable). The results will be published in a journal for health professionals to read.

For both studies, volunteers will be given as much time as they like to consider whether or not to take part, and they will provide written informed consent.

Finally, we will organise a workshop for a large number and wide range of health professionals where we will focus on the importance of food-related life in people with IBD. We will lecture on the findings of our research and hold workshop sessions for health professionals to discuss this. We will also develop a website where health professionals can access information on this issue, in order to encourage them to consider food related life during clinical consultations and during research.

People with IBD have been included in all stages of this research, from the initial ideas, to collecting the data and presenting the findings. This body of research will enable the design of future studies that aim to improve food-related QoL in people with IBD.