

Caption: Qualitative Supplementary Material

This supplementary material contains additional results from the qualitative interviews with patients suffering from late gastrointestinal symptoms of pelvic radiotherapy. These results help to demonstrate the impact these symptoms have on patients everyday life.

Participants welcomed the use of colloquial language in the screening tool. The word “poo” was suggested as an alternative to the phrase “controlling your bowels” in question one as this may be easier for others to understand (Participant 8). Ten participants discussed the difficulties they had controlling their bowels and the fear of having an accident in public. One participant felt that their fear of having an accident in public was holding them back from partaking in their usual activities and hobbies.

“I am afraid. If you are going out then I’ll have an accident when I am out and it would be so embarrassing like. Um and that’s what I feel like. It is holding me back like you know.”
(Participant 3)

The negative impact of the symptoms on participants’ lifestyles aided their recollection of relevant experiences. Diarrhoea was a common symptom that many of the participants spoke about during the interviews. Some participants experienced daily fluctuations in the number of bowel motions they passed. On days when symptoms were at their worst, one participant was unable to leave the house.

“It’s sporadic in the sense that some days you feel that you are just, it’s just normal and other days you feel like you are pooing for, you know Wales, so to speak.” (Participant 5)

Question two of the screening tool asked participants to consider whether they had experienced any rectal bleeding. On enquiry it emerged that there were variations in when participants would answer ‘yes’ to this question; a number of participants explained that they may not seek medical advice if they noted rectal bleeding. One participant, who attributed their rectal bleeding to haemorrhoids, did not believe their symptoms warranted medical advice. However, another participant explained that they would be concerned if they noticed blood in the stool itself rather than on the toilet paper.

Variations emerged in how participants defined ‘bleeding from your bottom’. A participant suggested clarifying that any amount or frequency of bleeding should prompt a ‘yes’ answer to the screening tool question. A rephrasing suggestion, from Participant 9, attempted to clarify to future respondents that they should answer ‘yes’ to question two if they had ever experienced any rectal bleeding.

Question three asks patients to consider whether they have had to adapt their lifestyle due to any bowel symptoms they experience and lists a number of lifestyle adaptations. Three participants were not aware that a radar key could be purchased to allow them access to locked disabled toilets around the UK. In addition, a number of participants did not think it relevant to ask patients if their caring duties are affected by bowel symptoms in the screening tool. The list of examples in the question helped participants recall any possible adaptations they had made. One participant described forming a fixation on locating the nearest toilet on trips out. The participant felt that this held them back from partaking in the hobbies they normally enjoy.

“It pulls you back from doing lots of things that you would normally rush out. It might be that you develop a bit of a phobia about toileting and the necessity of finding one and all the rest of it.” (Participant 5)

Two participants suggested changing the word ‘adapt’ as used in question three of the screening tool. One participant explained that the word adapt to them had negative connotations. The participant believed that patients may have made healthier lifestyle choices following their cancer diagnosis and radiotherapy treatment.

The term ‘social functioning’ in question four, was interpreted by participants as a technical term that may not be understood by all patients. A number of participants were able to offer rephrasing suggestions. The following participant proposed including whether the bowel symptoms impacted on any aspects of their daily life.

“Do your bowels and tummy problems affect your mood, social life and relationships or any aspects of your day to day life?” (Participant 9)

Mood was an important theme in the interviews with participants describing the emotional impact of their bowel symptoms. The interviews highlighted that even with a positive outlook

on life, the symptoms caused many to feel depressed as it restricted their ability to perform the activities they wished to do. In addition, many participants felt isolated as they felt unable to go out with friends who would normally provide emotional support.

Discussing these sensitive issues could cause some patients to become distressed. In order to gauge whether the screening tool was acceptable for patients, participants were asked whether they thought the ALERT-B screening tool could be upsetting and whether any potential distress was justifiable. Participant 8 believed that many patients would have a low mood especially upon commencement of treatment. However, the participant felt that it would still be valid to ask patients about their mood.

Overall, all participants found the tool straightforward and easy to use with no reported problems. A couple of participants stated they preferred answering a succinct screening tool; other questionnaires and screening tools that the participants have completed in the past were deemed to be quite lengthy and are therefore not always convenient to use in routine clinical practice.

Participants described their own experiences of challenging clinical consultations and hoped that this tool would help raise awareness for late gastrointestinal symptoms among healthcare professionals and patients. One participant felt frustrated that their symptoms were not taken seriously by one healthcare professional and that their expectations for the clinical consultation were not met.