

# Focus on bowel and bladder-control anxiety

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Most people can remember a time when they have been desperate to use the toilet and found one just in the nick of time. But imagine having this experience routinely, every time you went out. This kind of experience can create a tendency to experience unhelpful thoughts like "I need to get out of here or I will wet myself" and a general preoccupation with being incontinent. This is what happens to people who have bowel and/or bladder-control anxiety (BBCA). Their worst fear is that they will be incontinent in a public place.

BBCA is an understudied and largely unrecognised area in anxiety disorder research. It is not an official diagnosis but contains elements of panic, agoraphobia and social anxiety disorder. We started a series of studies on this problem because our clinical experience suggested that BBCA was actually not at all uncommon and we were frustrated to find that very little had been written about it. Although our research is continuing, we will outline some of our preliminary findings below. Our discussion is only about adults with BBCA. We know much less about children and adolescents who struggle with this problem.

## What is bowel and bladder-control anxiety?

People with BBCA often experience anxiety sensations most intensely in their gut or bladder (the viscera). As their anxiety intensifies, so do these visceral sensations and the possibility of having an 'accident' begins to feel very real. As a result, they tend to avoid situations where they might become anxious and therefore unintentionally feed a vicious cycle of anxiety and avoidance.

In addition to avoiding anxiety-provoking situations, people with BBCA tend to avoid unfamiliar places, or places where it might be difficult to find a toilet. They also avoid certain foods (e.g. spices) and may restrict the amount they eat and drink. One participant in our research study told us that she often restricted fluid intake for days in the belief that this would make it less likely she would have an accident. These kinds of behaviours can have their own negative (and potentially serious) health effects. Other symptoms of BBCA include checking the

environment for safety signs (e.g. exits or the locations of toilets) as well as checking the 'inside environment' (i.e. the body) for signs of anxiety, especially bowel/bladder sensations. People with BBCA will also use the toilet multiple times before going out to ensure they are completely 'empty.' This can become part of a 'preparation ritual' for people who live with BBCA and who need to work or go to school or college.

## How common is it?

Anxiety UK takes many calls relating to various aspects of toilet-related anxiety, which includes a fear of being incontinent in public. Anecdotally, NHS mental health practitioners have also noticed bowel and bladder-control anxiety amongst many clients. Despite this we still do not know how common BBCA is. Some previous research has estimated that 10% of people in an anxiety clinic were mainly concerned about losing bowel control.

The uncertainty about prevalence of BBCA is partly explained by its complexity. It is sometimes difficult to disentangle symptoms of BBCA from physical health problems such as irritable bowel disorder (IBS). It is likely that some people with bowel control anxiety will have an associated medical condition, like IBS, which means they may often need to use the toilet urgently but will also have a number of other symptoms, such as pain or discomfort and bloating. For others, BBCA may be mostly based on unrealistic and 'catastrophic' thoughts about the consequence of being incontinent in public, and possibly because they have a particularly sensitive visceral system. We clearly still have a lot to learn about how psychological processes and bodily reactions interact to produce symptoms of BBCA.

## Current research on BBCA

One of the first detailed studies of bowel and bladder-control anxiety was published this year, by our team at University College London.

This preliminary study of 140 people with BBCA anxiety found that there was an equal split between people who mainly had concerns about bowel control

(~40%) and bladder control (~40%), with a smaller proportion having concerns about both (20%). Fifty percent had actually had at least one episode of incontinence in public 'since school age,' so it may be that people begin to believe that a future occurrence of being incontinent in public is more likely.

BBCA fears tended to develop in people in their mid to late 20s and the majority of sufferers (75%) were women. A majority of the respondents also reported experiencing panic attacks (78%). One particularly striking finding from our research was the tendency of people to believe that being incontinent in public was very shameful and disgusting. They believed that other people would be unforgiving and unwilling to help them. While it may be natural to associate body waste with disgust, and losing control with shame, it was the level of shame and disgust that was noticeable. Many people indicated that being incontinent in public was the most shameful thing that could happen to someone; that it made them a disgusting person.

## What treatment approaches are available for BBCA?

Because many people who have BBCA also have panic attacks, it has been suggested that they should be treated in the same way as people with panic disorder (i.e. with Cognitive Behavioural Therapy). We think this is an excellent starting point because the 'catastrophic' beliefs about being incontinent in public are often unrealistic even though they are very believable in the midst of a panic attack. Our experience suggests that patients often respond well to this type of treatment. For other patients who have high levels of shame and beliefs about self-disgust, additional techniques might also be useful. We also need to be aware that some people will naturally have more sensitive bowels or bladder. The development of a fully integrated treatment for BBCA awaits a more complete understanding of the condition. We hope that our studies will provide the basis for future research to develop more effective treatment for a set of symptoms that has been neglected for too long.