



Alex Scott answers your questions on his talk 'Adapting Cognitive Behavioural Therapy for Insomnia for People with IBD'

Alex, how can I get involved with your project? It's been a BIG aspect of my life with IBD and I would love to be able to help with this in any way possible.

This research is in the early stages, so we are just seeking feedback from the IBD community and planning how we can answer the questions people want. However, when we are ready to recruit, we will make sure to ask C&CUK to help so that we can reach as many people as possible.

Due to personal experience, I now know that discussion about sleep would have been helpful to diagnosing a physical problem affecting sleep that was due to IBS/IBD problems. So, what about the role of sleep analysis in diagnosis?

To my knowledge, there have been no studies looking at sleep as a factor in diagnosis of IBD, but it's certainly an interesting point you raise. Sleep has been shown to be a useful predictor of some mental health diagnoses like depression, but I am not aware of it being used in IBD. We do have some preliminary evidence that poor sleep can predict future symptom flares though, so it does seem like there might be a role, but really, we need a lot more research before we can be sure of that.

Will you be looking at other factors like work, social life?

We will, we know the circumstances of our lives are really important for sleep and wellbeing. They are also really important when it comes to people being able to engage in interventions designed to support health and wellbeing. For this reason, we will absolutely try to understand these other factors as best we can.

A personal observation. When I get very tired it tends to come just before a flare up. Is this something that has been widely reported? And then of course during a flare, sleep continues to be poor.

I think you have described something that we see in the chronic health and sleep research a lot, although there is not much specifically in IBD. We do have some preliminary evidence that poor sleep can predict future symptom flares though, so it does seem like there might be a role, but really, we need a lot more research before we can be sure of that. What you have described is how we think that sleep and IBD symptoms are related, that both can impact each other in a vicious cycle. However, we really do need more evidence, which is why we want to do the work we are proposing.

Do you think sleep problems in IBD could also be leading to patients developing other conditions like Fibromyalgia?

I am afraid I am not sure about this one, it's something I will have to look out for so thank you for raising this.

Is it possible that a low-level anaemia causes sleep problems?

There is certainly an association between anaemia and problems sleeping, and also with fatigue, so it's one to watch out for.

Are extraintestinal symptoms a key driver to poor quality sleep in IBD patients?

The truth is there is just not the research to know for sure. It seems likely that they are on some level, but the question is can they be a key driver above and beyond the other factors that might play a role, which is why we would like to do the research we are proposing. However, anecdotally, people have told me that extraintestinal symptoms are affecting their sleep, particularly joint pain.

Another route to support this would be linking with the IAPT (psychological) services. I agree, and in my other strand of research we are arguing that adult mental health services should be doing more to include better interventions for sleep in services. Sleep is such an important thing that cuts across lots of health and wellbeing problems, so I really think we should be doing more to help people sleep.

Stoma management needs one to have a disturbed night...

Definitely, we think this is a big one and we will need to make sure we include information to mitigate the effect of having a stoma on sleep the best we can.

Will everyone with IBD be welcomed to take part or is it more specific recruitment?

This research is in the early stages, so we are just seeking feedback from the IBD community and planning how we can answer the questions people want. At this stage we have not decided who might be eligible to take part, but my feeling at the moment is that we want this research to be applicable to many, so we don't want to exclude people, so I would like anyone with IBD to be able to take part. The idea is that we create an intervention that can suit everyone, which will mean having different versions of the interventions for different people depending on their circumstances. For example, not everyone will struggle with mental health, so these elements of the intervention could be optional. That way, you can have an intervention that is tailored to you, where you choose the modules that you need.

Will it address gut brain axis role in poor sleep in IBD?

I don't think so, this is not really my area. We will focus more on trying to understand what things in are associated with poor sleep in IBD (e.g., symptoms, mental health, IBD features) and then try to develop an intervention that can improve sleep.

Would the study also potentially be able to help with understanding other forms of fatigue, for example people who are doing short or long-haul travel and how time zone changes might relate to IBD condition?

Our research will have a strong fatigue element because we know this is a key area in IBD and one that sleep is involved with. So, we will measure fatigue, and try to think of ways to help people use the intervention even if they are fatigued. However, we will not look at time zone changes and things like that. This is another area of sleep medicine called circadian research, and it's not something we are planning on looking at in this particular work (but I do think circadian research has a place here!).

Due to incontinence my sleep is very disturbed, I'd relish the opportunity to get some decent sleep and improve my sleep quality. I've also got PTSD due to a reaction to anaesthetic for an emergency procedure. I feel this will change many of us sleepless IBD peeps!

Thank you for sharing this, it's something that has come up in our previous PPI work. We know that there are many with IBD who experience PTSD, nightmares, and surgery related

traumas. In fact, its one of the reasons we are doing this work, because this is something specific to IBD that standard sleep interventions just won't address.

Do you think allergy to medication can cause lack of quality/ interruption/dreams etc to sleep?

I am afraid I am not sure about this one, so I can't give you a clear answer here. intervention. However, we do know that medications in general can impact sleep, and particularly medication for IBD is known to affect sleep quality, so we need to be able to address this in our study.

Has there been similar studies into other chronic health conditions?

I have searched high and low for studies that have adapted a CBTi intervention for other chronic health conditions, and there are really not many at all. The studies that have used CBTi in chronic health tend to use the standard, non-adapted interventions, and some work and some don't. I really think the interventions could be much better, and allow people to engage with them more if they are tailored and adapted towards the specific health problem, so that's why we want to do our work in IBD.

Will you be working with some of the specialist sleep centres and specialist psychological medicine units, like the one at St Marks?

We have a team of people working with us, but we won't be working with a specialist sleep centre. We have clinical psychologists, gastroenterologists, people who specialise in interventions to change behaviours around sleep, and people who are experts in developing interventions with people who have chronic health problems.

Really important area - fatigue and sleep major problem with visits to toilet at night!
Thank you, I am glad you think this work is important.

Will the study involve how people's sleep improved after Ostomy surgery? As for me, my first Ostomy gave me the best sleep in my IBD journey.

Whether people have/are having surgery is definitely something we are going to record, I really do think this is an important factor and its one we have measured in our previous research, thank you for the suggestion.

Would you also be looking into factors such as night sweats and how and why this affects sleep as it common among people with IBD?

Night sweats is not an area we are going to focus on specifically, but when we study which factors impact sleep this might be something that people tell us. Our research will mainly focus on insomnia as it's the most common problem sleeping, not only in IBD but in the wider population.

How could you separate the effect of the drug and the effect of the IBD in the study ?

Well, there are a few things we can do, but no method is perfect. The first and most common thing we can do is to simply measure the level of medication use, and also measure the important parts of IBD that might impact sleep. Then, we can use statistically modelling to try and separate the effects of each.

Will you be looking at dreams? I can wake up from a dream due to pain and incontinence and pick up where I left off when i get back to sleep.

We won't be looking at dreams, but we have looked at nightmares in the past and found that people with IBD report more severe nightmares than those without IBD. Our research going forward will focus on insomnia, as this is the area, we find most people struggle with.

Hi Alex, I would love to improve my sleep and would willingly participate and sign up please.

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