

Supplementary Table 1.

Summary of IBD Concepts: Symptoms and Impacts

Concept	Examples from participants
Physical signs and symptoms	<ul style="list-style-type: none"> • <i>“I get the pain in one specific spot.... if I'm kind of on the verge of a flare-up....it's usually 20 minutes or half an hour after I get up and it paralyzes me. I can't move...it's just like a brutal knife-sharp pain that you can't even move until it goes away.”</i> • <i>“I got real sick. I was 185 pounds and dropped down to 155...I'm going to the bathroom 18 times a day. And then, the week after is bleeding and you're like, ‘Wow, there's probably something wrong with me.’ And then you go to the doctor...”</i> • <i>“When a flare comes it's not just a couple of days... there goes 2 or 3 months... there have been 2 instances where for a day or 2 I got really fatigued, had a bit of a temperature but I just took a day off of work, slept and then within a day I was better.”</i> • <i>“And, so, for me, just a certain level is normal now. I don't consider that a flare, it's just the way I am.”</i>
Immediate impacts	<ul style="list-style-type: none"> • <i>“I'm like going to the bathroom 14 times a day and bleeding and doing just, like, awful.”</i> • <i>“... it's really debilitating. There's not much you can do...you have no energy and you can't really have a life because you could be running to the bathroom ... you have to plan all your activities around how you're feeling at that time.”</i> • <i>“For normal people, they'd be like, ‘Wow!’”</i>
Lifestyle impacts	<ul style="list-style-type: none"> • <i>“When I'm stressed out or depriving myself of sleep, that can start a flare...”</i> • <i>“...food is like a big trigger. I shut down off certain foods that are triggers for me.”</i> • <i>“No matter where you are you have to know where the bathroom is.”</i> • <i>“When I go through my everyday life, I have to think, like, when am I getting to bed, where am I going to sleep, how am I reducing my stress, because those are the things that I've found help me control it in addition to medicines.”</i>
Treatment	<ul style="list-style-type: none"> • <i>“I feel like I'm 80 because I have to take 16, 20, 30 pills a day. So, it's just a</i>

impacts	<p><i>pain that way.”</i></p> <ul style="list-style-type: none"> • <i>“It's a rectal medication that I have to do every night. It's a nuisance....definitely a life changer to do that every night.”</i> • <i>“I feel like a guinea pig 'cause there's no cure for it and they don't really know what to give you. If it works, it works. If not, try something else. Everything's experimental...There's no proven whatever.”</i> • <i>“Lately it hasn't been as effective, so I've had symptoms and they're not cleared up as fast as they used to be...[it's] just a matter of the disease and how it progresses.”</i> • <i>“Once I got to the pharmacy and they told me how much it was, I just had a complete breakdown...how I'm going to be able to pay for it forever...in terms of taking the medication on a consistent basis it's just - it seems really impossible.”</i> • <i>“It is a real financial burden.”</i>
Impacts on daily activities	<ul style="list-style-type: none"> • <i>“Missing work is like a big...nobody's guaranteed a job anywhere... if I miss 4 days, then they'll be like – wait: ‘How often is he gonna have this problem?’”</i> • <i>“How do I handle stress at work?...alright you're stressed now, something could be happening, make sure you take everything you can...do the [suppositories] every day.”</i>
Impacts on social and leisure activities	<ul style="list-style-type: none"> • <i>“Even just day to day, not knowing how I'm going to be...just like not being able to plan ahead 'cause I don't know how I'm going to feel. It's rough.”</i>
Impacts on relationships	<ul style="list-style-type: none"> • <i>“It's hard to talk about with people just because of what it involves.”</i>
Psychological impacts	<ul style="list-style-type: none"> • <i>“It's stressful not knowing how you're going to feel from day to day.”</i> • <i>“You're in remission and you feel great and one day you wake up and you're miserable and you're like, ‘Oh, here we go.’ So, it's always like a stress: Will I be able to use a men's room?”</i> • <i>“I'm like the guy that, when I get sick, I refuse to take anything. ...You think you're Superman, all of a sudden it's like: ‘Well, shit, I actually do need this to help me.’ And it bothers you. It genuinely bothers me.”</i> • <i>“...it requires me to take it twice a day; it's, like, literally like having to stop</i>

what I'm doing in life and being reminded that you have a chronic disease because every time you take a pill it's like a reminder that there's something wrong with you or you're broken..."

- *"My stomach will start rumblin' and tumblin'...If I'm in a meeting everyone laughs. You gotta kind of forfeit embarrassment when you have this disease."*
- *"Anytime I'm going anywhere overnight I have to remember to bring, like, 12 bottles of pills ... anyone who ever sees me get up in the morning thinks I'm dying."*
- *"I don't like to be seen taking pills at work because I don't want people to question my health. If my boss were to find out that I'm taking medication for something, then he might get worried that my job performance might be affected by my health."*
- *"I get worried because I know that I'm on some potent stuff and that I don't think that adding any of the 'lower stuff' like the [medication] would actually dramatically change my disease. So, the only thing that worries me is that I have found something that works really well and I worry about if that will ever stop working that well because if you look at like the pyramid of medications, I'm close to the top and the only way to go would be up and I don't necessarily really like seeing what those options are."*