Patient Preference and Adherence

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ORIGINAL RESEARCH

"I Probably Am Being a Naughty Boy, But…" Reasons for Non-Adherence to Prescribed Medication, as Perceived by People Living with Inflammatory Bowel Disease: A Qualitative Study

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Video Abstract

Point your SmartPhone at the code above. If you have a QR code reader the video abstract will appear. Or use: https://youtu.be/6YVc5v0ne1A

Purpose: Inflammatory bowel disease (IBD) is treated with medications to induce and maintain remission. However, many people with IBD do not take treatments as prescribed. Identifying and understanding reasons behind medication non-adherence in IBD is critical.

Patients and Methods: Semi-structured interviews were recorded and transcribed verbatim. Braun and Clarke's principles of reflexive thematic data analysis were followed.

Results: Twenty people living with IBD were purposively selected and interviewed. Four main themes were identified: 1) Context: adherence was impacted by the context of care individuals received, daily activities, physical and emotional well-being and relationship with others; 2) Battles: with IBD, with healthcare professionals and/or with IBD medication; 3) Medical treatment: treatment type, efficacy, side-effects and treatment requirements influenced adherence, as did an individual's treatment beliefs; and 4) Knowledge, learning, understanding and experience of IBD as a condition and its treatment typically promoted adherence. Yet treatment information was frequently not offered by healthcare professionals, leading individuals to self-educate and develop personal understanding, which with experience, influenced their adherence, both positively and negatively.

Conclusion: Medication adherence is a journey, influenced by multiple determinants. IBD diagnosis is a critical stage where individuals require compassionate care from both multidisciplinary health professionals and personal networks. Clear treatment information should be provided, with self-education encouraged through trusted resources. To promote adherence and establish treatment routines, patients must feel fully informed, confident and comfortable in their shared decision-making on treatment that will suit their lifestyle.

Plain Language Summary: Many people living with inflammatory bowel disease (IBD) do not take their medication as recommended. This is known as non-adherence. Numerous reasons for this exist, which may be down to the individual patient or influenced by healthcare professionals. Finding out more about these reasons for non-adherence to IBD treatment could support individuals living with IBD who are struggling physically or psychologically, help answer questions, strengthen patient–clinician relations, whilst saving costs and time on unused medications and healthcare resources.

Interviews with twenty people living with IBD were conducted 1:1, to find out more about why they do and do not take their IBD medications.

The interviews outlined four main themes relating to why people living with IBD may be non-adherent. Firstly, non-adherence was impacted by a range of contextual factors, also, by the "battles" patients had during their "IBD journey". Multiple treatment issues experienced affected non-adherence. Finally, knowledge, learning and understanding individuals gained, and experiences they went through, related to whether they took or did not take their IBD medication as prescribed.

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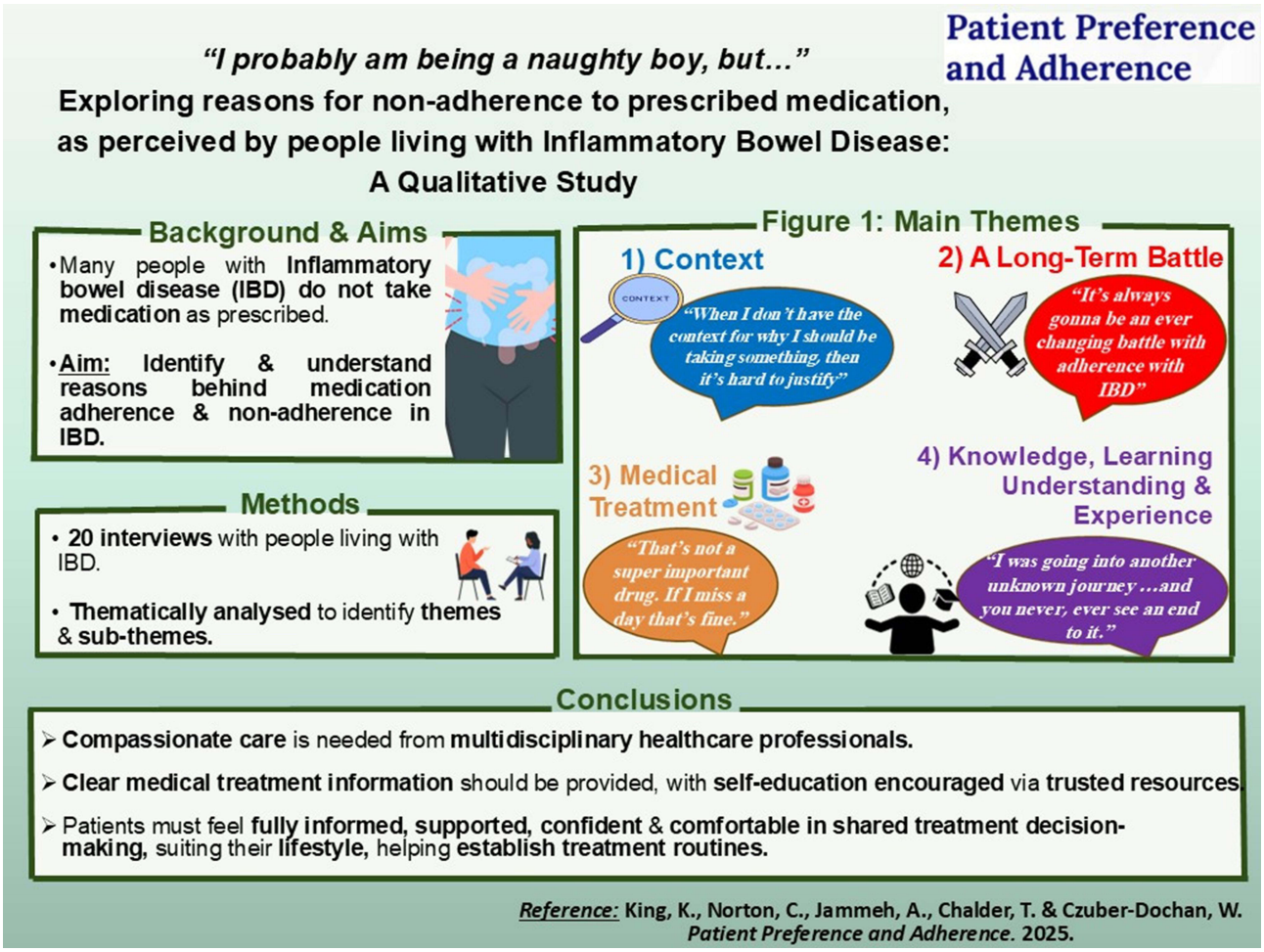
The IBD "journey" is challenging, with multiple physical, psychological and emotional influences. A critical time of this "journey" is when a patient is diagnosed with IBD. At this point, they require supportive, understanding care from their healthcare professionals, whilst being educated and advised on IBD and treatment. Patients must be part of this decision-making treatment process. Healthcare professionals and patients can then work together to develop a personalised treatment programme and help promote patient adherence.

Keywords: inflammatory bowel disease, medication adherence, medication compliance, medication concordance, qualitative research

Graphical Abstract



Introduction

Inflammatory Bowel Disease (IBD) is a chronic incurable, inflammatory disease characterized by relapsing-remitting presentation and includes predominantly Crohn's disease (CD) and Ulcerative Colitis (UC). Worldwide, there were 4.90 million cases of IBD in 2019,[1] an almost 50% increase since the 1990s.[2] In the United Kingdom, estimated prevalence of UC is almost 600 cases per 100,000 people and for CD, 400 per 100,000 people. Symptoms range from mild to severe, including acute illness, abdominal and joint pain and bloody diarrhoea.[3–5] IBD interventions encompass a range of therapies, including medication, nutritional and surgical approaches. Management of IBD aims for "tight control" of

inflammation,[6] inducing and maintaining symptomatic, endoscopic, and histological remission while minimising disease progression and complications.[7] However, optimal therapeutic efficacy requires strict adherence,[8] with non-adherence rates reaching up to 72% across different medications and healthcare settings.[9]

Non-adherence in people living with IBD is associated with more than a five-fold risk of relapse and increased disease severity.[10] Uncontrolled IBD can lead to loss of treatment response,[11] surgery,[6] disabilities[12,13] and psychological co-morbidities,[14,15] with high healthcare and societal costs.[15,16]

Despite extensive literature, the determinants of non-adherence remain complex and inconsistently reported.[17] Adherence barriers can be intentional or unintentional, modifiable or non-modifiable.[17] Non-modifiable factors include age, gender, and marital status.[18] Modifiable factors encompass practical barriers (forgetfulness, poor organisation, treatment inconvenience), insufficient treatment knowledge, psychological factors (depression, anxiety, negative treatment beliefs), and clinical variables such as treatment type (specifically aminosalicylates or biologics), regimen complexity, disease activity, and side-effects.[17]

Researching and understanding adherence is complex due to difficulties in defining and measuring adherence, identifying high-risk patients, and supporting medication-taking behaviours.[18] It is therefore important to assess attitudes towards taking medication for IBD, from the patients' point of view[19] to further appreciate their experiences. Understanding patients' engagement in medication prescribing and monitoring is also critical to appreciate non-adherent behaviours.

Aim

This study aimed to determine perceived factors contributing to intentional and unintentional non-adherence to prescribed IBD medications, in individuals living with IBD. Further, we sought to explore patient recommendations for adherence promotion strategies, support programmes, and aspirations for improved IBD management, informing future adherence interventions.

Materials and Methods

Study Design

In-depth, one-to-one semi-structured qualitative interviews were audio recorded and transcribed verbatim.

Participants

A target sample of approximately 20 adults (≥18 years) with a confirmed diagnosis of CD, UC, or IBD unclassified (IBDU) were recruited online via Crohn's and Colitis UK and Bowel Research UK. Eligibility criteria included current prescription of at least one IBD medication and the ability to provide informed consent.

Purposive sampling ensured diversity in diagnosis (UC, CD, IBDU) and duration, medication types (oral, injectable, rectal), adherence status (adherent or non-adherent), and demographic background. Efforts were made to include underserved populations,[20] as they may face greater adherence challenges.[21]

Data Collection

Individual online interviews were conducted via MS Teams (June–September 2023) using a piloted topic guide (Supplementary Table 1) informed by systematic and scoping reviews.[17,21] The guide covered demographic and clinical history, prescribed IBD medication, side-effects, adherence behaviours, medication access, and the impact of treatment on daily life.

Data Analysis

Data familiarisation involved repeated transcript reading and audio review.[22] Reflexive thematic analysis (RTA), following Braun and Clarke's principles,[23,24] was performed using inductive coding.[25]

Transcriptions were analyzed using a paper and pen method, Excel spreadsheets and NVivo software version 14.[26,27] Initial open coding identified emerging themes (e.g. "being a good patient" and "adherence honesty"), supplemented by

deductive coding informed by existing literature and researcher experience.[28] Preliminary themes and sub-themes were refined iteratively, with statements coded explicitly or implicitly. Description-focus coding identified recurring adherence-related themes and perspectives. Second level analysis involved construction of each major theme through aggregation of several focussed codes.

Figure 1 outlines the four main themes and accompanying sub-themes identified.

Attributes of IBD medication adherence and non-adherence were summarised to compare results[23,24,29] relating to the IBD "journey", mapped around a range of models and frameworks (Figure 2 and Supplementary Figures 1 and 2).[25,30–32]

Figure 2 outlines the cognitive constructs of the Health Belief.

Trustworthiness

Key components of qualitative research rigour (credibility, confirmability, dependability and transferability)[22] were addressed wherever possible. Reflexivity was integrated consistently throughout the designing, data collection and analysis to mitigate potential researcher bias.

The Thematic Analysis (TA) group included researchers with expertise in multi-method designs, qualitative interviews, nursing, and psychology, alongside three individuals with IBD, enhancing the authenticity of participants' voices, promoting rich and varied discussions regarding codes and themes. Coders received TA training and support from the lead researcher (KK).

All interviews were conducted by KK, with no prior participant relationships. Field notes and a reflexive journal were maintained. Data saturation determined the endpoint for interviews.[33] Verbatim transcription was performed by a professional transcriber, with anonymization prior analysis.

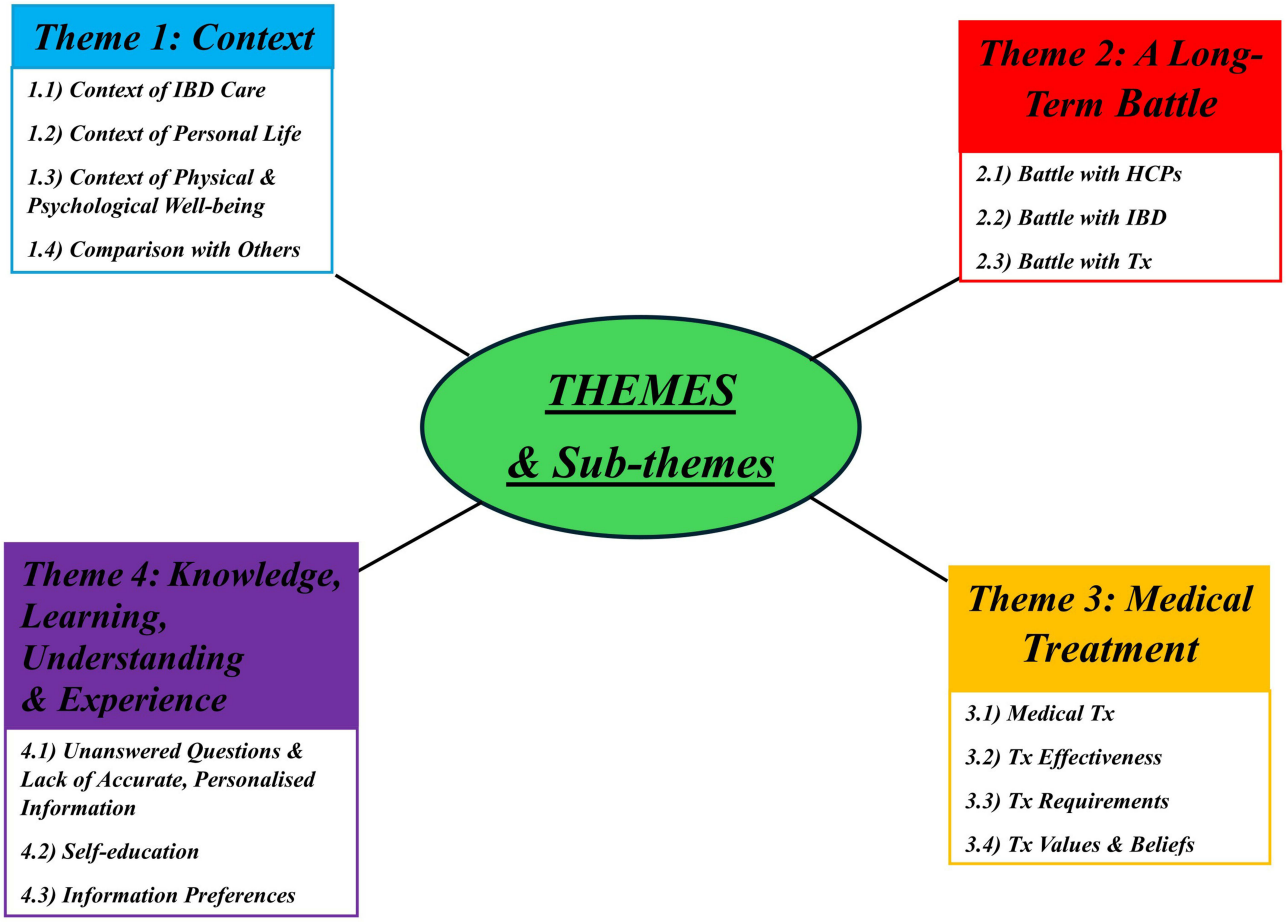


Figure 1 Themes and Sub-themes.
Abbreviations: HCPs, Healthcare Professionals; IBD, Inflammatory Bowel Disease; Tx, Treatment.

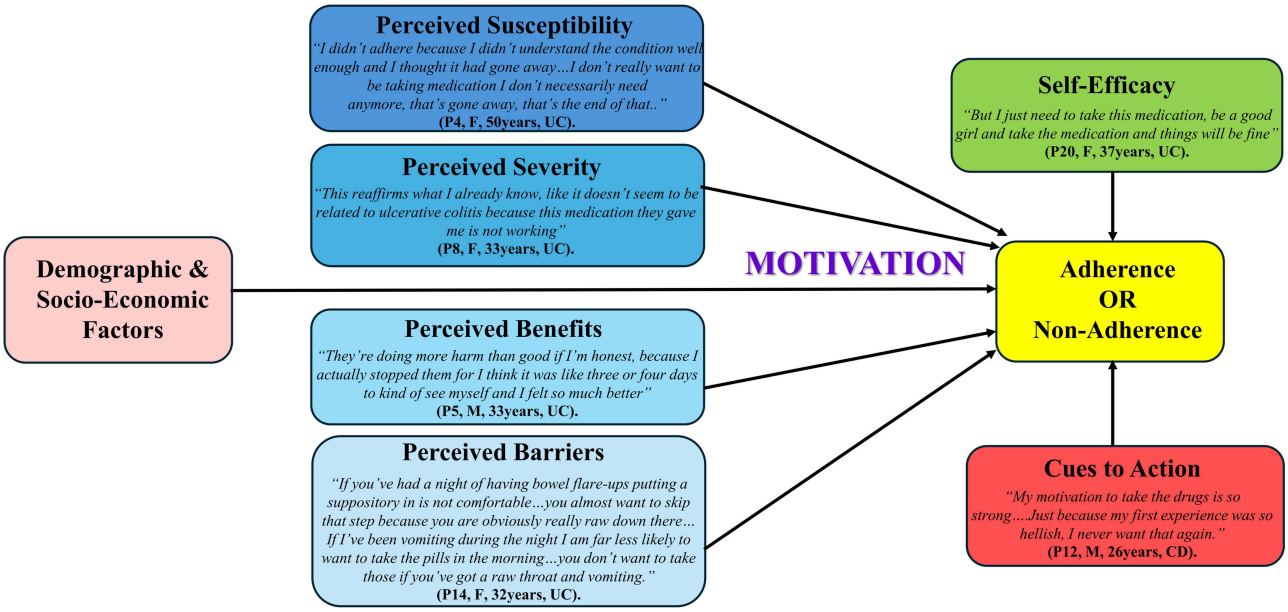


Figure 2 The Health Belief Model.
Abbreviations: CD, Crohn's Disease; F, Female; M, Male; P, Participant; UC, Ulcerative colitis.

Each transcript was independently coded by two TA group members. KK coded all transcripts, supported by three supervisors (WCD, TC, CN). Coders collaborated through online and face-to-face meetings, resolving discrepancies through discussion. Initially, 316 codes were identified and refined into themes and sub-themes.

Ethics

Ethical approval was granted by King's College London research ethics committee (HR/DP-22/23-34676). Informed written consent to take part in the research was obtained from all participants, prior to the commencement of the study. This included publication of anonymized responses / direct quotations. Anonymity and confidentiality were maintained by allocating participants numbers. Participants could withdraw at any time and request data withdrawal within two weeks post-interview. This study complies with the Declaration of Helsinki.

Results

Recruitment

Fifty-three individuals expressed interest in the study and received information sheets; two declined, six were not eligible and 15 did not complete the eligibility questionnaire. Of the 30 eligible participants, three were not invited due to purposive sampling saturation.

Twenty-seven were invited for interview, six did not respond and 21 were interviewed. One participant later withdrew. Nineteen participants consented to optional video recording, with one opting for audio recording only. Interviews lasted 60–133 minutes, (mean 85.5 minutes), totalling 28.5 hours.

Socio-Demographic and Clinical Data

Socio-demographic and clinical characteristics for the 20 participants are summarised in Table 1. Ages ranged from 25 to 65 years; 65% were female. Seventeen participants identified as White British, with the remainder identifying as Asian British or African. Most (12) were diagnosed with UC, and the mean duration since diagnosis was approximately 10 years.

Table 1 Participant Demographic and Clinical Characteristics

Items	Mean (Range) or Number
Age in years: mean (range)	39.2 years (25–65)
Sex (number)	
Female	13
Male	7
Confirmed Diagnosis of IBD (number)	
CD	7
UC	12
IBDU	1
Time since diagnosis in years, months (mean)	9 years, 11.5 months
IBD flares in the last 2 years (number)	
0	7
1–2	3
3–4	2
5	3
Ongoing disease activity without remission in the last 2 years	5
Year of last IBD flare (number)	
Pre 2016	1
2016–2017	1
2018–2019	2
2020–2021	4
2022–2023	12
Severity of IBD symptoms during last flare (number)	
Mild	4
Moderate	14
Severe	2
Maintenance / Flare-up Medication Type (number)	
5-ASAs: Mesalazine / Octasa / Asacol / Salofalk / Clipper / Mezavant / Pentasa	17
Steroids: Budesonide / Clipper / Prednisolone / Prednisone	12
Immunosuppressants: Azathioprine / Methotrexate	4
Biologics: Adalimumab / Infliximab / Ustekinumab / Vedolizumab	8
Additional Gastrointestinal medications: (number)	
Amitriptyline / Buscopan / CosmoCol / Docusate sodium / Loperamide / Mebeverine (x2) / Movicol / Omeprazole (x2) / Peptac liquid / Prucalopride / Rabeprazole	13
Maintenance Medication Administration Mode (number)	
Intravenous	3
Oral: Granules / Powder / Tablets	19
Rectal: Enema / Foam / Suppository	9
Subcutaneous	5
Additional Gastrointestinal medications: Oral liquid / powder / tablets	11
Flare-up Medication Administration Mode (number)	
Intravenous	0
Oral	4
Rectal: Foam / Suppository	2
Subcutaneous	0

Note: Values are mean (range), number, or range.
Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; IBDU, inflammatory bowel disease unclassified; UC, ulcerative colitis.

Table 2 Themes, Sub-Themes and Example Quotes Reflecting Participants' Experiences on Adherence to IBD Medication

Theme & Respective Quote	Sub-Themes and Respective Quotation	Example Quotes
(1) Context "**When I don't have the context for why I should be taking something, then it's hard to justify."** (P8, F, 33 years, UC).	**1.1) Context of IBD healthcare** "**Just another day in the office for them [HCPs]. So in terms of support, it was very minimal … here's your Crohn's and colitis booklet, you know, get out the door."** (P5, M, 33 years, UC).	**Diagnosis** a) "But I just need to take this medication, be a good girl and take the medication and things will be fine… Being a good girl in terms of sticking to schedule and making sure you do as you are told effectively… So I know I am not a bad person but you do not want to be disobedient to the advice you have been given…" (P20, F, 37 years, UC). b) "I was given a slap on the wrist by my IBD nurse for missing some enemas in the past. But at the moment, because it's making me feel better not having them, I'd say like, yeah, I probably am being a naughty boy but…" (P5, M, 33 years, UC). c) "The fact I was honest and I wasn't told off makes me think I'll carry on doing that [being non-adherent]." (P4, F, 50 years, UC). d) "The main reason is conflicting information amongst healthcare professionals and that's the reason I stopped. You know, my private doctor told me to stop taking my medication and then I went through a flare up. And then I started taking it again. But then I have my NHS doctor telling me that I had to take it for the rest of my life. You know the difference in opinion and practice." (P7, F, 26 years, UC).
	1.2) Context of personal life **"Sometimes you just forget, it's just one of those things. It's just another thing to remember isn't it?"** (P2, F, 44 years, CD).	a) "If for example we are on holiday or we do not have tea at home because we are going out for a meal or if anything happens that stops my routine then I am very likely to forget it. Holiday being the worst culprit, I think. I do take them with me but I usually end up bringing most of them back." (P6, F, 56 years, CD). b) "One of the reasons I miss taking my pills is because I have to request a prescription every month. Once a month is not often but it comes around quickly and quite often, I will have ran out of tablets before ordering them which means I miss a day or two of taking them." (P2, F, 44 years, CD). c) "Possibly the biggest challenge to adherence with erm, biologics is that reliance on dodgy companies that are meant to deliver and may not deliver." (P1, F, 34 years, CD). d) "That first year there were certainly times especially with a couple of the more expensive medications I'd maybe skip the last couple of days just to get to next pay day and make sure I could pay for that." (P14, F, 32 years, UC).

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Table 2 (Continued).

Theme & Respective Quote	Sub-Themes and Respective Quotation	Example Quotes
	1.3) Context of physical and psychological well-being **"I'm on the edge of a cliff…"** (P2, F, 44 years, CD).	a) "When you feel really, really well you think well I really didn't need to be taking all of that medication every day because I feel well. But then you get into a cycle of you become unwell. So that's not a good route to go down." (P11, F, 65 years, UC). b) "If you have had a night of having bowel flare-ups putting a suppository in is not comfortable… And you almost want to skip that step because you are obviously really raw down there… If I have been vomiting during the night I am far less likely to want to take the pills in the morning… You do not want to take those if you have got a raw throat and vomiting." (P14, F, 32 years, UC). c) "So ironically when I am feeling well, I tend to stop, that's when I am going to stop taking them even though they are the things that are going to stop me from getting ill. That does not make any sense does it but that's how it works I think… I am not quite sure what I think the medication is going to do to me, but just mentally I do not think you feel like you want to put something else in your body when your body is not feeling well, which is a bit weird if it could help you but…" (P2, F, 44 years, CD). d) "How I'm feeling in terms of my emotional and mental health. I'd say when I'm feeling low, I feel less motivated to look after myself and medication falls under that for me." (P13, F, 25 years, UC).
	1.4) Comparison with others **"Why me?… Why can't I just be like everyone else?"** (P21, F, 34 years, IBDU).	a) "The entire time I was on Azathioprine or the biologic, which was probably collectively 3½ years I never ever felt to a mildly normal human level of energy. I felt like a zombie." (P20, F, 37 years, UC). b) "I prefer to think it's normal what I am doing and I am not, because there is a lot of guilt as well about blaming yourself which I think you do with chronic disease to start with anyway… It takes away some of that, oh I am a bad patient. That's how I jokingly described myself." (P4, F, 50 years, UC). c) "I was lucky to have my partner and mum reminding me to take my meds, counting it out for me when I didn't feel up for it or I was a bit confused." (P13, F, 25 years, UC).

(2) A Long-Term Battle **"It's always gonna be an ever-changing battle with adherence with IBD."** (P5, M, 33 years, UC).	**2.1) HCP Battle** **"You just feel you are fighting constantly."** (P11, F, 65 years, UC).	a) "They did a stool test first just to check if I had any bacteria or anything like that and it was quite a battle, a long battle." (P21, F, 34 years, IBDU). b) "But to begin with you just go in like a lamb to the slaughter." (P11, F, 65 years, UC). c) "Really we're fighting about this… We [HCP and respondent] have this battle type of thing. So that's what I find." (P17, F, 54 years, UC). d) "That kind of like kicked off the chronic on and off, that like fighting for me pushing back every step of the way cause I'm like well look we just need more steroids to give the Mercaptopurine time." (P1, F, 34 years, CD).
	2.2) IBD Battle **"It's just gonna be a constant battle. A long-term battle."** (P5, M, 33 years, UC).	a) "At the point when you are taking medication and the flare-up is still raging…" b) "It's always gonna be an everchanging battle with adherence with IBD. Because you're gonna be changing medicines, you're gonna be, you know, up and down with your mental health, with how you feel, your flare ups." (P5, M, 33 years, UC). c) "Sometimes even despite doing all the right things and… You feel like you do all the right things, you take your medication on the right day, the right time as prescribed and you are still flaring up." (P14, F, 32 years, UC). d) "You have your down days where you just think oh my God why cannot I get rid of this? I am healthy-ish, I am working, I am trying to do the right thing and I just do not understand why it will not stop. On those days you do feel a little bit down and a bit defeated." (P17, F, 54 years, UC).
	2.3) Treatment Battle **"It's like a truck hit me. It was like my body was instantly a vegetable again and I couldn't even barely walk for six or seven weeks."** (P20, F, 37 years, UC).	a) "It seems like we've thrown the non-injectable drugs at me and now we've run out so now we're going to throw some injectable drugs at you and see what sticks." (P8, F, 33 years old). b) "You've got an arsenal of medications that you can use, and you vary the dose and vary which ones you are using as and when and that makes it a bit problematic to adhere to." (P4, F, 50 years). c) "I also know that I'm not seriously flaring at the moment so I'm thinking well let me save the big guns for when I'm seriously flaring." (P17, F, 54 years, UC). d) "I would say my game of adult chicken running into the road type of thing is seeing how far I can push it before it maybe is wrong… It's just seeing how far you can push it and then I suppose just not complying with everything because you do not fully want to comply." (P17, F, 54 years, UC).

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Table 2 (Continued).

Theme & Respective Quote	Sub-Themes and Respective Quotation	Example Quotes
(3) Medical Treatment **"That's not a super important drug. If I miss a day that's fine."** (P8, F, 33 years, UC).	**3.1) Treatment type** **"I really didn't like the steroids."** (P16, F, 32 years, CD).	a) "Don't get me wrong, they [steroids] do the trick and they do what they're supposed to do, and they definitely help, but it's definitely not something I want to be taking." (P5, M, 33 years, UC). b) "I felt horrendous, like horrible. I felt like I am this age and I am having to take this medication for the rest of my life, what about the side effects, what about the impact of this medication that's going to have on my body? I just did not like that idea of having to take medication at such a young age for the rest of my life every single day." (P21, F, 34 years, IBDU). c) "I was very anxious about taking the Prednisolone and very anxious about experiencing any of the side effects or potentially all of the side effects which on the sheet in the box ran for pretty much the whole length of it. So I definitely delayed that." (P10, M, 37 years, CD). d) "I'll do anything I can to not have to take them because I hate them." (P4, F, 50 years, UC).
	3.2) Treatment effectiveness **"The doctor said it's not doing much good, so I'll just skip a night."** (P6, F, 56 years, CD).	a) "If it's been successful from day one you will probably stick to it." (P17, F, 54 years, UC). b) "They didn't really make a difference and was like OK well this reaffirms what I already know, like it doesn't seem to be related to ulcerative colitis because this medication they gave me is not working." (P8, F, 33 years, UC). c) "They're doing more harm than good if I'm honest, because I actually stopped them for I think it was like three or four days just to kind of see myself and I felt so much better." (P5, M, 33 years, UC).
	3.3) Treatment requirements **"I'm definitely not taking them with food like I'm supposed to."** (P2, F, 44 years, CD).	a) "Some are before meals or some are after meals or some are with food, some are without food, some are morning. It's a nightmare to manage." (P19, M, 36 years, UC). b) "There was Mesalazine suppositories… I'd come back to the [hotel] room and they'd all melted." (P20, F, 37 years, UC). c) "I used to hate them because I couldn't bring myself to stick something into my own skin… Over time that has gone better but I'm still not comfortable with sticking needles into myself." (P9, M, 39 years, CD). d) "If they are a funny shape they can be a little difficult to swallow, which then half of it ends up in your mouth at which point does taste absolutely horrendous and you might need to find something very quickly to eat after you have downed to kind of get rid of that taste. It's also not fun when they get caught in your throat." (P1, F, 34 years, CD).

	3.4) Treatment values and beliefs **"I might have lied a bit in the past, like not majorly but I'd say, oh I'm taking four of those a day when I'm only taking two."** (P4, F, 50 years, UC).	a) "I'm so strict about trying not to let things fall back to that point [diagnosis], that I don't think I really let myself be anything other than completely adherent." (P10, M, 37 years, CD). b) "If there's no one following up, it's very easy to kind of lose the motivation and you think well no one's going to know no one's going to care if … I don't take it." (P1, F, 34 years, CD). c) "I'm probably a little bit sceptical about medication again because one size doesn't fit all… I think you've got to be treated as a whole as opposed to a part… You can't just expect a tablet to be the cure. It's never that simple." (P17, F, 54 years, UC). d) "As well as it just being sort of novel [taking treatment]. Whereas now, I suppose, it's not quite as exciting (laughs). It's just sort of a daily routine that I am vaguely aware of, probably with me for the rest of my life. Like, like brushing your teeth, I suppose… So probably one in four injections, I will have what we will call a wobble, (laughs) of some kind…" (P12, M, 26 years, CD).
(4) Knowledge, Learning, Understanding and Experience **"I was going into another unknown journey… And you never, ever see an end to it."** (P11, F, 65 years, UC).	**4.1) Unanswered questions and lack of accurate, personalised information** **"You are left in the dark with a lot of things… I've got colitis, so what does that mean, where do I go, what's going to happen? …"** (P11, F, 65 years, UC).	a) "I did not adhere because I did not understand the condition well enough and I thought it had gone away… I do not really want to be taking medication I do not necessarily need anymore, that's gone away, that's the end of that… I am not sure if I had been told this is forever or whether I just did not take that in." (P4, F, 50 years, UC). b) "She [Nurse] said something to me, which stopped me, which really changed my treatment viewpoint… She felt that there would be a cure within like 15 to 20 years… I am guessing intent like to try and be positive about like, this is gonna get better… But what that did was then made me more or less concerned about side effects because I was like it will be fine, I will be cured soon." (P19, M, 37 years, UC). c) "I don't have enough sufficient tailored advice here that I'm not confident I'm getting the full set of information about my specific condition… I would value the contribution of an individual more I think." (P3, M, 31 years, UC). d) "But initially I think that because it was not made clear to me what I had or why I was not given enough detail and context about being prescribed something so that made me more reluctant to take it especially when it was non-oral… I just did not take them because I am like what's the point? I do not know what I have, I do not know why I need this?…" (P8, F, 33 years, UC).

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Table 2 (Continued).

Theme & Respective Quote	Sub-Themes and Respective Quotation	Example Quotes
	4.2) Self-education **"It wasn't a healthcare professional that told me this, I know it was a friend… That was the best advice I ever got and that has made a huge difference."** (P4, F, 50 years, UC).	a) "I knew nothing about that. Nothing about it… Until I got a name for it and I looked it up. And a lot of things now you can look up yourself online to see the side effects and the dangers." (P11, F, 65 years, UC). b) "I would never take anything without reading when you get prescribed a tablet or whatever it is for something I never, ever would put it in my mouth until I had read the whole leaflet that came with it, because there are so many and also sometimes you have been prescribed things and it's said on it clearly not suitable if you have got colitis and I have been prescribed something and I think wait a minute." (P11, F, 65 years, UC) c) "…I fell down a hole on the internet and read that if you take less immunosuppressants it can cure your impaction, which was a crazy thing that I even believed but I did. I halved my immunosuppressant dose, did it for two weeks." (P13, F, 25 years, UC).
	4.3) Information preferences **"Super clear context for why I need to be adherent. That information is really helpful… Why this medication, because it will have this impact on my body."** (P8, F, 33 years, UC).	a) "To be told how important it is that they take them. But just to be trained on that would be helpful… It's that initial after you have been diagnosed that's the crucial part I think where you need to be told about, your medications explained to you, the adherence explained to you. That definitely was not done when I was diagnosed." (P2, F, 44 years, CD). b) "When I was on the steroids they said something like non-adherence may lead to bowel damage if we do not get your bleeding under control or it may lead to malnutrition. It links to scary things like it links to consequences… But also saying that yes it's your choice if you do not take them but if you do not adhere to it this will happen." (P13, F, 25 years, UC). c) "If I'd have known a lot of the things to begin with, I'd probably have said I'll not bother taking that." (P11, F, 65 years, UC). d) "It's quite important to get feedback from test results because I can decide then well maybe I should be taking these powders more regularly because I have got inflammation that needs bringing under control even if they are not doing much good maybe they are doing some good." (P6, F, 56 years, CD).

Abbreviations: CD, Crohn's Disease; GP, General Practitioner/Family Doctor; HCP, Healthcare Professional; IBD, Inflammatory Bowel Disease; IBDU, Inflammatory Bowel Disease Unclassified; F, Female; M, Male; P, Participant; UC, Ulcerative colitis.

Themes

Four main themes and corresponding sub-themes were identified (Figure 1). These are described below, supported by verbatim quotes (Table 2), referenced by participant details (eg., P (participant number), M/F (male/female), age, CD / UC / IBDU (Crohn's disease/ulcerative colitis/IBD unclassified)).

Theme 1: Context. "When I don't have the context for why I should be taking something, then it's hard to justify." (P8, F, 33 years, UC)

The context in which medication was prescribed was a key determinant of adherence. Influencing factors included IBD care, personal life, physical and psychological well-being and interpersonal relationships. In the absence of a supportive context, non-adherence was more likely (Table 2, Theme 1 quote).

Context of IBD Care. "Just another day in the office for them [HCPs]… it was just, here's your Crohn's and colitis booklet, you know, get out the door." (P5, M, 33 years, UC)

Many participants' "IBD journey" began with feeling dismissed by HCPs regarding their symptoms. This was often followed by painful investigations and multiple misdiagnoses, before receiving a confirmatory diagnosis, which for most brought relief.

At the point of initial medication prescription, considered critical for adherence support, many felt lost and unsupported. Guidance on treatment, particularly the necessity of long-term adherence for managing their chronic condition, was often insufficient (Table 2, sub-theme 1.1 quote).

Adherence was reported as high at diagnosis by all but one participant, driven by a strong desire to improve with HCPs' support and prescribed treatment.

Some patients, particularly women, sought to adhere to treatment instructions and be seen as a "good" patient, by "doing as they were told". This dynamic was perceived by some as paternalistic (Table 2, quote 1.1a). Non-adherent patients considered themselves, as "naughty", akin to a schoolchild, feeling "put in their place" or "kept in line" by their HCP, and unable to question their instructions (Table 2, quote 1.1b).

Several participants described non-adherence as "getting away with it", implying they had done something wrong, and might face consequences if discovered. One participant acknowledged that pressure of being a "good patient" could lead to adherence dishonesty. Occasionally participants admitted being non-adherent and anticipated reprimand from HCPs. When this did not occur, it encouraged their non-adherence (Table 2, quote 1.1c).

Participants often found contacting HCPs challenging, leading to feelings of being uncared for with a lack of monitoring, which impacted adherence. Younger females particularly expressed frustration with care, leading to isolation and decreased motivation to follow prescribed medication regimens. This disengagement intensified during the COVID-19 pandemic as limited face-to-face interactions prevented patients from discussing treatment concerns, increasing the likelihood of non-adherence.

The perceived lack of HCPs' empathy, reported by most participants, contributed to a diminished sense of trust and respect for their clinicians. Some questioned the HCPs' competence, amplified by unclear, inconsistent medication advice causing uncertainties and adherence barriers (Table 2, quote 1.1d).

In contrast, those who felt listened to, supported and respected as part of a reciprocal relationship with their healthcare team found this conducive to promoting adherence.

Context of Personal Life. "Sometimes you just forget, it's just one of those things. It's just another thing to remember, isn't it?" (P2, F, 44 years, CD)

Multiple individualised factors, including personal and professional roles, holidays and medication costs, were identified as impacting adherence. Often daily life was reportedly difficult to fit around treatment. Forgetting was a main contributor, typically due to unintentional lapses or remembering too late and feeling too "lazy" to take medication at that point (Table 2, sub-theme 1.2 quote).

Some females found themselves distracted with daily life, namely making dinner and childcare, working, leaving the house and socialising, thus affecting adherence. Most individuals emphasised the importance of routine for maintaining

adherence, with some noting that taking medication became automatic after many years. Almost half of participants found lack of or change in routine, such as travelling or holiday, led to unintentionally or intentionally non-adhering (Table 2, quote 1.2a). Conversely, one individual felt a scheduled disruption (e.g., holidays), enhanced their adherence.

Infusion treatments also disrupted routines, particularly for those working, due to attending hospital and the effect of the procedure. Inability to access medication was another barrier highlighted by many participants, particularly females. Some factors, such as planning, organisation and treatment prioritisation, were potentially within their control and contributed to management challenges, including running out of medication (Table 2, quote 1.2b). Some, particularly those with CD, had limited control of their treatment accessibility, whether due to pharmacists, General Practitioners (GPs) or "Homecare providers" delivery (Table 2, quote 1.2c).

Treatment costs posed an adherence challenge for several interviewees, particularly those diagnosed in their 20's and facing financial difficulties (Table 2, quote 1.2d). Even for individuals who were financially comfortable, the high cost of treatment impacted adherence. Some participants, however, felt their appreciation of treatment costs to the health service, made them conscious of wasting money, promoting adherence. Conversely, one participant expressed concerns regarding pharmaceutical companies profiting from drug sales, deterring her from adhering.

The importance of being in control of treatment on a day-to-day basis was emphasised by almost half of participants. Several found managing their condition and having responsibility for their treatment empowering. Experience with IBD also played a role, with patients understanding the importance of self-management, proactively advising HCPs on what worked for their body to facilitate adherence. A few males reported abdicating control over medication choices and demonstrated minimal adherence responsibility. A few also accepted taking their treatment as a necessity and pragmatically regarded it as something that had to be done.

Context of Physical/ Psychological Well-Being. "I'm on the edge of a cliff." (P2, F, 44 years, CD)

Adherence or non-adherence were influenced by varying degrees of physical and psychological wellness, with some participants describing their state as being vulnerable and at risk (Table 2, sub-theme 1.3 quote).

Medication was most likely missed when individuals felt physically well perceiving treatment as unnecessary (Table 2, quote 1.3a). Conversely, others experienced non-adherence when feeling physically unwell. Despite knowing their medication could help, they reported either not being motivated to take it or being concerned that medication may cause further discomfort or symptoms would persist (Table 2, quote 1.3b). Both reasons for non-adherence were difficult to explain logically for some (Table 2, quote 1.3c).

Many participants aimed to adhere to their treatment regime to maintain physical well-being. For two males, minimising future physical damage and regaining a better quality of life lost to IBD were critical, achievable through adherence as a preventive measure. Others expressed doubt about taking medication. Previous or other current health conditions and related treatments, healthcare or bodily choices (e.g., being pregnant), supported medication adherence in a few participants.

Being in a poor, changeable emotional state, described as a "rollercoaster", including depression, stress or experiencing treatment concerns, was an adherence barrier for some (Table 2, quote 1.3d).

Some females discussed how a lack of treatment control contributed to feelings of desperation and helplessness, with the IBD controlling their lives. This prompted them to seek complementary therapies in attempt to regain control. Many female participants expressed ongoing difficulty accepting their IBD diagnosis without a known cause and treatment serving as a consistent reminder of their chronic disease. They often remained in denial, unwilling to accept being "sick" with a chronic illness, not acknowledging the absence of a cure or viewing medication as a temporary measure; all of which promoted non-adherence. However, a few participants found that accepting their IBD and its associated challenges facilitated adherence.

Comparison with Others. "Why me?… why can't I just be like everyone else?" (P21, F, 34 years, IBDU)

Many participants compared themselves with others, both those living with IBD and those without (Table 2, sub-theme 1.4 quote). This comparison affected their relationships with family and friends, their willingness to disclose their condition, seek support and, ultimately, their adherence. This was influenced by the perceived severity of their IBD

diagnosis, their understanding of it, and a desire to "be normal". Half of participants did not consider themselves "normal" due to their diagnosis (Table 2, quote 1.4a). Language such as zombie, non-human and even naming their IBD "Hades" (God of the Underworld) were used to describe themselves, particularly in relation to treatment. Two participants felt singled out by their IBD, expressing the sentiment "why me?" However, even when medication made individuals feel "relatively normal", this paradoxically hindered adherence, as it led to them to focus on life, forget about their IBD and their treatment. The desire to be "normal" without treatment was another reason for non-adherence. Normalizing their IBD non-adherence was also important for reducing guilt and the feeling of being a "bad patient", while justifying their behaviours (Table 2, quote 1.4b).

Some interviewees, particularly females, experienced shame and embarrassment due to the lack of normality associated with IBD, especially in relation to sensitive and awkward treatments, such as rectal treatments. This prevented many from disclosing their condition, leading to less emotional support from others. Individuals often felt misunderstood, reinforcing feelings of loneliness.

In contrast, two younger males explicitly stated their IBD did not cause them embarrassment, with several participants emphasising the importance of accessing support for managing their condition. Adherence was often better when an individual's family, peers, employers, IBD services and charities were made aware of their IBD diagnosis. Appreciation for this adherence support received from family members and partners was reinforced by some younger participants (Table 2, quote 1.4c).

Listening and comparing their IBD journeys to others was particularly therapeutic for two females, having a powerful, positive impact on their adherence. Many positive comparisons were made with others. Some considered themselves "lucky", despite their chronic diagnosis, while others expressed feeling "grateful", or thought it was "good to have an answer". Gratitude was also expressed towards preferred treatment, particularly when it suited their daily life, allowing straightforward medication ingestion, and ultimately helped manage their IBD effectively.

Theme 2: A Long-Term Battle. "It's always gonna be an ever-changing battle with adherence with IBD." (P5, M, 33 years, UC)

Many participants described their journey as a battle, fight, conflict or collision, using intense terminology when reflecting upon their healthcare experiences (Table 2, Theme 2 quote). These were primarily female, of all ages and IBD diagnoses.

HCP Battle. "You just feel you are fighting constantly." (P11, F, 65 years, UC)

The "battles" commenced immediately, from the initial stages of the IBD journey during investigatory phases with patients consistently disagreeing with HCPs (Table 2, sub-theme 2.1 quote; quote 2.1a). Patients expressed feeling helpless, at the mercy of clinicians (Table 2, quote 2.1b).

The conflict continued when being prescribed treatment, with patients opposing their proposed regime. They visited their HCP, "armed" with information and sometimes situations "kicked off", increasing the likelihood of non-adherence (Table 2, quotations 2.1c, 2.1d).

IBD Battle. "It's just gonna be a constant battle. A long-term battle." (P5, M, 33 years, UC)

Others spoke of the ongoing, daily physical, psychological, emotional, social and practical battles they found themselves having (Table 2, sub-theme 2.2 quote), when their IBD was "raging" (Table 2, quote 2.2a). Treatment switching exacerbated this conflict with IBD (Table 2, quote 2.2b).

Some individuals were determined to persevere, viewing IBD as a fight to be won. Some believed victory lay in adherence to treatment, while others, despite strict compliance, still framed their experience as a struggle, raising concerns about medication efficacy (Table 2, quote 2.2c).

This feeling of defeat was also expressed when non-adherence was explicitly reported (Table 2, quote 2.2d).

Treatment Battle. "It's like a truck hit me. It was like my body was instantly a vegetable again and I couldn't even barely walk for six or seven weeks." (P20, F, 37 years, UC)

Interviewees described conflicts with their IBD medication, feeling that prescribed treatment was forcefully imposed by their care team, metaphorically "hitting" or "whacking" them (Table 2, sub-theme 2.3 quote, quote 2.3a). Some reported being "pumped full" of chemicals and "knocked" into remission, while enduring side-effects that affected adherence. To manage flare-ups, some relied on a "back-up" pack of emergency medication which supported adherence when needed.

However, even when treatment knowledge was classified as an "armoury", and treatment was weaponry to "battle through side-effects" and combat IBD, this still had potential to facilitate non-adherence (Table 2, quotations 2.3b, 2.3c).

An IBD diagnosis was described as a "game-changer" with medication perceived as the opposition when individuals resisted treatment. Non-adherence was sometimes framed as a strategic move against it (Table 2, quote 2.3d).

Theme 3: Medical Treatment. "That's not a super important drug. If I miss a day that's fine." (P8, F, 33 years, UC)

Many participants highlighted various factors influencing adherence to medical treatment, both positively and negatively.

Treatment Type. "I really didn't like the steroids." (P16, F, 32 years, CD)

Nearly half of individuals held preconceived ideas about certain medications and associated risks, particularly steroids, which affected adherence despite treatment effectiveness (Table 2, sub-theme 3.1 quote; quote 3.1a). This issue was extremely prevalent for immunosuppressants during and after the COVID-19 pandemic, as patients feared increased vulnerability due to a weakened immune system. Conversely, some viewed less potent drugs as less essential (e.g., Mesalazine), justifying non-adherence (Table 2, Theme 3 quote).

Concerns about long-term medication risk, including pancreatic failure, liver damage, cancer and reduced fertility, also deterred adherence (Table 2, quote 3.1b). Two females (aged 50 and 65 years) reflected on the potential risks they had exposed themselves and their unborn children to, after taking aminosalicylates and steroids long-term. They regretted their adherence and experienced guilt, which negatively affected their current adherence.

Awareness of side-effects even if not personally experienced, often led to concern, discouraging some from initiating treatment (Table 2, quote 3.1c), and prompting consideration of complementary and alternative therapies. Side-effects frequently impacted quality of life leaving many respondents feeling unwell. For several, this was the main reason for non-adherence, leading them to deprioritise medication and, in some cases, discontinue it (Table 2, quote 3.1d). This often led to ongoing anxiety about recurrent side-effects, increasing the likelihood of future non-adherence and prompting some to take treatment breaks despite the risk of flare-ups. However, if side-effects had minimal impact on life quality, a small number of participants would adhere.

Treatment Effectiveness."The doctor said it's not doing much good, so I'll just skip a night." (P6, F, 56 years, CD)

When treatment effectively managed an individual's IBD, adherence was highly likely, particularly when initiated at diagnosis (Table 2, quote 3.2a). A positive perception of medication, coupled with optimism about its potential to manage IBD, encouraged adherence and for some, was more influential on adherence than HCPs advice. Despite effective treatment, some individuals reported not adhering to their full regimen.

Ineffective medication was also a reason for non-adherence, particularly in those who felt worse after taking treatment. Reinforcement from HCPs that treatment was ineffective contributed to non-adherence in some respondents (Table 2, sub-theme 3.2 quote). This inability to manage IBD symptoms sometimes intensified doubts about the diagnosis and prescribed treatment (Table 2, quotations 3.2b, 3.2c). Two participants who reported non-adherence, likened treatment to a "sticking plaster", viewing it as merely "masking" the IBD rather than offering a cure.

Treatment Requirements. "I'm definitely not taking them with food like I'm supposed to." (P2, F, 44 years, CD)

Factors such as medication administration guidance (e.g., with or after food), dosage, regimen, frequency, access to treatment and storage were all potential determinants of non-adherence. The recommendation to take treatment with food caused daily difficulties for some individuals (Table 2, sub-theme 3.3 quote; quote 3.3a).

Transporting medication and necessary equipment (e.g., needles) while travelling and subsequent storage, also significantly influenced adherence, both intentionally and unintentionally (Table 2, quote 3.3b).

Many participants reported that administration methods impacted their adherence, most particularly the rectal route. This was considered a barrier especially for males and three females, due to it being "unfamiliar" and "uncomfortable" (both during and after insertion), often following a flare-up, as well as the associated "stigma". Subcutaneous treatment posed challenges for three interviewees, primarily due to a fear of needles (Table 2, quote 3.3c).

Oral medication, preferred by many, was easily managed and facilitated adherence. Yet, its simplicity led one participant to feel this was easier to forget. Issues such as difficulty swallowing, the size, shape and taste of tablets contributed to non-adherence in a few individuals (Table 2, quote 3.3d). Powdered or dissolvable treatments were particularly disliked due to their taste and preparatory requirements. Eight participants received intravenous treatment for their IBD. Half describing it as "fine" or "nice" preferring it over subcutaneous injections. Infusions were especially popular among male interviewees, who valued the face-to-face care. This, combined with receiving treatment in hospital, provided reassurance about effectiveness, maintaining motivation to adhere. A few felt intravenous treatment indirectly promoted adherence, as the decision to take the medication was made for them. No adherence concerns were reported regarding infusions. Practical challenges of attending hospital appointments were expressed but did not impact upon adherence.

Dosage or frequency of treatment regimen also impacted non-adherence. High dosages or frequencies and new regimes negatively affected taking medication for some. Males expressed mixed views regarding regimens; one considered a daily routine not as important to adhere to than an infrequent dose, which he would take greater care to avoid missing. Yet another felt a less regular regime was more challenging, due to not being as accustomed to it.

Treatment Values and Beliefs. "I might have lied a bit in the past like not majorly, but I'd say, oh I'm taking four of those a day when I'm only taking two." (P4, F, 50 years, UC)

Many participants discussed their beliefs and values regarding treatment priorities, and motivation. Multiple explicitly expressed a strong desire to prioritise their health, often citing the belief that taking treatment was the "right thing to do", motivating them to be adherent (Table 2, quote 3.4a).

For several participants, adherence involved making personal sacrifices or attempting to please HCPs. However, when interviewees felt their HCPs were less invested in their care due to insufficient monitoring, their motivation to adhere diminished (Table 2, quote 3.4b).

Some held strong beliefs regarding maintaining their health but were sceptical of medication "being the answer", feeling non-pharmaceutical approaches were more effective to treat IBD. Thus, they were not always adherent (Table 2, quote 3.4c).

A few individuals were strongly opposed to taking IBD treatment or perceived medication as "bad", even when physically unwell. This resistance was influenced by their upbringing, personal experiences, good health status, or negative preconceptions.

Others did not view their treatment as a high priority or considered it "serious". Three middle-aged participants expressed complacency about adherence, as they perceived the medication importance diminishing over time. Some joked about missing doses, trivialising their non-adherence or felt the "novelty" of taking medication had worn off, leading to reduced commitment (Table 2, quote 3.4d).

Downplaying non-adherence and / or their IBD symptoms to their HCPs, particularly if they believed it might affect their treatment plan, was reported by six individuals. Most could not justify this behaviour, while those who did, dismissed it as self-protection to avoid stronger medicine (Table 2, sub-theme 3.4 quote). One participant intentionally blamed other HCPs (GPs, Pharmacists) and their inaccessibility, for her non-adherence, considering this as not lying, but "extending the truth".

Theme 4: Knowledge, Learning, Understanding and Experience. "I was going into another unknown journey… and you never, ever see an end to it." (P11, F, 65 years, UC)

Being fully informed and reassured about IBD and its treatment from diagnosis was critical for adherence. The timing, source, and content of information had a significant influence, either positive or negative, on taking medication as prescribed.

Unanswered Questions and Lack of Accurate, Personalised Information. "You are left in the dark with a lot of things… I've got colitis, so what does that mean, where do I go, what's going to happen?" (P11, F, 65 years, UC)

Many participants reported uncertainty and unanswered questions about their condition and treatment when first diagnosed (Table 2, Theme 4 quote; sub-theme 4.1 quote). Four females initially underestimated the seriousness of their IBD, believing it would "go away" leading to their "recovery" (Table 2, quote 4.1a).

Inaccurate information about a potential IBD cure motivated adherence for two males, thinking medication was only temporary. One male was specifically advised by an IBD nurse that a cure for ulcerative colitis would be available within a set timeframe, influencing his decision to initiate treatment (Table 2, quote 4.1b).

Information received from participants' healthcare teams was often generic, unhelpful and minimal, lacking a person-centred approach, consequently reported as a main determinant for non-adherence (Table 2, quote 4.1c).

Several respondents recalled feeling confused and uncertain about their prescribed IBD treatments, with little explanation of why it should be taken. This lack of context increased the likelihood of not initiating, adhering to, or continuing medication (Table 2, quote 4.1d). Some participants did not fully understand the importance of adherence to an established routine for treatment effectiveness. Such modest awareness contributed to increased side-effects, poor quality of life, negative medication perceptions, and non-adherence. A few individuals reported not being informed about treatment costs or available support systems, such as prescription pre-payment certificates, leading them to non-adhere to save money.

Self-Education. "It wasn't a healthcare professional that told me this, I know it was a friend… that was the best advice I ever got and that has made a huge difference." (P4, F, 50 years, UC)

Lack of information from HCPs led many participants to self-educate about IBD and find "their own way" (Table 2, quote 4.2a). This independent research led some to reflect on and occasionally reconsider their medication choices. For others, it reinforced their belief that they knew what was best for their bodies, and subsequently distrusting medical advice. Yet, reading treatment information leaflets or participating in IBD research was infrequent and primarily done to obtain up-to-date, accurate guidance for making informed treatment decisions (Table 2, quote 4.2b).

Sharing of IBD advice and education through peers living with IBD was found by some participants to have greater influence on their medication adherence than information provided by HCPs, due to the delivery of information and different dynamic (Table 2, sub-theme 4.2 quote). However, one female strongly believed that treatment recommendations from peers could be potentially dangerous if incorrect. Seeking information from less reliable, opinion-based sources, such as websites and chat forums was also considered harmful by some, negatively shaping medication beliefs and behaviours (Table 2, quote 4.2c).

Information Preferences. "Super clear context for why I need to be adherent. That information is really helpful… why this medication, because it will have this impact on my body." (P8, F, 33 years, UC)

Overall, participants preferred to receive information directly from their HCPs. Having sufficient medication knowledge provided some with the sense of autonomy enabling them to express their care and treatment preferences whilst feeling heard. When treatment was clearly explained, how it worked and why adherence was important, taking it as prescribed appeared easier (Table 2, sub-theme 4.3 quote).

However, only one participant felt sufficiently reassured by their care team regarding their medication programme, ingesting techniques and potential side-effects. Many participants felt that explanation about treatment and the importance of adherence were lacking, yet would have been beneficial (Table 2, quote 4.3a). Being informed by HCPs that treatment plans are personalised, and that people respond differently to medication was also considered important. This reinforced the need for patience during the treatment journey while remaining adherent. Awareness of treatment risks had a variable influence on adherence. Some participants preferred detailed information, with individualised advice addressing their specific needs and concerns, which increased their likelihood of adhering to prescribed medication (Table 2, quote 4.3b). For others, being fully informed about treatment risks was considered "dangerous", as it could lead to non-adherence (Table 2, quote 4.3c). Instead, they preferred to place their trust in HCPs.

Self-advocating was widely encouraged as a means of increasing treatment awareness and potentially improving adherence. Although one female highlighted the difficulties in knowing what to ask.

Some patients emphasised the need for regular monitoring and meaningful feedback, particularly through test results, to enhance their adherence by keeping them informed with accurate data (Table 2, quote 4.3d).

Discussion

This study aimed to determine the perceived reasons behind both intentional and unintentional non-adherence to prescribed medications among individuals living with IBD. It provides a comprehensive account of the various factors influencing adherence, personal knowledge, and individual perceptions.

To understand medication-taking behaviours from diagnosis and throughout the IBD "journey", the study applies several models and frameworks to interpret the four identified themes. The Health Belief model (HBM)[30,31] explains which cognitive constructs determine adherence behaviours (Figure 2). The Necessity and Concerns Framework[32] (NCF) suggests that these behaviours are influenced by an individual's perceived medication need and concerns about potential side-effects and long-term consequences. Additionally, the COM-B model of behaviour change[25] offers a comprehensive perspective, identifying three key factors that influence adherence. These factors are "Capabilities" (appropriate resources), "Opportunities" (environment facilitating change) and "Motivation" (appropriate habits / decisions directing behaviours) (Supplementary Figures 1 and 2).

"The IBD Journey"

Diagnosis

The diagnostic stage of the IBD journey is stressful and overwhelming, comparable to any chronic condition. Patients along with family, partners, carers or friends may have numerous concerns and questions. The framework for interventions designed to support early treatment engagement[34] recommends utilising this critical period to identify and target causes of non-adherence prior medication initiation. By reinforcing treatment priority early on,[19] care can be personalised, making patients feel valued, increasing the likelihood of both initial and long-term adherence.[17] The development of trust, respect and empathy between HCPs and patients during this stage is crucial for fostering a supportive network (Supplementary Table 2, Clinical Practice Strategies & Tips). Yet, many interviewees in this study reported feeling that their symptoms were not taken seriously by HCPs. This led to repeated investigations, prolonged pain and diagnostic delays. It also undermined the patient-HCP relationship and limited the effectiveness of communication, ultimately increasing the risk of future non-adherence.[35] These issues were further exacerbated during the COVID-19 pandemic, when many participants reported feeling isolated and disconnected due to the inaccessibility of HCPs, leading them to neglect treatment adherence. Previous research has also highlighted instances where the authenticity of patients' symptoms was questioned.[36,37] Our findings align with other studies that emphasise the importance of HCPs genuinely listening to and validating patient concerns[38] (Supplementary Table 2, Communication with HCPs). The Necessity and Concerns Framework (NCF)[32] underscores the need for such understanding, suggesting that adequate consultation time is essential, especially for newly diagnosed patients.[39] This not only helps build stronger patient-clinician relationships but also reduces the need for unnecessary invasive procedures, fostering a more trusting and collaborative environment that supports adherence.[38]

Initial Prescription

When prescribing treatment, clear, supportive guidance, aligned with World Health Organisation (WHO) recommendations, enhances long-term adherence.[40] This guidance can be optimised through practical demonstrations, clearly labelled treatment packaging and open discussions that address patient concerns, all of which, strengthen the likelihood of long-term adherence[41] (Supplementary Table 2, Treatment).

Our findings showed that treatment type, such as steroids or immunosuppressants, often influenced decisions to adhere, based upon pre-conceived beliefs or direct experiences. If a medication is perceived as effective in managing IBD, adherence is typically reinforced, minimising future non-adherence.[34] This can be seen as a "perceived benefit" in

the HBM[30,31] (Figure 2). However, if medication is perceived as ineffective, associated with side-effects or entails complex requirements, this increases non-adherence; all potential "perceived barriers" of the HBM[30,31] (Figure 2). Some participants believed their IBD had "gone away" during remission, a finding consistent with previous research[42–44] leading them to discontinue treatment. This supports the "perceived susceptibility" component of the HBM[30,31] (Figure 2), whereas if an individual perceives a low probability of relapse ("perceived severity": Figure 2) adherence is less likely. To mitigate this risk, HCPs should engage in discussions with patients around the potential for treatment ineffectiveness, and alternative therapeutic options.

Simplifying regimens and aligning them with daily routines fosters adherence habits, as supported by research[34] (Supplementary Table 2, Treatment). Patient preference incorporation[17] enhances self-efficacy (Figure 2),[30,31] encouraging open dialogue and better clinical outcomes[45] (Supplementary Table 2, Communication with HCPs).

HCP Information Provision and Guided Learning

This study identified unmet educational needs regarding IBD treatment. Participants lacked information on medication type, efficacy, side-effects, risks and benefits. In response, individuals self-educated based on their capabilities and opportunities (COM-B),[25] utilising resources such as charities, peer experiences and the internet (Supplementary Table 2, Learning & Educational Resources). Peer support, often thought as more influential than HCP advice, has been previously recognized in promoting understanding and adherence.[46] However, inaccuracies and biases in patient forums serve as "cues to action" within the HBM (Figure 2), shaping beliefs and behaviours towards treatment and HCP team. To address this, HCPs must guide active learning and reinforce key facts (Supplementary Table 2, Clinical Practice), whilst providing accessible, accurate and supportive resources, in line with COM-B.[25] Yet patient education alone has shown inconsistent, short-term adherence promotion.[21] Educational services must therefore be diverse, including IBD charity contacts within patient correspondence, in-person groups, and both digital and print materials. Tools such as the "drug facts box", a simple diagram with side-to-side comparisons of medical interventions, can further enhance treatment understanding.[47]

Ongoing Monitoring and Screening

As the patient progresses through their journey, continuous monitoring allows HCPs to provide consistent support. Timely, meaningful feedback on test results helps patients stay informed and address queries. Home-test faecal calprotectin has been well received as an objective outcome measure.[48] Such care strengthens HCP-patient relationships, promotes patient accountability, and increases the likelihood of honest adherence reporting. Medication adherence and disclosure were influenced by treatment attitudes and HCP communication. Clinical language often reinforces patient passivity, positioning doctors in authority.[49] This fosters childlike narratives, as seen in participants describing themselves as "naughty" or "good" reflecting ingrained hierarchical perspectives.[36] Shifting towards collaborative terminology can enhance trust and shared decision-making, thereby addressing power imbalances (Supplementary Table 2, Communication with HCPs). Patient access to personal electronic health records, regardless of their condition, may further promote a patient-centred approach.[36] However, this may exclude individuals without internet access or appropriate electronic devices.[21]

Many participants described an ongoing "battle" with HCPs, where the intended support was perceived as obstacles.[25] This was more frequently reported by female interviewees, aligning with research linking female gender to greater healthcare dissatisfaction and treatment concern.[35,50] Participants also viewed their IBD as a struggle against both their condition and a perceived loss of normality, consistent with previous findings.[17] This distress was often exacerbated by treatment itself.[50,51] Psychological factors such as depression, anxiety, stress, and acceptance or denial of illness significantly impact adherence[17,38] (Supplementary Table 2, Emotions).

Given these challenges, identifying patients at risk of non-adherence is crucial.[52] A simple yet effective strategy is for clinicians to ask how often patients miss a dose, potentially encouraging more honest disclosure.[39] It is acknowledged, however, that clinical practice time restraints and prioritisation of patient issues may impact this recommendation.

Long-Term Care

As HCPs involvement decreased over time, many respondents became more independent, making personal treatment decisions and feeling confident in self-management. This aligns with COM-B[25] and the NCF,[32] where motivation and perceived treatment necessity may decline, affecting adherence.[53,54] Such behaviours arose from patient choice and / or insufficient monitoring, leading individuals to assume control, consistent with both the framework for interventions[34] and a systematic review.[17]

When long-term care remained accessible, with effective communication, treatment autonomy[55] and personalised guidance, participants felt supported (Supplementary Table 2, Communication with HCPs). This facilitated information sharing,[25] reassurance, and positive reinforcement, reducing feelings of isolation.[56] A scoping review of successful adherence interventions found that all effective strategies involved talking therapies.[21] Psychological support from trained HCPs, complemented IBD charity helplines, actively addressing concerns. While openness with care teams can be challenging, self-advocacy is encouraged (Supplementary Table 2, Communication with HCPs), as these approaches contribute to better adherence.[25,56–59] Personalised, in-person interventions were most effective and well-received by interviewees.[21]

External barriers, including limited treatment accessibility and delivery, also impacted adherence. A recent Crohn's and Colitis UK report found that 62% of respondents experienced homecare medicine service difficulties in the past six months.[60] Streamlining systems and improving medication access could reduce non-adherence. Similarly, a systematic review[17] identified planning and organisation as key modifiable risk factors in IBD non-adherence. Patients can mitigate these challenges through proactive treatment management, including ordering, storing, and scheduling doses. Calendars, diaries, and reminders, consistently effective adherence tools, were emphasised by interviewees as valuable aids[46] (Supplementary Table 2, Practicalities), with digital tools being increasingly popular. Yet, technology-based strategies can be restrictive, both in terms of functionality and usability.[21]

Strengths

The charity online recruitment procedure facilitated a spread of participants, attracting volunteers from diverse backgrounds, representing various ages, diagnoses, and IBD experiences. All interviews, conducted by one researcher, were held virtually promoting ease of participation. A wide range of IBD medication types were discussed, encompassing regimen, administration mode, storage and accessibility, each of which can determine adherence. Data saturation was reached, confirming comprehensive data collection.

Multidisciplinary HCPs within the analysis group collaborated with patient representatives ensuring the patient voice was clearly reflected, enhancing the depth of data exploration through rich and varied discussions. Thematic analysis was structured and rigorous, promoting the trustworthiness of the findings.

Multiple models and frameworks were employed to interpret findings, providing a nuanced understanding of the data.

Limitations

Most interviewees identified as White British, which limited diversity of our sample and reflects the typical demographics of IBD UK charity members volunteering for research. Future research should aim to explore the experience of under-represented cultural groups to ensure their voices are heard, and health services are aligned with their needs and requirements. Furthermore, self-selection of participants introduces bias, potentially representing specific adherence behaviours.

Interviewing individuals at a single time-point regarding their subjective IBD treatment experiences is susceptible to memory distortion and may not capture the evolution of their adherence "journey". Longitudinal qualitative research would be valuable in following individuals from diagnosis and beyond, providing insights into how medication adherence evolves over time.

Conclusion

IBD medication adherence is a journey, influenced by multiple determinants, which may be patient-centred or shaped by HCPs.

To promote adherence and avoid the "adherence battle", it is crucial for HCPs to provide sufficient context at the diagnostic stage, justifying the need for treatment and addressing any queries thoroughly. Establishing a strong HCP-

patient relationship, built on honest and open communication, is key to reinforcing the importance of maintaining adherence. The prescribed regimen should align with an individual's lifestyle, with their preferences considered to foster patient autonomy. Opportunities to educate patients about their IBD and treatment should be maximised, promoting self-advocacy and learning through the provision of trusted, evidence-based and clear resources. HCPs must consistently monitor both the physical and psychological well-being of their patients, ensuring they remain accessible, consistent and empathic.

Providing regular feedback is essential to keep patients informed and motivated. Only with these comprehensive and supportive strategies can the "adherence battle" be won.

Abbreviations

CD, Crohn's disease; GP, General Practitioner/Family Doctor; F, Female; IBD, inflammatory bowel disease; IBDU, inflammatory bowel disease unclassified; M, Male; P, Participant; RTA, Reflexive thematic analysis; UC, Ulcerative colitis.

Data Sharing Statement

All data collected for the purposes of this study are handled and stored in accordance with the United Kingdom's (UK's) General Data Protection Regulation (UK GDPR) and the UK's Data Protection Act 2018. The data underlying this article are available in the article and in its online Supplementary Material.

Identifying information about the participants were removed from the data. Each participant was assigned a unique participant code, which was used on all of their data. A separate document that links the study codes to the identifying information has been digitally stored and protected. Only the research team had access to this document.

Consent for Publication

The authors confirm that this manuscript, including related data, tables and figures, has not been published previously elsewhere or is under consideration for publication. The authors confirm that the article contents can be published.

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Author Contributions

To confirm, in line with your requirements, all authors have met the following criteria:

1. Made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas.
2. Have drafted or written or substantially revised or critically reviewed the article.
3. Have agreed on the journal to which the article will be submitted.
4. Reviewed and agreed on all versions of the article before submission, during revision, the final version accepted for publication, and any significant changes introduced at the proofing stage.
5. Agree to take responsibility and be accountable for the contents of the article.

The Lead author is prepared to explain the presence and order of these individuals.

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