



## “It’s just like putting your socks on”: patients’ perspectives on inflammatory bowel disease medication adherence

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### ABSTRACT

**Background:** A careful, often life-long, medication regimen is central to therapy for Inflammatory Bowel Disease (IBD) - a chronic gut disorder. Hence, medication adherence (MA) – patients taking medications in line with prescription – is important. Previous research indicates that a third of patients with IBD in southern New Zealand have poor medication adherence (MA).

**Objective:** This study investigated these patients’ experiences to determine factors that influence their MA, for the first time.

**Methods:** Two focus group discussions (FGDs) were held with IBD patients in Otago, New Zealand. Reflexive thematic analysis from a ‘direct realist’ viewpoint was used to analyse the data.

**Results:** Data were analysed in three segments: perceptions, experiences and support. Participants perceived MA as a “duty” that was very important to their wellbeing. The participants’ MA was centred around a routine requiring proactivity to maintain. MA was negatively impacted by side effects and regimen factors including (high) pill numbers/dose frequency, and getting refills was framed as challenging; whilst healthcare professionals were presented as major MA facilitators. Lastly, the support structures identified included family, friends and colleagues as well as targeted health system factors e.g. medication subsidies.

**Conclusions:** Factors spanning those related to the patients, their socioeconomic status, the disease, IBD therapy and the health system were presented as influencing IBD patients’ MA in southern NZ. Thus, multifaceted interventions are needed across the health system to overcome the inhibiting and promote the facilitating elements.

### 1. Introduction

Inflammatory Bowel Disease (IBD) is a chronic gut disorder comprising Crohn’s Disease (CD), Ulcerative Colitis (UC) and IBD-unclassified (IBD-U).<sup>1,2</sup> People with IBD may experience symptoms consistent with gut inflammation, such as abdominal pain, (bloody) diarrhoea, urgency, nutritional deficiencies amongst others.<sup>1,2</sup> IBD management mainly involves regular monitoring and a careful, often life-long medication regimen, besides surgical, dietary and other interventions.<sup>1,2</sup> Polypharmacy commonly characterises IBD therapy with varying doses of multiple medications used, resulting in complex medication regimens.<sup>2</sup>

Medication adherence (MA) is “the process by which patients take their medication as prescribed”.<sup>3</sup> Poor MA is a challenge across clinical disciplines, with adherence averaging around 50% across long-term diseases.<sup>4</sup> For IBD patients, evidence from southern New Zealand (NZ), Australia and South Korea, report poor MA levels of 31.1%, 28.7% and 36.2%, respectively.<sup>5–7</sup> Also, patient self-perception of MA can often be markedly different from that measured using standardised MA tools, with a third of patients over-/under- estimating their MA when compared to their MA measured with a validated MA questionnaire, ProMAS.<sup>5</sup> Poor adherence can lead to disease progression, especially in IBD, yet without the patient immediately experiencing noticeable symptoms, or with patients even being considered to be in remission.<sup>1</sup>

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Hence, MA is important irrespective of symptom severity.

In NZ, conventional IBD therapy involves the use of lower-potency medications, with gradual escalation to more advanced therapeutics if needed.<sup>8,9</sup> IBD medications include: 5-Aminosalicylic acid drugs - 5-ASAs (e.g., sulfasalazine, mesalamine); Corticosteroids (e.g., prednisone/prednisolone); and Immunomodulators (e.g., thiopurines - azathioprine, 6-mercaptopurine (6-MP) etc.).<sup>9-11</sup> Further therapeutics include biologic agents (e.g., infliximab, adalimumab (and its biosimilars), vedolizumab, ustekinumab etc.), and Janus kinase inhibitors (JAKi) (Tofacitinib etc.).<sup>9-13</sup> Others, e.g. antibiotics, may be used depending on the disease presentation. Access to the publicly funded advanced therapeutics, e.g., biologics, is restricted and requires special authority; hence, MA is essential in NZ.<sup>9</sup> Poor adherence to IBD therapy is linked with worse disease outcomes, therapy escalation, and increased morbidity, disability, mortality and health costs.<sup>14</sup> Social and medical factors impacting MA amongst IBD patients include medication side effects, dosing complexity, education, patients' beliefs, amongst others.<sup>15,16</sup>

The health system in Aotearoa New Zealand (NZ) is centralised, and mainly publicly run and funded. Manatū Hauora-Ministry of Health (MoH), headed by the Minister, has overall responsibility for all areas of health including medications.<sup>17</sup> Specialised parastatals reporting to the MoH handle different aspects of health. Introduced on 1st July 2022, Te Whatu Ora-Health NZ plans and commissions hospital, primary and community health services (including in pharmacies), Te Aka Whai Ora-Māori Health Authority makes sure the health needs of Māori are prioritised across the health system, and the Public Health Agency is responsible for safeguarding population health with a focus on the determinants of health and health equity matters.<sup>17</sup> The New Zealand Medicines and Medical Devices Safety Authority (MedSafe NZ)<sup>18</sup> is the medicines regulator, while the Pharmaceutical Management Agency (PHARMAC)<sup>19</sup> determines which medications are publicly funded on the 'schedule' and the criteria for accessing such funding.

Until 30th June 2023, all medications listed on the publicly-funded schedule attracted a \$5 NZD co-payment, but when a family received 20 dispensed items in a year, no further co-payments were levied until the next year.<sup>20</sup> Since 1st July 2023, this co-payment has been completely waived by the government, with the exception of prescriptions issued by non-publicly funded prescribers, and specialists, still commanding a \$15 co-payment for the first 20 items per family per annum.<sup>20</sup> Some medications on the publicly-funded schedule however are only able to be accessed once certain clinical parameters are met. Hence, prescribers must obtain 'special authority' from PHARMAC for their prescriptions of certain (more expensive) medicines (e.g. adalimumab,<sup>21</sup> budesonide,<sup>22</sup> and others) to be publicly financed; but most pharmaceuticals on the schedule are funded without requiring special authority. Patients also face point-of-care costs particularly as, although primary care does receive some government funding, most general practitioners (GPs) charge individually determined co-payments for consultations/prescription issuance/medicines administration, which can be material. While all public hospital and specialist treatments are government funded, there can be delays in time to be first seen. Health services are much quicker accessed in the private sector.

New Zealand had approximately 21,000 people with IBD as of 2016, which, growing yearly by 5.6%, is expected to double by 2028.<sup>8</sup> The cumulative financial cost of IBD to the country was calculated as NZD \$245 million yearly,<sup>8</sup> comprising direct (hospital admissions, medicines, general practitioner (GP) visits etc.) and indirect/societal (job loss, time off work, lost taxes etc.) costs. The direct patient costs specifically include GP consultation fees incurred repeatedly by (IBD) patients to collect refill prescriptions, as medications are prescribed for a maximum of three months,<sup>23</sup> and, previously, up to NZD \$100 per annum co-payments for medications.<sup>24,25</sup>

The Pharmaceutical Management Agency (PHARMAC) classifies the barriers to medicine access thus: barriers to healthcare access such as delayed access, costs, transport etc.; structural barriers encompassing

organisation of care - e.g., accessing appointments, wait times, completing referrals etc.; and provider capacity to address individual patients' needs (e.g. cultural safety and competency, knowledge and skills etc.).<sup>19</sup> These are congruent with those identified by the World Health Organisation (WHO) namely: patient-related, disease-related, therapy-related, socioeconomic and health system factors.<sup>4</sup> These manifest across the spectrum from patients making a GP appointment for a prescription, receiving the prescription, getting to the pharmacy and picking up the dispensings. This process is repeated for ongoing refills.

Considering these systemic and personal barriers to MA, and the NZ IBD therapy landscape, this study investigated the MA experiences of New Zealand IBD patients, for the first time, using focus group discussions (FGDs). This was to gain insights into the factors influencing MA and signpost areas needing attention to aid the IBD patients' adherence. Qualitative methods (e.g. FGDs) are well-suited to investigating people's experiences of phenomena,<sup>26</sup> and have specifically been used in studying chronic disease patients' experiences with MA.<sup>27,28</sup>

## 2. Methods

### 2.1. Recruitment

Following ethics approval by the University of Otago Human Ethics Committee (Health) (reference number: H21/091), IBD patients within Otago, New Zealand, were invited to partake in the study via advertisements posted over three months on the community/social media pages of the Otago Crohn's and Colitis Support Group (OCCSG) - a voluntary self-managed peer-support group. For improved response, patients visiting gastroenterology outpatient clinics of Dunedin Hospital, Dunedin, NZ were also invited in-person. In keeping with sample size guidance for research into lived experiences (<10 participants),<sup>29</sup> the discussants comprised a convenience sample of seven (7) patients. Written informed consent was provided by all discussants.

### 2.2. Focus Group Discussions (FGD)

Two FGDs, lasting around an hour and thirty minutes each, were conducted in November 2021 within the Department of Medicine, University of Otago, Dunedin Hospital, Dunedin, NZ. The venue was familiar and very accessible to the patients, and a NZ\$20 grocery voucher was provided to each discussant. The FGDs were split due to the strict covid-19 mitigatory physical distancing regulations. Guided by a moderator, FGDs are used for obtaining data via group-based dialogue allowing for the co-creation of knowledge by discussants.<sup>30,31</sup> FGDs are appropriate for gaining insights into experiences, behaviours and viewpoints on diverse issues and are regularly employed in health research to obtain deep and broad data on patients' perspectives on health systems and their lived experiences with disease, as is the purpose of the present research, amongst others.<sup>30-32</sup> FGDs create an atmosphere more natural than individual interviews as participants can interact amongst themselves in a manner similar to everyday settings.<sup>30</sup>

Both FGDs were moderated by Author 1 using the same pre-prepared discussion guide (See Supplementary Table). Audio recordings were taken and manually transcribed, *ipsisima verba*. The transcripts were anonymised pre-analysis, with each discussant assigned a number (D1 - D7).

### 2.3. Thematic analysis

The FGD transcript was analysed using thematic analysis (TA), which is "a method for identifying, analysing, and reporting patterns (themes) within data".<sup>33</sup> This reflexive technique views researcher subjectivity as a valuable resource, with the themes considered as generated by researchers rather than revealed from the data. The analysis was conducted in six steps as outlined by Braun and Clarke (2006). First,

familiarisation with the data via a read through. Second, highlighting fundamental details of the data through coding. Thereafter, generating themes by aggregating connected codes. Then, reappraising the themes for alignment with the data. Following this came naming and explaining the themes, and, finally, drafting this article on the findings.<sup>33</sup> An iterative manual process, done using Microsoft Word, was employed in executing these steps.

The first four steps were done separately by Authors 1 and 3, who then consolidated their themes to reach a consensus and resolve any discrepancies in themes generated. Author 1 completed the final two steps before review of the article by all four authors. A “direct realist” epistemological framework was adopted in conducting the TA; this holds that a specific reality exists which is purely reflected by the data.<sup>26</sup> Thus, the discussants’ words were taken at “face value” as a direct description of their realities.

### 2.3.1. Reflexivity

Recognising the influence of researcher subjectivity in generating themes, contemplation on their “construction of meanings” through reflexivity is important.<sup>26,34</sup>

Author 1 is male and Black African from Sub-Saharan Africa, while Author 3 is female and New Zealand European from Aotearoa New Zealand; hence, both brought a diversity of lived experience with MA in quite different health systems to the analysis. Author 1 is a PhD candidate in health science, with a background in biomedical sciences and public health. Author 3 is a professor of pharmacy working in pharmacovigilance and public health. Their research spans MA in general and specifically amongst IBD patients. Thus, both approached the analysis with a firm belief in modern medicine and the value of MA to the health of patients with IBD. Both interpreted the data with the expectation that patients needed to attain the highest possible level of MA to derive maximal benefit from their therapeutics. Neither were involved in the clinical care of the patients nor had any contact with the patients outside of the study.

## 3. Results

Six women and one man, five with CD and two with UC, partook in the FGDs; three in the first and four in the second. Aged between 20 and 70 years, six discussants identified as NZ European, and one as Māori and NZ European. They included students, workers and the self-employed.

The data was analysed in three segments: perceptions, experiences, and support. The first focused on how the discussants conceptualise adherence; the second explored the discussants’ lived experience with MA; whilst the third considered what factors aid the discussants’ adherence and what further support they desired.

### 3.1. Perceptions of Medication Adherence (MA)

#### 3.1.1. MA as a Duty

The discussants described MA as fulfilling their duty by following prescribers’ instructions and taking responsibility to secure and administer their medications themselves.

"For me it's...following a prescription and taking the medicine when you need to take it. And, ...not forgetting". (D2).

Trusting their prescribing healthcare professional (HCP) underpinned this their view of MA:

"...trusting what your doctors are saying and following them and the pharmacists...". (D3)

Again, the discussants overwhelmingly described good adherence as following the prescriptions of their HCPs:

"...good is doing everything as prescribed to you". (D2)

Poor adherence was couched as purposely not taking one’s medications but excluding occasionally forgetting to take them:

"...if you know that you forget often... making sure that you like set a

reminder or something is good. ...I don't think forgetting every now and again is you not adhering...". (D4)

The caveat to this is that patients should take steps to remember to take their medicines; doing so would then constitute good MA. There was consensus agreement on this point by all discussants.

#### 3.1.2. MA as Important

The discussants’ consensus view was that MA is very important both to preserve their health so they might enjoy a good quality of life and to avoid inimical health outcomes:

"Um, yeah it is hugely important, ...for me; primarily because... I have Crohn's but I also have terrible arthritis, ...and because I don't have a bowel, I can't take anti-inflammatory; so, there's a cocktail of different drugs that I'm on that I have to take every day to keep me moving...". (D7)

This framing shows that the discussants view therapeutics as effective and consider MA to be essential for enjoying their benefits. These include providing clarity on disease progression/aggravation, with good MA being essential for confirming that disease escalation is not due to poor MA. This then informs the nature of further therapy:

"It's really important to me, um, because I ...just made a pretty critical decision to have my bowel removed; so, getting to this point has meant trying medication; sticking to the... regime; while testing everything very carefully. Otherwise, I don't think my headspace would allow me to accept that decision so easily". (D5)

Here, the discussant presents MA as important for getting their mind to the position where they could accept having their bowel excised. This highlights a unique psychological dimension to MA beyond managing disease symptoms and quality of life.

Still on the psychological aspect of MA, accepting the disease status was portrayed as influencing patients’ adherence behaviours.

"...it's kind of a grieving process for who you were versus who you are now and I think tablets are like the thing there like tangible because you can see them; ...so you develop ...a intense dislike that you have to take them because it makes you angry, yeah". (D7)

Making peace with the reality of life-long medication taking was not just a challenge at the initiation of the drug regimen but even after years of MA. Several discussants endorsed this sentiment. Other influential factors mentioned were the need for disease control as well as understanding how medications work against the disease in the body.

### 3.2. Medication Adherence (MA): Experiences, approaches and challenges

#### 3.2.1. Routine: the nature of MA

All the discussants described MA as part of their routine; taking medication was something they did typically in the same way and/or at the same time daily.

"...with previous medications and stuff it's just always been that routine ... I just, um, have that by my bed at night-time, so in the morning I'm up, pill, away". (D1)

However, the effectiveness of this routine approach is limited when the patient’s day-to-day schedule is disrupted whether due to non-health or health-related reasons.

Furthermore, the discussants reported having their medication cycles on their minds or feeling certain internal sensations, such as “feeling more down time” (D1), as the time for their next administration approached.

"You know, ...it's always in the back of your mind that ...it's going to come up in the future; that sort of thing. So, how long has it been since, I better check... the paperwork, and check the phone in case it hasn't told you". (D2)

In all, the discussants framed medication-taking as a routine activity they performed, which made MA become a habit over time. They internalise their medication cycles; so, their minds/bodies begin to remind them to take the next dose.

### 3.2.2. Proactivity: the fulcrum of MA

MA was overwhelmingly portrayed as needing proactivity as all discussants adopted strategies to ensure that they had enough supply of their medications and remembered to take them.

"...I have my phone calendar, ...that also like syncs with my laptop ...I have an alarm on my phone ...and I also leave one like on my nightstand in a place that when I see it; so, when I wake up, I can just roll over, grab it, take it.... But it becomes part of routine, and I can see it, it's there". (D3)

The discussants employed multipronged strategies, including positioning of the medicines for visual cues and ease of reach, using (digital/manual) calendars, reminder alarms, weekly self-filled pill organisers, handwritten lists, hospital letters with regimen dates and more besides. All these required the patients to be intentional about their adherence but also showed the breadth of options available to help in remembering to take their medications.

This proactive approach is essential when travelling. All discussants maintained the use of (digital) reminders and calendars, besides pill boxes and similar portable aids. Some had their HCPs arrange for them to receive their infusions at hospitals in places they were visiting within NZ or just planned around their infusion dates to ensure they were back home at that time.

"...one of mine is my alarms so they keep going and I have to take it; and I try to put the meds near where I'm sleeping .... I'm on infliximab with the infusions so they have to organize that with the hospital, like [location] Hospital, um, which can be a bit of a issue". (D3)

When travelling overseas, the participants reported having to obtain prescriptions, typically with surplus doses, ahead of time, and collect pre-packaged medications from the pharmacy.

"...travelling is a pain, ...and then there's the boxes of medications that's just especially if you're travelling overseas, ...it makes for a very bulky parcel, ...and then there's sometimes you get to your hotel room, and you don't have a fridge ... it's pretty much a nightmare. I mean, ...I make sure that I book somewhere that's got a fridge (*chuckles*). The worst one was... trying to travel with [Medication], ...cos you have to keep it so..., cold. ...especially with going on plane trips that was, ...pretty challenging". (D7)

Overall, international travel was presented as especially challenging to MA due to the logistics of carrying/cold storing medications, alongside customs checks, underlining the need for forward planning.

Altogether, the participants took various proactive steps to ensure they adhered to their drug regimens, and they considered their approaches to be effective as they felt that their adherence was good as they seldom missed any doses.

### 3.2.3. Regimen factors and side effects: quite impactful

The side effects of certain medications were framed as majorly hampering MA. Sometimes their severity compelled the discussant to discontinue their use altogether.

"...ones that have given you terrible, ...side effects which, you know; I've had some that make me jerk like a puppet. I've had to stop because in public (*chuckles*) it's really embarrassing; so, you know, those sorts of things ...that have side effects that you didn't know, didn't need and don't want, and it's so bad for you; you just stop because it's... too much". (D7)

It was also underlined that negative side effects can sometimes arise after completing a drug regimen:

"...drugs and side effects..., that's a real thing. ...I had a problem with steroids, coming off those (D1: nasty (*chuckles*))". (D2)

There was broad consensus on the point that adverse side effects were a significant hindrance to MA amongst the discussants. Also mentioned were disease symptoms, such as "brain fog", which make forgetting to adhere more likely.

Still on challenges to MA, the discussants pointed to several practical elements of the regimens such as the mode of drug administration.

"I think I went through a little bit like that with..., the

[Medication]; like I was getting to that point where, those ones in the leg, would just, *aaaarghh* (*shudders*), and I know it's coming and it was really hard ...I felt sore, ...taking it all the time...". (D1)

Another discussant chose to have a nurse administer their infliximab infusions in-hospital as opposed to self-administering adalimumab injections at home as that was "a lot less scary to me than to have to stab myself." (D3). Having those in-clinic infusions also afforded patients "just a nice wee bit of moment in time" (D1) to themselves away from the stresses of their daily lives.

Furthermore, the number of medications alongside the pill size were highlighted as an encumbrance:

"...I take four of one kind twice a day; it would be awesome if that could be reduced down to one pill. ...'cos by the time you've had three devils, ...you choke on the pill. *Chuckles*. (D7: exactly... over the big horse ones which have a nice coating, but they still get stuck down your throat...) ...yeah". (D5)

The dose frequency also does impact MA as taking all medications once a day was presented as most convenient:

"It's not so much of the amount of it, it's the frequency. So, I prefer to take it all in one go". (D4)

The patients communicated these challenges to their prescribers to inform changes to the regimen. Notwithstanding, other participants considered their medications to be of a comfortable number and frequency for them to manage.

### 3.2.4. Getting refills: a mission in itself

A major bottleneck in the MA process for the discussants was in obtaining refill medications. The discussants considered having to obtain new prescriptions periodically (every 3 months) a redundant hindrance as IBD is a chronic life-long disease and they were often on the same regimens for extended periods.

The discussants also presented GPs as not always understanding IBD or being unfamiliar with their medical history. The latter was the case when the participant saw a different GP due to a change in the practice members or when they visited community/student health centres and thus did not have a regular GP/HCP they consistently saw.

The participants also reported challenges in securing appointments with their GPs and in affording the costs of getting the prescriptions from GPs or the medicines from the pharmacy.

"So, if you get a repeat prescription and you had to go to the GP and they said so that's gonna be \$60 or a \$100, I would go: I don't have a \$100 or I have a \$100 but it makes a kinda financial thing". (D2)

The discussants cited both the time and financial cost of obtaining a repeat GP prescription as hindering their MA. Available GP appointments were sometimes weeks away especially for those using student health facilities. Again, the process of obtaining refills was sometimes inefficient as there were occasional challenges with the GP acting on discussants' emailed requests to forward their prescription to the pharmacy, causing considerable stress.

"...the week before when you pick up your last repeat you've got to then email. And sometimes they get it, sometimes they don't ...or it could be in their spam box". (D7)

The process of getting medication refills has also been compounded by covid-19 mitigatory protocols especially for multiple discussants who had non-covid-19 respiratory symptoms:

"I couldn't get my drug ...for a couple of months because I was sick .... 'Cos I do have a cough, and I know it's not covid like I know it's fine, I could come see you but, you're not gonna let me...". (D3)

Altogether, most respondents described the refill process via GPs as stressful and fraught with multifactorial obstacles ultimately hindering their MA. Nonetheless, a minority of participants who mainly got their refill prescriptions from their specialist had no problems with that process. This suggests a dichotomy in the refill procedures of the two categories of HCP needing further exploration to advise improvements in the GP-facilitated refill process.

### 3.3. Support structures for Medication Adherence (MA)

#### 3.3.1. Healthcare Professionals: facilitators of MA

Healthcare professionals (HCPs) - specialist doctors (gastroenterologists), general practitioners (GPs), nurses and pharmacists alike - were highlighted as facilitating MA. MA came up mainly when dealing with HCPs who often inquired about the patients' adherence behaviours.

"Um, yeah, mainly my specialist will ask, ...what I am taking and kind of check-in then, ...perhaps at the pharmacy they'll ask: have you taken this before? How often do you take it? .... And then sometimes when I go to my GP he will ask as well just because there might have been changes from the specialist since I'd last been to see him". (D6)

HCPs also provide reassurance of their availability if patients need them, which the discussants consider a welcome comfort in aid of their adherence.

"[Specialist] has been a major... I know that if anything was too terrible; ...if I have his direct line, I would be ringing him and he would pick it up.... ... I have got the IBD nurse on my phone that I can text". (D1)

The discussants also mentioned that this interest in their adherence depended on the individual HCP, as some HCPs showed less concern than others, which meant that sometimes, as one respondent mentioned, no one had inquired about the patient's MA behaviours.

#### 3.3.2. Family and Friends: allies in MA

Family, partners, friends and colleagues were spotlighted as facilitating the participants' MA in diverse ways.

"...a lot of my friends and flatmates and ...the people around me do know what medications I'm on and so, they'll often go, 'when's your next infusion?' ...and check in with me after...". (D3)

Besides providing reminders, family and friends also assisted the discussants more practically including by collecting the medications from pharmacies and dispensing the medicines to the patients when they were indisposed.

"...my husband, ...if I'm out of the house a lot he will back up with picking stuff up from the chemist, ...but I do see it as my responsibility to... make sure I've got enough of it". (D5)

To facilitate this, the discussants sometimes made written lists of their medication regimens in simple terms for their family, especially when recovering from surgery. Notwithstanding, the discussants viewed MA as their own primary responsibility.

Employers and colleagues were also presented as supporting participants' MA, including by giving time off for medical visits and inquiring about their health, although a participant preferred to keep their health status private at work.

The influence of family and friends on the participants' MA was also nuanced as family duties such as childcare and the lack of support from family were mentioned as hampering MA. Some family members were cited as being alarmed by the volume of medications the patients were on and discouraging their use.

#### 3.3.3. Health Systems: essential for good MA

Health systems were framed as significantly aiding MA, with the support ranging from sending patients text reminders of upcoming refills to efficient health system processes:

"I email the GP, the script goes to the chemist, and I get a text to say that it is there, or they text me when it's ready, it's time for the refills; so, they've made it as easy as they can. And ...the chemist ...will also deliver if I needed them to deliver; ...which they have done ... when I've been really sick". (D5)

However, the efficiency of the system was dependent on the individuals working at that time suggesting a provider-based variation in service.

Medication subsidies provided by the NZ government were also spotlighted as a systemic aid to MA as this quote evinces:

"Once you get to \$100 then they make them free after that...". (D7)

The kinds of support the discussants desired were centred around the refill process and overcoming the challenges hereinbefore identified.

"...I ...keep sending the scripts for the same stuff to the GP who writes the scripts, who sends it to the chemist. ...it's almost like I wish someone would just tell them when it's stopping not having this constant repeat, ...because, I mean, some of this stuff I've been on for, I don't know, 12 years or more probably...". (D5)

The discussants concurred in the desire for a more automated process of securing prescription scripts for refills from the GP because of its repetitive nature and to avoid inefficiencies in the manual process leading to delays in getting the medications dispensed.

Another aspect was to be allowed to obtain a refill more than one week before the current supply runs out because obtaining a refill can sometimes take a week. Participants also spoke about wanting a generally more streamlined refill process including for controlled medications where several release forms have to be signed both at the GP's and the pharmacy. They also desired a refill process completely free of charge whether to obtain a script from a GP or in terms of co-payments at the pharmacy.

Additionally, the participants contended that drug-based therapy alone was insufficient for their holistic health, and desired more green prescriptions (prescriptions for non-pharmaceutical interventions e.g. dietary regimens) to promote physical activity and advice on their dietary needs. They also underlined the (six-month) delays experienced in accessing a dietician:

"it's one thing to stick to your meds but that's not gonna affect everything, ...it took from April until October to be able to see a dietician here and it's quite a long time to be waiting and trying to work out what does agree with me, what doesn't agree with me; trying to navigate on your own can be quite hard". (D3)

As IBD is a gut disease, it significantly impacts patients' diets, hence the need for dietary guidance, spotlighting room for improvement in the conventional IBD therapy needing system-based interventions to remedy. One patient had private medical insurance which allowed them quicker access to diverse private sector health services.

## 4. Discussion

This study provides insights into the medication adherence (MA) experiences of IBD patients within Otago, New Zealand. Their experiences align with the five clusters into which factors impacting MA are delineated by the World Health Organisation (WHO).<sup>4</sup>

Per the WHO, *patient-related factors* include beliefs, approaches, expectations, knowledge, perspectives and others.<sup>4</sup>

The discussants considered MA to be very important to their IBD management, viewing MA as helping to maintain their health and wellbeing, and prevent worse disease outcomes. This was buttressed by their accepting their IBD diagnosis and understanding how the medications functioned, within their bodies, in managing the disease. Poor MA is linked with worse treatment outcomes including flare-ups and complications necessitating escalation of therapy, e.g. via frequent corticosteroid use and surgery, alongside higher morbidity, mortality, disability and health costs.<sup>9,13</sup> These findings concur with the views of IBD patients in the UK,<sup>27</sup> diabetes patients in NZ<sup>28</sup> and UK guidelines which recommend that prescribers "clearly explain the disease ...and how the medicine will influence this", to aid MA.<sup>35</sup>

Moreover, as a patient expressed, sometimes (good) MA can provide psychological comfort that disease progression is not always the result of poor adherence and, hence, is unavoidable. This reinforced the discussants' view of MA as a duty to follow the medication regimen. Central to this was trusting their prescribing HCP, echoing the findings of an MA literature review that identified patients' trust in prescribers as essential to MA.<sup>36</sup> Prescribers can also help patients accept the long-term regimens by tailoring their approach to the patients' views of the disease and need for the regimen. As these patients' perspectives are unique,

prescribers should allow for robust communication and be patient with patients as they come to terms with their diagnosis and the need for MA.<sup>37</sup>

Good MA was understood to be diligently following the regimen although occasionally forgetting was permitted; whereas poor MA was not taking one's medications either on purpose or by consistently forgetting without making an effort to remember e.g. by using a reminder alarm etc. Taken together, the discussants' perspectives of MA align with its definition as "the extent to which patients take medications as prescribed by their health care providers".<sup>38</sup>

The participants all adopted a medication-taking routine; upon waking, with breakfast, at bedtime etc. The downside to this was forgetting to take their medication if their daily routine was disrupted, e.g. when working at irregular times. This routine approach was similarly employed by elderly interviewees of a Dunedin, NZ-based study, to aid their MA.<sup>39</sup>

The hallmark of MA was proactivity, from patients obtaining a prescription through to remembering to take them or, when travelling, pre-stocking up on medications, using cooler bags when in transit, ensuring hotel rooms had fridges, and making provision for customs checks and proper medicine storage. There was broad consensus that MA required conscious effort by the patient. American adolescent IBD patients, alongside their parents, reported taking similar proactive steps in aid of their MA.<sup>40</sup> Healthcare professionals can facilitate these processes e.g. by issuing prescriptions to cover time spent abroad, scheduling appointments based on patients' availability, amongst others. Instructively, programmes such as IBD Passport have been developed to support IBD patients' international travel with information, networks, resources and planning.<sup>41</sup> This can be recommended to support patients.

*Disease-related elements* include comorbidities, disease symptoms etc., per the WHO.<sup>4</sup> The discussants noted that disease symptoms such as "brain fog" associated with fatigue made forgetting to adhere more likely. Whereas, the subtle appearance of symptoms, e.g. tiredness, served as a reminder to take upcoming medication doses; thus presenting the impact of symptoms on MA as bidirectional.

Furthermore, *therapy-related factors* stated by the WHO include adverse effects, dosing complexity, amongst others.<sup>4</sup>

Adverse side effects of medications constituted a major hindrance to the discussants' MA and sometimes led to medicine use discontinuation - in consultation with their HCP - and a reluctance to use such medicines again especially when the effects arose at the end of the recommended regimen. This agrees with the findings of several studies that have repeatedly identified adverse effects as significantly inimical to MA in patients with IBD, cardiovascular diseases, diabetes, tuberculosis, amongst others.<sup>27,42-44</sup>

The nature of the drug regimen also impacted the participants' adherence, with factors including a high number of pills and complex dosing regimen, alongside the mode of administration - e.g. a [Medication] pen caused significant soreness at the application site - and large pill size, hindering MA. The discussants preferred simpler regimens as, for instance, a lower dose frequency, e.g. once a day, helped adherence as there were fewer opportunities to forget. US-based IBD patients also framed pill size and dosing frequency issues as hampering their MA.<sup>45</sup> Our discussants might benefit from the NZ Medication Use Review and Adherence Support Service (MUR) where a pharmacist interviews patients to assess MA and identify/proffer solutions to their individual barriers to MA.<sup>46</sup> The MUR would help identify avenues to streamline patients' medication regimens and suggest more palatable formulations. Unfortunately, this service is not available in the study District Health Board (DHB). Some HCPs encourage IBD patients to increase their dosage when having disease flares and reduce same when not experiencing active disease. This might lighten the pill burden on the patients. Such self-management is linked with better health outcomes across several chronic diseases.<sup>47</sup>

Moreover, the WHO classes family dynamics, employment, education status, age, race, etc., as *socioeconomic factors*.<sup>4</sup>

The discussants received moral/practical support from their family, partners, friends, employers and colleagues. This encompassed reminders to take their medication, help with collecting medicines from pharmacies and administering the drugs to the participants during times of illness by family/friends, and employers giving time off work for medical appointments etc. Nevertheless, family members sometimes opposed a patient's MA. This phenomenon has been reported in the literature, with non-supportive family members recommended as targets of education for HCPs on the importance of MA.<sup>36</sup> Similarly, NZ diabetes patients considered family/friends'/colleagues' support as aiding their MA, but also noted that not all of their family/friends were supportive.<sup>28</sup>

*Health system factors* including provider-patient communication/relationship and healthcare access, including cost of healthcare, constitute the fifth WHO category.<sup>4</sup>

HCPs significantly aided the discussants' MA through both active and passive means. These include by asking about the patients' MA behaviours and by being contactable by the discussants, thus giving them an opportunity to raise any MA-related issues. Similarly, NZ diabetes patients presented being familiar with/having access to their HCPs as essential to MA as this helped them build trust with their HCPs.<sup>28</sup> A respectful patient-HCP relationship has also been identified by USA/Sweden-based studies as an expectation of IBD patients, as supporting MA in patients with Acute Coronary Syndrome, and as necessary for creating a safe-space that allows patients raise issues like non-adherence behaviours and drug side effects.<sup>36,48,49</sup>

A major challenge the discussants had was in obtaining medication refills. Some had trouble securing appointments with a GP to get a new script and/or found the GP fees of \$18 - \$60, to be a barrier. The 2020/2021 New Zealand Health Survey found that 10.2% and 3.1% of the respondents reported not seeing a GP or not obtaining prescribed medications, respectively, due to the cost.<sup>50</sup> Other FGD discussants repeatedly experienced times when the GP either did not receive their emailed request for a new script or did not send the script to the pharmacy timeously. The covid19 mitigatory restrictions further hamstrung some participants as they were not permitted to visit the GP if they had any respiratory symptoms even when not covid19-related. Again, all participants considered having to secure new scripts every 3 months as unnecessary as they have a chronic disease needing lifelong therapy with regimens remaining unchanged for extended periods. This 3-month medication supply period is considerably shorter than in comparable countries. In the UK, repeat prescriptions are initially valid for six months and thereafter for as long as stated by the prescriber.<sup>51</sup> However, prescriber input may still be needed to approve the issuance of refills and the regulations might vary across the constituent nations of the UK. Thus, in NZ, consideration should be given to allowing continuation of dispensing by pharmacists where a patient is stable with a long-term condition. Notwithstanding, a small minority of participants who mainly received their scripts from a specialist found the process to be smooth and efficient. This specialist-prescribing service is freely available to all IBD patients in the region, but not all discussants seemed aware of this, suggesting a need for better communication of this.

The NZ health system facilitated the discussants' MA in diverse ways with discussants citing the subsidised medication costs as a significant MA facilitator. They also considered the refill process to be generally smooth; however, the efficiency of the process was dependent on the individual provider involved. This suggests a need for a better systemic approach which ensures consistent quality of service independent of the staff.

The participants highlighted systemic innovations that would aid their MA. They recommended an automated refill system not needing new prescriptions every few months. Instead, the pharmacy should be informed to stop dispensing the medications to the patients when the prescription is discontinued by the HCP. The participants would also welcome being allowed to pick up refill medications more than the standard one week in advance of exhausting the current supply as it sometimes takes a whole week to get a refill dispensed. As an aside, the

participants expressed an interest in non-medical prescriptions, such as green prescriptions for exercise, and access to a dietician. They considered drug-based interventions as effective but inadequate for their holistic health. This suggests failings in the system of IBD care needing attention because IBD care is best delivered by a multidisciplinary team comprising a gastroenterologist, dietician/nutritionist, mental health HCP, pharmacist, and nurses (IBD/specialist) etc.<sup>1,52,53</sup> Health system improvements to ensure sufficient availability of such multidisciplinary HCPs and resources within a seamlessly accessible system are needed. These will require health policy evaluations of the status quo and interventions to bridge gaps in service delivery.

As representative sampling is not the focus of qualitative studies,<sup>26</sup> we recognise that the experiences of other groups of IBD patients might differ from our discussants'. However, we are confident that our themes provide robust insights into the realities of people with IBD in Otago, New Zealand, as our sample size aligns with guidance for research into lived experiences ( $\leq 10$ )<sup>29</sup>; besides, our study was set in the small city of Dunedin surrounded by dispersed towns from which some participants came. Hence, all willing participants were included. Our discussants cut across the age spectrum and encompassed people in different occupations and family situations. Moreover, our findings concur with those of similar qualitative studies of IBD and other patients from NZ and overseas. Although we accepted all those available to partake in the FGD, we note that more respondents and further ethnic diversity would have enriched the discourse. However, our recruitment was limited by covid-19 mitigatory regulations that discouraged in-person gatherings. Future research should build upon this study, with a larger sample size, perhaps across locations. As the impacts of the pandemic have now eased, this would illuminate any more recent changes to the MA landscape. Virtual FGDs and/or qualitative questionnaires can also be adopted to improve accessibility for geographically dispersed patients.

## 5. Conclusion

Our findings indicate that NZ IBD patients are motivated to practice good MA but face systemic challenges needing multipronged interventions in health promotion policy to resolve. MA in IBD is complex with patients often taking several medicines in varying doses/frequencies, administered via different routes (oral, intravenous, suppository, subcutaneous) and needing different storage environments. MA is, however, essential as uncontrolled IBD can lead to serious surgeries including gut resection besides considerably impacting patients' well-being. As patients remain on long-term, sometimes unchanging, medication regimens, the utility of repeated GP appointments, within short intervals, solely for securing refill prescriptions is questioned. This imposes a material time, logistic and financial cost on patients, and burdens GP services, which are often strained to meet the general population health demands. This, amongst other matters, requires the attention of relevant (cross-sector) stakeholders to address.

## Ethics approval statement

Ethics approval was granted by the University of Otago Human Ethics Committee (Health) (reference number: H21/091).

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## Patient consent statement

All patients completed and signed written informed consent forms.

## CRedit authorship contribution statement

**Obreniokibo Ibifubara Amiesimaka:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Kristina Aluzaitė:** Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing. **Rhiannon Braund:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Resources, Supervision, Validation, Writing – review & editing. **Michael Schultz:** Conceptualization, Supervision, Writing – review & editing.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Data availability

The de-identified FGD transcript data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.rcsop.2023.100385>.

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