Patient Preference and Adherence

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ORIGINAL RESEARCH

Deprescribing 5-Aminosalicytes in Patients with Ulcerative Colitis on Concomitant Advanced Therapy: A Qualitative Analysis

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Purpose: Data suggests 5-Aminosalicytes (5-ASA) medication does not influence outcomes in patients with moderate to severe ulcerative colitis (UC) on advanced therapy and can be discontinued. However, patients' perspectives on discontinuing UC-related medications have not been evaluated and should be incorporated when considering therapy changes. This study explored patients' experiences with UC treatment (5-ASA) in combination with advanced therapy, and barriers, facilitators, and attitudes toward deprescribing 5-ASAs.

Patients and Methods: To qualitatively evaluate patients' views on 5-ASA medication discontinuation two focus groups were conducted for patients with UC on stable doses of 5-ASA medication and advanced therapy for at least 6 months. Patients were asked about their satisfaction with and barriers to current therapy, quality of life, and opinions about the potential medication deprescribing. Transcripts were analyzed using an iterative inductive/deductive approach.

Results: Ten patients participated with an average age 50 years (SD ± 11 years), 50% Female, and 80% White. Advanced therapy included tofacitinib (20%), vedolizumab (20%), or infliximab (20%). Qualitative analysis identified patient and clinician factors in the deprescribing process. Patient themes included emotions and coping, quality of life, attitudes and beliefs, experiences with the condition, and symptoms. Participants identify clinician themes including endorsement, communication, patient relationship, information distribution, and deprescribing readiness for change. The shared patient/clinician risk assessment was vital to moving towards deprescribing, however the decision to deprescribe was influenced by barriers and facilitators including further discussion with their clinician.

Conclusion: Patients with UC on advanced therapy and 5-ASA are open to deprescribing their 5-ASA but would have questions for their prescribing clinician including assurance of continued symptom management or ease of returning to the 5-ASA if needed.

Keywords: ulcerative colitis, deprescriptions, focus groups, risk assessment

Introduction

Ulcerative colitis (UC) is an inflammatory bowel disease (IBD) resulting in chronic, relapsing inflammation which affects the colon.[1] 5-Aminosalicytes (5-ASA) are the first line of therapy for patients with mild to moderate UC to induce and maintain remission.[2,3] Patients who progress to moderate to severe UC despite 5-ASA therapy require escalation to advanced therapy.[4] Several advanced therapies exist for the treatment of moderate to severe UC including anti-tumor necrosis factor (TNF) therapy, anti-integrin therapy, anti-IL12/23 therapy, anti-IL23 therapy, and small molecule treatments such as janus kinase inhibitor (JAKi) therapy.

For patients prescribed a 5-ASA who are escalated to an advanced therapy, recent research suggests that clinical outcomes are not influenced by 5-ASA discontinuation.[5] Discontinuing 5-ASA after starting advanced therapy is likely to benefit patients by lowering medication burden and cost.

Deprescribing medication is defined as the intentional dose reduction or discontinuation of a medication that may no longer be beneficial or when the potential benefit of treatment no longer outweighs the potential harm.[6] Although evidence

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suggests deprescribing can be safe and feasible to optimize medication use, several studies report barriers to deprescribing from the patient's perspective.[7–12] A systematic review evaluated patients prescribed various medication classes/therapeutic groups to identify barriers and enablers that could influence patients' deprescribing decision. Barriers included favorable perceptions of medications, fear of medication discontinuation, and discouragement from healthcare clinicians. Enablers included relationships with physicians, clear benefits of deprescribing, deprescribing education, and follow-up.[7]

Though limited deprescribing studies exist, none have explored the deprescribing of 5-ASA for patients with moderate to severe UC who are on advanced therapy. Given the potential benefit of reducing the number of medications patients are required to take to maintain UC remission, and recent clinical data suggesting lack of continued benefit of 5-ASAs with advanced therapy, research is needed to optimize the implementation of deprescribing opportunities. Therefore, the purpose of this study was to explore patients' experiences with UC treatment (5-ASA) in combination with advanced therapy, and barriers, facilitators, and attitudes toward deprescribing 5-ASAs.

Materials and Methods

This qualitative study was conducted at a single-center tertiary care multidisciplinary inflammatory bowel disease center. In November 2022 and February 2023, two focus groups were conducted with patients taking a 5-ASA oral medication in combination with an advanced therapy. Inclusion criteria consisted of 1) a diagnosis of UC, 2) an active prescription of an oral 5-ASA, 3) on advanced therapy for a minimum of six months and considered stable, and 4) patient's clinician approval for their recruitment for the study. Eligible patients were recruited through the electronic health record patient portal, receiving an inbox message from the research team describing the study and inviting them to participate in the focus groups. There were 210 patients who initially met inclusion criteria. After chart review, 90 patients were excluded, and recruitment messages were sent to 120 patients. The patient portal message contained information about the study and a link to sign up for the focus group.

After clicking the study invitation link, potential participants completed a REDCap questionnaire to complete as part of study enrollment.[13,14] Basic demographic information, including age, race, ethnicity, and gender were collected for each patient. Patients were asked to complete a one-time 13-item questionnaire. The Patient Attitudes Towards Deprescribing Questionnaire asked patients to answer questions on a 5-point Likert scale about their willingness to have medications deprescribed and satisfaction with their current pharmacotherapy.[15] Additionally, patients rated their comfort for having the deprescribing conversation with their pharmacist, and indicated what follow-up method they would prefer if one of their medications was stopped. Patients received a $40 gift card as compensation for their time.

A focus group moderator guide was developed by a team with expertise in specialty pharmacy, outcomes research, and qualitative methods. Open-ended scripted questions were created by the research team and informed by their professional experiences. The interview guide was pilot tested and revised among the study team members. Focus groups, lasting 60 minutes, were conducted virtually by two members (K.B., MA in Social Psychology, VU-QRC Senior Research Manager, female, 12 years qualitative research experience, no prior relationship with study participants; K.C. PhD in Health and Human Physiology, VSP Health Outcomes and Research Department Sr Project Manager, female, 7 years qualitative research experience, no prior relationship with study participants) of the research team. Focus group questions can be found in Appendix 1. Recruitment stopped when study personnel determined that thematic saturation was reached, and no additional themes were identified during qualitative analysis.[16,17] Focus groups were audio recorded and transcribed by an institutional review board (IRB)-approved transcription service (rev.com). Participants were told the focu groups were being recorded, and their quotes may be used when writing results for the focus groups. Transcripts were not reviewed by participants.

Qualitative data coding and analysis were managed by the Vanderbilt University Qualitative Research Core (VU-QRC). Data coding and analysis were conducted by following the consolidated criteria for reporting qualitative research (COREQ) guidelines, an evidence-based qualitative methodology.[18] A hierarchical coding system was developed and refined using the focus group moderator's guide, preliminary review of the transcripts, and was reviewed by team members with clinical expertise in 5-ASA pharmacology. The coding system was organized into major categories, then subcategorized to capture further thematic detail. Major categories included 1) Medication type, 2) Specific condition, 3) Experiences with the condition, 4) Medication regimen, 5) Deprescribing, 6) Information sources, 7) Quality of life, 8) Emotions and coping, 9) Attitudes and beliefs, 10) Barriers and facilitators, 11) Suggestions and needs, 12) World events, 13) Notable quotes, 14) Presentation, 15) List of advanced therapies, and 16) List of 5-ASA. Transcripts were coded by two experienced qualitative data coders (KC and KB). Coders first established

reliability in using the coding system on one transcript. The transcripts were compared, and discrepancies resolved through reconciliation. After consensus was reached, one coder (KC) independently coded the remaining transcript. Each statement was treated as a separate quote and assigned up to 14 different codes. The coded transcripts were combined and sorted by code. Transcripts, quotations, and codes were managed using Microsoft Excel 2016 and SPSS version 28.

Data were analyzed using an iterative inductive/deductive approach, resulting in a conceptual framework.[19–21] Deductively, themes were identified based on a previously published framework for the deprescribing process.[22] Inductively, we then coded quotes to identify higher-order themes and relationships between themes. The process was iterative in that the framework is theoretically informed, while the specific content is derived from qualitative data.

Results

Ten patients participated in one of the two focus groups. Patients were an average age of 50 years (SD ± 11 years), 50% Female, and 80% White. Advanced therapy consisted of tofacitinib (20%), vedolizumab (20%), or infliximab (20%) (Table 1).

Table 1 Patient Characteristics

	N=10 n (%)
Age [mean, (SD)]	49.9 (11.1)
Race	
White	8 (80%)
Black or African American	1 (10%)
Chinese	1 (10%)
Ethnicity	
Not Hispanic, Latino/a, or Spanish origin	10 (100%)
Gender	
Female	5 (50%)
Male	5 (50%)
5-ASA Prescription	
Balsalazide (Colazal, Giazo)	2 (20%)
Mesalamine (Apriso, Asacol HD, Delzicol, Lialda, Pentasa)	6 (60%)
Olsalazine (Dipentum)	1 (10%)
Missing	1 (10%)
Biologic Medication	
Vedolizumab (Entyvio)	2 (20%)
Adalimumab (Humira)	1 (10%)
I am not sure	1 (10%)
Infliximab (Remicade, Inflectra, Renflexis, or Avsola)	2 (20%)
Golimumab (Simponi)	1 (10%)
Ustekinumab (Stelara)	1 (10%)
Tofacitinib (Xeljanz)	2 (20%)

Abbreviation: ASA, aminosalicylate.

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Patient Attitudes Towards Deprescribing Questionnaire

Based on questionnaire responses, patient attitudes towards deprescribing are shown in Figure 1. In brief, most patients either disagreed (40%) or strongly agreed (30%) that they felt they were taking a large number of medications. Most patients agreed (60%) or strongly agreed (30%) with the statement, "I would like to reduce the number of medications I am taking". Almost all patients felt they had a good understanding of the reasons they were prescribed each of their medications, 40% strongly agreed, and 40% agreed. When asked the question, "Having to pay for fewer medications would play a role in my willingness to stop one or more of my medications", 30% agreed, 20% disagreed, strongly disagreed or were unsure, and 10% strongly agreed. Half of the patients stated they had tried to stop a regular medication. Sixty percent of patients stated 5–9 tablets or capsules per day would be considered a lot, and 40% of patients stated 8 tablets or capsules is the maximum number they would comfortably take per day. Patients were asked, "How comfortable would you be if a pharmacist was involved in stopping one or more of your regular medications and provided the follow-up (informing your doctor of the progress?"; 40% were unsure, 40% were uncomfortable, and 20% were comfortable Finally, if one or more of their regular medications were stopped, patients preferred a face-to-face appointment follow-up (30%) or telephone call follow-up (30%) (Table 2).

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
I feel that I am taking a large number of medications	0	4	1	2	3
I am comfortable with the number of medications that I am taking	0	0	2	7	1
I believe that all my medications are necessary	0	0	4	6	0
If my doctor said it was possible, I would be willing to stop one or more of my regular medications	0	0	0	6	4
I would like to reduce the number of medications that I am taking	0	0	1	6	3
I feel that I may be taking one or more medications that I no longer need	0	3	6	0	1
I would accept taking more medications for my health conditions.	0	0	6	4	0
I have a good understanding of the reasons I was prescribed each of my medications	0	1	1	4	4
Having to pay for fewer medications would play a role in my willingness to stop one or more of my medications	2	2	2	3	1
I believe one or more of my medications is giving me side effects	2	3	4	1	0

Figure 1 Patient Attitudes Towards Deprescribing. Darker shading represents higher values, and lighter shading represented lighter values.

Table 2 Additional Deprescribing Questions

Characteristic	N=10 n (%)
Have you ever tried to stop a regular medication?	
Yes	5 (50%)
How many different tablets or capsules per day would you consider to be a lot?	
Five to 9	6 (60%)
Ten to 14	3 (30%)
Missing	1 (10%)
What is the maximum number of tablets or capsules that you would be comfortable taking per day?	
4	3 (30%)
8	4 (40%)
12	1 (10%)
20	1 (10%)
24	1 (10%)
How comfortable would you be if a pharmacist was involved in stopping one or more of your regular medications and provided the follow-up (informing your doctor of the progress)?	
Comfortable	2 (20%)
Uncomfortable	4 (40%)
Unsure	4 (40%)
If one of your regular medications was stopped, what follow-up would you like?	
Face-to-face appointment	3 (30)
Other	2 (20%)
Telephone call(s)	3 (30%)
Written information sent by e-mail	2 (20%)

Focus Group Findings

A deprescribing framework from Linskey et al (2019) that includes patient, prescriber, and system influences was modified. Since focus groups were only conducted with patients, we did not have clinician discussions of system-level influences.[22] Therefore, our deprescribing framework encompasses risk assessment influenced by patient and clinician factors, barriers and facilitators, and advantages and disadvantages which all lead to the prescribing decision (Figure 2). Patient factors include emotions and coping, attitudes and beliefs, quality of life, experiences with the condition, and symptoms. Clinician factors include endorsement, communication, patient relationships, information distribution, and deprescribing readiness for change.

Patient Factors

Emotions and Coping

Patients expressed a range of emotions when it comes to their medication regimens. Several patients were happy with their current medication regimen as it was working well:

> I am very satisfied with the regimen that I currently have.

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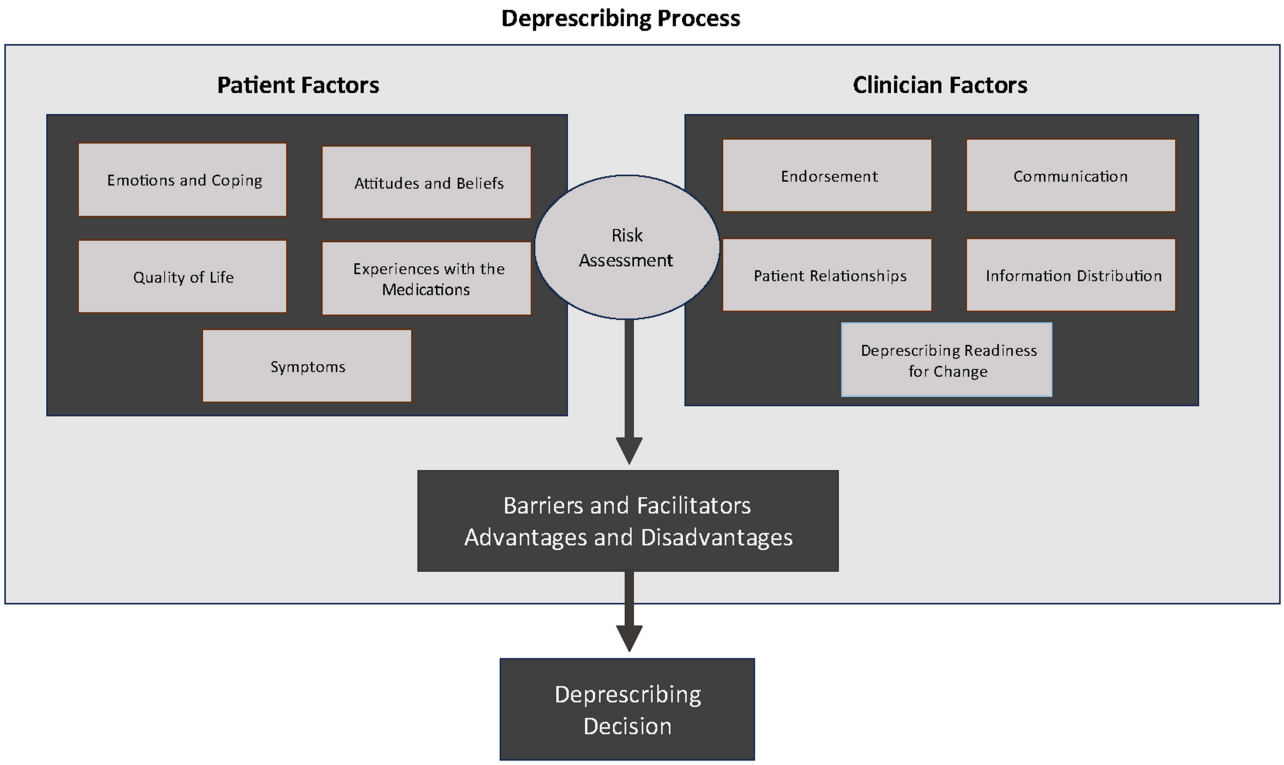

Figure 2 Deprescribing Process Framework. Patient and clinician factors, barriers and facilitators, and advantages and disadvantages that lead to the ultimate deprescribing decision.

Others expressed frustrations about non adherence and symptom recurrence.

Patients felt burdened by the number of pills and medications they had to take and expressed uncertainty surrounding taking these medications.

> It starts to stack up and be overwhelming. And so I have been guilty of when I start feeling better kind of skipping things…I can get distracted and not realize how long I've been bad until I start feeling sick and then I think, "Oh shoot, now I've screwed up my life".

Concerns included high cost of medication, adverse response to medication deprescribing, and long-term effects of taking multiple medications.

> I went to refill my meds and it was five, $600 and I was just, "No big deal, I'm just not going to take that med".

Finally, patients feared how switching their medication might affect their health.

> It is scary…I left off my evening dose of [advanced therapy] and I had a flare, not a bad one, but it was a flare. And that's when I thought, why did you go off of it?

Patients utilize many different coping strategies, including problem-based coping, avoidance, acceptance, and social support. Problem-based coping is making active efforts to manage stressful situations to modify or eliminate the sources of stress.[23] Avoidance strategies manage stressful situations by not addressing the problem directly and disengaging from the situation.[24] Acceptance is the process of learning to accept the reality of a stressful situation.[25] Social-support is getting moral or practice support, sympathy, or understanding from others.[25]

> I went to Mexico and forgot all my meds…when I got back I noticed that my skin was so much better…I decided that I was going to do my own little trial version of getting off my medications and reintroducing them each one at a time.

> I'm good with the pills in the morning, sometimes at night I'll fall asleep on the sofa and won't take them…So that's a challenge. Injections are a real challenge…I'm getting better at that, but for a while I would avoid that or procrastinate and then I'd look up and be like, "Oh crap, it's been two weeks". And I didn't realize I'd procrastinate that long…

> Just like everybody else, we do have our stints of non-inflammation so it makes us sometimes a little less compliant with our medicine regimens. We feel good, we don't really think about it until things start to go a little sideways…

Many have found social support in the form of Facebook™ groups and enjoyed talking to their peers during the focus group.

> I'll have to say I've enjoyed hearing everybody and discussing different things. It's interesting the Facebook® groups, but it does make you feel a little better. You're not alone.

Attitudes and Beliefs

Patients expressed a range of attitudes and beliefs about their current medications. Several patients stated their medication regimens have little adverse effect, and that they do not find taking medications problematic. While another patient expressed worry about long term side effects. Some patients said they would do anything to prevent new symptoms from occurring and are afraid of symptom recurrence if they stop taking the 5-ASA. They were concerned about changing their regimen given it works.

> Yeah, usually IBD is either on or off. And when it's on, nobody wants any of those problems. We would do whatever we got to do to turn it off.

> I'm more inclined to stay on regiment now just because, well, it's always been little to no cost to me, but I think it's more of a mental space you have to be in more than anything.

Quality of Life

Patients have mixed experiences on how taking their medications can interfere with their work or social life. However, several stated that quality of life was most affected when negative symptoms occur.

> And honestly, I've not thought that much about it being a big impact. The medicine is working well so I'm very happy to have whatever these little inconveniences are.

> I used to set a timer for the middle of the day. It happens right around 3:00 or 4:00 in the day. And that was a problem because I'd be in the middle of a meeting and my alarm would go off. So I stopped doing that.

> But I mean it got so bad, like [participant] said, you go to the bathroom 24 times in the day, that's not a quality life, especially if you're traveling, and it's hard, you can't eat anything.

Many patients expressed their current insurance coverage is the primary reason they are not willing to leave their current jobs to improve their quality of life. Some patients feel stuck at their dissatisfying job or are not able to branch off on their own to expand their career because their current insurance covers their medication.

> It would be the number one thing I would ask in an interview before accepting a job, absolutely.

> I'm working for state, I stay with the same one just in case maybe I had to go through this hassle to jump through hoops to get the medicine again.

> I think the insurance that I have at my current job is so good that I just don't think that I could find anything better at a corporate job. So you're kind of stuck where you are when you have good insurance.

The cost of these medications seemed to be a salient concern for patients. One participant considered not filling their prescription due to the cost, and others expressed they could not afford their medication if they did not have their insurance. Several patients receive financial assistance through copay card programs. Even with insurance, one patient meets his out-of-pocket maximum payment in January.

> If it wasn't for the copay cards, I would not be on it because even I swapped plans this year and I told mine if I was going to have to pay my deductible, I was not going to take it at all, not even consider it.

> And then it was the infusion center that told me about the [Manufacturer Copay Program]. So the finances was a big concern and I was thinking how am I going to sacrifice the health?

> And I remember first being prescribed the [5-ASA]…I was just going to take whatever they said just in hopes that it would work. But then when I went to my pharmacy and got the first prescription filled and the price was, I think, $700, I began to panic…that's just not something that I was able to cover every month.

Experiences with the Medications

Patients can receive their medications through four administration methods: infusions, oral medication, suppositories, and injections. Patients often take several oral medications, ranging from one to four times each day. Some have expressed being able to lower pill count would reduce perceived pill burden, admitting they do not like the number of pills they have to take.

> Of course, a lower pill count per day, that would be the biggest one…But for me, it would just actually be removing all of my oral medications.

> It's like eating a meal, you take so many pills.

> If you take the shot once a week or however often you have to take it…I don't want to have to take all those pills.

Additionally, a few patients mentioned they have lower adherence when it comes to taking their oral medications.

> When I was on [advanced therapy], I tried going off of them [5-ASA]…I just quit taking then, to be honest, I just got tired and the [advanced therapy] felt like it was working and I quit taking it.

One patient quit taking their 5-ASA medication when starting adalimumab, a self-administered subcutaneous injection. Less intentionally, some patients forget to bring their medication when traveling or forget to take their medication when they are feeling good and are symptom-free.

> It came from actually a long extended vacation that I was on, which I forgot my ASA and had no adverse side effects to being off of it for a month…And let them know that I had accidentally been off of it for a month and had no adverse side effects.

One patient did say their adherence has increased when they made it part of their morning routine.

> I used to be pretty inconsistent with it, but I think since I've really gotten in the habit of doing it in the morning right after breakfast every single morning with the pill box.

Patients were happy with their experience receiving infusions, stating that they worked well. Frequency of injections varies from patient to patient and can contribute to nonadherence. One patient said their injection was administered only as needed, while others must administer it at least once per week.

> I get infusions every six weeks…the infusion works fantastically and has ever since I started about seven years ago now.

Some patients expressed giving themselves the injection can be a challenge.

> Injections are a real challenge. I've been late on those a lot because sticking yourself in the needle in the stomach is, well, kind of hard.

Symptoms

When first diagnosed, patients experienced symptoms such as increased bathroom frequency, urgency, and excruciating pain.

> When you're first diagnosed, you are so sick, you take a drink of water, a drink of water will make you have to go to the bathroom and the pain is excruciating, intense, and it doesn't stop.

All do not want to get back to that level, which left some leery of changing their medication regimen. Patients reported experiencing those symptoms again when they forgot to take their medication.

> I would be going to the bathroom 20 times a day or more. And you're anemic and you're fatigued and all the symptoms that you would have with it.

> I went several days without them and that was very uncomfortable and a big problem. I had to stay close to a restroom, etcetera.

Clinician Factors

Endorsement

Physicians modify regimens based on patient response to therapy. One patient said their experience with more recent providers felt more like shared decision-making, considering all aspects of the patient.

> But the new [clinicians] are definitely. They do the research, they're not pushy with it. They tend to treat the patient and not the numbers, which is one thing that I do like about my new doctor…it's more of a conversation, more than a heavy handed leading.

Finally, patients expressed they were very happy with the university medical center pharmacy's customer service. One patient even reportedly switched from a large chain pharmacy to the university medical center pharmacy. Ultimately, patients trust their clinicians, and if the clinicians endorse deprescribing, patients would be more open to the idea.

> I'm fairly new, I'm not even a year in on [advanced therapy]. So every time I see him he's always reminding me, "Hey, if you think we need to be getting or you want to come off of it, we can try it for a trial period and see how that goes".

Communication

Patients liked to communicate with their clinicians through the university medical center electronic health record portal. Patients appreciate the portal's functionality and efficiency.

> Compared to other healthcare [clinicians] that haven't, they are 100% on response rate.

> I don't like talking to people on the phone because it's just a pain in the butt.

Patient Relationships

Patients fully trust their doctors and their treatment plans. They feel confident in them and appreciate the help they have received.

> You have to believe that the person who's treating you is going to get you well and keep you well.

> I'm very appreciative of the fact that they work together, they communicate, and that makes me feel very satisfied with my treatment.

Information Distribution

Patients would like to receive new information about the medications or their diagnoses from their clinicians. A couple of patients mentioned it would be nice to have their clinicians discuss new research or case studies, and their reasoning for deprescribing the 5-ASA now.

> I feel like the longer I'm on both the 5-ASA and the biologic, the harder it will be for me to entertain the idea of changing it…I would probably want to have the conversation about, so what's the research supporting that decision? Just given our

> communication in the past and being told "We're not changing anything if it's working", then I would want to know what's changed to change that opinion.

Clinician Deprescribing Readiness for Change

Several patients were interested in discontinuing their 5-ASA, but the change would come with several questions for their physicians. One patient expressed he would like to see clinical evidence and research explaining why it would be okay to stop the 5-ASA.

> I would really want to know what changed their mind. Is there a new study? I would love to hear that "Your case is similar to another one of my patients and we made this change and they had no effect so we don't see a lot of therapeutic value in continuing this 5-ASA".

Additionally, a few patients took notes during the focus groups and planned to ask their provider about stopping 5-ASA.

> I do think I would definitely bring it up to my doctor…This whole conversation, I'm taking notes of all the questions I'm about to ask my doctor after this call.

> I've written down about asking, again, if quitting that medication is an option or what his thoughts are on it. I highly respect my doctor.

Several patients have asked their clinician about removing the 5-ASA in the past, often when they got on a regular dose of their biologic. The general response was that if their medication regimen currently working, they do not want to change anything. Also, one clinician was reported to have communicated that continuing the 5-ASA would reduce the risk of colon cancer.

> I brought it up when [an advanced therapy] was the solution for me because I was thinking, let's start cutting back on some of this if it's working. But that's when I was told that if it's working we're not going to change anything.

> I've actually asked that question my provider before about why I'm still taking the 5-ASA if I take [5-ASA] and get [advanced biologic] infusions as well. And the response that I got was it decreases the risk of colon cancer.

However, some patients have either discussed deprescribing in the past and were not interested or would not be interested in removing their 5-ASA at all.

> But I've never asked my doctor if I could come off of it. I guess I was of the school of if it's working, don't rock the boat.

> At one point another one of my doctors wanted me to come off of the [advanced therapy], but it had helped me so much my quality of life that I refused to do it. So I'm just interested to know if my body is going to reject it at some point or reject any of these medications.

Barriers and Facilitators

Barriers

The primary barrier to deprescribing would be the possibility of symptoms coming back. Patients were more inclined to stay on their medication regimen that is currently working rather than switching anything up. Additionally, one patient said the longer they are on both 5-ASA and advanced therapy, the harder it would be to stop taking the 5-ASA.

> For me it's been sort of a full-blown all symptoms, or none. And I'm at the none right now. That's why I'm very leery about doing anything different because I don't want even one symptom to come back.

> I blindly trust their medical opinion, so even the thought of coming off of it, while there is the sense of "That would be great", there is a fear of I don't want to go back to where I was.

Facilitators

One patient mentioned that a facilitator to deprescribing would be having accessible information from their doctor, explaining why they have decided to make this change to their regimen.

> Having the accessible information continue to build the personal relationship that I have with them. That will increase my level of trust.

Patients who are interested in deprescribing would like the conversation to come from their clinician, through a face-to-face conversation. A good way to initiate the conversation would be through a patient portal message, or when they go through their medication list every 6 to 12 months.

> I highly respect my doctor and I think actually having that conversation face-to-face with him and being able to gauge his reactions would probably be the most comfortable way for me to talk to him about it.

> You asked a question about who would you want to communicate to you and for me that's for sure my clinician. I would want him to pretty clearly explain to me why dropping my 5-ASA would not change anything. And it would have to be pretty black and white.

Advantages and Disadvantages

Advantages

Several patients said that an advantage to removing the 5-ASA would be a lower pill count and reducing pill burden. One patient also mentioned avoiding their out of pocket max each year would be an advantage.

> I've never really thought about asking to do that but I agree with what everybody else has said. It would be fewer pills.

> I'd stop taking it. If it's duplicating it, I'd definitely want to stop taking it.

> …if I could avoid hitting my max every year, that'd be great.

Disadvantages

Disadvantages to deprescribing are similar to the barriers, where patients expressed fear of symptoms returning if their 5-ASA was removed. The general consensus has been if your medicine is working, stick with it.

> I never want to go back to those two years of, actually a year and a half, of just really tough life.

> And I don't want to change anything if I'm going to be at risk.

> I'm open to trying things but I might do more harm to my stress and my heart and who knows what else.

> If I can take less, I would love to take less, but not willing to sacrifice any additional symptoms, obviously, for one less medication.

Discussion

To our knowledge, this is the first study to examine patients' experiences with UC advanced therapy and 5-ASAs and barriers, facilitators, and attitudes towards deprescribing 5-ASA medications. While previous systematic reviews have described patients' barriers and enablers of deprescribing, the studies were focused on different medication classes[7] and patient populations (ie, older adults).[9] Because patients administering therapies for moderate to severe UC are often faced with a heavy medication burden yet fearful of previously experienced symptoms that significantly impact their quality of life, it is important to evaluate the needs, willingness, and preferences of this unique patient population. Deprescribing medications that are no longer needed helps reduce overall healthcare spending and can improve patient satisfaction and, potentially, adherence due to lower pill burden. Though 5-ASAs are frequently used for mild to moderate UC, many patients advance to moderate to severe disease that requires advanced therapies. Early research

has found similar clinical outcomes in patients who continue versus discontinue 5-ASAs after starting advanced therapies. In patients with UC, researchers found those who discontinued 5-ASA within 90 days of starting anti-TNF therapy did not have an increased rate of adverse clinical events, including new corticosteroid use, hospitalization, and surgery.[26] Similarly, Mak et al (2022) compared the risk of flares among patients with UC prescribed an anti-TNF who stopped 5-ASA, and those who continued 5-ASA over 5 years. Results showed there was no increased risk for flares in patients who stopped 5-ASA.[27] Additionally, continuing 5-ASA in patients on advanced therapy has not shown any clinical benefits.[5] Therefore, it is reasonable to consider stopping 5-ASAs when advanced therapies must be initiated. However, as consistently noted throughout the focus groups, patients with moderate to severe IBD have often undergone severe symptoms that impact their quality of life and are hesitant to change treatment that may be working. Understanding patient and clinician considerations can help drive appropriate deprescribing in a way that is acceptable to all parties.

Though the current study found that several patients were interested in stopping their 5-ASA medication, patients identified barriers, facilitators, advantages, and disadvantages regarding deprescribing 5-ASA. Advantages to deprescribing 5-ASA medication would be reducing pill burden and not hitting their out-of-pocket max each year. These results align with previous studies that reported patients were interested in deprescribing to reduce pill burden.[9–11,28–30] Additionally, patients expressed when negative symptoms were present, their quality of life was impacted. Removing the 5-ASA medication could lead to improved medication management. Prior studies have shown patients feel their oral medications are inconvenient and impact their day-to-day lives.[28,29,31] Patients expressed the impact of medication on travel, or their medication monitoring requirements, can be an inconvenience.[29] Barriers to deprescribing were similar to previous studies as well.[10,11,28–30] Bolt et al (2023) reported older adult patients were worried about symptoms returning after deprescribing. Researchers found patients who are happy with their current health status are more reluctant to accept deprescribing.[9] In the current study, patients were concerned about symptoms returning such as unintended weight loss, diarrhea, and frequent bathroom use and were also concerned about symptoms returning if stopping a medication.

Patients in the current study preferred deprescribing conversations to be had with their prescribing clinician, similar to previous study findings.[32] Based on the current study highlighting patient attitudes and preferences, clinicians should consider discussing deprescribing 5-ASA medications for patients on advanced therapies at clinical visits to allow for shared decision-making conversations. Patients in this study felt confident in their clinicians and appreciated their help, which aligns with prior deprescribing work suggesting the patient-clinician relationship is one of the most important enablers for deprescribing.[9] Finally, several patients in the current study had asked their doctor about removing the 5-ASA in the past when starting an advanced therapy. Evidence suggests that messaging from prescribers can shape patient's willingness to deprescribe.[9]

Limitations

The limitations of our study are similar to those in qualitative research. Our sample of 10 patients was small and recruitment yielding 10 out of 120 eligible may have introduced selection bias. However, we do believe we reached data saturation based on the content of our results and analysis. For future studies, follow-up messages could be sent to eligible patients in order to recruit a larger sample size. Another limitation is the racial and ethnic homogeneity of our sample. Patients were mostly White and all non-Hispanic/Latino. The demographics of our sample size limits the generalizability of our findings, as a more diverse population could have different feelings and experiences related to deprescribing.

Future Directions/Implications for Practice

Though deprescribing 5-ASA medications seems feasible, implementing effective deprescribing methods needs further support and exploration to ensure patients and clinicians are confident in removing medications. Based on our limited sample size, implementing a deprescribing conversation when patients are stable on therapy, at a follow-up appointment in person, and when reviewing the medication list could be an ideal time. Opportunities such as clinical decision support tools to alert patients or clinicians for de-prescribing opportunities could be considered. Standardized educational tools for clinicians to use to start the conversation with patients could be important. Some patients have sufficient health

literacy to ask to see studies supporting deprescribing. Larger studies are needed to further evaluate the outcomes of deprescribing 5-ASAs in patients stable on advanced therapy to better inform patient and provider decision making. Strategies should focus on highlighting the patient-clinician relationships to help support the decision-making process.

Conclusion

This study indicates that patients are open to deprescribing their 5-ASA but would have several questions for their prescribing physician including assurance of continued symptom management or ease of returning to the 5-ASA if needed. Larger and more diverse studies are needed to confirm or extend these findings. Additionally, future studies are needed to determine the efficacy of implementing a provider-led deprescribing intervention for patients on advanced therapy and 5-ASAs. If clinicians are able to address patient barriers to deprescribing, this can lead to a broader adoption of deprescribing and potentially to reduced medication costs for patients.

Ethical Approval and Informed Consent

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Vanderbilt University Medical Center institutional review board (July 13, 2022/No. 221090). Informed consent was obtained at the time of enrollment prior to focus group execution. The participant's informed consent covered the publication of their anonymized quotes.

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