

Perceptions Among Patients with Ulcerative Colitis: Treatment and Self Management Methods

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BACKGROUND

Individuals with Ulcerative Colitis (UC) use various methods to reduce gastrointestinal (GI) symptoms, achieve disease remission, and reduce the burden of illness on everyday life.

AIM

To describe patient perspectives and experiences with treatment and self-management methods.

METHODS

Qualitative, individual semi-structured interviews (n=21)

- Recruitment:
 - Prisma Health Gastroenterology department in Greenville, SC (n=9)
 - Carolina's Crohn's and Colitis support group (n=2)
 - Facebook groups: Ulcerative Colitis (n=8) & Ulcerative Colitis Support Group (n=1)
 - South Carolina Center for Integrative Medicine (n=1)
- Eligibility criteria:
 - 1.) diagnosis of UC
 - 2.) duration of illness ≥ 5 years
 - 3.) a minimum of one disease flare during the illness trajectory
- Thematic analysis using QSR International NVivo 12 software.



RESULTS: PERSPECTIVES AND EXPERIENCES OF TREATMENT & SELF MANAGEMENT METHODS

MEDICAL

Medication	<ul style="list-style-type: none"> • Primary treatment approach • Reluctance to try new medications due to potential side effects • Fear of long-term side-effects and lost effectiveness • Issues with treatment cost and insurance coverage 	<p><i>“I’m scared that the infusions one day are going to cause another problem, which is really scary, cause it’s like a really serious strong drug that I’m taking...but I’m okay with it cause it helps me right now.”</i></p>
Surgery	<ul style="list-style-type: none"> • Strong aversion to ostomy bag • Despite j-pouch surgery, residual symptoms required continual self-management 	<p><i>“I think just my self-esteem about having a bag...I know I’m not ready for it yet.”</i></p> <p><i>“You had an autoimmune...you’re never going to be normal”</i></p>
Self-Advocacy	<ul style="list-style-type: none"> • Speak up and communicate needs to physician • Research and study the disease and treatment options • Seek out help managing the emotional burden associated with UC <ul style="list-style-type: none"> • support groups, professional therapy, medication 	<p><i>“I would say things are going about the same. But the same was pretty bad. I realized that you’re not going to get these other medicines until you’re able to communicate to them that, no, this isn’t working.”</i></p> <p><i>“You got to know what you’re facing, and information is power.”</i></p>

COMPLEMENTARY/ALTERNATIVE

Supplements	<ul style="list-style-type: none"> • Hesitancy to add if medications working • Openness to finding “natural” treatments without “chemicals” and associated side effects • Probiotics to improve overall immune system • Vitamins, particularly vitamin D, are helpful 	<p><i>“Maybe one day I’ll try it. Right now, what I’m doing is working.”</i></p> <p><i>“If I could find a way that wasn’t chemically based, and I’m all for chemicals, they make lives a lot better, but they do all have side effects.”</i></p>
Chiropractic/ Acupuncture	<ul style="list-style-type: none"> • Interest in these methods as complements to physician care • Cost is a major barrier 	<p><i>“I feel like [acupuncture] would probably help...just with the stress...if you can get that stress out of your body...somehow it helps this weird autoimmune disease”</i></p>
Massage Therapy	<ul style="list-style-type: none"> • Strong desire for massage therapy to reduce joint pain and stress • Cost is a major barrier 	<p><i>“I felt it was more natural than taking pain medicine.”</i></p>

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LIFESTYLE

Diet	<ul style="list-style-type: none"> • Spectrum of approaches and attitudes towards diet • Doubt influence of diet • Skip or delay meals to avoid GI symptoms • Restrict food categories • Restrict trigger foods • Adopt healthier eating habits 	<p><i>“I tried fixing my diet of going gluten free...that didn’t do anything...I started doing dairy free. That didn’t do anything. So for me, diet hasn’t made me any better.”</i></p> <p><i>“...I switched over to eating brown rice every day instead of French fries, and...deep fried Okra...if I bake them, they won’t irritate my tummy”</i></p>
Stress Management	<ul style="list-style-type: none"> • Eliminating stress essential to manage and prevent flares • Many successful methods to reduce stress: reduce daily workload, retirement, change career, drop out of school, limit commitments, disability benefits, exercise, hobbies/outdoors, reframe thoughts, faith/prayer, pets 	<p><i>“...stress that’s prolonged over several weeks and it’s weighing on your mind,...I feel like that can be the precursor to a flair...”</i></p>
Physical Activity	<ul style="list-style-type: none"> • Physical activity used to: reduce stress, reduce joint pain, increase energy, and improve overall health 	<p><i>“I wanted to be healthier in general. I knew I had to change.”</i></p>
Sleep/Rest	<ul style="list-style-type: none"> • Sufficient sleep and rest to prevent and recover from flares 	<p><i>“I need to make sure I sleep. It sounds kind of lame, but I just lay around and try to heal...if you don’t get rest it gets worse.”</i></p>

CONCLUSIONS

- Self advocacy is vital to receiving sufficient care and successfully managing the burden of illness on daily life.
- Eliminating stress was widely believed to be essential to preventing flares.
- Spectrum of attitudes and approaches towards dietary change as a method to manage UC.
- Openness to complementary/alternative methods was evident, but cost is barrier