

Perceptions and Experiences of Ulcerative Colitis Patients

Hina Sultan¹, Maryam Gul², Uzma Sarwar³

¹Assistant Professor, Department of Psychology, Lahore Leads University, Lahore Pakistan.

²Assistant Professor, Department of Applied Psychology, Lahore College for Women University, Lahore Pakistan.

³Lecturer, Government College for Women University, Sialkot Pakistan.

Correspondence: hina.sultan91@yahoo.com¹

ABSTRACT

Objectives: The present research aimed to explore and comprehend the experiences of ulcerative colitis patients and how they feel, think, and react in response to it.

Method: The whole study was conducted by adopting qualitative research method called Interpretative phenomenological Analysis, by using constructivist approach. Data collected from outpatient department of a public hospital of Lahore in November, 2020. A purposive sample of six ulcerative colitis women (diagnosed with Proctosigmoiditis and left sided colitis), with age range of 24-30 years, was taken. First of all, semi-structured interviews (individually with each participants) were carried out which lasted for 50-60 minutes. Interviews were taped, transcribed, and separately analyzed. Themes were extracted and then clustered to from super ordinate themes for each interview. Finally, a master table of themes was developed to depict the clear picture of participants' lived experiences. To ensure the validity of results, views of three experts were taken on every step of analysis to interpret the true meaning of participants' words and intrinsic views.

Results: Findings resulted in three major themes including somatic complaints/physical cramps accompanied by rectal bleeding, anomalous colon cramps, dyspepsia, IV infusions, repeated medical examinations etc. another superordinate theme "Emotional/psychological outbursts, included subthemes, anxiety disorders, carcinophobia, trypanophobia and Nosocomophobia. The third major theme was "Aversive/escape reactions".

Conclusion: Interviewee's major concerns were that they were experiencing a lot of physical complications including inconvenient medical checkups. They also reported psychological disturbances like intense fear of developing colorectal cancer (CRC). This increased risk resulted in persistent inflammation of the colon. Thus, the current research explained the sufferings of UC patients to convert the attention of physicians to engage them in counseling and therapeutic programs to combat well with their illness.

Keywords: Ulcerative Colitis, Thematic Analysis, Somatic Grumbles, Psychological Issues.

Article History

Received:
February 06, 2024

Revised:
March 25, 2024

Accepted:
March 27, 2024

Published:
March 30, 2024

Introduction

Ulcerative colitis (UC) is an inflammatory bowel disease (IBD) that causes long-lasting inflammation and ulcers (sores) in digestive tract and affects the innermost lining of large intestine (colon) and rectum (Yanai, et al., 2016). There are usually five types of UC, including, Proctitis (inflammation is confined to the area closest to the anus which is considered as a mild form of UC), Proctosigmoiditis (inflammation involves the rectum and sigmoid colon (lower end of the colon), Left-sided colitis (a disease that extends beyond the rectum and splenic flexure). These types fall in the moderate category of UC. However, Extensive and Pan-colitis refers to severe inflammation in the whole intestine (Lohan, et al., 2019). A few researches have been conducted on its prevalence and associated risk factors like Nasim, Chawla, and Murtaza in Karachi focused on the prevalence of IBD among patients, taking surgical treatments, during the time span 1986-2010. Results showed that the prevalence of overall illness and mortality was 72% and 38.8% respectively which was relatively high than internationally reported records (Nasim, et al., 2016). Jafri conducted a meta-analysis of almost 30 studies and found that chronic UC patients are at higher risk of developing adenocarcinoma at any stage of their life (Jafri, 1994). Further, Majeed, Gohar, and Riaz selected 150 UC patients from different hospitals of Lahore. Researchers stated that 15-45 years of patients usually suffer from IBD after that it converts into cancer symptoms. Further, outcomes alarmingly revealed that almost 70% of patients were unaware about their disease such as they did not know about its complexities, better treatment sources, and intake of dietary food (Majeed, et al., 2018). As far as patients' psychological and physical issues are concerned, in UK, researchers found that patients with ulcerative colitis have poor quality of life (Vaizey, et al., 2014; Schreiber, 2012). In America, Brown conducted two internet surveys to examine the issues of UC patients. The surveys revealed that the major impact ulcerative colitis has on patients includes frequent disease manifestations, a substantial psychological burden, and disruption to daily activities (Dudley-Brown & Baker, 2012). No doubt, researchers have focused their attention on such types of diseases and patients' problems but there is still gap exists in literature to explain in detail the lived experiences of UC patients. Thus, the current research aimed to qualitatively investigate the physical, emotional and psychological sufferings of such patients. Different research questions were developed, for instance, what types of physical problems do you experience related to your illness? How do you feel about your disease, please, explain in detail? What are your thinking patterns regarding your illness? How do you react in response to your illness?

The significant of the study is that participants belonging to age group 24 and 30 years were taken because this is the actual time when physical strength is at the peak and young adults usually enjoy junk and fast food, and constructively progress in all spheres of life. Unfortunately, people inflicted with such life threatening diseases, at this stage of life, have more bad experiences as they get dependent on family members and specifically a stigma of having chronic disease is really shocking and overwhelming as patients' condition gradually gets worse and it is quite difficult to accept this diagnosis at a very young age. In short, the present research promisingly explained the bio-psycho-social problems of such patients.

Methodology

Participants

A homogenous purposive sample of six females, diagnosed with moderate level of ulcerative colitis (3 participants with proctosigmoiditis and 3 with left sided colitis), was selected from a government hospital of Lahore, visiting outpatient department. All participants were middle class, unmarried, aged between 24 and 30 years, and diagnosed with UC for almost five years. Patients having mild and intense form of UC (extensive colitis; an initial stage of having cancer) were excluded. Married, middle and over aged participants were also not taken.

Instruments

First of all, a screening question was developed to ask the patients about their illness. Also, the help of doctor was taken to select the required actual UC patients. Further, researchers developed semi-structured

questionnaire to get in-depth information from participants about their physical and psychological complications, and reactions. Due to semi-structured nature of questionnaire, the sequence of questions was changed during the interviews while a few new questions were asked according to participants' conversation and way of elaborating the problems. Interviews lasted for 50-60 minutes.

Procedure

Written permission was taken from the MS of hospital. Consent was also obtained from participants to confirm that they were participating in the research project by their own will. 3 patients gave interviews in hospital settings while for the ease and comfort of remaining 3 patients, interviews were conducted at their place. Researcher assured the participants that all information obtained will be kept confidential without revealing their identity. Data was analyzed through thematic analysis. Following this method, first of all, semi-structured interviews were conducted with women. Interviews were taped and transcribed in both Urdu and English languages. Interview transcripts were separately analyzed. Themes were extracted and then clustered for each interview. After that, super-ordinate themes were developed by merging the clustered themes, which were included in the master table. At each step of analysis, opinions of three experts were taken to interpret the true meaning of participants' extrinsic and intrinsic views.

Results

Table 1: *Master table of themes displaying the physical and psychological problems of Participants (n=6)*

Super ordinate themes	Clustered themes	Participants' Verbatims	n	f	Page no.
Somatic complaints/ Physical cramps	Rectal bleeding	Sometimes, I pass bloody stools, there are food pieces, and green liquid mixed in it (Interviewee 4). I find my disease more damaging when there are blood clots and mucus in stools (Interviewee 6).	6	50	1, 2, 5, 9, 8, 11,13,16,19, 25, 36, 44, 51, 55, 65,67, 76,100
	Anomalous colon cramps	I have recurrent episodes of loose stools and vomiting, and extreme pain in my gut (Interviewee 1). I feel severe pain in my lower left part of abdomen that I wish, I cut that part of my body (Interviewee 3).	6	46	1,3,5,7,13,21,18,54,56, 67
	Dyspepsia	Find it hard to swallow food, even taking plain water, my heart burns out (Interviewee 1), I feel my stomach is full all the time (Interviewee 2), There is acidity, burning, and cramps in my tummy, so, cannot able to eat even normal food (Interviewee 3)	6	45	1,2,4,5,10,18,19,20,23, 25, 30,43,66,89,104
	IV infusion	It is very difficult to insert needles in my veins; I feel	6	43	2,3,4,5,6,7,8,9,10,22,25

difficulties	intense pain (Interviewee 2). My hands swell out due to branula, one drip is completed in 5-7 hours, till then, it's very difficult to keep the arm in same direction and waiting so long feels like it will take my breath away (Interviewee 6).				, 27,34,36,37,40,62
Repeated colonoscopies and biopsies	Undergoing for internal examination twice or thrice a year, It is really hectic and troublesome (Interviewee 1). I am not allowed to take meal 2 days ago when I have to go for endoscopy (Interviewee 2).	6	42	4,6,7,10,12,13,15,16,20,21,45,58,67,77,81	
Poor physical appearance	Unfortunately, I do not look like normal people now, have lost weight, dark circles, and pale complexion (Interviewee 2). My reddish cheeks, fatty body, all declines away gradually (Interviewee 5).	6	41	1, 2,4,5,6, 9,10, 13, 23,29,30	
Fatigue/loss of energy	My daily routine is disturbed, I cannot go to job regularly and doing household chores also seem burdensome (Interviewee 1). Feeling lethargic most of the times, feeling like have no energy to complete any task (Interviewee 2).	6	36	3,5,8,15,30,42,44,46,53,58,61	
Joints pain	I have severe pain in my left knee and it is so difficult to climb on stairs (Interviewee 3). Sometimes, I can't move and open my fingers freely (Interviewee 4). Having muscle stiffness is another problem for me (Interviewee 2).	4	30	4,5,10, 16, 17, 21,	
Fever/sore throat	At times with diarrhea, I also have fever, and throat infection which disturbs me badly (Interviewee 5).	3	10	1,5,39,47,61	

Psychological/ emotional outbursts	Anxiety disorders	Whenever I even feel nausea or abdomen pain, my heart rate rapidly increases. There are range of negative thoughts, fears and worries. I feel like something terrible is going to happen (Interviewee 3). My mental state is out of control, I feel restless, irritable, and dizzy. Find it difficult to sleep because how a person can get relaxed when he/she has frequent loose stools and blood in vomit (Interviewee 5).	6	35	4,6,8,12,17,19,22,24,36, 71, 118, 131, 140
	Carcinophobia	Patients like us are more likely to develop cancer, most of the times, I think about it and get nervous, am obsessed with such thoughts (Interviewee 4). Yes, I know, my condition is getting severe day by day. It has been a long while, approximately six years. I have intense fear of developing cancer (Interviewee 5).	5	32	13, 17, 26, 34, 101, 106, 120, 133, 141.
	Trypanophobia	I cannot tolerate needles' pricks, not at all. I am extremely afraid of it. I do not want to talk about it (Interviewee 1). Just thinking about injections, I feel mouth dryness and sweating (Interviewee 6).	4	26	4, 5, 6, 31, 45, 60, 62, 73, 85.
	Nosocomephobia	I hate hospital settings; it messes up my whole body. I am afraid of being hospitalized. I think it is better to die at home than hospital (Interviewee 2). Living in hospital is very difficult either I admit in private room with good environment. It is heart wrenching. I feel immense fear, restless and heart palpitation even when thinking or talking about it (Interviewee 1).	3	23	11, 20, 24, 64, 81, 93.
	Thanatophobia	I am afraid of dying, I have stopped going into the funerals because I cannot	3	20	16, 18, 38, 90, 95

		see dead bodies (Interviewee 2).			
Depression		When dr. told me about UC, I was optimistic that will recover soon. But persistent relapses have made me hopeless. I feel like nothing can alter my internal state, no remedy will ever work. I keep crying and remain socially isolated (Interviewee 2). My source of happiness was eating favorite meals and outings. But I cannot eat pasta, spicy rice, red meat, and pizza. Everything is finished now. My whole life is affected and ruined (Interviewee 4). Am just 24 years old, at this age, people enjoy the springs of life, but I am at complete lost. I have no interest in studies, job, or social gatherings, and behave aggressively (Interviewee 3).	5	32	3, 4, 7, 15, 22, 58, 112, 115, 129, 134, 140.
Aversive/escape reactions	Non-adherence to medical regimens	I have stopped going for regular medical check-ups and tests. How long you can stick with all that, it is awful, expensive, and time consuming (Interviewee 1). I cannot tolerate anymore; I often skip medicines, cannot take it on daily basis (Interviewee 4). I don't want to go for surgery (Interviewee 2).	4	30	12, 105, 116, 117, 131, 133, 150.
	Non-co-operative social behaviors	At times, people pass negative comments regarding my illness; I just want to get rid of it. So, it is better to avoid public meetings (Interviewee 2). At times, your own siblings even parents get rude because they also get tired of all this, so, I try not to disturb them much (Interviewee 6).	3	22	13, 15, 18, 19, 34, 45, 50, 56.

Discussion

The present research qualitatively explored the sufferings of ulcerative colitis patients. First of all, a pool of themes was emerged from the transcriptions. The similar themes were clustered together. After that, superordinate themes were developed from combining the clustered themes which resulted in three major themes like “physical cramps” was the first most pertinent theme with reference to participants because almost every participant was having similar types of symptoms, causing intense pain and woes. It was revealed that rectal bleeding and other abnormalities like food pieces and mucus in stools were major concern for participants. They were also having frequent diarrhea, indigestion, and abdominal pain. Further, IV infusions were painstaking as it led to swelling of arms and hands. Participants explained that in usual routine, they take 5-6 doses of Mesalazine (Pentasa) which have numerous side effects like hair fall, mouth ulcers, renal/cardiac failure etc. Beside this medicine, Onset, Metronidazole, Omeprazole,

Librax, Ciprofloxacin, and Spasfon were also prescribed by doctors occasionally. Even though, all these tablets must cure the infections but participants described that they still got dependent on drips after every 2 or 3 months. Participants also explained the problems of undergoing for internal evaluations twice or thrice a year. Viewing the internal state on LED was quite terrible as colon bleeds from inside, ulcers, and scars became apparent in the microscopic examination. This medical procedure caused heavy bleeding via rectal path and patients got faint. Further, participants were concerned about their poor physical appearance. They lost weight and had pale complexion. A few participants also reported having joints pain and fever or aching throat.

Researchers further evaluated that physical constraints leading to numerous psychological pathologies. Anxiety disorders were noticed as they got panic. All participants elucidated that at times, they experienced shortness of breath, intense worry or fear, irritability, heart palpitation, and feeling like something terrible is going to happen. Different kinds of phobias were noticed like Carcinophobia (fear of developing colorectal cancer) was present in 5 while Trypanophobia (fear of needles) in 4 patients. Moreover, 3 participants were suffering from Nosocomophobia (fear of being hospitalized). For the convenience of such participants, interviews were conducted at their homes. Doctor told the researchers about such patients because he usually went in their homes for medical check-ups and drips insertion. Additionally, fear of death (Thanatophobia) had been found in 3 patients. Actually, participants were experiencing more such types of fears and depression because they were suffering from UC since four to five years and their conditions were getting worst day by day. They could just eat the dietary meal in the form of cereals, porridges, and soups (home-made food). They were even conscious about fruits having citric acid (oranges, sour pomegranate and lemons). So, the more adverse physical conditions were increasing the participants' anxiety and depression level. They were hopeless, having self-blame and guilt and lost temperament because they told that when they diagnosed with ulcer, they did not take it seriously, and skipped medicines which resulted in wickedest physical condition. A combination of psychological sufferings was leading to aversive or escape reactions as participants got exhausted and did not want to go for further medical tests and surgeries and also avoiding it due to lack of social support because participants explained that when one's has a long lasting, chronic illness, family members also get tired and irritated. At times, they pass sarcastic comments and show neglecting behaviors. So, participants elaborated their all experiences which also became a source of catharsis and relief.

Conclusion and Recommendations

It is concluded that ulcerative colitis causes intense physical and psychological sufferings for patients which also leads them to avoid medical regimens and go for proper follow-ups. First of all, it is necessary to spread awareness about the factors causing such diseases as primary prevention is better than secondary prevention but for patients who have developed these problems should be counseled to manage their psychological state by engaging in daily life activities and become productive for society.

Limitations

The first flaw of the study was lack of generalizability of results. Gender differences were not seen. Patients with co-morbidities, in different age groups, and belonging to other regions of Pakistan were not taken. Also, experimentation-based study was not carried out.

Acknowledgements

None.

Conflict of Interest

Authors declared NO conflict of interest.

Funding Source

The authors received NO funding to conduct this study.

ORCID iDs

Hina Sultan ¹  <https://orcid.org/0000-0002-1436-3115>

Maryam Gul ²  <https://orcid.org/0009-0002-2267-7939>

Uzma Sarwar ³  <https://orcid.org/0000-0003-3314-9816>

References

- Dudley-Brown, S., & Baker, K. (2012). Ulcerative colitis from patients' viewpoint: a review of two Internet surveys. *Gastroenterology Nursing*, 35(1), 54-63.
- Jafri, S. M. (1994). Dysplasia and surveillance in ulcerative colitis. *Journal of Pakistan Medical Association*, 44(9), 223.
- Lohan, C., Diamantopoulos, A., LeReun, C., Wright, E., Bohm, N., & Sawyer, L. M. (2019). Tofacitinib for the treatment of moderately to severely active ulcerative colitis: a systematic review, network meta-analysis and economic evaluation. *BMJ open gastroenterology*, 6(1), e000302.
- Majeed, S., Gohar, F., & Riaz, M. (2018). Prevalence of inflammatory bowel disease and associated predisposing factors. *International Journal of Applied Research*, 4(2), 208-11.
- Nasim, S., Chawla, T., & Sheikh, G. M. (2016). Surgical management of inflammatory bowel disease: A low prevalence, developing country perspective. *JPMA: Journal of Pakistan Medical Association*, 66(3), 247.
- Schreiber, S., Panés, J., Louis, E., Holley, D., Buch, M., & Paridaens, K. (2012). Perception gaps between patients with ulcerative colitis and healthcare professionals: an online survey. *BMC gastroenterology*, 12, 1-11.
- Smith, J. A., & Osborn, M. (2003). *Interpretative Phenomenological Analysis*. In J. A. Smith (Ed.), *Qualitative Psychology. A Practical Guide to Methods* (pp. 53-80). London: Sage.
- Vaizey, C. J., Gibson, P. R., Black, C. M., Nicholls, R. J., Weston, A. R., Gaya, D. R., ... & Fan, T. (2014). Disease status, patient quality of life and healthcare resource use for ulcerative colitis in the UK: an observational study. *Frontline Gastroenterology*, 5(3), 183-189.
- Yanai, H., Salamon, N., & Lahat, A. (2016). Complementary therapies in inflammatory bowel diseases. *CGR*, 18, 62.