



Patients' Experience of Living with Irritable Bowel Syndrome (IBS): A Hermeneutic Phenomenology

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Abstract

Introduction: Irritable bowel syndrome (IBS) is a chronic gastrointestinal disorder with a wide range of effects on the individual's quality of life, emotional state, and identity. Given the lack of knowledge about patients' perceptions of life with irritable bowel syndrome, this study aimed to describe and interpret patients' experience of living with irritable bowel syndrome

Methods: The present qualitative study was conducted using a hermeneutic phenomenological approach on 15 patients with irritable bowel syndrome who referred to three central clinics. The data were collected through in-depth semi-structured interviews with the participants who were selected through purposive sampling. Thematic analysis was carried out using Van Manen's six-step methodological framework as a guide. Besides, MAXQDA software was used for data management.

Results: The analysis of the data yielded four themes and eight subthemes. The patients' experiences of living with IBS were manifested through the themes of "crisis and transient release" (with "storm in the corporeality" and "relief" subthemes); "surrender and harassment" (with "mandatory submitting" and "feeling of helplessness" subthemes); "looking for adaptation" (with "struggle in obtaining insight" and "seeking help from coping strategies" subthemes); and "different self-perceptions" (with "threatened self" and "deep self-knowledge" subthemes).

Conclusion: Understanding the life experience of IBS patients can be effective in improving the interdisciplinary medical-care programs and reducing their psychological, social, and physical problems. Therefore, carrying out more studies to promote the quality of life of IBS patients is suggested.

Keywords: Irritable bowel syndrome, Experience, Phenomenology, Qualitative Research

Introduction

Irritable bowel syndrome (IBS) is one of the most common gastrointestinal disorders characterized by changes in bowel habits and

abdominal pain (1-3). The prevalence of this disorder in Iran was 4.2% (4) and in adults, over 35 years in Shiraz, it was 10.9% (5). In a review study, the human burden of irritable bowel



syndrome in patients affected with the disease was significantly lower than in non-affected patients (6). IBS also imposes a heavy financial burden on the patient (7). The cost of this disorder in Iran is estimated at \$ 2.8 million (8). Therefore, due to the inconsistency in statistics on the IBS prevalence (9,4-12), unknown IBS causes (13,14), the lack of definitive treatment (12,15-17), social, physiological, and mental consequences of the disorder (18-21), frequent visits to medical centers (22-24), huge costs incurred by the diseases (25), low quality of life of affected patients (26-31), and the unique experience of living with irritable bowel syndrome, exploring patients' experiences of living with this disorder is essential. Quantitative studies with a positivist paradigm on lifestyle recommendations, educational and pharmacological interventions, dietary adjustments, and eating habits, as well as psychological interventions for these patients, have somewhat improved the effects of this disorder on affected patients' lives (12,15,16,32-34). Since quantitative measurements often cannot capture people's thoughts, feelings, and experiences (35), it is possible to explore all aspects of life through qualitative studies (36). A review of qualitative research indicated that patients reported that the syndrome affected their daily functioning, thoughts, feelings, and behaviors (37). Patients also reported physical and psychological effects (38), socio-psychological consequences (39), and experiences of dietary changes (40, 41). In another survey, patients described how they adapted to the disorder (42). Most studies have explored the experiences of patients with irritable bowel syndrome and inflammatory bowel disease (which has an organic cause) or examined a particular aspect of the experience of these patients. In a few cases, the grounded theory (43) or descriptive phenomenology (44) has been used to capture the experience of patients with irritable bowel syndrome. On the other hand, qualitative research has been done only in developed countries such as the United States (37), Sweden (44), Norway (45), Canada (38), and Germany (39), and due to the type of

study or methods, they did not deal with the various dimensions of the life with irritable bowel syndrome or did not examine its nature in depth. Furthermore, none of the studies mentioned have been carried out using hermeneutic phenomenology which combines description and interpretation. Moreover, no qualitative study was found in Iran on irritable bowel syndrome. Given that there is still no clear understanding of the impact of this disorder on all personal, family, and social aspects of affected people in Iran, it is necessary to use qualitative methods to explain the lived experience of IBS patients. Therefore, the main question addressed in this study is: What is it like to live with irritable bowel syndrome? To this end, this study employed a hermeneutic phenomenological approach to explore and understand the daily life experiences of IBS patients.

Methods

The reasons for using the hermeneutic phenomenological (descriptive-interpretive) method with a focus on Van Manen's six-step framework in the present study include the possibility of exploring a common experience from several different perspectives and by interpreting the perceptions and lived experiences of different people and recognizing the common features and characteristics of the phenomenon of life with irritable bowel syndrome from an interpretive perspective to gain a deeper understanding of patients' experiences. In addition, the importance of the researcher's personal beliefs and experiences of the hermeneutic phenomenological approach was another reason for using the Van Manen's method in this study. Thus, given that this study sought to explore the meaning of life for patients affected with irritable bowel syndrome, it is possible to explore and come up with a deep understanding of life with irritable bowel syndrome through the interpretation of experiences expressed by affected patients, and then embed such an understanding in the context of one's experiences which were omitted in the first stage of the study. After obtaining permission from the Ethics Committee of Shiraz

University of Medical Sciences, the first interview was conducted with a patient with irritable bowel syndrome. The participants were selected using purposive and snowball sampling and according to the research purpose and inclusion criteria. The inclusion criteria were having irritable bowel syndrome for at least 1 year at the discretion of a gastroenterologist based on Rome III criteria, adults over 20 years of age, fluency in speaking Persian, rich experience of the disease, good communication skills, willingness to share their experiences with the researcher, the absence of acute cognitive and psychological illnesses, and the absence of organic diseases such as inflammatory bowel disease including Crohn's disease and ulcerative colitis. The participants in the study were 15 patients with irritable bowel syndrome who expressed a desire to participate in the study. The researcher selected educational clinics (Shahid Motahhari and Shahid Faghihi) and Kosar Clinic of Shiraz University of Medical Sciences as the research setting. The interviews were conducted in a quiet, non-commuted room in the Shiraz School of Nursing and Midwifery upon the consent of the participants. Only one interview was conducted in the prayer room of the workplace of one of the participants. During the interviews, the researcher made observations and took notes. All interviews were voice-recorded after obtaining permission from the participants. The audio files were quickly transcribed into text files. The criterion for ending the interviews was data saturation. Sampling continued until rich, deep, robust, and relevant data were collected. Each interview session lasted between 40 and 90 minutes. One patient was interviewed once, and only 2 of them were interviewed twice. At the end of each interview, a report was written in the interview process, important points, etc., which were also considered in the data analysis. An interview reminder form was prepared and used to ensure that the main subjects under the study were covered. Some of the main questions asked in the interviews are as follows:

1. What is life like with irritable bowel syndrome?

2. What does it mean to live with irritable bowel syndrome?

3. What comes to your mind when you hear the phrase irritable bowel syndrome?

4. Can you talk about living with this syndrome?

5. Can you describe your feelings when you learned you had been affected by this severe syndrome?

Van Manen's method was used as a framework to conduct this study in six steps: (1) Turning to the nature of lived experience, (2) Investigating experience as we live it, (3) Reflecting on the essential themes which characterize the phenomenon, (4) Describing the phenomenon in the art of writing and rewriting, (5) Maintaining a strong and orientated relation to the phenomenon, and (6) Balancing the research context by considering the parts and the whole (46).

The holistic and selective approach was used for data analysis and MAXQDA software (version 7) was used for data management. To check the robustness of the data, four criteria were used: trustworthiness (long-term involvement in the interview process and the review of the data by the participants and experts), credibility (using two external observers and three members of the research team for review), confirmability (providing rich and deep descriptions of the research procedure), and transferability (providing rich and deep descriptions of the data and findings) (47).

The attempts made to extract relevant and genuine themes by presenting genuine insights and reflecting on interpretive processes helped to increase the validity of the data (48).

To comply with ethical considerations, a permit was obtained from the Ethics Committee of Shiraz University of Medical Sciences to collect the data from the participants. Besides, written informed consent was obtained from the participants for conducting the interviews and recording them. The researcher explained the objectives of the study to the participants. They were told that their participation would be voluntary and they could leave the study at any time they wished. They were also ensured that

their information would be kept confidential. Furthermore, the findings of the study were shared with the participants to receive their feedback.

Results

The participants were 15 IBS patients aged 21 to 73 years and an average age of 37.53 years, including 10 women and 5 men. The duration of

irritable bowel syndrome was 1.5 to 30 years with a mean of 7.76 years. The analysis of the patients' experience of living with irritable bowel syndrome yielded 4 themes, 8 sub-themes, and 23 sub-subthemes emerging from about 1500 primary codes. These themes were crisis and transient release, surrender and harassment, looking for adaptation, and different self-perceptions (Table 1).

Table 1. Themes, subthemes, and sub-subthemes related to life with irritable bowel syndrome

Sub-subthemes	Subthemes	Themes
The body in pain and suffering	Storm in the corporeality	Crisis and transient release
The sequence of symptoms and tension		
Hardship in moments of life		
Releases from bodily symptoms	Relief	
Moments of joy		
Mandatory exercises	Mandatory submitting	Surrender and harassment
Mandatory compromise with gastrointestinal disorders		
Mandatory friendship with IBS disorders		
Mandatory diet		
Mandatory sleep patterns	Feeling of helplessness	
Harassed by the definitive diagnosis process		
Being tired of/fed up with the treatment process		
Financial burden		
Feeling bad about the disorder	Struggle in obtaining insight	Looking for adaptation
Etiology of the disorder		
Searching for the cause in times of uncertainty	Seeking help from coping strategies	
Turning to effective strategies		
Turning to ineffective strategies	The threatened self	Different self-conceptions
Fear of being stigmatized		
Feeling bad about oneself	Deep self-knowledge	
Knowing the body		
Self-acceptance		
Personal growth		

Crisis and transient release: According to patients' experiences, one of the dimensions of the concept of life with irritable bowel syndrome was the theme of "crisis and transient release" that was subcategorized into "storm in the corporeality" and "relief" subthemes. The following statement by one of the participants, for example, clearly reflects the concept of the storm in the corporeality in the mind of any reader. A 30-year-old married woman with a 1.5-year history of irritable bowel syndrome (mixed-type), with an unhappy face, said, "Living with

the syndrome ... is like a war on the body as if there is an earthquake". The experience of the storm in the corporeality for patients with irritable bowel syndrome meant "the body in pain and suffering", "sequence of symptoms and tension", and "hardship in moments of life". The participants' statement indicated strong, resilient, unpredictable symptoms, variable and painful bowel movements in addition to irritable bowel syndrome symptoms all illustrated by the concept of "the body in pain and suffering". The participants, who emphasized "the body in pain

and suffering” and “sequence of symptoms and tension”, also pointed out to “hardship in moments of life”. All of these cases exposed the patient with irritable bowel syndrome to a storm in the corporeality. The participants stated that they were suffering from a variety of conditions such as feelings of death from fear of not controlling their bodies, having the worst possible condition during fecal incontinence, feeling bloated due to constipation and bloating, not enjoying eating and living, delayed party time, and exasperation due to persistent mental distress with irritable bowel syndrome.

The second subtheme related to “crisis and transient release” was “relief” which was subdivided into “feeling free from physical symptoms” and “moments of pleasure”. In their experiences of feeling free from physical symptoms, the patients pointed to a sense of calm and lightness following a complete emptying of the gastrointestinal tract, a lack of fear of going anywhere, and a feeling of freedom and release when there were no symptoms. The moments of pleasure were one of the experiences that helped IBS patients feel relief and peace.

Surrender and harassment: One of the main themes emerged from our data was “surrender and harassment”. The survey of the participants’ experience showed that this theme consisted of two subthemes: “mandatory submitting” and “feeling of helplessness”. According to the participants in the present study, mandatory submitting meant mandatory exercise, mandatory diet, mandatory sleep patterns, and even mandatory friendship and mandatory compromise with irritable bowel syndrome. One of the participants described the concept of forced friendship as “[pauses] *A lawful life, you must follow laws to get along with it. You must keep an eye on it. You should make your life organized so that you can live with it*” (Participant 3).

The second subtheme of surrender and harassment was the “feeling of helplessness” which was subcategorized into “to be harassed by the definitive diagnosis process”, “fed up with and tired of the treatment process”, “financial burden”, and “feeling bad about the disorder”. For example, a 73-year-old single male

participant who was a retired paramedic with 30 years of experience with irritable bowel syndrome said in despair, *“I’ve been living with this digestive problem for 30 years now. Sometimes I start crying. What the hell is this pain?”*

Looking for adaptation: One of the themes that emerged from the patients’ experience of living with irritable bowel syndrome was “looking for adaptation” which reflected the IBS patients’ “struggle in obtaining insight” and “seeking help from coping strategies”. The theme of “looking for adaptation” means that the patient with irritable bowel syndrome, after being diagnosed with the disorder, is constantly looking for the reasons for the disorder and reviews their past life. Besides, the patient completes the structure of the world of living with irritable bowel syndrome by turning to effective and ineffective coping strategies. The second underlying theme of “looking for adaptation” to life with irritable bowel syndrome was “seeking help from coping strategies” which consists of two subthemes: “Turning to efficient strategies” and “turning to inefficient strategies”. One of the participants stated, *“I make herbal tea of chamomile, lavender, rosemary, and cypress, and drink it when I feel a pain in my stomach”* (Participant 8).

Different self-perceptions: Another major theme extracted from participants’ descriptions of their experience of living with the syndrome was “different self-perceptions”. This theme accounting for part of the construct of the patients’ experience of living with irritable bowel syndrome consists of two subthemes: “the threatened self” and “deep self-knowledge”. A person with irritable bowel syndrome tries to hide the symptoms because of shame and fear of the taboo associated with the symptoms since shame is inherently threatening and painful. The patient gradually withdraws from the community. Besides, these patients are not understood by others and they acknowledge that the Iranian culture and society have not gotten along with this disorder. “Fear of being stigmatized” and “feeling bad about oneself” were the two subthemes of “the threatened self”. Many participants talked about the fear of revealing their symptoms and its consequences

in social settings, which indicates a fear of being stigmatized. Several participants pointed out that they were different from others and were concerned about other people's perceptions of themselves, which made them feel bad. "Deep self-knowledge was the second subtheme of "different self-perceptions". This subtheme was categorized into three sub-subthemes "knowing the body", "self-acceptance", and "personal growth". Some participants were not only unwilling to upset others because of the IBS symptoms but also stated that they felt unhappy when others were bothered by their illness, reflecting the personal growth.

Discussion

The findings of the present study showed that one of the aspects of life with irritable bowel syndrome was a crisis and transient releases. In their study, Lamas et al. showed that middle-aged women described the experience of living with constipation as "turbulence between the feeling of torture and feeling of freedom and release" (49), which is in line with the results of the present study. Following Schneider and Fletcher's study (38), our findings indicated that the theme of "crisis and transient release" includes the two subthemes of "storm in the corporeality" and "relief". The participants in Bertram's study also acknowledged that the symptoms were fitful and unpredictable (50). The findings of the present study were comparable to the results of a study by Farndale and Roberts who examined the experience of patients with irritable bowel syndrome to determine the effect of this disorder on daily life and its socio-psychological consequences. The reason for this comparison is that researchers could assess the emotional effects of living with irritable bowel syndrome. These effects occur in the form of emotional cycles with the onset of fear of misdiagnosis in patients. Fear leads to stress in them, followed by worsening of symptoms and subsequent recurrence of fear (39). In this regard, irritable bowel syndrome periods as associated with stress as was described by Swedish patients with irritable bowel syndrome in a study by Jakobsson et al. (51). Therefore, the

psychological effects of this disorder should be taken into account by nurses and other healthcare providers. The participants in the present study described the storm in the corporeality as difficulty and hardship in the moments of life. Jakobsson et al. stated that the sequence of symptoms and stress was reflected in the participants' descriptions as feeling bad in moments of daily life that could be otherwise enjoyable (51). The two sub-subthemes of feeling free from physical symptoms and moments of joy formed the subtheme of "relief". This finding was in line with the results of studies by Bengtsson et al. (52) and Lamas et al. (49) The participants' descriptions of happy moments were similar to the results of Faulkner's study on the life of young adults with inflammatory bowel disease (53).

The theme of "surrender and harassment" emerged in the present study covered two subthemes of "mandatory submitting" and "feeling of helplessness". Similarly, in her doctoral dissertation entitled "Experience of living with chronic disease", Pogge discovered the theme of surrender in contrast acceptance (54). Pogge also stated that the effects of surrender are manifested as the feeling of acceptance (54). However, the present study showed that the IBS patients were forced to be friends with the syndrome, but never liked it, because they believe that the syndrome is not likable and they were forced to surrender to mandatory life. In a study by Ronnevig et al., Norwegian patients described life with irritable bowel syndrome as life with self-sacrifice which is consistent with the subtheme of "mandatory submitting" in the present study (45). It should be noted that in Schneider and Fletcher's study, Canadian women with irritable bowel syndrome or inflammatory bowel disease pointed to "feeling of helplessness" as one of the effects of emotional disorders, as was found in this study (38).

Another aspect of patients' experience of living with irritable bowel syndrome was the theme of "looking for adaptation". Bertram et al. studied the effects of irritable bowel syndrome on the lives of Pennsylvania patients and their

interactions with physicians and the healthcare system. The interviews with the patients in the focus groups to identify the cause of irritable bowel syndrome linked the symptoms of the disorder to specific events such as hernia or gallbladder surgery, food poisoning, or even cat bites. The symptoms were also attributed to childhood constipation or colic pain in infancy (50). Similarly, in a study by Bengtsson et al., the patients stated after years of seeking healthcare, they desperately sought to find out the causes of their disorder (52). Similar results were found in another study (55). Fletcher et al. also concluded that Canadian women used strategies to cope with the disease. A noteworthy point about the concept of support was that the patients received support from society and also from family and friends (42). However, the present study showed that community support was not regarded by IBS patients as a strategy for adapting to irritable bowel syndrome but also as a factor inducing the fear of being stigmatized. In addition, the theme of using adaptive and maladaptive coping strategies emerged from the descriptions of German patients suffering from irritable bowel syndrome (39).

The theme of “different self-conceptions” was identified as another aspect of the experience of life with irritable bowel syndrome. Feeling of embarrassment due to negative symptoms and taboos in interviews with Swedish patients in a qualitative study by Håkanson et al. confirms the findings of the present study (44). Besides, in a phenomenological study by Ronnevig et al., the analysis of the narratives of 13 Norwegian patients with irritable bowel syndrome showed the fear and embarrassment of the IBS symptoms in the public as a threat to the patient's privacy (45). However, Iranian patients pointed out to fear of being stigmatized due to the community's failure to get along with the disease, not going to religious places, and their concerns for the occurrence of the symptoms while doing religious practices, which were not mentioned in any of the studies. In their interviews in a phenomenological study, Canadian patients also pointed to the theme of embarrassment from the emotional effects of irritable bowel syndrome

and stigma (38). Another sub-subtheme related to the subtheme of the threatened self was feeling bad about oneself. A phenomenological study by Håkanson et al. showed that feeling of being physically and mentally different from others and the feeling of disgust for the negative and taboo signs make up the “different self-conceptions” as was stated by Swedish patients with irritable bowel syndrome (44). This finding supports the results of the present study. Following the results of the present study concerning deep self-knowledge, a phenomenological study by Jakobsson et al. showed that self-centeredness and regular self-care were related to the theme of “controlling daily life” that were emerged from interviews with Swedish patients with irritable bowel syndrome (51). Besides, the theme of “self-actualization” emerged in a qualitative study using thematic content analysis (52), as was evident in the present study. On the other hand, Sharp et al. found “self-redefinition” as one of the themes related to subthemes such as pain as part of the whole self and the attempt for self-acceptance from the narratives of Canadian women living with chronic pain (56). Similarly, the present study showed that participants with irritable bowel syndrome gained deep self-knowledge as a source of adaptation to the IBS symptoms. In the present study, the IBS patients' fear of being stigmatized due to the community's failure to get along with the disease, not going to religious places, and their concerns for the occurrence of the symptoms while doing religious practices were related to the concept of the threatened self. These factors have not been addressed in previous studies, as they are mostly related to the religious and cultural context of Iran and Iranian people's adherence to religious rites, which, in some cases, caused concern for the patients due to their failure to perform religious rites.

There were no specific limitations for conducting this study. However, the non-generalizability of the results could be one of the limitations of qualitative studies. The findings of this study can be applied in clinical, educational, and management fields and research in medical

sciences in internal clinics, psychiatry, neurology and psychiatry, and internal departments of gastroenterology and psychiatric, psychiatry, and gastrointestinal, and liver research centers in Iran. Besides, the results of this study can highlight the need to provide the necessary services and support to Iranian patients at home and abroad through the knowledge gained from their experiences and living conditions. It is suggested that the experiences of nurses and families of IBS patients be explored by future studies.

Conclusion

Based on the findings of this study, it can be argued that the experience of life with irritable bowel syndrome is a unique experience resulting in turbulent moments as the symptoms of the disorder that encompass release and crisis. The patient is sometimes forced to submit to the laws of irritable bowel syndrome and feel helpless in the face of tedious diagnostic and therapeutic processes. Therefore, the patient takes some steps to adapt to this disorder. The patient also considers the purpose of living with irritable bowel syndrome to be "self", whether it is threatened by the disorder or its symptoms, or reaches deep self-knowledge by gaining self-acceptance, personal growth, and knowledge of the body. The participants shared some of their unique experiences that can be taken into account by healthcare planners to provide comprehensive and effective care for these patients so that they could take steps to improve their health and quality of life.

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The Research Ethics Committee of Shiraz University of Medical Sciences approved this study to be conducted (Issue: IR.SUMS.REC.1394.S137).

Conflicts of Interest

There is no conflict of interest to be declared.

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