

presence of the disease), and social changes (difficulties in work and leisure activities, social isolation, or dependency) (Casellas, López-Vivancos, Badia, Vilaseca, & Malagelada, 2001; Haapamäki et al., 2010; Sajadinejad, Asgari, Molavi, Kalantari, & Adibi, 2012).

It has been reported that the severity of IBD is influenced by the interval since the diagnosis and its recurrence (Casellas, López-Vivancos, Casado, & Malagelada, 2002; Jaghult, Saboonchi, Johansson, Wredling, & Kapraali, 2011; Pizzi et al., 2006). However, few studies have addressed the quality of life of patients with IBD by analyzing their experiences (Peyrin-Biroulet, 2010) or subjective perspectives of life with the disease (Dorrian, Dempster, & Adair, 2009). Besides the patients' quality of life, it is important to understand dimensions of their life experiences that are potentially modifiable.

Knowledge of the ways in which individuals cope with IBD and construct their subjective experience is vital for understanding and reducing the effects of this disease on their daily life (Rønnevig, Vandvik, & Bergbom, 2009; Wolfe & Sirois, 2008). The aim of this study was to explore the personal factors that affect the quality of life of individuals with IBD.

Methods

Study Design

A qualitative study on the basis of grounded theory was undertaken (Corbin & Strauss, 2014) involving an in-depth analysis of the quality of life of individuals with IBD. The relationship of IBD with gender, time since diagnosis, and disease phase (active/inactive) was also explored. The data were collected between September 2012 and June 2013 in the Spanish provinces of Granada and Seville.

Participants

The study included individuals with CD or UC older than 18 years recruited from among members of the Inflammatory Bowel Disease Associations of Granada and Seville (provinces in Southern Spain) and from patients with CD and UC under treatment in the Clinical Management Units of Virgen de Rocio Hospital (Seville) and Virgen de las Nieves Hospital (Granada). Inclusion criteria were a confirmed medical diagnosis of CD or UC and the signing of informed consent to study participation. Heterogeneity criteria were established to select individuals with different profiles, considering variables reported to have a substantive effect on the subjective experience of individuals with IBD (i.e., gender, type of IBD, disease phase, and months since diagnosis).

Various authors have demonstrated that the phase of the IBD has a quantitative and qualitative effect on

the health-related quality of life of individuals (Keefer, Kiebles, & Taft, 2011; Lix et al., 2008; Pizzi et al., 2006). In the present study, the active or inactive phase of their disease was defined by the current medical diagnosis of IBD relapse or total remission, respectively. With regard to the period since diagnosis, previous studies have considered individuals with an IBD for less than 2 years (Gili & Bauza, 2009; Jaghult et al., 2011).

Sampling was continued until theoretical saturation was reached. The final number of participants was determined by combining the defined criteria in a way that was consistent with similar qualitative IBD studies (Fletcher, Jamieson, Schneider, & Harry, 2008a; Fletcher, Schneider, Van Ravenswaay, & León, 2008b; Pihl-Lesnovska, Hjortswang, Ek, & Frisman, 2010) and with other studies that have relied on participant interviews (Schneider, Jamieson, Fletcher, & Harry, 2009).

Fourteen individuals participated in this study. All of the participants fulfilled the selection criteria and the established profiles that were designed to ensure sample representativeness. Nine of the 15 participants were in inactive phase and five were in relapse phase. Table 1 displays the primary characteristics of the participants.

Data Collection

Data were collected in semistructured individual interviews, using a thematic script that was developed to address the research questions and relevant issues according to a review of the literature and the Inflammatory Bowel Disease Questionnaire (IBDQ-32) (Guyatt et al., 1989), which was previously adapted and validated for Spanish populations (Masachs, Casellas, & Malagelada, 2007). The interview was structured into the following four segments: (1) general data, (2) experience with the disease, (3) influence of the disease on a personal level, and (4) future expectations (Table 2).

After fulfillment of eligibility criteria was confirmed, each individual was contacted by telephone and informed of the nature of the study and its objectives. Individuals who agreed to participate were given an appointment to sign informed consent and undergo an interview at the respective association headquarters or hospital office. The duration of the interview was between 28 and 50 minutes.

Data Analysis

The interviews were analyzed in a sequential process that relied on deductive and inductive procedures, following Strauss and Corbin's approach (Corbin & Strauss, 2014) and based on a four-step constant comparison method. *Step 1* (deductive procedure) relies on previously defined themes and a set of pre-established questions; these themes shape a "map" of theoretical categories extracted

TABLE 1. Characteristics of the Participants

Code ^a	Type IBD	Gender	Age (in Years)	Months Since Diagnosis	Disease Phase ^b
I01	CD	Male	61	204	Relapse
I02	UC	Female	56	257	Inactive
I03	CD	Female	30	180	Relapse
I04	CD	Female	35	11	Inactive
I05	UC	Male	50	15	Inactive
I06	CD	Male	32	240	Inactive
I07	CD	Male	19	3	Relapse
I08	CD	Male	28	23	Relapse
I09	UC	Male	21	34	Inactive
I10	CD	Female	52	300	Inactive
I11	CD	Female	55	126	Relapse
I12	CD	Female	50	132	Inactive
I13	CD	Female	33	56	Inactive
I14	UC	Female	41	1	Inactive

Note. CD = Crohn disease; IBD = Inflammatory bowel disease; UC = ulcerative colitis.

^aAlphanumeric identification used to maintain the anonymity of the participants.

^bThe phase of the disease was established according to a confirmed medical diagnosis.

from the literature and the IBDQ-32. In *Step 2* (inductive procedure), significant text fragments of the participant narratives are analyzed and coded in an “open coding” step; the theoretical and emergent properties of each code are defined to allow comparison with other codes. In *Step 3*, the identified codes are grouped according to their characteristics and the theoretical categories established in Step 1. In *Step 4*, the categories obtained in the previous step are incorporated into the development of an explanatory theoretical approach to the phenomenon, producing the final categories (Table 3); this step is described by Strauss and Corbin as a “selective coding” procedure (Corbin & Strauss, 2014).

Analysis of the initial eight interviews yielded the first consistent findings, and the remaining six interviews were used to saturate the information and define the emergent theory that arose from analysis of the data. Two types of information triangulation were used to enhance the reliability and validity of the analysis. The first was conducted with the participants; after the transcription of each interview, a copy was given to the participants for its validation and the correction of any errors. The second type of triangulation was conducted among three researchers, who separately analyzed the data and then met to establish a consensus on the results.

In addition, an exhaustive analytical procedure was followed to overload all categories of the study in a deductive

and inductive manner, supporting all categories and codes with quotations from the interviews. This procedure was conducted using Atlas.ti Qualitative Analysis software.

Ethical Considerations

The study was conducted in accordance with the “Ethical Principles for Medical Research Involving Human Subjects” (World Medical Association, 2013). To ensure the confidentiality of the data and the anonymity of the participants, each participant was identified by an alphanumeric code. This research was approved by the Andalusia Ethical Committee and was authorized by the provincial Inflammatory Bowel Disease Associations.

Results

Experiences With the Disease

Health Status Perception

All participants were asked about their perception of their health status and quality of life. There were differences between individuals in the active versus inactive phase of the disease, with the former describing their disease in a more negative and vivid manner. Table 4 displays comparisons of descriptions by some participants during relapse with those by some participants in inactive phase.

TABLE 2. Interview Guide

Thematic Sections	Questions
1. Demographic data	<ul style="list-style-type: none"> • Diagnosed type of inflammatory bowel disease • Gender • Age • Months since initial onset • Current phase of the disease
2. Experience with disease	<ul style="list-style-type: none"> • What was your diagnostic process like? • What has the evolution of the disease been like? • What feeling have you most frequently experienced? • How would you describe your health status? • Do you frequently think about the disease? • What worries you most about the disease?
3. Influence of IBD on the personal sphere	<ul style="list-style-type: none"> • Do your friends and social network know you have IBD? • Do you have any limitations or difficulties in participating in social or leisure activities due to the disease? Which activities? • Is your workplace aware that you have IBD? • Do you consider your workplace to be rigid or flexible? • Do you experience any difficulty reconciling your work life with the disease? • Do you think that your daily life has changed since you were diagnosed with the disease? In what sense has it changed? • How would you describe your quality of life? What does quality of life consist of for you?
4. Expectations for the future	<ul style="list-style-type: none"> • What do you expect for the future in regard to the disease? • What do you expect for the future in your personal life?

Note. IBD = inflammatory bowel disease.

Personal Attitudes Toward the Disease

When asked how they coped with the disease, most participants had a positive attitude. These individuals may have reached an acceptance and adaption phase:

This disease has helped me to figure out what I want to do in my life and, in part, to be who I am. To enjoy [life], have a cup of coffee when I feel well and to do things. (I03)

With this disease and in almost everything, what I do is not give up but rather adapt. Depending on how I feel at any moment, that is what I will do. (I06)

I lived it with a lot of anxiety. First, because I was developing my own business and saw that I would not be able to carry on with it due to my lack of health. I had to leave all of that and change my life 180 degrees. Because they tell you that you either change your style of life or spend more time caring for yourself, because I used to work

TABLE 3. Categories and Codes

Categories	Codes
General data	Type of disease (TC) Gender (TC) Age (in years) Time course of the disease (TC) Status of the disease (TC)
Experience with the disease	Health status perception (TC) Personal attitude toward IBD (TC)
Impact of the IBD on a personal level	Social relationships (CT) Life before and after IBD (EC) Being and feeling normal (EC)
Future expectations	Future expectations regarding the disease (TC) Future personal expectations (TC)

Note. IBD = inflammatory bowel disease; TC = theoretical code; EC = emergent code.

TABLE 4. Differences in the Experiences of Individuals in Active Phase Versus Individuals in Inactive Phase of Inflammatory Bowel Disease

	With Relapse	With Inactivity
Health status perception ^a	<p><i>My health status? Poor, because emotionally you don't feel well, you don't want to eat and you don't want to do anything; actually, the word is "don't feel well." Psychologically and physically bad. (I01)^b</i></p> <p><i>Well, I don't know how to tell you about not knowing what awaits me and being worried about it; that's why I am always annoyed, because of not knowing what is going to happen to me. (I05)</i></p>	<p><i>I say I have a disease, but I am not a sick person. Most likely, I am psychologically well. (I04)</i></p> <p><i>I am handling it [the disease] all right because they haven't disallowed any foods. I can have a normal life within limits. I feel healthy. (I07)</i></p> <p><i>What I don't do is carry a placard saying "I have this disease." (I10)</i></p> <p><i>It is very relative. In comparison to what? In comparison to a person who doesn't have anything, I am not very well, but in comparison to someone with Crohn's disease I'm fine. (I13)</i></p>
Social relations ^c	<p><i>[Social relations are] completely out. From being an outgoing, very talkative, friendly person to a silent and unhappy person. I could not go out to buy toys for my children. I could not go out if I did not know how many restrooms were available on the way... And on some occasions, I would use my children's diapers to go somewhere without worrying. (I02)</i></p> <p><i>I go out when necessary, even during episodes, and it's just that you don't know when you are going to urgently need to use the restroom. (I05)</i></p> <p><i>My leisure activities are limited by the disease. Not always, just when I am not doing well. (I07)</i></p> <p><i>When you have an episode your morale goes down a little. You feel sad. When I'm like that it is more for my family than for me, because the truth is you can't go out anywhere. Then I am sorry for my poor husband who can't go out (I11)</i></p>	<p><i>Well, [friends] value my efforts a lot and are surprised that after being so active, I would have this disease. Nowadays, even if I feel bad, I go out. (I02)</i></p> <p><i>First off, with the people closest to me, there are no problems. For example, when I need to use the restroom, they know that when I disappear it's because I need to use the restroom and I'll be back. Or if I'm tired, I'll follow at my own pace, and they know that after a while I will need to sit or rest a bit. (I06)</i></p> <p><i>In fact, when I was in remission, I carried these astronaut-type feeding bottles and went out with my friends and saw everyone eating and me taking my bottles. But always at the level of close friends. (I10)</i></p> <p><i>I haven't given up everything. I was dancing in the gym and I go running, I have not left everything. (I14)</i></p>

^aHealth status perception code included in the category: experience with the disease.

^bAlphanumerical code used to identify participants.

^cSocial relations code included in the category: impact of IBD on a personal level.

14 hours a day. So either you change your lifestyle You quit smoking. You recognize what you have got. You study what is good for you and what is not. It meant changing everything (I10)

At the beginning I tell you I didn't take it well. Until you get to the moment when you say to yourself: "I have to die with the disease, but I don't have to die from the disease". From that moment on, good (I12).

However, participants with a shorter interval since the diagnosis and those in an active phase of the disease perceived their IBD as a continuous threat and expressed greater concern:

Well, I don't know how to describe what's waiting for me, and I'm concerned about it. I'm always unsettled by this (the disease), not knowing what will happen to me. Mostly, I have feelings of anger. The doctor and my colleagues used to tell me, "you'll be just the same," but it's far from true. (I05)

Influence of the Disease at a Personal Level

Social Relationships

The social relationships of the participants differed between the active or inactive phases of their disease. All participants agreed that their social interaction was

limited or nonexistent during a relapse and usually returned to normal during inactive periods (Table 4). All participants also considered their leisure activities to be severely constrained by their disease. Even during inactive phases, participants limited or modified their activities because of their fear of an unpredictable disease-related event (e.g., fatigue or the urgent need to use the restroom):

Under the circumstances, I go out only when it's necessary. I don't dare [go out for fun] because you never know when you will have to go to the toilet. (I05)

I used to play hockey, football, tennis, and basketball and I used to go swimming. I tried to go back to them after my first admission, but I couldn't. I was not in a condition to do it and I left it. ... I won't get back to regular sports activity. (I06)

Work Relationships

The participants reported on their work relationships, which were sometimes complicated by their colleagues' poor understanding of the limitations imposed by the disease. Their condition was also related to the repeated need for sick leave. In fact, some of the participants had decided to hide their condition at work in order to avoid conflictive situations.

I had lots of problems with my superiors at work that in the end led to me asking for a disability pension. Because it got to the point when the stress was too much. (I01)

My superiors at work are still not aware of what I've got.... I don't say anything about it. They would be flexible, but it is not possible to be flexible in my job. If I have to go out of the classroom I leave 25 children on their own. (I14)

It's true that at the beginning I had a problem with my immediate superior. When I returned to work, he sat me down and told me to go back for a health check to make sure that I would not be going on sick leave again. He said he had a trainee covering my job and told me to go home until he was certain I would not ask for more time off. (I02)

My Life Before and After IBD

Participants were questioned about their lives before and after the disease to describe how they rated their life change. Importantly, half of the participants had a positive opinion of the postdiagnosis changes, and some participants even reported a more positive experience than before its onset:

Being used to a life without a disease [compared] to one with a disease has been a total change in my life. What have I lost and what have I gained? I probably value

more what I've gained, but I've also lost a lot. Or so I thought. Now I don't see it so clearly. (I01)

It was bad at the beginning. However, truthfully, once I learned about the disease, I have learned to live with it and to take advantage of the good times. Now I live much better. (I02)

Most people will tell you that this experience is like a tsunami. Of course your life changes. In my case, the change was for the good. I mean, I wish it hadn't happened, because I would still have my company. It was my ideal life. However, my life has changed for good, because I realized many things about life, that I didn't realize when I was healthy. You value other things. Now I can say this, because I feel super-good. But if you had asked me when I was in hospital with a relapse [...] It's human nature, not to forget all the bad moments but to put them out of your mind. When people who tell you they feel worse, it's because they are very negative people, or because they are having an episode. (I10)

Well, it (my life) has changed and it is strange, but I think it has changed for the "better", in quotation marks. Now I have more limitations; before I did not have this control and anxiety, but the fact that this disease appeared has made me put the handbrake on the crazy life I was living and now my life is a little more organized in relation to food, sleeping habits, and everything. I now have a better life with more quality because of this control. (I12)

The impact of the disease on participants' lives and the way they experienced the changes were influenced by the interval since diagnosis and by its active or inactive phase. Participants with less than 24 months since the diagnosis and those in relapse tended to resist change and describe an impaired lifestyle after their IBD diagnosis:

My life has changed a lot for the worse, and I think it's impossible it will be like it was before. If I'm told that Crohn's disease disappears completely, then yes, but until then, no. This is because I know that the disease is there even if I don't have a relapse. It's psychological. (I08)

I don't want to change, I want my life to be the same as it was before, but there's no doubt that I have a chronic disease and it has also led me to have arthritis in my knees, hip, and hands, and I even had to have an operation. My life has got a bit worse. (I11)

It (my life) has changed during the colitis ... it has changed for the worse." (I14)

Being and Feeling Like a Normal Person

One of the central codes from the interviewees' discourses was the need to feel and be normal. This life perception refers to physical normality as the absence of symptoms, and to personal and social acceptance of

TABLE 5. Coding Results: Being and Feeling Normal

Life Context	Quotes From the Participants
Physical level	<p><i>I don't want to be a sick person. I don't feel like a sick person. I am positive, I'm a normal person, I'm normal, I eat like everybody else. (I04^a)</i></p> <p><i>Right now, I feel good, stable. My life is normal. (I05)</i></p> <p><i>I could do many more things. What I don't know is whether I will feel strong the next day, feeling able and willing or will have some problem, and because I don't want that, then I try to avoid it. (I12).</i></p>
Social level	<p><i>Maybe what worries me most is that there'll be a time when I will not be able to do the same things as my friends. I'm worried there will be a time when I will say, Uff! I am so tired that I can hardly keep up. (I03)</i></p> <p><i>It [the disease] has influenced me a little because since having it [Crohn disease], I have stopped going out, I don't have as much of a social life as before. Before, I had a normal life; I was with my friends all the time, and now I spend all my time inside. I have gone out only a very few times. (I07)</i></p> <p><i>I can't do what other people do. I go out every now and then, but less if I feel bad. (I09)</i></p> <p><i>What people don't see as normal is if they see you with a black eye or a patch on the nose, and they say "hey, what's happened to you". I don't go around giving explanations. (I10)</i></p>
Work level	<p><i>What happens now is that at work, colleagues tell me, "relax, girl," because it's different now. Yes, but it is different, it's like a loop, you need to prove that you're as useful as any of your colleagues that do not have the disease, which makes you make a greater effort. You get nervous and you feel bad; it's like a weird loop. (I03)</i></p> <p><i>I get up, I go to work, and I work a lot because I think that those of us who have this kind of disease are hard workers. (I02)</i></p> <p><i>What was normal at work before is now excessive. This disease changes everything. Before, I lived to earn money, and now I live to enjoy life itself. (I01)</i></p> <p><i>I had to give up my business and change my life completely. (I10).</i></p> <p><i>I decided to stop working and to look after myself. Then, in the long run, I could not go back to work. I couldn't have kept up with the pace of work. (I12)</i></p> <p><i>I've been very lucky in having a boss who understands me and has been very flexible with me ... Yes, it's true that my colleagues were also suffering my disease. Because I worked as a sales assistant and when I was not receiving treatment or anything and had to go to the toilet half the day. And they had to do my work. For this reason I took it very badly and I felt a burden on my co-workers. It was my own feeling, they never said anything themselves. (I13)</i></p>
Personal level	<p><i>Right now, I don't see it so clear, because I know that Crohn's disease will prevent me from having a normal life. You look a little different from the rest. Because you can have a normal life, but you know that the "bug" (the disease) is there and that at any moment it will wake up. I have had a little depression, especially on a relapse. You always have it here (he points to his head). You feel different from the rest because you know there are some things you cannot do. (I08)</i></p> <p><i>My life with the disease has been a struggle. I keep fighting and hoping I will win, even though it's unclear. I hope that what is now a rough patch is something I can conquer and live a few good years. (I01)</i></p> <p><i>I feel limited, especially when I feel bothered by it and have an episode. It is very complicated, and when I have an episode is when I have to adapt my life more to these moments. For example, this is not true at the moment. Now I could say I feel good and could go the cinema or for dinner and go out for a drink.; however, I don't do it because I think that if I go too far I will have some type of discomfort and I don't want it. So, instead of going out to the cinema or for dinner or for a drink, I will probably go out to the cinema and eat but then go home. (I12)</i></p>
<p><i>Note.</i> Being and feeling normal code included in the category: impact of IBD at a personal level. ^aAlphanumerical code used to identify the participants.</p>	

the life conditions that accompany the disease. The results are shown in Table 5.

Personal and Disease-Related Expectations

The interviewees preferred not to speak about the future, preferring to think about day-to-day living.

They preferred not to think about how the disease would impact their lives in the future:

The day-by-day with the disease is today, and tomorrow I don't know what will happen. I never think about future long-term plans. I always say, "well, today is over and we will see how tomorrow goes." If you dare to look

long-term, you may get upset. You get used to not thinking long-term. Live every day and as for tomorrow? It's very far away, very far away. (I01)

Most interviewees ranged between not knowing what would happen and hoping that their disease would remain stable:

(What I want) is that it (the disease), will leave me alone for a while [laughing]. As people say, "May I never suffer a relapse"... it's complicated, it's like asking for the impossible, any moment it can be here. The only thing I ask and hope for is that the relapse is the least painful possible. To relax and not have any more [hospital] admissions and not have to change treatment again. (I03)

I would love them to discover something fantastic and marvelous and tell me that the disease is going to disappear in two seconds. At least allow me to bear it with as much dignity as possible. That's the minimum, that it doesn't affect you too much, that it stays like it is. (I12)

However, the expectations of someone at the start of the disease that has just been diagnosed are considered to represent a transient episode.

I am hopeful, because the disease has been controlled after starting treatment. I want to think that I have had an occasional relapse and that's it. Although the doctor has already told me that the disease is there, occasional or not. I have stopped bleeding, which was very upsetting for me. Now I've seen that it has stopped—not cured—with the medication, I am hopeful. (I14).

Emergent Theory

The central category that reflects the subjective experience of individuals with IBD is "being and feeling normal," described as one of the most important personal factors influencing their life experience. This category is related both to the significance individuals attribute to their disease as a loss of normalcy and to the feeling of uncertainty about a possible relapse, with its unexpected and disruptive impact on normal life. The participants' perception of the illness (loss of normalcy) as transient (with periods of disease activity and inactivity) but also unexpected (abrupt onset of episodes) increases the yearning to be normal again, to be no longer sick as soon as possible.

The possibility of an unexpected eruption of this recurring disease was described as the factor that most strongly determined their perception of their health, personal life, and future. The length of time with an IBD had the greatest influence their adaptation to its presence (Figure 1).

Discussion

Among the primary findings of the study was the importance of the self-perception of the participants, not only in relation to their experience with the disease

and to being and feeling normal, but also in relation to the perception of others. The psychosocial aspects of IBD include the worries of patients and their feelings of guilt at not being able to lead a normal life (Gili & Bauza, 2009). Other authors observed that these patients express a specific need to be normal (Fletcher et al., 2008a). For this reason, professional care for these individuals has been aimed at normalizing different contexts of the individual, such as the maintenance of a normal health status (Hall, Rubin, Dougall, Hungin, & Neely, 2005). Patients describe their disease as an embarrassing and taboo experience that is poorly understood by others (Schneider et al., 2009), explaining why the appearance of normality is such an important objective.

This finding can be interpreted as a coping strategy on the basis of pursuing a normal daily life. Nonetheless, the fact that "being and feeling normal, like everyone else" was presented as a desire means that normalcy was more an ideal than a reality, described as an idealized state of being. In this idealization, being normal is equivalent to having no limitations or obstacles (i.e., being free of their disease).

The question arises as to whether the desire for normalcy represents an obstacle to acceptance of the disease and adaptation. As with other chronic or degenerative diseases that are invisible, patients can have the illusion of being normal (Kerstin, Wetzel, Hutchinson, Packer, & Versnel, 2014), making it more difficult for them to accept their condition. In this sense, the idealization of normalcy may be a covert form of denial of their disease. Evidence-based research is required to examine this hypothesis.

The pursuit of normality as a coping strategy offers interesting lines of action that could lead to specific therapeutic interventions that focus on acceptance of the disease and on the individual's ability to perform daily activities. A previous qualitative study (Devlen et al., 2014) reported the impact of IBD signs and symptoms on the lifestyle, daily activities, relationships, psychological status, and treatment of participants and their interrelationships. However, the emergent theory on the basis of the category "being and feeling normal" can act as a conditioning factor on the impact of the disease on these areas and should be taken into account in future research and in the planning of care for individuals with IBD.

Another key pattern in the interviews was the positive attitude toward their chronic disease expressed by some participants, who manifested a certain grade of acceptance at a personal level. Some researchers have considered this pattern to be paradoxical (Fletcher et al., 2008a, 2008b), although it is consistent with the idea that people who live with a chronic disease do not always maintain a negative point of view (Wolfe & Sirois, 2008). Nevertheless, a certain resistance to change was reported among individuals with a short

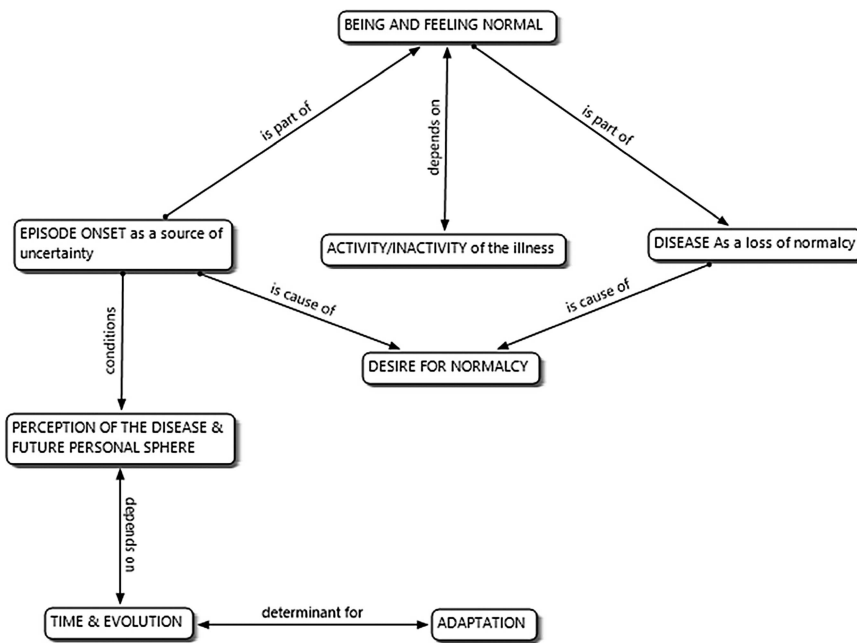


FIGURE 1. Emergent theory.

interval since their diagnosis and among those in active phase. There is a need for a personal adaptation period to face the losses imposed by chronic disease. These results are consistent with the suggestion by some researchers that the ability to adapt to an IBD is related to its severity (Casellas et al., 2002; Lix et al., 2008; Pizzi et al., 2006).

A further important aspect of this study was the essential role of the phase of the disease in relation to future life experiences, in agreement with previous reports (Casellas & López-Vivancos, 2004; Gili & Bauza, 2009; Lix et al., 2008; Pizzi et al., 2006; Rønnevig et al., 2009). The discourses of the participants depended on the phase of their disease at the time of the interview. Even among participants in an inactive phase, the language was more pessimistic when referring to past experiences or relapse phases, which may mean that they have not effectively coped with the disease.

The participants also reported on difficulties in their workplace, where they sometimes felt pressure to make special efforts to prove that they were not held back by their condition, which was often poorly understood by their colleagues and superiors. It has been reported that work disability and sick leave are more frequent in individuals with IBD than in the general population (Bernklev et al., 2006).

No gender differences were observed in the present investigation, in contrast to some reports of a tendency for women to have a lower perception of their quality of life (Haapamäki, Turunen, Roine, Farkkila, & Perttu, 2009; Saibeni et al., 2005). This discrepancy

may be attributable to the small sample size of our study and the lack of a direct evaluation of health-related quality of life.

Limitations

Study limitations include the fact that the participants were recruited from associations of individuals with IBD and were all therefore receiving support for their disease. It would be of interest to include individuals without this assistance in future studies. The difference in sample sizes between the participants with UC and CD should be taken into account, although we do not consider that it impacts on the overall findings of this qualitative investigation.

Relevance to Clinical Practice

This study evidences the need for an understanding of the perceptions and life experiences of individuals with IBD in order to deliver optimal nursing care. The present study is relevant to nursing practice and interventions in early stages and relapses of the disease. Individuals with IBD require support for self-management, self-care (Lovén Wickman et al., 2016), adaptation, and effective coping. These findings may be useful in the design of assessment and follow-up interviews conducted by gastroenterology nurses with this type of patient.

Conclusions

This research reveals a series of common elements in relation to the life experiences of people with IBD. A poor understanding of the experiences of individuals

with IBD may represent a barrier to their treatment and a limitation in their interaction with health professionals. The participants only consider themselves to be unhealthy during a relapse or active phase of their disease. However, the impossibility of predicting when and why an active phase will be triggered implicates living with the constant threat and uncertainty of becoming an unhealthy person. Hence, the primary coping strategy is the desire to feel and appear normal. This study describes the factors that impact the life experience of people living with IBD. Individuals in an active phase of their disease and individuals with a shorter interval since diagnosis evidence the worst adaptation to life changes. ✪

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