Research Article

Self-Care, Disease Activity and Health-Related Quality of Life Among Patients with Inflammatory Bowel Disease

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Abstract

Introduction: Self-care is needed for patients living with inflammatory bowel disease so that they can manage symptoms in the context of activities of daily living. The objective was to explore self-care in relation to disease activity and health-related quality of life in patients with inflammatory bowel disease.

Methods: We used a cross-sectional exploratory design and a total of 234 patients with inflammatory bowel disease participated. Disease specific measurements was used as, a newly developed self-care questionnaire, Harvey Bradshaw Index, the Simple Clinical Colitis Activity Index and Short Health Scale.

Results: The results revealed that patients reported a high frequency of self-care maintenance as medication adherence, diet adaptation, planning the day and

avoiding activities, self-care monitoring in symptom recognition and self-care management in managing stress and managing sleep. Higher disease activity was related to higher self-care activity. Compared to patients with ulcerative colitis, those with Crohn's disease planned their day to a higher degree when their bowel symptoms interfered with daily life. Disease activity and avoiding activities decreased their health-related quality of life.

Conclusion: Self-care was positively associated to higher disease activity. Higher disease activity highlight self-care maintenance as planning the day and avoiding activities in daily life what in turn decrease health-related quality of life. Regular discussions on symptoms in relation to self-care is of great importance for patients to adjust their daily activities.

Keywords: Disease activity; Health-related quality of life; Inflammatory bowel disease; Self-care

1. Introduction

Crohn's disease and ulcerative colitis are chronic Inflammatory Bowel Diseases (IBD) that most often have an early onset in life, between 15 and 35 years of age. In the last decades, the incidence and prevalence of IBD has increased worldwide, and approximately three million people in European countries live with these conditions [1]. For these patients, the disease activity and severity vary but for some patients the symptoms are debilitating, such as abdominal pain and bloody diarrhea, causing lifelong need for healthcare and contacts with healthcare professionals. The symptoms affect functioning in daily life and perceived health-related quality of life. Worries and concerns can influence this perception [2].

Ulcerative colitis affects the rectum and to various degree the colon, whereas Crohn's disease may involve any part of the gastrointestinal tract, although it in 90% of the cases affects rectum, colon or the distal ileum. The diseases are heterogenous in their clinical presentation depending on the degree of disease activity, extent and location of bowel inflammation and presence of intestinal complications or extraintestinal manifestations [3, 4].

Commonly experienced symptoms with IBD that need to be managed are both physical and psychological. Most gastrointestinal symptoms are quite unpleasant and include abdominal cramps, abdominal pain, diarrhea, urgency, fever and fatigue [5]. Extra-intestinal manifestations are frequently in patients with IBD, occurring in up to 50% [6]. The most frequent extra-intestinal complications are musculoskeletal, including arthritis and osteoporosis; dermatologic, such as erythema nodosum or pyoderma gangrenosum; and ocular as uveitis or episcleritis [3]. The disease course varies between individuals, but usually periods in remission are interrupted by flare-ups unless maintenance treatment can control the disease [4].

The symptoms from IBD and associated manifestations has the greatest influence on health-related quality of life since they negatively influence performance and participation in daily activities [7, 8]. Mood disorders such as depression, anxiety, and worry are common, with an incidence of 18.6%-40% among patients with IBD in both relapse and remission [9, 10]. Patients with IBD who are in remission experience a much better health-related quality of life than patients with active disease, and in fact like a background population [11]. Induction of remission should therefore be the mainstay of care regarding

improvement of health-related quality of life [12, 13]. To achieve this, many patients with IBD are motivated to care for themselves and patients with chronic illness benefit from engaging in activities of self-care in partnership with their IBD team [14].

In this study, self-care in daily life refers to an active process performed by a person living with a chronic disease to maintain and promote health [15].

The middle-range theory specifies that self-care involves three separate, linked concepts. Key concepts in the self-care process are self-care maintenance, self-care monitoring and self-care management. Self-care maintenance refer to positive health practices that help patients adhere to treatment and maintain health (e.g., taking medications and adapting their diet). These behaviors are either self-determined or advocated by the healthcare professionals. Self-care monitoring, is the process of paying attention to one's bodily functions and symptoms, including detecting and interpreting with the intention of recognizing changes that have occurred. Self-care management, involves an evaluation of changes in physical and emotional signals to determine whether any action is needed [15, 16]. Patients with chronic diseases need to be motivated and engaged in their own care, and self-care is important for successful treatment [15]. Self-care improves well-being and health-related quality of life in patients with chronic disease. The value of self-care is to be healthy, aiming at reducing symptoms. Self-care also gives the patient an opportunity to get involved with others and ask for help when needed [17].

High patient activation has been shown to be associated to remission. Self-care is important for

successful treatment and requires that patients are well informed about their disease, its treatment and the agreed care plan [18]. Self-care is crucial for patients with these conditions to maintain a good health-related quality of life. Patients with IBD engage in self-care activities mainly to control disease activity or to manage or adapt to the symptoms. Another challenge faced by patients with IBD is the need to manage side effects of the medications used to treat the illness [19]. Symptom recognition, handling of symptoms, planning one's life, and seeking new options have been described as self-care activities in daily life among patients with IBD. Self-care in daily life includes, for example, medication adherence and dietary adjustments [20]. Self-care also means planning for urgent access to a toilet, which affects daily functioning [8].

Until now, research exploring self-care in relation to disease activity and health-related quality of life among patients with IBD has been limited. The knowledge gap relates to how disease activity influences self-care. The gap also include how self-care affects health-related quality of life in these patients. Both patients and healthcare professionals need to understand why and when the symptoms occur to choose adequate self-care management [21].

Several factors, including skills, self-care confidence, and cultural beliefs, influence the self-care process [17]. An understanding of the patient's subjective symptom experience can improve the healthcare professional's ability to support self-care [22] and increase the patient's health-related quality of life [23]. Motivation, good health-promoting activities, and discussing medication adherence can contribute to achieving this goal. Thus, the objective of this study

was to explore self-care in relation to disease activity and health-related quality of life in patients with IBD. Research questions:

- Is self-care associated with self-reported disease activity?
- Does self-care differ between patients with ulcerative colitis and patients with Crohn's disease?
- Does the self-care affect the health-related quality of life in patients with IBD?

2. Methods

2.1 Design and sample

A cross-sectional exploratory design was used. The methods of this study are reported in accordance to STROBE guidelines [24]. Between December 2015 and April 2017, nurses or physicians from three gastroenterology clinics asked adult patients to participate via letter or in-person. Inclusion criteria were patients with IBD and language knowledge in reading and writing the language. Approval was obtained by the Regional Ethical Review Board.

2.2 Data collection

Nurses or the physicians at each gastroenterology clinic provided study information through an information letter that included study objectives and description, what volunteering entailed, and information about the ability to withdraw at any time. In the gastroenterology clinics, in total 480 patients were approached and invited to participate. Of these, 234 patients completed and sent the informed signed consent and the questionnaires in a postage-paid return envelope, and no reminders were used.

2.3 Measurements

Patient characteristics were measured through a patient-reported, study-specific form for description of age, sex, diagnosis, marital status, duration of IBD, education, occupational status, and surgery.

2.3.1 Self-care questionnaire: Self-care was measured with our newly developed 22-item disease-specific patient-reported questionnaire for patients with IBD [22]. The questionnaire measure what symptoms the patient is experiencing, how confident the patient is in being able to interpret the symptoms, how the patient adapts to everyday life and activities, what actions the patient takes to relieve the symptoms, such as trying to sleep well or managing stress, if the patient is following the medical treatment and knows where to turn in the treatment for symptoms. Questions on smoking and snuff are included, snuff use refer to smokeless tobacco and common used in Sweden, usually scented or flavoured. Responses were scored on categorical data as never, sometimes, often, always (range 1-4), or not relevant. Higher values indicate self-care maintenance, self-care monitoring or self-care management being performed more frequently. One open-ended question on other performed self-care management activities was used. Each item was analyzed separately. The questionnaire has been shown to be valid and reliable [22].

2.3.2 Disease activity: Disease activity was calculated using clinical disease activity indices. For patients with Crohn's disease, disease activity was patient-reported according to a modified version of the Harvey-Bradshaw Index that excluded the item related to abdominal mass. Disease activity was divided into remission (<5 points) or relapse. The maximum score is 22 because of exclusion of the abdominal mass item.

The Harvey-Bradshaw Index is validated for patients with Crohn's disease [25]. The Simple Clinical Colitis Activity Index is a 6-item disease activity index for ulcerative colitis with a maximum score of 19 [26, 27]. Disease activity was divided into remission (≤2 points) or relapse [26, 27]. This index is validated for assessing disease activity in ulcerative colitis [28].

2.3.3 Health-related quality of life: Patient-reported health-related quality of life was measured with the Short Health Scale, a 4-item, questionnaire measuring the subjective experience of how patients with IBD are influenced in four major health dimensions: symptom burden, social function, disease-related worry, and sense of general well-being [23]. Responses are scored on a 100-mm visual analogue scale, and results are presented for each of the four items. Higher values indicate worse symptom burden, social function, disease-related worry, and general well-being. The Short Health Scale has been validated for ulcerative colitis and Crohn's disease [23, 29].

2.4 Data analysis

Descriptive statistics are used to present self-care, patient characteristics, and disease activity. Data are expressed as mean and standard deviation, median and interquartile range or range, or frequency and percent, as appropriate [30]. To explore differences between groups, Student's t-test was used for continuous variables, such as age and duration of IBD. The Chi-square test was used for categorical variables, such as sex, diagnosis, marital status, education, occupation, and surgery. Fisher's exact test was used for calculating the difference between self-care and diagnosis, and Spearman's correlation was applied to explore bivariate associations between self-care, disease activity and health-related quality of life [30].

For assessing the relationship, a rho value of 0.1-0.3 was considered to indicate a weak correlation, 0.3-0.5 was classified as moderate, and 0.5-1.0 was classified as strong [31]. We performed a multiple logistic regression analysis to investigate whether an interaction effect was present for self-care maintenance in planning the day among patients with IBD [32]. As planning the day is common among patients with IBD [20], it was used as the dependent variable, dichotomized into "no planning" and "planning daily life". Independent variables were self-care, patient characteristics, disease activity, and health-related quality of life. A $p < 0.05$ was considered to indicate significance. Internal data missing refer to no answers in the questionnaire. Data were analyzed using SPSS Statistics for Windows (Version 24.0. Armonk, NY: IBM Corp).

3. Results

3.1 Patient characteristics

In total, 234 patients living with IBD completed the questionnaires (49% response rate). The median age was 48 (range 19-87) years, with no differences between the sexes, and 79% (n = 175) were married. Most patients had a diagnosis of ulcerative colitis (60%). For education, 36% (n = 83) reported having high school or university level education. Of all patients, 65% (n = 145) were employed (Table 1), 14% (n = 33) were smokers, and 17% (n = 40) used snuff.

3.2 Self-care in daily life among patients with IBD

Self-care maintenance was expressed in that most patients were taking medication for IBD as prescribed by a physician sometimes, often, or always (93%) (Table 2). Moreover, self-care monitoring were that the patients paid attention to their intestinal (95%) and other physical symptoms (41%). Self-care

maintenance were also expressed in adaptation of daily life as adapting the diet (82%), planning the day (61%), and avoiding activities (58%) and self-care management as managing stress (71%). In the open question, physical activities such as dancing, walking, exercise, gym, dog walking, meditation, regular physical activity, and being out in nature were described (n = 12). Diet adaptation was described as using a lactose-free diet and use of olive oil, honey, and omega 3 supplementation. Furthermore, patients reported using a strictly low-carb/high-fat diet, using rye porridge, avoiding bread, regularly eating, or eating at the right time. Self-care helped to relieve the symptoms of IBD sometimes, often, or always in 74%. The self-care questionnaire included one response option for each item as not relevant; of these, three items had a high response: "I pay attention to psychological symptoms," "I avoid sex," and "how often does self-care help you relieve symptoms of IBD" (internal data missing 18-22).

A majority (99%) answered that they knew whom to contact if they experienced symptoms of IBD, and 91% of the patients were familiar with the symptoms that should lead them to contact their IBD team (data not shown). The performed self-care activities showed differences related to diagnosis in self-care maintenance as adapting diet, avoiding various activities including sex, self-care monitoring as paying attention to psychological symptoms, and self-care management in looking for new approaches when living with IBD. The self-care activities were more frequent in patients with Crohn's disease ($p < 0.05$) (data not shown).

3.3 Self-care and disease activity

Patients with Crohn's disease (n = 93) had a median disease activity of 4 (range 0-20), according to the Harvey–Bradshaw Index; of these, 52% (n = 48) were in remission. Patients with ulcerative colitis (n = 137) had a median disease activity of 3 (range 0-13) according to the Simple Clinical Colitis Activity Index; of these, 49% (n = 67) were in remission. Higher disease activity was positively associated with self-care maintenance in the need to plan the day to always be near a toilet (rho = 0.491-0.580; $p < 0.001$) and planning the day in view of living with IBD (rho = 0.452-0.480; $p < 0.001$) and to avoid various activities (rho = 0.414-0.520; $p < 0.001$). High disease activity also was positively associated with self-care management when looking for new approaches among patients with ulcerative colitis (rho = 0.474; $p < 0.001$) (Table 3).

3.4 Self-care and health-related quality of life

Self-care activities were positively associated with worse health-related quality of life. Self-care monitoring in paying attention to intestinal symptoms was moderately associated with symptom burden, less social function, more worry, and worse well-being (rho values 0.348, 0.411, 0.429, and 0.319, respectively). Self-care maintenance in avoiding activities was also positively associated with worse health-related quality of life (greater symptom burden, more impaired social function, more worry, worse well-being: rho values 0.388, 0.605, 0.418, and 0.470, respectively), as self-care maintenance in planning the day to be near a toilet (rho values 0.451, 0.609, 0.494, and 0.437, respectively). Finally, planning the day when living with IBD had a positive correlation with each of these dimensions of health-related quality of life, as well (rho values: symptom burden, 0.378;

social function, 0.575; worry, 0.473; and well-being, 0.406). The results showed more frequent self-care in patients with Crohn's disease, manifested self-care maintenance as diet adaptation, avoiding various activities including sex, self-care monitoring as paying attention to psychological symptoms, and self-care management as looking for new approaches to living with their condition. The multiple logistic regression analyses showed that the variables paying attention to intestinal symptoms, adapting the diet, whether or not self-care helps to relieve symptoms, and avoiding various activities including sex, and avoid alcohol were associated with the extent to which the patient planned his or her life. There was an interaction effect (odds ratio, 0.966; $p = 0.039$) for social function according to planning the day in the face of living with IBD (Table 4). Thus, the relationship between planning the day and social function (if the bowel interferes with the activities in daily life) was different for the two diagnoses. A bivariate association between planning the day and social function was higher for Crohn's disease (rho = 0.709; $p < 0.001$) than for ulcerative colitis (rho = 0.444; $p < 0.001$).

Table 1: Characteristics of included patients with inflammatory bowel disease.

Characteristics	All	Crohn's disease	Ulcerative colitis	p
	n= 234	**n = 94**	**n = 140**	
Age, years				0.671†
Mean ± SD	48 ± 16.9	48.7 ± 17.2	47.5 ± 16.8	
Sex, *n (%)*				0.481‡
Male	110 (48)	41 (45)	69 (49)	
Female	122 (52)	51 (55)	71 (51)	
Marital status, *n (%)*				0.575‡
Married or partnered	175 (79)	69 (74)	106 (76)	
Single	59 (21)	25 (26)	34 (24)	
Duration of inflammatory bowel disease, years				0.326†
Mean ± SD	15.5 ± 13.5	16.4 ± 14.3	14.9 ± 12.9	
Education, *n (%)*				0.069‡
Compulsory school	53 (23)	19 (21)	34 (24)	
Upper secondary school	96 (41)	46 (50)	50 (36)	
High school or university	83 (36)	27 (29)	56 (40)	
Occupational status, *n (%)*				0.569ᵇ
Working	145 (65)	51 (55)	94 (67)	
Retired or unemployed	68 (31)	29 (32)	39 (29)	
Sick leave	10 (4)	4 (4)	6 (4)	
Surgery, *n (%)*	64 (27)	49 (53)	15 (11)	<0.001‡

† Student's t-test; ‡ Chi-square test; ᵇ Fisher's exact test; Internal data missing, 3-10

Table 2: Self-care in daily life among patients with inflammatory bowel disease.

Self-care	Never	Sometimes	Often	Always	Not relevant
	n (%)	n (%)	n (%)	n (%)	n (%)
Do you pay attention to symptoms of inflammatory bowel disease?					
I pay attention to intestinal symptoms.	9 (4)	87 (37)	70 (30)	65 (28)	1 (1)
I pay attention to physical symptoms unrelated to the intestines.	30 (13)	94 (41)	65 (28)	31 (13)	11 (5)
I pay attention to psychological symptoms.	61 (27)	95 (42)	38 (17)	16 (7)	18 (8)
How often do you feel confident that you are able to determine whether intestinal symptoms are due to inflammatory bowel disease?	8 (3)	42 (18)	123 (53)	59 (25)	2 (1)
How often do you adapt your day to problems caused by inflammatory bowel disease?					
I adapt my diet.	42 (18)	87 (37)	65 (29)	36 (15)	3 (1)
I avoid various activities.	94 (41)	95 (41)	35 (15)	5 (2)	2 (1)
I avoid sex.	105 (46)	71 (31)	21 (8)	11 (5)	22 (10)
I avoid alcohol.	67 (29)	78 (34)	46 (20)	31 (13)	9 (4)
I plan my day so that I am always near a toilet.	64 (28)	80 (35)	41 (18)	42 (18)	4 (2)
I plan my day in view of the fact that I have inflammatory bowel disease.	85 (36)	92 (39)	36 (15)	17 (7)	3 (1)
Do you take medication for inflammatory bowel disease as prescribed by a doctor?	2 (1)	9 (4)	2 (9)	185 (80)	15 (6)[a]
How often do you administer self-care to prevent or relieve symptoms of inflammatory bowel disease?					
Self-care to make sure I sleep well.	85 (37)	79 (34)	35 (15)	22 (10)	9 (4)
Self-care to manage stress.	64 (29)	98 (43)	50 (22)	15 (6)	3 (1)
I find out more about inflammatory bowel disease.	56 (24)	114 (49)	41 (18)	18 (8)	2 (1)
I look for new approaches to living with inflammatory bowel disease.	79 (34)	99 (43)	25 (11)	21 (9)	6 (3)
I use natural remedies.	191 (82)	28 (12)	3 (1)	7 (3)	3 (1)
How often does self-care help you relieve symptoms of inflammatory bowel disease?	36 (16)	101 (44)	61 (27)	9 (3)	22 (10)

Scored never, sometimes, often, always (range 1-4), or not relevant. Internal data missing 1-15. [a]No medication

Table 3: Self-care in relation to disease activity in patients with inflammatory bowel disease.

Self-care	Crohn's disease (n = 93)		Ulcerative colitis (n = 137)	
	Rho	*p*	Rho	*p*
I pay attention to intestinal symptoms.	0.340	0.001	0.429	<0.001
I pay attention to physical symptoms unrelated to the intestines.	-	-	0.390	<0.001
I adapt my diet.	-	-	0.336	<0.001
I avoid various activities.	0.414	<0.001	0.520	<0.001
I avoid sex.	0.360	<0.001	0.468	<0.001
I plan my day so that I am always near a toilet.	0.491	<0.001	0.580	<0.001
I plan my day in view of the fact that I have inflammatory bowel disease.	0.480	<0.001	0.452	<0.001
I use self-care to make sure I sleep well.	0.334	0.011	0.327	<0.001
I use self-care to manage stress.	0.384	<0.001	0.346	<0.001
I find out more about inflammatory bowel disease.	-	-	0.431	<0.001
I look for new approaches to living with inflammatory bowel disease.	0.330	0.002	0.474	<0.001

Scored never, sometimes, often and always. Three patients were excluded in Simple Clinical Colitis Activity index and one in Harvey-Bradshaw Index due to incomplete symptom registration. Internal data missing values 4-16. Only values with Rho >0.30 are shown.

Table 4: Multiple logistic regression for planning daily life.

Outcome	Outcome Odds Ratio (95%) CI	P-value
Diagnosis	1.628 (0.638-4.154)	0.308
Social function	1.104 (1.038-1.174)	0.002
Diagnosis * social function	0.966 (0.934-0.998)	0.039

4. Discussion

To the best of our knowledge, this cross-sectional study have explored self-care in relation to disease activity and health-related quality of life in patients with IBD. This study contributes with increased knowledge about the importance of self-care in patients with IBD. In the absence of self-care, patients with IBD need support to carry out

individually adequate self-care aiming to not avoid more restrictions in daily life than necessarily in daily life. Other studies have explored disease activity, social support and health-related quality of life and confirmed the positive relationship between social support and health-related quality of life, that psychological symptoms act as a mediator in the relation between disease activity, social support and health-related quality of life [11]. Further other studies have explored patient activation according to knowledge, skills, and confidence to manage daily life and showed an association for patient activation and remission [33].

The prevalence of self-care in this study was highest for self-care maintenance in medication adherence, diet adaptation, planning the day, and avoiding various activities. Symptom monitoring in paying attention to symptoms and self-care management in managing stress, making sure to sleep well, and finding out more about IBD. The most important results indicate that self-care maintenance as planning the day, avoiding various activities, and self-care management as looking for new approaches are consequences of living with IBD. Planning the day entails a challenge for the patients [34], and doing so to be near a toilet and determine when to eat or find a suitable diet are common tactics [20].

The majority (93%) of the participants cited self-care maintenance as medication adherence sometimes, often, and always. Of this group, 80% reported taking medication always but exactly what kind of medication was not asked for. Adherence to maintenance medication in other studies have reported less adherence up to 72% among patients with IBD [35]. Studies have also shown less

adherence and reported that poor medication adherence is related to increased level of disability in patients with IBD. Disability refers to a lack of ability to perform activities of daily life, and reported predictors for non-adherence have included mood disorder [36].

The frequency of self-care maintenance as diet adaptation was reported high in this study (82%). The recommendation for nutritional management of Crohn's disease in remission is a varied and well-balanced diet [37]. Patients often have beliefs about the role of diet, and large controlled trials are needed for further investigating appropriate diet recommendations [38]. Self-care behavior such as diet and lifestyle are discussed as influencing pathogenesis in IBD [39], but evidence is still lacking [40].

In this study, 59% cited self-care management as sleeping well sometimes, often, or always. The patients in this study viewed it as important to find out more about IBD. Patients want to receive information about medications, what to expect in the future, living with IBD, and diet. Standardized education is needed for patients with IBD, as education varies [41] and patients frequently turned to internet sources and smartphone applications [42, 43].

Symptoms motivate patients with chronic diseases as IBD to engage in self-care, and interpreting symptoms is viewed as a self-care skill that develops over time when having a chronic disease. Symptoms and disease activity are related and also integrated in self-care [17].

Symptoms caused of higher disease activity was related to self-care maintenance in avoiding activities both in patients with ulcerative colitis and Crohn's disease. We did not ask participants about specific avoidance behavior, why they chose to avoid activities, or what self-care they performed to be able to participate in social activities. Self-care maintenance in avoiding social activities may affect the patient, leading to loneliness and less social togetherness [20]. Challenges for patients are the physical symptoms, impacting negatively on their psychological and social well-being and reduce their quality of life [2]. Loneliness is described as challenging for patients with IBD because they can experience it as psychologically painful and distressing. Poor social relationships and social function in adolescence for patients with IBD can be related to health problems later in life [44]. Patients with IBD may avoid activities because of experiences such as losing control of the bowel with urgent defecation, blood in stool that smells, an inability to work, and feelings like they are not being believed or seen [8]. The experience of abdominal pain [45] and fatigue both in remission and in relapse [46] may also result in avoidant self-care behavior.

As noted, self-care maintenance as adapting diet and avoiding activities including sex were more frequently reported by patients with Crohn's disease as patients with Crohn's disease often have higher disease activity. Sexual function is affecting health-related quality of life and are influenced by symptoms, medication, body image, and surgery. However, most studies have explored sexual functioning after surgery, and the body image is a common issue. Women have reported experiencing a greater impact than men [47]. Screening for sexual disorders should be considered [48].

Disease activity was associated with self-care management in making sure to sleep well. In other studies, disease activity in patients with IBD has been proposed as being associated with sleep disturbances, poor sleep quality, and fatigue [49, 50]. Higher disease activity has been associated with self-care as better medication adherence. Causes of non medication adherence are believed to be, the complex treatment and risk groups have in studies been shown to be young people especially men and high education level [35]. Non medication adherence is associated with a more complicated disease course, which is why optimizing medication adherence is important for preventing relapse, hospital stays, surgery and colorectal cancer [4, 35].

Higher disease activity was associated with managing stress as self-care behavior. Likewise, other studies have reported that symptoms and high disease activity are associated with perceived stress [51, 52]. Paying attention to stress management is important because stress frequently can lead to anxiety and depression in patients with IBD, of whom 25%-30% report perceived anxiety and depression [53]. Patients with IBD with higher disease activity in the current study chose to perform more self-care in daily life and had lower health-related quality of life. Performance of self-care in patients with higher disease activity was expressed in self-care maintenance as planning the day to always be near a toilet, planning the day in view of the fact living with IBD, avoiding various activities including sex and self-care management as making sure to sleep well,

managing stress, and looking for new approaches to living with their condition.

Decreased health-related quality of life in terms of symptom burden, less social function, worry and worse well-being was related to higher self-care activity. Patients living with IBD need to adhere to medication and navigate a social life. Using patient-reported questionnaires on self-care can enhance the patient safety and the health-related quality of life for the patients [54]. A wide range of self-care activities influence daily life with the intention to enhance good health-related quality of life. The symptoms interact with the self-care activities, and to handle the symptoms, the patients used avoidant behavior and planned their day. It is essential for the patients to know which symptoms require attention, how to engage in good health-promoting behavior, and when to consult healthcare professionals. It is necessary to strengthen the patient to enhance health-related quality of life for the patient. When confidence in self-care abilities increases, the outcome of self-care activity does, as well [15].

Future research should encompass opportunities for the patients to find strategies to enhance good health-related quality of life. Further investigation of self-care in patients with IBD is needed, as our study indicates avoidant behaviors with a negative influence on health-related quality of life. A self-care intervention study may increase knowledge about self-care that has positive outcomes for patients.

5. Strengths and limitations

A variety of factors may have been involved in why half of the patients chose to not participate. No reminders were used, and we could not perform a

non-responder analysis. However, the response rate was low but assessed as acceptable and similar to that of other studies involving patients with IBD [5]. There are always limitations in self-reported data, anyhow nothing in the collected demographic or disease-related data indicates selection bias, but that we can still not rule it out [55]. Recruitment of patients with IBD was performed at three gastroenterology clinics in Sweden, which may strengthen the findings because a larger sample in healthcare settings in multiple centers is recommended [56]. Despite the limitations, this study provides new insights into self-care in a patient's daily life. The findings contribute to clinical and empirical knowledge about the association among self-care, disease activity, and health-related quality of life.

6. Conclusion

When meeting the patient with IBD, healthcare professionals need to discuss symptoms regularly and highlight self-care activities related to self-care maintenance, self-care monitoring and self-care management. Healthcare professionals need to identify which patients need the most support. Self-care maintenance, self-care monitoring and self-care management in patients with IBD are associated with disease activity and health-related quality of life. Self-care differ between patients with ulcerative colitis and patients with Crohn's disease. Self-care maintenance as planning the day and avoiding different activities in daily life were associated with disease activity, especially in patients with Crohn's disease. Higher self-care activity was associated to decreased health-related quality of life in terms of symptom burden, less social function, worry and worse well-being.

Implications For Practice

This study demonstrates the need for greater attention to supporting self-care practices in patients with IBD. This is an European study and all participants have health insurance and access to specialty care. Special attention is needed in relation to disease activity to preserve or increase the health-related quality of life for patients with IBD. In case of relapses or a change in disease activity a re-assessment regarding self-care could help the healthcare professional to encourage the patient to not introduce and retain more restrictions in life than necessary. Using the self-care questionnaire is recommended when discussing with the patients.

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Declaration of Conflicting Interests

The author(s) declare(s) that there is no conflict of interest to disclose

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