Effect of Illness Representations and Catastrophizing on Quality of Life in Adults With Irritable Bowel Syndrome

LeeAnne B. Sherwin, PhD, MS, FNP-BC; Emily Leary, PhD; and Wendy A. Henderson, PhD, MS, CRNP

ABSTRACT

There is limited understanding of the influence of psychosocial factors on irritable bowel syndrome (IBS), which contributes to management difficulties and ineffective long-term treatment. The goal of the current study was to assess the effect illness representations and coping had on health-related quality of life (HRQOL) in adults with IBS. Self-report data were collected from 101 adults with IBS. Illness representations were measured with the Revised Illness Perception Questionnaire; catastrophizing was measured with the catastrophizing subscale of the Coping Strategies Questionnaire; and HRQOL was measured using the IBS-Quality of Life Measure. Participants perceived their IBS to be a chronic, cyclical condition with negative consequences, moderate symptomatology, and strong negative emotional impact. Their quality of life was poor and catastrophic thinking was noted to be used. Therefore, integrating illness beliefs and coping style into the management of IBS may improve well-being and minimize suffering. [Journal of Psychosocial Nursing and Mental Health Services, 54(9), 44-53.]
Irritable bowel syndrome (IBS) is a chronic, recurring, and episodic gastrointestinal dysmotility disorder characterized by abdominal pain or discomfort and altered bowel habits (Longstreth et al., 2006). A high proportion of patients with IBS experience psychiatric comorbidity that often goes unrecognized (Pinto-Sanchez et al., 2015). Commonly seen by primary care providers and even more often by gastroenterologists (Manabe, Tanaka, Hata, Kusunoki, & Haruma, 2009), IBS is estimated to affect between 25 and 45 million individuals in the United States (Mayer, 2008), with women being disproportionately affected (Lovell & Ford, 2012). Patients’ perspectives and coping styles, in addition to their comorbid anxiety, depression, somatization, or history of sexual and physical abuse, have been found to influence IBS severity, treatment choices, and outcomes (Whitehead, Palsson, & Jones, 2002). Collaboration between primary care, gastrointestinal, and psychiatric providers is a mainstay to treatment. Psychiatric nurses, in particular, have the potential to establish and nurture therapeutic relationships that can provide guidance in the management of this difficult-to-treat population, resulting in positive psychological and functional outcomes. The goal of the current study was to examine the role of patients’ illness beliefs and their coping strategies, and the association of these with health-related quality of life (HRQOL) in adults with IBS.

BACKGROUND

The proposed cause of IBS has evolved over the past two decades. Initially, IBS was thought of as a psychosocial disorder involving the interaction of multiple body systems. In recent years, IBS pathogenesis has been expanded. The current theory regarding IBS development is a biopsychosocial model that unifies the complex interplay between genetic, environmental, physiological, and psychosocial factors (Chang, 2014; Mulak & Bonaz, 2004). Dysfunction of genetics, immunity, inflammation, gut microbiota, motility, sensation, and brain-gut interaction are considered biological defects, whereas disturbances in fundamental psychosocial aspects include early life stressors, psychological state (i.e., depression, anxiety, and somatization), coping strategies, learned health behaviors, and beliefs (Chang, 2014). Dysfunctions of the biopsychosocial model stimulate reactions in the neurological, immune, and endocrine systems through the brain-gut axis leading to heightened IBS symptoms. Furthermore, the brain-gut axis is bi-directional. An individual’s emotions, thoughts, and perceptions influence sensations, secretions, motility, immune regulation, mucosal inflammation, and intestinal permeability of the gastrointestinal tract. These dysfunctions within the gastrointestinal tract influence an individual’s perceptions and behaviors (Chang, 2014).

Due to the complexity and uncertainty of the pathophysiology of IBS, treatments have had limited success. Treatment challenges have led to discrepancies between patient and health care provider beliefs. Historically, some medical professionals believed IBS was not a pathological condition but rather an overreaction to normal bodily sensations (Longstreth & Burchette, 2003). Individuals with IBS have reported delegitimization of their symptoms by their health care providers (Bengtsson, Ohlsson, & Ulander, 2007) and a sense of stigma (Drossman et al., 2009), which results in the devaluing of the complexity and severity of the disorder.

Although IBS is not a life-threatening disease, patients’ perspectives of the nature of their IBS, in terms of symptom patterns, and their implications on daily functioning, cognitive, emotional, and behavioral responses impact their functional status and sense of well-being (Cain et al., 2009; Farndale & Roberts, 2011). Functional status and sense of well-being are considered components of HRQOL and individuals with IBS who seek medical care report poorer HRQOL compared to those without IBS (Seres et al., 2008).

Symptoms play an important role in IBS because diagnosis is based on the characteristics of the symptoms. Abdominal pain and discomfort are the most frequently reported gastrointestinal (GI) symptoms (Drossman et al., 2009; Seres et al., 2008), whereas psychological distress (i.e., anxiety, depression, and somatization) (Drossman et al., 2009) and cognitive and behavioral factors (i.e., coping and adapting) are the most frequently reported psychological factors affecting HRQOL (Jones, Wessinger, & Crowell, 2006) in those with IBS. The severity of IBS is contingent on not only the GI symptoms but also the effect on an individual’s quality of life, such as self-imposed restrictions of diet and social, work, and leisure activities. Drossman et al. (2009) reported that the direct impact of IBS on the physical, social, emotional, and behavioral functioning persists even without active symptoms. Therefore, understanding patients’ perspectives of the effect of this heterogeneous syndrome could contribute to outcome improvements.

THEORETICAL FRAMEWORK

The current study used the Common Sense Model of Illness Representation (CSM) as the theoretical framework to investigate the cognitive and emotional factors that influenced HRQOL (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Meyer, & Nerenz, 1980). The CSM has been used by researchers to understand patients’ perceptions and their influence on coping and outcomes in various
chronic diseases, including inflammatory bowel disease (Dorrian, Dempster, & Adair, 2009; Kiebles, Doerfler, & Keefer, 2010), chronic fatigue (Gray & Rutter, 2007), rheumatoid arthritis (Groarke, Curtis, Coughlan, & Gsel, 2004), asthma (Soﬁanou et al., 2013), and IBS (Rutter & Rutter, 2002, 2007).

The CSM conceptualizes that patients’ coping mechanisms and disease outcomes are facilitated by organized cognitive and emotional illness representations or beliefs (Leventhal, Brissette, & Leventhal, 2003). For example, as individuals experience their IBS, they determine the nature of this health threat, appraise their resources, and engage in cognitive and/ or emotional actions to cope to lessen the impact of their perceived health threat. This appraisal of the health threat is a result of one’s own personal construction of the illness, how it occurred, and potential outcomes. These perceptions and responses are a result of prior knowledge and experiences culminating in illness representations specific to the health threat. Central to this model is its dynamic nature; the continued appraisal of beliefs and coping influence future representations and appraisals (Leventhal et al., 1992).

There are eight components or beliefs that conceptually deﬁne the illness representations: (a) identity, the label and symptoms individuals associate with their illness; (b) timeline (acute/chronic), the perceived timeline for the development and duration of the illness; (c) timeline cyclic, the cyclical nature of the illness; (d) consequences, the negative effect the illness has on the psychological, social, physical, and economic functioning of the individual; (e) personal control, the beliefs regarding their ability to control symptoms; (g) treatment control, the belief in the ability of the health care provider to intervene and control symptoms; (h) illness coherence, the coherent understanding of the illness; and (i) emotional representations, the belief about the negative emotional impact of their illness. These components affect both adaptation to the illness and health-related outcomes (Moss-Morris et al., 2002).

Although coping styles are dynamic, those who experience IBS have been found to display greater tendency toward the use of catastrophizing coping style (Lackner, Quigley, & Blanchard, 2004). Catastrophizing coping style, a cognitive coping style, has been shown to be a robust predictor of outcomes such as pain levels, physical functioning, and depression in individuals with IBS (Drossman et al., 2000). Catastrophizing coping style is characterized by the propensity to focus on and overemphasize the threat of symptoms. In addition, individuals negatively evaluate their own ability to manage discomfort (Hunt, Milonova, & Mosher, 2009; Keefe et al., 2003). Nurses are often ideally poised to assess the unspoken or behaviorally expressed thoughts, feelings, and experiences of patients throughout a health threat (Spade, Fitzsimmons, & Houser, 2015). As a result, exploration into the nature of patients’ beliefs and coping can contribute to personalized interventions that address barriers to long-term treatment. Therefore, the current study was developed to answer the following research questions:

- What illness representation components are endorsed by participants with IBS in the current study?
  - What impact does IBS have on HRQOL?
  - What is the level of psychological distress reported in the current sample?
  - Do these participants use catastrophizing coping style thinking?
  - If so, what is the level of catastrophizing coping style thinking used during an IBS pain experience?
  - What is the level of abdominal pain (i.e., typical intensity) experienced?
  - What are the associations among the illness representation components, catastrophizing coping style, and HRQOL?

**METHOD**

**Study Design**

A cross-sectional, descriptive study design was used. The study variables were measured through self-report questionnaires completed in a place of participants’ choice. Participants were recruited from the authors’ association with community-based practices in Connecticut and Idaho, and through snowball recruitment in Michigan, Missouri, Pennsylvania, and New Jersey.

**Sample and Sampling Plan**

A goal of 100 participants was considered feasible and adequate for this descriptive study. One hundred ninety-two potential participants were invited to participate to meet the goal of 100 completed questionnaires obtained. To be eligible, participants must have met the following criteria: (a) age between 30 and 50 years, (b) IBS diagnosis consistent with Rome III criteria (Table 1), (c) able to read and speak English, and (d) without a new diagnosis (within the past 6 months) of an organic gastrointestinal disorder involving the lower gastrointestinal tract, such as, but not limited to, Crohn’s disease, ulcerative colitis, microscopic colitis, collagenous colitis, colonic strictures, or malignancy.

**Procedures**

Potential participants were identified through a review of the ICD-9 billing code database of those who had previously consented to participate in research while undergoing care at the participating facilities. The focus of the database search was for IBS diagnosis code (ICD-9 code 564.1). Those with an active IBS diagnosis from the previous 12 months were considered candidates for the current study. Participants who met the inclusion criteria received a direct mailing that included an introduction letter acknowledging their interest in participating in research and as result of a chart review they were invited to participate in the study. A detailed description of the study, study question-
naires, and an addressed postage-paid return envelope were also included in the mailing. Written informed consent was waived because return of the questionnaires was considered to imply consent for participation. The protocol was approved by the Oregon Health and Science University Institutional Review Board.

**Measures**

**Participant Characteristics.** Demographic information was collected to describe the sample by using an eight-item questionnaire. Characteristics assessed included age, gender, race/ethnicity, marital status, length of time since diagnosis, highest educational level, employment status, and medications taken for the treatment of depression and/or anxiety.

**Illness Representations.** The Illness Perception Questionnaire-Revised (IPQ-R) was used to quantify the components of illness representation that were endorsed by participants with IBS in the current study. The IPQ-R was chosen because it is the most comprehensive and psychometrically suitable tool to assess the endorsement of the specific components regarding the illness perceptions of participants. The items for the measurement of the eight components were rated by the respondent on a 5-point scale ranging from 1 = strongly disagree to 5 = strongly agree. Each component’s score was summed and divided by the number of items. Higher scores indicated a more strongly held belief of the specific component (Moss-Morris et al., 2002).

**Health-Related Quality of Life.** The level of HRQOL impacted by IBS was measured with a condition-specific questionnaire, the Irritable Bowel Syndrome–Quality of Life (IBS-QOL), which is a self-report, 34-item questionnaire that measures IBS symptom bothersomeness, functional status, perceived quality of life, and social disability specific to IBS. This measure was chosen as it addresses domains specific to IBS. It is widely used and accepted in the IBS field of research (Lea & Whorwell, 2001; Singh et al., 2015; Solem et al., 2016). Participants rated each item on a 5-point scale that assessed how much each item described the respondent’s feelings to a particular statement. The responses ranged from 1 = not at all to 5 = extremely or a great deal, with additional labels of slightly, moderately, and quite a bit. Summative scoring was used to determine an overall score in addition to eight subscales, including body image, dysphoria, food avoidance, health-worry, interference with activity, relationships, social reaction, and sexual activity. The total score range was transformed to a 0 to 100 scale, with a lower score implying a poorer HRQOL (Patrick, Drossman, Frederick, DiCesare, & Puder, 1998).

**Psychological Distress.** To measure the level of reported psychological distress in the current sample, the Brief Symptom Inventory-18 (BSI-18) was used. This instrument assesses the degree of psychological distress along three symptom dimensions: depression, anxiety, and somatization over the past week. This measure was chosen as it addresses all three of the psychological distress variables frequently noted in patients with IBS (Drossman, Camilleri, Mayer, & Whitehead, 2002; Ringström, Abrahamsson, Strid, & Simrén, 2007; van der Veek, van Rood, & Masclee, 2008). The questionnaire asked how much participants were bothered by each of the associated 18 symptoms. Responses were rated on a 5-point scale, where 1 = extremely bothered and 5 = never bothered. Higher scores indicated a higher level of the psychological distress dimension. In addition, a Global Severity Index was calculated through summation, which provided an overall level of psychological distress (Derogatis & Melisaratos, 1983).

**Catastrophizing Coping Style.** The six-item catastrophizing subscale of the Coping Strategy Questionnaire was used to assess the level of catastrophizing coping style thinking used during an IBS pain experience. The selection of this instrument was based on prior use in the IBS population and its excellent reliability (Drossman et al., 2000; Keefe, Brown, Wallston, & Caldwell, 1989; Lackner, Gudleski, & Blanchard, 2004; Robinson et al., 1997). This subscale measured the endorsement of belief statements regarding catastrophizing coping style (e.g., “It is awful and I feel that it overwhelms me,” “I worry all the time about whether it will end,” “It is terrible and I feel it is never going to get any better,” and “I feel I cannot go on”). Participants rated each item on a 7-point rating scale that ranged from 0 = never do that to 6 = always do that. A higher score indicated more fre-

---

**TABLE 1**

**ROME III DIAGNOSTIC CRITERIA FOR IRRITABLE BOWEL SYNDROME**

Recurrent abdominal pain or discomfort at least 3 days per month in the past 3 months associated with two or more of the following:

1. Improvement of pain/discomfort with defecation.
2. Onset of pain/discomfort is associated with a change in frequency of stool.
3. Onset of pain/discomfort is associated with a change in form or appearance of stool.

Note. Adapted from Longstreth et al. (2006).

a Criteria met for the past 3 months with symptoms beginning at least 6 months prior to diagnosis.

b Discomfort is defined as an uncomfortable sensation, not described as pain.
quent use of the catastrophizing coping style (Rosenstiel & Keefe, 1983).

Average Pain Numeric Rating Scale. An 11-point numeric rating scale (NRS), with anchors of 0 = no pain to 10 = worst pain possible, was used to rate the “typical intensity” of abdominal pain experienced in the past 7 days (Jensen, Karoly, & Braver, 1986). The NRS was chosen because it is simple to administer, score, and can be assessed in written form. In addition, it has been used previously in individuals with IBS (Lackner & Qiugley, 2005; Lackner et al., 2004; Spiegel et al., 2009). The NRS was used to describe the level of pain experienced by the current sample.

Statistical Analysis
Descriptive statistics and Pearson’s correlation coefficients (MacKinnon, Krull, & Lockwood, 2008) were analyzed using SPSS for Windows version 23.0.

RESULTS
Demographic Characteristics
Completed questionnaires were received from 101 participants (53% response rate); the majority (78%) were female. Participant age ranged from 30 to 50 years (mean age = 42 years). More than 50% of participants were employed full-time and 32% had a Bachelor’s degree or higher. More than one half (65%) took medication for the treatment of depression and/or anxiety. The greatest number of participants (75%) came from gastrointestinal specialty outpatient private practices, as well as from women’s health and family practice private outpatient settings (20%). The remainder of responses came from advertisements or snowball recruitment. The demographics of participants reflect the reported typical population of individuals who experience IBS (Cain et al., 2009; Longstreth et al., 2006; Lovell & Ford, 2012).

Endorsement of Illness Representation Components
Overall, participants experienced a number of symptoms since their IBS was diagnosed (Table 2). The most frequently endorsed symptoms reported were pain, upset stomach, headaches, and abdominal bloating. Of the components of illness representation, participants considered their IBS to be chronic, unpredictable, and cyclical, and have a substantial negative consequence on their life. They also reported a belief of a “lack of control” over their IBS and little faith in current medical treatments. A significant percentage reported having a poor understanding of their IBS and the associated symptoms. The emotional impact was noteworthy (Table 3).

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>SYMPTOMS EXPERIENCED BY PARTICIPANTS (N = 101)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom</td>
<td>%</td>
</tr>
<tr>
<td>Pain in past 7 days</td>
<td>91</td>
</tr>
<tr>
<td>Upset stomach</td>
<td>86</td>
</tr>
<tr>
<td>Headaches</td>
<td>73</td>
</tr>
<tr>
<td>Abdominal bloating</td>
<td>72</td>
</tr>
<tr>
<td>Nausea</td>
<td>58</td>
</tr>
<tr>
<td>Fatigue</td>
<td>56</td>
</tr>
<tr>
<td>Sleep difficulties</td>
<td>44</td>
</tr>
<tr>
<td>Loss of strength</td>
<td>42</td>
</tr>
<tr>
<td>Dizziness</td>
<td>38</td>
</tr>
<tr>
<td>Weight loss</td>
<td>33</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>ENDORSEMENT OF SPECIFIC ILLNESS REPRESENTATION COMPONENTS AS REPRESENTED BY QUESTION TOPIC (N = 101)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness Representation Component/Specific Question Topic</td>
<td>% of Participants</td>
</tr>
<tr>
<td>Timeline acute/chronic</td>
<td></td>
</tr>
<tr>
<td>Consider their IBS to be permanent</td>
<td>87</td>
</tr>
<tr>
<td>Timeline cyclical</td>
<td></td>
</tr>
<tr>
<td>Symptoms change day to day</td>
<td>71</td>
</tr>
<tr>
<td>Symptoms come and go in cycles</td>
<td>77</td>
</tr>
<tr>
<td>Their IBS is unpredictable</td>
<td>63</td>
</tr>
<tr>
<td>Consequences</td>
<td></td>
</tr>
<tr>
<td>Consider their IBS a serious condition</td>
<td>68</td>
</tr>
<tr>
<td>Their IBS results in major consequences on their life</td>
<td>70</td>
</tr>
<tr>
<td>Their IBS affects the way others view them</td>
<td>32</td>
</tr>
<tr>
<td>Their IBS causes difficulties for those close to them</td>
<td>38</td>
</tr>
<tr>
<td>Personal control</td>
<td></td>
</tr>
<tr>
<td>They have no control over their IBS</td>
<td>44</td>
</tr>
<tr>
<td>Treatment control</td>
<td></td>
</tr>
<tr>
<td>Very little can be done to improve their IBS</td>
<td>35</td>
</tr>
<tr>
<td>Illness coherence</td>
<td></td>
</tr>
<tr>
<td>Symptoms are puzzling to them</td>
<td>57</td>
</tr>
<tr>
<td>Do not understand their IBS</td>
<td>47</td>
</tr>
<tr>
<td>Emotional representation</td>
<td></td>
</tr>
<tr>
<td>Get upset when thinking about their IBS</td>
<td>45</td>
</tr>
<tr>
<td>Their IBS worries them</td>
<td>51</td>
</tr>
</tbody>
</table>

Note. IBS = irritable bowel syndrome.
Impact of IBS on Health-Related Quality of Life

Overall, HRQOL reported by participants was poor (Table 4). Of the eight subscales, food avoidance was noted to have the lowest score, indicating the greatest impairment. However, all remaining subscales (i.e., interference with activity, body image, health-worry, dysphoria, sexual activity, social reaction, and relationships) were noted to have low scores, indicating significant impairment of HRQOL.

Psychological Distress Level

Overall, participants endorsed symptoms of psychological distress; depression (mean = 3.61, SD = 4.82, range = 0 to 22) and anxiety (mean = 4.73, SD = 5.14, range = 0 to 24) were noted to have moderately low levels. The greatest level was noted in the somatization subcategory (mean = 5.92, SD = 5.72, range = 0 to 24). Global severity scores were relatively low (mean = 14.27, SD = 13.48, range = 0 to 68); however, 66% of participants were treated with pharmacological agents for depression, anxiety, or both.

Catastrophizing Coping Style Level Reported During an IBS Pain Experience

The four most frequently endorsed catastrophizing coping style statements included: “It is terrible and I feel it is never going to get any better” (82%); “It is awful and I feel that it overwhelms me” (76%); “I worry all the time about whether it will end” (54%); and “I feel I cannot stand it anymore” (52%). However, on the contrary, the final two statements, “I feel like I cannot go on” (25%) and “I feel my life isn’t worth living” (21%), were endorsed less frequently.

Abdominal Pain Intensity

The greatest number of participants reported a moderate pain level over the past 7 days (mean = 4.7, SD = 2.51, range = 0 to 10). Only four participants reported experiencing no pain within the previous 7 days and an equal number reported experiencing “the worst pain possible.”

Associations Between the Illness Representation Components, Catastrophizing, and HRQOL

Individuals who reported more symptoms (identity component) were noted to report more serious negative consequences, a greater negative emotional impact, less control, and a poorer understanding of their IBS (a weak illness coherence). Catastrophizing was associated with all of the illness representation components. Catastrophizing had the strongest correlations between the consequences and emotional impact representations. Of interest, as control (i.e., personal and treatment) and understanding (i.e., illness coherence) increased, catastrophizing decreased. A poor HRQOL was found to have the strongest associations with negative consequences, negative emotional impact, and catastrophizing coping style (Table 5). There were no significant associations with the timeline cyclical component.

DISCUSSION

The current study supports the hypothesis of the CSM and current lit-
Participants who viewed their illness with a greater number of symptoms and negative consequences, more chronic in nature, less control, and a more negative emotional impact were those who experienced poorer health-related quality of life.

chronic in nature, less control, and a more negative emotional impact were those who experienced poorer HRQOL. This reported level is consistent with HRQOL levels noted in current literature (De Gucht, 2015; Lackner et al., 2014). One difference in the current study from the Dutch study completed by De Gucht (2015) is that additional subscales of body image, health-worry, and relationships demonstrated significant impairment. Numerous factors have been found to influence HRQOL. Frequency and severity of symptoms, multiple comorbid conditions, and depression levels (independent of symptoms) in particular have been associated with poorer HRQOL (Lackner, et al., 2013; Lee et al., 2008). Psychological distress (e.g., depression) has been associated with increased symptom severity and can influence treatment-seeking behavior (Lea & Whorwell, 2001; Monnikes, 2011). In the current study, the reported number of symptoms and pain level were used as a proxy to quantify the severity of symptoms. Ninety-one percent of participants reported pain in the past 7 days, in addition to other multiple symptoms. Self-reported psychological distress level was relatively low; however, 65% of participants reported being treated for depression and/or anxiety. As noted by Kaplan, Franzen, Nickell, Ransom, and Lebo-vitz (2014), pharmacological treatments of psychological distress improve quality of life in those with IBS. It is possible that the pharmacological management of these participants was reflected in their self-reported level of HRQOL.

The use of a condition-specific questionnaire was advantageous in that it captured the specific concerns of these participants with IBS. As mentioned previously, the quality of life level reported was significantly impaired and noted to be lower than in other studies (De Gucht, 2015; Tang, Yang, Wang, & Lin, 2012). Interestingly, the lowest scoring subscale, food avoidance, demonstrated the greatest impairment. Food intolerances are widely reported in the IBS literature (Eswaran, Tack, & Chey, 2011). As a result, a new IBS therapy involving avoidance of fermentable sugars in the diet has been instituted since completion of the current study (Barrett et al., 2010; Magge & Lembo, 2012). It would be beneficial to investigate the influence of compliance with a low fermentable sugar diet on HRQOL, specifically the food avoidance subscale.

Coping also played an important role in HRQOL. The literature reports those with IBS tend toward catastrophizing coping strategies. This tendency to “catastrophize” has been found to contribute to more intense pain and greater emotional distress (Keefe et al., 1989). Although individuals in the current study reported a relatively low level of catastrophizing coping style, a significant proportion endorsed catastrophizing statements, and it is important to recognize endorsement of any of these statements is significant and can have a negative impact on functioning, pain, and psychological distress. Catastrophizing endorsement in the current cohort was similar to levels reported in the literature (Drossman et al., 2000; Keefe et al., 1989).

The correlations demonstrated that the illness representation variables were related to each other. Endorsement of multiple symptoms attributed to IBS was associated with more negative consequences. Negative consequences were associated with a strong belief the IBS would have a long duration, be poorly controlled, and have a negative emotional impact. Conversely, a strong belief of personal control was associated with strong treatment control belief, a better understanding of IBS, and less of a negative emotional impact. These findings are consistent with past research completed by Rutter and Rutter (2002) in an older IBS population identified through a support network, the majority of whom were retired or unemployed.

In addition, illness representations were related to HRQOL. A strong belief regarding the identity or number of symptoms associated with IBS, negative consequences, chronicity, and negative emotional impact were negatively associated with HRQOL, whereas a stronger belief in control and understanding were positively associated with HRQOL. This finding
is interpreted as individuals who reported fewer symptoms, fewer negative consequences, a shorter timeline, and less of an emotional impact were able to understand their disease, believed it could be controlled, and experienced a better HRQOL. This finding is consistent with De Gucht’s (2015) findings that daily symptoms impact patients’ beliefs regarding the consequences and emotional impact of IBS resulting in poorer HRQOL.

The components of illness representation were further associated with catastrophizing coping style. Individuals with a strong belief regarding the negative consequences and negative emotional impact were positively associated with catastrophizing coping style. These findings indicate that individuals who associated negative consequences and negative emotional impact would endorse catastrophic thinking.

There is a high symptom burden in these participants as reflected by the disease-specific HRQOL scores. These scores suggest impairment in everyday activities, mood, and personal relationships. These findings are consistent with results in similar studies (Drossman et al., 2007; Monnikes, 2011; Patel et al., 2016) noting significant impairment of HRQOL for patients with IBS. Unique to the current study, HRQOL levels were more greatly impaired than previous reports and significantly associated to catastrophizing coping style. This association has been reported in other chronic pain syndromes (Poulin et al., 2016), validating not only the pain or health-threat experience contributing to quality of life impairment but also the psychological and behavioral response.

RESEARCH AND CLINICAL IMPLICATIONS

The current findings suggest future research that focuses on the effectiveness of therapies for patients with IBS may have a beneficial effect if directed not only at their illness perceptions, such as consequences and emotional representations, but also at their coping skills. These are potential areas that can be modified and in turn enhance patients’ HRQOL and reduce the burden of IBS. Individuals with IBS comprise a significant proportion of patients seen, and health care providers have limited time available with patients. As Spade (2008) suggests, a broad assessment of psychosocial variables is essential for establishing holistic care of patients. Nurses have the unique skills to recognize the impact these determinants have on patients’ ability to establish and implement health care goals. Eliciting patients’ perceptions and an understanding of how they are coping are cues to their well-being. Their cognitive, behavioral, and emotional responses contribute to a difficult situation by impacting negatively on their daily life. By listening to and identifying both illness representations and coping, health care providers have the opportunity to facilitate better quality of life of their patients and potentially reduce the need for health care consumption.

LIMITATIONS

There are several methodological shortcomings of the current study that must be considered. First, the study was conducted with a population primarily from gastrointestinal specialty practices. This select group of patients with IBS may have been better informed and motivated and, as a result, their illness representations or levels of catastrophizing coping style may have been influenced. Second, the higher proportion of female participants in the study, compared to the typical IBS population (Cain et al., 2009; Longstreth et al., 2006), and the limited racial diversity reduce the generalizability of the results. Third, the study was a cross-sectional design; therefore, causation could not be determined. Longitudinal studies of illness representations for chronic illnesses are limited (Lee, Chaboyer, & Wallis, 2010; Rutter & Rutter, 2007) and create an opportunity to examine whether illness representations change over time and whether they are associated with changes in coping and outcomes. Given the premise of the CSM model, additional research using a prospective longitudinal design may prove beneficial. In addition, considering the influence of disease severity and treatment options on these beliefs is essential.

CONCLUSION

Given the current treatment challenges for IBS, the results of the current study support the useful benefits of the assessment of illness representations and catastrophizing coping in adults with IBS. Inquiring about patients’ beliefs and experiences of their IBS can equip the well-situated nurse in the clinical setting to positively affect outcomes in those with IBS. Listening and understanding patients’ illness experiences is indispensable and central to resulting outcomes. Incorporating patients’ beliefs into the plan of care has the potential to minimize discrepancies between patients and health care providers and validate the complexity and impact of this disorder, resulting in improved care and well-being of patients.

REFERENCES

De Gucht, V. (2015). Illness perceptions mediate the relationship between bowel symptom severity and health-related quality of life in IBS.
actions. Medical Science Monitor, 10, RA55-RA62.

Dr. Sherwin is Assistant Professor, Sinclair School of Nursing, University of Missouri, Columbia, Missouri; Dr. Sherwin is also Special Volunteer, Digestive Disorders Unit, and Dr. Henderson is Chief, Biobehavioral Branch, National Institute of Nursing Research, National Institutes of Health, Bethesda, Maryland; and Dr. Leary is Assistant Research Professor, Biostatistics & Research Design Unit, School of Medicine, University of Missouri, Columbia, Missouri.

The authors have disclosed no potential conflicts of interest, financial or otherwise. This study was financially supported by Grand Teton Gastroenterology, Idaho, and The Gastroenterology Center of Connecticut. The authors acknowledge the editorial support and guidance provided by Vicki Conn, PhD, RN, FAAN, and Todd Ruppard, PhD, RN, for manuscript preparation.

©2016 Sherwin, Leary, and Henderson; licensee SLACK Incorporated. This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International (https://creativecommons.org/licenses/by/4.0/). This license allows users to copy and distribute, to remix, transform, and build upon the article, for any purpose, even commercially, provided the author is attributed and is not represented as endorsing the use made of the work.

Address correspondence to LeeAnne B. Sherwin, PhD, MS, FNP-BC, Assistant Professor, $430, Sinclair School of Nursing, University of Missouri, Columbia, MO 65211; e-mail: sherwinl@missouri.edu.

Received: March 7, 2016
Accepted: July 25, 2016
doi:10.3928/02793695-20160803-01