Coping Behaviors of African Americans with Inflammatory Bowel Disease: A focused Ethnography

Patricia Scott

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COPING BEHAVIORS OF AFRICAN AMERICANS WITH
INFLAMMATORY BOWEL DISEASE: A FOCUSED ETHNOGRAPHY

A Dissertation
Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Patricia Denise Scott

May 2020
COPING BEHAVIORS OF AFRICAN AMERICANS WITH INFLAMMATORY BOWEL DISEASE: A FOCUSED ETHNOGRAPHY

By

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Approved March 27, 2020

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ABSTRACT

COPING BEHAVIORS OF AFRICAN AMERICANS WITH INFLAMMATORY BOWEL DISEASE

By

Patricia D. Scott

May 2020

Dissertation supervised by Professor Joan Such Lockhart

Background: Increasing numbers of African Americans are being diagnosed with inflammatory bowel disease (IBD) in the United States (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016). Little is known about the influence of culture on coping with the disease. Method: Twelve African American adults with IBD were interviewed and observed using a focused ethnography. Results: Data analysis resulted in four major themes: (1) spending time living in the bathroom; (2) time and food restricted eating practices and cultural food avoidance; (3) dealing with a life full of stress; and (4) the practice of seclusion to promote health. Discussion: Participants described coping and culture. Their experiences were similar to other IBD populations except in the area of perceived stress. Opportunities exist for nursing and the community to assist this population with stressors related to bathroom access, their eating practices, and participating in activities outside of their homes.
DEDICATION

I would like to dedicate this work to my family – whose prayers, support, and encouragement have allowed me to pursue my dream of academic research. Thank you so much; I love you!
ACKNOWLEDGEMENT

This study was a collaborative research effort between the School of Nursing at Duquesne University and the University of Pittsburgh Medical Center Visceral Inflammation and Pain Center. I am very grateful to: the key informants; the Division of Gastroenterology, Department of Medicine, University of Pittsburgh; Project Coordinators Kate Saucier and Meredith Saucier Strassburger from the UPMC Chief Medical and Scientific Office; and to all the men and women participants who spoke candidly about their experiences and allowed us to collect the data. I would like to personally thank: (a) my dissertation committee members Drs. Joan Such Lockhart, Karen Jakub, Geoffrey C. Nguyen, Eva Szigethy, and Rick Zoucha; (b) my mentor, Dr. Lenore Resick; (c) my family, Dr. Edward Scott, Ed Jr., Dr. Charles and Mary Scott, Louis McLain, and Curtisteen McLain (who is now in arms of Jesus); (d) Gumberg Library and Sigma Theta Tau (Epsilon Chapter); and (e) my Lord and Savior Jesus Christ.
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1.0 INTEGRATIVE REVIEW OF THE LITERATURE

Manuscript #1

Integrative Review of the Literature


Included with permission from the Executive Director of Society of Gastroenterology Nurses and Associates, Inc. (SGNA).
Abstract

Given the chronic nature of inflammatory bowel disease, understanding the coping behaviors of individuals affected with the disease is important to influence health outcomes. Although minorities comprise a significant portion of individuals with the disease, little is known about the potential influence of one’s culture, specifically among African Americans, on coping with inflammatory bowel disease. This integrative literature review examined the past decade of research related to the coping behaviors of African Americans living with inflammatory bowel disease to identify opportunities for further research. Five studies were identified via database searches of PubMed, PsychInfo, CINAHL, and the Cochrane Library and limited to studies published in English, full-text, peer-reviewed, and adult samples that included African Americans. Findings lacked information specific to coping in African Americans. Results were categorized by coping and disease activity, acquisition of knowledge, and personal coping. An association between poor coping behaviors and active disease was reported. The disease frequently hindered academic pursuits of college students, with increased knowledge about the disease associated with the use of better coping strategies. Personal coping behaviors were reported in stressful social situations, food choices, and religion. Results emphasized the need for future research to explore the influence of culture on the coping behaviors of African Americans with inflammatory bowel disease.
More than 3.1 million Americans have been diagnosed with inflammatory bowel disease (IBD) in the United States (U.S.). The term “inflammatory bowel disease” has been defined as the broad category encompassing two chronic inflammatory diseases of the gastrointestinal (GI) tract: Crohn disease and ulcerative colitis (Molodecky et al., 2012). Although IBD’s origin and pathogenesis are currently unknown, it is characterized by periods of remission and relapses of several symptoms such as rectal bleeding, diarrhea, weight loss, abdominal pain, and fatigue (Jordan, 2010). With no known cure, traditional medical treatment frequently consists of decreasing GI inflammation through medications and a multitude of GI surgeries (Casellas, Herrera-de Guise, Robles, Navarro, & Borruel, 2016; Harlan, Meyer, & Fisher, 2016). The unpredictable course of the disease, along with frequent physician visits, hospitalizations, and side effects of treatment or surgery, can significantly disrupt work routines as well as personal and social activities. This disruption also results in considerable impairment to overall health and quality of life (QOL) and often negatively affects management of the disease (Casellas et al., 2005; Ghosh & Mitchell, 2007).

**Background**

As people continue to live longer, the chronic nature of IBD has become a primary healthcare problem. Some researchers suggest that one possible solution to this problem might be to explore coping behaviors among people with IBD (McCormick, Reed-Knight, Lewis, Gold, & Blount, 2010; Parekh et al., 2015). Coping behaviors have been associated with medication adherence and disease activity that affect clinical outcomes of people with IBD. Therefore, it is important to understand how people with IBD are coping with this disease.

Minority populations in the U.S., particularly African Americans, have been underrepresented in IBD research; therefore, their experiences with IBD are relatively unknown.
Although more than 156,000 African Americans in the U.S. are currently living with IBD (Dahlhamer, Zammiti, Ward, Wheaton, & Croft, 2016), studies exploring the possible influence of culture and/or race/ethnicity on how this population perceives and manages IBD is lacking. In addition, there is a paucity of research that includes self-reports by African Americans about their IBD. Topics related to coping and IBD such as coping with the stigma, emotional burden, and the negative effects of IBD on social activities have been explored among Caucasians with IBD, but have not been explored among African Americans (Crohn’s & Colitis Foundation of America, 2014; Frohlich, 2014). Underrepresentation of African Americans in IBD research is problematic, as evidence is essential to determine whether they are receiving the care that they need for positive health outcomes.

**Aim**

The aim of this integrative review is to examine the current literature related to the coping behaviors of African Americans living with IBD. The second aim is to identify opportunities and ideas for further research on this topic.

**Methods**

**Problem identification**

Although IBD has been addressed in the medical literature since 1932, to date, little research has explored how African Americans are coping with the disease. More than 156,000 African Americans have been diagnosed with this chronic illness (Dahlhamer et al., 2016), and more information is needed about this population in order for healthcare professionals to determine their general health condition and to offer suggestions that might improve their health. The integrative review method of Whitlemore and Knafl (2005) was used to search and evaluate the evidence related to the coping behaviors of African Americans with IBD and to report the
findings of the literature regarding this problem. Aims of this integrative review are to answer the following questions: (a) What theoretical and research evidence exists that discusses coping in the African American IBD population? (b) What are African Americans’ personal perspectives of coping and how do they manage their disease? (c) What resources, if any, are African Americans accessing to help them cope with the disease? (d) How does African Americans’ perspective of coping compare to the Caucasian population with IBD? (e) What opportunities have been identified in the literature that might promote positive coping behaviors in this population?

**Literature search**

A literature search was conducted using PubMed, PsychInfo, CINAHL, and Cochrane Library. The Boolean connector AND was used to combine the key words inflammatory bowel disease, coping, self-management, self-care, self-care practices, Crohn’s, Crohn’s disease, and ulcerative colitis. These key words were selected because of their presence in the coping literature of psychologists Heppner (2008) and Heppner, Wei, Neville, and Kanagui-Muñoz (2014), who viewed coping from a cultural context. For example, the term ‘manage’ was simplified in the literature search to ‘self-management’ and ‘self-care’, which yielded the results listed on the flow diagram (Figure 1).

Peer-reviewed articles in English from 2006 to 2016 were screened to capture key information about the topic that was clinically current. A brief literature review of coping and IBD from 1932 to 2006 yielded no articles that discussed coping that included African American adult participants. The year of 1932 was selected because that was the date that IBD was introduced in the medical literature. Articles were excluded if they were abstracts only, duplicates, conference proceedings, reviews, editorials, or dissertations. Other resources were excluded if the sample
population was not primarily adult, the focus was not mainly related to experiences of coping, or if the article focused on validating an instrument. Articles were also evaluated to determine whether African Americans were recruited in each study.

A total of 443 abstracts were initially reviewed (Figure 1). After removing duplicates, 351 abstracts remained; 219 abstracts were excluded on the basis of criteria such as not being published in English, the inability to obtain a full text of the article, or if the article was older than 10 years. The search yielded 132 abstracts for further review, of which 127 articles were excluded on the basis of specific criteria listed in the matrix. As suggested by Whittemore and Knafl (2005), reference lists of full-text articles were also searched for additional studies; however, this approach did not yield any studies that met the inclusion criteria of African American participants. The final review resulted in five articles that were selected for evaluation and analysis.
The final sample for this integrative review included one qualitative and four quantitative studies (Table 1). The quantitative studies used cross-sectional and retrospective designs, whereas the qualitative study utilized an ethnographic design. Published articles that did not
qualify as data, such as IBD literature that described the coping behaviors of non–African American populations, were kept for purposes of discussion and development of future approaches (Sosa & Sethares, 2015). Because of the use of quantitative and qualitative designs as primary sources in the review, studies were coded according to the following criteria: methodological or theoretical rigor and data relevance on a 2-point scale: 0 was assigned as the lowest score and 2 was assigned as the highest score (Whittemore & Knafl, 2005). Lower scores (such as 1) indicated that a weaker study design or a weak amount of evidence was presented, and higher scores (such as 2) indicated that a more rigorous study design was performed that presented data with stronger evidence addressing the research question (Whittemore & Knafl, 2005).
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<td>Alexakis et al. (2015)</td>
<td>Increase understanding of issues and needs of people with IBD from BME communities. Qualitative, ethnographic</td>
<td>20 young adults with IBD; mean age, 20.1 years; 35% female, 65% male, 85% Asian (n = 13), 5% Asian/White (n = 1), 10% Black (n = 2).</td>
<td>Coping activities listed were religion, restricting their diets, and social isolation/exclusion. Concerns listed were lack of awareness of IBD by their families, in community, and by general practitioners.</td>
<td>Small sample size, Black people were underrepresented; ethnic mismatch between interviewers and interviewees; IBD severity or activity of disease not discussed; specific coping styles not discussed.</td>
<td>Q, 1.3 Medium quality Research Q A,B,C,E</td>
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<td>Faust et al. (2012)</td>
<td>Examine coping and social constraint to disease activity and HRQOL Retrospective analysis</td>
<td>80 adults with IBD; mean age, 37.2 years; 51% female, 78% White (n = 62), 15% Black (n = 12), 6% (n = 5) were Asian American, 1% (n = 1) did not report race.</td>
<td>Coping Measurement Tool: Modified Coping Inventory (COPE) questionnaire. Findings for coping: Correlations revealed a significant inverse relationship between HRQOL and coping and a positive relationship between social constraint and coping, engagement and disengagement coping, and anxiety and depression.</td>
<td>Sample obtained from a referral center where people had moderate to severe IBD; conclusions regarding causality were not possible given the design of the study; study did not compare results among ethnic groups.</td>
<td>QN, 1.3 Medium quality Research Q A,E</td>
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<td>Study</td>
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<td>Gandhi et al. (2014)</td>
<td>Examine IBD disease activity and association with coping styles, perceived health competence/preference for involvement in treatment</td>
<td>70 adults with IBD; mean age, 43.26 years; 59% female, 73% White (n = 51), 21% Black (n = 15), 4% (n = 3) Asian American, 2% (n = 3) Native Hawaiian/Pacific Islander.</td>
<td>Coping Measurement Tool: Coping Inventory for Stressful Situations</td>
<td>Findings for Coping: More active coping styles were found in people with disease remission/inactivity; they used more task-oriented coping.</td>
<td>Small sample size; cross-sectional study design that limited coping methods to only one point in time; all data were self-reported including disease activity; the sample comprised IBD people on biologics (more severe disease).</td>
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<tr>
<td>Moradkhani, Kerwin, Dudley-Brown, and Tabibian (2011)</td>
<td>Examine the relationship between IBD-related knowledge, coping strategies and medication adherence in people with IBD</td>
<td>111 U.S. adults with IBD recruited online; mean age, 31 years; 77% female, 81% Caucasian, 2% Hispanic, 2% Asian, 2% African American, 1% Native American, and 12% reported mixed race.</td>
<td>Coping Measurement Tool: Brief COPE Scale</td>
<td>Findings for Coping: Small but significant association found between IBD knowledge and active coping; people who were better informed about IBD were more likely to endorse adaptive coping strategies.</td>
<td>Cross-sectional design; the Brief COPE tool is a general scale not designed solely for use in IBD and may exclude some important IBD-specific coping strategies; self-reporting of IBD; potential selection bias.</td>
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(Continues)
For example, study designs with small or convenience samples were rated as 1 whereas designs with large sample sizes and statistical and correlational data were coded as 2. Studies that presented information that addressed the research questions were also given higher scores. Each study was rated and then kept for the data analysis stage. Studies with low scores contributed less to the final analysis. After an evaluation of the data, each study received a score of 1.3; therefore, the sample was comprised from tertiary centers where people tend to have higher disease severity; ethnic variation was not characteristic of the U.S. population; cross-sectional design.

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<td>Parekh et al. (2015)</td>
<td>Evaluate coping strategies and quality of life of people with IBD. Descriptive cross-sectional design</td>
<td>150 adult participants with IBD; mean age, 39.3 years; 51.3% male, 48.7% female; 73.3% White, 2% African American, 7.3% Hispanic, 4.0% Asian, 3.3% Middle Eastern, 10% Native American.</td>
<td>Coping Measurement Tool: Jalowiec Coping Scale. Findings for Coping: Primary coping strategies used were: confrontive, evasiveness, optimistic, and fatalistic. No statistical differences in coping styles used based on ethnicity, marital status, disease activity, type of IBD, or family history of IBD.</td>
<td>Self-reported data; the sample was comprised from tertiary centers where people tend to have higher disease severity; ethnic variation was not characteristic of the U.S. population; cross-sectional design.</td>
<td>QN, 1.3 Medium quality Research Q A,D,E</td>
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Note. 1 = low quality; 1.3–1.5 = medium quality; 2 = high quality; A = article’s discussion of research question: what theoretical and research evidence exists that discusses coping in the African American IBD population?; B = article’s discussion of research question: what are people’s personal perspectives of coping, and how do they manage their disease?; BME = Black and minority ethnic; C = article’s discussion of research question: what resources, if any, are they accessing to help them cope with the disease?; D = article’s discussion of research question: how does their perspective of coping compare to the Caucasian population with IBD?; E = article’s discussion of research question: what opportunities have been identified in the literature that might promote positive coping behaviors in this population?; HRQOL = health-related quality of life; IBD = inflammatory bowel disease; Q = qualitative; QN = quantitative; Research Q = research question.
Five research studies that discussed coping were reviewed and analyzed using Whittemore and Knafl’s (2005) approach. The five steps of this approach consisted of (a) extracting data from primary sources based upon sample characteristics, methodology, as well as any reference to the concept of coping; (b) selecting specific categories from the data such as the definition of coping and aspects of coping; (c) identifying terms similar to coping such as self-management and self-care and identifying proposed relationships of coping to other variables; (d) coding, analyzing, and comparing the data from each category; and (e) reviewing each primary source as data were conceptualized at higher levels of abstraction (Whittemore & Knafl, 2005).

Data were also labeled according to the applicability of the research questions (see “Methods” section and Table 1). No study addressed every research question; however, each study addressed at least two research questions.

**Results**

The five studies that were selected were published from 2011 to 2015. The sample populations of all five studies included from 2% to 21% of African Americans or Blacks as participants, and primarily utilized quantitative methods as their methodological design (Table 1). The studies did not provide any information specific to African Americans with IBD or any other ethnicity beyond listing “African Americans” or “Blacks” as a demographic variable. Therefore, each study’s findings were representative of the entire group of people included in the study rather than exclusively focusing on findings unique to African Americans with IBD.

Because no study focused primarily on the African American population with IBD, it is unclear whether the findings from the studies adequately addressed several of the proposed research questions. For example, Alexakis et al. (2015) discussed several aspects of coping
related to minorities with IBD such as personal perspectives, management of IBD, resources, and lack of resources available to IBD people in their study; how-ever, only two Black people out of 20 participants were recruited for this study that was not performed in the U.S. but in the United Kingdom (U.K.). It was unclear whether the small sample size of Blacks who were part of the study, healthcare system in the U.K., or influence of British culture on these people was an accurate representation of the African American population with IBD. This study’s findings did not address the research questions regarding African Americans’ personal perspectives of coping, management of their disease, resources that they used to manage their disease, or comparisons to the Caucasian population with IBD. Another study explored coping styles and ethnicity and reported that no differences existed; however, this study recruited only three African Americans out of a total of 150 participants (Parekh et al., 2015). Because of the small sample of African Americans with IBD who were part of this study, it is unknown whether the research question regarding opportunities to promote positive coping behaviors was properly addressed.

After extracting data related to coping from each of the studies, results were grouped into three categories:

1) coping and disease activity (relationship between these two variables, specific coping behaviors and disease activity, most frequently used coping behaviors);
2) acquisition of knowledge (access to information and adaptive coping, difficulty navigating educational pursuits and IBD); and
3) personal coping situations related to IBD (stress surrounding food, lack of social support, religion).
This integrative review was limited to only five articles that included African Americans with IBD and coping; however, according to Whittemore and Knafl’s methodology, “primary data should be categorized and summarized into unified and integrated conclusions about the research problem” (Whittemore & Knafl, 2005, p. 550). Therefore, these categories were selected on the basis of a particular aspect of coping, frequency, and presence in the literature, and then synthesized into manageable groups. Each of these categories will be explained in the following section.

Coping and disease activity.

Three of the five studies included in this review explored coping and disease activity (i.e., active IBD vs. IBD in remission) and identified a relationship between these two variables. Parekh et al. (2015) examined various coping strategies and their effects on the QOL of people with IBD and found that they primarily used four different coping styles: confrontive (46.7%), evasiveness (30%), optimistic (18.7%), and fatalistic (4.6%). No statistical differences were observed in coping styles used based on ethnicity, marital status, disease activity, type of IBD, or family history. Quality of life was significantly better for people who reported fewer flare-ups as well as for those who utilized adaptive coping versus maladaptive coping styles. The sample population was limited to three African Americans out of 150 participants (2%).

Although Parekh et al. (2015) focused on the relationship between IBD, coping styles, and QOL, Gandhi et al. (2014) examined the relationship between IBD activity and multiple psychosocial factors such as coping styles, perceived health competence, and preference for involvement in treatment among people in remission. Similar to the findings by Parekh et al. (2015), Gandhi et al. (2014) reported that people with IBD in remission were less likely to use maladaptive coping styles and were more likely to report higher QOL scores than IBD people.
with active disease. However, Gandhi et al. (2014) also reported that the scores of people in remission revealed more interest in participating in their treatment, more perceived health competence, less depressive symptoms, and more task-oriented coping than the IBD subjects with active disease. The sample in this study included 15 African Americans out of 70 participants (21%).

Similar to the previous researchers, Faust et al. (2012) examined the relationship between coping, QOL, and disease activity but differed from the other researchers by examining additional factors such as social constraint, anxiety, and depression. Their findings were similar to the findings of the previous researchers and revealed that disengagement coping was positively correlated with disease activity; therefore, greater use of disengagement coping was associated with increased odds of having active disease. They urged healthcare professionals to investigate people’s coping styles as part of their plan of care. The sample population of this study included 12 African Americans out of 80 participants (15%).

**Acquisition of knowledge.**

Two studies explored the topic of acquisition of knowledge from two different perspectives: access and outcome (Alexakis et al., 2015; Moradkhani et al., 2011). In terms of access, the qualitative study by Alexakis et al. (2015) sought to increase the understanding of the issues and needs of people with IBD from Black and minority ethnic communities and reported the following: 15 out of 20 people described a significant amount of difficulty pursuing educational goals in an academic setting due to IBD symptoms, two had to drop out of college, and five missed a year of college and had to repeat that year. Although some people persisted with their educational pursuits, others did not. The sample population in this study included two Blacks out of 20 participants (10%).
Moradkhani et al. (2011) explored the outcomes of people after acquiring knowledge about IBD. This descriptive study examined the relationship between IBD knowledge and coping and medication adherence of 111 adults with IBD in the U.S. Although no association was found between IBD knowledge and medication adherence, their findings showed a positive association between greater IBD knowledge and four coping categories on the Brief COPE instrument: active coping, instrumental support, planning, and emotional support. Greater IBD knowledge appeared to be associated with the use of more adaptive coping strategies, suggesting that increased IBD patient education might enhance coping in people with IBD (Moradkhani et al., 2011). The sample included two African Americans out of 111 participants (2%).

**Personal coping.**

Only one study explored the personal accounts of coping situations from minority people’s point of view. This study focused on Black minority ethnic groups, of which “Blacks” comprised 2% of the sample (Alexakis et al., 2015) and reported a significant amount of stress related to food and events centered on eating food, such as holiday and cultural events. For example, several participants reported the stress of not being able to eat the food that everyone else around them was eating and others around them were noticing that they were not eating (Alexakis et al., 2015).

Several participants voiced the lack of support that they experienced from their families and communities, as well as their primary care providers. Although the literature from nonminority people with IBD suggested the presence of social support from their families (Alexakis et al., 2015), this issue was not reported by most study participants, which comprised Black minority ethnic groups. One participant stated, “I’m not really open about it [IBD] because I don’t want them [parents] to worry about it” (Alexakis et al., 2015, p. 669), and another
participant’s father stated, “You have been going to that hospital for how long? Why haven’t they fixed you?” (Alexakis et al., 2015, p. 669) Similar responses were voiced in their communities as well. Several participants reported a lack of support in the medical community from misdiagnosis to perceived skepticism of their ailments by primary care practitioners. For example, one participant reported “I went back there [GP practice] quite a few times and the doctor was, my GP was trying to convince me that it was in my head and I was just imaging it” (Alexakis et al., 2015, p. 670).

Religion also played a role in coping with stressful events in their lives. Participants reported that their faith helped them to decrease some of the stress related to living with IBD.

**Discussion**

The purpose of this review was to examine the current literature related to coping behaviors of African Americans with IBD and to make recommendations for future research. Significant findings included different aspects related to the subject of coping such as the relationship of coping and disease activity, difficulty completing academic studies due to IBD activity, potential for enhanced coping strategies to emerge after obtaining IBD patient information, and the identification of personal coping situations related to IBD experienced by African Americans with IBD. Although every study included a small portion of African Americans (or Blacks) in their sample population, only one study (Alexakis et al., 2015) specifically explored the topic of IBD and coping among minority populations.

Although each study discussed coping from an IBD perspective, no researcher specifically identified coping from a theoretical or philosophical perspective and only one study operationally defined coping (Gandhi et al., 2014), which left readers to define coping on their own and question the researchers’ rationale for their selection of measurement tools,
methodology, and the thoroughness in answering the research question in their respective studies. Because none of the studies listed a theoretical model, each quantitative study’s measurement instrument was examined for evidence of a theoretical framework in hopes of identifying what theoretical approach the researcher supported (Faust et al., 2012; Gandhi et al., 2014; Moradkhani et al., 2011; Parekh et al., 2015). All of the coping measurement instruments utilized by the researchers were based on Lazarus and Folkman’s (1984) conceptual analysis of coping, which defined coping as an individual’s constantly changing cognitive and behavioral efforts to manage stress. Only one quantitative study actually defined coping and based it on Lazarus and Folkman’s (1984) theoretical framework (Gandhi et al., 2014).

Although hypotheses were given identifying the research question in the quantitative studies, no additional information was offered related to the rationale for the selection of their specific coping measurement tool. For example, questions remain as to why a specific tool was selected instead of another coping tool, or whether the tool had been utilized in similar IBD studies or sample populations. Only two studies addressed the potential limitations related to utilizing selected coping instruments (Faust et al., 2012; Moradkhani et al., 2011).

Similarly, the qualitative study did not immediately identify a philosophical underpinning or provide operational definitions of coping. However, the researcher did report that the aim of the study was “to understand the specific issues and needs of IBD people from Black minority ethnic communities” (Alexakis et al., 2015, p 665). Although the term “coping” was not listed in the study, the phrase “challenges faced by Black and minority ethnic communities with IBD” (Alexakis et al., 2015, p. 667) and the open-ended research question, “How does IBD affect your daily life?” (Alexakis et al., 2015, p. 667) resulted in the participants stating how they coped with IBD.
Studies that measured the coping variable utilized different measurement tools. For example, although both Parekh et al. (2015) and Gandhi et al. (2014) examined coping and disease activity, Parekh et al. (2015) measured coping using the Jalowiec Coping Scale (Jalowiec, Murphy, & Powers, 1984), whereas Gandhi et al. (2014) utilized the Coping Inventory for Stressful Situations (Endler & Parker, 1990). Although both of these instruments reported valid measures of coping styles, no information was provided regarding either tool being utilized in IBD populations or in culturally diverse populations such as African Americans. It is unknown whether these tools that measured different aspects of coping were adequately capturing the essence of coping present in minority IBD cultures such as African Americans.

Few researchers discussed the problem of capturing a representative sample of the U.S. IBD population, which includes African Americans. Only two studies discussed the underrepresentation of African Americans in their samples as a limitation (Alexakis et al., 2015; Parekh et al., 2015). No study offered suggestions regarding how to address this problem. Studies authored by nurses on this topic were minimal in the literature (Alexakis et al., 2015; Moradkhani et al., 2011). Given the holistic nature of the nursing profession, numerous opportunities exist for nurse researchers to explore this topic in areas such as improving access to IBD patient education materials for African Americans with IBD and collaborating with other resources to support the people, families, and communities affected by IBD.

Limitations

Although the focus of this integrative review examined coping behaviors of African Americans with IBD, the concept of coping was not operationally defined in four out of five of the studies in the integrative review. The definition of coping was inferred from the theoretical underpinnings of the measurement tools based on the conceptual analysis of coping and stress by
Lazarus and Folkman (1984). This approach was taken to include the limited number of studies available on the topic that did not define coping. Another limitation of this review was the sparse number of African Americans who were recruited in each study. Although most of the studies included other ethnicities in their results, only one study focused specifically on Black and minority ethnic people with IBD. This study was performed in the U.K., and only two Blacks were part of their sample population; it is unclear whether their health practices and influence of British culture were representative of African Americans with IBD (Alexakis et al., 2015). The results of the remaining four studies might reflect the Caucasian population that had greater representation in the sample study than the Blacks who were part of the study.

A final limitation of the data reported in the literature was the selection of study designs. Four of the five studies were cross-sectional designs with data gathered at only one point in time. Because of the long-term chronic nature of IBD, perhaps interventional or longitudinal studies might reveal different results related to coping compared with the findings from this review.

**Implications and Recommendations**

This integrative review highlighted the lack of presence of African Americans with IBD in research and revealed that little is known about them as an IBD population in terms of their individual coping strategies. Although the IBD literature reported that the disease is increasing among minorities (Dahlfamer et al., 2016; Nguyen, LaVeist, Gearhart, Bayless, & Brant, 2006; Veluswamy et al., 2010), IBD studies have recruited only a handful of African Americans as participants. African Americans were included as a demographic variable instead of the primary focus of the studies that were examined. Therefore, findings may or may not represent the cultural influences and coping behaviors of the African American population with IBD. Although the coping styles of African Americans have been explored in other chronic illnesses
such as diabetes mellitus and cancer (Agarwal, Hamilton, Crandell, & Moore, 2010; Samuel-Hodge, Watkins, Rowell, & Hooten, 2008), they have not been examined in IBD research. Because many of the studies did not compare or contrast the data between/among racial/ethnic groups, most researchers did not report the specific coping strategies of African Americans separate from other populations such as Caucasians. Perhaps the culture of African Americans may influence their coping strategies differently compared with other IBD populations.

Few studies have explored the coping strategies of African Americans with IBD from their perspective and in their own words. Perhaps qualitative research, such as ethnographic and phenomenological designs, might reveal different perspectives on coping strategies that have yet to be discovered in the current IBD literature. For example, these designs might provide us with insight regarding how African Americans with IBD manage their disease during large cultural events such as family reunions or while traveling out of town.

Finally, there is a paucity of nursing-led research on this topic. Although two nurse researchers contributed to two IBD studies (Alexakis et al., 2015; Moradkhani et al., 2011), overall, IBD studies by nursing researchers discussing African Americans and their coping strategies in the IBD literature were noticeably absent. The philosophical and holistic views of nursing research might add another perspective to the current IBD literature by improving awareness of the condition of African Americans with IBD by the health community at large.

**Conclusion and Future Directions**

For African Americans with IBD, there appears to be similarities with other IBD populations related to coping strategies. Due to reasons that are unclear at this time, differences may exist related to the support that they receive from their family, local community, and healthcare community; compared to other IBD populations. Several opportunities for nursing
research exist such as exploring opportunities to improve IBD sup- port in communities where people with IBD reside; increasing awareness within the medical community regarding the concerns of African Americans with IBD; conducting research exploring the IBD person’s perspective related to personal experience; and exploring the possible influence of culture on coping and health in African Americans with IBD. Research is needed on this topic to support African Americans faced with this debilitating chronic illness.

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REFERENCES


2.0 Dissertation Proposal

COPING BEHAVIORS OF AFRICAN AMERICANS WITH INFLAMMATORY BOWEL DISEASE: A FOCUSED ETHNOGRAPHY

2.1 Specific Aims

Problem of Interest

Inflammatory bowel disease (IBD), a chronic, debilitating disease of the gastrointestinal (GI) tract, has been increasing in both incidence and prevalence among people who live in industrialized countries (Ha & Katz, 2014). Although IBD has been present in the medical and health literature since 1932, very little research has explored the impact of IBD in minority populations in the United States (US), such as in the African American population (Veluswamy et al., 2010). Therefore, as chronic health care costs continue to rise and our country continues to become more ethnically diverse, more research is needed on this topic to determine if health disparities exist in this population.

It is estimated that over 156,000 African Americans have been diagnosed with IBD in the US (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016), yet few studies have explored: (a) how minority populations such as African Americans are coping with this chronic disease; (b) the possible influence of culture related to how this population perceives and manages IBD; and (c) the self reporting of personal coping experiences by a cohort of African Americans with IBD.

Long Term Objectives

Long term objectives of this study will be to: (a) increase awareness within the healthcare community about the current and potential needs and concerns of African Americans with IBD; (b) allow African Americans with IBD to give “voice to their experiences” in their own words
and pace and identify any similarities or differences between other populations; and (c) add to the body of knowledge in nursing and the IBD literature regarding African Americans with IBD.

**Aims of Research Study**

The aims of this research study are to: (Aim 1) explore how African Americans define and describe how they cope with the daily challenges of IBD; and (Aim 2) identify and describe examples where African American culture might influence IBD coping behaviors.

**Research Questions**

The research questions will be the following: (RQ1) what is the meaning and perceptions of coping in African Americans with IBD? (RQ2) What are the cultural health beliefs and health care practices utilized by African Americans to cope with IBD?

**2.2 Significance**

Inflammatory bowel disease, a chronic inflammatory disease of the gastrointestinal tract commonly known as Crohn’s disease or ulcerative colitis, is being diagnosed more frequently in people that live in industrialized countries such as Canada and the US, than ever before (Dahlhamer et al., 2016; Schneider & Fletcher, 2008). North America and Europe have reported the highest incidences of IBD than any other continents in the world (Nguyen, Chong, & Chong, 2014). Minority populations who live in North America such as African Americans, who live in the US, have also succumbed to this disease. However, there is little research that is available on this population in the IBD literature.

It is important to explore this topic for three primary reasons: 1) to increase awareness within the healthcare community about the current and potential health care needs of African Americans with IBD; 2) to allow African Americans with IBD to “tell about their experiences” in their own words as other populations with IBD in the US have done; and 3) to discuss if
similarities or differences exist related to coping styles among African Americans compared to other IBD populations.

Initial exploration of this topic began with a review of literature of African Americans with IBD and coping. In order to review and analyze both qualitative and quantitative literature related to African Americans with IBD and how they cope with the disease, an integrative review of the literature was performed on this topic.

**Critical Evaluation and Synthesis of the Literature**

Scott, Lockhart, Jakub, Zoucha, and Nguyen (2019) performed an integrative review of the literature on the coping behaviors of African Americans with IBD. A total of five studies were evaluated utilizing Whittemore and Knafl’s (2005) methodology of an integrative review.

Their findings revealed the following: a) African Americans with active IBD reported using poorer coping strategies compared to people with IBD in remission; b) a positive association between greater IBD knowledge and the use of more adaptive coping strategies was reported compared to people with little IBD knowledge, suggesting that increased IBD patient education might enhance positive coping strategies in IBD patients; and c) participants reported increased stress related to daily food choices, social gatherings where food was involved, and lack of family and community support; however, spiritual support received from their religious beliefs helped to decrease the stress in their lives.

This synthesis of the literature revealed: a) most of the studies did not provide any information specific to African Americans with IBD; and b) it remained unclear if the findings from the studies adequately addressed the coping behaviors of African Americans with IBD due to the extremely small number of African Americans that were recruited for each study (Scott et al., 2019). Because it is not known if coping or a lack of coping is an issue in African Americans
with IBD, Scott et al. (2019) suggested that more research was needed related to coping behaviors among African Americans with IBD.

**Gaps in knowledge.**

This proposed research will address some of the gaps in knowledge that exist within the IBD literature related to African Americans’ coping with IBD. More specifically, this proposal will address the lack of IBD evidence utilizing African Americans as the primary sample population in an IBD study; and explore the influence of culture on coping behaviors related to the management of IBD in African Americans.

Research has not addressed how over 156,000 African Americans affected with IBD are managing their disease within a cultural perspective (Dahlhamer et al., 2016). Significant gaps in knowledge regarding these individuals exist, such as: a) a description of their personal experiences related to IBD, and how it has affected their lives; b) if their IBD experiences are similar or different from other people with or without IBD; c) how this population defines and conceptualizes the terms *coping* and *staying well*; and d) how their coping behaviors affect their overall health compared to other IBD populations. Current IBD literature has discussed the needs, concerns, and experiences from the Caucasian IBD population’s perspective, but not from the African American perspective (Scott et al., 2019; Veluswamy et al., 2010). This research study will explore IBD utilizing African Americans as the primary population of study.

The influence of culture on coping behaviors in chronically ill populations has been explored in other chronic disease literature such as hypertension and diabetes mellitus (Agarwal, Hamilton, Crandell, & Moore, 2010; Samuel-Hodge, Watkins, Rowell, & Hooten, 2008; Yeh, Arora, & Wu, 2006), but it has not been addressed by IBD researchers in the US. This research
study will explore the influence of culture on the coping behaviors of African Americans living with IBD.

Importance to health and nursing.

The chronic nature of IBD along with its increasing prevalence worldwide has made IBD a primary health care problem (Ha & Katz, 2014). Therefore, it is important for nurses to understand how diverse populations such as African Americans are coping with this disease.

First, it is important for nurses to understand how African Americans cope with IBD due to the potential negative effects of this disease on their overall health and finances. Because IBD is a chronic condition, similar to diseases such as diabetes and hypertension, it is important that people with this disease seek out and receive appropriately managed healthcare shortly after diagnosis in order to: (a) maintain a good quality of life (QOL); (b) remain employable as long as possible; and, (c) prevent costly hospital admissions and other medical costs attributed to lack of appropriate medical care (Nguyen et al., 2014; Veluswamy et al., 2010). How African Americans are coping with IBD, their QOL, their employment status, and the quality of IBD health care received are currently unreported and, therefore, unknown through research.

It is well documented that the cost of treating a chronic illness can often be a significant financial burden for affected individuals, their families, and also for their health care insurers. During these times where people with chronic conditions such as IBD often place increasing demands on the health system, insurers and individuals alike are seeking viable solutions which will decrease the financial health care burden of this population (Jelsness-Jørgensen, Bernklev, & Moum, 2012; McCormick, Reed-Knight, Lewis, Gold, & Blount, 2010). For example, a considerable amount of health care uncertainty exists regarding millions of Americans with chronic illnesses that currently subscribe to Affordable Health Care in the US (McKee, Greer, &
Stuckler, 2017). With the possibility of having little or no health care coverage to manage their chronic illness, African Americans with IBD may be actively seeking alternative options to health care. It is anticipated that an exploration of their coping behaviors in this current study may guide patient centered treatment plans tailored to the cultural beliefs of this population.

Second, it is important to increase the awareness of nurses regarding the coping behaviors of African Americans with IBD in order to help them advocate for this population. Nurses can serve as catalysts to other professions as well as to the community, at large, by informing others of the concerns and needs of this population. For example, do African Americans perceive that they are receiving adequate health care that they need to stay well? Are nurses aware of the unique needs of African Americans with IBD? Do African Americans with IBD feel that nurses are listening to their concerns and meeting their health care needs?

Third, it is important for nurses to promote a healthcare environment which supports optimal quality of life for African Americans coping with IBD. The current IBD literature has reported that, from a holistic perspective, the quality of life of patients is very important and serves as the stated goal of these patients in the IBD literature (Jelsness-Jørgensen et al., 2012; McCormick et al., 2010).

Finally, nurses need to assume a leadership role in conducting IBD research, adding to the existing body of knowledge and documenting their perspectives in the literature. According to the integrative review by Scott et al. (2019), only two studies that explored IBD and coping in African Americans (Alexakis et al., 2015; Moradkhani, Kerwin, Dudley-Brown, & Tabibian, 2011) were authored by nurses. Since IBD is a chronic disease with increasing prevalence in the US, the nursing perspective regarding this topic could make a significant impact in patient
education, community awareness regarding IBD, and collaboration with other IBD stakeholders to implement resources to support the IBD patient and their families.

2.3 Innovation

The innovation proposed in this research will include an interactive component between the African American IBD community and the PI. The interactive component may be described as a collaborative process between the African American IBD participant and the PI that produces an authentic point of view on the topic from the participant’s perspective. For example, in this study, interactive components are anticipated to occur by: (a) the PI investing time into meeting and attempting to build a positive relationship with the participant, and the PI striving to objectively report the participant’s personal perspective on the topic; and (b) the participant verbally agreeing to commit and actively participate in the research process, agreeing to providing time to meet with the PI, candidly expressing his/her views on the topic, and collaborating with the PI to provide an accurate portrayal of the coping behaviors of African Americans with IBD.

This innovative approach is needed to address the difficulty researchers often encounter when trying to obtain participation and engaging discourse from difficult to access populations such as African Americans (Huang & Coker, 2010; Scharff et al., 2010). African Americans are often reluctant to participate in research studies (Branson, Davis, & Butler, 2007). It has been well documented in the literature that mistrust of the US healthcare system by African Americans may often be a primary barrier to their participation in research studies (Huang & Coker, 2010; Scharff et al., 2010). In response, experts suggest that “researchers incorporate strategies to reduce mistrust and increase participation among potential African American participants (Scharff et al., 2010, p. 1).
This study proposes to address the issue of mistrust by approaching this topic from a culturally sensitive and congruent context and relying on healthcare members to initially introduce this topic and purpose of the study to potential participants. For example, the PI will seek to reduce mistrust by: (a) attempting to cultivate a positive and collaborative relationship with the participants throughout the study in a culturally sensitive manner (Leininger & McFarland, 2006); (b) informing the participants about the purpose of the research and how it might benefit other African Americans with IBD; and (c) verbally asking for permission to perform the interview and being respectful to the participant in body language, conversation, and attire (Roper & Shapira, 2000). In addition, the PI will attempt to reduce participant mistrust by being introduced to potential participants by UPMC IBD staff who have previously established an existing and trusting relationship with the participants. This might minimize the suspicion associated with the PI being considered “an outsider” (Roper & Shapira, 2000, p. 34).

2.4 Approach

Design

A focused ethnography methodology will be used for this proposed research study design. Focused ethnography was selected due to its ability to not only describe the phenomenon of how African Americans cope with IBD but to identify the cultural aspects of this phenomenon as well (Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005).

This design will allow the PI to achieve the aims of this research study by: (a) collecting data from African Americans with IBD through semi-structured interviews conducted in various settings; (b) allowing participants to describe their responses related to each aim in a personal, unscripted manner; and (c) analyzing and evaluating the findings of the research based on a focused ethnographical approach.
In addition, focused ethnography will guide the PI during exploration of each research question by: (a) requiring the PI to provide a rich, descriptive narrative response to each research question during the phases of data collection and data analysis (Roper & Shapira, 2000); and (b) “allowing flexibility in this plan [or research design]. [The PI is guided by the concept that] ethnography is driven by what happens in the field [during data collection] and not by preconceived ideas [or hypotheses]” (Roper & Shapira, 2000, p. 46).

**Focused ethnography.**

Although different types of ethnography exist, focused ethnography was selected for this proposed study due to its ability to: (a) explore and describe how people from specific cultures integrate health beliefs and practices into their lives; and (b) “understand the meaning that members of a subculture or group assign to their experiences” (Roper & Shapira, 2000, p. 9; Spiers and Wood, 2010; Tzeng, Yang, Tzeng, Ma, & Chen, 2010). For example, focused ethnography will allow the PI to explore IBD from African Americans’ cultural perspectives and attempt to understand the experiences of African Americans with IBD and the meanings that they assign to them. It is appropriate for this study to accomplish these goals because: (a) no study has previously explored IBD experience from the African American cultural perspective; and (b) utilizing this study design will capture the essence of how this population actually copes with IBD.

Focused ethnography describes how people from specific cultures integrate health beliefs and practices into their lives (Cruz & Higginbottom, 2013; Roper & Shapira, 2000). Focused ethnography seeks to describe health beliefs and practices within a cultural context from a narrower perspective such as from a specific subculture, organization, or group. For example,
focused ethnography might describe the health beliefs and practices of African Americans with IBD.

Focused ethnography also seeks to understand the meaning that members of a specific subculture or group assign to their experiences (Cruz & Higginbottom, 2013; Roper & Shapira, 2000). It is important for nurses to understand the meaning of patients’ actions in order to provide adequate care for them based on their needs and concerns, and to avoid misinterpreting their actions as something else and based on another culture. This PI nurse researcher seeks to understand the meaning that African Americans with IBD assign to their life experiences related to their health.

Cruz and Higginbottom (2013), Morse (2007), and Spiers and Wood (2010) each discussed specific characteristics of focused ethnographies. More specifically, Cruz and Higginbottom (2013) reported the following six characteristics of focused ethnographies: “(a) context specific; (b) focused on a discreet community, organization, or social phenomena; (c) a conceptual orientation of a single researcher; (d) few people holding specific knowledge related to a topic; (e) episodic participation observation; and (f) use in academia and healthcare environments” (p. 38).

Researchers also reported that focused ethnographies should contain: (a) pre-selected topics of inquiry; (b) interview topics highly structured around the issue(s); and (c) short-term studies (Cruz & Higginbottom, 2013; Morse, 2007; Spiers & Wood, 2010). The characteristics discussed by Cruz and Higginbottom (2013) will be addressed during this proposed research study in order to compare this proposed focused ethnography to other ethnographies in the nursing literature, and to add to the body of IBD literature by the potential discovery of new knowledge about this population.
Setting

Approval for this study will be sought from the Institutional Review Boards (IRB) of Duquesne University and the University of Pittsburgh. The primary research setting will be IBD patient clinic(s) located within the University of Pittsburgh Medical Center (UPMC), a major health care system in the Pittsburgh, Pennsylvania. However, if recruitment numbers become insufficient at the UPMC IBD Center in Pittsburgh, Pennsylvania, permission and IRB approval to access additional IBD clinics at other hospitals affiliated with UPMC (as designated by Dr. Eva Szigethy) will be sought at a later date. Further information about the various settings where participant observations might occur is listed in the data collection section (see participant observation).

Sample

Purposeful sampling will be the sampling method used in this study. Initial selection of participants will be performed based on their willingness to participate; and if recruitment numbers are met, the PI will purposely select participants based upon her judgment about which participants will be most beneficial to the study. Purposeful sampling was selected to attempt to provide “maximum variation” within the sample population (Polit & Beck, 2012, p. 355). This term may be described as the PI selecting participants from diverse backgrounds within the African American IBD population such as people from different genders, age groups, socioeconomic backgrounds, and religious beliefs (Higginbottom, 2011). This type of sampling plan attempts to: obtain a more representative sample of the African American IBD population, document the various viewpoints that exist regarding coping and culture, and provide a complete description of the phenomenon (Gustafsson, Kristensson, Holst, Willman, & Bohman, 2013; Higginbottom, 2011; Polit & Beck, 2012).
Inclusion criteria for study participants will consist of the following self-reported data: 1) non-Hispanic African American female or male adult at least 18 years of age; 2) reside in the US; 3) able to read and write the English language; 4) has been diagnosed by a healthcare provider with IBD; and 5) has experienced active IBD disease within the past three years. Therefore, exclusion criteria will consist of participants who: 1) are children or adolescents under age 18 years; 2) do not self-identify as non-Hispanic African American; 3) unable to read and write the English language; 4) possess cognitive disabilities or other co-morbidities that could affect their ability to participate in this study; 5) have not been diagnosed by a provider with IBD; or 6) have not experienced active IBD symptoms within at least three years.

Data collection will continue until data saturation occurs, whereby “all that is or can be known by the informants about the phenomena [under study] has occurred” (Leininger & McFarland, 2006, p. 88). Sample sizes of ethnographic studies often rely on a smaller number of experts to interview in depth on the topic, usually about 12 – 25 individuals within a community (Alexakis et al., 2015; Guest, Bunce, & Johnson, 2006; Gustafsson, Kristensson, Holst, Willman, & Bohman, 2013; Trotter, 2012). Similar to other focused ethnographies, recruitment of participants in this study will continue until at least 25 African American participants have been recruited or saturation of the data occurs. Approximately 240 African Americans with IBD currently receive care from the UPMC IBD Center in Pittsburgh, Pennsylvania (E. Szigethy, personal communication, September 7, 2017). The sampling approach will receive oversight and approval by dissertation committee experts in IBD and qualitative research throughout the study.

**Entry into the IBD Community**

A general inquiry letter developed by the PI and supported by Dr. Eva Szigethy will be sent to IBD providers at UPMC seeking the opportunity to recruit African American participants
from people that visit their waiting rooms and/or receive medical care from their facility (Appendix A).

UPMC Healthcare providers knowledgeable of the African American IBD population will assist the PI in gaining access to participants/informants for this focused ethnography research study. Their collaboration with the PI in recruiting participants/informants is critical to the success of this research study (Munhall, 2012; Tzeng, Yang, Tzeng, Ma, & Chen, 2010).

Dr. Eva Szigethy, a co-investigator of the research study, will help the PI gain access to IBD health care providers and informants within the UPMC health system. For example, the co-investigator has agreed to help the PI gain access to potential participants/informants from the UPMC IBD Center.

In focused ethnography, an informant may be defined as “a person who is knowledgeable about the care [of a specific population]” (Leininger & McFarland, 2006, p. 349). For our study, informants will be described as participants that meet the inclusion criteria; therefore, they will: self-identify as a non-Hispanic African American male or female, be at least 18 years of age, reside in the US, be able to read or write the English language, have been diagnosed by a healthcare provider with IBD, and experienced active IBD disease within the past 3 years.

**Recruitment of Subjects**

Pending IRB approvals, participants will be recruited for the proposed study by: (a) the recruitment efforts of the UPMC co-investigator and other UPMC IBD providers, and (b) posting recruitment flyers in the appropriate locations approved by the UPMC IRB, where African Americans with IBD receive medical care (Appendices A and B). The co-investigator, Dr. Szigethy will coordinate efforts to recruit potential participants for the study by informing employees of the IBD Center front desk staff to: screen and identify individuals who meet the
inclusion criteria, briefly discuss the study, and offer them the opportunity to participate. If the potential participants agree, they will be given a recruitment flyer with the PI’s contact information listed, and the PI will receive the name and phone number of potentially interested individuals. The PI will briefly explain the study to the potential participants and ask them to complete a consent form prior to beginning data collection (Appendix C). The front desk staff will be trained to screen potential participants by the co-investigator and the PI. The PI will contact the front desk staff weekly to inquire about participant interest.

If the primary recruitment site yields fewer than 10 participants over (a three-month period), permission to recruit at additional hospitals affiliated with UPMC (as designated by Dr. Eva Szigethy) will be sought until data saturation occurs. However, if a sufficient number of participants (15 -25) occur in the primary setting, recruitment will continue at that site until data saturation occurs. If a large number of participants express an interest in participating in the study, the PI will select participants from different genders, age groups, and IBD diagnoses, in hopes of attracting a representative and diverse sample of the African American IBD population from the Pittsburgh region. Other focused ethnographers have also attempted to obtain “maximum phenomena variation” by including participants meet the inclusion criteria and represent different variables such as gender, age group, religious beliefs, and socioeconomic status (Higginbottom, 2011, p. 16). Individuals who are not selected by the PI to participate in the study will be sent a letter thanking them for their interest in the study (Appendix D).

Data Collection

Similar to other focused ethnographic studies, this PI will obtain data using the following approaches: (a) a semi-structured interview guide (Appendix E); (b) a demographic form (Appendix F); (c) Short Inflammatory Bowel Disease Questionnaire (SIBDQ) (Appendix G);
and (d) participant observation(s) by the PI and recorded using field notes during the data collection phase; but “the researcher will be the key instrument” that will collect, measure, and analyze the data (Creswell, 2014, p. 185). These approaches are described in more detail in the following section.

**Semi-structured interview.**

A semi-structured interview guide developed by the PI will be utilized as a data collection tool used for participant interviews (Appendix E). This guide was designed by the PI based on the study purpose and research questions to “... map participants’ responses, which is essential to subsequent coding and analysis” in ethnographic research (Cruz & Higginbottom, 2013, p. 37). The semi-structured nature of the guide will allow the PI to modify the interview in the field if the participant comments about something of interest that was not previously written on the guide, but the PI senses that the information might reveal more data about the topic of interest. Examples of questions and probes are listed in the interview guide. The interviews will be led by the participant; however, the PI may inquire about certain statements in order to gain more clarity from the informant and will take around 1 hour to complete. Interviews will be conducted face to face in a private location agreed upon by the participant and PI and audio recorded. Interviews will be transcribed by the PI as well as an experienced transcriptionist who will sign a confidentiality form (Appendix I).

**Demographic form.**

A demographic form developed by the PI will used to gather data to help the PI: understand the culture being studied (Cruz & Higginbottom, 2013), help validate inclusion criteria, and describe the study sample of participants (Higginbottom, 2011; Polit & Beck, 2012).
This form is similar in content to tools utilized in prior focused ethnography studies (Dupuis-Blanchard, Neufeld, & Strang, 2009; Green, Meaux, Huett, & Ainley, 2009; Robinson, 2015).

The demographic form, which takes fewer than 10 minutes to complete, contains 11 questions (forced selection and open ended) which asks participants about the following information: IBD diagnosis, years living with the disease, age, marital status, cohabitants, religious affiliation, educational level, employment status, and annual income. Responses to these questions will help the PI to gain a greater clinical understanding of the participant’s IBD diagnosis, what type of support systems might currently exist, and if these support systems might influence the coping behaviors of the participant.

The demographic form will be administered in a paper-pencil format. The participant will have the option to select “prefer not to answer” to several questions, and to offer additional information when selecting “other – please explain” responses.

**Short inflammatory bowel disease questionnaire.**

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ), a brief IBD symptom self-reporting tool (Irvine, Zhou, & Thompson, 1996), will be used to provide additional descriptive information about the sample population. The SIBDQ will help the PI obtain information about participants’ IBD symptoms that they might feel too embarrassed to discuss openly with the PI, such as the frequency of flatus and episodes of incontinence that they may experience. Previous qualitative researchers have also utilized IBD instruments in their studies to help describe their sample populations (Hall, Rubin, Dougall, Hugin, & Neely, 2005; Hall, Rubin, Hugin, & Dougall, 2007).

The SIBDQ contains 10 questions related to IBD symptoms and mood and takes fewer than 10 minutes to complete using paper-pencil. This tool has been validated, reporting a test-
retest reliability coefficient 0.65, Cronbach’s alpha 0.78, and an IBDQ variance of 91% in Crohn’s and UC patients (Irvine, Zhou, & Thompson, 1996) and is widely used in IBD health care settings and research environments (Cohen, 2002; Jowett, Seal, Barton, & Welfare, 2001). Due to the tool’s rich, descriptive nature of IBD questions, which will allow the PI to become more knowledgeable about this population, the tool will be used for descriptive purposes only; it will not be used to score and interpret each participant’s responses individually. Obtaining an accurate description of the population is crucial to the PI during the data collection and analysis phases, and is a primary goal of focused ethnographical research.

**Participant observation and field notes.**

Participant observation is a data collection method where the PI observes participants’ in their natural environment (Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005). In this study, participants’ might be observed in: (a) natural environments such as their homes or at social events (with permission); and (b) limited environments such as a clinical setting, which is often part of their weekly or monthly routine. Multiple participant observations may be necessary in order to observe the participants in these settings in addition to obtaining their interview. Ethnographic researchers utilize participant observation to become immersed in the culture being studied (Fetterman, 2010). For example (with permission), the everyday life of the participants will be observed by the PI while they participate in social events such as church services or neighborhood gatherings and/or while they are in their homes. Limited observation will also occur while they visit the IBD clinic area. Participant observation will be documented with the use of another tool, the field notes.

Field notes will be written by the PI during and after each participant observation and interview. Using a descriptive and reflective tone, the PI’s field notes will contain data regarding:
(a) the environment during the interview; (b) the participant; (c) the activities and interactions that occurred before, during, or after the interview; (d) the frequency and duration of the interview; (e) precipitating factors that occurred before, or during the interview; (f) what norms or rules are at work during the interview; and (g) any intangible factors that might be present during the interview (Emerson, Fretz, & Shaw, 2011).

**Data collection procedures.**

The PI will schedule a meeting with participants who meet the inclusion criteria; participants will be asked to complete the study tools and interview in the following order, beginning with the consent: 1) consent; 2) demographic form; 3) face to face interview; and 4) the Short Inflammatory Bowel Disease Questionnaire. An incentive in the form of a $20.00 gift card voucher will be provided to participants after completing each interview in exchange for their participation in the study. In addition, a parking voucher worth $10.00 will be provided to off-set any meeting costs that they might incur.

It is anticipated that the PI will utilize participant observations, semi-structured interviews, and field notes/logs throughout the data collection phase to: (a) develop a data collection procedure that follows the ethnographic tradition of previous focused ethnographers (Higginbottom, Pillay, & Boadu, 2013; Roper & Shapira, 2000) and (b) make decisions about various issues that may arise in the field such as how to collect data related to non-observable events such as a participant’s feelings about a particular topic (Roper & Shapira, 2000). The PI will conduct these aspects of the study under the guidance and support of the dissertation committee members as expert resources.

First, the PI will explain the study to the participants, obtain consents from participants who agree to participate in the study, and discuss with participants locations where participant
observations and interview(s) will occur. A demographic questionnaire will be administered to the participants prior to the semi-structured interview(s). Initially, each interview will be scheduled for about one hour. During the initial data collection phase, if it appears to the PI that participants are reluctant to share their experiences in the clinical setting, but are more comfortable to share their experiences in a less formal setting such as their local church or community gathering spot, adjustments might be made by the PI to perform the remaining semi-structured interviews of participants in the locations of their choosing, as long as privacy during the interview can be provided (Tzeng, Yeng, Tzeng, Ma, & Chen, 2010). Some informants may be asked to participate in a second interview for clarification and confirmation of the data. The PI will receive prior consent from all participants to audio record their interviews. The PI will conduct all of the interviews and analyze them with guidance from the dissertation committee.

Second, the PI anticipates performing a combination of the “observer-as-participant” and “participant-as-observer” roles in this study (Roper & Shapira, 2000). The observer-as-participant role may be described as a process that enables the PI to obtain information from the informant in brief encounters. In this role: (a) less time will be required in the observation process by the PI compared to other participant-as-observer ethnographic studies; (b) the PI can collect data “in settings where active participation is not allowed, thus making this well-suited for [focused ethnographic] research (Higginbottom, Pillay, & Boadu, 2013, p. 5); and (c) previous PI’s have collected data in locations such as hospitals and clinics while performing focused ethnographic research (Higginbottom, Pillay, & Boadu, 2013, p. 5). The PI also anticipates performing the participant-as-observer role which “increases the likelihood that the [PI] will obtain key ‘insider’ information about what it is like to be a member of the cultural group” (Roper & Shapira, 2000, p. 18). By the PI utilizing both roles during the study, she will
have “the best opportunity to perceive events and understand [their] meanings” (Roper & Shapira, 2000, p. 19).

Finally, data collection and data analysis will occur simultaneously (Dupuis-Blanchard, Neufeld, & Strang, 2009; Munhall, 2012; Roper & Shapira, 2000). Munhall (2012) reported, “Data analysis begins with the first field notes [during data collection] and continues throughout the time necessary for completion of ethnographic studies” (p. 315).

**Plans for Data Analysis**

In order for the PI to become immersed in the ethnographic data, data analysis will be guided by Leininger & McFarland’s (2006) phases of data analysis: (a) collecting, describing, and documenting raw data; (b) identification and categorization of descriptors and components; (c) pattern and contextual analysis; and (d) major themes, research findings, theoretical formulations and recommendations (p. 95). Experienced transcultural nursing mentor(s), who are familiar with performing ethnographic data analysis, will assist the PI throughout the data analysis and data evaluation phases of the research.

First, the PI will utilize the semi-structured interview guide audio recordings, participant observations, demographic forms, SIBDQs, and field notes to collect, describe, and document the raw data received during the data collection phase. Interview data will be transcribed by the PI and a transcription service; data will be managed by the PI using qualitative computer software program Nvivo 11. Focused ethnographic researchers Leininger and McFarland (2006) reported that this phase should include:

“Recording interview data from informants, making observations and having participatory [or collaborative] experiences, identifying contextual meanings, making
preliminary interpretations, recording data related to the phenomena under study, and entering data from field notes directly into a computer” (p. 95).

Second, after the data has been entered into Nvivo 11, the PI will code the data and categorize the data into smaller units (Leininger & McFarland, 2006). These categories may consist of characteristics of the participants, descriptions of the observational settings, or descriptive questions that may emerge after coding the data.

Third, the PI will review and analyze the data to discover the meaning of data contextually and if any patterns exist. During this phase, the PI will be examining if the data have “patterns of similar or different meanings, expressions, interpretations, or explanations of data related to the domain of inquiry” (Leininger & McFarland, 2006, p. 95).

Fourth, the PI will synthesize and interpret the data and provide the reader with major themes discovered from the data, findings from the research, and recommendations for future research (Leininger & McFarland, 2006). The PI will recheck the analyses continually during this phase “to be sure they are substantiated with grounded evidence and credibility from the raw data of the informants [or participants]” (Leininger & McFarland, 2006, p. 95).

All steps of the analytic process will be documented, and all documents will be reviewed for accuracy by the PI. The study design will include several components aimed to ensure study rigor: (a) the PI will serve as a reader and auditor for the data collection and analysis; (b) a comprehensive audit trail will be kept of all decisions and techniques; and (c) an emerging analysis (comprised of themes and categories) will be performed with the participants’ review and verification of the final analysis (Creswell, 2014).
Data Management and Protection of Human Subjects

Anonymity of participants’ identities and personal health information will be maintained throughout the study and after its completion. Participants’ names and addresses will be kept on one master list maintained in a locked file by the PI until the analysis and results of the study are completed and disseminated. All data collection forms, and transcription records will be identified by an assigned number; no other identifying information will be attached to the collected data, and kept in a locked file for a period of five years after the completion of the published results. All interviews will be transcribed verbatim into Microsoft Word by the PI and a transcription service staff member who will sign a confidentiality statement (Appendix I). All data will be coded, entered, and collected by the PI into a secure software program; Nvivo 11 and all computers used in the study will have restricted access to any user who is not directly involved in the study.

Protection of research participants will be performed by: (a) receiving ethical approval of the research study by IRBs of the University of Pittsburgh and Duquesne University, (b) obtaining informed consent from all participants prior to being interviewed (see Appendix E), (c) obtaining confidentiality consents from transcriptionists involved with the study (see Appendix H), and (d) identifying that no potential risks will occur to participants in the research study, informing them that they may stop participating in the study at any time, and if they experience any negative physical or emotional distress during the study, they will be referred to their healthcare provider to receive follow up care (see Appendix E).

Study Limitations

A potential limitation of this study might be participants’ providing socially acceptable responses instead of truthful responses during their interviews. Previous researchers have also
addressed the issue of truthful responses during participant interviews. Svedberg, Ropponen, Lichtenstein, and Alexanderson (2010) reported that self-reporting of information was often accurate and truthful when discussing the topics of disability and chronic illness. For example, participants’ might be too embarrassed to talk about how often they experience episodes of flatus and bowel incontinence, but would prefer to self-report these symptoms on a questionnaire such as the tool used in this study. Therefore, similar to Svedberg, Ropponen, Lichtenstein, & Alexanderson (2010), this study plans to utilize the self-reporting format, participant observations, and interviews to discuss the chronic illness of IBD and inform readers about any limitations that might have existed during the study.

**Potential Problems and Strategies to Address Them**

A potential problem that might occur with data collection could be a participant’s difficulty completing an interview during the allotted one-hour time period due to: (a) clinical symptoms of IBD that the participant might be experiencing during that time; (b) the participant might not feel like talking when the interview date arrives; and (c) the participant may not feel comfortable inviting the PI into their home for an interview. Strategies to address this potential problem might include: (a) being flexible and attempting to reschedule the interview to a more appropriate day and time for the participant; (b) offering to meet participants at a private location that they routinely frequent within the community such as their churches; (c) offering to perform a portion of the interview by telephone; and (d) decreasing the amount of interview time to two 30-minute sessions instead of a single 1-hour session.
References


Schneider, M., & Fletcher, P. (2008). 'I feel as if my IBS is keeping me hostage!' Exploring the negative impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) upon university-aged women. *International Journal of Nursing Practice, 14*(2), 135-148.


Appendix A

Inquiry Letter

From: Patricia Scott, MSN, RN
PhD Candidate, Duquesne University School of Nursing

To: IBD Center at UPMC

I am a PhD candidate at Duquesne University School of Nursing who is conducting research exploring how African Americans with inflammatory bowel disease (IBD) cope with this disease. I am seeking to recruit African Americans with IBD to participate in my research study that has been reviewed and approved by the Institutional Review Boards (IRBs) at the University of Pittsburgh and Duquesne University. If any of your patients meet this description, I need your help to gain access to these individuals, especially if they receive IBD care in the Pittsburgh area. I would like to post recruitment flyers in your office waiting area with information about the research study. Participants will be interviewed for approximately 30 to 60 minutes. In appreciation of their time, participants will receive a $20.00 gift voucher and a $10.00 parking voucher.

Dr. Eva Szigethy, Director of Visceral Inflammation and Pain Center in the Division of Gastroenterology and Co-Director of IBD Total Care Program at the University of Pittsburgh Medical Center (UPMC), will be contacting within two weeks regarding this request. I can be contacted via email at scottp1@duq.edu.

Thank you in advance for your help.

Patricia Scott, MSN, RN
PhD Candidate
Duquesne University School of Nursing
Scottp1@duq.edu
Appendix B

Recruitment Flyer

Are you over 18 years of age?
- Are you African American?
- Diagnosed with Crohn’s disease or ulcerative colitis?

If you answered YES to these questions, you may be eligible to participate in a research study to learn how African Americans cope with these diseases. Participants will receive compensation for their time at the completion of the study.

Both men and women are eligible to participate.
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE:
Coping Behaviors of African Americans with Inflammatory Bowel Disease (IBD)

INVESTIGATOR:
Patricia Scott, MSN, RN
PhD Candidate
Duquesne University School of Nursing
Scottp1@duq.edu

ADVISOR:
Joan Such Lockhart, PhD, RN, AOCN, CNE, ANEF, FAAN
Clinical Professor
Duquesne University School of Nursing
311 Fisher Hall
600 Forbes Avenue
Pittsburgh, PA 15282
lockhart@duq.edu

SOURCE OF SUPPORT:
This study is being performed as partial fulfillment of the requirements for the doctoral (PhD) degree in the School of Nursing at Duquesne University.

PURPOSE:
You are being asked to participate in a research project that seeks to investigate how African Americans cope with inflammatory bowel disease, such as Crohn’s disease or ulcerative colitis. In addition, you will be asked if you will allow the researcher to interview you. If you agree, you will meet with a researcher in a private room and location agreed upon by you and the researcher. Prior to the interview, you will be asked to complete a brief demographic survey. The interview may take approximately 1 hour and will be audio-taped and transcribed. You will be asked questions about what it is like to live with inflammatory bowel disease (IBD), your thoughts about this topic, and complete 2 brief surveys. You may also be asked to participate in
a second interview for clarification and confirmation. The researcher may also take notes about your environment to help in understanding what you share in the interview.

These are the only requests that will be made of you.

**RISKS AND BENEFITS:**

There are minimal risks to your participation in this study. You could tire during the data collection sessions. If that occurs, the data collector will allow time for rest or reschedule the data collection session at another agreed upon time. You can decline to answer any question. You can change your mind about participating in the study at any time by simply saying you wish to stop and you may leave without any consequence to you. If you experience any negative physical or emotional distress during the study, you will be referred to your healthcare provider to receive follow up care.

**ALTERNATIVE TREATMENTS:**

Your private healthcare provider is still responsible for your healthcare needs. Please talk to them if you have questions about your healthcare. This study does not replace any of these sources of help; therefore, you should continue to use them.

**COMPENSATION:**

A gift card voucher of $20.00 for each completed interview will be provided to you to participate in this study. A $10.00 parking voucher will be offered to you as well. There will be no cost to you for your participation.

**CONFIDENTIALITY:**

Your name will never appear on any survey or research instrument used for this study. No names will be utilized; you will receive a code number from the transcribed data. Your responses to questions may appear as de-identified quotes, so anything that could identify you or anyone to which you refer will be removed. The study may be published or presented at professional meeting, but at no time will your identity be shared or known. The person who will assist in transcribing the tapes will sign a confidentiality agreement and will not have access to your names. No identity will be made in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's office. All materials and tapes will be destroyed five years after the completion of the published results.

**RIGHT TO WITHDRAW:**

You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time by contacting the researcher by telephone, in writing, or in person. All data obtained from participants who have withdrawn from the study will be destroyed and will not be included in the research study.

**SUMMARY OF RESULTS:**

A summary of the results of this research will be supplied to you, at no cost, upon request.

**VOLUNTARY CONSENT:**
I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project. I understand that should I have any further questions about my participation in this study, I may contact the Principal Investigator Patricia Scott at and Advisor Dr. Joan Lockhart. Should I have any questions regarding protection of human subject issues, I may contact Dr. David Delmonico, Chair of the Duquesne University Institutional Review Board.

_________________________________________
Participant’s Signature

_________________________________________
Participant’s Printed Name

INVESTIGATOR’S CERTIFICATION: I certify that I have explained the nature and purpose of this research study to the above-named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise.

_________________________________________
Printed Name of Person Obtaining Consent

_________________________________________
Role in Research Study

_________________________________________
Date
Appendix D

Dear Potential Study Participant:

Thank you for agreeing to participate in the “Coping Behaviors in African Americans with IBD” research study. Due to the large number of individuals who were recruited, your participation will not be needed at this time.

Thank you so much for your interest and willingness to participate.

Sincerely,

Patricia Scott, PhD Candidate
Duquesne University School of Nursing
Scottp1@duq.edu
Appendix E

Semi-structured Interview Guide

The interview will begin with “I am interested in learning more about you.” Then continue with introductory questions such as: (a) “Can you tell me a little about yourself?” (b) “Can you tell me about your family?” (c) “What things in life are important to you?” (d) “Whom do you look to for support?” (e) “Can you tell me more about…?”

Next, the PI will transition into questions about IBD by stating, “Now that we have had a chance to get to know one another a little, I would like to ask you a few more questions…” The participant will be asked additional open-ended questions such as: (f) “Tell me about your experiences related to IBD – How did you first find out that you had IBD?” (g) “Can you tell me about your IBD experiences from then until right now?” (h) “What is it like living with IBD every day?” (i) “What needs or concerns do you have related to your disease?” (j) “How do you define the term culture?” (k) “How does being African American influence how you manage your disease? If so, what are these influences?” (l) “How do you define the term coping?” (m) “How do you cope with IBD?” (n) “What resources, if any, are you accessing to help you cope with your disease?” (o) “Is there anything that you want to share that I did not ask you today?”

The interviewer will use probes such as “Tell me more about that,” “Go on…,” “Can you give me and example,” to prompt and elicit complete responses from the participant.
Appendix F

Demographic Form

Please fill in the blank, circle (or place an “x” next to) one answer for each of the 11 questions.

Q1. What type of inflammatory bowel disease (IBD) do you have?
   □ I have been diagnosed with Crohn’s Disease
   □ I have been diagnosed with Ulcerative Colitis
   □ Other – please explain ____________________________

Q2. How many years has it been since you were first diagnosed with IBD?
   □ _____ year(s)
   □ Prefer not to answer

Q3. What previous IBD surgeries have you had since your IBD diagnosis?
   □ None
   □ Yes (please list) __________
   □ Prefer not to answer

Q4. Are you currently taking any prescribed medications for your IBD?
   □ No
   □ Yes (please list) __________
   □ Prefer not to answer

Q5. What religion do you currently practice?
   □ (Please list) __________
Q6. What is your current age?

☐ ____ years of age
☐ Prefer not to answer

Q7. What is the highest degree or level of education that you have completed?

☐ No formal schooling completed
☐ Less than 9th grade
☐ Some high school
☐ High school graduate
☐ Some college credit
☐ Trade/Vocational Education
☐ Associate degree
☐ Bachelor’s degree
☐ Master’s degree or higher
☐ Prefer not to answer

Q8. What is your current marital status?

☐ Single/Never married
☐ Married/Living with Partner
☐ Widowed
☐ Divorced
☐ Separated
☐ Prefer not to answer

Q9. With whom do live in your home?

☐ No one
☐ Roommate(s)
☐ Spouse/Significant other
☐ Child/Children
☐ Spouse/Significant Other AND Children
☐ Other- please explain _________
☐ Prefer not to answer

Q10. What is your current employment status? Are you currently…?

☐ Employed
□ Unemployed
□ A homemaker
□ A student
□ Retired
□ Unable to work
□ Other- please explain
□ Prefer not to answer

Q11. What is your current annual household income?
□ 0 - $25,000
□ $25,001 - $50,000
□ $50,001 - $100,000
□ > $100,000
□ Prefer not to answer
Appendix G

Short Quality of Life in Inflammatory Bowel Disease Questionnaire (SIBDQ)

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ), authored by Dr. Jan Irvine et al, is the copyright of McMaster University (copyright 1989, McMaster University). The SIBDQ has been provided under license of McMaster University. The author has received written approval by McMaster University to use this instrument for academic purposes only and not to publish this instrument in any format.
Appendix H

Confidentiality Agreement for Transcription Services

Research Study: Coping Behaviors of African Americans with Inflammatory Bowel Disease

1. I, ________________________________ transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to this research study.

2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents.

3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher.

4. I will not provide the research data to any third parties without the client's consent.

5. I will store all study-related data in a safe, secure location as long as they are in my possession. All video and audio recordings will be stored in an encrypted format.

6. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team or permanently deleted. When I have received confirmation that the transcription work I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team.

7. I understand that Duquesne University has the right to take legal action against any breach of confidentiality that occurs in my handling of the research data.

Transcriber’s name (printed)________________________________________________

Transcriber’s signature ______________________________________________

Date __________________________ __________________________

COPING BEHAVIORS OF AFRICAN AMERICANS WITH INFLAMMATORY BOWEL DISEASE: A FOCUSED ETHNOGRAPHY

3.1 Background and Significance

Background

Inflammatory bowel disease (IBD), a chronic, debilitating disorder of the gastrointestinal (GI) tract, has been increasing in both incidence and prevalence among people who live in industrialized countries (Ha & Katz, 2014). These patients frequently report symptoms of a sudden onset of diarrhea, fatigue, rectal bleeding, severe abdominal cramping and debilitating pain. These symptoms may last hours, days, weeks, or even months at a time depending upon the severity of the disease progression and exacerbation of the symptoms (Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Skrastins & Fletcher, 2018). Although IBD has been present in the medical and health literature since 1932, very little research has explored the impact of IBD in the African American population (Veluswamy et al., 2010). It is estimated that over 156,000 African Americans have been diagnosed with IBD in the US (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016), however there are no studies (to date) that have investigated the self-reporting of personal coping experiences and potential cultural influences of African Americans with IBD. This type of data and findings would be needed by nurses providing care for this population group.

Scott and colleagues (2019) performed an integrative review of the literature regarding African American adults with IBD and coping. Their findings revealed only five studies had explored the topic of African Americans with IBD and coping behaviors (Alexakis et al., 2015;
Faust et al., 2012; Gandhi et al., 2014; Moradkhani et al., 2011; Parekh et al., 2015). These IBD researchers reported pertinent information about coping with IBD: (a) coping activities consisted of practicing one’s religion, diet restriction, and social isolation; IBD patients were concerned about lack of awareness of IBD among their families, community, and the healthcare system (Alexakis et al., 2015); (b) the presence of an inverse relationship between health-related quality of life (HRQOL) and coping and a positive relationship between social constraint and coping, engagement and disengagement coping, and anxiety and depression (Faust et al., 2012); (c) more active coping styles such as task-oriented coping were found in IBD people who were in remission (Gandhi et al., 2014); (d) an association between IBD knowledge and active coping; better informed IBD people were more likely to use adaptive coping strategies (Moradkhani et al., 2011; and (e) people with IBD used the coping styles of confrontive, evasiveness, optimistic, and fatalistic; people in remission expressed higher quality of life (QOL) scores than those with active disease (Parekh et al., 2015). Although IBD researchers explored coping in adults with IBD which included subsets of African Americans (or Black people) in their samples, their studies did not focus solely on the African American IBD population. In fact, African Americans were only identified as one of several ethnic groups in the demographic sections of these studies. Only one of these studies (Alexakis et al., 2015) focused on minorities as their primary population sample, however this study was performed in the United Kingdom (UK) not in the US. Therefore, no studies have recruited African Americans adults with IBD, as a primary population sample, to explore how they cope with IBD.

As chronic health care costs continue to rise and increases in ethnic diversity gradually occur within the US, more research is needed on this topic to explore if health disparities exist in this population. IBD researchers Nguyen, Chong, and Chong (2014) also suggested that further
exploration from the medical and research community was needed regarding the health care practices of African Americans with IBD. They reviewed data from the 1999 National Health Interview Survey and reported that, although more non-Hispanic Whites were diagnosed with IBD in the US compared to non-Hispanic Blacks, the rate of IBD hospitalizations and IBD-related mortality was more prevalent among non-Hispanic Blacks compared to non-Hispanic White and Hispanic IBD populations (Nguyen, Chong, & Chong; 2014). Researchers suggest the need to explore African Americans with IBD (Veluswamy et al., 2010) and the cultural influences and coping behaviors of the African American population with IBD in their own words (Scott et al., 2019). Exploration of the personal experiences of African Americans with IBD may lead to an increased awareness about this population among researchers, as well as in the healthcare and lay communities.

3.2 Purpose and Research Questions

The purpose of this study was to explore and understand the beliefs, perceptions, and experiences of African Americans with IBD in the context of their environment and culture. The research questions guiding this study were:

Research Question 1: What is the meaning and perceptions of coping in African Americans with IBD?

Research Question 2: What are the cultural health beliefs and health care practices utilized by African Americans to cope with IBD?

3.3 Method and Design

A qualitative focused ethnography method was used for this study to understand “the meaning that members of a subculture or group assign to their experiences” (Roper & Shapira, 2000, p. 9). A focused ethnography allowed the researchers to explore IBD from African
Americans’ unique cultural perspectives, their experiences with IBD, and the meanings that they assigned to them. The design for this study included: field work, participant observation, individual interviews, data analysis, and confirmation of data and findings. Institutional Review Board approval and informed consent were obtained for this study. Participation was voluntary and the participants were free to withdraw from the study at any time. The interviews were audio taped. Interviews were conducted by the researcher with experience in gastroenterology and qualitative research.

Setting

Participants were recruited from IBD patient clinic(s) located in a large urban health care system and the community in the Northeastern region of the US. Recruitment flyers were posted in approved clinical areas within the study health care system and libraries, community centers, free clinics, churches, and minority businesses throughout the local community.

Informants

Purposeful and snowball sampling was used to recruit participants for this study (Polit & Beck, 2012). Inclusion criteria for this study included: self-identified as a non-Hispanic African American, 18 years of age or older, currently living in the US, able to read and write the English, diagnosed with IBD by a healthcare provider, and experienced active IBD symptoms within the past three years. Initially, 18 participants contacted the primary researcher, five did not meet the eligibility requirements and one participant did not participate after the initial phone call. A total of 12 participants were considered eligible for the study.

Instruments

The following documents were collected as part of data collection: (a) a demographic form including: age, education, people living in the home, marital status, religious preference,
employment, income, type of IBD, number of years since diagnosis, and past IBD surgeries; (b) a Short Inflammatory Bowel Disease Questionnaire (SIBDQ), developed by Irvine, Zhou, and Thompson (1996), to describe the participant’s current IBD status; and (c) a contact information form. Next, a semi-structured interview guide was used by the first author to elicit data that would reflect each participant’s beliefs, perceptions and practices regarding coping with IBD as an African American.

**Data Collection**

Recruitment for this study began after obtaining IRB approval. After the individual expressed interest in the study they were contacted by the first author via telephone. Participants who met the inclusion criteria were invited to participate in the research study. Most participants requested to be interviewed in a private office at the IBD center or in a private conference room at their community library. Data collection began in the private area of their choosing prior to the interview, and continued throughout the interviews and observational meetings. Confidentiality and anonymity of the participants were maintained, and participants were free to refuse to participate at any time during the interview. Participants were referred to their healthcare provider if they experienced difficulty during the interview. Semi-structured interview questions were used to prompt participants to discuss their beliefs, perceptions and practices regarding coping with IBD as African Americans. The interviews were audio-taped and ranged from 40 and 90 minutes. Field notes were recorded about participants’ activities and their environment during observations. Most participants were observed on two different occasions (n=11), in order for the researcher to obtain more data about the “everyday life of the participant” in different environments (Munhall, 2012). Data collection continued until data saturation occurred. Saturation of data occurred after the 11th interview but one more interview was conducted to
confirm saturation of the data. The researchers attempted to reduce the potential issue of sampling bias by placing recruitment flyers in clinical sites and in community settings where participants might frequent, and inviting all qualified participants to participate in the study from both locations.

**Trustworthiness of Data**

Trustworthiness of the data, related to the issues of confirmability and credibility, were addressed by: (a) contacting two participants and sharing the preliminary themes and their rationale with them and receiving their validation of the findings; and (b) utilizing triangulation, or multiple means of data collection (such as interviews, observations, and SIBDQ questionnaires) to understand the topic (Polit and Beck, 2012).

**Data Analysis**

Data collection and analysis were done concurrently for this study. Audio files were transcribed verbatim and uploaded to the qualitative data manager Nvivo 12®. Leininger’s Four Phases of qualitative data analysis was used to analyze the data and included: (1) collecting, describing and documenting raw data into a field journal; (2) identifying descriptors, categorizing and coding the data (according to the domains of inquiry and research questions), coding emic and etic data to identify similarities and differences; (3) identifying patterns and contextual analysis, discovering saturation of ideas and recurrent patterns, and data were examined for credibility and confirmability; and (4) identifying themes based on theoretical formulations (Leininger & McFarland, 2006).

**3.4 Findings**

All 12 participants, seven women and five men, self-identified as African American adults between 25 to 68 years of age. Ten participants were 40 years of age or older. Most
participants had been diagnosed with Crohn’s disease for at least three to ten years (n=9), had experienced some type of IBD surgery (n=9), and were currently taking IBD medications for their condition (n=8). Most participants were not employed (n=7), reported an annual household income of less than $50,000 (n=7), had no children living with them in their homes (n=10), had some type of education post high school (n=10), and identified with the Protestant religion (n=9). Five participants reported being married, five reported being single, one reported being separated, and one reported being a widow (Table 1). Additional descriptive information about the IBD sample population was also collected (Table 2). Participants reported: feeling tired (n=11); bowel problems (n=8), pain (n=9), depression (n=8), flatus problems (n=8), maintaining weight (n=9), and anger (n=7). Six participants reported having to cancel engagements due to IBD issues over the last two weeks.

Data analysis resulted in 14 categories, nine patterns and four themes (Table 3). The 14 categories consisted of: self-description, family, importance to you, IBD diagnosis, IBD experiences, living with IBD, African American influence, support, resources, suggestions to others with IBD, culture, coping, and how you cope; while the identified patterns were: Pattern of negative responses to most topics, Pattern of additional stress, Pattern of lack of support, Pattern of African American culture, Pattern of avoiding cultural foods, Pattern of coping, Pattern of bathroom frequency and access, Pattern of eating and food as a negative activity, and the Pattern of isolation. Four themes emerged from the data about coping behaviors in this population, which were: spending time living in the bathroom, food and time restrictive eating practices and cultural food avoidance, dealing with a life of stress, and the practice of seclusion to promote health (Table 3).
Theme 1: Spending Time Living in the Bathroom

Preoccupation with the bathroom was such a priority, that many participants felt that most of their lives were spent looking for and/or using the bathroom (n=11). To cope with frequent bowel movements, several participants (n=7) preferred to remain at home and close to their own bathrooms.

“My life now is really centered around rest rooms. Access to rest rooms… and I kind of have a rule of thumb, that after using public facilities three times, then it’s time to go home. Because you know, it’s just the conditions of cleanliness, and you know, the smell you leave behind. I just try the three-strike rule. Three times, yeah I go [home].” (Participant B)

Six participants reported needing to use the bathroom so frequently that they could not maintain stable employment or participate in any activities outside of their homes.

“You can’t do a lot of activities because you might have to run to the bathroom or…that’s part of me not working. I couldn’t be there because sometimes in the mornings it would start right before I go out the door or stuff like that. It happens like whenever it wants to ..and you have no control over it.” (Participant D)

“I couldn’t do anything outside because there was no bathrooms. So, it was constantly having to go to the bathroom. Having to plan everything around going to the bathroom. Having to be near bathrooms that were not occupied. It doesn’t matter if the bathroom is here, I pull on the door and somebody is in there, I’m done.” (Participant K)

Theme 2: Food and Time Restrictive Eating Practices and Cultural Food Avoidance

All 12 participants discussed eating from an unpredictable perspective, such as: (a) eating or drinking anything could make one sick at any time; (b) eating anything outside of the home...
could cause one to become sick, or to have increased bowel movements; and (c) restricting and/avoiding certain foods, especially foods commonly found in the African American culture.

“You have to go through the pains and can't eat certain foods; and if you eat certain foods you don't know you're going to get sick and then you get sick because the food don't agree with you because of the Crohn's.” (Participant D)

Most participants discussed restricting or avoiding eating African American cultural foods, referred to as Soul food. Every participant associated the African American culture with Soul food. Participants restricted or avoided eating Soul food because many of the ingredients and how it is prepared causes increased GI upset resulting in increased bowel movements and potential bowel incontinence. For example, eating pork, black-eyed peas, fried meats, and collard greens with ham hocks are foods that IBD patients’ reported that they should avoid; however, these foods are the staple of Soul food.

No one reported eating or eating out with friends as a positive experience. In fact, one participant stated that she became angry if anyone “invited her to go out to dinner”.

“.. I get calls like, ‘Hey girl, come on, let’s go to dinner.’ Those are like trigger words for me. You say dinner and go out; I’m just like, grrrr… or I’ll find myself lying and making excuses [so I won’t have to eat out with them].” (Participant G)

**Theme 3: Dealing with a Life Full of Stress**

All but one participant (n=11) reported several stressful events that had occurred throughout their lifetime which they attributed to IBD. For example, participants stated the following stressful events occurred in their lives due to their illness: job loss (n=7), financial insecurity (n=8), inability to obtain effective IBD medications (n=8), and a negative impact on personal relationships and their social life (n=11). Several participants (n=10) also discussed the
constant stressors in their lives as African Americans in society, in addition to living with IBD. One participant described his stress as “an added layer of struggle” [being an African American with IBD].

“‘Yes, because I believe there's an added layer of struggle. Just you know, being Black in America. I mean, cops are out there shooting us like it's hunting season, like we're deer. Stresses of that, just knowing that you know that I mean, that any time you could be thrown on the ground and killed by these people who are here to serve and protect. Yeah, that was how it's just been hell, and there's just I think there's a gap in the treatment that whites receive versus African Americans.’”

(Participant B)

**Theme 4: Practice of Seclusion to Promote Health**

Seven participants reported secluding themselves in their homes to avoid: (a) the need to find a bathroom immediately; (b) feelings of anxiety and/or talking about it [IBD] to people; and (c) the embarrassment of potential bowel incontinence episode(s). This type of behavior often limited their attendance at social events, access to IBD support, and IBD resources. In addition, participants also reported feeling isolated from others such as family, friends, and coworkers. One participant reported spending more time at home during flare ups.

“It prevents me from going out a lot because I'm afraid what might happen.” (Participant J). Only one participant discussed how she fought against the practice of seclusion:

“And so, if I let it [IBD] control me then that means I would be home all the time. Just sitting in my house waiting to go to the bathroom… so, you just have to turn everything around. Say, okay my stomach hurts today but, suck it up and go.”

(Participant I)
3.5 Discussion

This study provides a glimpse into how African Americans with IBD cope with the daily challenges that often accompany the disease. The detailed accounts of their personal experiences allowed the researchers to gain a greater understanding of their values and beliefs which influenced their coping behaviors related to IBD. The participants were open to speaking about their experiences and candidly expressed their thoughts, even while discussing the sensitive topic of personal bowel habits. The findings regarding their constant preoccupation with (use and seeking out the nearest location of) bathrooms suggested they valued symptom-free days, but believed that they might not occur; therefore, a bathroom plan was always needed to be in place. The constant pressure to secure a bathroom plan often resulted in a sense of captivity, burden, and an ongoing struggle to maintain control of their lives while coping with IBD. These findings were consistent in previous IBD literature (Alexakis et al., 2015; Czuber-Dochan et al., 2019; Devlen et al., 2014; Larsson, Loof, & Nordin, 2017; Moradkhani et al., 2011). However, an additional sense of burden was reported by our IBD population, suggesting few supportive resources were in place to help them with their problems.

Spending time living in the bathroom illustrated a form of captivity the disease [IBD] subjected them to, as they were constantly being forced to seek out and to use the bathroom because they were being held hostage by their fears of bowel incontinence. This type of coping behavior was not only used by African Americans with IBD, but by reports of other IBD patients as well (Larsson, Loof, & Nordin, 2017); they believed this type of behavior was necessary in order to “deal with” any type of activity outside of the home.

A life full of stress revealed a two-fold burden: the burden of living with IBD, which was reported in previous IBD literature (Devlin et al., 2014), as well as the burden of being an
African American living in a racially unjust society. Participating in religious and stress-reducing activities, along with spending time with family members helped them to minimize this burden. Although no IBD researchers have addressed the complex issue of stress related to racial injustice, sociologists Ellis, Griffith, Ober, Thorpe, and Bruce (2015) reported findings similar to this study such as African American men perceived that “We’re the sickest, we die the youngest….the pressures of society have caused an unreasonable amount of stress on us [African American men]” (Ellis et al., 2015, p. 10).

Restrictive eating practices, cultural food avoidance, and seclusive behavior illustrated participants’ struggles to maintain some control over their lives by diminishing and controlling their IBD symptoms through diet, and utilizing social isolation as a type of protective mechanism. Although most IBD participants could no longer eat African American cultural food, many of their restrictive eating practices were similar to other IBD populations (Alexakis et al., 2015; Tanaka, Iwao, Fukushima, & Yamamoto-Mitani, 2016). Similar to other IBD studies, the participants were extremely interested in learning more about nutrition and diet, hoping that this newfound information would result in diminished IBD symptoms and increased opportunities to participate in activities outside of their homes (Alexakis et al., 2015; Moradkhani et al., 2011).

The practice of seclusion to promote health also represented participants’ attempts to maintain control over their lives. This type of reclusive behavior was used to insulate themselves from the potential negative IBD symptoms that might occur, and as a safe place to retreat to – where a bathroom was readily available, and where there was no need to constantly remind their family, friends, and coworkers about their restrictive eating practices and bathroom needs. This type of behavior was also reported in the IBD literature (Alexakis et al., 2015). Only one
participant reported how she limited using this type of coping behavior, because she viewed seclusion as a form of retreat, not as a form of control.

3.6 Limitations

All of the participants of this study had access to IBD medications and IBD healthcare. Perhaps the beliefs and life experiences of African Americans with IBD who did not have access to IBD medications and IBD healthcare might be different from our study’s findings.

3.7 Implications and Recommendations

The constant burden of stress that this population reported suggests that nurses should encourage patients to participate in at least one type of stress relieving intervention such as yoga, online counselling, or an online support group. Because this population reported family and religion as two positive influences in their lives (Table 3), nurses and healthcare providers could help mobilize both of these entities to help improve the QOL for this population (Luo, Shang, & Li, 2019). Nurses could educate the patient’s family about the disease process and inform them that their help is necessary to improve the patient’s outcome with this disease. Families could begin to learn new ways to support patients with IBD, including: how to prepare cultural foods in new ways that an IBD patient could eat, become more aware of the foods that their family member should avoid, be understanding of their loved one’s “new normal” of increased bathroom use, be flexible when their loved one cannot attend social activities due to bowel issues, and replacing food related family activities with nonfood social activities that the entire family could attend. Religious communities could also assist this population by starting an IBD support group, designating some bathrooms for IBD use only, sponsoring IBD related social events, educating the congregation and community about IBD and their needs, and providing an online format to participate in services and meetings when they are unable to leave their homes.
Nurse researchers could also add to the body of African American IBD literature regarding this topic. Perhaps exploring African Americans with IBD in other regions of the US might reveal similar or different results compared to our findings.

3.8 Conclusion

African Americans with IBD described their coping behaviors as activities that allowed a person to just manage or to complete a task. Bathroom plans were created every day to prepare for unexpected episodes of bowel incontinence which often resulted in a sense of captivity, burden, and struggle. Coping behaviors in this population were similar to other IBD populations, except for their: (a) reports of additional stress being present in their lives due to the perceived racial inequality present in the US; and (b) participation in religious activities was considered a positive influence in their lives. While many of the themes endorsed in this study are common problems across many IBD patient populations, this study illustrates how cultural and ethnic factors can amplify these challenges. Opportunities exist for nurses to encourage them to participate in stress reducing activities and to collaborate with others regarding their needs and concerns.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.
4.0 FUNDING

COPING BEHAVIORS OF AFRICAN AMERICANS WITH INFLAMMATORY BOWEL DISEASE: A FOCUSED ETHNOGRAPHY

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References


Table 1

Demographic Characteristics of Participants \( (n=12) \)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of Participants ( (n=12) )</th>
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</thead>
<tbody>
<tr>
<td>Age in years</td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>2</td>
</tr>
<tr>
<td>30-39</td>
<td>0</td>
</tr>
<tr>
<td>40-49</td>
<td>5</td>
</tr>
<tr>
<td>&gt;50</td>
<td>5</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
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<td>Male</td>
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</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
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</tr>
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<td>Employed</td>
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<tr>
<td>Retired</td>
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<td>Disabled</td>
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<tr>
<td>Religion</td>
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<td>None</td>
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</tr>
<tr>
<td>Islam</td>
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<td>Jehovah’s Witness</td>
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<td>Protestant</td>
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<td>IBD Type</td>
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<td>Crohns</td>
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<td>Ulcerative Colitis (UC)</td>
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<tr>
<td>Both</td>
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Table 1

Demographic Characteristics of Participants (continued)

<table>
<thead>
<tr>
<th>Characteristic</th>
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<td>Years diagnosed with IBD</td>
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</tr>
<tr>
<td>3 -10</td>
<td>7</td>
</tr>
<tr>
<td>11 - 20</td>
<td>1</td>
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<td>21-30</td>
<td>0</td>
</tr>
<tr>
<td>&gt;31</td>
<td>4</td>
</tr>
<tr>
<td>IBD Surgeries</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Take Medications for IBD</td>
<td></td>
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<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
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<tr>
<td>No Answer</td>
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</tr>
<tr>
<td>Household Income</td>
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<td>0 - $25,000</td>
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<tr>
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<tr>
<td>$50,001 - $100,000</td>
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</tr>
<tr>
<td>&gt;$100,000</td>
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<td>No answer</td>
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Table 2

*Description of Events Occurring Over a Two-Week Period (n=12)*

<table>
<thead>
<tr>
<th>Event</th>
<th>Number of Participants (n=12)</th>
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</thead>
<tbody>
<tr>
<td>Feeling Tired</td>
<td></td>
</tr>
<tr>
<td>All of the time</td>
<td>1</td>
</tr>
<tr>
<td>Most of the time</td>
<td>4</td>
</tr>
<tr>
<td>A good bit</td>
<td>1</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2</td>
</tr>
<tr>
<td>Little bit</td>
<td>3</td>
</tr>
<tr>
<td>Hardly Ever</td>
<td>1</td>
</tr>
<tr>
<td>Cancelled an Engagement</td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2</td>
</tr>
<tr>
<td>Little bit</td>
<td>1</td>
</tr>
<tr>
<td>Hardly Ever</td>
<td>4</td>
</tr>
<tr>
<td>None of the time</td>
<td>2</td>
</tr>
<tr>
<td>Bowel Problems</td>
<td></td>
</tr>
<tr>
<td>Great deal</td>
<td>2</td>
</tr>
<tr>
<td>Lot of difficulty</td>
<td>1</td>
</tr>
<tr>
<td>Fair amount</td>
<td>2</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>1</td>
</tr>
<tr>
<td>Little difficulty</td>
<td>2</td>
</tr>
<tr>
<td>Hardly any difficulty</td>
<td>2</td>
</tr>
<tr>
<td>No difficulty</td>
<td>2</td>
</tr>
<tr>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>All of the time</td>
<td>2</td>
</tr>
<tr>
<td>Most of the time</td>
<td>2</td>
</tr>
<tr>
<td>A good bit</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2</td>
</tr>
<tr>
<td>Little bit</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td>Depressed</td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>2</td>
</tr>
<tr>
<td>A good bit</td>
<td>1</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3</td>
</tr>
<tr>
<td>Little bit</td>
<td>2</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
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</table>
Table 2

*Description of Events Occurring Over a Two-Week Period (continued)*

<table>
<thead>
<tr>
<th>Event</th>
<th>Number of Participants (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flatus Trouble</td>
<td></td>
</tr>
<tr>
<td>Big problem</td>
<td>1</td>
</tr>
<tr>
<td>Major trouble</td>
<td>1</td>
</tr>
<tr>
<td>Significant</td>
<td>1</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4</td>
</tr>
<tr>
<td>Little bit</td>
<td>1</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>3</td>
</tr>
<tr>
<td>No trouble</td>
<td>1</td>
</tr>
<tr>
<td>Problem Maintaining Weight</td>
<td></td>
</tr>
<tr>
<td>Big problem</td>
<td>2</td>
</tr>
<tr>
<td>Major trouble</td>
<td>2</td>
</tr>
<tr>
<td>Significant</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>2</td>
</tr>
<tr>
<td>No trouble</td>
<td>1</td>
</tr>
<tr>
<td>Relaxed/Not Anxious</td>
<td></td>
</tr>
<tr>
<td>Almost all the time</td>
<td>2</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit</td>
<td>3</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3</td>
</tr>
<tr>
<td>Little bit</td>
<td>3</td>
</tr>
<tr>
<td>Trouble with Bowel Evacuation</td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit</td>
<td>3</td>
</tr>
<tr>
<td>Little bit</td>
<td>1</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>6</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Feeling Angry</td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
</tr>
</tbody>
</table>

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Table 3

*Categories, Patterns, and Themes*

<table>
<thead>
<tr>
<th>Category</th>
<th>Pattern</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Description</td>
<td>Negative responses to most topics were reported except when discussing “family” and “faith/religion”</td>
<td>Dealing with a life full of stress</td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Important to you</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IBD diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IBD experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with IBD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>Many felt being African American added another layer of stress to their lives</td>
<td></td>
</tr>
<tr>
<td>Influence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>Little support was available for many of the participants; those that received professional support reported it was helpful</td>
<td></td>
</tr>
<tr>
<td>Resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestions to others with IBD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Culture</td>
<td>Culture was described as “traditions, lifestyles, and values” of a person, or “a way” a group of people live</td>
<td>Time and food restrictive eating practices and cultural food avoidance</td>
</tr>
<tr>
<td></td>
<td>African American cultural foods [Soul food] should be avoided, because it increased flare ups, IBD symptoms</td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td>How you cope</td>
<td></td>
</tr>
</tbody>
</table>
### COPING BEHAVIORS

Table 3

*Categories, Patterns, and Themes (continued)*

<table>
<thead>
<tr>
<th>Category</th>
<th>Pattern</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns</td>
<td>Coping was described as “dealing with something” or “learning to deal with it”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bathroom frequency &amp; access, side effects from drugs, and no cure for IBD</td>
<td>Spending time living in the bathroom</td>
</tr>
<tr>
<td></td>
<td>Eating and food was frequently described as a negative activity</td>
<td></td>
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<tr>
<td></td>
<td>Isolation from most social activities became a way of life</td>
<td>Practice of seclusion to promote health</td>
</tr>
</tbody>
</table>