

SOCIAL SUPPORT AND SELF-MANAGEMENT BEHAVIORS AMONG EMERGING
ADULTS WITH INFLAMMATORY BOWEL DISEASE

By

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ABSTRACT

SOCIAL SUPPORT AND SELF-MANAGEMENT BEHAVIORS AMONG EMERGING ADULTS WITH INFLAMMATORY BOWEL DISEASE

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The purpose of this dissertation is to examine the relationship between social support and self-management behaviors of medication adherence and diet modification among emerging adults (ages 18-29) with Inflammatory Bowel Disease (IBD).

Manuscript one is a systematic review of the relationship between social support and self-management behaviors among adults with IBD. The review of literature identified 430 articles; seven articles met review inclusion criteria of adults (age 18 or older) with a diagnosis of IBD and measured social support and self-management behaviors. Articles with significant findings reported a positive relationship between social support and self-management behaviors. As age decreased, self-management behaviors also decreased. These findings informed the emphasis on emerging adults in manuscripts two and three.

Manuscripts two and three used a convenience sample of emerging adults (ages 18-29) with a health care provider diagnosis of ulcerative colitis or Crohn's disease. All participants were recruited through Research Match, Facebook, and word of mouth. Participants were excluded if they were pregnant or lived outside of the United States. Sixty-one emerging adults met study criteria; the majority of participants were female ($n=55$, 90%), single ($n=47$, 77%), and diagnosed with Crohn's disease ($n=39$, 64%).

Manuscript two examines the individual, condition-specific, and emerging adulthood factors influencing received social support among emerging adults with IBD. Increased total received social support was associated with decreased age ($p = 0.001$), being married ($p = 0.039$)

and having employment full-time compared to being unemployed or a student ($p = 0.007$).

Increased emotional support was associated with decreased age ($p = 0.033$) and being married ($p = 0.001$). For condition-specific factors, the use of immunomodulators ($p < 0.001$), biologics ($p = 0.002$) and the interaction between immunomodulators and biologics ($p < 0.001$) was associated with increased tangible social support when controlling for time since diagnosis and symptom frequency. Finally, emerging adulthood factors were not associated with received social support.

Manuscript three examines the relationship between received social support and self-management behaviors of medication adherence and diet modification and examines how perceived availability of social support may moderate this relationship. Seventy-three percent of participants reported medication adherence and sixty-four percent reported modifying their diet. Low informational received social support was associated with medication non-adherence compared to high informational received social support ($p = 0.023$). Perceived availability of social support did not moderate the relationship between social support and self-management behaviors. Received social support was not associated with diet modification.

The findings from these manuscripts advance science by demonstrating the need to improve self-management behaviors among emerging adults with IBD. Results can assist healthcare providers in identifying emerging adults who may receive less social support. Also, interventions aimed at improving informational received social support may improve medication adherence. Future research should examine received social support among emerging adults with IBD who are experiencing more frequent symptoms or increased symptom severity and those who are recently diagnosed. Additional research is needed to determine the factors which influence self-management behaviors of medication adherence and diet modification among emerging adults with IBD.

This dissertation is dedicated to my husband, Scott Kamp,
who lives a grace-filled life while dealing with the symptoms and challenges associated with
inflammatory bowel disease.

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CHAPTER 1: INTRODUCTION

Self-management of chronic conditions is increasingly critical as individuals spend less time in healthcare systems and must learn how to manage their disease (through behaviors such as medication adherence and diet modification) at home (Grady & Gough, 2014). Factors that influence self-management, such as social support, are important for understanding how nurses can intervene to improve self-management among patients with chronic conditions (Gallant, 2003). While research demonstrates the importance of social support for self-management among older adults with chronic conditions, limited information is available on emerging adults (ages 18 to 29) with chronic conditions who experience developmental transitions, which may influence social support (Arnett, 2015). One chronic condition which disproportionately affects emerging adults is inflammatory bowel disease; thus, further investigation of self-management and the benefits of social support is warranted within the inflammatory bowel disease population (Plevinsky, Greenley, & Fishman, 2016).

Currently, 3.1 million Americans have been diagnosed with inflammatory bowel diseases (IBD). IBD includes two main disease types: 1) ulcerative colitis, a continuous inflammation of the inner lining of the colon and 2) Crohn's disease, patchy inflammation of any area of the gastrointestinal tract, which can occur in all layers of the bowel walls (Crohn's and Colitis Foundation, 2015). Individuals with ulcerative colitis and Crohn's disease experience similar symptoms including diarrhea, abdominal pain, cramping, bloody stool, and fatigue (Farrell, McCarthy, & Savage, 2016). Most individuals are diagnosed between the ages of 15 and 29 (Crohn's and Colitis Foundation of America, 2015; Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016). Compared to individuals diagnosed with IBD as adults, those individuals diagnosed at younger ages (under 40) report more severe bowel-related symptoms (such as gastrointestinal

pain, diarrhea, gas/bloating, bloody stool, and decreased energy), increased stricture and fistula complications, and an increased likelihood of requiring advanced treatment (Bager, Julsgaard, Vestergaard, Christensen, & Dahlerup, 2016; Goodhand et al., 2010; Torres et al., 2016). Each of these are negative disease outcomes and lead to increases in both direct and indirect costs (Actis & Pellicano, 2017; Van Limbergen et al., 2008).

Even though individuals are most likely to be diagnosed with IBD as an emerging adult (individuals ages 18–29), previous research has focused on adolescents and those diagnosed later in adulthood (Loonen, Grootenhuys, Last, Koopman, & Derkx, 2002; Mackner & Crandall, 2006; Trivedi & Keefer, 2015). Focusing on emerging adults with IBD is critical since emerging adults experience greater negative disease outcomes compared to older adults and, therefore, may benefit from developmentally appropriate interventions aimed at improving self-management behaviors of medication adherence and diet modification. Social support is one potential factor to examine since research in self-management with older adults has shown that social support is essential (Boger et al., 2015; DiMatteo, 2004). The relationship between social support and self-management behaviors within this emerging adult population is neither heavily investigated or understood.

IBD patients, regardless of age, have identified the importance of social support in managing their disease; due to this, many in-person and online support groups have been established to promote positive IBD outcomes (Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Lynch & Spence, 2008; Swarup et al., 2017). Although identified as important by IBD patients, little empirical evidence has tested the relationship between social support and self-management behaviors, such as medication adherence and diet modification, within the emerging adult population. Nor is there a robust understanding of what makes certain people

receptive to more social support than others. Understanding social support and self-management behaviors among emerging adults is critical in developing interventions for this population and advancing the science of self-management. Therefore, the purpose of this dissertation is to examine social support and self-management behaviors of medication adherence and diet modification among emerging adults with IBD.

Background and Significance

This section will describe the significance of emerging adulthood, self-management behaviors, and social support, and relate these concepts to IBD.

Emerging Adulthood

Individuals with IBD are most commonly diagnosed during emerging adulthood (Crohn's and Colitis Foundation of America, 2015; Dahlhamer et al., 2016). Arnett (2015) coined the term “emerging adulthood” to refer to individuals ages 18–29. Arnett (2015) identified five features of emerging adulthood, which are most prevalent and prominent during these adult years. The five features include: identity explorations (answering the question “who am I?” and trying out various life options, especially in love and work), instability (in love, work, and place of residence), self-focus (focusing on the self since obligations to others decrease), feeling in-between (in transition, neither adolescent nor adult), and possibilities/optimism (when hopes flourish and people have an unparalleled opportunity to transform their lives).

Emerging adulthood should be a central topic within the IBD literature due to disease prevalence and poor health outcomes such as an increased likelihood of advanced treatment, emergency room utilization, and bowel stricture and fistula complications compared to older adults (Molodecky et al., 2012; Shivashankar, Tremaine, Harmsen, & Loftus, 2017). Research on emerging adulthood was introduced into the IBD community by Trivedi and Keefer (2015) and

focuses on transitioning emerging adults from pediatric to adult gastroenterologists to ensure emerging adults obtain a smooth transition of care (Clarke & Lusher, 2016; Fu et al., 2017; Klostermann, McAlpine, Wine, Goodman, & Kroeker, 2017). The transition to adult care typically begins during adolescence (Mowat et al., 2011); yet, the greater symptoms and disease complications that emerging adults face occur across emerging adulthood and not just during the transition from adolescent to emerging adult (Crohn's and Colitis Foundation of America, 2015; Dahlhamer et al., 2016). The proposed research will move beyond the period of care transitions to examine the self-management behaviors necessary throughout emerging adulthood.

The five features of emerging adulthood can influence one's ability to engage in self-management behaviors (Arnett, 2015; Trivedi & Keefer, 2015). Emerging adults experience changing social relationships and transitions which may include moving away from home to independent living situations, beginning careers, full-time employment, schooling, and/or establishing homes and families (identity explorations, instability, and self-focus). Emerging adults may question who is responsible for managing the disease (feeling in-between) or feel like their disease is not that bad (possibilities/optimism). All of these factors make it important to manage their disease well (Joly, 2016; Lenz, 2001; Trivedi & Keefer, 2015).

Many emerging adults begin taking responsibility for health, self-care, and health behaviors and may for the first time, be taking accountability for their own self-management behaviors of medication adherence and diet modification (Lenz, 2001; Trivedi & Keefer, 2015). Accepting accountability for self-management along with the five distinctive characteristics of emerging adulthood means that research pertaining to middle age and older adults may not accurately reflect the developmental transitions experienced by emerging adults. Thus, research

that focuses specifically on emerging adults is needed to create developmentally appropriate interventions.

Self-Management

Self-management behaviors among IBD patients are key to reducing inflammation, decreasing symptoms, and improving quality of life (Kamat, Ganesh Pai, Surulivel Rajan, & Kamath, 2017). Self-management is defined as a process in which patients assume responsibility for their disease management and includes the “the day-to-day management of chronic conditions by individuals over the course of an illness” (Grady & Gough, 2014, p. e26; Ryan & Sawin, 2009). Individuals with IBD engage in multiple self-management behaviors, such as medication adherence, diet modification, stress management, exercise, and sleep hygiene. This dissertation will focus on two important self-management behaviors: medication adherence (important from a provider standpoint due to the effectiveness of medication) and diet modification (important from a patient standpoint due to interest in natural treatment methods and suggestions that a gastrointestinal disease is related to foods introduced to the gastrointestinal tract).

Medication adherence. Medication adherence, using medications as prescribed by a provider, is a key self-management behavior since the use of medication is one of the few methods shown to reduce symptoms and induce remission; therefore, medication is important for managing IBD from a provider’s standpoint (Horne & Weinman, 2002; Kamat et al., 2017). Individuals who are nonadherent experienced a threefold increase in costs and a fivefold increased risk of disease relapse compared to adherent patients (Hommel et al., 2017; Mitra, Hodgkins, Yen, Davis, & Cohen, 2012; Testa, Castiglione, Nardone, & Colombo, 2017). Furthermore, emerging adults are more likely to be nonadherent to medication compared to older

adults, which may be due to having a more recent diagnosis and less experience with self-management (Coenen et al., 2016; Severs et al., 2017).

Diet modification. Diet modification, as a self-care strategy, is the most common self-management behavior because patients believe in its effectiveness in reducing symptoms (Tanaka, Kawakami, Iwao, Fukushima, & Yamamoto-Mitani, 2016; Vagianos et al., 2014).

Dietary research has shown benefits of diet modification on symptom reduction (including stool frequency, pain, bloating, and diarrhea) and quality of life (Charlebois, Rosenfeld, & Bressler, 2016; Lee et al., 2015; Olendzki et al., 2014; Wong, Harris, & Ferguson, 2016). Yet, healthcare providers typically do not recommend diet modification due to the limited quantity of rigorous IBD dietary research. However, there is a growing interest in improving the quality of dietary studies to better understand the potential role of diet within disease management (Tanaka et al., 2016; Vagianos et al., 2014).

Patients who do not engage in self-management behaviors have an increased likelihood of disease relapse, rising direct and indirect costs, productivity losses, and decreased quality of life (Kamat et al., 2017). Among pediatric and adult IBD patients, hospitalizations and medication (especially prednisone treatments) increase both patient and system costs, although exact cost estimates vary (Cohen et al., 2015; Gibson et al., 2008; Sin et al., 2015). In addition, costs may be higher for emerging adults due to fewer outpatient and office visits and greater utilization of emergency services and subsequent hospitalizations compared to middle age and older adults (Bollegala, Brill, & Marshall, 2013; Karve et al., 2012). These healthcare utilization differences may be due to lack of adherence to treatment regimens, patient-provider relationships, recency of diagnosis, and patient financial challenges (Ananthakrishnan, McGinley, Saeian, & Binion, 2010). Therefore, there is a need to understand self-management

behaviors among *emerging adults* in order to address the challenges of cost and the utilization of healthcare services.

Emerging adults with IBD are more likely to have decreased medication adherence and increased diet modification compared to older adults (Coenen et al., 2016; Ediger et al., 2007; Goodhand et al., 2013; Hilsden, Verhoef, Rasmussen, Porcino, & DeBruyn, 2011; Nahon et al., 2011; Testa, Castiglione, Nardone, & Colombo, 2017). IBD self-management is essential for preventing and reducing symptoms, increasing regimen adherence, improving health-related quality of life (HRQoL), and decreasing healthcare costs (Goodhand et al., 2013; Lachaine, Yen, Beauchemin, & Hodgkins, 2013; Robinson, Hankins, Wiseman, & Jones, 2013; Schurman, Cushing, Carpenter, & Christenson, 2011). Particularly, examining processes to improve self-management among emerging adults with IBD remains an understudied and not well-understood area.

Social Support

Social support has been shown to improve self-management and increase HRQoL among individuals with chronic conditions (Boger et al., 2015; DiMatteo, 2004). Within the limited IBD and social support research, increased social support has been associated with improved health-related quality of life (Katz et al., 2016). To determine the relationship between social support and self-management behaviors, two types of social support will be examined: a) received social support, which is the supportive behaviors that an individual obtains; and b) perceived availability of social support, which is an individual's *perception* that support is available. A variety of sources can provide social support; however, social support typically refers to support provided by lay people including friends and family members. Due to the limited social support

research within the IBD population, literature on chronic conditions in general is included as well as IBD-specific literature.

Received social support. Among individuals with chronic conditions, an increase in received social support can improve self-management behaviors of medication adherence and diet modification (Marquez et al., 2016; Plevinsky et al., 2016; Rad, Bakht, Feizi, & Mohebi, 2013). Common types of received social support include informational support such as providing information and giving advice, emotional support such as encouragement and comfort, and tangible support such as assistance and reminders. In online IBD communities, informational and emotional support are the most common types of social support received (Britt, 2016).

Although the most common types of social support received within IBD communities have been examined, little is known regarding the individual, condition-specific, and emerging adulthood factors that make an emerging adult with IBD more or less likely to receive social support (Plevinsky et al., 2016). Individual factors (age, sex, marital status, employment, and education), condition-specific factors (type of IBD, time since IBD diagnosis, symptoms, medications currently using, and surgeries), and emerging adulthood factors (possibilities/optimism, instability, identity explorations, and feeling in-between) have the potential to influence the receipt of social support (Williamson & O'Hara, 2017). Previous research has indicated that individual factors of being female, married, employed, and having higher education are associated with receiving more social support (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Davis, Anthony, & Pauls, 2015; Nordgren & Soderlund, 2017; Williamson & O'Hara, 2017). The relationship between age and received social support is mixed and perhaps developmental stages, such as emerging adulthood, may be a better predictor of received social support (Jason, 2007; Luong, Charles, & Fingerman, 2011; Williamson &

O'Hara, 2017). Individuals with a more recent time since diagnosis are more likely to receive social support (Arora et al., 2007). Type of IBD, medications, symptoms, and surgeries each could influence received social support. For instance, individuals with an increase in symptoms and those with a greater number of surgeries may receive more social support than those with less symptoms and fewer surgeries; however, these factors have not been examined within the literature.

Perceived availability of social support. Perceived availability of social support has been shown to influence self-management behaviors. Among older adults with chronic conditions, children, and adolescents with IBD, lower perceived availability of social support was associated with decreased medication adherence (DiMatteo, 2004; Janicke et al., 2009). Perceived availability of social support can also lead to the adaptation of beneficial dietary behaviors such as improved dietary quality and adherence to dietary recommendations among youth and adults with chronic conditions (Anderson Steeves, Jones-Smith, Hopkins, & Gittelsohn, 2016; Gallant, 2003; Strom & Egede, 2012). Although the current research primarily focuses on the main effect of perceived availability of social support on self-management behaviors, there is the potential that perceived availability of social support may serve to moderate the relationship between received social support and self-management behaviors. For example, an emerging adult with IBD who perceives that social support is available may have improved self-management behaviors even if minimal support was received. This is potentially due to perceptions of support having more consistent ties to health and chronic conditions since perceived availability of social support is generally stable over time (Sarason, Sarason, Shearin, & Pierce, 1987; Uchino, 2004, 2009). Therefore, perceived availability of social support may strengthen the relationship between received social support and self-management behaviors.

Despite the known benefits of social support among individuals with chronic conditions, the current literature has limited information on social support and self-management behaviors among *emerging adults* with chronic conditions, and especially among those with IBD (Gallant, 2003; Leung, Smith, & McLaughlin, 2016; Staniute et al., 2015; Zhou et al., 2017). Social support is important to understand within the emerging adult context due to life changes (e.g., moving, starting a family, starting a new job) and the dimensions of emerging adulthood which may influence receipt and perceptions of social support (Arnett, 2015; Erikson, 1994). Therefore, additional research is needed to focus on emerging adults with a chronic condition such as IBD. This dissertation examines social support (both received social support and perceived availability of social support) and self-management behaviors of medication adherence and diet modification among emerging adults with IBD using a nursing self-management theoretical framework.

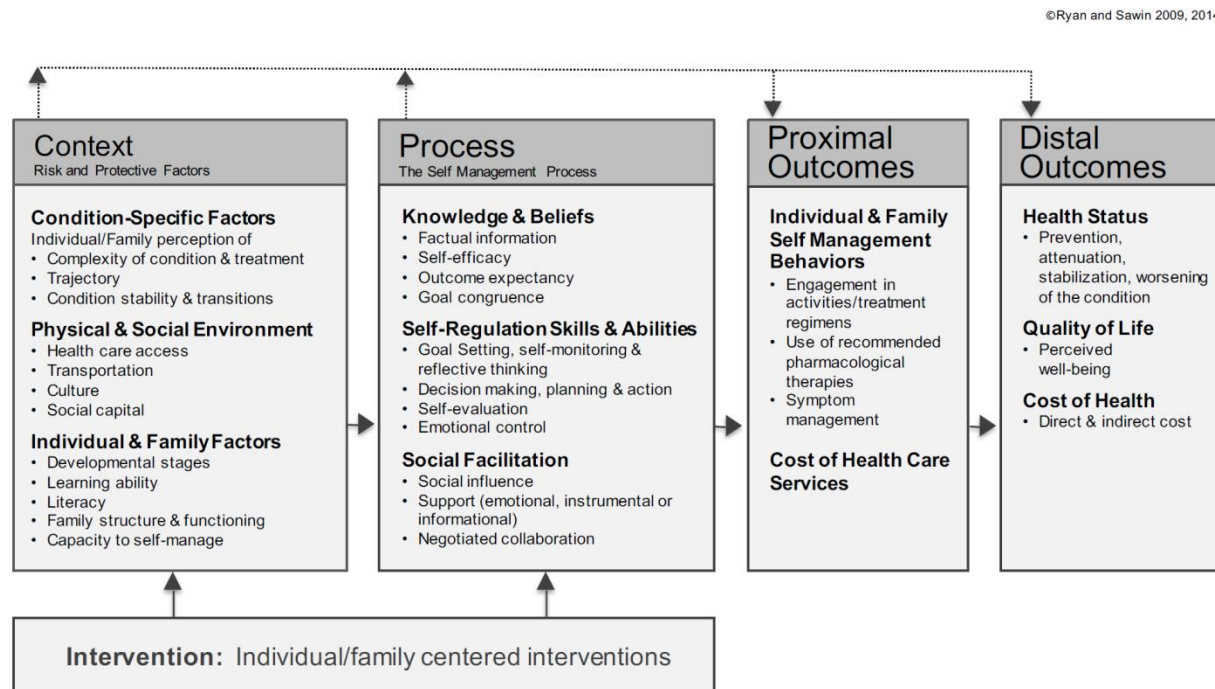
Theoretical Framework

A theoretical model is presented to provide a framework for the variables to consider when approaching self-management among emerging adults with IBD. The Individual and Family Self-Management Theory (IFSMT) by Ryan and Sawin (2009) provides the theoretical foundation for this dissertation since the framework integrates the major concepts of social support and self-management behaviors. The IFSMT describes self-management as a phenomenon that can be beneficial in chronic conditions such as IBD. Within this model, the accountability for managing a chronic condition is placed on the individual and family (Ryan & Sawin, 2009).

Individual and Family Self-Management Theory

The IFSMT (see Figure 1.1) has three broad dimensions: context, process, and outcomes, which includes both proximal and distal outcomes. Each dimension will be briefly discussed followed by an explanation of the relationships between dimensions.

Figure 1.1: Model of the Individual and Family Self-Management Theory



Ryan, P.A., & Sawin, K. J. (2014). Individual and Family Self-Management Theory [Figure]. Retrieved from www.nursing.uwm.edu/smsc

Context. Context factors challenge or protect engagement in self-management. These factors include: condition-specific factors, physical and social environment, and individual and family factors.

Process. Process refers to activities used to enhance disease management (Ryan & Sawin, 2009). The process dimension of self-management includes facilitation of knowledge and beliefs, enhancement of self-regulation skills and abilities, and social facilitation. This dissertation places a special emphasis on social support, which is a component of social facilitation.

Proximal outcomes. Proximal outcomes are specific behaviors an individual or family undertakes to manage a condition, disease risk, symptoms, and/or drug therapies, and the cost of health care services. Self-management behaviors can include the engagement in activities/treatment regimes, use of recommended pharmacological therapies, and symptom management.

Distal outcomes. Distal outcomes are the end point of this model. Distal outcomes include health status (prevention, attenuation, stabilization, or worsening of the condition), quality of life (perceived well-being), and costs of health (direct and indirect costs).

Model relationships. The IFSMT as presented by Ryan and Sawin represents a linear approach to self-management. Context factors can directly impact process, proximal outcomes, and distal outcomes. By enhancing the process of self-management, both proximal and distal outcomes can be improved. The theory indicates that interventions can influence both context and process variables. Proximal outcomes lead to the attainment and success of distal outcomes. No feedback loops are included in the original model.

The original IFSMT has been used in a variety of populations. Previous studies using the model have focused on adolescents, parents of hospitalized children, middle-age adults, and frail older adults. The theory was tested among adolescents with Type 1 diabetes finding that depressive symptoms, self-efficacy, and self-management behaviors significantly predicated health-related quality of life (Verchota & Sawin, 2016). For Sawin and colleagues (2017), the IFSMT guided the development of a discharge intervention for parents of hospitalized children. Among frail older adults, the IFSMT guided variable selection and analysis of an intervention using nurse care coordination to improve self-management of medications (Marek et al., 2013). The process dimensions of the IFSMT were used as intervention components to increase calcium

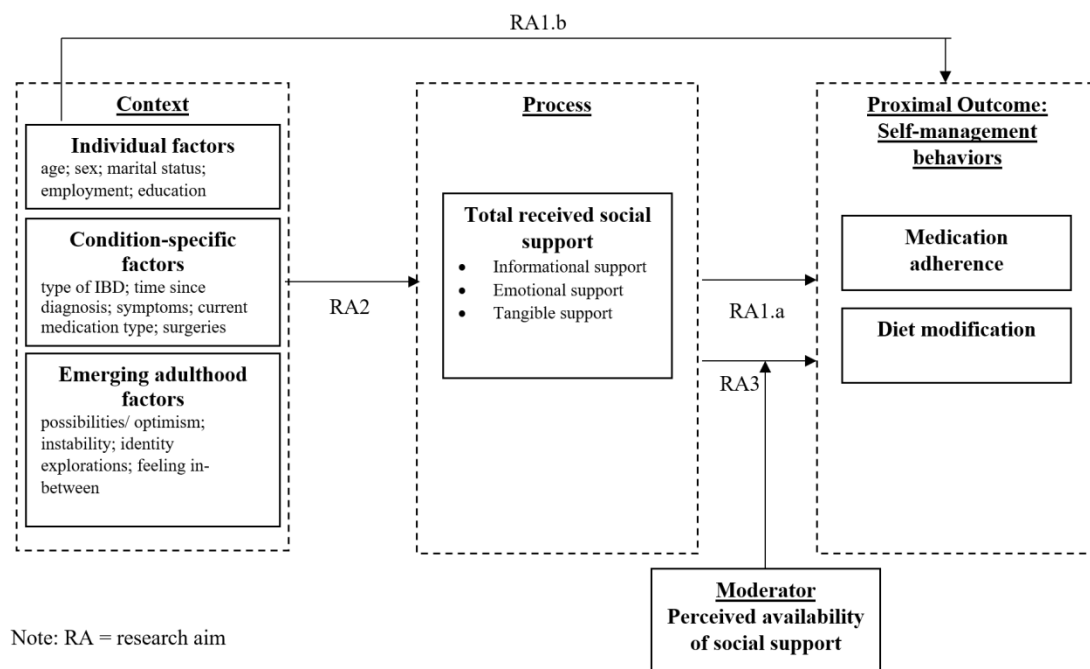
and vitamin D intake among middle-age women (Ryan, Maierle, Csuka, Thomson, & Szabo, 2013). This dissertation study extends the components of the IFSMT to address both received and perceived availability of social support, incorporating a moderation hypothesis.

Limitations. The IFSMT provides an approach to examining social support and self-management behaviors but also has limitations. The model appears to include medication adherence, a critical outcome variable for emerging adults, within the self-management behaviors of “engagement in activities/treatment regimens” and “use of recommended pharmacological therapies.” Yet, the authors’ publications have noted that these outcomes do not include adherence (Marek et al., 2013; Ryan & Sawin, 2009). The authors of the theory suggest that concepts of adherence, alliance, and compliance are opposing to self-management since they dismiss the patient’s responsibility for management (Ryan & Sawin, 2009). Yet, this assumption does not occur in other self-management frameworks and even appears to be implied within the original IFSMT model (Grey, Schulman-Green, Knafl, & Reynolds, 2015; Modi et al., 2012). Although medication adherence appears to be synonymous with “engagement in activities/treatment regimens” and “use of recommended pharmacological therapies”, the authors of the theory differentiate between these concepts. This is a limitation as the differences are not well-articulated and other self-management theories incorporate medication adherence. In addition, the IFSMT approaches support as a general category and does not differentiate between received social support and perceived availability of social support which are conceptually different. Finally, the original IFSMT approaches the process of self-management in a linear format. In reality, feedback loops may exist such that outcomes, in turn, influence context and process variables.

Individual and Family Self-Management Theory applied to IBD

This dissertation utilized select variables from the IFSMT to focus specifically on the relationship between context, process (received social support), and proximal outcomes (self-management behaviors of medication adherence and diet modification) and to incorporate the moderating effect of perceived availability of social support (see Figure 1.2). The original theory did not include variables that may moderate the relationship between process and outcomes; therefore, the theory applied to IBD includes perceived availability of social support which may moderate the relationship between received social support (process) and self-management behaviors (outcomes; Uchino, 2004). The theory will be referred to as the Individual and Family Self-Management Theory (IFSMT) applied to IBD.

Figure 1.2: Individual and Family Self-Management Theory applied to IBD



Context. The IFSMT applied to IBD includes individual, condition-specific, and emerging adulthood factors as context variables. Individual factors are factors that are specific to the patient and include age, sex, marital status, employment, and education. Condition-specific

factors are specific to the disease. Within the IBD population, the condition-specific factors have been adapted to include type of IBD (ulcerative colitis or Crohn's disease), time since diagnosis, symptoms (frequency, severity, and interference), current medication use, and surgeries. The original model includes developmental stages within individual factors, but previous research operationalized developmental stages as age (Marek et al., 2013; Verchota & Sawin, 2016). To clarify the distinction between development as a chronological age and development as a psychological stage, emerging adulthood factors were included as a context factor separate from individual factors (although some overlap between age and emerging adulthood factors does occur, for the purposes of this dissertation age and emerging adulthood factors are presented separately). Emerging adulthood factors refer to the features that are associated with emerging adulthood and include possibilities/optimism, instability, identity explorations, and feeling in-between (Stéphanie, Katia, Joseph, & Gerhard, 2014).

Process. The original model was simplified to focus on the effects of one specific social facilitation process, received social support. Previous research has focused on knowledge, beliefs, and self-regulation (Conley & Redeker, 2016; Eaden, Abrams, & Mayberry, 1999; Keefer, Kiebles, & Taft, 2011). While future research may be needed to clarify these process variables; this dissertation focuses specifically on the potential role of received social support. In the IFSMT applied to IBD the process variable of received social support directly influences self-management behaviors of medication adherence and diet modification (Marquez et al., 2016; Ryan & Sawin, 2009). The IFSMT applied to IBD acknowledges that the relationship between the process and outcome variables have the potential to be moderated by perceived availability of social support (Uchino, 2004). Perceived availability of social support can be conceptualized in multiple ways. Within the IFSMT applied to IBD, perceived availability of

social support will be examined as a potential moderator of the relationship between process and outcome variables in order to determine how perceptions of support interact with receiving social support.

Outcome. Proximal outcomes are specific to IBD and include the self-management behaviors of medication adherence and diet modification. Although the authors of the IFSMT do not include adherence as a part of self-management, a number of other self-management theories have included adherence (Grey et al., 2015; Modi et al., 2012; Ryan & Sawin, 2009). In the IFSMT applied to IBD, “use of recommended pharmacological therapies” (from the original model) is medication adherence and “engagement in activities/treatment regimens” is diet modification.

Medication adherence. Medication adherence, use of medication as prescribed by a provider, has been included within the IFSMT applied to IBD due to the central role of medication in the IBD disease management process. Medication adherence is especially important for IBD patients since without medication many patients will experience an increased number of exacerbations and hospitalizations as well as decreased HRQoL (Herman & Kane, 2015; Higgins, Rubin, Kaulback, Schoenfield, & Kane, 2009; Kane, Huo, Aikens, & Hanauer, 2003).

Diet modification. Patients with IBD often believe modifying their diet may influence IBD symptoms (Knight-Sepulveda, Kais, Santaolalla, & Abreu, 2015; Lee et al., 2015; Wong, Harris, & Ferguson, 2016); furthermore, studies have shown the benefits of diet modification on symptom reduction (including reduced bowel frequency, pain, bloating, and diarrhea) and improved quality of life in IBD patients (Charlebois et al., 2016; Lee et al., 2015; Olendzki et al., 2014; Wong et al., 2016). The relationship between diet modification and disease activity is less

clear (Haskey & Gibson, 2017; Konijeti et al., 2017; Olendzki et al., 2014). Both medication adherence and diet modification will be examined. Distal outcomes are not the focus of this dissertation and are not shown in the IFSMT applied to IBD.

Model relationships. In the IFSMT applied to IBD, context factors are hypothesized to influence both the process of received social support and the outcomes of self-management behaviors. The process of received social support can directly influence self-management behaviors (main effect model), and can also be moderated by perceived availability of social support (moderating model). The dotted lines indicate the variables are in the same dimension (e.g., context, process, or outcome). Although not included in Figure 1.2, a feedback loop is hypothesized to exist since the self-management behaviors of medication adherence and diet modification can then influence the context of condition-specific factors. For instance, medication adherence may lead to decreased surgeries and improved symptoms. While this potential is acknowledged, the feedback loop will not be examined in this dissertation due to the cross-sectional design. Future work will address the hypothesized feedback loop and examine distal factors such as health-related quality of life and cost.

Purpose

The purpose of this dissertation is to examine the relationship between social support and self-management behaviors of medication adherence and diet modification among emerging adults with IBD. This dissertation addresses three significant gaps in the literature.

First, the dissertation will update the state of the science on the relationship between social support (both general social support and types of social support) and self-management behaviors among adults with IBD through a systematic literature review (**Aim 1.a**). Although social support has been shown to influence self-management behaviors among individuals with

chronic conditions, this relationship has not been examined within younger chronic condition populations such as those with IBD. Additionally, this dissertation will examine how patient age and developmental stage may influence the relationship between social support and self-management behaviors (**Aim 1.b**). Typically, adults are examined as a homogenous group without acknowledgement of the impact of developmental stages. The developmental stage of emerging adulthood may have a unique influence on social support and self-management behaviors different than individuals in middle or older adulthood.

Second, the dissertation will determine the individual, condition-specific, and emerging adulthood factors which influence received social support within an emerging adult IBD population (**Aim 2**). Within the IBD literature, patients have acknowledged the importance of received support (Dur et al., 2014; Plevinsky et al., 2016). Since little is known regarding the factors that make some emerging adults more likely to obtain social support, this chapter will expand the science by examining individual, condition-specific, and emerging adulthood factors that influence received social support among emerging adults with IBD. Findings from this study have implications for the development of future social support interventions and can inform healthcare providers of which individuals may need additional supportive resources.

Third, the dissertation will examine the relationship between received and perceived availability of social support and self-management behaviors among emerging adults with IBD while controlling for individual, condition-specific, and emerging adulthood factors (**Aim 3**). Received social support has been associated with self-management behaviors among older adults with chronic conditions but has not been examined among emerging adults with chronic conditions (Marquez et al., 2016; Plevinsky et al., 2016; Rad et al., 2013). The developmental changes experienced by emerging adults may influence received social support (Arnett, 2015;

Erikson, 1994). The purpose is to evaluate the role of received social support and self-management behaviors of medication adherence and diet modification among emerging adults with IBD and examine the potential moderating effect of perceived availability of social support. Describing this relationship will enhance the existing literature by focusing on the self-management behaviors of emerging adults with IBD.

Research Questions

The Individual and Family Self-Management Theory applied to IBD has guided the research questions addressed in this dissertation:

1. What is the relationship between social support (overall social support and type of social support [e.g., informational, emotional, and tangible]) and self-management behaviors among adults with IBD?
2. How does patient age influence the relationship between social support and self-management behaviors among adults with IBD?
3. Which **individual factors** (age, sex, marital status, employment, education) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?
4. Which **condition-specific factors** (type of IBD, times since diagnosis, symptoms, medication types, and surgeries) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?
5. Which **emerging adulthood factors** (possibilities/optimism, instability, identity exploration, and feeling in-between) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?

6. Among emerging adults with IBD, what is the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?
7. Among emerging adults with IBD, does perceived availability of social support moderate the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?

Dissertation Format

A multiple manuscript format is used for this dissertation. Chapters 2, 3, and 4 represent separate publishable manuscripts that address the central theme of social support among emerging adults with inflammatory bowel disease. The remaining chapters in this dissertation include:

Chapter 2 (Manuscript 1)

Chapter 2 is a systematic review to assess the effects of social support on self-management behaviors among adults with IBD. A secondary aim of the review is to determine if patient age impacts the relationship between social support and self-management behaviors for this population. In the systematic review, patient age will be used as a proxy for developmental stage due to a lack of studies addressing developmental stages in adults. The review is guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009). A variety of databases were searched including PubMed, Web of Science, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, Communication and Mass Media Complete, and Communication Abstracts.

Keywords included: social support, emotional support, esteem support, tangible support, instrumental support, affection support, family support, parental support, friend support, social network, structural support, inflammatory bowel disease, IBD, Crohn's, and colitis. Articles were limited to the date range of January 2000–December 2017. This manuscript is formatted to meet the author guidelines of the Journal of Advanced Nursing.

Chapter 3 (Manuscript 2)

Chapter 3 examines the individual, condition-specific, and emerging adulthood factors that influence received social support among emerging adults with IBD. This manuscript focuses on the relationship between the context and process of the IFSMT applied to IBD. Survey data was collected from emerging adults (age 18-29) with a self-reported diagnosis of IBD.

Participants were recruited from ResearchMatch, a national health volunteer registry created by several academic institutions, which is supported by the United States National Institutes of Health as part of the Clinical Translational Science Award Program. Participants were also recruited from Facebook using posts within groups and advertisements and through word of mouth.

Individual, condition-specific, and emerging adulthood factors are examined in this study. Individual factors include age, sex, marital status, employment, and education. Condition-specific factors include type of IBD (ulcerative colitis or Crohn's disease), time since diagnosis, symptoms (frequency, severity, and interference), medications currently using, and surgeries. Emerging adulthood factors of possibilities/optimism, instability, identity explorations, and feeling in-between were measured using the short form of the Inventory of Dimensions of Emerging Adulthood; a higher score indicates individuals are experiencing more of the features associated with emerging adulthood.

Received social support was measured using the Inventory of Socially Supportive Behaviors (ISSB). The ISSB asks participants to rate how often supportive activities occurred within the last four weeks and contains three subscales: informational support (guidance), emotional support, and tangible support. Data analysis includes descriptive statistics and multivariable linear regression. The model was built according to the stepwise process of purposeful selection of covariates as outlined in Hosmer, Lemeshow, and Strudivant (2013). Manuscript two is formatted to meet the author guidelines of Clinical Nursing Research.

Chapter 4 (Manuscript 3)

Chapter 4 enhances the knowledge of received social support by examining the influence of received social support on the self-management behaviors of medication adherence and diet modification (main effects) and determining if perceived availability of social support buffers this relationship (moderating effect). This chapter uses online survey-data collected from emerging adults (ages 18-29) with a self-reported diagnosis of IBD who are currently prescribed medication to manage their IBD. ResearchMatch, an online database of participants, and Facebook, a social media site, and word of mouth were used for recruitment.

Received social support, perceived availability of social support, and self-management behaviors of medication adherence and diet modification are examined. Received social support is defined as the supportive behaviors that an individual obtains and is measured with the Inventory of Socially Supportive Behaviors. Perceived availability of social support is defined as an individual's perception that support is available if needed and is measured with the Medical Outcomes Social Support Survey. Medication adherence is whether patients use their medication as prescribed by a provider (four-item Medication Adherence Report Scale) and diet modification is an individual's alteration of food intake (Dietary Screener Questionnaire).

Individual, condition-specific, and emerging adulthood factors are controlled for in the analysis. Individual factors include age, sex, marital status, employment, and education. Condition-specific factors include type of IBD, time since diagnosis, symptoms (frequency, severity, and interference), medications currently using, and surgeries. Emerging adulthood factors of possibilities/optimism, instability, identity explorations, and feeling in-between will be measured using the short form of the Inventory of Dimensions of Emerging Adulthood. Higher scores indicate that individuals are experiencing more of the features associated with emerging adulthood. Descriptive statistics will be calculated for the variables. Both outcomes are dichotomous; therefore, a multivariable logistic regression is used. Manuscript three is formatted to meet the author guidelines of Nursing Research.

Chapter 5

The conclusion, synthesis of all findings, and recommendations for future research will occur in chapter 5. Conclusions will be discussed in relationship to their impact on future nursing research, practice, and health policy.

Contribution to Science

This project contributes to advancing the science in three major areas: a) social support and self-management among adults with IBD; b) factors which influence received social support among emerging adults with IBD; and c) integrating both medication adherence and diet modification behaviors among emerging adults with IBD.

First, although emerging adults with IBD are more likely to have poorer health outcomes, research specific to this developmental stage is lacking. This lack of knowledge means emerging adults may not be receiving developmentally appropriate care. This dissertation seeks to advance the science of self-management by systematically reviewing the literature between social support

and self-management behaviors, and examining differences based on patient age. Previous literature has not addressed potential age differences; therefore, maintaining a “one-size-fits-all” approach to self-management.

Second, previous literature has indicated that receiving social support can be beneficial in improving health outcomes. Yet, there is a gap in the knowledge regarding what individual, condition-specific, and emerging adulthood factors are associated with an increase in received social support. Understanding this relationship would enable clinicians to more easily identify patients in need of additional supportive resources.

Finally, self-management behaviors are critical for improving symptoms and decreasing disease activity. This dissertation provides a unique contribution by examining self-management behaviors that are important to both providers (medication adherence) and patients (diet modification). In addition, previous IBD literature has primarily focused on perceived availability of social support. This dissertation advances the science by focusing on received social support and examining perceived availability of social support as a potential moderator of the relationship between received social support and self-management behaviors. This dissertation advances the science of social support by examining both received and perceived availability of social support as well as the science of self-management among emerging adults with IBD. Both medication adherence and diet modification are examined to create a more holistic approach to self-management from the patient’s view.

Emerging adults with IBD are in need of developmentally appropriate interventions aimed at improving self-management behaviors. Received social support serves as one potentially modifiable factor, which could improve self-management behaviors among emerging

adults with IBD. This dissertation provides the foundation to establish a program of research aimed at improving self-management behaviors among emerging adults with IBD.

CHAPTER 2: SYSTEMATIC REVIEW OF SOCIAL SUPPORT ON SELF-MANAGEMENT BEHAVIORS AMONG ADULTS WITH INFLAMMATORY BOWEL DISEASE

Introduction

Inflammatory Bowel Disease (IBD), which is comprised of Crohn's disease and ulcerative colitis, is a chronic disease of the gastrointestinal tract (Crohn's and Colitis Foundation of America, 2015). Symptoms of IBD include diarrhea, abdominal pain, urgency, cramping, and fatigue (Crohn's and Colitis Foundation of America, 2015). Individuals with IBD may face the embarrassment of potential bowel accidents, hesitate to accept social invitations, and feel like a burden to friends and family members when social activities are modified because of the severity and interference of symptoms (Czuber-Dochan, Dibley, Terry, Ream, & Norton, 2013; Kemp, Griffiths, Campbell, & Lovell, 2013; Maunder, Greenberg, Lancee, Steinhart, & Silverberg, 2007). Many patients, therefore, choose to avoid social interactions. However, since social support can improve health and well-being through enhanced self-management, it is important to improve social support (Pihl Lesnovska, Hollman Frisman, Hjortswang, & Börjeson, 2016).

Self-management behaviors are part of the daily routine of IBD patients and are necessary for reducing inflammation, decreasing symptoms, and improving quality of life (Grady & Gough, 2014; Kamat, Ganesh Pai, Surulivel Rajan, & Kamath, 2017; Ryan & Sawin, 2009). IBD patients engage in a variety of self-management behaviors such as medication adherence, stress management, and diet modification to manage their disease (Plevinsky, Gumidyala, & Fishman, 2015). Among other chronic disease populations, social support has been shown to improve self-management behaviors including medication adherence and diet modification (Boger et al., 2015; DiMatteo, 2004; Garipey, Honkaniemi, & Quesnel-Vallee, 2016; Hand, Law, McColl, Hanna, & Elliott, 2014). Although the IBD literature includes support group

interventions to help patients cope and adjust to living with IBD (Coulson, 2013, 2015; Leshem, 2003), a lack of clarity exists regarding types of social support provided or available if needed (e.g., informational, emotional, or tangible social support) and the impact of social support on self-management behaviors. Examining the specific types of social support will add depth to the knowledge of the relationship between social support and IBD self-management behaviors.

Examination of social support relative to patient age and developmental stage is also needed, e.g., emerging adults (ages 18-29), since these factors may influence the ability to successfully manage IBD (Arnett, 2015; Coenen et al., 2016; Severs et al., 2017; Trivedi & Keefer, 2015). Individuals with IBD are typically diagnosed at a younger age (15-29 years old) than those with other chronic conditions; therefore, the relationship between social support and self-management behaviors may be different within the IBD population. While social support may be helpful, particularly as an intervention, the lack of consistent findings within the IBD population necessitates a systematic approach to analyzing the literature (Camara, Lukas, Begre, Pittet, & von Kanel, 2011; Katz et al., 2016). Currently, the IBD literature primarily focuses on qualitative reports of social support. Thus, it is necessary to examine quantitatively, within an IBD population, the relationship between social support and self-management behaviors and how this relationship may be influenced by type of social support and patient age.

Background

Social support is any process through which social interactions may influence health and well-being (Cohen, Underwood, & Gottlieb, 2000). Social support can be provided by a variety of sources, such as family members or friends (Cohen et al., 2000; Rosland, Heisler, & Piette, 2012). There are several types of social support which further elucidate its meaning: 1) informational support: providing facts or advice; 2) emotional support: conveying love, caring,

esteem, value, encouragement, and sympathy; and 3) tangible support: providing behavioral or material assistance with tasks (Lakey & Cohen, 2000). Although the types of social support have been identified within social support theories and incorporated into measurement items, researchers most often focus on total social support.

The types of support (informational, emotional, and tangible) can impact self-management in different ways; therefore, it is necessary to review the relationship between types of social support and self-management behaviors. Findings can inform the creation of targeted interventions that incorporate various types of social support. For instance, tangible and informational social support have a stronger association with medication adherence among individuals with chronic conditions than emotional social support (DiMatteo, 2004; Rico et al., 2017). The IBD literature has focused on social support in general; therefore, a systematic approach to understanding the types of social support in relationship to self-management behaviors brings clarity to designing supportive interventions.

The systematic review was guided by the Individual and Family Self-Management Theory applied to IBD. The theory is based on the Individual and Family Self-Management Theory by Ryan and Sawin (2009) and consists of context, process, and outcome variables in which social support can influence the outcome of self-management behaviors (Ryan & Sawin, 2009). Context includes individual factors such as age or developmental stage and condition-specific factors which challenge or protect engagement in self-management. Although the theory presents multiple contextual factors, the contextual factor of developmental stage is not well understood since, typically, patient age is used as a proxy for developmental stage. Process includes the activities used to enhance self-management behaviors; this systematic review will focus on the process variable of social support including informational, emotional, and tangible

social support. Outcomes refer to the specific behaviors that are used to manage a condition, disease risk, symptoms, and/or drug therapy. Specific self-management behaviors will be identified in the review process, with medication adherence and diet modification being central to IBD.

In summary, social support serves as a potentially modifiable factor; yet, without a systematic understanding of the relationship between social support and self-management behaviors it will be difficult to develop social support interventions aimed at improving self-management for individuals with IBD. Therefore, there is a need for a systematic review of the relationship between process factors of social support (overall social support and types of social support) and outcomes of self-management behaviors while examining how the individual context factor of age influences this relationship.

The Review

Aim

The primary aim of this systematic literature review was to determine the relationship between social support and self-management behaviors among adults with Inflammatory Bowel Disease. The review was guided by two research questions:

Research Question 1: What is the relationship between social support (overall social support and type of social support [e.g., informational, emotional, and tangible]) and self-management behaviors among adults with IBD?

Research Question 2: How does patient age influence the relationship between social support and self-management behaviors among adults with IBD?

Design

This systematic review was framed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009). The PRISMA statement includes a 27-item checklist to promote transparent conduct and reporting of systematic reviews (see Appendix A for PRISMA checklist). A protocol for this review was prepared and registered with PROSPERO, the international prospective register of systematic reviews (Kamp, 2018).

Search Methods

The first author developed the initial search strategy in collaboration with a university health sciences librarian. The search was performed in December 2017. The following bibliographic databases were searched: PubMed, Web of Science, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, Communication and Mass Media Complete, and Communication Abstracts. Key words used in the search process included: social support, emotional support, esteem support, tangible support, instrumental support, affection support, family support, friend support, social network, structural support, inflammatory bowel disease, IBD, Crohn's, and colitis (an example of the full search process for PubMed is found in Table 2.1). The search was limited to articles published between January 2000 and December 2017 since new medication types were introduced in the early 2000s.

The inclusion criteria were full-text, original, quantitative studies published in English that measured both social support and self-management behaviors among adults (aged 18 and above) with IBD, ulcerative colitis, and/or Crohn's disease. Articles were excluded if they were qualitative or focused on children or adolescents under age 18 since children/adolescents may not be responsible for their self-management behaviors (see Table 2.2 for inclusion and exclusion criteria). Articles were also excluded if they measured social support but not self-

management behaviors. The self-management behaviors were broadly defined as the daily processes patients engage in to manage their disease, such as engagement in treatment and symptom management (Grady & Gough, 2014; Ryan & Sawin, 2009).

After the initial search, duplicates were removed using the online Covidence software. Two authors independently screened title and abstracts against the inclusion and exclusion criteria. After consensus was reached on abstracts that met the criteria, full-text articles were assessed for eligibility.

Search Output

Four hundred and thirty abstracts were found through database searching. After duplicates were removed, 268 abstracts remained. One hundred and five were identified as potentially meeting inclusion and exclusion criteria based on title and abstract review. Full text articles were assessed for eligibility and 98 studies were excluded. See Figure 2.1 for a flow diagram of the search process as recommended by the PRISMA guidelines, along with rationale for the excluded full-text articles. A total of seven studies met the full inclusion criteria for the review. A description of these studies is found in Table 2.5.

Quality Appraisal

Each study was appraised for quality based on the Critical Appraisal Skills Programme for cohort studies tool (Critical Appraisal Skills Programme, 2013). The checklist contains 12 questions (see Appendix B), which were collapsed into four criteria based on previous research (Barnett, van Sluijs, & Ogilvie, 2012; Laird, Fawcner, Kelly, McNamee, & Niven, 2016; Schoultz, Atherton, Hubbard, & Watson, 2013). The four criteria include: external validity assessment of selection bias, internal validity assessment of measurement bias for exposure, internal validity assessment of measurement bias for outcome, and internal validity assessment

of confounding variables. Studies that meet the thresholds for each criteria received a point; studies that did not meet the thresholds or were unclear did not receive any points. Overall quality was determined as a sum of the four criteria and could range from 0–4: low quality was 0–1, modest quality was 2, and high quality was 3–4 (Barnett et al., 2012).

Data Abstraction

Data were extracted from the articles. Extracted information included: participant demographics including age; details of social support instruments and outcome measurements; study methodology; study objectives; and results on the relationship between social support and self-management behaviors. After data extraction, the data were synthesized.

Data Synthesis

The data were synthesized using a narrative synthesis technique. Narrative synthesis refers to a qualitative synthesis method which uses text and words to explain findings (as opposed to a meta-analysis which uses a data-based approach). The goal of narrative synthesis is to “tell the story” of the data (Popay et al., 2006; Snilstveit, Oliver, & Vojtkova, 2012).

Guidance on conducting the narrative synthesis was obtained from Popay and colleagues (2006). First, the authors determined the role of theory in evidence synthesis. As previously discussed, the Individual and Family Self-Management Theory guided the discussion of the self-management behaviors. Based on the model and the aims of the review, key variables were focused on, i.e., age, types of social support. Second, a preliminary synthesis was conducted. During the preliminary synthesis, the data were extracted from the articles (see data abstraction) and an initial description of the studies was drafted. Third, relationships between and within studies were examined keeping the focus on age and types of social support. Finally, the robustness of the synthesis was assessed by examining the quality of the studies (see quality

appraisal for scoring information). Any disagreements were resolved through discussion among the authors.

Results

Quality Assessment/Risk of Bias

The quality assessment examined selection bias, self-management behaviors measurement bias, social support measurement bias, and confounding variables (see Table 2.3). Articles had a low risk of selection bias if participants were from a random sample, had a non-response rate of less than 30%, and loss of follow up less than 50%. Four articles were classified as low risk of bias. High risk of selection bias included a non-random sample and/or nonresponse greater than 30%. One article met the criteria for high risk of selection bias. Two articles did not include enough information to determine selection bias and were classified as unclear.

Overall, studies had low measurement bias. Articles were considered a low risk of measurement bias if previously validated questionnaires were used and high risk of measurement bias if a custom questionnaire or single-item questionnaire was used. For self-management behaviors, five studies had low risk of measurement bias. Two articles had a high risk of bias due to the use of a custom questionnaire developed specifically for the research study and the use of staff report. For social support measurement bias, six articles had a low risk due to using previously validated questionnaires. One article had a high risk of social support measurement bias because social support was measured indirectly as participation in a supportive intervention.

Four articles had a low risk of confounding variables. Studies were classified as low risk if they adjusted for confounders such as age, socioeconomic status, or ethnicity through analysis, stratification, or study design. Two articles were classified as high risk having adjusted for some

or none of the confounders. One article was not clear on methods to control for potential confounding variables. Risk of bias assessments are presented in Table 2.3.

Articles also received an overall quality score, ranging from 0–4. One study had overall low quality (total score was 0–1). Three studies were of modest quality (total score was 2). Three studies were high quality (total score was 3–4). Although studies were not excluded based on overall quality, study results should be examined in light of these quality scores.

Setting and Design

The studies occurred in Canada ($n = 3$), the United States ($n = 2$), Austria ($n = 1$), and Japan ($n = 1$). Six studies had a cross-sectional descriptive design and one study was a prospective cohort study in which participants were followed for six months. Sample sizes ranged from 81–302. Publication dates ranged from 2001–2010. No identified articles were published within the past five years (see Table 2.4 for a description of setting, design, and participant characteristics).

Participant Characteristics

Three studies examined participants with ulcerative colitis (Maunder et al., 2007; Moss et al., 2010; Tanaka & Kazuma, 2005), one study compared Crohn’s disease to a control group (Vallis & Leddin, 2004), two studies examined both types of IBD (Rini, Jandorf, Valdimarsdottir, Brown, & Itzkowitz, 2008; Sewitch et al., 2001), and one study compared IBD to rheumatoid arthritis (Miehsler et al., 2008). The mean age of participants was 40. Studies ranged from 44.4% to 65.4% female. One study did not report mean age or sex. Only one study reported race with the sample being 86% non-Hispanic white and 11% other (Rini et al., 2008).

Of the studies reporting mean time since diagnosis ($n = 5$), participants were diagnosed for an average of 9.3 years (Miehsler et al., 2008; Moss et al., 2010; Rini et al., 2008; Sewitch et

al., 2001; Tanaka & Kazuma, 2005). Four studies reported patient disease status such as active or inactive disease, each using a different metric (Maunder et al., 2007; Moss et al., 2010; Sewitch et al., 2001; Tanaka & Kazuma, 2005). Three studies reported treatment methods with one study focusing solely on mesalamine use (Moss et al., 2010), another reported on partial and complete colon removal (Rini et al., 2008), and one reported on medication use (87.5% salazosulfapyridine or 5-aminosalicylic acid; 9.7% immunosuppressive; 5.6% steroids; Tanaka & Kazuma, 2005). Additional information on participant characteristics is provided in Table 2.4.

Key Findings

Social support. This review identified a variety of social support conceptualizations including perceptions of support, perceptions of satisfaction with support, network size, and received support. A variety of scales were used to measure social support: Social Support Questionnaire ($n = 2$), German Questionnaire assessing social support (SOZU-K22, $n = 1$), presence in support group intervention ($n = 1$), Interpersonal Support Evaluation List ($n = 1$), Emotional Support Network Scale ($n = 1$), and Life Stressors and Social Resources Inventory ($n = 1$). The Social Support Questionnaire, which assesses network size and perceived satisfaction with support, was the only measurement used in more than one study (Maunder et al., 2007; Sewitch et al., 2001).

The Interpersonal Support Evaluation List, used by Rini and colleagues (2008), included subscales of perceived availability of social support: tangible, appraisal, belonging, and self-esteem; however, Rini and colleagues focused on overall perceived availability of social support and did not report on the types of social support. The Emotional Support Network Scale was the only instrument that focused on a specific type of social support: emotional support.

Two studies focused on received social support (Moss et al., 2010; Tanaka & Kazuma, 2005). Moss and colleagues (2010) used participants' presence in a support group to assume receiving social support. Tanaka and colleagues (2005) used an emotional support network scale to report the presence or absence of emotional support. Finally, one social support scale examined social resources using The Life Stressors and Social Resources Inventory which included the following support scales: financial, work, spouse or partner, children, extended family, friends, and positive life events (Vallis & Leddin, 2004).

Self-management behaviors. Although individuals with IBD engage in multiple self-management behaviors, few of the most common self-management behaviors (e.g., medication adherence and diet modification) were identified in this review (see Table 2.5 for the purpose, measurements, and results of articles within the systematic review). This review identified self-management behaviors related to: medication adherence, illness intrusiveness, need for psychological treatment, symptoms of distress, and functioning. Medication adherence, the degree to which patients use their medication as prescribed, was calculated based on pharmacy refill data (Moss et al., 2010). Illness intrusiveness refers to disruptions in lifestyle, activities, and interests due to IBD and was measured with the Illness Intrusiveness Rating Scale (Maunder et al., 2007). The “need for psychological treatment” variable examines participants' subjective need for psychological interventions and was measured with the Assessment of the Demand for Additional Psychological Treatment (Miehsler et al., 2008). Symptoms of distress refers to a group of psychological symptoms, including anxiety and depression, and was measured in multiple ways: Symptom Checklist-90R, Mental Health Inventory, Impact of Events Scale (specific to colorectal cancer), and Perceptions of Difficulties of Life scale (Rini et al., 2008;

Sewitch et al., 2001; Tanaka & Kazuma, 2005). Functioning refers to how well a patient was managing his/her disease and was measured by staff report (Vallis & Leddin, 2004).

Although a wide variety of self-management behaviors were described among the seven studies, the systematic review did not identify commonly used IBD self-management behaviors such as diet modification, stress management, gastrointestinal symptoms, or physical activity (Conley & Redeker, 2016; Kane, 2010; Keefer & Kane, 2016). Even though individuals with IBD face a variety of gastrointestinal and systemic symptoms, this review did not identify any studies focusing on gastrointestinal symptoms. Instead, identified studies focused on psychological symptoms (Rini et al., 2008; Sewitch et al., 2001; Tanaka & Kazuma, 2005). Furthermore, only one article focused on medication adherence, a central self-management behavior within the IBD population (Moss et al., 2010).

Relationship between social support and self-management behaviors. Findings related to social support were mixed, likely due to the variation in conceptualization of social support and types of self-management behaviors. Decreased social support was significantly related to a greater need for psychological interventions (Miehsler et al., 2008), symptoms of distress (Rini et al., 2008; Tanaka & Kazuma, 2005) and poorer functioning (Vallis & Leddin, 2004). Social support was not found to be associated with medication adherence (Moss et al., 2010) or illness intrusiveness (Maunder et al., 2007). Studies reporting significant findings all demonstrated a positive relationship between social support and self-management behaviors such that when social support increased, the self-management behaviors improved (Miehsler et al., 2008; Rini et al., 2008; Tanaka & Kazuma, 2005; Vallis & Leddin, 2004).

Social support was also shown to moderate several types of relationships (Maunder et al., 2007; Sewitch et al., 2001). For example, Sewitch and colleagues (2001) found that social

support moderated the relationship between stress and distress. For individuals with low levels of stress, social support did not influence psychological distress. Among individuals with high perceived stress, those satisfied with social support had reduced psychological distress (Sewitch et al., 2001). Social support may also moderate the relationship between marital status and illness intrusiveness since low social support was associated with a higher illness intrusiveness in single or separated UC patients but not among married patients (Mauder et al., 2007). These single article findings should be replicated prior to generalization of these findings.

Differences based on type of social support. Although a variety of types of social support have been studied in the literature, the majority of the studies reviewed (6 out of 7) focused on overall social support. The only study that examined type of social support found that a decrease in emotional support was associated with a decline of vitality and vigor (Tanaka & Kazuma, 2005). With only one study examining type of social support, differences between types of social support and self-management behaviors were inconclusive.

Differences based on age. The studies identified in this review included individuals with a mean age of 40 (range: 34.6–45.5). Younger age (age ≤ 40) was associated with greater perceived illness intrusiveness, an increased need for psychological interventions, and greater symptoms of distress (Mauder et al., 2007; Miehsler et al., 2008; Sewitch et al., 2001), whereas age was not associated with medication adherence (Moss et al., 2010). Studies with significant relationships between age and self-management behaviors all demonstrated that a lower age was associated with worse self-management behaviors (Mauder et al., 2007; Miehsler et al., 2008; Sewitch et al., 2001). No studies focused on developmental stages.

Discussion

The aim of this systematic review was to determine the relationship between social support and self-management behaviors among adults with IBD. Overall, there is some evidence for a beneficial effect of social support on self-management behaviors, decreasing symptoms of distress and the need for psychological interventions and improved functioning. Therefore, social support may be beneficial for improving psychological symptoms experienced by IBD patients.

Previous systematic reviews and meta-analysis among adults with chronic conditions have demonstrated that an increase in social support can improve chronic disease self-management behaviors including medication adherence (DiMatteo, 2004; Gallant, 2003). In addition, IBD patients have reported that social support is important to medication adherence and that poor support systems can lead to medication non-adherence (Hall, Porrett, & Cox, 2006). Patients have also reported that increased social support can improve coping and daily functioning (Coulson, 2013; Fletcher et al., 2008; Lynch & Spence, 2008). This review found that social support was not associated with medication adherence; however, only one article focused on medication adherence and used presence in a support group to assume receiving social support (Moss et al., 2010). Future work should incorporate actual social support measures instead of using presence in a support group as a substitute measurement for support received. Since medication adherence is critical to achieving mucosal healing and decreasing inflammation, additional research is needed to examine factors such as social support, which may influence medication adherence.

The lack of conclusive findings may be due to the definition and measurement variety in both social support and self-management behaviors. Furthermore, the overall limited quantitative research on self-management behaviors reduces the number of studies that met search criteria

(Conley & Redeker, 2016; Plevinsky, Greenley, & Fishman, 2016). A common self-management behavior, diet modification, was not found within the current literature search. Research indicates that around 70% of IBD patients assume diet influences their IBD; yet, patients also acknowledge the lack of dietary advice from IBD providers (Holt, Strauss, & Moore, 2016; Wong et al., 2012). Understanding and improving self-management behaviors among adults with IBD is becoming increasingly important as patients become more responsible for managing their disease (Plevinsky, Gumidyala, & Fishman, 2015). Future research needs to incorporate common self-management behaviors such as medication adherence and diet modification.

The findings did, however, highlight the relationship between social support and psychological variables. Individuals with increased social support reported decreased symptoms of distress and a reduced need for psychological interventions. Therefore, social support may serve as a method for improving the psychological components of disease management such as coping, anxiety, and depression. This finding is consistent with previous literature in which indicates that social support may have stronger relationships with psychological outcomes (Uchino, 2004). Therefore, social support interventions can be utilized to address the multiple psychological comorbidities that exist with IBD (Bannaga & Selinger, 2015; Byrne et al., 2017).

Previous research has indicated that the type of social support (e.g., informational, emotional, and tangible) may influence self-management behaviors (DiMatteo, 2004). Only one article in this systematic review focused on a specific type of social support, emotional support; therefore, comparisons across different types of social support were unable to be made. Research question 1 was unable to be fully answered: What is the relationship between social support (overall social support and type of social support [e.g., informational, emotional, and tangible]) and self-management behaviors among adults with IBD? Examining the types of support would

provide detailed insight and evidence to developing interventions and providing support recommendations to patients.

In addition to types of social support, the review also examined the role of age (research question 2: How does patient age influence the relationship between social support and self-management behaviors among adults with IBD?). The mean age of participants was 40, even though individuals with IBD are most likely to be diagnosed at a younger age (typical age range of diagnosis: 15-29 years old; Crohn's and Colitis Foundation of America, 2015). Studies with significant findings regarding age consistently demonstrated that young adults experienced poorer self-management behaviors. This aligns with other research, which indicates that young adults may be in need of specialized interventions in order to improve self-management behaviors (Plevinsky et al., 2015; Trivedi & Keefer, 2015).

The age range of 18-29 has been referred to as emerging adulthood (Arnett, 2000). Individuals in this developmental stage has exhibit five developmental characteristics: identity explorations (answering the question “who am I?”), instability (in love, work, and place of residence), self-focus (focusing on the self), feeling in-between (neither adolescent nor adult), and possibilities/optimism (opportunity to transform their lives; Arnett, 2000). These characteristics may influence self-management behaviors as demonstrated by increased medication nonadherence among emerging adults compared to adults over 30 years of age (Arnett, 2015; Coenen et al., 2016; Severs et al., 2017; Trivedi & Keefer, 2015). Future research incorporating emerging adulthood developmental characteristics is needed to better understand self-management behaviors and the potential relationship between social support and self-management behaviors.

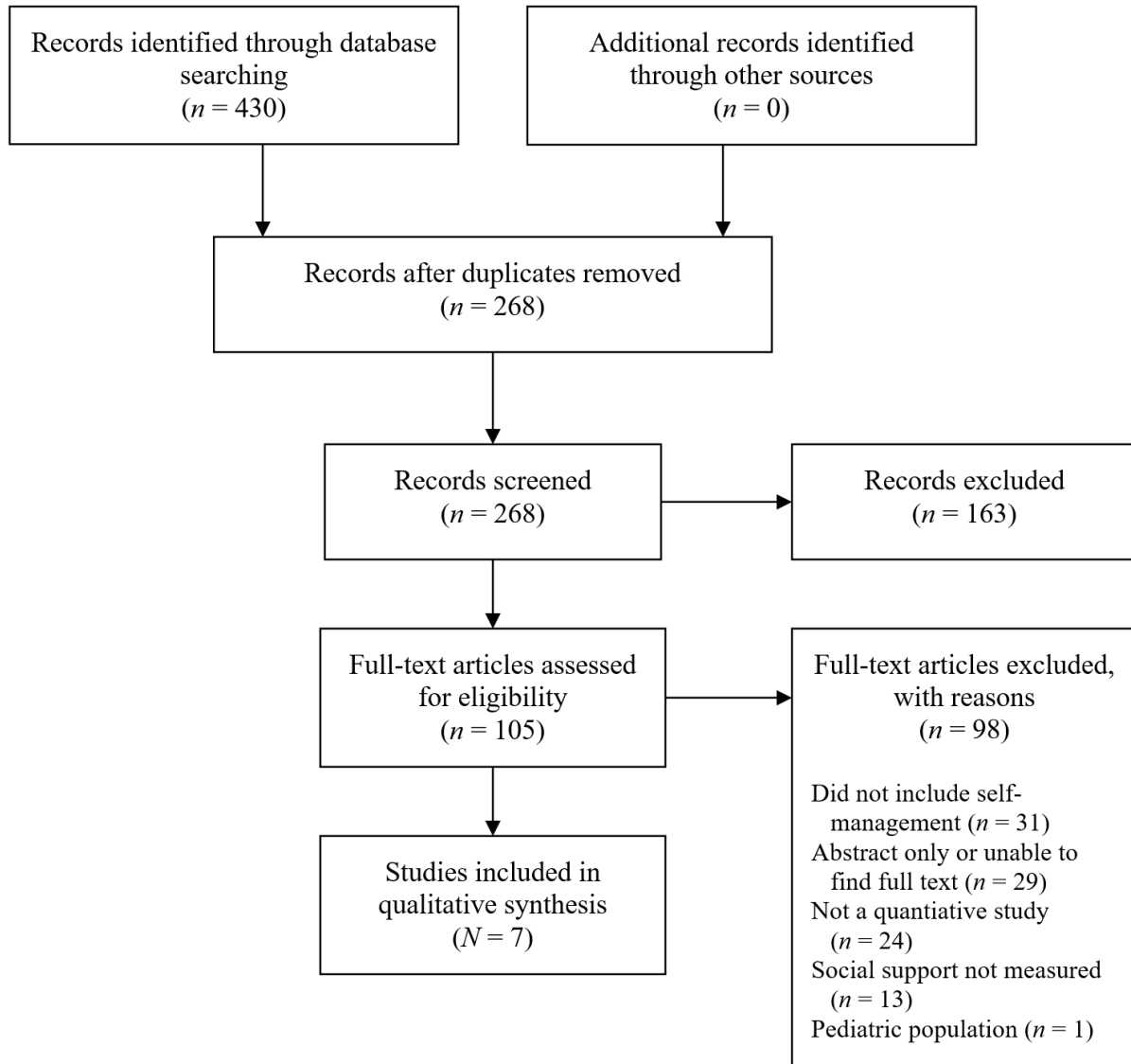
This systematic review has several limitations. Few studies met the study inclusion criteria. The studies that did meet the criteria contained a variety of social support definitions and measurements and included diversity of self-management behaviors. This lack of consistency creates issues in generalization. Replication to validate findings and more current studies could be of value. Of additional concern, the majority of studies included in this review were descriptive. One social support intervention was included in this review; however, the intervention measured social support indirectly through group membership (i.e., assignment to support group intervention). Individuals in the support group intervention may not have actually experienced an increase in support since social support was not directly measured. The current findings which indicate that increased social support may lead to improved self-management behaviors are generalizable to middle age adults with IBD who have been diagnosed for around nine years; results may differ among young adults and older adults as inconsistent reporting of personal and disease characteristics (such as race and remission status) make comparisons across groups difficult.

Conclusion

This review indicates that social support may have the potential to improve self-management behaviors among adults with IBD. However, more insight is needed regarding: the relationships between social support and both medication adherence and diet modification, the types of social support, and the role of age on social support and self-management behaviors. Future research is needed to address these gaps and promote the science of self-management by addressing the self-management behaviors that are important to both providers and patients. Next steps in this line of inquiry could be guided by self-management frameworks including the Self- and Family Management Framework (Grey, Schulman-Green, Knafl, & Reynolds, 2015) or the

Individual and Family Self-Management Theory (Ryan & Sawin, 2009). Social support could serve as a modifiable factor to improve self-management behaviors; however, the current review revealed several gaps in the literature that should be addressed prior to implementing supportive interventions.

Figure 2.1 Flow of Information through the Phases of the Search Process



Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097.
doi:10.1371/journal.pmed1000097

Table 2.1

Example Search Process for PubMed Database

Search Category	Key Words and MeSH Headings
Key concept: social support	("Social support" or "informational support" or "emotional support" or "tangible support" or "esteem support" or "instrumental support" or "affection support" or "family support" or "parental support" or "friend support" or "social network" or "structural support" or "Social Support"[Mesh])
Participant disease characteristic: Inflammatory Bowel Disease	("inflammatory bowel disease" or Crohn's or colitis or IBD or "Crohn's disease" or "ulcerative colitis" or "Inflammatory Bowel Diseases"[Mesh] or "Crohn Disease"[Mesh] or "Colitis, Ulcerative"[Mesh])
Limited by: Publication date and language (English)	Filters activated: Publication date from 2000/01/01 to 2017/12/31, English.

Table 2.2
Systematic Review Inclusion and Exclusion Criteria

Inclusion Criteria
• Adults over age 18 • Diagnosis of Inflammatory Bowel Disease (such as: ulcerative colitis and/or Crohn's disease) • Quantitative study including randomized control trials, longitudinal studies, and cross-sectional studies • Study measured social support • Study measured self-management behavior
Exclusion criteria
• Children or adolescents (less than 18 years old) • Editorials, conference abstracts, clinical guidelines, case reports, review studies, protocol only, dissertations, qualitative studies

Table 2.3

Risk of Bias Assessment for Included Studies (N = 7)

Study	Selection Bias	Self-Management Behavior Measurement Bias	Social Support Measurement Bias	Confounding Variables	Total score
Maunder et al., 2007	High	Low	Low	Unclear	2
Miehsler et al., 2008	Low	Low	Low	Low	4
Moss et al., 2010	Unclear	Low	High	Low	2
Rini et al., 2008	Low	Low	Low	Low	4
Sewitch et al., 2001	Low	Low	Low	Low	4
Tanaka et al., 2005	Unclear	High	Low	High	1
Vallis et al., 2004	Low	High	Low	High	2

Note: Low = low risk of bias, High = high risk of bias, unclear = insufficient information to permit judgment of 'low risk' or 'high risk.'

Table 2.4

Systematic Review Description of Setting, Design, and Participant Characteristics

Study	Design	Country and Setting	Sample size	IBD participant characteristics
Maunder et al., 2007	Descriptive (cross-sectional)	Canada Outpatient clinic	155	Mean age: not reported as mean Sex: not reported Race: not reported Disease type: 100% UC Time since diagnosis: not reported as mean Remission: 87% (St. Mark's Index) Treatment methods: not reported
Miehsler et al., 2008	Descriptive (cross-sectional)	Austria Outpatient IBD clinic	<i>N</i> = 411 <i>n</i> = 302 IBD <i>n</i> = 101 rheumatoid arthritis	Mean age: 37.3 (11.8) Sex: 56% female Race: not reported Disease type: 73.5% IBD; 24.5% rheumatoid arthritis Time since diagnosis: 9.5 (7.7) years Remission: not reported Treatment methods: not reported
Moss et al., 2010	Prospective Cohort Study Participants were followed for 6 months	United States Outpatient IBD clinic	81	Mean age: 45.5 (16.5) Sex: 56.8% female Race: not reported Disease type: 100% UC Time since diagnosis: 7.5 years Remission: mean 2.9 (baseline Simple Colitis Activity Index) Treatment methods: 100% mesalamine

Table 2.4 (cont'd)

Study	Design	Country and Setting	Sample size	IBD participant characteristics
Rini et al., 2008	Descriptive (Cross-sectional)	United States Colon Disease Family Registry	223	Mean age: 43.9 (14.0) Sex: 52% female Race: 86% non-Hispanic white; 11% other Disease type: 25% CD; 61% UC; 14% indeterminate colitis Time since diagnosis: 12.8 (11.9) years Remission: not reported Treatment methods: 22% partial colon surgery; 44% complete colon removal
Sewitch et al., 2001	Descriptive (cross-sectional)	Canada Gastrointestinal clinics of University Hospitals	200	Mean age: 37.3 (14.5) Sex: 60% female Race: not reported Disease type: 68.5% CD; 31.5% UC Time since diagnosis: 8.4 years Remission: 44% (Harvey Bradshaw Index) Treatment methods: not reported
Tanaka et al., 2005	Descriptive (cross-sectional)	Japan Outpatient clinic of a University Hospital	72	Mean age: 38.8 (14.2) Sex: 44.4% female Race: not reported Disease type: 100% UC Time since diagnosis: 8.3 (7.7) years Remission: 100% (modified Truelove index) Treatment methods: 87.5% salazosulfapyridine or 5-aminosalicylic acid; 9.7% immunosuppressive; 5.6% steroids

Table 2.4 (cont'd)

Study	Design	Country and Setting	Sample size	IBD participant characteristics
Vallis et al., 2004	Descriptive (cross-sectional)	Canada Tertiary gastrointestinal service	<i>N</i> = 49 <i>n</i> = 32 CD <i>n</i> = 17 healthy controls	Mean age: 34.6 (7.52) Sex: 65.4% female Race: not reported Disease type: 65.3% CD; 34.7% healthy controls Time since diagnosis: not reported Remission: not reported Treatment methods: not reported

Note: CD = Crohn's disease, UC = ulcerative colitis, mean age measured in years, time since diagnosis measured in months

Table 2.5

Purpose, Measurements, Results of Articles within Systematic Review

Study	Purpose	Social Support Measurement	Self-Management Behavior Concept and Measurement	Results
Maunder et al., 2007	To determine whether the perceived impact of ulcerative colitis (UC) on activities of living (illness intrusiveness) is greater for people who are not living in a married or common-law relationship.	<i>Social Support Questionnaire, short form</i> : Size of person's support network and perceived quality of support.	<i>Illness Intrusiveness</i> : Illness Intrusiveness Rating Scale, which quantifies illness-induced disruptions to lifestyle, activities, and interests.	Social support was not statistically significantly related to illness intrusiveness ($p = 0.07$). Low social support was associated with a higher illness intrusiveness in single or separated UC patients ($p = 0.04$). Among single or separated patients, the illness had the greatest impact on health, diet, and work. Younger age was associated with greater illness intrusiveness within single or separated individuals ($p = 0.013$).
Miehsler et al., 2008	To investigate the quantity and quality of the need for psychological interventions in patients with IBD compared to rheumatoid arthritis (RA), another chronic inflammatory disorder which shares biological similarities but affects another target organ.	Short form of a German questionnaire assessing social support (SOZU-K22). The SOZU-K-22 was used to assess social support as perceived by the patient.	<i>Need for Psychological Treatment</i> : The Assessment of the Demand for Additional Psychological Treatment scale which assesses the patient's subjective need for psychological interventions.	Individuals with IBD are twice as likely to report needing a psychological intervention compared to individuals with RA. Anxiety, an age of less than 45 years old, and impaired social support independently accounted for the need for psychological intervention.

Table 2.5 (cont'd)

Study	Purpose	Social Support Measurement	Self-Management Behavior Concept and Measurement	Results
Moss et al., 2010	To determine whether a patient-support program over 23 weeks would improve mesalamine adherence at 3 and 6 months in patients with ulcerative colitis	Presence or absence in patient support intervention.	<i>Medication adherence:</i> Calculated based on refill data from pharmacies according to Steiner's formula. Only patients with adherence >80% of the time at 3 and 6 months were considered adherent.	There was no difference in the mean refill percentage between the groups at three and six months. Age, gender, disease extent, mesalamine dose, and initial disease activity score were not associated with adherence.
Rini et al., 2008	To examine three factors (disease duration, family history of cancer, and perceived social support) expected to influence IBD patients' vulnerability to distress.	<i>Interpersonal Support Evaluation List:</i> Perceived availability of four types of social support: tangible, appraisal, belonging, and self-esteem.	<i>Symptoms of Distress:</i> Colorectal Cancer Specific Distress: Impact of Event Scale <i>Generalized distress:</i> Mental health Inventory	Greater perceived social support strongly predicted lower generalized distress but did not predict colorectal cancer specific distress. Age was not included in the model.

Table 2.5 (cont'd)

Study	Purpose	Social Support Measurement	Self-Management Behavior Concept and Measurement	Results
Sewitch et al., 2001	The objectives of this study were the following: 1) to assess psychological status of patients with active and inactive IBD; 2) to measure structural and functional aspects of social support; and 3) to identify independent correlates of psychological distress using advanced statistical techniques.	<i>Social Support Questionnaire:</i> Assess network size and satisfaction with support	<i>Symptoms of distress:</i> Symptom Checklist-90R	Social support was significantly correlated with psychological distress in the univariate analysis but became non-significant in the multiple regression. Age was also associated with social support in the univariate analysis. The multiple regression showed that active disease, less time since diagnosis, greater weekly stress, and the interaction between social support and perceived stress were related to distress. The interaction term indicates that for people with low levels of stress, social support did not influence psychological distress. Among individuals with high perceived stress, those satisfied with social support had reduced psychological distress.
Tanaka et al., 2005	To investigate the real state of affairs concerning such UC related difficulties of life and psychological well-being of affective patients, and the factors affecting these variables	Emotional Support Network Scale Presence or absence of emotional support.	<i>Symptoms of Distress:</i> Perception of difficulties of life, developed by authors	Social support predicted the subscale decline of vitality or vigor in the difficulties of life measure. In addition, social support predicted depression/dejection and fatigue. Age was not significant.

Table 2.5 (cont'd)

Study	Purpose	Social Support Measurement	Self-Management Behavior Concept and Measurement	Results
Vallis et al., 2004	To determine if psychosocial factors differentiate the CD patients who function poorly from the typical CD patient.	Life Stressors and Social Resources Inventory Support scales: financial, work, spouse or partner, children, extended family, friends, and positive life events	<i>Functioning:</i> Based on clinic staff report.	No difference in functioning based on age. The poorly functioning vs average functioning only experienced difference on the financial resources scale.

Note: CD = Crohn's disease, UC = ulcerative colitis, IBDQ = Inflammatory Bowel Disease Questionnaire, QoL = quality of life, HRQoL = health-related quality of life

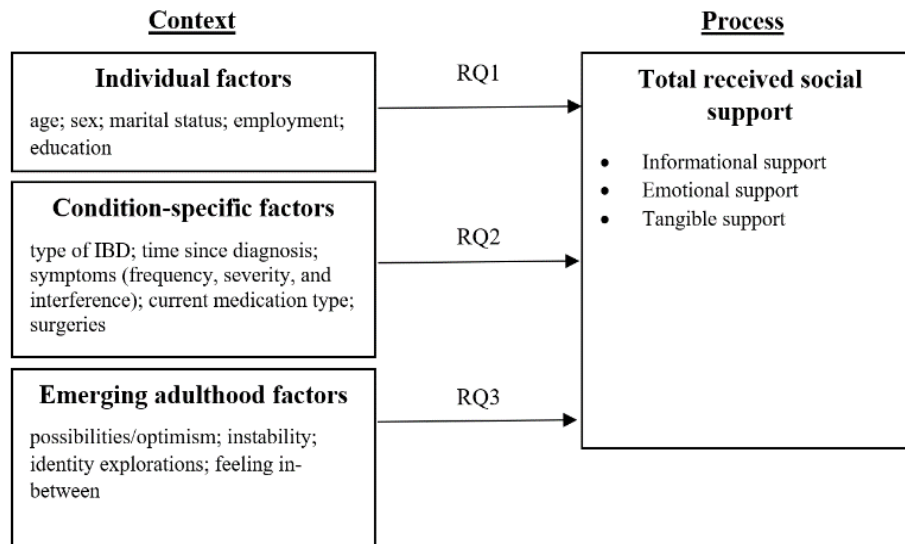
CHAPTER 3: INDIVIDUAL, CONDITION-SPECIFIC, AND EMERGING ADULTHOOD FACTORS WHICH INFLUENCE RECEIVED SOCIAL SUPPORT AMONG EMERGING ADULTS WITH INFLAMMATORY BOWEL DISEASE

Introduction

Inflammatory Bowel Diseases (IBD; ulcerative colitis and Crohn's disease) are chronic diseases of the gastrointestinal system. IBD incidence and prevalence are increasing worldwide and individuals are diagnosed at younger ages (ages 15-29; Crohn's and Colitis Foundation of America, 2015; Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016; Johnston & Logan, 2008). Individuals with IBD experience periods of flairs and remissions. Symptoms can include diarrhea, abdominal pain, cramping, bloody stool, and fatigue (Farrell, McCarthy, & Savage, 2016). The unpredictable nature of IBD creates an environment in which "the bowels rule life" (Pihl Lesnovska, Hollman Frisman, Hjortswang, & Börjeson, 2016). To cope with this encompassing condition, receiving social support (the supportive behaviors that an individual obtains from others) can be beneficial by promoting engagement in social activities, improving self-management behaviors, and increasing periods of remission and health-related quality of life (Pihl Lesnovska et al., 2016; Plevinsky, Greenley, & Fishman, 2016).

Yet, individuals receive different levels and types of social support which could be influenced by contextual factors such as age or disease type. Understanding the contextual factors which influence receiving social support is important because these factors contribute to self-management of this complex condition. In addition, contextual factors could be used to identify patients within clinic and hospital settings which could benefit from additional supportive resources and interventions. Three types of contextual factors are proposed by the Individual and Family Self-Management Theory applied to IBD (Figure 3.1).

Figure 3.1: Individual and Family Self-Management Theory applied to IBD: Context and Process



These three factors are posited to influence received social support: individual, condition-specific and emerging adulthood factors (Ryan and Sawin, 2009). The individual factors are characteristics unique to each person, condition-specific factors are related to the disease, and emerging adulthood factors refer to the developmental stages of emerging adults (ages 18-29; Arnett, 2000; Ryan and Sawin, 2009). The purpose of this study was to determine the individual, condition-specific, and emerging adulthood factors of self-management that influence received social support (total received social support, informational support, emotional support, and tangible support) among emerging adults with IBD as guided by the Individual and Family Self-Management Theory applied to IBD.

Background

Within the IBD population, social support has been identified as important to coping with IBD disease and treatment, increasing disease knowledge and quality of life, addressing fears and concerns, and influencing dietary modification and medication use (Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Lynch & Spence, 2008; Swarup et al., 2017). Dur et al. (2014)

found that 93% of participants with Crohn's disease identified social support as an important determinant of health. Women and young adults with IBD also acknowledged social support as a vital component to daily functioning and their ability to cope with IBD (Fletcher et al., 2008; Lynch & Spence, 2008). Social support may have physiological benefits by slowing down disease progression and influencing parasympathetic activity for IBD patients (Camara, Lukas, Begre, Pittet, & von Kanel, 2011; Maunder et al., 2012). Identifying individuals who are able to receive more social support than others is important since social support is beneficial for improving self-management behaviors and health-related quality of life among adults with chronic conditions (Uchino, 2004; Uchino, Bowen, Carlisle, & Birmingham, 2012). An examination of potential individual, condition-specific, and emerging adulthood factors which influence received social support is needed to help identify which individuals may be "at risk" of low social support and may benefit from supportive interventions.

Received social support, the supportive behaviors an individual obtains, can be separated into types of social support: informational social support, emotional social support, and tangible social support (Uchnio, 2009). Informational social support includes providing information and giving advice. Emotional social support is the actions that make someone feel cared for such as encouragement and comfort. Tangible social support consists of providing physical support such as assistance and reminders. These types of social support may be influenced by the different contextual factors, i.e., individual, condition-specific, and emerging adulthood factors.

This study is guided by an adapted version of the Individual and Family Self-Management Theory applied to IBD (Ryan & Sawin, 2009) which focuses on context (individual, condition-specific, emerging adulthood) and process (received social support) specific to IBD. Although self-management behaviors are the outcome of the IBD specific

model, the research questions for the current study focus on the context and process dimensions; thus, the figure of the model [Figure 3.1] focuses on the variables specific to the research questions. The model demonstrates that the context components influence the process of received social support. For example, a married (individual) optimistic person (emerging adult) who is initially diagnosed with IBD (condition-specific factor) may experience an increase in received social support (one of the three types) compared to an unmarried (individual), pessimistic (emerging adult) who has been diagnosed for 5 years (condition-specific factor). Understanding these individual, condition-specific, and emerging adulthood factors can assist healthcare providers identify individuals who may need additional supportive resources, particularly among emerging adults who already experience more severe bowel-related symptoms and advanced treatment compared to older adults (Bager, Julsgaard, Vestergaard, Christensen, & Dahlerup, 2016).

Individual factors

Individual factors of interest include age, sex, marital status, employment, and education. The relationship between age and received social support is not fully understood since the literature is conflicting as to whether younger adults experience more or less social support than older adults (Jason, 2007; Luong, Charles, & Fingerman, 2011; Williamson & O'Hara, 2017). Sex may influence receiving social support since females typically receive more social support than males, particularly emotional support (Williamson & O'Hara, 2017). This circumstance may be due to women being more likely to express emotional needs and seek social support (Norberg, Lindblad, & Boman, 2006; Simon et al., 2004). By contrast, a study examined received social support on Facebook and found that among middle age adults (mean age 45)

being married was associated with receiving more social support; whereas age and sex were not associated with received social support (Davis, Anthony, & Pauls, 2015).

Information on employment and education indicate that being employed and having a higher educational level have the potential to also influence received social support (Nilsson et al., 2013; Nordgren & Soderlund, 2017). Being employed and having a higher education may contribute to greater access receiving social support and supportive resources (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Gudbergsson, Fossa, Lindbohm, & Dahl, 2009; Nilsson et al., 2013; Nordgren & Soderlund, 2017). However, most of the previous work cited has been conducted with older populations which leave a gap in the literature regarding individual factors of age, sex, marital status, employment, and education within an emerging adult population. Similar research is needed to characterize emerging adults with IBD who most likely have unique social support needs based on their individual characteristics (Davis et al., 2015; Trepte et al., 2015).

Condition-specific factors

Condition-specific factors are distinct to the condition and include type of IBD, time since diagnosis, symptoms (including frequency, severity and interference), current medication use, and surgeries. Emerging adults with chronic conditions may differ based on disease severity. According to Arora et al. (2007), when individuals (mean age 44) were newly diagnosed with cancer, they experienced an increase in receiving social support. However, received social support may decrease as time since diagnosis increases (Arora et al., 2007). For patients undergoing hemodialysis, an association between decreased depressive symptoms and increased received social support indicates that symptoms may influence received social support (Liu et al., 2018). Within the IBD population, symptoms may also influence the level of received social

support. For instance, individuals who experience increased frequency and intensity of symptoms may receive a greater amount of social support compared to those with decreased symptom frequency and intensity. Emerging adults with IBD may also experience differences in received social support based on time since diagnosis and symptoms since these factors have influenced received social support in older adult populations (Arora et al., 2007; McCombie, Mulder, & Gearry, 2015).

Disease severity (type of IBD, symptom frequency, symptom severity, symptom interference, current medication use, and surgeries), although not examined in relationship to received social support among IBD patients, is related to increased hospitalizations and disease complications among IBD patients (Guizzetti et al., 2017; Limsrivilai et al., 2017; Torres et al., 2016; Waljee et al., 2017). Even though the current social support literature does not focus on condition-specific factors within the IBD population, there are reasons to hypothesize that condition-specific factors may influence received social support. For instance, biological medications, which are often administered via infusions or injections, are most often used among emerging adults with moderate/severe disease to induce remission (Kornbluth et al., 2010; Lichtenstein et al., 2009; Terdiman et al., 2013). Other medication types such as immunomodulators and aminosaliclates are used as maintenance medications. Corticosteroids are acutely used to manage flares. Individuals with greater disease severity who are taking biologics may receive more tangible social support compared to individuals not taking biologics; received tangible social support may include someone to drive to infusion center or someone to help inject medication. Therefore, as disease severity increases and others become more aware of the disease, an emerging adult may receive more tangible social support compared to an

emerging adult whose disease is less visible. The relationship between condition-specific factors and types of social support remains to be tested.

Emerging adulthood factors

Emerging adults experience developmental factors which may influence received social support. These developmental factors include: 1) possibilities/optimism: when hopes flourish and people have an unparalleled opportunity to transform their lives; 2) instability: in love, work, and place of residence; 3) identity explorations: answering the question “who am I?” and trying out various life options, especially in love and work; and 4) feeling in-between: in transition, neither adolescent nor adult (Arnett, 2000, 2015). The unique needs and challenges of the emerging adulthood population has been introduced in the IBD literature by examining care transitions (Trivedi & Keefer, 2015); however, few studies have examined how emerging adulthood factors could influence other factors such as the amount of social support received.

Emerging adulthood features, specifically identity explorations, instability, and feeling in-between, have the potential to decrease the amount of social support received since emerging adults in transition may have a smaller support network from which to obtain social support (Benson & Elder, 2011; Heinze, Kruger, Reischl, Cupal, & Zimmerman, 2015; Mattanah et al., 2010; Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013). For instance, emerging adults with IBD have poorer adjustment to college compared to healthy students – potentially due to the combination of developmental, disease transitions, and lack of received social support (Almadani et al., 2014). The emerging adulthood factor of possibilities/optimism may lead to increased received social support due to a more extensive and supportive network (Vollmann et al., 2001). These emerging adulthood factors have not been explored as the previous literature focuses primarily on chronological age and social support (Jason, 2007; Williamson & O’Hara, 2017).

Although the individual factor of age has some overlap with emerging adult factors, the developmental stage of emerging adulthood may influence received social support differently than age since receiving social support may be based on developmental needs. Therefore, both age and emerging adulthood will be included within the study.

In summary, social support has the potential to influence engagement in social activities, self-management behaviors, remission, and health-related quality of life (Pihl Lesnovska et al., 2016; Plevinsky, Greenley, & Fishman, 2016). Yet, little is known regarding the contextual factors of individual, condition-specific, and emerging adulthood factors which could influence received social support. Previous literature has primarily examined individual factors and received social support among middle age and older adults but has not focused on emerging adults. In addition, there is a gap in knowledge regarding the role of condition-specific and emerging adulthood factors. Examining the relationship between individual, condition-specific, and emerging adulthood factors would provide the foundation for identifying individuals who may be in need of supportive interventions.

Guided by the Individual and Family Self-Management Model, this study had three research questions examining the relationship between context factors and the process of social support:

Research Question 1: Which **individual factors** (age, sex, marital status, employment, education) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?

Research Question 2: Which **condition-specific factors** (type of IBD, times since diagnosis, symptoms, medication types, and surgeries) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?

Research Question 3: Which **emerging adulthood factors** (possibilities/optimism, instability, identity exploration, and feeling in-between) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?

Methods

This study used a non-experimental, cross-sectional design to examine the individual, condition-specific, and emerging adulthood factors that may influence received social support among emerging adults with IBD.

Participants

A convenience sample of emerging adults ages 18 – 29 with a self-reported healthcare provider diagnosis of IBD (ulcerative colitis or Crohn’s disease) were included in this study. Participants were recruited from an online database of participants who expressed interest in participating in research studies (ResearchMatch), a social networking site (Facebook), and word of mouth. Participants were included if they were between the ages of 18 – 29, self-reported a healthcare provider diagnosis of ulcerative colitis or Crohn’s disease, were currently prescribed medications to manage their IBD, lived in the United States, understood written English, and had access to the internet. Potential participants were excluded if they were hospitalized within the past month or were currently pregnant.

Procedure

Individuals were recruited through ResearchMatch, Facebook, and word of mouth from January 2018 - February 2018. ResearchMatch is funded by the National Institutes of Health and the Clinical and Translational Science Award program and includes a database of individuals who have expressed interest in participating in research studies. The general public is able to join ResearchMatch as a participant, but only researchers from approved universities can use

ResearchMatch. Both participants and researchers have secure password protected accounts. After obtaining institutional review board approval, the researcher uploaded a recruitment message to the site. An institutional liaison reviewed the information and provided approval to contact participants. The researcher searched by eligibility criteria (e.g., age and disease status). Potential participants received a recruitment email through the ResearchMatch website (see Appendix C). Interested participants provided permission for ResearchMatch to share their contact information with the researcher. Those interested in the study received an email from the researcher with a link to the survey. The email was set up to thank participants for their interest and briefly described the purpose of the study (Appendix D).

Participants were also recruited through Facebook. The recruitment message and survey link were posted to IBD support groups and Facebook advertisements were used to share the survey information. In addition, participants were encouraged to share the survey with others who had a diagnosis of ulcerative colitis and Crohn's disease. Participants were not compensated.

The first page of the online survey contained the informed consent (Appendix E). Participants were provided with an email address and phone number to contact the researchers with any questions. The survey took approximately 45 minutes to complete. Data were collected using Qualtrics, a secure online survey software. When participants completed the survey, the data were automatically saved on the Qualtrics server. The raw data were downloaded and stored in electronic format in a password-protected drive maintained by the investigator's institution. No identifiable data were collected. The analysis dataset included raw data, total scale, and subscale scores.

Measures

Prior to conducting the survey, the investigator-developed measures were pre-tested using a cognitive interviewing procedure. Nine participants used think-out loud techniques and the interviewer asked questions on words that could be misinterpreted and question difficulty as participants completed the questionnaires. This procedure led to the addition of more detailed instructions, clarified the timeframe of the questions, and reduced the cognitive burden of the questions. For example, the time since diagnosis question initially read “how long has it been since your diagnosis?” Participants identified this question as challenging since it involved recalling the month and year of their diagnosis and then performing mental math; therefore, the question was re-worded to “What month and year were you diagnosed with this disease?” Screening criteria is included in Appendix F; survey questions are presented in Appendix H.

Individual factors. Individual factors were demographic data specific to the participant and included age, sex, marital status, employment, and education. Age is a continuous variable that was calculated based on the individuals’ birthdate. Sex is a dichotomous variable (male/female). Marital status is a categorical variable that includes single, married/domestic partnership, widowed, and divorced/separated. Employment status is a categorical variable reported as full-time employed, part-time employed, unemployed/student, and homemaker. Education is a categorical variable of high school or less, some college, completed college, and graduate or professional degree.

Condition-specific factors. Condition-specific factors are characteristics related to the IBD and include type of IBD, time since diagnosis, symptoms (prevalence, severity, and interference), medications currently using, and surgeries for IBD. Type of IBD is a dichotomous variable (ulcerative colitis/Crohn’s disease). Time since diagnosis is a continuous variable.

Participants reported the month and year they were diagnosed with the disease. The data were recoded into the number of months since diagnosis based on the date the survey was completed.

Symptoms were measured using a Cancer Symptom Inventory, developed by Given and Given (2008), that was modified to 15 symptoms associated with IBD including: diarrhea, constipation, abdominal pain, abdominal tenderness, abdominal cramps, bloating, passing gas, blood in your stool, weight loss, weight gain, reduced appetite, increased appetite, nausea or vomiting, fatigue, and fever (Singh et al., 2011). Participants were asked if they experienced the symptom within the past two weeks (yes/no). If participants experienced the symptom, participants rated the severity (symptom at its worst) and interference (how much the symptom interfered in daily activities) on 0 – 9 point scale. Three symptom components were reported: prevalence, severity, and interference. Prevalence of symptoms refers to the average number of symptoms that patients are experiencing (potential range: 0 – 15). Severity ratings were summed for all 15 symptoms, with higher sores indicating greater symptom severity (potential range: 0 – 135). Interference ratings were also summed for all 15 symptoms, with higher scores indicating greater symptom interference with daily activities (potential range: 0 – 135).

Medications the participants were currently taking were reported as a categorical variable based on the medication types (note: additional medication information such as reasons for stopping included in Appendix H were not examined in this study). Medication types included: biologics, immunomodulators, corticosteroids, and aminosaliclates (some participants may be taking more than one medication type). Number of surgeries is a continuous variable that measures the total number of IBD-related surgeries that an individual has experienced.

Emerging adulthood factors. The 8-items short form of the Inventory of Dimensions of Emerging Adulthood (IDEA) measures psychological issues associated with emerging adulthood

(Stéphanie, Katia, Joseph, & Gerhard, 2014). Participants were asked to think of a five-year period and respond to questions such as: “is this period of your life a time of many possibilities?” on a 4-point Likert scale (strongly disagree, somewhat disagree, somewhat agree, and strongly agree). The 8-item short form contains four (of the 5) dimensions of emerging adulthood. These dimensions include: possibilities/optimism, instability, identity exploration, and feeling in-between. Participants receive a score for each dimension; a higher dimension score indicates that an emerging adult more strongly agrees that they are experiencing this dimension of emerging adulthood (potential ranges: 2 – 8).

Received social support. Received social support is defined as the supportive behaviors that an individual obtains and will be measured by the Inventory of Socially Supportive Behaviors (ISSB). The ISSB is a 40-item self-report scale in which participants rate how often activities occurred during the past four weeks such as someone “provided you with some transportation” or “told you who you should see for assistance.” Subscales measure specific types of support: informational support (guidance; 14 items), emotional support (14 items), and tangible support (12 items; Stokes & Wilson, 1984). The instrument uses a 5-point Likert scale (1=not at all, 2=once or twice, 3=about once a week, 4=several times a week, and 5=about every day). The original instrument was found to have good psychometric properties with an overall Cronbach’s alpha of 0.93 (Barrera, Sandler, & Ramsay, 1981). The scale was summed into a total received social support (potential range: 40 – 200) score as well as subscales of: informational support (potential range: 14 – 70), emotional support (potential range: 14 – 70), and tangible support (potential range: 12 – 60) with a higher number indicating higher received social support. The analysis examines the total received social support score as well as the individual subscales. The descriptive analysis includes the mean scores to assist in interpretation.

Statistical analysis

Data analysis was performed using STATA statistical software version 15.0. The level of significance was set at $\alpha = 0.05$. The pattern of missing data was examined. Descriptive analyses of the results were performed using numbers and percentages for categorical variables (sex, marital status, employment status, education, type of IBD, and medication type) and mean and standard deviation for continuous variables (age, time since diagnosis, previous surgeries, symptom prevalence, summed symptom severity, summed symptom interference, and received social support). See descriptive statistics in Table 3.1 for individual factors, Table 3.2 for condition-specific factors, and Table 3.3 for received social support.

Multivariable linear regression was used. A separate regression was built for each category of context factors (individual, condition-specific, and emerging adulthood factors) to determine which of the variables are predictive of total received social support and subscales of received social support (total received social support and each subscale will be modeled separately). The goal of the analysis is to select the independent variables that result in the best-fit model for received social support (for both the total score and subscales) and to create the most parsimonious model. The model was built based on the stepwise process of purposeful selection of covariates as outlined in Hosmer, Lemeshow, and Strudivant (2013).

The same procedures were used to answer each of the research questions. First, univariable linear regressions were conducted. Second, variables with a p-value of <0.25 in the first step were included in an initial multivariable model. Variables not reaching the traditional level of significance ($p < 0.05$) were removed; a reduced model was fit and compared to the initial model using the likelihood ratio test. Third, the preliminary main effects model was produced by adding the independent variables not selected in step one into the reduced model and testing for

significance. Variables with $p < 0.05$ were included in the model since while the variable on its own may not have been significantly related to received social support, the variable may provide a contribution in the presence of the other variables. Once the main effects model was determined, step four involved checking for functional forms and interactions among independent variables. The final step was to evaluate the model fit using residual diagnostics and adjusted R^2 . The purposeful selection procedure allows inclusion of variables of clinical significance based on literature and is not simply guided by statistical considerations.

Findings

Descriptive Statistics

Participants were recruited from Facebook (67%), ResearchMatch (25%) and word of mouth (8%). No differences existed between study variables based on recruitment site (Facebook compared to ResearchMatch).

Individual characteristics. A total of 61 emerging adults who met the study criteria were included; participant characteristics are shown in Table 3.1. The mean age of participants was 24.7 ($SD = 2.9$) with a range of 18 - 29. The majority of participants were female ($n=55$, 90%) and single ($n=47$, 77%). In terms of employment, 49% had full-time employment ($n=30$), 16% had part-time employment ($n=10$), and 34% were unemployed or a student ($n=21$). Sixteen percent had education of high school or less ($n=10$), 26% some college ($n=16$), 36% completed college ($n=22$), and 21% had a graduate or professional degree ($n=13$).

Condition-specific characteristics. Sixty-four percent ($n=39$) of participants had a diagnosis of Crohn's disease whereas 35% had a diagnosis of ulcerative colitis ($n=22$). Participants were diagnosed for an average of 76 ($SD = 57.3$) months and most never had surgery ($n=46$, 75%). Medications types used included biologics ($n=37$, 61%), aminosaliclates

($n=22$, 36%), immunomodulators ($n=16$, 26%) and corticosteroids ($n=11$, 18%) See Appendix J for specific medications used. Participants reported experiencing an average of 5.9 symptoms. The top three symptoms included: fatigue ($n=44$, 72%), cramps ($n=42$, 69%), and abdominal pain ($n=39$, 64%). See Table 3.2 for additional condition-specific characteristics.

Emerging adulthood characteristics. Emerging adulthood characteristics included possibilities/optimism ($M = 6.8$, $SD = 1.4$, range = 2 – 8), instability ($M = 6.9$, $SD = 1.3$, range = 2 – 8), identity exploration ($M = 6.7$, $SD = 1.4$, range = 2 – 8), and feeling in-between ($M = 6.5$, $SD = 1.5$, range = 2 – 8). Additional information on emerging adulthood factors are included in Table 3.3.

Received social support. Emerging adults with IBD reported obtaining mean social support between “once or twice” (in the past 4 weeks) and “about once a week” ($M = 2.5$, $SD = 0.7$). Emerging adults receive emotional social support slightly more than once a week ($M = 3.2$, $SD = 1.0$), informational social support slightly more than once or twice a month ($M = 2.4$, $SD = 0.9$), and tangible social support is received slightly less than once or twice a month ($M = 1.8$, $SD = 0.6$). Information on total and mean received social support scores and subscores are included in Table 3.4.

Factors which influence received social support

The individual, condition-specific, and emerging adulthood factors were related to the total and subscales for received social support. See Table 3.5 for total received social support, Table 3.6 for informational received social support, Table 3.7 for emotional received social support, and Table 3.8 for tangible received social support.

Individual factors. In the multivariable analysis for total received social support, decreased age ($p = 0.001$), being married ($p = 0.039$), and being employed (compared to being

unemployed or a student, $p = 0.007$) were significantly associated with increased total received social support ($F(4, 56) = 4.43$, $p = 0.004$, $R^2 = 0.24$, adjusted $R^2 = 0.19$). For the emotional social support subscale, being married ($p = 0.001$) and a decreased age ($p = 0.033$) were associated with greater emotional social support ($F(2, 58) = 6.72$, $p = 0.002$, $R^2 = 0.19$, adjusted $R^2 = 0.16$). Individual factors did not significantly predict the subscales of informational support or tangible support.

Condition-specific factors. Condition-specific factors did not predict total received social support, informational support, or emotional support. For tangible support, the univariable analysis identified that biologic medication ($p = 0.014$), immunomodulators ($p = 0.005$), aminosaliclates ($p = 0.025$) and number of surgeries ($p = 0.047$) were significantly positively associated with tangible social support. Multivariable analysis indicated that while controlling for time since diagnosis ($p = 0.18$), and symptom interference ($p = 0.114$), the use of immunomodulators ($p < 0.001$), the use of biologics ($p = 0.001$) and the interaction between immunomodulators and biologics ($p = 0.002$) were associated with increased tangible social support ($F(5, 55) = 6.57$, $p < 0.000$, $R^2 = 0.37$, adjusted $R^2 = 0.32$). Time since diagnosis and symptom interference were kept due to clinical considerations. The interaction indicates that the impact of biologics on tangible received social support was increased in the presence of immunomodulator medications. Table 3.9 shows the interaction between immunomodulators and biological medication for tangible social support.

Emerging adulthood factors. Linear regression analyses indicated that emerging adulthood factors of possibilities/optimism, instability, identity exploration, and feeling in-between were not statistically significantly associated with total social support or subscales.

Discussion

The purpose of this study was to examine the individual, condition-specific, and emerging adulthood self-management factors which influence received social support among emerging adults with IBD. The main study findings guided by the Individual and Family Self-Management Theory applied to IBD included: 1) individual factors of decreased age, being married, and full-time employment were related with increased total received social support; 2) the condition-specific factors of immunomodulator medications, biological medications, and the interaction between immunomodulators and biological medications were related to increased tangible support when controlling for time since diagnosis and symptom frequency; and 3) emerging adult factors were not associated with any aspect of received social support. The individual and condition-specific factors varied based on the type of social support. For example, condition-specific factors were only related to tangible support. Previous IBD literature has primarily focused on social support in general; these findings indicate that the factors which influence received social support vary based on the type of social support. Although total received social support may be helpful for obtaining an overall assessment of level of social support, specific types of social support may be beneficial for intervention development and evaluation. Future use of the Individual and Family Self-Management Theory should continue to incorporate specific types of social support.

Individual factors predicting total received social support and emotional support were primarily in alignment with previous research. Being married was associated with more received social support than being single (Nordgren & Soderlund, 2017), specifically total received social support and emotional support. Adults who were employed compared to those who were unemployed or a student, typically reported receiving more social support, even within the

emerging adult population (Arora et al., 2007; Gudbergsson et al., 2009; Nilsson et al., 2013; Nordgren & Soderlund, 2017). Emerging adults who are married and employed full-time may have access to larger support networks to draw on for support compared to single and unemployed emerging adults. Although previous literature found mixed results regarding received social support and age, this study aligns with research in which a younger age was associated with greater received social support (Williamson & O'Hara, 2017). Younger adults typically have access to more sources of support and larger support networks than older adults; however, older adults typically report higher quality of support and more meaningful support compared to younger adults (Scholz et al., 2012). Future research could examine differences in levels of received social support among adults with IBD.

Healthcare providers and researchers should be aware that emerging adults with IBD who are unemployed/students, single, and/or have an increased age may be at higher risk for lower received social support than individuals who are employed, married, and/or have a decreased age. Nursing assessments can be conducted to identify emerging adults with IBD who may have low informational, emotional, or tangible received social support. However, this study, like other social support research, has assumed that higher received social support is beneficial. It may be that ideal levels of received social support are situation, context, and/or person dependent. Support gap literature has identified a need to match the level of desired support with the support that is received (High & Crowley, 2018; Song et al., 2013). Determining levels of desired support promotes an individualized approach to assessing and understanding social support. In addition, the quality of social support may differ. Examining the characteristics of the support messages can help identify quality of social support. For instance, high person-centered messages, which encourage elaborating on thoughts and feelings, are a higher quality of support

(Bodie & Burleson, 2008). The current study only examined received support levels and did not account for differences in the quality of social support. Research is needed to determine optimal levels of informational, emotional, and tangible received social support in general and among emerging adults with chronic conditions. In addition, a focus on quality of the support message and the support providers' perspective would enhance IBD social support research.

Individuals with higher disease severity (condition-specific factors such as greater symptom severity and interference and increased surgeries) were expected to receive more social support; however, condition-specific factors did not demonstrate statistically significant relationships in the majority of types of social support (total received social support, informational support, and emotional support). When controlling for time since diagnosis and symptom frequency, the use of immunomodulators, biological medications, and the interaction of immunomodulators and biologics were associated with increased tangible support. Taking immunomodulators had the greatest relationship with tangible support perhaps due to the special considerations that occur while using immunomodulators. Emerging adults taking immunomodulators may need to obtain vaccinations prior to medication initiation, and while taking the medication they may be monitored for drug metabolite levels (Axelrad, Roy, Lawlor, Korelitz, & Lichtiger, 2016; Bär, Sina, & Fellermann, 2013). In other words, emerging adults who are sicker may need additional support, especially tangible support. These special considerations may lead to greater tangible social support than individuals on other medications; although, additional research is needed to characterize the types of tangible support which are provided.

Most participants were medically managed with two medication types and never had surgery, even though around 35% of Ulcerative Colitis and 80% of Crohn's disease patients

eventually require surgery (Bernell, Lapidus, & Hellers, 2000; Crohn's and Colitis Foundation of America, 2010; Ma et al., 2017). Although participants experienced an average of six symptoms, the symptoms had moderate severity and interference with daily activities. Since no comparisons are available in the IBD literature, cancer studies will be used as a comparison. In cancer studies, symptom interventions often occur among individuals whose symptom severity is a 4 or higher indicating moderate or severe symptom severity (Given et al., 2008; Oldenmenger, de Raaf, de Klerk, & van der Rijt, 2013; Zick et al., 2016). The current study had a mean symptom severity of 4.2 and symptom interference of 2.3. Therefore, individuals within this study appeared to have mild to moderate symptom severity and interference which may indicate well-controlled disease, especially since emerging adults typically experience greater symptom severity than older adults. However, a better understanding of symptom cut-points within the IBD population is needed.

Also, a recent diagnosis was associated with increased received social support among cancer research (Arora et al., 2007). Among the emerging adults with IBD recruited for this study, the average time since diagnosis was 6.3 years. These individuals may be better adjusted to the disease and thus receive less social support since IBD coping research has indicated that, when used as a coping mechanism, instrumental and emotional support decrease during the first 6 months of a diagnosis (McCombie et al., 2015). The social support literature, primarily, has not examined condition-specific factors which may influence received social support; this study provides preliminary findings related to this topic to assist in determining disease-specific factors which could be used to screen for low received social support. However, future work is needed to assess the relationship between condition-specific factors and received social support among newly/recently diagnosed and those emerging adults with greater symptom severity and interference.

The majority of emerging adults in the present study with IBD agreed or strongly agreed with the factors of emerging adulthood; yet, emerging adulthood factors were not significantly related to received social support. Age, however, was associated with received social support. Dyad research involving both support providers and support receivers would enhance the literature by examining factors which influence the support providers, the quality of interactions between dyads, and the role of emerging adulthood factors in the receipt of social support. Previous research among emerging adults focused on perceptions of social support and did not include developmental status (Martínez-Hernández, Carceller-Maicas, DiGiacomo, & Ariste, 2016; Pettit, Roberts, Lewinsohn, Seeley, & Yaroslavsky, 2011); the current study expanded the literature by focusing on received social support and incorporated emerging adulthood factors. The low variance of the emerging adulthood factors may account for the lack of relationship.

Limitations

This study has several limitations. First, the study has limited generalizability as the sample was predominantly female and included emerging adults whose disease was well-controlled with minimal symptom severity and interference. Participants were diagnosed for an average of 6.3 years. Emerging adults who were recently diagnosed and experience increased symptom severity and interference may have a different relationship between individual and condition-specific factors and received social support. A selection bias may have occurred in which healthier individuals were more willing to complete the survey. The received social support measurement used within the study was a general measure which may not capture the support items that are specific to IBD. In addition, the recall period of the measures differed with symptoms referring to the past 2 weeks and received social support referring to the past 4 weeks. Finally, the cross-sectional design limits the interpretation of the results.

Conclusion

In conclusion, the factors which influenced received social support differed based on the type of social support. The Individual and Family Self-Management theory applied to IBD examined how individual, condition-specific, and emerging adult factors are related to received social support. Individual factors of age, marital status, and employment were shown to influence total received social support. Age and marital status were related to increased emotional support. Currently taking immunomodulators and biologics, when controlling for time since diagnosis and symptom frequency, was associated with increased tangible support. Finally, emerging adulthood factors were not associated with received social support.

Next steps for research include examining emerging adults with IBD who are recently diagnosed as well as emerging adults with higher symptom severity and interference, as the factors which influence received social support may differ for these groups. A comprehensive examination of the relationship between emerging adulthood factors and received social support among adults with and without chronic conditions would enhance the science of emerging adulthood. Healthcare providers and researchers can be aware of these individual and condition-specific factors that are related to increased received social support and can assist in identifying emerging adults who may be at risk for lower received social support.

This research contributes to science by determining factors within the Individual and Family Self-Management Theory applied to IBD that could identify emerging adults who may benefit from supportive interventions. These findings also advance the science by drawing attention to the types of received social support: informational, emotional, and tangible. Since individual and condition-specific factors influence the types of social support differently, there may be a need to focus on the types of social support in future research. Finally, previous IBD

social support research has primarily focused on perceived availability of social support; this study contributes to enhancing the body of literature on received social support among individuals with IBD.

Table 3.1

Individual Factors among Emerging Adults with Inflammatory Bowel Disease (n=61)

Characteristic	N	%
Sex		
Male	6	9.8
Female	55	90.2
Marital Status		
Single	47	77.1
Married/domestic partnership	14	22.9
Employment Status		
Full-time employed	30	49.2
Part-time employed	10	16.4
Unemployed or student	21	34.4
Education		
High school or less	10	16.4
Some college	16	26.2
Completed college	22	36.1
Graduate or professional degree	13	21.3
	Mean (SD)	Potential range
Age (years)	24.7 (2.9)	18-29

Table 3.2

Condition-specific Factors among Emerging Adults with Inflammatory Bowel Disease (n=61)

Characteristic	N	%
Type of IBD		
Ulcerative Colitis	22	36.1
Crohn's disease	39	63.9
Medication type		
Aminosalicylates	22	36.1
Biologics	37	60.7
Corticosteroids	11	18.0
Immunomodulators	16	26.2
	Mean (SD)	Potential range
Time since diagnosis (months)	76.3 (57.3)	2 – 227
Number of previous surgeries	0.6 (1.4)	0 – 8
Symptoms		
Symptom prevalence (avg. number of symptoms experienced)	5.9 (3.1)	0 – 15
Mean symptom severity	4.2 (1.5)	0 – 9
Mean symptom interference	2.3 (1.5)	0 – 9

Table 3.3

Emerging Adulthood Factors (n=61)

Subscales	Mean (SD)	Potential range
Possibilities/optimism	6.8 (1.4)	2 - 8
Instability	6.9 (1.3)	2 - 8
Identity exploration	6.7 (1.4)	2 - 8
Feeling in-between	6.5 (1.5)	2 - 8

Note: Emerging adults indicated their agreement with experiencing the features associated with emerging adulthood by responding to a 4 level Likert item with options from strongly disagree, somewhat disagree, somewhat agree, and strongly agree. Subscales could range from 2-8. A higher score indicates experiencing more of the dimensions associated with emerging adulthood.

Table 3.4

Levels of Received Social Support among Emerging Adults with Inflammatory Bowel Disease (n=61)

Variable	Sum score (SD)	Sum score potential range	Mean score (SD)	Mean score potential range	Cronbach's alpha
Total received social support (received)	99.4 (29.7)	40 – 200	2.5 (0.7)	1 – 5	0.96
Informational social support (received)	33.0 (12.4)	14 – 70	2.4 (0.9)	1 – 5	0.93
Emotional social support (received)	45.3 (14.3)	14 – 70	3.2 (1.0)	1 – 5	0.94
Tangible social support (received)	21.1 (6.9)	12 – 60	1.8 (0.6)	1 – 5	0.81

Note: Emerging adults indicated how often they received social support within the past month. Responses were on a 5-point Likert scale and included: not at all (=1), once or twice in the past month (=2), about once a week (=3), several times a week (=4), or about every day (=5). A higher score indicates that emerging adults received social support more often.

Table 3.5

Unadjusted and Adjusted Linear Regression Analysis of Individual, Condition-specific, and Emerging Adulthood Factors on Total Received Social Support

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Research Question 1: Individual factors				
Sex (ref: male)				
Female	-1.8 (-27.5, 24.0)	0.892		
Marital Status (ref: single)				
Married/domestic partnership*	14.7 (-3.2, 32.5)	0.105	18.2 (1.0, 35.5)	0.039
Employment Status (ref: full-time employed)				
Part-time employed	0.7 (-20.8, 22.2)	0.948	-3.8 (-23.6, 16.0)	0.703
Unemployed*	-14.0 (-30.7, 2.8)	0.101	-24.1 (-41.3, -6.8)	0.007
Education (ref: high school or less)				
Some college	5.7 (-17.8, 29.1)	0.631		
Completed college	-2.7 (-24.9, 19.5)	0.806		
Graduate or professional degree	-19.64 (-44.1, 4.8)	0.114		
Age (years)*	-2.3 (-4.9, 0.4)	0.091	-4.8 (-7.6, -2.0)	0.001
Constant			104.1 (92.9, 115.3)	0.000
Research Question 2: Condition-specific factors^a				
Type of IBD (ref: ulcerative colitis)				
Crohn's disease	11.8 (-2.3, 26.0)	0.099	7.2 (-8.3, 22.6)	0.355
Medication types				
Biologics (ref: no biologic)	9.3 (-5.0, 23.6)	0.198	6.5 (-8.6, 21.6)	0.392
Immunomodulators (ref: no immunomodulator)	1.1 (-14.9, 17.2)	0.887		
Corticosteroids (ref: no corticosteroid)	5.2 (-13.0, 23.4)	0.572		
Aminosalicylates (ref: no aminosalicylates)	1.4 (-13.4, 16.3)	0.847		
Time since diagnosis (months)	0.1 (-0.03, 0.2)	0.143	0.1 (-0.1, 0.2)	0.357
Number of previous surgeries	3.5 (-1.5, 8.5)	0.162	1.71 (-3.7, 7.1)	0.530
Symptoms				
Symptom prevalence (avg. number of symptoms experienced)	0.6 (-1.8, 2.8)	0.628		
Summed symptom severity	0.003 (-0.3, 0.4)	0.983		

Table 3.5 (cont'd)

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Summed symptom interference	-0.05 (-0.6, 0.5)	0.856		
Constant			94.6 (78.8, 110.4)	0.000
Research Question 3: Emerging adulthood factors^a				
Possibilities	0.8 (-4.7, 6.2)	0.775		
Instability	2.4 (-3.2, 8.0)	0.393		
Exploration	-1.2 (-6.6, 4.3)	0.670		
In-between	2.4 (-2.8, 7.6)	0.353		

^a Regression is controlling for age, marital status, and employment

*statistically significant at p=0.05

Note: The following variables were centered at the mean: age (mean: 24.7), time since diagnosis (mean: 76.3), and surgeries (mean: 0.6).

Table 3.6

Unadjusted and Adjusted Linear Regression Analysis of Individual, Condition-specific, and Emerging Adulthood Factors on Informational Received Social Support

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Research Question 1: Individual factors				
Sex (ref: male)				
Female	0.6 (-10.2 – 11.3)	0.916		
Marital Status (ref: single)				
Married/domestic partnership	0.5 (-7.1, 8.2)	0.889		
Employment Status (ref: full-time employed)				
Part-time employed	0.5 (-8.6, 9.6)	0.913		
Unemployed	-3.4 (-10.5, 3.7)	0.345		
Education (ref: high school or less)				
Some college	4.3 (-5.4, 14.0)	0.377	6.3 (-4.0, 16.6)	0.222
Completed college	1.2 (-8.0, 10.4)	0.797	4.7 (-6.3, 15.6)	0.397
Graduate or professional degree	-7.23 (-17.34, 2.88)	0.158	-2.4 (-15.5, 10.7)	0.717
Age (years)	-1.0 (-2.1, 0.1)	0.068	-0.8 (-2.3, 0.6)	0.252
Constant			30.2 (21.2, 39.2)	0.002
Research Question 2: Condition-specific factors				
Type of IBD (ref: ulcerative colitis)				
Crohn's disease	4.4 (-2.1, 11.0)	0.182	4.4 (-2.1, 11.0)	0.182
Medication types				
Biologics (ref: no biologic)	2.6 (-4.0, 9.1)	0.434		
Immunomodulators (ref: no immunomodulator)	-0.8 (-8.1, 6.5)	0.830		
Corticosteroids (ref: no corticosteroid)	4.4 (-3.8, 12.7)	0.289		
Aminosalicylates (ref: no aminosalicylates)	-1.0 (-7.7, 5.6)	0.760		
Time since diagnosis (months)	0.01 (-0.04, 0.1)	0.680		
Number of previous surgeries	1.1 (-1.1, 3.4)	0.308		
Symptoms				
Symptom prevalence (avg. number of symptoms experienced)	0.3 (-.07, 1.4)	0.555		
Summed symptom severity	-0.001 (-0.2, 0.2)	0.987		
Summed symptom interference	0.02 (-0.2, 0.2)	0.890		

Table 3.6 (cont'd)

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Constant			30.2 (24.9, 35.4)	0.000
Research Question 3: Emerging adulthood factors				
Possibilities	1.1 (-1.3, 3.5)	0.351		
Instability	0.4 (-2.0, 2.8)	0.771		
Exploration	-0.3 (-2.7, 2.1)	0.816		
In-between	1.9 (-0.2, 4.0)	0.069	1.9 (-0.2, 4.0)	0.069
Constant			20.6 (6.7, 34.4)	0.004

Note: Age (mean: 24.7) was centered at the mean.

Table 3.7

Unadjusted and Adjusted Linear Regression Analysis of Individual, Condition-specific, and Emerging Adulthood Factors on Emotional Received Social Support

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Research Question 1: Individual factors				
Sex (ref: male)				
Female	-1.3 (-13.7, 11.1)	0.832		
Marital Status (ref: single)				
Married/domestic partnership*	11.7 (3.5, 20.0)	0.006	14.4 (6.1, 22.8)	0.001
Employment Status (ref: full-time employed)				
Part-time employed	-0.6 (-10.8, 9.6)	0.907		
Unemployed	-8.4 (-16.4, -0.4)	0.039		
Education (ref: high school or less)				
Some college	-1.3 (-12.8, 10.3)	0.829		
Completed college	-2.6 (-13.6, 8.3)	0.631		
Graduate or professional degree	-9.0 (-21.0, 3.1)	0.142		
Age (years)*	-0.7 (-2.0, 0.6)	0.266	-1.4 (-2.6, -0.1)	0.033
Constant			42.0 (38.1, 45.9)	0.000
Research Question 2: Condition-specific factors ^a				
Type of IBD (ref: ulcerative colitis)				
Crohn's disease	5.4 (-1.5, 12.3)	0.126	4.4 (-2.7, 11.5)	0.219
Medication types				
Biologics (ref: no biologic)	3.2 (-3.7, 10.1)	0.352		
Immunomodulators (ref: no immunomodulator)	-3.4 (-11.1, 4.3)	0.376		
Corticosteroids (ref: no corticosteroid)	-0.9 (-9.7, 8.0)	0.841		
Aminosalicylates (ref: no aminosalicylates)	-0.1 (-7.1, 7.0)	0.987		
Time since diagnosis (months)	0.04 (-0.02, 0.1)	0.140	0.04 (-0.03, 0.1)	0.247
Number of previous surgeries	0.6 (-1.8, 3.0)	0.631		
Symptoms				
Symptom prevalence (avg. number of symptoms experienced)	0.04 (-1.1, 1.2)	0.933		
Summed symptom severity	-0.05 (-0.2, 0.1)	0.578		
Summed symptom interference	-0.1 (-0.3, 0.2)	0.506		

Table 3.7 (cont'd)

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Constant			39.0 (33.2, 44.9)	0.000
Research Question 3: Emerging adulthood factors^a				
Possibilities	1.7 (-0.9, 4.3)	0.188	1.5 (-1.0, 4.1)	0.234
Instability	-0.3 (-3.0, 2.4)	0.839		
Exploration	-0.2 (-2.9, 2.4)	0.863		
In-between	1.7 (-0.8, 4.1)	0.173	1.5 (-0.9, 4.0)	0.215
Constant			43.7 (-1.9, 89.4)	0.060

^a Controlling for age and marital status

*statistically significant at p=0.05

Note: The following variables were centered at the mean: age (mean: 24.7) and time since diagnosis (mean: 76.3)

Table 3.8

Unadjusted and Adjusted Linear Regression Analysis of Individual, Condition-specific, and Emerging Adulthood Factors on Tangible Received Social Support

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Research Question 1: Individual factors				
Sex (ref: male)				
Female	-1.0 (-7.0, 5.0)	0.736		
Marital Status (ref: single)				
Married/domestic partnership	2.4 (-1.8, 6.6)	0.260		
Employment Status (ref: full-time employed)				
Part-time employed	0.8 (-4.3, 5.9)	0.754		
Unemployed	-2.2 (-6.1, 1.8)	0.276		
Education (ref: high school or less)				
Some college	2.6 (-2.9, 8.0)	0.347	3.4 (-2.5, 9.2)	0.254
Completed college	-1.3 (-6.4, 3.9)	0.621	0.04 (-6.2, 6.3)	0.990
Graduate or professional degree	-3.4 (-9.1, 2.3)	0.231	-1.6 (-9.1, 5.8)	0.666
Age (years)	-0.5 (-1.1, 0.1)	0.095	-0.3 (-1.1, 0.5)	0.443
Constant			20.5 (15.4, 24.6)	0.003
Research Question 2: Condition-specific factors				
Type of IBD (ref: ulcerative colitis)				
Crohn's disease	3.0 (-0.6, 6.7)	0.101		
Medication types				
Biologics (ref: no biologic)*	4.3 (0.8, 7.8)	0.018	5.4 (2.0, 8.8)	0.002
Immunomodulators (ref: no immunomodulator) *	5.1 (1.3, 9.0)	0.01	19.8 (11.4, 28.1)	0.000
Corticosteroids (ref: no corticosteroid)	0.01 (-4.7, 4.7)	0.996		
Aminosalicylates (ref: no aminosalicylates)	-2.0 (-6.6, 0.8)	0.118		
Biologics x Immunomodulators*			-19.0 (-28.2, -9.7)	0.000
Time since diagnosis (months)	0.02 (-0.006, 0.1)	0.114	0.02 (-0.005, 0.04)	0.125
Number of previous surgeries	1.2 (0.01, 2.4)	0.047		
Symptoms				
Symptom prevalence (avg. number of symptoms experienced)	0.3 (-0.3, 0.9)	0.283		
Summed symptom severity	0.04 (-0.1, 0.1)	0.453		

Table 3.8 (cont'd)

Variable	Unadjusted		Adjusted	
	Coeff. (95% CI)	P value	Coeff. (95% CI)	P value
Summed symptom interference	0.1 (-0.04, 0.2)	0.180	0.07 (-0.03, 0.2)	0.169
Constant			15.8 (13.0, 18.6)	0.000
Research Question 3: Emerging adulthood factors^a				
Possibilities	0.9 (-0.3, 2.0)	0.127	0.7 (-0.5, 1.8)	0.234
Instability	0.5 (-0.6, 1.6)	0.356		
Exploration	-0.3 (-1.1, 1.1)	0.956		
In-between	0.8 (-0.2, 1.8)	0.106	0.7 (-0.3, 1.8)	0.193
Constant			2.5 (-11.9, 16.9)	0.734

^a Controlling for biological medication, immunomodulator medication, time since diagnosis, and symptom interference.

*statistically significant at p=0.05

Note: The following variables were centered at the mean: age (mean: 24.7), time since diagnosis (mean: 76.3), and summed symptom interference (mean: 15.8).

Table 3.9

Interaction between Immunomodulators and Biological Medication for Tangible Received Social Support

Medication Status	Total Tangible Received Social Support (95% Confidence Interval)
Immunomodulator only	36.7 (28.8, 44.7)
Immunomodulator plus biologic	23.2 (20.0, 26.2)
Biological only	22.4 (20.0, 24.8)
Not immunomodulator or biologic	17.0 (14.6, 19.4)

Note: Adjusted for time since diagnosis (mean: 76.3) and symptom interference (mean: 15.8) which were centered at the mean. Emerging adults on immunomodulator medication alone have the greatest receipt of tangible social support.

CHAPTER 4: RECEIVED AND PERCEIVED AVAILABILITY OF SOCIAL SUPPORT AND SELF-MANAGEMENT BEHAVIORS AMONG EMERGING ADULTS WITH INFLAMMATORY BOWEL DISEASE

Introduction

Inflammatory bowel disease (IBD) including ulcerative colitis and Crohn's disease is a chronic condition without a cure that can be managed through medication, surgery, and daily routines (Kaplan, 2015). Patients commonly experience symptoms of diarrhea, abdominal pain, cramping, blood in stool, and fatigue (Farrell, McCarthy, & Savage, 2016). The disease course includes relapsing and remitting stages in which the patient cycles through periods of feeling better and then worse (Kaplan, 2015). The goal of IBD management is to treat symptoms, induce "deep remission" (mucosal healing), and improve health-related quality of life (Levesque et al., 2015). To meet these goals, patients may engage in a variety of self-management behaviors both with and without healthcare providers (Plevinsky, Greenley, & Fishman, 2016). Self-management can be a challenging task especially for emerging adults, individuals ages 18 – 29, who are becoming responsible for the management of their own disease at a time in which they are also facing numerous developmental transitions (Arnett, 2000, 2015). In addition, emerging adults face increased disease activity with greater symptoms and disease complications compared to older adults (Goodhand et al., 2010; Grover, De Nardi, & Lewindon, 2017; Liverani, Scaioli, Digby, Bellanova, & Belluzzi, 2016; Torres et al., 2016; Van Limbergen et al., 2008). As a result of the complex disease trajectory and complications, emerging adults with IBD experience decreased health-related quality of life (HRQoL) and increased morbidity compared to older adults (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016). Thus, there is

a need to examine emerging adulthood within the IBD literature and determine which factors influence critical self-management behaviors.

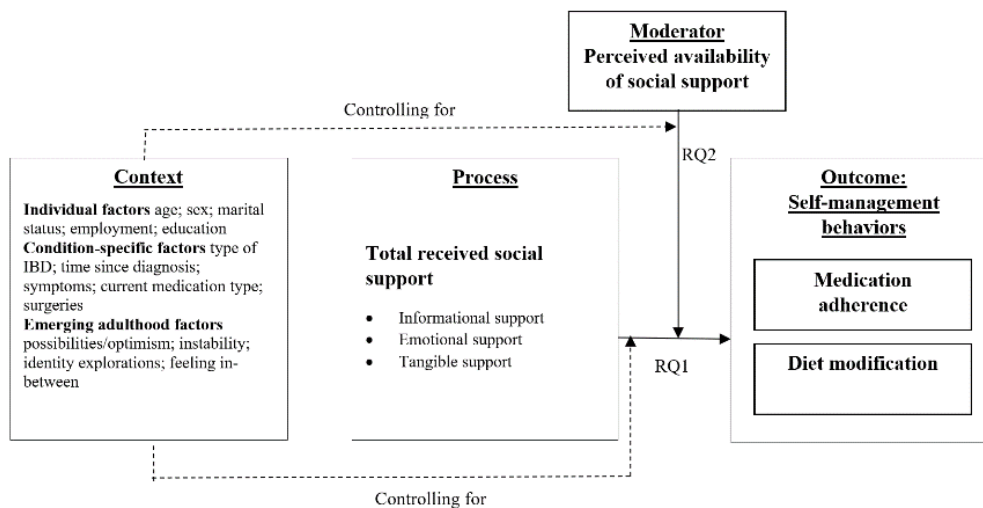
Two of the main self-management behaviors are medication adherence and diet modification. Systematic reviews have identified a positive relationship between social support, supportive behaviors obtained or available if needed, and self-management behaviors, but little is published in the IBD literature. The lack of knowledge on social support and various age groups prevents the advancement of tailored interventions to address self-management behaviors. Thus, there is a need to examine the relationship between social support and self-management behaviors of medication adherence and diet modification among emerging adults to determine the role of social support in promoting or hindering self-management behaviors. The purpose of this study was to examine the relationship between social support and self-management behaviors among emerging adults with IBD.

Findings of a systematic review indicated the majority of social support research among IBD patients focuses on middle age adults (40-60 years; Kamp et al., 2018). Social support and self-management behaviors may differ among an emerging adult population compared to older adults since emerging adults experience life transitions such as starting a job or college and becoming a spouse/partner and/or parent (Arnett, 2000; Trivedi & Keefer, 2015). Although these transitions occur in other developmental stages, they are more prevalent and prominent in emerging adulthood (Arnett, 2015). These changing social roles may influence an emerging adult's ability to receive social support and their perceptions of available support and, therefore, emerging adults may be in need of unique supportive interventions during this developmental stage (Benson & Elder, 2011; Heinze, Kruger, Reischl, Cupal, & Zimmerman, 2015; Mattanah et al., 2010; Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013).

Background

Guiding this study, the Individual and Family Self-Management Theory (IFSMT) applied to IBD is a framework that presents self-management as a complex and dynamic phenomenon and can guide an exploration of the relationship between social support and self-management among IBD individuals. The model has three primary dimensions: context, process, and outcomes (Ryan & Sawin, 2009). Select variables were chosen from the IFSMT in order to focus on individual self-management and outcomes specific to IBD. The adapted model is referred to as the Individual and Family Self-Management Theory applied to IBD. The theoretical underpinnings of the model hypothesize several pathways between process and outcomes when controlling for context: a) process factors impact outcomes; and b) the relationship between process and outcomes is moderated by perceived availability of social support which is an individual's perception that social support is available if needed.

Figure 4.1: Individual Self-Management Theory applied to IBD: Process and Outcomes



Context

The Individual Self- Management Theory applied to IBD (Figure 4.1) will be used within the context of individual, condition-specific, and emerging adulthood factors. The individual

factors are specific to the individual and include age, sex, marital status, employment, and education. Condition-specific factors are related to the disease, IBD, and include type of IBD, time since diagnosis, symptoms (including frequency, severity and interference), current medication use, and surgeries.

Emerging adulthood is a developmental stage characterized by: possibilities/optimism (when hopes flourish and people have an unparalleled opportunity to transform their lives), instability (in love, work, and place of residence), identity explorations (answering the question “who am I?” and trying out various life options, especially in love and work), and feeling in-between (in transition, neither adolescent nor adult; Arnett, 2015; Arnett, Watts, & Ghosh, 2002). Previous research on emerging adults with chronic conditions, although somewhat limited, has identified that individuals in emerging adulthood have difficulties with self-management and negative health outcomes (Majumder, Cogen, & Monaghan, 2017; Monaghan, Helgeson, & Wiebe, 2015; Park, Paul Mulye, Adams, Brindis, & Irwin, 2006). In addition, emerging adults with IBD often experience greater disease-related symptoms, stricture and fistula complications, and advanced treatment compared to individuals diagnosed at older ages (Goodhand et al., 2010; Liverani et al., 2016; Torres et al., 2016; Van Limbergen et al., 2008). This difference may be due to younger adults being more likely to be non-adherent to medication compared to older adults, even though younger adults are more likely to have active disease (Severs et al., 2017; Weizman et al., 2012). The developmental stage of emerging adulthood may influence self-management behaviors due to the life priorities and understanding of treatment necessity among emerging adults (Butow et al., 2010). Therefore, emerging adulthood factors were added as a separate context factor to better understand this relationship. Other individual and condition-specific factors have also been associated with self-management behaviors

(Coenen et al., 2016; Severs et al., 2017). Contextual factors will be controlled for within the analysis.

Process

Received social support is the key process component and consists of three types: informational, emotional, and tangible social support. The original IFSMT identifies processes that can influence engagement in self-management behaviors. These include knowledge and beliefs, self-regulation skills and abilities, and social facilitation (Ryan & Sawin, 2009). Within the IBD literature, researchers have examined the concepts of knowledge, beliefs and self-regulation (Conley & Redeker, 2016; Eaden, Abrams, & Mayberry, 1999; Keefer, Kiebles, & Taft, 2011). Social facilitation (which includes social influence, social support, and negotiated collaboration) has been less often studied within the IBD population even though increased social support has been associated with improved self-management behaviors among adults in the general literature (DiMatteo, 2004; Gallant, 2003; Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012). Received social support, particularly among emerging adults with chronic conditions, has the potential to influence self-management behaviors. Yet, little is known regarding the relationship between received social support, the actual supportive behaviors an individual obtains, and self-management behaviors within the IBD population.

Received social support is important to study since most social support interventions focus on improving received social support. Received social support can be separated into types of social support: informational support (providing information or advice), emotional support (conveying encouragement and comfort), and tangible support (providing physical assistance with tasks; Lakey & Cohen, 2000). Each type of social support may influence self-management behaviors through different methods. Examining both specific types and overall received social

support in relationship to self-management behaviors is needed to design targeted self-management interventions.

The instability of emerging adulthood may influence the relationship between received and perceived availability of social support and self-management behaviors since emerging adults may not receive as much social support or they may not perceive that social support is available compared to older adults (Arnett, 2000, 2015). Thus, it is necessary to examine the relationship between received social support and self-management behaviors within the context of emerging adulthood.

Moderation

Perceived availability of social support, an individual's perception that social support is available if needed, has been associated with self-management behaviors of medication adherence and diet modification among individuals with chronic conditions (Boger et al., 2015; DiMatteo, 2004; Gariepy, Honkaniemi, & Quesnel-Vallee, 2016; Hand, Law, McColl, Hanna, & Elliott, 2014; Zhang, Norris, Gregg, & Beckles, 2007). Perception refers to an individual's unique method of viewing a phenomenon (such as social support) which includes incorporating memories of past experiences (McDonald, 2012). The relationship between received social support and self-management behaviors may be increased in the presence of higher perceived availability of social support (Cohen, Underwood, & Gottlieb, 2000; Uchino, 2004), and this interaction has the potential to influence self-management behaviors (Melrose, Brown, & Wood, 2015). Perceived availability of social support is generally stable over time and therefore may serve to strengthen the relationship between received social support, which has the potential to vary, and self-management behaviors (Sarason, Sarason, Shearin, & Pierce, 1987; Uchino, 2004,

2009). Research is needed to examine both received and perceived availability of social support within the context of self-management behaviors among emerging adults with IBD.

Outcomes

Self-management behaviors are day-to-day management of chronic disease and often include medication adherence and diet modification (Grady & Gough, 2014; Ryan & Sawin, 2009). Medication adherence is defined as a patient taking medication as prescribed (Horne & Weinman, 2002). IBD patients take a variety of medication types including biologics, aminosalicylates, corticosteroids, and immunomodulators (Crohn's & Colitis Foundation, 2017). The regimen complexity is dependent on disease severity with some individuals needing multiple medication types. Medication adherence leads to positive health outcomes, such as fewer symptoms and complications, and decreased healthcare costs among adults with chronic diseases (Simpson et al., 2006).

Diet modification is altering food intake to control symptoms, manage disease, and improve quality of life (Charlebois, Rosenfeld, & Bressler, 2016; Lee et al., 2015). Younger IBD patients may be more likely to engage in diet modification than older patients for reasons not yet understood (Weizman et al., 2012). However, providers have been hesitant to provide recommendations due to the lack of a dietary gold standard, even though some dietary studies have shown benefits in reducing symptoms (Aleksandrova, Romero-Mosquera, & Hernandez, 2017; Holt, Strauss, & Moore, 2016; Lee et al., 2015). Though most gastroenterologists focus on medication adherence, many IBD patients consider diet modification crucial to symptom management since patients have experimented with diet and have self-reported symptom relief (Suskind et al., 2016). To address the concerns of both patients and gastroenterologists, the self-

management behaviors of provider-recommended medication adherence and patient-initiated diet modification should be examined together.

In summary, self-management behaviors of medication adherence and diet modification are critical to improving symptoms and decreasing disease activity among emerging adults with IBD (Charlebois et al., 2016; Lee et al., 2015; Simpson et al., 2006). Evidence suggests that receiving social support may impact self-management behaviors and that perceived availability of social support may buffer (moderate) this relationship (Cohen et al., 2000; Melrose, Brown, & Wood, 2015; Uchino, 2004); however, research is needed to examine this relationship among emerging adults with chronic conditions who may differ from older adults.

Research Questions

The purpose of this study was to examine the relationship between social support and self-management behaviors among emerging adults with IBD.

Research Question 1: Among emerging adults with IBD, what is the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?

Research Question 2: Among emerging adults with IBD, does perceived availability of social support moderate the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?

Methods

Design

A cross-sectional study was conducted using an online survey among emerging adults with IBD who were currently using medication to manage their disease. Data were collected between January 2018 – February 2018.

Sample and Recruitment

Participants were recruited online using ResearchMatch, Facebook, and word of mouth. ResearchMatch is funded by the National Institutes of Health and the Clinical and Translational Science Award program and includes a database of individuals who have expressed interest in participating in research studies. Anyone is able to join ResearchMatch as a participant, but only researchers from approved universities can use ResearchMatch. Both participants and researchers have secure password protected accounts. After obtaining institutional review board approval (see Appendix I for institutional review board approval letter), a researcher can upload a recruitment message to the site. An institutional liaison reviews the information and provides approval to contact participants. Researchers search by eligibility criteria (e.g., age and disease status).

In the present study, individuals meeting the criteria received the recruitment message (see Appendix C) and decided whether or not to share their contact information with the researchers. Individuals interested in the study received an email with a link to the survey (Appendix D). Recruitment messages with the survey link were shared using Facebook groups and advertisements. Potential participants were encouraged to share the survey.

Individuals were eligible for the study if they were emerging adults (ages 18 – 29) with a self-reported healthcare provider diagnosis of ulcerative colitis or Crohn's disease, lived in the

United States, understood written English, had access to the internet, and were currently prescribed medication to manage their IBD. Exclusion criteria was hospitalization within the past month or currently pregnancy. Participants completed the screening questions online and the Qualtrics software calculated which participants met the inclusion/exclusion criteria and allowed these participants to proceed to the survey (see Appendix F: Screening Criteria Table).

Data Collection and Ethical Considerations

Data were collected online through Qualtrics. The first page of the survey included the informed consent introducing participants to the purpose of the study, explaining the research was voluntary, and informing that they could stop completing the survey at any time (see Appendix E for informed consent). Participants indicated consent by continuing with the survey. Participants were able to contact researchers via phone, text, or email if they had questions (see Appendix H for contact message). Two participants emailed the researcher asking about compensation; compensation was not provided. Screening data were mandatory to ensure that participants met the inclusion and exclusion criteria. All data were stored securely on password protected databases. Personal identifiable information was not collected. The datasets included raw data and scores for subscales and total scales. All data will be archived, according to university policy (<http://rio.msu.edu/research-data>).

Measurements

All investigator-designed measurements underwent pre-testing using a cognitive interviewing procedure. This procedure led to the addition of more detailed instructions and clarified the timeframe of the questions. For example, a timeframe of “in the past 2 weeks” was added for the symptom questions. See Appendix H for survey questions.

Individual factors. Individual factors include age, sex (male/female), marital status (single/married), employment (full-time employment/part-time employment/unemployed or student), and education (high school or less/some college/completed college/graduate or professional degree). See Appendix G for information on individual factors, level of measurement, and scoring information.

Condition-specific factors. Condition-specific factors include type of IBD (ulcerative colitis/ Crohn's disease), time since diagnosis (measured as months since patient was diagnosed with IBD by a provider), symptoms (prevalence, severity, and interference), medications currently using (biologics, immunomodulators, corticosteroids, and/or aminosalicylates), and number of surgeries for IBD. See Appendix G for information on condition-specific factors, level of measurement, and scoring information.

Symptoms were measured using a modified Cancer Symptom Inventory (Given et al., 2008). The specific symptoms were modified to include those associated with IBD: diarrhea, constipation, abdominal pain, abdominal tenderness, abdominal cramps, bloating, passing gas, blood in your stool, weight loss, weight gain, reduced appetite, increased appetite, nausea or vomiting, fatigue, and fever (Singh et al., 2011). If participants experienced the symptom within the past two weeks (prevalence), participants rated the symptom at its worst (severity) and how much the symptom interfered with daily life (interference) on 0-9 point scale. Three symptom components were reported: prevalence (potential range: 0 – 15), severity (potential range: 0 – 135), and interference (potential range: 0 – 135).

Emerging adulthood factors. Emerging adulthood factors were measured with the short form of the Inventory of Dimensions of Emerging Adulthood (IDEA) that measures psychological issues associated with emerging adulthood (Stéphanie, Katia, Joseph, & Gerhard,

2014). Participants were asked to think of a five-year period and respond to questions such as: “is this period of your life a time of many possibilities?” on a 4-point Likert scale (strongly disagree, somewhat disagree, somewhat agree, and strongly agree). The 8-item short form contains four (of the 5) emerging adulthood subscales (potential range: 2 – 8): possibilities/optimism, instability, identity exploration, and feeling in-between. Participants receive a score for each subscale. A higher score indicates that an individual is experiencing more of the features associated with emerging adulthood.

Received social support. Received social support is the supportive behaviors that an individual obtains and was measured by the Inventory of Socially Supportive Behaviors (ISSB). The ISSB is a 40-item self-report scale in which participants rate how often activities occurred during the past four weeks such as someone “provided you with some transportation” or “told you who you should see for assistance.” Subscales measure specific types of support: informational support (guidance; 14 items, potential range: 14 – 70), emotional support (14 items, potential range: 14 – 70), and tangible support (12 items, potential range: 12 – 60; Stokes & Wilson, 1984). The instrument uses a 5-point Likert scale (1=not at all, 2=once or twice, 3=about once a week, 4=several times a week, and 5=about every day). The original instrument was found to have good psychometric properties with an overall Cronbach’s alpha of 0.93 (Barrera, Sandler, & Ramsay, 1981). Both a total score (potential range: 40-200) and subscales were calculated as a sum score with a higher value indicating greater received social support. Scores were dichotomized into high and low received social support based on distribution.

Perceived availability of social support. Perceived availability of social support is an individual’s perception that support is available if needed and was measured using the 18-item Medical Outcomes: Social Support Survey (MOS-SS). Questions asked about how often in the

past two weeks support is available to you if you needed it including “someone to confide in or talk to about yourself or your problems” or “someone to take you to the doctor if you needed it.” The MOS-SS subscales measure specific types of support: emotional/informational (8 items), tangible/instrumental (4 items), affectionate (3 items), and positive social interaction (3 items). The instrument uses a 5-point Likert scale in which 1=none of the time, and 5=all of the time. The original instrument was found to have good psychometric properties with an overall Cronbach’s alpha of 0.97 and subscale Cronbach’s alphas ranging from 0.91 to 0.96 (Sherbourne & Stewart, 1991; Giangrasso & Casale, 2014). Although the MOS-SS has been used within the IBD population, Cronbach’s alpha has not been reported (Moskovitz, Maunder, Cohen, McLeod, & MacRae, 2000; Rogala et al., 2008). For descriptive statistics, total score and subscale scores will be calculated; a higher score indicates a greater perception that support is available if needed. For regression analysis, a total score was calculated as a sum score (potential range: 18 – 90); the score was dichotomized, based on the 50th percentile, into low perceived availability of social support and high perceived availability of social support to assist in interpretation of the interaction.

Self-management behaviors. Self-management behaviors are defined as the day-to-day management of IBD carried out by the individual and, for this study, include medication adherence and diet modification.

Medication adherence is whether patients use their medication as prescribed by a provider and will be examined with the 4-item Medication Adherence Report Scale (MARS; Horne & Weinman, 2002). Participants report agreement with four statements such as “I decided to miss a dose of these IBD medicines.” Responses are on a 5-point Likert scale ranging from 1=always to 5=never. A sum score is calculated and ranges from 4 to 20; a higher score indicates

higher level of adherence. For analysis, a dichotomous score was used, which is consistent with previous IBD literature. Participants with a score of 4 – 16 will be classified as low adherers (=0) and scores of 17-20 will be classified as high adherers (=1) according to previous IBD research (Ediger et al., 2007; Horne, Parham, Driscoll, & Robinson, 2009; Jeganathan et al., 2017; Tiao et al., 2017).

Diet modification was defined as an individual's alteration of food intake and measured by the Dietary Screener Questionnaire (Charlebois et al., 2016; Thompson, Midthune, Kahle, & Dodd, 2017). The questionnaire includes 19 food-group items and 7 subscales: fruits and vegetables, dairy, whole grains, added sugars, sugar-sweetened beverages, meat, and dietary fiber. The questions ask participants to rate how often each item was consumed in the past month. Participants can select number of times consumed per day, week, or month. The questionnaire has been validated by a 24-hour food recall and scoring algorithms were developed to predict intake (Thompson et al., 2017). For each item, participants were asked to respond to the following statement: "I alter my intake of [name of food item] due to my IBD" based on a 5-point Likert scale ranging from never to always. Responses were averaged for each subscale (potential range: 1-5) and participants reporting never or rarely were recoded to 0=no diet modification; participants reporting sometimes, often, or always were recoded to 1=diet modification. Subscales were added to create a total diet modification score (potential range: 0 – 7; a higher score indicating greater diet modification). The total score was dichotomized into individuals who do not modify their diet (0-2) and individuals who modify their diet (3-7).

Data Analysis

STATA 15.0 was used for data analysis. Patterns of missing data were examined. Descriptive analysis of the results were performed using numbers and percentages for the

categorical variables of sex, marital status, employment status, ethnicity, education, type of IBD, and medication type. Mean and standard deviation were used for the continuous variables of age, time since diagnosis, previous surgeries, symptom prevalence, summed symptom severity, summed symptom interference, received social support, and perceived availability of social support. Separate logistic regression models were built for each self-management behavior and each social support subscale.

The logistic regression models were built based on the stepwise process of purposeful selection of covariates as outlined in Hosmer, Lemeshow, and Strudivant (2013).

Research Question 1: *Among emerging adults with IBD, what is the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?* First, univariable logistic regressions were conducted and those with a p-value of <0.25 were included in an initial multivariable model. Variables not reaching the traditional level of significance ($p < 0.05$) were removed from the model. A reduced model was fit and using the likelihood ratio test compared to the initial model. The independent variables not selected for the initial model in the first step were added one at a time into the reduced model and tested for significance (preliminary main effects). Variables with $p < 0.05$ were included in the model since the variable provided a contribution in the presence of the other variables. Once the main effects model was determined, step four involved checking for linearity assumption. The final step evaluated the model adequacy and fit using the Hosmer-Lemeshow test. For research question 1 (main effects model), an increase in received social support is hypothesized to lead to an increase in self-management behaviors.

Research Question 2: *Among emerging adults with IBD, does perceived availability of social support moderate the association between received social support and self-management*

behaviors (medication adherence and diet modification) while controlling for contextual variables? First, univariable logistic regressions were conducted and those with a p-value of <0.25 were included in an initial multivariable model. Second, variables that did not meet the traditional level of significance ($p<0.05$) were removed from the model. A reduced model was fit and using the likelihood ratio test compared to the initial model. Third, the independent variables not selected in step one were added one at a time into the reduced model and tested for significance (preliminary main effects). Variables with $p<0.05$ were included in the model since the variable provided a contribution in the presence of the other variables. Once the main effects model was determined, step four involved checking for linearity assumption. Step five assessed interactions between covariates. The final step was to evaluate the model adequacy and fit using the Hosmer-Lemeshow test. The final model without the interaction term between received social support and perceived availability of social support was compared to the final model with interaction. For research question 2 (moderation model), a high level of perceived availability of social support is hypothesized to strengthen the relationship between received social support and self-management behaviors, thus the models with interaction will be reported regardless of statistical significance.

Results

Participant Characteristics

Emerging adults had a mean age of 24.7 ($SD = 2.9$, range: 18-29). The sample was primarily female ($n=55$, 90%), single ($n=47$, 77%), full-time employed ($n=30$, 49%), and diagnosed with Crohn's disease ($n= 39$, 64%). Medication types included biologics ($n=37$, 61%), aminosalicylates ($n=22$, 36%), immunomodulators ($n=16$, 26%) and corticosteroids ($n=11$, 18%). See Appendix J for specific medications used. Seventy three percent were adherent to

their medication; emerging adults who were adherent to their medication were more likely to have a shorter time since diagnosis ($M = 64.3$, $SD = 50.2$) compared to individuals who were non-adherent ($M = 110.0$, $SD = 64.0$; $t(59) = 2.9$, $p = 0.005$). Sixty-four percent of participants ($n=39$) reported modifying their diet. Of those modifying their diet, the most commonly modified food groups included: fruits and vegetables ($n=41$, 67%), fiber ($n=40$, 65%), dairy ($n=37$, 61%), and grains ($n=37$, 61%). There was no statistically significant relationship between medication adherence and diet modification ($p = 0.456$). See Table 4.1 for individual, condition-specific, and emerging adulthood factors.

Both perceived availability of social support and received social support were reported on a 5-point Likert scale. Participants reported higher total perceived availability of social support ($M = 3.9$, $SD = 1.0$) compared to total received social support ($M = 2.5$, $SD = 0.7$). Within received social support, participants reported the greatest amount of emotional received social support ($M = 3.2$, $SD = 1.0$) and the least amount of tangible received social support ($M = 1.8$, $SD = 0.6$). Within perceived availability of social support, participants reported the greatest amount of perceived availability of affectionate social support ($M = 4.1$, $SD = 1.3$) and the least amount of perceived availability of tangible/instrumental social support ($M = 3.7$, $SD = 1.3$), although perceived availability of social support subscales were consistent with a small range from 3.7 – 4.1. Total perceived availability of social support and received social support had a correlation of 0.54 ($p < 0.001$). Mean, ranges, and Cronbach's alpha on received and perceived availability of social support can be found in Table 4.2

Preliminary Analysis

To control for contextual variables within the research questions, the individual, condition-specific, and emerging adulthood factors which influenced the self-management

behaviors (medication adherence and diet modification) were determined. For the medication adherence model, the use of biological medication ($p = 0.026$), decreased time since diagnosis ($p = 0.006$), increased symptom frequency ($p = 0.022$), and feeling in-between ($p = 0.038$) significantly influenced medication adherence (Hosmer-Lemeshow $\chi^2(8) = 5.5$, $p = 0.7029$). Therefore, these variables were controlled for when assessing the relationship between received social support and medication adherence. For the diet modification model, no individual, condition-specific, or emerging adulthood factors were found to influence diet modification; therefore, these factors were not controlled for within the regression model.

Research Question 1: Main effect model

For the medication adherence model, emerging adults with high informational support reported greater medication adherence ($p=0.023$) compared to emerging adults with low informational support when controlling for context factors of biological medication, time since diagnosis, symptom frequency, and the emerging adulthood factor of feeling in-between adolescence and adulthood (Hosmer-Lemeshow $\chi^2(8) = 6.38$, $p = 0.605$). High total received social support ($p = 0.575$), high emotional received social support ($p = 0.804$), and high tangible received social support ($p = 0.741$) were not significantly associated with improved medication adherence when controlling for context factors. See Table 4.3 for the association between total and subscales of received social support and medication adherence.

For the diet modification model, high total received social support ($p = 0.38$), high informational received social support ($p = 0.923$), high emotional received social support ($p = 0.383$), and high tangible received social support ($p = 0.437$) were all not statistically significantly associated with diet modification. See Table 4.4 for the association between total and subscales of received social support and diet modification.

Research Question 2: Moderating model

Interactions between received social support (total and subscale) and perceived availability of social support were used to determine if perceived availability of social support was an effect modifier. Perceived availability of social support did not modify the relationship between received social support and self-management behaviors of medication adherence and diet modification. The relationship between high informational received social support and diet modification ($p=0.024$) remained significant when controlling for high perceived availability of social support ($p=0.85$). However, when including the interaction between high informational received social support and high perceived availability of social support ($p=0.517$), the relationship between high informational received social support and medication adherence became non-significant ($p=0.129$). See Table 4.3 for medication adherence and Table 4.4 for diet modification.

Discussion

The purpose of this study was to examine the relationship between social support and self-management behaviors among emerging adults with IBD. High informational received social support was associated with medication adherence compared to low informational received social support. Received social support was not associated with diet modification.

Within the process dimension of the model, high informational received social support compared to low informational received social support was associated with medication adherence. Systematic reviews among individuals with chronic conditions have identified the importance of tangible received social support and medication adherence; this relationship was not found in the current study focused on emerging adult IBD patients (DiMatteo, 2004; Scheurer et al., 2012). The previous systematic reviews have focused on older adults. Within an

emerging adult population, tangible social support was not associated with medication adherence. Tangible support may be less influential due to emerging adulthood being a time of identity explorations; receiving tangible support could limited feelings of autonomy among emerging adults. In addition, emerging adults may simply need less tangible support than older adults. Informational received social support may enable the emerging adult to obtain support while still feeling empowered to make independent decisions. However, this should be further examined as research has also indicated that informational support can threaten self-esteem (MacGeorge, Feng, & Thompson, 2008). Additional research is needed to better understand the reasons that informational support appears to be related to medication adherence among emerging adults and tangible support is related to medication adherence among older adults. In summary, improving informational received social support may serve as one method to improve medication adherence among emerging adults with IBD.

The interaction term indicates that the relationship between high informational received social support and medication adherence became non-significant in the presence of high perceived availability of social support. This is most likely because high perceived availability of social support was trending towards being related to medication nonadherence, although this observation should be interpreted with caution as perceived availability of social support was not statistically significantly related to medication adherence. Increased perceived availability of social support may hinder self-management behaviors among an emerging adult population and therefore researchers should carefully consider the conceptualization and measurement of social support within the emerging adult population. Although most social support and health research focuses on perceptions of social support, these findings might indicate that high perceptions of

social support may not necessarily be related to self-management behaviors although additional research is needed to confirm this.

When examining the contextual dimensions of the model, i.e., individual, condition-specific, and emerging adulthood factors that also influence medication adherence, individual factors were not associated with medication adherence. Condition-specific factors of biological medication, decreased time since diagnosis, and increased symptom frequency were associated with improved medication adherence. Emerging adults may be more adherent to biological medications compared to other medication types for multiple reasons. Biological medications comprise the most expensive category of IBD medications (Yu et al., 2018). Therefore, skipping or missing a dose represents a large cost burden to the emerging adults. In addition, biologic medications have a lower dosing frequency and different administration modes including injections and intravenous administrations compared to other IBD medication types (immunomodulators and aminosalicylates). For instance, Humira (adalimumab), the most commonly used biologic in the emerging adulthood sample, is administered via injection every two weeks (AbbVie, 2017); decreased dosing can lead to improved medication adherence (Coleman et al., 2013; Iglay et al., 2015). Emerging adults who have a shorter time since diagnosis may view their disease as a greater health threat than emerging adults with a longer time since diagnosis and therefore are more engaged in disease management. As the disease progresses, emerging adults may experience greater medication side effects which may increase concerns about the medication. Furthermore, IBD medications have the potential to lose effectiveness even among adherent patients (Dalal & Cohen, 2015). Emerging adults who experienced a greater number of symptoms (increased symptom frequency) were more likely to be adherent to medication. A previous integrative review indicated that symptoms are the most

important factor influencing patients' decisions regarding IBD management (Kamp & Brittain, 2018). Condition-specific factors, but not individual factors, were related to medication adherence among emerging adults with IBD.

Furthermore, the emerging adulthood factor of decreased levels of feeling in-between was associated with improved medication adherence. This is one of the first known studies to examine emerging adulthood factors that may influence medication adherence within the IBD population. The emerging adulthood factor of feeling in-between is the transition in which an emerging adult is neither an adolescent nor an adult (Arnett, 2000, 2015). Previous research has identified that younger adults, in terms of chronological age, are more likely to be non-adherent to medication (Coenen et al., 2016; Severs et al., 2017). The current study did not identify age as a significant predictor; however, emerging adults who felt in-between adolescence and adulthood were more likely to be non-adherent to medication. Emerging adults who are in-between may feel they are not responsible for disease management. The condition-specific and emerging adulthood factors, use of biological medication, time since diagnosis, symptom frequency, and feeling in-between, can be used by providers to identify emerging adults who may be in need of additional informational support or other interventions aimed at improving medication adherence.

The majority of the sample reported modifying their diet; yet, received and perceived availability of social support were not associated with diet modification. Previous research in other populations has shown both positive and negative associations between social support and diet modification. Dietary research among cancer survivors has shown that increased social support is associated with greater fruit and vegetable intake (Coleman, Berg, & Thompson, 2014) although other research has identified that family dietary patterns can serve as a barrier to

eating healthy (Crookes et al., 2016). Emerging adults, in general, are known to have decreased dietary quality due to an increase in caloric beverages and snacks and a decrease in fruits and vegetables (Blondin et al., 2015). In fact, consumption of food and beverages increases when emerging adults perceive their friends regularly consume those same food and beverage; therefore, there is the potential that the source of social support, rather than type of social support, may have a greater influence on diet modification (Pelletier, Graham, & Laska, 2015). Furthermore, diet modification may be more strongly influenced by internal factors such as autonomous (intrinsic) motivation, a sense of choice in which individuals engage in an activity due to satisfaction, interest, or challenge (Badh et al., 2015; Silvia et al., 2010). Autonomous motivation has been found to regulate food choices (Hartmann, Dohle, & Siegrist, 2015; Marta et al., 2009); therefore, autonomous motivation may have a stronger association with diet modification.

Although sixty-three percent of the sample engaged in diet modification, individual, condition-specific and emerging adulthood factors examined in this study were not associated with diet modification. Hence, it appears as though emerging adults with a variety of individual characteristics and condition-specific factors are engaging in diet modification; little is known regarding what influences an emerging adult with IBD to modify their diet. Current IBD diet research has focused on diet and disease development (Ananthakrishnan et al., 2015; Rashvand, Behrooz, Samsamikor, Jacobson, & Hekmatdoost, 2018) as well as diet modification and symptom and flare reduction (Barnes, Nestor, Onyewadume, de Silva, & Korzenik, 2017; Charlebois et al., 2016; Lee et al., 2015; Olendzki et al., 2014; Wong, Harris, & Ferguson, 2016). In addition, research teams are beginning to examine the relationship between diet, other environmental factors, and treatment outcomes (Andersen, Hansen, & Heitmann, 2017;

Christensen et al., 2018). Other factors, such as beliefs about diet or the cause of IBD, may be key to understanding the types of emerging adults who are engaging in diet modification. Examining factors which influence diet modification is essential to enhancing the science of diet modification within the IBD population.

Although individuals with high informational received social support compared to low informational received social support were more likely to be adherent to medication, total received social support, emotional support, and tangible support did not exhibit statistically significant relationships with self-management behaviors. Two reasons may contribute to the lack of relationship. First, social support may be more beneficial for self-management behaviors during times of disease or treatment transitions. For instance, individuals who are changing medications, beginning a diet, experiencing an increase in symptoms, or newly/recently diagnosed may benefit from received social support. The emerging adults in this sample were diagnosed for an average of 6.3 years, had low symptom severity and interference and therefore may have well-controlled disease. Second, social support may have an indirect relationship with self-management by influencing depression (Fuller-Thomson & Nimigon, 2008); depression may then influence self-management behaviors (Calloway et al., 2017). Other potential mediators may include self-efficacy, anxiety, or coping and could be incorporated into the Individual and Family Self-Management Theory applied to IBD. Therefore, more robust studies utilizing longitudinal designs and incorporating diverse samples are needed to further examine the relationship between social support and self-management behaviors among emerging adults with IBD. This study contributes to science by indicating that received social support may not be directly associated with self-management behaviors, except for the relationship between informational received social support and medication adherence.

Limitations

This study has several limitations. First, the cross-sectional nature limits the ability to predict medication adherence based on social support; therefore, associations were used. Second, the study is limited by a small sample size as evidenced by large confidence intervals. Third, limitations existed within the measures. Medication adherence was measured as a self-report and therefore adherence may be over-reported (Lam & Fresco, 2015; Nguyen, La Caze, & Cottrell, 2014). Different recall periods (2 weeks versus 4 weeks) may also influence participant responses and statistical comparisons. This study only examined level of social support; other aspects of social support such as source or support or quality of support was not measured. A more knowledgeable source of support, such as a fellow patient, could provide more helpful support compared to a friend or family member who has not experienced the disease. Examining the support message could help determine the quality of social support. The current study is limited understanding relationships regarding to the level of received social support that was obtained; future research could examine additional aspects of social support.

To participate in the survey, emerging adults had to be currently prescribed medication although they did not need to be currently taking their medication. There is the potential for selection bias where emerging adults who were more adherent to their medications were more likely to complete the survey. Furthermore, emerging adults who completed the survey had well-managed disease; most participants did not have surgery and had limited symptom severity and interference. Thus, the study findings have limited generalizability based on the data collection techniques (i.e., self-report) and characteristics of sample recruited (i.e., well-managed disease).

Conclusion

This study contributes to the knowledge of the relationship between received social support and the self-management behaviors of medication adherence and diet modification as presented in the Individual and Family Self-Management Theory applied to IBD. Received social support was not associated with diet modification; therefore, additional research is needed to determine the factors which influence diet modification. High levels of informational received social support are associated with medication adherence compared to low levels of informational received social support. Seeking to improve informational received social support may be one method to influence medication adherence among emerging adults with IBD.

Table 4.1

Individual, Condition-specific, and Emerging Adulthood Factors of Adults with Inflammatory Bowel Disease (n=61)

Characteristic	%	N
Sex		
Male	6	9.8
Female	55	90.2
Marital Status		
Single	47	77.1
Married/domestic partnership	14	22.9
Employment Status		
Full-time employed	30	49.2
Part-time employed	10	16.4
Unemployed	21	34.4
Education		
High school or less	10	16.4
Some college	16	26.2
Completed college	22	36.1
Graduate or professional degree	13	21.3
Type of IBD		
Ulcerative Colitis	22	36.1
Crohn's disease	39	63.9
Medication type^a		
Aminosalicylates	22	36.1
Biologics	37	60.7
Corticosteroids	11	18.0
Immunomodulators	16	26.2
Medication adherence		
Non-adherent	16	26.2
Adherent	45	73.8
Diet Modification		
No diet modification	22	36.1
Diet modification	39	63.9
	Mean (SD)	Potential range
Age (years)	24.7 (2.9)	18 – 29
Time since diagnosis (months)	76.3 (57.3)	2 – 227
Number of previous surgeries	0.6 (1.4)	0 – 8
Symptoms		
Symptom prevalence (avg. number of symptoms experienced)	5.9 (3.1)	0 – 15
Summed symptom severity	4.2 (1.5)	0 – 9
Summed symptom interference	2.3 (1.5)	0 – 9
Emerging adulthood		
Possibilities	6.8 (1.4)	2 – 8
Instability	6.9 (1.3)	2 – 8
Exploration	6.7 (1.4)	2 – 8
In-between	6.5 (1.5)	2 – 8

^a Medication types equal more than 100%

Table 4.2

Means, Standard Deviations, Potential Ranges, and Cronbach's Alpha for Total Scale and Subscales of Received Social Support and Perceived Availability of Social Support

Variables (n=61)	Mean score (SD)	Mean score potential range	Cronbach's alpha
Total received social support	2.5 (0.7)	1 – 5	0.96
Informational social support (received)	2.4 (0.9)	1 – 5	0.93
Emotional social support (received)	3.2 (1.0)	1 – 5	0.94
Tangible social support (received)	1.8 (0.6)	1 – 5	0.81
Total perceived availability of social support	3.9 (1.0)	1 – 5	0.96
Emotional/information social support (perceived)	3.8 (1.0)	1 – 5	0.93
Tangible/instrumental social support (perceived)	3.7 (1.3)	1 – 5	0.95
Affectionate social support (perceived)	4.1 (1.3)	1 – 5	0.92
Positive social interactions (perceived)	3.9 (1.3)	1 – 5	0.97

Table 4.3

Logistic Regression Analysis of Received and Perceived Availability of Social Support on Self-Management Behaviors of Medication Adherence while Controlling for Individual, Condition-specific, and Emerging Adulthood Factors

Variables (n=61)	Medication Adherence ^a		Medication Adherence (Model with Interaction) ^a	
	OR (95% CI)	P value	OR (95% CI)	P value
Received Social Support (ref: low)				
High received social support	1.4 (0.2, 8.4)	0.706	1.2 (0.1, 10.3)	0.891
High perceived availability of social support	1.2 (0.3, 5.6)	0.791	0.8 (0.03, 21.0)	0.882
High received social support x high perceived availability of social support			1.8 (0.04, 70.9)	0.762
Informational social support (ref: low)				
High informational social support*	9.3 (1.3, 66.0)	0.025	6.1 (0.6, 62.2)	0.129
High perceived availability of social support	1.0 (0.2, 4.8)	0.955	0.4 (0.02, 8.4)	0.565
High informational social support x high perceived availability of social support			3.2 (0.1, 111.3)	0.517
Emotional social support (ref: low)				
High emotional social support	1.2 (0.3, 5.6)	0.838	0.6 (0.07, 4.8)	0.614
High perceived availability of social support	1.3 (0.3, 5.8)	0.746	0.7 (0.1, 5.0)	0.714
High emotional social support x high perceived availability of social support			4.2 (0.2, 83.9)	0.347
Tangible social support (ref: low)				
High tangible social support	1.0 (0.2, 5.0)	0.966	0.5 (0.05, 4.9)	0.567
High perceived availability of social support	1.3 (0.3, 5.8)	0.699	0.6 (0.1, 6.5)	0.704
High tangible social support x high perceived availability of social support			3.5 (0.2, 69.2)	0.418

^a Controlling for biologic medication, time since diagnosis, symptom frequency, and feeling in-between

Table 4.4

Logistic Regression Analysis of Received and Perceived Availability of Social Support on Self-Management Behaviors of Diet Modification

Variables (n=61)	Diet Modification ^a		Diet Modification (Model with Interaction) ^a	
	OR (95% CI)	P value	OR (95% CI)	P value
Received Social Support (ref: low)				
High received social support	2.2 (0.6, 7.4)	0.216	2.0 (0.4, 9.9)	0.380
High perceived availability of social support	0.5 (0.1, 1.5)	0.197	0.4 (0.1, 3.4)	0.416
High received social support x high perceived availability of social support			1.2 (0.1, 14.6)	0.897
Informational social support (ref: low)				
High informational social support	1.2 (0.4, 3.5)	0.755	0.8 (0.2, 3.7)	0.745
High perceived availability of social support	0.6 (0.2, 1.7)	0.313	0.4 (0.1, 1.8)	0.221
High informational social support x high perceived availability of social support			2.2 (0.3, 19.3)	0.467
Emotional social support (ref: low)				
High emotional social support	2.4 (0.7, 8.3)	0.162	2.6 (0.4, 15.8)	0.292
High perceived availability of social support	0.4 (0.1, 1.4)	0.147	0.4 (0.1, 2.6)	0.358
High emotional social support x high perceived availability of social support			0.8 (0.1, 10.1)	0.895
Tangible social support (ref: low)				
High tangible social support	1.5 (0.5, 4.4)	0.461	1.4 (0.3, 6.6)	0.691
High perceived availability of social support	0.6 (0.2, 1.7)	0.350	0.6 (0.1, 2.4)	0.432
High tangible social support x high perceived availability of social support			1.2 (0.1, 9.9)	0.889

^a No individual, condition-specific, or emerging adulthood factors were significantly associated with diet modification; therefore, contextual factors were not controlled for

CHAPTER 5: CONCLUSIONS

This dissertation used a multiple manuscript option to address the central theme of social support among emerging adults with inflammatory bowel disease. Manuscript one (chapter two) is a systematic review of the relationship between social support and self-management behaviors among adults with IBD. Manuscript two (chapter three) and manuscript three (chapter four) are data-based papers which address elements of the Individual and Family Self-Management Theory applied to IBD including social support and self-management behaviors.

Summary of Manuscript 1

Research has identified the potential of social support to influence self-management behaviors; yet, this relationship has not been systematically examined within the IBD population. The majority of IBD patients are diagnosed at younger ages than individuals diagnosed with other chronic conditions; thus, it is essential to examine how age can influence social support and self-management. Manuscript 1 summarized the current research findings examining relationships between overall social support and types of social support (e.g., informational, emotional, and tangible) and self-management behaviors among adults with IBD. Seven articles met the inclusion and exclusion criteria. The systematic review indicated some evidence for a relationship between increased overall social support and improved self-management behaviors. However, findings are still inconclusive due to the variety of conceptualizations of both social support and self-management behaviors. Consistency in the use of social support definitions and measurements is needed. The relationship between types of social support and self-management behaviors was unable to be determined due to only one article examining a type of social support. Examining the types of social support would provide a better understanding of the

relationship between informational, emotional, and tangible social support and self-management behaviors.

Notably missing from the literature review were articles that focused on medication adherence and diet modification as self-management behaviors. Only one article addressed medication adherence; however, this article indirectly assessed social support through membership in a supportive intervention group. Future research is needed to understand the relationship between social support and medication adherence since medication adherence is a vital component of self-management for this disease. Diet modification, although frequently used by patients, was also not identified during the review process. Addressing the gap of the relationship between social support and the self-management behaviors of medication adherence and diet modification is important to determine if social support interventions may improve self-management behaviors and, therefore, became the focus of manuscript 3.

In addition, the systematic review examined the role of patient age. Although individuals with IBD are typically diagnosed between the ages of 18-29, the mean age of participants in the systematic review was 40 (range: 34.6-45.5). Lower age (age <40) was associated with poorer self-management behaviors. Thus, it became apparent that future research is needed to specifically address the needs of an emerging adult (ages 18-29) population and inform interventions to improve self-management behaviors among this developmental stage of emerging adulthood. This manuscript contributes to science by emphasizing the role of age and developmental stage on self-management behaviors. Enhancing the literature on emerging adults, social support, and self-management behaviors was the focus of manuscripts 2 and 3.

Summary of Manuscript 2

Although social support has the potential to influence a variety of health outcomes, researchers have not examined the factors which influence levels of received social support. The factors have the potential to identify patients in need of supportive interventions. Without an understanding of who receives social support, the development of interventions is hindered. Manuscript 2 focused on the individual, condition-specific, and emerging adulthood factors which influenced total and subscales of received social support among emerging adults with IBD. Emerging adults (ages 18-29) with a diagnosis of IBD were recruited through ResearchMatch, Facebook, and word of mouth. The sample included 61 emerging adults with a mean age of 24.7 (SD=2.9). Participants were mostly female (n=55, 90%), single (n=47, 77%), and employed full-time (n=30, 49%). Most were diagnosed with Crohn's disease (n=39, 64%) for an average of 76 months (SD=57.3).

Findings indicated that decreased age, being married, and having full-time employment were associated with increased total received social support; age and marital status were also associated with emotional received social support. When controlling for time since diagnosis and symptom interference, the use of immunomodulator medication, biological medication, and both immunomodulators and biologics was associated with increased tangible social support. Emerging adulthood factors were not associated with total or subscales of received social support. The factors which influenced social support varied based on the type of social support. This manuscript contributes by focusing on the impact of individual and condition-specific factors on types of received social support.

Summary of Manuscript 3

Social support and self-management behaviors have not been examined specifically within an emerging adulthood population; emerging adults are in a unique developmental stage which may influence the relationship between social support and self-management behaviors. The self-management behaviors of medication adherence and diet modification are necessary for reducing symptoms and improving quality of life. Innovative interventions are needed to address the poor self-management behaviors among emerging adults; social support could potential serve as one such intervention. Yet, research is needed to examine the relationship between received social support and self-management behaviors. Therefore, manuscript three examined the association between received social support and self-management behaviors of medication adherence and diet modification and how perceived availability of social support may moderate this relationship. Emerging adults with a self-reported healthcare provider diagnosis of ulcerative colitis or Crohn's disease were recruited through ResearchMatch, Facebook, and word of mouth. Participants were currently prescribed medication to manage their IBD (although not all participants were adherent to the medication), could understand written English, and had access to the internet. Emerging adults hospitalized within the past month or currently pregnant were excluded. Engaging in diet modification was not an inclusion criteria for the study.

Sixty-one participants were included in the analysis. Seventy-three percent of emerging adults were adherent to their medication (n=45). The most common types of medications were biologics (n=37, 61%), aminosaliclates (n=22, 36%), immunomodulators (n=16, 26%), and corticosteroids (n=11, 18%). In addition, seventy-five percent (n=46) never had surgery. When controlling for biological medication, time since diagnosis, symptom frequency, and feeling in-between, having high informational received social support compared to low informational

received social support was associated with medication adherence ($p = 0.023$). Perceived availability of social support did not moderate the relationship between received social support and medication adherence. Although when controlling for the interaction between received social support and perceived availability of social support, the relationship between informational received social support and medication adherence became non-significant ($p=0.129$).

Sixty-four percent of emerging adults reported modifying their diet ($n=39$). The most commonly modified food groups included: fruits and vegetables ($n=41$, 67%), fiber ($n=40$, 65%), dairy ($n=37$, 61%), and grains ($n=37$, 61%). Received social support was not associated with diet modification. Perceived availability of social support did not moderate the relationship between received social support and medication adherence. In addition, individual, condition-specific, and emerging adulthood factors were not associated with diet modification. To better determine the types of emerging adults who engage in diet modification, future research is needed to examine other factors, such as beliefs about diet and cause of IBD, which have the potential to influence diet modification.

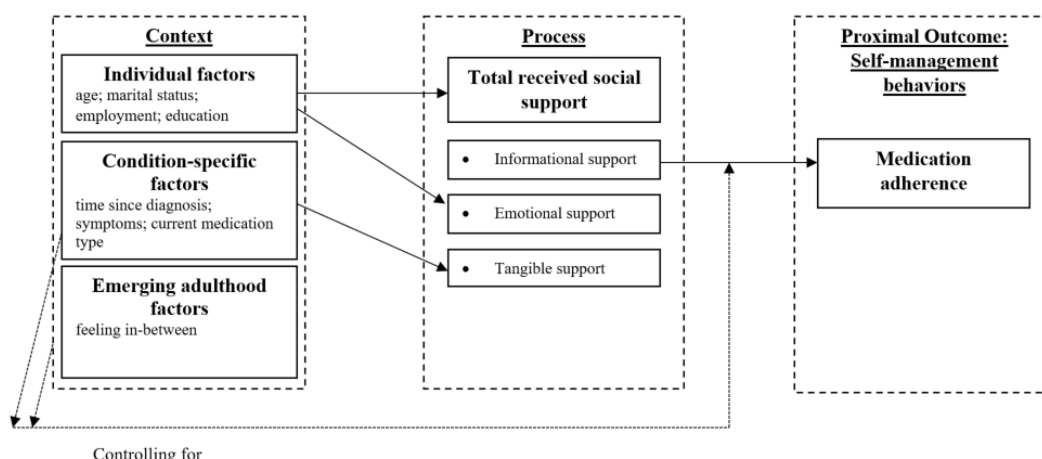
Overall Summary

The purpose of this dissertation was to examine the relationship between social support and self-management behaviors of medication adherence and diet modification among emerging adults (ages 18-29) with IBD (see Table 5.1 for Research Questions and Findings). This dissertation utilized select variables from the Individual and Family Self-Management Theory to address the research questions. The selected variables were specific to IBD and the resulting model was referred to as the Individual and Family Self-Management Theory applied to IBD. The hypothesized model included context factors (individual, condition-specific, and emerging adulthood factors), process factors (received social support), outcome factors (medication

adherence and diet modification) as well as a potential moderation of perceived availability of social support between process and outcome factors.

Figure 5.1 provides a summary of the significant relationships within the Individual and Family Self-Management theory applied to IBD. The figure is specific to the findings of this dissertation. Within this dissertation, individual and condition-specific factors, but not emerging adulthood factors, influenced received social support. Condition-specific factors and emerging adulthood factors influenced medication adherence. None of the context factors were found to influence diet modification. The relationship between received social support and self-management behaviors was not significant, except for the relationship between informational received social support and medication adherence. Future work related to this model could examine other process variables beyond social support which were included in the original model such as knowledge and beliefs, self-regulation skills and abilities, and social facilitation. In addition, received social support may influence self-management behaviors indirectly through self-efficacy, anxiety, or depression (Calloway et al., 2017; Fuller-Thomson & Nimigon, 2008).

Figure 5.1: Individual and Family Self-Management Theory applied to IBD: Significant Findings



The systematic review in Chapter 2 indicated that social support may influence self-management behaviors. When the relationship between social support and self-management

behaviors was examined within emerging adults with IBD (chapter 4), a high degree of received informational support compared to a low degree of received informational support was associated with medication adherence. Total received social support, emotional received social support, and tangible received social support were not associated with medication adherence. Received social support was not associated with diet modification. Furthermore, perceived availability of social support did not modify the relationship between received social support and self-management behaviors. These insignificant findings may be due to the sample which appeared to have well-managed disease. The received social support measure used in this dissertation was a measure of global received social support, perhaps including a social support measure specific to self-management behaviors or tasks related to IBD would yield different results. Received social support and self-management behaviors may be related indirectly through a different variable or perhaps social support and self-management behaviors are just not related.

Younger age (age <40), as identified in the systematic review, has been associated with poor self-management behaviors. However, the emerging adulthood factor of feeling in-between was associated with medication adherence whereas age was not associated with medication adherence among emerging adults. A younger age was also associated with greater total received social support. The factors which influenced received social support differed based on the received social support subscale being examined. For instance, individual factors influenced total received social support and emotional received social support whereas condition-specific factors influenced tangible received social support.

Future research using the Individual and Family Self-Management Theory applied to IBD should examine relationships over time to examine how received social support may vary based

on disease trajectory and other environmental factors. For this dissertation, other process variables were removed to focus specifically on received social support. Future work could integrate these process variables which include knowledge and beliefs, self-regulation skills and abilities, and other social facilitation variables.

Limitations

This dissertation has several limitations. The systematic review identified few articles that examined social support and self-management behaviors; all seven of the articles meeting inclusion criteria were older than 5 years. The studies included within the review used a variety of conceptualizations of social support and self-management behaviors.

Participant recruitment methods, for manuscripts two and three, focused on online modalities and therefore cannot, necessarily, be generalized to clinic populations. The average participant was female, diagnosed with Crohn's disease, using biological medication, and adherent to medication. In addition, the sample had low symptom severity and interference and had been diagnosed for an average of 6.3 years. Therefore, findings from this dissertation cannot be generalized to all IBD patients. Selection bias may have occurred; healthier and more adherent patients may have been more likely to complete the survey. The cross-sectional nature of this data is another limitation since causality cannot be determined.

Participants self-reported a healthcare provider diagnosis of ulcerative colitis or Crohn's disease. Thus, it is possible that individuals without IBD completed the survey. Objective measures such as colonoscopy results and fecal calprotectin levels should be used to confirm disease status and disease activity.

The measures used within the study also presented limitations. Received social support was a global measure of received social support; using a social support related to IBD self-

management behaviors scale may provide greater precision. In addition, the scale measured total amount of support. Therefore, this dissertation was unable to identify sources of social support or quality of support. Medication adherence was also measured as a self-report and therefore adherence may be overreported. Findings would be strengthened by the use of objective measures.

Although studies have examined validity and reliability of the Dimensions of Emerging Adulthood, most previous research has focused on healthy emerging adults. Additional research is needed to validate this measure among emerging adults with chronic conditions. Furthermore, differences existed in recall periods with symptoms measures referring to the last 2 weeks and received social support referring to the last 4 weeks.

Implications

This dissertation has implications for research, policy, and practice.

Research

Future work should continue to focus on emerging adults since the systematic review identified that lower age was associated with lower self-management behaviors. The emerging adulthood sample within the IBD population are experiencing the typical demands of emerging adulthood, measured by the short form of the Inventory of Dimensions of Emerging Adulthood. In addition, the emerging adulthood factor of feeling in-between negatively influenced medication adherence. Therefore, there is some indication that developmental stage may influence self-management behaviors, although developmental stage did not directly influence received social support. Trivedi and Keefer (2015) introduced emerging adulthood to the IBD literature. Yet, most of the literature continues to focus on chronological age, specifically the transition between pediatric and adult IBD care that typically occurs between 18-22 years old

(Cho et al., 2018; Gumidyala et al., 2018; Stollon et al., 2017; van Groningen, Ziniel, Arnold, & Fishman, 2012). Whereas, improving this transition is important, a paradigm shift needs to occur from focusing on chronological age to examining developmental stages that may affect emerging adults' transition readiness and ability to self-manage their IBD.

This dissertation examined social support as one process that could influence the self-management behaviors of medication adherence and diet modification. However, only informational received social support was associated with medication adherence. To better understand the relationship between received social support and self-management behaviors, social support should be examined longitudinally as there is the potential that social support is beneficial during transition times. For instance, emerging adults may benefit from additional social support when switching medication types, beginning a new diet, or experiencing an increase in symptoms. A longitudinal, observational study could help identify periods along the disease trajectory in which patients would benefit from additional types of received social support. In addition, other components of social support such as the quality of support, source of support, or ideal support levels may be essential to understanding the role of social support on self-management behaviors. Receiving social support from a fellow patient may have a different effect that receiving support from a family member.

Social support may have a stronger effect on psychological/emotional components of health such as depression, anxiety, self-efficacy, or coping and could indirectly influence self-management behaviors. Another possibility is that social support influences other health outcomes such as health-related quality of life (Katz et al., 2016) and simply is not related to self-management behaviors. Further investigation of types of social support can clarify these

relationships and determine if informational, emotional, and tangible social support influence outcomes differently.

Increased symptom frequency was associated with medication adherence; yet, symptom measures (frequency, severity, and interference) were not associated with received social support. The lack of relationship between symptoms and received social support may be due to support providers not being aware of symptoms or the stigma associated with IBD (Groshek et al., 2017; Taft et al., 2009). Follow-up work is needed to understand symptom severity and interference within emerging adults with IBD since the low symptom severity and inference in this sample may be due to recruitment methods and selection bias in which healthier individuals completed the survey. IBD symptom science is a relatively new area of research. A 2010 conceptual paper outlined symptom burden within IBD (Farrell & Savage, 2010); however, only in recent years has research begun to focus on examining symptoms within the IBD population including examining symptom frequency, severity, and distress (Farrell, McCarthy, & Savage, 2016) and symptom clusters (Conley, Proctor, Jeon, Sandler, & Redeker, 2017). Thus, there is a need to enhance IBD symptom science research focusing on symptom cut points, symptoms across the lifespan and disease trajectory, and biological underpinnings of symptoms (McCall et al., 2018).

Future research should examine other processes identified in the original theory such as knowledge and beliefs, self-regulation skills and abilities, and social facilitation. In addition, other models which incorporate biological mechanisms may be better suited to examine the relationship between symptoms and self-management behaviors (McCall et al., 2018). Potential models include the National Institute of Health Symptom Science Model (Cashion & Grady,

2015) and the University of California at San Francisco Symptom Management Model (Dodd et al., 2001).

Finally, none of the contextual or process variables included within this dissertation influenced diet modification. There is a need to better understand what promotes an emerging adult to modify their diet. Since such a high percentage of emerging adults are modifying their diet, future interventions should seek to incorporate psychoeducational interventions including managing symptoms and diet together with the typically medical interventions of medications. Incorporating both components will provide researchers with a better understanding of the overall picture of IBD self-management.

Future research questions could include:

1. How does the relationship between social support and self-management behaviors differ between emerging, middle-aged, and older adults with IBD?
2. What is the relationship between social support (source of support and quality of support) and self-management behaviors among adults with IBD?
3. Among emerging adults with IBD, does self-efficacy mediate the relationship between received social support and self-management behaviors (medication adherence and diet modification)?
4. Among newly diagnosed emerging adults with IBD, what is the relationship between received social support and self-management behaviors (medication adherence and diet modification)?

Policy

Emerging adults face unique challenges and barriers to self-management. Most patients within the study were on biological medications and had minimal symptoms and surgeries

indicating the medication was effective in managing their disease. Policy makers should seek to improve emerging adults' access to these necessary medications including increasing access to insurance and decreasing co-pays. Emerging adults commonly face barriers in which patients must fail insurance-preferred medications before obtaining coverage for provider-prescribed medications. Eliminating insurance company driven medication protocols would promote patient access to necessary medication without insurance company delays.

Twenty-six percent (n=16) of the sample were non-adherent to medication. Informational received social support may influence medication adherence; therefore, insurance companies should expand coverage to include support groups and other psychoeducational interventions. Telehealth could be used to extend these interventions to emerging adults with IBD who do not live close to a specialized IBD-center.

In addition, the emerging adulthood factor of feeling in-between was associated with medication non-adherence. Patient programs, offered by insurance companies, schools, or employers, can be tailored to meet the developmental needs of emerging adults. These programs could be used to assist emerging adults transition to adulthood by providing skills and competencies needed to effectively self-manage their disease.

Finally, policy makers should seek to expand funding of IBD research. Additional research funds would contribute to better understanding the role of IBD symptoms, the relationship between diet and medication, and the influence of diet and nutrients on health outcomes within the IBD population.

Practice

Nurses and other healthcare providers should be aware that emerging adults are at risk for negative self-management behaviors. The need to improve self-management behaviors extends

past the transition period from pediatric to adult gastroenterology. Specifically, emerging adults who are feeling in-between are more likely to be non-adherent to medication. Other potential risk factors for medication non-adherence include: low informational social support, not using biological medications, increased time since diagnosis, and decreased symptom frequency. Emerging adults with these condition-specific and emerging adulthood factors may be in need of educational programs to improve medication adherence.

Although receiving social support had minimal associations between self-management behaviors of medication adherence and diet modification, social support is related to health-related quality of life within the IBD literature (Katz et al., 2016; Oliveira et al., 2007). Therefore, providers can assess for characteristics that are associated with increased received social support. Age, marital status, and employment are associated with total received social support; age and marital status are also associated with emotional received social support. The use of immunomodulator medication, biological medication, and both immunomodulators and biologics was associated with increased tangible social support when controlling for time since diagnosis and symptom interference. These individual and condition-specific factors can be used to help identify emerging adults who may benefit from improved social support.

Most importantly, healthcare providers should recognize that individuals diagnosed at younger ages (under 40) report greater symptoms and disease complications (Bager, Julsgaard, Vestergaard, Christensen, & Dahlerup, 2016; Liverani, Scaioli, Digby, Bellanova, & Belluzzi, 2016; Torres et al., 2016). In addition, a younger age (age <40) is associated with decreased self-management behaviors (Coenen et al., 2016; Severs et al., 2017). The Theory of Emerging Adulthood by Arnett (2000) can provide an overview of the developmental stages faced by

emerging adults. There is a need for individuals in practice settings to work with researchers to design interventions to address the challenges faced by emerging adults.

Contribution to Science

The research in the proceeding chapters enhances the science in three ways: 1) synthesis and identification of gaps in the literature regarding the influence of social support and self-management behaviors, finding that research primarily focuses on older adults and neglects the emerging adult population (manuscript one/chapter two); 2) examining the factors which influence received social support among emerging adults with IBD (manuscript two/chapter three); and 3) determining the relationship between received and perceived availability of social support and self-management behaviors (medication adherence and diet modification) among emerging adults with IBD (manuscript three/chapter four). The findings from this dissertation serve to build the science by focusing on emerging adults and emerging adulthood factors which may influence social support and self-management behaviors, identifying types of social support which may be important to incorporate into future interventions, and examining how social support has the potential to influence self-management behaviors of medication adherence and diet modification.

This dissertation focused on emerging adults since previous research has identified that a younger age is associated with decreased self-management behaviors among IBD patients. Examining emerging adulthood factors in addition to age is a unique contribution to the literature as this is one of the first known studies to examine emerging adulthood factors related to social support and self-management behaviors in chronic conditions. Age, not emerging adulthood factors, was associated with total received social support and emotional received social support.

Emerging adulthood factors, and not age, were associated with medication adherence. These findings contribute to the development of the emerging adulthood literature.

Based on previous literature indicating that receiving social support can be beneficial in improving health outcomes, the contextual factors that influence received social support were examined. It was found that the contextual factors varied based on the type of social support. These findings advance science by determining the potential individual and condition-specific factors that may identify patients in need of additional supportive resources. Since these factors vary based on type of social support, this dissertation also highlights the importance of examining not only total social support but also the types of social support. Total social support provides an overview of social support levels; however, informational, emotional, and tangible social support provide detailed information regarding potential support areas that may need improvement.

High informational received social support compared to low informational received social support was associated with increased medication adherence. Total received social support was not significant; therefore, when examining self-management behaviors, it is essential to examine the specific types of social support which may influence outcomes differently. This dissertation helped advance understanding of the relationship between social support and self-management behaviors among emerging adults with IBD.

In conclusion, the developmental stage of emerging adulthood may influence the ability to engage in self-management behaviors. This dissertation contributes to science by examining the potential of social support to influence self-management behaviors among emerging adults with IBD. A continued focus on developmental stages is needed to advance personalized healthcare in the area of IBD self- and symptom management.

Table 5.1
Research Questions and Findings

Research Questions	Finding
Chapter 2 / Manuscript 1	
1. What is the relationship between social support (overall social support and type of social support [e.g., informational, emotional, and tangible]) and self-management behaviors among adults with IBD?	A positive relationship between social support and self-management behaviors. As social support increased, self-management behaviors increased. Unable to examine types of social support since only one study addressed emotional social support.
2. How does patient age influence the relationship between social support and self-management behaviors among adults with IBD?	Age was associated with self-management behaviors. As age decreased, self-management behaviors decreased.
Chapter 3 / Manuscript 2	
3. Which individual factors (age, sex, marital status, employment, education) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?	Total received social support: decreased age ($p = 0.001$), being married ($p = 0.039$) and having employment full-time compared to being unemployed or a student ($p = 0.007$) are predictive of greater total received social support Informational support: none Emotional support: decreased age ($p = 0.033$) and being married ($p = 0.001$) are predictive of greater emotional social support Tangible support: none
4. Which condition-specific factors (type of IBD, times since diagnosis, symptoms, medication types, and surgeries) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?	Total received social support: none Informational support: none Emotional support: none Tangible support: the use of immunomodulates ($p = 0.000$), the use of biologics ($p = 0.002$) and the interaction between immunomodulators and biologics ($p = 0.000$) when controlling for time since diagnosis and symptom interference are predictive of greater tangible social support

Table 5.1 (cont'd)

Research Questions	Finding
5. Which emerging adulthood factors (possibilities/optimism, instability, identity exploration, and feeling in-between) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?	Total received social support: none Informational support: none Emotional support: none Tangible support: none
Chapter 4 / Manuscript 3	
6. Among emerging adults with IBD, what is the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?	Only informational received social support is positively associated with medication adherence Received social support is not associated with diet modification
7. Among emerging adults with IBD, does perceived availability of social support moderate the association between received social support and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?	Perceived availability of social support did not moderate the relationship between received social support and self-management behaviors.

APPENDICES

APPENDIX A: PRISMA Checklist

Table A.1

PRISMA Checklist for Reporting of Systematic Reviews

Section/topic	#	Checklist item
TITLE		
Title	1	Identify the report as a systematic review, meta-analysis, or both.
ABSTRACT		
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.
INTRODUCTION		
Rationale	3	Describe the rationale for the review in the context of what is already known.
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).
METHODS		
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.

Table A.1 (cont'd)

Section/topic	#	Checklist item
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.
RESULTS		
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.
Synthesis of results	21	Present the main results of the review. If meta-analyses are done, include for each, confidence intervals and measures of consistency.
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).

Table A.1 (cont'd)

Section/topic	#	Checklist item
DISCUSSION		
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.
FUNDING		
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.

Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

APPENDIX B: Risk of Bias Assessment

Table A.2

Risk of Bias Assessment Thresholds for Systematic Review Quality Assessment

12-question checklist	Criteria	Thresholds for criteria
1. Did the study address a clearly focused issue? 2. Did the authors use an appropriate method to answer their question?	Initial screening questions	
3. Was the cohort recruited in an acceptable way? 4. A) Was the follow-up of the subjects complete enough? B) Was the follow-up of the subjects long enough?	Criterion 1: External validity assessment of selection bias	Random sample, non-response < 30% and loss of follow-up < 50% = Low risk (1 point) Non-random sample and/or nonresponse ≥ 30% = high risk (0 points)
5. Was the exposure (social support) accurately measured to minimize bias?	Criterion 2: Internal validity assessment of measurement bias for exposure	Self-report previously validated questionnaire (e.g. author references validation study in-text or known validated scale) = low risk (1 point) Custom questionnaire or single question = high risk (0 points)
6. Was the outcome accurately measured to minimize bias?	Criterion 3: Internal validity assessment of measurement bias for outcome	Self-report previously validated questionnaire (e.g. author references validation study in-text or known validated scale) = low risk (1 point) Custom questionnaire or single-item questionnaire = high risk (0 points)

Table A.2 (cont'd)

12-question checklist	Criteria	Thresholds for criteria
7. Have the authors identified all important confounding factors?	Criterion 4: Internal validity assessment of confounding	Adjusted for confounders (age, SES, ethnicity, disease characteristics) through analysis, stratification, or study design = low risk (1 point) Adjusted for some or none of the confounders = high risk (0 points)
8. What are the results of this study? 9. How precise are the results? 10. Do you believe the results? 11. Can the results be applied to the local population? 12. Do the results of this study fit with other available evidence?	Overall quality assessment of the results and transferability of the study findings (as determined by likelihood of selection bias (Criterion 1); measurement biases (Criteria 2 and 3); and confounding (Criterion 4). No additional quality criterion was used.	

Source: Assessment checklist obtained from the CASP Toolkit:

http://media.wix.com/ugd/dded87_36c5c76519f7bf14731ed1985e8e9798.pdf

Tool for quality appraisal obtained from Barnett, I., van Sluijs, E. M. F., & Ogilvie, D. (2012). Physical activity and transitioning to retirement: A systematic review. *American Journal of Preventive Medicine*, 43(3), 329-336. doi:10.1016/j.amepre.2012.05.026

Note: unclear = insufficient information to permit judgment of 'low risk' or 'high risk' (0 points)

APPENDIX C: Recruitment Email

Are you a young adult (ages 18–29) diagnosed with ulcerative colitis or Crohn’s disease?

Are you interested in participating in a research study to understand about life with your disease?

Researchers from Michigan State University are conducting a research study with young adults. Participating in this research study will involve completing an online questionnaire that should take no longer than 45 minutes.

You may be eligible for the study if:

- You are between the ages of 18 – 29
- Have a diagnosis from a healthcare provider of ulcerative colitis or Crohn’s disease
- Are currently using medications to manage your disease
- Are living in the United States

Please contact Kendra Kamp if you have any questions: Kendra.kamp@hc.msu.edu

APPENDIX D: Email with Survey Link

Dear Research Match Volunteer,

Thank you for your interest in our study of young adults (ages 18 – 29) with ulcerative colitis and Crohn’s disease! We are interested in learning how patients with ulcerative colitis and Crohn’s disease manage their disease.

You may be eligible for the study if:

- You are between the ages of 18 – 29
- Have a diagnosis from a healthcare provider of ulcerative colitis or Crohn’s disease
- Are currently using medications to manage your disease
- Are living in the United States

Participating in this study involves completing an online survey. The survey has questions about your disease, management strategies that you may use, social support, and demographics. This online survey should take around 45 minutes to complete.

Please follow the link below to take the survey:

[link location]

Thank you for your willingness to complete this survey! We hope that the results will help improve care for young adults with ulcerative colitis and Crohn’s disease.

Please let me know if you have any questions,

Kendra Kamp, RN

Graduate Student

Michigan State University

APPENDIX E: Informed Consent

Thank you for your interest in our research project. Please review the following information for an overview of our project:

1. EXPLANATION OF THE RESEARCH and WHAT YOU WILL DO:

The Michigan State University College of Nursing is conducting a research project to understand the factors which influence an individual with ulcerative colitis or Crohn's disease to take medication or change their diet. We are asking for your help in this research project because you are between the ages of 18 – 29 and have been diagnosed with either ulcerative colitis or Crohn's disease.

If you choose to take part in this study, you will be asked to complete a set of surveys either using a pen or pencil or online via qualtrics, an online, secure survey website. The set of surveys will take approximately 45 minutes to complete. After you complete the set of surveys, then your participation in the study is complete.

2. YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW:

Participation in this research project is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

3. COSTS FOR BEING IN THE STUDY:

- There is no cost to participate in this research study.
- Although you may not directly benefit from participating in this research, your responses will help improve care for other patients with ulcerative colitis or Crohn's disease.

4. CONTACT INFORMATION FOR QUESTIONS AND CONCERNS:

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researcher: Kelly Brittain, PhD, RN at (517) 432-8356 or e-mail kelly.brittain@hc.msu.edu or mailing address at 1355 Bogue Rd. Rm C348, Michigan State University College of Nursing, East Lansing 48824

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at Olds Hall, 408 West Circle Dr Rm 207, East Lansing, MI 48824.

5. DOCUMENTATION OF INFORMED CONSENT.

You indicate your voluntary agreement to participate by completing the surveys.

APPENDIX F: Screening Criteria

Table A.3
Screening Criteria

Category	Question	Inclusion	Exclusion
Age	What is your age	18 – 25 25 – 29	Under 18 30 – 35 36 – 45 46 – 55 46 or older
Diagnosis	What type of Inflammatory Bowel Disease do you have?	Ulcerative Colitis Crohn's Disease	I do not have Inflammatory Bowel Disease
Diagnosis	Have you received this diagnosis from a physician, gastroenterologist, nurse practitioner, physician's assistant or nurse?	Yes	No
Location	Do you currently live in the United States?	Yes	No
Medication use	Are you currently prescribed medication to manage your IBD?	Yes	No
Pregnancy	Are you currently pregnant?	No	Yes

Note: access to the internet and understanding written English will be assumed if a participant is able to complete the survey.

APPENDIX G: Individual and Condition-specific Variables

Table A.4

Individual and Condition-specific Variables, Level of Measurement, and Scoring Information

Variable	Level of measurement	Scoring Information
Individual Factors		
Age	Continuous	
Sex	Dichotomous	Male (Ref) Female
Marital Status	Categorical	Single (Ref) Married/domestic partnership
Employment	Categorical	Full-time employed (Ref) Part-time employed Unemployed or student
Education	Categorical	High school or less (Ref) Some college Completed college Graduate or professional degree
Condition-specific Factors		
Type of IBD	Dichotomous	Ulcerative Colitis (Ref) Crohn's Disease
Time since diagnosis	Continuous	Number of months since diagnosis
Symptom frequency	Continuous	The average number of symptoms that patients are experiencing (Range: 0 -15)
Symptom severity	Continuous	Severity ratings will be summed for all 15 symptoms; each items severity is rated on a 0 – 9 Likert scale, with higher sores indicating greater symptom severity (Range: 0 – 135)
Symptom interference	Continuous	Interference ratings will be summed for all 15 symptoms; each items interference is rated on a 0 – 9 Likert scale, with higher scores indicating greater symptom interference with daily activities (Range: 0 – 135)
Medications currently taking	Categorical	Biologics Immunomodulators Corticosteroids Aminosalicylates

Table A.4 (cont'd)

Variable	Level of measurement	Scoring Information
Previous surgeries	Continuous	Total number of IBD-related surgeries that an individual has experienced

Note: Classification of variable used for analysis is presented for dichotomous and categorical variables with the reference group indicated

APPENDIX H: Survey Questions

Thank you for your willingness to take this survey!

My name is Kendra and I am a nursing student at Michigan State University. I am so thankful that you are taking time out of your busy day to fill out this survey. The goal of this survey is to learn about how you manage your disease.

The survey could take around 45 minutes to complete, so if you need to take a break and finish later, that is okay. The survey may seem long, but please know that your answers are important for helping us improve care! If any of the survey questions do not make sense, feel free to text/call: 517-885-3171 or email: kendra.kamp@hc.msu.edu

Individual Factors

What is your birthday? (MM/DD/YYYY)

What is the highest grade or level of school you have completed or the highest degree you have received? (please select one)

- ☐ High school or less
- ☐ Some college
- ☐ Completed college
- ☐ Graduate or professional degree

Employment status: are you currently? (select all that apply)

- ☐ Full-time employed
- ☐ Part-time employed
- ☐ Unemployed
- ☐ Student
- ☐ Prefer not to answer

What is your marital status? (please select one)

- ☐ Single, never married
- ☐ Married or domestic partnership
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Prefer not to answer

What is your sex? (please select one)

- ☐ Male
- ☐ Female
- ☐ Prefer not to answer

Condition-specific factors

What type of Inflammatory Bowel Disease do you have? (please select one)

Ulcerative Colitis

Crohn's Disease

What month and year were you diagnosed with this disease? (example: January 2011)

Month of diagnosis

Year of diagnosis

IBD Symptoms

The next questions ask about the symptoms you have experienced in the past two weeks due to IBD or its treatment, and how these symptoms may have affected you.

If you have not experienced that symptom in the past two weeks, please select "no" and proceed to the next symptom.

1. In the past 2 weeks have you experienced **diarrhea** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your diarrhea at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did diarrhea interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

2. In the past 2 weeks have you experienced **constipation** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your constipation at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did constipation interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

3. In the past 2 weeks have you experienced **abdominal pain** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your abdominal pain at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did abdominal pain interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

4. In the past 2 weeks have you experienced **abdominal tenderness** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your abdominal tenderness at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did abdominal tenderness interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

5. In the past 2 weeks have you experienced **abdominal cramps** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your abdominal cramps at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did abdominal cramps interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

6. In the past 2 weeks have you experienced **bloating** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your bloating at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did bloating interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

7. In the past 2 weeks have you experienced **passing gas** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your passing gas at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did passing gas interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

8. In the past 2 weeks have you experienced **blood in your stool** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, the blood in your stool at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did blood in your stool interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

9. In the past 2 weeks have you experienced **weight loss** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your weight loss at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did weight loss interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

10. In the past 2 weeks have you experienced **weight gain** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your weight gain at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did weight gain interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

11. In the past 2 weeks have you experienced **reduced appetite** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your reduced appetite at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did reduced appetite interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

12. In the past 2 weeks have you experienced **increased appetite** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your increased appetite at its **WORST** in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did increased appetite interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

13. In the past 2 weeks have you experienced **nausea or vomiting** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your nausea or vomiting at its **WORST** in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did nausea or vomiting interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

14. In the past 2 weeks have you experienced **fatigue** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your fatigue at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did fatigue interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

15. In the past 2 weeks have you experienced **fever** related to your IBD or its treatment? (please select one)

- Yes
- No

If yes:

Please rate on a scale from 1-9, your fever at its WORST in the past 2 weeks.

1	2	3	4	5	6	7	8	9
Very little								Worst possible

Overall, how much did fever interfere in your daily activities in the last 2 weeks? (please rate)

0	1	2	3	4	5	6	7	8	9
Did not interfere									Interfered completely

Medications

The following questions ask about specific types of medications. The question asks if you have used this medication: currently taking medication, only take medication when needed, stopped taking medication (and reasons for stopping), and never tried.

The following medications are all Aminosalicylates (select all that apply)

	Currently taking	Only when needed	Stopped because it was ineffective	Stopped because of side effects	Stopped for another reason	Never tried
Azulfidine	☐	☐	☐	☐	☐	☐
Asacol	☐	☐	☐	☐	☐	☐
Lialda	☐	☐	☐	☐	☐	☐
Rowasa	☐	☐	☐	☐	☐	☐
Canasa	☐	☐	☐	☐	☐	☐
Colazal	☐	☐	☐	☐	☐	☐
Dipentum	☐	☐	☐	☐	☐	☐
Pentasa	☐	☐	☐	☐	☐	☐

The following medications are all Corticosteroids (select all that apply)

	Currently taking	Only when needed	Stopped because it was ineffective	Stopped because of side effects	Stopped for another reason	Never tried
Prednisone (deltasone)	☐	☐	☐	☐	☐	☐
Hydrocortisone	☐	☐	☐	☐	☐	☐
Budesonide (entro cort or uceris)	☐	☐	☐	☐	☐	☐

The following medications are all Biologics (select all that apply)

	Currently taking	Only when needed	Stopped because it was ineffective	Stopped because of side effects	Stopped for another reason	Never tried
Remicade (Infliximab)	☐	☐	☐	☐	☐	☐
Humira (Adalimumab)	☐	☐	☐	☐	☐	☐
Cimzia	☐	☐	☐	☐	☐	☐
Simponi	☐	☐	☐	☐	☐	☐
Entyvio (Vedolizumab)	☐	☐	☐	☐	☐	☐
Natalizumab	☐	☐	☐	☐	☐	☐
Ustekinumab	☐	☐	☐	☐	☐	☐

The following medications are all Immunomodulators (select all that apply)

	Currently taking	Only when needed	Stopped because it was ineffective	Stopped because of side effects	Stopped for another reason	Never tried
Imuran/azathioprine	☐	☐	☐	☐	☐	☐
Methotrexate	☐	☐	☐	☐	☐	☐

Since you have been diagnosed, how many surgeries related to your IBD or its treatment have you had? (please select one)

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7 or more

Emerging Adulthood Factors

First, please think about this time in your life. By “time in your life,” we are referring to the present time, plus the last few years that have gone by, and the next few years to come, as you see them. In short, you should think about a roughly five-year period, with the present time right in the middle.

- For each phrase shown below, please place a check mark in one of the columns to indicate the degree to which you agree or disagree that the phrase describes this time in your life. For example, if you “Somewhat Agree” that this is a “time of exploration,” then on the same line as the phrase, you would put a check mark in the column headed by “Somewhat Agree” (3).
- Be sure to put only one check mark per line

Is this period of your life a....

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
Time of many possibilities?				
Time of exploration?				
Time of feeling stressed out?				
Time of high pressure?				
Time of defining yourself?				
Time of deciding on your own beliefs and values?				
Time of feeling adult in some ways but not others?				
Time of gradually becoming an adult?				

Received Social Support

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the past four weeks. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks. Please read each item carefully and indicate how often these activities happened to you during the past four weeks. Please select one answer for each statement.

	<i>Not at all</i>	<i>Once or twice</i>	<i>About once a week</i>	<i>Several times a week</i>	<i>Almost every day</i>
Looked after a family member when you were away.					
Was right there with you (physically) in a stressful situation.					
Provided you with a place where you could get away for awhile.					
Watched after your possessions when you were away (pets, plants, home, apartment, etc.).					
Told you what she/he did in a situation that was similar to yours.					
Did some activity with you to help you get your mind off of things.					
Talked with you about some interests of yours.					
Let you know that you did something well.					
Went with you to someone who could take action.					
Told you that you are OK just the way you are.					
Told you that she/he would keep the things that you talk about private - just between the two of you.					
Assisted you in setting a goal for yourself.					
Made it clear what was expected of you.					
Expressed esteem or respect for a competency or personal quality of yours.					
Gave you some information on how to do something					
Suggested some action that you should take.					
Gave you over \$25.					

	<i>Not at all</i>	<i>Once or twice</i>	<i>About once a week</i>	<i>Several times a week</i>	<i>Almost every day</i>
Comforted you by showing you some physical affection.					
Gave you some information to help you understand a situation you were in.					
Provided you with some transportation.					
Checked back with you to see if you followed the advice you were given.					
Gave you under \$25.					
Helped you understand why you didn't do something well.					
Listened to you talk about your private feelings.					
Loaned or gave you something (a physical object other than money) that you needed.					
Agreed that what you wanted to do was right.					
Said things that made your situation clearer and easier to understand.					
Told you how he/she felt in a situation that was similar to yours.					
Let you know that he/she will always be around if you need assistance.					
Expressed interest and concern in your well-being.					
Told you that she/he feels very close to you.					
Told you who you should see for assistance.					
Told you what to expect in a situation that was about to happen.					
Loaned you over \$25.					
Taught you how to do something.					
Gave you feedback on how you were doing without saying it was good or bad.					
Joked and kidded to try to cheer you up.					
Provided you with a place to stay.					

	<i>Not at all</i>	<i>Once or twice</i>	<i>About once a week</i>	<i>Several times a week</i>	<i>Almost every day</i>
Pitched in to help you do something that needed to get done.					
Loaned you under \$25.					

Perceived Availability of Social Support

People sometimes look to others for companionship, assistance, or other types of support. Thinking about the last two weeks, how often is each of the following kinds of support available to you if you need it? Please select one answer for each statement.

	<i>None of the time</i>	<i>A little of the time</i>	<i>Some of the time</i>	<i>Most of the time</i>	<i>All of the time</i>
Someone you can count on to listen to you when you need to talk					
Someone to give you information to help you understand a situation					
Someone to give you good advice about a crisis					
Someone to confide in or talk to about yourself or your problems					
Someone whose advice you really want					
Someone to share your most private worries and fears with					
Someone who understands your problems					
Someone to help you if you were confined to bed					
Someone to take you to the doctor if you needed it					
Someone to prepare your meals if you were unable to do it yourself					
Someone to help with daily chores if you were sick					
Someone who shows you love and affection					
Someone to love and make you feel wanted					
Someone who hugs you					
Someone to have a good time with					
Someone to get together with for relaxation					
Someone to do something enjoyable with					
Someone to do things with to help you get your mind off things					

Medication Adherence

Please select how much you agree with the following statements. Select one answer for each statement.

	Always	Often	Sometimes	Rarely	Never
I forget to take these IBD medicines	☐	☐	☐	☐	☐
I alter the dose of these IBD medicines	☐	☐	☐	☐	☐
I stop taking these IBD medicines altogether	☐	☐	☐	☐	☐
I decide to miss a dose of these IBD medicines	☐	☐	☐	☐	☐

Diet Modification

These questions are about foods you ate or drank during the past month, that is, the past 30 days. When answering, please include meals and snacks at home, at work or school, in restaurants, and anyplace else.

During the past month, how often did you eat hot or cold cereals? Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

During the past month, what kind of cereal did you usually eat? Print cereal, if none leave blank.

I alter my intake of hot or cold cereals due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you have any milk (either to drink or on cereal)? Include regular milks, chocolate or other flavored milks, lactose-free milk, buttermilk. Please do not include soy milk or small amounts of milk in coffee or tea. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

I alter my intake of milk due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, what kind of milk did you usually drink? Mark one

- Whole or regular milk
- 2% fat or reduced-fat milk
- 1%, ½%, or low-fat milk
- Soy milk
- Other kind of milk _____

During the past month, how often did you drink regular soda or pop that contains sugar? Do not include diet soda. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

I alter my intake of regular soda or pop due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you drink 100% pure fruit juices such as orange, mango, apple, grape and pineapple juices? Do not include fruit-flavored drinks with added sugar or fruit juice you made at home and added sugar to. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

I alter my intake of 100% pure fruit juices due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you drink coffee or tea that had sugar or honey added to it? Include coffee and tea you sweetened yourself and presweetened tea and coffee drinks such as Arizona Iced Tea and Frappuccino. Do not include artificially sweetened coffee or diet tea. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

I alter my intake of drink coffee or tea that had sugar or honey due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you drink sweetened fruit drinks, sports or energy drinks, such as Kool-Aid, lemonade, Hi-C, cranberry drink, Gatorade, Red Bull or Vitamin Water? Include fruit juices you made at home and added sugar to. Do not include diet drinks or artificially sweetened drinks. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

I alter my intake of sweetened fruit drinks, sports or energy drinks due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat fruit? Include fresh, frozen or canned fruit. Do not include juices. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of fruit due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat a green leafy or lettuce salad, with or without other vegetables? Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of green leafy or lettuce salad due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat any kind of fried potatoes, including French fries, home fries, or hash brown potatoes? Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of fried potatoes due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat any other kind of potatoes, such as baked, boiled, mashed potatoes, sweet potatoes, or potato salad? Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of other kind of potatoes due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans? Do not include green beans. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat brown rice or other cooked whole grains, such as bulgur, cracked wheat, or millet? Do not include white rice. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of brown rice or other cooked whole grains due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, not including what you just told me about (green salads, potatoes, cooked dried beans), how often did you eat other vegetables? Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of other vegetables due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you have Mexican-type salsa made with tomato? Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of Mexican-type salsa made with tomato due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat pizza? Include frozen pizza, fast food pizza, and homemade pizza. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of pizza due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you have tomato sauces such as with spaghetti or noodles or mixed into foods such as lasagna? Do not include tomato sauce on pizza. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of tomato sauces due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat any kind of cheese? Include cheese as a snack, cheese on burgers, sandwiches, and cheese in foods such as lasagna, quesadillas, or casseroles. Do not include cheese on pizza. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of cheese due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat red meat, such as beef, pork, ham, or sausage? Do not include chicken, turkey or seafood. Include red meat you had in sandwiches, lasagna, stew, and other mixtures. Red meats may also include veal, lamb, and any lunch meats made with these meats. Mark one

- Never
- 1time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of red meat due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat any processed meat, such as bacon, lunch meats, or hot dogs? Include processed meats you had in sandwiches, soups, pizza, casseroles, and other mixtures. Processed meats are those preserved by smoking, curing, or salting, or by the addition of preservatives. Examples are: ham, bacon, pastrami, salami, sausages, bratwursts, frankfurters, hot dogs, and spam. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of processed meat due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat whole grain bread including toast, rolls and in sandwiches? Whole grain breads include whole wheat, rye, oatmeal and pumpernickel. Do not include white bread. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of whole grain bread due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat chocolate or any other types of candy? Do not include sugar-free candy. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of chocolate or any other types of candy due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat doughnuts, sweet rolls, Danish, muffins, pan dulce, or pop-tarts? Do not include sugar-free items. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of doughnuts, sweet rolls, Danish, muffins, pan dulce, or pop-tarts due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat cookies, cake, pie or brownies? Do not include sugar-free kinds. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of cookies, cake, pie or brownies due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat ice cream or other frozen desserts? Do not include sugar-free kinds. Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of ice cream or other frozen desserts due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

During the past month, how often did you eat popcorn? Mark one

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

I alter my intake of popcorn due to my IBD. Mark one

- Always
- Often
- Sometimes
- Rarely
- Never

APPENDIX I: IRB Approval

MICHIGAN STATE UNIVERSITY

Initial IRB Application Determination *Exempt*

February 9, 2017

To: Kelly Brittain
1355 Bogue St.
C348

Re: **IRB# x17-107e** Category: Exempt 2
Approval Date: February 9, 2017

Title: Self-management of Provider Recommended Medication Adherence and Patient Initiated Diet Modification among Young Adults with Inflammatory Bowel Disease

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been deemed as exempt** in accordance with federal regulations.

This letter also notes that this project involves the use of ResearchMarch.com.

The IRB has found that your research project meets the criteria for exempt status and the criteria for the protection of human subjects in exempt research. **Under our exempt policy the Principal Investigator assumes the responsibilities for the protection of human subjects** in this project as outlined in the assurance letter and exempt educational material. The IRB office has received your signed assurance for exempt research. A copy of this signed agreement is appended for your information and records.

Renewals: Exempt protocols do not need to be renewed. If the project is completed, please submit an *Application for Permanent Closure*.

Revisions: Exempt protocols do not require revisions. However, if changes are made to a protocol that may no longer meet the exempt criteria, a new initial application will be required.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects and change the category of review, notify the IRB office promptly. Any complaints from participants regarding the risk and benefits of the project must be reported to the IRB.

Follow-up: If your exempt project is not completed and closed after three years, the IRB office will contact you regarding the status of the project and to verify that no changes have occurred that may affect exempt status.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.



**Office of Regulatory Affairs
Human Research
Protection Programs**

**Biomedical & Health
Institutional Review Board
(BIRB)**

**Community Research
Institutional Review Board
(CRIRB)**

**Social Science
Behavioral/Education
Institutional Review Board
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c: Kendra Kamp, Barbara A. Given

APPENDIX J: Medications

Table A.5

Medication Types used among Emerging Adults with IBD

	%	n
Aminosalicylates		
Azulfidine	0	0
Asacol	4.9	3
Lialda	21.3	13
Rowasa	0	0
Canasa	4.9	3
Colazal	3.3	2
Dipentum	0	0
Pentasa	3.3	2
Corticoosteroids		
Prednisone (deltasone)	13.1	8
Hydrocortisone	1.6	1
Budesonide (entro cort or uceris)	3.3	2
Biologics		
Remicade (Infliximab)	14.8	9
Humira (Adalimumab)	26.2	16
Cimzia	3.3	2
Simponi	0	0
Entyvio (Vedolizumab)	14.8	9
Natalizumab	0	0
Ustekinumab	1.6	1
Immunomodulators		
Imuran/azathioprine	13.1	8
Methotrexate	13.1	8

APPENDIX K: Copyright Permissions

Theory: Individual and Family Self-Management Theory

Obtained permission from Dr. Kathleen Sawin.

Personal communication March 5, 2018

Emerging Adulthood factors: Inventory of the Dimensions of Emerging Adulthood

The Inventory of the Dimensions of Emerging Adulthood can be used freely; there is no need to ask for permission.

http://www.webpages.ttu.edu/areifman/IDEA_instrument.htm

Received Social Support: Inventory of Socially Supportive Behaviors

The Inventory of Socially Supportive Behaviors is in the public domain and can be used for research purposes without charge. It may be reproduced and modified to meet the needs of specific research projects.

<http://www.midss.org/content/inventory-socially-supportive-behaviors-issb-long-and-short-form>

Perceived Availability of Social Support: Medical Outcomes Survey – Social Support

All of the surveys from RAND Health are public documents, available without charge.

http://www.rand.org/health/surveys_tools/mos/social-support.html

Medication Adherence: Medication Adherence Report Scale

Contacted Professor Horne on October 12, 2017 and December 5, 2017, no response obtained.

Diet Modification: Dietary Screener Questionnaire

The Dietary Screener Questionnaire (DSQ) is available for public use.

<https://epi.grants.cancer.gov/nhanes/dietscreen/questionnaires.html>

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