

## 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 instead (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 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, blood in 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 35) report more severe bowel-related symptoms (such as gastrointestinal

pain, diarrhea, gas/bloating, blood in the stool, and decreased energy), increased stricture and fistula complications, and an increased likelihood of requiring advanced treatment. Each of these are negative disease outcomes and lead to increases in both direct and indirect costs (Bager, Julsgaard, Vestergaard, Christensen, & Dahlerup, 2016; Goodhand et al., 2010; Kim et al., 2016; Liverani, Scaioli, Digby, Bellanova, & Belluzzi, 2016; Torres et al., 2016; 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, Grootenhuis, Last, Koopman, & Derkx, 2002; Mackner & Crandall, 2006; Trivedi & Keefer, 2015). Focusing on emerging adults with IBD is essential since these adults experience negative disease outcomes and may benefit from an intervention 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 an essential factor (Boger et al., 2015; DiMatteo, 2004). The relationship between social support and self-management behaviors within this emerging-adult population is neither heavily researched nor understood.

IBD patients, regardless of age, have identified the importance of social support in managing their disease and 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 receive 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 in emerging adulthood. These 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 needing 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). 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

which 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 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 (Kamat et al., 2017). In addition, individuals who are nonadherent experience 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 and try modifying their diet on their own to reduce symptoms (Tanaka, Kawakami, Iwao, Fukushima, & Yamamoto-Mitani, 2016; Vagianos et al., 2014). Dietary research has shown benefits of diet modification on symptom reduction (including bowel 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. Although, 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 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 are more likely to have decreased medication adherence and increased diet modification (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, IBD self-management among emerging adults 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). 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. 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. Specifically, tangible support is associated with medication adherence among individuals with chronic conditions (DiMatteo, 2004; Rico et al., 2017). In online IBD communities, informational and emotional support are the most common types of social support received (Britt, 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; however, these factors have not been examined within the literature. 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).



**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 diet 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.

**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.

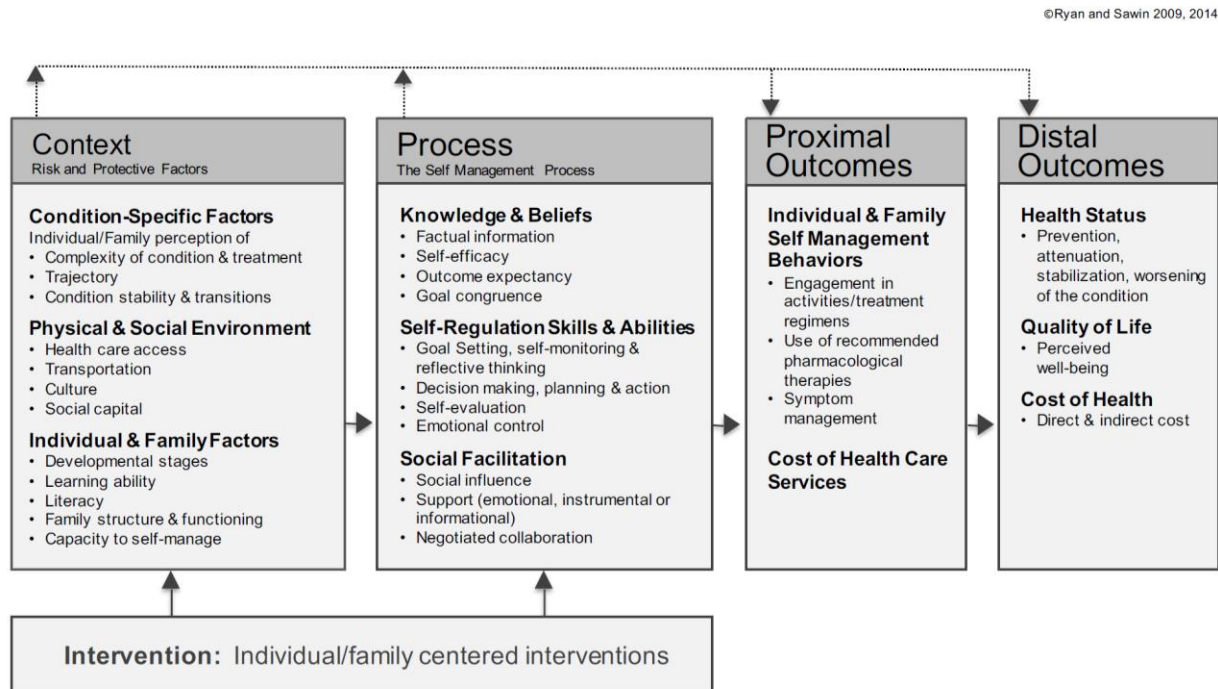
**Process.** Process refers to the factors which make an individual more or less likely to engage in self-management behaviors (Ryan & Sawin, 2009). The process dimension of self-

management is comprised of knowledge and beliefs, 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).

**Figure 1.1: Model of the Individual and Family Self-Management Theory by Ryan and Sawin (2009)**



**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. The theory was tested among adolescents with Type 1 diabetes finding that depressive symptoms, self-efficacy, and self-management behaviors significantly predicted 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). The theory has previously focused on adolescents, parents of hospitalized children, middle-age adults, and frail older adults. 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 critical outcomes variables for emerging adults such as medication adherence 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 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). 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**

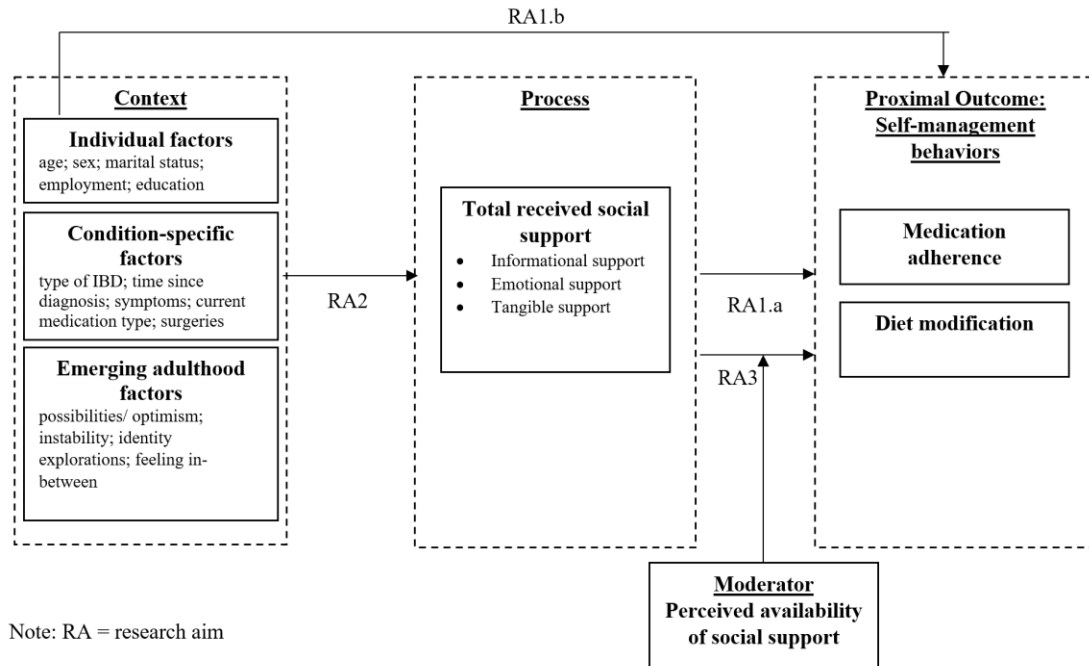
This dissertation utilized select variables from the IFSMT to focus specifically on the relationship between context, process (received social support), and proximal outcomes (self-management behaviors of medication adherence and diet modification) and to incorporate the moderating effect of perceived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

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



**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 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, hospitalizations, and 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 diets 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), but 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 hospitalizations 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.



## 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 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 in older adult chronic condition populations, 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**

Several research questions will be 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. In addition, 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 eight-item 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 will be 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 will be 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 eight-item 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 to 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.



## 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.

### **Summary of Manuscript 1**

Manuscript 1 summarized the current research findings examining relationships between overall and type of social support (e.g., informational, emotional, and tangible) and self-management behaviors among adults with IBD. The systematic review indicated some support 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 was 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). In addition, a lower age (age <40) was associated with poorer self-management behavior. Thus, it became apparent that future research is needed to specifically address the needs of an emerging adult (ages 18-29) population in order to inform interventions to improve self-management behaviors among this age group. 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**

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 age, marital status, and employment were associated with 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; thus, the type of social support may provide a more precise understanding 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**

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%), aminosalicylates (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 becomes non-significant ( $p=0.129$ ).

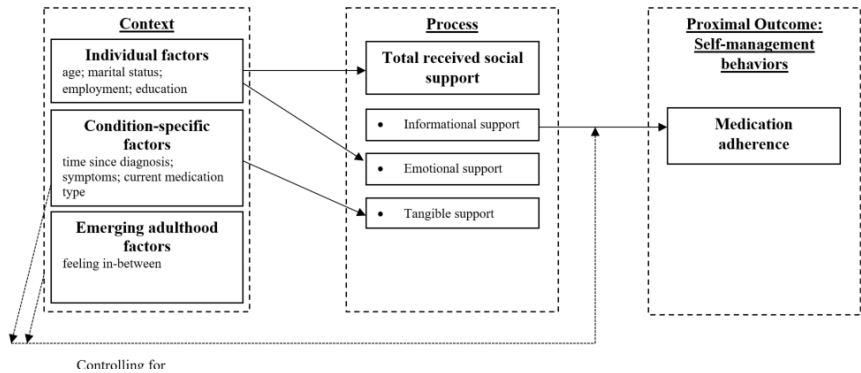
Sixty-four percent of emerging adults reported modifying their diet ( $n=39$ ). The most commonly modified food groups included: fruits and vegetables ( $n=41$ , 67%), fiber ( $n=40$ , 65%), dairy ( $n=37$ , 61%), and grains ( $n=37$ , 61%). Received social support was not associated with diet modification. 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 also 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**

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 [See Figure 5.1 for the IFSMT applied to IBD with significant variables only]. The 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: Individual and Family Self-Management Theory applied to IBD: Significant Findings



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).

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 Inflammatory Bowel Disease (IBD) [see Table 5.1 for Research Questions and Findings]. The systematic review indicated that social support may influence self-management behaviors. Among emerging adults with IBD, a high degree of received informational support compared to 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. 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 based 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 negatively associated with self-management behaviors. A younger age was also associated with greater received social support. 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. 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.

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.<br><br>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 is negatively associated with self-management behaviors.  |
| Chapter 3 / Manuscript 2  |   |
| 3. Which <b>individual factors</b> (age, sex, marital status, employment, education) are predictive of received social support (total received social support, informational support, emotional support, and tangible support)?   | <b>Total received social support:</b> decreased age ( $p = 0.001$ ), being married ( $p = 0.039$ ) and having employment full-time compared to being unemployed or a student ( $p = 0.007$ )<br><b>Informational support:</b> none<br><b>Emotional support:</b> decreased age ( $p = 0.033$ ) and being married ( $p = 0.001$ )<br><b>Tangible support:</b> none              |
| 4. Which <b>condition-specific factors</b> (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)?     | <b>Total received social support:</b> none<br><b>Informational support:</b> none<br><b>Emotional support:</b> none<br><b>Tangible support:</b> 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 |
| 5. Which <b>emerging adulthood factors</b> (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)? | <b>Total received social support:</b> none<br><b>Informational support:</b> none<br><b>Emotional support:</b> none<br><b>Tangible support:</b> none   |
| Chapter 4 / Manuscript 3  |   |
| 6. Among emerging adults with IBD, what is the association between received social support and self-  | Informational received social support is associated with medication adherence   |

| <b>Research Questions</b>  | <b>Finding</b>  |
|--|---|
| management behaviors (medication adherence and diet modification) while controlling for contextual variables?  | 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. |

**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. The cross-sectional nature of this data is another limitation.

**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 negatively associated with self-management behaviors. The



emerging adulthood sample highly endorsed the factors of emerging adulthood demonstrating that these individuals are experiencing the typical demands of emerging adulthood. In addition, the emerging adulthood factor of feeling in-between influenced medication adherence.

Therefore, there is some indication that developmental stage may influence self-management behaviors, although developmental stage did not 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 which 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 which 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 received social support.

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 influence 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 factors 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. Among emerging adults with IBD, does self-efficacy mediate the relationship between received social support and the self-management behaviors of medication adherence and diet modification?
2. Among newly diagnosed emerging adults with IBD, what is the relationship between received social support and the self-management behaviors of medication adherence and diet modification?
3. How does symptom frequency, severity, and interference change over time among adults with IBD?
4. What is the relationship between beliefs about diet 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 well-managed 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 step therapy 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 (non-adherence was not associated with greater symptoms than those who were adherent). 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 closed 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.

Policy makers should seek to expand funding of IBD research; research is needed to develop psychoeducational interventions with components tailored to the needs of emerging adults. In addition, research funds would contribute to better understanding the role of symptoms, the relationship between diet and medication, and the influence of diet and nutrients 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 may be more likely to have medication non-adherence. 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, IBD research has indicated the relationship between received social support and quality of life (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 35) 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 negatively associated with 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 specifically 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 negatively associated with 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.



## REFERENCES

- Ananthakrishnan, A. N., McGinley, E. L., Saeian, K., & Binion, D. G. (2010). Trends in ambulatory and emergency room visits for inflammatory bowel diseases in the United States: 1994-2005. *The American Journal of Gastroenterology*, *105*(2), 363-370. doi:10.1038/ajg.2009.580
- Anderson Steeves, E., Jones-Smith, J., Hopkins, L., & Gittelsohn, J. (2016). Perceived social support from friends and parents for eating behavior and diet quality among low-income, urban, minority youth. *Journal of Nutrition Education and Behavior*, *48*(5), 304-310.e301. doi:10.1016/j.jneb.2015.12.014
- Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469-480.
- Arnett, J. J. (2015). *Emerging adulthood: The winding road from the late teens through the twenties* (2 ed.). New York, NY: Oxford University Press.
- Arora, N. K., Finney Rutten, L. J., Gustafson, D. H., Moser, R., & Hawkins, R. P. (2007). Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-Oncology*, *16*(5), 474-486. doi:10.1002/pon.1084
- Bager, P., Julsgaard, M., Vestergaard, T., Christensen, L. A., & Dahlerup, J. F. (2016). Adherence and quality of care in IBD. *Scandinavian Journal of Gastroenterology*, *51*(11), 1326-1331. doi:10.1080/00365521.2016.1195870
- Boger, E., Ellis, J., Latter, S., Foster, C., Kennedy, A., Jones, F., . . . Demain, S. (2015). Self-management and self-management support outcomes: A systematic review and mixed research synthesis of stakeholder views. *PloS One*, *10*(7), 1-25. doi:10.1371/journal.pone.0130990
- Bollegala, N., Brill, H., & Marshall, J. K. (2013). Resource utilization during pediatric to adult transfer of care in IBD. *Journal of Crohn's and Colitis*, *7*(2), e55-60. doi:10.1016/j.crohns.2012.05.010
- Britt, R. K. (2016). Online social support for participants of crohn's and ulcerative colitis groups. *Health Communication*, 1-10. doi:10.1080/10410236.2016.1234539
- Calloway, A., Dalal, R., Beaulieu, D. B., Duley, C., Annis, K., Gaines, L., . . . Horst, S. (2017). Depressive symptoms predict anti-tumor necrosis factor therapy noncompliance in patients with inflammatory bowel disease. *Digestive Diseases and Sciences*, *62*(12), 3563-3567. doi:10.1007/s10620-017-4800-y
- Cashion, A. K., & Grady, P. A. (2015). The National Institutes of Health/National Institutes of Nursing Research intramural research program and the development of the National

Institutes of Health Symptom Science Model. *Nursing Outlook*, 63(4), 484-487.  
doi:10.1016/j.outlook.2015.03.001

Charlebois, A., Rosenfeld, G., & Bressler, B. (2016). The impact of dietary interventions on the symptoms of Inflammatory Bowel Disease: A systematic review. *Critical Reviews in Food Science and Nutrition*, 56(8), 1370-1378. doi:10.1080/10408398.2012.760515

Cho, R., Wickert, N. M., Klassen, A. F., Tsangaris, E., Marshall, J. K., & Brill, H. (2018). Identifying needs in young adults with inflammatory bowel disease: A qualitative study. *Gastroenterology Nursing*, 41(1), 19-28. doi:10.1097/sga.0000000000000288

Clarke, T., & Lusher, J. (2016). Transitioning patients with inflammatory bowel disease (IBD) from adolescent to adult services: A systematic review. *Frontline Gastroenterology*, 7(4), 264-270. doi:10.1136/flgastro-2015-100575

Coenen, S., Weyts, E., Ballet, V., Noman, M., Van Assche, G., Vermeire, S., . . . Ferrante, M. (2016). Identifying predictors of low adherence in patients with inflammatory bowel disease. *European Journal of Gastroenterology and Hepatology*, 28(5), 503-507. doi:10.1097/meg.0000000000000570

Coenen, S., Weyts, E., Ballet, V., Noman, M., Van Assche, G., Vermeire, S., . . . Ferrante, M. (2016). Identifying predictors of low adherence in patients with inflammatory bowel disease. *European Journal of Gastroenterology and Hepatology*, 28(5), 503-507. doi:10.1097/meg.0000000000000570

Cohen, R., Skup, M., Ozbay, A. B., Rizzo, J., Yang, M., Diener, M., & Chao, J. (2015). Direct and indirect healthcare resource utilization and costs associated with ulcerative colitis in a privately-insured employed population in the US. *Journal of Medical Economics*, 18(6), 447-456. doi:10.3111/13696998.2015.1021353

Conley, S., Proctor, D. D., Jeon, S., Sandler, R. S., & Redeker, N. S. (2017). Symptom clusters in adults with inflammatory bowel disease. *Research in Nursing and Health*, 40(5), 424-434. doi:10.1002/nur.21813

Crohn's and Colitis Foundation of America. (2015). The facts about inflammatory bowel diseases. Retrieved from <http://www.crohnscolitisfoundation.org/assets/pdfs/updatedibdfactbook.pdf>

Dahlhamer, J. M., Zammitti, E. P., Ward, B. W., Wheaton, A. G., & Croft, J. B. (2016). Prevalence of inflammatory bowel disease among adults aged  $\geq 18$  years - United States, 2015. *Morbidity and Mortality Weekly Report*, 65, 1166-1169. doi: <http://dx.doi.org/10.15585/mmwr.mm6542a3>

Davis, M. A., Anthony, D. L., & Pauls, S. D. (2015). Seeking and receiving social support on Facebook for surgery. *Social Science and Medicine*, 131(Supplement C), 40-47. doi:https://doi.org/10.1016/j.socscimed.2015.02.038

- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychology, 23*(2), 207-218. doi:10.1037/0278-6133.23.2.207
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., . . . Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*(5), 668-676.
- Dur, M., Sadlonova, M., Haider, S., Binder, A., Stoffer, M., Coenen, M., . . . Stamm, T. A. (2014). Health determining concepts important to people with Crohn's disease and their coverage by patient-reported outcomes of health and wellbeing. *Journal of Crohns & Colitis, 8*(1), 45-55. doi:10.1016/j.crohns.2012.12.014
- Ediger, J. P., Walker, J. R., Graff, L., Lix, L., Clara, I., Rawsthorne, P., . . . Bernstein, C. N. (2007). Predictors of medication adherence in inflammatory bowel disease. *The American Journal of Gastroenterology, 102*(7), 1417-1426. doi:10.1111/j.1572-0241.2007.01212.x
- Erikson, E. H. (1994). *Identity and the life cycle*. New York, NY: W.W. Norton & Company.
- Farrell, D., & Savage, E. (2010). Symptom burden in inflammatory bowel disease: Rethinking conceptual and theoretical underpinnings. *International Journal of Nursing Practice, 16*(5), 437-442. doi:10.1111/j.1440-172X.2010.01867.x
- Farrell, D., McCarthy, G., & Savage, E., (2016). Self-reported symptom burden in individuals with inflammatory bowel disease. *Journal of Crohn's and Colitis, 10*(3):315-22. doi: 10.1093/ecco-jcc/jjv218
- Fletcher, P. C., Schneider, M. A., Van Ravenswaay, V., & Leon, Z. (2008). I am doing the best that I can! Living with inflammatory bowel disease and/or irritable bowel syndrome (part II). *Clinical Nurse Specialist, 22*(6), 278-285.
- Fu, N., Jacobson, K., Round, A., Evans, K., Qian, H., & Bressler, B. (2017). Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease. *World Journal of Gastroenterology, 23*(29), 5405-5411. doi:10.3748/wjg.v23.i29.5405
- Fuller-Thomson, E., & Nimigon, J. (2008). Factors associated with depression among individuals with chronic fatigue syndrome: Findings from a nationally representative survey. *Family Practice, 25*(6), 414-422. doi:10.1093/fampra/cmn064
- Gallant, M. P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education and Behavior, 30*(2), 170-195.
- Gibson, T. B., Ng, E., Ozminkowski, R. J., Wang, S., Burton, W. N., Goetzel, R. Z., & Maclean, R. (2008). The direct and indirect cost burden of Crohn's disease and ulcerative colitis.

*Journal of Occupational and Environmental Medicine*, 50(11), 1261-1272.  
doi:10.1097/JOM.0b013e318181b8ca

- Goodhand, J., Dawson, R., Hefferon, M., Tshuma, N., Swanson, G., Wahed, M., . . . Lindsay, J. O. (2010). Inflammatory bowel disease in young people: the case for transitional clinics. *Inflammatory Bowel Diseases*, 16(6), 947-952. doi:10.1002/ibd.21145
- Goodhand, J., Kamperidis, N., Sirwan, B., Macken, L., Tshuma, N., Koodun, Y., . . . Lindsay, J. O. (2013). Factors associated with thiopurine non-adherence in patients with inflammatory bowel disease. *Alimentary Pharmacology and Therapeutics*, 38(9), 1097-1108. doi:10.1111/apt.12476
- Grady, P. A., & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, 104(8), e25-31. doi:10.2105/ajph.2014.302041
- Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. R. (2015). A revised self- and family management framework. *Nursing Outlook*, 63(2), 162-170. doi:10.1016/j.outlook.2014.10.003
- Groshek, J., Basil, M., Guo, L., Ward, S.P., Farraye, F.A., & Reich, J. (2017). Media consumption and creation in attitudes toward and knowledge of inflammatory bowel disease: Web-based survey. *Journal of Medical Internet Research*, 19(12):e403 doi: 10.2196/jmir.7624
- Gumidyala, A. P., Greenley, R. N., Plevinsky, J. M., Pouloupoulos, N., Cabrera, J., Lerner, D., . . . Kahn, S. A. (2018). Moving on: transition readiness in adolescents and young adults with IBD. *Inflammatory Bowel Diseases*, 24(3), 482-489. doi:10.1093/ibd/izx051
- Haskey, N., & Gibson, D. L. (2017). An examination of diet for the maintenance of remission in inflammatory bowel disease. *Nutrients*, 9(3), 259. doi:10.3390/nu9030259
- Herman, M. L., & Kane, S. V. (2015). Treatment nonadherence in inflammatory bowel disease: Identification, scope, and management Strategies. *Inflammatory Bowel Diseases*, 21(12), 2979-2984. doi:10.1097/mib.0000000000000581
- Higgins, P. D., Rubin, D. T., Kaulback, K., Schoenfield, P. S., & Kane, S. V. (2009). Systematic review: Impact of non-adherence to 5-aminosalicylic acid products on the frequency and cost of ulcerative colitis flares. *Alimentary Pharmacology and Therapeutics*, 29(3), 247-257. doi:10.1111/j.1365-2036.2008.03865.x
- Hilsden, R. J., Verhoef, M. J., Rasmussen, H., Porcino, A., & DeBruyn, J. C. (2011). Use of complementary and alternative medicine by patients with inflammatory bowel disease. *Inflammatory Bowel Diseases*, 17(2), 655-662. doi:10.1002/ibd.21360

- Hommel, K. A., McGrady, M. E., Peugh, J., Zacur, G., Loreaux, K., Saeed, S., . . . Denson, L. A. (2017). Longitudinal patterns of medication nonadherence and associated health care costs. *Inflammatory Bowel Diseases*, *23*(9), 1577-1583. doi:10.1097/mib.0000000000001165
- Janicke, D. M., Gray, W. N., Kahhan, N. A., Follansbee Junger, K. W., Marciel, K. K., Storch, E. A., & Jolley, C. D. (2009). Brief report: The association between peer victimization, prosocial support, and treatment adherence in children and adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology*, *34*(7), 769-773. doi:10.1093/jpepsy/jsn116
- Jason, S. (2007). Look (closely) at all the lonely people: Age and the social psychology of social support. *Journal of Aging and Health*, *19*(4), 659-682. doi:10.1177/0898264307301178
- Joly, E. (2016). Integrating transition theory and bioecological theory: A theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity. *Journal of Advanced Nursing*, *72*(6), 1251-1262. doi:10.1111/jan.12939
- Kamat, N., Ganesh Pai, C., Surulivel Rajan, M., & Kamath, A. (2017). Cost of illness in inflammatory bowel disease. *Digestive Diseases and Sciences*. doi:10.1007/s10620-017-4690-z
- Kane, S., Huo, D., Aikens, J., & Hanauer, S. (2003). Medication nonadherence and the outcomes of patients with quiescent ulcerative colitis. *The American Journal of Medicine*, *114*(1), 39-43.
- Karve, S., Candrilli, S., Kappelman, M. D., Tolleson-Rinehart, S., Tennis, P., & Andrews, E. (2012). Healthcare utilization and comorbidity burden among children and young adults in the United States with systemic lupus erythematosus or inflammatory bowel disease. *Journal of Pediatrics*, *161*(4), 662-670.e662. doi:10.1016/j.jpeds.2012.03.045
- Katz, L., Tripp, D. A., Ropeleski, M., Depew, W., Curtis Nickel, J., Vanner, S., & Beyak, M. J. (2016). Mechanisms of quality of life and social support in Inflammatory Bowel Disease. *Journal of Clinical Psychology in Medical Settings*, *23*(1), 88-98. doi:10.1007/s10880-015-9431-x
- Kim, S. B., Kim, K. O., Jang, B. I., Kim, E. S., Cho, K. B., Park, K. S., . . . Jeon, S. W. (2016). Patients' beliefs and attitudes about their treatment for inflammatory bowel disease in Korea. *Journal of Gastroenterology and Hepatology*, *31*(3), 575-580. doi:10.1111/jgh.13155
- Klostermann, N. R., McAlpine, L., Wine, E., Goodman, K. J., & Kroeker, K. I. (2017). Assessing the transition intervention needs of young adults with inflammatory bowel diseases. *Journal of Pediatric Gastroenterology and Nutrition*. doi:10.1097/mpg.0000000000001677

- Knight-Sepulveda, K., Kais, S., Santaolalla, R., & Abreu, M. T. (2015). Diet and inflammatory bowel disease. *Gastroenterol Hepatol (N Y)*, *11*(8), 511-520.
- Konijeti, G. G., Kim, N., Lewis, J. D., Groven, S., Chandrasekaran, A., Grandhe, S., . . . Torkamani, A. (2017). Efficacy of the autoimmune protocol diet for inflammatory bowel disease. *Inflammatory Bowel Diseases*, *23*(11), 2054-2060.  
doi:10.1097/MIB.0000000000001221
- Lachaine, J., Yen, L., Beauchemin, C., & Hodgkins, P. (2013). Medication adherence and persistence in the treatment of Canadian ulcerative colitis patients: Analyses with the RAMQ database. *BMC Gastroenterology*, *13*(1), 1-8. doi:10.1186/1471-230x-13-23
- Lee, D., Albenberg, L., Compher, C., Baldassano, R., Piccoli, D., Lewis, J. D., & Wu, G. D. (2015). Diet in the pathogenesis and treatment of inflammatory bowel diseases. *Gastroenterology*, *148*(6), 1087-1106. doi:10.1053/j.gastro.2015.01.007
- Lenz, B. (2001). The transition from adolescence to young adulthood: A theoretical perspective. *Journal of School Nursing*, *17*(6), 300-306. doi:10.1177/10598405010170060401
- Leung, J., Smith, M. D., & McLaughlin, D. (2016). Inequalities in long term health-related quality of life between partnered and not partnered breast cancer survivors through the mediation effect of social support. *Psycho-Oncology*, *25*(10), 1222-1228.  
doi:10.1002/pon.4131
- Liverani, E., Scaioli, E., Digby, R. J., Bellanova, M., & Belluzzi, A. (2016). How to predict clinical relapse in inflammatory bowel disease patients. *World Journal of Gastroenterology*, *22*(3), 1017-1033. doi:10.3748/wjg.v22.i3.1017
- Loonen, H. J., Grootenhuis, M. A., Last, B. F., Koopman, H. M., & Derkx, H. H. (2002). Quality of life in paediatric inflammatory bowel disease measured by a generic and a disease-specific questionnaire. *Acta Paediatrica*, *91*(3), 348-354.
- Luong, G., Charles, S. T., & Fingerman, K. L. (2011). Better with age: Social relationships across adulthood. *Journal of Social and Personal Relationships*, *28*(1), 9-23.  
doi:10.1177/0265407510391362
- Lynch, T., & Spence, D. (2008). A qualitative study of youth living with Crohn disease. *Gastroenterology Nursing*, *31*(3), 224-230. doi:10.1097/01.sga.0000324114.01651.65
- Mackner, L. M., & Crandall, W. V. (2006). Brief report: psychosocial adjustment in adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology*, *31*(3), 281-285.  
doi:10.1093/jpepsy/jsj023
- Marek, K. D., Stetzer, F., Ryan, P. A., Bub, L. D., Adams, S. J., Schlidt, A., . . . O'Brien, A. M. (2013). Nurse care coordination and technology effects on health status of frail older

- adults via enhanced self-management of medication: Randomized clinical trial to test efficacy. *Nursing Research*, 62(4), 269-278. doi:10.1097/NNR.0b013e318298aa55
- Marquez, B., Anderson, A., Wing, R. R., West, D. S., Newton, R. L., Meacham, M., . . . Evans-Hudsnall, G. (2016). The relationship of social support with treatment adherence and weight loss in Latinos with type 2 diabetes. *Obesity (Silver Spring)*, 24(3), 568-575. doi:10.1002/oby.21382
- McCall, M. K., Stanfill, A. G., Skrovanek, E., Pforr, J. R., Wesmiller, S. W., & Conley, Y. P. (2018). Symptom science: Omics supports common biological underpinnings across symptoms. *Biological Research for Nursing*, 20(2), 183-191. doi:10.1177/1099800417751069
- Mitra, D., Hodgkins, P., Yen, L., Davis, K. L., & Cohen, R. D. (2012). Association between oral 5-ASA adherence and health care utilization and costs among patients with active ulcerative colitis. *BMC Gastroenterology*, 12, 132. doi:10.1186/1471-230x-12-132
- Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., . . . Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics*, 129(2), e473-e485. doi:10.1542/peds.2011-1635
- Molodecky, N. A., Soon, I. S., Rabi, D. M., Ghali, W. A., Ferris, M., Chernoff, G., . . . Kaplan, G. G. (2012). Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology*, 142(1), 46-54.e42. doi:https://doi.org/10.1053/j.gastro.2011.10.001
- Nahon, S., Lahmek, P., Saas, C., Durance, C., Olympie, A., Lesgourgues, B., & Gendre, J. P. (2011). Socioeconomic and psychological factors associated with nonadherence to treatment in inflammatory bowel disease patients: Results of the ISSEO survey. *Inflammatory Bowel Diseases*, 17(6), 1270-1276. doi:10.1002/ibd.21482
- Nordgren, L., & Soderlund, A. (2017). Received and needed social support in relation to sociodemographic and socio-economic factors in a population of people on sick leave due to heart failure. *ESC Heart Failure*, 4(1), 46-55. doi:10.1002/ehf2.12121
- Olendzki, B. C., Silverstein, T. D., Persuitte, G. M., Ma, Y., Baldwin, K. R., & Cave, D. (2014). An anti-inflammatory diet as treatment for inflammatory bowel disease: A case series report. *Nutrition Journal*, 13, 5. doi:10.1186/1475-2891-13-5
- Oliveira, S., Zaltman, C., Elia, C., Vargens, R., Leal, A., Barros, R., & Fogaca, H. (2007). Quality-of-life measurement in patients with inflammatory bowel disease receiving social support. *Inflammatory Bowel Diseases*, 13(4), 470-474. doi:10.1002/ibd.20071
- Plevinsky, J. M., Greenley, R. N., & Fishman, L. N. (2016). Self-management in patients with inflammatory bowel disease: strategies, outcomes, and integration into clinical care. *Clinical and Experimental Gastroenterology*, 9, 259-267. doi:10.2147/ceg.s106302

- Rad, G. S., Bakht, L. A., Feizi, A., & Mohebi, S. (2013). Importance of social support in diabetes care. *Journal of Education and Health Promotion, 2*, 62. doi:10.4103/2277-9531.120864
- Rico, T. M., Dos Santos Machado, K., Fernandes, V. P., Madruga, S. W., Noguez, P. T., Barcelos, C. R. G., . . . Dumith, S. C. (2017). Text messaging (SMS) helping cancer care in patients undergoing chemotherapy treatment: A pilot study. *Journal of Medical Systems, 41*(11), 181. doi:10.1007/s10916-017-0831-3
- Robinson, A., Hankins, M., Wiseman, G., & Jones, M. (2013). Maintaining stable symptom control in inflammatory bowel disease: A retrospective analysis of adherence, medication switches and the risk of relapse. *Alimentary Pharmacology and Therapeutics, 38*(5), 531-538. doi:10.1111/apt.12396
- Ryan, P., & Sawin, K. J. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook, 57*(4), 217-225. doi:10.1016/j.outlook.2008.10.004
- Ryan, P., Maierle, D., Csuka, M. E., Thomson, A., & Szabo, A. (2013). Computer-based intervention to enhance self-management of calcium and Vitamin D intake in women. *Western Journal of Nursing Research, 35*(8), 986-1010. doi:10.1177/0193945913483369
- Sarason, I. G., Sarason, B. R., Shearin, E. N., & Pierce, G. R. (1987). A Brief Measure of Social Support: Practical and theoretical implications. *Journal of Social and Personal Relationships, 4*(4), 497-510. doi:10.1177/0265407587044007
- Sawin, K. J., Weiss, M. E., Johnson, N., Gralton, K., Malin, S., Klingbeil, C., . . . Schiffman, R. F. (2017). Development of a Self-Management Theory-Guided discharge intervention for parents of hospitalized children. *Journal of Nursing Scholarship, 49*(2), 202-213. doi:10.1111/jnu.12284
- Schurman, J. V., Cushing, C. C., Carpenter, E., & Christenson, K. (2011). Volitional and accidental nonadherence to pediatric inflammatory bowel disease treatment plans: Initial investigation of associations with quality of life and disease activity. *Journal of Pediatric Psychology, 36*(1), 116-125. doi:10.1093/jpepsy/jsq046
- Severs, M., Mangen, M. J., Fidder, H. H., van der Valk, M. E., van der Have, M., van Bodegraven, A. A., . . . Oldenburg, B. (2017). Clinical predictors of future nonadherence in inflammatory bowel disease. *Inflammatory Bowel Diseases, 23*(9), 1568-1576. doi:10.1097/mib.0000000000001201
- Shivashankar, R., Tremaine, W. J., Harmsen, W. S., & Loftus, E. V., Jr. (2017). Incidence and prevalence of Crohn's disease and ulcerative colitis in Olmsted County, Minnesota from 1970 through 2010. *Clinical Gastroenterology and Hepatology, 15*(6), 857-863. doi:10.1016/j.cgh.2016.10.039



- Sin, A. T., Damman, J. L., Ziring, D. A., Gleghorn, E. E., Garcia-Careaga, M. G., Gugig, R. R., . . . Park, K. T. (2015). Out-of-pocket cost burden in pediatric inflammatory bowel disease: A cross-sectional cohort analysis. *Inflammatory Bowel Diseases*, *21*(6), 1368-1377. doi:10.1097/mib.0000000000000374
- Staniute, M., Brozaitiene, J., Burkauskas, J., Kazukauskienė, N., Mickuviene, N., & Bunevicius, R. (2015). Type D personality, mental distress, social support and health-related quality of life in coronary artery disease patients with heart failure: A longitudinal observational study. *Health Qual Life Outcomes*, *13*, 1. doi:10.1186/s12955-014-0204-2
- Stéphanie, B., Katia, I., Joseph, S., & Gerhard, G. (2014). An 8-Item short form of the Inventory of Dimensions of Emerging Adulthood (IDEA) among young swiss men. *Evaluation and the Health Professions*, *38*(2), 246-254. doi:10.1177/0163278714540681
- Stollon, N., Zhong, Y., Ferris, M., Bhansali, S., Pitts, B., Rak, E., . . . van Tilburg, M. A. L. (2017). Chronological age when healthcare transition skills are mastered in adolescents/young adults with inflammatory bowel disease. *World Journal of Gastroenterology*, *23*(18), 3349-3355. doi:10.3748/wjg.v23.i18.3349
- Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. *Current Diabetes Reports*, *12*(6), 769-781. doi:10.1007/s11892-012-0317-0
- Swarup, N., Nayak, S., Lee, J., Pai Raikar, S., Hou, D., Sockalingam, S., & Lee, K. J. (2017). Forming a support group for people affected by inflammatory bowel disease. *Patient Prefer Adherence*, *11*, 277-281. doi:10.2147/ppa.s123073
- Taft, T.H., Keefer, L., Leonhard, C., & Nealson-Woods, M. (2009). Impact of perceived stigma on inflammatory bowel disease outcomes. *Inflammatory Bowel Diseases*, *15*(8): 1224-32. doi: 10.1002/ibd.20864.
- Tanaka, M., Kawakami, A., Iwao, Y., Fukushima, T., & Yamamoto-Mitani, N. (2016). Coping strategies for possible flare-ups and their perceived effectiveness in patients with inflammatory bowel disease. *Gastroenterology Nursing*, *39*(1), 42-47. doi:10.1097/sga.0000000000000201
- Testa, A., Castiglione, F., Nardone, O. M., & Colombo, G. L. (2017). Adherence in ulcerative colitis: An overview. *Patient Preference and Adherence*, *11*, 297-303. doi:10.2147/PPA.S127039
- Torres, J., Caprioli, F., Katsanos, K. H., Lobaton, T., Micic, D., Zeroncio, M., . . . Colombel, J. F. (2016). Predicting outcomes to optimize disease management in inflammatory bowel diseases. *Journal of Crohn's and Colitis*, *10*(12), 1385-1394. doi:10.1093/ecco-jcc/jjw116

- Trivedi, I., & Keefer, L. (2015). The emerging adult with inflammatory bowel disease: Challenges and recommendations for the adult gastroenterologist. *Gastroenterology Research and Practice*, 2015, 260807. doi:10.1155/2015/260807
- Uchino, B. N. (2004). *Social support and physical health: Understanding the health consequences of relationships*. New Haven, Connecticut: Yale University.
- Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science*, 4(3), 236-255.
- Vagianos, K., Clara, I., Carr, R., Graff, L. A., Walker, J. R., Targownik, L. E., . . . Bernstein, C. N. (2014). What are adults with inflammatory bowel disease (IBD) eating? A closer look at the dietary habits of a population-based Canadian IBD Cohort. *Journal of Parenteral and Enteral Nutrition*. doi:10.1177/0148607114549254
- van Groningen, J., Ziniel, S., Arnold, J., & Fishman, L. N. (2012). When independent healthcare behaviors develop in adolescents with inflammatory bowel disease. *Inflammatory Bowel Diseases*, 18(12), 2310-2314. doi:10.1002/ibd.22937
- Van Limbergen, J., Russell, R. K., Drummond, H. E., Aldhous, M. C., Round, N. K., Nimmo, E. R., . . . Wilson, D. C. (2008). Definition of phenotypic characteristics of childhood-onset inflammatory bowel disease. *Gastroenterology*, 135(4), 1114-1122. doi:10.1053/j.gastro.2008.06.081
- Verchota, G., & Sawin, K. J. (2016). Testing components of a self-management theory in adolescents with type 1 diabetes mellitus. *Nursing Research*, 65(6), 487-495. doi:10.1097/nnr.0000000000000180
- Williamson, J. A., & O'Hara, M. W. (2017). Who gets social support, who gives it, and how it's related to recipient's mood. *Personality and Social Psychology Bulletin*, 43(10), 1355-1377. doi:10.1177/0146167217711936
- Wong, C., Harris, P. J., & Ferguson, L. R. (2016). Potential benefits of dietary fibre intervention in Inflammatory Bowel Disease. *International Journal of Molecular Science*, 17(6). doi:10.3390/ijms17060919
- Zhou, K., Li, H., Wei, X., Yin, J., Liang, P., Zhang, H., . . . Zhuang, G. (2017). Relationships between received and perceived social support and health-related quality of life among patients receiving methadone maintenance treatment in Mainland China. *Substance Abuse Treatment, Prevention, and Policy*, 12(1), 33. doi:10.1186/s13011-017-0116-3