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Self-management Through Social Support among Emerging Adults with Inflammatory Bowel Disease

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Abstract

Background: Emerging adulthood is a unique developmental stage, which may affect individuals' self-management behaviors, social support, and the relationship between these two constructs. Among older adults, social support has been shown to improve self-management behaviors for individuals with chronic conditions; however, this relationship has not been examined with emerging adults (age 18–29) who have inflammatory bowel disease (IBD).

Objectives: To examine the relationship between two conceptualizations of social support (received and perceived availability of social support) and IBD-related self-management behaviors among emerging adults with IBD.

Methods: A convenience sample of emerging adult IBD individuals (currently prescribed medication to manage IBD) were recruited from ResearchMatch, Facebook, and by word of mouth. The study was guided by key elements of the Individual and Family Self-Management

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Ethical Conduct of Research: The primary investigator has been trained in and followed the procedures of responsible conduct of research. This research study obtained approval from the Michigan State University Institutional Review Board (IRB# x17–107e).

Theory. Participants responded to demographic and condition-specific questionnaires: the Inventory of Dimensions of Emerging Adulthood; the Inventory of Socially Supportive Behaviors; the Medical Outcomes: Social Support Survey; the Medication Adherence Report Scale; and the Dietary Screener Questionnaire.

Results: Emerging adults with high-received informational support reported greater medication adherence compared to those with low-received informational support when controlling for biological medications, time since diagnosis, symptom frequency, and feeling in-between adolescence and adulthood. Neither type of social support was associated with diet modification.

Discussion: Received informational social support, medication type, time since diagnosis, symptoms, and emerging adulthood factors have the potential to influence medication adherence. Received informational social support interventions, such as patient-to-patient or group-based mentoring, may serve to improve medication adherence among emerging adults with IBD.

Keywords

social support; self-management; inflammatory bowel diseases; young adult

Approximately, 3.1 million Americans have been diagnosed with inflammatory bowel diseases (IBD), with the majority of individuals diagnosed between the ages of 18–29 (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016). This category of bowel conditions includes ulcerative colitis and Crohn's disease which are chronic conditions without a cure, but can be managed through medication, surgery, and daily routines (Kaplan, 2015). Individuals with IBD commonly experience symptoms of diarrhea, abdominal pain, cramping, bloody stool, and fatigue (Farrell, McCarthy, & Savage, 2016). The disease course includes relapsing and remitting stages in which the individual cycles through periods of feeling better and then worse (Kaplan, 2015). The goal of IBD management is to treat symptoms, induce "deep remission" (mucosal healing), and improve health-related quality of life (Levesque et al., 2015). To meet these goals, individuals with IBD may engage in a variety of self-management behaviors (including medication adherence, diet modification, and stress reduction), both with and without healthcare providers (Plevinsky, Greenley, & Fishman, 2016).

Self-management can be a challenging task especially for emerging adults—individuals ages 18–29—who are in developmental transitions as they become responsible for the management of their own lives, including their health issues (Arnett, 2015). Specifically, among individuals with IBD, emerging adults face increased IBD disease activity with greater symptoms and disease complications compared to older adults (Goodhand et al., 2010). As a result of the increased disease activity and its complications, it is essential to improve the self-management behaviors of emerging adults with IBD; one avenue showing promise within the IBD population is increased social support (Plevinsky et al., 2016).

Social support is a complex area to understand in the context of disease. There are two main conceptualizations of social support: received social support and perceived availability of social support. The former, received social support, can be thought of as the supportive behaviors that an individual gets from others. For example, patient-to-patient or group-based

interaction has been suggested to improve received social support (Swarup et al., 2017), indicating that patients prefer to receive support from other patients who have experienced similarities in terms of disease.

Received social support can be separated into specific types of support: informational support (providing information or advice); emotional support (conveying encouragement and comfort); and tangible support (providing physical assistance with tasks; Lakey & Cohen, 2000). The latter, perceived availability of social support (also referred to as perceived social support), is an individual's perception that social support is available if needed, and has been associated with self-management behaviors of medication adherence and diet modification among individuals with other chronic conditions (DiMatteo, 2004; Gariépy, Honkaniemi, & Quesnel-Vallée, 2016). As with received support, perceived availability of social support may also be separated into the specific types of informational, emotional, and tangible perceived availability of social support. While perceived social support has a beginning evidence-base within chronic conditions, neither received nor perceived availability of social support have been adequately studied for their utility with IBD self-management.

Conceptually guiding this study was the Individual and Family Self-Management Theory (IFSMT; see Figure 1). As applied to IBD, this framework presents self-management as a complex and dynamic phenomenon. The model has three primary dimensions: context, process, and outcomes (Ryan & Sawin, 2009). Select variables were chosen from the IFSMT allowing focus on individual self-management and outcomes specific to IBD. The contextual dimension includes individual, condition-specific, and emerging adulthood factors which may have an influence on self-management behaviors for the unique condition of IBD. Individual factors are factors that are specific to the patient and include age, sex, marital status, employment, and education, which have been shown to influence self-management behaviors among adults with chronic conditions (Schulman-Green, Jaser, Park, & Whittemore, 2016). 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), medications currently using (biologics, immunomodulators, corticosteroids, and/or aminosalicylates), and surgeries. These condition-specific factors have been associated with better medication adherence (Chan, Chen, Tiao, Selinger, & Leong, 2017).

Emerging adulthood factors include: possibilities/optimism (when hopes flourish and people have an unparalleled opportunity to transform their lives); instability (in love, work, and place of residence); identity explorations (answering the question "who am I?" and trying out various life options, especially in love and work); and feeling in-between (in transition, neither adolescent nor adult) (Arnett, 2015). Previous research on emerging adults with chronic conditions, although somewhat limited, has identified that emerging adults may have difficulties with self-management due to life priorities and lack of understanding of treatment regimens (Majumder, Cogen, & Monaghan, 2017). In addition, IBD research on emerging adulthood has identified this developmental stage as an important transition point for improving self-management (Plevinsky et al., 2016).

The process dimension of the guiding model for this study is represented by received social support from others and consists of informational, emotional, and tangible social support. This is the area within the model where interventions could be considered, due to the dynamic process component and the potential for dimensions of social support to be modified to enhance outcomes. The outcome dimension includes self-management behaviors such as day-to-day medication adherence, using medication as prescribed by a provider, and diet modification (an individual's alteration of food intake; Grady & Gough, 2014; Ryan & Sawin, 2009). Medication adherence and diet modification are the most common self-management behaviors and therefore were selected as the primary outcomes. The potential moderating component is perceived availability of social support which may influence the relationship between received social support and self-management behaviors. These key variables from the IFSMT model provided the structure for this study. Thus, the purpose of this study was to examine the relationship between two types of social support (received and perceived availability of social support) and self-management behaviors among emerging adults with IBD.

Research questions (RQs):

1. Among emerging adults with IBD, which **contextual factors** (individual, condition-specific, and emerging adulthood) are predictive of self-management behaviors (medication adherence and diet modification)?
2. Among emerging adults with IBD, is **received social support** (informational, emotional, and tangible) predictive of self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?
3. Among emerging adults with IBD, does **perceived availability of social support** moderate the association between received social support (informational, emotional, and tangible) and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?

Methods

Design and Participants

This cross-sectional study implemented an online survey enrolling 61 emerging adults with IBD. Data were collected between January 2018–February 2018. Individuals were eligible for the study if they were emerging adults (ages 18–29) with a self-reported healthcare provider diagnosis of ulcerative colitis or Crohn's disease, lived in the United States, understood written English, had access to the Internet, and were currently prescribed medication to manage their IBD. Exclusion criteria was hospitalization within the past month or currently pregnant due to the potential of dietary modification for non-IBD reasons.

Procedures

Recruitment involved ResearchMatch, Facebook, and word of mouth. Individuals had the possibility to participate if they signed up for ResearchMatch or Facebook or had a friend

referring him/her to the study. Data were captured through a secure online survey software: Qualtrics, which is endorsed by many health science departments as a valid data collection tool (Qualtrics, Provo, UT). Potential ResearchMatch (www.researchmatch.org) participants received a recruitment message and decided whether to share their contact information with the researchers. On Facebook, the recruitment message was shared in Facebook groups and advertisements. Potential participants were encouraged to share the survey. The first page of the survey included the informed consent introducing participants to the purpose of the study, explaining the research was voluntary, and informing that they could stop completing the survey at any time. During data collection, the data was monitored for completeness. Participants indicated consent by continuing with the survey in keeping with the approval from the institutional review board of the author's university. Participants were able to contact researchers via phone, text, or email if they had questions. Compensation was not provided.

Measures

All investigator-designed measurements (individual and condition-specific) underwent pretesting using a cognitive interviewing procedure (Kamp et al., 2018).

Context Measures

Individual factors.: Individual factors include age, sex (male/female), marital status (single/married), employment (full-time employment/part-time employment/unemployed, or student), and education (high school or less/some college/completed college/graduate or professional degree).

Condition-specific factors.: Condition-specific factors include type of IBD (ulcerative colitis/Crohn's disease), time since diagnosis (measured as months since individual was diagnosed with IBD by a provider), medications currently using (biologics, immunomodulators, corticosteroids, and/or aminosalicylates), and number of surgeries for IBD. For symptoms (prevalence, severity, and interference), an established measure was used.

Cancer Symptom Experience Inventory (Given et al., 2008): A modified version was used including those symptoms associated with IBD: diarrhea, constipation, abdominal pain, abdominal tenderness, abdominal cramps, bloating, passing gas, blood in stool, weight loss, weight gain, reduced appetite, increased appetite, nausea or vomiting, fatigue, and fever. If participants experienced the symptom within the past two weeks (prevalence), participants rated the symptom at its worst (severity) and how much the symptom interfered with daily life (interference) on 0–9-point scale. Three symptom components were reported: prevalence (potential range: 0–5), mean severity (potential range: 0–9), and mean interference (potential range: 0–9). A higher score indicates greater symptom prevalence, severity, or interference. The Cancer Symptom Experience Inventory is an index and therefore internal consistency reliability is not applicable. The Cancer Symptom Experience Inventory modified for IBD was pretested within the IBD population prior to use in the survey.

Emerging adulthood factors.

Inventory of Dimensions of Emerging Adulthood (Baggio, Iglesias, Studer, & Gmel, 2014): Emerging adulthood factors were measured with the short form that measures psychological features associated with emerging adulthood. Participants were asked to think of a five-year period and respond to questions such as: “Is this period of your life a time of many possibilities?” on a 4-point Likert scale (*strongly disagree*, *somewhat disagree*, *somewhat agree*, and *strongly agree*). The 8-item short form contains four (of the 5) emerging adulthood subscales (potential range: 2–8): possibilities/optimism, instability, identity exploration, and feeling in-between. Participants receive a score for each subscale. A higher score indicates that an individual is experiencing emerging adulthood. The short form was significantly correlated to the original scale; the scale demonstrated construct validity with adulthood markers (Baggio et al., 2014). Within this study, Cronbach’s alpha subscales ranged from .65 to .86.

Process Measure

Received social support.

Socially Supportive Behaviors (Barrera, Sandler, & Ramsay, 1981): Subscales measure specific types of support received in the past 4 weeks: informational support (guidance; 14 items, potential range: 14–70), emotional support (14 items, potential range: 14–70), and tangible support (12 items, potential range: 12–60). The instrument uses a 5-point Likert scale (1 = *not at all*, 2 = *once or twice*, 3 = *about once a week*, 4 = *several times a week*, and 5 = *about every day*). The original instrument was found to have good psychometric properties with an overall Cronbach’s alpha of .93 (Barrera et al., 1981). Both a total score (potential range: 40–200) and subscales were dichotomized into high and low received social support based on distribution.

Outcome Measures

Medication adherence.

Medication Adherence Report Scale (MARS; Horne & Weinman, 2002): Participants report agreement with four statements such as, “I decided to miss a dose of these IBD medicines.” Responses are on a 5-point Likert scale ranging from 1 = *always* to 5 = *never*. A sum score is calculated and ranges from 4 to 20; a higher score indicates higher level of adherence. For analysis, a dichotomous score was used, which is consistent with previous IBD literature. Participants with a score of 4–16 were classified as low adherers (= 0) and scores of 17–20 were classified as high adherers (= 1) (Horne, Parham, Driscoll, & Robinson, 2009). The instrument has a Cronbach’s alpha of .83 (Ohm & Aaronson, 2006).

Diet modification.

Dietary Screener Questionnaire (Charlebois, Rosenfeld, & Bressler, 2016; Thompson, Midthune, Kahle, & Dodd, 2017): For each item (25 items), participants responded on a 5-point Likert scale ranging from never to always to the following statement: “I alter my intake of [name of food item] due to my IBD.” The questionnaire includes 7 subscales: fruits and vegetables, dairy, whole grains, added sugars, sugar-sweetened beverages, meat, and dietary fiber. The dietary screener has demonstrated acceptable internal and external validity and

test–retest reliability (Thompson et al., 2017). For each subscale, participants were classified as no diet modification behavior if they reported an average of *never* or *rarely*; participants reporting *sometimes*, *often*, or *always* were classified as modifying their diet. Subscales were added to create a total diet modification score (potential range: 0–7; a higher score indicating greater diet modification). The total score was dichotomized into no diet modification (0–2) and diet modification (3–7).

Potential Moderator of Self-Management Outcome

Perceived availability of social support.

Medical Outcomes: Social Support Survey (Sherbourne & Stewart, 1991): Perceived availability of social support was measured by 18 items including subscales measuring specific types of support available in the past 2 weeks: emotional/informational (8 items; potential range: 8–40), tangible/instrumental (4 items; potential range: 4–20), affectionate (3 items; potential range: 3–15), and positive social interaction (3 items; potential range: 3–15). The instrument uses a 5-point Likert scale in which 1 = *none of the time*, and 5 = *all of the time*. The original instrument was found to have good psychometric properties (Cronbach's alpha: overall = .97; Sherbourne & Stewart, 1991). A sum score was calculated (higher score indicating greater support) and then dichotomized based on the 50th percentile to assist in interpretation of the interaction effect.

Data Analysis

Stata 15.0 was used for data analysis. Descriptive statistics (Table 1) of contextual variables were shown using numbers and percentages for categorical variables of sex, marital status, employment status, education, type of IBD, and medication type. Mean and standard deviation were used for the continuous contextual variables of age, time since diagnosis, previous surgeries, symptom prevalence, mean symptom severity, mean symptom interference, possibilities/optimism, instability, identity exploration, and feeling in-between. Twenty-one individuals stopped completing the survey midway and, therefore, did not have data for the process and outcome variables. These participants were excluded in the analysis and did not differ from completers on age, sex, employment, and type of IBD.

RQ1: Among emerging adults with IBD, which contextual factors (individual, condition-specific, and emerging adulthood) are predictive of self-management behaviors (medication adherence and diet modification)?—The logistic regression models were built based on the stepwise process of purposeful selection of covariates as outlined in Hosmer, Lemeshow, and Sturdivant (2013). First, univariable logistic regressions were conducted for each contextual variable and self-management behavior; contextual variables with a p -value of < 0.25 were included in an initial multivariable model. Variables not reaching the traditional level of significance ($p < 0.05$) were removed from this initial model. A reduced model was fit and using the likelihood ratio test compared to the initial model. The contextual factors not selected for the univariable analysis in the first step were added one at a time into the reduced model and tested for significance (preliminary main effects). Variables with $p \leq .05$ were included in the model since the variable provided a contribution in the presence of the other variables. Once the

main effects model was determined, step 4 involved checking for linearity assumption. Step 5 assessed interactions between covariates. The final step was to assess the model adequacy and fit using the Hosmer-Lemeshow test.

RQ2: Among emerging adults with IBD, is received social support (informational, emotional, and tangible) predictive of self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?—RQ2 used the same analysis procedures as RQ1; the total and types of received social support were the independent variables and the self-management behaviors of medication adherence and diet modification remained as the dependent variables. Separate logistic regression models were built for each self-management behavior and each social support subscale. Contextual factors found significant in RQ1 were controlled for in the analysis.

RQ3: Among emerging adults with IBD, does perceived availability of social support moderate the association between received social support (informational, emotional, and tangible) and self-management behaviors (medication adherence and diet modification) while controlling for contextual variables?—RQ3 used the final model from RQ2 and added the perceived availability of social support variable. To model the moderation effect, an interaction (product of the two variables) between received social support and perceived availability of social support was included. The final model without the interaction term between received social support and perceived availability of social support was compared to the final model with interaction.

A sensitivity analysis was performed for the diet modification variable using different cutoff values because there was no clear guideline for the cutoff to be used for dichotomizing the sum score. The results are shown in the online supplementary materials. The odds ratio decreases slightly as the cutoff increases, but none of the effects were statistically significant (consistent with the primary analysis with a cutoff of 3).

Results

Participant and Clinical Characteristics

Sample characteristics are seen in Table 1. The sample was primarily female ($n = 55$, 90%), single ($n = 47$, 77%), full-time employed ($n = 30$, 49%), and diagnosed with Crohn's disease ($n = 39$, 64%). Most participants used biological medications ($n = 37$, 61%). Seventy-three percent were adherent to their medication. Sixty-four percent of participants reported modifying their diet.

RQ1: Contextual Factors and Self-management Behaviors

The contextual factors of the use of biological medication ($p = .026$), decreased time since diagnosis ($p = 0.006$), increased symptom prevalence ($p = .022$), and decreased feeling in-between adolescence and adulthood ($p = .038$) positively influenced medication adherence (Hosmer-Lemeshow $\chi^2(8) = 5.5$, $p = .7029$). For the diet modification model, no

individual, condition-specific, or emerging adulthood factors were found to influence diet modification (Table 2).

RQ2: Received Social Support and Self-Management Behaviors

Emerging adults with high received informational social support reported greater medication adherence ($p = .023$) compared to emerging adults with low received informational social support when controlling for context factors of biological medication, time since diagnosis, symptom prevalence, and the emerging adulthood factor of feeling in-between adolescence and adulthood (Hosmer-Lemeshow $\chi^2(8) = 6.38$, $p = .605$). The other types of received social support (emotional and tangible) and total received social support were not significantly associated with improved medication adherence when controlling for context factors (Table 3). Further, all types of received social support were nonsignificant in predicting diet modification (see Table 4).

RQ3: Effect of Perceived Availability of Social Support

Perceived availability of social support did not moderate the relationship between received social support and self-management behaviors of medication adherence and diet modification (see Tables 3 and 4).

Discussion

The purpose of this study was to examine the relationship between social support and self-management behaviors among emerging adults with IBD. Within the sample of predominantly educated single females, contextual factors of biological medication use, decreased time since diagnosis, increased symptom prevalence, and decreased feeling in-between adolescence and adulthood were associated with improve medication adherence. Context and process variables were not associated with the outcome variable of diet modification.

When examining the contextual dimensions of the model that influence self-management behaviors within the sample, condition-specific factors of biological medication, decreased time since diagnosis, and increased symptom prevalence predicted improved medication adherence. Individual factors were not associated with medication adherence. The sample may be more adherent to biological medications compared to other medication types since biologic medications have a lower dosing frequency and decreased dosing can lead to improved medication adherence (Iglay et al., 2015). Those participants who have a shorter time since diagnosis may view their disease as a greater health threat; therefore, more engaged in medication adherence for disease management, compared to longer term use by adults who may have experienced medication side effects (Dalal & Cohen, 2015). Consistent with previous research, emerging adults in the sample who experienced a greater number of symptoms (increased symptom prevalence) were more likely to engage in treatment decisions such as being adherent to medication (Kamp & Brittain, 2018). Although intestinal inflammation is not always correlated with symptoms, patients still rely on symptoms—not inflammatory markers—to determine disease severity and inform behavioral change.

Among the emerging adulthood factors, a decreased level of feeling in-between adolescence and adulthood was associated with improved medication adherence. Emerging adults who are feeling in-between adolescence and adulthood may also feel that others are responsible for their disease management until they reach adulthood. The current study did not identify age as a significant predictor; however, emerging adults in the sample who felt higher levels of being in-between adolescence and adulthood were more likely to be nonadherent to medication. This finding is similar to the work by Arnett (2015) who reported emerging adults who sense being in between feel less responsible for disease management. Further, while age and developmental stage are not identical, others have identified that younger adults, in terms of chronological age, are more likely to be nonadherent to medication (Severs et al., 2017). Examining developmental stages in future research may enable tailoring of self-management interventions across the lifespan.

Contextual factors examined in this study were not associated with diet modification. While the emerging adults in this study reported engaging in diet modification, little is known regarding what influences an emerging adult to modify their diet. Other contextual factors, such as beliefs about diet or the cause of IBD, may be key to understanding the types of emerging adults who are engaging in diet modification. Examining factors which influence diet modification is essential to enhancing the science of diet modification within the IBD population.

When considering received social support, individuals with high received informational social support compared to low received informational social support were more likely to be adherent to medication. Although previous systematic reviews among older adults (age 60) with chronic conditions have identified the importance of received tangible social support in improving medication adherence (DiMatteo, 2004; Gallant 2003; Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012), by contrast this relationship was not found in the current study focused on emerging adults with IBD. Tangible support may be less influential due to emerging adulthood being a time of identity explorations; receiving tangible support could limited feelings of autonomy among emerging adults. In addition, emerging adults may simply require less tangible support than older adults. Informational received social support interventions which may include patient-to-patient or group mentoring have the potential assist in improving medication adherence among educated, single females (Swarup et al., 2017). Although additional research is needed to better understand the reasons that informational support appears to be related to medication adherence among this sample of emerging adults whereas tangible support is related to medication adherence among older adults.

Total received social support, emotional support, and tangible support did not exhibit statistically significant relationships with the self-management behaviors of medication adherence or diet modification. Two reasons may contribute to the lack of relationship. First, social support may be more beneficial for self-management behaviors during times of disease or treatment transitions. For instance, individuals who are changing medications, beginning a diet, experiencing an increase in symptoms, or newly/recently diagnosed may benefit from received social support. Second, social support may have an indirect relationship with self-management. For instance, social support may influence depression

(Fuller-Thomson & Nimigon, 2008) and depression, in turn, may then influence self-management behaviors (Calloway et al., 2017). Other potential mediators may include self-efficacy, anxiety, or coping and could be incorporated into the Individual and Family Self-Management theory applied to IBD. Therefore, more robust studies utilizing longitudinal designs and incorporating diverse samples are needed to further examine the relationship between social support and self-management behaviors among emerging adults with IBD.

Perceived availability of social support did not moderate the relationship between received social support and self-management behaviors. Even more perplexing, the relationship between high received informational social support and medication adherence became nonsignificant in the presence of high perceived availability of social support. One possibility is that high perceived availability of social support was trending towards being related to medication nonadherence, although this observation should be interpreted with caution as perceived availability of social support was not statistically significant. Increased perceived availability of social support may hinder self-management behaviors among an emerging adult population by providing a sense that others can assist in the management behaviors; therefore, researchers should carefully consider the conceptualization and measurement of social support within the emerging adult population.

Perceived availability of social support was not associated with diet modification. Other research has reported consumption of food and beverages increased when emerging adults perceived their friends regularly consume those same foods and beverages (Blondin et al., 2016); hence, there is the potential that the source of social support, rather than type of social support, may have a greater influence on diet modification (Pelletier, Graham, & Laska, 2014). It may also be that diet modification is largely influenced by internal factors, such as autonomous (intrinsic) motivation, a sense of choice in which individuals engage in an activity due to satisfaction, interest, or challenge (Silva et al., 2010), since others have reported that autonomous motivation regulated food choices (Hartmann, Dohle, & Siegrist, 2015).

Based on the findings of this study, the factors associated with self-management behaviors of medication adherence among emerging adults with IBD are received informational social support, medication type (biological medication), time since diagnosis, symptom prevalence, and feeling in between. The key process variable of received informational social support indicated the greatest promise for future research efforts. High levels of received informational social support were associated with medication adherence. Neither social support nor contextual factors were associated with diet modification.

Limitations

The study was limited by a small sample size as evidenced by large confidence intervals and a lack of a priori sample size analysis. We conducted a post-hoc power analysis (Faul et al., 2009) for the test that the proportion of variance of a dependent variable (e.g., total support) explained by a set of predictors (e.g., contextual factors) R^2 is zero. The results indicated that with 61 observations and the number of predictors ranging from 3 to 10, we can detect an R^2 of .16 to .24, that is we have a sample size to detect a medium (.15) to large (.35) effect size.

Measurement limitations exist as medication adherence was measured via self-report and therefore adherence may be overreported (Nguyen, La Caze, & Cottrell, 2014). To participate in the survey, emerging adults had to be currently prescribed medication although they did not need to be currently taking their medication. There is the potential for selection bias where emerging adults who were more adherent to their medications were more likely to complete the survey. Furthermore, emerging adults who completed the survey had well-managed disease; most participants did not have surgery and had limited symptom severity and interference. The survey consisted of 122 questions and took approximately 20–25 minutes to complete.

In terms of demographics, the sample was predominantly educated single females. The use of an online data collection method led to 21 surveys with incomplete data on key study variables. Although participants did not differ on age, sex, education, or type of IBD, it could be that participants without high levels of social support were less willing to complete the survey, although this information cannot be determined. Thus, the study findings have limited generalizability based on the data collection techniques (i.e., self-report) and characteristics of sample recruited (i.e., well-managed disease and female).

Conclusion

This study contributes to the knowledge of emerging adulthood for individuals living with IBD, especially among educated females. Further, the relationship between two conceptualizations of social support and the self-management behaviors of medication adherence and diet modification were presented through the lens of the Individual and Family Self-Management Theory as applied to IBD. While both received and perceived social support were explored, only received social support demonstrated beneficial evidence for emerging adults although a sample with more diverse demographics may yield different results. This study contributes to science by enriching the research available on emerging adulthood, which has been an understudied population. It further demonstrates the potential to benefit select emerging adults through the use of received social support—specifically informational support interventions such as patient-to-patient or group mentoring—to enhance IBD management behaviors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Individual Self-Management Theory applied to IBD

This figure displays the Individual Self-Management Theory applied to IBD in which context, process, and outcomes are outlined.

Note. RQ = research question, IBD = inflammatory bowel disease

Table 1

Participant and Clinical Characteristics (N = 61)

Characteristic	<i>n</i>	%
Sex		
Male	6	9.8
Female	55	90.2
Marital Status		
Single	47	77.1
Married/domestic partnership	14	22.9
Employment Status		
Full-time employed	30	49.2
Part-time employed	10	16.4
Unemployed or student	21	34.4
Education		
High school or less	10	16.4
Some college	16	26.2
Completed college	22	36.1
Graduate or professional degree	13	21.3
Type of IBD		
Ulcerative Colitis	22	36.1
Crohn's disease	39	63.9
Medication type ^a		
Aminosalicylates	22	36.1
Biologics	37	60.7
Corticosteroids	11	18.0
Immunomodulators	16	26.2
Medication adherence		
Non-adherent	16	26.2
Adherent	45	73.8
Diet Modification		
No diet modification	22	36.1
Diet modification	39	63.9
	Mean (<i>SD</i>)	Potential minimum-maximum
Age (years)	24.7 (2.9)	18 – 29
Time since diagnosis (months)	76.3 (57.3)	2 – 227
Number of previous surgeries	0.6 (1.4)	0 – 8
Symptoms		
Symptom prevalence (avg. number of symptoms experienced)	5.9 (3.1)	0 – 15
Mean symptom severity	1.8 (1.3)	0 – 9
Mean symptom interference	1.1 (0.9)	0 – 9
Emerging adulthood		

Characteristic	<i>n</i>	%
Possibilities	6.8 (1.4)	2 – 8
Instability	6.9 (1.3)	2 – 8
Exploration	6.7 (1.4)	2 – 8
In-between	6.5 (1.5)	2 – 8

^aNote. Medication types equal more than 100%

Table 2

Logistic Regression of Contextual Factors on Medication Adherence

Predictor	Odds Ratio	Standard Error	95% Confidence Interval	<i>p</i>
Biological medication	5.44	4.15	(1.22, 24.25)	.026
Time since diagnosis	0.98	0.007	(0.97, 0.99)	.006
Symptom prevalence	1.38	0.19	(1.05, 1.8)	.022
Feeling In-between	0.57	0.15	(0.33, 0.97)	.038

Note. Hosmer-Lemeshow $\chi^2(8) = 5.5$, $p = .7029$

Table 3
Logistic Regression of Social Support and Perceived Availability of Social Support on Medication Adherence

Variables (<i>n</i> = 61)	Medication Adherence, Model 1 ^a		Medication Adherence, Model 2 ^a		Medication Adherence, Model 3 ^a	
	Odds Ratio (95% CI)	<i>p</i> value	Odds Ratio (95% CI)	<i>p</i> value	Odds Ratio (95% CI)	<i>p</i> value
Received Social Support (ref: low)						
High received social support	1.5 [0.3, 8.4]	.638	1.4 [0.2, 8.4]	.706	1.2 [0.1, 10.3]	.891
High perceived availability of social support						
High perceived availability of social support			1.2 [0.3, 5.6]	.791	0.8 [0.03, 21.0]	.882
High received social support x high perceived availability of social support					1.8 [0.04, 70.9]	.762
Informational social support (ref: low)						
High informational social support*	9.2 [1.4, 62.5]	.023	9.3 [1.3, 66.0]	.025	6.1 [0.6, 62.2]	.129
High perceived availability of social support			1.0 [0.2, 4.8]	.955	0.4 (0.02, 8.4)	.565
High informational social support x high perceived availability of social support					3.2 [0.1, 111.3]	.517
Emotional social support (ref: low)						
High emotional social support	1.2 [0.3, 5.6]	.770	1.2 [0.3, 5.6]	.838	0.6 [0.07, 4.8]	.614
High perceived availability of social support			1.3 [0.3, 5.8]	.746	0.7 [0.1, 5.0]	.714
High emotional social support x high perceived availability of social support					4.2 [0.2, 83.9]	.347
Tangible social support (ref: low)						
High tangible social support	1.0 [0.2, 5.0]	.998	1.0 [0.2, 5.0]	.966	0.5 [0.05, 4.9]	.567
High perceived availability of social support			1.3 [0.3, 5.8]	.699	0.6 [0.1, 6.5]	.704
High tangible social support x high perceived availability of social support					3.5 [0.2, 69.2]	.418

Note.

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Controlling for biologic medication, time since diagnosis, symptom prevalence, and feeling in-between. Model 1 includes received social support only (RQ2), model 2 includes the main effects of received social support and perceived availability of social support (RQ3), and model 3 includes the main effects of received social support and perceived availability of social support as well as the interaction between the social support variables (RQ3)

Table 4
Logistic Regression of Received Social Support and Perceived Availability of Social Support on Diet Modification

Variables (<i>n</i> = 61)	Diet Modification, Model 1		Diet Modification, Model 2		Diet Modification, Model 3 ^a	
	Odds Ratio (95% Confidence Interval, CI)	<i>p</i> value	Odds Ratio (95% CI)	<i>p</i> value	Odds Ratio (95% CI)	<i>p</i> value
Received Social Support (ref: low)						
High received social support	1.7 [0.5, 5.1]	.380	2.2 [0.6, 7.4]	.216	2.0 [0.4, 9.9]	.380
High perceived availability of social support			0.5 [0.1, 1.5]	.197	0.4 [0.1, 3.4]	.416
High received social support x high perceived availability of social support					1.2 [0.1, 14.6]	.897
Informational social support (ref: low)						
High informational social support	1.0 [0.4, 3.0]	.923	1.2 [0.4, 3.5]	.755	0.8 0.2, 3.7]	.745
High perceived availability of social support			0.6 [0.2, 1.7]	.313	0.4 [0.1, 1.8]	.221
High informational social support x high perceived availability of social support					2.2 [0.3, 19.3]	.467
Emotional social support (ref: low)						
High emotional social support	1.6 [0.6, 5.0]	.383	2.4 [0.7, 8.3]	.162	2.6 [0.4, 15.8]	.292
High perceived availability of social support			0.4 [0.1, 1.4]	.147	0.4 [0.1, 2.6]	.358
High emotional social support x high perceived availability of social support					0.8 [0.1, 10.1]	.895
Tangible social support (ref: low)						
High tangible social support	1.5 [0.5, 4.4]	.437	1.5 [0.5, 4.4]	.461	1.4 [0.3, 6.6]	.691
High perceived availability of social support			0.6 [0.2, 1.7]	.350	0.6 [0.1, 2.4]	.432
High tangible social support x high perceived availability of social support					1.2 [0.1, 9.9]	.889

Note. Model 1 includes received social support only (RQ2), model 2 includes the main effects of received social support and perceived availability of social support (RQ3), and model 3 includes the main effects of received social support and perceived availability of social support as well as the interaction between the social support variables (RQ3)