Original Article

A Comparison of Internet-Based Versus Clinic Sampling in Inflammatory Bowel Disease Research

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Abstract

Background: Young adults with inflammatory bowel disease (IBD) recruited outside of specialty clinics may not have access to optimal care. New to the practice of independent self-management, young adults with IBD have increased risk for pain, suffering, and elevated healthcare cost. Because the complex nature of IBD care and the incredible healthcare burden on patients and the healthcare system, a national sample was sought.
Objective: The purpose was to compare the results of stress, transition readiness (self-management ability), disease activity, and healthcare utilization (HCU) from a national sample (n=284; mean age 27.6) of young adults with IBD (ages 18-35-years-of-age) composed primarily of highly-educated (72.9% college degree), white (91.9%), females (84.6%) with other samples.
Methodology: Online surveys launched through social media evaluated stress (Perceived Stress Scale: PSS-10), transition readiness (IBD Self-Efficacy Scale for Adolescents and Young Adults: IBDSES-A), disease activity (Manitoba IBD Index: MIBDI), and IBD-related HCU defined as IBD-related emergency department visit or inpatient hospitalization in the prior 12 months. Findings from the study sample were compared to research samples from the literature.
Results: PSS-10 mean score (22.0), IBDSES-A mean score (47.2), MIBDI mean score (3.05), and a high rate of HCU (40.1%) established that the internet-based sample had poor transition readiness with increased stress, disease activity, and healthcare cost when compared with other samples.
Conclusions: The significant health disparity found in the current sample may have implications for researchers seeking to understand the health needs of young adults with chronic illness. Findings from broad and inclusive internet-based samples have potential to inform health policies that impact access to care. Clinically, there is urgent need for improved access to IBD homes.

Keywords: internet-based sampling, young adults, inflammatory bowel disease, streA

Introduction

IBD is a complex autoimmune disorder characterized by inflammation, unpredictable diarrhea, abdominal pain, and fatigue (Walsh, Mabee, & Trivedi, 2011). Young adults (ages 18-35-years-of-age) during the transition to independent self-management, at increased risk for pain, suffering, and increased healthcare cost (Gajendran et al., 2016), need access to regular care within an IBD specialty clinic with a qualified IBD specialist (Bernstein et al., 2017). In a national database of adults, 42.5% of all IBD-

related emergency department (ED) visits occurred in adults between age 18-35-years-of-age (Gajendran et al., 2016). Sample recruitment outside of a speciality clinic provides access to unique samples with increased pain and suffering.

Understanding populations with chronic illness will remain limited if recruitment is confined to specialty clinics where patients likely receive optimal medical care. National samples using online recruitment may more aptly represent the broader population and may serve to uncover influences affecting health that are specific to the population but may not be evident in specialty clinic samples. Results from an internet-based sample demonstrated concerning findings.

The purpose was to compare the results of stress, transition readiness (self-management ability), disease activity, and healthcare utilization (HCU) from a national sample (n=284; mean age 27.6) of young adults with IBD (ages 18-35-years-of-age) composed primarily of highly-educated (72.9% college degree), white (91.9%), females (84.6%) with other samples.

Background

At a time when people routinely access the internet for all types of information, many young adults turn to the internet for health information. Reich et al. (2016) found that 55% of patients prefered receiveing IBD education through social media, and 44% believed information from internet sources could improve illness management. Bernstein et al. (2017) noted that participants with higher levels of anxiety and IBD-related ED use were more likely to conduct internet searches for information on IBD. Internet-based sampling may attract those who struggle with chronic illness self-management. Improved transition readiness in adolescents and young adults should be reflected in health care behaviors (Schwartz et al., 2014) that decrease disease activity, reduce stress, and result in fewer IBD-related ED visits and inpatient hospitlaization.

Samples recruited from within IBD homes where research is valued and care is ideal may exhibit better health outcomes than the population at large. Keefer et al. (2011) found the online sample (n=80) experienced statistically significant higher rates of active disease, lower transition readiness scores, and lower disease-specific quality of life than the clinic sample (n=42) even though the samples were similar with regard to disease duration, age, and marital status. In a second adult sample (n=136) with IBD recruited through online surveys, high stress levels, frequent IBD relapses, and hospitalization were commonly reported in a two-year period (Tabibian et al., 2015). Neither study focused on young adults.

Internet samples with IBD have been found to have a higher percentage of females. An online sample recruited 82% females (Tabibian et al., 2015). In a study with a clinic and online sample, 73% (n=58) females were enrolled through internet recruitment while 55% (n=23) females were enrolled from the IBD clinic (Keefer et al. (2011). Conversely, in a clinic population of adolescents and young adults, Rosen et al. (2016) recruited 56.5% (n=46) females. In an epidemiological study from the United States, approximately 57% of the IBD sample were females (Dahlhamer et al., 2016). In a systematic review of studies (n=110) using internet-based recruitment, Thornton et al. (2016) found that samples included more females (62.2%; range 13% to 89%); however, 86% of the studies maintained that the recruited sample was similar to samples recruited by other methods (Thornton et al., 2016), a claim not substantiated in the IBD literature (Keefer et al., 2011; Tabibian et al., 2015).

Data from the 2015 National Interview Survey of adults, estimated that 80.0% of the nearly 3.1 million adults with IBD were white (Dahlhamer et al., 2016). Park, Bhattacharya, and Park (2014) in a Medical Expenditure Panel Survey (n=276,702) in the United States found 73% of the population with IBD were white, 13% were black, and 13% were Hispanic. Izaguirre, Taft, and Keefer (2017) recruited 79% white participants (n=95). A high percentage of whites were found in multiple IBD studies. A registry database (n=400) from an IBD center included 95.6% whites (Click et al., 2016) and Clara et al. (2009) described a sample with 95% whites, while Tabibian et al. (2015) recruited an online sample that also included 95% whites. Some IBD studies did not include race or ethnicity discussions when describing sample demographics, likely due to the lack of racial diversity in the sample (Cohen et al., 2015; Graff et al., 2016; Rosen et al., 2016).

The ability to recruit participants through internet-based methods has grown exponentially with improved internet accessibility. Internet-based samples of adults with IBD exhibit self-selection bias. The current study is the first study found to compare stress levels, transition readiness, disease activity, and HCU in samples of young adults with IBD.

Methodology

Study Design and Population: The study was approved by the Institutional Review Board of the University of Mississippi Medical Center. Young adults with IBD were recruited through social media advertisements including Facebook ads, Google ads, and unpaid methods using Facebook snowballing and Twitter. Participants were not compensated for participation and no protected health information (PHI) was collected. Inclusion criteria included an IBD diagnosis (CD, UC, or indeterminate colitis) for at least one year, between 18 to 35-years-of-age, having required at least one IBD-medication during the prior 12 months, English-reading, and United States residency. After answering the qualifying questions, participants completed the online survey. The survey collected self-reported demographics, disease information, a psychological stress survey, a transition readiness measure, a measure of disease activity, and an assessment of IBD-related ED visits and inpatient hospitalizations in the prior 12-months. Data were collected in Research Electronic Data Capture (REDCap).

Measures

Perceived Stress Scale (PSS-10), a 10-item instrument which quantifies psychological stress through the perception of stress over the prior month, was used to measure stress (Cohen, Kamarck, & Mermelstein, 1983). Summed results from the PSS-10 provided ordinal data where higher scores represented higher levels of stress (range 0-40). The Inflammatory Bowel Disease Self-Efficacy Scale for Adolescents and Young Adults (IBDSES-A), a 13-item instrument that measures self-efficacy for self-management of IBD, was used to measure transition readiness (Izaguirre & Keefer, 2014). Summed results provided ordinal data so that higher scores represent higher levels of transition readiness (range 13-65).

The Manitoba Inflammatory Bowel Disease Index (MIBDI), a single-item instrument, was used to measure disease activity (Clara et al., 2009). The MIBDI provides ordinal data with lower scores representing higher levels of symptoms over the prior 6 months (range 1-6) and a score of 6 defines a lack of any symptoms (remission). When classified categorically, having symptoms at least 1-2 days/month are “consistently active” while rare symptoms or remission in the prior 6 months are “consistently inactive”.

IBD-related ED visits and inpatient hospitalization in the prior 12-months was used to measure healthcare utilization (Kim et al., 2018). Participants reported the number of occurrences for each of these events from the options “none”, 1, 2, 3, 4, or 5 times, or “more than 5 times.” Responses were categorized into “no occurrence” and “one or more occurrences” for data analysis. A third variable describing healthcare utilization (HCU) was created by grouping participants as having had either an ED visit and/or overnight hospitalization versus those without either event.

Results

An online, nationwide recruitment effort yielded 284 completed survey data from participants in all but six states. The six week recruitment effort began April 29th, 2019 and cost $1,249.13. Targeted Facebook ads were the most effective recruitment method and resulted in the majority of participants. Four-hundred participants accessed and began the survey; however, 49 did not meet study criteria. The mean age of the sample was 27.6 years. A vast majority of the sample (91.9%, n=261) were white, only 1.8% (n=5) were of Hispanic or Latino ethnicity, and 1.4% (n=4) were black or of African American ethnicity. Most were females (84.6%; n=236), holding a college degree or higher (72.9%; n=215). A majority had group insurance through school or work (52.5%; n=149). While 15.1% (n=43) had a lapse in insurance coverage in the past 12 months, only 2.5% (n=7) endorsed currently being uninsured. The majority (92.9%; n=264) endorsed having seen a gastroenterologist in the past 12 months. Based on study findings and projected IBD-related ED and

hospitalization cost (Ballou, et al., 2018; Xu, et al., 2019), the internet-based sample spent over 1.21 million dollars in ED visits (280 incidence x $4,342) and approximately $1.56 million in hospitalizations (136 incidence/$11,500) totaling an estimated 2.77 million dollars during a 12-month period. Perceived stress scores (PSS-10), transition readiness scores (IBDSES-A), disease activity measures (MIBDI), and IBD-related HCU were compared with findings from the literature.

Stress (PSS-10)

The recruited sample exhibited a mean stress level of 22.0 (PSS-10). As depicted in table 1, the sample from the current study had the highest mean stress score found in the literature. In two other studies of young adults with IBD, the mean scores ranged from 17.1 (Sewitch et al., 2001) to 20.3 (Tabibian et al., 2015). The scores in the current study not only had a higher mean but a range of 8-40 when compared to a range of 1-37 found in a similar sample where online recruitment was also utilized (Tabibian et al., 2015). One potential reason for high-stress levels in the current study and that of Tabibian et al. (2015) may be related to recruiting participants who searched the internet for help with self-management. The paradox does not seem to stem from education levels as 72.9% of the current study participants had earned a college degree while Tabibian et al. (2015) only had 57.7% having achieved a college degree.

When evaluating the current study with the other two studies that assessed stress in adults with IBD, an increase in stress levels is noticed over time (Sewitch et al., 2001; Tabibian et al., 2015). Interestingly, the current study participants had the lowest mean age and highest stress scores while Sewitch et al. (2001) with mean age of 36.7 described the lowest stress scores (range 17.1-18.3). Stress levels may be highest in the young adults, yet this idea was not supported by the literature describing stress levels in nursing students (Ratanasiripong et al., 2015; Foster et al., 2018). Based on this limited data, young adults today appear to experience more stress (Table 1). The reason for why stress levels are elevated in these well-educated young adults with IBD is unknown.

Table 1 : *Comparison of Stress Scores*

Research study reference:	Population (n) Mean age (SD)	Mean score (SD)
Current study (2019)	IBD (n=284) Mean age: 27.6 (4.68)	22.0 (6.9) Range: 8-40 (32)
Sewitch et al. (2001)	IBD (n=200) Mean age: 36.7 (14.7)	CD 17.1 (7.6) UC 18.3 (6.7)
Tabibian et al. (2015)	IBD (n=136) Mean age: 32.5 (9.9)	20.3 (7.2) Range: 1-37
Foster et al. (2018)	Students (n=203) Nursing: 26.96 (9.37) Pharmacy: 21.11 (2.4) Dentistry: 26.00 (3.06)	Nursing: 15.0 (5.9) Pharmacy: 20.0 (6.9) Dentistry: 19.8 (7.6)
Ratanasiripong et al. (2015)	Nursing students (n=60) Mean age: 19.3 (9.37) 97% female	12.5 (3.9)

Table 2: Comparison of Disease Activity (MIBDI)

Study (n; age range/years)	Mean age (SD)	MIBDI Consistently active (%)	MIBDI Mean (SD)
Current study (2019) (n=284; 18-35)	27.6 (4.7)	79.6%	3.1 (1.6) CD 3.0 (1.5) UC 3.2 (1.7)
Clara et al. (2009) (n=353; 17-79)	41 (14.5)	69.9%	3.5 (1.7)
Targownik et al. (2015) (n=478; adults)	CD 54.4 (13.0) UC 56.6 (13.0)		CD 3.9 (1.5) UC 4.2 (1.6)
Graff et al. (2016) (n=229: 25-85)	48.7 (14.7)	37.3%	
Longobordi et al. (2016) (n=352; adults)	Not described	56% 1-year period	
Graff et al. (2003) (n=312, 19-85)	43 (14.8)	45% 2-year period	
Lix et al. (2008) (n=356; 18-83)	38.5 (14.6)	30.6% 2-year period	

Table 3 : *Comparison of IBD-Related Healthcare Utilization*

	Age range:	Sample number	ED visits: %/12 months	Hospitalization: %/12 months	HCU:[1] %/12 months
Current study (2019)	18 - 35	284	38.2%	23.2%	40.1%
Current study (2019)	18 - 26	110	40.9%	28.2%	45.5%
Rosen et al. (2016)[2]	18 - 25	95			19%
Bernstein et al. (2017)	18 - 65	1,143	9%		
Nugent et al. (2016)[3]	Adults	3,394	15.0%		
Longobordi et al. (2011)	Adults	352		10%	

Note: [1]HCU describes having either an IBD-related ED visit or inpatient hospitalization; [2]Adjusted from 9.5%/6 months; [3]Adjusted from 48.7%/3.25 years

Transition readiness (IBDSES-A)

Higher transition readiness equate to improved self-efficacy to manage IBD (Izaguirre et al., 2017). Mean transition readiness scores using the IBDSES-A were compared to two other studies using this measure (Carlsen et al., 2017; Izaguirre et al., 2017). The study sample had lower scores (47.2) than in two comparative studies of adolescents and young adults which ranged from 48.7-53.0 (Carlsen et al., 2017; Izaguirre et al., 2017). The highest mean (53.0) was found in a sample having a mean age 19 years (Carlsen et al., 2017). Higher transition readiness scores were expected in a sample of highly educated young adults than in adolescents who are not only younger but also less educated. Surprisingly, mean transition readiness score (47.2) was lower than in the adolescent sample (12-17-years-of-age) recruited from an IBD specialty clinic (48.7) (Izaguirre et al., 2017).

Disease Activity (MIBDI)

Means and percentages from the current study were compared with other studies that used the MIBDI (Table 2). Several studies assessed the MIBDI multiple times over a year or more and described those participants who varied between active and inactive disease as having fluctuating disease activity (Lix et al., 2008; Longobardi et al., 2011; Graff et al., 2013). Comparison with these studies is inaccurate as the additional category decreased those found to be consistently active. When compared to the similar studies the current study's participants had a higher incidence of consistently active disease (79.6%).

Mean scores from the MIBDI are compared in Table 2. An increase in the MIBDI describes less disease activity while lower scores are indicative of active disease so that a score of one describes daily symptoms while a six describes remission or absence of symptoms. The lower mean MIBDI score (3.1) in the current study demonstrated more IBD disease activity when compared with ranges between 3.5-4.2 in the other research (Clara et al., 2009; Targownik et al., 2015). In summary, the participants in the current study had the lowest mean MIBDI score (more disease activity) found to date and the highest percentage with active disease when assessing the MIBDI categorically.

Healthcare Utilization

The participants with IBD-related HCU, including ED visits and/or hospitalizations, were compared to other samples from the literature (Table 3). In the current study, 38.2% of participants noted at least one IBD-related ED visit as compared to 9% from Bernstein et al. (2017) and 15% from Nugent et al. (2016). Almost one-fourth (23.2%) of the participants in the current study experienced hospitalization, compared to 10% (Longobardi et al., 2011).

In a clinic sample (n=95) between 18-25 years-of-age, 9.5% had either an IBD-related ED visit or hospitalization in a 6-month period (Rosen et al., 2016). When adjusted to a 12-month period, 19% of Rosen's sample would have had HCU. When compared with those in the current study ages 18-26 years (n=110), a 2.4 times higher HCU incidence (45.5%) was noted.

Discussion

When compared with prior research, the sample had the highest stress levels (PSS-10) (Sewitch et al., 2001; Ratanasiripong et al., 2015; Tabibian et al., 2015; Foster et al., 2018;), the lowest transition readiness scores as measured by the IBDSES-A (Carlsen et al., 2017; Izaguirre et al., 2017) more disease activity (MIBDI), (Lix et al., 2008; Clara et al., 2009; Longobardi et al., 2011; Graff et al., 2013; Graff et al., 2016; Targownik et al., 2015), and the highest incidence of IBD-related HCU (Bernstein et al., 2017; Longobardi et al., 2011; Nugent et al., 2016; Rosen et al., 2016). Because these young adults were highly educated with poor health, the recruited sample may have been accessing IBD social media sites to find help with illness management. Clinically, the findings reflect pain, suffering, poor health, and increased cost of caring for those recruited outside the IBD specialty clinic. While the majority endorsed a clinic visit in the prior 12-months, the survey did not define if the provider was a qualified IBD specialist and did not ask if the visit was scheduled after a hospitalization since a clinic visit should routinely occur several weeks after hospitalization.

The study findings can only be generalized to young adults with IBD, more specifically, to populations with similar characteristics. The sample did not mirror the population of the United States. The current study sample had a higher

percentage of females (84.6%) than the registry study by Dahlhamer et al. (2016). The study sample was not reflective of the racial diversity within adults with IBD in the United States; however, racial diversity was more diverse than some IBD research (Clara et al., 2009; Keefer et al., 2011). Selection bias is apparent in this highly educated sample of predominately white females with poor health.

Inclusion criteria could have affected study findings. The exclusion of subjects *(*n=16) who did not need at least one IBD medication in the prior 12-month period would have resulted in an increase in disease activity and HCU in the sample. The exclusion of the four potential participants with a diagnosis of less than one year would mediate the effect since ED visits are significantly higher in the first three months following an IBD diagnosis (Nugent et al., 2016). These two exclusions were not found in the comparison studies that evaluated disease activity or HCU (Lix et al., 2008; Clara et al., 2009; Longobardi et al., 2011; Graff et al., 2013; Targownik et al., 2015; Graff et al., 2016; Nugent et al., 2016; Bernstein et al., 2017).

In the current study, young adults with IBD self-reported all study information. Longobardi et al. (2011) found that patient self-report of IBD-related hospitalization correlated highly with registry data. A second study reported that adults with IBD accurately described hospitalizations, surgeries, diagnostics, and the use of anti-TNF compounds (Severs et al., 2016). All self-report data depends on the participant's desire and ability to accurately describe reality (Polit & Beck, 2010).

A key strength of using online recruitment strategies comes from increased distance between the researchers. Anonymity nearly eliminates researcher bias and social desirability. The lack of an incentive for participation diminished the temptation for people who do not meet study criteria to participate.

Conclusions - Suggestions

In summary, internet-based recruitment as used in this study resulted in a primarily Caucasian female sample with a need for improved chronic illness management and stress reduction. Specialty clinics, such as IBD clinics, have a vested interest in improving health in young adults with IBD through research. However, IBD researchers should consider alternative recruitment strategies as a means to provide greater understanding of the population. Clinically, access to a qualified IBD specialty clinic should be evaluated in all young adults with moderate or severe IBD. Many young adults with IBD struggle with poor health. Additional research to appraise the cause of the health disparity in an internet-based sample is needed. Potential issues may include difficulty transitioning from pediatric to adult care, a lack of access to an IBD home, a lack of self-management ability, health insurance not covering expensive medications, loss of parental support, substance abuse, and out of pocket cost for healthcare. Even with health insurance, patients with IBD incurred three times the direct cost of care than similar people without IBD (Park et al., 2019). Evaluation of young adults with other types of chronic illness such as diabetes mellitus type 1 and asthma could add insight into the problems young adults with chronic illness face. Internet-based recruitment for research is a viable method for data collection. Researchers may be able to reach more vulnerable subjects that provide a truer picture of the state of health. In this study, 284 subjects utilized an estimated 2.8 million dollars of HCU within one year. Utilizing online recruitment may be helpful in identifying modifiers of key health outcomes such as ED visits and hospitalizations. Without internet-based recruitment, the enormous finacial impact of this chronic disease would be less clear.

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