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REVIEW ARTICLE

Higher than anticipated Health Literacy in Patients with Inflammatory Bowel Disease: A Single Center Experience

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Abstract

Background & Aim: Health literacy is important in any chronic disease. Inadequate or limited literacy is a major barrier to optimum medical care. Our aim in this study is to evaluate the level of literacy in patients with inflammatory bowel disease (IBD), measure physician's assessment of the patient's literacy and if any patient related factors are predictive of health literacy.

Methods: This is a prospectively designed survey based study. Patients seen in the IBD clinic at a tertiary care center were asked to fill out an interactive literacy survey. Adequate health literacy was defined at 75% or higher. Clinician perception of patient's literacy was recorded by the physician the same day. Demographic and disease characteristics were abstracted from the medical record.

Results: 165 patients were included in the study. Average age was 36.1; 87 were females; 122 were Caucasian; 159 with private insurance; 103 had Crohn's disease, 60 had Ulcerative colitis and 2 had Indeterminate colitis. 70.9% patients noted to have adequate health literacy score while 60.0% patients were evaluated by physician to have adequate health literacy score. Poor agreement noted between physician's evaluation and patients health literacy assessment score (kappa = 0.0212; CI -0.1276 to 0.1699). Age was the only variable predictive of adequate health literacy (p= 0.0154).

Conclusion: A significantly higher proportion of IBD population in our study had adequate health literacy. Clinicians underestimated the literacy level. The disproportionate demographic and administration of surveys after the clinic visit may have skewed the results towards the unexpected higher health literacy rate.

Keywords: IBD, Health literacy, Interactive health literacy, CCKNOW

Abbreviations: CCKNOW: Crohn's and Colitis knowledge; IBD: Inflammatory Bowel disease; VAS: visual analog scale; SD: Standard deviation

Introduction

Health literacy is defined in the Affordable Care Act of 2010, Title V, as the degree to which an individual has the capacity to obtain, process, understand and communicate basic health information to make appropriate health decisions[1]. These decisions require the patient's understanding on how to find appropriate information and services, processing those choices as well as subsequent possible consequences and then using this information to make a decision as to which choices match their health and social needs the best. It is also crucial that the health care provider understands the health literacy level of each individual patient and develops means to communicate effectively at a level at which the patient would understand [2].

Health literacy is extremely relevant in any chronic disease where the pathology and treatment options are complex. Patient understanding and involvement in their own healthcare is of significant value. Limited health literacy is associated with poor health outcomes [3] and increased mortality noted in other chronic diseases [4]. Prior to understanding how to overcome barriers in communication, it is important for the physician to understand the literacy level of each individual patient and to communicate at the level of the patient to make vital information understood [5]. Inadequate or limited literacy and failure of the physician to recognize the literacy level of the patient are both major barriers to optimum medical care [5].

Medical management of inflammatory bowel disease (IBD) is challenging because of the need for long term medication use with complicated side effect profiles and the need for patient adherence even if disease is in remission [6]. Adherence rates rise when patients understand the potential complications associated with their disease[6]. Interestingly, increased general IBD education does not yield an adherence benefit [7]. Similar data from the Swiss IBD cohort showed that although almost two-thirds of the patients were information seekers, there

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was still a high degree of non-adherence among that group (OR 2.44; 95%CI: 1.34-4.41) [8]. A prospective study of patients with IBD identifying determinants of non-adherence to medication showed a direct correlation between patient–physician discordance and intentional non-adherence (OR = 1.59, p =.0120) amongst other things [9].

Pediatric gastroenterologists at the University of California in San Diego looked at the transition readiness of children with IBD by assessing both functional (basic reading and writing skills to be able to understand and use health information) and interactive (more advanced cognitive and literacy skills to interact with health care providers and to interpret and apply information to changing circumstances) health literacy. They found that functional health literacy was indeed present in the majority of their patients (74%); however, only 11% of the children exhibited health literacy–related readiness for transition defined as adequacy in both functional and interactive health literacy [10].

Aim

Our goal in this study was to assess interactive health literacy in patients with IBD at a single center and compare this with the physician's assessment of the patient's literacy. In addition, we assessed patient-related factors that may predict adequate health literacy. We also evaluated the correlation between physicians' perception of patient literacy and the actual health literacy of the patient.

Methods

The study was registered and approved by the Medstar IRB prior to starting. Between December 2014 and May 2015, successive patients older than 18 years with a documented history of IBD who were seen in clinic at MedStar Georgetown University Hospital were recruited. They were asked to complete *a survey* on an electronic tablet immediately after their clinic visit. Exclusion criteria included diagnosis of IBD within 90 days, age less than 18 years, non-English speaking, and lack of consent. Clinician perception of patient's literacy was recorded by the physician who saw the patient in clinic. The physician was blinded to the patient's survey at the time of the clinic visit. The study was approved by the institutional review board at MedStar Georgetown University Hospital. Informed consent was obtained from all the patients prior to administering the survey.

Interactive health literacy was assessed using a 24-item abbreviated form of the Crohn's and Colitis Knowledge (CCKNOW) scale, which has been previously validated [11]. The interactive health literacy survey (total 300 points) measured personal health knowledge (200 points), general IBD knowledge (75 points) and relevant medical history (25 points). Examples of questions from the personal health knowledge are listed in [Table 1]. Interactive health literacy scores were then added and scaled from 1-100. An additional questionnaire measured patient's perception of their own self efficacy in their ability to perform tasks for disease self-management on a 5 point Likert scale (100 points). Adequate health literacy was defined at 75% or higher.

Clinicians were asked to globally assess the health literacy of a given patient on a visual analogue scale (VAS). Clinicians were asked to select their level of agreement with the following statement, "My patient is able to obtain, process, and understand basic health information and services to make appropriate health decisions re: his/her inflammatory bowel disease," on the basis of the Institute of Medicine's[2] and Healthy People 2010 [12] definition of health literacy. This score was then converted on a scale of 1-100. Again, adequate literacy assessment was defined as 75% or higher. The evaluating physician was blinded to patient's responses on the survey. Both the physician and the patient filled out the survey immediately after the clinic visit was complete. Demographic and disease characteristics of the patients were abstracted from the electronic medical record.

Statistical Methods

All components of interactive health literacy were summarized using mean, median and standard deviation. Scores were analyzed both as continuous variables as well as dichotomized into adequate vs non adequate score; adequate score being 75% or higher as described earlier. The dichotomized variables are presented using median and inter quartiles (25th and 75th percentiles) and compared using non parametric Wilcoxon rank sum test or Kruskal Wallis test. Association between categorical variables is tested using Chi square test or fisher exact test for small cell sizes. Agreement between total patient literacy score and physician evaluation score is tested using sign rank sum test for paired differences. For dichotomized adequate vs non adequate groups, agreement was tested using Kappa statistic of agreement and the marginal proportions were compared using McNemar test.

Results

165 patients were included in the study. Demographic data is presented in [Table 2]**.** In summary, average age at the time of

Questions
What is the Illness you have?
What parts of your body are affected?
Who is your doctor for this illness? Name and correct spelling
What allergies do you have? Identify the correct medication and the specific allergic reaction
What medications are you on? Include the correct spelling, correct dose and regimen and know how the medication works
How do you know if the medication is working? List resolution of at least two symptoms or 2 specific things
How do you know if you are sick? List at least three symptoms

Table 1: Relevant Personal Health Knowledge Questionnaire.

Age (years) [a]	36.1 (32; 18-81)	Race/Ethnicity % (n)	Caucasian 79.93% (122) African American 12.12% (20) Hispanic 2.42% (4) Asian 1.81% (3) Other 9.96% (16)
Age at Diagnosis [b]	25.6 +/- 12.2	Type of Disease % (n)	Crohn's 62.42% (103) Ulcerative Colitis 36.36% (60) Indeterminate Colitis 1.21% (2)
Duration of Disease [a]	10.53 (8; 0-46)		
Gender % (n)	Male 47.27% (78) Female 52.73% (87)	Highest Education % (n) n=110	Less than High School: 0% (0) Completed High School: 7.27%(8) Completed College: 40.90% (45) Graduate degree: 51.81% (57)
Family History % (n) n=163	Yes 21.47% (35) No 78.52% (128)	Average Family Income (IRS tax bracket) n=106	25%: 45.14% (29) 28% : 52.83% (56) 33%: 26.46% (17) higher than 33%: 3.77% (4)
Health Insurance % (n)	Private 93.4% (159) Medicare 6.36% (6)		

[a] Mean (Median; minimum - maximum)

[b] Mean +/- SD

Table 2: Demographic data on the study patients (n=165).

survey was 36.1 (SD=13.5 years); average age at diagnosis was 25.6 (SD 12.2 years). About half were female (52.73%); 79.93% (122/165) were Caucasian. Crohn's diseases affected 62.42% (103/165) of participants 36.36% (60/165) with ulcerative colitis and 1.21% (2/165) with indeterminate colitis. Most of the patients (69.70%) had moderate to severe disease and the remaining 30.30% had mild to moderate disease at the time of first presentation; 93.4% (159/165) had private insurance.

Health Literacy Assessments

Interactive health literacy assessment results are presented in [Table 3]. Adequate overall interactive health literacy was observed in 70.9% of the patients, while 97.58% of the patients had a perception of adequate self-efficacy. The majority of the patients demonstrated adequate literacy with general IBD knowledge (55.15%) and relevant medical history (91.52 %) but a smaller minority showed adequate literacy with specifically personal health knowledge (48.48%).

Age was the only variable predictive of adequate health literacy (p= 0.0154) with the age group 25-34 with the highest median score of 81.5% compared to 76.7-78.0% in other age groups (p=0.0006). This held true even when literacy scores were separated into personal health knowledge (p=0.016), general IBD knowledge (p=0.0034) and relevant medical history (p=0.05). However, in terms of patient's perception of their own self-efficacy in managing disease, there was no statistically significant difference in the age groups (p=0.1818). None of the other demographic variables were associated with health literacy (p=0.58).

From the physicians' evaluations, 60.0% of the patients were understood to have adequate health literacy scores. Overall, poor agreement was noted between the physicians' evaluation and patients' overall health literacy assessment scores (kappa = 0.0212; CI -0.1276 to 0.1699) with the patients' literacy scores significantly higher than physicians' evaluation score by an average of 5.11% score (p<0.0001**).**

Percent Total Score	Frequency (n)	Percent (%)
<75	48	29.09
75+	117	70.91
Percent Self Efficacy		
<75	4	2.42
75+	161	97.58
Physician Evaluation		
<75	66	40
75+	99	60

Table 3: Interactive Health Literacy Assessment results.

Discussion

We present the largest study to date evaluating interactive health literacy in patients with IBD. Our patient population was mostly suburban, from a tertiary-care academic medical center in a major metropolitan city, Caucasian and with private insurance coverage. The total interactive literacy in our study was significantly higher than what has been noted in previous studies. This may be partly explained by the fact that the surveys were administered after the office visit. Querying the patients prior to the office visit would remove any education provided by the physician during the clinic visit. A study on health literacy in a pediatric IBD population did note adequate literacy in 74% of the patients, although their pediatric population had limited general IBD knowledge compared with our population (16% vs 55%) [10]. Interim data from Boston Medical Center revealed a limited health literacy in 38% of their patients, with sample size of 53 patients utilizing a validated short and basic 6-question survey [13]. Interestingly, a recently presented abstract in patients with IBD, no association was seen between patients' education level and the CCKNOW scores [14]. Studies in other chronic diseases have shown significantly less literacy as well: in patients with Hepatitis B only 11% were aware of risk of cirrhosis and 18% were aware of risk of liver cancer [15]; in patients with hypertension about 59% of the patients had inadequate or marginal literacy [16] In the same study of 114 patients with diabetes, 55% had inadequate or

marginal literacy [16]. Therefore, it is unclear if the skewed demographics of the population in our cohort led to higher literacy rates than previously seen.

Previous studies have shown that clinicians tend to over-estimate the literacy level of the patient [17]. In our study, however, there was poor correlation between physician assessment and actual literacy in that the physicians tended to underestimate the literacy level by an average of 5.11% (60% assessment by physician vs 70.9% actual). Patients had significantly higher scores on self-efficacy (97.58%), meaning that their own perception of being able to perform tasks related to the disease was quite high. This may be of significance in terms of better patient outcomes. Dahl and their group showed that higher knowledge scores were present amongst patients routinely seeing the same clinician [15] and patients with limited literacy are more likely to defer decisions to their physician [18] despite having interest in shared decision making [19]. This is important especially in IBD where shared decision making is needed for complicated decisions such as initiation of biologic therapy where the patient has to understand the risks of the therapy and the need to continue therapy even in remission [20].

Adequate literacy is of tremendous value not only for important end points such as disease related patient outcomes [21] and mortality [22], but also for other variables related to overall quality of life [23]. Inadequate literacy has been identified as an independent risk factor for re-hospitalization and readmission [24, 25]. Berkman, et al showed in a systematic review that poor health literacy was not only associated with poor ability to take medications appropriately and interpret labels, but also increased hospitalizations and greater emergency care use[21]. Limited health literacy was also associated with lower quality of life related to IBD, higher depression scores and poorer overall subjective health status [13]. Literacy also affects how patients perceive the quality of communication with their physician, as well as their own ability to respond to physician's use of patient centered approach [19]. In this study, patients with low literacy asked less medical questions and had significantly lower perception of participatory decision making [19]. A collaborative approach to shared decision-making is important as it improved health outcomes of common symptoms [26]. Understanding a patient's literacy is important on many different levels and affects outcomes regardless of physicians' involvement in educating the patient.

Conclusion

There is little knowledge in the literature on how to educate health professionals in ways to enable their patients to self-manage and understand their disease [27]. There is clearly a need for developing tools to measure health literacy and develop mediators for increasing interactive health literacy [21]. However, there continues to be a large discrepancy between how physicians assess their patient's literacy and actuality [17]. We look forward to more studies like this to objectively measure literacy in the IBD population utilizing more validated assessment tools and to eventually utilize this information to improve outcomes. [Figure 1]

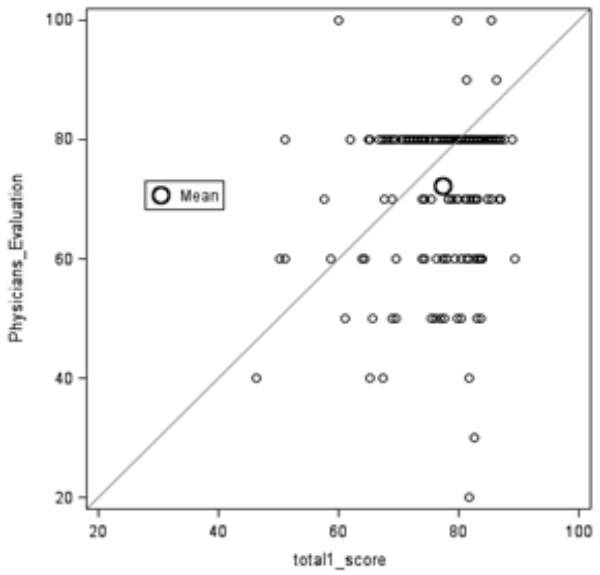

Figure 1: Poor agreement between physician's evaluation and patient's health literacy assessment score kappa = 0.0212; CI -0.1276 to 0.1699.

Disclosures

None for any of the authors. There is no conflict of interest for any of the authors.

Writing assistance

None

Author Contributions

Nidhi Malhotra: Acquisition of data, analysis and interpretation of data, drafting of the manuscript, critical revision of the manuscript for important intellectual content.

Gaurav Sahay: Acquisition of data.

Aline Charabaty: analysis and interpretation of data, critical revision of the manuscript for important intellectual content, study supervision.

Mark C. Mattar: Study concept and design, analysis and interpretation of data, critical revision of the manuscript for important intellectual content, obtained administrative and technical support, study supervision.

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