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Examining the Impact of Design Features of Electronic Health Records Patient Portals on the Usability and Information Communication for Shared Decision Making

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EXAMINING THE IMPACT OF DESIGN FEATURES OF ELECTRONIC HEALTH RECORDS PATIENT PORTALS ON THE USABILITY AND INFORMATION COMMUNICATION FOR SHARED DECISION MAKING

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Presented to
the Graduate School of
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Doctor of Philosophy
Industrial Engineering

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by
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ABSTRACT

The use of the Electronic Health Records (EHR) patient portal has been shown to be effective in generating positive outcomes in patients' healthcare, improving patient engagement and patient-provider communication. Government legislation also required proof of its meaningful use among patients by healthcare providers. Typical patient portals also include features such as health information and patient education materials. However, little research has examined the specific use of patient portals related to individuals with specific diseases such as inflammatory bowel diseases (IBDs). IBDs are life-long, not curable, chronic diseases that can impact the whole population. Individuals with IBDs may have higher needs to acquire health information from their EHR portals to properly self-manage their health conditions. The research aims of the present dissertation are to understand the online health information-seeking behaviors of a target group (IBDs) of patients, the use of EHR patient portals, and the impact of design features of EHR patient portals on the usability and information communication for shared decision making.

Through this dissertation, I conducted four studies to address the above research aims. First, I identified how individuals with inflammatory bowel disease (IBD) used the internet for health information seeking, the factors impacting their use of the internet to obtain health information, and how they used the internet for health-related tasks. The purpose of this study is to get a general understanding of the online health information-seeking behaviors and to guide the study of health information presentation of EHR portals in the following research. Second, I examined what factors influenced an EHR patient portal user

to believe that the portal is a valuable part of their health care. This part of the dissertation aimed to reveal the critical design factors that help design an EHR portal perceived as valuable in managing health. Third, I looked at how patients used EHR patient portals, what features of the portals facilitated their use and encouraged Shared Decision Making (SDM) and engagement in health management and what features acted as barriers to SDM and their engagement in health management. This part of my dissertation focused on a broad understanding of EHR portals usage by introducing more specific factors such as features of EHR portals. Fourth, I conducted an eye-tracking study to examine how information presentation methods and chatbots impact the use and effect of patient portals. This part of my dissertation built on the other studies within my dissertation and deepened the understanding of the influence of different EHR portal designs on their effectiveness and people's willingness to participate in SDM.

The results of this dissertation contribute to the literature of understanding the information-seeking behaviors of IBD patients and the use of portals, as well as the design considerations of how to make a suitable EHR portal to support the information-seeking needs of IBD patients. The results of this dissertation can be used to guide building proper patient education materials to support their health information needs of their specific health condition, especially for individuals with chronic diseases that require a certain amount of self-management. Meanwhile, examining artificial intelligence (AI) based chatbots use in EHR portals reveals a potential path of AI use in healthcare, such as information acquisition and patient education. Designing good usable EHR may also facilitate the process of

informing patients of the advantages and disadvantages of treatment plans for their disease and, therefore, may increase their willingness to participate in SDM.

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INTRODUCTION

Promoted by technology development and government policy, healthcare providers are now enabling their patients to access their electronic health records online using electronic patient portals (Kruse, Bolton, & Freriks, 2015). However, the design and usability of patient portals raise concerns, some of which may be related to the use of medical language (Sox et al., 2010), lacking technical support (Irizarry, Dabbs, & Curran, 2015), and human factors design issues in the interface (Goldzweig et al., 2013a). Ideally, a properly designed patient portal should provide enough information to the patients so that they can manage their health care and health-related tasks. Shared Decision Making (SDM) is a promising method to inform patients better, encourage patients' engagement in their own healthcare, and subsequently engage in shared decisions with their medical professionals during medical services (Sepucha et al., 2016). The SMD approach allows patients and their health care providers to discuss the potential benefits and risks associated with treatment decisions, and together make a decision that can best support patients' interest according to their distinct individual requirements. More details about the background information could be found later in this chapter, which presents a broader literature review of this dissertation.

Inflammatory Bowel Diseases (IBD) are chronic conditions that cannot be fully cured, which impact the intestines, colon, and bowel (Best, Becktel, Singleton, & Kern, 1976). IBD may lead to life-long disability or even death (Kaplan, 2015). An increasing number of patients are impacted by IBD across the US, including both adults and children, both male and females (K. T. Park et al., 2020). Ng et al. (2017) reported that more than 0.3% of the population are impacted by IBD across North America and many European countries, and experts are expecting higher prevalence (Kaplan, 2015). Patients with IBD have a higher risk of infection, and having active diseases and therapy may worsen this issue (Bezzio et al., 2020). Especially during the global pandemic of COVID -19, factors like active IBD disease, older age and comorbidities are reported to have a negative impact on COVID-19 outcomes, leading to pneumonia, respiratory support, hospitalization and even death (Bezzio et al., 2020). Self-management of chronic diseases like IBD is vital for patients to get better health outcomes, while proper self-management requires the patients to have correct information to understand their current situation and corresponding treatment methods (e.g., diets, medicines or therapy). Thus, understanding and assisting the information acquisition of IBD patients are vital in aiding their self-management of IBD.

Past research (Baker, Wagner, Singer, & Bundorf, 2003; Cassell, Jackson, & Cheuvront, 1998; Claridy et al., 2018; Grady & Gough, 2014; Kreps, 2017) has found that using the internet to search for health information leads to better health outcomes, and the internet is believed to be a good source of health information to support developing health knowledge, ongoing long-term self-management of care, and monitoring the condition of patients. However, very few health websites provide self-management information of IBD (Promislow, Walker, Taheri, & Bernstein, 2010), leading to the increased importance of Internet searching behaviors to get relevant health information. Thus, there is a need to understand how IBD patients use the internet for health information seeking, specifically what factors impact their information searching behaviors. This is addressed in Chapter 2 of this dissertation. The results of Chapter 2 were published in the Journal of Medical Internet Research (Yin & Neyens, 2020).

Before narrowing down to designing specific EHR portals to assist the usage of IBD patients, a general understanding of portal use of public users is necessary. Chapter 3 of this dissertation examined what factors have an influence on patient portal users’ perceived value of

EHR portals. Chapter 3 includes the standard demographic variable such as age, gender, marriage status, income, and education level, as well as users' opinions on their current use of patient portals. Chapter 3 also targets to reveal potential design factors that can contribute to designing a valuable EHR portal for the general public of EHR portal users. The results of Chapter 3 were published in Proceedings of the 64th Human Factors and Ergonomics Society Annual Meeting (Yin, Neyens, & Law, 2020).

As this dissertation examines the impact of design features of electronic health records (EHR) patient portals on the usability and information communication for shared decision making, part of the overall process in Chapter 4 examines 1) how patients use patient portals, 2) what features of the portals facilitate their use and encourage SDM and patient engagement in health management, and 3) what features act as barriers to SDM and engagement in health management. Specifically, Chapter 4 explores what population use patient portals and how do they use their portals, such as what features they used and desired, what factors hinder their use, what online information source they use, what information presentation method they preferred, how they trust their patient portals and what features would encourage their use. The results of Chapter 4 were published in the Journal of Medical Internet Research Human Factors (Yin, Law, & Neyens, 2021).

Chatbots are one technique that provides interactive communication services for websites or applications. Chatbots are seeing an increased usage, including government websites, business websites, and healthcare apps. The role of chatbots is usually providing assistance of using the websites and/or directly answering users' questions related to information searching and acquisition. The application of eye-tracking based research has shown power in the field of human-computer interaction research. This dissertation uses eye-tracking approaches and other research method like surveys to evaluate the usability of electronic patient portals and to identify ways to better support shared decision making through the use of patient portals. Specifically, this research applies eye-tracking methods to understand the effect of changing the information presentation method in patient portals and chatbot communication on the efficiency of information communication and perceived usability, especially for individuals who have various experiences in using patient portals. The willingness of EHR portal users to be engaged in SDM is also examined. A proof of concept eye-tracking study is presented in Chapter 5.

LITERATURE REVIEW

Electronic health records and patient portals

The development of modern information technology is providing promising opportunities for improving healthcare efficiency and quality by using electronic health record (EHR) systems (Chaudhry et al., 2006). Along with the popularity of EHR systems in the healthcare services (Latha, Murthy, & Sunitha, 2012; Linder, Ma, Bates, Middleton, & Stafford, 2007), currently more and more healthcare providers give their patients the option to check their electronic health record online by using some web-based tools like the electronic patient portal (Ancker et al., 2011; Earnest, Ross, Wittevrongel, Moore, & Lin, 2004; Sands, Halamka, & Pellaton, 2001). Studies have shown the effectiveness of those patient portals in promoting provider-patient communication (Goldzweig et al., 2013b; Zickmund et al., 2008). Also, healthcare providers have demonstrated positive attitudes about the impact of patient portals, especially on the patient-provider communication process (Kittler et al., 2004). Enabling patients to access their electronic health records using the patient portal is also believed to be a promising way to improve the active engagement of patients in their own healthcare and health management (Ancker et al., 2011; Irizarry et al., 2015). Specifically, patient portals have been shown to significantly benefit patients with chronic diseases by facilitating patients in monitoring and understanding their health conditions and increasing their ability to self-manage chronic diseases (Kruse, Argueta, Lopez, & Nair, 2015). This may be related to the fact that patients with chronic diseases may benefit from the continual use of information sources in the management of chronic conditions more than patients with non-chronic diseases. For example, a web-based patient portal for diabetes patients has been reported to be successfully developed, which enables the direct access of the patient with their electronic health record and has good medical outcomes (Schnipper et al., 2008). Research also reveals the positive attitude on patient portals from patient's family with chronic diseases such as children with cystic fibrosis (CF), diabetes mellitus (DM), and juvenile idiopathic arthritis (JIA) (Byczkowski, Munafo, & Britto, 2014).

Aside from the concerns of increasing cost and added workload for providers (Emont, 2011), the design and usability problems of the patient portal also remains an issue (Ancker et al., 2011; Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010; Koivunen, Välimäki, Pitkänen, & Kuosmanen, 2007; L. S. Liu, Shih, & Hayes, 2011). Although the patient portals may be carefully and professionally designed, it is hard to conclude that the design can be easily adopted by the patients (Greenhalgh et al., 2010; L. S. Liu et al., 2011; Middleton et al., 2013). One case study in the UK shows that patients have negative opinions on the usefulness of a nationwide EHR system, and patients perceived the system as "not easy to use" with fewer than 100 out of 30,000 patients reported having an interest in using the email-style messaging (Greenhalgh et al., 2010).

Some usability issues may exist in practical daily use of the patient portals. These kinds of problems may include the following problems: the confusion of the display layout design, the hardness and barriers of key information searching (Haggstrom et al., 2011), the efficiency of the learning process of using patient portals for a novice user, and the accuracy of the perceived information.

Inflammatory Bowel Disease (IBD) treatment options and decision making

Crohn's disease and ulcerative colitis are collectively referred to as inflammatory bowel diseases (IBD) (Sartor, 2006; Hugot et al., 2001). IBD is a chronic condition that affects the intestines, colon, and bowel (Best, Becktel, Singleton, & Kern, 1976), and is a complex and incurable disease (Boyapati, Satsangi, & Ho, 2015) that can result in long term disability or mortality (Kaplan, 2015). The highest incidence of Crohn's disease occurs in younger adults (Kaplan, 2015; Loftus, 2004), and is estimated to be about one out of one thousand in western countries (Calkins & Mendeloff, 1986; Hugot et al., 2001). Some treatment methods like surgical interventions or medications (e.g., Budesonide or sulfasalazine) can be effective for managing active Crohn's disease, but do not cure Crohn's disease and often have side effects of their own (Travis et al., 2006).

It has been hypothesized that IBD is an interaction of environmental triggers, genetic susceptibility, luminal microbial antigens and adjuvants, and immune response (Sartor, 2006). Sartor (2006) also argued that "IBD results from the failure to appropriately downregulate nonspecific inflammation initiated by an environmental trigger". Patients with IBD may suffer from other diseases that are closely related to IBD. Studies have shown that Crohn's disease has a close relationship with cancer (Gyde et al., 1980; Lakatos & Lakatos, 2008; Rhodes & Campbell, 2002; Weedon, Shorter, Ilstrup, Huizenga, & Taylor, 1973). Individuals with Crohn's disease are twenty times higher than the regular population to have colorectal cancer (Weedon et al., 1973).

Generally, most studies related to IBD focus more on its pathology and medical impact. Although there are studies that focus on the diagnosis of IBD (e.g., the widely used Crohn's disease activity index - CDAI (Best et al., 1976)), predictors of the disabling process (Morrison, Haas, Shaffner, Garrett, & Fackler, 2003) and pathogenesis such as gene associated with Crohn's disease (Hugot et al., 2001; Ogura et al., 2001) and ulcerative colitis (Sartor, 2006; Stoll et al., 2004), few studies have examined what factors may influence patients with IBD to use the internet to search for healthcare-related information. Yet, the management of IBD depends on self-management of the disease and a level of health literacy. This dissertation will examine how patient portals could support shared decisions making for individuals with IBD.

Eye tracking technique for usability problems

The usability of patient portals has been identified as a critical issue. If research approaches like interviews, think-aloud sessions and focus groups are solely applied, it may not completely reveal the usability issues of this problem (Morgan, 1993). For example, interviews may yield subjective results according to different participants, and think-aloud sessions may have an influence on the information processing process during the experiment (Susac, Bubic, Kaponja, Planinic, & Palmovic, 2014). The application of eye tracking based research has shown its power in the field of human factors research (Duchowski, 2002; Ehmke & Wilson, 2007; Hwang & Lee, 2018) and has been used in studies related to online searches (Lorigo et al., 2008). Eye tracking technology records the eye movements when the participant looks at certain content (Bojko & Stephenson, 2005; Ehmke & Wilson, 2007). According to Ehmke & Wilson (2007), sample metrics of eye tracking data include: fixation, where the participant’s eye stare at the same position of the screen and a saccade or scan path, when the participants move eyes from one position to another position. For example, fixation duration is used to evaluate the cognitive effort in the information searching and processing process, as well as the engagement of users (Sargezeh, Tavakoli, & Daliri, 2019; Tullis & Albert, 2013). The fixations in an Area of Interest (AOI) are widely used in eye tracking studies to examine users' visual attention and information processing in a specific area of the visual stimulus (Orquin, Ashby, & Clarke, 2016; Salminen et al., 2018).

Decision aids

Decision aids have been developed to support patients in making decisions to balance the benefits and risks of medical options to best serve their personal goals and preference (O'Connor et al., 2009) and are an important aspect of SDM. Decision aids have high flexibility in that they can be easily accessed by patients through portals by using their mobile devices or laptops (Légaré & Witteman, 2013). Thus, patients could benefit from SDM in a more straightforward and convenient way by using decision aids through platforms like patient portals. However, as communication technology is dynamically changing, similar to other information technology and health information technology systems (Gustafson et al., 1999), the best strategy to overcome the barriers to using electric decision aids remains unclear.

Decision aids have been used online in assisting patients who have diseases like osteoarthritis of the knee to make decisions (Elwyn et al., 2010). Guidelines for the design of decision aids tools have been provided in the literature (Oshima Lee & Emanuel, 2013; Sepucha et al., 2018). For example, it has been suggested that decision aids need to be written at an eighth-grade reading level and should be brief (Oshima Lee & Emanuel, 2013). Sepucha et al. (2018) also provided a checklist on reporting decision aids evaluation studies (see Sepucha et al., 2018). However, there is no evidence that more expensive decision aids tools (e.g., video presentations) yield better results of SDM than simple and less expensive tools (e.g., a decision aid board) (Frosch & Kaplan, 1999). A decision aids board is a poster or whiteboard that displays clinical information like treatment options, long-term treatment effects and treatment benefits and risks (Whelan et al., 2004) for use during a consultation or appointment.

Chatbots

Artificial intelligence (AI) based chatbots are machine agents that can interact with people in their natural language to satisfy users' information and communication needs (Brandtzaeg & Følstad, 2017) and have simulated conversations with the users through the internet (Adamopoulou & Moussiades, 2020). The first chatbot was called Eliza and was developed in 1966 (Weizenbaum, 1966). There are many different chatbots and chatbot platforms that exist today (e.g., Microsoft's XiaoIce (Shum, He, & Li, 2018), Symptoma (Martin et al., 2020)). Many large companies, such as Google, Facebook, Amazon, and Apple, have utilized chatbots in their online services to support interacting with large numbers of users (Brandtzaeg & Følstad, 2017; Caldarini, Jaf, & McGarry, 2022). It has been suggested that the use of chatbots can improve customer satisfaction, trust and loyalty to business companies (Jenneboer, Herrando, & Constantinides, 2022). Additionally, research suggests chatbots may be appropriate for use in education organizations such as in higher education and is perceived as highly useful for information acquisition by college students (Meyer von Wolff, Nörtemann, Hobert, & Schumann, 2019). Using chatbots for studying and test preparation was also valued by college students, and it was suggested that these tools might improve engagement in studying (Pereira, 2016).

Chatbots are expected to communicate with users as if the chatbot was another person that was helping to assist with information seeking and problem-solving (Adam, Wessel, & Benlian, 2021). Brandtzaeg & Følstad (2017) suggested that chatbot users intended to use chatbots for multiple reasons, such as the potential to improve their productivity (68% of participants), obtain quick and convenient answers to their questions (42%), and assistance in information seeking (41%). Another study suggested that most participants expressed their interest in using chatbots for minor health issues due to the convenience of using chatbots, although some participants reported concerns about the information quality, technology, and information security (Nadarzynski, Miles, Cowie, & Ridge, 2019). The use of chatbots in healthcare has been increasing due to the increasing demand for convenient conversational service at all hours (Jovanović, Baez, & Casati, 2020) in varies aspects of healthcare domain (e.g., medical consultation and self-diagnosis, (Fan et al., 2021), adolescent health education (Rahman et al., 2021), mental health evaluation (Deshpande & Warren, 2021; Potts et al., 2021), and COVID-19 screening (Martin et al., 2020; Srivastava, 2021)). For example, in a study of healthcare providers, the majority of participants reported positive attitudes related to the usefulness of chatbots to assist mental healthcare and assist self-management for their patients (Sweeney et al., 2021). During the COVID-19 pandemic, the US Centers for Disease Control and Prevention (CDC) developed chatbots to assist users in self-evaluating their COVID-19 conditions and made suggestions on whether or not an individual needed to seek medical assistance (Miner, Laranjo, & Kocaballi, 2020). Chatbots have been used in studies with both patients and healthcare providers (Dolianiti et al., 2020; Potts et al., 2021). For example, a conversational chatbot that acted as a virtual patient was developed for training medical students in making medical decisions related to specific diseases (Dolianiti et al., 2020).

The development of AI and machine learning has enhanced the ability of chatbots to provide accurate responses as AI systems learn via engagement with users (Ayanouz, Abdelhakim, & Benhmed, 2020; Schmidlen, Schwartz, DiLoreto, Kirchner, & Sturm, 2019). However, in another study, physicians reported concerns about using chatbots in patient care because chatbots are not able to completely account for all patients’ needs and human emotions, as well as risks triggered by frequent self-diagnosis and misinterpretation of the diagnosis results (Palanica, Flaschner, Thommandram, Li, & Fossat, 2019). Another study asked the participants to take action to medical problems after consulting and interacting with three currently being used chatbots (Siri, Alexa, and Google Assistant), and the study found that 29% of the users' actions to the medical problems (after taking responses from the chatbots) might lead to patient harm and some (16%) might be lethal (Bickmore et al., 2018). In a mixed-methods study using questionnaires and a semi-structured interview (A. C. Griffin et al., 2021), participants' (individuals who reported having hypotension) interests in using a chatbot also varied. Most participants in that study were interested in using chatbots in managing their health conditions and would like to have chatbots installed in patient portals, although some participants also had some concerns such as excessive information, data security, and privacy issues (A. C. Griffin et al., 2021). Schmidlen et al. (2019) showed that participants reported that their chatbot security concerns could be reduced if the chatbot was integrated within patient portals. Chen & Decary (2019) developed a chatbot that can be integrated within patient portals and communicate with patients in both voice and text format. The integration of chatbots within patient portals is believed to be an important feature in future patient portal designs (Chen & Decary, 2019).

Shared Decision Making

Shared Decision Making (SDM) is believed to be a replacement of the concept of the "doctor knows best" approach (Coulter, 1997) and is considered to be "the pinnacle of patient-centered care" (Barry & Edgman-Levitan, 2012). SDM has multiple synonymous names and definitions, such as informed shared decision making and informed decision making (Charles, Gafni, & Whelan, 1997). One definition is that: SDM is "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2010).

Elwyn et al. (2012) provided a model (see Figure 1 below) of SDM which has three major steps: 1) choice talk, when the physicians inform the patients of the available medical choice, 2) option talk, when the physicians and patients talked about the detailed information of the treatment options and 3) decision talk, when the physicians and patients jointly choose the best option to the patients according to the preference of the patients and to meet the patients' values (Elwyn et al., 2012). However, prior to, or in conjunction with, any discussions, the patient needs to have a reasonable health literacy about their condition and be aware of the implications of treatment for an effective discussion.

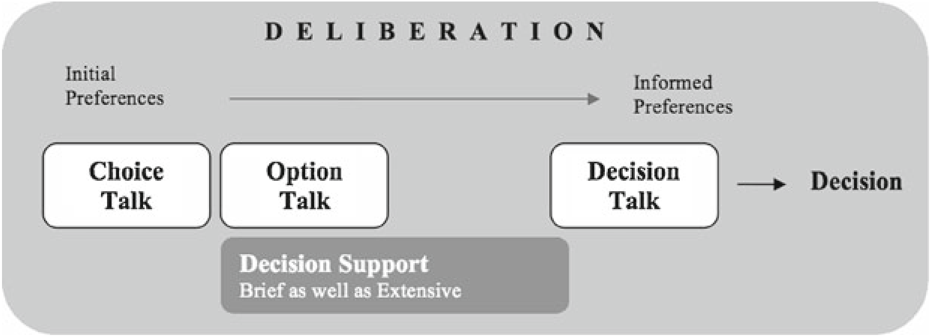


Figure 1 Elwyn et al.'s (2012) model of Shared Decision Making

In many cases, multiple treatment options may be suitable for the patients with no single option clearly more appropriate than the others (Barry & Edgman-Levitan, 2012; Frosch & Kaplan, 1999). For example, this kind of situation can occur with medical uncertainty or when treatment is in the early progression of the disease. These situations can include decisions about early treatment options of breast cancer (Barry & Edgman-Levitan, 2012) and prostate cancer (Barry & Edgman-Levitan, 2012; Elwyn et al., 2010). SDM works well in helping the patients and physicians to jointly select the optimal treatment in the best interest of the patients, according to their various individual values and preferences (Elwyn et al., 2010; Frosch & Kaplan, 1999; Oshima Lee & Emanuel, 2013).

SDM helps to introduce the active engagement of patients in the process of their own health care rather than passively accept the treatment decision made by their physicians (Elwyn et al., 2010; O'Connor et al., 2009) and remain unknowledgeable about their health problems and treatment options (Barry & Edgman-Levitan, 2012). The promotion and development of SDM are expected to improve the quality of health care and increase patients' satisfaction while potentially decreasing the cost of health care (Légaré & Witteman, 2013; Oshima Lee & Emanuel, 2013). SDM can enable patients to choose appropriate treatment options according to their values regarding avoiding the unnecessary cost of alternative treatment, and it works especially well for decisions dramatically dependent on patient values (Sheridan, Harris, Woolf, & Force, 2004).

Research suggests that, through SDM, patients are able to make more informed choice and have better understanding of the benefits and risks of their medical choice compared to patients with usual care (Man-Son-Hing et al., 1999; O'Connor et al., 2009). Patients received good quality of SDM process are more likely to have correct expectation of the potential risks associated with their diseases than patients treated in traditional medical routine (Man-Son-Hing et al., 1999).

Although SDM is expected to be an effective strategy to improve the quality of health care (Elwyn et al., 2012; Oshima Lee & Emanuel, 2013), the implementation of SDM in medical practice are not always smooth. In one study that involved 3552 medical decision, only 9% of the decisions made were determined to be completely informed decision making while the assessment rate of patient understanding of the medical problem was only 1.5% (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). Time constraints are considered as a key barrier in implementing SDM (Légaré & Witteman, 2013). However, time constraints are believed to be the same as the implementation of other clinical changes (Légaré & Witteman, 2013), which may be relevant to factors like staff training and new technique adaptations. A study suggests that the duration of a consultation with a physician increases by 2.6 minutes when applying decision aids in medical consultation, and the cost are generally lower than regular health care (O'Connor et al., 2009).

Although new techniques and theories are intended to improve patient satisfaction and safety, there are factors that influence an individual's ability or willingness to adapt to SDM approaches. For example, study suggested younger and highly educated patients may be more adaptable to SDM (Frosch & Kaplan, 1999), while older individuals and individuals with lower education levels may be less willing to engage in SDM (Kiesler & Auerbach, 2006; Légaré & Witteman, 2013). There is a call to develop better SDM strategies that may improve healthcare access, quality, and satisfaction for those who currently have barriers to engage in SDM and those who are believed to potentially benefit more from SDM (Légaré & Witteman, 2013). However, not all patients express their willingness to be engaged in the decision-making process (Levinson, Kao, Kuby, & Thisted, 2005). The individual preference of participating in the medical decision-making process varies (Levinson et al., 2005). Another study suggests that around half of the patients prefer to let their physicians to make the final decision, with 44% of them preferring to ask their physicians questions rather than trying to identify and address the problems themselves (Levinson et al., 2005). Therefore, one of the primary purposes of this dissertation is to figure out a possible strategy to increase the patients' willingness to participate in SDM and thus promote the usage of SDM.

RESEARCH AIMS AND APPROACH METHOD

The objective of this dissertation is to explore the impact of design features of electronic health records patient portals on the usability and information communication for shared decision making of IBD patients, to evaluate suitable strategies to provide information on patient portals with the objective of supporting the factors that can facilitate better SDM. The first initial step of this dissertation is to understand how individuals with IBD use the internet for health information seeking, then identify the potential barriers and expected functions when using patient portals and factors that may impact the decision-making process of patients. Then, identify suitable decision aids for patient portals that could be used in clinical practice. Finally, this dissertation will evaluate strategies that could improve the design of patient portals to supply information to fulfill the requirement of information communication of SDM in a longer-term usage. The following research questions will be addressed:

Research Questions:

1. How do patients with IBD use the internet for health information seeking behaviors?
2. What factors impact the users' perceived value of EHR portals?
3. How do portal users report using their portals and what are the factors associated with obtaining health information from the internet?
4. What format of information provided (e.g., textual, video, audio) through patient portals can best support the knowledge acquisition of shared decision making? What kind of information resource could improve patients' trust in the information provided?

SUMMARY

By addressing the above research questions, a more comprehensive understanding of how patient portals users can benefit from the design of patient portals are expected to be generated. The results are expected to provide guidelines of usable, effective, and efficient design of future patient portals. The results of this dissertation are expected to add value to the literature of understanding the information seeking behaviors of IBD patients and the use of EHR portals, guiding the design considerations of how to make a suitable EHR portal to support the information seeking needs of specific (e.g., IBD and other chronic diseases) patients. The results of this dissertation could be used to guide building proper patient education materials to support their health information needs of their specific health condition, especially for individuals with chronic diseases like IBDs that require a certain amount of self-management. Meanwhile, examining artificial intelligence (AI) based chatbots use in EHR portals may contribute to revealing a potential path of AI use in healthcare, such as information acquisition and patient education, to save the efforts of health providers to repeatedly answer the same questions and provide 24/7 readily available health information source for patients to access, and thus assist provider-patient communication. Designing good usable EHR may also facilitate the process of informing patients the trade-offs of treatment plans of their disease, which may help patients to be easier to be “fully informed” and therefore may increase their willingness to participate in SDM.

CHAPTER TWO

ONLINE HEALTH RESOURCE USE BY INDIVIDUALS WITH INFLAMMATORY BOWEL DISEASE: ANALYSIS USING THE NATIONAL HEALTH INTERVIEW SURVEY

INTRODUCTION

The purpose of this study presented within this chapter is to examine how individuals with inflammatory bowel disease (IBD) use the internet for health information seeking. IBDs are the target diseases examined in Chapter 5 of this dissertation. In Chapter 5, I present an eye-tracking study examining how individuals use patient portals to acquire information related to knowledge of IBD. The research questions to be answered in this chapter are: 1) How do individuals with IBD use the internet to search for health information? 2) What factors impact their use of the internet to acquire health information? 3) how do they use the internet for health-related tasks? The work presented in this chapter was published in the Journal of Medical Internet Research (Yin & Neyens, 2020).

Background

The internet is seen as a reliable alternative source of health information (Mayer et al., 2007; Medlock et al., 2015), and people seek health information online to gain additional information about health conditions or procedures (Sillence, Briggs, Harris, & Fishwick, 2007), as well as to discuss their specific condition and health status through online discussion groups (Xiao, Sharman, Rao, & Upadhyaya, 2014). The internet may provide a convenient method for patients to obtain health information regardless of geographical restrictions (Bessell, Anderson, Silagy, Sansom, & Hiller, 2003; Brochu et al., 2019; Manierre, 2015) or access to care providers. Past research (Baker et al., 2003; Cassell et al., 1998; Claridy et al., 2018; Grady & Gough, 2014;

Kreps, 2017) has found that using the internet to search health information leads to better health outcomes, and the internet is believed to be a good source of health information to support developing health knowledge, ongoing long-term self-management of care, and monitoring the condition of patients. Research (Morahan-Martin, 2004) has found that most people use the internet to acquire specific information regarding their own health status or that of their family or friends.

Individuals with chronic diseases are a unique user population in terms of their potential use of online health information in self-management of their health. The prevalence of chronic diseases is high in the United States; Ward et al. (2014) reported that nearly 50% of adults have one chronic disease, and 25% have multiple conditions. Past research suggests that searching health information online may be a common behavior for people with chronic health conditions (Weaver III et al., 2010) and that online information seekers' health literacy and engagement may correlate with their ability to manage their chronic health conditions (K. Lee, Hoti, Hughes, & Emmerton, 2014). It has been shown that individuals with chronic diseases are more willing to search health information on the internet than those without such conditions (Bundorf, Wagner, Singer, & Baker, 2006). In addition, patients who have chronic diseases but who do not have health insurance are more willing to search for health information on the internet than individuals with insurance (Bundorf et al., 2006), supporting results from other studies (S.-Y. Park & Go, 2016; Sillence et al., 2007) that suggest that the involvement and motivation of users impact their engagement in online health information searching, with highly motivated users, such as those with chronic diseases, applying more effort in the information searching task. Additionally, there are multiple factors, including a person's gender, age, and socioeconomic status that influence an individuals' online information searching behavior and internet usage (Andreassen et al., 2007; Beck et al., 2014;

Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Mayer et al., 2007; Neter & Brainin, 2012; Renahy, Parizot, & Chauvin, 2008; Weaver III et al., 2010).

To ensure the effectiveness of the internet related to health information, the US Department of Health and Human Services (U.S. Department of Health and Human Services, 2010) has provided design guidelines to improve the user experience of individuals with various levels of health literacy, paying special attention to people with limited abilities. Not only are those with low health literacy less likely to use the internet for information searching and emailing (Jensen, King, Davis, & Guntzviller, 2010), they are also more likely to forget information and experience working memory overload when interacting with websites (U.S. Department of Health and Human Services, 2010) compared to internet users with higher health literacy. These users have been found to spend 9 times longer conducting information searching tasks than higher literacy users, and they tend to read word by word rather than glancing at the entire page for the more relevant information (Kodagoda & Wong, 2008). In addition, there are other barriers for all online health information seekers including limited accessibility to the content published in research journals, the complexity of the clinical language used, and the inability to evaluate the reliability of health information websites (K. Lee et al., 2014). Lee et al (K. Lee et al., 2014) argue that these barriers could be reduced by increasing the involvement of health professions in guiding the health information seeking process and improving general health literacy.

Crohn Disease and Ulcerative Colitis

Crohn disease and ulcerative colitis are collectively referred to as inflammatory bowel disease (IBD) (Hugot et al., 2001; Sartor, 2006), a chronic condition that affects the intestines, colon, and bowel (Best et al., 1976). It is a complex, incurable disease (Boyapati et al., 2015) that can result in long-term disability or mortality (Kaplan, 2015), and its highest incidence occurs in younger adults (Kaplan, 2015; Loftus, 2004). A recent study (Ng et al., 2017) suggested that the incidence of IBD has seen a dramatic increase to over 0.3% in North America and many European countries, and the incidence of IBD is expected to continuously increase (Kaplan, 2015).

Generally, the majority of studies related to IBD focus on its pathology and medical treatment. Although some studies have focused on the diagnosis of IBD (Best et al., 1976), predictors of its disabling consequences (Colombel, 2013), its pathogenesis (Hugot et al., 2001; Ogura et al., 2001; Sartor, 2006; Stoll et al., 2004), and the dietary habits of those with IBD (de Vries, Dijkhuizen, Tap, & Witteman, 2019; Vagianos et al., 2016), few have examined which factors may influence individuals with IBD to search the internet for health care–related information. Yet, the management of IBD depends on self-management of the disease and a level of health literacy. It has been found that many health websites did not provide appropriate coverage of prognoses, side effects, and additional health risks associated with IBD but did cover symptoms, complications, and treatment options (Promislow et al., 2010). Additionally, it was reported that information related to self-management of IBD was not widely included in health websites (Promislow et al., 2010), and thus the use of online search behavior associated with IBD is an important area of research.

Research Objectives

The overall objective of this chapter was to investigate the factors that influence the use of the internet to acquire health information for individuals with IBD. I examined two types of internet-related activities: searching the internet for health information and using the internet for health-related tasks such as scheduling appointments with health care providers and communicating with a health care provider by email. I evaluated a number of potential factors that might impact how an individual with IBD uses the internet for health information. Previous research has shown that a number of factors impact internet usage for health information in general populations including: gender (Baumann, Czerwinski, & Reifegerste, 2017; Brochu et al., 2019; Manierre, 2015; Newhouse, Lupiáñez-Villanueva, Codagnone, & Atherton, 2015), age (Baumann et al., 2017; Newhouse et al., 2015), level of education (Ryan & Lewis, 2017), health literacy (Jensen et al., 2010), health insurance coverage (Bundorf et al., 2006), and level of income (Andreassen et al., 2007; Beck et al., 2014).

METHODS

Data Source: National Health Interview Survey

The National Health Interview Survey (NHIS), which is conducted by the National Center for Health Statistics, covers broad health topics ("National Health Interview Survey Brochure," 2011). (CDC/National Center for Health Statistics, 2017)The data that are collected are weighted to represent the general population of the United States. The topics and the questions in the survey have evolved over time, and thus, the type of data collected each year varies. The 2016 NHIS ("National Health Interview Survey Brochure," 2011) included questions asking respondents to self-identify as having IBD (Crohn's disease and ulcerative colitis). For this study, several variables in the original data were recoded and combined to form categories to support the analysis and interpretation of the results of the statistical models. The original variable names in the NHIS data files are included in parentheses to facilitate an understanding of how I coded and used the data.

Dependent Variables

This chapter focused on the behaviors and experiences, during the year preceding the interview, of adult individuals who reported having IBD (ULCCOLEV). The dependent variables in this study were related to internet usage: (1) individuals searching for health information on the internet (HIT1A), (2) individuals using the internet to schedule appointments with health care providers (HIT3A), and (3) individuals using the internet to communicate with health care providers via email (HIT4A). All dependent variables were recoded as binary variables (1, they reported that they had done the activity in the previous 12 months; 0; they had not).

Independent Variables

Demographic variables such as sex (SEX) and age (AGE_P) were used in the analysis. The age variable was recoded into 3 groups: younger adults (18-35 years old), middle-age adults (36-55 years old), and older adults (older than 55). I recoded marriage status (R_MARITL) as a binary variable (1, married; 0, not married) where not married included never married, divorced, widowed, separated, as well as preferred not to answer and nonresponses. Parental status (PAR_STAT) of participants was recoded as being a parent of a child or not a parent of a child. Work status (DOINGLWA) of participants was recoded as employed or not employed.

It is possible that individuals with multiple chronic conditions may use the internet differently than those with a single chronic condition because of the complexity of managing multiple conditions. It is possible that they may receive conflicting medical advice for diverse chronic conditions (Benjamin, 2010; Wolff, Starfield, & Anderson, 2002). Therefore, 7 other chronic conditions were also included in the analysis as binary variables: hypertension (HYPEV), high cholesterol (CHLEV), coronary heart disease (CHDEV), asthma (AASMEV), cancer (CANEV), diabetes (DIVEV1) and chronic/long-term liver conditions (LIVEV).

Other variables that may impact an individual's online information searching behaviors were also included in the analysis such as socioeconomic considerations, the level of satisfaction with health care services, and internet usage frequency. Whether the respondent reported having trouble finding a care provider in the previous 12 months (APRVTRYR) was recoded as reported trouble in finding a care provider and reported no trouble in finding a care provider. The respondents who reported being worried about paying medical bills (AWORPAY) were recoded as worried and not worried, with the former category including those who were very worried and those who were somewhat worried. A new variable was created to indicate whether participants were self-regulating care in a number of possible ways. This self-regulating care included whether the respondents reported doing at least one of the following actions: skipping medication doses (ARX12_1), taking less medicine (ARX12_2), delaying filling a prescription (ARX12_3), asking a doctor for less expensive medication (ARX12_4), and using alternative therapies (ARX12_6). A binary variable was created to identify whether the participants reported having seen or talked to a general practitioner in the prior year (AHCSYR9). A variable was also created to determine whether the participants tried to purchase health insurance directly in the prior 3 years by combining the 2 relevant variables of "Tried to purchase health insurance directly" (AINDINS2) and "Purchased health insurance directly" (AINDPRCH). The satisfaction of participants in their health care (ASISATHC) was recoded as satisfied and not satisfied, with the satisfied category including those who reported being very or somewhat satisfied with their health care services. A variable was created identifying frequent internet users based on the respondent's frequency of internet usage (AWEBOFNO and AWEBOFTP). Frequent internet users were identified as such if the internet was used at least once a day (i.e., at least 7 times per week) and were classified as not frequent internet users otherwise.

Statistical Analysis

The data were analyzed using R (version 3.5.0). Specifically, the svyglm function (Survey package; version 3.34) (Lumley, 2004) was used for logistic regression, and stepwise deletion was used to remove insignificant parameters from the model in order to identify the best model for each dependent variable. As the weighted sample size was large, $\alpha=0.01$ was used to assess significance.

RESULTS

Descriptive Statistics

After applying the data weights, the sample size of individuals who reported having IBD was 3,155,477 (approximately 1.29% of all the adults in the weighted data set); approximately 64.4% (2,032,022) of the respondents were female, the average age of the respondents was 52.8 (SE 0.87) years, and approximately 49.9% of the respondents (1,575,168) reported being married. Approximately 80.7% (2,544,995/3,155,477) of the respondents reported having seen or talked to a general practitioner in the previous year, with very few (273,977/3,155,477, 8.7%) reporting having trouble finding a provider in the previous 12 months, although 14.7% (464,376/3,155,477) reported being dissatisfied with their health care. Approximately 42.6% (1,344,253/3,155,477) and 41.2% (1,288,836/3,155,477) of the respondents also reported having hypertension or high cholesterol, respectively, which were the 2 highest prevalence of comorbidities examined for individuals who had IBD. More than half of the respondents (1,965,639/3,155,477, 62.3%) reported looking up health information online, and approximately 66.3% (2,090,505/3,155,477) reported being frequent internet users, using it at least daily. In terms of the health-related tasks, 16.3% (515,253/3,155,477) of those with IBD reported scheduling an appointment with a health care provide online, and 21.6% (680,872/3,155,477) reported having used computer to communicate with a health provider by email. The complete demographic information of the respondents is in **Table 1**.

Table 1 The characteristics of the sample of survey respondents who reported having IBD.

Variable	**Weighted, n (%)**
Age	
Younger adults (18-35 years old)	454,950 (14.4)
Middle-aged adults (36-55 years old)	1,159,430 (36.7)
Older adults (>55 years old)	1,541,097 (48.8)
Sex	
Male	1,123,455 (35.6)
Female	2,032,022 (64.4)
Married	1,575,168 (49.9)
Employed	1,548,101 (49.1)
Has at least one child	670,310 (21.2)
Looked up health information online	1,965,639 (62.3)
Used computers to schedule an appointment with a health care provider	515,253 (16.3)
Used computer to communicate with a health care provider by email	680,872 (21.6)
Reported having hypertension	1,344,253 (42.6)
Reported having high cholesterol	1,298,836 (41.2)
Reported having coronary heart disease	320,715 (10.2)
Reported having asthma	636,538 (20.2)
Reported having cancer	491,356 (15.6)
Reported having diabetes	564,795 (17.9)
Reported having chronic/long-term liver conditions	127,679 (4.0)
Reported having trouble in finding a provider in the previous 12 months	273,977 (8.7)
Reported being worried about paying medical bills	1,732,203 (54.9)
Reported multiple types of self-regulating care	1,192,446 (37.9)
Reported having seen or talked to a general doctor in the previous year	2,544,995 (80.7)
Reported trying to purchase health insurance directly in the previous 3 years	426,541 (13.5)
Reported being unsatisfied with their health care	464,376 (14.7)
Used the internet frequently (at least daily usage)	2,090,505 (66.3)
Reported being worried about medical costs	1,618,723 (51.3)

Looking Up Health Information on the Internet

A binary logit model was created to evaluate how individuals with IBD use the internet for information seeking (Table 2). Among the individuals with IBD, those who also had asthma were more likely to look up health information online compared to others (adjusted odds ratio [OR] 2.97, 99% CI 1.17 to 7.54). Although several different types of chronic conditions were initially included in the model, only the variable indicating asthma was a significant predictor impacting the likelihood of those with IBD looking up health information online.

Both middle-aged and older women were less likely to look up health information online compared to others (adjusted OR 0.07, 99% CI 0.004 to 0.96 and adjusted OR 0.02, 99% CI 0.001 to 0.29, respectively). Women with IBD who reported self-regulating care were more likely to look up health information online than others (adjusted OR 9.87, 99% CI 1.49 to 65.37). Both middle-aged (36-55 years old) and older (over 55 years old) adults who were married were more likely to look up health information online (adjusted OR 22.20, 99% CI 1.46 to 336.97 and adjusted OR 23.81, 99% CI 1.75 to 327.01, respectively). Both middle-aged and older adults who were unsatisfied with their current health care were less likely to look up health information online (adjusted OR 0.03, 99% CI 0.002 to 0.58 and 0.03, 99% CI 0.001 to 0.71, respectively). Individuals who were employed and were unsatisfied with their current health care were less likely to look up health information online (adjusted OR 0.07, 99% CI 0.007 to 0.62). Additionally, frequent internet users who were worried about the medical costs of an illness/accident were more likely to look up health information online (adjusted OR 12.18, 99% CI 2.08 to 72.24).

Table 2 Binary logit model for the likelihood of looking up health information on the internet.

Parameter	**Estimate**	**99% CI**	**SE**	**t value**	***P* value**	**Adjusted OR[a]**	**99% CI**
Intercept	–2.95	(–4.91, –0.99)	0.76	–3.87	<.001	0.05	(0.007, 0.37)
Female	3.08	(0.75, 5.42)	0.91	3.40	.001	21.76	(2.12, 225.88)
Middle-aged adults	0.98	(–1.11, 3.08)	0.81	1.21	.228	—[b]	

Older adults	1.43	(–0.59, 3.44)	0.78	1.83	.068	—	
Married	–2.72	(–5.03, –0.42)	0.90	–3.04	.002	0.07	(0.007, 0.66)
Employed	0.95	(–0.06, 1.95)	0.39	2.42	.016	—	
Had asthma	1.09	(0.16, 2.02)	0.36	3.02	.003	2.97	(1.17, 7.54)
Self-regulating care	–1.30	(–2.72, 0.13)	0.55	–2.34	.019	—	
Unsatisfied with health care	4.15	(1.08, 7.22)	1.19	3.49	.001	63.52	(2.94,1366.49)
Worried about medical costs of illness/accident	–1.30	(-2.57, -0.02)	0.50	–2.62	.009	0.27	(0.08, 0.98)
Frequent internet users	2.60	(1.47, 3.73)	0.44	5.92	<.001	13.42	(4.35, 41.68)
Female × middle-aged adults	–2.72	(–5.40, –0.04)	1.04	–2.62	.009	0.07	(0.004, 0.96)
Female × older adults	–3.91	(–6.59, –1.23)	1.04	–3.76	<.001	0.02	(0.001 ,0.29)
Female × self-regulating care	2.29	(0.40, 4.18)	0.73	3.12	.002	9.87	(1.49, 65.37)
Middle-aged adults × married	3.10	(0.38, 5.82)	1.06	2.93	.004	22.20	(1.46, 336.97)
Older adults × married	3.17	(0.56, 5.79)	1.01	3.13	.002	23.81	(1.75, 327.01
Middle-aged adults × unsatisfied with health care	–3.51	(–6.47, –0.55)	1.15	–3.06	.002	0.03	(0.002, 0.58)
Older adults × unsatisfied with health care	–3.48	(–6.61, –0.34)	1.22	–2.86	.004	0.03	(0.001, 0.71)
Employed × unsatisfied with health care	–2.72	(–4.97, –0.48)	0.87	–3.12	.002	0.07	(0.007, 0.62)
Worried about medical costs of illness/accident × frequent internet users	2.50	(0.73, 4.28)	0.69	3.64	<.001	12.18	(2.08, 72.24)

[a] OR: odds ratio.

[b] No statistically significant differences were found at α=.01.

Using Computers to Schedule an Appointment with a Health Care Provider

A binary logistic regression model was created to predict the likelihood that an individual with IBD used a computer to schedule an appointment with their care provider (see Table 3). Those who reported self-regulating their care were more likely to use the internet to schedule an appointment with a provider than those who did not self-regulate (adjusted OR 2.61, 99% CI 1.05 to 6.49). Those who were frequent internet users were more likely to use the internet to schedule an appointment with a provider than nonusers or infrequent users (adjusted OR 15.18, 99% CI 3.56 to 64.72). Women who reported being married were less likely to use the internet to schedule an appointment with a provider (adjusted OR 0.07, 99% CI 0.007 to 0.75).

Table 3 Binary logit model for the likelihood of using the internet to schedule an appointment with a health care provider

Parameter	**Estimate**	**99% CI**	**SE**	**t value**	***P* value**	**Adjusted OR[a]**	**99% CI**
Intercept	–5.82	(–8.23, –3.42)	0.93	–6.24	<.001	0.003	(<0.001, 0.03)
Female	1.84	(–0.12, 3.79)	0.76	2.42	.016	—[b]	
Married	2.10	(0.09, 4.11)	0.78	2.69	.007	8.17	(1.09, 60.95)

Self-regulating care	0.96	(0.05, 1.87)	0.35	2.72	.007	2.61	(1.05, 6.49)
Frequent internet users	2.72	(1.27, 4.17)	0.56	4.82	<.001	15.18	(3.56, 64.72)
Female × married	–2.60	(–4.92, –0.29)	0.90	–2.90	.004	0.07	(0.007, 0.75)

[a]OR: odds ratio.

[b]No statistically significant differences were found at α=.01.

Using Email to Communicate with a Health Care Provider

A binary logistic regression model was created to predict the likelihood that an individual with IBD used email to communicate with their care provider (see Table 4). Those who were frequent internet users were more likely to report using email to communicate with a provider (adjusted OR 8.41, 99% CI 3.22 to 21.76). Women who reported being married were less likely to report using email to communicate with a care provider than others (adjusted OR 0.15, 99% CI 0.02 to 0.93).

Table 4 Binary logit model for the likelihood of emailing a health care provider

Parameter	**Estimate**	**99% CI**	**SE**	**t value**	***P* value**	**Adjusted OR[a]**	**99% CI**
Intercept	–4.02	(–5.60, –2.43)	0.61	-6.54	<.001	0.02	(0.003, 0.09)
Female	1.36	(–0.10, 2.83)	0.57	2.41	.017	—[b]	
Married	1.42	(–0.07, 2.91)	0.58	2.45	.014	—	
Frequent internet users	2.13	(1.17, 3.08)	0.37	5.75	<.001	8.41	(3.22, 21.76)
Female × married	–1.88	(–3.69, –0.07)	0.70	–2.67	.008	0.15	(0.02, 0.93)

Notes: [a]OR: odds ratio, [b]No statistically significant differences were found at α =.01

DISCUSSION

Principal Findings

This study examined the use of the internet by individuals with IBD to seek health information and to perform health-related activities. The population of interest was examined because these chronic conditions are often self-managed (Kennedy et al., 2004), and for those with IBD, understanding their own chronic conditions, experiences, and psychosocial factors can be a critical aspect of their treatment process (Casati, Toner, De Rooy, Drossman, & Maunder, 2000).

Therefore, information acquisition and use are vital for those with chronic conditions to be able to self-regulate their health conditions (Lorig et al., 1999).

In general, previous studies (Baumann et al., 2017; Brochu et al., 2019; Morrell, Mayhorn, & Bennett, 2000; Newhouse et al., 2015; Ryan & Lewis, 2017) suggest that the gender and age of individuals impact their internet usage for health information. In the model, women who self-regulated their care were more likely to look up health information online. Whereas, women in the middle-age and older age groups were both less likely to look up health information online. It has been suggested that younger individuals are more likely to use the internet than older individuals (Casati et al., 2000), and the same may be true for using the internet for health information seeking. Future research should continue to examine how the gender and age interaction influence searching for health information on the internet. The main effect of age was not significant in this study which is inconsistent with the findings of previous studies (Lorig et al., 1999; Ryan & Lewis, 2017). This may due to the fact that I defined age as a 3-level categorical variable (younger adults, middle-age adults, and older adults) and not as a continuous variable. Future studies could examine the impact of age as a continuous variable on the internet usage by individuals with specific chronic conditions including those with IBD.

As the literature suggests, individuals in poor health tend to use the internet more frequently than healthy individuals to look up health information (Ahadzadeh, Sharif, Ong, & Khong, 2015; Brochu et al., 2019; Houston & Allison, 2002). Previous research (Bundorf et al., 2006; Weaver III et al., 2010) has suggested that individuals with multiple chronic health conditions are more likely to use the internet to acquire information with the expectation that it will help improve their condition. The results suggest that individuals who reported having asthma in addition to IBD were more likely to use the internet for health care information searching. No other comorbidities were significant predictors in the models. Future research should more comprehensively examine comorbidity categories and types to identify if the results for IBD mirror those from previous studies (Bundorf et al., 2006; Weaver III et al., 2010).

Those who reported self-regulating their care were more likely to use the internet to schedule appointments with health care providers. Additionally, women who self-regulated their care were more likely to look up health information on the internet. This may relate to the fact that those who self-regulated care may utilize these online resources as part of their self-regulating behaviors, for example, searching for suggestions to support self-regulating their care through self-medicating (Bessell et al., 2003). There are a number of potential reasons that an individual self-regulates care, such as trying to avoid medication side effects or trying to switch to alternative medication or treatment plans (McMullan, 2006). This type of behavior is critically important for individuals with IBD as self-management is a major aspect of the treatment plans (Plevinsky, Greenley, & Fishman, 2016). Future work should further evaluate the underlying mechanisms that lead to individuals choosing to self-regulate their care and how the design of health information and internet-supported health tasks support those types of behaviors. Additionally, being dissatisfied with health care has been shown to influence the likelihood of using the internet for health information seeking (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010; Tan & Goonawardene, 2017). This study suggests those who were unsatisfied with their current health care and who were employed were less likely to look up health information online, the same was true for middle aged and older adults who were unsatisfied with their current health care. This may also relate to different information needs when trying to find a reasonable alternative treatment plan or trying to switch health providers (McMullan, 2006).

Identifying factors that might impact the use of the internet for health-related tasks and health information searching can identify demographic and specific issues that might lead to targeted interventions and an examination of how online information is designed for and presented to these populations. According to Kittler et al. (Kittler et al., 2004), in 2004, 38% of physicians exchanged emails with their patients regularly, and Hobbs et al (Hobbs et al., 2003)found that approximately 37% of patients would have agreed to pay out of pocket to be able to communicate with their physicians by email. The estimates of email communication rates with health care providers are likely much higher today than in 2004. In fact, in 2015, a study of patient email communication with health providers suggested that the email use rate ranged from 18.7% to 50.7% among in 14 European countries and that men were found to be more likely to email health providers than women (Newhouse et al., 2015). In this study, I found that 21.6% had emailed a health provider and that those who were frequent internet users were more likely to use email to communicate with their doctors, whereas married women with IBD were less likely to use email in this way. Future research should evaluate if there are other factors that impact the use of these services.

As expected, frequent internet users were shown to be more likely to use the internet to seek health information, schedule an appointment, and email health providers. In this study, I categorized frequent internet users as individuals who used the internet at least daily, yet many people currently use the internet on a more constant basis, and this variable may not capture differences between daily users and more constant users of the internet. Future research should more specifically examine the impact of internet usage frequency on how individuals with IBD use the internet for health care related activities. It would also be interesting to examine the frequency of internet use as a continuous variable and how that would impact the estimates of using the internet for health care tasks for those with IBD.

Limitations

There are several limitations of this study that should be addressed in future research. The focus of the NHIS survey was not specifically related to the use of the internet for health care–related tasks, nor was it specifically focused on individuals with IBD. Future work could specifically focus on this clinical population and on specific internet-related tasks. Additionally, with the frequent changes to health IT and in the adoption of health technology, it is possible that this survey did not capture some of the specific uses of technology for health-related purposes or possible technologies (e.g., smartphones and health-related apps). There may also be other factors that influence the use of the internet for health-related activities that were not captured by the survey, and thus, were not included in this analysis. For example, some insurance companies require that their customers refill their medications online, a situation not captured by the survey. Nor were socioeconomic variables related to internet access included. Additionally, there are other factors that may impact the use of the internet in conducting health-related tasks (e.g., mental health comorbidities, cognitive abilities, health literacy skills (Taha, Czaja, Sharit, & Morrow, 2013), complexity of the information search tasks, and credibility of target website (T. Hong, 2006) that should be evaluated in future studies. The specific underlying mechanisms for self-regulating care, the way self-regulating care can be defined and implemented, and other related behaviors should be evaluated in future research.

In addition, to facilitate this analysis, most of the survey responses were categorized into binary variables that combined some answers with non-answers and “I don’t know” responses. For example, internet use was transformed into a binary variable of frequent internet use versus infrequent internet use. These dichotomized variables may impact the findings associated with specific variables. Thus, future research could also examine the variables on a broader continuum in order to identify any additional nuances in the data. Additionally, future research should use different methods to identify why some relationships between variables were significant and also to identify the underlying causes so that future information strategies account for these differences and leverage what I know about the individuals with IBD and their internet health-related behaviors.

CONCLUSIONS

As the use of health information technology increases and evolves, it is critical to understand what specific clinical groups are using these resources, how they are doing so, and how those resources can best support health care self-management and disease prevention. This study examined using the internet for health information seeking tasks by individuals with IBD. As expected, frequent internet users were more likely to use the internet for health-related tasks. This study demonstrates there are a number of factors and complex subgroups that impact the likelihood of individuals with IBD using the internet for information seeking. Future research should further investigate how these factors and groups (e.g., women trying to self-regulate care) use the internet for health information and how the use of the internet shapes self-management of their health. Future research should also attempt to identify information design strategies and specific health-related task strategies for this population. In addition, human factors studies should be conducted to identify if and how online resources can support these populations in ways that improve access to information and health outcomes.

In this chapter, the factors that influence the use of the internet to acquire health information for individuals with IBD was examined. By analyzing the weighted data of National Health Interview Survey, some relatively national representative information was obtained. In the data, I found the majority of IBD patients used the internet for health information seeking, which again reflected the necessity of understanding their internet use behaviors. Also, we got a general sense of which user groups may use internet more. Throughout this chapter, a general understanding of the characteristics of online health information seeking behaviors of IBD patients were sensed. Before moving on to apply the results of health information seeking behaviors of IBD patients to support EHR portal design, a general understanding of how common public users of EHR portals use EHR portals is necessary. Specifically, I want to understand 1) what population (s) are using patient portals, and 2) what factors make EHR portal users think the portal is valuable in managing their health. Chapter 3 will address these questions.

CHAPTER THREE
FACTORS INFLUENCING USERS' PERCEIVED VALUE OF ELECTRONIC HEALTH RECORD PATIENT PORTALS

In Chapter 2, I examined how individuals with IBD use the internet for health information seeking. In order to design effective EHR portals to support SDM, the health information presented in the EHR portal is important, but the overall perceived value of the EHR portals is fundamental to encourage patients to use EHR portals. This chapter is going to look at what factors impact users' perceived value of EHR portals and gain a more insightful idea of their EHR portal use. This chapter was published in Proceedings of the 64th Human Factors and Ergonomics Society Annual Meeting (Yin et al., 2020).

INTRODUCTION

Electronic Health Record (EHR) portals are designed to provide patients access to their electronic medical records (Osborn, Mayberry, Mulvaney, & Hess, 2010), which is an important aspect of patient centered care (Shah & Liebovitz, 2017). EHR portals are believed to support improving healthcare outcomes and patient-provider communications (Hong, Jiang, & Liu, 2020; Lyles et al., 2013; Peacock et al., 2017). The application of EHRs are believed to reduce health care costs and medical errors as well as improve health (Hillestad et al., 2005). EHR portals enable patients to gain access to their health records electronically, thus enhancing self-monitoring and self-management of their own health conditions (Shah & Liebovitz, 2017).

Communication between healthcare providers and patients—such as via EHR portals—has been suggested as a critical component in improving healthcare quality, with better communication expected to yield better healthcare outcomes and patient satisfaction (Jenssen, Mitra, Shah, Wan, &

Grande, 2016; Lee et al., 2016; Wanzer, Booth-Butterfield, & Gruber, 2004). Current EHR portals include several relevant functions such as secure messaging with providers, appointment records, lab results, and bill payments (Elkind & Higgins, 2018). However, the use of some EHR portal features for provider-patient communication may not be easily adopted (Kruse, Kothman, Anerobi, & Abanaka, 2016). For example, although secure messaging is a demonstration of "meaningful use" via government legislation (Lee et al., 2016; Marcotte et al., 2012), patients may still prefer traditional personal email more than the secure messaging systems in EHR portals (Lee et al., 2016).

Patients' attitudes towards adopting EHR portals can also be a challenge in promoting its use, where patients can sense the convenience of EHR portals but do not want to be "pushed" to it and prefer to get help in person (Irizarry et al., 2017). According to a study using Health Information National Trends Survey, most people believe access to online personal health records is important, yet only 34% of patients were provided this access and even fewer (28%) actually accessed their EHR within the last year (Peacock et al., 2017). Although an increasing number of healthcare organizations are providing patients access to EHR portals (Kruse, Bolton, et al., 2015), recent work suggests that portal use is still relatively low (Hong et al., 2020). By identifying factors that contribute to these phenomena and understanding the current patient use of EHR portals may identify opportunities for improvement that better promote its use.

According to a study involving almost 24,000 participants in an urban hospital, 64% of respondents were not interested in using an EHR portal (Sadasivaiah, Lyles, Kiyoi, Wong, & Ratanawongsa, 2019). About 30% of those who were not interested in using portals reported a lack of regular internet access. In contrast, only a small percentage reported security concerns or perceived the EHR portal to be useless (0.03% and 0.16% respectively) (Sadasivaiah et al., 2019).

Trust in the EHR portals is another commonly examined factor to understand how patient portals are used (Lyles et al., 2013; Sieck, Hefner, & McAlearney, 2018).Typically the trust of EHR portals could be summarized into two categories including trust in the systems itself or trust in the health information provided in the EHR systems (Simons, Fleischman, Zhan, Gao, & Xi, 2017). Patients' trust in EHR portals may be impacted by information accuracy, the speed at which information is updated, and the frequency of system downtime or system maintenance (Simons et al., 2017). Patients' trust in the EHR portals may potentially impact their engagement with and routine use of their patient portals.

One potential barrier to use that has not received as much attention is patients' perceived value of the EHR patient portals. If the effort and engagement with such a system is perceived as non-value added, then it may not matter how impactful the system components (e.g., test results, communication with providers, and bill payment) are in terms of health outcomes. Therefore, the objective of this study was to investigate how current EHR portal users' opinions about current typical portals relate to the perceived value of the systems in their health care.

METHODS

Participants

As different countries have different legislation and requirements for patient portals as well as heath systems, only individuals within the US were recruited for this study. In total, 500 participants were initially recruited and participated in the survey including both EHR portals users and those that did not use the HER portals. The surveys were conducted using Mechanical Turk and each participant was compensated $1 USD for participating. This study was determined to be exempt for human subjects research by the Clemson University Institutional Review Board, as the survey was anonymous and did not collect any identifiable demographic data.

There were 46 participants that were removed from the analysis that failed the verification questions for the survey. This left 454 participants with valid survey responses.

Study design and subjects

An online survey was designed to understand how EHR portals users use their portals and their opinion of the EHR portals. The survey contains a number of questions for respondents who had used a patient portal before and for those who had not used patient portals in the past. The survey included several verification questions to ensure that participants were not using straight line or random responses. This included several questions that requested that the participant answer in a specific way, for example, one question asked: “Please select disagree for this statement”.

Procedures and Data collection

The survey was distributed via Amazon’s Mechanical Turk (MTurk) to recruit participants for an online survey created using Qualtrics, as a large number of online survey participants can be recruited relatively quickly (Barnhoorn, Haasnoot, Bocanegra, & van Steenbergen, 2015). The quality of the data obtained from Amazon’s Mechanical Turk have been shown to be reliable, and multiple studies have demonstrated that Amazon’s Mechanical Turk can be a reliable data source of experiment data (Buhrmester, Kwang, & Gosling, 2011; Huo, Hong, Grewal, & Yadav, 2019; Paolacci, Chandler, & Ipeirotis, 2010).

The survey started by introducing the researcher and explaining the purpose of the study. Thirty-four questions were included in this survey. Some of the questions were presented in a table combining multiple Likert scale questions. The questions were separated with conditional branching for responses to questions. For example, those who did not use patient portals were not asked questions about their specific patient portal.

Data analysis

The outcome measure used in this study was a binary dummy variable that indicated whether the survey responders believed that their portals were a valuable part of their health care. The participant responded to a 5-point Likert-scale variable and was recoded into binary dummy variable, where responses of ‘somewhat agree’ and ‘strongly agree’ were converted to 1 as ‘yes’ and 0 otherwise.

In my initial statistical model, I included 13 different explanatory factors. These included whether the users reported that they believed their portals were easy to use, if using portals became habitual, and if the portals were useful in helping them find information. Additionally, there were explanatory factors related to the participants reporting that the portals facilitated decision-making about their healthcare, if they trusted their portal, and if they believed the portal was important to manage health and how long it took to become familiar with the portal. Demographic factors were included in the initial model as explanatory factors including: age, gender, income, marital status, education, frequency of using the internet. The explanatory factors were also converted to binary variables during the data analysis. For example, if the participants reported “somewhat agree” or “strongly agree” to the statement “I trust the current EHR portals that I am using”, then their response would be recoded as 1 (I trust the patient portals) or 0 otherwise.

Statistical analysis

A logistic regression model was used to predict whether a current portal user found the portal to be valuable to their overall health care or not. Stepwise Akaike Information Criterion (AIC) selection method (Akaike, 1987; Burnham, Anderson, & Huyvaert, 2011) was used to select the best fit model. The data analysis was conducted in R using the GLM package and stepAIC function in the MASS package. A significant level of $\alpha=0.05$ was used.

RESULTS

Descriptive statistics

Participant demographics

Overall, 87% (395) of all of the survey participants reported that they use or had used patient portals in the past. Those (59 participants) who reported that they were not or had not used an EHR patient portal were excluded from the analysis and statistical model. Of those who reported using an EHR patient portal, 24.1% reported that they believe it was a not valuable part of their health care (see Table 5). Most (53.9%) of the responders were adults less than 35 years old, 36.2% falls in age group of 35-55 years old and 9.9% are more than 55 years old. Women accounted for 48.6% of the participants. Of all of the respondents, 63.5% reported being married. Most of the responders (90.1%) have attended some college or graduated from college and most reported using the internet at least daily (93.4%).

Table 5 Descriptive statistics

Variable	Count	Percent (%)
The portal is not valuable	95	24.10%
It is not easy to use my portal	27	6.80%
Using the portal has not become a habit	93	23.50%
EHR portal is not useful in finding information	24	6.10%

Not helping users to make decisions about their healthcare needs	46	11.60%
I do not trust the portal	29	7.30%
The EHR portal is not important in managing my health	39	9.90%
Time to become familiar with portal		
Less than a week	313	79.20%
A week to one month	60	15.20%
More than a month	22	5.60%
Age		
Less than 35 years old	213	53.90%
35-55 years old	143	36.20%
More than 55 years old	39	9.90%
Gender		
Male	203	51.40%
Female	192	48.60%
Income		
Less than $52,000	223	56.50%
Over $52,000	172	43.50%
Married	251	63.50%
Education		
High school or less	39	9.90%
Some college or graduate	356	90.10%
Internet use frequency		
Less than daily	26	6.60%
At least daily	369	93.40%
Total Sample size (n)	395	

Opinions on portal use

Only about 6.8% of respondents reported believing that their portals were not easy to use, and 23.5% of respondents reported that using portals have not become habitual. Also, 79.2% of the respondents reported becoming familiar with their portals in less than a week, with 15.2% reported spending about a week to one month and 5.6% reported needing more than a month to be familiar with their portals. When asked about the usefulness of portals in finding information that they needed, only 6.1% of the responders consider portals to be not useful. There were 11.6% of the respondents who agreed that portals do not help them to make decisions about their healthcare needs. However, less than 8% of the respondents reported not trusting their patient portal and less than 10 % reported that they agree that the EHR portal is not important in managing their health.

Predicting the perceived value of patient portals

A logistic regression model (see Table 6) was used to examine the factors that impacting whether individuals think the EHR portals are a valuable part of their health care. Those who reported that their EHR portals are easy to use were more likely to consider the EHR portals as a valuable part of their health care (OR=4.78). Those who reported that their EHR portals were useful in helping them to find the information they needed were more likely to consider the EHR portals as a valuable part of their health care (OR=19.93). Individuals who reported trusting their EHR patient portal were more likely to consider the EHR portals as a valuable part of their health care (OR=11.62). Individuals who considered the EHR portals important in managing their health were more likely to consider the EHR portals as a valuable part of their health care (OR=18.25). Those who reported using portals as a habit were more likely to consider the EHR portals as a valuable part of their health care (OR=4.30). Interestingly, individuals who use the internet at least daily, which are categorized as frequent internet users, were less likely to consider the EHR portals as a valuable part of their health care (OR=0.15).

Table 6 Logistic regression model of predicting perceived value of patient portals

	Estimate	Std. Error	z-value	p-value	Odds Ratio (95% CI)
Intercept	-2.81	0.71	-3.96	<0.001	0.06 (0.02, 0.24)
Easy to use	1.56	0.69	2.26	0.024	4.78 (1.23, 18.59)
Useful in finding information	2.99	0.74	4.05	<0.001	19.93 (4.68, 84.96)
Trust the portals being used	2.45	0.64	3.85	<0.001	11.62 (3.33, 40.53)
Important in managing my health	2.9	0.59	4.93	<0.001	18.25 (5.75, 57.86)
Using portal is a habit	1.46	0.53	2.76	0.006	4.3 (1.53, 12.09)

Frequent internet users	-1.92	0.73	-2.62	0.009	0.15 (0.03, 0.62)

DISCUSSION

The research objective of this study was to examine what factors may impact whether EHR portals users consider their EHR portal to be a valuable part of their health care.

Although previous literature has suggested multiple benefits of using EHR portals such as improving patient satisfaction, health information tracking and patient engagement (Huang, Chen, Landis, & Mahoney, 2019; Masterson Creber et al., 2018; Schnock et al., 2019; Sieck et al., 2018), the results suggest that only 24.1% of the responders think EHR portals are not a valuable part of their health care. Also, as suggested by Dumitrascu et al. (2017), the use of EHR portals may not improve hospital outcomes such as 30-day readmissions and mortality, although literature suggests that EHR portals are likely to improve general health outcomes (A. Griffin, Skinner, Thornhill, & Weinberger, 2016). It is necessary for future studies to examine the exact benefits of EHR portals and what factors moderate the potential benefits for different patients and patient populations.

The results are consistent with usability design principles of making human computer interaction systems easy to use (Gould & Lewis, 1985). Individuals who think their current portals are easy to use are more likely to consider portals as a valuable part of their health care. Although the majority of the participants claim that they became familiar with portals in less than a week, less than 7% of them believe that their portals are easy to use. This implies that the design of portals needs to be improved such that it supports ease of learning (or to be easily familiar with), but also should support ease of use. Additionally, the cause of portals users' perceived value of EHR portals may be complex but we found a strong link between ease of use and perceived value.

While less than 25% of the participants stated that using their patient portals had not become a habit, those that did report a habit of use were more likely to treat the portals as a valuable part of their health care. This may due to that the users are not required to use EHR portals for their healthcare, although many health organizations are encouraging their patients to use them according to government requirements (A. Griffin et al., 2016; Thompson, Martinko, Budd, Mercado, & Schentrup, 2016). It has been suggested in the literature that older adults tend to not want to be pushed for technique changes (Irizarry et al., 2017), which may also be true for other user groups.

As mentioned earlier, the use of EHR patient portals may still be relatively low (Hong et al., 2020). This study suggested that even for individuals who use EHR portals, only a few (7.3%) of them trust the current portals they are using. However, the results suggest that for those who do trust their current portals, they are more likely to consider their portals as a valuable part of their health care. Research has shown that frequent portal users also report better collaboration and experience more trust in their health providers (Sieck et al., 2018).

This study was conducted in the format of an online survey, so in general the responders have access to the internet. In fact, 93.5% of the responders confirm that they use the internet at least daily. Surprisingly, we noticed that these frequent internet users (which we define as using the internet at least daily) are less likely to consider the portals as a valuable part of their health care. There are several possible situations that may be related to this result. Frequent internet users are better in online information seeking (Savolainen & Kari, 2004), which may lead them to use other online information resources in managing the health care rather than merely relying on the EHR portals. Additionally, previous work has suggested that individuals who search for online health information are more likely to not be satisfied with the health information provided by their healthcare providers (Bianco, Zucco, Nobile, Pileggi, & Pavia, 2013). Individuals dissatisfied with their health providers' information may not want to use the portals provided by their health providers, which in turns may decrease their intention to use the EHR portals for health information seeking behaviors. Overall, the future work should future explore the relationships between these variables to better understand how internet users use their EHR portals and identify opportunities to improve EHR portal design to increase the perceived value of EHR portals by its users. The time that the participants reported it taking to become familiar with portals was not significant in the regression model. However, future studies may examine how long it takes the users to be fully aware of all the functions of their portals, which may be important in predicting users' perceived value of portals.

LIMITATIONS

Many different EHR portal systems exist such as MyChart (Winstanley et al., 2017) and Kaiser Permanente Northern California (KPNC) (Gordon & Hornbrook, 2016), and therefore we did not limit to only one type of system. Different systems may vary regarding to specific features such as test results summary and online bill payment. Thus, the results of this study may not assess user preferences related to specific EHR portal systems but rather across all possible systems.

In the original survey design, we only asked participants about their general internet use and did not specify the purpose of internet use. Future studies may consider internet use in a more specific way, such as specific tasks and activities that individuals perform using the internet, both in general and in health care specific tasks. For example, refilling prescriptions (McInnes et al., 2017) or cognitive–behavioral therapy (Kazdin, Fitzsimmons-Craft, & Wilfley, 2017), as a treatment method for bulimia nervosa via therapeutic chat groups (Zerwas et al., 2017), or for therapist-led support groups following breast cancer treatment (Stephen et al., 2017).

Most of the explanatory factors were converted to binary variables to perform logistic regression analysis. Some socioeconomic factors such as education was recoded as “high school or less” and “some college or graduated”. Future studies can expand these analyses to better understand the impact of socioeconomic factors, such as their mediating effect through health literacy and digital divide (Graetz, Gordon, Fung, Hamity, & Reed, 2016). The survey respondents may not fully represent the population of potential users of EHR portals and future research should ensure that an appropriate representative sample is obtained. Additional work could examine more continuous measures of the factors in predicting users’ perceived value of EHR portals. Future work should also expand on the results to consider the impact of specific features of portals on users’ perceived value which may lead to a more complete understanding of perceived value of these portals. This study does not take into considerations of other platforms such as mobile apps of current EHR portals.

CONCLUSIONS

The importance of EHR portals as a component of patients’ health care systems is widely recognized. This study suggests that to design a valuable EHR portal, special attention should focus on facilitating ease of use, information seeking, and trust. The patients’ perceived value of their EHR portal also depends on the role that the EHR portal plays in managing an individual’s health. By illustrating the factors that influence how individuals’ value and use their EHR patient portal help identify ways portals can be improved to increase patient access of their health information and being engaged in managing their own health. Designing effective EHR patient portals is critical to improve the perceived value of portals users. Future studies should examine desired features of EHR portals and how users’ perceived value of portals change based on different portal design considerations.

In this chapter, I examined what population(s) are using patient portals and what factors impact EHR portal users think the portal is valuable in managing their health. To examine the impact of design features of EHR patient portals on the usability and information communication for shared decision making, a further understanding of how to better design patient portals to support IBD patients' health information seeking needs is necessary, and the natural follow-up question will be: 1) How individuals use and trust their EHR patient portals? 2) Which features do they use and encourage their use of EHR portals? 3) What factors serve as barriers to their use? These research questions will be addressed in next chapter (Chapter 4).

CHAPTER FOUR

EXAMINING HOW INTERNET USERS TRUST AND ACCESS ELECTRONIC HEALTH RECORD PATIENT PORTALS: SURVEY STUDY

An online survey using online survey tools (e.g., Amazon Turk) was conducted. The purpose of this survey is to examine how patients use patient portals, what features of the portals facilitate their use and encourage SDM and engagement in health management and what features act as barriers to SDM and engagement in health management. Through this online survey study, I hope to identify which participants use patient portals and how often participants access their patient portals. I also assessed what kinds of features were expected (or desired) in patient portals and what features acted as barriers for the participants, what type of health information formats (audio, video, text or images) did participants prefer, and if the participants used the Internet to communicate with care providers (e.g., email, online chat, video chat). I also assessed the participants' use and trust in other online health information sources (e.g., webMD, Mayo Clinic, Wikipedia). This chapter was published in the Journal of Medical Internet Research: Human Factors (Yin et al., 2021).

INTRODUCTION

Patient portals are websites or mobile applications that are designed to help patients access their Electronic Health Record (EHR), health summary, pay bills, schedule appointments and, in some cases, interact with care providers (Lafata et al., 2018). The use of patient portals has been associated with generating positive healthcare outcomes in recent studies (Jha et al., 2009; Peacock et al., 2017). For example, individuals and families have been shown to be more actively engaged in their health management (Sieck et al., 2018) and better information communication (Miller Jr, Latulipe, Melius, Quandt, & Arcury, 2016). Using EHR portals may also contribute to increase efficiency and effectiveness of health care providers (Jha et al., 2009).

The US government has been promoting the use of patient portals through federal law such as Health Information Technology for Economic and Clinical Health (HITECH) Act of the American Reinvestment & Recovery Act (ARRA) (Sherer, Meyerhoefer, & Peng, 2016), which requires the health providers to prove their meaningful use of EHR (defined as using EHR in a meaningful manner) through a three stages process (Centers for Disease Control and Prevention, 2020) . The adoption of "meaningful use" of EHR portals is believed to have positive impact on improving the quality of healthcare (Lin, Lin, & Chen, 2019).The government promotion was suggested as one of the major reasons for providers to encourage their patients to register for EHR portals despite the positive benefits of EHR portals (Miller Jr et al., 2016). Due to these requirements, the adoption of EHRs in hospitals increased from 9% in 2008 to 80.5% in 2015 (Adler-Milstein et al., 2017). Moreover, a recently published study suggested that 64% of US hospitals have implemented EHR systems designed specifically for elderly users in at least one units of the hospital, and 41.5% US hospitals implemented the systems designed for elderly patients across all of their units (Adler-Milstein, Raphael, Bonner, Pelton, & Fulmer, 2020).

Although some research has shown a potential correlation between low health literacy and lower likelihood of using patient portals, the results are inconsistent across studies (Baldwin, Singh, Sittig, & Giardina, 2017; Coughlin, Stewart, Young, Heboyan, & De Leo, 2018; McAlearney et al., 2019). Meanwhile, vulnerable patients may also require that portals have higher usability (e.g., that are easy to use) and intensive training may be necessary (Lyles et al., 2019). Demographics such as gender, education, and income have been shown to impact the EHR usage rates (Y. A. Hong et al., 2020). Additionally, other barriers such as digital divide, concerns related to privacy and data security have also been shown to impact EHR usage rates (Irizarry et al., 2015). A recent study suggested that the use of EHR portals is still low, although it has been increasing (e.g., from 25.6% to 31.4% from 2014 to 2018 using the data of the Health Information National Trends Survey (HINTS) (Y. A. Hong et al., 2020)). Addressing the barriers associated with using portals may not only increase the use rate of patient portals but may also contribute to improving patients' trust in their providers, encouraging patient providers communications (Anthony, Campos-castillo, & Lim, 2018) and potentially improve patient health outcomes. Younger adults and individuals who have more trust of the internet have been shown to have an easier time adopting patient portals (Goldzweig et al., 2013a). Additionally, patients who highly trust their healthcare providers are more likely to use their portals (Anthony et al., 2018).

Few studies have focused on the factors that impact a patient's trust in their patient portal. Specifying the features of EHR portals for certain primary care patient groups recommended by a scoping review of multiple studies (M. Z. Huang, Gibson, & Terry, 2018). Thus, the purpose of this study is to examine how users report using their patient portals and what factors impact how much they trust their portal. In this study I aim to examine characteristics of EHR patient portal users, how they use patient portals, how EHR patient portal users access health information online, and how all of these factors impact users' trust in their patient portal. Additionally, several features and design characteristics are evaluated in terms of their impact on EHR users' willingness to continue to use EHR systems.

METHODS

Survey Design

The survey was designed using Qualtrics and was distributed by using Amazon MTurk. The survey was designed with specific questions for patient portal users and also from individuals who have not used a patient portal in the past. The participants were only able to view the questions designed for portals users or non-users depending on their experience of using a portal and only the survey participants who were portal users were included in the analysis. The survey included questions that asked what the participants thought about their portals. For example, I used 5-point Likert scale questions to ask about how the EHR portal helps the participants make decisions about their healthcare needs. I included questions that assessed why the participants used their EHR portals, as well as where participants sought health information. I also included questions about what the participants believe causes difficulty in using their patient portal (e.g., data safety and security, difficulty in understanding information on the portal). Two quality check questions were included in the survey to ensure that the participants were answering the questions carefully rather than randomly choosing an answer (e.g., I asked the participants to choose “yes” for a subitems of a question and asked participants to select ‘strong agree’ to another question).

Participants

The participants were recruited online using Amazon Mechanical Turk (MTurk) in order to recruit a large sample of participants. The participants were required to be adult residents living inside U.S. who were over 18 years-old. Five hundred participants were recruited to participate in the survey and that included both portal users and non-users. After removing participants (46 participants) who failed the quality check question in the survey and those who were not EHR patient portals users (60 participants), 394 participants were included in this analysis (one additional participant from Chapter 3 was excluded from the analysis because of missing data). This study was identified as a research activity involving human subjects that met exemption criteria under 45 CFR 46 and 21 CFR 56 by the Clemson University's Institutional Review Board, as the survey was anonymous, and no identifiable data was collected.

Procedures

After being recruited through Amazon Mechanical Turk, the participants were able to view the Qualtrics survey, which started with an explanation of the study purpose. The data was collected in January 2020. The participants were asked to identify if they were current or former users of an EHR patient portal, and then were asked to answer a series of questions about using their portal or what features would make them more likely to use a patient portal. After finishing the survey, each participant received $1 as compensation for completing the survey from Amazon Mechanical Turk. As previously mentioned, the responses were removed for participants who did not answer the quality check questions correctly. Additionally, only responders who self-identified as EHR portals users were included in the data analysis.

Data analysis

Simple statistics were used to describe the survey population along with a number of different parameters. In the data analysis, some of the subjective rating questions that used 5-point Likert scale options were converted to binary answers. For example, the Likert scale options of "agree" and "strongly agree" were combined into a single category that was compared to all other Likert scale responses. Logistic regression was used to explore what factors impact a portal user's trust on their portals. I used the Stepwise Akaike Information Criterion (AIC) selection method

(Akaike, 1998) to identify the best fit model. Ten explanatory variables were included in the final model after applying the AIC section method. I used α=0.05 as the statistically significant level. The data analysis was conducted using R version 4.0.2.

RESULTS

Descriptive statistics

Demographics

Around half of the participants (53.8%) were younger (less than 35 years-old), followed by 36.3% that were middle aged (35-55 years-old), and 9.9% that were older (over 55 years-old) (see Table 7). Female portal users account for 48.5% of the participants. Most (90.4%) of the participants reported having attended at least some college or were a college graduate. Additionally, almost all of the participants (94.4%) reported being employed, followed by 3.0% that reported being retired and 2.5% reported being unemployed. Internet usage was reported as at least daily among most of the participants (93.4%) with only 6.6% of the responders reported using internet less than every day. Most (94.4%) of the participants reported being covered by a health insurance plan. Most (72.6%) of the participants had their most recent healthcare appointment within the last 6 months.

Overall, 23.9% of the participants reported using EHR portals weekly or more frequently, while 46.7% reported having used portals monthly and 29.4% of the participants reported only using their portals yearly or less often. Participants who reported sending a message through the EHR portals to their care provider annually or more frequently accounted for 48.7% of the participants. Meanwhile, 54.3% of the participants reported receiving a message through the EHR portals from their care provider at least annually.

Table 7 Characteristics of participants who are current portal users

Factors	Count (n=394)	Percent
Age		
Younger adults (<35)	212	53.8%
Middle age adults (from 35 to 55)	143	36.3%
Older adults (>55)	39	9.9%
Gender		
Male	203	51.5%
Female	191	48.5%
Education		
High school or less	38	9.6%
Some college or graduate	356	90.4%
Income		
Less than $52,000	222	56.3%
Over $52,000	172	43.7%
Married	251	63.7%
Not married	143	36.3%
Employment status		
Employed	372	94.4%
Unemployed	12	3.0%
Retired	10	2.5%
Internet use frequency		
At least daily	368	93.4%
Less than daily	26	6.6%
Insurance status		
Insured	372	94.4%
Uninsured	22	5.6%
Last healthcare appointment		
Less than 6 months	286	72.6%
More than 6 months	108	27.4%
Portal use frequency		
Weekly or more frequently	94	23.9%
Monthly	184	46.7%
Yearly or less	116	29.4%
Message exchange		
Send message to providers annually or more frequently	192	48.7%
Received message from providers annually or more frequently	214	54.3%

Participants views of their portals

Most of the participants (300/394, 76.1%) consider their portals as a valuable part of their health care, with 93.4% (368/394) of the participants believing that their portals were easy to use. Overall, 76.6% (302/394) of the participants reported that they believed using portals had become habitual in managing their health. Additionally, most of the participants (366/394, 92.9%) reported trusting their portals, and 90.4% (356/394) of the participants reported believing that their portals were important in managing their health. Furthermore, 93.4% (368/394) of the participants thought that it was important to have a record of past health information (ego, visit history, lab results, and appointments) on their EHR portals. A total of 92.4% (364/394) of the participants reported that they were comfortable with their portals.

Portal features used by participants

I collected data about the reasons why participants reported using their portals, specifically the features in portals that they used. The participants were allowed to choose multiple answers that fit their conditions. There are primarily 10 features that were used by portals users (see Table 8). The most frequently used features of portals are 'view lab results' (58.1%), 'Make/check appointments' (54.6%) and 'View/Pay bills' (51.0%). Around half of the participants (49.5%) reported using portals to check their visit history. Meanwhile, 33.3% of the participants reported using their portals to contact their health providers, and 27.4% of the participants reported having requested prescription refill through portals. Only a few participants have used other features including educational materials (13.7%), immunization reports (10.4%), and review allergies and alerts (8.4%).

Table 8 Portal features used by participants

Factor	**Count (n=394)**	**Percent (%)**
View lab results	229	58.1%
Make/check appointments	215	54.6%
View/Pay bills	201	51.0%
Check my visit history	195	49.5%
Contact my health providers	131	33.3%
Prescription refill request	108	27.4%
Medications	83	21.1%
Educational materials	54	13.7%
Immunizations	41	10.4%
Document/review allergies and alerts	33	8.4%

Factors leading to difficulty in using portals

The survey included questions about what design features or factors lead to difficulty using patient portals. The most frequently reported factor making portals hard to use as reported by the participants were concerns about data safety and security (34.5%) (see Table 9). Some (28.2%) participants reported limited access to the internet as a factor that lead to portals being difficult to use. Irrelevant messages (22.3%) and being unable to view enough patient information (20.6%) were the other two leading factors that made portals difficult to use. As a common issue of most of the online products, spam and too many messages (14.0%) and lost password (12.9%) were also noted as resulting in difficulties. Difficulty in understanding the health information on their patient portals was reported by 11.7% of the participants, while only 3.3% of the participant reported that they did not trust the information displayed in the patient portal. Additionally, 7.6% of the participants reported preferring to use other websites (such as WebMD, Wikipedia, Google) rather than their portals.

Table 9 Factors that participants reported that made their portals are hard to use

Factors	**Count (n=394)**	**Percent (%)**
Concerns about my data safety and security	136	34.5%
Limited access to the internet	111	28.2%
Messages that are not relevant to me	88	22.3%
Unable to view enough patient information	81	20.6%
Spam and too many messages	55	14.0%
Lost password	51	12.9%
It is hard for me to understand the information in portals	46	11.7%
I prefer to use other websites instead (e.g., WebMD, Wikipedia, Google)	30	7.6%
I do not trust the information displayed	13	3.3%

Information source for health information

The participants were asked whether they have ever used other online information sources to get health information (see Table 10) and were allowed to choose multiple answers. Most participants (84.0%) reported having used WebMD for health information. Online medical articles were used by 76.4% of the participants and Wikipedia was used by 68.0%. More than half (56.1%) of the participants reported having used health blogs to get health information. About half of the participants reported using government websites and also about half used hospital websites to get health information. Meanwhile, some of the participants also reported having used social media platforms such as Facebook (32.5%), Twitter (26.9%) and Instagram (24.9%) to get health information.

Table 10 Online information sources that participants used to get health information

Factors	**Count (n=394)**	**Percent (%)**
WebMD	331	84.0%
Online medical articles	301	76.4%
Wikipedia	268	68.0%
Health blogs	221	56.1%
Government websites	200	50.8%
Hospital website	200	50.8%
Facebook	128	32.5%
Twitter	106	26.9%
Instagram	98	24.9%

Since one of the goals of this research was to examine EHR portal users' trust in portals, I was interested in examining their trust on the other online health information sources. Across several internet sources of health information, WebMD and online medical articles were reported the most frequently trusted online health information sources, with 79.2% and 77.9% of the respondents reported trust WebMD and online medical articles respectively (see Table 11). Hospital system websites and government websites were also highly trusted, with 75.6% and

68.3% trusting the sources, respectively. Although 68.3% of the participants used Wikipedia for health information, only 59.1% trusted Wikipedia. Health blogs are also trusted by more than half of the participants (54.6%). Other social media platforms like Facebook (27.4%), Twitter (25.1%) and Instagram (25.1%) were trusted by fewer participants than the other information sources.

Table 11 Online sources of health information sources that participants reported trusting

Factors	Count (n=394)	Percent (%)
WebMD	312	79.2%
Online medical articles	307	77.9%
Hospital system website	298	75.6%
Government websites	269	68.3%
Wikipedia	233	59.1%
Health blogs	215	54.6%
Facebook	108	27.4%
Twitter	99	25.1%
Instagram	99	25.1%

Information presentation method

The participants were asked to identify their preferences for the presentation of health educational materials and were allowed to choose multiple answers. Most of the participants (63.5%) believed that videos are the most effective way to present health educational materials, followed by words (49.8%), photos (32.0%) and drawings or charts (26.7%).

Accessing EHR patient portals

Participants (46.7%) use their EHR portals on a monthly basis. Around 23.1% of the participants reported using EHR portals on a yearly basis. About one fifth (19.0%) of the participants used their portals weekly. Meanwhile, daily portals use was reported by 4.8% of the participants. Only about 6.4% of the participants reported that they used their patient portal once.

In terms of how the participants accessed their portal, the majority of the participants (77.4%) used their portals through home computers (the participants were allowed to select more than one option). The other two common EHR portal access approaches were mobile devices (28.9%) and work computer (24.1%). Very few participants reported using EHR portals through public computers such as library computer (3.6%) and school computer (1.0%).

Contacting health providers with questions

I assessed how many participants used secure messaging through their portal to contact their healthcare providers. The participants reported that ‘messages through portals’ are used by most of the participants (39.6%) to contact their healthcare providers. Another widely reported method for contacting their healthcare providers was through the use of phone calls (37.1%). Meanwhile, only 12.9% and 9.9% of the participants, respectively, reported using email or scheduling an in-person visit when they have health related questions to contact their health providers.

Predicting users’ trust in the EHR patient portal

I built a logistic regression model to predict the EHR portal users’ trust in their patient portal (see Table 12). Compared to others, participants who are frequent internet users (i.e., used the internet at least daily) are significantly more likely to trust their portals (Odds Ratio (OR)=43.72, 95% CI 1.83 to 1046.43). Participants who are comfortable using their EHR portals are more likely to trust the portals that they are currently using (OR=7.97, 95% CI 1.11 to 57.32). Participant who believe their portal is important in terms of managing their health (OR=28.13, 95% CI 5.31 to 148.85) or who believe that their EHR portal is a valuable part of their health care (OR=6.75, 95% CI 1.51 to 30.11) are more likely to trust their portals. Participants who used Wikipedia (OR=12.87, 95% CI 2.23 to 74.26) or social media (such as Facebook, Twitter and Instagram, OR=4.44, 95% CI 1.14 to 17.24) for health information are also more likely to trust their EHR portals. Meanwhile, the participants’ trust in some online health information sources are positively related to their trust in their portals. Participants who trust WebMD (OR=3.98, 95% CI 1.11 to 14.32) or government websites (OR=7.73, 95% CI 1.92 to 31.19) to get health information are also more likely to trust their EHR portals. Some factors that lead users to believe that their portals are hard to use was negatively associated with participants’ trust in their portals. Participants who believe that they received irrelevant message (spams or too many messages) through their portal were less likely to trust their portals (OR=0.05, 95% CI 0.005 to 0.61). In contrast, participants who find their portals easy to use are more likely to trust their portals (OR=7.40, 95% CI 1.12 to 48.84). Although gender has been identified as a potential significant factor that impacts portal use [21,22], I did not find any evidence to suggest a significant effect for gender on the likelihood of trusting an EHR patient portal.

Table 12 Logistic regression model to predict users' trust in EHR portals

	Estimate	Standard Error	z-value	*P*-value	Odds Ratio (95% CI)
Intercept	-12.21	2.54	-4.81	<.001	
Comfortable in using my EHR portals	2.08	1.01	2.06	.04	7.97 (1.11, 57.32)
EHR portal is important in managing my health	3.34	0.85	3.92	<.001	28.13 (5.31, 148.95)
Used Wikipedia for health information	2.56	0.89	2.86	.004	12.87 (2.23, 74.26)
Trust WebMD to get health information	1.38	0.65	2.12	.03	3.98 (1.11, 14.32)
Spam made my portal hard to use	-2.94	1.25	-2.36	.018	0.05 (0.005, 0.61)
Trust government websites	2.05	0.71	2.88	.004	7.73 (1.92, 31.19)
EHR portal is a valuable part of my health care	1.91	0.76	2.50	.01	6.75 (1.51, 30.11)
Hard to understand information in my portals	-2.03	1.10	-1.84	.07	ns[a]
Irrelevant message made my portals hard to use	-1.02	0.82	-1.24	.22	ns
Frequent internet users (daily use)	3.78	1.62	2.33	.02	43.72 (1.83, 1046.43)
Used social media to get health information	1.49	0.69	2.16	.03	4.44 (1.14, 17.24)
It is easy to use my EHR portal	2.00	0.96	2.08	.04	7.40 (1.12, 48.84)
Older adults	-1.62	1.17	-1.39	.17	ns
Likelihood ratio test (-2log likelihood)					-84.64, df=14
Model *P*-value					<.001
χ^2 value					117.396, df=13
AIC					112.64

[a] ns indicates that no statistically significant differences were found at α=.05.

Features that would encourage future portal use

In addition to assessing the participants' evaluation of their current patient portal, the participants were also asked about features (or potential features) that would encourage the participants to use their portals more. The participants were able to select unlimited potential portal features that might encourage them to use the system more. Among all the features, more than one third of the participants agreed that they would use their portals more if it included real-time chats with physicians, safe and secure messaging, and prevention and follow up reminders (see Table

13). Other features including real time virtual appointments, lab results, and appointment requests were also important factors that might lead to increased portal use.

Table 13 Features that participants reported wanting in their EHR patient portals.

Factors	Count (n=394)	Percent (%)
Real time chat with physicians	154	39.1
Safe and secure messaging	151	38.3
Reminders: preventive and follow-up	135	34.3
Real time virtual appointment	126	32.0
Lab results	124	31.5
Appointment requests	121	30.7
Access or download materials (e.g., lab reports, bills or educational materials)	119	30.2
Prescription refill requests	119	30.2
Appointment reminders	103	26.1
Billing	99	25.1
Diagnostic test results	90	22.8
Insurance information	80	20.3
Patient-specific educational materials and web resources	77	19.5
Wellness/preventive care	74	18.8
Medications	66	16.8
Appointment log	65	16.5
Exercise information	65	16.5
Virtual therapy	64	16.2
Mental health resources and education	59	15.0
Mental health self-assessment	52	13.2
Immunizations	48	12.2
Problems lists	47	11.9
Calorie calculator/diet manager	44	11.2
Smart watch or Fitbit data entry	42	10.7
Public health information	40	10.2
Self-monitoring data entry	38	9.6
Allergies and alerts	32	8.1
Sexual health information	28	7.1

DISCUSSION AND CONCLUSIONS

This study sought to investigate how individuals accessed heath information and their EHR patient portal as well as identify barriers and facilitates for portal use. I used an internet-based survey that asked EHR portal users about their behaviors associated with using their EHR portals, as well as their opinions about their use of portals, and their thoughts about current and potential future features of EHR portals. Generally, the sample of portal users included more younger and middle-aged adults which is consistent with the population of EHR portal users in other survey studies (El-Toukhy, Méndez, Collins, & Pérez-Stable, 2020; Tavares & Oliveira, 2018). The participants tended to have education beyond high school, were employed, used the internet at least daily, had health insurance covered, and had a healthcare appointment in the last 6 months. The gender distribution was fairly equal in the survey participants, and I did not detect gender differences in the survey participants across the analyses. However, other studies have shown gender differences in access and use of EHR portals (El-Toukhy et al., 2020). The use of EHR patient portals among more specific gender and age groups for specific diseases should be examined to reveal the specific user needs and characteristics, such as individuals who have multiple chronic conditions who may need a closer monitoring on their EHR (Greenberg et al., 2017). Around half of the participants have had direct message communication with their healthcare providers through EHR portals at least once a year. Not everyone reported having access to fast and reliable internet and there are populations of potential EHR portals users who may not be represented in the survey sample. Thus, the survey participants reflect internet users with access to the internet and may not represent all potential users of EHR portals.

As reported above, most of the participants were frequent internet users who used internet at least daily. Among the EHR portal users, most used their EHR portals at home, while some of the responders were accessing their portals through mobile devices. Several studies have proposed the potential improvement of self-health management through mobile health apps (Marceglia, Fontelo, Rossi, & Ackerman, 2015), and the integration of mobile-apps with computer based EHR has been demonstrated (Bloomfield, Polo-Wood, Mandel, & Mandl, 2017; Day et al., 2019). Future studies should examine the factors related to internet characteristics in different locations (e.g., home, public, or work) or platforms (e.g., mobile, tablet, or computer). Designing EHR patient portals for effective displays for both computer and mobile may make the design of EHR portals more complex and introduce additional usability issues. Also, this study suggests that most EHR users used their portals about monthly. Thus, the design of EHR portals needs to support easy learning and the ability to retain the knowledge about how to engage with the system.

It is critical that users trust their EHR patient portals and the information and instructions contained in these portals, otherwise the systems are not valuable (Bhuyan, Bailey-DeLeeuw, Wyant, & Chang, 2016). Identifying the factors and groups that have high trust and those who do not trust EHR patient portals can lead to designing better systems for users and working to build the trust in the EHR portals, which can eventually improve the use of EHR portals (Lazard et al., 2016). The regression model suggests that many factors contribute to users' trust in EHR portals. Several of the significant factors were usability related, such as a user's comfort of using the portal and also the portal's ease of use. The use and trust of some other online health information source were also found significant in predicting the likelihood of trust the EHR portals, including using Wikipedia for health information, using social media for health information, trusting WebMD, and trusting government websites. This suggests that building a trustworthy EHR portals depends on the overall trust that a potential user has in other online health information resources. Improving the safety and trustworthiness of the overall internet environment for health information may lead to an improvement of trust with EHR portals indirectly. In contrast, spam, irrelevant messages, and hard to understand information within the portals were identified as factors that lead to a decrease in the likelihood of users' trust on EHR portals. Thus, there are ways to design and manage future EHR systems that support patients to develop trust within their EHR portal. For example, when it is necessary to refer to an outside educational health information (such as the definition, detection and symptoms of hypertension) in EHR portals, referring to trusted information source such as WebMD may potentially increase the users' trust on EHR portals. This is consistent with the literature that health care providers, internet and government health agencies are the top three trusted health information source (Marrie, Salter, Tyry, Fox, & Cutter, 2013). One study suggested that around one third of the patients reported having difficulties in finding health information and concerning about the information quality (Marrie et al., 2013). Thus, providing necessary health information within EHR has its potential value, and choosing the trusted health information source as references is vital in designing trustworthy EHR. Maintaining good quality of usability such as easy-to-use and easy-to-understand may contribute to the trust on EHR portals (Lazard et al., 2016).

Consistent with a previous study (Sakaguchi-Tang, Bosold, Choi, & Turner, 2017), data security concerns and limited internet access are the top two barriers that the participants reported as relating to perceiving portals to be hard to use, which was followed by irrelevant message and being unable to view enough patient information. Future EHR portals designers should pay special attention to address the security concerns, avoid irrelevant messages such as advertising messages, and provide comprehensive health information.

In the sample, very few EHR portal users were older adults and thus I do not have a comprehensive representation of older adults. It has been shown that elder adults have many potential barriers in using EHR portals such as limited health literacy, limited access to health technology and preference of in-person communications (Tieu et al., 2015; Wildenbos, Maasri, Jaspers, & Peute, 2018). Additionally, I did not detect a significant effect of age on a users' trust in their EHR portal. Since this study was conducted using an online survey, that naturally leads to the fact that most of the respondents already had access to the internet. Limited access to the Internet and limited ability to use computer-based EHR technology was reported as one of the major barriers for elder people to use EHR portals (Sakaguchi-Tang et al., 2017). Yet, modern health technology such as EHR portals may potentially benefit more for vulnerable user groups such as elder people who may have more needs to track their health record more frequently due to multiple complex health conditions (Casillas et al., 2020; Wildenbos et al., 2018). Thus, supporting the use of EHR portals among elder people who have limited access to internet remains an important problem to examine. A recent study suggests that most interventions (e.g., intervention that used one-on-one training of EHR has been suggested leading to increased EHR portals use (Lyles et al., 2020)) could improve EHR portals use among vulnerable users (Grossman et al., 2019). Future studies may look at the EHR portals use among different age groups with different internet accessibility, as well as interventions to promote the use of EHR portals.

The majority of the survey participants reported using their EHR portals relatively frequently. However, there are also about one third of the participants who used their portals rarely. Although secure messaging communication through EHR portals is believed to have positive impact on the patient-provider communication (Dendere et al., 2019), the overall message communication between portal users and health providers was reported as infrequent in the study (less than half of the participants send message through portals annually or more frequently, although slightly more of them received message through portals). The communication through portals between patients and providers did not replace traditional communication approaches such as email, phone call, or text messages. I can see both emerging methods like messages through EHR portals and traditional methods like phone calls are both commonly used when the participants have questions to ask their healthcare providers. Yet, messaging through portals was ranked highest by the participants when asking how they would like to contact their healthcare providers. Although the use of EHR portals is believed by healthcare providers to positively impact information delivery and improve patient-provider communication according to a recent study (Casillas et al., 2020), the actual use of EHR portals messaging communication is still not widely used and there are a number of opportunities to improve how the messaging can be improved.

In general, there is not a comprehensive understanding of how users feel about their patient portals and what factors are associated with their use. This study suggested that viewing lab results, checking appointments and paying bills are the most commonly used portal features by the responders. Each were used by more than half of the responders, followed by reviewing their visit history and contacting health providers. These features are common features in most current portals and are wildly used. Additionally, there are other features that participants reported either wanting to use or would lead them to using their portals more often. For example, the ability to have real time chats with care providers is an uncommon feature for most EHR portals, but it was reported as the most requested feature by the survey participants. This type of feature could help patients connect to their clinicians and not always require an office visit, which would help reduce the burden on clinics while also providing individualized care. Additionally, reducing clinical visits when not necessary is critical during periods with highly infectious disease (e.g., COVID-19, or the annual flu season). Under the special circumstances associated with the COVID-19 pandemic, minimizing unnecessary in person visits and using remote discussions are particularly valuable

(Greenhalgh, Koh, & Car, 2020; Jnr, 2020; Li et al., 2020). Based on the results of this study, these features may further encourage use of EHR systems and help patients remain connected to their healthcare providers. Another online communicating feature, safe and secure messaging, was also a highly ranked feature of EHR portals users. In fact, among the top 10 desired features in the results, 4 related to documentation (e.g., lab results and billing), 3 related to communication with healthcare providers, and 3 related to appointments and scheduling such as appointment reminder and request. Thus, there is value in continuing to develop tools for online communication between EHR portal users and their care providers.

Within the backdrop of the COVID-19 pandemic, the close monitoring of patients' health conditions in a virtual or online modality is important for public health. For example, a negative result for a COVID-19 test may be considered as evidence for employees of organizations to be enabled to go back to their workplace. Thus, frequent, safe, and easy access to their test results (e.g., lab results section) is a critical design feature for use of EHR patient portals. Special design attention should be paid to these features to satisfy the user needs and expectations, thus future research should examine how to design and implement these types of features and what features may be important for future portal users.

This study also examined the methods that the survey participants reported preferring for the presentation of educational health information. The majority of the participants reported preferring videos, which exceeded the other methods of information presentation. Written text (or using words) was ranked second and was viewed as a better way than photos or drawings and charts. Future studies should further evaluate these preferences and how best to design information in multimodal strategies. Additionally, as videos were reported as the most preferred information presenting method, future research should examine what types of health information can be presented in video format. Future research should also examine how video presentation impacts the comprehension of health information, considering how the design of video presentations may facilitate the information exchanging process and improve communicating efficiency. Videos have been shown to be effective for online education and do not require the ability to read and facilitate repeated viewing for comprehension, may support different leaning styles and lead to better learning outcomes (Furini, Galli, & Martini, 2019; Zhang, Zhou, Briggs, & Nunamaker Jr, 2006).

Conclusion

This study examined the use of EHR portals for those who were internet users. This study provides some insights into some desired features, what factors lead to users trusting their EHR patient portals, and some preliminary desires for health information presentation. Additionally, I identified some of the frequently identified barriers to using EHR patient portals. It should be noted that the survey was administered prior to the COVID-19 pandemic and thus it may not reflect current trends in the availability and use of online health information and virtual healthcare appointments. In conclusion, designing good, usable EHR portals may be the most effective approach to improve users' trust in the portals. Some principles in usability design may be highly suitable to be generalized in EHR portals design, such as designing easy-to-use products and properly communicating the purpose through visual interfaces (Eppinger & Ulrich, 2015). The features and interface design of EHR portals are critical factors that contribute to the improvement of users' trust on EHR portals. Future work should evaluate how to most effectively design these features to continue to extend the benefits of using EHR patient portals on individuals' health.

In Chapter 2, how IBD patients use the internet for health information seeking was examined. How individuals with IBD use the internet for health-related tasks is identified as well. These results could provide potential assistance in designing patient portals. For example, we learned more than half of the IBD patients had searched health information online, which implies their information seeking demand might not easily be satisfied offline or it is just easier to do it online. Thus, providing IBD related health information such as self-management information that corresponding to some symptoms may be valuable in the patient portals and satisfy their demands for obtaining health information. In Chapter 5, I examine how different information presentation and chatbots impact the use and effect of patient portals to get information about IBD.

CHAPTER FIVE
EXAMINING HOW DIFFERENT INFORMATION PRESENTATION METHODS AND CHATBOT IMPACT THE USE AND EFFECTIVENESS OF PATIENT PORTALS

INTRODUCTION

Based on a review of the literature, how information presentation methods and chatbots impact the use and effectiveness of EHR portals needs further research. Thus, examining how information presentation methods and chatbots impact the use of EHR portals is the target research objective of this chapter.

In Chapter 2, 62.3% of the IBD patients reported having looked up health information online, which suggested their potential needs for health information seeking. Meanwhile, WebMD and medical articles were reported as the most frequently trusted web-based health information source among all other internet-based health information sources such as hospital websites, government websites and Wikipedia in Chapter 4 (Yin et al., 2021). Therefore, in the EHR portal used in Chapter 5, most of the health information presented on the patient education materials page of the patient portals came from these most trusted health information sources.

Although many patient portals share similar features, the features of portals are not always the same. Thus, it is not feasible to cover all the possible features in the designed portals within this experiment. From the survey study in Chapter 4 (Yin et al., 2021), I examined the participants' reports of their use of portal features and identified the most frequently used features are: viewing lab results, viewing and paying bills, messaging with care providers, patient education materials, and visit history. Each of these frequently used features was included in the portal in this study, which is also consistent with the current popular EHR portal features in use today.

In Chapter 4, most participants believed that videos were the most effective way to present health educational materials, followed by text and others. In this study, I examined the effectiveness of these top two (i.e., video and text) selected information presentation method when presenting health information (e.g., patient education materials) specifically related to IBD, as well as the effect of using the EHR with and without a chatbot.

The research objective of this study is to evaluate how different information presentation methods and the use of chatbots impact the use and effectiveness of patient portals. Specifically, the research questions to be answered are: How do the information presentation modality and chatbots influence users':

1) information searching behavior?

2) subjective ratings of the EHR portal?

3) trust in information and patient portals?

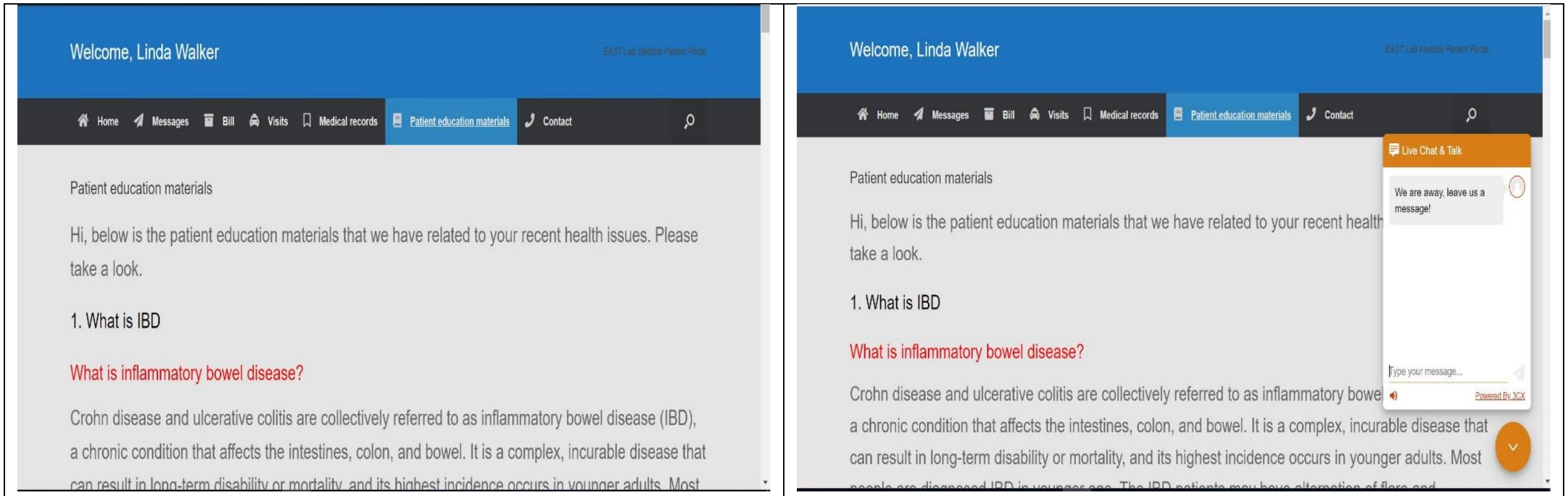
METHODS

Experiment design

This study is a 2 x 2 randomized factorial between-subjects experiment. The two levels were information presentation condition (Video and Text) and chatbot condition (with and without chatbot). The participants were randomly assigned to one of four groups: Text with a chatbot group, Text without a chatbot group, Video with a chatbot group, and Video without a chatbot group (see Figure 2). Figure 3 illustrates the sample screenshot of the portals used in this experiment. The exact same information was populated in the portals, such as test results, bills information, visit history, patient educational material about IBD and treatment methods, as well as the self-management information of IBD across all experimental conditions. The participants were asked to assume the role of helping a hypothetical friend (identified in this study as Linda Walker) to access and use her patient portal. The hypothetical friend has just been diagnosed with Inflammatory Bowel Disease (IBD), and she has some questions related to her heath condition. The participants need to be able to understand the information presented in the EHR so that they can answer questions that they were asked to answer for their friend Linda Walker. The answers to all questions were contained in the information presented in the patient portal. The participants were asked to familiarize themselves with the disease and answer questions based on the information learned from the patient portals. After interacting with the patient portals and finding all the answers to the question list from the hypothetical friend, the participants were given a questionnaire regarding to their opinions about the patient portal, and their comfortableness and confidence in helping the hypothetical friend to make medical decisions by using the patient portal. This study is approved by the Institutional Review Board of Clemson University (IRB Number: IRB2021-0600).

	No chatbot	with chatbot
Text	Group 1	Group 2
Video	Group 3	Group 4

Figure 2 A 2 x 2 factorial experiment design



Patient education materials

Hi, below is the patient education materials that we have related to your recent health issues. Please take a look.

1. What is IBD

What is inflammatory bowel disease?

Crohn disease and ulcerative colitis are collectively referred to as inflammatory bowel disease (IBD), a chronic condition that affects the intestines, colon, and bowel. It is a complex, incurable disease that can result in long-term disability or mortality, and its highest incidence occurs in younger adults. Most

Patient education materials

Hi, below is the patient education materials that we have related to your recent health take a look.

1. What is IBD

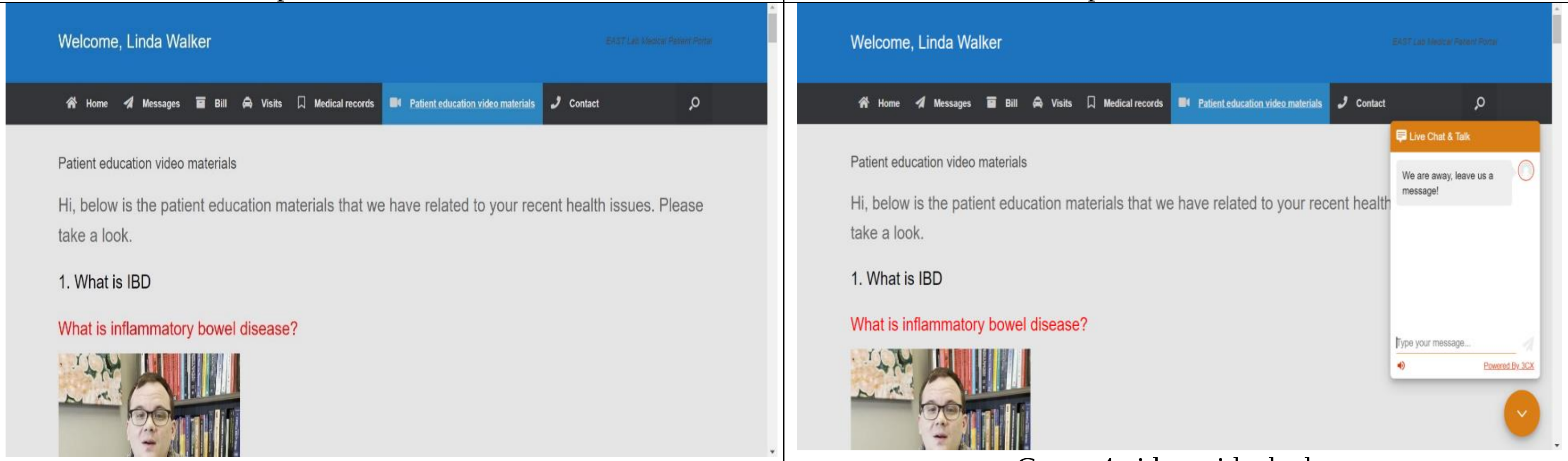
What is inflammatory bowel disease?

Crohn disease and ulcerative colitis are collectively referred to as inflammatory bowe a chronic condition that affects the intestines, colon, and bowel. It is a complex, incurable disease that can result in long-term disability or mortality, and its highest incidence occurs in younger adults. Most people are diagnosed IBD in younger age. The IBD patients may have alternation of flare and

We are away, leave us a message!

Group 1 text without chatbot

Group 2 text with chatbot



Patient education video materials

Hi, below is the patient education materials that we have related to your recent health issues. Please take a look.

1. What is IBD

What is inflammatory bowel disease?

Patient education video materials

Hi, below is the patient education materials that we have related to your recent health take a look.

1. What is IBD

What is inflammatory bowel disease?

We are away, leave us a message!

Group 3 video without chatbot

Group 4 video with chatbot

Figure 3 Sample screenshot of experiment portals

The functionality of the Chatbot used in this study

Participants who were in the conditions with a chatbot were informed that a chatbot is available on the bottom right of the screen (see Figure 3) for them to use if they have any questions during the information searching process. The chatbot used a Wizard of Oz technique where an experimenter responds to the participants' questions rather than an AI or computer agent. The Wizard of Oz technique is widely used in human-machine interaction studies (Jurewicz & Neyens, 2017; Law et al., 2017; Sirithunge, Muthugala, Jayasekara, & Chandima, 2018; Steinfeld, Jenkins, & Scassellati, 2009; Thunberg et al., 2021). In this approach, the researchers could focus on the features and usefulness of the chatbot rather than pre-investing efforts in the automatic response function of the systems (Jurewicz, Neyens, Catchpole, & Reeves, 2018). The chatbot used in this study was a live chat WordPress plugin developed by 3CX (3CX, n.d.). Prior to the study, a question bank was created related to the potential questions that could be asked by the participants during the experiment. Answers to these questions were created and were included in the question bank. When a participant typed a question in the chat window, an experimenter in another room searched in the question bank to identify the answers to the participants' questions. The experimenter copied and pasted the exact answer into the chat with the participant. The question bank included answers to the questions list mentioned in the Experimental Design, general health information related to IBD, and also instructions on how to use the patient portal. The experimenters practiced engaging with participants as the Wizard of Oz chatbot with pilot participants before the start of the study to ensure prompt response times. During the experiments, all the information searching tasks could be answered with information provided in the patient portal. The question bank additionally included some pre-defined answers for non-related questions and for situations where the questions could not be easily answered.

Equipment

This study used a Gazepoint GP3 eye-tracker to capture eye-tracking data. This low-cost eye-tracker has been shown to be appropriate for research purposes (Coyne & Sibley, 2016; Zugal & Pinggera, 2014). The EHR patient portal was displayed on a 22 inches Acer desktop monitor (see Figure 4). The participants accessed a web-based patient portal with or without a chatbot, and each group of participants is only able to see one information presentation method (text or video) for the patient educational material during their participation (with or without chatbot).

Figure 4 Experiment setup with a Gazepoint GP3 eye-tracker and an Acer monitor

Procedures

The participants were recruited using email and flyers. In total, 92 participants who were over 18 years old were recruited. Because the patient portal was designed in English, all participants were required to be able to read and speak in English. Additionally, all participants were required to have normal or corrected-to-normal visions as they need to get information from the patient portal. All the participants were randomly assigned into one of the four study conditions mentioned above. All the participants were asked to complete the informed consent process which was approved by Clemson University's Institutional Review Board before the formal start of the experiment.

After the consent process, all participants completed a demographic survey (see Appendix A) and health literacy test (Lee, Stucky, Lee, Rozier, & Bender, 2010) (see Appendix B) before starting the experiment. After a brief explanation of what the participants needed to do with the patient portal, the participants sat in front of a laptop with an eye tracker installed under the monitor in the lab room (see Figure 4). This study used Gazepoint GP3 to capture eye-tracking data. The eye tracker used in this experiment does not require any direct contact with the participants. The participants sat in a chair at a desk and interacted with the patient portal using an external Bluetooth mouse and keyboard. The electronic patient portal was displayed on a 22-inch Acer desktop monitor. The participants accessed the patient portal with different information presentation methods and with or without a chatbot for patient education materials. For study conditions that used videos for information presentation, the videos were recorded using transcripts with the same content as the text condition. Eighteen videos were recorded, and the average length of the videos was 35.2 (SD=17.3) seconds. The participants in this study were not aware of different group settings. The patient portal contained information about the participants' hypothetical friend who needed their help to figure out some information. A pre-printed question list (see Appendix C) mentioned above in the experiment design section was read to the participants to inform what questions they needed to help to answer. For example, "What are the two main types of IBD diseases?” and “What are the symptoms of IBD?”. The participants who had a chatbot in their patient portals were informed that they could use the chatbot at any point during the study but were not required to engage with the chatbot if they didn’t want to. The transcript of the conversation between the participant and chatbot was saved for each participant that was actually engaged with the chatbot for qualitative analysis. The participants were informed to use their participant ID (e.g., 12) as their name when interacting with the chatbot. Any identifiable information provided by the participant during the interaction with the chatbot was removed before the chatlog was saved.

The experiment took approximately 30 mins for each participant. A post-activity survey was conducted after the participants completed the patient portal task. The survey includes the participants' subjective ratings of the patient portals and how they like the systems in completing the information searching tasks in the task list, such as the Post-Study System Usability Questionnaire (PSSUQ) (Lewis, 1995) to learn their subjective ratings of the usability of the portals, trust survey (Corritore, Marble, Wiedenbeck, Kracher, & Chandran, 2005), decisional conflict scale (O’Connor, 1995), SDM questionnaire (Kriston et al., 2010), and willingness to participate in decision making (Levinson et al., 2005). Each participant received a $10 Amazon gift card as compensation for their time.

As this study was conducted during the COVID-19 epidemic, additional safety precautions were used to protect the participants and the experimenters. These are outlined as follows:

Masks: The participants were Clemson University students/faculty/staff who were required to provide weekly negative COVID-19 test results to access university buildings, including where the study was conducted. All the participants were required to wear a mask during the experiment process according to the university policy. Masks were provided for the participants if needed.

Social distancing: The researcher ensured all communication was conducted at a certain distance and minimized direct contact. Social distancing was feasible as the instruction of the experiment was very simple, and it was not necessity for the researcher to be in close proximity of the participant. Only one participant was allowed in the lab at any given time, and there were plexiglass barriers used to separate the participant from the experimenters. Figure 5 illustrates the lab settings of the experiment.

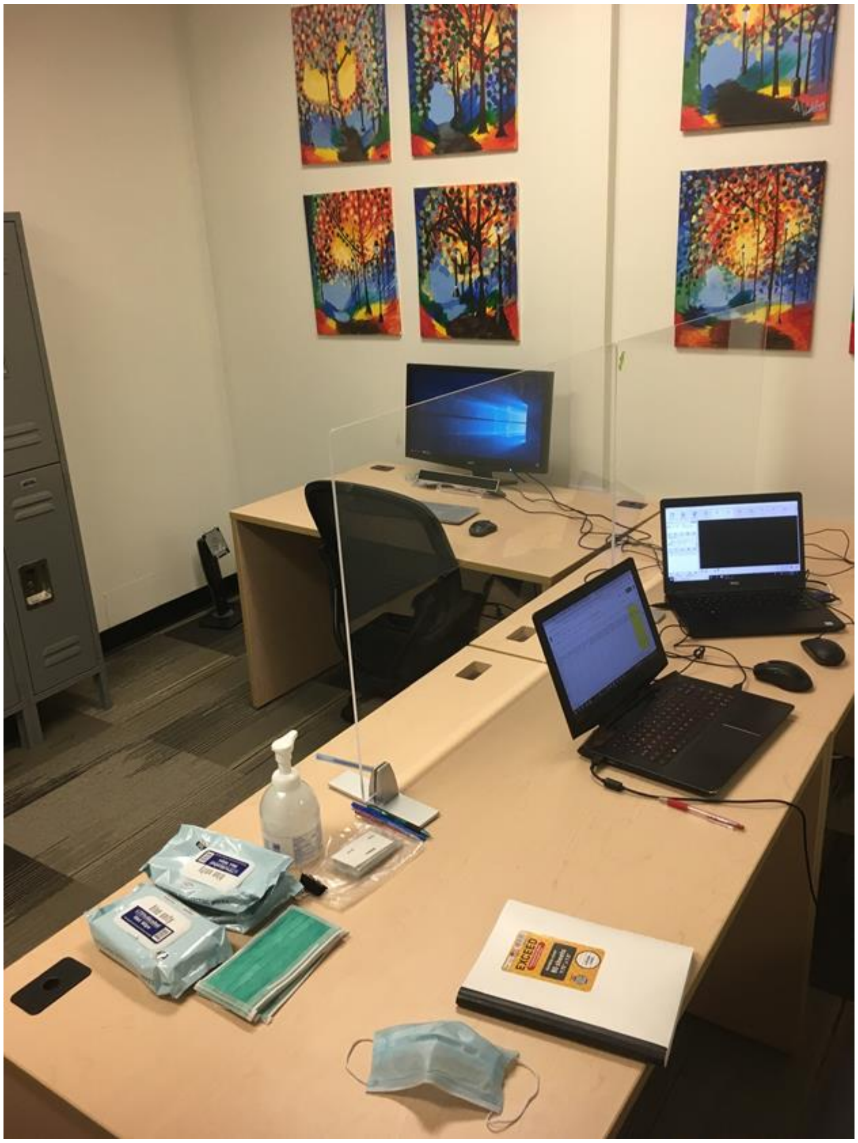


Figure 5 Experiment lab room settings

Disinfections: Hand sanitizing and disinfection wipes were provided for the participants in the experiment room. The devices (i.e., keyboard, mouse, chairs, table, health literacy cards, and pens) was disinfected using 75% alcohol disinfection wet wipes before and after each participant participated in their experiment. Additionally, restrooms were available within 30 seconds walk from the lab room for handwashing if needed.

Other: Visual reminders (poster and printed-out notice) were posted in the lab to remind the participants of social distancing, mask requirements, and frequent use of hand sanitizer or washing hands. The participants were allowed to withdraw without any penalty whenever they felt uncomfortable or wanted to quit, whether physically or mentally. The experiment itself has no additional risk for the health or safety of the participants other than using a laptop.

Measurements

Independent variables in this study are information presentation method (video or texts), and chatbot conditions (chatbot or no chatbot). A detailed list of measured variables and the corresponding measurement approach is shown in Table 14 (not including demographic variables).

Table 14 Measured variables and approaches

Variables	Measurement approach	Scale/unit of variable measurement
Health literacy (independent variable)	Short assessment of health literacy-English (SAHL-E) score (Lee et al., 2010)	Low health literacy (scores 0-14); High health literacy (scores 15-18)
Time to search for target information	Eye tracking data	Seconds
Total fixations in AOI	Eye tracking data	Numerical numbers
Average fixation durations	Eye tracking data	Milliseconds
Accuracy	Correction rate of the task list provided to the participants	Percent
Usability	Post-Study System Usability Questionnaire (PSSUQ) (Lewis, 1995)	Likert scale
Trust	Trust survey (Corritore et al., 2005)	Likert scale
Comfortableness in decision making	Decisional conflict scale (O’Connor, 1995)	Likert scale
Shared Decision-Making comfortableness	SDM questionnaire (Kriston et al., 2010)	Likert scale
Willingness to participate in shared decision-making	A questionnaire developed by Levinson et al. (2005)	Likert scale

Data analysis

Data analysis was conducted using the R software package version 4.1.4. Descriptive statistics, ANOVA, and linear regression were used to test the influence of different information presentation methods and chatbots on the use of patient portals. The variable Health literacy is a numeric variable ranging from 0-18 based on the score of SAHL-E (S. D. Lee et al., 2010), where scores from 0-14 were categorized to be low health literacy versus scores from 15-18 were categorized to be high health literacy as suggested (S. D. Lee et al., 2010). Health literacy, information presentation condition, chatbot condition and demographic variables such as age, gender, and race were used as independent variables in building models to evaluate the impact of different information presentation methods and chatbots. The post-study survey results were used to identify the effects of different information presentation formats and chatbots.

RESULTS

Descriptive statistics

In total, this study recruited 92 participants, with an equal sample size of 23 participants in each of the four experimental conditions. Table 15 describes the participants that participated in this study. The participants' average age is 22.6 (SD=5.2) years old. Women accounted for 51.1% of all the participants. Overall, most (90.2%) of the participants had relatively high health literacy, and 9.8% had low health literacy with a SAHL-E score of less than 15. About 14.1% of the participants self-identified as Hispanic or Latino. Most (68.5%) of the participants reported having used patient portals in the past, and about half (51.1%) of the participants reported using a patient portal within the last year. More than half (62%) of the participants reported using a chatbot before the experiment. About 16.3% of the participants reported knowing someone (including themselves) who had experienced the sample disease used in this study (i.e., IBD). All the information searching tasks were correctly completed, thus the information searching accuracy were 100% for all the participants.

Table 15 Descriptive statistics

Variable	Counts	Percentage
Age	Mean=22.6	SD=5.2
Gender		
Female	47	51.1%
Male	43	46.7%
Other (non-binary/third gender)	2	2.2%
Race		
American Indian or Alaska Native	1	1.1%
Asian	22	23.9%
Black or African American	4	4.4%
Multicultural	6	6.5%
White	59	64.1%
Hispanic/Latino		
Yes	13	14.1%
No	79	85.9%
Health literacy		
High	83	90.2%
Low	9	9.8%
Have used patient portal		
Yes	63	68.5%
No	29	31.5%
Use portal within 1 year		
Yes	47	51.1%
No	45	48.9%
Have used chatbot		
Yes	57	62%
No	35	38%
Trust the portal being used		
Yes	88	95.7%
No	4	4.3%
Know someone experienced IBD		
Yes	15	16.3%
No	77	83.7%
Total sample size	92	

Usability of the portal

During the experiment, most participants had no opportunity to make errors that required the portal to respond to the errors, so many participants chose “Not applicable” to that question in the PSSUQ (i.e., “The system gave error message that clearly told me how to fix problems.”). Thus, only two sub-score measures (System Usefulness and Interface Quality) of the PSSUQ were included in the data analysis. The average score of System Usefulness was 1.69 (SD=0.97), which indicates the portals are generally believed as useful by the participants. The Interface Quality of the portal was also reported as relatively high (mean=2.22; SD=1.23) across the participants. No statistically significant differences were found for usability between conditions.

Trust in the portal

Participants’ trust in the portal was assessed using the question “I trust this patient portal.” A large portion (95.7%) of the participants indicate that they trust the patient portal. The mean trust score of the patient portals was 1.85 (SD=0.82) on a Likert scale from 1 to 7, where 1 meant strongly trust and 7 meant strongly distrust. Most participants believed the portals used in this study were easy to use (mean=1.42; SD=0.67). No significant differences between study conditions were found in the participants’ trust in the patient portal at $\alpha=0.05$.

Comfortableness in decision making

As the participants were asked to assume the role of helping their hypothetical friend Linda Walker, they were asked how comfortable and how confident they were to help the hypothetical friend to make a medical decision using the information provided in the patient portals. For example, whether surgery or medication is necessary for the IBD conditions of the hypothetical friend. The Decisional Conflict Scale (DCS) (O'Connor, 1995) was used to assess the decisional conflicts of the participants in this process. The total score of DCS ranged from 0 to100, with 0 meaning no decisional conflict and 100 meaning extremely high decisional conflict. Overall, the participants reported an average DCS score of 24.76 (SD=15.41), which indicated a relatively low decisional conflict in the decision-making process. Several sub scores of the DCS were included in the data analysis as appropriate. Similarly, those sub scores ranged from 0 to 100, and smaller values generally suggested better results. The informed sub score (mean=23.1; SD=18.66) suggested participants felt informed about the decision making on average. The support sub score (mean=23.01; SD=19.23) suggested that the participants felt relatively supported in decision making by using the information provided in the patient portal in this study. Compared to the total score and other sub scores, participants were relatively less confident in the effectiveness of the best decision, where their average effective decision sub score (score ranged from 0-100, where 0 meant good decision and 100 meant bad decision) was slightly higher (mean=36.5; SD=23.27) than other scores.

Two-way ANOVAs were used to examine all of the DCS scores. Only the informed sub score was significantly impacted by different study conditions. The results of the two-way ANOVA for the informed sub score suggested there was no statistically significant interaction ($F_{1,88}$=2.814; p=0.097) between the effects of the information presentation condition and the chatbot condition. The information presentation condition had a statistically significant main effect on the informed sub score (p =0.027). The main effect of the chatbot condition was not statistically significant. According to the Tukey HSD test results, participants in the video condition had a statistically lower informed sub score (mean=18.8; SD=17.6) than participants in the text condition (mean=27.4; SD=18.9), which suggested that participants using videos reported feeling more informed of the information presented in the patient portal than those using textual information.

SDM comfortableness

The 9-item Shared Decision Making Questionnaire (SDM-Q-9) (Kriston et al., 2010) was used to measure the effectiveness of different patient portal design conditions to provide information to assist SDM, (i.e., whether the information presentation condition and chatbot condition impact the information communication to make the participants to be informed in the SDM process). The SDM-Q-9 survey was modified to fit this study as I was examining the effect of different patient portal design conditions. The average score of SDM was 80.22 (SD=15), where 0 meant the lowest possible level of SDM and 100 meant the highest level of SDM (Kriston et al., 2010). The results suggested that the patient portal used in this study was relatively effective in helping participants in the potential information acquirement process in implementing SDM. The SDM score was not statistically different between different study conditions.

Willingness to participate in SDM

Participants' willingness to participate in SDM was measured using Levinson et al.'s (2005) survey. The survey responses were 6-point Likert scale options from completely agree to completely disagree. The options of completely agree, strongly agree, and somewhat agree were transformed to be Agree, and the other three options were transformed to be Disagree. About two third (65.2%, 60/92) of the participants prefer to rely on their doctors' knowledge regarding to information about their health issues. Most (94.6%, 87/92) of the participants would like their doctor to offer their treatment options and ask their opinion about those options. Regarding to the decision making associated with their health care, slightly more than half (53.2%, 49/92) of the participants reported that they would prefer to let their doctors to make the medical decision, which indicates a low intention to participate in the decision making process regarding to their health care across all participants. All these three factors described above (knowledge, options and opinions, and decision making) were not statistically different between different study conditions.

Evaluating the use of the patient portals using eye tracking

Information searching time

A Shapiro-Wilk normality test was conducted for total information searching time, the p-value (0.11) of the Shapiro-Wilk normality test was greater than 0.05, which suggests that the data distribution is not significantly different from the normal distribution. Thus, we can assume the normality of the total information searching time data. The average information searching time of all participants is 573.41 (SD=189.47) seconds.

Participants in Text with a chatbot condition spent shortest time in the information searching tasks (mean=472.6; SD=146.8, seconds), followed by Text without a chatbot condition (mean=488; SD=174.2; seconds), Video without a chatbot condition (mean=659.5; SD=148.2), and Video with a chatbot condition (mean=673.6; SD=195.3) (see Table 16). A two-way analysis of variance (ANOVA) test was conducted for participants' total information searching time across four study conditions. The results suggest there was not a statistically significant interaction ($F_{1,88}=0.178$; $p=0.674$) between the effects of the information presentation condition and the chatbot condition. Simple main effects analysis showed that the information presentation condition had a statistically significant effect on information searching time ($p < 0.001$). Post hoc test using Tukey HSD test suggested participants in the video condition (mean=666.5; SD=171.6, seconds) spent significantly longer time in information searching task than in the text condition (mean=480.3; SD=159.5, seconds). The main effect of the chatbot condition was not statistically significant.

Table 16 Eye-tracking measurements

	Information searching time	**Total fixations**	**Average fixation duration**
Conditions	Mean (SD) (seconds)	Mean (SD) (number)	Mean (SD) (milliseconds)
Text with a chatbot	472.6 (146.8)	1139.8 (214.7)	410.6 (61.2)
Text without a chatbot	488 (174.2)	1246.0 (406.4)	389.7 (37.4)
Video with a chatbot	673.6 (195.3)	1453.6 (382.0)	463.5 (54.9)
Video without a chatbot	659.5 (148.2)	1376.7 (350.6)	484.1 (49.9)

Linear regression model to predict information searching time

A linear regression model was built (see Table 17) to understand the impact of other demographic variables on the total information searching time. The interaction term of information presentation condition and chatbot condition was not statistically significant and thus was removed from the linear regression model. Participants who have used chatbot previously (p=0.046), and participants who reported knowing someone (including themselves) that had experienced IBD (p=0.039) spent less time on the information searching task compared to those who did not. Compared to participants who were in the text condition (reference condition), participants in the video condition (p<0.001) spent longer time in the information searching task. Participants who preferred to leave medical decisions up to their doctors (i.e., were less willing to participate in SDM) spent more time on the information searching task than participants who did not (p=0.006).

Table 17 Linear regression model of total information searching time

Parameter	Estimate	SE	t value	p value
Intercept	446	59.66	7.476	<0.001
Have used portal	36.76	39.34	0.934	ns[a]
Have used chatbot	-74.85	37.02	-2.022	0.046
Know someone experienced IBD	-98.66	46.93	-2.102	0.039
Video as information presentation method	151.56	34.31	4.417	<0.001
Without chatbot in patient portal	24.91	33.38	0.746	ns
System ease to use	43.22	24.84	1.739	ns
Prefer to rely on doctors' knowledge	-60.18	37.61	-1.6	ns
Prefer to leave medical decisions up to doctors	102.32	36.51	2.802	0.006
Model statistics parameters				
R^2	0.38			
F test value	$F_{8,83}=6.47$			
Model p value	<0.001			

[a] ns: The result is not statistically significant at $\alpha=0.05$.

Total fixations

Table 16 illustrated that the total fixations number from smallest to largest belonged to text with a chatbot condition (mean =1139.8, SD=214.7), text without a chatbot condition (mean =1246, SD=406.4), video without a chatbot condition (mean =1376.7, SD=350.6), and video with a chatbot condition (mean =1453.6, SD=382). The average total fixations of all the participants were 1304 (SD=361.57). The p-value (0.30) of the Shapiro-Wilk normality test was greater than 0.05, which suggested that the data distribution of total fixations was not significantly different from the normal distribution. A two-way ANOVA test suggested there was no significant interaction effect between the information presentation condition and chatbot condition ($F_{1,88}=1.605$, p=0.209). Information presentation condition had a statistically significant effect on total fixations numbers (p =0.003). The main effect of the chatbot condition was not statistically significant.

Fixation duration

In this study, the average fixation duration was used to measure how engaged the participants were (Tullis & Albert, 2013). Longer fixation duration usually suggests more cognitive effort as well as a greater level of engagement (Doherty, O'Brien, & Carl, 2010; Tullis & Albert, 2013). The average fixation duration of all the participants was 437 (SD=63.7) milliseconds. From Table 16, we can see that participants in the text without a chatbot condition had the shortest average fixation duration (mean=389.7, SD=37.4 milliseconds) and participants in the text without a chatbot condition had the longest average fixation duration (mean=484.1, SD=49.9 milliseconds). A two-way ANOVA test suggested no significant interaction effect existed between the information presentation condition and chatbot condition ($F_{1,88}$=3.73, p=0.057). Information presentation methods had a statistically significant main effect on average fixation duration (p <0.001). The participants in text conditions (mean= 400.1, SD=51.2 milliseconds) generally had shorter fixation duration (p<0.001) than participants in the video conditions (mean= 473.8, SD=52.9 milliseconds). The main effect of the chatbot condition was not statistically significant.

Fixations in Area of Interest of Chatbot

An Area of Interest (AOI) was created to examine how participants in chatbot conditions use the chatbot. Overall, for those who used the chatbot, the average number of fixations in the chatbot AOI was 220.19 (SD= 213.55). To measure how often the participants looked at the chatbot AOI, the percent of fixations in the chatbot AOI over all the fixations on the patient portal was calculated. The result suggested that about 16% of the total fixations of the participants who used chatbot were in the chatbot AOI.

Qualitative transcript analysis

The participants were informed that there was a chatbot that they could use to help them find the requested information. Most participants did not use the chatbot unless they struggled to find an answer to the questions being asked. About 56.5% (26/46) of the participants who have a chatbot in their patient portal have used the chatbot when interacting with the patient portal. A qualitative transcript data analysis was conducted. In total, 198 transcript lines between chatbot and twenty-six participants were included. Generally, most participants interacted with the chatbot using a less formal format when asking questions. Seventeen participants asked questions without capitalizing the first word of the question, such as “can we cure IBD disease?”. Twelve participants asked questions without question marks such as “Is there a cure for IBD”. Fourteen participants asked more than one question during their information searching process. Although the participants were clearly informed that they were using their hypothetical friend’s (Linda Walker) patient portal in the study, six participants tended to use first-person voice (i.e., use “I”) when asking the chatbot questions. For example, “Do I need to take medication even if I feel well”. Some participants tried to simplify their questions when interacting with the chatbot by using incomplete questions and keywords. Seven participants asked incomplete questions to the chatbot, such as “cure for IBD?” and “the age of IBD”. Six participants used keywords to interact with the chatbot rather than a complete sentence of a question, such as “two types of IBD” and “ibd treatment options”.

DISCUSSION

This study examined how different information presentation methods and the use of chatbots impacted the use of patient portals. The participants’ demographic information such as age, gender, health literacy, and experience of using patient portals and chatbots were examined to understand their impact on participants' use of patient portals. The results suggested most of the participants were highly educated (college) younger adults who had used patient portals and chatbots in the past. White and Asian individuals accounted for the largest proportion of the participants. This study used the information about IBD as patient educational materials for the information searching task. The prevalence of IBD is estimated at over 0.3% in North America and is continually increasing (S.-Y. Park & Go, 2016), and a higher percent (16.3%) of the participants in this study reported they knew someone (including themselves) who experienced IBD. As IBD is a lifelong incurable disease with unknown causes (Fourie, Jackson, & Aveyard, 2018) and also potentially has the risk of causing some psychological problems such as post-traumatic stress disorder (PTSD) and post-traumatic stress symptoms (PTSS) (Pothemont et al., 2021), the ongoing research about IBD prevalence, treatment and related health information communication should draw more public attention.

Between the four study conditions, the differences between the patient portal were the information presentation method and the presence of a chatbot, with all the other user interfaces and content being the same. The usability of patient portals in the four study conditions was evaluated as relatively high and not statistically different from each other. Both the System Usefulness and Interface Quality were believed to be relatively high. This may contribute to the high trust in the patient portals presented in this study. Previous studies also suggest that patients' trust in their health providers may positively impact their trust in online services (Cao, Zhang, Ma, Qin, & Li, 2020; Meng, Guo, Peng, Lai, & Zhao, 2019). Thus, designing a trustworthy patient portal may possibly start from building usable patient portals and building good offline provider-patient trust.

People’s willingness to participate in the decision-making process of their health care is different (Levinson et al., 2005). Consistent with Levinson et al.’s study (2005), this study had a very similar proportion of participants who preferred to be provided treatment options by their doctors (96% vs. 94.6%) and who preferred to let their doctors make medical decisions (52% vs. 53.2%). No statistically significant evidence was found to suggest the willingness to participate in decision making differed between the four study conditions. Although SDM has multiple benefits, such as increasing patient knowledge and the potential to lead to better health outcomes (Hughes et al., 2018; Stiggelbout et al., 2012), the patients may not easily adopt to SDM from the traditional “doctor knows best” (Coulter, 1997) concept as at least around half of the participants prefer to let their doctors to be the final decision maker according to the results of this study and Levinson et al.’s study (2005).

The results suggested that participants in video condition had significantly lower DCS informed sub scores of their decision making, which meant those participants felt more informed of the IBD-related health information presented in the video format. In a previous study, videos were believed to be the most effective way to present health information compared to text and others by the study participants (Yin et al., 2021). Additionally, a study suggests that video is more effective than text in teaching clinical procedures in an e-learning environment (Buch, Treschow, Svendsen, & Worm, 2014). This study further examined the advantage of using videos to help information communication in health care. Previous studies have demonstrated that videos could improve the knowledge level as well as consumer engagement (Krämer & Böhrs, 2017). In this study, the average fixation duration of participants in video conditions was significantly higher than those in text conditions, which means the participants in the video conditions were more engaged in the information acquirement process (Tullis & Albert, 2013). One explanation may be that the participants in text conditions just read the information as soon as they find it without further thinking about it, and they may pay less cognitive attention to consuming the information. This result is consistent with studies suggesting that the use of video generates better learning outcomes than text (Buch et al., 2014; Teng, 2019). Making sure that patients are fully informed of the available medical choice (such as benefits and risks) is a critical step in SDM (Elwyn, Edwards, Kinnersley, & Grol, 2000). Thus, built-in videos in patient portals as patient educational materials may provide a convenient pathway to assist the SDM process. Meanwhile, the eye-tracking data in this study suggested that the information searching time was generally higher in the video condition than in the text condition. This result indicated that participants were less efficient in completing the information searching tasks using video than text. Thus, when using video as an information presentation method in patient portals, there are trade-offs between effectiveness (more effectively informing patients of the health information) and efficiency (the time used to search the target information of interest). Future studies should also examine the impact of information amount on the effectiveness and efficiency of using videos as a health information presentation method in patient portals, as longer videos may introduce additional difficulties in information searching (M. Liu et al., 2018). Additionally, fully captioned videos were suggested to be more effective in video-based teaching events (Teng, 2019). Thus, whether the videos need to be fully captioned to provide better learning outcomes in patient portals should also be evaluated in future studies.

The participants' total information searching time was impacted by multiple factors. The linear regression model suggested that study conditions, the experience of using chatbots, knowing someone who has IBD, and preferring to leave medical decisions up to doctors had a significant impact on total information searching time. As mentioned above, participants in video conditions were more informed of the information about IBD, although they spent longer time searching the health information. Participants who previously knew someone who had IBD spent less time finding the target information. This is consistent with a previous study that suggests that knowledge of the specific disease area improves information-seeking efficiency through better navigation strategies (Sanchiz et al., 2017). Participants who preferred to let their doctors make final decisions about their health conditions spent longer in the information searching task. The relationship of information searching efficiency and willingness to participate in the decision- making process of healthcare was positively related in this study, which is consistent with the previous study that suggests higher information seeking ability of patients is expected to lead to more willingness to be involved in medical decision making (Tan & Goonawardene, 2017). Therefore, designing a patient portal that can enhance patients' information-seeking ability may be an effective way to encourage patients' engagement in the decision-making process regarding their health care.

LIMITATIONS

This study has several limitations. As all the participants were college students or faculty, the average education level and health literacy were relatively higher than the population. The descriptive statistics also suggested most of the participants in this study were younger adults. Future studies should examine how different education levels, age, and health literacy impact the use of patient portals and chatbots. This study examined IBD as the topic of the health information presented in patient educational materials within a patient portal. As this study focused on the information searching process, rather than learning, no pre- or post- knowledge test of IBD were included. Instead, this study used the participants' subjective ratings of how informed they felt by searching for the IBD-related information in the patient portal. A pre/post-experiment knowledge test would provide an objective measure of the effectiveness of each study condition on knowledge acquisition. As this study has taken place during the COVID-19 pandemic, more people have had opportunities to use patient portals associated with COVID-19 test results and limited in-person interactions. Most of the participants had used their patient portals, and about half of the participants had used patient portals within the last year. The participants’ experience of using patient portals does not necessarily reflect on the patient portals use in the general US population in regular situations. A larger range of samples that could generate nationally representative results is recommended for more insightful conclusions for the US population.

CHAPTER SIX
CONCLUSION

The overall objective of this dissertation was to examine the impact of design features on EHR portals and the information communication for SDM. Specifically, this dissertation explored how individuals with IBD use the internet for health information seeking and health-related tasks, how the public populations use EHR portals and how they trust and value EHR portals, and how design features and chatbots impact the effectiveness of EHR portals for IBD patient education. This dissertation constructed models to understand online health information seeking for IBD patients, factors associated with user trust and perceived value of EHR portals, desired features of EHR portals, information presentation methods and AI-based chatbots impact the use and effectiveness of EHR portals. The results have shown the important impact of different design considerations on designing trustworthy, usable, and effective EHR patient portals.

BROADER IMPACTS AND INTELLECTUAL MERIT

With the development of modern healthcare technologies, computer-based and mobile-based websites and apps are more and more used in healthcare management. EHR enables patients to access their health records in a much more convenient way than previous paper-based health records. The positive impact of using EHR has been recognized by both academia and governments (Goldzweig et al., 2013a; Irizarry et al., 2015; Kruse, Bolton, et al., 2015). However, the use rate of EHR portals among patients is believed to be low (Y. A. Hong et al., 2020). Patients have various (positive or negative) opinions on the value and usefulness of EHR portals, as well as barriers and concerns in using EHR portals. For example, I found data security concerns and limited internet access are the top two barriers for EHR portal users, which alerts the EHR portal designers to recognize the importance of data security and the internet conditions of users. This dissertation suggests that designing easy-to-use and usable EHR portals are important approaches to improve patients' trust and perceived usefulness. Within the background of a pandemic like COVID-19, monitoring patients’ health conditions in a virtual way is important for public health to minimize risks for in-person visits. This dissertation provided an understanding of how EHR portal users use, trust, and value their EHR portals. The results provide insights to the design strategies of EHR portals. Similar healthcare websites and apps may take advantage of these results in their usability design. This dissertation is one step in systematically examining the use of EHR portals and evaluating design considerations for EHR portals. The different information presentation methods for patient education materials and AI-based chatbot usage are initial steps in facilitating information communications through EHR portals. This dissertation examined the usefulness of embedding additional modern techniques like chatbots in EHR portals. This dissertation examined EHR portals usage in multiple aspects, such as patients’ general opinions on EHR portals, factors leading to difficulty in using portals, patients’ desired features, and patients trusted online information sources. The results could provide a reference for similar domains of human-computer interactions.

FUTURE WORK

Future work of this dissertation includes examining the use of EHR portals with experience and on mobile apps, AI-based chatbot use in mobile EHR portals, and practical features for patients with specific health conditions. Future studies should also look at how information presentation methods and chatbots impact the use and effectiveness of EHR portals with exposure to time. For chronic health conditions such as IBD, hypertension, and diabetes, close monitoring of health conditions, proper self-management instructions, and frequent medication refills may be necessary for long-term healthcare. Additionally, with the development of mobile health techniques, the design considerations of mobile apps of EHR portals may be different, because the location and purpose of using mobile EHR portal apps may be very different from computer-based portals. Thus, understanding how EHR portals are used in the mobile version is critical to providing a comprehensive and usable EHR service to patients. As the potential customers of healthcare are the whole population, future studies should develop a national representative sampling strategy to include diverse participants. Besides patients, health providers are also another primary group of EHR portals users who need to input their patients' health information. Future work should also consider how to design EHR portals for health providers to effectively input and retrieve patient health information, especially for healthcare professionals in a complex dynamic environment like operating rooms.

LIMITATIONS

Although I looked at how general users use EHR portals in Chapters 3 and 4, individuals with specific health conditions or under a specific global environment may have different user needs for EHR portals. For example, during the COVID-19 pandemic, people may need to access their test results more frequently to provide evidence that they are tested negative for COVID-19 to be approved to enter facilities or take flights, which may make their needs of quickly and securely accessing their test results to be slightly higher than other needs in previous routine life. Thus, EHR portals use under specific conditions should be examined to provide accurate service to satisfy user needs. This dissertation used college students as participants of the experiment for Chapter 5 as convenient samples. However, college students may not reflect on the health literacy level of the general population. In designing the patient portals features, I chose the most frequently used features with reflecting on the study results in Chapter 4 (Yin et al., 2021), as different currently used EHR portals have slightly different features from each other.

APPENDIX

Appendix A Demographic survey

Participant ID number: _____________

1. How old are you?

_______________ years old

2. How do you describe your gender?

○ Male (including transgender men) (1)

○ Female (including transgender women) (2)

○ Non-binary/ third gender (3)

○ Prefer to describe myself as: ____________________________

○ Prefer not to answer (4)

3. Which of the following racial designations best describes you? (You may select more than one choice.)

○ White (1)

○ Black or African American (2)

○ Asian (3)

○ American Indian or Alaska Native (4)

○ Native Hawaiian or Other Pacific Islander (5)

○ Some other race (6)

○ Prefer not to answer (7)

4. Do you consider yourself Hispanic/Latino?

○ Hispanic/Latino (1)

○ Not Hispanic/Latino (2)

○ Prefer not to answer (3)

5. Have you ever used a doctor's office or hospital patient portals?

○ Yes (1)

○ No (2)

○ Prefer not to answer (3)

6. Have you ever used chatbots before?

○ Yes (1)

○ No (2)

○ Prefer not to answer (3)

If yes, when is the last time you used a chatbot? _____________

7. Do you know anyone (including yourself) that has experienced IBD (inflammatory bowel disease)?

○ Yes (1)

○ No (2)

○ Prefer not to answer (3)

Appendix B Short Assessment of Health Literacy – English (SAHL-E) By (Lee et al., 2010)

The 18 items of *SAHL-E*, ordered according to item difficulty (keys and distractersare listed in the same random order as in the field interview)

Stem	**Key or Distracter**		
1. kidney	__urine	__fever	__don’t know
2. occupation	__work	__education	__don’t know
3. medication	__instrument	__treatment	__don’t know
4. nutrition	__healthy	__soda	__don’t know
5. miscarriage	__loss	__marriage	__don’t know
6. infection	__plant	__virus	__don’t know
7. alcoholism	__addiction	__recreation	__don’t know
8. pregnancy	__birth	__childhood	__don’t know
9. seizure	__dizzy	__calm	__don’t know
10. dose	__sleep	__amount	__don’t know
11. hormones	__growth	__harmony	__don’t know
12. abnormal	__different	__similar	__don’t know
13. directed	__instruction	__decision	__don’t know
14. nerves	__bored	__anxiety	__don’t know
15. constipation	__blocked	__loose	__don’t know
16. diagnosis	__evaluation	__recovery	__don’t know
17. hemorrhoids	__veins	__heart	__don’t know
18. syphilis	__contraception	__condom	__don’t know

Appendix B-continued: Instruction for Administering SAHL-E (Lee et al., 2010)

SHORT ASSESSMENT OF HEALTH LITERACY-ENGLISH (*SAHL-E*)

Interviewer's Instruction

The Short Assessment of Health Literacy-English, or SAHL-E, contains 18 test items designed toassess an English-speaking adult's ability to read and understand common medical terms. The test could help health professionals estimate the adult's health literacy level. Administration of the test could be facilitated by using laminated 4"×5" flash cards, with each card containing a medical term printed in boldface on the top and the two association words—i.e., the key and the distracter—at the bottom.

Directions to the Interviewer:

Before the test, the interviewer should say to the examinee:
"I'm going to show you cards with 3 words on them. First, I'd like you to read the topword out loud. Next, I'll read the two words underneath and I'd like you to tell me which of the two words has a closer association with the top word. If you don't know,please say 'I don't know'. Don't guess."

Show the examinee the first card.

The interviewer should say to the examinee:
"Now, please, read the top word out loud."

The interviewer should have a clipboard with a score sheet to record the examinee's answers. The clipboard should be held such that the examinee cannot see or be distractedby the scoring procedure.

The interviewer will then read the key and distracter (the two words at the bottom of thecard) and then say:
"Which of the two words has a closer association with the top word? If you don't knowthe answer, please say 'I don't know'."

The interviewer may repeat the instructions so that the examinee feels comfortable withthe procedure.

Continue the test with the rest of the cards.

A correct answer for each test item is determined by both correct pronunciation and accurate association. Each correct answer gets one point. Once the test is completed, theinterviewer should tally the total points to generate the SAHL-E score.

A score between 0 and 14 suggests the examinee has low health literacy.

Appendix C Task list of the participants to help their hypothetical friend

Please answer the following questions for your hypothetical friend in the patient portal by telling the experimenter the answers

1. What are the two main types of IBD diseases?
2. What is the current health issue of Linda Walker?
3. Is there a cure?
4. What is the main aim of IBD treatment?
5. What are the symptoms of IBD?
6. How is IBD diagnosed?
7. Most people are diagnosed IBD in which age groups (younger age, middle age or older age?)?
8. How long does IBD last?
9. What can reduce IBD symptoms?
10. What kind of treatment options are there for IBD?
11. Does Linda need to keep taking medicine even when she feels well?
12. How should Linda contact her health providers? How does she make an appointment?

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