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To the Graduate Council:

I am submitting herewith a dissertation written by Kimberly Ryan Powell entitled "Using the Electronic Patient Portal to Engage Patients with Multiple Chronic Conditions." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Carole R. Myers, Major Professor

We have read this dissertation and recommend its acceptance:

Donald E. Lighter, Sadie P. Hutson, Tami H. Wyatt

Accepted for the Council:

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(Original signatures are on file with official student records.)

Using the Electronic Patient Portal to Engage Patients with Multiple Chronic Conditions

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Kimberly Ryan Powell
May 2017

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Dedication

This dissertation is dedicated to my husband Ben and our daughters Kathryn and Paige. Ben, thank you for not letting me give up on this goal and for all of the times you made it possible for me to focus on school. Kathryn and Paige, thank you for being my biggest cheerleader's throughout this journey. I am honored to be your mother.

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Abstract

Three in four Americans aged 65 and older is living with multiple chronic conditions. These patients have complex care needs and stand to benefit from tools facilitating engagement in their healthcare. Little is known regarding use of the electronic patient portal as a tool to support self-care in patients with multiple chronic conditions. The purpose of this multiple-methods study was to (1) explore characteristics and patterns of portal use by patients with multiple chronic conditions and (2) to understand the perceived usefulness of this tool to improve self-care. In phase 1, the quantitative phase, data from electronic health records and web server log files were analyzed. Patients ($n=500$) who were 45 years or older, registered portal users, and diagnosed with at least two chronic conditions were included in the analysis. No significant differences in portal use were found according to demographic characteristics, distance separating the patient from their primary care provider, and practice size and location. There was a significant difference between patients who accessed the portal to send a message to the provider and patient entered data in regards to logins ($p < .001$ and $p = .03$). In phase 2, the qualitative phase, semi-structured interviews with patients ($n=9$) and providers ($n=7$) were conducted to understand how patients learn about the portal and their perceptions of usefulness for improving self-care in patients with multiple chronic conditions. Twelve categories related to four broad themes: 1) how patients are introduced to the EPP, 2) perceived benefits of the EPP, 3) perceived barriers to using the EPP, and 4) perceptions of using EPP for self-management of chronic illness were revealed. Implications for further research, policy, and practice are presented.

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Abbreviations and Symbols

APP	Application
CMS	Centers for Medicare and Medicaid Services
EHR	Electronic Health Record
EPP	Electronic Patient Portal
HIE	Health Information Exchange
HIT	Health Information Technology
HITECH	Health Information for Economic and Clinical Health Act
MACRA	Medicare Access and CHIP Reauthorization Act
MCC	Multiple Chronic Conditions
MIPS	Merit-Based Payment System
MU	Meaningful Use

CHAPTER I: Introduction

One of the most complex challenges in healthcare is caring for patients with chronic disease. As of 2012, about half of all adults or 117 million people had at least one chronic condition and almost one in three had multiple chronic conditions.¹ Chronic diseases are responsible for seven of ten deaths each year and the number of patients with multiple chronic conditions is predicted to reach 157 million adults by the year 2020.²

The resource implications for caring for patients with multiple chronic conditions are staggering. 71% of the total healthcare spending in the United States (U.S.) is associated with care for people with multiple chronic conditions.¹ Multiple chronic conditions (MCC) is defined as two or more conditions that last a year or more and limit activities of daily living. Increased spending on chronic diseases among Medicare beneficiaries is a key factor driving the overall growth in spending in the traditional Medicare program. Among Medicare fee-for-service beneficiaries, people with MCC account for 93% of total Medicare spending.³ As a person's number of chronic conditions increases, his or her risk for dying prematurely, being hospitalized, and receiving conflicting advice from healthcare providers also increases.¹ People with MCC are faced with complex care needs including adherence to complicated medication regimens, daily self-care routines, and the need to track and coordinate health information from different health care providers.⁴ Patients with MCC experience the complex and ongoing health needs associated with living with chronic disease and typically consult more providers and require more care coordination than those with single disease. There is a critical need for tools to support the self-management activities required by patients with MCC.

Electronic Patient Portals

Electronic patient portals (EPP) give patients access to their electronic health record, creating opportunities for improved healthcare engagement. EPPs are web-based accounts

patients can use to access data from their electronic health record. These ‘tethered’ portals provide patients with convenient and reliable access to information and offer resources to improve patient-provider communication.⁵ Typical features of the EPP include secure access to visit summaries, medication lists, test results, and appointment requests. More advanced functions such as secure messaging, access to educational resources, and the ability to share information among multiple providers are becoming pervasive.

Portals have the potential to promote health by facilitating collaborative relationships between patients and providers, granting people access to and allowing them control over their personal health data, and promoting improved engagement in their healthcare.⁶ Improving patient engagement has been identified as a priority of transforming the U.S. healthcare system by organizations such as the Institute of Medicine and the National Quality Forum.^{7,8} The Center for Advancing Health defines patient engagement as “actions that individuals take to obtain the greatest benefit from the healthcare services available to them”.⁹ A growing body of evidence suggests that patient engagement can lead to better health outcomes. Patients who are actively involved in their own care and adhere to treatment regimens are more likely to have improved survival, decreased readmission rates, and experience better quality of life.¹⁰ Using the EPP has potential to improve care coordination, build trust between the patient and provider, encourage more frequent office visits, and expand access to care, especially for patients who live in remote areas.¹¹

HITECH, Meaningful Use, and MACRA

Adoption and use of the electronic patient portal (EPP) has grown dramatically in recent years as the result of national policy efforts to advance health information technology. The Health Information Technology for Economic and Clinical Health (HITECH) Act was enacted in

2010 as a part of the American Recovery and Reinvestment Act¹². The HITECH act was developed to promote the adoption and Meaningful Use (MU) of health information technology. This legislation included a financial incentive program regulated by the Centers for Medicare and Medicaid Services (CMS) which allowed hospitals and other eligible providers to collect financial incentives for early adoption and for meeting specific benchmarks or objectives.

The EHR Incentive Programs are phased in three stages with increasing requirements. Stage one includes 13 core measures and five selected measures such as computerized provider order entry, maintaining an active medication list, and providing patients with the ability to view, download, or transmit their health information online. After three consecutive years of meeting stage one criteria, providers are able to advance to stage two. The earliest a provider could meet stage two was 2014. Stage two included 17 core objectives, including the use of secure electronic messaging to communicate with patients and providing patients with specific educational resources.⁶

The proposed rule for MU stage three was entered into the federal register and made available for public comment on March 30, 2015. CMS received over 2,500 comments including serious concerns related to lack of flexibility and all-or-nothing approach to attestation. Many providers, hospitals, health systems, and organizations such as the American Medical Association and the American Hospital Association released stark criticisms of the MU program and stage two requirements.¹³ Criticisms included diverting resources from other activities with greater patient benefit and forcing technology in a way that limits innovation and lacks emphasis on outcomes. Despite these criticisms, as of September 2016, more than 509,000 health care providers have received over \$23 billion in incentive payments for participating in the CMS MU program.⁶

As the result of stakeholder feedback, CMS revised the MU timeline and made stage three requirements optional in 2017 and required by all participating providers beginning in 2018. The revised stage three requirements include flexible reporting and reduced the number of objectives to eight. On April 27, 2016, the United States Department of Health and Human Services issued a notice of proposed rulemaking to implement key provisions of the Medicare Access and CHIP reauthorization act of 2015 (MACRA).¹⁴ The proposed rule would streamline Medicare's measures of value and quality and increase clinical flexibility by allowing providers and hospitals to choose measures and activities appropriate to the type of care they provide. The proposed rule imposed under MACRA would implement broad changes through a framework called the Quality Payment Program and consists of two paths: (1) The Merit-based Incentive Payment System (MIPS) and Advanced Alternative Payment Models (APMs).

The MIPS pathway allows Medicare clinicians to be paid for providing high quality care through success in four performance categories including Advancing Care Information which replaces the MU program. The Advancing Care Information category would include required reporting on six measures: (1) protect patient health information, (2) patient electronic access, (3) coordination of care through patient engagement, (4) electronic prescribing, (5) health information exchange, and (6) public health and clinical data registry reporting.¹⁵ The first performance period under MIPS opens January 1, 2017 and closes December 31, 2017. In order to earn the 5% incentive payment for participating in MIPS, data must be reported to CMS by March 31, 2018. Providers who elect not to submit any 2017 data will receive a negative 4% payment adjustment for the 2019 payment year with increasing adjustments thereafter.

The health information technology landscape is evolving at a rapid pace with much uncertainty surrounding sustainability. The EPP is no longer a feature of convenience but rather

a necessary tool that can be used to empower and engage patients in their healthcare. While providers may be motivated in the near term by incentive payments, long-term benefits of the patient portal may include enhanced quality, efficiency, and cost-effective coordinated care. Understanding how providers encourage patient engagement in self-care through use of the EPP is the overarching goal of this study. Despite recent studies linking the EPP to improved outcomes (i.e. care coordination, building trust between patient and provider, more frequent office visits, expanding access to care), patient use of this technology remains low.¹⁶ A clear gap in knowledge exists regarding the most effective training processes that are least disruptive to the clinical workflow and result in long-term portal users.

Summary

This dissertation is divided into three chapters, or scholarly papers, and a concluding section. The first chapter provides a systematic review of the literature related to patient perceptions of the EPP and includes a discussion of gaps in the literature and policy implications. The second and third chapters report on findings of a multiple methods study divided into two phases. The second chapter describes the results of phase 1, the quantitative phase, aimed at exploring how portal use by patients with MCC varies according to practices size, location, and demographic variables. The third chapter consists of the results of phase 2, a qualitative study aimed at exploring perceptions of strategies used by different healthcare providers to encourage patient with MCC to use the EPP and their perceived effectiveness of those strategies.

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**CHAPTER II: Patient Perceived Facilitators and Barriers of Electronic Portal Use: A
Systematic Review**

This manuscript (Scholarly Paper #1) has been submitted for publication to the journal
Computers, Informatics, Nursing.

Abstract

This systematic review describes characteristics of portal users and their perceptions of this emerging technology. Recent empirical evidence (2010-2016) was reviewed to answer three questions: (1) What are characteristics of electronic patient portal (EPP) users? (2) What are patient perceived facilitators of EPP use? (3) What are patient perceived barriers to EPP use? Three categories and five themes were identified and will be discussed in this paper.

Characteristics of portal users are described according to three broad categories: (1) demographic characteristics, (2) patterns of use, and (3) complexity and duration of disease. Three themes were found related to patient perceived facilitators of use: (1) provider encouragement, (2) access/control over health information, (3) enhanced communication; two themes were found related to patient perceived barriers of use: (1) lack of awareness/training, (2) privacy and security concerns. Understanding a patient's perception of technology is paramount in optimizing utilization. These insights will allow for development of better products and clinical processes that facilitate broad goals of improved use of information technology. Policy and practice implications are discussed as well as suggestions for future research.

Keywords: patient portal; patient engagement; electronic health record; personal health record; patient perceptions

Electronic patient portals (EPP) are web-based accounts that patients can use to access data from their electronic health record. Access to basic information including visit summaries and medication lists are common; in many cases, more advanced patient-oriented functions such as secure messaging, access to educational resources, and appointment scheduling are available via the portal. The purpose of this systematic review is to synthesize findings describing EPP users and their perceptions of this emerging technology. EPP use has grown dramatically in recent years as the result of national efforts to advance health information technology. The Health Information Technology for Economic and Clinical Health (HITECH) Act and Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 have resulted in requirements for health care providers to attest to objectives that demonstrate meaningful use of this technology.¹

2

Meaningful Use

The driving force behind expanded portal adoption is the federal Electronic Health Record (EHR) incentive program. The EHR incentive program, also known as meaningful use (MU), was designed by the Centers for Medicare and Medicaid Services (CMS) to encourage adoption, implementation, and use of EHRs to improve patient care. Attestation to MU requires eligible providers to meet a set of objectives that evolve in three stages with increasing requirements. Eligible providers were first able to attest to MU stage one in 2011. After three consecutive years of meeting stage one, providers were able to advance to stage two criteria. The earliest a provider could meet stage two was 2014.³ As of September 2016, more than 509,000 health care providers have received over \$23 billion in incentive payments for participating in the MU program.⁴

In addition to incentives offered for providers who choose to attest to MU, the program also includes penalties for non-participation. Medicare eligible providers who did not demonstrate MU were subject to a 1% penalty beginning in 2015. The payment reduction increases each year an eligible provider does not demonstrate MU to a maximum of 5%. Approximately 209,000, or two in five, providers eligible for the MU program received a 2% penalty in 2016 which equates to approximately \$600 million.⁵

On March 30, 2015 the proposed rule for MU stage three was published in the Federal Register. CMS received over 2,500 comments on the proposed rule, many of which contained stark criticisms of the MU program from key stakeholders such as the American Medical Association and the American Hospital Association.⁶ Lack of flexibility and payment adjustments were the basis for much of the criticism received. As the result of this feedback, CMS revised the timeline for implementation and made stage three requirements optional in 2017 and required by 2018. Beginning in 2018 all providers will report on the same definition of MU at stage three regardless of prior participation.³

MACRA

On November 4, 2016, the Department of Health and Human Services issued a notice of final rulemaking pertaining to implementation of key provisions of the Medicare Access and CHIP Reauthorization Act (MACRA) of 2015. MACRA repeals the Medicare sustainable growth rate methodology and replaces it with a new approach to payment called the Quality Payment Program. The Quality Payment Program authorizes CMS to measure performance through a new Merit Based Incentive Payment System (MIPS). By the end of 2018 the MU program will be phased out and replaced by the Advancing Care Information section of MIPS. The MIPS program is similar to MU in that providers will be eligible for incentive payments or

will face downward payment adjustments based on their participation. However unlike MU, the new program is designed to offer greater flexibility and focus more on improved patient care. Providers will select measures that best fit their practice from objectives that emphasize patient engagement and information access via the EPP.⁵

While providers may be motivated in the near term by incentive payments, long-term benefits of the EPP may include enhanced quality, efficiency, and cost-effective coordinated care.⁷ The MU program has undoubtedly incentivized adoption of patient portals but the impact on outcomes such as patient engagement, communication, and care coordination remain unknown. As providers continue working to enhance their use of this technology, it is important to understand portal users and how they perceive the EPP.

Objective

The aim of this paper is to describe portal users and to discuss patient perceptions of the electronic patient portal. As providers continue to expand their rates of adoption and scope of portal technology, it is important to understand patient perceived facilitators and barriers in order to create a sustainable infrastructure. Three questions were formulated to guide the systematic review of scientific literature:

- (1) What are characteristics of electronic patient portal (EPP) users?
- (2) What are patient perceived facilitators of use of the EPP?
- (3) What are patient perceived barriers to use of the EPP?

Methods

Due to advances in technology as the result of the HITECH act, this review was limited to studies published between 2009 and November 2016. Pre-HITECH patient portals lack modern design and functionality making a poor comparison with post-HITECH portals. A

search was conducted in the databases CINAHL, PsycInfo, and Medline-Pubmed using different combinations of search terms related to patient portals, patient engagement, patient perceptions, and electronic health records. The search was limited to empirical studies in the English language published in peer-reviewed journals. Studies that did not include the patient's perspective as an outcome variable or studies that did not describe portal users were excluded. The initial search yielded 163 publications. After eliminating duplicates and screening of titles, abstracts, and keywords, the search was reduced to 58 publications. The stipulation that the portal used in the study be tethered, that is, connected to the patient's electronic health record and used in an outpatient setting was an additional inclusion criterion. All studies were reviewed for scientific rigor and reference lists scanned to identify additional studies relevant to this review. Seventeen studies were excluded because they did not meet the criteria after further analysis for a final total inclusion of 37 publications.

Results

Of the 37 studies included in the final review, nine employed qualitative methods, 22 were quantitative and six used mixed or multiple methods. Thirty of the studies were conducted in the United States while the remaining eight were conducted in countries such as the United Kingdom, Netherlands, and Finland.

Characteristics of portal users are described according to three broad categories: (1) demographic characteristics, (2) patterns of use, and (3) complexity and duration of disease. Three themes were found related to patient perceived facilitators of use: (1) provider encouragement, (2) access/control over health information, (3) enhanced communication; two themes were found related to patient perceived barriers of use: (1) lack of awareness/training, (2) privacy and security concerns.

Portal Users

The majority of studies included in this review (n=19) sought to describe portal users according to a variety of characteristics. Specific characteristics and outcomes measured in the study varied considerably, therefore, results were organized according to three broad categories: (1) demographic characteristics, (2) patterns of use, and (3) complexity and duration of disease.

Demographic Characteristics

Demographic variables were used to compare portal users with non-users in 16 studies. Age, gender, and race were the most commonly explored demographic variables. In all but one study that used age as a variable to predict portal use, younger patients were more likely to use a patient portal compared to older patients.⁸⁻¹⁷ Gender was another commonly explored demographic variable used to compare portal users to non-users. Multiple studies found female patients were more likely portal users compared to males.^{8, 9, 13, 15, 18} Racial differences resulted in significant differences in portal users in six studies. All six examined differences in portal use according to race and found white users to be more likely than non-whites to use the portal.^{8, 11, 15, 19-21}

In addition to age, gender, and race, other demographic characteristics were found to have noteworthy associations with portal use. Insurance type was included in two studies which both found portal users to be more likely to have private insurance.^{19, 21} Osborn and colleagues²¹ conducted a study to explore how the portal could be used to improve medication management and adherence support in adults with type 2 diabetes. They found portal users were more likely to have private insurance and higher levels of education compared to non-users. Similar findings were revealed in a study among parents of children with asthma in which portal users were more

likely to have private insurance, more severe asthma, and on more medications compared to nonusers.¹⁹

Patterns of Use

Two studies included in this review attempted to describe portal users, not only in term of demographic characteristics, but also by patterns of use. In order to describe both types and patterns of portal users, Jones, et al.²² conducted a quantitative study using a sample of patients with cardiovascular disease or diabetes (n=2282). Findings revealed the most prevalent user groups among this sample were patients who spend a short amount of time in the portal, those who had infrequent but intense use, and those who used a specific function of the portal such as electronic messaging or appointment scheduling. Overall, portal users were found to be highly heterogeneous in their patterns of use with a clear gap in understanding the link between portal use and patient outcomes.

Similarly, Schneider, Hill, & Blandford²³ identified different parent groups according to coping style and use of a patient-controlled electronic health record (PCEHR) in the United Kingdom. Semi-structured interviews with parents of children with chronic illness revealed four different PCEHR use patterns: (1) collaborating, (2) cooperating, (3) avoiding, and (4) controlling. The PCEHR met the needs of parents from the controlling group (defined as approach-oriented and highly motivated to use the PCEHR) and the collaborating group (approach-oriented and motivated to use the PCEHR) more than the needs of the cooperating group (avoidance-oriented, less motivated) and avoiding group (very avoidance oriented, not motivated). The difference in patterns of use according to coping style have important implications for designing future systems to meet patient needs. Patients do not all respond in

the same way to being given access to their health information and consideration of basic needs such as autonomy, competence, and relatedness must be taken into account.²³

While most studies define portal use by the number of logins, there are other important characteristics of use to consider. Variability in the frequency of use over time, consistency of use, and specific feature or functions used provide insight into opportunities for more robust use of this technology.

Complexity and Patterns of Disease

Variables related to complexity of disease and time since diagnosis were included in several studies. In three studies, patients who used the portal were more likely to have complex care needs requiring more frequent office visits compared to non-users.^{8, 14, 19} Higher rates of portal use were also found in patients who had been diagnosed with a chronic disease within one year.^{16, 24} Conflicting evidence was found in regard to portal use and office visit rates. While Ketterer and colleagues¹⁴ found portal users to have more office visits compared to non-users, Riipa and colleagues²⁴ found non-users of the portal to have more office visits. In addition to the number of visits, the timing of the office visit was found to impact portal use. Buist and colleagues⁹ examined use of the portal among early adopters and found patients who had had a recent well-visit were more likely to be portal users.

Patient Perceived Facilitators of Use

Understanding patient perceived facilitators of portal use is a necessary prerequisite to establishing a link between portal use and improved patient outcomes. Patient-perceived facilitators of portal use include provider encouragement, having control of/access to health information, and enhanced communication.

Provider Encouragement

Patients whose provider encouraged them to use the portal, either for a specific task or general use, perceived this as a stimulus for portal use.^{15, 25-28} Patients who received individualized instructions regarding use of the portal from their provider were more likely to use specific features such as secure messaging.^{15, 28} Phelps et al.²⁶ found provider encouragement and assistance with the first login resulted in improved use of the portal after three years. This result is especially noteworthy as most studies in this review used cross-sectional data and did not study variations of portal use across time. The importance of provider involvement and encouragement is an important facilitator of portal use thus development of clinical workflow processes that support this are needed.

Access/Control over Health Information

Perceived access to and control over personal health information was found to be a facilitator of portal use in twelve studies included in this review.^{10, 28-38} Patients value the convenience and immediate access to their health information and report feelings of empowerment and increased engagement when this information is readily available.^{31, 37} While perceived improvements in engagement are important, even more noteworthy were patient perceptions of the portal as a tool for improving confidence in self-management activities.^{31, 35, 37} These results suggest potential in using portal technology to engage patients in self-care and disease self-management.

Another important finding related to patient perceived access/control was the patient's ability to identify and correct errors. Findings from multiple studies revealed that patients recognize the importance of error correction in the electronic health record via the patient portal and value the opportunity to potentially avert a safety event.^{30, 33, 36}

Enhanced Communication

Enhanced communication between patient and provider was identified as a common patient perceived facilitator of portal use.^{20, 23, 30-32, 35, 37, 39} In one study, the potential for enhanced communication was identified as the most important feature of the portal.³¹ Using the portal to enhance communication has important implications for the patient-provider relationship. Lyles et al.²⁰ hypothesized that patients who used the portal would have enhanced communication and trust in their provider. Findings revealed a positive association between trust and being a registered portal user.

The portal offers an additional channel of communications which is perceived by patients as enhancing access to their provider. Patients reported that secure messaging, available via the portal, improved access to their provider, especially between in-office visits. Patients reported this expanded access as contributing to more efficient and higher quality face to face visits as patients could keep their provider informed of changes that occurred between visits.²⁸ These findings are significant as we continue to refine and expand portal features and improve usability. In addition, expanded access to the provider is critical especially in rural areas and in areas where providers are in short supply.

Patient Perceived Barriers of Use

The synthesis of findings from studies included in this review reveal two themes related to patient perceived barriers of portal use: (1) lack of awareness of the portal and (2) privacy and security concerns.

Lack of Awareness/Training

A lack of awareness of the portal was the most consistent perceived barrier to portal use, in fact it was the main reason patients identified for not using the portal in six studies.^{21, 25, 27, 31,}

^{34, 40} Six additional studies included reports of patients that felt they were not given sufficient training or instructions regarding use of the portal.^{19, 23, 29, 31, 35, 41}

Ronda et al.²⁷ conducted a study to identify perceived barriers of portal use among patients with diabetes. Patients with a login (n=1500) were compared with patients who had no login (non-users) (n=3000). Among patients without a login, not knowing the portal existed was the reason 72.4% of respondents indicated that they did not use the portal. Turvey et al.³⁴ surveyed patients who were registered users of the portal and compared those patients who actively used it to those who did not. Of the total sample (n=18,398), 33% were current users and 63% had never used the portal. When non-users were asked the reason they did not use the portal, 61.3% said they were not aware that it existed.

A lack of awareness of the portal was also found in two qualitative studies. Black et al.²⁵ conducted focus groups consisting of patients with asthma in a low-income urban setting in order to explore portal use. Findings revealed a lack of awareness of the portal was the main barrier to portal enrollment. Similarly, Mishuris et al.⁴⁰ conducted semi-structured interviews (n=14) with patients receiving home-based care to identify barriers of portal use. Patients stated they did not know about the functionality of the portal or how to gain access. These findings are especially noteworthy because these patients had acknowledged being mailed a flyer or seen a poster about the portal yet perceived a lack of awareness. Furthermore, when asked how they would like to learn more about the portal, most were enthusiastic about having a provider describe its functionality and how it might benefit them personally.

Privacy and Security Concerns

Privacy and security concerns were perceived to be another barrier of portal use.^{25, 28, 32, 37, 42} Zarcadoolas et al.³⁷ conducted focus groups with low-education patients (n=28) from New

York City to identify their perceptions regarding utility and value of a patient portal. Privacy concerns were raised in three of the four focus groups. Participants voiced concern regarding their health information being compromised by hackers and password security. Similar privacy concerns were noted in a qualitative study of low-income patients (n=21) with asthma where patients distrust of technology and threat of identity theft was perceived to be a barrier of use. Despite these concerns, participants seemed willing to accept the risk of security breach for the benefit of a convenient and accessible health record.²⁵

Discussion

The aim of this systematic review was to describe portal users and to discuss patient perceptions of the electronic patient portal. Understanding the patient's perception of this technology is a necessary prerequisite to future work aimed at optimal utilization. Understanding why and how patients use electronic portals will allow for development of better products that facilitate broad goals of improved use of information technology. Ultimately patient demand for portal features perceived as useful will be necessary to achieve widespread portal adoption and realization of potential benefits.

The MU incentive program is currently the primary driver of portal functionality and adoption, however, the program has been criticized for lacking emphasis on outcomes and a one size fits all approach to effective use.⁶ Stage one and two of the MU program included a number of objectives focused on increasing patient access to health information. Stage three objectives place continued emphasis on access but also include a focus on patient-centered communication for care planning and care coordination through patient engagement.³ While the changes proposed under MACRA, namely the Merit-based Incentive Payment Systems (MIPS) continue to focus on improving engagement via the portal, the proposed rule does not address long-term

sustainability of the EPP once the incentive program is expired. In order to continue to use this technology to improve access, contain cost, and improve patient-centered care, we must consider future needs of both patients and providers and develop ways to evaluate this technology.

A consistent limitation noted throughout this review was the lack of theoretical framework and inconsistent conceptual definitions. In order for health care providers to track success of the EPP and evaluate specific functions, concept development is necessary. Many studies in this review identified ‘portal use’ as the outcome variable, however, I would argue that use is multi-dimensional and should be considered beyond simply the number of logins. The conceptual model for understanding the link between portal use and changes in patient outcomes is not adequately developed and must be improved in order to identify appropriate outcome measures. Correlations between portal use, behavior change, decreased resource utilization, improved quality of care, cost containment, medication adherence, and patient satisfaction are only some of the possible outcomes that need to be considered in future research. Development of a conceptual framework that allows for the testing of robust hypotheses must be done to advance the science related to portal use and salient outcomes.

Several studies in this review found patient and provider perceptions of the portal are correlated and interdependent.^{15, 20, 25} Patients want their provider to encourage and explain to them how to use the portal as well as provide multiple opportunities for training. Despite this desire, providers are not adequately exposing and training their patients to use the portal. Lack of awareness of the portal was the most common patient perceived barrier to use.

Another important finding from this review is that patients are more likely to use the EPP when they are encouraged to do so by their provider. Simply providing patients with assistance for their first login was found to be strongly associated with being a persistent user even after

three years.²⁶ Incorporation of the EPP into provider workflow is a pivotal step toward developing sustainable and relevant use. Workflow processes must be developed so that providers do not feel the EPP is a hindrance but rather an asset to their practice.

The EPP use has potential benefits for both patient and provider. Portal use has been found to build trust between the patient and provider, encourage more frequent office visits, and expand access especially to patients who live in remote areas.^{14, 20} However, none of these benefits will be realized if providers do not train patients to use the portal and do not have the information necessary to analyze outcomes. A clear gap in knowledge exists in regard to the most effective training processes that are least disruptive to the clinical workflow and result in long-term portal users.

Conclusion

Understanding EPP users and their perceived facilitators and barriers of use is important to realize the benefit of this emerging technology. Variations in demographics, patterns of use and the complexity and duration of disease were found to differentiate portal users from non-users. In addition, this review revealed important facilitators of use such as provider encouragement, having access to and control over health information, and enhanced communication. Barriers to portal use identified by this review include concerns regarding privacy of personal health information and perhaps more significantly a lack of awareness or training to use the portal. Further research is needed in order to understand educational strategies currently being used by providers and interventional studies to determine which strategy is most effective at encouraging persistent and productive EPP use. In addition, further development of a conceptual framework is necessary in order identify appropriate outcome measures associated with persistent portal use.

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**CHAPTER III: Predictors and Patterns of Portal Use in Patients with Multiple Chronic
Conditions**

This manuscript (Scholarly Paper #2) has been submitted for publication to the Journal of the American Medical Informatics Association.

Abstract

Background Three in four Americans aged 65 and older is living with multiple chronic conditions. These patients have complex care needs and stand to benefit from tools facilitating engagement in their healthcare. Little is known regarding use of the electronic patient portal as a tool to support self-care in patients with multiple chronic conditions.

Objective To explore characteristics of portal use by patients with multiple chronic conditions and predictors and patterns in using specific features that support self-care.

Methods Two data sources were used in this quantitative analysis: electronic health records and 12 months of data from web server log files. Patients ($n=500$) included in the analysis were 45 years or older, registered portal users, and diagnosed with at least two chronic conditions.

Results No significant differences in portal use were found according to demographic characteristics, distance separating the patient from their primary care provider, and practice size and location. There was a significant difference between patients who accessed the portal to send a message to the provider and patient entered data (e.g. weight, blood glucose, blood pressure readings) pertaining to logins ($p < .001$ and $p = .03$).

Conclusion A gap remains in maximizing the potential of the portal, specifically to help patients with multiple chronic conditions manage their increasingly complex care. Further research, specifically aimed at developing a conceptual model for understanding the link between portal use and improved outcomes, is necessary to optimize portal value.

Keywords: *electronic patient portal, chronic disease, self-care, patient engagement*

It is undisputed one of the greatest challenges facing the United States (U.S.) healthcare system is the management of chronic illness. More people today than ever before are living with not just one chronic illness, such as heart disease or diabetes, but with two or more. In fact, three of four Americans, aged 65 and over, are living with multiple chronic conditions (MCC).¹ Patients with MCC have complex care needs including adherence to complicated medication regimens, daily self-care routines, and the need to track and coordinate information from different health care providers.²⁻⁵ Active participation in the management of disease by engaging in self-care activities is especially critical for people with MCC.

The electronic patient portal (EPP) is a powerful tool with potential to facilitate self-care support for patients with MCC. EPPs are web-based accounts that give patients access to their electronic medical record from any location with an internet connection. EPPs have the potential to promote health by facilitating collaborative relationships between patients and providers, granting people access to and allowing them control over their personal health data, and promoting improved engagement in their healthcare.^{6, 7}

Improving patient engagement has been identified as a priority for transforming the U.S. healthcare system by organizations such as the Institute of Medicine and the National Quality Forum.^{8,9} The role of patients in health care is changing as more emphasis is placed on patient-centered care and shared decision making. Patients are transitioning from the role of passive recipients of care to more active and informed consumers. A growing body of evidence demonstrates patient engagement can lead to improved health outcomes.¹⁰ Patients who are actively involved in their own care and adhere to treatment regimens are more likely to have improved survival, decreased readmission rates, and experience higher quality of life.^{11, 12}

Engaging patients through use of the EPP has gained much attention recently as the result of federal incentives aimed at expanding adoption and meaningful use.¹³ To this end, understanding characteristics of portal users has been the aim of many recent studies. Demographic variables such as age, gender, insurance, and race have all been studied as predictors of portal use, however, few have attempted to account for variance in amount or frequency of use.¹⁴⁻¹⁶ There is little empirical evidence exploring portal use according to differences in practice size and location despite the perception by patients that the portal expands access to their provider and can, in some cases, reduce the need for a face to face office visit.^{7, 17} Additionally, there is a gap regarding the use of specific functions of the EPP, those relevant to self-care, by patients with MCC. The purpose of this study was to explore characteristics of portal use by patients with MCC and to explore predictors and patterns of use of specific features that support self-care.

Theoretical Perspective

Self-Care is conceptually defined as a naturalistic decision-making process used by patients to promote health and manage illness.¹⁸ The middle range Theory of Self-Care of Chronic Illness includes three key concepts: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance includes behaviors used by patients with chronic illness to maintain physical and emotional health. Self-care monitoring is the process of observing for changes in signs and symptoms and self-care management is the response to those changes as they are detected.¹⁸ Self-care maintenance, monitoring, and management occur in a linear sequence, each requiring mastery before the patient moves to the next. In the case of chronic illness, self-care maintenance often includes behaviors that follow provider recommendations. Adherence to the treatment plan is the cornerstone of self-care maintenance

and often adaptation is necessary as conditions change. The theoretical concepts of self-maintenance, self-monitoring, and self-care management can be operationalized in features of the EPP. First, the EPP gives patients access to their medical record, giving them opportunities to review the treatment plan, including lab results, which is consistent with the concept of self-maintenance. Active participation by way of monitoring and tracking symptoms or entering data such as weight, blood glucose results, and blood pressure can be operationalized as self-monitoring activities. Finally, patients can take action (self-care management) by communicating with their provider using the secure messaging feature of the portal.

Research Questions

The following research questions were formulated to guide this study:

1. Does the practice size and location (IV), specific use of the portal (IV), or demographic characteristic (IV) have an effect on the number of portal logins (DV)?
2. How does portal use increase for each additional mile of distance separating the patient from his or her primary care provider?

Methods

Overview

This study was conducted at a large primary care organization located in the Southeast U.S. This primary care organization has over 300,000 active patients and has been using AllScripts FollowMyHealth[®] patient portal since 2014. The FollowMyHealth[®] portal is a secure, web-based portal that allows a patient to directly access portions of their EHR including medications, allergies, problem lists, and visit summaries all of which can be accessed by the patient via the web or mobile device. In addition, the FollowMyHealth[®] portal allows patients to enter data (e.g. weight, blood glucose readings) directly into the EHR and interact with a

provider via secure messaging. Patients can also use the portal for administrative tasks such as requests for medication refills, appointments, and referrals. Registration for the FollowMyHealth® portal is voluntary and requires patients to complete a two-step process. Patients must first create a portal account and request a connection to their EHR. Once the connection is made, patients are able to login to their portal using their username and password. Currently this primary care organization has over 75,000 registered portal users.

Study Population and Sample

The analysis cohort included patients who met the following inclusion criteria: (1) 45 years of age or older, (2) a registered user of the EPP, (3) had ICD-9/10 diagnoses of two or more of the following: diabetes, hypertension, or heart disease, and (4) was an active patient (seen within the past year) by their primary care provider. A priori power analysis was conducted using GPower® to estimate the sample size needed for this study. Using a moderate effect size and power of 0.80 for a 2-tailed, fixed effects, linear multiple regression, the sample size for this study was estimated to be 127.

Data Sources

Two sources of data were used in this study: EHR data and patient portal server log files. Data obtained from the EHR included age, gender, race, type of insurance, zip code, primary care provider, and diagnosis (based on inclusion criteria). Log files were used to collect portal specific data. All patient-level usage (including accessing a specific function of the portal by clicking on a link) are automatically recorded and time stamped in the log files maintained by the web-server. Log files from July 1, 2015-July 1, 2016 were used in this study. For each patient included in the analysis, log files were used to obtain the login count, instances of patient entered data, and patient use of secure messaging feature.

Statistical Analysis

To analyze differences in portal use according to practice type and location, practices were classified as small (≤ 2 providers), medium (3-5 providers), and large (>5 providers) and as either urban or rural according to the U.S. Census Bureau urban-rural classifications.¹⁹ An application program interface (API) built using Google Mapping software was used to calculate distance in miles between the patient's zip code and the primary care practice they attended. The patient's age, distance from the practice, number of logins, and number of chronic conditions were treated as continuous variables. Use of secure messaging, patient entered data, race, insurance, and diagnosis were treated as categorical variables. Due to violating the assumption of normality for the primary outcome variable, number of logins, non-parametric Kruskal-Wallis tests were used to analyze differences between practice size and location. When significant main effects were found, non-parametric Mann-Whitney U tests were used in a post hoc fashion to make pairwise comparisons. All statistical analyses were completed using SPSS version 22 (Armonk, NY: IBM Corp.) and statistical significance was assumed at an alpha value of .05. The institutional review board of the University of Tennessee, Knoxville approved the study protocol and materials.

Results

A total of 9,785 patients met inclusion criteria, therefore, a random sample was taken to reduce the final analysis cohort to 500. Mean age was 66 years (SD=10) and 57% (n=287) of patients in the sample were male. Additional characteristics are described in Table 1. The total number of logins was 9,518, however, 178 patients (35%) included in the sample had zero logins. The total number of logins per patient are shown in Figure 1.

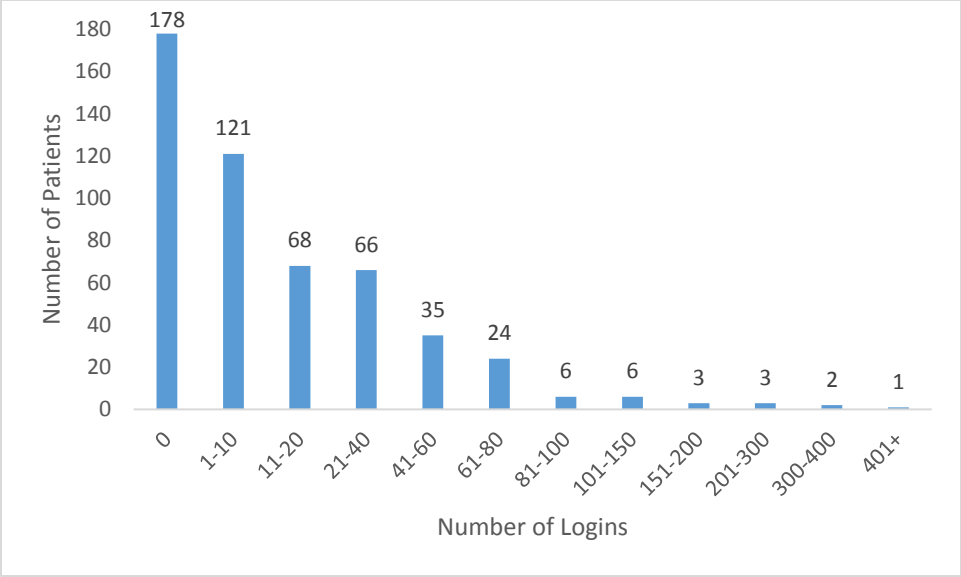


Figure 1. Number of Logins per patient enrolled in FollowMyHealth®.

Table 1. Characteristics of Patients
Enrolled in FollowMyHealth® Patient
Portal

Characteristics	No.	%
Total patients in sample	500	
Age, years		
Mean		66
SD		10
Gender		
Male	287	57
Female	213	43
Race		
White	483	97
Black	14	3
Asian	1	0
Other	2	0
Insurance		
Private	204	41
Medicare	291	58
Self-Pay	5	1
Diagnosis		
DM	394	
HTN	490	
HF	34	
CAD	185	
Chronic Conditions (count)		
2	407	81
3	83	17
4	10	2

The Kruskal-Wallis test was performed to determine if the practice size and location (IV), specific use of the portal, or demographic variables had an effect on the number of logins (DV). There was a non-significant main effect between the six types of practices regarding logins, $p=.80$. The median total logins was highest for small rural practices (median=13, IQR 28) and lowest for medium urban and large rural practices (median =4, IQR 23).

The secure messaging feature of the portal was used by 30% (n=149) of patients. There was a significant difference between people who accessed the portal for patient messages in regards to logins, $p<.001$. Patients with higher logins were more likely to send a secure message to their provider. Fixed-effect ANOVA with two between-subjects factors was performed in order to predict portal use based on practice size/location and use of secure messaging. This resulted in a non-significant interaction between practice location and use of the secure messaging feature of the EPP, $p = .41$.

Only eight patients included in the sample (1.6%) used the patient entered data function of the portal. Despite overall low use of this function, there was a significant association between number of logins and using the patient entered data function, $p = .03$. There were no instances of patient entered data for small-urban, medium-urban, and small-rural practices. Large-rural practices accounted for 62% of instances of patient entered data.

Next, demographic variables as well as type and number of chronic conditions were analyzed to determine effects on the number of logins. Age was normally distributed, and therefore, the parametric Pearson's r measured the relationship between age and number of logins. There was no association between patient's age and number of logins, $r = .004$, $p = .93$. For the variables of gender, race, type of insurance, and each diagnosis, Mann-Whitney U tests were performed. There was no significant association between gender ($p = .40$), type of

insurance ($p = .73$), whether or not the patient had diabetes mellitus ($p = .91$), hypertension ($p = .89$), or heart failure ($p = .25$). Differences in portal use and coronary artery disease was also not significant, $p = .12$. To determine how the number of chronic conditions effected portal use, Spearman's rank correlation was done and revealed a non-significant relationship between number of chronic condition and portal use, $r = .05$, $p = .26$.

Lastly, a nonparametric Spearman's rank correlation coefficient method determined the relationship between portal use and the distance separating the patient and their assigned primary care office. There was no relationship whatsoever between logins and the distance separating the patient and their primary care office, $\rho = .00$, $p = .99$.

Discussion

This study demonstrated no significant differences in portal use according to demographic characteristics, distance separating the patient from their primary care provider, and practice size and location. One plausible explanation is the large number of patients ($n=178$) who registered but never logged in to the portal. Similar rates of registered non-users have been reported in recent studies.²⁰ Because the number of logins was treated as a continuous variable in the study, the large number of registered non-users creates skewness in the data, which complicates the detection of differences according to factors such as practice size, location and demographic characteristics. This raises the question: Why are so many patients registering their account but not using the portal? Further research is needed to understand why patients are taking the time to register but not use the portal. As healthcare continues to move in the direction of patient centered care and shared decision making, it is increasingly important to solicit the input of front-line stakeholders. Patients, nurses, and providers are best situated to offer feedback and insight for using the portal as a tool to facilitate engagement in self-care.

Variance in portal use according to demographic characteristics has been widely reported. In a recent systematic review, 19 studies were identified using variables such as age, gender, race, and type of insurance to predict portal use. Findings from these studies revealed portal users were more likely to be younger, female, white, and have private insurance compared to non-users.²¹ It is important to note in all of these studies, portal use was treated as a categorical variable (e.g. user versus nonuser) unlike in the present study where portal use was treated as a continuous variable. Considering portal use as a continuous variable enables more sophisticated analyses, which help to understand how the portal can be of value to different patient populations. Jones²⁰ and colleagues used hierarchical cluster analysis to identify eight portal user groups based on their frequency, intensity, and consistency of use. They were able to group portal users into clusters based on factors such as frequency, intensity, and duration of use as well as the average number of times a member of a cluster used a specific function of the portal (e.g. secure messaging, viewing labs, etc.). Future research should attempt to measure portal use beyond the number of logins and implement strategies, such as clustering, which will allow for more sophisticated statistical analysis. Understanding different groups or types of portal users and how they use specific functions of the portal creates opportunities for portal developers and providers to leverage this tool in a way that fosters improved patient engagement and perhaps patient outcomes.

Further, we identified no association between portal logins and the distance separating patient and provider. This is contrary to recent data by Ketterer¹⁶ and colleagues who determined the odds of portal activation was higher for patients living further away from the practice. A notable difference in these studies is the outcome measure of portal enrollment or activation of the account rather than number of logins. Regardless, the potential for the portal as a tool that

expands access to the provider warrants further inquiry. Patients living in rural or underserved areas who may have difficulty traveling to see their provider could potentially benefit from portal features such as secure messaging, patient entered data, and reminders. More work is needed to understand the unique needs of these patients, their potential for using the portal, and what specific features they can use to improve health outcomes. Future research should explore risk stratification as interventions are developed targeting high-risk, high-cost portal users.

Prior studies exploring differences in portal use according to practice size and location are limited. In fact, no previous study was found that aimed to predict portal use according to the size of practice and whether the practice was located in a rural or urban area. Using a qualitative approach, Wade-Vuturo²² and colleagues conducted focus groups to explore how patients with type 2 diabetes benefit from the portal. Patients reported the secure messaging feature, in particular, expanded access to their provider by extending, and in some cases, replacing face-to-face visits. For example, patients used the portal to collaborate with their provider and engage in shared decision making outside of a face-to-face visit. While it was hypothesized that patients living in rural areas or those who lived a greater distance from their provider would use the portal more often, in this case, it was not a significant predictor of portal use.

The relationship between complexity of disease and portal use has potential implications in chronic disease self-management. In this study, it was hypothesized that having a greater number of chronic conditions would result in more logins. This hypothesized relationship was based on previous studies that found portal users were more likely than non-users to have more complex care needs. Two prior studies, both conducted in the pediatric population, found portal users had more severe disease compared to non-users.^{15, 16} One feasible explanation for this difference is portal use by proxy rather than by the patient. Since these studies were conducted

in the pediatric population, parents or caregivers were the portal users. Use of the portal by a proxy rather than by the patient could explain the difference in these studies and the present study that revealed no significant relationship between the number of logins and number of chronic conditions.

Despite the lack of significance associated with number of chronic conditions and logins, there was a significant difference in logins by patients who used the secure messaging and patient entered data features of the portal. While these features were used by few patients (n=149 and n=8, respectively), the statistically significant finding has important implications for patient engagement and self-care. Using the EPP as a tool to improve patient engagement was one of the original goals of the meaningful use incentive program. Criticisms related to the lack of flexibility in reporting and complexity of attestation have resulted in recent changes to the program.²³ Regulations are shifting from a one-size-fits-all approach to *meaningful use* to a new process allowing providers to self-select measures that best fit their practice and patient population. At this time, it is unknown if these changes will result in improved utilization. Regardless of the regulatory metrics, evaluation strategies focusing on outcome rather than process measures are critical to sustainment.

The middle range Theory of Self-Care of Chronic Illness offers some insight into the conceptual relationship linking portal use and self-care. According to Riegel¹⁸ and colleagues, patients who engage in self-care monitoring are able to communicate information to a health care provider potentially impacting the plan of care. The conceptual proposition linking symptom monitoring and self-care management should be explored in the context of the EPP. Patients have the ability to engage in symptom monitoring and take action using the EPP. My findings support a relationship between increased engagement and self-care management, however, due

to limited data regarding other specific function use, it is not known if this relationship is further supported. The conceptual model linking use of the portal, self-care, and improved outcomes requires further development, with particular attention paid to the perceived value of the portal as a tool to improve self-care.

Advancing portal adoption and implementation in the U.S. has come with a lofty price tag. The HITECH act, part of the American Recovery and Reinvestment Act of 2009, allocated \$19 billion for the Centers for Medicare and Medicaid Services to create an electronic health record incentive program²⁴. As of September 2016, over \$23 billion in incentive payments were transferred to 509,000 health care providers¹³. Considering the extraordinary investment in taxpayer dollars on implementation and meaningful use of portal technology, the large number of registered non-users is especially troubling. Portal adoption rates are higher than ever and continue to rise.²⁵ As we continue to make progress in achieving the initial goals of adoption and implementation, sustainability requires the focus be shifted to value. How we define value (patient satisfaction, outcomes, return on investment, market share) is paramount. Value according to patients, providers, policy makers, and other stakeholders should be assessed and evaluated.

Limitations

This study is subject to several limitations. First, although a random sample was taken that included patients associated with 147 different primary care providers, they were all affiliated with a larger primary care organization. This limits the generalizability of the results to the study cohort, as these patients differ from the larger population by factors including geographic location, socioeconomic status, and diagnosis. Second, only select chronic conditions were included (heart failure, hypertension, coronary artery disease, and diabetes) in this study,

therefore findings would not generalize to those with other chronic conditions such as cancer, stroke, or arthritis. For these reasons, findings cannot be generalized to the larger population of portal users with multiple chronic conditions.

Available portal data are another limitation of this study. Data related to specific functions of the portal were limited to patient entered data and secure messaging. Furthermore, the content of the secure message sent was not known. Future studies should examine the patient entered data feature of the EPP and consider how different features are used in combination. For example, a patient monitoring his symptoms or entering his own data and, in response, communicating with his provider via the EPP, offers stronger evidence linking the theoretical proposition of self-care monitoring and self-care management.

Using the number of logins as the outcome variable is considered a strength compared to others who used a binary outcome measure. However, number of logins does not capture duration and intensity of use and, for this reason, should be considered a limitation. In order to develop a more complete understanding, future studies should consider that ‘use’ is a multidimensional variable that includes frequency, intensity, and duration.

Conclusion

EPPs are in their infancy. Significant progress in patient enrollment has been made, however, a large gap remains in maximizing the potential of this tool to specifically help patients with MCC manage their increasingly complex care. Further research, aimed at developing conceptual relationships that can be tested, are necessary to maximize the return on investment of the portal. While this study found no significant relationships between portal use and demographics, distance between patient and provider, and size and location of the practice, it contributes to the science by raising important questions to measure portal use and implications for patient-centered portal design.

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CHAPTER IV: Electronic Patient Portals: Patient and Provider Perceptions

This manuscript (Scholarly Paper #3) has been submitted for publication to the Online Journal of Nursing Informatics.

Abstract

Background: The electronic patient portal (EPP) is a potentially powerful tool to facilitate self-management support for patients with multiple chronic conditions, however, patients are not taking advantage of this resource. Little is known about how patients are introduced to and learn about the EPP and how patients and providers perceive the usefulness of the EPP in the context of chronic illness self-management support.

Methods: A qualitative, descriptive design using semi-structured interviews with patients (n=9) and healthcare providers (n=7) was used to understand how patients are introduced to the EPP and perceived usefulness of the EPP to support self-management of chronic illness. Data were analyzed using conventional content analysis.

Results: Twelve categories related to four broad themes: 1) how patients are introduced to the EPP, 2) perceived benefits of the EPP, 3) perceived barriers to using the EPP, and 4) perceptions of using EPP for self-management of chronic illness were revealed.

Conclusions: While providers perceived little current value in the EPP for improving care of patients with MCC, we believe that with improved utilization, the EPP has the potential to improve patient engagement in self-care management. This can be achieved in part by providing opportunities to learn about the EPP, taking a proactive approach to integrating the EPP in patient care, and shifting focus from process to outcomes.

Keywords: *patient portal, self-care, self-management, multiple chronic conditions, perceptions*

Building a sustainable health information technology infrastructure has been a broad goal in the United States (U.S.) in recent years. Seamless flow of information within a digital healthcare infrastructure has the potential to transform the way care is delivered and compensated.¹ The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted in 2010 as part of the American Recovery and Reinvestment Act, has resulted in requirements for health care providers to attest to objectives that demonstrate Meaningful Use (MU) of electronic health records (EHRs).² Electronic patient portals (EPPs) are web-based platforms that give patients direct access to their electronic health record, potentially creating opportunities for improved engagement in their healthcare.³ Effective use of the EPP could result in improved access, self-management, care coordination, and reduced costs. These potential benefits are especially critical for meeting the complex needs of patients with multiple chronic conditions (MCC).

Chronic illness is responsible for seven of 10 deaths in the U.S.⁴ Three of four Americans, aged 65 and over, are living with multiple chronic conditions (MCC), that is, two or more conditions that require ongoing medical care.⁵ The resource implications for caring for patients with MCC are staggering. Two-thirds of all health care spending or 71% of the total healthcare spending in the U.S. is associated with care for people with MCC. Among Medicare fee-for-service beneficiaries, people with multiple chronic conditions account for 93% of total Medicare spending.⁶ The management of chronic illness in the U.S. is undergoing a shift from emphasis on provider-focused care to self-management. This shift comes as the result of both necessity and demand: necessity as the U.S. healthcare system is burdened with the extensive resources needed to care for this growing populace and demand for more patient-centered care.

Patient and family-centered care includes integrating healthcare goals, preferences, and values by forming active partnerships between patients and providers. This requires a culture shift where patients are no longer subjects of care but rather active participants.⁷ Many patients do not participate in decisions regarding their care because they do not understand the plan of care or they are not aware that taking an active role in managing their condition can positively impact their quality of life. Self-management support encourages patients with chronic conditions to make daily decisions that foster healthy behaviors and improve clinical outcomes.⁸ A growing body of literature provides evidence that self-management support improves clinical outcomes and can reduce costs.⁹ The EPP is a potentially powerful tool to facilitate self-management support for patients with MCC, however, patients are not taking advantage of this resource.

While the MU program has resulted in improved adoption¹⁰, patient use of the EPP is disappointingly low. A 2-year study found that only 10% of patient's in the VA system authenticated their EPP account.¹¹ Even among large integrated health systems, portal adoption is typically around 30-40%¹² and even less for older patients and those from disadvantaged populations.^{13, 14}

Provider endorsement and engagement with the EPP is critical to achieve the intended outcomes of enhanced quality, safety, and efficiency. Little is known about how patients are introduced to and learn about the EPP and how patients and providers perceive the usefulness of the EPP in the context of chronic illness self-management support.

Methods

A qualitative, descriptive study design¹⁵ using semi-structured interviews with patients and healthcare providers was used to understand how patients are introduced to the EPP and

perceived usefulness of the EPP to support self-management of chronic illness. Design features of qualitative descriptive studies include use of maximum variation in the sampling approach, data collection in the form of individual interviews, and data analysis using variants of qualitative content analysis. In qualitative descriptive research, interpretations of data are much less transformed compared to grounded theory yet the result is detailed and nuanced interpretations. Data were analyzed using conventional content analysis as it is the analysis of choice in qualitative descriptive research.¹⁵ The study protocol was approved by the University of Tennessee Institutional Review Board and signed consent forms were obtained from all participants prior to being interviewed.

Interview Guide

Based on the goal of understanding how patients with MCC learn about and use the portal, an interview guide was developed for patients and providers. The patient interview guide focused on four areas: 1) how the patient learned about the portal, 2) perceived benefits of the portal, 3) barriers to using the portal, 4) perceptions of using the portal as a tool to manage MCC. The provider interview guide focused on four areas: 1) how patients are introduced to the EPP, 2) perceived effectiveness of that approach, 3) incorporation of the EPP into the clinical workflow, 4) perceived usefulness of the EPP as a tool to help manage MCC.

Study setting and participants

Convenience sampling was used to recruit patient participants who were 45 years of age or older, a registered user of the electronic patient portal, diagnosed (according to ICD-9 or 10) with two or more of the following: diabetes, hypertension, heart disease, or coronary artery disease, and an active patient (i.e. seen within the last 12 months) of a primary care provider at one of three practices selected practices. Participants were recruited from three different primary

care offices, all affiliated with the same larger primary care organization. The different practices were selected based on results from a previous study exploring predictors and patterns of portal use by patient with MCC. Practices size (i.e. number of providers), location (i.e. rural or urban) and variance of portal use were to identify practices thought to represent diversity in perspectives.

Organizational participation was granted by establishment of a business associate agreement. Once specific practices for participant recruitment were identified by the primary investigator (PI), the central organization put the PI in contact with the office manager at each location to assist with logistics such as establishing a date for the PI to conduct interviews and arranging a private location for interviews to take place. Office staff screened patients for inclusion criteria and presented them with a flyer inviting them to participate in the study. The flyer instructed interested patients to notify a member of the staff if they were interested in participating. Patients who expressed interest were directed to a private location to meet with the primary investigator (PI) immediately following their appointment. Providers employed at one of the three selected practice sites were also invited to participate. Providers were sent an email with details of the study and asked to contact the PI if they were willing to participate. Provider participants were interviewed in the same private location as patients at a time convenient for them. After reviewing the study protocol with the PI, participants were asked to sign an informed consent statement. All interviews were audio recorded and transcribed verbatim to ensure accuracy. The qualitative literature suggests that 12 interviews are needed to achieve saturation of findings, however, the number is ultimately determined by the researcher.¹⁷ Saturation, that is, the point in which no new concepts arise from the interviews¹⁸, was reached at 13 interviews; three additional interviews were conducted to ensure no new data emerged.

Analysis

Conventional content analysis was the data analysis approach used in this study. Conventional content analysis was selected because it is the analysis of choice in qualitative descriptive research when existing theory or research literature on a phenomenon is limited.¹⁵ Meaning is developed inductively from the data by allowing categories and names for categories to flow directly from the data.¹⁹ The expected outcome of this analysis is a descriptive summary of the information contained in the data.

The analysis consisted of immersion in the data beginning with listening to each digital recording within 24 hours of the interview. Digital recordings were transcribed verbatim by a professional transcriptionist. All transcribed recordings were then compared to the digital recording to ensure accuracy. Identifying information (i.e. names of people or places) were removed at the same time the recordings were checked for accuracy. The coding process began by highlighting exact words from the text that appeared to capture key thoughts or concepts. Next, codes thought to be reflective of more than one key thought were developed. The preliminary codebook was iteratively refined as additional transcripts were analyzed. A sample of four transcripts (two patient and two provider) were independently reviewed by a second researcher and then discussed with the PI until consensus was met. Preliminary codes were sorted into categories by identifying relationships between codes and groupings of codes. An audit trail was maintained as categories were combined and collapsed. Over the course of the analysis, 58 open codes were developed. These were combined into four broad themes and twelve categories (see Figure 2). The results section contains exemplars for each category identified from the data.

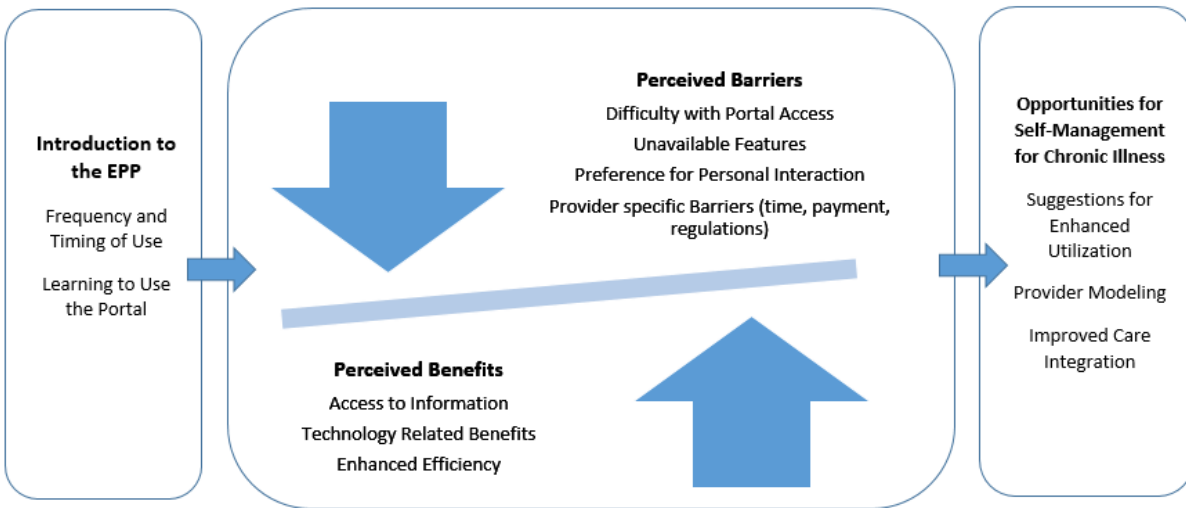


Figure 2. Categories of findings from patient and provider interviews.

Results

Individual interviews ranged in length from approximately 5 to 30 minutes with a mean time of 14 minutes. In all, nine patients and seven providers were interviewed. Provider participants included four primary care physicians, one physician’s assistant, one registered nurse, and one office manager. The three selected sites from which participants were recruited included a small-rural practice, a medium-urban practice, and a large-rural practice.

The small-rural practice was located in a suburban area despite the U.S. Census Bureau’s classification of rural.¹⁶ This practice consisted of one primary care physician and one physician’s assistant (PA), both of whom agreed to participate in this study. The physician participant had been part of the larger primary organization since 2008 and had a well-established practice. The PA participant identified herself as a new-graduate, having only been

practicing for a little more than one year. Three patient participants were recruited from the small-rural practice and all three reported some portal use.

The medium-urban practice was located in an affluent area of a large metropolitan city. This practice consisted of approximately ten physicians and five nurse practitioners and PA's. Two physicians from this practice agreed to participate in the study. The physicians were both male and one was close to retirement (per participant self-report). Four patients were recruited from this medium-urban practice. One patient reported frequent portal use and the other three reported little or no portal use. In addition to the providers and patients recruited from this location, one office manager was interviewed.

The third location was classified as a large-rural practice. The office was located within a regional hospital of a rural county. There were over 20 primary care providers made up of physicians, nurse practitioners, and PAs at this location. One physician, one registered nurse, and two patients were recruited from this practice. Among the two patient participants, one reported frequent use of the EPP and the other reported no use. Following the structure of the interview guide, findings are organized along four broad themes: 1) introduction to the EPP, 2) perceived benefits, 3) perceived barriers, and 4) perceptions of usefulness related to self-management of chronic illness.

Introduction to the EPP

Frequency and Timing of Use

Participants reported variance in their overall frequency and timing of use of the EPP. Six out of nine patients reported logging in to the EPP about once per month. The other three participants reported having never logged on since registering the account. When asked to describe their frequency of use, several participants commented on variance in use based on their

perception of their current health. Patients who perceived themselves as healthy reported fewer logins compared to times when something active was happening:

[The portal] doesn't come into consideration to remember to check or look at unless there's an appointment or something active going on. I did it more (logged on) when I was having scans and a lot of lab work a few years ago. Most of the time my lab results are good and I'm in good health. I don't know why I'd be accessing it.

Learning to Use the Portal

This category describes how the EPP was first presented to patients and how they learned to use it. Patients reported a variety of sources for their initial exposure to the EPP including the physician, nurses, and office staff (i.e. receptionist or person checking them out upon conclusion of the appointment). Some providers described an active approach to introduce patients to the EPP:

The way I usually get a patient charged about it is, of course we have in every exam room, we have a sign on the door and it talks about the portal and ease of access and all that and so if they're a new patient, I'll tell em that. If they're not a new patient, a lot of times, when we're talking about getting their lab results to em, I'll say "Now, are you on the portal?" and they say "Well, no" or "What's that?" and I'll kind of show em the sign and I'll say..."I recommend it and I think you should do it."

Other providers described taking a more passive approach: "There was an incentive to get so many people signed up so we were trying to talk to everybody initially but not anymore so I kind of leave it up to them if they're interested in that."

Patients who reported using the EPP were asked to describe how they learned to use it. The majority of patients reported learning to use the EPP on their own. They used phrases such

as “trial and error”, “hook or crook” or “played around with it” to describe learning to navigate the website. None of the patient participants stated that someone oriented them to the portal or described the functionality to them.

Perceived Benefits of the EPP

Access to Information

The most frequently reported patient perceived benefit of the EPP was having access to their personal health information. This category includes having access to specific health information with the ability to archive data and make comparisons. Almost all of the patient-users mentioned the ability to access their data. Both patients and providers valued the ability to archive and compare trends in data. In addition, patients reported the perceived benefit of greater depth of information when viewing results via the EPP versus receiving a call from the provider’s office: “You do all these test results and in the past, you get a call from the doctor and he says “It’s good. Don’t worry about it. It’s good but some people want to know more.”

Having access to information made patients feel more informed in their healthcare. One patient described how the EPP facilitates active involvement, “It’s really nice to be able to pull up my cholesterol level and see what it was last time around and you know, and do some comparisons.” Several patients mentioned the benefit of being able to access data by proxy, that is, for a family member. One participant described how he is responsible for monitoring the portal for both himself and his wife: “I don’t think she has (logged in). She counts on me to do it.” Another participant gave a similar account: “I like to keep up with my information, and of course, my husband. I do for both of us.”

Providers also mentioned the benefit of the EPP in providing opportunities for active participation. Providers reported benefits related to patients being more self-aware and having the ability to formulate questions (related to test results) prior to the face-to-face appointment.

Technology-Related Benefits

The category of technology-related benefits refers to the perceived benefits of the EPP as a technological tool. Perceptions of the technological benefits varied considerable among patients and providers. The majority of patient participants made favorable comments regarding the technological benefits of the EPP. One patient stated: “I use my computer quite a bit and so I like learning new and different things.” Another patient stated “One of the biggest things, I like, the technology, I’m interested in that.”

The benefit of technology was perceived differently by providers. Some providers made favorable comments regarding the technology of the portal. They made comments such as “I have a lot of Medicare aged patients, they’re better on the computer than I am.” In many instances, providers were quick to point out technological limitation according to the age of the patient. Providers perceived the technology as a benefit only to younger patients:

It really depends on age, patients in their 60s and 70s are not going to use it but the ones in their 20’s and 30’s really like it...When you get much past the 50’s and you get more into the 60’s and 70’s, it’s not beneficial. Most of those generations don’t know how to use a computer.

Enhanced Efficiency and Accuracy

Both patients and providers described enhanced efficiency as a benefit of the EPP. Providers were asked about how the portal had been incorporated into the clinical workflow. Providers overwhelmingly reported easy integration and little or no disruption in their clinical

workflow: “It’s integrated easily. It’s just part of the normal workday.” Providers perceived using the portal to communicate as more efficient than making a phone call which often results in leaving a message and awaiting a return call: “it saves us more work on our end cause then we’re not gonna have to chase em (patients) down.” Several patient participants mentioned cutting down on paperwork as an efficiency of the EPP. In addition, one patient described the potential benefit of improved accuracy:

One thing that I would like to do obviously is avoid all this paperwork when it comes to the doctor’s office, having to type it in and read you know. I mean there is incorrect information and simply because people use their hands to write. When you write things down, it’s inevitable that 6 to into an A, or a 5 turns into a 6 and a 7 or an 8, so there’s incorrect information in there. Ideally, it would be ideal if it could be done electronically.

Specific uses of the portal often came up when patients were describing the efficiency of the EPP. Overall patients perceived viewing lab results, requesting medication refills, scheduling appointments, and using the secure messaging feature as benefits. Similarly, providers most often mentioned viewing lab results followed by communication capabilities (secure messaging).

Perceived Barriers of the EPP

Difficulty with Portal Access

Difficulty accessing the EPP due to password, computer, or server problems was frequently identified as a barrier by both patients and providers. Problems typical of any website such as forgetting the user’s password and server downtime were reported. Problems with portal access were described by patients who used the portal and those who did not. One patient who reported little, if any, portal use had this response to being asked about barriers to using the EPP,

I've got too many passwords. I can't never remember and then, lots of times, it just, just would freeze up and not let me have anything once I would you know get my new password and go back in and then it was like, there's nothing there. So it's like it just wouldn't update right or something.

Similar problems were reported by other patient participants: "I tried to get on it once and I couldn't get all the way in for some reason on my computer and I don't know what happened there. I was busy so I didn't have time to come back and check again."

Providers also described problems related to the first login: "I have a lot of patients tell me they almost never can get on the first time. So a lot of people have signed on, they get frustrated and they say "You know I tried that and I never could get anything."

Unavailable Features

In addition to problems accessing the portal, portal users and provider described instances of the portal not having the capability to do something they perceived as useful. Correcting errors in the medical record, changing the preferred pharmacy, and making a payment online were some examples of unavailable features. Some features perceived as valuable were either unavailable or the participant did not realize they existed. One patient, who reported using the portal frequently (at least once per month) described wanting access to disease-specific information:

There's a lot of potential there for instance, if there was some way that something could be set up so, that if I have osteopenia. What if something was offered to me, a link on you know on that to explain it to me and tell me what I could do about it...that would be helpful.

It is important to note that the EPP currently includes this feature. A nurse participant offered another incorrect perception of portal functionality pertaining to patient entered data (e.g. the ability of the patient to enter their weight, blood pressure, blood glucose readings, etc.):

They (patients) can't add data from home. They can um request us to add like a change in pharmacy or a change in phone number or things like that but they can't do anything from home. They can just look at it.

The portal allows patients to enter data directly into the medical record although no patient participants in this study reported having done so. When patients were asked why they did not use this feature, every participant said it was because they did not realize the function was available. Despite not using this specific feature, most patients agreed this would be a feature they would consider using in the future.

Preference for Personal Interaction

Many patients and providers described their preference for interacting with a person rather than via the EPP. Patients reported enjoyment in talking to someone and having the ability to ask follow up questions if needed. When describing his preference to communicate by phone rather than via the portal, one patient said:

I always enjoy talking to em when they call. We have a good conversation and a good thing about em is that they ah, you know, you can ask em things that ah, usually you don't have time maybe to ask your doctor about.

The preference for personal interaction was shared by patients and providers across the different practice sites. One provider described this preference, “Patients in my practice, like to talk to a real person. They like that personal interaction and frankly, we do too.”

Provider-Specific Barriers

There were several barriers reported only by providers. These barriers were categorized as provider specific barriers with three subcategories: lack of time, payment concerns, and regulatory barriers. Concerns over lack of time were frequently discussed by providers. Every provider interviewed mentioned time as a constraint in encouraging or teaching patients to use the EPP. One provider described feeling guilty, “People don’t know how to do this (use the portal) and so I feel kind of guilty that I really don’t know how to do it either but frankly I don’t have time to sign em up.” Other providers described lack of time as a barrier to reviewing data entered into the EPP by the patient. Providers were concerned about the amount of time it would take to review data entered by the patient.

Providers were also concerned with integrating the EPP into the current payment structure. Multiple providers mentioned the need for payment reform, specifically capitated payments, so that providers could be compensated for their work via the EPP. One provider stated,

I think the barrier for us is just staying in business. I mean, if I did everything on portal and people didn’t come see me, then I wouldn’t be able to keep my office open so I mean we don’t, there’s no way to ah get reimbursed for the work you do on the portal.

In describing the need for payment reform, another provider said,

I think what’s gonna happen is we’re gonna start getting paid if they keep going the way it’s gonna be paid on more of a capitated rate, more on patients, so keeping patients healthy is gonna be better so the more we do that, the better we’ll be paid. It won’t be fee for service forever.

Regulatory barriers were raised by several physicians when asked about barriers to using the EPP. Several providers mentioned the Centers for Medicare and Medicaid Services Meaningful Use program specifically. One provider who described the portal as “a good tool” described being frustrated by the amount of data required to be monitored for the MU program as well as being told how to practice:

I think the reason providers get so frustrated is, if we needed somebody to come in and tell us which tools to use, why did we go to school in the first place? Why do I go get 40 CME as a minimum every two years? Why do I um, go through a residence program to learn how to use the tools in my toolbox?

Another provider discussed similar regulatory barriers to using the portal:

One of the things I would say with the portal is the government’s pushing it out maybe before it’s ready for prime time and so what I found is a lot of people were excited about it initially but because it didn’t work as well as you would expect it to, then they quit using it and then once you quit using it, it’s like some email address that you signed up for and never go check it anymore.”

Perceptions of the EPP for Self-Management of Chronic Illness

Suggestions for Enhanced Utilization

Patients and providers alike offered suggestions to enhance the utilization and effectiveness of the EPP. Patients described how creating a more user-friendly interface could improve the EPP and make the tool more beneficial to them. Several patients discussed the need for the portal to be easier to use. As one patient noted, “It just needs to be easy, easier to navigate through”. Patients noted that tabs, especially on the mobile interface, were not labeled clearly

and it was not obvious to the patient how the information was organized. Patients expect using the portal to be like using any other app on their smart-phone with clear and simple instructions.

Provider Modeling

Patients indicated in response to direct questions that they want their provider to make specific recommendations of how using the EPP could benefit their health. Patients were asked questions regarding their interest in using features (such as patient entered data) if recommended to do so by their provider. Patient responses included “most definitely” and “I would use that if he (provider) asked me to.” Rather than just encouraging general use, patients described wanting their provider to recommend using the portal in a way that has the potential to benefit their particular situation. Based on the patient’s diagnosis or level of engagement, the provider might encourage the patient to track their lab results, enter their weight on a regular basis, or enter blood pressure readings.

Improved Care Integration

Provider participants described future opportunities for using the EPP in chronic illness management. Providers indicated a need for supported through training and exposure to opportunities for use beyond those required by regulations. Multiple providers described their lack of training and familiarity with the portal as an opportunity for improved use. Providers admitted that they had little experience with the portal and some had never even seen it. Providers made statements like, “I’ve never signed on to the portal and I don’t know what’s involved” and “I personally have never actually gotten on it”.

Lack of provider experience using the portal lead to mixed perceptions of its potential as a tool to improve self-management in patients with MCC. Some providers had generally favorable opinions of the portal while others took a more defensive position as they perceived

the portal was being forced on them. One physician explained, “I haven’t thought much about it. Ah, you know, I got by for 34 years without it.” Several providers recognized value in the portal in the present but even more so in the future. Providers described the EPP as “in its infancy” and were hopeful in the future benefits for patients with chronic illness.

Despite frustration with the regulations set forth in the MU program, providers remained hopeful that the EPP would benefit the care of patients with MCC. One provider summarized, “It’s the rules. We live by it. I hope that some of it has the ah, the intended result of better patient care.” Another provider had positive perceptions of the potential for using the EPP in chronic illness management. She described the value specifically for patients with chronic conditions being able to track small improvements:

I really do feel like they (portal users) have more of a grasp on what’s going on and the continuum of their care because a lot of these diseases, you don’t fix overnight and a lot of em get discouraged I think because they’re, they’re not making progress, you know the great leaps and bounds like you can do if you have an upper respiratory tract infection or something, but I think that through communication of the portal and then being able to communicate back with us, and talking about the plan of care, I think that would certainly help in chronic disease management.

Discussion

This qualitative study identified twelve categories describing perceptions of how patients are introduced to the EPP and how patients and providers view the tool in the context of chronic illness management. By interviewing patients and providers from practices that varied in both size and location, we were able to capture a broad perspective of perceived usefulness of the EPP and identify areas of opportunity for the future. We postulate that with improved utilization, the

EPP has the potential to improve patient engagement in self-care management. Such improvements can be achieved through understanding how patients use the EPP, mindful integration of the EPP into chronic care management, addressing the reactive nature of portal adoption and implementation, and shifting focus from process to outcomes.

Data from this study revealed overall low rates of portal use. Three of nine (33%) patient participants reported never logging in despite activating their EPP account. Understanding why patients registered but never used the EPP was important to our study thus we welcomed the perspective of these registered non-users. In most cases, patients who did not use the portal perceived it to be of limited value. Patients who perceived their health as good, despite having MCC, were not aware of how the portal might be useful to them. Patients were optimistic about using the portal if their provider suggested they do so. This finding is consistent with others who report improved rates of use when providers recommend a specific feature of the EPP or explain how it might benefit a particular patient.^{20, 21} There is a need for further research, specifically, outcome-focused, interventional studies examining the effects of provider encouraged use of the EPP for self-management in chronic illness.

Patient participants who reported using the portal on a regular basis reported at most, logging in once per month. The most frequent reason patients cited for not using the portal more often was a lack of knowledge surrounding available features and how to use them. Phelps²² and colleagues conducted a study in the U.K. examining factors related to persistent use of a portal by patients with chronic kidney disease. They found providing assistance with the first login was strongly associated with becoming a persistent user even after three years. Similarly, Weisner²³ and colleagues report on a study in which patients were taught portal skills including how to send a secure message, view test results, and access educational materials. Patients who received this

instruction had more EPP logins and engaged in these tasks more often than those who did not receive the training. Future studies should explore effective teaching strategies aimed at both patients and providers to maximize their use of this tool. Teaching patients how to use the EPP requires a different approach to integration than providers in the current study described.

Every provider interviewed in this study reported that the EPP was easily integrated into their practice. Patients and providers described enhanced efficiencies in using the portal for administrative tasks such as refilling prescriptions and scheduling appointments, however, most practices were using the EPP in addition to, rather than in place of, traditional communication approaches (i.e. phone calls, paper reporting). Providers were concerned that patients would not receive the communication sent via the EPP but did not have that same concern regarding a phone call or result sent through the mail. It was not clear if this concern was related to a distrust in technology, lack of confidence on the part of the provider, or some other factor. Future research should explore these factors and other that may influence provider confidence in the EPP.

One concern raised frequently by providers was that older patients would not be interested in using the EPP. Multiple providers, including physicians, a physician's assistant, and a nurse mentioned age as a barrier to using the EPP. Older adults, those age 65 and older, have been the fastest growing group of internet adopters since the year 2000.²⁴ A 2012 Pew Research survey²⁵ reported over half of Americans age 65 and older were internet users. None of the patients interviewed in this study mentioned internet or computer access as a barrier to using the EPP. In fact, they made positive statements regarding technology in general. Patients made statements such as "I like the technology" and "I like learning new and different things". The overwhelming reason patients reported not using the EPP was that they were unaware of how it

might benefit them. While we realize the EPP will not be embraced by everyone, those who are interested in using it deserve a more proactive approach to clinical integration.

When asked to describe EPP integration, providers spoke of the process of getting patients enrolled but none talked about integration into patient care. Providers had not considered using the portal outside of administrative tasks. When asked to share their thoughts for using the EPP to improve care of patients with MCC, responses included statements like, “I haven’t really thought about the portal a whole lot” and “I’ve gotten by for 34 years without it”. It is widely reported in the literature that patients with chronic illness such as heart failure and diabetes, who are actively involved in their care and adhere to treatment plans, are more likely to have improved health and quality of life.^{26, 27} The ability to track and enter personal data, monitor symptoms, and communicate with the healthcare team are some of the existing functions within the EPP that facilitate self-care management. Findings from this study add to the existing evidence that these features are underutilized and under-evaluated.²⁸ Providers must look past the short-term benefits of incentive payments and consider the EPPs value in improving patient care. Provider recommendations are critical as portal developers improve current functionality and create new products that facilitate self-management support.

Throughout the course of provider interviews, it was clear that integration of the EPP was a reactive process. EPP deployment, thus far, has occurred under the auspice of federal regulations. The federal Meaningful Use (MU) incentive program used a sequential approach that first focused on adoption and later implementation and patient engagement.³ As regulations were imposed, portal developers focused their attention to creating systems to meet those requirements. The result was a portal with the technological capability of meeting the MU requirements but with underwhelming attention to patient needs. While the portal design met the

provider's needs for MU attestation, it did little to facilitate other provider needs such as clinical-care integration and improved outcomes. Despite harsh criticisms regarding the lack of flexibility and complexity²⁹, the MU program made significant strides in facilitating adoption of EHRs. Since the first MU reporting period in 2010, office-based physician adoption of any EHR increased by almost 40% and, as of 2015, 3 in 4 office-based physicians had adopted a certified EHR with an EPP.¹⁰ As providers now prepare for the new merit-based incentive payment system (MIPS), they will be able to customize a set of measures that best represents how they use EHR technology in their day-to-day practice.³⁰ While the MIPS program appears to offer greater flexibility for providers, it continues to incentivize processes rather than outcomes.

A shift from process to outcomes is critical to maximize the potential of the EPP. Providers in this study did not seem to consider using the EPP to improve any outcome, rather perceived it as a federally mandated tool they were prescribed to use. One plausible explanation for this perception is the current structure of the MU incentive program. The providers interviewed in this study focused on the process of getting patient enrolled into the EPP but had little interest in patient's continued use once enrolled. This is likely the result of early objectives targeted at portal implementation and adoption. As providers prepare to report on new MIPS objectives, we hope to see focus shift from process to patient engagement and improved outcomes. This shift will require continued support of providers and policy makers. Provider must buy-in to the capability of the portal in improving care of patients with MCC and policy makers must look for ways to directly incentivize improvements in quality, safety, and efficiency.

Limitations

This study has several limitations. First, because participants were recruited from primary care practices located in one geographic area, findings may have limited transferability. Although the sample was drawn from multiple practices varying in size and located in both rural and urban settings, all practices were located in the same state. Regional differences may account for different perceptions of usefulness and barriers to using the EPP. A decision was made not to collect demographic data for participants of this study. At the time, it was thought this information would add little value in answering the research questions proposed, but in hindsight that information would have been helpful in establishing differences in perception according to factors such as age and gender.

Conclusions

The purpose of this qualitative descriptive study was to understand how patients are introduced to the EPP and perceived usefulness of the EPP to support self-management of chronic illness. By interviewing patients and providers in both urban and rural settings, we were able to identify twelve categories surrounding how patients are introduced to the EPP, perceived benefits and barriers, and perceptions of the EPP for self-management of chronic illness.

The main reason patients cited for not using the EPP was because they did not perceive it to be useful to them or did not understand what features were available. Patients reported being more likely to use the portal when their provider encouraged them to use a specific features. Providers described barriers including lack of time to teach patients to use the EPP as well as payment concerns and regulatory barriers. Providers also made numerous comments regarding their own lack of training and overall lack of familiarity with portal functionality.

Patients and providers were optimistic regarding the benefits of the portal in giving them direct access to health related data, technology related benefits, and opportunities for enhanced efficiency. While providers perceived little current value in the EPP for improving care of patients with MCC, we believe that with improved utilization, the EPP has the potential to improve patient engagement in self-care management. This can be achieved in part by providing opportunities to learn about the EPP, taking a proactive approach to integrating the EPP in patient care, and shifting focus from process to outcomes.

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CHAPTER V: Conclusion

Conclusion

This dissertation consists of three manuscripts exploring use of the EPP by patients with MCC. The first manuscript, a systematic review of the literature, was completed to assess the current state of the science related to patient perceptions of the EPP. Three research questions were formulated to guide the review: (1) what are characteristics of EPP users? (2) What are patient perceived facilitators of EPP use? (3) What are patient perceived barriers to EPP use? Variations in demographics, patterns of use, and the complexity and duration of disease were found to differentiate portal users from non-users. Furthermore, important facilitators of portal use such as provider encouragement, having access to and control over health information, and enhanced communication were identified. Barriers to portal use included concerns regarding privacy of personal health information and, perhaps more significantly, a lack of awareness or training to use the portal. This review revealed a need for further research to understand how patients learn to use the portal and which strategies result in persistent and productive use.

The second manuscript contains results from a quantitative study aimed at exploring characteristics of portal use by patients with MCC and predictors and patterns in using specific features that support self-care. The middle range Theory of Self-Care of Chronic Illness¹ was the theoretical perspective used to guide the study. Twelve months of data from electronic health records and web server log files from patients ($n=500$) were analyzed. Patients included in the analysis were 45 years or older, registered portal users, and diagnosed with at least two chronic conditions. There was a significant difference between people that used the portal for messages in regards to number of logins, $p < .001$. Patients who sent a secure message to their provider had more logins compared to those who did not use the secure messaging feature. Patients who entered their own data (e.g. weight, blood glucose, blood pressure readings) also had more logins

compared to patients who did not enter data ($p=.03$). No significant differences in portal use were found according to demographic characteristics, distance separating the patient from their primary care provider, and practice size and location. This study revealed a need for further research, aimed at understanding why a large number of patients registered their portal account but never logged into the portal. Both patient and provider perspectives are necessary to gain insight into portal integration and use in chronic illness management.

The third manuscript reports on a qualitative study designed to understand how patients are introduced to the EPP and perceived usefulness of the EPP to support self-management of chronic illness. Semi-structured interviews with registered portal users ($n=9$) and providers ($n=7$) were analyzed using conventional content analysis. Twelve categories related to 1) how patients are introduced to the EPP, 2) perceived benefits of the EPP, 3) perceived barriers to using the EPP, and 4) perceptions of using EPP for self-management of chronic illness were revealed. While providers perceived little current value in the EPP for improving care of patients with MCC there is support for using the EPP to improve patient engagement in self-care management. Improved use of the EPP to support self-care management can be achieved in part by providing opportunities to learn about the EPP, taking a proactive approach to integrating the EPP in patient care, and shifting focus from process to outcomes. The cumulative results of these studies have important implications for practice, research, and policy.

Implications for Practice

There are important implications for clinical practice derived from this work, first and foremost, opportunities for improved integration of the EPP into chronic care management. Improving the use of the EPP begins with addressing the narrow perception of using the tool simply as an administrative adjunct. When providers described benefits of the EPP, they focused

on how the tool was beneficial to them (i.e. as a Meaningful Use requirement) and gave little consideration to how it might benefit patients. Provider perceptions of the EPP were consistently self-centric and lacking the necessary patient-centric approach to care, which focuses on engagement and outcomes. A shift in provider perspective to a more customer-centric model of care is needed to consider other possible benefits of the tool in chronic illness management. This shift requires adequate opportunities for training and buy-in from different members of the healthcare team.

Providers and patients interviewed in this study consistently described a need for additional training to use the EPP. Extending use of the EPP as a tool to support chronic illness management begins with educational initiatives aimed at various members of the healthcare team. A recent review of the literature examining the integration of EHRs into medical education revealed learners do not develop the skills they need by ambient exposure. Rather, they need deliberate instruction and guidance, not only in using basic functions of the EHR, but also in using it to promote patient-centered care.² These results are consistent with the qualitative results from this study which revealed the perception of inadequate provider training to use the EPP. All members of the healthcare team including the primary care provider, registered nurses, and other office staff would benefit from more comprehensive training and understanding of the functionality of the EPP. Regulating bodies (e.g. medical boards, boards of nursing) should consider addressing this training gap by prescribing specific technology-related continuing education requirements for licensure.

While this study focused on primary care providers (i.e. physicians, advanced practice registered nurses, physicians assistants), there are ample opportunities for registered nurses to become more active in EPP training and clinical integration. Effective chronic illness

management requires multidisciplinary care teams consisting of primary care providers, registered nurses, and other healthcare professionals with strong clinical and behavioral skills.³ In the qualitative phase of this study, physicians rarely mentioned involvement of other members of the healthcare team in supporting patient use of the EPP. When providers discussed the role of the “nurse”, it was related to administrative tasks such as helping the patient to reset their password or changing a preferred pharmacy. When physician primary care providers described following up on a patient’s clinical question, they made statements like, “if it’s a clinical response then it comes from me”. Findings from this study as well as others⁴ reported in the literature demonstrate that physicians are challenged with increasing demands. Providers specifically mentioned lack of time as a barrier to teaching patients to use the EPP for self-management. Improved efficiency in primary care can be achieved by encouraging registered nurses to perform skills that are certainly within their capability and scope.⁵ The registered nurses role in engaging patients via the EPP for the support of self-management of chronic illness should be explored.

Existing evidence strongly suggests that multidisciplinary healthcare teams, rather than primary care providers or specialists alone, have potential to deliver high-quality, lower-cost care to patients with chronic illness.⁶ Registered nurses are well-suited to engage patients and family members in the shared decision making that primary care providers lack the time to offer. In a quasi-experimental pilot study, patients with MCC experienced improved outcomes including reduced emergency department visits, hospitalizations, and spending after receiving collaborative care led by a registered nurse.⁷ An expanded role of the registered nurse in chronic illness management should be considered in the future, especially given the increased burden of caring for patients with MCC. Ensuring the nursing workforce is prepared for this expanded role

will require adjustments in nursing curricula, specifically, ensuring nurses enter the workforce with the knowledge, skills, and attitudes necessary to lead collaborative teams and to integrate technical tools such as the EPP into patient care.

Implications for Research

Implications for research from this work are abundant. The exploration of relationships and perspectives related to the EPP has led to far more question than answers. While suggestions for further research have been made throughout the three manuscripts, this section will focus on opportunities for outcome-focused, evaluative research and theoretical development.

While some outcomes-based evidence related to the EPP exists, it is limited and findings are mixed. Some studies have reported improvements in outcomes such as medication adherence, patient satisfaction, and clinical measures such as glycemic control among patients using an EPP.⁸⁻¹⁰ Other studies have found no significant improvement in outcomes such as hospital resource utilization and quality of life.¹¹ Studies demonstrating improved outcomes seem to be related to the type of EHR used and strategies targeting a specific patient population. Some of the most compelling outcomes come from institutions that have highly customized EHRs that have been in place for decades.¹² There is a need for additional evaluation-based studies using exemplars of successful EPP integration in chronic illness management. As portal development continues to evolve, researchers must broaden their focus to include outcomes as well as process improvement. High-quality, interventional studies that focus on specific patient populations are needed to extend and expand the evidence related to the EPP.

In addition to the need for outcome-based, evaluative research, future studies should attempt to capture differences among types of primary care providers. In this study, 4 of 5

primary care provider participants were physicians and only one was a physician's assistant. None of the provider participants were advanced practice registered nurses. Little, if any, evidence exists exploring differences in perceptions of the EPP according to type of primary care provider. Existing research is largely limited to studies focused on physician perceptions and pay little attention to potential differences that may exist according to the type of primary care provider.^{13, 14} Future research is needed to attempt to capture nuances in perceptions of using the EPP according to type of primary care provider. In addition, research aimed at differentiating EPP-based outcomes among well-integrated clinical teams and those that emphasize physician dominated care should be considered.

Theoretical development is necessary to develop the high-quality, interventional studies described above. Findings from the systematic review (manuscript 1) revealed a lack of theoretical framework and inconsistent conceptual definitions. Most studies included in the review defined portal use along one dimension: number of logins. This operational definition fails to take into account other dimensions of portal use such as specific function of the portal being used, duration, and intensity of use. The conceptual model for understanding the link between portal use and patient outcomes is not adequately developed and must be improved to identify appropriate outcome measures. Measureable outcomes such as decreased resource utilization, medication adherence, patient satisfaction, and improved patient self-management are only some that should be considered in future research.

In the quantitative phase of this study, portal use was situated within the middle range Theory of Self-Care of Chronic Illness.¹ According to the theory, patients who engage in self-care monitoring are able to share information with their provider, which in turn, leads to improved self-care management. Using the EPP, patients are able to monitor symptoms (self-

care monitoring) and then take action (self-care management). Findings from this study support this theoretical relationship, however, due to limited data regarding use of specific functions and the inability to review message content, further research is needed. Future studies should focus on evaluating the response of patients who use the EPP for symptom monitoring to determine if there is an improvement in self-care management.

Of the 500 patients included in the quantitative analysis, only eight patients entered their own data into the EPP. This finding generated many questions surrounding specific use of the EPP, especially as this feature was one that has direct implications related to self-management of chronic illness. Fortunately, some insight into the lack of use of this feature was captured during the qualitative phase of the study. All patients interviewed were unaware of the patient-entered data capability of the EPP. Furthermore, the one registered nurse participant also was not aware that this feature was available. Aside from this study, no other studies were found in the literature that focused on the EPPs capability for patient entered data. Further research is needed to explore how patients and providers can benefit from optimal utilization of this feature.

Recent popularity of consumer health information technology has resulted in a growing body of evidence on personal data tracking by patients. Computerized, disease-management applications (APP) for diabetes have shown only limited efficacy.¹⁵ In addition, studies of the effectiveness of self-management apps to improve outcomes, such as weight loss and asthma control, frequently find that participants stop using the technology after a short period of time.¹⁶ ¹⁷ In a recent qualitative study, Ancker¹⁸ and colleagues explored perceptions of data-tracking by patients with MCC. Findings include patients with MCC consider data-tracking work, perceive the data to be emotionally charged, and some patients perceived that their provider did not welcome the patient-generated data.

While tracking data using a smartphone APP uses the same technology as the EPP, it is different in that the EPP is tethered to the patient's EHR. It is not known if patients and providers would perceive patient-entered data using the EPP the same or different compared to a smartphone app. Providers interviewed in the current study had little if any experience with patient-entered data and when asked about it, usually responded with indifference. However, it did seem that younger providers, in general, had more favorable views of using the EPP in chronic illness management. Further research is needed to explore provider perceptions of patient-generated data and to evaluate the relationship between patient-generated data and health outcomes.

Implications for Policy

Maximizing EPP value to patients and providers should be the primary objective of underlying policies intended to increase use. Many policy implications can be derived from this multiple methods study related to creating a usable and sustainable health information technology infrastructure. In order to give context to the forthcoming policy implications, it is necessary to review the legislation that has shaped the current climate.

The HITECH Act, part of the American Recovery and Reinvestment Act of 2009, included a \$30 billion allocation for increasing use of health information technology.¹⁹ As the result of this legislation, a regulatory body, the National Coordinator for Health Information Technology (ONC) was established.²⁰ Regulated by ONC and administered by CMS, the federal EHR incentive program, also known as Meaningful Use, was created for the purpose of using technology to improve patient care.²¹ The MU incentive program was designed to roll-out in three stages each with increasing requirements. Providers who achieved certain benchmarks were able to collect incentive payments and those who did not, were subject to downward

payment adjustments. Stage 1 objectives focused on adoption of a certified EHR and capture of clinical data.²¹ Building upon the foundation established in Stage 1, Stage 2 included 17 core objectives, including the use of secure electronic messaging to communicate with patients and providing patients with specific educational resources. The proposed rule for MU stage 3 was entered into the federal register and made available for public comment on March 30, 2015.

CMS received over 2,500 comments including stark criticisms of the MU program from providers, hospitals, health systems, and organizations such as the American Medical Association and the American Hospital Association. The program was criticized for limiting innovation, lacking flexibility, and focusing on pass-fail requirements rather than outcomes.²² On November 4, 2016, CMS replaced the MU program with a new Merit-based Incentive Payment System (MIPS) program. The new MIPS program claims to allow providers to report on customizable measures appropriate for the type of care they provide. Payment adjustments (upward or downward) under the MIPS program measures will begin in 2019 using measurements from 2017-2018.²³ The HITECH Act provided necessary infrastructure to improve care by supporting the adoption of EHRs, however, findings from this study and others should be considered as policy makers evaluate existing policy and develop new ones. This work has resulted in specific recommendations related to ensuring the EPP is patient-centric, allows interaction between multiple providers, and is assimilated into delivery system reform.

Qualitative findings from this study revealed the need for a shift from provider-centric focus of the EPP to a patient-centric focus. Provider participants described a myopic view of the EPP as a tool they were mandated to use and as a means to an incentive payment. Providers reported giving little consideration to how the tool might benefit their practice (beyond incentive payments) and improve care of patients with MCC. This perception raises concern regarding the

sustainability of the incentive program and that actions (such as patient enrollment), rather than outcomes, are being incentivized. The MIPS program, for which providers must begin gathering data in 2017 and will report on performance measures in 2018, has attempted to mitigate some of these concerns.²³ Under MIPS, providers are given more flexibility in reporting and specific measures are designed to encourage patient engagement through improvements in the EPP. The performance category, beneficiary engagement, rewards providers who use their EHR to capture patient reported outcomes such as home blood pressure, blood glucose, and food diaries.²⁴ Changes like this are encouraging, however, sustainability requires consideration of other market drivers outside of financial incentives.

Patient value is imperative to future EPP development. Engaging patients using the EPP is dependent upon patients' perception that the EPP enhances their care and the patient-provider relationship.²⁵ The indifference by providers to interact with patients via the EPP revealed in this study suggest that incentive payments alone may not be enough to maximize the potential of this tool. Patient demand for online tools that offer adequate functionality and meaning may be the ultimate driving force behind optimal use. Opportunities to integrate other mobile technologies, such as exercise tracking and health management applications, are needed to personalize the EPP-users experience thus creating added value. Finding ways to ensure patient-valued EPP capacities and functionalities are integrated into health care services is necessary to achieve desired outcomes.

This study revealed that patients value having access to their healthcare information online and opportunities for improve efficiency. Therefore, giving patients access to more sections of their EHR and creating more opportunities for online interactions with the healthcare team should be considered. However, additional opportunities for patient interactions via the

EPP create concerns related to accountability. For example, expanded use of the patient-entered data feature of the EPP could result in provider concerns regarding data accessibility and retrieval. Providers must feel confident that appropriate notifications are in place when patient-entered data is available to avoid fear that missing it could lead to poor outcomes or legal consequences. In the current climate of information overload, clinical teams must address accountability and mitigate concerns that could impede EPP integration.

The opportunity for patient portals connecting multiple providers was not a focus of this study, however, findings have implications related to health information exchange (HIE). The majority of patients interviewed in this study reported having only one EPP, however, a few patients noted other portals available to them via specialty providers (e.g. optometrists) and acute inpatient facilities. None of the providers mentioned HIE in any context related to the EPP. State-level or regional health information exchanges facilitate information sharing among participating physicians and hospitals.²⁶ A 2013 survey of health information data exchange reported 90 community-based and 45 statewide HIEs in the United States.²⁷ HIEs have potential to improve integration of care across providers, especially for patients with complex care needs who see multiple providers. Achieving potential benefits of HIE such as availability of additional data to inform physician decision making, sparing patients of needless tests, and improved population health requires widespread stakeholder support.

HIE buy-in from providers, organizations, patients, and the public will require an effective and efficient business model that includes legislative, regulatory, and funding support. Incentive programs should be modified to encourage widespread provider participation. Achieving anticipated benefits for the public will require an inclusive approach to HIE. Some groups, for example, post-acute care providers and long-term acute care hospitals, who were

excluded from participating in the federal MU program, now lag in adoption by more than half compared to their acute-care counterparts.²⁸ Policy makers should consider additional measures that encourage and reward participation in HIE by providers across the continuum of care.

Concurrent with the HITECH Act which created a program to improve adoption of EHRs, the 2010 Affordable Care Act (ACA) supported development and implementation of new delivery and payment models such as the patient-centered medical home (PCMH) and accountable care organizations (ACO). Although providers who participate in these innovative delivery systems are not required to use EHRs, there is some evidence demonstrating benefits of their combined use. Findings from a 2012 study revealed physicians who were using an EHR in combination with participation in an PCMH or ACO had a high likelihood of performing care processes related to population management, quality measurement, patient communication, and care coordination.²⁹ As new delivery and payment systems emerge and existing systems are evaluated, use of the EPP in facilitating improved patient-provider communication and patient engagement should be explored.

The EPP is an emerging technology that is in its infancy. While federal policy has certainly hastened development, integration into chronic disease management requires time. As new generations of interdisciplinary team members enter the workforce, perceptions of technological tools like the EPP are likely to evolve. This study has resulted in many opportunities for enhanced use of the EPP for supporting patients with MCC. The millions of Americans whose daily life is impacted by chronic disease need and deserve tools to help them manage their care and to help lessen the burden that caring for them imposes on our limited healthcare resources. As patient-centered care continues to be a priority in healthcare, clinicians,

researchers, and policy makers should focus on using technology, like the EPP, to engage patients and improve outcomes.

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Vita

Kimberly Ryan Powell earned her Bachelors of Science in Nursing from Purdue University in 2001 and began her career as a critical care Registered Nurse. After working in the Intensive Care Unit and Open Heart Recovery Unit for one year, Ms. Powell transitioned to a career in travel nursing. As a travel nurse, Ms. Powell completed assignments in San Diego, CA, New Haven, CT, Honolulu, HI, and Athens, GA. In 2007, Ms. Powell returned to her home in Louisville, KY and received her first academic appointment as a didactic and clinical instructor in a Licensed Practical Nursing program.

Since her first academic appointment in 2007, Ms. Powell has held various faculty and administrative position in nursing education. She has taught in a two-year associate degree RN program, a LPN-RN bridge online program, and currently she is an associate professor in an RN-BSN online program. Ms. Powell has also held academic leadership positions and served as a Test Development Specialist where she was responsible for evaluation and development of nursing exams for a multi-state college.

In June of 2013, Ms. Powell earned her Master's Degree in nursing education and earned the credential of Certified Nurse Educator. In May of that same year, she enrolled in the PhD program at the University of Tennessee, Knoxville. As a doctoral student, Ms. Powell has served as a peer reviewer for *Issues in Mental Health Nursing* and was first author in a manuscript published in *Issues in Mental Health Nursing*. This manuscript focused on emotional intelligence in mental health nurse leaders.

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