USING GROUNDED THEORY TO DEFINE PATIENT ENGAGEEMNT FROM THE

PATIENT'S PERSPECTIVE

By

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Patient engagement has been found to lead to significant improvements in patient health, reduced costs, and improved patient experiences and has been the focus of healthcare research and policy change for over two decades as healthcare researchers, providers, and agencies strive to capitalize on its powerful effects. Initially, definitions and theories regarding what patient engagement is, how it works, and why it is important were generated from the perspective of healthcare providers and researchers, often missing what patients themselves thought about their own healthcare engagement. Even after researchers began to focus more on the patient perspective, most research has included patients who are already highly engaged in healthcare. This dissertation seeks to expand past research by adding the perspective of patients who vary in how often they use healthcare services and how engaged they feel.

This dissertation is comprised of the following seven chapters: (a) an introduction to the dissertation, (b) a systematic review examining the effectiveness of patient education through PHRs on patient engagement and health outcomes, (c) a literature review that outlines how theories and definitions of patient engagement developed, (d) a proposed methodology for the original research study, (e) an original research study using grounded theory to define patient

engagement from the perspective of a wide range of patients, (f) a discussion of implications for researchers, healthcare providers, and patients regarding patient engagement.

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"There is no such thing as a self-made man. You will reach your goals only with the help of others." – George Shinn

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CHAPTER 1: INTRODUCTION

The Commonwealth Fund regularly analyzes healthcare systems around the world using 71 performance measures across five domains — access to care, care process, administrative efficiency, equity, and health care outcomes (Schneider et al., 2021). While each country is unique and the results of the complex analyses should be interpreted with caution, the United States consistently spends more on healthcare than other high-income countries, and yet has worse outcomes (Schneider et al., 2021). Over two decades ago the Institute of Medicine made "patient-centered care" one of their six aims for quality improvement (Institute of Medicine, 2001) in an effort to revitalize healthcare systems in the United States and address this disparity between spending and outcomes. Since that time many attempts have been made by researchers, organizations, and providers to try and engage patients more completely in their own healthcare (Abbasgholizadeh, 2019; Daniel et al., 2020; Hibbard & Greene, 2013). While the factors that contribute to this disparity in the U.S. healthcare system are complicated, and no simple change will completely resolve such an issue, research has found that patient engagement is associated with significant improvements in patient health, reduced costs, and improved patient experiences (Hibbard & Greene, 2013), and has therefore generated a lot of excitement as a potential solution (Graffigna, 2017).

After an initial wave of research provided evidence to support policies focused on patient engagement, researchers began to recognize a need to develop foundational theories that explain what patient engagement is, why it is important, and how it impacts patient health (Phoenix et al., 2018; Rowland et al., 2017). Initially these definitions and theories came from providers or researchers who were familiar with the relevant literature and the current healthcare system and could offer their expert opinion on how to best conceptualize patient engagement (AHRQ, 2017;

Carman et al., 2013; Coulter, 2011; Higgins et al., 2017; Harrington et al., 2020). While relying on these providers and their expertise was a natural first step, a noticeable gap began to emerge in the research; the voice of the patient was often missing. The existing literature relied almost exclusively on the providers defining patient engagement without engaging the patient in that process (Pomey et al., 2015). To try and address this gap, other researchers have sought the perspective of the patients themselves (Brown et al., 2015; Fiction et al., 2008; Mercer et al., 2020; Walters et al., 2017). While these studies have helped expand our understanding of patient engagement, they also have some limitations.

In a qualitative study done by Pomey et al. (2015), patients who were educated specifically on how to act as engaged partners on their healthcare team were asked their views of their engagement with healthcare professionals throughout their care. The authors identified:

> That patient engagement includes only those patient activities that are in line with health practitioners' prescriptions and implicitly excludes attitudes or activities that raise contestation and resistance…what is missing from the literature is an empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care. (pg. 3)

In other words, while certain aspects of a provider generated definition of patient engagement may be corroborated by the patient's perspective, patients may also define engagement in ways that contradict our current understanding or offer additional ideas of what may constitute engagement in their care. What's more, the studies that capture the patient's perspective in defining patient engagement typically rely on patients who are accessible, or who are more likely to already be highly engaged in their care (Brown et al., 2015; Pomey et al.,

2015). There could be yet another layer of perspectives from patients who are less engaged in their care.

This study explored this gap in the literature using a grounded theory methodology (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018) to gather the perspective of patients who range in their level of engagement. These perspectives will build on our current understanding of what patient engagement is, why it's important, and how it affects patients' health. In this first chapter, I will briefly introduce the concept of patient engagement before outlining the chapters of this dissertation and presenting my research questions.

Patient Engagement

In addition to research on patient engagement's positive effects on patient health outcomes (Hibbard & Greene, 2013), healthcare experiences (Hibbard & Greene, 2013), healthcare costs (Hibbard & Greene, 2013), and provider care experiences (Goel et al., 2016), researchers have been trying to establish a consistent theoretical definition of what patient engagement actually entails (Cene et al., 2016). Over the years, patient engagement has been studied by several different disciplines, including medicine, nursing, political science, management, psychology, social science, and even computer science (Barello et al., 2014), leading to many different definitions and theories about how to maximize its effect. The Agency for Healthcare Research and Quality has even tried creating a standard definition, defining patient engagement as, "a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations" (2017, pg. 10). However, a systematic review in 2020 found that definitions in research and healthcare still vary widely (Harrington et al., 2020).

It is also important to realize that patient engagement has also become an umbrella term for similar concepts such as patient activation (Hibbard et al., 2009) and patient-centered care (Institutes of Medicine, 2001). Patient activation focuses on patient behaviors that help them manage their own health whereas patient-centered care focuses on provider behaviors and organizational policies that enable patients to be engaged in their care. Researchers have explored many facets of patient engagement and realized that engaging a patient in their care relies on the systemic interplay of multiple factors, such as the patient's effort to be engaged, as well as healthcare providers' and organizations' willingness to allow them to be engaged (Graffigna and Barrello, 2018).

My interest in patient engagement stems from my training as a medical family therapist (MedFT). Clinically, the two central aims of MedFT are empowering a sense of agency and communion for patients (McDaniel et al., 2014). McDaniel and colleagues define agency as empowering the patient to have a say in the treatment they receive and be included in the decision-making process. They define communion as the idea that patients feel they understand and are understood by their care team and are welcomed and involved in the process (McDaniel et al., 2014). I have personally experienced the improvements in patient health outcomes (Hibbard & Greene, 2013), healthcare experiences (Hibbard & Greene, 2013), healthcare costs (Hibbard & Greene, 2013), and provider care experiences (Goel et al., 2016), that come when patients are more engaged in their care, or in other words when they feel a sense of agency and communion.

A Systematic Review of Patient Education through Personal Health Records

This project began with a question regarding patients' use of patient education materials through personal health care records and how that influenced patient's outcomes. With the

advent of new consumer health technologies, patients have had more access to their healthcare information than ever before (Hoyt et al., 2018). Personal health records (PHRs) are online portals that give patients access to their providers' electronic health record (EHR), allowing them to view lab results, medication refills, educational materials, appointment scheduling, send secure messages to their team, and engage in telehealth visits. Each of these features is designed to help increase patients' ability to take an active role in their healthcare decisions and management (Hoyt et al., 2018). Chapter 2 is a systematic review examining the effectiveness of patient education through PHRs on patient engagement and health outcomes. The search for all relevant literature was run using five electronic databases (PubMed, CINAHL, Scopus, PsychINFO, Embase). Initial results ended with the review of 17,807 articles before identifying 52 that met the inclusion criteria. Results of the review found that efforts are indeed being made to raise awareness of educational resources in PHRs, that patients are increasingly utilizing these resources, that patients are finding them useful, and that they are improving health outcomes.

While the purpose of that review was to explore outcomes associated with PHRs, it became clear, as I was reviewing the literature, that the very concept of patient engagement was limited based on the heavy reliance of provider perspective and the relatively little contribution from patients. Each time, patients were only asked whether they liked the features provided in the new PHR or how they impacted their health (Day et al., 2019; Ector et al., 2020; Fiks et al., 2014; Hess et al., 2006; Jones et al., 1992; Lum et al., 2019; Martinez et al., 2018; Navaneethan et al., 2017; Warrington et al., 2015; Zhang et al., 2016). Even when one study included patients earlier in the process, asking them to vote for which features should be included in a PHR product (Fricton et al., 2008), they were asked to select their favorite features from a

predetermined list of options. This made me wonder what features patients would ask for if they were allowed to submit their own ideas of what they find useful. Some of their ideas may not be feasible with the given technology, but it would still be interesting to see how their suggestions were similar or different from those suggested by providers and software developers. It would also be interesting to see how this might redirect the development of future systems and products. This thought evolved into a larger realization, that our current understanding of patient engagement developed in a similar way. This realization became the foundation for this study.

A Review of Literature Regarding Patient Engagement

Chapter three is a literature review that outlines how theories and definitions of patient engagement developed initially from the providers' perspective (Carman et al., 2013; Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017), with the patient perspective being added later to determine if it aligned with providers' definitions (Mercer et al., 2020; Walters et al., 2017). In the studies that did include patients' perspectives, patients were often selected from populations who have frequent interactions with the healthcare system, also known as high utilization (Brown et al., 2015), or who were already highly engaged (Pomey et al., 2015). Conceptually, patients' perspectives of their engagement could differ depending on whether they have high or low utilization, or whether then feel high or low levels of engagement. Someone who frequently visits the doctor could still feel relatively unengaged in their care, while someone who only visits the doctor for annual wellness visits or on an as needed basis might consider themselves highly engaged. Pomey et al. (2015) found that patients they interviewed were ill long before they felt engaged by healthcare providers but were actively engaged or managing their health in other ways. In fact, even patients' noncompliant responses to healthcare providers recommendations could be considered a form of engagement (Pomey et al., 2015), especially by

populations who have historically experienced discrimination in healthcare and may therefore have more barriers to feeling engaged (Parameshwaran et al., 2017). Capturing the perspective of patients who range across high and low levels of utilization and engagement could help us better understand what it really means to be engaged, why it's important, and how they go about doing it.

Grounded Theory Methodology and Research Questions

Chapter four outlines the methodology for this dissertation. The gap in the research identified in chapter three was filled by a grounded theory study capturing the perspective of patients who range in their level of engagement. Grounded theory methodologies are specifically designed to build theory around a specific concept (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018). They accomplish this by interviewing a variety of different voices to help provide the most robust emerging theory possible when exploring either a new concept or trying to expand an old one. Because the focus of this study was on understanding the concept of patient engagement as defined by patients, rather than focusing on each patient perspective itself, we used a grounded theory methodology to synthesize the qualitative perspectives of multiple patients into a theoretical definition of patient engagement that can be transferred to the general population (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018). Using a snowball sampling technique, we recruited patients with different levels of utilization and engagement in order to more fully capture ways that patients feel they are engaged that may not fit into traditional provider-driven views of what constitutes patient engagement. This chapter will include an explanation of grounded theory methodology and what makes it particularly suited to answer these questions, as well as the intended procedures for sampling, conducting the qualitative interviews, and data analysis.

Specifically, this study sought to answer the questions:

1. How do patients define or describe patient engagement?

2. How important do patients think patient engagement is?

3. How do patients explain the effect patient engagement has on their health outcomes?

Using Grounded Theory to Define Patient Engagement from the Patient's Perspective

Following this proposed methodology, chapter five the findings from an original research study using grounded theory to define patient engagement from the patient's perspective were presented in. This will be structured as a publishable manuscript, with a brief introduction and review of the literature, the proposed methodology, the reported results and a discussion of the implications of the study. Lastly, Chapter six will again summarize the entirety of this dissertation and further discuss the noteworthy findings of both the systematic review and the original research study and their implications for research and practice.

Summary

This dissertation addresses the gap identified by Pomey et al. (2015) to add an "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). Using a grounded theory methodology (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018), it captured the perspectives of patients who range across high and low levels of engagement to discover a more robust understanding of what patient engagement is, why it's important, and how it affects patients' health. This will build on the preexisting work that has been done to develop a theoretical understanding, first from healthcare researchers' and providers' perspectives (Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017) and then from highly engaged patients

(Brown et al., 2015; Pomey et al., 2015), as it will add the perspective of patients who range across different levels of activation and utilization, and whose efforts to be engaged in their healthcare may differ from providers prescriptions or expectations (Pomey et al., 2015). This enhanced theoretical understanding has the potential to help us better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on both organizational and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

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CHAPTER 2: SYSTEMATIC REVIEW

Introduction

Patient education is an effective way to increase *patient engagement* (Carman et al., 2013). It has been shown to a) improve patient outcomes, b) improve patient experience, c) reduce costs, and d) improve provider experience (Bodenheimer et al., 2014). Since the Institute of Medicine (IOM) established new aims for an improved healthcare system, efforts have been made to make healthcare safe, effective, patient-centered, timely, efficient, and equitable (IOM, 2001). One of these efforts included attempts to increase patient engagement (Carman et al., 2013). Healthcare providers and organizations believe that using education to increase patient engagement would improve patients' knowledge, skill, and confidence in managing their own health and health care (Carman et al., 2013; Gilliam et al., 2017).

Current research shows that patients are interested in and want education and information about their health and how to manage it (Friction et al., 2008; Kildea et al., 2019). They are turning more frequently to online sources for information about their condition, especially when they feel providers fail to answer their questions (Aguirre et al., 2017; Delic et al., 2006; Kraschnewski et al., 2014). While the internet can be helpful (Alhuwail et al., 2019; Fiksdal et al., 2014) sources such as YouTube, Wikipedia, Google, and social media are also unfiltered and sometimes contain information that is either less accurate or inaccurate (Aguirre et al., 2017; Ferreiara et al., 2019; Smith, 2020). This is potentially problematic because studies indicate that patients with lower health literacy have a harder time distinguishing between reputable and unreputable sources (Chen et al., 2018).

To offset this, healthcare providers and organizations created personal health records (PHRs), which are apps or online portals, which are tethered, or

connected, directly to the electronic health records (EHRs) of these providers and organizations (Hoyt et al., 2018). These PHRs provide patients access to their health records, lab results, medication refills, educational materials, and telehealth visits, increasing patients' ability to take an active role in their health care decisions and management (Hoyt et al., 2018). Healthcare providers can leverage PHRs to meet the rising demand for health education and information by providing reputable resources to the patients online in a controlled and tailored manner (Aguirre et al., 2017; Delic et al., 2006; Fiksdal et al., 2014).

Unfortunately, despite attempts to expand PHRs, patient use and adoption of these resources has been relatively low (Nambisan, 2017). Social location factors such as age, race, and socioeconomic status can limit patients' ability to access or understand PHRs (Graetz et al., 2016). A common barrier to accessibility is providing resources at a literacy level that the average patient can understand (Nambisan, 2017). To date, the percentage of patients who are registered to use their PHR is typically less than 50% of the total patient population, and the number of patients who use it routinely is even lower (Ancker et al., 2016). There appears to be a disconnect between the resources provided and the patients' use of these resources. In order to achieve the aims of healthcare, providers need to know how effective PHRs are, what factors determine whether patients are using them, and how to increase their effectiveness in the future. The objective of this study was to systematically review all the literature studying the effectiveness of patient education through PHRs on patient engagement and ability. In this case, effectiveness will be measured by a) availability and awareness of educational resources in the PHR, b) patient utilization of these educational resources, c) patient perceived usefulness of these educational resources, and d) the effect of the educational resources on health outcomes.

Research Question

1. What is the effectiveness of educational resources within PHRs?

    a. Are patients aware of the educational resources within the PHR?

    b. Are they utilizing the educational resources?

    c. Do the patients find the content useful?

    d. Does use of the educational resource in patient portals increase patients' understanding of their own health condition and improve their self-management or health outcomes?

Method

PHRs are sometimes referred to as online patient portals. In this study, the terms are treated as synonymous, but the term PHR will be used primarily.

Search Strategy and Screening

One author (CH), who is an information specialist/librarian, iteratively designed the search strategy using recommended controlled vocabulary and keywords for patient education and PHRs (see Table 1). The search was initially mapped in PubMed using MeSH terms and then subsequently mapped to controlled vocabulary for the other identified databases (CINAHL, Scopus, PsychINFO, Embase). No limitations were placed on the search (i.e., date, peer review, geography or language). The date of the original search was June 2, 2020, with a follow-up search on March 8, 2021 to ensure any new studies published during that time were included. All studies produced by the initial search were loaded into Endnote X9 (Clarivate Analytics, USA) for manual deduplication. After deduplication, the studies were loaded into Covidence (www.covidence.org), which identified additional duplicates missed during initial deduplication.

Two reviewers (AJ & EJ) independently screened all the titles and abstracts against the inclusion and exclusion criteria (see Table 2). Conflicts were resolved by discussion until consensus was reached. Articles that passed the initial screening were then included in a second round of screening, where studies underwent a full-text review to determine their inclusion into the final review. Any discrepancies between the reviewers (AJ & EJ) were discussed until consensus was reached. The PRISMA flow diagram (Figure 1) provides a record of the article selection process for the review. A systematic review protocol is available online (https://osf.io/uey5c/?view_only=b3a792a77ab64fc8a5e5a39cec0cdfbd).

Table 1. *Reproducible Search Terms for PubMed*

("Medical Records" [mh] OR Patient Access to Records"[mh] OR "health record"[tiab] OR "health records"[tiab] OR "Patient portal"[tiab] OR "Patient portals"[tiab] OR "Patient Web Portal"[tiab] OR "Patient Web Portals"[tiab] OR "Patient Internet Portal"[tiab] OR "Patient Internet Portals"[tiab] OR "Patient access to records"[tiab] OR ((electronic[tiab] OR automated[tiab] OR medical[tiab]) AND record*[tiab]) OR EHR[tiab] OR EMR[tiab] OR PHR[tiab] OR e-PHR[tiab]) AND ("Patient Participation"[mh] OR "health literacy"[mh] OR "consumer health information"[mh] OR "consumer health informatics"[mh] OR "patient education as topic"[mh] OR "Patient Involvement"[tiab] OR "Patient Empowerment"[tiab] OR "Patient Participation" [tiab] OR "Patient Activation"[tiab] OR "Patient Engagement"[tiab] OR "health literacy"[tiab] OR "patient education"[tiab] OR "patient guideline"[tiab] OR "patient guidelines"[tiab] OR "teaching material"[tiab] OR "teaching materials"[tiab] OR "instructional material"[tiab] OR "instructional materials"[tiab] OR "educational materials"[tiab] OR "educational material"[tiab] OR "consumer health information"[tiab] OR "consumer health informatics"[tiab] OR "consumer health materials"[tiab])

Table 2. *Criteria for Inclusion and Exclusion*

Inclusion	Exclusion
(1) Tethered personal health records or patient portals only (PHR's as an extension of the EHR system of a healthcare organization).	(1) Not tethered to provider/organization's EHR (i.e. online registry creates record of patient reported outcomes, not from provider)
(2) Educational resources provided by the organization to the patients through the tethered PHR system.	(2) No education about health conditions
	(3) provider oriented, not patient facing
	(4) different research question (health literacy assessments of PHR educational resources, or provider perceptions of PHRs)
	(5) based on provider communication (providers use PHR to send education. Not included in the PHR)
	6) not a PHR (apps can be tethered, draw information, without allowing patients access back to their record)
	(7) duplicate study
	(8) No patient data (product meets criteria, but does not answer the questions of this review)

Data extraction and Synthesis

Data extraction was done using Covidence and Microsoft Excel. Extracted data elements include: author(s) last name(s), year of publication, country and language in which published, patient portal used, population size and characteristics, sampling method, study design, outcomes, and findings. Data extraction was performed by the primary investigator (AJ), and confirmed by another author (EJ). Data were synthesized using narrative synthesis methods (Popay et al., 2006). One author (AJ) synthesized findings and one author (AB) checked the results and provided recommendations for any needed changes.

Risk of Bias and Inter-Rater reliability

Due to the heterogeneity of study designs, aims, and characteristics, no quality assessment was performed. Interrater reliability analysis using the Kappa statistic was performed to determine consistency among the screeners. Interrater reliability for the title and abstract screening was found to be Kappa = 0.275, and title abstract screening for the full text review was found to be Kappa = 0.499. These measurements are considered to be fair and moderate, respectively (McHugh, 2012).

<div align="center">

Results

</div>

The initial search retrieved 17,807 total articles across the five identified databases. Following manual and machine-driven deduplication, there were 12,062 unique articles remaining for title and abstract screening. Following title and abstract screening, 180 articles were retained for full text review. Fifty-two articles were retained for full inclusion in this review. A follow-up search was performed March 8, 2021, which identified 759 articles for screening which had been published since the original search. Since I wanted to do the follow-

up search as close as possible to submitting this study for publication, there has not yet been time to analyze these articles before the competency exam defense.

Due to the large number of studies included (n = 52), a master table with the information from all the studies is included as an appendix (see Appendix A). Results are organized by the research questions, with smaller tables describing the articles relevant to each of the four sub questions guiding the review. Of the studies included, 36 (69.2%) were based on US healthcare systems and 16 (30.8%) were based on other countries. Forty-four of the PHR systems (84.6%) were utilized in outpatient settings, while nine (17.4%) were for inpatient treatment (one was utilized in both, and so double counted). Forty-three (82.7%) provided education for the patient, eight provided education for both the patient and the caregiver (15.2%), and one targeted only the caregivers (0.02%). The populations targeted in the included studies varied across several health conditions (i.e., diabetes, cancer, pregnancy, etc.). Another important finding was that 40 of the studies (77%) of the articles included in the review were published between 2013-2020, with only one being published before the year 2000 (Jones et al., 1992), indicating that PHR's are still a relatively new resource being developed.

Figure 1. PRISMA Flowchart of the Inclusion/Exclusion Process.
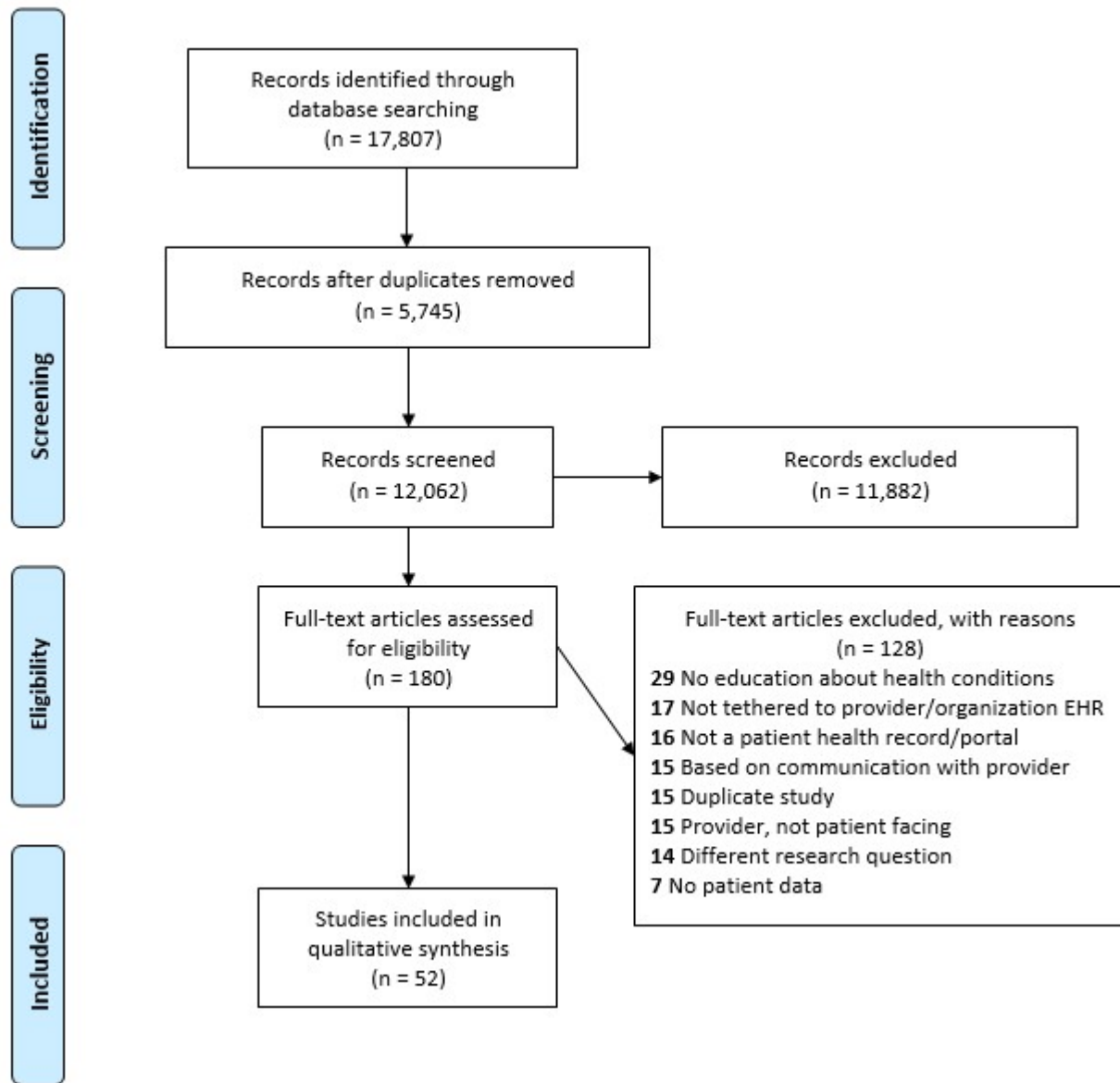
Figure 2. Number of Included Articles Relevant to each of the 4 Research Questions.
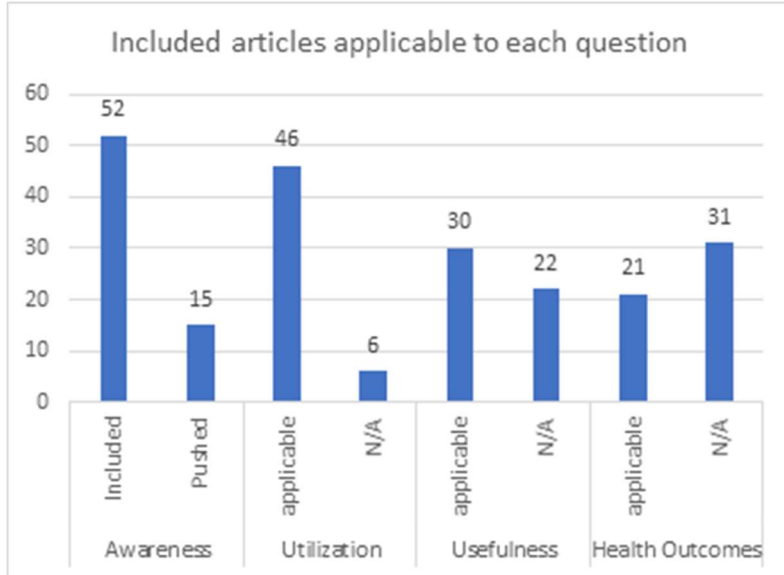
Results are sectioned according to research question. "Applicable" represents the number of articles included in the review, which relate to each of the four questions. N/A indicates the number of included articles which did not include results relevant to each question.

Question 1 - Are patients aware of the educational resources within the PHRs?

The primary factor determining whether an article was included was its use of patient education within the PHR. As a result, all 52 studies had some educational features as a portion of their PHR and each made attempts to inform their patients about its availability (see Figure 2). Of these studies, 15 (28.8%) had content pushing features, meaning that the PHR automatically linked patients with relevant educational resources based on their medical information, such as diagnoses (Abidi et al., 2000; Ahmed et al., 2020; Arcia, 2017; Borbolla et al., 2014; Cameron et al., 2016; Chen et al., 2015; Hulse et al., 2013; Ma et al., 2005; Navaneethan et al., 2017; Sridhar et al., 2017; Warrington et al., 2015; 2017; 2019; Wells et al., 2014; Zhang et al., 2016). The impact of this feature will be further explored in the discussion section. While these studies confirm that patients were notified of the educational

resources available, especially those who were enrolled in the 15 studies relying on push notifications, it doesn't necessarily provide insight into the awareness of the typical patient who is not enrolled in an ongoing study measuring the use of PHRs. It may be that non-participant patients still are not aware of these features and therefore they remain underutilized.

Question 2 - Are patients utilizing the educational resources?

While all included PHR studies had educational resources and made patients aware of them, utilization of these resources remained low. Of the 52 studies included in the review, 46 (88.5%) reported on patient's utilization of the educational resources (see Figure 2). They obtained this data in a variety of ways, including a) survey data relying on patient self-report (n = 16; 30.8%); b) required utilization for pilot studies (n = 11; 21.2%), c) qualitative statements simply saying that resources were used (n = 10; 19.2%); and d) metadata audits of PHR systems and how often resources were clicked on or accessed online (n = 9; 17.3%).

The most common form of data collection (survey data) revealed that, according to patients' self-report, utilization rates varied from as low as 20% (Steiner et al., 2017) to 95% (Zhang et al., 2016) with an overall average of 47% across 12 studies (see Table 3). This finding excludes the 11 studies whose utilization rates were 100% because participants were required to use it as part of the study for pilot testing (Baek et al., 2018; Day et al., 2019; Fiks et al., 2014; Haggerty et al., 2013; Hess et al., 2006; Martinez et al., 2018; Smallwood et al., 2017; Warrington et al., 2015; Zide et al., 2017). The variability in utilization rates seems to be associated with sample size, as studies with smaller samples typically experienced higher utilization rates. There also appears to be some discrepancy between desire for resources and the actual rate at which participants use them. Patients reported wanting educational resources included in the PHR between 84% (Friction et al., 2008; Kildea et al., 2019) and 89% (Wiljer et

al., 2006) of the time, and planned on using them "very often" (Hefner et al., 2017). It's also worth noting that 78% of caregivers also indicated that they wanted educational resources (Friction et al., 2008). Although many participants reported wanting educational resources, and felt they would use them frequently, the data does not support this.

Metadata audits of the PHR software reported the number of times educational resources were accessed over varying amounts of time (Ancker et al., 2016; Benson et al., 2019; Borbolla et al., 2014; Cunningham et al., 2014; Ector et al., 2020; Huerta et al., 2019; Jordan et al., 2019; Lafreniere et al., 2020; Lum et al., 2019) but the nondescript nature of the audit made it hard to interpret how frequently educational resources were utilized by individual patients. However, one of the studies specifically reported that patients who accessed educational resources through the PHR made up only 42% of registered PHR users, and 10% of the entire patient population of that site (Ancker et al., 2016). This finding, along with varying rates of utilization found from survey data (see Table 3), raise an interesting dilemma. If the utilization rates are this low and vary this drastically among patients who are actively being asked to test PHRs, it is likely that utilization could be even lower in the general patient population.

Table 3. *Rates of Utilization.*

Author	Utilization
Arcia (2017)	75% (12/16)
Cameron et al. (2016)	47% (55/116)
Cho et al. (2019)	42% (84/201)
Groen et al. (2016)	89% (33/37)
Jones et al. (1992)	24% (17/70)

Kelly et al. (2017)	61% (111/181)
Naveethan et al., 2017	47% (99/209)
Roelofsen et al. (2014)	27% (110/405)
Steiner et al. (2017)	20% (43/216)
Warrington et al. (2019)	78% (276/354)
Woollen et al. (2016)	85% (12/14)
Zhang et al. (2016)	95% (19/20)

*Parentheses show the number of patients who reported utilizing the PHR education over the total sample size. The total number of patients who utilized PHR education in these studies was 871/1839 (47%).

Question 3 - Do the patients find the content useful?

Only 30 of the 52 studies included in the review included some aspect that measured the patients' perception on the usefulness of the data (see Figure 2). Based on the review of those articles, it appears that patients find educational resources in PHRs to be extremely useful. Like utilization rates, these reports were received using a variety of methods, including a) surveying the study sample to see what percentage of participants perceived education resources as useful (n = 13, 43%), b) qualitative statements simply stating that patients thought they were useful (n = 9, 30%), c) having participants report how useful they thought the resources were using Likert scale measurements (n = 6, 20%), and d) utilizing validated measures to see how useful the resources were to patients (n = 2, 7%).

Of the four different styles of measurement, the two most informative were the survey studies reporting overall use by the sample and those who relied on Likert scales to quantify the

degree of usefulness (see Table 4). The survey studies showed that patients thought

the educational resources within the PHR were very useful, with 78% of the combined

samples (540/689) reporting that they were useful. Scores from the Likert scales indicated that

participants strongly agreed that the educational resources were very useful (see Table 4). While

this review focuses on patient perceptions, it is also worth noting that Friction et al. (2008) found

that 70% of caregivers thought it was useful too, as caregiver engagement can have enormous

impacts on patient outcomes (Carr et al., 2010).

Two studies used the Net Promoter Score (NPS; Cho et al., 2019) and the System

Usability Scale (SUS; Lum et al., 2019) to measure patient's perceptions of usefulness, and both

reported that patients found educational resources included in the PHR to be very useful. While

this only makes up 7% of the included studies measuring perceptions of usefulness, they

are noteworthy because they represent a shift in the field to more standardized methods of

measurement. The importance of this will be discussed further as implications for future

research. The remaining nine simply stated that patients thought the resources were useful, often

with quotations from qualitative studies (Benson et al., 2019; Collins et al., 2017; Ector et al.,

2020; Goldberg et al., 2003; Jordan et al., 2019; McAlearney et al., 2020; Smallwood et al.,

2017; Steiner et al., 2017; Warrington et al., 2017).

Table 4. *Patient's Report of Education Resources' Usefulness*

Authors	Percentage	Authors	Likert
Benhamou (2011)	74% (13/18)	Martinez et al. (2018)	5.8/7
Warrington et al. (2015)	42% (5/12)	Baek et al. (2018)	4.23/5
Groen et al. (2016)	69% (26/37)	Ahmed et al. (2020)	4.3/5
Day et al. (2019)		Arcia (2017)	4.7/5

Yeh et al. (2008)	78% (7/9)	Hefner et al. (2017)	4.5/5
Friction et al. (2008)	70% (35/50)	Fiks et al. (2014)	8.4/9
Hess et al. (2006)	70% (128/182)		
Wiljer et al. (2006)	71% (15/21)		
Wiljer et al. (2010)	79% (37/46)		
Woollen et al. (2016)	98% (123/125)		
Jones et al. (1992)	86% (12/14)		
Kelly et al. (2017)	84% (59/70)		
Zhang et al. (2016)	68% (61/90)		
	96% (19/20)		

* Parentheses show the number of patients reporting PHR education as useful over the total sample size. The total number of patients who said PHR education was useful across these studies was 540/689 (78%).

** Likert scale shows the average score of patient reports of usefulness of the PHR education resources. A score above the midpoint of the scale (i.e. < 3/5, < 4/7, < 5/9) indicates patients reporting that the education was useful.

Question 4 - Does use of the patient education information in patient portals increase patients' understanding of their own health condition and improve their self-management or health outcomes?

The use of patient education resources provided through the PHR did have a positive effect on patient outcomes. Of the 52 articles included in the review, 21 (40.4%) reported on the association between patient education and patient self-management and health

outcomes (see Figure 2). Patient outcomes were measured in three ways, including a) improvement in self-management of health conditions (n = 12, 57%), b) changes in patient lab values (n = 5, 24%), and c) adoption of desired health behaviors (n= 4, 19%).

The most common measure of patient outcomes, self-management of health, was determined in two different ways; quantitative measures that scored improvement (n = 6) and qualitative reports from patients (n = 6). The six studies that used measured outcomes quantitatively found that use of educational resources in the PHR were associated with significant increases in a) patient activation (Groen et al., 2016); b) knowledge of conditions (Chen et al., 2015; Zide et al., 2017); c) self-management (Zhang et al., 2016); d) adoption of desired health behaviors (Chen et al., 2015); e) decision making (Smallwood et al., 2017); and f) decreased anxiety (Wiljer et al., 2010). The patients in the qualitative self-report studies indicated that they felt that education through the PHR a) increased their knowledge of their health (Arcia, 2017; Ector et al., 2020; Jordan et al., 2019; Kelly et al., 2017; Woollen et al., 2016); b) increased their confidence in their ability to take care of themselves or those in their care (Arcia, 2017; Ector et al., 2020; Jordan et al., 2019; Kelly et al., 2017; Warrington et al., 2017); c) improved safety during and after hospitalization (Kelly et al., 2017; Woollen et al., 2016); d) improved decision making and ability to communicate with healthcare providers (Kelly et al., 2017); and e) decreased anxiety around treatment and prognosis (Warrington et al., 2017; Woollen et al., 2016).

As for improvements in health behaviors and lab values, four studies reported significant improvements in patients adopting positive health behaviors such as receipt of vaccination (Cameron et al., 2016), use of effective contraception (Sridhar et al., 2017), medication compliance (Chen et al., 2015), and decision to do a preventative screening

procedure (Day et al., 2019). Changes in patient lab values (i.e. HgA1c) following use

of educational resources were positive, though not always significantly so. Two studies

associated significant improvements (Benhamou, 2011; Goldberg et al., 2003) in intervention

groups who were given educational resources, while three found improvements that were not

significantly better than control groups (Cho et al., 2019; Gilliam et al., 2017; Navaneethan et al.,

2017). While on the subject of non-significant findings, three studies listed earlier also included

non-significant positive findings for impact of education on self-efficacy (Ross et al.,

2004; Wiljer et al., 2010), adherence (Ross et al., 2004), knowledge (Gilliam et al., 2017), and

health behaviors such as physical exercise (Groen et al., 2016). In each of these cases, non-

significant results still showed slight positive changes and were often

presented alongside significant findings in other aspects of patient health, so it seems that use of

educational resources in the PHR is generally associated with improvements in patient

outcomes.

Discussion

This review sought to evaluate the effectiveness of educational resources within PHR

systems by determining availability and patients' awareness of resources, their utilization of

those resources, the perceived usefulness of those resources, and the effect of those resources on

patient outcomes. We found that many providers and healthcare organizations have developed

PHRs to provide more accurate and reliable sources of information in response to patients'

increased interest in their own healthcare (Friction et al., 2008; Kildea et al., 2019). Although

this field is relatively new, preliminary research shows discrepancies exist between patients'

desire for information and their actual utilization of those resources (Ancker et al., 2016; Hefner

et al., 2017). While a discrepancy exist, current research does suggest that patients found these

resources useful (see Table 4), and when used, they had a significant impact on patient outcomes (Benhamou, 2011; Cameron et al., 2016; Chen et al., 2015; Day et al., 2019; Goldberg et al., 2003; Sridhar et al., 2017).

The variability of the types of findings included in this review may be due to the fact that research regarding patient education through PHR systems is still in its infancy. Most of the articles included in the review (77%) were published between 2013-2020, because PHR's themselves are a relatively new technology. Up to this point, most research has focused on development, design, implementation, and beta testing new systems and resources, and so have used a wide variety of methods and measures of effectiveness. While these studies have added to the existing literature the fact that they are measuring different variables makes is hard to establish a consistent message regarding utilization rates and effectiveness. One benefit of a systematic review is it provides a comprehensive summary of the literature that exists around a specific topic and highlights some of the potential gaps. One finding this review highlights is that patients who are using the educational resources found in PHRs are finding them helpful. How helpful is hard to determine because researchers have typically used a variety of different methods to measure both utilization and effectiveness. Different measurements make it difficult to develop a cohesive argument regarding the effectiveness of these resources, especially when fighting for limited resources. Future research in this area should consider using standardized measures to help strengthen the argument surrounding PHRs and their effectiveness.

In addition to strengthening the idea that patient education through PHRs improves patient experiences and patient outcomes, these findings, together with additional research that PHRs improve providers' experiences in healthcare (Goel et al., 2016), and reduces costs of care (Popovich et al., 2008), suggest that PHRs are an effective means

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of achieving the quadruple aim of healthcare (Bodenheimer et al., 2014). However, it seems that utilization of educational resources is low (see Table 3; Ancker et al., 2016) even after patients are made aware of them. These findings highlight a common finding in effectiveness research. Utilization rates are potentially inflated because attempts to study PHRs require that participants are enrolled in studies where they are being asked, as part of the study, to use the resources. This was especially true in pilot studies where utilization rates were 100% because participants were required to use them. However, in studies where they simply measure rates of use (i.e., metadata studies) utilization rates are relatively low. These findings present an interesting dilemma for professionals in this field that needs to be addressed. Strategies for increasing use by the average patient need to be developed. A couple of strategies that seem to make a difference, based on this review, is including additional resources, like patient navigators, automating connection of patients with relevant resources, or keeping the sample small. Studies who had smaller samples seemed to figure out ways to increase utilization rates; rates that seem to drop as the sample increases. Considering that this technology is still relatively new, there is hope that patient utilization will increase as patients become more aware of its availability. Like many new technologies, utilization rates might continue to be low for the average American until a tipping point occurs that shifts use from early adopters (those who are either technologically savvy or heavily invested in their health) to a part of the mainstream culture. Efforts to raise this awareness will be essential if PHRs are ever going to realize the full potential these resources have to increase patient health. Also, it is important to recognize that, given the rapid pace of technological advances, new technologies will continue to expand and develop, thus, requiring research to evolve with it.

Limitations

While this systematic review had several strengths there is an important limitation to consider. The majority of articles that match our criteria are from the US (69.2%). There are several possible explanations for this realization. First, all of the authors on this project are from the US and therefore may be more familiar searching systems based on literature published predominantly in the United States. Second, the search was limited to PHRs that were tethered. Other countries may have several good studies related to patient education that operate differently enough to not meet the inclusion criteria for this review (i.e. Australia's patient-owned record, which is not tethered to an organization).

Implications for Future Research

Now that PHR's are more common and established, future researchers should seek to use more uniform methods of measurement so that results can be easily compared between studies and systems. We are already seeing the beginning of this trend, with some studies using validated measures of effectiveness rather than just using participant self-report (Cho et al., 2019; Lum et al., 2019). What's more, after beta testing PHRs with small sample populations, studies should move to observe rates of utilization in the general population so that we can observe their impact in everyday contexts, rather than in controlled settings (Ancker et al., 2016).

In response to the issue of low utilization, future research should study the effect of interventions (i.e. pushing education or patient navigators) on PHR patient education utilization. Providers and organizations can raise awareness and utilization by programing PHRs to push, or connect, relevant education to patients. Relying on push notifications may help providers avoid the existing problem that is happening where an amazing library of educational

resources lies dormant while patients are seeking unreliable sources to answer many of their health care questions because they don't know where else to look (Fomous et al., 2006; Fountain et al., 2016). Personalized or patient-relevant education can be pushed to patients based on diagnosis (Abidi et al., 2000; Ahmed et al., 2020; Ma et al., 2005; Wells et al., 2014), lifespan stage (Arcia, 2017; Timmer, 2011), prevention for at-risk populations (Cameron et al., 2016; Sridhar et al., 2017), or any other personal health information (Borbolla et al., 2014; Zhang et al., 2016). This can be done by providers, sometimes known as patient navigators (Naveethan et al., 2017), but can also be automated to reduce costs (Warrington et al., 2015; 2017; 2019). It may be beneficial for future research to focus more on specific strategies that help increase utilization rates.

Patient reported outcomes (PROs) are another rising feature in PHRs that may help connect or push relevant resources with the patients who need them. PHRs now often include the ability for patients to input health data into their record themselves, allowing them to track outcomes such as HgA1c or blood pressure from home (Benhamou, 2011; Roelofsen et al., 2014). Warrington et al. (2015; 2017; 2019) developed a way for the PHR to tailor patient education and pushed resources to patients based on PROs, thus increasing their capacity for self-management. Future research should continue to study the ability to tailor education to the patient based on health outcomes, especially as patients begin to be able to record those outcomes themselves. This could lead to greater utilization and patient engagement through use of the PHR.

A word of caution. One of the problems often discussed about PHRs are barriers to adoption (Graetz et al., 2016; Hemsley et al., 2018). Disparities have been found in patient use of PHRs and educational resources by age, race, and socioeconomic status (Graetz et al.,

2016). While PHRs present a low risk of harm to patients if misused, researchers should

consider the risk of widening health disparities by providing yet another tool to privileged

populations (Veinot et al., 2018), and thus widening what has been dubbed "the digital divide"

(Graetz et al., 2016) between privileged and underprivileged populations. Simple interventions

such as providing visual summaries of personal health information, such as charts or picture

descriptions (Morrow et al., 2019), have been found to help neutralize disparities in health

literacy (Hemsley et al., 2018). Future researchers need to be cognizant of issues of privilege

and oppression that may be accentuated by interventions with PHRs and other rising technology

in healthcare.

Conclusion

This review found that efforts are indeed being made to raise awareness of educational

resources in PHRs, that patients are increasingly utilizing these resources, that patients

are finding them useful, and that they are improving health outcomes. It seems that PHRs are

becoming a powerful tool for patient engagement and show promise as a means of achieving the

quadruple aim of healthcare (Bodenheimer et al., 2014). Continued efforts need to be made

to raise awareness of patient educational resources in PHRs so that patients utilize these

resources to increase their knowledge, skills, and confidence for managing their own health and

health care (Carmen et al., 2013).

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CHAPTER 3: LITERATURE REVIEW

The Commonwealth Fund regularly analyses healthcare systems around the world using 71 performance measures across five domains — access to care, care process, administrative efficiency, equity, and health care outcomes (Schneider et al., 2021). While each country is unique and the results of the complex analyses should be interpreted with caution, the United States consistently spends more on healthcare than other high-income countries, and yet has worse outcomes (Schneider et al., 2021). While the factors that contribute to this are complicated, and no simple change will be a complete solution to such an issue, research has found that patient engagement leads to significant improvements in patient health, reduced costs, and improved patient experiences (Hibbard & Greene, 2013).

As researchers hypothesized and tried to understand why engaging patients in their care leads to improved health outcomes, many definitions and explanations of patient engagement have been presented (e.g. Cene et al., 2016; Graffigna et al., 2017). At first, these definitions originated predominantly from the providers themselves, rather than the patients (Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017). Relying on healthcare provider's expertise and familiarity with the healthcare system was a natural first step, but eventually researchers realized the importance of adding the patient's perspective in research defining patient engagement, how it works, and why it's important (Phoenix et al., 2018; Roland et al., 2017). Again, as a natural first step in adding the patient perspective to developing theories, researchers relied on patients who are already highly engaged and accessible, either through frequent healthcare utilization (Brown et al., 2015) or specific education (Pomey et al., 2015).

This has been a valuable addition, but has identified further gaps in our understanding of patient engagement, specifically, the perspectives and ideas of patients who utilize healthcare

less frequently or may be engaged in ways not included in what is typically considered patient engagement (Pomey et al., 2015). Their perspective could confirm what providers have already speculated about patient engagement, but it could also differ in ways that either conflict with or elaborate on our current understanding of the concept (Brown et al., 2015; Fiction et al., 2008; Mercer et al., 2020; Walters et al., 2017). It could shed light on what barriers patients experience as they try to engage with their providers, as well as generate new ideas that providers may not have considered. While there is a chance that not all their ideas may be possible given the current limitations of the healthcare system, adding the patients' voice and perspective to define why patient engagement is important and how it improves health could add new ideas to our current understanding that could then be incorporated into our future research and efforts to improve the healthcare system.

This literature review will first describe our current definitions of patient engagement and its effects on patient outcomes before outlining why patient engagement has become such an important concept in recent years. The process by which theories on patient engagement began to develop, first with provider's perspectives and then with the addition of patient perspectives, will then be explored. Finally, the argument for the addition of the perspective of patients from a variety of different levels of engagement with and utilization of healthcare will then be presented.

Patient Engagement

On the surface, patient engagement seems self-explanatory; it's the process of engaging the patient in their care. Over the years, however, researchers have made efforts to break this concept down and examine it more closely. Graffigna and Barello (2018), for example, pointed out that like any relationship, all members of the healthcare system have to do their part for a

patient to be successfully engaged. They identify patient-related factors, healthcare provider-related factors, organization-related factors, and even community-related factors that foster patient engagement.

Patient-related factors emphasize factors of patient engagement that are inherent to the patient. For example, patient engagement has been thought to improve outcomes through its effect on cognitive factors related to the patient, such as self-efficacy, perceived locus of control, and health literacy (Légaré and Witteman, 2013; Mittler et al., 2013; Smith et al., 2013; Prey et al., 2014). If a patient better understands how to take care of their health, their health will improve, and engaging them more in their care can help with that understanding (Rodriguez, 2013). Patient engagement has also been seen as an effort to foster and harness the motivation of the patient to lead to better outcomes (Graffigna, 2017). There are even protocols, such as motivational interviewing (Miller & Rollnick, 2013) dedicated to getting patients to champion changes in their own lives, as this has been shown to have better outcomes than when providers recommend things patients are unmotivated to do. Interestingly, some studies have even looked for associations between patient engagement and socio-cultural characteristics of the individual such as gender, age, level of education (Hibbard et al., 2008; Bos-Touwen et al., 2015) and level of income (Skolasky et al., 2008; Rask et al., 2009), to see if patient engagement could be included in theories surrounding social determinants of health.

For healthcare provider-related factors, researchers have found that improvements in health outcomes are associated with improvement in the therapeutic alliance, or doctor-patient relationship (Higgins et al., 2017; Rodriguez, 2013). The more patients feel respected, genuinely cared for, and believed in by their providers, the more engaged they are likely to be (Greene et al., 2016; Rodriguez, 2013). On a similar note, provider's implicit biases and discrimination

have been identified as strong barriers to patient engagement (Parameshwaran et al., 2017). There is strong evidence for the positive impact a physician's ability to communicate clearly and on a level that is understandable has for patient engagement and health outcomes (Zolnierek et al., 2009). Greene et al. (2016) identified 5 strategies used most commonly by physicians whose patients showed the highest level of engagement in their care: (a) emphasizing patient ownership, (b) partnering with patients, (c) identifying small steps, (d) scheduling frequent follow-up visits to cheer successes, problem solve, or both, and (e) showing caring and concern for patients.

Organizational-related factors are connected to the policies, processes, and administration of a healthcare organization, rather than to an individual provider or patient (Graffigna and Barello, 2018). This includes innovations such as personal health records (PHRs), which provide patients access to their health records, lab results, medication refills, educational materials, and provide a secure way to message their care team and conduct telehealth visits, increasing patients' ability to take an active role in their health care decisions and management (Hoyt et al., 2018). These factors can also include policy efforts, such as the personalization of healthcare (Borghi et al., 2016), where organizations prioritize and provide resources for the tailoring of treatment to each patient and their life situation. The push for shared decision making (Barello et al., 2014) fits into this category as well, where organizations encourage their patients to play an active role as members of their care team and share their opinion when making treatment decisions. Carman et al. (2013) noted that organizations may be at different levels of readiness to engage patients, depending on their size, location, structure, role in the community, and other factors.

Community-related factors include things like characteristics of family (i.e. informal caregivers), peer networks and government resources, and even predominant cultural beliefs and

influences (Graffigna and Barello, 2018). Research into social determinants of health, which are non-medical factors that influence health outcomes such as education, income and job security, housing, food insecurity, and access to quality healthcare (World Health organization, n.d.), have found that these have a greater impact on patient engagement and outcomes than almost any other factor discussed so far (Hibbard et al., 2008; Bos-Touwen et al., 2015). It would make sense that even just patients' financial situations or insurance coverage would have profound effects on their willingness to utilize and engage with the healthcare system (Rodriguez, 2013). For this reason, governments are often called upon to help provide community supports to try and meet these needs (Rodriguez, 2013). Beyond this, however, even cultural beliefs about the role of the patient and the healthcare system can affect engagement. For example, there is a push for patients to be seen as the experts on their own life experiences when partnering with providers and the medical expertise in making healthcare decision. (Cosgrove et al., 2013; Pomey et al., 2015). As stated earlier, patient engagement is not as simple as patients deciding to be engaged in their care. Patient engagement as a concept has come to represent the interaction of patient, provider, organizational, and community-related factors that enable a patient to be more or less engaged in their care (Graffigna and Barello, 2018).

Patient engagement being multifactorial like this has led to it becoming an umbrella term for similar concepts such as patient activation and patient-centered care (Carman et al., 2013). Though they are related, these terms emphasize different aspects of patient engagement and should not be used interchangeably. Patient activation generally aligns more with the focus on the patient's behaviors, with Hibbard et al., (2009) defining it as "the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health" (pg. 377). Patient-centered care focuses more on the provider and organizational factors related to

engagement and traces its popularity back to the Institutes of Medicine naming it one of the six aims of quality improvement (Institute of Medicine, 2001). There it was defined as, "a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care" (pg. 7).

Another difficulty when defining patient engagement is that it has been studied by a number of different disciplines, including medicine, nursing, political science, management, psychology, social science, and even computer science (Barello et al., 2014). Higgins et al. (2017) and Harrington et al. (2020) performed reviews in an effort to synthesize these definitions. Higgins et al. (2017) did a concept analysis of scientific literature across health disciplines to define common attributes of patient engagement. Harrington et al., (2020) went one step further by systematically reviewing all definitions of patient engagement published between 2006-2018, extracting and qualitatively analyzing common themes, and then offering a synthesized definition. They both found that different studies seemed to emphasize different aspects of patient engagement, with some focusing on patient-related factors and others on provider, organizational, or societal-related factors. The resulting definitions, along with other important definitions from foundational books and articles are included in Table 1.

Table 1. Definitions of Patient Engagement		
Citation	Definition	Method for Developing Definition
Agency for Healthcare Research and Quality (AHRQ, 2017)	a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations (pg. 10).	Agency backed definition based on scientific literature. No patient's consulted about this definition.

Coulter, 2011	Patients and providers working together to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels. (pg. 10)	An often-cited book chapter written by an expert in the field. Did not include the patient's perspective.
Carman et al., 2013	We define patient and family engagement as patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care. (pg. 224)	A proposed framework developed by researchers and leaders in the field of healthcare. No patients were involved in developing the framework, nor were they consulted about it afterwards.
Brown et al., 2015	Patient and family engagement [in the ICU] is an active partnership between health professionals and patients and families working at every level of the healthcare system to improve health and the quality, safety, and delivery of healthcare. Arenas for such engagement include but are not limited to participation in direct care, communication of patient values and goals, and transformation of care processes to promote and protect individual respect and dignity. PFE comprises five core concepts: Collaboration, Respect and Dignity, Activation and Participation, Information Sharing, and Decision Making. (pg. 359)	Patients provided feedback about the proposed elements of patient engagement which were then incorporated into the definition.
Higgins et al., 2017	Based on the thematic reflection in our analysis, four overarching attributes of patient engagement were defined: (1) personalization; (2) access; (3) commitment; and (4) therapeutic alliance. (pg. 32)	Concept analysis of scientific literature across health disciplines to define common attributes of patient engagement. No patients were involved in the process.
Harrington et al., 2020	The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their specific experiences, values, and expertise. (pg. 682)	Systematically reviewed all definitions of patient engagement published between 2006-2018. Extracted and qualitatively analyzed common themes before synthesizing their definition. No patients were involved in the process.

Patient Engagement Improves Patient Health Outcomes

Researchers have been so interested in patient engagement mainly because it has been

strongly associated with positive health outcomes (Hibbard et al., 2013). This section will review

existing literature reviews to summarize the body of patient engagement research. Findings from

these reviews will be organized using the quadruple aim of healthcare (Berwick et al., 2008;

Bodenheimer et al., 2014). The quadruple aim is a derivative of the triple aim of healthcare

(Berwick et al., 2008), which is to (a) improve patient outcomes; (b) improve patient experience;

and (c) reduce costs. The quadruple aim simply adds a fourth goal: to improve the providers

experience as well (Bodenheimer et al., 2014). Patient engagement has been shown to influence

each of these aims by improving health outcomes (Hibbard & Greene, 2013; Sharma et al.,

2017), improving patients' healthcare experience (Hibbard & Greene, 2013; Sharma et al.,

2017), reducing costs (Hibbard & Greene, 2013; Sharma et al., 2017), and improving the

healthcare experience for the providers (Goel et al., 2016; Sharma et al., 2017). Often these aims

are systemic in nature, with a change in one area inherently influencing the others (Bodenheimer

et al., 2014). While the purpose of this study is to focus specifically on patient engagement it is

assumed that some elements of each of these aims might be discussed. As such, this section will

provide a review of each of these aims and what is known regarding patient engagement.

Patient Engagement Improves the Patients' Experience

Patient engagement has arguably the largest and most immediately apparent impact

on the patient experience. One example of this that has been a focus of patient engagement

efforts is shared decision making (Barello et al., 2014; Smallwood et al., 2017). Patients

are invited and encouraged to collaborate with providers to determine what the best course

of treatment is for their personal situation. This has been shown to improve patients'

satisfaction with their care (Barello et al., 2014; Smallwood et al., 2017). What is more,

that sense of empowerment may contribute to enhancing the patient's quality of life by

fostering an ownership of their wellness that is more resilient to the stress of acute events

(Haywood et al., 2017). Studies found that engaged patients tend to trust their healthcare

team more (Becker et al., 2008) which can lead to them asking questions or collaborating

with their healthcare providers as partners (Barello et al., 2014; Kelly et al., 2017). This

can dramatically reduce miscommunications that lead to missed opportunities or the need

for clarification (Zolnierek et al., 2009). Patients frequently want to be engaged in their

care (Barello et al., 2014; Smallwood et al., 2017), and so taking the time to address

intrinsic factors such as their understanding (Greene et al., 2016), and the extrinsic factors

such as the patient-provider relationship (Rodriguez, 2013), can lead to significant

improvements in their experience, as evidenced by the increase in patient satisfaction

(Barello et al., 2014; Smallwood et al., 2017).

Patient Engagement Improves Health Outcomes

Regarding health outcomes, patient engagement has been found to have a positive impact

across disease conditions (Saft et al., 2008; Munson et al., 2009; Green et al., 2010; Stepleman et

al., 2010; Begum et al., 2011; Skolasky et al., 2011; Alexander et al., 2012). One striking

example of this is a study that found that patients with coronary artery disease had an 88%

reduced risk of dying of a cardiac-related cause within 90 days of a heart attack when enrolled in

a patient engagement program, compared to those not in the program (Sadhoff et al., 2008).

This may be explained by patients' performance of health promoting behaviors in their personal

lives (Barello et al., 2014, Cosgrove et al., 2013) such as taking prescribed medications (i.e.,

insulin, contraception) (Chen et al., 2015; Sridhar et al., 2017), or modifying lifestyle behaviors to promote their health (i.e., diet, exercise) (Groen et al., 2016). Engaged patients may also be more likely to learn new information about their health conditions (Barello et al., 2014; Chen et al., 2015; Gilliam et al., 2017; Zide et al., 2017) enabling them to better manage their health long-term. Interestingly, these improvements in health outcomes associated with health outcomes have been found in patients across different social and demographic factors, such as age, gender, race, socioeconomic status, etc. (Hibbard et al., 2013).

Patient Engagement Reduces Costs

Patient engagement often has an indirect effect on healthcare costs, with patient engagement leading to behaviors that either enhance a patient's health or prevent them from getting sick (Hibbard et al., 2013). It is therefore hard to say exactly how much money patient engagement saves, so research has focused on the ways patient engagement can keep patients healthier and reducing the need for healthcare services. For example, taking preventative measures such as getting vaccinations or early screenings for cancer (Cameron et al., 2016; Day et al., 2019) can prevent or identify problematic health conditions early on. This can lead to enormous cost savings by either avoiding problems that will require resources and care, or by enabling problems to be addressed in earlier stages when treatment might be less intense or have a higher likelihood of success (Neumann et al., 2009). What's more, the money and resources saved by this can be reallocated to other areas of the healthcare system to reduce waste (Fisher et al., 2011, Graffigna, 2017). Patient engagement can also reduce adverse clinical events and hospital readmissions (Hibbard et al., 2008) as patients are more proactively managing their health on their own.

Patient Engagement Improves the Providers' Experience

Providers have also expressed that having patients who are actively engaged in their care make their experience as providers better too (Goel et al., 2016). As mentioned before, patients who are actively involved in their care are more likely to adhere to treatment prescriptions (Hibbard and Greene, 2013) and less likely to experience adverse clinical events and hospital readmissions (Hibbard et al., 2008). This can reduce the time and resources required of providers to care for the patient and allow them to allocate those resources to serving more patients (Laurance et al., 2014).

In summary, there is no shortage of evidence to show that engaging patients in their healthcare does in fact help achieve the outcomes associated with the quadruple aim (Bodenheimer et al., 2014). It's worth noting, however, that while research has been developing the concept of patient engagement for some time, the bulk of these outcome studies initially came in response to policy initiatives (Institutes of Medicine, 2001; Graffigna, 2017) rather than as evidence of developing theory, as will be explained in the following section.

The Historical Explanation for the Emphasis on Patient Engagement.

Patients have always been engaged to some extent in their care, but the current patient engagement movement traces its beginnings in the United States back to the 1960's with the establishment of federally funded community health centers (Nickitas et al., 2010). These community health centers aimed to achieve, "maximum feasible participation of residents of the area and members of the groups served (Nickitas et al., 2010, pg. 263)." With time, traditional doctor-patient roles and relationships began to shift from a provider driven to a more collaborative model (Stewart et al., 1995) and decisions

regarding treatment plans began to be co-authored by healthcare providers partnered with patients (Graffigna, 2017). While providers are still considered the experts in the field of medicine, the increasing amount of information available to patients about treatment options allows the patients opportunities to provide insight into what treatment plans are most likely to work given their unique circumstances (Graffigna, 2017).

The emphasis of engaging patients in their healthcare increased again after the Institutes of Medicine named patient-centeredness as one of the six essential components of quality care (Institutes of Medicine, 2001). Following this initiative, patient engagement became a major focus of research from a number of different fields, including medicine, nursing, political science, management, psychology, social science, and even computer science (Barello et al., 2014). Organizations and researchers are constantly researching new ways to implement (Carman et al., 2013; Hamilton et al., 2018), measure (Abbasgholizadeh, 2019) and improve (Daniel et al., 2020) patient engagement, and the increasing wave of research found that it was strongly associated with improved patient health outcomes and experiences (Hibbard & Greene, 2013; Sharma et a., 2017).

It is possible that researchers, in response to these policy agendas, skipped taking time to develop a theory and moved so quickly to outcomes research simply because the concept of patient engagement makes intuitive sense (Phoenix et al., 2018). Patients who are more actively engaged in taking care of themselves will likely live healthier lives and require less assistance and resources from the healthcare system, thus reducing costs while improving outcomes (Hibbard & Greene, 2013). In any case, researchers seemed to respond quickly to new policy initiatives, exploring how to capitalize on patient engagement rather than defining what it is or why it helps. While there is ample evidence to support policy emphasis on patient engagement,

there has been an added emphasis on developing theories that explain why patient engagement leads to improved health outcomes, patient experiences, and reduced costs, rather than simply providing evidence that it does (Graffigna et al., 2018).

Development of a Theoretical Foundation

Rowland et al., (2017) said it well when they said, "to rely almost exclusively on policy frameworks as the means to both justify and design patient engagement programs may be problematic. Without understanding the theoretical underpinnings, it becomes difficult to make claims about how a program works" (pg. 77). Initially, most of the research seeking to provide a unifying foundation for the study of patient engagement came in the form of frameworks rather than theories (Carman et al., 2013; Hamilton et la., 2018). These frameworks often prioritized outlining procedures for the implementation of patient engagement programs, rather than theorizing how patient engagement works (Hamilton et al., 2018). A good example of this is a framework produced by Carman et al. (2013) that has been particularly popular. In it, they conceptualize patient engagement as a continuum, with successive phases of patient engagement starting with consultation and then progressing from involvement to partnership and then eventually to shared leadership. They acknowledge that different organizations may be at different levels of readiness or ability to fully integrate patients into some aspects of their care, and so provide suggestions for how to maximize what engagement is possible at every level. They also examine this continuum of engagement at different levels of healthcare, including direct patient care (providers helping patients), organization design and governance (healthcare systems and administrations), and policy making (legislators and advocacy groups) (Carman et al., 2013).

While this was helpful for showing organizations how to engage patients in practical ways, they fell short in the fact that they lack "theoretical underpinnings [that] inform the practice of patient engagement," (Phoenix et al., 2018, pg. 2) and explain why patient engagement improves outcomes (Rowland et al., 2017). In short, they focused too much on how to engage patients without explaining how or why patient engagement works in the first place. As with the outcome research highlighted earlier, these frameworks show a tendency the field had to pursue ways to respond to policy emphasis on patient engagement rather than explore the theoretical foundations that explain how it works (Rowland et al., 2017). Again, while this approach to research can justify the emphasis on patient engagement by providing evidence of success of implemented programs, researchers began to see the need to strengthen the justification for patient engagement through a sound theoretical understanding.

Following a narrative review of literature, Cene et al. (2016) suggested that a consistent definition could be the first step towards uniting the field in a more collaborative and constructive way toward studying patient engagement. As shown earlier in table 1, definitions of patient engagement have addressed aspects of patient engagement inherent both to the patient and to the healthcare system. However, it's also worth noting how these definitions were developed (Table 1). Often these definitions were and are being produced by providers or researchers who are familiar with the current literature and the current healthcare system and offering their expert opinion on how to best conceptualize patient engagement (AHRQ, 2017; Carman et al., 2013; Coulter, 2011; Higgins et al., 2017; Harrington et al., 2020).

Hearing from the providers and relying on their experiences is important. They do have valuable insight, especially since they interact more frequently with the current healthcare system and may know its current limitations and possibilities. However, if the entire goal of

patient engagement is to increase the working relationship between the provider and the patient and to increase the patient's involvement, then it is also important to include the voice of the patient. Their perspective could confirm what providers have already considered or it could differ in ways that either conflict with or elaborate on our current understanding of the concept (Brown et al., 2015; Fiction et al., 2008; Mercer et al., 2020; Walters et al., 2017). It could shed light on what barriers they experience as they try to engage with their providers, as well as generate new ideas that providers may not have considered. While there is a chance that not all their ideas may be possible given the current limitations of the healthcare system, adding the patients' voice and perspective to define why patient engagement is important and how it improves health could add new ideas to our current understanding that could then be incorporated into our future research and efforts to improve the healthcare system. Some researchers have recognized this need to involve patients in defining patient engagement, and their work has indeed confirmed some aspects of our understanding of patient engagement (Brown et al., 2015; Fiction et al., 2008), as well as identified some aspects that patients either disagree with (Mercer et al., 2020; Walters et al., 2017) or that simply need to be explored further (Pomey et al., 2015).

Adding the Patient's Perspective to Theories of Patient Engagement

There have been a few different approaches when involving patients in the process of researching and defining patient engagement. One simple way is simply asking patients to review the results of research projects (Mercer et al., 2020; Walters et al., 2017) or provide feedback as part of a pilot program (Day et al., 2019; Ector et al., 2020; Fiks et al., 2014; Hess et al., 2006; Jones et al., 1992; Lum et al., 2019; Martinez et al., 2018; Navaneethan et al., 2017; Warrington et al., 2015; Zhang et al., 2016). While this is a good first step, it has a few key

limitations. The first is the lack of a fair comparison when asking patients who are part of a pilot program whether they feel more engaged than they did before joining the pilot group. While it's good to hear that these programs are working, it doesn't provide much insight into the patient's perspective or generate any new ideas. Even when one study included patients earlier in the process, asking them to vote for which features should be included in a PHR product (Fricton et al., 2008), they were asked to select their favorite features from a predetermined list of options, rather than asked for their own ideas about how they would like to be engaged.

More recent research has asked patients for their thoughts and opinions about the programs and definitions for patient engagement, rather than simply asking them if they felt engaged or not (Mercer et al., 2020; Walters et al., 2017). For example, Walters et al. (2017) presented their definition of patient engagement to patients for review and made a few amendments after they found that the patients felt strongly about the way some aspects were worded. In this case, they wanted to ensure that the research team described the patients' involvement in their safety as a right, not an obligation, and also suggested that the word "patient" obscures the message by implying that you can only be engaged in your health after interacting with the healthcare system in the role of the patient, and that it should be replaced with something more encompassing like "person" (Walters et al., 2017). Mercer et al. (2020) studied patients' engagement in the pan-Canadian Oncology Drug Review (pCODR) process. Patient engagement in the process had been advertised as one of its great strengths that improved the outcomes for the patients (Mercer et al., 2020). When asked, however, participants said they appreciated the transparency of the process and the efforts made to allow them to participate, but the process required to submit their comments represented a considerable drain on the time and

resources, and the impact of their submissions was unclear, which actually discouraged patient engagement in the end (Mercer et al., 2020).

Brown et al. (2015) involved patients earlier on to see if that led to increased insight from the patients throughout the process than studies that simply asked patients to review the end results. They included lay person advisors in their exploration of patient and family engagement on an intensive care unit. They found that patients tended to agreed with the definition provided them by the research team and suggested few changes. This study highlights another important limitation. While adding patients into the process for defining patient engagement is a great development, studies are often relying on patients who already interact frequently with the healthcare system, are highly motivated, or heavily engaged because they are the easiest patients to access and involve in the process. That means that when asking patients about ways they want to be engaged, we're gaining the perspective of patients who are most likely to have strong relationships with their healthcare providers or be familiar with the traditional ways patients are encouraged to be engaged. We may be missing the perspective and ideas of patients who interact with the healthcare system less frequently or may feel they are engaged in non-traditional ways (Pomey et al., 2015).

Pomey et al. (2015) found that patients disagree with the idea that they need to interact with a provider in order to be considered engaged. Patients from this study shared that they were ill long before they felt engaged by healthcare providers but were actively engaged or managing their health in other ways. In fact, even patients' noncompliant responses to healthcare providers recommendations could be considered a form of engagement, if those recommendations are contraindicated to something the patient feels is important to them and their treatment experience. Often, these patients can be labeled as non-compliant, and their behaviors seen as

disengaged or deliberately counterproductive (Eckstrand & Potter, 2017). This can be especially

true in populations who have historically experienced discrimination in healthcare and may

therefore have more barriers to feeling engaged (Parameshwaran et al., 2017). If research is to

truly gain the patient's perspective on patient engagement, studies must consider ways patients

might feel engaged that do and don't fit with traditional provider-driven definitions of patient

engagement (Pomey et al., 2015). Pomey et al. (2015) describe this conundrum as follows,

> Overall, two assumptions appear to underlie the literature on patient engagement.
> First, that patient engagement includes only those patient activities that are in line
> with health practitioners' prescriptions and implicitly excludes attitudes or
> activities that raise contestation and resistance. In other words, a patient in
> partnership is often seen as a patient who follows treatments as prescribed and
> does not challenge healthcare professionals. The second assumption is that the
> degree of patients' involvement in their health care is dependent upon the degree
> of health professionals' willingness to encourage patient engagement. In other
> words, patients are portrayed as passive agents who need to be motivated,
> mobilized, invited, or convinced to be more active and to take part in their own
> health care. What is missing from the literature is an empirical study of patients'
> perspectives on what they themselves consider to be useful engagement practices
> for actively enhancing their health care (pg. 3).

Potential Differences in Patient Perspectives to Consider

This study by Pomey et al. (2015) highlights the idea that there is a range of patient

experiences that remains to be explored if we consider other perspectives than only those of

patients who are already highly engaged (Pomey et al., 2015) or frequent utilizers (Brown et al.,

2015). In trying to define patient engagement in a way that can be generalizable to the larger

population, it needs to be recognized that engagement may look very different between groups of

people. For example, patients >65 years old typically have much higher rates of utilization,

meaning they use healthcare resources more often. However, higher utilization doesn't

necessarily equate to higher engagement. Within this group there may be patients who take

personal responsibility for their health and are very involved in their care, while others may be

more passive and do little. In other populations, some patients may seldomly utilize healthcare resources for routine visits or on an as needed basis, and yet be highly engaged in their health by staying physically active, eating right, adhering to treatment regimens and learning as much as they can about their own health conditions (Hibbard et al., 2009). This continuum of patient engagement may include, but not be limited to, patients who have frequent check-ups for management of chronic health conditions, patients who are generally healthy and so only attend annual wellness checks, patients who only engage with the healthcare system when needed to address acute or urgent problems, or even those who purposefully avoid engaging with or mistrust the healthcare system.

Imagine, for example, how definitions of patient engagement might differ for someone from a population who has historically experienced discrimination in healthcare and may therefore have more barriers to feeling engaged (Parameshwaran et al., 2017). As mentioned earlier, studies have found that patient engagement has been found to have positive effects on patients across social and demographic characteristics, such as gender, age, race, level of education (Hibbard et al., 2008; Bos-Touwen et al., 2015) and level of income (Skolasky et al., 2008; Rask et al., 2009). However, it's also very clear that there are significant discrepancies in levels of engagement across these same factors (Graetz et al., 2016). If research could discover, "patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (Pomey et al., 2015, pg. 3), we could learn what barriers patients might be facing to being engaged, as well as what they are already doing to be engaged or take care of their own health that may not fit into our current definitions or understanding of what constitutes patient engagement. This more robust understanding could then better inform patient engagement efforts and bring those improved health outcomes to more people.

Patient's experiences could obviously vary widely, as each individual's experience could be considered unique. However, patients' perspectives being engaged in their care could theoretically range across high and low levels of utilization and personal activation (see figure 1). Remember that activation is, "the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health" (Hibbard et al., 2009, pg. 377), while utilization is simply how often patients use healthcare resources, most commonly through appointments with providers. Patients from each of these four quadrants may have different perspectives on what it means to be engaged, both by healthcare providers through their utilization as well as on their own through personal activation. This could be the next step in developing our understanding of what patient engagement is, how it works, and why it is important, by adding the perspectives of patients other than those who are already highly activated or high utilizers.

Figure 1. Four Quadrants of Patient Engagement
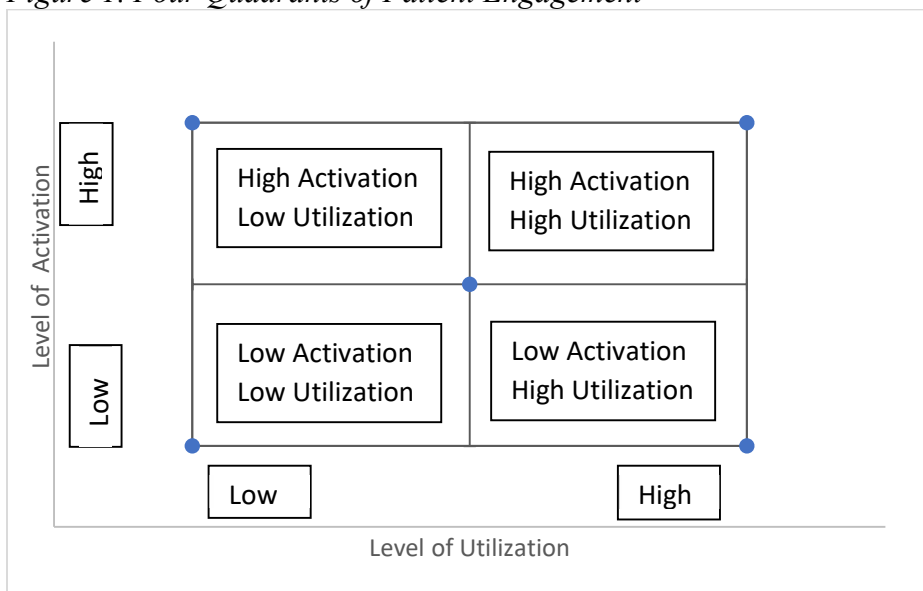
Conclusion

The next chapter will outline the proposed study to address the gap identified by Pomey et al. (2015) to add an, "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). This will build on the work that has been done to develop a theoretical understanding, first from healthcare researchers' and providers' perspectives (Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017) and then from highly engaged patients ((Brown et al., 2015; Pomey et al., 2015), as it will add the perspective of patients who range across different levels of activation and utilization, and whose efforts to be engaged in their healthcare may differ from providers prescriptions or expectations (Pomey et al., 2015). This enhanced theoretical understanding will help use better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on both organizational and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

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CHAPTER 4: METHODS

In addition to proving the effectiveness of patient engagement in improving patient health outcomes (Hibbard et al., 2013), past research has begun to both define and theorize about how and why patient engagement has this effect (Abbasgholizadeh, 2019; Carman et al., 2013; Daniel et al., 2020). Beginning with the perspectives and hypotheses of healthcare researchers and providers (Graffigna et al,. 2018), and eventually adding the perspective of highly engaged patients (Brown et al., 2015; Pomey et al., 2015), our understanding of what patient engagement is has begun to broaden. The goal of this study was to build on the addition of the patient's perspective by capturing the voice of patients with a wide range of engagement in and utilization of healthcare, rather than just those who are already familiar and engaged with the healthcare system.

When discussing how to fill the theoretical gap in patient engagement research, Phoenix et al. (2018) recommended using qualitative perspectives to inform the theoretical underpinnings of patient engagement. Qualitative methodologies, and grounded theory in particular, are especially well suited for these types of questions (Charmaz, 2014; Corbin & Strauss, 2015). While most qualitative methodologies enable researchers to elicit and understand the unique perspective of an individual (Creswell & Poth, 2018), this study is seeking to understand a concept or phenomenon rather than an individual experience. Unlike phenomenology, grounded theory methodology uses the qualitative perspective of many subjects to better understand the phenomenon in general rather than thoroughly exploring each person's unique experience (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018). It seeks to include as many people as necessary to understand the phenomenon from multiple perspectives rather than interviewing the same person multiple times to understand that person's lived experience. Since

the purpose of this study was to expand our understanding of patient engagement from a variety of perspectives it was deemed that grounded theory would be the most appropriate. This methodology allows us to elicit the patient's perspective from patients who range in their levels of utilization and engagement in healthcare (see figure 1), and therefore better represent the general population in defining what patient engagement is, why it's important, and how it impacts patient health in current, every-day healthcare settings. The diversity of patient's experiences and thoughts about patient engagement helped this grounded theory be more representative of the concept of patient engagement generally, rather than trying to be representative of any one group's experience or perspective on the subject.

Grounded Theory

Grounded theory methodology was originally developed by Glaser and Strauss (1967; Corbin & Strauss, 2015) as a way to generate a theory from raw data. This is an inverse process to other methods, which typically use existing theories to help interpret or make sense of data (Hylander, 2012). Grounded theory shares the strength of other qualitative methodologies, in that it discovers new insight from the shared experience of participants, however, rather than striving to be representative of the lived experience of those interviewed, grounded theory strives to be representative of the concept, gathering multiple perspectives to develop a theory of the concept that can be better transferred to the general population (Creswell & Poth, 2018). Instead of validating our current understanding of patient engagement, this study sought to expand our understanding but by including different voices that will help us understand new aspects of the overall concept of patient engagement and not rely solely on a few voices. Doing so made the theory richer and more useful in its ability to be applied by providers to different patient populations.

Sensitizing Concepts & Bracketing

In qualitative research, such as grounded theory, it is important to note the impact the researcher themselves have on the data, as their experience and perspective become part of the data in a very real sense through their participation in the interviews to generate the data, and then again through their influence during the data analysis process (Creswell & Poth, 2018). While quantitative researchers are typically encouraged to influence the data as little as possible, qualitative methodologies openly acknowledge the researcher's influence on the study. It is seen as a tool to be harnessed, rather than a limitation to be mitigated (Tufford & Newman, 2012). The researcher's beliefs, values, biases, preconceptions, and assumptions are shaped by their own experiences as well as their exposure to the subject matter and current research (Tufford & Newman, 2012). These all shape the impetus the researcher has for studying the topic at hand and their approach to studying it, including what questions they seek to answer in their study and how data is gathered, interpreted, and presented (Tufford & Newman, 2012). Often, their experiences with and familiarity with relevant literature about a concept are what give the researcher the sensitivity needed to make sense of new data and find new or emerging connections. These experiences and ideas are therefore referred to as sensitizing concepts (Bowen, 2006; Charmaz, 2014).

Acknowledging and encouraging the use of sensitizing concepts in the research process does not mean that the study is left completely vulnerable to the subjective experience of the researcher conducting the study (Charmaz, 2014; Corbin& Strauss, 2015). The researcher must utilize their prior knowledge and expertise to make sense of what participants are reporting, while still trying to make their interpretations representative of the data and not just their own opinions (Hylander, 2012). In the delicate balance between objectivity and sensitivity, the

influence of the researcher's perspective is seen as a useful bridge to connect the real-world experience of the participants and the theories and knowledge of previous research (Creswell & Poth, 2018; Corbin & Strauss, 2014).

In order to accurately capture the subjective experience of the participant and use it to develop new insight, researchers ensure their own preconceptions do not overshadow the interpretation of the data through a process known as bracketing (Tufford & Newman, 2012). Bracketing involves researchers reflecting on their own experiences, assumptions, preconceptions, and biases that might influence their interpretation of the data (Tufford & Newman, 2012). This improves their ability to recognize situations where their own biases might prevent them from accurately portraying the participants experience, and to encourage them to remain open to perspectives and insights that may be unexpected or that differ from their own (Creswell & Poth, 2018). The goal is not to eliminate their influence, as it is impossible to completely eliminate any biases from research (Corbin & Strauss, 2014). Instead, the goal is to make both the researcher and the reader aware of how these sensitizing concepts may be affecting the way data is gathered, interpreted and presented, and to make their influence as transparent as possible (Tufford & Newman, 2012).

I will do this by reflexively journaling about my own background, social location, beliefs, and biases that might have affected the questions I asked, the way I gathered data, and the way I interpreted the data. These initial reflections are included here so that readers can be aware of the possible influence the researcher's experiences might have had on the presentation of this study. I also bracketed my experience throughout the data gathering process by noting my impressions and including them in the analysis (Tufford & Newman, 2012).

Self of the Researcher

In addition to the familiarity with current literature regarding patient engagement demonstrated in the literature review, it is also important to be transparent about any sensitizing concepts that come from the first author's personal life and experiences. I, the first author, am a PhD candidate in a Medical Family Therapy program, and an educator in a family medicine residency. I provide family therapy to patients in an outpatient family medicine clinic as well as in an inpatient hospital setting. I also educate primary care providers in areas of bedside manner and doctor communication, managing mental health conditions as a physician, interacting with patients and their extended family support systems, physician burnout and wellbeing, and developing long-term patient-provider relationships. Through these clinical experiences, I have observed the impact patient, provider, organization, and community-related factors can have on patient engagement (Graffigna and Barello, 2018). I've seen how strongly qualities like patient motivation can improve patients' outcomes (Graffigna, 2017) and their experience with their care as well as my experience providing that care (Hibbard et al., 2008). I've noticed how provider communication styles can either encourage or discourage patients' engagement (Zolnierek et al., 2009). I've participated in committees designed to improve our organization's patient engagement efforts, and I've studied societal factors such as social determinants of health that can facilitate or act as barriers to patient engagement regardless of what providers or organizations do with their patients (Hibbard et al., 2008; Bos-Touwen et al., 2015).

I am clinically trained as a marriage and family therapist, and so have a worldview and theoretical foundation that is deeply rooted in family systems theory. As such, I am deeply interested in what makes the healthcare system or relationships between patients, their families, and the healthcare team members work as efficiently as possible. This has led to my interest in patient engagement as a means of improving patient-provider relationships and improving health

outcomes. My theoretical background and my career goals and motivations strongly influence my desire to understand and capitalize on the potential benefits of patient engagement, and I recognize that this may bias my interpretation of the data to present it in a positive light.

As a patient myself, I grew up with a privately purchased insurance plan that had a high deductible. This combined with the blessing of good health and a reasonable active lifestyle meant that I only utilized healthcare services when absolutely necessary, and often preferred to wait until my body healed itself when sick or injured. While my insurance status has improved, and career as a healthcare provider has certainly shifted my perspective on the value of utilization and engagement in one's healthcare, it is still my natural tendency to be engaged in my health in ways other than traditional utilization methods. As such, I would probably fall in the highly engaged, low utilizing group myself, which may affect which aspects of patient engagement resonate with me when shared by participants of this study.

Agency and Communion. Of all the factors that influence my preconceptions about patient engagement, my commitment to fostering a sense of agency and communion (McDaniel et al., 1992; 2014) for patients serves as the foundation for my desire to study patient engagement. In all settings, two central aims of medical family therapy are empowering a sense of agency and communion for patients. Agency is defined as empowering the patient to have a say in the treatment they receive and be included in the decision-making process (McDaniel et al., 2014). Communion is the idea that patients feel they understand and are understood by their care team and are welcome and involved in the process (McDaniel et al., 2014). Essentially, I see agency and communion synonymously with aspects of patient engagement such as patient activation and shared decision making. I also have a strong disposition to believe that when patients are engaged in their care, or when they feel a sense of agency and communion, there's a

better chance of achieving the quadruple aim of healthcare, meaning patients experience better health outcomes, better care experiences, lower costs, and providers have a better care experience as well (Bodenheimer et al., 2014; Hibbard & Greene, 2013).

Research Questions

This grounded theory study sought to take the next step in defining and developing a theory of patient engagement by exploring the perspective of patients who range in their level of engagement. As discussed in the literature review, this was conceptualized as a range across high and low levels of utilization and personal activation (see figure 1). Remember that activation is, "the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health" (Hibbard et al., 2009, pg. 377), while utilization is simply how often patients use healthcare resources, most commonly through appointments with providers. Patients from each of these four quadrants may have different perspectives on what it means to ben engaged, both by healthcare providers through their utilization as well as on their own through their activation. This could be the next step in developing our understanding of what patient engagement is, how it works, and why it is important, adding to the perspectives of patients who are already highly activated or high utilizers by answering the following research questions from a variety of perspectives:

1. How do patients define or describe "patient engagement?"

2. How important do patients think patient engagement is?

3. How do patients explain the effect patient engagement has on their health outcomes?

Theoretical Saturation

Many qualitative methods seek a homogeneous sample with which they can explore a unique phenomenon in depth, such as a group of people suffering from a similar medical

condition in a similar environment, so the unique lived experience of that group can be captured (Creswell & Poth, 2018). In addition, many qualitative methods, like phenomenology, will complete multiple interviews with the same participant because their primary objective is to ensure that they have a clear understanding of that individual's personal experience. Grounded theory, however, seeks a little more variety in its sampling because the goal is to create a theory explaining a phenomenon that can then be generalized to help explain other people's experiences in similar conditions (Creswell & Poth, 2018). Although a perfect representation of the general population cannot be realistically achieved, certain sampling techniques can be used to help increase the transferability of the results (Creswell & Poth, 2018).

In quantitative methodologies this is done by randomization, stratification, and other statistical manipulations to ensure that the sample is representative of the population (Howell, 2018). Qualitative methodologies, on the other hand, seek to make the sample representative of the phenomenon rather than just representative of the population, meaning sampling is considered representative when it captures most aspects of the concept being studied, or in other words, until saturation is reached (Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth, 2018). From the perspective of phenomenology, a common qualitative method, saturation would occur when researchers believe they have achieved the depth necessary to understand each participants' lived experience. For example, if they were interviewing John about his level of engagement with his medical team, they might interview John 2-3 times giving him multiple opportunities to share his personal experience. These interviews would continue until the researchers had confidence that they had a pretty detailed understanding of John and how he viewed this phenomenon.

The difference with grounded theory is the focus of understanding is not on the individual participant. Rather, the focus is on understanding the concept. In this case, researchers would interview John and ask him about his experiences with patient engagement. However, rather than interviewing John multiple times, to be able to capture his personal lived experience, they would use John's experience and then specifically recruit another participant, one who had a slightly different experience, to understand patient engagement better. In this instance, saturation occurs when researchers have interviewed enough variability among participants' experiences that they begin to see consistent themes around the concept of patient engagement. While the goal is to achieve theoretical saturation, Strauss and Corbin (1998) describe saturation as follows:

> A category is considered saturated when no new information seems to emerge during coding, that is, when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data. However, this statement is a matter of degree. In reality, if one looked long and hard enough, one always would find additional properties or dimensions. There always is that potential for the "new" to emerge. Saturation is more a matter of reaching the point in the research where collecting additional data seems counterproductive; the "new" that is uncovered does not add much more to the explanation at this time. (p. 136)

So, rather than focusing on sampling the correct number of participants to make the sample generalizable, the goal is to sample participants until no new themes are emerging, and the resulting theory is considered saturated, or able to be generalized with some confidence to fit the experience of others in similar circumstances (Creswell & Poth, 2018).

Participants

As mentioned in the literature review, there is a lot of variation in patients' utilization and potential engagement in healthcare. In order to get a clear understanding and provide a definition that is representative of the larger population, this study gathered participants who ranged in their levels of activation and utilization and therefore had different perspectives than

those patients who are already highly engaged (Pomey et al., 2015). The patient activation measure (Hibbard et al., 2004) is a validated tool to determine a patient's level of activation that many organizations and researchers use to better understand their patients. It was not used in this study however, as it is not open source and provides a level of accuracy in measuring patient activation that was unnecessary for the purposes of this study. This study needed only to ensure that we were recruiting a sample of patients that represented both ends of a spectrum of patients who are both highly and lowly engaged. Patients were, therefore, simply asked how healthy they consider themselves to be and how well they feel their health is managed. The wording of these questions intentionally does not assign responsibility of the patient's health to either the provider or the patient, both to avoid social desirability bias.

Researchers and practitioners have not decided on a single definition of what is considered high utilization, as confounding variables such as complexity of health conditions, age, gender, and setting make it harder than just providing a base number of visits. For example, if defining utilization based on costs, two visits to the ER may cost more than six visits to a primary care provider, especially if the cause of the ER visits could have been prevented by more routine primary care (Long et al., 2017). This raises the question of whether high utilization should be determined by total usage or the appropriateness of the utilization, as it would be preferred that patients have more frequent, low cost, preventative appointments than less frequent but more costly appointments in moments of crisis and more costly acute care settings. Similar to determining levels of activation, for the purposes of this study, it is ultimately less important to determine a precise level of utilization that takes the complex variables into account and more important to ensure that we are simply recruiting a sample of patients that represent both ends of a spectrum of patients who are both highly and lowly engaged. High utilization was

therefore differentiated from low utilization if a patient had more than three visits to a healthcare provider in the last year or who average more than three visits per year over the last few years. This had the added benefit of being a measure that does not require participants to have a high literacy level of the complexity of health conditions or healthcare costs, and as therefore easier to use in recruitment.

Consistent with the goals of grounded theory methodology (Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth, 2018), inclusion criteria for this study were intentionally broad to increase the diversity of our sample so that our theory is saturated and more generalizable (Creswell & Poth, 2018). Participants needed to be fluent in English, as the interviews were conducted in English. Beyond that, however, no limitation was set on what is considered an engaged patient, as we wanted to include multiple perspectives.

The sample consisted of 27 participants, 21 of whom were interviewed individually and 6 of whom were interviewed with their romantic partner (three couples). This was done in order as participants referred their partners, in order to gain the added benefit of seeing how engagement experiences were similar or different within family relationships. Of the three couples, each had different experiences and none of the participants ended up in the same group as their partner.

Of these, ten were in the high activation, high utilization group, eight were in the high activation, low utilization group, five were in the low activation, high utilization group, and four were in the low activation, low utilization group (see tables 1, 2, and 3). The average age of all participants was 35.67 years old. There were more female participants ($n = 16$) than male ($n = 11$). Based on participants' reports of racial demographics, a majority of participants were White/Caucasian ($n = 17$; 63%). The remaining participants reported that they were either Black/African American ($n = 9$; 33.3%) or preferred not to say ($n = 1$; 3.7%). The average

annual income of the sample was $77,828. Types of insurance varied among participants with

the following options reported: a) employer provided insurance (n=13; 48.2%); b) government

insurance (Medicaid/Medicare, n=9; 33.3%); c) uninsured (n=3; 11.1%); and d) paid for private

insurance (n=2; 7.4%).

Table 1. Sample Demographic Information

High Activation, High Utilization Group Demographic Information (n = 10)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance status
Jill	50	Female	White	30,000	Employer provided
Genny	50	Female	White	150,000	Employer provided
Patricia	32	Female	White	140,000	Employer provided
Meg	34	Female	White	50,000	Other
Aiden	24	Female	Black	35,000	Uninsured
Judith	50	Female	White	170,000	Employer provided
Goodman	35	Male	Black	35,000	Medicaid/Medicare
Flo	29	Female	Black	45000	Medicaid/Medicare
James	28	Male	Black	55000	Medicaid/Medicare
Monica	37	Female	Prefer not to say	30,000	Medicaid/Medicare
High Activation, Low Utilization Group Demographic Information (n = 8)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Meri	72	Female	White	retired	Medicaid/Medicare
Sarge	57	Male	White	230,000	Employer provided
Molly	38	Female	White	90,000	Employer provided
Favoretta	29	Female	White	200,000	Employer provided
Amy	31	Female	White	100,000	Employer provided
Eric	44	Male	White	150,000	Employer provided
Trent	31	Male	White	60,000	Employer provided
Connor	29	Male	White	60,000	Private
Low Activation, High Utilization Group Demographic Information (n = 5)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Jack	24	Male	Black	75,000	Medicaid/Medicare
Izz	25	Male	Black	50,000	Medicaid/Medicare
Jerryj	26	Female	Black	5,000	Medicaid/Medicare
Joggy	33	Male	Black	26,355	Uninsured
Dana	27	Female	White	60,000	Private
Low Activation, Low Utilization Group Demographic Information (n = 4)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Scottie	45	Female	White	140,000	Medicaid/Medicare
Patty	32	Male	White	140,000	Employer provided

Jarob	25	Male	Black	15,000	Uninsured
Tammy	31	Female	White	20,000	Employer provided

Table 2. Sample Utilization Information

High Activation, High Utilization Group Demographic Information (n = 10)				
Pseudonym	Last visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Jill	5	1	High	High
Genny	1	24	High	High
Patricia	Did not answer	Did no answer	High	High
Meg	2	12	High	Above Average
Aiden	2	8	High	Average
Judith	2	7	Above Average	High
Goodman	1	48	High	Above Average
Flo	2	10	Above Average	Above Average
James	2	15	High	High
Monica	2	20+	Above Average	Above Average
High Activation, Low Utilization Group Demographic Information (n = 8)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Meri	1	2	High	Low
Sarge	3	2	High	Below Average
Molly	3	5	Above Average	Average
Favoretta	3	2	Average	Average
Amy	1	3	Average	Below Average
Eric	3	2	Average	Average
Trent	1	20	Above Average	Average
Connor	2	6	Above Average	Low
Low Activation, High Utilization Group Demographic Information (n = 5)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Jack	1	18	Average	Above Average
Izz	1	6	Below Average	Above Average
Jerryj	1	9	Above Average	Above Average
Joggy	3		Average	High
Dana	1	15	Below Average	Above Average
Low Activation, Low Utilization Group Demographic Information (n = 4)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Scottie	5	1	Low	Low
Patty	3	1	Average	Low

Jarob	3		Low	Low
Tammy	3	6	Below Average	Below Average

* Answers for "when was your last healthcare visit?" are coded as follows: (1) within the last week, (2) within the last month, (3) within the last 6 months, (4) within the last year, (5) between 1-5 years, (6) longer than 5 years

Table 3. Sample Health Information

High Activation, High Utilization Group Demographic Information (n = 10)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Jill	3	3	4
Genny	4	3	4
Patricia	Did not answer	Did not answer	Did not answer
Meg	3	4	4
Aiden	3	3	4
Judith	4	4	5
Goodman	4	5	4
Flo	3	3	4
James	4	4	4
Monica	3	3	2
High Activation, Low Utilization Group Demographic Information (n = 8)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Meri	4	4	3
Sarge	5	5	5
Molly	4	4	5
Favoretta	4	4	4
Amy	4	4	5
Eric	5	5	4
Trent	3	4	3
Connor	5	5	4
Low Activation, High Utilization Group Demographic Information (n = 5)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Jack	5	5	5
Izz	2	3	4
Jerryj	3	4	4
Joggy	3	5	2
Dana	4	4	4
Low Activation, Low Utilization Group Demographic Information (n = 4)			

Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Scottie	4	3	5
Patty	3	5	4
Jarob	2	3	2
Tammy	4	4	4

* Answers for "how well is your healthcare managed?" are coded as follows: (1) Not well at all, (2) Slilghtly well, (3) Moderately well, (4) Very well, (5) Extremely well
** Answers for "How healthy do you consider yourself to be?" are coded as follows: (1) Very unhealth, (2) moderately unhealthy, (3) Neutral/Neither healthy nor unhealthy, (4) Moderately healthy, (5) Very healthy
*** Answers for "How satsified are you with your healthcare experience?" are coded as follows: (1) Extremely dissatisfied, (2) Somewhat dissatisfied, (3) Neither satisfied nor dissatisfied, (4) Somewhat satisfied, (5) Extremely satisfied

Recruitment

Based on the principle of theoretical saturation, a predetermined number of participants

for the study was not required, but rather, recruitment continued until saturation was achieved

(Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth, 2018). A snowball sampling

technique (Parker et al., 2019) was used in an effort to recruit multiple participants to represent

each of the four quadrants outlined in Chapter 3. This means that participants helped identify

and recruit people they knew who may share a similar or different perspective, thus saturating

each of the groups representing the four quadrants or levels of patient engagement. Four

different recruitment strategies were used to sample patients from each of the four quadrants.

To help this snowball sampling technique, an advertisement was distributed with

instructions on how to participate. Social media resources were heavily utilized to distribute

these advertisements in each of the four strategies as we wanted to reach as many people as

possible to make sure our sample was diverse and not representative only of people who interact

with these locations in person. A google voice phone number and the first author's email

address were included for patients to contact if they were interested in learning more about

participating in the study. When people who were interested in participating contacted the first author, he thanked them warmly and introduced the study as well as what was required of participants. Informed consent was obtained verbally over the phone as well as in writing on a document that was emailed to the participants after the initial phone call to sign and email back to the first author. Before ending the initial phone call, the first author scheduled a time for them to meet for the interview and sent the participant a demographic survey to fill out before the interview.

For people who have high levels of utilization and activation, advertisements were distributed at clinics and community centers who agreed to place them on their notice boards to gather an initial pool of participants, and then participants themselves were able to pass them along after their interviews. Organizations who were willing and had a social media presence were also asked if they would also post the flyer on their sites.

For people who have high levels of utilization but low levels of activation, a strategy similar to that of the high utilization high activation group was used, as high utilizers of healthcare are often found at the same places, regardless of whether they are highly active in their own care.

For people who have low levels of utilization but high activation, advertisements were distributed to local fitness centers, as their members are likely to represent a population of people who are actively engaged in maintaining their own health, and yet may not necessarily utilize healthcare resources that often. Again, organizations who were willing and had a social media presence were also asked if they would post the flyer on their sites.

For people who have low levels of utilization and activation, advertisements were distributed to community centers for marginalized populations, such as the LGBTQ+ community

and other minorities. Populations who have historically experienced discrimination in healthcare may have more barriers to feeling engaged or may even have reason to distrust or avoid the healthcare system, and often experience significant health disparities (Parameshwaran et al., 2017). Again, organizations who were willing and had a social media presence were asked if they would post the flyer on their sites, and the first author distributed advertisements using his own social media account in an effort to recruit people representing all four quadrants of patient engagement.

Procedure

IRB approval was received through East Carolina University. The first author managed all communication with participants, scheduling of interviews, as well as conducted and transcribed the interviews, and led the coding team. These processes will be outlined in the following sections.

Interviews

Interviews were conducted, recorded, and transcribed using WebEx©, as this provided flexibility for the interviews to be conducted despite potential barriers raised by geographic location of the interviewer or interviewee or any restrictions that may be caused by quarantine requirements while conducting this study during a pandemic. WebEx software can also record and transcribe interviews, which sped up the transcription process. Transcripts were still checked and edited to ensure accuracy, as well as to redact any identifying information. Phone interviews were also offered so that internet access did not prevent participation, but no such cases arose during this study.

Following the initial phone call, participants were emailed a link for an interview conducted on WebEx and a link for a demographic survey to be completed before the interview.

This survey asked questions regarding the inclusion criteria for each of the four quadrants, helping delineate where participants fell along the spectrum from low to high utilization and activation. Once they successfully logged into the interview, participants were informed that answers would remain confidential, that they would be given as much time as necessary to answer each question, and that they may be asked to clarify or expand their response. In order to encourage participants to continue exploration, the interviewer remained open and prompted further explanation. After informed consent was confirmed, the interviewer followed up on the survey questions to confirm which quadrant the participant fell in. Then the interviewer asked questions following a semi-structured format:

1. Can you share your thoughts on how important it is to you to feel engaged in your healthcare?

2. What do the words "patient engagement" mean to you in relation to your healthcare?

3. Tell me about a time when you feel like you were really engaged in your healthcare?

4. What other ways could you be engaged that you think would be helpful?

5. Tell me about things that have prevented you from feeling engaged in your healthcare in the past.

6. How does engagement in your healthcare affect your health?

The interviews lasted 22 minutes on average but continued until the participants had shared all that they wanted to share regarding each of the interview questions. Once completed, participants were compensated with $20 gift cards.

The transcripts from the interviews were transcribed and deidentified by the interviewer and the research team. The interviewer also took field notes during the interviews to track responses and possible emerging themes. The interviewer also noted any important non-verbal

communications so that these could be included for consideration during the coding process. The interviewer's notes and impressions from the interview were added to the transcript so that they could be included in the analysis.

Pilot Interview

Before beginning to collect data, a pilot interview was conducted to test the logistics of setting up interviews and conducting them online, as well as to test the flow of the interview questions and their ability to elicit the full experience of the participant. Adjustments to the procedures were then made based on the participant's feedback to improve the study. A family member of the first author agreed to participate in the pilot study, as the conflict of interest would deter their inclusion in the study. Their experience engaging with the healthcare system, however, made them an ideal candidate to respond to the interview questions as well as provide additional insight as to what else should be included in the procedure to capture the full patient perspective. They interact regularly with the healthcare system in managing their own chronic health conditions (i.e., epilepsy, diabetes) and those of their daughter who has epilepsy.

The couple was contacted as if they were a participant with an initial phone call where the first author thanked them and obtained informed consent. They also reviewed the informed consent form and set up an interview time. A link to the survey and a WebEx meeting was then sent by email to see if they were able to log into the interview meeting without any problems. They then provided feedback regarding the effectiveness of the process, including:

A) Flow of the initial phone call.

B) Comprehension of the informed consent form.

C) Ease of using WebEx for the interview and any helpful instructions that could be included to walk participants through how to use the WebEx software.

D) Appropriateness and flow of the interview questions, and any additional questions that should be included to more fully capture their experience engaging in their care.

Data Analysis

Coding is "aggregating the text or visual data into small categories of information… and then assigning a label to the code" (Creswell & Poth, 2018. pg. 193). There are several different ways to conduct the coding process (Corbin & Strauss, 2015). This study utilized two ways that have been recommended for reading through the transcripts and assigning codes, including an initial scan and line-by-line coding (Charmaz, 2014; Corbin & Strauss, 2015). Researchers first read straight through the transcript, looking for overarching themes of the interview, patterns that emerged repeatedly, sections that seemed particularly insightful, or "in vivo codes" which are "catchy terms that immediately draw our attention to them" (Strauss & Corbin, 1998. pg. 115).

After this initial reading of the transcript, researchers read through and assigned codes line-by-line, by highlighting phrases or thoughts from the participants and assigning a label or theme to them (Charmaz, 2014). This kept the coding process based closely on the exact words of the participants and helped facilitate the generation of general themes that connect throughout and between transcripts (Charmaz, 2014).

Open, Axial, and Selective Coding

Open coding is an analytical process that builds on the line-by-line coding done previously by identifying overarching themes and subthemes that are emerging from the data (Corbin & Strauss, 2015). A variety of terms are used to describe the coding process, but for the purposes of this study, *themes* was used interchangeably with concepts and categories, and *subthemes* were used interchangeably with dimensions or properties (Creswell & Poth, 2018). Codes are understood to be the word that best captures the meaning of a line or phrase (Creswell

& Poth, 2018). Themes are groupings that help make connections between codes, and subthemes are smaller groupings within an overarching theme that add a richness to the understanding of the different dimensions or properties of that theme (Creswell & Poth, 2018). Rather than just listing codes, researchers began to identify codes, themes, and subthemes that were consistent across participants. Once consistent codes, themes, and subthemes were established, the research team began developing the theory that connected these using axial coding. Axial coding involved defining themes and subthemes identified during open coding to determine which groupings organized the data most completely and accurately and helped us make the most sense of the experience. Selective coding was, then, the part of the process when codes, themes, and categories were organized and developed into an emerging theory (Corbin & Strauss, 2015) complete with tentative hypotheses.

Codebook

All codes found in the transcripts were recorded in a codebook (Creswell & Poth, 2018). The codebook included the list of codes, as well as direct quotations from the transcripts, that were considered good representations of the codes. Codes were organized this way to make them easily accessible for inclusion in writing up the results. The codebook was also used to facilitate open and axial coding, with codes being grouped and organized into major overarching themes and sub themes. The research team used the codebook to analyze the developing theory as it emerged from transcript to transcript.

Increasing Trustworthiness of Data

Multiple processes were used to ensure that the personal biases and interpretations of the researchers were checked and bracketed (Tufford & Newman, 2012), and the interpretation of the data closely represents and explains the phenomenon as experienced by the participants

(Corbin & Strauss, 2015; Creswell & Poth, 2018). First was the use of multiple coders in analyzing the data. Participant feedback was then sought to confirm that these analyses were representative of the participants' experiences through a process called member checking (Corbin & Strauss, 2015). Lastly, internal and external auditors were used to ensure that the proposed procedure was followed and that the data analysis and resulting theory remained true to the shared experience of the participants. Each of these processes will be described in more depth here.

Multiple Coders

The first author filled the role of interviewer, transcriber, and primary coder, meaning he read through all transcripts first and assigned codes line-by-line. However, rather than relying entirely on the perspective of the first author, a coding team was created to help increase the likelihood that the coding process remained as close to the data as possible. Two graduate students and one undergraduate student were invited to be a part of the coding team. Each transcript was reviewed and coded by two members of the coding team. All transcripts were reviewed by the first author. The other members of the coding team were randomly assigned to be the secondary coder for 9 transcripts a piece. Each secondary coder read their assigned transcript (after the primary coder had assigned codes) to see if they agreed with the assigned codes or if they would recommend any changes. After the initial round of coding, all four members of the coding team met to identify and organize themes, and subthemes into a developing theory. The first author provided training, using the transcript from the pilot interview to help teach them the appropriate method for conducting the coding process and met regularly with them to orchestrate the processes of open, axial, and selective coding to ensure that the process remained credible and trustworthy.

Decisions regarding how codes were defined and then grouped into themes and subthemes were discussed amongst the research team until consensus was reached (Creswell & Poth, 2018). Researchers described how they coded the transcript, compared them with the codes used by other members of the coding team, and discussed which code best captured the meaning of a particular aspect of the data. The way codes were grouped into themes was also decided by discussion and consensus. If the primary and secondary coder for each transcript could agree on a code or theme, this was considered consensus, with the other members of the coding team being available to settle all decisions should consensus not be reached, though this proved unnecessary. Agreed upon codes were then used for all transcripts going forward when a similar experience or opinion was expressed.

Participant Feedback

In addition to including multiple coders, research participants were also included to provide feedback on the analysis through a process called *member checking* (Corbin & Strauss, 2015). Feedback was elicited from participants at two points during the study. Immediately after the interview was transcribed and deidentified, a summary of the transcript and any interviewer notes were sent to the participant. Participants were invited to partake in a short follow up interview to make sure they felt like their experience was accurately recorded. Participants were also encouraged to add any additional insight they may have left out or remembered after the interview. This ensured that as much of the patient's perspective was captured before analysis began.

After coding was completed and the resulting theory was developed, a summary of the results was sent to participants via email, along with a visual depiction of the results that illustrated the emerging theory. Participants were encouraged to provide their feedback regarding

whether they felt the theory aligned with the experience they shared during the interview.

Requesting participant feedback was another proactive choice to increase the likelihood that the

researchers' biases were successfully bracketed, and the interpretation of the data closely

represents and explains the phenomenon as experienced by the participants (Corbin & Strauss,

2015; Creswell & Poth, 2018). Participants were asked to correct anything that was not in line

with their experience and to add any additional information that emerged since the interview or

while reviewing the materials. Any feedback was included and integrated into the emerging

theory.

Internal and External Auditors

A member of the first author's dissertation committee who specializes in qualitative

methodology acted as internal auditor. Three transcripts and summaries were randomly selected

from the participants' data. This committee member read all of the materials belonging to each of

these participants in order to see if a logical path could be seen between the participants' data

and the emerging theory described by the first author. This ensured that the personal biases and

interpretations of the researchers were checked and bracketed (Tufford & Newman, 2012).

Separate meetings were held between the first author and the internal auditor to ensure the

validity of the coding process as well as to make adjustments to the interview questions, methods

of coding, or drafts of the manuscript.

An external auditor, who is an expert in qualitative methodology, was also asked to

review the research procedure to ensure credibility and trustworthiness. They followed the same

process outlined for the internal auditor where they reviewed transcripts, interview notes, and

drafts of the final manuscript to make sure that a rigorous method was followed. These steps

were included in order to increase the confirmability of the study. Any feedback from the internal and external auditors was incorporated into the procedures and manuscripts of the study.

Conclusion

In conclusion, grounded theory methodology (Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth, 2018), was selected to help develop a theory that provides a theoretical foundation of what patient engagement is, why it's important, and how it impacts patient health from the patient's perspective. Participants who range in their levels of engagement were gathered from the general population using advertisements in local primary care offices and community centers, and through snowball sampling. The first author set up interviews with them when they contacted either the phone number or email address provided. Interviews were conducted, recorded, and transcribed using WebEx software, and a group of researchers analyzed the resulting data using open, axial, and selective coding processes. Bracketing, participant feedback, and auditors were used to ensure the process remained credible and trustworthy and that the theory emerged from the data.

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CHAPTER 5: USING GROUNDED THEORY TO DEFINE PATIENT ENGAGEEMNT FROM THE PATIENT'S PERSPECTIVE

Introduction

The Commonwealth Fund regularly analyzes healthcare systems around the world using 71 performance measures across five domains — access to care, care process, administrative efficiency, equity, and health care outcomes (Schneider et al., 2021). While each country is unique and the results of the complex analyses should be interpreted with caution, the United States consistently spends more on healthcare than other high-income countries, and yet has worse outcomes (Schneider et al., 2021). Over two decades ago the Institute of Medicine made "patient-centered care" one of their six aims for quality improvement (Institute of Medicine, 2001) in an effort to revitalize healthcare systems in the US and address this disparity between spending and outcomes. Since that time many attempts have been made by researchers, organizations, and providers to try and engage patients more completely in their own healthcare (Abbasgholizadeh, 2019; Daniel et al., 2020; Hibbard & Greene, 2013). While no simple change will completely resolve the complicated factors that contribute to the disparities in the US healthcare system, research has found that patient engagement is associated with significant improvements in patient health, reduced costs, and improved patient experiences (Hibbard & Greene, 2013). Given these exciting findings, patient engagement has generated significant excitement as a potential solution (Graffigna, 2017).

After an initial wave of research provided evidence to support the policies focused on patient engagement, researchers began to recognize a need to develop foundational theories that explain what patient engagement is, why it is important, and how it impacts patient health (Phoenix et al., 2018; Rowland et al., 2017). At first, these definitions originated predominantly

from the providers themselves, rather than the patients (AHRQ, 2017; Carman et al., 2013; Coulter, 2011; Higgins et al., 2017; Harrington et al., 2020). While relying on healthcare provider's expertise and familiarity with the healthcare system was a natural first step, researchers eventually realized the critical importance of adding the patient's perspective (Phoenix et al., 2018; Roland et al., 2017).

As with most emerging research, initial attempts to include patients relied on patients who were already highly engaged and accessible, either through frequent healthcare utilization (Brown et al., 2015) or specific education (Pomey et al., 2015). Adding the perspective of patients has been a valuable addition but it also illuminated additional gaps in our understanding of patient engagement, specifically, the perspectives and ideas of patients who utilize healthcare less frequently or who engage in ways not included in traditional definitions of patient engagement (Pomey et al., 2015). Including these perspectives could help confirm what providers have already developed but it could also help resolve potential conflicts that exist or elaborate on our current understanding of the concept (Brown et al., 2015; Fiction et al., 2008; Mercer et al., 2020; Walters et al., 2017). Adding additional perspectives could also shed light on what barriers patients experience as they try to engage with their providers, as well as generate new ideas that providers may not have considered. Given the current limitations of the healthcare system, there is a possibility that some of the suggestions provided by patients may not be feasible. However, it seems important to develop the most robust understanding of patient engagement possible to help inform future research, increase collective understanding, and drive efforts to improve the healthcare system.

Using grounded theory methodology, the purpose of this study was to explore this gap in the literature (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018) and to gather the

perspective of patients who experience different levels of engagement. These perspectives will build on our current understanding of what patient engagement is, why it's important, and how it affects patients' health.

Patient Engagement

Over the years, patient engagement has been studied by several different disciplines, including medicine, nursing, political science, management, psychology, social science, and even computer science (Barello et al., 2014). Exploring this concept from several perspectives has resulted in a variety of definitions and theories about how to maximize its effect. As it has evolved, patient engagement has become an umbrella term for similar concepts such as patient activation (Hibbard et al., 2009) and patient-centered care (Institutes of Medicine, 2001). Patient activation focuses on patient behaviors that help them manage their own health whereas patient-centered care focuses on provider behaviors and organizational policies that enable patients to be engaged in their care. Researchers have explored many facets of patient engagement and realized that engaging a patient in their care relies on the systemic interplay of multiple factors, such as the patient's effort to be engaged, as well as healthcare providers' and organizations' willingness to allow them to be engaged (Graffigna & Barrello, 2018). Patient engagement has also been found to have positive effects on patient health outcomes (Hibbard & Greene, 2013), healthcare experiences (Hibbard & Greene, 2013), healthcare costs (Hibbard & Greene, 2013), and provider care experiences (Goel et al., 2016).

Patient Perspectives Across a Range of Engagement Levels

While the general concept of patient engagement has been found to have positive effects, a study by Pomey et al. (2015) highlights the idea that the current research relies heavily on highly engaged patients, or frequent utilizers (Brown et al., 2015), and has yet to include other

perspectives (Pomey et al., 2015). In trying to generalize patient engagement to the larger population, it needs to be recognized that engagement may look very different across patient groups. For example, patients older than 65 typically have much higher rates of utilization and use healthcare resources more often. However, higher utilization does not necessarily equate to higher engagement. Within this group there may be patients who take personal responsibility for their health and are very involved in their care, while others may be passive and engage little. In other populations, some patients may be highly engaged in their health (i.e., staying physically active, healthy eating, researching their own health conditions) but rarely utilize healthcare resources like routine visits (Hibbard et al., 2009). This continuum of patient engagement may include, but not be limited to, patients who have frequent check-ups for management of chronic health conditions, patients who are generally healthy and only attend annual wellness checks, patients who only engage with the healthcare system when needed to address acute or urgent problems, or even those who purposefully avoid engaging with or mistrust the healthcare system.

Consider, for example, how definitions of patient engagement might differ for someone from a population who has historically experienced discrimination in healthcare and may therefore have more barriers to feeling engaged, such as African-Americans or members of the LGBTQ+ populaiton (Parameshwaran et al., 2017). As mentioned previously, higher levels of patient engagement have typically resulted in positive effects on patients across social and demographic characteristics, such as gender, age, race, level of education (Hibbard et al., 2008; Bos-Touwen et al., 2015) and level of income (Skolasky et al., 2008; Rask et al., 2009). However, it is also very clear that there are significant discrepancies in levels of engagement across these same factors (Graetz et al., 2016). If research could discover, "patients' perspectives on what they themselves consider to be useful engagement practices for actively

enhancing their health care" (Pomey et al., 2015, p. 3), we could learn what barriers exist to patient engagement, as well as what some patients are doing to take care of their own health that may not fit into our current definitions of patient engagement. This more robust understanding could then better inform patient engagement efforts and bring those improved health outcomes to more people.

The current study conceptualized patient engagement using level of utilization and personal activation/level of personal engagement. When combined, these two variables create four quadrants (see figure 1). Activation is, "the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health" (Hibbard et al., 2009, p. 377), while utilization is simply how often patients use healthcare resources, most commonly through appointments with providers. Based on their level of utilization and activation, patients from each of these four quadrants may have different perspectives on what it means to be engaged, both in their own health and by healthcare providers. Relying on grounded theory methodologies, specific strategies were used to recruit participants from each of these quadrants to intentionally expand our current understanding of what patient engagement is, how it works, and why it is important.

Figure 1. Four Quadrants of Patient Engagement
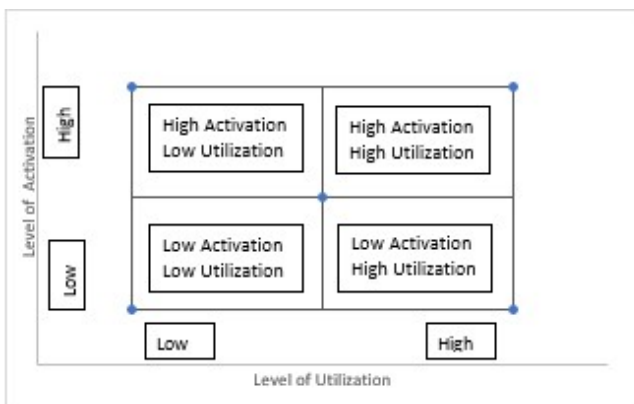
Conclusion

In summary, this study sought to address the gap identified by Pomey et al. (2015) to add an, "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). This will build on the work that has been done to develop a theoretical understanding, first from healthcare researchers' and providers' perspectives (Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017) and then from highly engaged patients ((Brown et al., 2015; Pomey et al., 2015), as it will add the perspective of patients who range across different levels of activation and utilization, and whose efforts to be engaged in their healthcare may differ from providers prescriptions or expectations (Pomey et al., 2015). This enhanced theoretical understanding will help use better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on both organizational and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

Methods

When discussing how to fill the theoretical gap in patient engagement research, Phoenix et al. (2018) recommended using qualitative perspectives to inform the theoretical underpinnings of patient engagement. Qualitative methodologies, and grounded theory in particular, are especially well suited for these types of questions (Charmaz, 2014; Corbin & Strauss, 2015). While most qualitative methodologies enable researchers to elicit and understand the unique perspective of an individual (Creswell & Poth, 2018), this study is seeking to understand a concept or phenomenon rather than an individual experience. Unlike phenomenology, grounded

theory methodology uses the qualitative perspective of many subjects to better understand the concept rather than thoroughly exploring each person's unique experience through multiple interviews (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018). Since the purpose of this study is to expand our understanding of patient engagement from a variety of perspectives it was deemed that grounded theory would be the most appropriate. This methodology allows us to elicit the patient's perspective from patients who range in their levels of activation and utilization (see Figure 1). The diversity of patient's experiences and thoughts about patient engagement helped this grounded theory be more representative of the concept of patient engagement generally, rather than trying to be representative of any one group's experience or perspective on the subject.

Research Questions

1. How do patients define or describe "patient engagement?"

2. How important do patients think patient engagement is?

3. How do patients explain the effect patient engagement has on their health outcomes?

Participants

Consistent with the goals of grounded theory methodology (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018), inclusion criteria for this study were intentionally broad to increase the diversity of our sample (Creswell & Poth, 2018). Participants needed to be fluent in English, as the interviews were conducted in English. Beyond that, however, no limitation was set on what is considered an engaged patient, as we sought to include multiple perspectives. Participants were asked to self-identify based on various questions about their interactions with healthcare.

The sample consisted of 27 participants (see Appendix G), 21 of whom were interviewed individually and 6 of whom were interviewed with their romantic partner (three couples). This was done as participants referred their partners, in order to gain the added benefit of seeing how engagement experiences were similar or different within family relationships. Of the three couples, each had different experiences and none of the participants ended up in the same group as their partner.

Each quadrant was represented in the sample: a) high activation, high utilization (n=10; 37.1%); b) high activation, low utilization (n=8; 29.6%); c) low activation, high utilization (n=5; 18.5%); and d) low activation, low utilization (n=4; 14.8%). The average age of all participants was 35.67 years old. There were more female participants (n = 16) than male (n = 11). Based on participants' reports of racial demographics, a majority of participants were White/Caucasian (n = 17; 63%). The remaining participants reported they were either Black/African American (n = 9; 33.3%) or preferred not to say (n = 1; 3.7%). The average annual income of the sample was $77,828. Types of insurance varied among participants with the following options reported: a) employer provided insurance (n=13; 48.2%); b) government insurance (Medicaid/Medicare, n=9; 33.3%); c) uninsured (n=3; 11.1%); and d) paid for private insurance (n=2; 7.4%).

Recruitment

Based on the principle of theoretical saturation, a predetermined number of participants for the study was not required. Instead, recruitment continued until saturation was achieved, meaning that enough participants had been interviewed and there was enough variability among their experiences that consistent themes emerged across interviews about the concept of patient engagement (Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth, 2018). A snowball sampling technique (Parker et al., 2019) was used to recruit several participants representing

each of the four quadrants. This means that participants helped identify and recruit people they knew who shared similar or different perspectives, thus saturating each of the groups representing the four quadrants or levels of patient engagement.

To help this snowball sampling technique, an advertisement was distributed with instructions on how to participate. Advertisements were strategically distributed at a variety of locations to recruit participants from each quadrant. This included healthcare clinics for patients with higher utilization rates and fitness centers for patients with higher activation. Social media recruitment was heavily used to invite other communities that might not actively engage in health or healthcare settings.

Procedure

Once IRB approval was received, a google voice phone number and the first author's email address were included for patients to contact if they were interested in learning more about participating in the study. Interested participants were greeted warmly and the first author introduced the study and explained what was required of participants. Informed consent was obtained verbally over the phone as well as in writing on a document that was emailed to the participants after the initial phone call to sign and email back to the first author. Before ending the initial phone call, the first author scheduled a time for them to meet for the interview and sent the participant a demographic survey to fill out before the interview. The first author managed all communication with participants, scheduling of interviews, as well as conducted and transcribed the interviews, and led the coding team. These processes will be outlined in the following sections.

Interviews

Interviews were conducted, recorded, and transcribed using WebEx$^©$. Conducting interviews online provided flexibility for the participants and reduced potential barriers (i.e.,

geographical locations, quarantine restrictions, etc.). WebEx software also recorded and transcribed interviews, which sped up the transcription process. Transcripts were additionally edited to ensure accuracy, as well as to redact any identifying information. Phone interviews were also offered so that internet access did not prevent participation, but no such cases arose during this study.

Following the initial phone call, participants were emailed a link for an interview and a link for the demographic survey. This survey asked questions regarding the inclusion criteria for each of the four quadrants, helping delineate where participants fell in relation to their personal utilization and activation. These classifications were confirmed by the participants. Once they successfully logged into the interview, participants were informed that answers would remain confidential, that they would be given as much time as necessary to answer each question, and that they may be asked to clarify or expand their response. The interviewer asked questions following a semi-structured format.

The interview lasted between 10-50 minutes but continued until the participants had shared all that they wanted to share regarding each of the interview questions. Once completed, participants were compensated with $20 gift cards. The transcripts from the interviews were transcribed and deidentified by the interviewer and the research team. The interviewer also took field notes during the interviews to track responses and possible emerging themes. The interviewer also noted any important non-verbal communications, such as smiling, laughter, or hand gestures, so these could be included for consideration during the coding process.

Data Analysis

Using the transcript from a pilot interview, the first author taught the coding team appropriate methods for conducting the coding process. Once training was complete, each

transcript was reviewed and coded by two members of the coding team. The first author filled the role of interviewer, transcriber, and primary coder, meaning he read through all transcripts first and assigned codes line-by-line, which he then recorded in a codebook. The other three members of the coding team consisted of two graduate students and one undergraduate student. The transcripts were evenly distributed between the three secondary coders (n=9 transcripts). Secondary coders were asked to read the transcript and determine if they agreed with the emerging codes or if they would code any part of the transcript differently. All members of the coding team then met to compare themes and subthemes across groups. The coding team met regularly to ensure that the process remained credible and trustworthy.

Decisions regarding how codes were defined, grouped into themes and subthemes, as well as tentative hypotheses from the emerging theory were discussed amongst the research team until consensus was reached (Creswell & Poth, 2018). Researchers described how they coded the transcript, compared them with the codes used by other members of the coding team, and discussed which code best captured the meaning of a particular aspect of the data. The way codes were grouped into themes was also decided by discussion and consensus. If the primary and secondary coder agreed on a code or theme, this was considered consensus. If consensus was not reached, a third member of the coding team was available to settle any disputes, though this proved unnecessary.

In an effort to increase the trustworthiness of the theory, research participants were also included to provide feedback on the analysis through a process called *member checking* (Corbin & Strauss, 2015). Transcripts along with a summary of the results were sent so that participants could provide their feedback regarding whether they felt the theory aligned with the experience they shared during the interview. Transcripts along with the proposed methodology and a

summary of the results were also sent to both an internal and external auditor to confirm that the study procedure and coding process were consistent, and the interpretation of the data closely represented the experience of the participants (Corbin & Strauss, 2015; Creswell & Poth, 2018). The internal auditor was a research advisor to the primary investigator who has expertise in qualitative methodologies. He participated in the study design but not the interview or coding. The external auditor was an expert in qualitative methodology who was unaffiliated with this project. These efforts ensured that the personal biases and interpretations of the researchers were checked and bracketed (Tufford & Newman, 2012).

Results

Four major themes emerged and were common across each of the four groups: patient definitions of patient engagement, factors of patient engagement related to the patient, factors of patient engagement related to the provider, and factors of patient engagement related to their environment. Each of the themes, with the exception of the definitions theme, included aspects that either facilitated or prevented engagement. Within each of these four overarching themes, a common set of subthemes also emerged, which were consistent across all four quadrants, though patient's perspective on these subthemes varied from group to group. As all four groups had much more in common regarding the emerging themes than they had in contrast, the presentation of the results will be organized by theme rather than by group, and the minor differences between groups will be listed regarding each theme. Participant quotes will be distinguished using italicized font, and their group will be indicated as an abbreviation in parentheses (i.e. high activation, low utilization will be HA-LU).

A working definition emerged from patients' responses regarding what patient engagement is and why it is important, including a number of responses regarding how it can be

facilitated or prevented by factors relating to the patient, provider, and environment. The

resulting theory describes patient engagement as a relationship between patient related factors

and their sense of engagement that is influenced by provider related factors, and environmental

related factors (see Figure 2).

Figure 2. Grounded Theory of Patient Engagement from the Patient's Perspective
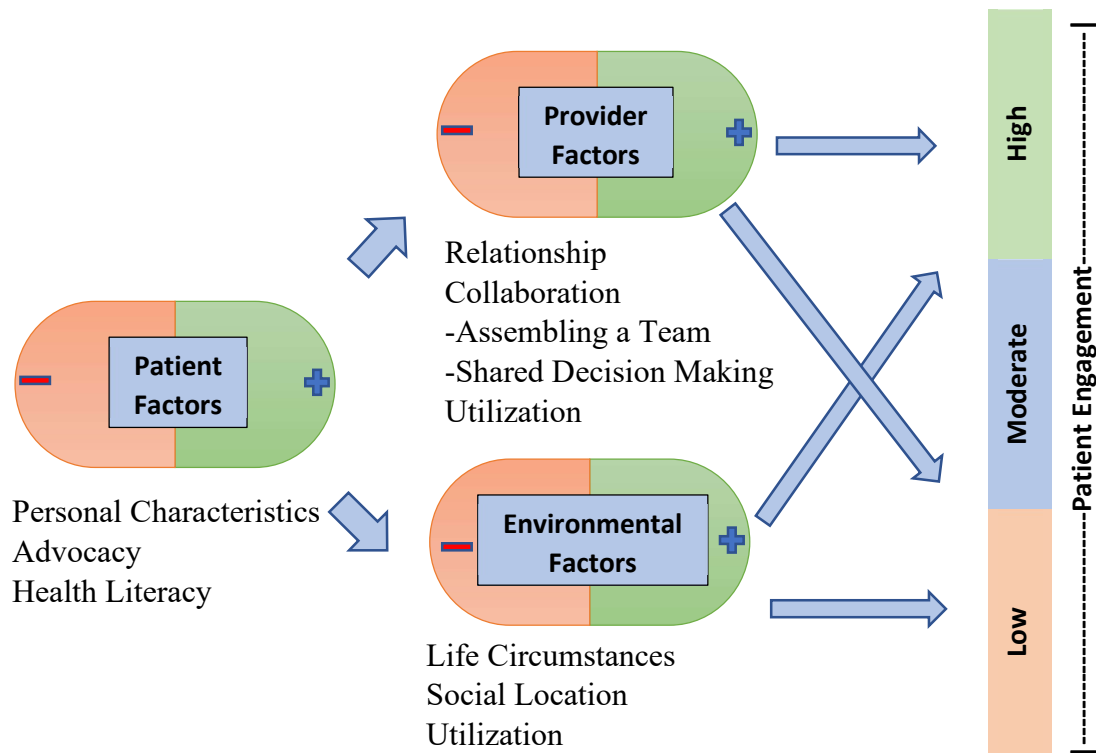
Participants emphasized that the impetus for engagement was their responsibility, and

that they could be more or less engaged depending on personal characteristics such as taking

responsibility for their health or being proactive, as well as their health literacy level and their

concurrent ability to advocate for themselves and their needs with providers. This personal

effort to be engaged was then either encouraged or barred by factors related to providers, such as

their relationship with their providers or their ability to collaborate and be involved in healthcare

discussions and decisions. In a similar way, their engagement was facilitated or prevented by circumstances of their environment, such as how healthy they were or what access they had to healthcare depending on resources related to their social location, such as insurance status, gender, race, and the areas they lived in. This all combined to determine their sense of engagement, ranging from high to low. In this section, the results of how participants defined what patient engagement is and why it is important will be shared before each part of this theory will be presented in more depth.

Definitions

When asked what they thought patient engagement meant, how important it was to them, or how it affected their health, participants identified aspects of being engaged in their healthcare that led to a rough definition of patient engagement from the patient perspective.

What Patient Engagement Is

Regarding *what* patient engagement is, participants in all four groups emphasized the ability to be informed about their health, be able to make decisions for themselves regarding treatment, a collaborative relationship with their healthcare team, and an ability to manage their health conditions on their own. James (HA-HU) provided the most succinct definition provided by any of the participants, capturing most of these points when he said, *"Patient engagement for me is the desire and the capability to actively choose or to participate in the healthcare in a way that is appropriate to me, in cooperation with the healthcare provider or the institution for the purpose of maximizing the outcomes and the experiences of care."*

Interestingly, members of both low utilization groups made a point of differentiating between being engaged in their healthcare and being engaged in their health. Scottie (LA-LU) said, *"I guess I'd probably have two definitions. The one I would default to is-- I think of*

healthcare, it's like, hospitals clinics, You know, normal, like follow up exam, type stuff. Instant care that kind of stuff. The second one…could involve, like us being active in trying to do things that promote care for our personal health from, like, things that we do…that would all be included. So maybe a gym would be included in like, taking care of yourself or not. you know what I mean? Like Diet, sleep all that.'' Participants from both these groups emphasized what they do on their own to maintain their health as a key component of their sense of engagement as a patient.

Why Patient Engagement is Important

Participants listed several reasons for *why* patient engagement was important, including the positive effect being engaged can have on both their health outcomes and their experience as a patient. The most common code by far in each group were the benefits patients saw to being engaged, such as improved health outcomes, improved experience with their healthcare, and reduced costs. Flo (HA-HU) summarized this well when she said, *"Being engaged in health care has been something great to me because I've been able to improve my health outcomes…I am able to make informed decisions about my care…and I have a better patient care because compared to before, I was not engaged at all…like everything was just a mess. But now, I can say, it's very important to me, because I've been able to improve my healthcare outcomes and even the costs."*

In addition to improved health outcomes in general, participants also talked about engagement improving the quality of care and improving their health literacy. Within the improved patient experience, participants talked about engagement providing them with a sense of empowerment and ability to advocate for their needs, as well as engagement increasing their ability to access services. However, many participants noted that these benefits come at a cost,

as being engaged in healthcare requires more effort than being a passive recipient of care. Meg (HA-HU) identified this negative aspect of patient engagement, saying, *"I hope it has a positive effect. I think it does. But it is stressful because it sometimes feels like, because I've never had a doctor follow up, and if I dropped the ball, no one would."*

How Patient Engagement Works

Discussions of how participants could be engaged were largely captured in the remaining major themes. They shared ideas of what patients can do to either increase or decrease their engagement, as well as things that either facilitate or prevent their engagement that were related either to healthcare providers or factors of their environment (see Figure 2).

Patient Factors

Patients described several factors that either facilitated or prevented how much they felt engaged in their care. These included: a) personal characteristics of the patient; b) their level of health literacy; and c) their ability to advocate for themselves. From the perspective of the participants, these three factors had the greatest influence on their overall sense of engagement. Participants reported that from their perspective they have the least amount of control over provider and environment related factors. Since they felt they had more control over patient factors, they saw it as the most productive way to personally engaged. Meri (HA-LU) said, *"I think you have to be proactive. You have to stand up for yourself. For the most part, I believe doctors are really honestly trying to help you, but they don't sometimes know what questions to ask. They can't spend very much time with you and so a lot of water goes under the bridge that isn't being addressed."*

Personal Characteristics Facilitating or Preventing Engagement

There were a number of intangible personal characteristics that participants identified as traits that would either facilitate or prevent engagement. Characteristics such as engagement being a value or priority for them, a sense of motivation and initiative in their care, a sense of ownership over their health, and being proactive in their engagement and maintaining their health. For example, when talking about whether the ownership of engagement rested with the patient or the provider, Monica (HA-HU) said, "*at the end of the day, we're both humans, but this is their job and this is my life.*" There were also a number of personal characteristics that could prevent patient engagement, such as not knowing how to advocate for oneself or if it is even allowed, lack of initiative or not seeing engagement as a priority in their lives, low health literacy, fear, having too much trust and simply accepting what the provider says, frustration with and distrust of the healthcare system sometimes due to discrimination, and the cost of effort it takes to be engaged An exhausted Genny (HA-HU) expressed, "*It's become my other job: Managing my healthcare.*" These personal characteristics seemed to be the foundation for their sense of engagement. Every participant mentioned experiencing both facilitating and preventing factors related to themselves, their providers and their environment. However, if the facilitating factors were more important to them than the preventing ones and they made their decision to be engaged a priority, they were more likely to push through any barriers and persist in their efforts to be engaged. Sarge (HA-LU) portrayed this well, saying, "*I see plenty of people that have barriers, and a more timid person would-- they do get shut down. but that just couldn't happen with me. I would just insist on being fully engaged.*"

Health Literacy Facilitating or Preventing Engagement

Health literacy also played an important role, as it affected how prepared participants felt to both engage with providers at their visits as well as manage their own health afterwards.

There seemed to be three parts to health literacy: (a) how informed participants were about their health conditions or treatment options, (b) the act of learning, researching, or asking questions to increase one's literacy about their health, and (c) being able to apply that knowledge to manage their health at home. Meg (HA-HU) talked about the effect having higher health literacy can have on her sense of engagement when she said, *"I think it's just a little bit easier because I know what to expect and I know what I want."* Limited health literacy was also seen as a great barrier to patient engagement in this way, as participants often didn't know how involved they were allowed to be or what they could do to manage their health. Molly (HA-LU) shared the following regarding this lack of health literacy baring her engagement, *"there are times when I haven't been as engaged with my own health partially because I didn't know what was available to me."*

Advocacy Facilitating or Preventing Engagement

Participants also saw advocacy as a primary action related to their engagement. Amy (HA-LU) said, *"I feel like being an advocate for yourself, in terms of health care is the action behind being engaged."* Advocacy included sharing your preferences or concerns with providers, as well as speaking up when you don't understand or disagree with a treatment decision. In fact, while some trust in healthcare providers was seen as part of a healthy relationship and shared decision making, having too much trust and not advocating for yourself was seen as a great barrier to engagement that often resulted in poorer health outcomes. Genny (HA-HU) shared, *"I have like my mother-in-law and people I know who just will do* [what the provider says]*, they will spin their wheels for years because 'that's what the doctor said I should do."*

Connections between Patient Factors

The identifying aspect of patient factors was that they were within the participants influence, meaning they had more control over whether or not they advocated for themselves or strove to increase their health literacy. Factors related to their environment or to providers were more dependent on external influences they couldn't always control. Thus, while participants expressed frustration about preventative factors related to the environment or providers, they talked about preventative factors related to themselves with more of a sense that these were areas they could or should do better in. This again reinforced the feeling that if they ultimately decided for themselves that they wanted to be engaged, then there were things they could do to accomplish this and persist through any barriers they experienced.

Provider Factors

As strong as the relationship was between the patient related factors and their sense of engagement, it was influenced, for better and for worse, by factors related to healthcare providers. These factors included the quality of the relationship between patients and providers and the quality of the collaboration. Participants noted that when being engaged in their healthcare, they needed to collaborate in two ways, first by coordinating care between different members of the healthcare team, and second by taking an active part in the decision-making process. Providers had a large influence on patient's by either encouraging or discouraging patients' engagement, and participants noted how much effort they put into finding providers who are willing to collaborate and allow them to engage in the ways they wanted to.

Patient-Provider Relationship Facilitating or Preventing Engagement

Participants noted some of the things providers can do to help foster patient engagement through their relationship with the patient, including being collaborative, listening and communicating well, being caring, encouraging, engaging with the patient, and inspiring a sense

of trust in their patients. For example, regarding characteristics of the provider or the relationship they have with the patient, Judith (HA-HU) said, *"I think the way that the provider interacts with you helps the engagement."* Molly (HA-LU) added, *"if I have a doctor that I trust, it's a lot easier to be open with questions or concerns or to seek advice."* The main barriers that participants identified were providers being disengaged, dismissive, having poor communication or bedside manner, or being prescriptive rather than collaborative. Sarge (HA-LU) said, *"The main barrier, I think, that would keep a person from being engaged is a practitioner that just sort of is not what he or she should be and is putting up roadblocks and sending nonverbal cues to shut people down and all the things that you're not supposed to do. There are plenty out there that do it."* Meri (HA-LU) shared, *"I think, if you've got the feeling that the medical personnel cared about you, it would help a lot. Some do, you can tell and some don't. And I understand why they disengage because I worked as a nurse's aid myself, and it nearly tore me apart emotionally in some cases. So, I understand why they have to disengage, but I think it's very helpful to the patients."*

Collaboration with a Team of Providers Facilitating or Preventing Engagement

The subtheme 'collaboration with a healthcare team' involved assembling providers who both had the expertise and were willing to engage with the patient. While these qualities were important, the participants reported that they wanted to be seen as an equal member of the team, if not the leader. Genny (HA-HU) described the need for the patient to act as the hub of the team, carrying information to other providers between visits, *"I have a blood pressure heart person, and a cardio-physio person and, then I have my erythromelalgia, which is a rheumatological disorder and that person is on my team. And then my GI person is on my team, and they don't talk to each other. It would be nice to have them all in one room, but it seems like*

I'm kind of the hub, where any information I get from any one of them, I have to be the one that then carries that and tells everyone else." This seemed to work best if participants felt they were treated as equal members of the team, with Meg (HA-HU) saying, *"not, everyone knows you the way that you know you, and so I think it's really important that the patient's voice is prioritized in order for good outcomes to happen."* This leads into the idea that patients should be seen as experts in their own lives and experiences, which will be discussed more as part of shared decision-making below.

This collaboration process is prevented by the struggle of working with providers in multiple healthcare systems, as Genny (HA-HU) said that they're all *"using different electronic health records."* Unwilling providers could also prevent this process, and many participants talked about switching between providers until they found someone willing to listen and engage with them. For example, Patricia (HA-HU) said, *"When our son had hand foot and mouth, right before Christmas, 2 years ago, he was like, oh, no, it's just a normal cold. And, like, I called our ped right after and he's like, I'll just write you the prescription."*

Participants also talked about utilization of mental health services and their collaboration with mental health providers as part of their team. Meg (HA-HU) shared, *"Overall, I've had a better experience feeling like I have choice and that kind of thing with the mental health therapist."* Patty (LA-LU) advocated for an even more holistic view of healthcare and patient engagement in it, *"there's a more holistic view of healthcare, it doesn't just include your physical health it includes your mental health. It includes all aspects of health. Maybe even like, you know, relationships and your... I don't know. things like that. (Interviewer) Like a sense of spirituality or purpose? (Patty) yeah, that too. Like, a lot of that stuff. I think health is an all-inclusive term. Probably most of the time gets focused on like, are you alive or not?"*

Shared Decision-Making Facilitating or Preventing Engagement

In addition to collaborating with different members of their healthcare team, participants identified collaborating with providers regarding treatment decisions, often referred to as shared decision-making, as a core component of patient engagement. Trent (HA-LU) said, *"patient engagement means that to me, as a patient, I'm doing something with the healthcare professional, not letting them do something to me."* Four aspects of shared decision making emerged from the participants' responses: (a) educating the patient and providers giving their expert recommendations, (b) patients being seen as experts in their own lives and experiences, (c) providers accepting patient influence and allowing them to make decisions, and (d) balancing the provider and patient expertise and roles in the decision-making process. Monica (HA-HU) talked about the balance between providers sharing their expert opinions and the patient using their own expertise regarding their lives and situations to make a decision together, *"That your doctor is there to advise you and educate, but you get to choose."* Providers simply prescribing their recommendations without allowing patients to be involved in the decision was seen as a serious barrier to their engagement. Molly (HA-LU) described, *"some doctors just kind of think they know what's best and they're doing it on their schedule, and they don't really give opportunities for patients to be engaged."*

Connections between Provider Factors

The main commonality between provider factors seemed to be its relational aspect. Whether that be in the sense of trust in the patient-provider relationship, or their ability to collaborate as part of a team or in shared decision making, participants saw the facilitative and preventative factors of providers as playing out in their interactions and relationship with the patient.

Environmental Factors

Participants also saw some aspects of their lives or environment as outside of their control, but very influential on their ability to be engaged in their healthcare. Their life circumstances, especially their state of health, seemed to drive the need for engagement while their social location presented unique resources or obstacles in their effort to be engaged.

Life Circumstances Facilitating or Preventing Engagement

Many times, participants expressed that, depending on what was happening in their lives, their engagement in healthcare moved up and down on their priorities list. Participants' health strongly influenced their need for engagement, as was the case for Monica (HA-HU) when her health was, "*so intense that I kind of got into this groove of forgetting that the chiropractor was supposed to heal me, not just maintain me. And so, there was quite a period there where I didn't advocate for myself as much.*" Compare this to Tammy (LA-LU) who was less engaged because, "*I feel like overall I, I enjoy pretty good health and so I haven't had to worry too much about that.*" At other times, it was other aspects of their lives, unrelated to their health, as it was for Scottie (LA-LU) when she said, "*we've been in a unique situation this last few years, with our income being so extreme up and down. With us moving around, it's just been a little bit different. So, normally at least once a year to take my kids in to do wellness checks and stuff. But to be honest, I don't think I've done that for my kids for a couple of years.*" For many participants, the pandemic had an effect on their engagement, like Jarob (LA-LU) who said, "*I really wasn't engaged during the pandemic.*"

Social Location Facilitating or Preventing Engagement

Social location seemed to have a big impact on what resources participants were able to access as well as what barriers they were likely to face when trying to be engaged. For example,

Eric (HA-LU) said, "*unfortunately, I think it is that my wife and I, we have higher levels of education we've known how to work through processes to come up with solutions and so it is more of just -I hate to say it,- our demographic and our other things like that, because I think of others I go, 'how could they possibly know how to navigate this?' We have high speed Internet that we can access things on. We have time in our schedule, where during office hours, we can make phone calls and we can afford to do that. But if we were, you know, a line worker somewhere, I don't know where they find the time to make those calls to schedule those appointments because they work the same time as the doctor's offices do.*"

Participants noted a few barriers related to the social determinants of health including the need for translation services, transportation, limited resources in rural areas, and insurance status. Insurance, or the lack thereof, was a huge factor in participants' utilization of healthcare and their willingness to prioritize engagement, a point that Genny (HA-HU) summarized well when she said, *"I am in the most privileged position to get health care and it's still really hard, and I acknowledge that if it's this hard for me, how hard is it for somebody who has either no insurance or really crappy insurance or Medicaid?"* Goodman (HA-HU), Joggy (LA-HU), and Jarob (LA-LU) all shared experiences where discrimination by healthcare providers made it harder for them to feel engaged. Lastly, social support was an aspect of social location that could facilitate engagement. Favoretta (HA-LU) shared the example of her husband who would likely be less engaged if not for her support, *"it's finally at that point, that I set up the appointment and I do all the talking. He shares what he's feeling, but for the most part, he's very like, 'okay, Favoretta, let's go. Set it up. Whatever, I don't care. Just tell me when I need to be there.*"

Connections between Environmental Factors

Like provider factors, environmental factors were seen as outside the participants ability to control, and circumstantially facilitated or prevented their efforts to be engaged. Unlike provider factors, where patients can exert some influence by improving relationships or switching doctors, environmental factors were seen as more fixed, random, or as simply part of life that was happening to the participants regardless of their decisions or efforts. One can't always control when they might get sick, or what social location they're born into, and efforts to influence or change these are much slower and involved than just making a decision to do something different. So, while environmental factors could have a positive or negative impact on their engagement, the focus was much more on how to navigate or cope with the circumstances you were in, when trying to be engaged, rather than change them.

Integration of Theory and Tentative Hypotheses

In this theory of patient engagement from the patient's perspective, patient engagement is seen as an interaction between their personal factors, provider factors, and environmental factors. Participants viewed personal factors as the most important in determining how engaged the patient ended up being. In fact, if a participant felt that being engaged was important to them or if they had a sense of responsibility to be engaged or ownership of their health, this often provided a resilience to the different barriers that prevented that engagement. If a participant decided engagement was enough of a priority to them as to be worth the cost of effort it takes to be involved, they would find a way to do it, as captured in the statement by Sarge (HA-LU), *"I see plenty of people that have barriers, and a more timid person would-- they do get shut down. but that just couldn't happen with me. I would just insist on being fully engaged."*

This process of striving for engagement could be hypothesized in a few ways. For example, patient's ability to advocate for themselves could flow naturally from having higher

health literacy about their condition, and therefore feeling like they could be more involved in the treatment process, or it could flow from a personal conviction that they would not simply be passive agents when it comes to their own health, as both sentiments have been expressed above. This could start a chain reaction, where patients could focus on learning about their health conditions or treatments in order to be more prepared to advocate for themselves, resulting in a more collaborative relationship with their provider, ultimately resulting in them feeling more engaged. Alternatively, this same increased health literacy and ability to advocate could result in an increased capacity to share in their decision-making, cycling back to reinforce their personal sense of ownership in their health that could lead to continued efforts to increase health literacy. This process would again lead to an increased sense of engagement in their healthcare.

Barriers to engagement, however, have potential to negate facilitating factors related to the patient, provider, or environment at any point. For example, even a strong desire to be engaged can be tempered by a lack of resources such as insurance. A statement by Eric (HA-LU) captured well how finances played a key role in the patient engagement experience for every participant, both in the sense of how expensive it was and how insurance either facilitated or prevented them from being able to navigate that barrier, *"Really, in the United States, to talk about how the health care and to try to separate out the experience of the doctor's office with the insurance, it's almost impossible."* While an argument could be made that with enough health literacy, patients could find ways to navigate around the largest financial barriers, the point of this hypothesis is that these barriers can discourage engagement in very real ways, despite even the strongest of facilitating factors.

Another example of this is the effect barriers related to social location, such as discrimination of gender or race, can have on engagement. Goodman (HA-HU) shared how

small implicit biases can make it harder to foster a sense of engagement in patient-provider relationships, *"You know, when a white doctor sees a white patient, they feel more at home, but when a white doctor sees a black patient, there is this little gap in relationship between them."* Even small experiences like this, added with others, can culminate in a weakening of facilitating factors like a strong patient-provider relationship or patient's sense of safety advocating for themselves, likely leading to lower levels of engagement.

When confronted with barriers to engagement, participants found creative ways to overcome and be engaged in their healthcare in other ways. For example, telehealth was shared as a way to avoid access barriers such as limited time or high costs. Patty (LA-LU) shared that, *"I think nowadays, I don't know that all healthcare needs to occur at a doctor's office. If there's a way to message them or an app or something for things that you might think are more minor. Like, you'd probably be more willing to pursue that or more willing to engage with your healthcare provider."* Technologies have also been an alternative resource to help increase health literacy when providers are either unavailable or disengaged. Many participants actively sought ways to research their conditions on their own, often turning to the internet for information. While Amy (HA-LU) used the internet as much, if not more, than most participants, she pointed out the potential detriment of this practice, saying, *"it's almost easier to just trust the doctor, because trying to figure out how to be informed yourself is really hard since there's a lot of unreputable or disreputable information out there if you just go on Google or on the Internet or something like that."* These creative solutions presented an interesting shift in the relationship of healthcare utilization and engagement.

The Relationship between Utilization and Engagement

Participants associated utilization with both provider factors and environmental factors, and overall, the relationship between utilization and engagement seems to be strong, but not absolute. For example, Amy (HA-LU) shared how her life circumstances increased the frequency of her utilization, providing more opportunities for engagement, *"I feel like when you're dealing with complex health or chronic conditions, which is kind of the same, you're being engaged is so much more involved and so much more important because you're dealing with stuff."* However, utilization was not a prerequisite for engagement, as evidenced by a number of participants feeling that they were engaged in their healthcare despite low utilization. They felt that they could manage their health conditions on their own and still maintain a healthy lifestyle.

Limited access to healthcare services was seen as the most common preventative factor of utilization, with participants sharing issues of limited availability leading to long wait times for appointments, providers being hard to get ahold of as well as limited time during appointments. Genny (HA-HU) shared, *"even a heart problem doesn't get you in the door to the big specialist at the university hospital for three or four months. I guess unless your life flighted with an imminent death."* Judith (HA-HU) found a work around for this, saying, *"we will use urgent care if it's hard to get into primary care doctors very quickly."* Environmental barriers included high costs, insurance denials and a lack of transparency about expenses was a common concern, with Trent (HA-LU) saying, *"there's got to be some solution somehow to make that easier for people to be engaged in healthcare without having to worry too much about hidden costs coming out of nowhere."* In summary, despite utilization level being used as an inclusion and exclusion criteria for our four groups, it did not have a definitive relationship with participants sense of engagement.

Similarities and Differences between groups

       While this study intentionally recruited participants who ranged in their levels of activation and utilization (see figure 1), the four groups had much more in common than they had in contrast. For example, the barriers related to the patient, provider, and environment were largely the same between groups. The factors that counteracted them or facilitated engagement, however, had more variation. While the subthemes listed in this results section were consistent between groups, the way each group talked about these factors of patient engagement was different. While participants in the two highly activated groups talked about how engagement has helped them and how they've been engaged in the past, the two groups with low engagement spoke of patient engagement on a much more hypothetical level, emphasizing what they thought it should be, or what they wish their experience was like. What's more, comments made by participants defining what patient engagement is, and why it is important had very little variation between groups, but highly activated participants tended to emphasize the power and importance of patient factors on their resulting sense of engagement, while less activated participants tended to emphasize things they wished providers would do. This could be because those with higher levels of activation and engagement feel like they can advocate for themselves and trust that their voice will be heard, while those in in the lower activation groups didn't have that same experience, nor the same relationship with their care team, and as a result, only could speak to it as a potential possibility rather than their actual experience.

       This dynamic was highlighted in the interviews with romantic partners interviewing together. Of the three couples, none of the participants ended up in the same group as their partner. There was some level of agreement between partners, meaning that after their partner shared something the other would sometimes report that they experienced or thought the same

thing. However, in response to each interview questions, each partner would take it in turn to share their personal experience, often highlighting how it differed from the other's. This difference was seen in both how important the partners thought patient engagement was and in explaining how they went about engaging in their care. Again, mirroring the larger sample, the partner with higher activation typically talked about how engagement has helped them and how they've been engaged in the past, while the partner with lower activation spoke of patient engagement on a much more hypothetical level, emphasizing what they thought it should be, or what they wish their experience was like. While this insight was valuable, the 3 couples included in this sample are not enough to draw conclusions about the influence of family relationships on personal experiences of engagement, and a follow up study of the topic is recommended.

Discussion

The purpose of this study was to address the gap identified by Pomey et al. (2015) to add an, "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). In this grounded theory, a working definition emerged from the perspective of participants' who range in their level of engagement regarding what patient engagement is and why it's important, as well as a number of responses regarding how it can be facilitated or prevented by factors relating to the patient, provider, and environment. The resulting theory describes patient engagement as a relationship between patient related factors and their sense of engagement that is influenced by provider related factors, environmental related factors, and their utilization of healthcare. The main contributions of this added theory of patient engagement from the patient perspective are the confirmation of and addition to many aspects of patient engagement identified in past research

using the perspective of healthcare providers and researchers (AHRQ, 2017; Carman et al., 2013; Coulter, 2011; Graffigna and Barrello, 2018; Higgins et al., 2017; Harrington et al., 2020). This enhanced theoretical understanding also enables us to better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on individual, organizational, and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

Adding the Patient Perspective to Theories of Patient Engagement

It was not the aim of this study to provide one authoritative definition to be used over any other, rather to provide a definition of patient engagement derived from the perspective of patients who range in their experiences with and levels of engagement, that could be interwoven with other definitions and theories to provide a more comprehensive understanding of patient engagement. The definition that emerged from this grounded theory, that patient engagement is the relationship between patient related factors and their sense of engagement that is moderated by provider related factors, and environmental related factors, had much in common with other common definitions of patient engagement from the current literature.

While the organization of codes in this grounded theory into overarching themes of patient, provider, and environmental related factors could be seen as confirmation bias, as it drew its inspiration from the work of Graffigna and Barello (2018), many of the sub-themes that emerged from the participants responses matched aspects of patient engagement that have been emphasized by past research. The fact that participants emphasized concepts such as health literacy, the patient-provider relationship, shared decision-making, and collaboration in fostering patient engagement confirms the efforts of many past policy and research efforts (Graffigna and

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Barello, 2018). It also affirms many aspects of past definitions of patient engagement as well

(AHRQ, 2017; Brown et al., 2015; Coulter, 2011), while adding valuable contributions in our

understanding of how the patient's personal characteristics, life circumstances, and social

location influence their personal level of engagement.

Additional Insight into How Patient Engagement Improves Outcomes

Participants in this study provided anecdotal evidence from their lived experience that

corroborates research that has shown patient engagement to improve health outcomes (Hibbard

& Greene, 2013; Sharma et al., 2017), improve patients' healthcare experience (Hibbard &

Greene, 2013; Sharma et al., 2017), and reduce costs (Hibbard & Greene, 2013; Sharma et al.,

2017). Participants did not mention anything about the effect of patient engagement on the

provider's experience as they were only asked to share their own experience, but this study does

support the claim that patient engagement does help to achieve the triple aim of healthcare

(Berwick et al., 2008), if not the quadruple aim (Bodenheimer et al., 2014).

This theory also provides additional insight as to why patient engagement may have this

effect that help satisfy gaps in the current research identified by Rowland et al., (2017) and

Phoenix et al., (2018) where current definitions "rely almost exclusively on policy frameworks

as the means to both justify and design patient engagement programs… without understanding

the theoretical underpinnings… about how a program works" (pg. 77) The improvement in

patient health outcomes can be attributed to the development of personal characteristics, such as

a sense of ownership and responsibility to manage their health and the motivation to be proactive

in living a healthy lifestyle. The increase in health literacy from both the patient's efforts to

learn and the providers efforts to educate about the patient's health conditions and treatment can

also lead to improved health outcomes. Participants also talked about an increase in compliance

to treatment plans when they felt they were able to share in the decision making and when they had a relationship with a provider they knew cared for them and whom they trusted.

When it comes to an improved patient experience, one of the most obvious explanations for how engagement improves their experience is the reduction of barriers to their engagement. Many participants talked about the relief and gratitude they felt when they finally assembled a team of providers who were willing to let them engage the way they wanted in their care. Many participants talked about feeling depersonalized by providers who were dismissive or disengaged, and the sense of power and validation that came from strong relationships with providers who facilitated their engagement. A cyclical pattern was described in which an improvement in the patient experience fostered an empowered sense of engagement and activation to manage their own health, which then led to improved health outcomes which in turn improved their experience in their healthcare.

As mentioned before, the outcomes of the triple aim are interrelated, with an improvement in one leading to an improvement in the others. Thus, this cycle of improving experiences, engagement, and outcomes also leads to a reduction of healthcare related costs. A few patients talked about a reduction in their utilization when in better health, which would naturally equate to fewer healthcare related expenditures. This was attributed to changes in life circumstances, such as pregnancy ending after nine months or an injury that healed, but there were also many cases in which increased engagement in their care empowered patients to better manage their treatment and health on their own without needing to visit providers as frequently. There's also the potential for an increase in health literacy to enable patients to know what they need and how to advocate for it that can help them get the care they need sooner and more

efficiently, avoiding unnecessary visits to the wrong specialists or time wasted "spinning their wheels."

The Value of Gathering Perspectives from Patients who Range in their Level of Engagement

In building on past research that captured the perspective of patients who are already highly engaged (Pomey et al., 2015) or frequent utilizers (Brown et al., 2015), this study strove to see if patients who felt less engaged or who utilized healthcare services less often differed from those who felt more engaged or who utilized healthcare more often in their definition of what patient engagement is, why it's important, and how it works. There could of course be other ways of differentiating groups than just activation and utilization, but the principles outlined here should still be applicable. In assessing the value of this addition, the four groups were surprisingly similar to each other. The themes and subthemes were consistent across groups, with many of the individual codes even being expressed by participants from each group. The definitions of what patient engagement is and why it's important were nearly identical, and many of the factors that facilitated or prevented engagement were felt universally.

In the end, while the use of four groups didn't seem to add much variety or additional insight in defining patient engagement, the main utility of considering patient engagement across a range of patient experiences will likely come in the application of these findings in future efforts to increase patient engagement by both providers and by patients. For example, when seeking to improve patient engagement with patients who are already frequent utilizers of healthcare, it may help to focus more on increasing their health literacy so they can participate more effectively on collaborative teams or in shared decision making, or so they can better manage their health on their own. This approach may elicit less interest and participation from

patients who are frustrated or distrustful of the healthcare system, in which case focusing more on the patient-provider relationship and addressing any barriers related to that or the patient's characteristics such as ownership of their health or an ability to advocate for themselves might prove to be a more productive first step towards increased patient engagement. This will be discussed further in the implications for practice section below.

Implications for Patients and Providers wanting to Increase Patient Engagement

The grounded theory that emerged from this study provides a few important implications for patient, providers, and any other entity attempting to increase patient engagement. While there are unique applications for patients and providers, there is an overarching pattern to this recommendation, and that is: in order to increase patient engagement, increase the patient, provider, environmental, and utilization related factors that facilitate engagement and reduce the factors that prevent it. That is obviously easier said than done, but here are a few specific recommendations.

For patients, seek to develop a sense of ownership for your health and healthcare. Know that you can advocate for yourself and ask to be more engaged in collaborative teams and shared decisions regarding your care. Be proactive in learning about your health conditions and treatment, and ask what resources are available to you. Work to reduce barriers to your engagement that are in your control, such as being dissuaded by the cost of effort it takes to be engaged or any fear, frustration, or distrust of the healthcare system. Obviously, you will not be able to entirely resolve some of these barriers on your own, especially ones related to access, social location, or things outside your control, but in such cases, ask for help either from individual providers you interact with or from policy makers and organizational leaders. Your striving can make a difference.

For providers, do all you can to facilitate patient engagement and be aware of things that you can control that might be preventing patients from engaging in their healthcare. Some specific areas for constant improvement identified by participants were communicating at appropriate health literacy levels, having good bedside manner, actively listening and being collaborative rather than prescriptive or dismissive, and continuing to show genuine interest and caring for patients, and encouraging them to engage in their own ways. This could start with a discussion with patients about how engaged they feel in their healthcare, as well as personal characteristics such as a sense of ownership, motivation, or proactivity in their healthcare. In addition to teaching them how to manage their own health, teach them how to engage and collaborate with healthcare providers. Invite and expect them to share in the decision-making and let them know that they can seek out providers who are willing to collaborate and allow them to engage on their teams.

For healthcare organizations, tailor your engagement programs and initiatives to target specific populations with different levels of engagement. While resources for increasing health literacy might be readily accepted by some, others may still need to develop a sense of motivation to take ownership of their health and healthcare. Encourage patients to advocate for what they want and include them in efforts to increase access by reducing or finding work arounds to barriers such as limited provider availability and time, provider burnout, high costs of care, insurance coverage, and social location.

Implications for Medical Family Therapy

Medical Family Therapists (MedFT's) are uniquely positioned to influence engagement at the level of patients, providers, and organizations. The central aims of medical family therapy are empowering a sense of agency and communion for patients (McDaniel et al., 2014), both of

which can be better informed the findings of this grounded theory of patient

engagement. McDaniel and colleagues define agency as empowering the patient to have a say in

the treatment they receive and be included in the decision-making process. They define

communion as the idea that patients feel they understand and are understood by their care team

and are welcomed and involved in the process (McDaniel et al., 2014). This closely mirrors

factors identified by the participants of this study, such as advocacy, shared decision making, and

strong patient-provider relationships.

What's more, participants also mentioned the growing prevalence of mental health

providers as part of their healthcare teams, both in therapeutic treatment of mental health

conditions, but also as part of a collaborative effort to holistically manage patients' health.

MedFT;s strive to view health holistically using the biopsychosocial-spiritual model (BPSS;

Engle 1977; 1980; Wright Watson, & Bell, 1996) to address the connection between physical

health and other aspects of patients' lives such as their mental, social, and spiritual health. For

example, it was very apparent from this study that participant's environmental factors, such as

social location, influenced their engagement, and MedFT's can remain socioculturally attuned

(McDowell et al., 2018) to these factors in order to help maximize engagement. Participants in

this study specifically identified this inclusive perspective as something they wanted in their

healthcare, and MedFT's can help both patients and providers to integrate that effectively.

MedFT's can help foster patients' engagement in their healthcare by empowering their

sense of agency and communion. They can help patients develop a sense of ownership for their

health and healthcare. That can teach patients how to advocate for themselves and ask to be

more engaged in collaborative teams and shared decisions regarding their care. MedFT's can

encourage patients to be proactive in learning about their health conditions and treatment and

connect them with reputable resources. MedFT's should work with patients to reduce barriers to

engagement that are in the patient's control, such as being dissuaded by the cost of effort it takes

to be engaged or any fear, frustration, or distrust of the healthcare system. They can also raise

awareness of barriers related to access, social location, or things outside your control, as well as

coach them on how to ask for help in efforts to navigate them either from individual providers or

from policy makers and organizational leaders. The systemic perspective of MedFT's enables

them to influence patient engagement both in their role as a healthcare provider, but also to raise

the patient's awareness of patient and environment related factors and coach them on how to

maximize their engagement and reap the benefits.

Limitations and Suggestions for Future Research

Two of the main limitations to this study were related to the recruitment of participants.

As outlined in the methods section, the grouping of participants was determined by largely

subjective questions inquiring about activation and utilization (Hibbard et al., 2009). While this

was done intentionally, and for practical reasons (Long et al., 2017), finding more reliable

methods for measuring these or any other criteria used to differentiate patient populations could

reduce bias introduced in the sampling process (Hibbard et al., 2004). This could also lead to a

potential quantitative study could be considered, measuring a person's level of health literacy

and see if that is directly related to the level of engagement they report. What's more, additional

analyses could be considered comparing between groups divided by gender, race, socioeconomic

status, and other demographic variables.

Due to the similarities between the groups, theoretical saturation was considered achieved

after 27 interviews, when participants' experiences began to be fully captured by the theory that

emerged from previous interviews (Charmaz, 2014; Corbin& Strauss, 2015; Creswell & Poth,

2018). The 27 interview was used to check for saturation, and recruitment was stopped, despite the group sample sizes being unequal. The high activation, high utilization group had 10 participants. The high activation, low utilization group at nine participants. The low activation, high utilization group had 5 participants. And the low activation, low utilization group had 4 participants. Future studies should continue to gather more data from groups who are traditionally less engaged or who utilize healthcare less often. It should also be noted that the sample included only one participant older than 65 and all the participants who identified as Black also had a lower socioeconomic status and government insurance. Continuing to recruit a more diverse sample would ensure that the theory is both theoretically and demographically representative of the population.

One suggestion for future research would be to further explore the difference between patients' engagement in their own care compared to their engagement in the care of others for whom they are responsible. Beginning in the pilot interview, it quickly became apparent that engagement in the care of family members or others they help care for was a very important aspect of the participants' experience with patient engagement. An interview question was added, asking participants how their responses would have changed if they had been answering regarding their experience being engaged in someone else's care rather than their experience being engaged as the patient themselves. While about half the participants said the experience was the same, many said it would be different, both in level of importance to them and in how they are engaged. As the focus of this study was to create a theory that explained patients' experience being engaged in their own healthcare, the responses to this question were not included in the definition presented here. However, the interest the participants showed in this distinction indicates that this would be a valuable aspect of patient and family engagement in

healthcare to add in a follow up study. A future study could use a similar approach to this study to explore a definition of what caregiver engagement is, why it's important, and how it works.

<h2 style="text-align:center">Conclusion</h2>

This grounded theory from the patient's perspective describes patient engagement as a relationship between patient related factors and their sense of engagement that is influenced by provider related factors, environmental related factors, and their utilization of healthcare. This confirms many aspects of patient engagement identified in past research using the perspective of healthcare providers and researchers (AHRQ, 2017; Carman et al., 2013; Coulter, 2011; Graffigna and Barrello, 2018; Higgins et al., 2017; Harrington et al., 2020). This enhanced theoretical understanding also helps us better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on individual, organizational, and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

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CHAPTER 6: IMPLICATIONS

Dissertation in Review

This dissertation addressed the gap identified by Pomey et al. (2015) to add an "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). Using a grounded theory methodology (Charmaz, 2014; Corbin & Strauss, 2015; Creswell & Poth, 2018), it captured the perspectives of patients who range across high and low levels of engagement to discover a more robust understanding of what patient engagement is, why it's important, and how it affects patients' health. This built on the preexisting work that has been done to develop a theoretical understanding, first from healthcare researchers' and providers' perspectives (Cerezo et al., 2016; Harrington et al., 2020; Higgins et al., 2017) and then from highly engaged patients (Brown et al., 2015; Pomey et al., 2015), as it adds the perspective of patients who range across different levels of activation and utilization, and whose efforts to be engaged in their healthcare may differ from providers prescriptions or expectations (Pomey et al., 2015). This enhanced theoretical understanding has the potential to help us better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, may better inform patient engagement efforts on individual, organizational, and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

Chapter one identified the need for this study by introducing the concept of patient engagement, its benefits, and its development. Chapter two was a systematic review examining the effectiveness of patient education through PHRs on patient engagement and health outcomes. Then in chapter three, the literature about patient engagement was further explored, highlighting

the development of definitions and theories about it, and the current need to add the perspective

of patients whose understanding of patient engagement may differ from providers prescriptions

or expectations (Pomey et al., 2015). Chapter four presented the proposed methodology for the

grounded theory to capture the perspective of patients who range across different levels of

engagement. Then, following this proposed methodology, the findings from an original research

study using grounded theory to define patient engagement from the patient's perspective were

presented in chapter five. Lastly, this sixth chapter summarizes the noteworthy findings of both

the systematic review and the original research study.

Noteworthy Findings from Chapter Two

The objective of this study was to systematically review all the literature studying

the effectiveness of patient education through PHRs on patient engagement and ability. In this

case, effectiveness was measured by a) availability and awareness of educational resources in the

PHR, b) patient utilization of these educational resources, c) patient perceived usefulness of

these educational resources, and d) the effect of the educational resources on health outcomes

The search for all relevant literature was run using five electronic databases (PubMed, CINAHL,

Scopus, PsychINFO, Embase). Initial results ended with the review of 17,807 articles before

identifying 52 that met the inclusion criteria.

This review found that many providers and healthcare organizations have developed

PHRs to provide more accurate and reliable sources of information in response to patients'

increased interest in their own healthcare (Friction et al., 2008; Kildea et al., 2019). Although

this field is relatively new, preliminary research shows discrepancies exist between patients'

desire for information and their actual utilization of those resources (Ancker et al., 2016; Hefner

et al., 2017). While a discrepancy exist, current research does suggest that patients found these

resources useful, and when used, they had a significant impact on patient outcomes (Benhamou, 2011; Cameron et al., 2016; Chen et al., 2015; Day et al., 2019; Goldberg et al., 2003; Sridhar et al., 2017). It seems that PHRs are becoming a powerful tool for patient engagement and show promise as a means of achieving the quadruple aim of healthcare (Bodenheimer et al., 2014). Continued efforts need to be made to raise awareness of patient educational resources in PHRs so that patients utilize these resources to increase their knowledge, skills, and confidence for managing their own health and health care (Carmen et al., 2013).

While the purpose of that review was to explore outcomes associated with PHRs, it became clear that these PHR designs were limited based on the heavy reliance of provider perspective and the relatively little contribution from patients (Day et al., 2019; Fricton et al., 2008). This thought evolved into a larger realization that our current understanding of patient engagement in general developed in a similar way, which eventually served as the foundation for the next part of this dissertation.

Noteworthy Findings from Chapter Five

In this grounded theory, a working definition emerged from the perspective of participants' who range in their level of engagement regarding what patient engagement is and why it's important, as well as a number of responses regarding how it can be facilitated or prevented by factors relating to the patient, provider, and environment. The resulting theory describes patient engagement as a relationship between patient related factors and their sense of engagement that is influenced by provider related factors, environmental related factors, and their utilization of healthcare. The main contributions of this added theory of patient engagement from the patient perspective are the confirmation of and addition to many aspects of patient engagement identified in past research using the perspective of healthcare providers and

researchers (AHRQ, 2017; Carman et al., 2013; Coulter, 2011; Graffigna and Barrello, 2018; Higgins et al., 2017; Harrington et al., 2020). This enhanced theoretical understanding also enables us better understand why patient engagement has such a positive impact on patient outcomes (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). This, in turn, could better inform patient engagement efforts on individual, organizational, and national levels (Institutes of Medicine, 2001; Carman et al., 2013) to capitalize on this powerful tool, and improve our healthcare system (Schneider et al., 2021).

Implications for Research

It was not the aim of this study to provide one authoritative definition to be used over any other, rather to provide a definition of patient engagement derived from the perspective of patients who range in their experiences with and levels of engagement, that could be interwoven with other definitions and theories to provide a more comprehensive understanding of patient engagement. The definition that emerged from this grounded theory, that patient engagement is the relationship between patient related factors and their sense of engagement that is moderated by provider related factors, and environmental related factors, had much in common with other common definitions of patient engagement from the current literature.

While the organization of codes in this grounded theory into overarching themes of patient, provider, environmental related factors could be seen as confirmation bias as it drew its inspiration from the work of Graffigna and Barello (2018), many of the sub-themes that emerged from the participants responses matched aspects of patient engagement that have been emphasized by past research. The fact that participants emphasized concepts such as health literacy, the patient-provider relationship, shared decision making, collaboration in fostering patient engagement confirms the efforts of many past policy and research efforts (Graffigna and

Barello, 2018). It also affirms many aspects of past definitions of patient engagement as well (AHRQ, 2017; Brown et al., 2015; Coulter, 2011), while adding valuable contributions in our understanding of how the patient's personal characteristics, life circumstances, and social location influence their engagement as well.

In building on past research that captured the perspective of patients who are already highly engaged (Pomey et al., 2015) or frequent utilizers (Brown et al., 2015), this study strove to see if patients who felt less engaged or who utilized healthcare services less often differed from those who felt more engaged or who utilized healthcare more often in their definition of what patient engagement is, why it is important, and how it works. There could of course be other ways of differentiating groups than just activation and utilization, but the principles outlined here should still be applicable. In assessing the value of this addition, the four groups were surprisingly similar to each other. The themes and subthemes were consistent across groups, with many of the individual codes even being expressed by participants from each group. The definitions of what patient engagement is and why it is important were nearly identical, and many of the factors that facilitated or prevented engagement were felt universally. While the subthemes listed in this results section were consistent between groups, the way each group talked about these factors of patient engagement was different. While participants in the two highly activated groups talked about how engagement has helped them and how they've been engaged in the past, the two groups with low engagement spoke of patient engagement on a much more hypothetical level, emphasizing what they thought it should be, or what they wish their experience was like.

In the end, while the use of four groups didn't seem to add much variety or additional insight in defining patient engagement, the main utility of considering patient engagement across

a range of patient experiences will likely come in the application of these findings in future

efforts to increase patient engagement by both providers and by patients. For example, when

seeking to improve patient engagement with patients who are already frequent utilizers of

healthcare, it may help to focus more on increasing their health literacy so they can participate

more effectively on collaborative teams or in shared decision-making, or so they can better

manage their health on their own. This approach may elicit less interest and participation from

patients who are frustrated or distrustful of the healthcare system, in which case focusing more

on the patient-provider relationship and addressing any barriers related to that or the patient's

characteristics such as ownership of their health or an ability to advocate for themselves might

prove to be a more productive first step towards increased patient engagement. This will be

discussed further in the implications for practice section below.

Implications for Practice

Participants in this study provided anecdotal evidence from their lived experience that

corroborates research that has shown patient engagement to improve health outcomes (Hibbard

& Greene, 2013; Sharma et al., 2017), improve patients' healthcare experience (Hibbard &

Greene, 2013; Sharma et al., 2017), and reduce costs (Hibbard & Greene, 2013; Sharma et al.,

2017). Participants did not mention anything about the effect of patient engagement on the

provider's experience as they were only asked to share their own experience, but this study does

support the claim that patient engagement does help to achieve the triple aim of healthcare

(Berwick et al., 2008), if not the quadruple aim (Bodenheimer et al., 2014).

This theory also provides additional insight as to why patient engagement may have this

effect that helps satisfy gaps in the current research identified by Rowland et al., (2017) and

Phoenix et al., (2018) where current definitions "rely almost exclusively on policy frameworks

as the means to both justify and design patient engagement programs… without understanding the theoretical underpinnings… about how a program works" (pg. 77) The improvement in patient health outcomes can be attributed to the development of personal characteristics, such as a sense of ownership and responsibility to manage their health and the motivation to be proactive in living a healthy lifestyle. The increase in health literacy from both the patient's efforts to learn and the provider's efforts to educate about the patient's health conditions and treatment can also lead to improved health outcomes. Participants also talked about an increase in compliance to treatment plans when they felt they were able to share in the decision making and when they had a relationship with a provider they knew cared for them and whom they trusted.

When it comes to an improved patient experience, one of the most obvious explanation for how engagement improves their experience is the reduction of barriers to their engagement. Many participants talked about the relief and gratitude they felt when they finally assembled a team of providers who were willing to let them engage the way they wanted to in their care. Many participants talked about feeling depersonalized by providers who were dismissive or disengaged, and the sense of power and validation that came from strong relationships with providers who facilitated their engagement. A cyclical pattern was described in which an improvement in the patient experience fostered an empowered sense of engagement and activation to manage their own health, which then led to improved health outcomes which in turn improved their experience in their healthcare.

As mentioned before, the outcomes of the triple aim are interrelated, with an improvement in one leading to an improvement in the others. Thus, this cycle of improving experiences, engagement, and outcomes also leads to a reduction of healthcare related costs. A few patients talked about a reduction in their utilization when in better health, which would

naturally equate to fewer healthcare related expenditures. This was attributed to changes in life circumstances, such as pregnancy ending after 9 months or an injury that healed, but there were also many cases in which increased engagement in their care empowered patients to better manage their treatment and health on their own without needing to visit providers as frequently. There's also the potential for an increase in health literacy to enable patients to know what they need and how to advocate for it that can help them get the care they need sooner and more efficiently, and avoid unnecessary visits to the wrong specialists or time wasted "spinning their wheels."

Implications for Healthcare Providers and Organizations

In order to capitalize on these benefits of patient engagement, providers should do all they can to facilitate patient engagement and be aware of things that you can control that might be preventing patients from engaging in their healthcare. Some specific areas for constant improvement identified by participants were communicating at appropriate health literacy levels, having good bedside manner, actively listening and being collaborative rather than prescriptive or dismissive, and continuing to show genuine interest and caring for patients, and encouraging them to engage in their own ways. This could start with a discussion with patients about how engaged they feel in their healthcare, as well as personal characteristics such as a sense of ownership, motivation, or proactivity in their healthcare. In addition to teaching them how to manage their own health, teach them how to engage and collaborate with healthcare providers. Invite and expect them to share in the decision making and let them know that they can seek out providers who are willing to collaborate and allow them to engage on their teams.

For healthcare organizations, it could be more productive to tailor engagement programs and initiatives to target specific populations with different levels of engagement. While

resources for increasing health literacy might be readily accepted by some, others may still need to develop a sense of motivation to take ownership of their health and healthcare. Encourage patients to advocate for what they want, and include them in efforts to increase access by reducing or finding work arounds to barriers such as limited provider availability and time, provider burnout, high costs of care, insurance coverage, and social location.

Implications for Medical Family Therapy

The central aims of medical family therapy are empowering a sense of agency and communion for patients (McDaniel et al., 2014), both of which can be better informed the findings of this grounded theory of patient engagement. McDaniel and colleagues define agency as empowering the patient to have a say in the treatment they receive and be included in the decision-making process. They define communion as the idea that patients feel they understand and are understood by their care team and are welcomed and involved in the process (McDaniel et al., 2014). This closely mirrors factors identified by the participants of this study, such as advocacy, shared decision making, and strong patient-provider relationships. What's more, participants also mentioned the growing prevalence of mental health providers as part of their healthcare teams, both in therapeutic treatment of mental health conditions, but also as part of a collaborative effort to holistically manage patients' health.

MedFT's can help foster patients' engagement in their healthcare by empowering their sense of agency and communion. They can help patients develop a sense of ownership for their health and healthcare. That can teach patients how to advocate for themselves and ask to be more engaged in collaborative teams and shared decisions regarding their care. MedFT's can encourage patients to be proactive in learning about their health conditions and treatment and connect them with reputable resources. MedFT's should work with patients to reduce barriers to

engagement that are in the patient's control, such as being dissuaded by the cost of effort it takes to be engaged or any fear, frustration, or distrust of the healthcare system. They can also raise awareness of barriers related to access, social location, or things outside your control, as well as coach them on how to ask for help in efforts to navigate them either from individual providers or from policy makers and organizational leaders. The systemic perspective of MedFT's enables them to influence patient engagement both in their role as a healthcare provider, but also to raise the patient's awareness of patient and environment related factors and coach them on how to maximize their engagement and reap the benefits.

Conclusion

The purpose of this study was to address the gap identified by Pomey et al. (2015) to add an, "empirical study of patients' perspectives on what they themselves consider to be useful engagement practices for actively enhancing their health care" (pg. 3). In this grounded theory, a working definition emerged from participants' perspective regarding what patient engagement is and why it's important, as well as a number of responses regarding how it can be facilitated or prevented by factors relating to the patient, provider, and environment. The resulting theory describes patient engagement as a relationship between patient related factors and their sense of engagement that is moderated by provider related factors, environmental related factors, and their utilization of healthcare (see figure 1). This study has broadened the understanding of patient engagement by adding the perspective of patients who range in their levels of engagement and utilization and has provided additional explanation as to how patient engagement improves health outcomes and patient experiences in healthcare while also reducing costs (Hibbard et al., 2013; Phoenix et al., 2018; Roland et al., 2017). Healthcare providers,

organizations, and patients are encouraged to apply the implications of this study in their efforts

to increase patient engagement.

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APPENDIX A: IRB APPROVAL LETTER

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** 📧 · Fax **252-744-2284** 📧 · **rede.ecu.edu/umcirb/**

Notification of Initial Approval: Expedited

From: Biomedical IRB

To: Adam Johnson

CC: Andrew Brimhall
     Adam Johnson

Date: 2/1/2023

Re: UMCIRB 22-000007
     Patient Engagement Definition

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 1/31/2023. The research study is eligible for review under expedited category # 6,7. The Chairperson (or designee) deemed this study no more than minimal risk.

 As the Principal Investigator you are explicitly responsible for the conduct of all aspects of this study and must adhere to all reporting requirements for the study. Your responsibilities include but are not limited to:

1. Ensuring changes to the approved research (including the UMCIRB approved consent document) are initiated only after UMCIRB review and approval except when necessary to eliminate an apparent immediate hazard to the participant. All changes (e.g. a change in procedure, number of participants, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the UMCIRB before they are implemented;

2. Where informed consent has not been waived by the UMCIRB, ensuring that only valid versions of the UMCIRB approved, date-stamped informed consent document(s) are used for obtaining informed consent (consent documents with the IRB approval date stamp are found under the Documents tab in the ePIRATE study workspace);

3. Promptly reporting to the UMCIRB all unanticipated problems involving risks to participants and others;

 4. Submission of a final report application to the UMICRB prior to the expected end date provided in the IRB application in order to document human research activity has ended and to provide a timepoint in which to base document retention; and

 5. Submission of an amendment to extend the expected end date if the study is not expected to be completed by that date. The amendment should be submitted 30 days prior to the UMCIRB approved expected end date or as soon as the Investigator is aware that the study will not be completed by that date.

The approval includes the following items:

Name	Description
Dissertation manuscript	Study Protocol or Grant Application
Flyer	Recruitment Documents/Scripts
Greenphire Exemption Approval	Additional Items
Informed consent form	Consent Forms
Interview Questions	Interview/Focus Group Scripts/Questions
language to be used in the email and in the social media script.	Recruitment Documents/Scripts
Survey Questions	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

Informed Consent to Participate in Research
Information to consider before taking part in research that has no
more than minimal risk.

Title of Research Study: Using Grounded Theory to Define Patient Engagement from the Patient's Perspective

Principal Investigator: Adam Johnson (Person in Charge of this Study)
Institution, Department or Division: East Carolina University -- Human Development and
Family Science
Address: 610 E 10th St., Greenville, NC 27858
Telephone #: 435-200-5833

Researchers at East Carolina University (ECU) study issues related to society, health problems,
environmental problems, behavior problems and the human condition. To do this, we need the
help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?
The purpose of this research is to discover patients' perspectives regarding patient engagement in
healthcare. You are being invited to take part in this research because we are seeking
participants with various levels of involvement with the healthcare system. The decision to take
part in this research is yours to make. By doing this research, we hope to learn how patients
define what patient engagement is, why it's important, and how it impacts their health. Your
participation is completely voluntary. If you volunteer to take part in this research, you will be
one of about 20 people to do so.

Are there reasons I should not take part in this research?
 You should not participate in this research if you are under 18 years of age or cannot speak
English.

What other choices do I have if I do not take part in this research?
You can choose not to participate.

Where is the research going to take place and how long will it last?
The research will be conducted online via Qualtrics and WebEx. You will need to participate
twice, once to take the survey and once to participate in the interview. The total amount of time
you will be asked to volunteer for this study is about 90 minutes.

What will I be asked to do?

You will be asked to do the following: Schedule an interview and complete a short survey asking about your demographic information and some of the ways you use the healthcare system. Then, during the interview using WebEx, you will be asked questions that relate to your experience with the healthcare system and ways you have or would like to be engaged in caring for your health. Your interview will be recorded so it can be transcribed. During transcription, all names, dates, and other identifying information taken out. The recordings will then be deleted. The transcript and your responses to the survey will be saved on a secure cloud storage server associated with the university.

What might I experience if I take part in the research?
We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. You will earn a $20 gift card for taking part in this study. There may not be any other personal benefit to you but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?
We will be able to pay you for the time you volunteer while being in this study. This will come in the form of a $20 Amazon gift card which will be emailed to the address you provided when scheduling the interview.

Will it cost me to take part in this research?
It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?
ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:
The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?
Audio-visual records of your interview will be transcribed, with all names, dates, and other identifying information taken out. The recordings will then be deleted. The transcript and your responses to the survey will be saved on a secure cloud storage server associated with the university for a minimum of 3 years after the study is completed.

What if I decide I don't want to continue in this research?
You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 435-200-5833 during normal business hours.

If you have questions about your rights as someone taking part in research, you may call the University & Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director for Human Research Protections, at 252-744-2914.

Is there anything else I should know?
Your information collected as part of the research, even if identifiers are removed, will not be used or distributed for future studies. The research results will be provided to you, including the definition and theory generated by the shared experience of all participants. These results will be shared with you after all the data has been collected and analyzed, but before the results are published.

I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

I have read (or had read to me) all of the above information.
I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
I know that I can stop taking part in this study at any time.
By signing this informed consent form, I am not giving up any of my rights.
I have been given a copy of this consent document, and it is mine to keep.

_____   _____
Participant's Name (PRINT)   **Signature**   **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

_____
Person Obtaining Consent (PRINT)   **Signature**   **Date**

APPENDIX C: DEMOGRAPHIC SURVEY

Demographic survey: Defining Patient Engagement
Q21 In order to protect your confidentiality, please select a name we can use instead of your actual name to connect with your responses in the survey and interview.
(for example: Jane Doe, AJ93, etc.)

_____

Q10 What is your age?

_____

Q22 What is your gender?

    Male (1)

    Female (2)

    Non-binary (3)

    Prefer to self-describe, below (4) _____

    Prefer not to say (5)

Q31 Which race or ethiniciy best describes you?

    American Indian or Alaskan Native (1)

    Asian/Pacific Islander (2)

    Black of African American (3)

    Hispanic or Latino (4)

    White/Caucasian (5)

    Multiple ethnicity/Other (pleas specify) (6)
    _____

    Prefer not to say (7)

Q11 What is your average annual income?

_____

Q16 What is your insurance status?: employer/private/uninsured (flow logic to percentage)
what percentage does your insurance cover (scale)

Employer provided (1)

Private (2)

Mediciad/Medicare (3)

Uninsured (4)

Other (5) _____

Q27 What percentage of your healthcare costs does your insurance typically cover?

0   10   20   30   40   50   60   70   80   90   100

1 ()
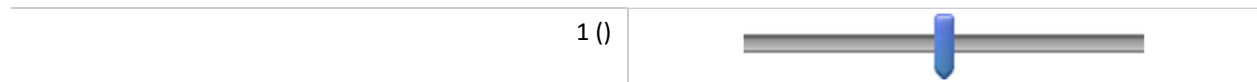
Q25 The next few questions will refer to your utilization of healthcare resources. When you think of "healthcare" what types of providers do you include in your definition?

_____

Q14 When was your last Healthcare visit?

Within the last week (1)

Within the last month (2)

Within the last 6 months (3)

Within the last year (4)

Between 1-5 years (5)

Longer than 5 years (6)

Q17 On average, how many times per year do you have a healthcare appointment?

_____

Q32 In which settings do you usually utilize healthcare? (You may select more than one)

☐   Primary Care Office (1)

☐   Urgent Care/Emergency Department (2)

☐   Specialty Care Office (3)

☐   Other (4) _____

Q15 What do you typically utilize healthcare services for? (You may select more than one)

☐   Annual Wellness Visits (1)

☐   Management of chronic health conditions (2)

☐   Urgent/Emergency services (3)

☐   Other (4) _____

Q23 Patients' utilization (or how often they use healthcare resources) and their engagement (how involved they feel in their care) can vary. Some people may feel highly engaged, even if they don't often utilize healthcare services, while some may not feel very engaged even though they frequently utilize healthcare services. Please indicate how engaged you feel in your care (scale: low to high), as well as if you feel you have higher or lower levels of utilization of healthcare services.

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	
Low Engagement						High Engagement
Low Utilization						High Utilization

Q19 Overall, how well do you feel your health is managed?

Not well at all (1)

Slightly well (2)

Moderately well (3)

Very well (4)

Extremely well (5)

Q26 how healthy do you consider yourself to be?

Very unhealthy (1)

Moderately unhealthy (2)

Neutral/Neither healthy nor unhealthy (3)

Moderately Healthy (4)

Very healthy (5)

Q20 Overall, how satisfied are you with your healthcare experience?

Extremely dissatisfied (1)

Somewhat dissatisfied (2)

Neither satisfied nor dissatisfied (3)

Somewhat satisfied (4)

Extremely satisfied (5)

APPENDIX D: SEMI-STRUCTURED INTERVIEW LIST

Semi-structured Interview Question List

1. Can you share your thoughts on how important it is to you to feel engaged in your healthcare?

2. What do the words "patient engagement" mean to you in relation to your healthcare?

3. Tell me about a time when you feel like you were really engaged you in your healthcare?

4. What other ways could you be engaged that you think would be helpful?

5. Tell me about things that have prevented you from feeling engaged in your healthcare in the past.

6. How does engagement in your healthcare affect your health?

7. How would your answers have changed if you had been answering for a family member you help care for rather than sharing your own experience being engaged as a patient?

APPENDIX E: RECRUITMENT FLYER

Recruitment Flyer

SHARE YOUR PERSPECTIVE
ABOUT
PATIENT ENGAGEMENT

We're looking for community members to share their perspective on Patient Engagement in this research study.

Patient engagement has been the focus of many initiatives in healthcare recently, and we want to know what it means to you and what aspects of it are important to you.

We understand that people's utilization (or how often they use healthcare resources) and their engagement (how involved they feel in their care) can vary. Some people may feel highly engaged, even if they don't often utilize healthcare services, while some may not feel very engaged even though they frequently utilize healthcare services.

We want to know your experience in your own healthcare interactions, as well as your ideas for how providers can make it easier for you to feel engaged in your care. This is your chance to share your voice as we seek to inform future patient engagement efforts to be more beneficial for you! Volunteers will be paid $20 for their participation.

Topic: Patient Engagement in Healthcare

————

Who: Participants will not be excluded based on the frequency of their interaction with the healthcare system, but they do need to be able to speak English.

————

What you need to do: share your experience in a 45-90 minute interview via WebEx (face will be visible).

————

How you sign up: contact the email address below

CONTACT:
Adam Johnson

Telephone:
+1 (435) 200-5833

Email:
johnsonada19@students.ecu.edu

Email Recruitment Script
 SEEKING PEOPLE TO SHARE THEIR EXPERIENCE BEING ENGAGED IN THEIR HEALTHCARE

My name is Adam Johnson, and I'm asking for people to share their experiences being engaged in their healthcare. I realize that Patients' engagement (how involved they feel in their care) and their utilization (or how often they use healthcare resources) can vary. Some people may feel highly engaged, even if they don't often utilize healthcare services, while some may not feel very engaged even though they frequently utilize healthcare services. I want to better understand how patient's experiences being engaged varies across these ranges of high and low utilization and engagement, and so am asking anybody to please participate in this study and share your experience.

The title of this research study is Using Grounded Theory to Define Patient Engagement from the Patient's Perspective (ECU IRB: 22-000007)This study will include a brief survey as well as 45-90 minute interview (conducted online via WebEx, face will be visible) where I will ask you more about your experience being engaged in your health and healthcare, whether high or low. Participants will not be excluded based on the frequency of their interaction with the healthcare system, but they do need to be able to speak English, as the interview will be conducted in English. Participants will be given a $20 amazon gift card as compensation for their participation in this study.

If you're interested, contact Adam Johnson (Primary Investigator, Telephone: +1 (435) 200-5833, Email: johnsonada19@students.ecu.edu), and please pass this request to other people who might be willing to participate. Thank you so much for your help. Your experience and opinions are valuable!

APPENDIX G: DEMOGRAPHIC TABLES

Table 1. Sample Demographic Information

High Activation, High Utilization Group Demographic Information (n = 10)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance status
Jill	50	Female	White	30,000	Employer provided
Genny	50	Female	White	150,000	Employer provided
Patricia	32	Female	White	140,000	Employer provided
Meg	34	Female	White	50,000	Other
Aiden	24	Female	Black	35,000	Uninsured
Judith	50	Female	White	170,000	Employer provided
Goodman	35	Male	Black	35,000	Medicaid/Medicare
Flo	29	Female	Black	45000	Medicaid/Medicare
James	28	Male	Black	55000	Medicaid/Medicare
Monica	37	Female	Prefer not to say	30,000	Medicaid/Medicare
High Activation, Low Utilization Group Demographic Information (n = 8)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Meri	72	Female	White	retired	Medicaid/Medicare
Sarge	57	Male	White	230,000	Employer provided
Molly	38	Female	White	90,000	Employer provided
Favoretta	29	Female	White	200,000	Employer provided
Amy	31	Female	White	100,000	Employer provided
Eric	44	Male	White	150,000	Employer provided
Trent	31	Male	White	60,000	Employer provided
Connor	29	Male	White	60,000	Private
Low Activation, High Utilization Group Demographic Information (n = 5)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Jack	24	Male	Black	75,000	Medicaid/Medicare
Izz	25	Male	Black	50,000	Medicaid/Medicare
Jerryj	26	Female	Black	5,000	Medicaid/Medicare
Joggy	33	Male	Black	26,355	Uninsured
Dana	27	Female	White	60,000	Private
Low Activation, Low Utilization Group Demographic Information (n = 4)					
Pseudonym	Age	Gender	Ethnicity	Average Annual Income (USD)	Insurance Status
Scottie	45	Female	White	140,000	Medicaid/Medicare
Patty	32	Male	White	140,000	Employer provided
Jarob	25	Male	Black	15,000	Uninsured
Tammy	31	Female	White	20,000	Employer provided

Table 2. Sample Utilization Information

High Activation, High Utilization Group Demographic Information (n = 10)				
Pseudonym	Last visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Jill	5	1	High	High
Genny	1	24	High	High
Patricia	Did not answer	Did no answer	High	High
Meg	2	12	High	Above Average
Aiden	2	8	High	Average
Judith	2	7	Above Average	High
Goodman	1	48	High	Above Average
Flo	2	10	Above Average	Above Average
James	2	15	High	High
Monica	2	20+	Above Average	Above Average
High Activation, Low Utilization Group Demographic Information (n = 8)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Meri	1	2	High	Low
Sarge	3	2	High	Below Average
Molly	3	5	Above Average	Average
Favoretta	3	2	Average	Average
Amy	1	3	Average	Below Average
Eric	3	2	Average	Average
Trent	1	20	Above Average	Average
Connor	2	6	Above Average	Low
Low Activation, High Utilization Group Demographic Information (n = 5)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Jack	1	18	Average	Above Average
Izz	1	6	Below Average	Above Average
Jerryj	1	9	Above Average	Above Average
Joggy	3		Average	High
Dana	1	15	Below Average	Above Average
Low Activation, Low Utilization Group Demographic Information (n = 4)				
Pseudonym	Last Visit	Average number of visits per year	Self-Reported Engagement	Self-Reported Utilization
Scottie	5	1	Low	Low
Patty	3	1	Average	Low
Jarob	3		Low	Low
Tammy	3	6	Below Average	Below Average

Table 3. Sample Health Information

High Activation, High Utilization Group Demographic Information (n = 10)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Jill	3	3	4
Genny	4	3	4
Patricia	Did not answer	Did not answer	Did not answer
Meg	3	4	4
Aiden	3	3	4
Judith	4	4	5
Goodman	4	5	4
Flo	3	3	4
James	4	4	4
Monica	3	3	2
High Activation, Low Utilization Group Demographic Information (n = 8)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Meri	4	4	3
Sarge	5	5	5
Molly	4	4	5
Favoretta	4	4	4
Amy	4	4	5
Eric	5	5	4
Trent	3	4	3
Connor	5	5	4
Low Activation, High Utilization Group Demographic Information (n = 5)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Jack	5	5	5
Izz	2	3	4
Jerryj	3	4	4
Joggy	3	5	2
Dana	4	4	4
Low Activation, Low Utilization Group Demographic Information (n = 4)			
Pseudonym	How well is your health care is managed?	How healthy do you consider yourself to be?	How satisfied are you with your healthcare experience?
Scottie	4	3	5

Patty	3	5	4
Jarob	2	3	2
Tammy	4	4	4

* Answers for "how well is your healthcare managed?" are coded as follows: (1) Not well at all, (2) Slilghtly well, (3) Moderately well, (4) Very well, (5) Extremely well

** Answers for "How healthy do you consider yourself to be?" are coded as follows: (1) Very unhealth, (2) moderately unhealthy, (3) Neutral/Neither healthy nor unhealthy, (4) Moderately healthy, (5) Very healthy

*** Answers for "How satisfied are you with your healthcare experience?" are coded as follows: (1) Extremely dissatisfied, (2) Somewhat dissatisfied, (3) Neither satisfied nor dissatisfied, (4) Somewhat satisfied, (5) Extremely satisfied