

Communication and Quality of Care: An Overview

Alyssa Jordan, BA
Harvard School of Public Health (HSPH)/Dana-Farber Cancer Institute (DFCI)

Rachel McCloud, ScD
Harvard School of Public Health/Dana-Farber Cancer Institute

K. Viswanath, PhD
Professor of Health Communication
Harvard School of Public Health/Dana-Farber Cancer Institute
Faculty Director
Health Communication Core
Dana-Farber/Harvard Cancer Center (DF/HCC)
Director, Center for Translational Health Communication, DFCI-HSPH

A White Paper prepared by Dr. K. Viswanath, HSPH/DFCI and his team for Jayne Koskinas Ted Giovanis Foundation for Health and Policy, Washington, DC.

This White Paper was supported by the Jayne Koskinas Ted Giovanis Foundation for Health and Policy, a private foundation dedicated to effecting change in the health care industry for the greater good of the public. The opinions, findings, and conclusions or recommendations expressed in this material are those of the authors and not necessarily those of the Jayne Koskinas Ted Giovanis Foundation for Health and Policy, its directors, officers, or staff.

Table of Contents

Table of Contents	2
About the Authors	3
Executive Summary	4
Introduction	7
Defining Quality of Care	8
Theoretical Definition	8
Consumer Definition	10
Working Definition	12
Health Information Seeking	12
General Characteristics of Information Seeking	12
Off-line Information Sources	13
Online Information Sources	14
Types of Information Engagement Behaviors	16
Factors Relating to Information Seeking	16
Health Information Seeking Inequalities	17
Information Seeking for Patient Engagement	19
Quality of Care Information Seeking	20
Background	20
Consumer Side of Quality Reporting	22
Barriers to Health care Quality Information Seeking	23
Consumer Awareness	24
Consumer Context	25
Accessibility of Quality Reports	26
Measurement Issues	27
Comprehension of Quality Reports	28
Relevance of Quality Reports	30
Presentation of Quality Reports	31
Recommendations	33
References	35

About the Authors

Alyssa Jordan is a Master of Science student in the Department of Social and Behavioral Sciences at the Harvard School of Public Health. Previously, she obtained her undergraduate degree in communication from Simon Fraser University in Burnaby, British Columbia. She is a research assistant in the Viswanath Lab.

Dr. Rachel McCloud is a recent graduate of the Harvard School of Public Health, receiving a Doctor of Science from the Department of Social and Behavioral Sciences in May 2014. She received her MPH from the Emory School of Public Health in Behavioral Science and Health Education in 2009. She has worked as a research assistant in the Viswanath Lab for over 3 years, assisting on projects regarding health communication and community-based participatory research. Prior to her doctoral work, she served as a communication strategist fellow for the Prevention Research Centers Program at the Centers for Disease Control and Prevention.

Dr. K. “Vish” Viswanath is a Professor of Health Communication in the Department of Social and Behavioral Sciences at the Harvard School of Public Health (HSPH) and in the McGraw-Patterson Center for Population Sciences at the Dana-Farber Cancer Institute (DFCI). He is also the Faculty Director of the Health Communication Core of the Dana-Farber/Harvard Cancer Center (DF/HCC). Dr. Viswanath is also the Leader of the Cancer Risk and Disparities (CaRD) Program of the DF/HCC. He is the founding Director of DF/HCC’s Enhancing Communications for Health Outcomes (ECHO) Laboratory. He chairs the Steering Committee for the Health Communication Concentration (HCC) at HSPH and teaches health communication courses within this concentration.

Executive Summary

Introduction

Quality of care reporting has the potential to provide consumers with the information needed to choose the best performing providers for their care and motivate system-wide quality improvement. Given the rapid increases in both the availability and popularity of online information, internet-based reporting of quality of care information may be best positioned to reach healthcare consumers with timely, relevant information to inform their healthcare decisions. However, despite the promise of online reports, several factors may impact their acceptance and use among varied consumer audiences. This report provides a standardized definition of quality of care and reviews relevant literature to provide a context for the best practices of reporting quality measures to consumer audiences.

Definition of Quality of Care

Quality of care may be perceived differently by industry and consumer-based audiences, which may impact the type of metric valued when making decisions. For the purposes of this report, quality of care was defined as:

1. Appropriate, timely, and equitable care
2. Effective care processes that produce favorable outcomes
3. Safe provision of care in a clean, adequately equipped environment
4. Patient-centered care that prioritizes open communication and respect

Use of the Internet for Health Information Seeking

eHealth technologies have been lauded in their ability to reach wide audiences and narrow health disparities by increasing access to information. This becomes increasingly salient as more US adults are turning to the internet for health information, which is often used in conjunction with

physician-based information to make healthcare decisions. Patients who integrate online health information into their care often have increased healthcare engagement, reporting more satisfactory medical encounters and higher frequency of healthy behaviors. Online quality of care data serves as an important resource for patient engagement, providing access to information that may inform consumers' healthcare choices.

Challenges to Online Quality of Care Reporting

Despite the promise of online quality reporting, barriers to both general internet use and specific engagement with online quality of care information may lessen the beneficial impact of this resource for consumers. Those with lower income and education are least likely to have access to the internet and use it for health purposes, due to barriers ranging from literacy to technology issues that impede use. Furthermore, difficulties specific to quality of care information have limited its use among the general population; only 14% of U.S. adults annually integrate this information into healthcare decisions, with even lower rates among underserved populations. Common challenges in engagement with quality of care information span several dimensions. Awareness of such resources is low, and trustworthy reports are often difficult to locate within the over-saturated world of online health information. Complexity in reporting may also inhibit comprehension, particularly when patients must interpret diverse measures of quality, performance, and cost that are reported using technical terms. Such barriers may be particularly salient among audiences from lower socioeconomic position (SEP).

Recommendations for Quality of Care Online Reporting

Several strategies may be enacted to increase the use of online quality reports among consumers, with particular focus on providing proper context and interpretability of available metrics. These include:

- Bridge the gap between health care provider and patient understanding of “quality of care” by introducing new quality measures that prioritize patient perspectives
- Make quality reports accessible for consumers with a wide range of literacy, numeracy, and digital literacy skills through the use of plain language and appropriate presentation formatting
- Incorporate customization, contextualization, and interpretation tools into quality reports to articulate how health care quality data can be meaningful to consumers’ health decision-making
- Improve the “findability” and consumer awareness of evidence-based health care quality information from credible online sources
- Improve the usability of websites that offer QOC information with a specific focus on the underserved
- Enable patients across all socio-economic positions and racial and ethnic backgrounds to use internet technology as a platform for shared decision-making and as a tool to engage with both the management of their health care, and the management of their health

Introduction

In light of the communications revolution (Viswanath, 2005) and ubiquity of messages through a variety of media platforms, people have never before been so inundated with health information as they are now. With an estimated 50 million health-related web pages now online (Cochrane, Gregory, & Wilson, 2012), accessing health information is one of the most common activities for which individuals rely on the internet (National Telecommunication and Information Administration, 2013). Major technological advancements in patient access to medical records, test results, and valuable health information are, in theory, empowering health care consumers to play an increasingly active role in their health care. Online approaches have quickly become the primary vehicle for disseminating quality of care information, as internet resources are easily accessible by a vast audience, facilitate regular information updates, and are easily tailored to meet specific audience needs (Yegian et al., 2013).

Publically accessible reports on the quality of U.S. health care provide consumers with the information they need to effectively choose the best-performing providers for their care and motivate system-wide quality improvement as a result. Mere availability of information online, does not however, lead to access to and use of this information by the consumers. Several challenges including awareness of the availability, communication inequalities, difficulties in navigation and construction or packaging of information in ready-to-use format could potentially deter its use. Engaging consumers with effective health care quality information is an important challenge that should be addressed to take advantage of the current information revolution.

This paper will review consumer perceptions of “quality of health care”, consumers’ health information seeking behaviors, and common barriers that inhibit consumers’ search for and use of health care quality information. The overall objective is to illuminate the underlying

factors that contribute to consumers' engagement with the planning and process of their health care through health care quality information seeking.

Defining Quality of Care

Theoretical Definition

Despite spending significantly more on health care than any other Organization for Economic Cooperation and Development (OECD) country, people of the United States (US) do not benefit from substantial gains in positive health outcomes (OECD, 2013). While many factors contribute to this state, one important influence is that Americans do not always receive high-quality care that meets their needs and is based on the best available scientific knowledge (Institute of Medicine (IOM), 2001). In fact, there is strong evidence that US patients are frequently harmed or do not see consistent benefits from their health care services (IOM, 2001). It has long been the mission of health professionals, researchers, non-governmental organizations, US governmental agencies, and patients to improve the quality of US health care to meet the needs and expectations of all health care consumers. However, as a subjective construct, "quality of care" does not have a widely accepted definition and corresponding system of measurement amongst health professionals or laypeople. Various definitions of "quality of care" have been proposed, adopted, and amended to conceptualize and measure the quality of particular health services.

Avedis Donabedian (1988) outlined three key categories under which quality of health care can be assessed: structure, process, and outcome. Structure refers to the environment in which care is provided, including resources and organizational structure (Donabedian, 1988). Process involves how care is delivered by the providers and received by patients (Donabedian, 1988). Once care has been provided, the outcome refers to the consequences of care on the health status of patients and populations (Donabedian, 1988). Donabedian's argument is that "good

structure increases the likelihood of good process, and good process increases the likelihood of a good outcome” (Donabedian, 1988, p. 1745). While Donabedian is recognized for this systems-based framework to conceptualize quality, he also outlined seven attributes that determine health care quality: efficacy, effectiveness, efficiency, optimality, acceptability, legitimacy, and equity. Many similar quality of care definitions involving multiple dimensions have been proposed since Donabedian’s assessment.

In 2000, Campbell, Roland, and Buetow argued that two primary domains are at the core of all multidimensional definitions of health care quality: access and effectiveness. The authors assert that at its most fundamental level, quality is dependent on whether an individual can get the care they need when they need it, and whether that care is effective on both a clinical and an interpersonal level. In this definition, access encompasses the physical accessibility, affordability, and availability of services encountered by an individual consumer as they navigate a health system (Campbell, Roland, & Buetow, 2000). Effectiveness refers to the effective application of evidence-based, legitimate care that prioritizes a patient-centered process.

In a similar vein to Campbell, Roland, and Buetow, the Agency for Health care Research and Quality (AHRQ), the federal government’s leading agency tasked with improving the safety and quality of health care for all Americans, offers consumers a plain-language definition: doing the right thing, at the right time, in the right way (Clancy, 2007). Accordingly, high quality health care providers avoid the underuse and overuse of services, and strive to eliminate the misuse of any service delivered (Clancy, 2007). To further assist consumers in recognizing high quality care, the Department of Health and Human Services and the Centers for Medicare Services (CMS) developed the online “Hospital Compare” quality tool to provide data on hospital processes, outcomes, and patient satisfaction (www.hospitalcompare.hhs.gov). As

quality is a complex construct to conceptualize, operationalize, and measure, the quality tools that individual quality reports utilize are diverse. For example, Hospital Compare measures the quality of hospitals based on their timeliness; effectiveness; readmissions, complications, and deaths; use of medical imaging; number of Medicare patients treated; and results from a patient experience survey (CMS, 2013).

Arguably the most widely accepted definition of health care quality was developed by the Institute of Medicine (IOM) in its 2001 landmark report, “Crossing the Quality Chasm.” The report was a call to action to restructure the American health care system with the goal of closing the gap between the current state of US health care and the high quality system that could be in place (IOM, 2001). The IOM argued that key health care constituencies need to adopt a shared vision of quality of care that prioritizes six aims for improvement in the 21st century: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity (IOM, 2001).

Consumer Definition

As health care consumers today are expected to play an increasingly active role in their care, it is important to give weight to consumers’ definitions of health care quality. Health care consumers bring a unique perspective to quality of care that does not necessarily mirror the definitions provided by experts and industry leaders such as the IOM (Hibbard, Greene, & Daniel, 2010).

For an individual, quality of care is a subjective judgment grounded in individual values, beliefs, life experience, and culture (Piligrimiene & Buciuniene, 2008; Oermann, 1999). While institutional definitions and objective clinical measures can play a significant role, it has become clear that a consumers’ understanding is based on the responsiveness of a provider to their needs

and fulfillment of their expectations (Piligrimiene & Buciuniene, 2008). The literature to date has shown that when asked to define quality health care, consumers prioritize:

- Access to care
- Open lines of communication with competent and skilled providers
- Receiving appropriate treatment in a well-kept environment
- Being cared for with respect (Piligrimiene & Buciuniene, 2008; Sofaer et al., 2005; Oermann & Templin, 2000; Oermann, 1999; Cleary & Edgman Levitan, 1997; Edgman Levitan & Cleary, 1996).

Returning to the Donabedian Model, it is primarily the process aspects (e.g. patient-provider communication and patient involvement in decision-making), and structure aspects (e.g. responsiveness in a safe environment) of health care that are most relevant to patients' perceptions of quality (Rademakers, Delnoij, & de Boer, 2011). Conversely, health care providers typically emphasize patient outcomes, appropriate services, and provider competence in their definitions of quality (Piligrimiene & Buciuniene, 2008; Rademakers, Delnoij, & de Boer, 2011).

Studies to date have found that consumers often do not have fixed ideas about the aspects of care that are most important to them; for example, even the quality preferences of a single focus group tend to shift over time (Hibbard, Greene, & Daniel, 2010). Some studies believe this is because patients do not fully understand their health service needs and therefore, patient perceptions of quality do not reflect what is in their best interests (Piligrimiene & Buciuniene, 2008; Hibbard, Greene, & Daniel, 2010). Because of this, researchers have advocated for a plain language quality of care framework to assist consumers in making meaning from quality of care indicators (Hibbard, Greene, & Daniel, 2010).

Little research has been done to highlight vulnerable populations' perceptions of quality, but one article reported that vulnerable populations may also have unstable quality preferences

(Raven et al., 2012). The same article reported that vulnerable populations assess quality primarily based on their personal experiences with equitable care delivery, adequate illness prevention, and patient-centered decision-making (Raven et al., 2012).

Overall, individual consumers prefer care that responds to their needs in a patient-centered manner, particularly in terms of humaneness, kindness, communication, and access (Campbell, Roland, & Buetow, 2000).

Working Definition

This paper will focus specifically on the quality of care in formal health care institutions; as such, “care” is defined as medical assistance provided by a health professional (Campbell, Roland, & Buetow, 2000). Based on the literature to date, for the purposes of this paper, we conceptualize “quality of care” to include the following domains:

- Appropriate, timely, and equitable care
- Effective care processes that produce favorable outcomes
- Safe provision of care in a clean, adequately equipped environment
- Patient-centered care that prioritizes open communication and respect

Health Information Seeking

Consumer demand on quality of care information implies active seeking of and engagement with such information by patients and care-givers. Considerable research has been done to understand factors that influence information seeking by patients, care-givers and the general population.

General Characteristics of Information Seeking

Information seeking may be defined as the “purposive acquisition of information from selected information carriers,” (Johnson et al, 1995, p.275) and represents the active search for

information through a particular channel. Information seeking is often triggered by an external stimulus, such as a need for information once an individual or their loved one experiences a medical event or receives a diagnosis (Galarce et al., 2011). This awareness of a need and subsequent preference for health information represents an interaction between health status, type of health problem, psychological factors, and social context (Galarce et al., 2011). There may be a complex range of personal and structural factors that impact information seeking.

Health information seeking has been linked to improved health knowledge (Kontos et al., 2012) and health outcomes (Pluye et al., 2013). More informed patients have higher emotional, social, and cognitive functioning and lower reports of side effects (Schou et al., 2005). Among cancer patients, acquiring cancer-related information has been found to reduce feelings of anxiety and uncertainty (Stark & House, 2000), increase participation in medical decision making (Czaja et al., 2003), and enhance patients' ability to cope with diagnosis and treatment (Arora et al., 2002). Health information seeking has also been strongly linked to engaging in healthy behaviors such as exercise (Ramirez et al., 2013), cancer screening (Kelly et al., 2010), and fruit and vegetable consumption (Kelly et al., 2010) in the general population.

Offline Information Sources

Traditionally, information seekers have used a number of channels to search for information. In a nationally-representative study by the Pew Internet & American Life Project, it was found that clinicians were a central source for information for serious health issues, with 70% of adults reporting they turned to doctors or health care professionals first for health information (Fox, 2013). Individuals may also frequently rely on their social networks for health information (Fox, 2013; Viswanath, Randolph, & Finnegan, 2006), as well as mass media sources such as television and newspapers (Galarce et al., 2011). Choosing a source to obtain

health information depends on its accessibility, trustworthiness, and the type of information sought by the individual (Galarce et al., 2011). When seeking information about a serious disease, such as cancer, most people will refer to a health care professional (Johnson & Meischke, 1991), whereas for information about a pandemic disease, individuals typically refer to news media, government officials or health institutions (Galarce et al., 2011). In a comparison of doctors and social network sources, health professionals mattered most to individuals when there was a need for information on accurate diagnoses, alternative treatments, prescription drugs, or a recommendation for a specialist or hospital (Fox, 2013). In contrast, fellow patients, friends, and family were valued for emotional support and for advice on a quick remedy for an everyday health issue (Fox, 2013).

Online Information Sources

New Information and Communication Technologies (ICTs), such as the Internet, represent critical channels in reaching those seeking Quality of Care information. The so-called eHealth technologies, including health information websites, decision aids, and tailored health education programs, may have the potential to reach wide audiences and the ability to narrow health disparities through increasing access to important information. The internet also provides the opportunity for dynamic, interactive ways of engaging with health information. This shifts the online information environment from a top-down approach of individuals solely gathering information from scientific or academic sources, to a participatory setting where patients, citizens, and organizations can contribute content and communicate with one another (Viswanath et al., 2012). This structure has the promise to transcend the barriers of time and geography that limit traditional media to reach more people with health information (Viswanath et al., 2012).

According to the Pew Internet and American Life Project, of the 85% of US adults who use the internet, 72% have looked for health information within the past year. Among this group, 77% started their search from a search engine such as Google or Yahoo, while 13% first visited a specialized health site such as WebMD (Pew Internet, 2014: Available at <http://www.pewinternet.org/fact-sheets/health-fact-sheet/>). Common topics include disease-specific information, treatments and procedures, and looking to diagnose a problem (Pew Internet, 2014; Schwartz et al., 2006). When searching for health information, the sites most frequently visited by lower income individuals include hospital sites and local health clinics (Viswanath et al., 2013), suggesting that using the internet to connect to local resources may be key with this population. Compared to healthy internet users, those living with one or more chronic conditions are more likely to use the internet to gather information online about medical problems and treatments, consult online reviews about drugs and treatments, access stories of someone else's personal health experiences, and bring information found online to their doctor (Fox & Duggan, 2013).

In addition to patient information seeking, caregivers of patients are found to be heavy technology users, often engaging with online medical information in conjunction with or on behalf of the patient at high levels (Weaver, 2009). When compared to other healthy adults, caregivers more frequently search for drug reviews, support, diagnoses, and other types of health information on behalf of their loved one (Fox, 2013).

Often, people turn to online sources to obtain more information after an unsatisfactory medical encounter (McMullan, 2006). Individuals who perceive their medical encounters to be less patient-centered may be more likely to turn to online health information to search for health

care providers and to rely on the internet as an important communication channel for health information (Hou & Shim, 2010).

Types of Information Engagement Behaviors

Not all individuals seek health information equally at all times. Researchers have conceptualized a range of health information seeking behaviors: active information seeking; information scanning, or coming across information in routine use of media for other purposes (Kelly et al., 2010); information avoidance, or the active and purposeful avoidance of information exposure (Miller, 1995); and information non-seeking, which represents not looking for information at times that it would be expected (Ramanadhan & Viswanath, 2006). Past research indicates that patterns of information seeking and avoiding may not remain constant along the illness trajectory (Butow et al., 1997; Ehemann et al., 2009; Rees and Bath, 2001); for example, patients may avoid information about their disease directly after diagnosis (McCaughan & McKenna, 2007). Information seeking behaviors may also vary by disease characteristics (Mayer et al., 2007; Nagler et al., 2010), or progression (Smith-McLallen et al., 2011). Lack of engagement with information may have negative consequences for a patients' health (Jung et al., 2013).

Factors Relating to Information Seeking

Health communication literature has examined several factors that are associated with information seeking. For example, an individual's decision to seek health information may depend on the salience of the information as relevant and applicable to their situation (Case et al., 2005) A person's belief and confidence in their ability to seek and act upon health information may positively motivate their health seeking behaviors (Case et al., 2005; Galarce et al., 2011). Conversely, an extensive body of research has linked the limiting of information, particularly

through avoidance, to mental discomfort (Case et al., 2005), fear (Case et al., 2005; Rees & Bath, 2001), receipt of confusing information (Brashers et al., 2002), resisting overexposure (Barbour et al., 2012), or preference to defer to their doctor for information gathering and decision-making (Czaja et al., 2003). Avoiders may choose not to engage in health behaviors depending on how health information is presented and interpreted (Miller, 1996); in one study, one-third of patients reported avoiding information about health when they felt the outcome could not be altered (Miller, 1987).

Health Information Seeking Inequalities

In addition to psychosocial factors of information seeking, socioecological factors influence seeking or avoiding information with broader implications to health disparities. This has been discussed under the rubric of communication inequalities: differences among groups in accessing, manipulating and distribution information at the group and organizational level, and differences in accessing, processing and taking advantage of the information at the individual level (Viswanath, 2006). For example, socioeconomic position (SEP), which includes characteristics such as income, debt, and education, plays a major role in determining who is best situated to look for and act upon health information (Rutten et al., 2007; Viswanath, 2011; Viswanath et al., 2012). Individuals who look for information have been found to have higher income and education compared to non-seekers (Ramanadhan & Viswanath, 2006) or information avoiders (McCloud et al., 2013). Lower SEP patients are less likely to look for second opinions (Galarce et al., 2011b) or to seek information outside of the medical encounter (Ramanadhan & Viswanath, 2006). Furthermore, among patients who actively look for information, socioeconomic status may drive the types of information sought. For example, post-

treatment survivors from a lower socioeconomic status may look for other types of information such as financial or employment resources, rather than medical resources (Galarce et al., 2011b).

Importantly, differences in broadband access also contribute to disparities in who may have the opportunity to seek online health information, with higher education and income groups obtaining and benefiting from these services more often than their lower SEP counterparts (Viswanath, 2011). Those who are more educated, have a higher income, are white, and have a home computer and internet access are more likely to have access and use the internet for health information (Atkinson et al., 2009; Weaver et al., 2009). Using the internet for a first source of health information is also associated with younger age and higher education and income (Koch-Weser et al., 2010).

Such social determinants impact both the access to information channels and the subsequent ability to process and use this information once access has been achieved (Viswanath et al., 2006). These communication inequalities span domains such as access, attention to health information, seeking of information, and processing information, and serve to create and perpetuate disparities by influencing both health knowledge and health outcomes (Viswanath et al., 2006). Once access has been achieved, low SEP individuals may face myriad challenges, including inadequate computer technology, frequent moves that disrupt service, lack of internet training, and lack of confidence in engaging with the internet (Viswanath et al., 2013; Zach et al., 2011). Users may need to be linguistically literate (Berland et al., 2001), digitally literate (Eshet Alkali, 2004), and have high level of numeracy, or the ability to use and understand numbers in everyday life (Rothman et al., 2006), in order to fully engage with health information content. As cyberinfrastructure continues to develop, close attention should be paid to how this structure

impacts the underserved, with efforts made to deliver accessible, understandable, and relevant online information to low SEP groups (Viswanath et al., 2012).

Information Seeking for Patient Engagement

As the health care climate shifts to a more participatory model, patients are expected to actively engage as informed consumers in their own care. Such patient engagement may require a number of actions on the part of the consumer. For example Gruman and colleagues (2010) have conceptualized patient engagement as requiring two sets of behaviors: 1) managing *health care*, which involves activities such as creating relationships with health care professionals, gathering expert opinions, and comparing coverage options; and 2) managing *health*, which involves seeking opportunities to treat/improve disease, managing symptoms, seeking prevention opportunities, and regularly engaging in healthy behaviors. In order to optimally benefit from care, the authors propose that these behaviors are expected to integrate seamlessly with one another as an individual moves through different needs within the health care system.

The use of internet technology for dynamic, interactive functions between patients and the health care system may be key for highest levels of patient engagement. Shared decision making, a process through which clinicians and patients work together to make decisions on treatments or disease management, may contribute to more participation, increased understanding, more accurate risk perception, and greater comfort with decisions (Coulter, 2013). E-health information seekers are more likely than non-seekers to engage frequently with the health care system, which may indicate that patients are encouraged to discuss online health information with their doctors out of concern for their health (Suziedelyte, 2012). Patients who look for information online prior to health care visits and discuss this information with their physician have been found to have higher appointment satisfaction (Hay et al., 2008).

Individuals may integrate online advice with other information sources, such as friends, family, and physicians, to arrive confidently at medical decisions (Sillence et al., 2007); for example, cancer patients may navigate between clinicians and nonmedical sources, such as the internet, to satisfy their multidimensional needs for information (Moldovan-Johnson et al., 2013). This sort of movement between sources may indicate that information found on the internet may trigger a need for clarification from physicians, or vice versa (Nagler et al., 2010). However, the amount of information sought outside of the medical encounter may fluctuate based on level of interest for both information and involvement in health care decisions; patients may differ in their desire for involvement in the acquisition of information about their disease and in their participation in treatment decision-making, and may delegate varying levels of these functions to their physicians (Czaja et al., 2003). Individuals with chronic diseases may be motivated to proactively engage with their health care team through provision of interactive health information technology tools including online appointment requests, secure messaging, and internet-based tools to provide self-learning and social support (Ahern et al., 2011).

Quality of Care Health Information Seeking

Background

Online reporting of quality of care data provides an important resource for patient engagement and the stimulation of system-wide quality improvement (Faber et al., 2009). Public reporting systems on health care quality and cost information became popularized by the success of New York State's annual report on risk-adjusted mortality following coronary artery bypass graft surgery for state hospitals and surgeons beginning in 1989 (Chassin, 2002). This quality reporting initiative prompted many hospitals to reexamine and improve their cardiac surgery programs, which ultimately led to a significant decline in statewide mortality (Chassin, 2002). Since the 1990s, public reporting of quality and cost information has been integrated into the

activities of almost all US health care stakeholders, including federal and state governments, nonprofit organizations, insurance companies, and hospitals (Commonwealth Fund, 2007).

Such quality and cost reports address the specific needs of five primary audiences: 1) consumers of health care services gain information for health decision making, 2) providers identify areas for performance improvement, 3) health insurance purchasers (e.g. employers) select between health plans based on service quality, 4) health plans compare performance benchmarks and costs with their competitors, and 5) policymakers monitor overall system performance (Commonwealth Fund, 2007). Public reporting initiatives can improve overall system quality by enabling patients to actively select transparent providers that uphold high quality of care standards and efficiency (Sick & Abraham, 2011). With the aid of accessible quality of care data, consumers are made aware of the large variation between the quality of providers, and can make informed decisions about their trajectory of care (Faber et al., 2009). If patients are increasingly selective about their health providers and plans based on public reports, it is assumed that providers and plans will make performance improvements to remain competitive and maintain their reputations, thereby accelerating system-wide improvement (James et al., 2012). Economics theories (Stigler, 1961) and behavior change theories (Grol, 1997) underlie the key assumption that public reporting will advance system-wide health care quality. According to economic theory, public reporting levels form information hierarchies (Stigler, 1961). With accessible health care quality information, behavioral theories posit that individuals and organizations are motivated to act on quality improvement (AHRQ, 2011).

To facilitate this positive change, over the past 30 years professional associations, federal and state governments, and health care institutions have made significant investments in public reporting systems that measure, analyze, and disseminate quality of care information (Sick &

Abraham, 2011; Yegian et al., 2013). Online public reporting tools are often in the form of a “report card” that allows for the comparison of health providers and plans according to their costs, quality, and patient satisfaction scores (James et al., 2012) For example, Medicare’s Hospital Compare website reports on quality measures related to cardiovascular events, surgical care, and pneumonia in US acute care hospitals as well as patients’ assessments of staff communication, responsiveness, and cleanliness (James et al., 2012). A significant number of provisions related to public reporting were contained in the 2010 Patient Protection and Affordable Care Act, including a national strategy for quality improvement that calls for public reporting of performance measures on hospitals, physicians, insurance plans, and other health care providers (Yegian et al., 2013). This important quality performance data, along with similar comparison tools for individual physicians, nursing homes, and home health agencies, will be made publically available on an annual basis at www.healthcare.gov (James et al., 2012).

The Consumer Side of Quality Reporting

Much to the dismay of those who celebrate the potential of health care quality reports, quality of care data does not constitute the type of health information consumers most actively seek online; US adults primarily search online for health information about a specific disease or medical problem that they or someone they know might have, such as skin problems, allergies, and heart disease (Pew Research Center, 2011). Despite significant efforts to put quality of care at the forefront of consumer engagement, public reporting has not yet proved to be “conclusively effective [at] stimulating consumers to choose their health care provider based on performance information” (Faber et al., 2009, p.1). In fact, a 2008 Henry J. Kaiser Family Foundation report found that only 30 percent of the American public had viewed any type of health quality information in the past year, and only 14 percent actually used that information to compare the

quality of different health providers or plans. After declining for years, the low percentage of Americans who have seen and used quality information has now fallen to levels last recorded in 2000. Moreover, persistent communications inequalities are highlighted by the fact that individuals with a higher SEP are most likely to say they have seen and used quality information (Kaiser Family Foundation, 2008). Americans with lower SEP, who have the most to gain from patient engagement through information seeking, are least likely to benefit with only 11 percent of this population using quality information (Kaiser Family Foundation, 2008).

Without active information seeking and use of quality data by health care consumers, it is unclear if public reporting on quality of care will have the desired impact on quality and costs that investors and developers anticipate (James et al., 2012).

Barriers to Health Care Quality Information Seeking

Despite consumers' minimal use of publically available health quality information, research suggests that consumers do care about comparative quality information and are capable of using this information to make informed health care decisions (Yegian et al., 2013). Many factors have been attributed to the disjunction between the quality information consumers are interested in and the low rates by which consumers actually utilize health quality reports.

Research has shown that consumers underutilize quality of care information primarily because the information is inaccessible, incomprehensible, irrelevant and/or unfamiliar to those in need (Yegian et al., 2013; James et al., 2012; Sick & Abraham, 2011; Hibbard et al., 2010). Real and lasting engagement with consumers requires meeting patients on their own terms, which are often unique to their changing health needs and experiences. To make a difference in quality of care information uptake, producers need to prioritize the widespread promotion of

their quality reports, and make their information easily accessible, comprehensible, and relevant to their target audiences.

Consumer Awareness

Despite significant growth in the number of comprehensive quality of health care reports available over the past 30 years, public awareness about these valuable resources has remained low (Sick & Abraham, 2011; Yegian et al., 2013). Because provider quality information is disseminated almost exclusively via the internet, and website producers rely primarily on word of mouth and media press releases for publicity, many individuals are unaware that such quality information exists (Harris & Buntin, 2008). Given the current state of digital inequalities, such information is even less likely to be used by those from lower SEP groups who also suffer from disproportionate burden of disease and who may have even greater need for such information (Viswanath, 2006). Even amongst patients for whom the quality information available would be extremely relevant, such as cardiac patients, awareness is consistently low (Harris & Buntin, 2008). Awareness also varies greatly by education, income, and health status, further emphasizing the health communication gap that exists between individuals with high and low SEP (Harris & Buntin, 2008), an example of communication inequalities (Viswanath, 2012).

Studies have shown that through an ongoing dialogue, employers and primary health care providers can significantly increase consumer awareness of quality information (Abraham, Feldman, & Carlin, 2004). Producers of validated health care quality information need to employ effective dissemination and marketing tools available to reach their target audiences and increase consumer awareness of these valuable resources.

Consumer Context

Public reports on health care provider performance are often underutilized because they fail to deliver relevant information in an appropriate context for their target audience (Shaller et al., 2013). Shaller and colleagues (2013) suggest three factors that are common to health care choices. First, the consumer's emotional state may be influenced by how the medical context evokes positive or negative emotions, such as hope or anxiety. Second, the consumer's capacity to interpret complexity, particularly intricate measures that incorporate quality, cost, performance, and other attributes of provider practices, and many may be overwhelmed by the need to interpret diverse types of information. Within this state, consumers may focus selective attention on attributes shaped by past health care experiences instead of engaging with the full range of available data. Finally, the consumer's need for sources for trusted advice to make sense of health care experiences may play a crucial role in their consumer engagement. Given these factors, the authors provide practical tips for use, including 1) identifying a target audience for decision making, 2) using emotional cues to engage consumers, 3) providing relevant content, 4) integrating and summarizing information and measures, and 5) providing personal navigation and support.

Consumers' cultural context can also play a significant role in shaping their attitudes toward quality information and common misconceptions held about U.S. health care. Many citizens are simply unaware that significant variation exists in quality of care provided by different US health providers, and often have preconceived ideas about how health care quality can be easily identified (Sick & Abraham, 2011; Yegian et al., 2013). A recent study found that consumers tend to assume more care, newer treatments, and more expensive care inherently indicates "high-quality," while in actuality, researchers assert that quality is best evidenced by

the provision of efficient care with well-established clinical outcomes at relatively low costs (Carman et al., 2010). Similarly, when a recent survey asked 1400 consumers to choose a health care provider based on cost and quality data, most perceived that low costs indicated low quality of health care services (Hibbard et al., 2012). Consumers consistently use this similarity heuristic “because higher cost is typically equated with higher quality in most other consumer goods and services” (Hibbard et al., 2012, p.561). To recognize and prioritize high-value health care providers, consumers need significant visual cues in the presentation of quality reporting, namely a clear display of cost information with easily interpretable quality data (Hibbard et al., 2012).

Accessibility of Quality Reports

Considering the overwhelming amount of health information available online, in addition to being aware that quality reports are available and valuable in health decision-making, consumers must also know where to access them. Health care quality information seekers face information overload and significant “findability” barriers as evidenced by a recent study from Sick and Abraham (2011). The researchers simulated a consumer’s search for quality information on health providers, from an initial Google search to an analysis of the accessibility, credibility, nature of the information encountered (Sick & Abraham, 2011). Conducting a general Google search with such basic keywords as “doctor,” “ratings,” “quality,” and “hospital” yielded significant variation in the types of websites recommended, including some websites that had little to do with health care (Facebook, Myspace, and YouTube). Using these consumer-simulated search methods, the researchers were only able to identify 15 easily found websites with information on health care quality, cost, or patient experience, and many of the top sites lacked objective quality data. Most quality information websites were accessible free of charge, but the source credibility of each website would likely be challenging for a consumer to

determine as they may be unfamiliar with the difference between anecdotal reports versus objective quality information. To ensure that evidence-based, validated health care quality information is easily findable by consumers online, producers should ensure that key terms are embedded in their resources and recognizable by search engines, as well as increase the number of links to their pages from other popular sites (Sick & Abraham, 2011). Since this study was published, Medicare's Hospital Compare Quality of Care web resource has become the first quality information tool listed on Google when a search for "quality hospital" is conducted (accessed on February 24, 2014).

Measurement Issues

As previously discussed, how an organization conceptualizes, operationalizes, and measures health care quality varies greatly. The National Quality Forum (NQF), a nonprofit organization, has worked to build consensus for a definitive set of health care quality and efficiency measures since the 1990s, and currently endorses 653 total measures (NQF, 2014). Measures have evolved from a limited selection of performance measures to more concrete indicators of favorable health outcomes (James et al., 2012). Providers have also successfully advocated for measures that fairly reflect their performance by taking into account the risk profile of the population they treat. Accordingly, hospitals that frequently attend to complex medical problems within high-risk populations (e.g. in poor urban areas) are assessed fairly compared to hospitals with low-risk populations (James et al., 2012).

While the breadth of NQF-endorsed quality measures available provide essential tools to deepen researchers' quality of care knowledge, the majority of quality measures require an intermediate to advanced level of medical knowledge to interpret (e.g. "Fibrinolytic Therapy received within 30 minutes of hospital arrival," and "Venous Thromboembolism Prophylaxis").

These quality measures may resonate with quality experts and health professionals, but previous research has demonstrated that most quality indicators are either too technical or too ambiguous to be well understood by consumers (Hibbard & Jewett, 1997; Jewett & Hibbard, 1996). Health care consumers often fail to comprehend key terms, are confused about whether high or low rates of a measure indicate good performance, and misunderstand how particular measures relate to quality of care (Hibbard & Jewett, 1997). Research has shown that consumers are most able to understand measures of patient-centered care and least able to understand hospital effectiveness indicators (Hibbard, Greene, & Daniel, 2010).

Dissonance between the results produced by quality data using different web resources can be another source of confusion for health care information seekers. A 2008 study comparing five widespread public reporting services in Boston, Massachusetts (Hospital Compare, Health-Grades, Leapfrog Group, US News and World Report, and Massachusetts Health Care Quality and Cost) found inconsistent ranking of the top- and bottom-performing hospitals, primarily due to variations in rating methods, reporting periods, and patient populations utilized to compare hospitals on each site (Rothburg et al., 2008). Consequently, the authors argue that consumers are more likely to be confused, rather than informed by, these public reporting services (Rothburg et al., 2008).

Comprehension of Quality Reports

Numerous reports have documented the difficulties consumers have with understanding and synthesizing the overwhelming amount of quality information available in various reports (Faber et al., 2009). These comprehension issues pose a major challenge to producers of health quality reports that aim to facilitate patient engagement. While complex medical information can be challenging for anyone, it is those with low levels of literacy and numeracy that are the most

significant cause for concern. The 2003 National Assessment of Adult Literacy found that only 12% of US adults have proficient health literacy skills, or the ability to obtain, process, and understand basic health information and services to make appropriate health decisions (U.S. Department of Health and Human Services (DHHS), 2008). This poses a significant barrier to quality reporting as an individual's health literacy level is one of the most influential factors affecting their effective comprehension and use of quality of care information (Zwijnenberg et al., 2012). Consumers tend to experience the most difficulty with unfamiliar medical terms and quality-related outcomes, interpretations of quantitative measures (e.g. risk ratios, probabilities, mortality trends), and complicated care processes (DHHS, 2008; Ancker et al., 2006).

To assist health care consumers, quality measures must be placed in context and written in a way that makes it clear to consumers exactly what is being measured, why it is important, and how to interpret a particular hospital's measurement. By placing quality information in context, consumers can more easily grasp how the application of such information can be useful in their personal situation (Yegian et al., 2013). Contextual information also helps consumers make more informed choices about their health care providers by illustrating correct interpretations of quality data and correcting common misconceptions (Yegian et al., 2013). For instance, Medicare's Hospital Compare website offers extensive information for consumers on how to compare various measures, including helpful interpretation tips such as "higher percentages are better" (CMS, 2014). An online reporting environment is particularly valuable as contextual information can be easily tailored to consumers with different levels of need; for instance, offering links to "interpretation tips" in the page margins or a helpful reminder that "higher costs do not necessarily imply higher quality" (Yegian et al., 2013). Research has also found that providing patient experience measures can help consumers engage with more

unfamiliar quality measures because they feel empowered to delve deeper into the quality report (Yegian et al., 2013). To be appropriate for patient engagement, all public reporting efforts need to carefully consider the literacy demands they pose to US consumers, and address the additional needs of those with low prose, quantitative, or digital literacy skills (Hibbard & Jewett, 1995).

A strong advocate for contextualizing quality indicators, researcher Judith Hibbard has dedicated the past fifteen years to testing approaches that engage consumers in their health care processes. Recently, Hibbard and her colleagues Greene and Daniel (2010) investigated a method to make the overall concept of health care quality more understandable for consumers with the hope that participants would see greater value in the information as a result. The researchers used an experimental design to test the effect of providing a quality framework on understanding of quality of care. The framework developed to help consumers conceptualize quality and what to consider when choosing a health care provider was based on the IOM 2001 definition that quality care is 1) effective, 2) safe, and 3) patient centered. The authors observed that by providing participants with this contextual framework and by using plain language to describe quality measures, consumers were better able to understand the information and see the value in quality of care reports, compared to participants who were given a basic quality of care report. The positive outcomes found in this study were observed for participants from all SEP levels and demographic groups (Hibbard, Greene, & Daniel, 2010). Providing consumers with a contextual framework for understanding is one effective tool that can be harnessed to engage consumers in the use of comparative quality reports.

Relevance of Quality Reports

In addition to the comprehension issues consumers face, the measures summarized in quality reports do not often resonate with consumers as important to their health care decision

making. Consumers identify measures of patient experience and provider service quality as the most relevant to their needs (Yegian et al., 2013), whereas performance measures of adverse health outcomes, the most commonly reported quality measures, are viewed as least relevant (Hibbard & Jewett, 1997). Additionally, the majority of health care quality reports provide general performance data for hospitals or health plans, whereas consumers are most interested in condition or procedure-specific information reported at the individual physician level (Yegian et al., 2013). Multiple studies have suggested that future quality reports be as customizable as possible to account for the many constraints consumers face in terms of their resources and provider options (Faber et al., 2009). Such an expanded consumer choice model of public reporting could sort and compare data by a wide range of individual factors, including health care system characteristics (e.g. out-of-pocket costs, wait times, travel distance), type and source of data (e.g. hospital aggregate, governmental, patient experience), and consumer characteristics (e.g. age, health status, SEP) (Faber et al., 2009). Customizable, user-friendly tools may also empower financially constrained, vulnerable populations to consider quality when selecting a provider (Faber et al., 2009; Hibbard & Jewett, 1997).

Presentation of Quality Reports

Closely linked to the literacy barriers faced by information seekers are the presentation and formatting issues plagued by many online health care quality reports (Damman et al., 2011; Yegian et al., 2013; Harris & Buntin, 2008). While making quality information publicly available online is relatively simple, presenting the information in a way that is useful to consumers can be a significant challenge (Robert Wood Johnson Foundation (RWJF), 2010). To be of value to quality of care information seekers, producers need to ensure that their health quality reports are clear, concise, contextualized, and easy to use (RWJF, 2010). Careful

consideration of how quality information is visually displayed can have a strong influence on consumers' ease of interpretation and use of the data, while inappropriate displays can discourage and frustrate consumers (Yegian et al., 2013). Design strategies are most effective when they capture the consumer's attention, facilitate understanding of quality measures, and empower the consumer to apply the information (RWJF, 2010).

In contrast to the leadership exhibited by organizations such as the NQF in standardizing health care quality measurements, the presentation of quality information remains irregular (Damman et al., 2011). To gain an overall understanding of which presentation techniques have the greatest positive impact on consumer comprehension and decision making, a systematic review was recently conducted by Hildon, Allwood, and Black (2012). The authors found that in terms of consumer-friendly formatting of quality data, tables and pictographs were the most conducive for comprehension and decision accuracy, except when consumers were faced with complex data, in which case bar charts were more appropriate (Hildon, Allwood, & Black, 2012). Ultimately, the review emphasized the importance of consistency and clarity in visual displays (e.g. use of colors and symbols), and called for clear instructions or decision aids to assist consumers with interpretation (Hildon, Allwood, & Black, 2012). Visual complexity in terms of overusing graphics, typefaces, and colors, and having an excessive amount of information on one page often obscures and distracts consumers from the quality information presented (Yegian et al., 2013). Most importantly, consumer-friendly presentation methods can work to reduce health disparities: elderly individuals and those with low literacy and numeracy skills benefit most from effective presentation in quality reports (Faber et al., 2009).

The Robert Wood Johnson Foundation (2010) drew from the research evidence to date to compile a comprehensive guide for providers outlining how comparative information can be

displayed in a way that people can understand and use. The guide outlines the complexities of presenting health care quality information, and how complexity can be addressed through the use of symbols, word icons, explicit points of comparison, limiting the number of providers being compared, rank ordering, and composite measures. Ultimately, the foundation recognizes seven key recommendations for the presentation and formatting of quality reports moving forward:

- keep information short, clear and easy to use;
- address diversity in the target audience;
- help consumers understand the fundamental features of their choices;
- assist consumers in determining and differentiating their preferences;
- minimize complexity by breaking the choice task into a series of small components;
- help consumers understand why and how to use quality information; and
- more information is not necessarily better (Harris & Buntin, 2008, p. 10).

Recommendations

Based on this review of consumers' "quality of health care" perceptions, health information seeking behaviors, communication inequalities and barriers to finding and using quality information, the following are recommended approaches for producing and disseminating health care quality information in an online environment:

- Bridge the gap between health care provider and patient understandings of "quality of care" by introducing quality measures that prioritize patient perspectives
- Make quality reports accessible for consumers with a wide range of literacy, numeracy, and digital literacy skills through the use of plain language and appropriate presentation formatting

- Incorporate customization, contextualization, and interpretation tools into quality reports to articulate how health care quality data can be meaningful to consumers' health decision-making
- Improve the “findability” and consumer awareness of evidence-based health care quality information from credible online sources
- Empower patients across all socio-economic positions and racial and ethnic backgrounds to use internet technology as a platform for shared decision-making and as a tool to engage with both the management of their health care, and the management of their health

It is only through these essential advancements in the accessibility, comprehensibility, and relevance of quality of care information that consumer engagement and informed health care decision-making can motivate systematic improvement in the quality of U.S. health care.

References

- Abraham, J., Feldman, R., & Carlin, C. (2004). Understanding employee awareness of health care quality information: How can employers benefit? *Health Services Research* 39:6, 1799-1815.
- Agency for Healthcare Research & Quality (2011, August 17). *Public Reporting as a Quality Improvement Strategy: A systematic review of the multiple pathways public reporting may influence quality of health care*. Retrieved from http://effectivehealthcare.ahrq.gov/ehc/products/343/763/CQG-Public-Reporting_Protocol_20110817.pdf
- Ahern, D.K., Woods, S., Lightowler, M., Finley, S. & Houston, T. (2011) Promise of and potential for patient-facing technologies to enable meaningful use. *American Journal of Preventive Medicine*, 40(5S2):S162-S172.
- Apter, A., Paasche-Orlow, M., Remillard, J., Bennett, I., Ben-Joseph, E., Batista, R., Hyde, J., & Rudd, R. (2008). Numeracy and communication with patients: they are counting on us. *Journal of General Internal Medicine*, 23(12), 2117-2124.
- Arora NK, Johnson P, Gustafson DH, McTavish F, Hawkins RP, Pingree S. (2002) Barriers to information access, perceived health competence, and psychosocial health outcomes: Test of a mediation model in a breast cancer sample. *Patient Education & Counseling* 47:37-46.
- Atkinson, N. L., Saperstein, S. L., & Pleis, J. (2009). Using the internet for health-related activities: findings from a national probability sample. *Journal of Medical Internet Research*, 11(1).
- Barbour JE, Rintamaki LS, Ramsey JA, Brashers DE. (2012) Avoiding health information. *Journal of Health Communication* 17:212-29.

- Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., McGlynn, E. A. (2001). Health information on the Internet: accessibility, quality, and readability in English and Spanish. *JAMA*, 285(20): 2612-21.
- Brashers DE, Goldsmith DJ, & Hsieh E. (2002) Information seeking and avoiding in health contexts. *Health Communication Research*;28:258-71.
- Butow PN, MacLean M, Dunn SM, Tattersall MH, Boyer MJ. (1997) The dynamics of change: Cancer patients' preferences for information, involvement, and support. *Annals of Oncology* 8:857-863.
- Campbell, S. M., Roland, M. O., & Buetow, S. A. (2000). Defining quality of care. *Social Science & Medicine*, 51, 1611-1625.
- Carman, K. L., Maurer, M., Yegian, J. M., Dardess, P., McGee, J., Evers, M., & Marlo, K. O. (2010). Evidence That Consumers Are Skeptical About Evidence-Based Health Care. *Health Affairs*, 29(7), 1400-1406
- Case DO, Andrews JE, Johnson D, Allard SL. (2005) Avoiding versus seeking: The relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc* 93:353-62.
- Centers for Medicare & Medicaid Services (2013). Measures displayed on Hospital Compare. Medicare.gov: Hospital Compare. Retrieved from <http://www.medicare.gov/hospitalcompare/Data/Measures-Displayed.html>
- Centers for Medicare & Medicaid Services (2014, April 17). *Find a Hospital*. Medicare.gov: Hospital Compare. Retrieved from <http://www.medicare.gov/hospitalcompare>
- Chassin, M.R. (2002). Achieving and sustaining improved quality: Lessons from New York state and cardiac surgery. *Health Affairs*, 21(4), 40-51. doi: 10.1377/hlthaff.21.4.40

- Clancy, C. (2007). Recognizing high-quality health care. Agency for Healthcare Research and Quality. Retrieved from <http://www.ahrq.gov/news/columns/navigating-the-health-care-system/101607.html>
- Cleary, P. D., & Edgman Levitan, S. (1997). Health care quality - incorporating consumer perspectives. *JAMA-Journal of the American Medical Association*, 278(19), 1608-1612. doi:10.1001/jama.278.19.1608
- Cochrane, Z. R., Gregory, P., & Wilson, R. (2012). Readability of consumer health information on the internet: A comparison of U.S. government-funded and commercially funded websites. *Journal of Health Communication*, 17, 1003-1010. doi: 10.1080/10810730.2011.650823
- Colmers, J. M. (2007). Public Reporting and Transparency. Conference paper from *The Commonwealth Fund/Alliance for Health Reform 2007 Bipartisan Congressional Health Policy Conference*. Retrieved from http://www.commonwealthfund.org/usr_doc/Colmers_pubreportingtransparency_988.pdf
- Coulter, A. (2012) Patient engagement: What works? *Journal of Ambulatory Care Management*, 35(2): 80-89
- Czaja R, Manfredi C, Price J. (2003) The determinants and consequences of information seeking among cancer patients. *Journal of Health Communication*;8:529-62.
- Damman, O. C., Hendriks, M., Rademakers, J., Spreeuwenberg, P., Delnoij, D. M. J., & Groenewegen, P. P. (2011). Consumers' interpretation and use of comparative information on the quality of health care: The effect of presentation approaches. *Health Expectations*, 15(2), 197-211. doi:10.1111/j.1369-7625.2011.00671.x

- Donabedian, A. (1988). The quality of care: How can it be assessed? *Journal of the American Medical Association*, 260(12), 1743-1748.
- Edgman Levitan, S., & Cleary, P. D. (1996). What information do consumers want and need? *Health Affairs*, 15(4), 42-56. doi:10.1377/hlthaff.15.4.42
- Eheman CR, Berkowitz Z, Lee J, Mohile S, Purnell J, Rodriguez EM, Roscoe J, Johnson D, Kirshner J, Morrow GG.(2009) Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun* 14:487-502.
- Eshet Alkali, Y. A.-H., Y. (2004). Experiments in digital literacy. *Cyber Psychology & Behavior*, 7, 421-42.
- Faber, M., Bosch, M., Wollersheim, H., Leatherman, S., & Grol, R. (2009). Public reporting in health care: How do consumers use quality-of-care information? A systematic review. *Medical Care*, 47(1), 1-8.
- Fox, S. (July 1, 2013). Pew Internet: Health. Pew Internet & American Life Project. Retrieved from <http://www.pewInternet.org/Commentary/2011/November/Pew-Internet-Health.aspx>
- Fox, S. Duggan M. (2013) The diagnosis difference. Retrieved January 30, 2014 from <http://www.pewinternet.org/Reports/2013/The-Diagnosis-Difference/Summary-of-Findings.aspx>
- Galarce, E. M., Ramanadhan, S., Weeks, J., Schneider, E. C., Gray, S. W., & Viswanath, K. (2011b). Class, race, ethnicity and information needs in post-treatment cancer patients. *Patient Education and Counseling*, 85(3), 432-439. doi:10.1016/j.pec.2011.01.030

- Galarce, E., Ramanadhan, S. R., & Viswanath, K. (2011a). Health information seeking. In T. L. Thompson, R. Parrott & J. F. Nussbaum (Eds.), *Handbook of health communication* (2nd ed., pp. 167-180). New York: Routledge.
- Grol, R. (1997). Beliefs and evidence in changing clinical practice. *British Medical Journal*, *315*(7105):418-21. PMID: 9277610.
- Gruman, J., Rovner, M., French, M., Jeffress, D., Sofaer, S. Shaller, D. & Prager, D. (2010) From patient education to patient engagement: Implications for the field of patient education. *Patient Education and Counseling*, *78*, 350-356.
- Harris, K. M., & Buntin, M. B. (2008, May). Research Synthesis Report No.14, *Choosing a health care provider: The role of quality information*. Retrieved from <http://www.cahpf.org/GoDocUserFiles/530.Choosing%20a%20healthcare%20provider.pdf>
- Hay, M., Cadigan, R., Khanna, D., Strathmann, C., Leiber, E., Altman, R., McMahon, M., Kokhab, M., & Furst, D. (2008) Prepared patients: Internet information seeking by new rheumatology patients. *Arthritis & Rheumatism*, *59*(4): 575-582.
- Hibbard, J. H., & Jewett, J. J. (1996). What type of quality information do consumers want in a health care report card? *Medical Care Research and Review*, *53*, 2847.
- Hibbard, J. H., & Jewett, J. J. (1997). Will quality report cards help consumers? *Health Affairs*, *16*(3), 218-228. doi:10.1377/hlthaff.16.3.218
- Hibbard, J. H., Greene, J., & Daniel, D. (2010). What is quality anyway? performance reports that clearly communicate to consumers the meaning of quality of care. *Medical Care Research and Review*, *67*(3), 275-293. doi:10.1177/1077558709356300

- Hibbard, J. H., Greene, J., & Daniel, D. (2010). What is quality anyway? performance reports that clearly communicate to consumers the meaning of quality of care. *Medical Care Research and Review*, 67(3), 275-293. doi:10.1177/1077558709356300
- Hibbard, J.H., Greene, J., Sofaer, S., Firminger, K., & Hirsh, J. (2012). An experiment shows that a well-designed report on costs and quality can help consumers choose high-value health care. *Health Affairs*, 31(3): 560–8.
- Hildon, Z, Allwood, D, & Black, N. (2012). Impact of format and content of visual display of data on comprehension, choice, and preference: a systematic review. *International Journal for Quality in Health Care*, 24(1):55–64.
- Hou, J. & Shim, M. (2010) The role of provider-patient communication and trust in online sources in internet use for health-related activities. *Journal of Health Communication*, 15, 186-199.
- James, J. (2012, March 8). Public reporting on quality and costs: Do report cards and other measures of providers' performance lead to improved care and better choices by consumers? *Health Affairs*. Retrieved from www.healthaffairs.org/healthpolicybriefs
- Jewett, J. J., & Hibbard, J. H. (1996). Comprehension of quality care indicators: differences among privately insured, publicly insured, and uninsured. *Health Care Financial Review*, 18(1), 75-94.
- Johnson, J. & Meischke, H. (1991). Women's preferences for cancer information from specific communication channels. *The American Behavioral Scientist*, 34, 742-755.
- Johnson, J.D., Donohue, W.A., Atkin, C.K., & Johnson, S. (1995). A comprehensive model of information seeking. *Science Communication*, 16, 274-303.

- Jung, M., Ramanadhan, S., & Viswanath, K. (2013). Effect of information seeking and avoidance behavior on self-rated health status among cancer survivors. *Patient Education and Counseling*, 92(1), 100-106. doi:10.1016/j.pec.2013.02.008
- Kaiser Family Foundation. Summary and chartpack: 2008 update on consumers' views of patient safety and quality information. Menlo Park (CA): KFF. Retrieved from <http://www.kff.org/kaiserpolls/upload/7819.pdf>
- Kelly, B., Hornik, R., Romantan, A., Schwartz, J., et al. (2010) Cancer information scanning and seeking in the general population. *Journal of Health Communication*, 15, 734-753.
- Koch-Weser, S., Bradshaw, Y., Gualtieri, L., Gallagher, S. (2010) The internet as a health information source: Findings from the 2007 Health Information National Trends Survey and implications for health communication. *Journal of Health Communication*, 15, 279-293.
- Kontos, E. Z., Emmons, K. M., Puleo, E., & Viswanath, K. (2012). Contribution of communication inequalities to disparities in human papillomavirus vaccine awareness and knowledge. *American Journal of Public Health*, 102(10), 1911-1920
- Kontos, E., Bennett, G., & Viswanath, K. (2007) Barriers and facilitators to home computer and Internet access among urban novice computer users of low socioeconomic position. *Journal of Medical Internet Research*, 9(4): e31.
- Kreps, G. L., & Neuhauser, L. (2010). New directions in eHealth communication: opportunities and challenges. *Patient Education and Counseling*, 78(3), 329-336.
- Mayer DK, Terrin NC, Kreps GL, Menon U, McCance K, Parsons SK, Mooney K. (2007) Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer. *Patient Education Counseling* 65:342-350.

- McCaughan E, McKenna H. (2007) Never-ending making sense: Towards a substantive theory of the information-seeking behavior of newly diagnosed cancer patients. *Journal of Clinical Nursing* 16:2096-2104.
- McCloud, R. F., Jung, M., Gray, S. W., & Viswanath, K. (2013). Class, race and ethnicity and information avoidance among cancer survivors. *British journal of cancer*, 108(10), 1949-1956.
- McMullan, M. (2006). Patients using the Internet to obtain health information: how this affects the patient–health professional relationship. *Patient education and counseling*, 63(1), 24-28.
- Miller SM (1995) Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. *Cancer* 76: 167–177.
- Miller SM. (1996) Monitoring and blunting of threatening information: Cognitive interference and facilitation in the coping process. In: Sarason IG, Pierce GR, Sarason BR, editors. *Cognitive interference: Theories, methods, and findings*. Mahwah, NJ: Erlbaum; pp. 175-190.
- Miller, S.M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, 52, 345–353.
- Muldovan-Johnson, M., Tan, A., Hornik, R. (2013) Navigating the cancer information environment: The reciprocal relationship between patient-clinician information engagement and information seeking from nonmedical sources. *Health Communication*, [epub ahead of print]

- Nagler RH, Gray SW, Kelly BJ, DeMichele A, Armstrong K, Schwartz JS, Hornik RC. (2010) Differences in information seeking among breast, prostate, and colorectal cancer patients: Results from a population-based survey. *Patient Education & Counseling*, 81:S54-S62.
- National Quality Forum (2014). *Measures, Reports, & Tools*. Retrieved from https://www.qualityforum.org/Measures_Reports_Tools.aspx
- National Research Council (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press.
- National Telecommunications and Information Administration (June 2013). Exploring the digital nation: America's emerging online experience. Retrieved from: http://www.ntia.doc.gov/files/ntia/publications/exploring_the_digital_nation_-_americas_emerging_online_experience.pdf
- Niederdeppe, J., Hornik, R. C., Kelly, B. J., Frosch, D. L., Romantan, A., Stevens, R. S., & Schwartz, J. S. (2007). Examining the dimensions of cancer-related information seeking and scanning behavior. *Health Communication*, 22(2), 153-167.
- Oermann, M. H. (1999). Consumers' descriptions of quality health care. *Journal of Nursing Care Quality*, 14(1), 47-55.
- Oermann, M. H., & Templin, T. (2000). Important attributes of quality health care: Consumer perspectives. *Journal of Nursing Scholarship*, 32(2), 167-172. doi:10.1111/j.1547-5069.2000.00167.x
- Organization for Economic Co-operation and Development (OECD) (2013). *OECD Health Data 2013: How Does the United States Compare*. Retrieved from <http://www.oecd.org/health/health-systems/oecdhealthdata.htm>

- Pew Internet Project (2013). *Health Fact Sheet*. Retrieved from <http://www.pewinternet.org/fact-sheets/health-fact-sheet/>
- Pew Research Center (2011, February 1). *Health Topics: 80% of internet users look for health information online*. Retrieved from <http://pewinternet.org/Reports/2011/HealthTopics.aspx>
- Piligrimiene, Z., & Buciuniene, I. (2008). Different perspectives on health care quality: Is the consensus possible? *Inzinerine Ekonomika-Engineering Economics*, (1), 104-110.
- Pluye, P., Grad, R., Repchinsky, C., et al. (2013) Four levels of outcomes of information-seeking: A mixed methods study in primary healthcare. *Journal of the American Society for Information Science and Technology*, 64(1): 108-125.
- Rademakers, J., Delnoij, D., & de Boer, D. (2011). Structure, process or outcome: Which contributes most to patients' overall assessment of healthcare quality? *BMJ Quality & Safety*, 20(4), 326-331. doi:10.1136/bmjqs.2010.042358
- Ramanadhan, S., & Viswanath, K. (2006). Health and the information nonseeker: A profile. *Health Communication*, 20, 131-139.
- Ramirez, A.S., Freres, D., Martinez, L.S., Lewis, N., Bourgoin, A., Kelly, B.J., Lee, C.J., Nagler, R., Schwartz, J.S., Hornik, R.C. (2013) Information seeking from media and family/friends increases the likelihood of engaging in healthy behaviors. *Journal of Health Communication*, 18(5): 527-42.
- Raven, M. C., Gillespie, C. C., DiBennardo, R., Van Busum, K., & Elbel, B. (2012). Vulnerable patients' perceptions of health care quality and quality data. *Medical Decision Making*, 32(2), 311-326. doi:10.1177/0272989X11421414
- Rees CE & Bath PA. (2001) Information-seeking behaviors of women with breast cancer. *Oncology Nursing Forum*; 28:899-907.

- Robert Wood Johnson Foundation (2010). *How to Display Comparative Information that People can Understand and Use*. Retrieved from forces4quality.org/af4q/download-document/2557/196
- Rothberg, M. B., Morsi, E., Benjamin, E. M., Pekow, P. S., & Lindenauer, P. K. (2008). Choosing The Best Hospital: The Limitations Of Public Quality Reporting. *Health Affairs*, 27(6), 1680-1687. doi: 10.1377/hlthaff.27.6.1680
- Rothman, R. L., Housam, R., Weiss, H., Davis, D., Gregory, R., Gebretsadik, T & Elasy, T. A. (2006). Patient understanding of food labels: the role of literacy and numeracy. *American Journal of Preventive Medicine*, 31(5), 391-398.
- Rutten LJ, Squiers L, Hesse B. (2006) Cancer-related information seeking: hints from the 2003 Health Information National Trends Survey (HINTS). *J Health Communication* 11 Suppl 1:147-156.
- Schou I, Ekeberg O, Sandvik L, Hjermsstad MJ, Ruland CM. (2005) Multiple predictors of health-related quality of life in early stage breast cancer: Data from a year follow-up study compared with the general population. *Qual Life Res*;14:1813-23.
- Shaller, D., Kanouse, D & Schlesinger, M. (2013) Context-based strategies for engaging consumers with public reports about health care providers. *Medical Care Research and Review*, 1-21.
- Sick, B., & Abraham, J. M. (2011). Seek and ye shall find: Consumer search for objective health care cost and quality information. *American Journal of Medical Quality*, 26(6), 433-440. doi:10.1177/1062860611400898
- Sillence, E., Briggs, P., Harris, P., & Fishwick, L. (2007) How do patients evaluate and make use of online health information? *Social Science & Medicine*, 64, 1853-1862.

- Smith-McLallen A, Fishbein M, Hornik R. (2011) Psychosocial determinants of cancer-related information seeking among cancer patients. *Journal of Health Communication*, 16:212-25.
- Sofaer, S., Crofton, C., Goldstein, E., Hoy, E., & Crabb, J. (2005). What do consumers want to know about the quality of care in hospitals? *Health Services Research*, 40(6), 2018-2036. doi:10.1111/j.1475-6773.2005.00473.x
- Stark, D. P. H., & House, A. (2000) Anxiety in cancer patients. *British Journal of Cancer* 83:1261-1267.
- Stigler, G.J. (1961). The economics of information. *Journal of Political Economy*, 69(3):213-25.
- Suziedelyte, A. (2012) How does searching for health information on the internet affect individuals' demand for health care services? *Social Science & Medicine*, 75, 1828-1835.
- U.S. Department of Health and Human Services (2008). *America's Health Literacy: Why we need Accessible Health Information*. Retrieved from <http://www.health.gov/communication/literacy/issuebrief/>
- Viswanath K (2005). The communications revolution and cancer control. *Nature Reviews Cancer*, 5(10), 828-835.
- Viswanath K (2006) Public communications and its role in reducing and eliminating health disparities. In: Thomson GE, Mitchell F, Williams M, editors. *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*. Washington, DC: Institute of Medicine.
- Viswanath, K. (2011). Cyberinfrastructure: An extraordinary opportunity to bridge health and communication inequalities? *American Journal of Preventive Medicine*, 40(5S2), S245-S248. doi: 10.1016/j.amepre.2011.02.005

- Viswanath, K. McCloud, R.F., Minsky, S., Puleo, E., Kontos, E., Bigman-Galimore, C., Rudd, R., & Emmons, K. (2013). Internet use, browsing, and the urban poor: Implications for cancer control. *JNCI Monographs* (47), 199-205.
- Viswanath, K., Nagler, R., Bigman, C., McCauley, M., Jung, M. & Ramanadhan, S. (2012) The communications revolution and health inequalities in the 21st century: Implications for cancer control. *Cancer Epidemiology Biomarkers and Prevention*, 21(10): 1701-1708.
- Viswanath, K., Randolph, W., & Finnegan, J. R. (2006). Connecting the dots between social capital and public health outcomes: The role of communication and community pluralism. *American Journal of Public Health*, 96, 1456–1461.
- Weaver, J., Mays, D., Lindner, G., Eroglu, D., Fridinger, F., & Bernhardt, J. (2009). Profiling characteristics of internet medical information users. *Journal of the American Medical Association*, 16, 714-722.
- Yegian, J. M., Dardess, P., Shannon, M., & Carman, K. L. (2013). Engaged patients will need comparative physician-level quality data and information about their out-of-pocket costs. *Health Affairs*, 32(2), 328-337. doi:10.1377/hlthaff.2012.1077
- Yegian, J. M., Dardess, P., Shannon, M., & Carman, K. L. (2013). Engaged patients will need comparative physician-level quality data and information about their out-of-pocket costs. *Health Affairs*, 32(2), 328-337. doi:10.1377/hlthaff.2012.1077
- Zach, L., Dalrymple, P., Rogers, M. & Williver-Farr, H. (2011) Assessing internet access and use in a medically underserved population: Implications for providing health information services. *Health Information and Libraries Journal*, 29, 61-71.
- Zwijnenberg, NC, Hendriks, M, Damman, OC, Bloemendal, E, Wendel, S, de Jong, JD, & Rademakers, J. (2012). Understanding and using comparative health care information; the

effect of the amount of information and consumer characteristics and skills. *BMC Medical Informatics and Decision Making*, 12:101. doi: 10.1186/1472-6947-12-101