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Building the Science of Healthcare Public Reporting: Integrating Anecdotal Information to Enhance Sensemaking

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BUILDING THE SCIENCE OF HEALTHCARE PUBLIC REPORTING:
INTEGRATING ANECDOTAL INFORMATION TO ENHANCE SENSEMAKING

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ABSTRACT

Anecdotal information about a healthcare consumers' interaction with care providers and hospital facilities is becoming increasingly available to the public in the form of YouTube videos and as discussion posts on peer-support groups. This form of information can potentially jeopardize the utility of reports generated by Federal entities as it potentially diverts consumer attention from more reliable measures of quality. This dissertation investigates how a health consumer's choice of care is influenced by anecdotal information on the care process available on YouTube. This research then investigates the effect of information presentation methods such as narratives and active engagement with quality metrics to support the consumer's ability to comprehend public report information.

An initial study investigated the characteristics of information healthcare consumers are searching for on a peer-support group. By analyzing the discussions available on the support community of a major ovarian cancer support group, the Ovarian Cancer National Alliance (OCNA), this study investigated the type of information that newly diagnosed ovarian cancer patients and their supporters seek. Using content analysis, 206 publicly available discussions exchanged on OCNA were analyzed by two researchers. Each discussion point was classified into one of the three broad themes that emerged: ovarian cancer-specific, treatment-related, or coping information. The discussion points were further analyzed using a multinomial logit model to predict the type of the desired information based on the role of the person looking for the information, the disease phase in which the information was sought, the emotional status of the information seeker, and

the stage of the cancer. Treatment-related material was the most sought-after information by patients, while coping information was most sought by supporters. When forum posts were negative in tone, the information seekers were more likely to be looking for ovarian cancer-specific information than either treatment-related information or coping information.

The second study investigated the effect of the role of the sequence in which such public report statistics and anecdotal information are viewed by health consumers during the sensemaking process. The study used the scenario of a patient looking for health facility-related information and employed a 2 *(anecdotal information presented as videos supporting and contradicting public report information)* * 2 (*phase of introduction of anecdotal information: early, late*) between-subjects experimental design. The results found that when the phase of introduction of anecdotal information changed from early to late, and when the anecdotal information contradicted the public reports, the probability of choosing the correct facility changed from 0.41 to 0.69. The probability of choosing the correct facility was reduced by more than half, changing from 0.85 to 0.41, when contradicting, rather than supporting, anecdotal information was presented before the public reports. Participants placed significant emphasis on this initial information and found it difficult to change their initial perceptions when presented with the more reliable public reports.

The third study investigated ways to enhance consumer understanding by integrating standardized quality metrics with anecdotal information using user experience design methodologies. Two-hundred individuals participated in this study. This study employed

a 2 *(public report information presented in the standard way, presented within an anecdote) * 2 (engagement with each quality metric: none, active)* between-subjects experimental design. The results of the study found that the probability of choosing the correct facility changes from 0.71 to 0.88 when information was presented within a narrative rather than with the standard public report format.

A final study evaluated whether the influential nature of inaccurate anecdotal videos could be attenuated by presenting public report information within a narrative with active engagement. The study used the scenario of a patient looking for dialysis facility-related information and employed between-subjects experimental design – inaccurate anecdotal information was presented either early or late in the sensemaking process. Ninety-eight individuals participated in the study. The results found no significant differences in the choice of the dialysis facility and level of confidence in the choice. Given that narratives have the power to impact choice and comprehension, there exists a need to conduct further investigation to develop comprehensive guidelines for the presentation of narratives that support the use of public report information.

DEDICATION

This dissertation is dedicated to my beloved parents, Haridasan Chenicheri Veettil and

Ramani Chalil Madathil, my uncle Narayanan Chalil Madathil and my beloved wife,

Aparna Ashok.

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CHAPTER ONE

THE IMPACT OF THE INTERNET ON HEALTHCARE INFORMATION
DISSEMINATION

The last quarter of the 20th century witnessed the introduction of Internet-based

resources intended for disease management and healthcare-related services. Recent

studies have found that consumers are increasingly using these resources (Atkinson,

Saperstein, & Pleis, 2009; Fox & Purcell, 2010; Kreps et al., 2011). The results from the

biennial Health Information National Trends Survey (HINTS, 2008) suggest a shift in the

manner in which patients look for healthcare information, with the majority accessing

information online before talking to their doctors (Kreps et al., 2011). These results are

supported by surveys conducted by Fox et al. (2009) which showed that healthcare

consumers are increasingly resorting to the Internet for information to manage chronic

conditions. Past studies have suggested consumers use search engines to obtain this

information (Rutten, Squiers, & Hesse, 2006) from sources such as research literature

published in the media, reports provided by governmental agencies, resources provided

by such entities as the Mayo Clinic and the National Institutes of Health (NIH), online

social networks, and websites run by individuals.

Traditionally, consumers access research literature published in the media, for

example case studies and statistics, which are often impersonal, hard-to-understand, and

only partially relevant to their condition. Though such statistics and case studies provide

important insights about healthcare, consumers with low statistical and reading skills

have trouble comprehending them and subsequently using them to make a decision

(Nelson et al., 2004). Federal agencies have begun providing data comparing the quality

of healthcare systems/providers to enable consumers to make informed choices about their healthcare needs, revealing the variability among providers (Marshall, Shekelle, Leatherman, & Brook, 2000; Sinaiko, Eastman, & Rosenthal, 2012). These data, referred to as public reports or consumer reports, are an effort to compare providers in a specific specialty within a certain geographic region.

The initial effort to provide governmental healthcare information, the cardiac interventional surgery reporting program, began publishing surgeon-specific data annually on the technical outcome measure of risk-adjusted mortality following coronary artery bypass graft surgery in the late 1980s for the state of New York (Hannan, Kilburn, Racz, Shields, & Chassin, 1994). The past decade has seen a proliferation of such systems providing summaries of quality-of-care data. However, recent studies suggest that such reports are seldom used by consumers (Kolstad & Chernew, 2008). Rather, these studies suggest that consumers primarily rely on recommendations from friends, relatives and physicians as their sources of information when selecting a provider (Gibbs, Sangl, & Burrus, 1996). To better understand the lack of effectiveness of these systems, Hibbard et al. (2002) developed a consumer choice model to depict the process that should be used by people when using comparative quality information in decision making. This model suggests that healthcare consumers should be aware of the availability of the information; should have a basic knowledge of quality and its differences; and should be able to perceive and comprehend the information as valid, reliable and relevant to their decision-making process. Although numerous surveys and focus groups have suggested that consumers highly value information provided in public

reports (Hibbard & Jewett, 1996; Longo & Everet, 2003), very few use it when making a decision (Fung, Lim, Mattke, Damberg, & Shekelle, 2008; Hibbard, 2008; Sinaiko et al., 2012).

Since the late 1990s, websites by private and public healthcare entities featuring information on symptoms; pharmacy and drug information; the latest health news; illustrated medical dictionaries; directories of doctors, dentists and hospitals; videos and interactive health tutorials have proliferated. MedlinePlus, WebMD, MedicineNet, MayoClinic, and NetWellness are a few such sites frequently accessed by the public. A study conducted by Elkin et al. (2010) suggests that healthcare consumers use these resources more than they talk to their healthcare providers. A common belief of consumers is that the information on the Internet offering healthcare advice is trustworthy and accurate (Mead, Varnam, Rogers, & Roland, 2003). However, studies conducted by Eysenbach et al. (2002) have suggested that there are problems with the quality of information on the Internet. Though websites maintained by Federal agencies such as MedlinePlus offer accurate and current medical information that has been reviewed by the National Library of Medicine, the quality of other information available on the Internet and the decisions based on it are open to question. For example, the results of a study on the accuracy of the WebMD symptom checker in diagnosing ENT complaints found that it diagnosed only 70% of the patients correctly (Farmer, Bernardotto, & Singh, 2011). Research has found that 30% of Internet healthcare consumers use this website on a monthly basis (Holstein & Lunderberg, 2003). Recent studies have indicated that YouTube is increasingly being used as a medium for promoting unapproved materials

(Elkin et al., 2010; Freeman & Chapman, 2007; Kim, Paek, & Lynn, 2010) and, thus, has the potential to change the beliefs of patients on controversial topics such as vaccination (Ache & Wallace, 2008; Hayanga & Kaiser, 2008; Keelan, Pavri-Garcia, Tomlinson, & Wilson, 2007).

More recently, Internet-dependent social networks such as PatientsLikeMe and KnowCancer have been developed. According to Elkin et al. (2010), the majority of Internet adopters resort to social media such as Internet forums to better understand their health-related issues. Features of these portals such as online communities and discussion forums enable healthcare consumers to share opinions, insights, perspectives and experiences with one another. A few such online networks even provide ways for patients to collaborate privately with people experiencing similar conditions. Healthcare consumers use these social networks to identify patients with a similar health condition and discuss their situation with them before making a healthcare decision (Keckley & Hoffmann, 2010; van Uden-Kraan et al., 2008). Thirty-six percent of healthcare consumers rely on these perspectives and this knowledge before making such decisions (Deloitte Center for Health Solutions, 2010). A key finding in this report was that this "consumer-generated content appeals to consumers in decision mode." These sites promote disease awareness and provide information on ways of staying healthy while coping with disease. Like other social networks, patient social networks help people to feel less isolated, especially house-bound patients. For these patients, the network provides a social life they might not otherwise have.

Seeking, filtering and integrating useful, trustworthy and valid sources of Internet health information is a complex cognitive activity. Healthcare consumers must develop skills for accessing, comprehending and effectively using the information available on the Internet. In addition, as consumers use information which is primarily anecdotal in nature, issues such as trustworthiness and credibility become important considerations when making a decision. Hence, there is a need to understand how consumers make healthcare-related decisions and to identify effective ways for integrating anecdotal information on the Internet with authoritative information, to enhance the healthcare decision making process. The goal of this dissertation is to better understand how patients make decisions based on information from multiple sources on the Internet. Klein et al.'s (2006b) sensemaking model is used to characterize the human behavior of collecting and organizing information. Specifically, this study explores the following research issues:

1. Understanding and characterizing the types of information sought by healthcare consumers on the Internet by analyzing discussions on an online peer-support group.

2. Investigating the effect on the sensemaking process when anecdotal and public report information are encountered by the healthcare consumer at the initial and the later stages of the sensemaking process.

3. Identifying effective ways of integrating authoritative information with anecdotal information for enhanced sensemaking.

This dissertation is structured as follows: Chapter 2 discusses the types of information available in Internet-based resources, focusing on public reports, MedlinePlus, information from peer-support groups and videos from YouTube. Chapter 3 reviews

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theories of sensemaking with a particular emphasis on Klein et al.'s (2006b) sensemaking model. Chapter 4 investigates the types of information that newly diagnosed ovarian cancer patients and their supporters seek by analyzing discussions available in the support community of a major ovarian cancer support group. Chapter 5 investigates the effect of anecdotal information on YouTube that contradicts public report statistics on the healthcare sensemaking process. Chapter 6 investigates the effect of information presentation techniques as story-telling and user engagement on the integration of public report data and anecdotal information to support the sensemaking process. Chapter 7 investigates the effect of the phase of the introduction of inaccurate anecdotal information on the sensemaking process when public report information is presented within a narrative.

CHAPTER TWO

HEALTH INFORMATION ON THE INTERNET

Consumers use Internet search engines to obtain information from such sources as the reports provided by Federal agencies known as public reports (Medicare Hospital System Comparison Report), resources from entities like the National Library of Medicine (MedlinePlus), online social networks (for example, PatientsLikeMe.com) and video-sharing websites (for example, YouTube.com). The aim of this chapter is to analyze the healthcare information available on these Internet sources.

PUBLIC REPORTS

Dialysis Facility Compare is one of the reports shared by Medicare that provides data about dialysis facilities to support the informational needs of kidney disease patients, their families and their health care providers. This site presents information about dialysis facilities certified by Medicare. Combining data gathered from three sources, Medicare claims, Standard Information Management Systems (SIMS) and Renal Management Information System (REMIS), it includes such material as the address and telephone number of the facility, the number of treatment stations, and the type of dialysis offered (e.g., in-center hemodialysis, peritoneal dialysis, and home hemodialysis training) as shown in Figure 2.1.

Learn why these characteristics and services are important.	ABBEVILLE DIALYSIS 904 W GREENWOOD ST ABBEVILLE, SC 29620 (864) 459-0347 Add to my favorites Map and Directions	AIKEN DIALYSIS 775 MEDICAL PARK DRIVE AIKEN, SC 29801 (803) 641-4222 Add to my favorites Map and Directions
Shifts starting after 5PM [?]	No	No
In-Center Hemodialysis [?]	Yes	Yes
Number of Hemodialysis Stations [?]	10	22
Peritoneal Dialysis [?]	Yes	Yes
Home Hemodialysis Training [?]	No	Yes
Type of Ownership [?]	Profit	Profit
Corporate Name	DAVITA	DAVITA
Facility's Initial Date of Medicare Certification	12/17/2010	07/07/1980

Figure 2.1. Basic information on two dialysis facilities (from Dialysis Facility Compare)

Regulatory agencies have mandated that kidney disease patients undergoing dialysis should have a hemoglobin level in the range of 11.0-12.0g/dl (Singh & Fishbane, 2007). This is based on the finding that the risk of heart failure and stroke increases when hemoglobin levels are raised above 12 g/dL in kidney disease patients (Singh & Fishbane, 2007). The anemia management measure provides the percentage of patients who had a hemoglobin level greater than 12.0g/dL. When comparing two facilities using this measure, the facility with the lower percentage is safer than the one with the higher percentage (see Figure 2.2).

View Graphs	ABBEVILLE DIALYSIS 904 W GREENWOOD ST ABBEVILLE, SC 29620 (864) 459-0347 Add to my favorites Map and Directions	AIKEN DIALYSIS 775 MEDICAL PARK DRIVE AIKEN, SC 29801 (803) 641-4222 Add to my favorites Map and Directions
Patient(s) who had an average hemoglobin value greater than 12.0 g/dL **Lower** *percentages are better*	0%	2%

Figure 2.2 Anemia Management

The measures in Figure 2.3 characterize the dialysis adequacy. Typically, a blood test is done prior to and after the dialysis procedure to evaluate the Urea Reduction Ratio (URR). The first measure shows the percentage of patients who had an adequate amount of urea removed from the blood (the amount should be at least 65%).

View Graphs	ABBEVILLE DIALYSIS 904 W GREENWOOD ST ABBEVILLE, SC 29620 (864) 459-0347 Add to my favorites Map and Directions	AIKEN DIALYSIS 775 MEDICAL PARK DRIVE AIKEN, SC 29801 (803) 641-4222 Add to my favorites Map and Directions
Hemodialysis patients who had enough wastes removed from their blood during dialysis: Urea Reduction Ratio greater than or equal to 65% **Higher** *percentages are better*	100%	98%
NEW Adult hemodialysis patients who had enough wastes removed from their blood during dialysis: Kt/V greater than or equal to 1.2 **Higher** *percentages are better*	91%	80%
NEW Adult peritoneal dialysis patients who had enough wastes removed from their blood: Kt/V greater than or equal to 1.7 **Higher** *percentages are better*	Not Available[2]	Not Available[1]

Figure 2.3. Dialysis Adequacy

The second measure is the percentage of hemodialysis patients with a Kt/V value greater than or equal to 1.2, the target value. The third measure is the percentage of peritoneal dialysis patients with a Kt/V value greater than or equal to 1.7, the target value.

The measures in Figure 2.4 show the percentage of people who had either an arteriovenous (AV) fistula or a venous catheter.

View Graphs	ABBEVILLE DIALYSIS 904 W GREENWOOD ST ABBEVILLE, SC 29620 (864) 459-0347 Add to my favorites Map and Directions	AIKEN DIALYSIS 775 MEDICAL PARK DRIVE AIKEN, SC 29801 (803) 641-4222 Add to my favorites Map and Directions
NEW Adult patients who received treatment through an arteriovenous fistula **Higher** percentages are better	51%	52%
NEW Adult patients who had a catheter (tube) left in a vein longer than 90 days, for their regular hemodialysis treatments **Lower** percentages are better	0%	9%

Figure 2.4. Vascular access

An AV fistula is a connection created between an artery and a vein for hemodialysis treatments. A venous catheter is a tube inserted either in the chest or the leg for hemodialysis treatments. The AV fistula is the preferred method of vascular access, as it reduces the chances of forming clots or becoming infected. However, construction of a properly formed AV fistula requires planning and is dependent on the care provider at the dialysis facility. Accordingly, Medicare has devised two quality measures: the percentage of adult patients who received treatment through an AV fistula and the percentage of the adult patients who had a venous catheter in a vein for longer than 90 days. A facility should have a high percentage of patients who underwent treatment using an AV fistula and low percentage of patients treated for an extended period using a venous catheter.

Medicare also provides information on hospitalization rate and patient mortality rate (see Figure 2.5).

Figure 2.5. Hospitalization and deaths

Hospitalization rate is graded as "Better than Expected", "As Expected", or "Worse than Expected." This measure compares a dialysis facility's expected number of hospital admissions (based on the gender, age, kidney disease stage, presence of other health conditions and body mass index) with its actual number of hospital admissions for its Medicare dialysis patients. The measure for patient death rate compares the expected number of patient deaths with the actual number of patient deaths.

As seen in this analysis, public reports provide specific data concerning patient care and medical conditions, providing consumers with information to help in their decision making process about where to receive treatment. However, this information is technical and impersonal. It may offer little help and support to the lay person. In addition, choosing a dialysis facility becomes a daunting task for a health consumer as they need to compare and contrast a number of different measures. Thus, it is not surprising that patients often rely on other types of information available on the Internet for their healthcare information.

MEDLINEPLUS

Web-based resources developed by Federal organizations have become an important reference for medical information. With almost sixty million page hits a month,

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one such resource available on the Internet is MedlinePlus (Marill, Miller, & Kitendaugh, 2006). This site, developed by the National Library of Medicine, provides authoritative healthcare information reviewed by medical professionals and health organizations. In addition to healthcare information, MedlinePlus contains information about drugs, a medical encyclopedia, news feeds and tutorials. Table 2.1 provides a list of the types of information available on this site.

MedlinePlus combines information from multiple entities, providing something of a one-stop shop for health information. Although Medline Plus manages its health information on the Web well, recent studies have suggested that its website needs to be redesigned to facilitate the retrieval of information that answers specific context-based consumer questions (Marill et al., 2006). The National Library of Medicine is in the process of enhancing the portal to integrate licensed content from other online healthcare resources into the health topic pages (Marill et al., 2006). More recently, the National Library of Medicine developed MedlinePlus Connect, an Application Programming Interface (API) that provides high-quality, context-relevant health information for integration into custom developed healthcare software (Ma, Dennis, Lanka, Miller, & Potvin, 2012). This feature allows custom developed healthcare applications to send a code-based request to MedlinePlus Connect, which can then provide relevant information on diagnoses, medications, and laboratory tests (Ma et al., 2012).

Table 2.1. Types of information available on MedlinePlus (U.S. National Library of Medicine, 2012)

	Information	Description
1	Health Topics	Information on conditions, diseases and wellness
2	Interactive Health Tutorials	Interactive health tutorials from the Patient Education Institute.
3	Easy-to-Read	Health information in non-technical language
4	Games	Interactive health games to enhance health knowledge
5	Health Check Tools	Quizzes, calculators, self-assessments for checking the patient's knowledge and health status
6	Drug Information	Information on prescription and over-the-counter medicines
7	Herbs and Supplements	Evidence-based information about herbs and supplements
8	Medical Encyclopedia	Pictures and diagrams
9	Dictionary	Definitions of medical words
10	News	The latest health news categorized by both date and health topic
11	Surgery Videos	Links to pre-recorded webcasts of surgical procedures
12	Anatomy Videos	Information on the anatomy of body parts and organ systems and the effect of diseases and conditions on them
13	Multiple Languages	Health information in languages other than English
14	Directories	Information for finding doctors, dentists and hospitals
15	Libraries	Addresses of libraries in the United States (categorized by state) that consumers can contact for health information.
16	Organizations	A collection of organizations providing health information, arranged by topic

MedlinePlus is a highly reliable resource for healthcare information. It is an information source that both consumers and custom-developed software system can access for authoritative information.

ONLINE SOCIAL MEDIA

Social media are now an established segment of the online Internet environment. Though they are less than ten years old, recent surveys suggest that they are among the most frequently accessed sites globally (Gold et al., 2012). Even though social media were initially considered primarily as recreational tools, healthcare institutions have recently realized their potential, and various organizations have begun focusing on social media-based approaches to reach stakeholders, aggregate health information and leverage collaboration (Eytan, Benabio, Golla, Parikh, & Stein, 2011). Social media can be powerful tools for engaging healthcare consumers. Recent studies have found that people spend much time on social networks updating their status and looking at information posted by other members (Nyimanu, 2012). In this section, two popular forms of social media (1) Internet-based peer-support groups, and (2) Video-sharing sites are discussed from a healthcare perspective.

Peer support groups

Internet-based peer support groups, a form of online social media that enables healthcare consumers to share their problems and experiences, include forums, discussion groups, chat rooms and listservs. Most peer support groups are forums, where users can create accounts and post discussion "threads" to which other users can reply. These support groups feature both active and passive participation: healthcare consumers can post a question, provide answers to questions posted by others or read through discussions without actively adding to them.

Recent studies have found that users of such peer support groups share personal experiences, encourage one another, and exchange advice (Hoch & Ferguson, 2005). Based on interactions with patients, Hoch found that healthcare consumers with chronic illnesses are taking a more active role in their own care and the care of others with similar diseases, suggesting that peer support groups can be a promising and sustainable healthcare resource (Hoch & Ferguson, 2005). Coulson (2005) examined the information sought by participants in a peer support group for irritable bowel syndrome using a thematic analysis of 572 posted discussions, and found that information dissemination was the primary function of the group. Additionally, the results suggested that the majority of the information accessed involved symptom interpretation and disease management, including treatment options and coping information (Coulson, 2005).

After studying the types of information available on such social networks, researchers began exploring the types of social support exchanged by the members of these groups. A qualitative study conducted by Coulson et al. (Coulson, Buchanan, & Aubeeluck, 2007) analyzed the content of the discussions available on a peer support group for Huntington's Disease, a genetic disorder characterized by the progressive degeneration of the brain. Results indicated that the most common social support mechanisms for this peer support group were informational and emotional. These studies demonstrate that through an online peer support group, patients have new opportunities for information retrieval and social support. The results also suggest that exchanging informational and emotional support represent key functions of such online groups.

Video Sharing Sites

Video sharing sites such as YouTube are popular sources of information. YouTube, founded in 2005, is a free service through which people can upload videos and broadcast them to a large audience. YouTube exceeds more than two billion views per day (Shiels, 2012) with videos being uploaded every minute and an average user spending at least 15 minutes a day on the site (Metekohy, 2012).

A platform like YouTube has the potential to be an important vehicle for sharing and disseminating timely health-related information. YouTube is not just a repository of videos; it is also a social network where users can interact and socialize. The potential benefits of using YouTube as a healthcare informational source are numerous, including its use (i) as a diagnostic aid; (ii) as a tool to educate consumers on healthcare conditions and provide information on when to seek medical advice and (iii) to obtain anecdotal information on how patients experiencing similar illnesses are coping with their conditions (Fat, Doja, Barrowman, & Sell, 2011).

However, healthcare providers and government agencies have expressed concerns about the veracity and quality of the information available on this platform (Allen, Nguyen, Nagalla, & Jensen, 2012; Briones, Nan, Madden, & Waks, 2012; Lewis, Heath, Sornberger, & Arbuthnott, 2012; Singh, Singh, & Singh, 2012). YouTube is being accessed by people around the globe, and as minimal interventions monitor content upload, the extent to which an uploaded video corresponds to guidelines and standards can vary. This raises concerns about the trustworthiness of this information source, and the risk of disseminating misleading information.

A systematic review conducted to understand the information available on YouTube suggested that it hosts healthcare-related video clips and includes information on the pathogenesis, diagnosis, treatment and prevention of health conditions (Chalil Madathil, Rodriguez, Greenstein, & Gramopadhye, in press). This review provided the following insights on the characteristics of healthcare-related information available on YouTube, (i) YouTube is increasingly being used for healthcare-related communication; (ii) Public service announcements from organizations, documentaries and television shows, and user-generated content in which users discuss their perspectives and their experiences were the most commonly found content categories; (iii) Misleading information exists on YouTube and the probability of healthcare consumers encountering such material during the information seeking process is high; (iv) Reliable postings from government/professional organizations are available; (v) There were no differences in the frequency of viewings of misleading and accurate posts; (vi) There has been little research on developing interventions for the effective dissemination of YouTube videos for healthcare communication.

Three major safety concerns were identified for consumers using information from YouTube for healthcare decision making: (i) YouTube is used as a medium for promoting unapproved materials; (ii) YouTube contains information contradicting reference standards/guidelines (for example, a content analysis of the CPR videos on YouTube found methods that contradicted the standard procedure), and (iii) YouTube has the potential to change ideas and beliefs of patients about controversial topics such as vaccination.

Studies have suggested that pharmaceutical companies have a presence on YouTube and are increasingly using YouTube to advertise their products (Pant et al., 2012; Singh et al., 2012). YouTube also contains videos on the use of non-FDA approved drugs, and complementary and alternative medicines (Sajadi & Goldman, 2011) that are dangerous when used without medical supervision. Companies are using social media portals such as YouTube to circumvent government regulations (Elkin et al., 2010; Freeman & Chapman, 2007; Kim et al., 2010). For example, studies have suggested that YouTube is being used (Elkin et al., 2010; Freeman & Chapman, 2007) to promote pro-tobacco content though government agencies have banned pro-tobacco advertisements following the adoption of the World Health Organization's Framework Convention on Tobacco Control.

YouTube users create and upload videos to express their thoughts and opinions on healthcare topics. Many of these videos contain information negatively portraying public health interventions. The results of content analyses suggest that the majority of video clips addressing vaccination portrayed it negatively, with these videos receiving a higher number of views than the positive ones (Keelan et al., 2007). The results of early studies conducted by Ache and Wallace (2008) in 2008 found 32% of the videos on HPV vaccination were negative portrayals. A more recent study conducted by Briones *et al*. (2012) suggests that 51.7% of the videos on HPV vaccine portray it negatively. This suggests an increased proliferation of content with a negative tone over the last few years. In addition, with all three studies (Ache & Wallace, 2008; Briones et al., 2012; Keelan et al., 2007) suggesting that the negative videos had a higher average number of likes than

their positive counterparts, the probability of a lay user perceiving such videos as the ones they should watch may significantly reduce the effectiveness of health campaigns (Lau, Gabarron, Fernandez-Luque, & Armayones, 2012).

The educational value of showing videos providing instruction on healthcare procedures has been demonstrated for both professionals and laypersons. People rely on YouTube to find demonstration videos to learn specific procedures such as cardiopulmonary resuscitation (CPR) (Murugiah, Vallakati, Rajput, Sood, & Challa, 2011), pelvic floor muscle exercises (Stephen & Cumming, 2012) and music therapy (Gooding & Gregory, 2011).

The typical information available on YouTube from guideline bodies included such information as symptoms, treatment and preventive methods and risk factors. A few organizations interviewed patients, who narrated their experience with the disease/condition. Singh et al. (2012) recommend that government and professional organizations, and healthcare professionals actively participate on YouTube by developing and uploading such videos.

Only minimal barriers can realistically be applied to video uploads due to the nature of such video hosting portals as YouTube. There is a need to develop better algorithms and design interfaces to indicate whether information is trustworthy, contextual and valid. In addition, integrating verified information available from Federal agencies, such as MedlinePlus and the medical information glossary maintained by the National Library of Medicine, might increase the trustworthiness and veracity of the information available. Incorporating features such as crowdsourcing, whereby current YouTube users are

encouraged to report inaccurate and misleading information, might be another strategy to prevent the spread of misinformation.

DISCUSSION

In general, the Internet provides many opportunities for consumers to gain information on healthcare. These resources can provide ways for consumers to gain information and share their experiences on the investigation, diagnosis, and treatment of disease. Table 2.2 summarizes the relationships between the four information sources reviewed in this chapter and the types of information available from them.

Table 2.2. Relationship Matrix

	Public report	Medline Plus	Peer support group	YouTube
Disease-specific information	~	ʘ	O	O
Symptom-specific information	~	ʘ	Ө	O
Treatment-related information	□	ʘ	Ө	O
Prognosis information	O	O	□	□
Rehabilitation information	~	O	□	~
Information on maintaining physical and mental health	~	O	□	□
Coping information	~	□	Ө	O
Information on managing a social life	~	~	□	□
Financial/legal information	~	~	~	~
Information on the quality of care provided by healthcare systems	Ө	□	~	□
Body image/sexuality information	~	□	□	□
Anecdotal information	~	~	Ө	Ө

Ө - Strong relationship
O – Moderate relationship
□ – Weak relationship
~ - No relationship

CHAPTER THREE

PERSPECTIVES ON SENSEMAKING

Sensemaking is a multi-step process triggered by events or unexpected occurrences that challenge a person's previous understanding (Klein, Moon, & Hoffman, 2006b; Klein, Phillips, Rall, & Pelus, 2007). It involves gathering, organizing and creating representations of complex information sets to develop and support the mental models needed to understand a situation (Pirolli & Russell, 2011). Weick et al. (2005) argue that this sensemaking process, which is initiated as a response to an inadequate understanding of a situation, consists of developing meanings, arranging events into a specific framework and questioning the initial perception. Asking questions about the prior perception of the problem or situation aids in better understanding the perceived information, followed by further attempts to gather and integrate more information, thus, leading to an even fuller understanding of the situation. The ultimate goal of sensemaking is to develop an understanding that includes adequate information about the current state of the situation to support informed decision making (Battles et al., 2006). Sensemaking, thus, is the process of creating situation awareness (Adams, Tenney, & Pew, 1995; Endsley, 1995) in uncertain situations. Table 3.1 shows the different functions of sensemaking including relevant examples (Klein et al., 2007).

Research analyzing how people make sense of information has a long history, with multiple models having been developed to characterize this mechanism (Dervin, 1998; Klein et al., 2007; Pirolli & Card, 2005; Russell, Stefik, Pirolli, & Card, 1993; Weick, 1995). In addition, sensemaking has been extensively researched in multiple

domains including human-computer interaction (Russell et al., 1993; Russell, Pirolli, Furnas, Card, & Stefik, 2009), science education (Sarmiento & Stahl, 2006), military (Jensen, 2009), aviation (Kontogiannis & Malakis, 2012; Malakis & Kontogiannis, 2012) and healthcare (Battles et al., 2006).

Table 3.1 Sensemaking for different functions (Adapted from Klein *et al.* (2007))

	Functions	Example
1	Detecting a problem (to evaluate if a specific pattern is of concern or not)	Weather forecasters trying to understand if the potential storm pattern should be a concern
2	Connecting dots and making discoveries	A military general trying to make sense of the situation after receiving discrete information from different operatives.
3	Forming explanations	A physician diagnosing an illness
4	Anticipatory thinking	A fire fighter trying to prevent potential accidents
5	Projecting future states	Pilots engaging in activities to understand future events
6	Finding the levers	Managers deciding what type of projector to buy when the decision is a tradeoff among factors such as size, cost and functionality
7	Seeing relationships	Using a map to understand one's location
8	Identifying a problem	A student trying to find a way to portray the variables in a physics problem as a drawing/text to find a solution strategy

Though several models representing the sensemaking process have evolved, (Dervin, 1998; Klein et al., 2007; Pirolli & Card, 2005; Russell et al., 1993; Weick, 1995), the macrocognitive model proposed by Klein et al. (2006a; 2006b; 2007) provides the best understanding of the cognitive phenomena found in real world scenarios. This framework consists of 6 elements: planning, problem detection, sensemaking, adaptation,

coordination and naturalistic decision making. One of the key functions in this model, the sensemaking, is based on the data/frame theory of knowledge representation proposed by Minsky (1977), who suggested that when a person identifies a new situation or a context that requires a substantial change to his current viewpoint, he selects a structure from his memory, called a frame, which is then adapted to fit the context.

According to Klein (2007), humans try to make sense of a situation by starting from an explanatory framework which organizes relationships as causal (stories), spatial (maps), temporal (plans) or functional (scripts). Specifically, a frame facilitates defining the elements in the scenario, identifying their significance to the context. An important characteristic of this model is the closed loop process introduced through the data/frame theory, which suggests that data is used to identify a frame, which in turn determines what data is considered next as shown in Figure 3.1 (Klein et al., 2006b). This model presents seven types of sensemaking activities including mapping the data to the frame, elaborating a frame, questioning a frame, preserving a frame, comparing frames, reframing, and constructing or finding a frame, any one of which can be the starting point of the process.

As this analysis of the data/frame model suggests, sensemaking is a complex cognitive mechanism triggered by a need to find more information and involving finding data based on an initial framework, organizing information into representations, and refining and modifying these representations based on the new information. Seeking reliable healthcare information is such a complex process, one that consumers are increasingly doing themselves rather than relying on professionals. Given the importance

of ensuring that reliable and accurate information is used in healthcare decision making, it is critical that we understand the process consumers use. Thus, this research proposes to explore the healthcare sensemaking process using the data/frame theory.
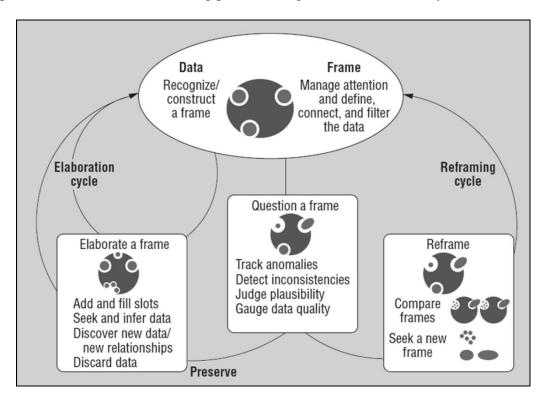
Figure 3.1. Data/Frame theory (Adapted from (Klein et al., 2006b))

Tools supporting sensemaking

One of the earliest tools developed to facilitate increased understanding of information on the web was Sensemaker (Baldonado & Winograd, 1997), an instrument for exploring information within a conceptual area. Sensemaker pools information from multiple sources on the Internet, addressing the evolving nature of user goals depending on the changing nature of the information context. The search services included feeds from web search providers such as AltaVista, bibliographic search providers such as Dialog, a map and a video search service. One of the key features of this system is that

when new information is found, it provides suggestions for further exploration. These, in turn, support the conception and formulation of a new query.

Sensemaking-Information Gathering System (SIGS), a tool developed by Qu et al. (2003), supports sensemaking by representing information as hierarchical tree-like structures, with each folder representing a topic of interest. Developed based on Russell's sensemaking theory (Russell et al., 1993; Russell et al., 2009), SIGS supports modification and reconstruction of the tree representation based on new information (Qu, 2003). A similar tool, ScratchPad, was developed by Gotz *et al.* (2007) to support the collection, organization and utilization of information in the sensemaking process. This browser add-on visually displays the information collected to enhance the sensemaking activity. In addition, ScratchPad includes an algorithm that provides information about the relevance of the user's previously captured information to the current browsing behavior. More recently, Muralidharan and Hearst (2012) developed WordSeer to support sensemaking for literature and language study. Its search and visualization mechanisms also support such activities as the collection and organization of information.

Klein et al. (2006a) suggested that sensemaking has become an umbrella term for efforts involving data fusion and the development of adaptive "intelligent" interfaces. They argue that data fusion algorithms can have detrimental effects since the information has been filtered and packaged through different perspectives. In addition, Klein et al. (2006a; 2007), emphasize that though such algorithms can effectively counter information overload, they present challenges for users who do not understand how they work. Klein et al. (2006a; 2006b; 2007) suggested that intelligent sensemaking systems

should be developed by placing significant emphasis on the key characteristics of the sensemaking process shown in Table 3.2. These were synthesized by Klein et al. (2006a; 2006b; 2007) from their cognitive task analyses investigating how humans make complex decisions in dynamic environments.

Table 3.2. Characteristics of the sensemaking process (Adapted from Klein et al. (2007))

	Characteristics of Sensemaking
1	Satisfies a need or drive to comprehend
2	Helps us test and improve the plausibility of our explanations and explain apparent anomalies
3	Involves a retrospective analysis of events
4	Anticipates the future
5	Deliberates over alternate plausible explanations
6	Guides in the exploration of information
7	Often a social activity that promotes the achievement of common ground

Concerns with healthcare information seeking

The Internet has the potential of playing a key role in making healthcare consumers more informed, and as better informed consumers, they can take a more active role in preventing disease and managing their conditions. In addition, with the availability of Internet-based resources such as Wikipedia and WebMD, the reliance of consumers on healthcare providers for information may be reduced. However, there is a risk of relying upon misleading information, typically anecdotal in nature, with healthcare providers already expressing concerns about the trustworthiness and veracity of this vast amount of data (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). There exists a need to develop techniques and tools to support the sensemaking process of novice healthcare consumers that ultimately supports effective awareness and understanding of the

situation. The sensemaking model posited by Klein *et al.* (2006b; 2007) appears to be a viable theory for guiding such an investigation. Since healthcare consumers may encounter inaccurate information which could serve as an anchor at any time during the sensemaking process, research is needed to understand the impact of inaccurate information both early and late in the process on sensemaking accuracy.

CHAPTER FOUR

AN INVESTIGATION OF THE INFORMATIONAL NEEDS OF OVARIAN CANCER
PATIENTS AND THEIR SUPPORTERS*

The Ovarian Cancer National Alliance (OCNA) support community was studied
to better understand the characteristics of the information that healthcare consumers are
searching for on the Internet. The OCNA support community is an effort to connect
ovarian cancer patients, families, friends, and caregivers. Content analysis (Hsieh &
Shannon, 2005), a research technique that provides useful and pertinent information
about conversations was employed to better understand the types of information searched
for by ovarian cancer patients and their supporters.

METHOD

Study sample and data collection

I collected publicly available information from September 2007 to
September 2010 on the characteristics of the discussion occurring in the OCNA support
community. This ovarian cancer discussion group features threads started by individual
members asking specific questions. The group permits other community members to
contribute information as comments. We used discussion points with an informational
intent under the category "Newly Diagnosed" and available for public use in this study,
as we were interested in understanding the informational needs of people recently
diagnosed with ovarian cancer.

The study sample included 206 individual posts in discussion threads written by
members of the support community. Two researchers evaluated all of the discussion

points using content analysis to develop coding themes based on broad themes in the data. The information classification created by Rutten et al. (2006) guided the development of themes. The researchers read the discussion threads and assigned each discussion point a code based on the themes. Table 4.1 shows a few examples. There was a high level of agreement, and any discrepancies were discussed by the two researchers until a consensus was met. Since this study was exploratory in nature, no formal hypotheses were formulated for this study.

Table 4.1. Examples of categorized discussion points

Category	Discussion point
Ovarian cancer-specific	"My sister just found out that she has a tumor the size of a small watermelon her OBGYN strongly suspects ovarian cancer. But I know someone else in almost the exact same situation as my sister and it turned out NOT to be OVCA. I'm hoping to hear from some of you to see if your tumor or tumors were large like this?"
Treatment-related	"Scheduled for surgery 3/19….. My diabetes has been out of control prior to diagnosis. It is now in control. How will diabetes affect and treatment?" [sic]
Coping information	"I have had some people including family members avoid me since my diagnosis. My sister-in-law will not talk to me but gives me messages through my brother. I've had other people who would call or drop by disappear, has anyone had this happen?"

Independent variables

The independent variables were the primary role of the information seeker, information seeking phase, emotional level of the person looking for information, and the stage of cancer. Information seekers were classified as patients or supporters. Information seeking phase was broadly divided into the phases of before diagnosis, after diagnosis and waiting for treatment, during treatment, and after treatment/remission, based on the characteristics of the discussion point. Though the category analyzed in this study was the

section titled "Newly Diagnosed", 34.5% and 11.7% of the discussions in this category, respectively, were categorized under the phases "during treatment" and "after treatment/remission".

The emotional tone of the discussion point was analyzed and classified as negative or neutral. Phrases such as "Please help me" and "I am losing my mind" were classified as negative. Table 4.2 shows a few examples. Perhaps because the discussion points analyzed were in the "Newly Diagnosed" category, no questions were found with a positive emotional tone.

Table 4.2 Examples of discussion points with negative and neutral tones

Category	Discussion point
Comments with negative tone	"I received the devastating news from my doctor that my results are back and I have stage II OC. I was advised to do chemotherapy as soon as possible... How should I prepare myself? Can I work while undergoing chemo? Fellow sufferers, Please help!!"
Comments with neutral tone	"Has anyone dyed their hair during Gemzar/Carbo? Does anyone know about great natural hair dye products? My gray roots with my brown hair are looking bad."

The stage of cancer was coded based on the International Federation of Gynecology and Obstetrics (FIGO) staging system, a classification mechanism for gynecologic cancer that conveys how far the cancer has spread (Odicino, Pecorelli, Zigliani, & Creasman, 2008). The FIGO system ranges from 1 to 4, with 1 being cancer inside the ovaries and 4 being cancer that has spread to other body organs such as the lungs.

Dependent variable

The type of information sought was divided into three broad categories based on the primary themes that emerged in this analysis. Ovarian cancer-specific, treatment-related, and coping information represented 30.6%, 41.3%, and 28.2% of the total discussion respectively. These themes were used as categories of the dependent variable for further analysis.

A total of 206 discussion points were analyzed. Due to the discrete nature of the dependent variable, a multinomial logistic regression model was used. Such a model allows prediction of multiple unordered categories based on the same combination of categorical predictor variables.

RESULTS

A multinomial logistic regression analysis was performed using SPSS 19.0 to predict membership of a discussion point in one of the three categories of information being sought: ovarian cancer-specific, treatment-related, and coping information. The characteristics of the predictor and outcome variables are shown in Tables 4.3 and 4.4 respectively. Outcomes of this model were used to predict the odds that a discussion point would be in one category as opposed to another. Thus, for this analysis, there were three group contrasts: (1) treatment-related information vs. ovarian cancer-specific information; (2) coping information vs. ovarian cancer-specific information; and (3) coping information vs. treatment-related information.

Table 4.3. Characteristics of the independent variables ($N = 206$)

Variable	%
Role of person looking for information	
Patient	68.9
Supporter	31.1
Phase	
Before diagnosis	27.2
After diagnosis and waiting for treatment	26.7
During treatment	34.5
Treatment completed	11.7
Emotional tone	
Negative	48.1
Neutral	51.9
Stage of cancer	
Stage 1	36.4
Stage 2	11.2
Stage 3	45.6
Stage 4	6.8

Table 4.4. Characteristics of the dependent variable ($N = 206$)

Variable	%
Category of information	
Ovarian cancer-specific information	30.6
Treatment-related information	41.3
Coping information	28.2

All three relationship contrasts are shown in the multinomial logit model presented in Appendix A.

A Chi-squared test was conducted to test the reduction in model fit from the baseline model (-2 Log Likelihood = 242.076) to the final model (-2 Log Likelihood = 183.755) with all the predictors included. This yielded $\chi^2(16) = 58.321$, $p < 0.001$, suggesting that the final model explained a significant amount of the original variability. A Chi-square change test was conducted to identify the predictors that were significantly able to predict the informational needs of the ovarian cancer patients and their supporters. The results suggested that there was a significant main effect of the role of the person looking for information, $\chi^2(2) = 11.790$, $p = 0.003$, the phase in which information was sought, $\chi^2(6) = 27.070$, $p < 0.001$, and the emotional tone of the person posting information, $\chi^2(2) = 10.290$, $p = 0.006$.

Individual parameter estimates were further analyzed to better understand these effects. The ovarian cancer-specific information category was taken as the initial reference category, meaning the treatment-related and coping information categories were compared to the cancer-specific information category. Then treatment-related information was taken as the reference category, and coping information was compared to it.

The role of the person looking for information approached significance, when comparing looking for ovarian cancer-specific and treatment-related information, $b = -0.830$, Wald's $\chi^2(1) = 3.410$, $p = 0.065$. A supporter is 0.44 times as likely as a patient to look for treatment-related information versus ovarian cancer-specific information. Supporters are 3.87 times more likely than patients to look for coping related information versus treatment-related information, $b = 1.35$, Wald's $\chi^2(1) = 10.930$, $p = 0.001$.

The phase of the treatment process is also associated with differences in the type of information that people sought as shown in Figure 4.1.
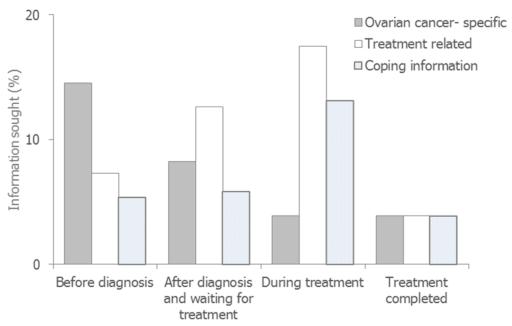
Figure 4.1. Information sought categorized by information seeking phase

A person looking for information during the *after diagnosis and waiting for treatment* phase is 3.01 times more likely than a person in the *before diagnosis* phase to look for treatment-related information versus ovarian cancer–specific information, b = 1.100, Wald's $\chi^2(1)$ = 5.600, p = 0.001. A person in the *during treatment* phase is 8.35 (Odds Ratio) times more likely than a person in the *before diagnosis* phase to look for treatment-related information versus ovarian cancer-specific information, b = 2.120, Wald's $\chi^2(1)$ = 16.600, $p < 0.001$. Finally, a person in the *during treatment* phase is 8.65 times more likely than a person in the *before diagnosis* phase to look for coping information versus ovarian cancer-specific information, b = 2.160, Wald's $\chi^2(1)$ = 14.840, $p < 0.001$.

When a person's forum post had a negative tone the person was 0.31 times as likely as a person making an emotionally neutral post to be looking for treatment-related information versus ovarian cancer-specific information, $b = -1.190$, Wald's $\chi^2(1) = 9.275$, $p = 0.002$. If the tone of the forum post was negative then the person was 0.38 times as likely to be looking for coping information versus ovarian cancer-specific information, $b = -0.973$, Wald's $\chi^2(1) = 5.196$, $p = 0.023$.

The stage of cancer did not predict the specific type of information sought.

DISCUSSION

Ninety-nine percent of the discussion threads evaluated received at least one response. Treatment-related information was the type of information most commonly sought by patients. This included information on side effects of procedures such as chemotherapy and oophorectomy. Patients were often concerned about the effect of a specific procedure on their daily life. Supporters primarily looked for coping information. Commonly sought coping information included the diet to be given to the patient during chemotherapy, how to deal with the emotional responses of patients, and how to provide emotional support. Only 2.42% of the posts were written by males, who looked primarily for coping information.

When forum posts were negative in tone, information seekers were more likely to be looking for ovarian cancer-specific information than either treatment-related information or coping information. This may suggest that the negative tone is at least partly associated with a lack of knowledge regarding ovarian cancer and the progression of the condition. As knowledge of the condition increases and the individual focuses more on

treatment-related or coping information, the tone of the post is less likely to be negative. This suggests that the presentation of ovarian cancer-specific information should be particularly sensitive to the negative emotional state of the people seeking this information.

People focused on treatment-related information in the *after diagnosis and waiting for treatment* phase and on treatment-related and coping information in the *during treatment* phase. This suggests the need for context-related information to support consumer decision making. For example, information on how the majority of OCNA support community members who used Gemzar chemotherapy mitigated a specific side effect could support an information seeker's choice of coping strategy. In addition, this study calls for developing interventions to relate a particular discussion to the information seeker's health condition. Integrating discussion points into stories rather than lists could be one way to enhance assimilation of healthcare information.

This study has limitations. Many of the discussions on the OCNA support community were marked as private and were not included in the study. Members also had the option to send each other private messages. These information exchanges were also not included in this study.

Internet-based resources can provide novel ways for consumers to gain information and share their experiences of investigation, diagnosis, and treatment of disease. However, interventions need to be developed to assure that consumers are able to critically assimilate the anecdotal information posted in peer support groups with more authoritative information sources to make effective healthcare decisions.

CHAPTER FIVE

AN INVESTIGATION OF THE EFFECT OF INACCURATE ANECDOTAL
INFORMATION ON THE HEALTHCARE SENSEMAKING PROCESS

The Internet has the potential of playing a key role in making healthcare consumers more informed. As better informed consumers, they can take an active role in preventing disease and managing their healthcare conditions. With the availability of healthcare information from Internet-based resources such as healthcare public reports, MedlinePlus, online peer-support groups and YouTube, the reliance of consumers on healthcare providers for information may be reduced. However, there is the risk of the dissemination of misleading information, with healthcare providers expressing concerns about the trustworthiness and veracity of data from unmoderated Internet sources, primarily from anecdotal information (Eysenbach et al., 2004).

When making sense of a situation, people rely on pieces of information. During the healthcare sensemaking process, consumers may find inaccurate information as anecdotes and narratives which could serve as an anchor during the sensemaking process. Past studies (Enkin & Jadad, 1998; Fagerlin et al., 2005) have identified that such information can have an undue influence on the health consumer in understanding a health condition, subsequently impacting the decisions made. One of the salient features of anecdotal information is that it shows the sequence of events and the consequences of making a specific healthcare decision. For example, on YouTube a consumer may talk about his personal experience with a procedure in a healthcare institution and how it improved/degraded his condition. Public reports typically provide an overall estimate of

effectiveness as a percentage based on a large number of cases. Consumers may find it difficult to relate to this statistical presentation.

This study investigates the effect of integrating anecdotal patient accounts with public reports on consumer perceptions. According to the data/frame theory, anecdotes and scientific information found during the sensemaking process could be instrumental in defining a frame (Klein, 2008). Inaccurate information, typically anecdotal, can be accessed either early or late in the information seeking process. It is potentially useful to understand the effect of the stage at which such information is consumed during the sensemaking process.

The goal of this experiment is to determine whether the stage at which inaccurate anecdotal information is consumed has an effect on the sensemaking process. A simulated environment was created to test the impact of anecdotal information presented to the participant with authoritative information on the participant's sensemaking process.

Research Hypotheses

According to the data-frame theory (Klein et al., 2007), when a person encounters a new situation, the initial data elements serve as anchors for developing an understanding of the situation, subsequently leading to the development of the initial frame. The data-frame theory (Klein et al., 2006b; Klein et al., 2007) further suggests that this initial frame plays an important role during the sensemaking process, as a person relies on it to explain new data encountered. Based on this theory, it is hypothesized that anecdotal information found early in the information stream will have more influence on the decision making process than that found later. In addition, the interaction between the

consistency of the anecdotal information with public reports and the phase of introduction of anecdotal information is also considered in this study. Specifically, it is hypothesized that a consumer will weigh inaccurate anecdotal information more heavily when it is presented before accurate public report information than when it is presented after that information.

METHOD

Participants

This research used Amazon Mechanical Turk (AMT) to recruit participants, announcing on its site a study of people's perceptions of online healthcare information. Residents of the United States who were eighteen years or older could sign up to participate. A total of 192 individuals were recruited, their ages ranging from 18 to 76 years (M=37.61, SD=13.10). Of the 192 responses, 23 responses were removed from the analysis because the participants did not watch the anecdotal videos completely. Time stamp analysis of the videos indicated that these participants watched only a short portion of the 2 to 3 minute long narratives. Thus, 169 observations were included in the data analysis, of which 93 were from females and 76 were from males.

Apparatus

The study used the Qualtrics research suite, an online data collection tool, in conjunction with AMT, a popular online crowdsourcing service that has seen recent use by researchers for recruiting large numbers of participants for their studies. Recent research investigating its effectiveness as a behavioral testing platform demonstrates that behavioral studies can be conducted online through AMT (Buhrmester, Kwang, &

Gosling, 2011; Paolacci, Chandler, & Ipeirotis, 2010). More importantly, the results generated are similar to those obtained from conventional laboratory studies (Buhrmester et al., 2011). The study required the participants to have a computer connected to the Internet with audio and video playback capabilities.

Independent Variables

This study involved two independent variables:

Consistency of anecdotal information with public reports (2 levels): Anecdotal information was presented using videos at two levels: (1) anecdotal information supporting public report statistics and (2) anecdotal information contradicting the report statistics. These videos addressed a consumer's experience with a specific healthcare facility, a common form of anecdotal information available on YouTube.

Phase of Introduction of anecdotal information (2 levels): Anecdotal information was introduced either early or late in the sensemaking process.

Dependent Variables

The objective outcomes of interest were the consumer's choice between the two health facilities, level of confidence in the decision and his/her knowledge acquired as measured through a comprehension quiz. In addition, the workload was measured by the NASA-TLX questionnaire (Hart & Staveland, 1988). A choice of health facility was considered consistent with public reports if it was supported by the quality measures presented for the two health facilities.

Experimental Tasks

The study used the scenario of a patient looking for health facility-related information and employed a 2 *(anecdotal information as videos supporting and contradicting public report information)* * 2 (*phase of introduction of anecdotal information: early, late*) between-subjects experimental design. The public report statistics were displayed to the participant as shown in Appendix B.

For the purpose of this study, dialysis facility information was provided to the participants. Videos were created by the researcher, and dialysis facility quality measures available on Medicare Dialysis Facility Compare (Medicare.gov, 2013) were used for this study. Figure 5.1 below presents the scenario given to the participants.

Imagine that you have had diabetes for a while, and you are now suffering from a chronic kidney disorder. You need kidney dialysis twice every week, and you must select a dialysis center to provide it. There are two dialysis centers nearby that you can choose from: Facility A and Facility B.

Best treatment practices are services that healthcare facilities provide to help patients avoid hospitalization and death. You will be provided information on the best treatment practices at both facilities in the form of a report and as a narrative from two patients (one for Facility A and one for Facility B) about their experiences with the facilities.

Figure 5.1. Scenario

Table 5.1 shows the script used for the contradictory video. This anecdotal video included statements contradicting the public report data. Specifically, the anecdotal video suggests that the patient was on a catheter for two years and had complications during the care process at Facility A. However, the public report data suggested that Facility A was

better at metrics such as removing enough wastes from the blood and using appropriate procedure for vascular access.

Table 5.1 Script for the contradictory video

At first, I was devastated when I was told that my kidneys weren't functioning adequately. My first time on dialysis did not help me feel any better. I had a difficult time watching my blood leave my body. However, after 10 months of dialysis treatments, I have become more comfortable with the process. I receive my treatments at Dialysis Facility A. At first, the other patients and staff at the facility seemed like strangers. Everything was new and unfamiliar, and I hated having to spend so much time there. But with patience and the support of my dialysis team, my sessions started to become a familiar routine. The staff at dialysis facility A made me very comfortable.
My doctor advised me to receive hemodialysis. He told me that in hemodialysis, an artificial kidney would be used to remove waste products, extra chemicals and fluids from my blood. My doctor inserted a catheter into my neck. I have been using the catheter for the past 2 years.
I spend a lot of time at the dialysis facility: three times each week, with each session lasting three or four hours. I have had several complications. A few times the nurses reported that I did not have enough urea removed from my body, and my doctor recently told me that I've experienced hemoglobin cycling, where my hemoglobin levels are low before I begin hemodialysis and high afterwards, putting me at increased risk for cardiovascular problems. I usually watch TV, catch up on work, or talk with other patients during dialysis. The staff at dialysis facility A is amazing. I would certainly recommend them to anyone who needs dialysis.

Participants were then provided with one of the following stimuli:

1. Anecdotal videos (supporting public report statistics) → Public report information

2. Public report information → Anecdotal videos (supporting public report statistics)

3. Anecdotal videos (contradicting public report statistics) → Public report information

4. Public report information → Anecdotal videos (contradicting public report statistics)

Procedure

Participants were assigned to one of the four conditions randomly using a JavaScript code embedded on AMT. Participants were first asked to read an informational letter and to complete a pre-test demographic questionnaire as shown in Appendix C. The participants then viewed the stimuli. For instance, if the participant was assigned to the fourth condition, he/she saw a hypothetical scenario of the participant looking for a care provider (Table 5.1), followed by public report information comparing the quality measures of the two dialysis facilities (Appendix B), followed by two anecdotal videos, one video on Facility A (as in Table 5.2) and one on Facility B with one of the videos contradicting the public report information. The videos were presented in a random order.

This presentation was followed by a post-test questionnaire (Appendix D) which included a question asking the participants which facility they would choose for their care and their level of confidence in their choice followed by a the NASA-TLX survey measuring the workload experienced while making the choice, a usability questionnaire, and a knowledge quiz evaluating how the participants interpreted the information presented to them. A CAPTCHA was utilized at the end of the study to ensure bots were not used to complete the tasks.

Analysis

SPSS 21.0 was used to analyze the data. The participant choice of facility was evaluated using a binomial logistic regression. A between-subjects Analysis of Variance

(ANOVA) was conducted on the dependent variables of confidence, comprehension and total workload level. When interactions were significant, simple effects analysis was conducted to analyze the effect of one independent variable at individual levels of the other independent variable.

RESULTS

The demographic characteristics of the participants in the study are provided in Table 5.2:

Table 5.2. Demographic characteristics (N=169)

Variable	N	%
Gender		
Male	76	45
Female	93	55
Race		
White	125	74
Other	44	26
Education		
Less than high school	0	0
High school degree or equivalent	21	12.43
Some college but no degree	40	23.67
Associate's degree	20	11.83
Bachelor's degree	67	39.64
Graduate degree	21	12.43

Participant choice. A binomial logistic regression was conducted using the choice of the facility as an outcome with three predictors: *Phase of Introduction of anecdotal information, consistency of anecdotal information with public reports,* and the interaction

term between the *consistency of anecdotal information with public reports* and the *phase of introduction of anecdotal information,* as shown in Table 5.3.

Table 5.3. Binomial logistic regression model

Variable	B	SE	$\Delta\chi^2_{removal}$	Odds ratio	95% CI for odds ratio Lower	Upper
Constant	1.76 [++]	0.44		5.83		
Introduction of anecdotal information			0.55			
Late	-0.64	0.56		0.5	0.17	1.59
Early [reference]	0					
Consistency of anecdotal information with public reports			12.01[++]			
Inconsistent	-2.13	0.54		0.12	0.04	0.34
Consistent [reference]	0					
Introduction of anecdotal information ∗ Consistency of anecdotal information with public reports	1.81	0.73	6.46[+]	6.13	1.47	25.55

[++]p=0.001; [+]p<0.05   -2LL $_{(null)}$ = 37.032; -2LL $_{(model)}$ = 21.37; R^2L=0.58

A test of the full model with all three predictors against an intercept-only model was statistically significant, χ^2 (2, N = 169) = 15.66, p < .001, indicating that the predictors, as a set, reliably distinguished between people who made the correct choice and those who did not. To test the significance of each predictor, each variable was

removed from the model and the change in the chi-square statistic was analyzed. There was a main effect for the independent variable *consistency of anecdotal information with public reports* ($\Delta \chi2 = 12.01$, p = .001). The interaction between the two independent variables *consistency of anecdotal information with public reports* and the *phase of introduction of anecdotal information* was also significant ($\Delta \chi2 = 6.46$, p = .01). The independent variable *phase of introduction of anecdotal information* was not a significant predictor of choosing the correct facility ($\Delta \chi2 = 0.06$, p = 0.46). Parameter estimates were used to understand the direction of each relationship.

The effect of consistency of anecdotal information and the phase of introduction of anecdotal information on the choice of the dialysis facility are summarized in Table 5.4.

Table 5.4. Probability of choosing the correct dialysis facility

	Anecdotal information presented before public reports (Early)	Anecdotal information presented after public reports (Late)
Anecdotal information supporting public reports	0.85	0.75
Anecdotal information contradicting public reports	0.41	0.69

When the phase of introduction of anecdotal information changed from early to late, and when the anecdotal information contradicted the public reports, the probability of choosing the correct facility changed from 0.41 to 0.69 (p = 0.01). This suggests that it is better for the participant to view the inaccurate anecdotal information later in the information seeking process than earlier to reduce its undue influence on the decisions made.

The probability of choosing the correct facility changes from 0.85 to 0.41 (p < 0.001) when contradicting anecdotal information is presented before public reports rather than supporting information.

Level of confidence. There was no significant effect of the independent variables on the level of confidence in the choice of dialysis facility, p > 0.05.

Comprehension score. The comprehension score was calculated as the percentage of questions answered correctly. There was no main effect of the phase of introduction of anecdotal information on the comprehension score, F (1,165) = 0.43, p = 0.51. However, there was a main effect of the consistency of anecdotal information with public reports on the comprehension score, F (1,165) = 4.140, p = 0.04. Post-hoc analysis determined that the comprehension score was higher when anecdotal information supported public reports (M=54.89, SD=18.07) than when anecdotal information contradicted the public reports (M=49.04, SD=19.67) (p=0.04). No significant interaction effect was found between the two independent variables on the comprehension score, F (1,165) = 0.609, p = 0.44.

Workload. There was no main effect of the phase of the independent variables on the workload experienced by the participants, p > 0.05. There were also no significant differences for the workload subscale indices. The average scores for these subscales across all the conditions are shown in Figure 5.2:
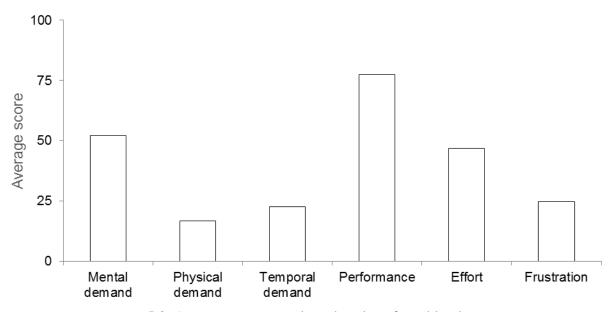
Figure 5.2. Average scores on the subscales of workload

DISCUSSION

The results of this study support the hypothesis that the relationship between the phase of introduction of the anecdotal information and the choice of dialysis care facility is moderated by the consistency of anecdotal information with public reports. When the phase of introduction of anecdotal information changed from early to late, and when the anecdotal information contradicted the public reports, the probability of choosing the correct facility changed from 0.41 to 0.69. Participants also weighed the contradictory anecdotal information more heavily when it was presented before the public reports. The probability of choosing the correct facility is reduced by more than half, changing from 0.85 to 0.41, when contradictory anecdotal information, rather than supporting information, is presented before public reports.

These results can be explained by the data-frame theory (Klein et al., 2006b; Klein et al., 2007). According to this theory, participants tend to respond to stimuli by

constructing a story or a script interpreting the sequence of events presented. The data-frame theory emphasizes the importance of the initial few data elements when faced with a new situation. In the study reported here, participants were presented with the task of identifying a dialysis facility. According to the data-frame theory, when participants encounter this new situation, the initial one or two key data elements serve as anchors for developing an understanding of the situation. In this study, when participants were first presented a video of a person narrating an experience that was not consistent with the best practice element, they may have placed significant emphasis on this initial data element, using this frame to develop a mental model. After the development of this initial frame, when presented with public report information, participants may have focused on searching for data elements in the report to support their initial flawed mental model.

Sensemaking theory (Klein et al., 2007) predicts that healthcare consumers are surprised when presented with information contradicting their understanding, leading to a process called "questioning the frame." If participants in this study realized that the data in the public reports did not match their frame, they might have begun to consider whether their previous understanding was wrong. This questioning of the accuracy of their existing frame may lead to the development of a new one. Klein et al. (2006b; 2007) observed that novices in particular are confused when they see information contradicting their initial understanding. This may explain the reduced comprehension score of participants when the anecdotal information was not consistent with the public report.

Since the dialysis facility public reports consist of multiple metrics, they may have challenged the healthcare consumer's ability to comprehend and use them for effective decision making, even though they provided a more thorough picture of the care process than the anecdotal videos. Due to the heavy cognitive demand and the frustration caused by current methods of presenting the public report information, the participants may have made a decision primarily based on the anecdotal information they found. The many quality measures presented on a single page may have increased the mental demand associated with the choice of the dialysis care facility, perhaps also explaining the high average mental demand associated with the task. The average value of performance measured across the conditions was high. This may have been due to the participants' belief that their choice was correct as they placed significant emphasis on the anecdotal information, which was personal and much easier to understand.

When a person looks for healthcare information, the chance of finding anecdotal information is high. The results from the Pew Research Center's Internet and American Life Project's 2012 Health survey suggest that consumers typically resort to popular search engines such as Google, Bing and Yahoo to find healthcare-related information. The results of this study suggest that when making healthcare choices, health consumers heavily weigh anecdotal information. Should healthcare consumers find a public report at a later phase of their sensemaking process, they may not give it serious consideration, because of the point in their sensemaking process at which they saw the information. The predilection for anecdotal information can have serious consequences in healthcare decision making.

The results of this study indicate that when inconsistent anecdotal information is provided to the healthcare consumers, they tend to weigh it heavily, especially when it is presented first, a conclusion important for both Federal agencies and moderators of social media sites. Both entities need to take steps to ensure the veracity of the healthcare information being provided to consumers, though it may be difficult to institute monitoring techniques for video uploads due to the unmoderated nature of these hosting portals.

A recent report by the Agency for Healthcare Research and Quality (AHRQ) provides nine general recommendations for designing public reports to ensure that healthcare information is clear, meaningful and usable by consumers (Sofaer & Hibbard, 2009). However, in spite of these and similar recommendations, healthcare consumer reports are still not clear and usable. To foster enhanced consumer engagement, new approaches are needed to ensure healthcare consumers have appropriate comprehensible content at the time they are making a healthcare decision. Report providers need to develop a means to educate users of the significance of the multiple metrics provided in reports and how the scores on these metrics could affect their care process.

It is not easy to engage patients with public reports, partly due to the challenges of developing comprehensible formats for presenting complex performance metrics. There is a need for the form and nature of the metrics in the public reports to be fitted to patients' varied circumstances with a focus on their cognitive limitations while making a healthcare decision. One potential approach might be to present the information as a story. A key advantage of a story is its ability to take abstract data and convert it into

meaningful information by presenting it in a compact package with context, meaning, and emotion (Gershon & Page, 2001). This format could potentially be used to integrate consumer narratives into the data, complementing the statistical quality information provided by Federal entities with equally trustworthy anecdotal information from patients. This integrated approach can have the potential to make the content engaging, accurate, and useful for a wide range of healthcare consumers. Within the story, report providers also need to develop data displays that educate users on the significance of the multiple metrics provided and their impact on the outcomes of the care process.

The way consumers make healthcare decisions has changed with the advent and growth of the Internet. No longer do they rely solely on their medical professionals for information and advice. Studies such as this one may contribute to our understanding of the extent to which healthcare consumers turn to peers for support. With that knowledge, appropriate entities, both medical and Federal, can ensure that patients have access to the valid, reliable information necessary to make thoughtful healthcare decisions.

CHAPTER SIX

AN INVESTIGATION OF THE EFFECT OF NARRATIVES AND ACTIVE
ENGAGEMENT TO SUPPORT PUBLIC REPORT SENSEMAKING

Public report presentation formats are based on the faulty assumption that consumers know the factors important to them and how each measure influences their specific condition (Slovic, 1995; Hibbard & Peters, 2003). As a majority of healthcare consumers are novices in terms of the health information they are seeking, there is a need to develop interface designs to support their sensemaking needs. Since informed decisions are critical to both individual health and effective operation of the healthcare system, it is imperative to identify approaches to design effective public report presentation and dissemination mechanisms. When making an infrequent choice of choosing a dialysis care facility, for example, the healthcare consumer who has seldom experienced the consequences of this choice may not be able to accurately predict its impact on their life (Hibbard & Peters, 2003).

One of the key factors that influence the consumer's engagement with public reports is the capacity to interpret the complexity of the measures presented in the public reports (Shaller, Kanouse, Schlesinger, 2013). When multiple quality measures are provided, for example, the consumers may focus on a small subset of selected items that they feel are most relevant to their condition. The decision making literature suggests that when humans are faced with decisions that involve extensive cognitive demand they may tend to take shortcuts to reduce the burden placed on their information processing resources (Montgomery & Svenson, 1989). Tvesky et al., (1981) have found that one of the most common shortcuts is focusing on a single factor, leaving other key factors out of

the decision. A recent study by Armstrong et al. (2009) suggests that this selective attention is shaped by the consumer's specific experiences in the past with healthcare facilities. This may render a few quality measures salient over the others. One potential way to support decision making when users are consuming information is to use stories to convey information and to include engagement mechanisms that increase the salience of inconsistencies in the quality of the care process at two facilities.

Research Hypotheses

Stories are compelling (Gershon & Page, 2001). A story can convey much information in relatively few words (Gershon & Page, 2001). A key advantage of a story is its ability to take abstract data and convert it into meaningful information by presenting information in a compact package with context, meaning, and emotion (Gershon & Page, 2001; Goral & Gnadinger, 2006). They can be used to convey factual information on options and outcomes, to exemplify a range of values or opinions, and to illustrate the steps in decision making. A recent review of functional magnetic resonance imaging (fMRI) studies found that there is a significant overlap in the neural networks employed to comprehend stories and those used to understand the thoughts and emotions of other people (Mar, 2011). Studies conducted by Sanfie and Hastie (1998) suggested that participants made a more accurate judgment when information was provided within a narrative than when the same information was provided in a graphical and tabular format. Hence, I hypothesize that a consumer will find it easier to understand public report information when it is integrated into a narrative.

The decision making literature suggests that one of the strategies that consumers use when they are presented with multiple alternatives is to count the times each alternative has a higher score across all the attributes and select the alternative with the most wins (Bettman, Luce & Payne, 1998). I hypothesize that actively engaging the user with each informational attribute will reduce the demands on the workload and support the sensemaking process (Anderson, 2011; Hibbard & Peters, 2003). An interaction between the style of information presentation and the level of user engagement with the information is also hypothesized for this study. I expect that a better understanding of the situation will be achieved when information is presented as a story and the user actively interacts with the information that is presented, subsequently leading to a correct choice of the healthcare facility.

METHOD

Participants
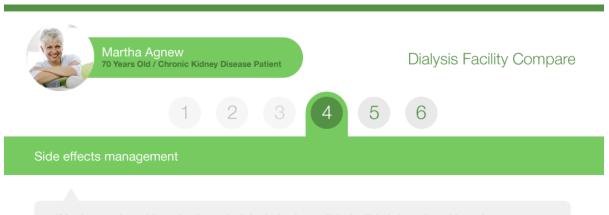
This study also used Amazon Mechanical Turk (AMT) to recruit participants, announcing on its site a study of people's perceptions of online healthcare information. A total of 200 individuals were recruited, of which 96 were females and 104 were males. Their ages ranged from 18 to 72 years (M=35.42, SD=12.24).

Apparatus

The study used the Qualtrics research suite, an online data collection tool, in conjunction with AMT. The study required the participants to have a computer connected to the Internet.

Independent Variables

Information presentation: This independent variable was tested at two levels: (1) public report information presented in the standard way, (2) public report information presented within a narrative in which a patient described her experiences while undergoing treatment for chronic kidney disease, as shown in Figure 6.1. Appendix E shows the complete stimuli in which public report information is presented within a narrative.

Figure 6.1. Public report information presented within a narrative.

User engagement: This independent variable was tested at two levels: (1) no engagement with the quality measures, (2) active engagement with every quality measure followed by feedback (see Figure 6.2).

Martha Agnew
70 Years Old / Chronic Kidney Disease Patient

Dialysis Facility Compare

1   2   3   **4**   5   6

Side effects management

"**My doctor** also told me that I may feel tired after hemodialysis. This fatigue, he told me, is common among dialysis patients. If my hemoglobin drops too low, I could be given transfusions or medication to help my body produce hemoglobin; however, it's preferred that the hemoglobin levels in dialysis patients remain below 12.0 g/dl to keep the risk of complications during dialysis low. Based on this information, I want the facility with the fewer number of patients with hemoglobin levels above 12.0g/dL. If you were me, which facility below would you choose?"

Anemia Management

Anemia is common in people with kidney disease. Healthy kidneys produce a hormone called erythropeoitin, or EPO, which stimulates the bone marrow to produce the proper number of red blood cells needed to carry oxygen to vital organs. Diseased kidneys, however, often donít make enough EPO. As a result the bone marrow makes fewer red blood cells. Other common causes of anemia include blood loss from hemodialysis and low levels of iron and folic acid.

Criteria	Facility A	Facility B
Patients who had an average hemoglobin value greater than 12.0 g/dL *Lower* percentages are better.	4%	3%

Which dialysis facility would you choose for your care process?

○ Facility A

○ Facility B

Figure 6.2. Narratives with active engagement.

User engagement was elicited by providing the user a means to select the better facility in terms of each quality metric and feedback was provided before they made their final choice using an infographic consisting of bullet charts (see Appendix F) that presented the facility they chose on the basis of each quality. Bullet charts were used in the feedback infographic to lower cognitive demands by transforming the information to an evaluative scale.

Dependent Variables

The outcomes of interest were the consumer's choice between two health facilities and the knowledge acquired by the consumer. In addition, the level of confidence in the decision, workload (NASA-TLX) (Hart & Staveland, 1988) and usability of the interface were measured. The level of confidence in the decision was measured using a Likert scale ranging from 1 to 7, with 7 being very confident. A choice was marked consistent with public reports if it was supported by the quality measures presented for the two health facilities.

Experimental Tasks

This study used the scenario of a patient looking for dialysis facility related information and employed a between-subjects experimental design. The dialysis facility quality measures available on Medicare Dialysis Facility Compare were used for this study. A personal story was created by the researcher. Participants were then provided one of the following stimuli:

1. Information presented in the standard public report format without active engagement

2. Information presented within a story without active engagement

3. Information presented in the standard public report format with active engagement

4. Information presented within a story with active engagement

Procedure

Participants were assigned to one of the four conditions randomly using a JavaScript code embedded in AMT. Participants were first asked to read an informational letter and to complete a pre-test demographic questionnaire. The participants then viewed the scenario, as shown in Figure 6.3, followed by the experimental task.

Imagine that you have had diabetes for a while, and you are now suffering from a chronic kidney disorder. You need kidney dialysis twice every week, and you must select a dialysis center to provide it. There are two dialysis centers nearby that you can choose from: Facility A and Facility B.

Best treatment practices are services that healthcare facilities provide to help patients avoid hospitalization and death. You will be provided information on the best treatment practices at both facilities in the form of a report.

Figure 6.3. Scenario

This presentation was followed by a question asking the participants which facility they would choose for their care and their level of confidence in their choice. Subsequently, a knowledge quiz evaluating how the participants interpreted the information presented to them, the NASA-TLX survey measuring the workload experienced while making the choice, and a usability questionnaire were administered. A

CAPTCHA was utilized at the end of the study to ensure bots were not used to complete the tasks. All the post-test questionnaires are shown in Appendix D.

Analysis

SPSS 21.0 was used to analyze the data. The participant choice of facility was evaluated using a binomial logistic regression. A comprehension score was calculated as the percentage of questions answered correctly. A 2 (*information presentation*) X 2 (*user engagement*) between-subjects ANOVA was conducted on the dependent variables of level of confidence, workload, and comprehension. When interactions were significant, simple effects analysis was conducted to analyze the effect of one independent variable at individual levels of the other independent variable.

RESULTS

The demographic characteristics of the participants in the study are provided in Table 6.1:

Table 6.1. Demographic characteristics (N=200)

Variable	N	%
Gender		
Male	104	52
Female	96	48
Race		
White	158	79
Other	42	21
Education		
Less than high school	2	1.0
High school degree or equivalent	25	12.5
Some college but no degree	58	29.0
Associate's degree	28	14.0
Bachelor's degree	66	33.0
Graduate degree	21	10.5

Participant choice. A binomial logistic regression was conducted using the choice of the facility as an outcome with three predictors: *Information Presentation, user engagement* and the interaction between *information presentation* and *user engagement* as shown in Table 6.2.

Table 6.2. Binomial logistic regression model

Variable	B	SE	$\Delta\chi^2_{\,removal}$	Odds ratio	95% CI for odds ratio	
					Lower	Upper
Constant	0.90[+]	0.33				
Information presentation			12.65[++]	3.05	1.05	8.87
Within a narrative	1.11	0.55				
Standard [reference]	0					
Engagement			0.001	0.81	0.35	1.92
Active	-0.21	0.44				
No engagement [reference]	0					
Information presentation *			0.25			
Engagement	0.390	0.78		1.48	0.32	6.77

[+]p<0.05; [++]p=0.001; -2LL (null) = 28.6; -2LL (model) = 13.28; R_2L=0.46

A test of the full model with all three predictors against an intercept-only model was statistically significant, $\chi2$ (2, N = 200) = 13.282, p = .004, indicating that the predictors, as a set, reliably distinguished between people who made the correct choice and those who did not. To test the significance of each predictor, each variable was removed from the model and the change in the chi-square statistic was analyzed. There was a main effect for the independent variable *information presentation* ($\Delta \chi2$ = 12.65, p < .001). The independent variable *engagement* was not a significant predictor of choosing the correct facility ($\Delta \chi2$ = 0.001, p = 0.974). The interaction between the independent variables *engagement* and *information presentation* was also not a significant predictor of choosing the correct facility ($\Delta \chi2$ = 0.253, p = 0.615). Further analysis of the parameter

estimates suggested that the probability of choosing the correct facility with no engagement changes from 0.71 to 0.88 when information was presented within a narrative rather than with the standard public report format. The probability of choosing the correct facility with active engagement changes from 0.67 to 0.9 when information was presented within a narrative rather than with the standard public report format. The effect of information presentation and engagement on choice of the dialysis facility is summarized in Table 6.3.

Table 6.3 Probability of choosing the correct dialysis facility

	No engagement	Active engagement
Standard public report format	0.71	0.67
Within a narrative	0.88	0.90

Level of confidence: There was no significant effect of the independent variables on the level of confidence in the choice of dialysis facility, p > 0.05.

Comprehension score: A main effect of information presentation was found for the comprehension score, F(1,196) = 10.77, p = 0.001. The comprehension score was higher when information was presented within the narrative (*M* = 54.58, *SD* = 18.51) than when presented in the standard public report format (*M* = 44.57, *SD* = 25.13) (p = 0.001). There was no main effect of the engagement on the comprehension score, F(1,196) = 1.49, p = 0.22. No significant interaction was found between the two independent variables on the comprehension score, F (1, 196) = 0.10, p = 0.75.

Workload: There was a main effect of information presentation on the workload experienced, F(1,196) = 5.26, p = 0.02. Total workload was higher when information was

presented within the narrative (M = 53.63, SD = 17.59) than when presented in the standard format (M = 47.65, SD = 18.90) (p = 0.02). The main effect for engagement was not significant, $F(1,196) = 0.003$, p = 0.96. The interaction between information presentation and engagement was also not significant, $F(1,196) = 0.01$, p = 0.91.

Mental Demand: There was a main effect of information presentation on mental demand, $F(1,196) = 7.91$, p = 0.005. Mental demand was higher when information was presented within the narrative (M = 60.57, SD = 26.80), than when presented in the standard format (M = 49.41, SD = 27.07). The main effect of engagement on mental demand was also significant, $F(1,196) = 4.349$, p = 0.038. Mental demand was higher with no engagement (M = 59.43, SD = 26.12), than with active engagement (M = 51.01, SD = 28.13). The interaction between information presentation and engagement was not significant, $F(1,196) = 0.38$, p= 0.54.

Physical Demand: There was no significant effect of the independent variables on the physical demand experienced, p > 0.05.

Temporal Demand: There was no significant effect of the independent variables on the temporal demand experienced, p > 0.05.

Performance: There was no significant effect of the independent variables on the performance subscale, p > 0.05. The mean performance score across all conditions was 77.5, suggesting that the participants found that they performed well in their respective conditions – meaning they thought that they made the correct decision.

Effort: There was no significant effect of the independent variables on the effort required to complete the task, p > 0.05. The mean effort score across all conditions was 54.78.

Frustration: There was no significant effect of the independent variables on the frustration level, $p > 0.05$. The mean frustration level across conditions was 26.01.

Usability score. There was a main effect of information presentation on the total usability score, $F(1,196) = 3.94$, $p = 0.049$. The usability score was higher when information was presented within the narrative ($M = 77.28$, $SD = 12.22$), than when presented in the standard format ($M = 73.66$, $SD = 12.56$). There was no main effect of engagement on the usability score, $F(1,196) = 1.67$, $p = 0.20$. No significant interaction was found between the two independent variables on the usability score, $F(1, 196) = 0.05$, $p = 0.83$.

DISCUSSION

The results of this study support the hypothesis that presenting public report information within a narrative enhances comprehension, subsequently increasing the probability of making a correct decision. When quality measures were presented within a narrative, participants may have found it easier to relate it to the conditions they may experience while undergoing dialysis. When participants read the narrative, they may have also found the task more engaging, subsequently enabling them to employ the specifics learned in their decision making process. Sensemaking theory (Klein, 2008b) suggests that participants tend to run simulations in their mind when they find new information. In this scenario, while trying to make sense of the quality metrics, participants may have been better able to relate to the quality measures when it was presented with a story by treating the experience of the fictional person as an experience that they might also encounter. When information was presented to the participants within a narrative, it may have enabled the participants to visualize themselves as the

person depicted in the narrative and this may have increased the perceived relevance of the quality measures. The high comprehension score in the narrative condition relative to the non-narrative condition also suggests that consumers attended to the quality measures and were better able to comprehend them in the narrative condition.

The hypothesis that active engagement would enhance the sensemaking process was not supported. Though it reduced the mental demand, the probability of choosing the correct facility was not significantly different when public report information was presented with active engagement, rather than with no engagement. One potential reason for this finding may be due to the result of a deficiency in our implementation of the feedback using multiple bullet charts. The feedback phase provided participant with bullet charts based on their respective choices and this may have led to an information overload. Though bullet graphs has the ability to pack both quantitative and qualitative information in a compact space, this advantage might have been offset due to the difficulty for the participants to comprehend the information in the bullet graph when comprehending such graphs the first time.

The high workload experienced when public report information was presented within the narrative was higher than when it was presented in its standard format. Further analysis suggested that participants experienced high mental demands when information was presented within the narrative. This could have been due to the demands placed on the information processing channels while reading a narrative and trying to relate it to the quality measures. The technical terms involved in the narrative, comparisons of multiple options on the different quality measures, and the effort to understand how various

factors should be weighted in their individual circumstances may have led to the increased mental demand.

The mental demand experienced by the participants was higher for the no engagement condition than with active engagement. With multiple quality metrics presented, it may have been difficult for the participant to keep track of all the measures presented at the time the final choice was made. Breaking the decision task into steps and presenting feedback on these steps prior to asking for a final choice may have reduced the cognitive demands placed on the participants. Specifically, when the participants were asked to actively engage with each quality measure they may have found it easier to make a decision based on a single quality measure. Later, when they were asked to make a decision with feedback on their choices for all the measures, it may have been easier for them to integrate all the measures into their final decision making task.

Usability scores were high when information presented within a narrative. When public report information is presented within a narrative, it may ease its comprehension subsequently leading to higher a usability score.

According to the data-frame theory (Klein et al., 2007), when a person encounters a new situation, the initial data elements serve as anchors for developing an understanding of the situation, subsequently leading to the development of the initial frame. The data-frame theory (Klein et al., 2006b; Klein et al., 2007) further suggests that this initial frame plays an important role during the sensemaking process, as a person relies on it to explain new data encountered. A final study will evaluate whether the

influential nature of inaccurate anecdotal videos reported in Chapter 5 may be attenuated

by presenting public report information within a narrative with active engagement.

CHAPTER SEVEN

AN INVESTIGATION OF THE EFFECT OF INACCURATE ANECDOTAL
INFORMATION ON THE SENSEMAKING PROCESS WHEN PUBLIC REPORT
INFORMATION IS PRESENTED WITHIN A NARRATIVE

The decision to choose a healthcare option could be influenced by anecdotal information - leading to choices based on another person's experience rather than on objective public report information. In the study reported in Chapter 5, I found that when the phase of introduction of anecdotal information changed from early to late, and when the anecdotal information contradicted the public reports, the probability of choosing the correct facility changed from 0.41 to 0.69. The probability of choosing the correct facility was reduced by more than half, changing from 0.85 to 0.41, when contradicting, rather than supporting, anecdotal information was presented before the public reports. When participants were presented a video of a person narrating an experience that was not consistent with the best practice element that followed, they placed significant emphasis on this initial data element, subsequently making a flawed decision. The results of the study reported in Chapter 6 reported that the probability of making a correct decision changed from 0.71 to 0.88 when public report information was presented within a narrative rather than in the standard format.

According to the data/frame theory, narratives and scientific information found during the sensemaking process could be instrumental in defining a frame (Klein, 2006b). Since inaccurate anecdotal information may be accessed either early or late in the information seeking process, the goal of this experiment is to determine if impact of the

stage at which inaccurate anecdotal information is accessed during the sensemaking process is attenuated when public report information is presented within a narrative.

Research hypotheses

Hypothesis 1: There will be no significant difference in the choice of the healthcare facility when inaccurate anecdotal information is presented before and after public report information when public reports are presented within a narrative.

Hypothesis 2: There will be no significant difference in the confidence level in the decision when inaccurate anecdotal information is presented before and after public report information when public reports are presented within a narrative.

Hypothesis 3: There will be no significant difference in comprehension when inaccurate anecdotal information is presented before and after public report information within a narrative when public reports are presented within a narrative.

METHOD

Participants

This study also used Amazon Mechanical Turk (AMT) to recruit participants, announcing on its site a study of people's perceptions of online healthcare information. A total of 100 individuals were recruited, their ages ranging from 22 to 68 years (*M*=38.09, *SD*=11.97). Two responses were removed from the analysis because the participants did not watch the anecdotal videos completely. Time stamp analysis of the videos indicated that these participants watched only a short portion of the 2 to 3 minute long anecdotes. Thus, 98 observations were included in the data analysis, of which 49 were from females and 49 were from males.

Apparatus

The study used the Qualtrics research suite, an online data collection tool, in conjunction with AMT. The study required the participants to have a computer connected to the Internet with audio and video playback capabilities.

Independent Variable

Phase of introduction of anecdotal information: Inaccurate anecdotal information was introduced in a YouTube video either early or late in the sensemaking process. This anecdotal video included statements contradicting the public report data.

The public report information was presented within a narrative in which a patient describes her experiences while undergoing treatment for chronic kidney disease. Participants were also provided with radio buttons to select the better facility in terms of each quality metric as shown in Figure 7.1. Feedback was provided using an infographic consisting of bullet charts showcasing the performance of the facility they chose with respect to each quality metric before they made the final choice as shown in Appendix F.

Martha Agnew
70 Years Old / Chronic Kidney Disease Patient

Dialysis Facility Compare

1 2 3 **4** 5 6

Side effects management

"**My doctor** also told me that I may feel tired after hemodialysis. This fatigue, he told me, is common among dialysis patients. If my hemoglobin drops too low, I could be given transfusions or medication to help my body produce hemoglobin; however, it's preferred that the hemoglobin levels in dialysis patients remain below 12.0 g/dl to keep the risk of complications during dialysis low. Based on this information, I want the facility with the fewer number of patients with hemoglobin levels above 12.0g/dL. If you were me, which facility below would you choose?"

Anemia Management

Anemia is common in people with kidney disease. Healthy kidneys produce a hormone called erythropeoitin, or EPO, which stimulates the bone marrow to produce the proper number of red blood cells needed to carry oxygen to vital organs. Diseased kidneys, however, often don't make enough EPO. As a result the bone marrow makes fewer red blood cells. Other common causes of anemia include blood loss from hemodialysis and low levels of iron and folic acid.

Criteria	Facility A	Facility B
Patients who had an average hemoglobin value greater than 12.0 g/dL *Lower* percentages are better.	4%	3%

Which dialysis facility would you choose for your care process?

○ Facility A

○ Facility B

Figure 7.1. Narratives with active engagement.

Dependent Variables

The outcomes of interest were the consumer's choice between two healthcare facilities and the knowledge acquired by the consumer. In addition, the level of confidence in the decision, workload (NASA-TLX) (Hart & Staveland, 1988) was measured. The level of confidence in the decision was measured using a Likert scale ranging from 1 to 7, with 7 being very confident. A choice was marked consistent with public reports if it was supported by the quality measures presented for the two healthcare facilities.

Experimental Tasks

This study used the scenario of a patient looking for dialysis facility related information and employed a between-subjects experimental design. The dialysis facility quality measures available on Medicare Dialysis Facility Compare were used for this study. A narrative was created by the researcher. Participants were then provided one of the following stimuli:

1. Anecdotal videos (contradicting public report statistics) → Public report information

2. Public report information → Anecdotal videos (contradicting public report statistics)

For the purpose of this study, dialysis facility information was provided to the participants. Videos were created by the researcher, and dialysis facility quality measures available on Medicare Dialysis Facility Compare (Medicare.gov, 2013) were used. Figure 7.2 below presents the scenario given to the participants.

Imagine that you have had diabetes for a while, and you are now suffering from a chronic kidney disorder. You need kidney dialysis twice every week, and you must select a dialysis center to provide it. There are two dialysis centers nearby that you can choose from: Facility A and Facility B.

Best treatment practices are services that healthcare facilities provide to help patients avoid hospitalization and death. You will be provided information on the best treatment practices at both facilities in the form of a report and as a narrative from two patients (one for Facility A and one for Facility B) about their experiences with the facilities.

Figure 7.2. Scenario

Procedure

Participants were assigned to one of the two conditions randomly using a JavaScript code embedded on AMT. Participants were first asked to read an informational letter and to complete a pre-test demographic questionnaire. The participants then viewed one of the stimuli. For instance, if the participant was assigned to the second condition, he/she was presented a hypothetical scenario of the participant looking for a care provider (Figure 7.2), followed by public report information comparing the quality measures of the two dialysis facilities presented within a narrative with active engagement (see Appendix E), followed by two anecdotal videos, one video on Facility A and one on Facility B with one of the videos contradicting the public report information. Videos were presented in a random order. Table 7.1 shows the script used for the contradictory video.

This presentation was followed by a question asking the participants which facility they would choose for their care and their level of confidence in their choice, followed by a knowledge quiz evaluating how the participants interpreted the information

presented to them and the NASA-TLX survey measuring the workload experienced while making the choice. A CAPTCHA was utilized at the end of the study to ensure bots were not used to complete the tasks.

Table 7.1 Script for the contradictory video

At first, I was devastated when I was told that my kidneys weren't functioning adequately. My first time on dialysis did not help me feel any better. I had a difficult time watching my blood leave my body. However, after 10 months of dialysis treatments, I have become more comfortable with the process. I receive my treatments at Dialysis Facility A. At first, the other patients and staff at the facility seemed like strangers. Everything was new and unfamiliar, and I hated having to spend so much time there. But with patience and the support of my dialysis team, my sessions started to become a familiar routine. The staff at dialysis facility A made me very comfortable.

My doctor advised me to receive hemodialysis. He told me that in hemodialysis, an artificial kidney would be used to remove waste products, extra chemicals and fluids from my blood. My doctor inserted a catheter into my neck. I have been using the catheter for the past 2 years.

I spend a lot of time at the dialysis facility: three times each week, with each session lasting three or four hours. I have had several complications. A few times the nurses reported that I did not have enough urea removed from my body, and my doctor recently told me that I've experienced hemoglobin cycling, where my hemoglobin levels are low before I begin hemodialysis and high afterwards, putting me at increased risk for cardiovascular problems. I usually watch TV, catch up on work, or talk with other patients during dialysis. The staff at dialysis facility A is amazing. I would certainly recommend them to anyone who needs dialysis.

Analysis

SPSS 21.0 was used to analyze the data. The participant choice of facility was evaluated using a binomial logistic regression. A between-subjects Analysis of Variance (ANOVA) was conducted on the dependent variables of confidence, comprehension and total workload level.

RESULTS

The demographic characteristics of the participants in the study are presented in Table 7.2:

Table 7.2. Demographic characteristics (N=98)

Variable	N	%
Gender		
Male	49	50
Female	49	50
Race		
White	80	81.6
Other	18	18.4
Education		
High school degree or equivalent	16	16.3
Some college but no degree	22	22.4
Associate's degree	10	10.2
Bachelor's degree	42	42.9
Graduate degree	8	8.2

Participant choice. A binomial logistic regression was conducted using the choice of the facility as an outcome with one predictor: *Phase of introduction of anecdotal information.*

A test of the full model with the predictor against an intercept-only model was not statistically significant, $\chi2$ (1, N = 98) = 1.81, p = 0.18. To check whether our non-significant results were due to a lack of statistical power, we conducted power analyses using GPower 3.1 with an alpha = .05, incorporating the effect sizes found in the second study. The results found that the sample size of 98 provided a power of 0.79, suggesting a 21% chance of making a type II error. The results found that the sample size of 98 provides a power of 0.79. This suggests that there is a 21% chance of making a type II error. The results found that independent variable *phase of introduction of anecdotal information* was not a significant predictor of choosing the correct facility (Δ $\chi2$ = 1.80, p = 0.18), as shown in Table 7.3.

Table 7.3. Binomial logistic regression model

Variable	B	SE	$\Delta\chi^2_{removal}$	Odds ratio	95% CI for odds ratio	
					Lower	Upper
Constant	1.05	0.31				
Phase of introduction of anecdotal information			1.80			
Late	-0.58	0.44		0.56	0.24	1.31
Early [reference]	0					

-2LL (null) = 10.19; -2LL (model) = 1.807; R^2L=0.17

The percentage of people who chose Facility A and Facility B when anecdotal information was presented early and late as shown in Table 7.4.

Table 7.4. Percentage of people who chose the two facilities

	Anecdotal information presented before public reports	Anecdotal information presented after public reports
Facility A	74%	62%
Facility B	26%	38%

Level of confidence. There was no significant effect of the independent variable on the level of confidence in the choice of dialysis facility, $F(1,96) = 0.074$, $p = 0.79$.

Comprehension score. The comprehension score was calculated as the percentage of questions answered correctly. There was a main effect of the phase of introduction of anecdotal information on the comprehension score, $F(1,96) = 5.18$, $p = 0.025$. Post-hoc analysis determined that the comprehension score was higher when anecdotal information was presented after the public report information ($M = 54.67$, $SD = 16.22$) than when presented before the public report information ($M = 49.31$, $SD = 19.49$) ($p = 0.025$).

Workload. There was no main effect of the phase of introduction of anecdotal information on the workload experienced by the participants, $p > 0.05$. There were also no significant differences for the workload subscale indices. The average scores for these subscales across all the conditions are shown in Figure 7.3:
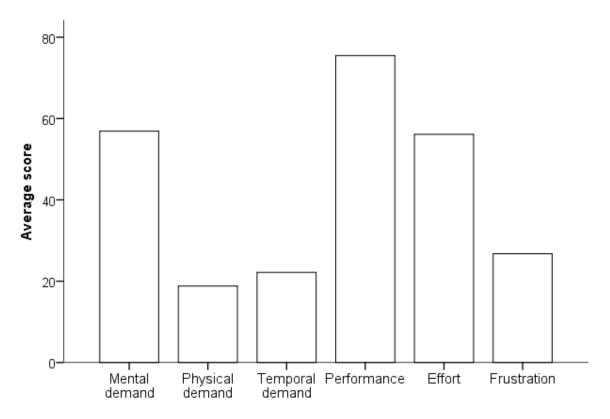
Figure 7.3. Average scores on the subscales of workload

DISCUSSION

The results support the hypothesis that the influential nature of inaccurate anecdotal videos may be attenuated to some degree by presenting public report information within a narrative with active engagement. The probabilities to choose the correct dialysis facility when contradictory anecdotal information was presented before and after were 0.74 and 0.61 respectively. However, this change was not significant. This finding could have been partly due to the presentation of information within a narrative that focused on the importance and meaning of the quality measures portrayed in the dialysis facility compare. Narratives provided an illustrative example of a person's experience with illness, including living with a chronic condition, going through the steps

of decision making to manage a condition, and experiencing the consequences of one's decisions. This could have created a better understanding of the healthcare condition. The results of the study reported in Chapter 5 suggested that the probability of choosing the correct facility was reduced by more than half, changing from 0.85 to 0.41, when contradicting, rather than supporting, anecdotal information was presented before the public reports. This finding may indicate the effectiveness of presenting information within narratives than in the standard public report format. However, this result should be deciphered with caution, since we are comparing the results from two different studies.

This study also found that comprehension was higher when anecdotal information was presented after the public report information. It appears that even with the introduction of a narrative within the presentation of public report data, participants are better able to discount incorrect anecdotal information when it is presented after they view objective healthcare information than when it is presented before.

The results are consistent with Klein's (2007) data-frame theory. Based on this theory when participants were provided with a scenario to choose a dialysis facility, the initial few key data elements may have served as anchors to develop an understanding of the situation. In this study, when participants were first presented an anecdotal video that was not consistent with the best practice element, they may have placed significant emphasis on this initial data element, using this frame to develop a mental model, leading to more incorrect responses to the comprehension questions.

The story used to present public report information in this study included both process and experience narratives. That is it included information suggesting how a

consumer made a healthcare decision, as well as information about what it was like to receive a specific treatment. Future studies could investigate the effect of each of these types of narratives on the quality of decisions.

CHAPTER EIGHT

CONCLUSION

One of the key challenges for public report designers is to communicate accurate information to the healthcare consumers by presenting it in a format that supports their informational needs. This dissertation first analyzed the discussions available in the forum of a major ovarian cancer support group, the Ovarian Cancer National Alliance (OCNA), to understand the type of information that newly diagnosed ovarian cancer patients and their supporters seek. The results suggested that there is a wide variety of information seekers with divergent goals. Treatment-related material was the most sought-after information by patients, while coping information was most sought by supporters. When forum posts were negative in tone, the information seekers were more likely to be looking for ovarian cancer-specific information than either treatment-related information or coping information. This suggests that the presentation of disease-specific information should be particularly sensitive to the negative emotional state of the people seeking this information.

Next, this dissertation investigated the effect of inaccurate anecdotal information on the healthcare sensemaking process. When the phase of introduction of anecdotal information changed from early to late, and when the anecdotal information contradicted the public reports, the probability of choosing the correct facility changed from 0.41 to 0.69. The results of this study also found that participants weighed inaccurate anecdotal information more heavily when it was presented before public reports. Specifically, the probability of choosing the better kidney dialysis facility was reduced by more than half,

decreasing from 0.85 to 0.41 when contradictory anecdotal information, rather than supporting information, was presented before public reports. In contrast, the probability of choosing the better kidney dialysis facility decreased from 0.75 to 0.69 when contradictory anecdotal information is presented after the public reports rather than supporting information.

A third study explored whether presenting public report information within narratives and with active engagement supported the sensemaking process. The results of this study indicated that presenting public report information within a narrative enhances comprehension, subsequently increasing the probability of making a correct decision. The probability of choosing the correct facility with no engagement increased from 0.71 to 0.88 when information was presented within a narrative rather than with the standard public report format. The probability of choosing the correct facility with active engagement increased from 0.67 to 0.9 when information was presented within a narrative rather than with the standard public report format. This study also found that the mental demand experienced by the participants was higher for the no engagement condition than for the active engagement condition.

A final study then evaluated whether the influential nature of early exposure to inaccurate anecdotal information identified in the second study might be attenuated by presenting public report information within a narrative with active engagement, a presentation technique that displayed positive outcomes in the third study. The results suggested that incorporating public report information within a narrative with active

engagement does attenuate the negative influence of early exposure to inaccurate anecdotal information on healthcare decisions.

A recent article by Shaller et al. (2013) identifies three key factors that influence consumer engagement with public reports. They are mechanisms focusing on the emotional state of the consumer, incorporating trusted sources for advice while understanding their health condition, and mechanisms to support interpretation of the quality measures. The results of this research suggest that the presentation of information within a narrative promotes consumer engagement with public reports. The emotional content in the narrative may engage consumer interest in the factual context, as well as attenuate the influence of inaccurate anecdotal information. Presenting information within a narrative also appears to support interpretation of the quality measures portrayed in a public report. Hence, based on the results of this research, it is recommended that narratives be used to present public report information to enhance consumer engagement with the data presented and to subsequently support an informed healthcare decision.

Limitations and future work

The studies depicted in this dissertation have limitations. In the first study, focusing on the informational needs of ovarian cancer patients, many discussions on the OCNA support community were marked as private and were not included in the study. Members also had the option to send each other private messages. Such information exchanges were also not included in this study.

To my knowledge, the second study investigating the effect of inaccurate anecdotal information on healthcare decision making is the first study to focus on

decisions made using the quality measures provided in the Centers for Medicare and Medicaid services' Dialysis Facility Compare. This was a preliminary exploration to understand the impact of anecdotal information on the decision making process and to understand how the complexity of the public report quality measures affects healthcare decision making. This study provided the participants with only two facilities to choose from. Future work should expand on the scope of this investigation to include multiple facilities with a wider array of relevant performance metrics such as cost and other non-healthcare provider attributes. The hospitalization and death measures shown in the public report currently consist of three categories: "Better than Expected", "As Expected" and "Worse than Expected." In this study, the two facilities presented both had the rating "As Expected". Future studies might investigate how healthcare consumers' choice of a dialysis facility is affected when such general qualitative descriptions are supplemented with numerical measures.

Narratives provide illustrative examples of a person's experience with illness, including living with a chronic condition, going through the steps of decision making to manage a condition, and experiencing the consequences of one's decisions. The narrative used to present public report information in this study was a combination of both process and experience narratives: it included information suggesting how a consumer made a healthcare decision, as well as what it was like to receive a specific treatment. Future studies should investigate the effect of each of these types of narratives on the quality of healthcare decisions. Given that narratives have the power to impact choice and comprehension, there exists a need to conduct further investigation to develop

comprehensive guidelines for the presentation of narratives that support the use of public

report information.

Appendix A

Parameter Estimates and Odds Ratios

Likelihood of information sought based on the role of information seeker, information seeking phase, emotional level, and stage of cancer

Variable	Treatment-related information vs. ovarian cancer-specific information [a]				Coping information vs. ovarian cancer-specific information [a]				Coping information vs. treatment-related information [a]			
	Contrast estimate	S.E.	Adjusted odds ratio	p	Contrast estimate	S.E.	Adjusted odds ratio	p	Contrast estimate	S.E.	Adjusted odds ratio	p
Intercept	0.33	0.49		0.496	-0.77	0.57		0.180	-1.11	0.55		0.043
Role of person looking for information												
Supporter	-0.83	0.45	0.44	0.065	0.53	0.45	1.69	0.243	1.35	0.41	3.87	0.001[+]
Patient [a]	0[a]				0[a]				0[a]			
Phase												
After treatment	0.39	0.62	1.47	0.535	0.99	0.66	2.70	0.133	0.61	0.67	1.84	0.367
During treatment	2.12	0.52	8.35	<.001[+]	2.16	0.56	8.65	<.001[+]	0.04	0.49	1.04	0.943
After diagnosis and waiting for treatment	1.10	0.47	3.01	0.018[+]	0.61	0.54	1.85	0.255	-0.49	0.55	0.62	0.375
Before diagnosis [a]	0[a]				0[a]				0[a]			
Emotional tone												
Negative	-1.19	0.39	0.31	0.002[+]	-0.97	0.43	0.38	0.023[*]	0.21	0.38	1.24	0.574
Neutral [a]	0[a]				0[a]				0[a]			
Stage of cancer												
Stage 4	1.52	1.16	4.58	0.190	1.77	1.18	5.87	0.133	0.25	0.68	1.28	0.713
Stage 3	-0.16	0.41	0.85	0.696	0.23	0.45	1.26	0.609	0.38	0.39	1.47	0.331
Stage 2	-0.90	0.60	0.41	0.134	-0.79	0.71	0.45	0.269	0.11	0.70	1.12	0.872
Stage 1[a]	0[a]				0[a]				0[a]			
Number of observations	206											

Note. [a] Reference group for each of the categorical variables   +Significantly different from the referenced categorical group

-2 Log-likelihood (null model) = 242.08; -2 Log-likelihood (final model) = 183.76

Appendix B

Public report statistics presented to the participant

Medicare.gov
The Official U.S. Government Site for Medicare

Dialysis Facility Compare

General Information

	FACILITY A	FACILITY B
Shifts starting after 5PM	No	No
In-Center Hemodialysis	Yes	Yes
Number of Hemodialysis Stations	10	11
Peritoneal Dialysis	Yes	Yes
Home Hemodialysis Training	No	No
Type of Ownership	Profit	Profit
Facility's Initial Date of Medicare Certification	12/16/2004	11/13/2004

Best Treatment Practices

Best Treatment Practices

Best treatment practices are services that dialysis facilities provide that can help patients avoid hospitalization and death.

Anemia Management

Anemia is common in people with kidney disease. Healthy kidneys produce a hormone called erythropoietin, or EPO, which stimulates the bone marrow to produce the proper number of red blood cells needed to carry oxygen to vital organs. Diseased kidneys, however, often don't make enough EPO. As a result, the bone marrow makes fewer red blood cells. Other common causes of anemia include blood loss from hemodialysis and low levels of iron and folic acid.

	FACILITY A	FACILITY B
Patient(s) who had an average hemoglobin value greater than 12.0 g/dL **Lower** percentages are better	4%	3%

Dialysis Adequacy

When kidneys fail, either hemodialysis or peritoneal dialysis is necessary to remove waste products from the blood. To learn whether dialysis is removing enough waste products, the dialysis clinic should periodically test a patient's blood to measure dialysis adequacy. The measures in this section feature the two methods that are generally used to assess dialysis adequacy: Urea Reduction Ratio (URR) and Kt/V.

	FACILITY A	FACILITY B
Hemodialysis patients who had enough wastes removed from their blood during dialysis: Urea Reduction Ratio greater than or equal to 65% **Higher** percentages are better	96%	95%
Adult hemodialysis patients who had enough wastes removed from their blood during dialysis: Kt/V greater than or equal to 1.2 **Higher** percentages are better	95%	93%
Adult peritoneal dialysis patients who had enough wastes removed from their blood: Kt/V greater than or equal to 1.7 **Higher** percentages are better	95%	94%
Children who had enough wastes removed from their blood during hemodialysis: Kt/V greater than or equal to 1.2 **Higher** percentages are better	71%	77%

Vascular Access

Before patients with kidney failure can start regular hemodialysis, a site on the body has to be prepared where blood can be removed and returned during dialysis (vascular access). To maximize the amount of blood cleansed during hemodialysis treatments, the vascular access should allow continuous high volumes of blood flow. The three basic kinds of vascular access for hemodialysis are a venous catheter, an arteriovenous (AV) graft, and an arteriovenous (AV) fistula. The measures in this section are meant to determine whether patients are treated using the most beneficial type of vascular access.

	FACILITY A	FACILITY B
Adult patients who received treatment through an arteriovenous fistula **Higher** percentages are better	55%	54%
Adult patients who had a catheter (tube) left in a vein longer than 90 days, for their regular hemodialysis treatments **Lower** percentages are better	3%	5%

Hospitalizations & Deaths

Hospitalizations & Deaths

Even with regular dialysis treatments, patients with kidney failure often get sick and must to go to the hospital because of infections or other problems that may be related to the dialysis treatment itself. Facilities whose patients have lower ratio of hospital admission or death may be better at helping their patients avoid these serious outcomes.

The Standardized Hospital Admissions Ratio, the Standardized Mortality Ratio, and ranges of uncertainty show you whether patients who were being treated regularly at a certain dialysis facility were admitted to the hospital or died more often, less often, or about the same as would be expected, compared to similar patients treated at other facilities.

	FACILITY A	FACILITY B
Rate of Hospital Admission	As Expected	As Expected
Patient Death Rate	As Expected	As Expected
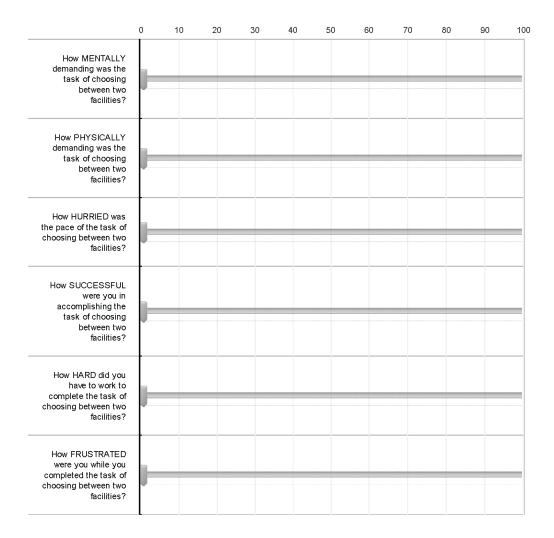
Are you a male or female?
_____

◯ Male

◯ Female

What year were you born?
_____

[▼]

What is the highest level of school you have completed or the highest degree you have received?
_____

◯ Less than a high school degree

◯ High school degree or equivalent (e.g., GED)

◯ Some college but no degree

◯ Associate's degree

◯ Bachelor's degree

◯ Graduate degree

Which of the following categories best describes your employment status?
_____

◯ Employed, working 1-39 hours per week

◯ Employed, working 40 or more hours per week

◯ Not employed, looking for work

◯ Not employed, not looking for work

◯ Retired

◯ Disabled, not able to work

Are you White, Black or African-American, American Indian or Alaskan Native, Asian, Native Hawaiian or other Pacific islander, or some other race?
_____

◯
White

◯ Black or African-American

◯ American Indian or Alaskan Native

◯ Asian

◯ Native Hawaiian or other Pacific Islander

◯ From multiple races

◯ Some other race (please specify)

[   ]

Have you ever read someone else's commentary or experience about health or medical issues online?

○ Yes

○ No

Have you ever consulted online rankings or reviews of doctors or other providers?

○ Yes

○ No

Have you ever consulted online rankings or reviews of hospitals or other medical facilities?

○ Yes

○ No

Have you ever posted a review online of a doctor?

○ Yes

○ No

Have you ever posted a review online of a hospital?

○ Yes

○ No

Which dialysis facility will you choose for your care process?

⊙ Facility A

⊙ Facility B

What is your confidence level in this decision?

1 (Not confident)	2	3	4	5	6	7 (Very confident)
⊙	⊙	⊙	⊙	⊙	⊙	⊙

	0	10	20	30	40	50	60	70	80	90	100

How MENTALLY demanding was the task of choosing between two facilities?

How PHYSICALLY demanding was the task of choosing between two facilities?

How HURRIED was the pace of the task of choosing between two facilities?

How SUCCESSFUL were you in accomplishing the task of choosing between two facilities?

How HARD did you have to work to complete the task of choosing between two facilities?

How FRUSTRATED were you while you completed the task of choosing between two facilities?

I felt comfortable using this Dialysis Facility Compare tool

_____

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

It was easy to learn to use this Dialysis Facility Compare tool

_____

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

I believe I became productive quickly using this Dialysis Facility Compare tool

_____

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

It was easy to find the information I needed to make the decision

_____

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

The information provided by the Dialysis Facility Compare tool was easy to understand

_____

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

The information provided by the Dialysis Facility Compare tool was effective in helping me complete the tasks

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

The organization of information on the Dialysis Facility Compare tool was clear

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

The interface of this Dialysis Facility Compare tool was pleasant

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

I liked using the interface of the Dialysis Facility Compare Tool

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

The Dialysis Facility Compare tool had all the functions and capabilities I expect it to have

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

Overall, I was satisfied with this Dialysis Facility Compare tool

○ Strongly Disagree

○ Disagree

○ Neither Agree nor Disagree

○ Agree

○ Strongly Agree

A URR value above 65% indicates enough blood was filtered properly in a hemodialysis patient.

○ Agree

○ Disagree

○ I am not sure

A Kt/V value below 1.2 indicates enough blood was filtered properly in a hemodialysis patient.

○ Agree

○ Disagree

○ I am not sure

A Kt/V value below 1.7 indicates enough blood was filtered properly in a peritoneal dialysis patient.

○ Agree

○ Disagree

○ I am not sure

I would prefer receiving care at a facility that has a higher number of patients using catheters.

○ Agree

○ Disagree

○ I am not sure

I would prefer receiving care at a facility that has a greater number of patients with hemoglobin levels above 12.0 g/dL.

○ Agree

○ Disagree

○ I am not sure

Dialysis adequacy is used to describe whether or not enough waste products have been removed from the blood.

○ Agree

○ Disagree

○ I am not sure

High hemoglobin levels are common among anemic patients.

○ Agree

○ Disagree

○

○ I am not sure

During dialysis, the arteriovenous fistula is the preferred form of vascular access.

○ Agree

○ Disagree

○ I am not sure

Dialysis adequacy is generally measured with the URR or the Kt/V.

○ Agree

○ Disagree

○ I am not sure

Martha Agnew
70 Years Old / Chronic Kidney Disease Patient

Dialysis Facility Compare

1 2 3 4 5 6

About Martha Agnew

"**Hello. I am Martha Agnew.** I was diagnosed with chronic kidney disease almost two years ago, so it came as no surprise when my kidneys failed this past year. My prior condition however, in no way helped me accept the fact that I would have to begin dialysis. When I began looking for dialysis care facilities near my home, I found two. Facility A and Facility B. The information I found provided me with a broad overview of each."

General Information

Criteria	Facility A	Facility B
Shifts Starting After 5PM	No	No
In-Center Hemodialysis	Yes	Yes
Number of Hemodialysis Stations	10	11
Peritoneal Dialysis	Yes	Yes
Home Hemodialysis Training	No	No
Type of Ownership	Profit	Profit
Facility's Initial Date of Medicare Certification	12/16/2004	11/13/2004

Creating an access point

"**My physician described the various forms of dialysis** available to me. My first option was peritoneal dialysis, which would use the lining of my abdomen to filter out various substances from my blood, flushing these wastes out through a tube in my stomach. He told me that for this process, the blood flowing through this permanent tube in my abdomen would be flushed out every night while I slept. It sounded tempting, especially since it was cost-effective and it allowed me to have my dialysis treatments at home, but I honestly didn't like the thought of having a tube sticking out of my abdomen, especially since it could easily become infected. In addition, I was told the training for peritoneal dialysis takes months to complete, and I would receive hemodialysis in the meantime. In that procedure, my blood would be drawn out and filtered by a dialysis machine, much like an artificial kidney, and sent back to my body. Because it requires a special machine, hemodialysis is only performed at dialysis facilities, and my husband and I both agreed this would be a better, safer option.

My doctor also said that once I identified a dialysis facility, I needed to make an appointment to prepare the access point for the removal and return of my blood. He went on to say that this access point should be able to support high volumes of blood flow, giving me three options - an arteriovenous fistula, venous catheter or an arteriovenous graft.

When the doctor first explained the procedure for the fistula and how the surgeon would directly connect one of the veins in my forearm to one of my arteries, I was quite worried. However, he reassured me that this procedure is very short, safe, performed on an outpatient basis with only local anesthetics, and worth undergoing since a fistula is very unlikely to clot or become infected and will last for many years. He also explained that this fistula would take some time to develop, so in the meantime I would use a venous catheter, a tube inserted into a vein in the neck, to allow blood to properly flow during dialysis. However, once my fistula formed, the catheter would be removed due to its higher risk of clogging and infection. In the event that the surgeon could not create a fistula, I would have a synthetic tube, called a graft, implanted to connect my vein and artery. My doctor informed me that an arteriovenous graft is better than a catheter, but more prone to clogging and infection than a fistula.

My procedure was successful, and while I was waiting for my fistula to develop, I began hemodialysis using my catheter. As I was also told that it is not advisable to use the catheter for an extensive period of time, I looked at the public report information on which facility, A or B, reported the higher number of patients being treated with a fistula. Which facility would you choose based on the following information? "

Vascular Access

Before patients with kidney failure can start hemodialysis, a site on the body has to be prepared where blood can be removed and returned during dialysis (vascular access). To maximize the amount of blood cleansed during hemodialysis treatments, the vascular access should allow continuous high volumes of blood flow. The three basic types of vascular access for hemodialysis are a venous catheter, an arteriovenous (AV) graft, and an arteriovenous (AV) fistula. The measures in this section are meant to determine whether patients are treated using the most beneficial type of vascular access.

Criteria	Facility A	Facility B
Adult patients who received treatment through an AV fistula **Higher** percentages are better.	55%	54%
Adult patients who had a catheter tube left in a vein longer than 90 days for their regular hemodialysis treatments **Lower** percentages are better.	3%	5%

1 2 **3** 4 5 6

Waste Removal From the Blood

"**My doctor warned me beforehand** that most patients experience some initial symptoms, and I would have to get used to low blood pressure and headaches. Many of my fellow patients told me not to worry because they experienced similar symptoms at first, but they went away over time. My doctor also told me the two primary methods of measuring dialysis adequacy were the Urea Reduction Ratio (URR) and Kt/V. Basically, if someone receives hemodialysis three times a week, as I do, the minimum acceptable URR is 65%, which indicates the patient received the proper dose of dialysis, and the proper amount of waste was removed. The minimum Kt/V value is 1.2 for both adults and children. If a patient has a Kt/V below 1.2 or an URR below 65% he or she risks having excess waste in his or her blood. I never fully understood all the parameters associated with the two measurements, but I know I'll be fine as long as I don't fall below those two minimum values."

Dialysis Adequacy

When kidneys fail, either Hemodialysis or Peritoneal Dialysis is necessary to remove waste products from the blood. To learn whether dialysis is removing enough waste products, the dialysis clinic should periodically test a patient's blood to measure dialysis adequacy. The measures in this section feature the two methods that are generally used to assess dialysis adequacy: Urea Reduction Ratio (URR) and Kt/V.

Criteria	Facility A	Facility B
Hemodialysis patients who had enough wastes removed from their blood during dialysis: Urea Reduction Ratio greater than or equal to 65% *Higher* percentages are better.	96%	95%
Adult Hemodialysis patients who had enough wastes removed from their blood during dialysis: Kt/V greater than or equal to 1.2 *Higher* percentages are better.	95%	93%
Children who had enough waste removed from their blood during hemodialysis: Kt/V greater than or equal to 1.2 *Higher* percentages are better.	71%	77%
Adult Peritoneal Dialysis patients who had enough wastes removed from their blood: Kt/V greater than or equal to 1.7 *Higher* percentages are better.	95%	94%

1 2 3 **4** 5 6

Side effects management

"**My doctor** also told me that I may feel tired after hemodialysis. This fatigue, he told me, is common among dialysis patients. If my hemoglobin drops too low, I could be given transfusions or medication to help my body produce hemoglobin; however, it's preferred that the hemoglobin levels in dialysis patients remain below 12.0 g/dl to keep the risk of complications during dialysis low. Based on this information, I want the facility with the fewer number of patients with hemoglobin levels above 12.0g/dL. If you were me, which facility below would you choose?"

Anemia Management

Anemia is common in people with kidney disease. Healthy kidneys produce a hormone called erythropeoitin, or EPO, which stimulates the bone marrow to produce the proper number of red blood cells needed to carry oxygen to vital organs. Diseased kidneys, however, often don't make enough EPO. As a result the bone marrow makes fewer red blood cells. Other common causes of anemia include blood loss from hemodialysis and low levels of iron and folic acid.

Criteria	Facility A	Facility B
Patients who had an average hemoglobin value greater than 12.0 g/dL *Lower* percentages are better.	4%	3%

1 2 3 4 **5** 6

Hospitalization and Deaths

"**I go to the dialysis center three times a week** and stay for about three or four hours at a time. Initially, I had a hard time getting used to the process. I would usually just watch television until I fell asleep and then would take naps after my dialysis as well because of the headache and fatigue.

A year has passed since I first started dialysis. I've been using my fistula and have not experienced any complications. I'm very familiar with the process and everything it entails. I've become good friends with my nurses, doctors, and a few other patients at the dialysis center who are part of my support group. At first, I didn't pay attention to the facility's hospitalization and death rates, which were rated as expected and, thus, equivalent to the national average, but after being treated for so long and having been hospitalized only once, I truly appreciate the effort my care team puts in towards my wellbeing."

Hospitalizations and Deaths

Even with regular dialysis treatments, patients with kidney failure often get sick and must go to the hospital because of infections or other problems that may be related to the dialysis treatment itself. Facilities whose patients have lower ratio of hospital admission or death may be better at helping their patients avoid these serious outcomes.
The Standardized Hospital Admissions Ratio, the Standardized Mortality Ratio, and ranges of uncertainty show you whether patients who were being treated regularly at a certain dialysis facility were admitted to the hospital or died more often, less often, or about the same as would be expected, compared to similar patients treated at other facilities.

Criteria	Facility A	Facility B
Rate of Hospital Admission	As Expected	As Expected
Patient Death Rate	As Expected	As Expected

Appendix F
Feedback

Martha Agnew
70 Years Old / Chronic Kidney Disease Patient
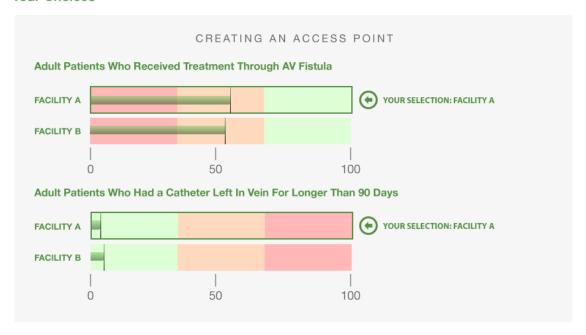
Dialysis Facility Compare

1 2 3 4 5 **6**

Summary

"**I now bring my laptop with me** so I don't fall behind on my work while receiving dialysis, and handle the fatigue and headaches associated with dialysis quite well. Though it was very challenging at first, thanks to the support from my care team and loved ones, I was able to assimilate dialysis treatment into my time and now lead a full life."

Your Choices

CREATING AN ACCESS POINT

Adult Patients Who Received Treatment Through AV Fistula

FACILITY A ────────────── ← YOUR SELECTION: FACILITY A

FACILITY B ──────────────

0   50   100

Adult Patients Who Had a Catheter Left In Vein For Longer Than 90 Days

FACILITY A ────────────── ← YOUR SELECTION: FACILITY A

FACILITY B ──────────────

0   50   100

WASTE REMOVAL FROM THE BLOOD

Hemodialysis Dialysis Patients Who Had Enough Wastes Removed From Blood
Urea Reduction Ratio >= 65%

FACILITY A   YOUR SELECTION: FACILITY A

FACILITY B

0   50   100

Adult Hemodialysis Dialysis Patients Who Had Enough Wastes Removed From Blood
Kt/V >= 1.2

FACILITY A   YOUR SELECTION: FACILITY A

FACILITY B

0   50   100

Children who had enough wastes removed from blood during Hemodialysis
Kt/V >= 1.2

FACILITY A   YOUR SELECTION: FACILITY A

FACILITY B

0   50   100

Adult Peritoneal Dialysis Patients Who Had Enough Wastes Removed From Blood
Kt/V >= 1.7

FACILITY A   YOUR SELECTION: FACILITY A

FACILITY B

0   50   100

SIDE EFFECTS MANAGEMENT

Anemia Management
Patients with average hemoglobin value > 12.0 G/dL

FACILITY A   YOUR SELECTION: FACILITY A

FACILITY B

0   50   100

HOSPITALIZATION & DEATH

Patients Who Were Admitted to the Hospital

FACILITY A | Less Than Expected | **As Expected** | More Than Expected | ← YOUR SELECTION: FACILITY A
▲

FACILITY B Less Than Expected | **As Expected** | More Than Expected
▲

Deceased Patients

FACILITY A | Less Than Expected | **As Expected** | More Than Expected | ← YOUR SELECTION: FACILITY A
▲

FACILITY B Less Than Expected | **As Expected** | More Than Expected
▲

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