MEDICAL DECISION MAKING: THE USAGE OF MEDICAL REGISTRIES

AND THE INFLUENCE OF EDUCATIONAL BACKGROUND

By

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DEDICATION

To my precious children, Tino and Trevi, who are the joys of my life

And to my husband, Tom, for his endless support and love.

To my parents, Les and Joan Burch, for always believing in me

To my mother- in- law, Ida, for her encouragement

And to my late father- in- law, Dr. Redento "Tino" Ferranti, whose wisdom and

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TABLE OF CONTENTS

LIST OF TABLES

List of Figures

LIST OF APPENDICES

CHAPTER I

DISSERTATION OVERVIEW

1.1   Introduction & Research Question

Medical decision making is a complex cognitive process involving multiple

stakeholders and factors. This research will focus on two factors that may potentially

affect the quality of this process: 1) the timeliness and amount of the information

available and 2) the decision making rules of the decision makers. The increased amount

of information, pace at which information is obtained, and the experience of the decision-

maker, both provider and patient, can affect the process of medical decision making. The

purpose of my research is to investigate the above two independent factors through: 1)

the usage of medical registries and 2) evaluating the decision making choices of the

decision makers based on their educational discipline background, particularly with

respect to the numeracy skills.

Medical decision making options have increased over the years where in the early

1900's, physicians typically practiced their "art" based on their years of experience

(Simon 1976), without the current means of communication, their choice of treatment

options usually relied on past experience of such treatment successes. However, as

technology and communication has progressed the number of influences on a provider's

decision making has increased, with providers initially sending surface post "snail mail"

to their colleagues followed by telephone calls and conference interactions, and now with

technology, providers can email their colleagues, consult medical libraries, and even

access medical registries of current clinical trials and treatment options, frequently

receiving instantaneous responses.

While the previous situations all identify the role of the provider as the primary

decision maker, more recently, shared decision making between patients and their health

care providers and the inclusion of patient preferences in their care have been, in theory,

embraced as models for good clinical practice (Rutland and Bakken 2001). However, the

move towards increasing patient involvement has not been driven simply by a theoretical

concern of respect for patient autonomy (Ford, Schofield et al. 2003). Rather it is the

recognition that individuals differ in what they value, how they make their decisions, and

in their propensity to take risks (Hope 1996; Clemen and Reilly 2001) hence,

standardized solutions are not always acceptable to patients in the new era of

personalized medicine (Rosen, Anell et al. 2001). There is empirical evidence that

providing patients information and involving them in decisions about their health care

can result in beneficial psychological and physical outcomes (Ford, Schofield et al.

2003).

However, engaging the patient in the active decision process evokes additional

concerns that must be acknowledged. These concerns, which include the potential for

inaccurate information or an abundance of information obtained by the patient requiring

interpretation, has necessitated an even greater level of understanding for both the

provider and patient.

Although the availability of additional information has increased, this does not

necessarily mean that the utilization of the additional information has increased or that

this additional information is actually helpful in the decision making process. It is for

these reasons, that my research will first address how a medical registry may impact

medical decision making, through the use of a survey, whether those stakeholders who

participate in registries make decisions differently than those who chose not to participate

in a registry. In addition, another survey evaluates the second independent factor of how

the decision maker's educational background may affect their decision choices. The last

chapter addresses mathematical skills of the decision maker as the translation of

numeracy is an important aspect of decision making as well as one of the primary ways

that information is collected and distributed in a medical registry.

Formally, the research questions posed for my dissertation are (Fig 1-1):

1. Is Medical Decision Making influenced by the Use of a Medical
   Registry?

2. Is Medical Decision Making different depending on the Educational
   Background of the Decision Maker?

1.2   Theoretical Model

1.2.1   Registry Overview

The theoretical model for this research is gleamed from both the technology

acceptance model and sociology model literature. Each of the independent factors of the

model is addressed separately. First for the impact of registry use in medical decision

making, this research relies on three registry characteristics constructs as primary factors

in determining registry usage, while acknowledging that the more frequently studied user

constructs as well as other registry constructs may be applicable. The three construct

chosen are based on the literature streams of technology performance (Davis 1989), registry data quality (Du, Freeman et al. 2000), and technology design (Davis 1989), and their relationship to technology (registry) usage and subsequent potential affect on medical decision making.

Simply the presence of a medical registry alone is not adequate for usage; other elements must be present within the registry and the practice of those using the registry. While much of the literature defines performance in financial terms (Ghayayini and Noble 1996), or productivity (Chow and Heaver 1994), my research applies Lippert and Forman's (2005) (2005) performance of the technology definition, differing only in that my research defines performance in the context of the registry and not only the perceived performance by its users.. The registry and its users should have congruent performance assumptions and uses for the registry (Davis 1989; Millenson 1999; Schmittdiel, Bodenheimer et al. 2005). Specific items addressed in this construct include: Does the registry meet the needs of its users or achieve what it is intended to accomplish (Rogers 1995; Lippert and Foreman 2005)? Does the registry provide feedback to its users, or does the registry maintain or provide access to a list of accepted guidelines (Schmittdiel, Bodenheimer et al. 2005).

The second major construct is data quality, which is a concern found in much of both the registry and information systems literature (Davis 1989; Davis and Taylor-Vaisey 1997; Du, Freeman et al. 2000; Marriott, Palmer et al. 2000; Institute of Medicine 2001; Margo 2004; Domino and Huskamp 2005). Registry data must maintain data accuracy for the majority of the cases and this accuracy should be verified by either chart reviews or comparisons (Fine, Keogh et al. 2003). For this research, specific items or

questions will include data accuracy (Aronsky, Haug et al. 2005), timeliness of the data and its evaluation with comparable sources (Arom, Petersen et al. 1997; Dahl, Rudjord et al. 2006).

Third, the registry design must meet its intended user's needs. For this research, the registry design addresses primarily technology attributes of the registry. This construct addresses ease of use technology (Millenson 1999; Department of Health & Human Services 2001; Department of Health & Human Services 2003; Elmasri and Huskamp 2005). Items addressed with this construct include: is the registry web-based? Does the registry permit its users to interact with peers? Does the registry have standard nomenclature or is it compatible with current IT systems already in place (Arts, De Keizer et al. 2002; Dahl, Rudjord et al. 2006)? (See Table 1: Items and Constructs).

1.2.2   Registry Usage

There are two literature streams to investigate the usage of a medical registry. The first is looking at technology acceptance literature such as Davis (1989) with a primary focus on the technology aspects and the characteristics of the technology users. The second addresses why there is a gap between expected registry usage and physicians using registry data in their clinical decision making. (Figure 1-2)

Davis (1989) first introduced the Technology Acceptance Model (TAM), which was later expanded to include social influence processes (TAM2)(Venkatesh and Davis 2000). The main TAM components thought to drive usage behavior are Perceived Usefulness and Perceived Ease of Use. Both of these components are directed towards the user's viewpoint of the technology. For this research, these are evaluated via survey responses from registry users and non-users.

Although most of the TAM2 are socially driven, some of the constructs in the TAM2 model are applicable as they relate to the registry's purpose. One key finding of Venkatesh and Davis (2000) is that when developing information systems, and organizing the social structure and environment, social influences appear more influential over time than mandatory participation, prompting one to at least consider a registry design with a more open access. However, this finding is contrary to the initial data from my pilot interviews with Health Data Researchers, whose registry participation has increased since the mandatory reporting participation required in California (HDR maintains and evaluates California's health registries). For this research, medical registry adoption rates are important only as they affect usage and its affect on medical decision making. Marriott (2000) cites others in factors that affect dissemination of information and adoption rates, including the environment (Triplett 1898) the information flow (Lazarsfeld, Berelson et al. 1948) and the role of peers and the media, the intended audience such as general group or specialty, and the influence of existing attitudes and practices.

Having reviewed registry use, the next step is to assess its potential impact on decision making, "It has been shown conclusively that the differences in practice patterns cannot be explained by undetected case mix, inadequacies of data analysis, confounding factors or technical errors of study design" {Margo, 2004 #17. While previous research has identified technology use and user characteristics, little research is found examining the application of these theories with medical registry usage, and no research was evident studying the connection between registry usage and medical decision making.

1.2.3 Technology Adoption and Acceptance

As this research questions whether medical registries, when purposeful driven, pose an impact on registry usage and subsequent medical decisions, it also brings to light other potential barriers when evaluating if a group or institution will adapt new practices or innovations, particularly if they challenge the current state of practice and information dissemination.

The Schmittdiel et al. (Schmittdiel, Bodenheimer et al. 2005) survey found that 47% of the physician organizations with 20 or more physicians reported having at least one chronic illness registry, most often a diabetes registry. Interestingly, of those with at least one registry, 51% of the practices did not link their registry to clinical data, thus rendering it as primarily a retrospective registry. Schmittdiel et al (2005) also found similar externalities as Bower and Hillestad (2005)that affects adoption rates. These include incentives such as performance recognition, peer utilization, uses.

This research acknowledges the previous work of institutional theorists, which hypothesizes multiple reasons why an institution does or does not accept certain practices or beliefs; and technology acceptance models, which hypothesize various adoption obstacles as well as the importance of the technology interface usability. My research investigates the nuances of the technology users, and the differences that exist between the users and non-users in their decision making practices.

Technology theories such as Davis Technology Acceptance Model (TAM) illustrate the importance of ease of use and useful. Addressing these two aspects are essential for future technology acceptance, especially disease based registries, which do not have a transparent financial incentive for their acceptance.

Technology adoption in the healthcare industry has been a slow and arduous

process. According to Geoffrey Moore's technology adoption life cycle classification

schema, the healthcare industry is defined as a laggard adopter or late majority at best

(Moore 2000). Technological advances in other industries have surpassed what is an

emerging technology in today's healthcare industry (Institute of Medicine 2000; Institute

of Medicine 2001). Even further, behind other medical technology advances, such as

radiology (84% per Dorenfest (2000)), are the adoption rate of bedside database systems

and electronic medical records. Although electronic medical records have been slow to

diffuse, Bower's Diffusion and Value of Healthcare Information Technology report

concludes that, thus far, it is following a similar path of other innovations as predicted by

Rogers with accelerating adoption rates rising more sharply between the 15-20% rate

(Bower and Hillestad 2005). Building upon this slow adoption, this research will also

explore what barriers prevent non-users from using a registry or prevent registry users

from incorporating the registry information into their clinical practice, if in fact they do

not use the information.

1.2.4 Educational Background Theoretical Component

The second factor evaluated in this research is the influence of educational

discipline in medical decision making, i.e., does the decision maker's area of study

prompt them to arrive at different decisions from other professional groups? General

decision making theory as well as medical decision making and shared decision making

are the main theoretical lens used for the foundation of the influence of educational

background.

Decision making research put forth that the quality of a decision is a product of many factors including personal values and judgments of uncertainty (Clemen and Reilly 2001). Part of my research will address this through investigation of the impact of educational background of the decision maker. It is known that the decision making process is greatly affected by the information available and interpreted in the decision analysis. The first two steps include 1) "identify the decision situation and to understand the objectives" and 2) identify alternatives (Clemen and Reilly 2001).

In recent years shared decision making between patients and their health care providers and the inclusion of patient preferences in their care have been, in theory, embraced as models for good clinical practice (Rutland and Bakken 2001). However, the move towards increasing patient involvement has not been driven simply by a theoretical concern of respect for patient autonomy (Ford, Schofield et al. 2003). Rather it is the recognition that individuals differ both in what they value and in their propensity for risk and also that standardized solutions are not always acceptable to patients with divergent needs and preferences (Rosen, Anell et al. 2001). There is empirical evidence showing that giving patients information and involving them in decisions about their health care can result in beneficial psychological and physical outcomes (Ford, Schofield et al. 2003). However, their comfort level of understanding the information and risk involved may influence their decision (Ancker and Kaufman 2007).

Based on decision making theory, acknowledging patients' experiences, values, and preferences as important pieces of evidence for appropriate medical decision making (Rutland and Bakken 2001) , health services researchers have begun developing decision aids to help people understand complex medical information (Ubel 2002). Decision aids

enable patients to consider their own values or preferences for particular treatments or outcomes, rather than only providing information of the options and outcomes relevant to their state of health (Dowding and Thompson 2003). To help people understand their treatment alternatives, decision aids usually include not only general information about particular diseases but also quantitative information about risk for the disease, benefits of various treatment options, as well as testimonials from patients who have already received the available treatments.

Despite the advantage of information availability, there is a concern that decision aids may lead to bad choices. More specifically, a large body of psychology research has shown that people make systematic errors when asked to make certain kinds of decisions (Ubel 2002), for example, those dealing with mathematical concepts. Such innumeracy issues are addressed as most recommendations for medical decisions are structured on the assumption that patients understand quantitative information (Schwartz, Fisher et al. 1997). One of the central principles of decision analysis is that uncertainty of any kind can be represented and comprehended through the appropriate use of probability (Clemen and Reilly 2001). Thus, for patients who face hard medical decisions, the ability to interpret probability statements in terms of the uncertainty that they represent is crucial.

It has been found that decisions are difficult to assess based solely on numerical data provided by the subjects, which required a degree of computation (Slovic, Fischhoff et al. 1977; Kahneman and Tversky 1982). The indifference factor was integrated into the framing of the study based on previous acknowledgements that indifference judgments were difficult to evaluate quantitatively (Larichev 1992). This research not only draws upon the research streams listed above, but also utility theory, prospect theory and risk

uncertainty theories. The previous research lens illustrates that although medical registry usage and educational backgrounds have been explored before, research investigating their combined use in medical decision making is lacking. This research will attempt to fill this gap and evaluate both factors as they influence the medical decision making process.

1.3   Research Propositions

1.3.1 Medical Registries: A Systematic Review of the Literature

Building upon my previous research, the first chapter of this research will address the primary purposes of medical registries as found through a systematic review of the literature.

The design of a registry may affect how it is used in medical decision making. The registry must be accepted by its targeted community (Institute of Medicine 2000; Haynes, Devereaux et al. 2002; Hersh 2004). Regularly, physicians state that out-dated treatment information or delayed access to emerging treatments and knowledge [through inefficient dissemination methods], limit their treatment options and play a role in their decision making in providing medical care for their patients (Berwick 2003; Baker, Salas et al. 2005). My previous research yielded two main types of registries: passive retrospective and active real-time registries. A passive retrospective registry provides the decision maker with large quantities of past data, which are frequently used for research studies, but not in current decision making practices as much of these data are at least two years old (Ferranti and Dilts 2003). However, active registries provide real time data access, with at least annual updates of the aggregate populations.

Therefore, this design may be available in current patient decision making

treatment options. The design of the registry must also take into account the users

intended purpose (Bastardi and Shafir 1998; Berwick 2003; Brailer 2004).

If the medical registry is designed to provide more timely information access for

its users, then does the registry user make use of the information attained in their decision

making process? Previous research indicates that if a registry permits ongoing

information and opportunities to evaluate treatment options, its use could be life altering

(Lewis, Robinson et al. 2003; Kantor Family Foundation 2004). This chapter evaluates

whether registry users engage in different practice patterns than those who choose not to

participate in a registry. It has been shown that differences in practice patterns cannot be

explained by undetected case mix, inadequacies of data analysis, or technical errors of

study design (Margo 2004). As wide decision making practices continue to flourish, does

the use of a registry increase the usage of evidence based medicine and potentially lessen

the differences in decision making? (Table 1-1) Previous research has shown that

physicians receiving timely feedback and peer comparisons with practice variations

adhere to guidelines (such as possible with an active registry) had lower mortality rates

and better outcomes.

Proposition 1: The design of medical registry will affect how a medical registry is used in medical decision making

1.3.2 Impact of Registry Use in Medical Decision Making: The Case of the Society of Thoracic Surgeons

Medical registries are a collection of patient medical information from multiple healthcare providers, potentially from multiple sites, used for tracking prevalence of conditions, evaluating outcomes from various treatment options, or assisting in selection of treatment options. However, such information is of little effectiveness if it is not used by its intended user community or for its intended purpose. To achieve these outcomes, theory dictates that a registry should achieve at least three primary constructs. First, a registry must be accepted by its targeted medical community (Institute of Medicine 2001; Haynes, Devereaux et al. 2002; Hersh 2004). Second, a registry must have the requisite quality required by the user community (Institute of Medicine 2001; Haynes, Devereaux et al. 2002; Berwick 2003; Hersh 2004; Schmittdiel, Bodenheimer et al. 2005). Finally, a registry must be designed with the intention to achieve the above specified outcomes (Bastardi and Shafir 1998; Berwick 2003; Brailer 2004). These constructs are evaluated in both propositions one registry characteristics and proposition two registry user characteristics in Chapter 3.

Survey methodology was employed to assess the decision making behaviors of medical registry users and non-users. The survey was developed based on previous technology surveys, such as The Harris Interactive survey, expert interviews, and the literature results. The survey was piloted in a university setting and administered at the Society of Thoracic Surgeons annual conference. The survey was also placed online for another professional organization of physicians.

The impact of a medical registry in decision making has not fully been realized as studies indicate that 51% of registries do not provide linkages to clinical data

(Schmittdiel, Bodenheimer et al. 2005); and even fewer are active registries (Ferranti and

Dilts 2005). However, as this research will show the use of a medical registry may assist

in the timeliness and quality of data received necessary to make an informed decision.

Little research is available reviewing the characteristics of medical registry users, most of

the research available addresses the use of all health information technologies or the

implementation of electronic medical records (Berwick 2003; Bower and Hillestad 2005).

As proposition one focuses on the left circle of the dyad, registry characteristics,

proposition two, addresses the registry user characteristics (Figure 1.2)

Proposition 2: Medical decision making practices are different between
registry users and non-users.

1.3.3 Medical Decision Making: Impact of Educational Background

Medical decision making has changed over the years, and the factors influencing

decision making may vary depending on the decision maker's educational background.

For example, up until twenty-five years ago, most of the major medical decisions in

United States were exclusively in the hands of the physicians, with little participation of

the patient (Quill and Brody 1996). More recently, shared decision making between

patients and their health care providers and the inclusion of patient preferences in patient

care have been, in theory, embraced as models for good clinical practice (Rutland and

Bakken 2001).

Recent studies indicate that how a medical student learns his or her "craft" in

medical school and residency greatly affects their future practice patterns and decision

14

making (Cox, Smith et al. 2005). Another study, reviewing physician practice patterns, indicates that clinical training as well as experience are significant factors in what it describes as Stage 1 of influence, i.e., the most basic heuristic level in determining physician practice clinical decision making (O'Neill and Kuder 2005).

Jimison (1998) noted that patients had four major reasons for wanting information, 1) treatment compliance, 2) to veto physician's decision 3) enhancement of their own decision making, and 4) respect for their wishes ; three of these reasons may be directly applicable to medical treatment options (Lidz, Meisel et al. 1983) and to the ultimate treatment decision. This list highlights the necessity that both providers and the patient understand the information communicated and presented. Several factors have been identified as impactful on medical decision making by patients, including education level, gender, and severity of health status. (Damberg, Hiatt et al. 2003). Interestingly, little research was discovered concerning the impact on medical decision making of the training, or the educational background, of the provider or patient. Recognizing that the specialty of ones education may affect their eventual treatment choice, this research evaluates whether educational background changes the decision makers treatment choice. This question is addressed in Chapter 4 using two surveys [A, B] of medical scenarios that were developed grounded in previous decision making research studies (Redelmeier, Shafir et al. 2001), testing four specific constructs: 1) Information Pursuit- the influence of additional information, 2) Information source, 3) Experience, and 4) the availability of an alternative option. These surveys were randomly distributed with the participants unaware that separate surveys were distributed. The three educational background groups were not aware of other group participants.

1.3.4 Medical Decision Making: Impact of Innumeracy

Most medical decision recommendations are structured on the assumption that

patients understand quantitative information (Schwartz, Fisher et al. 1997). Ubel

(2002)cites a 1997 Schwartz et al. study of the public's ability to understand probabilities

in medical scenarios -- where only one third of the respondents answered three

quantitative questions correctly -- as an obstacle in patient participation in medical

decision making, particularly when decision alternatives are presented as probabilities or

likelihoods (Clemen and Reilly 2001). Merely presenting patients with numerical data

does not guarantee that they understand the information provided or can correctly

interpret the values, numbers, probabilities, or outcome likelihoods provided (Skinner,

Kreuter et al. 1998; Ubel 2002; Gurmankin, Baron et al. 2004). As noted in Bramwell et

al. (2006) , even those providing the statistics may not accurately interpret the results;

they found an average 86% of incorrect responses provided by obstetricians, midwifes,

pregnant women, and companions accompanying the pregnant women.

Part of the problem may lie with healthcare providers in disseminating such

numeracy information because, as Chao et al. (2003) suggest, risk and benefit

quantitative information can be confusing even for medically knowledgeable participants.

Yet, this has not hindered the pharmaceutical industry or the national media in inundating

the public with "health statistics" such as: 1 in 10 people develop a certain disease; that

the "western diet" i.e., fried foods, salty snacks and meat, accounts for approximately

30% of heart attack risk worldwide. (AmericanHeart 2008); or that individuals should buy a home defibrillator since "less than 1 in 20 people survive largely because a defibrillator was not available" (Philips 2005). It is for these reasons, this research will evaluate the mathematical skills of three distinct highly educated groups with different educational specialties.

> Proposition 4: The Educational Background will affect the numeracy proficiency in medical decisions.

1.3.5 Medical Registry Usage and Educational Background

While each factor was independently assessed for its impact on medical decision making, it is believed that both factors affect the process. Additionally as shown in my research, the use of a medical registry will necessitate that the user understand basic mathematical and statistical interpretations.

Historically, most major physician-patient healthcare decisions were made by physicians, with limited patient participation (Quill and Brody 1996). However, with direct-to-consumer advertising for pharmaceuticals (Toop and Mangin 2007; Evans and McCormack 2008) increase in privacy and safety issues(Rothstein and Talbott 2006; Department of Health & Human Services 2008), and dramatic rise in availability of patient-obtained medical information (Xie, Dilts et al. 2006), the current trend in medical decision making is to inform and involve patients intimately in their medical treatment plan. This is considered a top priority in the medical community to promote shared decision making (Lipkus, Samsa et al. 2001).

It is well documented that the quality of a decision builds upon improving our decision making process; and during this process, information is critical in the first two decision making steps 1) "identify the decision situation and understand the objective and 2) identify alternatives" (Clemen and Reilly 2001), while registries may assist in identifying similar situations and circumstances, the second step provides the greatest opportunity for registries to assist in decision making by providing both additive as well as singular alternative treatments for potential improved outcomes.

Even though many physician's claim that lack of information (Domino and Huskamp 2005), affects their decision making; it may also be a "Google" problem, in which case, the problem is not lack of information, but too much information that is not in a "usable useful" form (O'Neill and Kuder 2005; Holland-Barkis, Forjuoh et al. 2006). Therefore, it is not only the information found in a registry, but also the type of information presented that impact the eventual decision.

Unfortunately, even the best medical registry will not suffice if providers and patients do not understand how to correctly interpret the medical data provided. Thus, those supplying information for medical decision making require an understanding of the ways in which provider's and patient's background may impact such understanding. This research will illustrate that both the use of a medical registry and the educational background of the decision maker may influence the final medical decision treatment choice.

1.4   Organization of the Dissertation

The following chapters address the above propositions in five chapters that are formatted based on their targeted peer-reviewed journal. The findings related to proposition one are found in chapter 2, "Medical Registries: A Systematic Review of the Literature". As chapter 2 identified characteristics and uses of a medical registry, chapter three evaluates the second dyad, registry user characteristics, these findings of proposition two are found in chapter 3 "Impact of Registry Use in Medical Decision Making: The Case of The Society of Thoracic Surgeons" see also (Figure 1-2: Registry characteristics/Registry user characteristics.). Registry purposes were first identified in previous research and subsequently validated in chapter 3. The effect of medical registries and its user's characteristics in decision making are evaluated in the first two propositions. Propositions three and four evaluated the influence of educational discipline background on medical decision making. The findings of proposition three are found in chapter 4 "Medical Decision Making: Impact of Educational Background". Research findings related to proposition four are detailed in chapter 5 "Medical Decision Making: Impact of Innumeracy". Finally, a summary of findings and future research is found in the last chapter.

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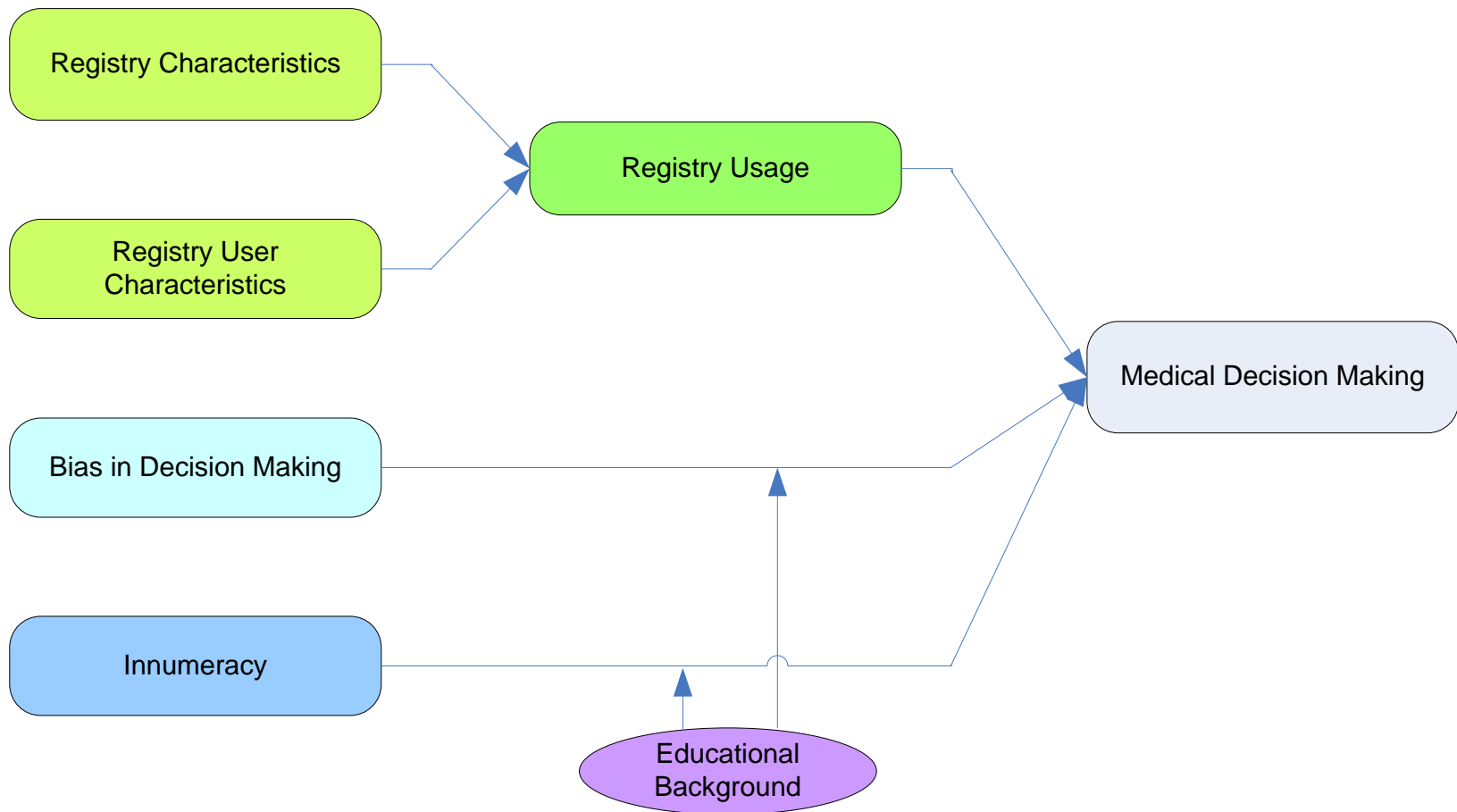
Figure 1-1: Research Model

Registry Characteristics verses User Characteristics
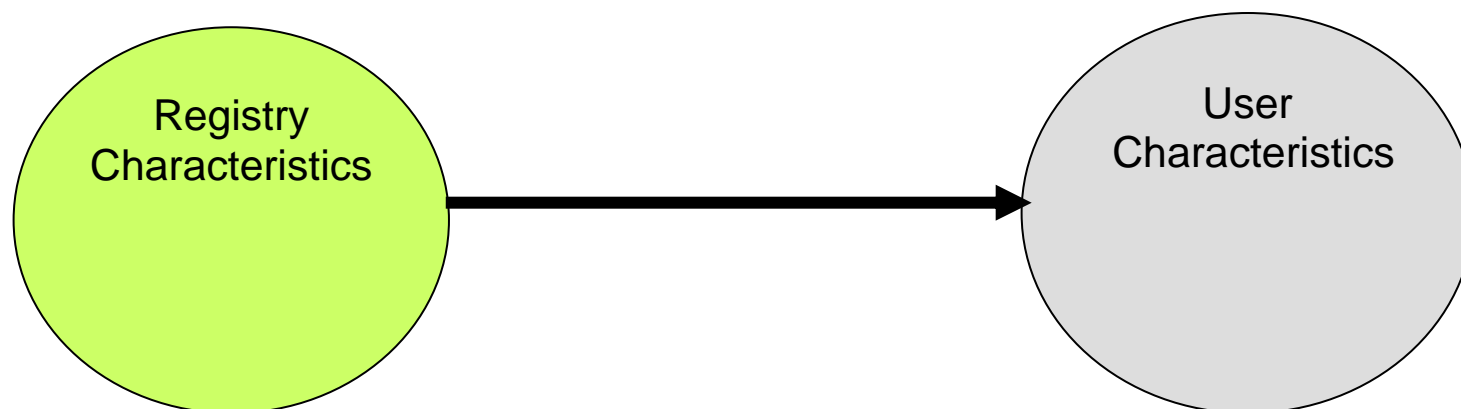
Potential characteristics of the registries that are used
•Berwick's (2003) Application of Roger's Diffusion of Innovation
•Brailer, D. J. (2004). "Perspective: Translating Ideals For Health Information Technology Into Practice." Health Affairs:
•Bower, A. (2005). The Diffusion and Value of Healthcare Information Technology. Santa Monica, RAND.
•Anderson, J. G. and S. J. Jay (1985). "Computers and clinical judgment: the role of physician networks." Soc Sci Med **20**(10): 969-79.

Most research explores the Registry users characteristics
• Davis (1989)Technology Acceptance Model theory
•Rogers (2003)Diffusion Of Innovation theory.
•Millenson, M. (1999). Saving Lives, Bit by Byte. Demanding Medical Excellence: Doctors and Accountability in the Information Age. M. Millenson. Chicago, The University of Chicago Press**:** 74-93.

FIGURE 1-2 MEDICAL REGISTRY USAGE

TABLE 1-1

Cause of Gap	Potential Causes a Medical Registry may address
1.1. Lack of Information access (Domino and Huskamp 2005) (Holland-Barkis, Forjuoh et al.) Marriott, Palmer et al. 2000), (Berwick, 2005)	Yes, A medical registry provides a means to gather the data and evaluate it in a timely fashion as well as provides an avenue for members to access their own data and comparisons.
1.2. Know-Doing Gap waiting on others first (Holland-Barkis, Forjuoh et al.; O'Neill and Kuder 2005) (Coleman, Katz et al. 1966; Davis and Taylor-Vaisey 1997	May impact

if MR permits physician earlier access to increasing number of physicians using new knowledge |
| 1.3.   No Incentive (Financial) (Schmittdiel, Bodenheimer et al. 2005) (Horne, Saarlas et al. 2000; Rask, LeBaron et al. 2001). | MR will not directly address incentives

(only if future research shows that using MR reduces practices expenses or permit more efficient work time) |
| 1.4.   Patient-Population Unique (Pearson, Ganz et al. 2002) (Meadows 2001) | Yes

MR provide opportunity to gather specific populations in central database and create a larger "sample size" |
| 1.5.   Practice Inertia (Always practiced a specific way) (Schoemaker 2000) (Mangione-Smith, Elliott et al. 2004) | No

MR will not address reluctance to change behaviors |

Medical Registry Example: From the users view

The example below illustrates how the acceptance of technology and the social cultural factors and educational teachings have positively influenced the way that pediatric oncologists practice medicine.

The Children's Oncology Group's Acute Lymphoblastic Leukemia Model

An example of how a medical registry has been incorporated into medical decision making and accepted into general practice is the Children's Oncology Group (COG) Acute Lymphoblastic Leukemia (*ALL*) registry. The *ALL* registry is widely recognized by those in the childhood cancer arena as a very powerful registry contributing to a decrease in childhood *ALL* mortality rates (Miles 1999; Simone and Lyons 2001; Miles, Dilts et al. 2002; Berwick 2003).

Thirty years ago childhood leukemia was almost always a fatal disease, today it remains the most common cause of cancer among children less than 15 years old, with 2400 children diagnosed per year in the United States (National Cancer Institute 2005). While the incidence of *ALL* has gradually increased the past 25 years, the once fatal diagnosis, now maintains a 95 % remission rate, with 75-85% remaining in remission for at least five years (National Cancer Institute 2005).

The system of care that has led to these outstanding results has several unique attributes, one of which is its medical registry. "Beginning in the 1960's, a standard developed that virtually all *ALL* children (>90%) were enrolled in clinical trials"(Miles, Dilts et al. 2002). This has not occurred to the same degree in any other area of medicine, including in other types of cancer where <4% of patients participate in clinical trials(Simone and Lyons 1998; Miles, Dilts et al. 2002; National Cancer Institute 2005). For the past twenty- five years, virtually every child in America with *ALL* has been entered into a national database, where outcomes have been tracked.

Practicing pediatricians and pediatric oncologists caring for children with *ALL* willingly gave up their autonomy to make individual treatment decisions in favor of a collaborative practice around the current best scientific evidence in the organized clinical trial"(Miles, Dilts et al. 2002). Addressing attached Table of factors affecting registry use: Cause of GAP 1.1 Lack of Information access and 1.4 Patient-Population uniqueness, the *ALL* registry permitted this collaborative group of pediatric physicians, who rarely see multiple *ALL* patients at any given time, a place to pool their patient's data in order to evaluate current and future patient treatments and options more effectively. Over the period from the 1970's to the mid-1990's during which there were no new therapeutic agents introduced, the cure rate for *ALL* still improved by 30% (from 40% to 70%) (Simone and Lyons 2001; Miles, Dilts et al. 2002). What is different about this group of practicing physicians is the willingness to participate in the *ALL* model(Miles 1999) while many of other groups continue to experience wide practice variation and poor adoption of evidence based medicine (Cabana, Rand et al. 1999).

A recent study reviewing physician practice patterns indicate that clinical training as well as experience are significant factors in what it describes as Stage 1 of influence. Stage 1 is the most basic heuristic level in determining physician practice clinical decision making (O'Neill and Kuder 2005). This characteristic addresses another factor in how a medical registry may affect the *GAP* of new knowledge to use, factor 1.2 know-doing gap. This factor is based on the premise that as the number of practicing physicians using the information or MR, then those "pragmatist" or conservatives waiting for others to adopt the practice first, will slowly begin to adopt the practice of using the MR. This is evident in the participation rates of oncologists participating in the *ALL* registry.

Pediatric residents are taught that the standard of care practice is that their leukemia patients will be entered into the registry, thus when they enter their own practice, they continue to learn the process learned in medical school and residency(Coleman, Katz et al. 1966; Robbins 1981). One pediatric study (Cox, Smith et al. 2005) indicates that when a physician is exposed to certain literature and learns a practice in medical school, it transcends into their future practice patterns. This practice is different from other specialties where the registry does not play a major role in the delivery of care.

This is but one example of a group utilizing its registry and data to positively affect their patients treatments, other noted groups including a registry in its practice, are The National Kidney Foundation for End Stage Renal Disease (National Kidney Foundation Registry 2009), The American Society of Thoracic Surgeons (Society of Thoracic Surgeons 2008), and the Vermont Oxford Network(Vermont Oxford Network 2009).

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MEDICAL REGISTRIES:
A SYSTEMATIC REVIEW OF THE LITERATURE

2.1 Preface and Research Model

Little research has studied the impact of medical registries in medical decision making and no research has investigated the potential use of active medical registries in medical decision making, hence there is a need to investigate these questions. Research in this chapter extends my previous research investigating the purposes of medical registries and type of registry design: passive or active. This research identified data quality as the most frequent cited reason for registry purpose and passive registries were noted as the most prevalent design of registries, although active registries were linked most frequently to outcomes. From this research and from expert interviews, key registry issues including performance, design, and data quality were identified as three constructs requiring further evaluation with respect to their influence on usage of a registry.
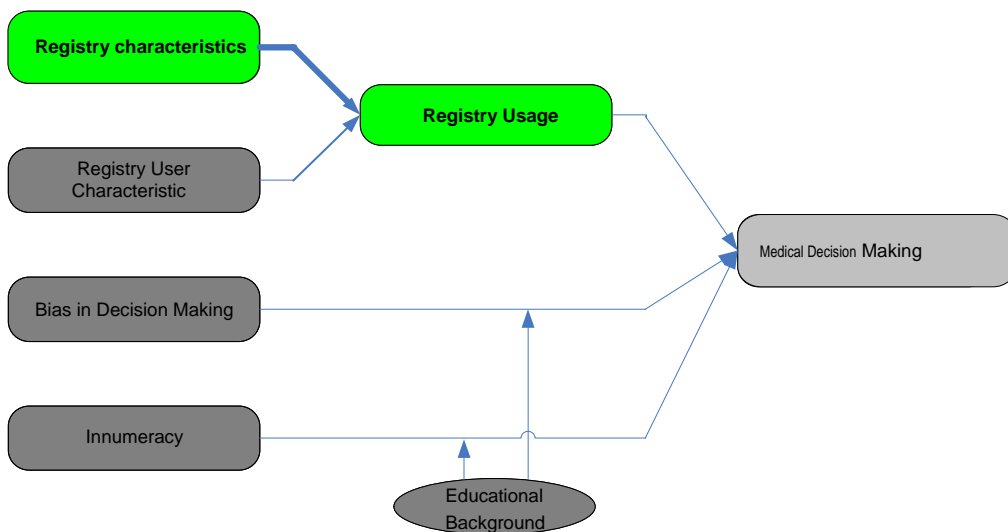
2.2   Introduction

Medical registries are collections of patient medical information from multiple healthcare providers, potentially from multiple sites, used for tracking prevalence of conditions, evaluating outcomes from various treatment options, or assisting in selection of treatment options (Kibbe 1999; Institute of Medicine 2000; Miles 2000; Institute of Medicine 2001). The precise medical registry definition is dependent on the actual operations and purpose of the established registries. While others, such as Chaudhry et al. (2006) have studied the impact of health information technology on quality, efficiency and costs of health care, specific reviews on medical registry importance are sparse.

2.3   What is a Medical Registry?

In general, medical registries permit identification and ongoing surveillance of larger sample populations of rare diseases or diagnosis, and identification of high- risk populations. Medical registries are not a new phenomena, Dr. John Spratt, a surgeon initiated "The Tumor Registry" in 1966 as a way to help quality control effects in the diagnosis and treatment of cancer (Spratt 1966). The precise medical registry definition is dependent on the operations and purpose of the established registry (Kibbe 1999; Institute of Medicine 2000; Miles 2000; Institute of Medicine 2001; Rice 2003). Registries can be *geographic* such as state or national cancer registries, *disease or diagnosis specific* such as Children's Oncology Group's Acute Lymphocytic Leukemia (ALL) registry, as well as *demographic*. Medical registries have the greatest initial potential in rare disease or diagnosis, where providers do not see the repetitive symptoms or diagnosis sufficiently often to gain experience for quick diagnosis and treatment as they provide an excellent

resource for data compilation and evaluation. In addition, medical registries, in particular "active" registries, have the ability to provide timely access to medical information that may affect the quality of the physician's decision when investigating available treatment options.

Postulating that the way that a registry is built may affect the dissemination level, we divided medical registries into three groups. The group definitions were derived from various national healthcare and government groups as well as pioneers in the healthcare field's registry definitions. The resulting three categories are: 1) Retrospective population based, data evaluated after the fact, if ever, such as the National Cancer Registry, or geographic based registries (Department of Health & Human Services 2002; Department of Health & Human Services 2002), 2) population research based, data gathered for another reason and/or clinical trials, such as the Manitoba registry or hospital administrative databases (Manitoba 2002), and 3) prospective observational study registry, also known as real time science-based medicine, or "active" registry, ongoing evaluation of patient outcomes as collection continues, such as the Vermont Oxford Group, or End Stage Renal Disease registry (National Kidney Foundation Registry 2009; Vermont Oxford Network 2009). The retrospective population based and the population research based are both passive registries; with passive registries differing from active (prospective) registries in that the data evaluation occurs at a much later date (Ferranti and Dilts 2003). A more detailed look at these categories follows.

2.3.1 Passive Registries

Pure data collection registries, a type of retrospective population or research-based registry, are excellent for and commonly used for data mining; data mining uses discovery based approaches to explore the important complex relationships in large datasets (Boxon 1996). However, these registries are purely passive in nature. That is, while passive registries are superb for completing advanced research and for impacting future patient treatment, they do not affect current patients with the condition.

2.3.1.1 Retrospective- Population Based

The retrospective population based registries include the epidemiological registries, which consist of mostly of Centers for Disease Control type data collections. This includes immunization registries (Center For Disease Control 2001), and state cancer registries. Immunization registries "are confidential, population- based, computerized information systems that attempt to collect vaccination data about children within a geographic area"(Center For Disease Control 2001). In previous research, this group represented the largest group of registries at 60.4% (n=224) (Ferranti and Dilts 2003). These registries do not impact patient care until the data are analyzed. The need for changes in recommended practice is not immediately or timely observable. However, these registries provide valuable information on disease incidence and prevalence rates, as many of their participation (in government backed registries) is mandatory, not voluntary.

2.3.1.2   Population- Research Based

As our previous research indicates, many of these current registries evolved from the process of analyzing the data differently than its intended collection purpose, often from varied sources and then forming the relationships. An example of this is the demographic and diagnosis patient information gathered for financial billing purposes that are later analyzed for diagnoses frequency and patient length of stay relationships. This category provides a single resource to search for either diagnosis research clinical trials, such as CenterWatch®, or population registries, such as the Manitoba Research Registry, which was developed to facilitate longitudinal studies; populations registries generated for administrative purposes combined into a research registry" (Manitoba 2002).

Previous research indicates that of the 371 medical registry references uncovered, these comprised 32.3% (n=120) of the registries (Ferranti and Dilts 2003). The distinction between this category and the other passive registries is registry purpose and how its data are queried. For example, if a hospital registry system developed for administrative purposes is queried for diagnosis data mining, it is a population-research based registry because it is utilized as a research population, although it is not its intended purpose.

Another example is evident in the analysis of the French health's ministry's national registry involving medical device incidents indicates how a population database can provide useful information through a retrospective analysis (Beydon, Conreux et al. 2001). Although not "real time" as evidenced in real-time database systems, the

information gained through a legacy population system can impact future care and decisions although the timeliness is not as efficient as with prospective (active) registries.

The first two types of registries, retrospective- population based and population-research based, are both passive as data collection and data evaluation are completed at significantly different times (Ferranti and Dilts 2003). Prospective- observational based, also known as Real- Time Science- Based Registries are "active" registries that permit an ongoing timely evaluation of the data permitting ongoing treatment evaluation and regimen changes.

2.3.2   Active "Real-Time Science- Based" *(Prospective)*

This "current impact" as evident in the pediatric oncology model's extraordinary clinical trials enrollment rate, greater than 90%, as well as its publication of ongoing progress reports to participating physicians (Bleyer, Tejeda et al. 1997; Miles, Dilts et al. 2002), is the realm of active registries. This enrollment rate is far greater than the 2% enrollment rate for adults and the 21% rate for adolescents between 15-19 years old (Bleyer, Tejeda et al. 1997). For the purpose of this research, "science –based medicine" is defined as the application of research investigations and the conversion of theory into practice (Robbins 1981). And "on-going practice" is the continuous interchange of information from bench to bedside to population, a real time feedback loop of current practices and research.

Our previous research defined the limits of active registries as those registries, which will have ongoing data evaluation, within one year and continuous data entry of

those patients entering treatment, undergoing treatment, or considering their treatment options.

Specifically, two parameters must be met to be including in the active registries category: 1) data must collected within one year, if not, the default is a passive registry, and 2) the data collected must be evaluated and reported within one year of collection. Collection was defined as entry into the registry system, not the collection on the patient medical record. The collection time from the record to the registry must occur within one year, although most are required to enter the information at least quarterly. Evaluation was defined by timing of reports, i.e., quarterly reports from the registry administrators; published articles using registry information collected within the past year or stated evaluation within the past year. For the purpose of this research, if the registry did not meet both the collection and evaluation time limits, the registry defaulted to the passive group.

The pediatric oncology specialty model, a specific real-time-science-based registry, intertwines clinical and research medicine, via an active registry utilization coupled with a recognition by the researcher, the clinician, and the patient that each is interested in and available for research and practice in the elimination of cancer (Miles 1999; Rustgi 1999). This model originated in part due to its populations need for improved survival rates. Because of the high morbidity and mortality rates of the pediatric oncology population, the practicing physicians and families are often open to cooperation and information sharing with other physicians and specialists (Simone and Lyons 1998). This data compilation permits the evaluation of practices as well as the impact of the various treatments tracked on the registry database. The initial

characteristics of the pediatric oncology model that promote the model's success include physician and patient compliance, "high-risk decision making", and the patient population (Simone and Lyons 1998). " It is instructive to learn that the cure rate for childhood acute lymphoblastic leukemia rose from about 40% in the early –1970's to about 70% in the mid-1990's without a single new frontline agent" (Simone and Lyons 2001). A major component of the model, which is expected to have broad applicability, is its technology infrastructure, permitting an "active registry". Found in real-time-science-based registries such as New England Cardiovascular Group, Vermont Oxford Network, and Pediatric Oncology Group, such an infrastructure permits manipulating the database as well as providing the structural data definitions (Elmasri and Huskamp 2005), which are necessary for timely data evaluations. These are key advantages to utilizing medical registries in the Institute of Medicine's quality improvement initiatives.

The active real-time science-based registries, which comprise chronic disease registries such as diabetes management, and continuous quality improvement registries, such as The Pediatric Oncology Group, capture active clinical decision making and encourage continuous ongoing involvement. This group comprised a mere 7.3% (n=27) of the registries in the literature review study in 2003 (Ferranti and Dilts 2003) and an even smaller percentage of total registries in a later study with 2.4% (n=26) of the registries meeting the active registry criteria (Ferranti and Dilts 2005). Continuous Quality Improvement registries, also active, capture relevant data, as well as focus on outcomes and their relationships; thus, permitting active relevant decision making for enrolled patients' currently undergoing treatment or nearing treatment time.

As our previous research has shown that the literature references medical registries for many reasons, such as a resource for a patient population for a specific disease type study, a study of disease prevalence and incidence, ways to track new conditions, data quality or quality of care (Ferranti and Dilts 2003). The purpose of this study is to systematically review the medical literature for the content and usage of medical registries. In doing so, I will also attempt to show any linkage of the literature of registries and outcomes.

2.4   Methodology

2.4.1   Search Strategy and Article Selection

An electronic PubMed Medline ® search was conducted. Utilizing previous literature search methodology presented at Academy Health, we performed initial separate searches for each of the years from 2004 -2007; these searches were limited to MESH® Major topic "registry", human subjects, and English (Appendix A). A content analysis from a second review strategy identified and rejected all results that did not have accessible abstracts and those which were not directly related to medical conditions. Those included such non-medical definitions as DNA registries, environmental registries, and employment registries. The remaining results were then reviewed to ensure that they met the inclusion criteria for the "medical" category. Only those remaining articles meeting the "medical" criteria were included in the subsequent queries.

2.4.2 Data Extraction

The detailed methodology was developed and tested by the primary author. Four

reviewers (in addition to the primary author) independently conducted a pilot test for

inter-rater reliability where it was found to be .9 kappa. In addition, data extraction and

results were verified randomly across all variables. Discrepancies were resolved or

omitted from the data synthesis. Final data synthesis and compilation were performed by

the first and second authors (Figure 2-1).

2.5 Data Synthesis

Of the 2046 articles identified, only 1482 met the inclusion criteria for medical

related and were included in further article analysis. These articles were then evaluated

for three primary constructs: 1) Outcomes related 2) Specific Registry type and 3)

Registry Purpose; each construct was evaluated independently with those articles missing

data rejected.

2.5.1 Construct 1: Outcomes Related

Outcome assessment is a common method within the healthcare quality

improvement arena for measuring the quality of care provided and identifying areas

needing improvement. AHRQ defines outcomes research importance as "*Outcomes

research seeks to understand the end results of particular healthcare practices and

interventions"* For clinicians and patients, outcomes research provides evidence about

benefits, risks, and treatment results so they can make informed decisions. For healthcare

managers and purchasers, outcomes research can identify potentially effective strategies they can implement to improve the quality of care.

Interestingly, while both medical registries and medical outcomes are referenced frequently in medical literature, previous research show that the two are rarely referred to together only 16.7% of 2002 literature (Ferranti and Dilts 2003) and 28.7% of the reviewed articles in the 1998-2002 literature review study (Ferranti and Dilts 2005).

Articles referring to outcomes are frequently found in the medical literature often with the emphasis to improve these outcomes. One example is the RAND sponsored Damberg study designed to evaluate the best way to start an outcomes database that will assist patients in their decision making treatment choices. This study identifies the disease state and condition to initially capture as well as potential obstacles the developers may encounter (Damberg, Hiatt et al. 2003). Some registries are being developed as a method to capture information for the purpose of measuring specific outcomes (White 1999; Hayashi 2008). In addition, other registries are set as a means to attempt to capture physician practice variation (Gray, Yadav et al. 2007). Registry usage is a major component of identifying potential avenues a registry can assist in translational medicine.

An indirect correlation was applied to ascertain the number of articles that address registries and outcomes. First, each article's keyword section was searched for *any* of the following terms: outcomes, outcome, outcome assessment, outcomes assessment, if these terms were not in the keywords section then the articles abstract was reviewed for outcomes, outcome, outcome assessment, outcomes assessment, or outcome implications. One of these conditions must be met in order to meet outcomes related inclusion criteria.

Of the 1482 articles reviewed, only 25.6% (n=379) showed a relationship between outcomes and registry. These results are similar to previous research where 28% (n=313) identified cross references between registry and outcomes (Ferranti and Dilts 2005). While many studies have been funded to evaluate outcomes, there remains a gap in the literature addressing ways a registry may positively impact outcomes such as improving data capturing and timeliness of data evaluation.

2.5.2   Construct 2: Specific Registry Types

In addition to evaluating each medical related article for outcomes criteria, they were also independently assessed for specific registry type: active or passive. An active registry is defined as a registry that permits ongoing collection and evaluation of data. For our definition, Active registries are evaluated within one year. This evaluation can occur with publication of results within the following year of data collection, or organization or government reports of quarterly or annual reports. Perhaps the broadest and most well known group of active registries is the clinical trials databases. Clinical Trials Databases permit physicians to access the database to ascertain the specific types of trials ongoing for a particular diagnosis or condition. Clinical Trials data are one of the most entered, tracked, and analyzed data collected in the medical field (Haug, Gotzsche et al. 2005; Zarin, Tse et al. 2005; Fisher 2006) and as such, its registry meets the criteria for an active registry (Miles 2000; Department of Health & Human Services 2002; Ferranti and Dilts 2003).

Passive registries also known as retrospective registries include administrative or public health databases, and hospital administrative databases. A specific type of passive

registry includes generalized retrospective population based registries (GRPB), which include the Centers for Disease Control (CDC) registries and The National Cancer Registries. Of the 1482 articles reviewed, 161 met active registry criteria, 717 passive criteria, and in 604 of the articles, the type of registry could not be positively identified. Of the passive registries, 78% (562) were GRPB registries. When excluding those articles where the type of registry could not be determined, the remaining 48.7% of the registries were comprised of 18.3% active registries and 81.7% passive registries. Pearson, Ganz et al. (2002) discuss the limitations of retrospective (passive) registries in quality of care analysis. Schmittdiel finding indicates that organizations with registries are apt to provide more feedback as well as have other Information Technologies, such as patient reminder systems. This feedback is an important aspect in a physician's performance as multiple studies have shown that feedback improves practice (Myers, Turner et al. 2004; Schmittdiel, Bodenheimer et al. 2005; Sender Liberman, Liberman et al. 2005). Table 2-1 illustrates several examples of both active and passive registries.

2.5.2.1 Specific Types across the Years

Of the 878 registries classified, passive registries were at least 75.2% (n=185, 2004) of the registries classified (p=0.015). The number of total registries classified for each year remained close to one –fourth of the total with a high of 28% in 2004 and low of 23.1% in 2007.

Active registries was the highest percentage of all registries with 24.8% of the total (n=61) registries in 2004 as well as the highest percentage of all active registries classified at 37.9% in 2004, and the least with 13.7% (n=28) in 2006. Passive registries

remain the primary design of registries throughout the years studied supporting previous research findings.

The outcomes related and specific registry type relationship were cross-tabbed and illustrated that 37.3% (n=60) of the active registries were outcomes related, and merely 20.6% (n=713) of the passive registries were outcome driven (p < 0.001).

2.5.3   Construct 3: Registry Purpose

Previous research indicated that a large portion of the articles included single reference to the registry or registries as a primary data source from disease study, this research parsed the article's reference to a registry according to its purpose in the article; the articles were divided into two categories: 1) Data Source and 2) Disease or Diagnosis Focus. Seven articles were excluded, as the reviewers were not able to clearly classify their intent into one of the two above categories. Recognizing that the high percentage of data source references may influence the remaining article registry results, we decided to evaluate those articles separately. This separation permitted a more accurate picture of the current literature landscape of registry purposes.

Data Source references included a default of *all* those references to the Surveillance, Epidemiology and End Results (SEER) database, which collects cancer incidence and survival data for 26% of the United States population (National Cancer Institute 2005). In addition, any article referencing more than one registry as its data source was classified as a data source article; whereas, disease focus driven often has limited populations or develops its own registry to obtain an appropriate population.

Data Source references were 25.2% (n=373) with SEER references accounting for more than a third of the data source references (36.7%, n= 137). All registries mentioned were recorded for future indications and cross-references (Table 2-2).

If the article did not qualify as a simple data source, then the article was assessed whether it focused on a particular diagnosis or disease. One search strategy employed article title and abstract review. Data Source references often mentioned more than one registry as their data source in the articles abstract, for example the multiple times that the SEER database was mentioned as a data source for breast cancer studies. Disease focus driven articles often mentioned the sole registry in its title and abstract. In addition, these articles are often disease or diagnosis specific. Disease focus driven articles comprised 74.1% (n=1102) of the 1482 articles evaluated. These 1102 articles were later reviewed again and placed in one of seven categories for a secondary purpose of the article and registry reference. These will be discussed in the following section. These specific criteria questions and sample articles are noted in Table 2-3.

2.5.3.1 Specific Article Purpose

Only those articles meeting the disease focus or diagnosis specific group from construct 3: Registry Purpose (n=1090) were further evaluated and placed into a category based on the primary purpose of the article. Previous research yielded the seven most common topics of articles referencing registries and each of the qualifying articles was assigned a category (Ferranti and Dilts 2003). Each category has specific inclusion and exclusion criteria (Appendix B). In determining the article's motivation, reviewers were asked to answer questions such as "What is the author's primary purpose for writing the

article? Does the author make assumptions about the registries data quality? Each of the seven categories contains keywords and questions to assist in correct assignment.

Of the 1090 articles evaluated, 668 of the articles main points include registry quality and completeness, keywords examples leading this category include comparison, validate, and data quality. The second largest category was Registry Uses with 227 references. This category assumes that the quality of data is acceptable and focuses on the potential impact of the registry such as linkage of two registries and reporting findings. This group often includes those articles where the author is proposing using the registry for something other than the registry's primary purpose.

The articles were also classified as geographical (n=18) if they mentioned a specific region or area. Only 10 of the 1090 articles primary intention were in the financial cost category. The remaining groups include how to build a registry (n=85), technical focus (n=34), and other (n=48). Due to the uniqueness of the registry reference, some articles were classified as other. This other group includes privacy concerns, consumer factors, and registry use frequency.

2.5.3.2 Specific Registry Type and Use of Registry

Registry Quality was the primary category when evaluating article purpose and registry type, it comprised 62.3% (n=86) of the articles referencing active registries, this was also the case with passive registries at 67.7% (n=350). In both the active and passive registries, quality was followed by use of registry (16.7%, 22.6%) and how to build a registry (13.8% and 22.6%). Interestingly, cost financial interest was not identified in the

articles referencing active registries (n=0) and only a total of 10 times (less than 1%) in the passive registry and unknown references.

2.6   Discussion

Do medical registries serve a single purpose or are they more generalizable to aid in more global health-related efforts? (Table 2-4). In general, medical registries permit identification and ongoing surveillance of larger sample populations of rare diseases or diagnosis, and identification of high- risk populations. This research indicates that most continue to utilize a registry as a way to access a specific population whether by diagnosis, disease, or demographic domain.

This research has illustrated, most of the current research utilizes retrospective registries, which are passive and do not reach the full potential of registries. While passive registries are excellent for completing advanced research and for impacting future patient treatment, they do not affect current patients with the condition.

However, medical registries have the greatest initial potential in rare disease or diagnosis, where providers do not see the repetitive symptoms or diagnosis sufficiently often to gain experience for quick diagnosis and treatment. This potential is most likely to occur with active registries. Prospective- observational based, also known as Real Time Science Based are "active" registries that permit an ongoing timely evaluation of the data permitting ongoing treatment evaluation and regimen changes.

Active registries provide an excellent learning opportunity for both the researcher and the practitioner. For example, pediatric residents are taught that the standard of care practice is that their leukemia patients will be entered into the registry, thus when they

enter their own practice, they continue to learn the process learned in medical school and residency (Coleman, Katz et al. 1966; Robbins 1981). One pediatric study indicates that when a physician is exposed to certain literature and learns a practice in medical school, it transcends into their future practice patterns (Cox, Smith et al. 2005). This practice is different from other specialties where the registry often does not play a major role in the delivery of care.

Real-Time Science Based registries, which comprise chronic disease registries such as diabetes management, and continuous quality improvement registries, such as The Pediatric Oncology Group, capture active clinical decision making and encourage continuous ongoing involvement. Continuous Quality Improvement registries capture relevant data, as well as focus on outcomes and their relationships. The End Stage Renal Disease Model and the New England Cardiovascular Group Model also fall into this category.

Utilizing active registries to assess or track patient outcomes is an area that is yet to be fully realized. Outcomes research, as defined by AHRQ is "*Outcomes research seeks to understand the end results of particular healthcare practices and interventions.*" This research has shown that the ties between outcomes and registries have yet to fully penetrate the scholar literature with less than 26% of the literature mentioning both items.

Another important finding of this literature review is that the quality of data within the registry is not circuitous. This research supports the auspice that data quality is an important aspect of medical registries with similar findings in Chaudhry et al. (2006), whose research indicates that a major effect of health technology is on quality of care and guideline adherence with process improvements in the range of 12 to 20 %.

While many articles reference the cost of technology as an impediment to adoption, our research did not reflect any cost or financial articles whose primary purpose was registry quality utilizing an active registry (p=0.003). So, while it is a known fact that active registries can be resource intensive, this is a tradeoff that may be accepted by those concentrating on maintaining real time registries and improving registry quality and data use.

The limitations of this research include that only one search engine was utilized and did not include other synonyms for a registry. The literature search has revealed many opportunities for researchers to delve further into the usage of registries and the desire of many to monitor data quality. With registries providing much of our research sample populations, not only is it imperative that the data within the registry remains superb, but also that we now explore the options of disseminating that data more efficiently and timely. Future research should include assessing the impact of registries on practice patterns and decision making as well as performing the same methodology utilizing other search engines.

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TABLE 2-1: Selected Active and Passive Registries

Active
Children's Oncology Group: Acute Lymphoblastic Leukemia Registry
Health Data Research Registries
Vermont Oxford Network
Clinical Trials databases
EUROCAT (European Congenital abnormalities 29% of European birth population) 43 registries
Passive
SEER
National Cancer Registry
State vital statistics registries
Most of the Center For Disease Control Registries
Hospital Discharge Registries

TABLE 2-2: Some of the Registry Categories References

Surveillance, Epidemiology, and End Results (SEER)
Cancer Registries (California Cancer Registry, National Breast Cancer Registry)
Immunization Registries
Numerous Center for Disease Control Registries
American College of Cardiology Registries
Danish Registries
Transplant Registries
Swedish Registries
Pediatric and Children's Registries (Cancers, tumors, congenital defects)
Administrative hospital discharge Registries
A complete list provided upon request

TABLE 2-3: Articles Primary Purpose Based on Seven Main Categories

Article Purpose	Decision Questions	Selected References		
Registry Quality	Data Quality and completeness. Articles main emphasis is data, quality control through comparisons *KEYWORDS: Comparison, Validate, Evaluate, Data Quality and completeness*	J. R., J. Ryu, et al. (2007). "Lung transplantation in the management of patients with lymphangioleiomyomatosis: baseline data from the NHLBI LAM Registry." J Heart Lung Transplant 26(12): 1293-9. Cecka, J. M. (2004). "The OPTN/UNOS renal transplant registry	Aharonson-Daniel, L., M. Avitzour, et al. (2007). "A decade to the Israel National Trauma Registry." Isr Med Assoc J 9(5): 347-51. Chia, S. K., C. H. Speers, et al. (2004). "Ten-year outcomes in a population based cohort of node-negative, lymphatic, and vascular invasion negative early breast cancers without adjuvant systemic therapies.JCO	Behrens, E. M., T. Beukelman, et al. (2008). "Evaluation of the presentation of systemic onset juvenile rheumatoid arthritis: data from the Pennsylvania Systemic Onset Juvenile Arthritis Registry (PASOJAR)." J Rheumatol 35(2): 343-8. Yoon, S. S., M. G. George, et al. (2006). "Analysis of data-collection methods for an acute stroke care registry AM J Prev Med, 2006
Registry Uses/Potential uses	Alternative use of registry than its intended purpose. Purpose is potential impact of registry on various uses such as linkages that extend the use of a registry *KEYWORDS: Reporting, Identifying, Influence, Use comparison*	Dutton, R. P., R. Lefering, et al. (2006). "Database predictors of transfusion and mortality Westerinen, H., M. Kaski, et al. (2007). "Prevalence of intellectual disability: a comprehensive study based on national registers. I Intellect Disabil Res	Kauf, T. L., E. J. Velazquez, et al. (2006). "The cost of acute myocardial infarction in the new millennium: evidence from a multinational registry AM Heart J Stollberger, C., I. Exner, et al. (2005). "Stroke in diabetic and non diabetic patients: Ann Med	Tomson, T., D. Battino, et al. (2007). "Antiepileptic drug exposure and major congenital malformations: the role of pregnancy registries. Epilepsy Behaviors Reinhold-Keller, E., K. Herlyn, et al. (2005). "Stable incidence of primary systemic vasculitides over five years
Registry Quality + Outcomes	Articles that state Registry Quality and have outcomes data presented	Kalkat, M. S., M. B. Edwards, et al. (2007). "Composite aortic valve graft replacement: mortality outcomes in a national registry." Circulation 116(11 Suppl): I301-6.	Abbott, Vlachos, et al. (2007). "Gender-based outcomes in percutaneous coronary intervention with drug-eluting stents (from the National Heart, Lung, and Blood Institute Dynamic Registry)." Am J Cardiol 99(5): 626-31.	
Registry Uses + Outcomes	Articles that state Registry Use and have outcomes data presented	Rodriguez-Granillo, G. A., M. Valgimigli, et al. (2005) One year clinical outcome after coronary stenting of very small vessels	Deer, T., I. Chapple, et al. (2004). "Intrathecal drug delivery for treatment of chronic low back pain: report from the National Outcomes Registry for Low Back Pain	

TABLE 2-3 (continued): Articles Primary Purpose Based on Seven Main Categories

Article Purpose	Decision Questions	Selected References		
How To Build	Purpose is creating a registry. Often identifies key limitations and advantages of creating a registry *KEYWORDS: Creating, Establishing*	Cameron, P. A., C. F. Finch, et al. (2004). "Developing Australia's first statewide trauma registry: what are the lessons. ANZ J Surg Silver, F. L., M. K. Kapral, et al. (2006). "International experience in stroke registries: lessons learned in establishing the Registry of the Canadian Stroke Network Am J Prev Medi	Wei, S. J., J. M. Metz, et al. (2004). "Recruitment of patients into an internet-based clinical trials database: the experience of OncoLink and the National Colorectal Cancer Research Alliance. JCO Kolling, C., B. R. Simmen, et al. (2007). "Key factors for a successful National Arthroplasty Register. J Bone Joint Surg	Schmitt-Egenolf, M. (2006). "Psoriasis therapy in in real life: The need for registries Dermatology Bentley, S. M., J. L. Melville, et al. (2007). "Implementing a clinical and research registry in obstetrics: overcoming the barriers Gen Hosp Psychiatry
Geographical	Region Specific *KEYWORDS: Regional, any directional + country*	Cronenwett, J. L., D. S. Likosky, et al. (2007). " A regional registry for quality assurance and improvement: the Vascualt Study Group of Northern New England J Vasc Surg Hillner, B. E., D. Liu, et al. (2007). "The National Oncologic PET Registry (NOPR): design and analysis plan J Nucl Med	Miller, E. (2006). "Evaluation of the Texas Birth Defects Registry: an active surveillance system" Birth Defects Res A Clin Mol Teratol	Lowel, H., A. Doring, et al. (2005). "The MONICA Augsburg surveys--basis for prospective cohort studies. Gesundheitswesen
Technical	Focus is technical aspects of registry. Includes software applications, legacy systems *KEYWORDS: Information Systems, technology, software programs*	Chen, R., G. Enberg, et al. (2007). "Julius--a template based supplementary electronic health record system. BMC Med Inform Decis Mak Vrancken Peeters, M. P. Quality Control of colorectal surgery with an extensive complication registration system. Dig Surg	Glatard, T., J. Montagnat, et al. (2006). "Medical image registration algorithms assessment: Bronze Standard application enactment on grids using the MOTEUR workflow engine	Mehls, O., R. A. Donckerwolcke, et al. (2004). "Re-establishment of the ERA-EDTA Registry. Pediatr Nephrol
Cost/Financial	The primary motivation is the cost of the registry or finical implications of the registry to its users *KEYWORDS: Cost, cost-estimations, resource costs, finance, financial*	Reynolds, M. R., V. Essebag, et al. (2007). "Healthcare resources utilization and costs associated with recurrent episodes of atrial fibrillation: the FRACTAL registry	Woolley, I., P. Jones, et al. (2006). "Cost-effectiveness of a post-splenectomy registry for prevention of sepsis in the asplenic, Aus NZJ Public Health	Glazner, J. E., B. L. Beaty, et al. (2004). "Using an immunization registry: effect on practice costs and time. Ambul Pediatr
Other	Privacy, people using the registries *KEYWORDS: Privacy, consumers*	Sucurovic, S. (2007). "Implementing security in a distributed web-based EHCR Int J Med Inform Day, S., L. M. Christensen, et al. (2007). "Identification of trauma patients at a level 1 trauma center utilizing natural language processing	Fritzell, P., B. Stromqvist, et al. (2006). "A practical approach to spine registers in EuropeL the Swedish experience Eur Spine J	Sokka, T. (2004). "National databases and rheumatology research 1

60

TABLE 2-4: Key Summary Points

Medical Registries are frequently referenced in the medical literature
Although Registries and outcomes are frequently referenced in the literature, the connection between registry use and outcomes assessment continues to be unexplored
Registry use references are primarily for data source or specific population searches
Passive Registries are the primary source of registry references
Registry data quality is an important aspect of the registry
Little evidence available on the physicians views on registry design
Limitations include search conducted on Pub Med search engine and only for registry
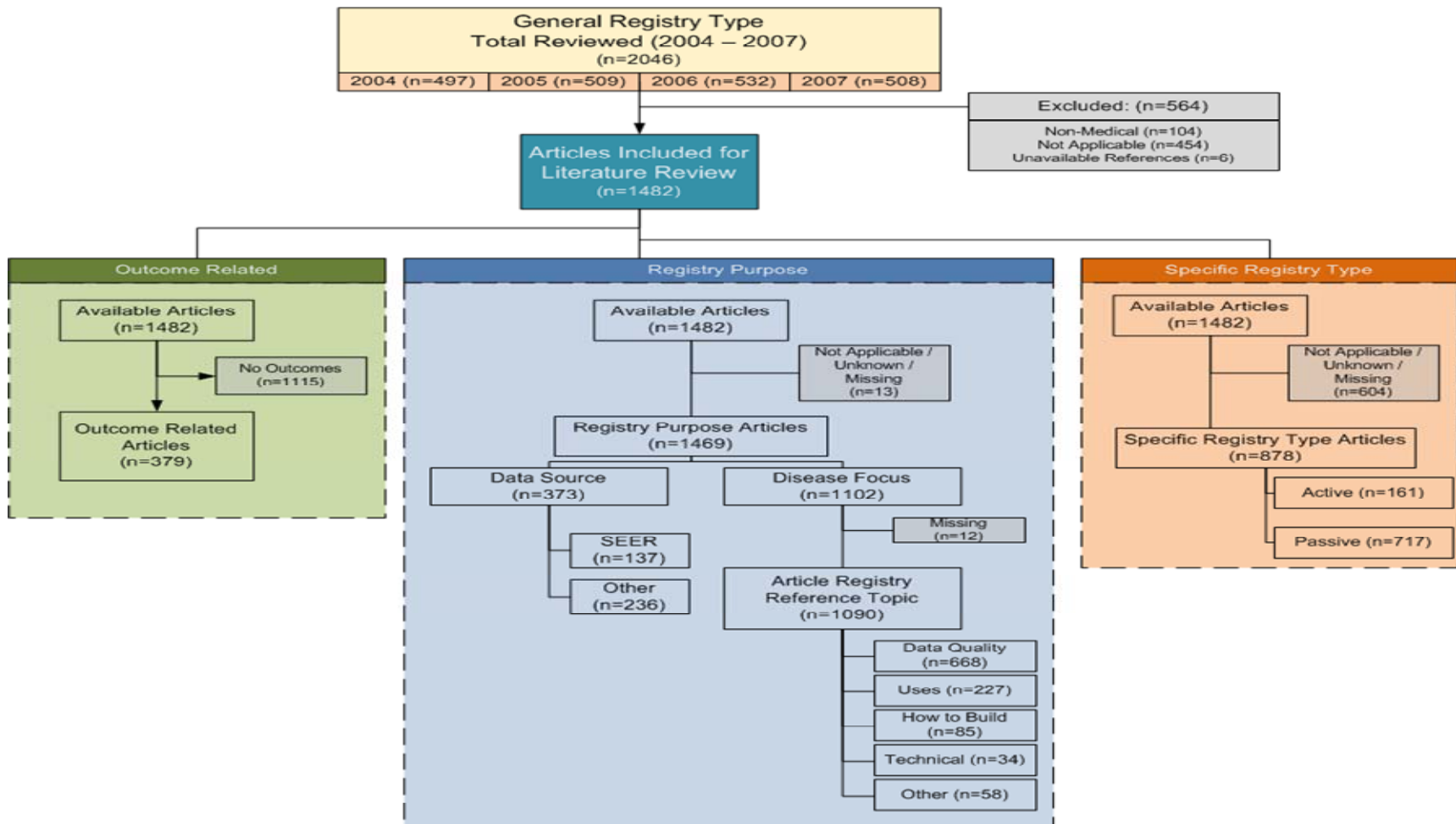
FIGURE 2-1: Identification of Articles used for Literature Review of Medical Registries

Systematic Review of the Registry Articles

Objective: To systematically review registry articles to determine first if the registry is medically related; second, outcomes related; and third, the specific type of registry referenced in the article. Other areas reviewed include the role of the medical registry in the article, whether the articles are focus driven, disease or diagnosis related, followed by categorization of the article's purpose into one of seven categories.

Medical Registry Definition
Medical Registries revolve around the translation of data. The precise medical registry definition is dependent on the actual operations and purpose of the established registries (IOM, 2001; Kibbe, 1999; Medicine, 2000; Miles, 2000). For our research, we will use:
> "   *"A medical registry includes patient level, population-based medical*
> *data, management processes for these data, and the interfaces to enter, manipulate,*
> *and query the data for research and other purposes.*"Medical Registries can be
geographic such as state or national cancer registries, disease or diagnosis specific such as children's ALL registry, healthy outcomes, and disease prevention such as CDC and DHHS Healthy Children 2010 initiative, as well as demographics such as adolescent pregnancy or mortality age prevalence.

Methods
An independent systematic review was undertaken with a content analysis of each article from the search results. A defined, PubMed search strategy was identified after piloting various database strategies.

> *Search Strategy*

We identified registry studies by searching the electronic PubMed database. This search was restricted to 1998- 2003. Searching was also limited to keyword MESH Major topic "*registry*", *human subjects*, and only those articles in *English*. For, this analysis, we used only one keyword, <u>*Registry*</u>, for precise definitions and to decrease the potential of erroneous captures.

> *Detailed Methods*

<u>Part A (Article search):</u>

> > 1. Utilizing only the electronic PubMed database
> > a. Search for the term: *registry*
> > b. Setting Limits (click on the "Limits" word below the search space) on:
> > > i. Change "All Fields" to: *MESH major topic*

         ii. Change "Publication Date From" to: *2002/01/01* "and To" *to 2002/12/31*

        iii. Change "Languages" to: *English*

        iv. Change "Human or Animal" to   *Human subjects*

c. Do not limit:
  i. Publication types
  ii. Ages
  iii. Entrez date
  iv. Subsets
  v. Gender

d. Leave unchecked "Only items with abstracts"

e. Click the "Go Button"

f. RECORD this Number. This will be the master reconciliation value.

2. For each article, you are to complete one line in the coding sheet. The sheet is divided into columns. Each column represents one characteristic of the article. The columns of interest are:

a. Article authors

b. Title

c. Date of publication

d. Publication source

e. General Registry type(Coding)
  i. Not-Applicable (0) or
  ii. Medical (1) or
  iii. Non-Medical (2)

f. Outcomes related? (Code: 0=blank, 1=related, 2=not related)

g. Specific Registry type: (Coding)
  i. Blank (0)
  ii. Active (1)
  iii. Generalized retrospective population-based (GRPB) (2a)
  iv. Population/ condition retrospective research based (PRRB) (2b)
  v. Unknown (3)

h. Registry Purpose: (Coding)
  i. N/A (0)
  ii. Data source (1) oriii, Focus on disease or condition (2)

i. For articles as data sources:
  i. Code the article in the spreadsheet for the purpose of the registry and stop

j. For articles with focus on condition
  i. Code the article in the spreadsheet for the purpose of the registry and continue to next step.

k. Disease or diagnosis related (Coding)
  i. Not related (0)

   ii. Yes (1)

   iii. Unknown (2)

  l. Code Secondary Category

     3.

     0. Not Categorized

     1. Registry Quality or

     2. Uses/potential uses or

     3. How To Build or

     4. Geographic coverage or

     5. Technical or

     6. Cost/financial or

     7. Other

   ii. Code 3rd category (if appropriate)

  b. Record Registry Names

Part B. General Registry Type:

  a. Divide this list into the following: Medical related, Non-medical related registry, N/A

    a. Medical: (1) Any article that addresses a medical condition, disease or state

      Includes: Cancer registries, emergency medical services, accident/trauma topics, and all medical data source registries

    b. Non-Medical: (2) Articles not primarily related to the medical field or health care.

      a. Includes: Environmental registries, nurse agency registries, biological DNA registries

    c. Not- Applicable (N/A) (0)

     Those articles without an abstract

  b. Code the article in the spreadsheet.

  c. Complete the following sections for Medical Registry articles only.
    Non-Medical and N/A articles STOP, do not complete the following sections.

Part C (Registry +Outcomes):

Because outcome is not a MESH term, an indirect correlation will be applied to ascertain the number of articles that address registries and outcomes. (Article dependent)

  1. Search each article's keyword section for the following terms: outcomes, outcome, outcome assessment, outcomes assessment or

  2. Search each of the article's abstract for the terms: outcomes, outcome, outcome assessment, outcomes assessment, and outcome implications.

  3. Code the article in the spreadsheet

Part D (Specific Registry Type):

1. Classify the Registries that are referenced in the articles remaining at the end of Part A, into one three types or unknown: 1) Active, 2) Generalized retrospective population-based (passive), or 3) Population/condition retrospective research based, (passive) or 4) Unknown.

For the purpose of this analysis, the first type is classified, as active, while the second and third types are both classified as passive registries. Although, both of these last two groups are passive, they will be maintained separately, at least initially, for the data compilation. (Article and Registry dependent). The purpose and type of registry utilized in the article. Medicare registries development purpose is not for medical research therefore their registries would be classified as 2b; whereas a breast cancer registry referenced for breast cancer research would be classified as 2a.

Coding:

0=Blank

1=Active

2a=GPRB

2b=PRRB

3=Unknown

Definitions

1. *Active*: Registries that permit ongoing collection and evaluation of data, real-time-science-based- medicine. Active, prospective observational study registry (Department of Health & Human Services 2002), ongoing evaluation of patient outcomes as collection continues. Active registries are evaluated within one year.

   - Potential for greatest impact on patient health and safety

   - Real- Time Science-Based Medicine

   - Examples: 1) End Stage Renal Disease, and 2) The Pregnancy Exposure registry that was established to monitor the outcomes of pregnancies exposed to specific medical products"(Department of Health & Human Services 2002), 3) New England Cardiovascular Group Registry, and 4) The Children's Oncology Group Registry.

   - Such registries, that we characterize as an active registry, allows for the current, real-time change in the care of active patients because the registry is *prospective*.

   - Key emphasis is the *ongoing collection AND evaluation* of the data. Evaluation must be completed within one year. One way to determine this is the article published date is within *one year* from the study dates.

2. *Passive*: Registries that provide a retrospective analysis of data, or provide a simple statistical data bank. Examples include 1) A pure data collection registry such as the Center for Disease Control Immunization registry that is a: "confidential, population- based, computerized information systems that attempt to collect vaccination data about children within a geographic area" (Center For Disease Control 2001), and 2) An extension of the pure collection registry that is also used for population-based research, The Manitoba research registry, developed to facilitate longitudinal studies, "contains a vast array of population based and health status information available for a variety of research purposes (Manitoba 2002)". Pure data collection registries are excellent for completing advanced research; they are purely passive in nature. That is, while they may impact future patient treatment, they do not impact current patients with the condition because the registry is <u>retrospective</u>. Key emphasis is that these registries are reviewed for content retrospectively, often as a data source for population studies. The evaluation is much later than the collection. There is not a concurrent data collection and evaluation; it is frequently years between data collection and its evaluation.

   a. (2a) Generalized Retrospective Population-Based (GRPB)(Department of Health & Human Services 2002) data evaluated after the fact, if ever.
      i. Most common registry
         1. CDC, or geographic region database
         2. Examples: National Cancer Registry, State Mortality Registry
      ii. Registry is usually used and developed for research
   b. (2b) Population / condition retrospective research based (Manitoba 2002) data   gathered for another reason and/or clinical trials.
      i. Gathered for another reason
      ii. Hospital Administrative database
      iii. Examples: Wilson C. Susan L. Lynch A. Saria R. Peterson D. Patients with diagnosed diabetes mellitus can be accurately identified in an Indian Health Service patient registration database. Public Health Reports. 116(1):45-50, 2001 Jan-Feb.
      Leppala, J. M.Validation of stroke diagnosis in the National Hospital Discharge Register and the Register of Causes of Death in Finland. European Journal of Epidemiology15(2)155-160.

   2. Code the article as active, or generalized population (passive), or retrospective research (passive) registries or unknown.

Part E (Medical Registry Purpose Division):
   1. Review each article for its purpose, focus only on whether 1) the registry is mentioned only because it is used as a data source and 2) the focus of the article is not the registry, but the disease or condition. All SEER references will be classified as data source. Data Source tends to reference more than one registry as its study population source. Focus driven often has limited populations or develops its own registry to obtain an appropriate population.

2. If the article is utilized for a _data source_ only,
    a. Provide a separate" Data Source Only" category and DO NOT assign to one of the seven categories below.
    b. Code the article in the spreadsheet
    c. Review this category for reoccurrence of specific types of registries i.e.
        i. SEER
        ii. Immunization registry
        iii. Cancer registry
        iv. Twin Registry
    d. Record Specific Registry Name (record all registries referenced) in the article on the spreadsheet
    e. Code the article in the spreadsheet
3. For the remaining Medical Registry Articles (Focus Driven)
    a. Determine whether the article and registry are disease or diagnosis related.
        i. Definition: _Diagnosis/Disease:_ Does the article focus on a specific disease or diagnosis to study the diagnosis or disease. Key category emphasis includes articles discussing specific disease or diagnosis registry development or why the registry was developed, or a specific disease registry used to evaluate a disease or diagnosis. Articles whose intent is to identify limitations of the registry or a disease network. These registries are disease or diagnosis specific and the articles need to address specific disease statistics. Examples include 1) MD Mayes' article "Establishing and utility of population-based registry to understand the epidemiology of systemic sclerosis" and 2) C. Darke's article "An overview of the Welsh bone marrow donor registry: 10 years of bone marrow donor provision".
        ii. Disease or diagnosis is frequently referenced in the title or abstract or references one primary registry
    a. **KEYWORDS**: Disease focused registry, any specific disease, or diagnosis registry.
    Code relationship in spreadsheet
4. Divide each Disease/Diagnosis Related article according to its purpose into one of seven categories.
    a. Code the category in the spreadsheet

    (Defined on next 2 pages), permitting multiple categorizations when appropriate, with a _maximum_ of two categories per article.
        1. When determining if more than 1 primary motivation ask the question
            i. "Does the article have more than one purpose or main focus?"

5. If the article has multiple categorizations go to step 3

6. Assign the article purposes by answering the questions
    a. "The article's primary or main motivation is…"
    b. "What is the author's purpose for writing the article?"

    c.   Geographical area is automatically moved to second as article motivation, when the article has multiple motivations; other two categories prioritized for best fit as detailed above.
7. Code the article in the spreadsheet into secondary and tertiary categories. (Attached table)

The seven categories and their inclusion criteria are as follows:

0. Not Categorized

    1.   Registry Quality: Data quality and completeness are the main points of this category. The main emphasis of the article is data; focus is to validate the registry's quality often through comparisons with other data sources such as Medicare claims, clinical trials enrollments, and other registries. Examples include 1) reconciliation of a medical registry with a clinical database and 2) National Cancer Data Base/ SEER: potential insensitive –measure bias. Key emphasis is that this group does *not* assume that the data is good; it attempts to prove that the data is reliable by evaluating the registry.

        a.   **KEYWORDS**: Comparison, Validate, Evaluate, Data Quality

    2. Uses/Potential Uses: Key difference between Uses and Registry Quality is that Uses/Potential Uses *assumes* that the registry's data is "good" and reliable. The purpose is not the data, but the potential impacts of the registry on various uses such as linkages that extend the registry. This linkage includes only those linkages that provide extension of the registry and not a linkage of information that one would expect in the registry. An example is linking police records and trauma registries. (If the linkage were necessary to close a gap in the registry's data, then would fall into registry quality). Other key emphases include uses that identify high- risk populations, influence policy, and identify cost-savings, reporting. Found is this area, are alternative purposes for the registry other than its inceptions purpose.

        a. KEYWORDS: Reporting, Identify, Influence, Use comparison.

    3. How to Build: Purpose is creating a registry. Provides detail concerning necessary elements in creating or establishing a registry, often identifies key limitations and advantages of registry creation. This area does not contain comparisons of registry, only intellectual, technical, and resource sufficiency needed to build a registry. An example in this category is establishing a tissue composite registry.

        a. KEYWORDS: Creating, establishing

    4. Geographical Coverage: Must be region specific, not country specific. Country specific is too broad. An example classified in geographical coverage is Northern Ireland registry.

        a. KEYWORDS: Regional, any directional, plus a country. I.e. Northern, Southern, Eastern, Western +Country (Ireland, USA).

    5. Technical: Focus is technical aspect of the registry. Includes software applications, and integrating legacy systems. Examples classified as technical includes software programs for registry or integrating data from legacy systems using technology.

Primary statement answers: "This technology permits the registry or information system to do …"

       a. KEYWORDS: Information systems, technology, software programs.

6. Cost/Financial: The primary article motivation is to identify financial implications of the registry. Often the financial costs to providers and resource costs. The finances are related to the registry itself including upkeep, and resources. Examples include costs of immunization registries and cost of participating in registries. Only applies to costs directly related to the registry or operation of the registry

       a. KEYWORDS: Cost, cost-estimations, resource costs, finance, financial.

7. *Other:* The primary motivation for these articles do not fit into the above categories however, they also do not qualify for omission under the exclusion criteria. The focus of these articles includes, but not limited to registry privacy issues, are people using the registries, the people using the registries, and any other topic not covered in the more specific categories.

       a. KEYWORD: Privacy, consumers

 *Keywords are guides; some articles can be identified with the keywords in more than one category. In this case, additional criteria as stated above are utilized to discern the most appropriate primary and secondary category.

3. Code the article in the spreadsheet for each registry type in the seven categories. (Secondary)

<u>Part F (Additional years)</u>
Repeat *ALL* above steps for each individual year 1990-2003. Total for each year; do not add totals from year to year.

CHAPTER III

IMPACT OF REGISTRY USE IN MEDICAL DECISION MAKING:
THE CASE OF THE SOCIETY OF THORACIC SURGEONS

3.1   Preface and Research Model

This chapter addresses the impact of medical registry on medical decision making

practices. The setting to investigate this issue was the Society of Thoracic Surgeons.

When evaluating the potential use of a medical registry in medical decision making, key

characteristic differences between a medical registry user and non-user must be

investigated. To address this question, a survey was developed based on medical registry

constructs from the systematic review in Chapter 2, along with the factors of: user

demographics, the use of evidenced-based medicine in decision making practices, and

use of other technologies. While the medical registry provides access to information that

may assist in medical decision making, this chapter illustrates that other factors are

involved in the medical decision making process and that medical registry users follow

different decision making practices than non-users, namely registry users incorporate the

information gained from the registry into their clinical decision making process.
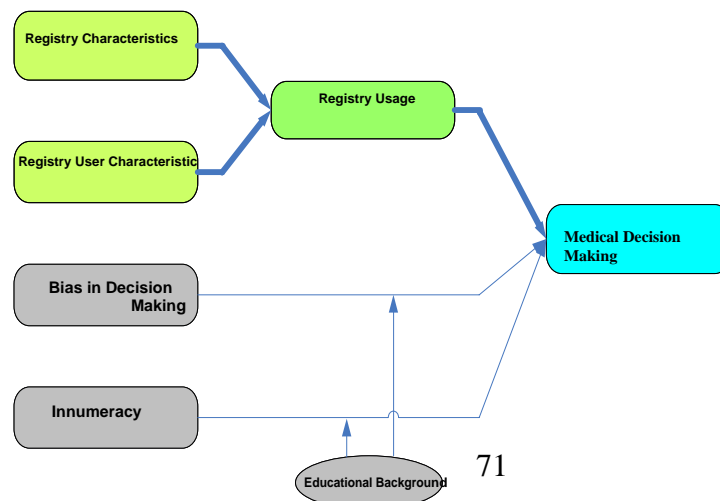
3.2 Introduction

Is medical decision making different between those physicians using a medical registry and those not participating? And, what factors affect medical registry utilization? Furthermore, does the propensity of the physician to follow evidenced based medicine dictate whether he or she is more apt to utilize a registry? It is well acknowledged that wide variations in medical decisions exist in the medical community and that physicians arrive at decisions differently. This research postulates that one aspect of decision making is the available information and the timeliness of the information necessary to make a decision varies depending on the physician's decision making practices.

Medical registries have the potential to provide information more quickly and accurately than the traditional methods of data information transfer. There are two basic designs of a medical registry: passive (retrospective data analysis available) and active, (real time data availability). Currently, most passive medical registries are frequently accessed to obtain a sample population for a research study, and less often as a means to evaluate outcomes.(Ferranti and Dilts 2003; Ferranti and Dilts 2005) One such passive registry is the frequently cited cancer incidence and survival registry The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registry, which was started in 1973 and currently collects data on 26% of the United States population.(2005) An example of an active registry often cited as a source for cardiovascular and thoracic surgery studies with more than 40 publications since 1994, is The Society of Thoracic Surgeons (STS) National Registry; this active registry contains more than 3 million patient records with a participation rate of eighty percent of adult cardiac surgery (2008;

2008). Both types of registries are utilized for sample populations to conduct studies to

determine the efficacy of various treatments and patient outcomes, which may later

contribute to the development of practice guidelines or influence their future treatment

decisions. However, one issue that has plague medical registries is the lack of

participation. While the SEER registry and the STS adult cardiac surgery registry have

exemplary participation rates, other registries are not as fortunate.

My previous research illustrated that much of the registry literature focuses on

data quality, and registry use, or how to build a registry (Ferranti, Dilts 2009). With the

exception of childhood immunization registries, previous research indicates that surveys

evaluating registry usage and physician participation are less studied (Ferranti and Dilts

2003; Ferranti and Dilts 2005; Clark, Cowan et al. 2006). A 2006 Yarbrough meta-

analysis study indicated that only 18 articles studied physician technology acceptance

during the previous 10 years (Yarbrough and Smith 2007). Furthermore, Schmittdiel et

al. identified that the use of chronic disease registries are not utilized by half of physician

organizations (Schmittdiel, Bodenheimer et al. 2005). This is one of the few studies that

assess the utilization of an active registry and the key components of the registry.

Additionally, this research identified positive health care provider responses by those

who receive email or notification alerts. However, their research does not delve into the

registry or user characteristics affecting the registry usage. My research intends to build

upon this short fall in studies, and expand it to include registry usage and the potential

influence in medical decision making. Furthermore, recognizing that cultural influence

or user perception are influential elements in determining characteristics for the long-

term success of a registry in achieving high participation rates and usefulness, this study

will identify the purposes that physicians' access the STS registry and barriers to its use (Davis, Bagozi et al. 1989; Venkatesh and Davis 2000; Ferranti and Dilts 2003; Domino and Huskamp 2005; Ferranti and Dilts 2005). This research will also explore the differences in the use active "real-time" registries and passive "only retrospective access" and their impact on medical decision making; this proposition has not been investigated.

Our previous systematic review of the literature identified major constructs, which assisted in developing the survey questionnaire. These three constructs are primarily tested in the medical registry section included the performance, quality and accessibility of the registry. The same survey was distributed to all participants.

3.3   Methodology

The survey questions were developed based on previous literature findings (Ferranti, Putnam et al. 2008), tools validated in previous technology surveys (Poon, Jha et al. 2006),multiple expert interviews, and utilizing general survey methodology. The survey design consisted of three main multiple-choice areas: 1) the demographics of the respondents, 2) the respondent's views of the STS registry, and 3) evidence based medicine practice participation and technology usage of the survey respondents. A fourth open–ended question area provided respondents with an opportunity to elaborate on any area of the registry that contributed to its usage or lack thereof. A pilot test was conducted prior to distribution to targeted sample population.

A survey questionnaire was distributed and collected by this researcher at a booth provided by the STS organization during 2007 January STS annual meeting in San Diego California. Prior to distributing the survey, the potential respondents were asked their

profession to ensure they met inclusion criteria, vendors and family members were excluded, the survey was only distributed to the medical professionals. The survey was distributed and collected over a period of 3 days. An incentive of winning an IPOD nano was provided; however, survey completion was not required for entry into the drawing.

Of the surveys distributed, 248 surveys were returned. Thirteen surveys were excluded from the analysis due to incompletion of the survey and attendee profession, which were reduced to 235 usable surveys for this analysis. The data were divided further to include only STS members (n=175). Next the data was filtered according to STS members participating in the registry (n=124) and those choosing not to participate in the registry (n=50); n=1 was omitted for missing data points. A second analysis was performed, with the control group including non-STS member responses as well as the STS member responses. The subsequent filtering remained constant between the two analyses, separating the registry users from non-users.

The data were analyzed using parametric independent sample t-tests (with equal variance not assumed), non-parametric Chi-Square test, Spearman Correlation, or Fisher's Exact Test for binomial responses. Level of statistical significance was set at an alpha of 0.05. Due to the survey construct, the sample size is different for many questions, as some responses require the respondents to skip the following set of questions. (See Appendix A Survey). Since the second analysis results were similar to the STS member responses, this chapter will only discuss the STS member results.

3.4   Results

3.4.1   Demographics

Of the survey respondents, 75.8% (n=175) are STS members and 48.5% (n= 83) of these members practiced in an academic hospital setting. A total of 17.1% (n=30) of the STS members' hospital setting has less than 250 beds. Of the STS registry participation of the member respondents, 71.3% (n=124) participate in the STS National Registry, 87.9% (n=109) in the Adult Cardiac Surgery, 27.4% (n=34) in the Thoracic Surgeons and 10.5% (n=13) in the Congenital Heart Surgery registry. A total of 26.3% (n=30) participate in more than one of the STS registries.

Of the respondents not participating in the STS national registry, 41.3% (n=19) participate in another registry, of which 28.3% (n=13) responded that their affiliations required mandatory participation in their primary registry. While 28.7% (n=50) do not currently participate in the STS registry, 39% (n=18) plan to implement a registry program participation within the next year.

Forty eight percent (48.3%, n=84) of the physicians that were STS members performed greater than 200 surgical procedures during the previous year; while physician experience varied with 9.7% (n=17) of the surgeons having more than 30 years of experience and 15.4% (n=27) with less than five years of licensed practice. All but 4 STS members were located in the United States with the following distribution: 25.7% (n=44) are located in the Midwest, 25.7% (n=44) in the west, 18.1% (n=31) south, 18.7% (n=32) from the east, 9.4% (n=16) in the northeast and 2.3% (n=4) international respondents. However, this distribution is vastly different between those choosing to participate in the STS registry and those not participating as 32.8% (n=40) of those

participating are located in the Midwest, whereas only 8.2% (n=4) of those not

participating are located in the Midwest. Of those not participating the east coast

maintained the highest non- participating rate at 24.5% (n=12) (p<0.001). (Table 3-1)

3.4.2 STS National Registry Importance and Usage

Evaluating the frequency of interaction between the registry and the physician

practices were measured based on eight factors including frequency of access, executive

summary accuracy of specific practice, early identification of quality improvement areas,

data accuracy to physicians current individual practice, comparison accuracies, data

reports understandability, and registry meeting user needs. Four specific factors were

identified to be statistically significant when comparing the responses between the

registry users and nonusers: early identification of areas needing quality of care

improvement (p=0.023), data comparison accuracy (p=0.002), ease of understanding

generated data reports (p=0.024), and the registry meeting the respondents needs

(p=0.010) (Table 3-2).

STS members who participate in the registry access information with greater

frequency compared to STS members who do not participate. When asked on the level of

frequency one accesses the medical registry (registry), 35.9% (n=14) of the STS members

not participating in the STS registry replied that they never or rarely access their primary

registry, compared to STS registry participants where 17.1% (n=21) responded as never

or rarely accessing the STS registry (Chi Square p=0.045), indicating that availability of

the information is not the primary factor affecting registry utilization. As even when the

information is supplied and readily available, the physicians willingness to obtain or use

the information in the decision making process varies.   Overall, sixty-six percent (66.5%, n=103) of the STS respondents state that the executive summary reports often or always reflect their specialty practice and patient population.

One distinguishing difference between the users and nonusers is that according to 40.5% (n=49) of the STS registry participants, the registry often permits early identification of areas of improvement in quality of care; this is in contrast to 18.4% (n=7) of those not participating in the registry who state that the registry never permits early identification of improvement areas (Spearman p=0.026). In addition, 44.2% (n=53) and 60.8% (n=73) of the STS registry participating members state that the registry data often provides an accurate view of their practice patterns, and an accurate comparison of individual's data to the registry's aggregate data, respectively. The non-participating members could not answer this question because they do not provide their individual data for aggregate comparison.

The participating physician's views and trust in the data are reflected in the frequency they access the registry and those questions addressing data quality and accuracy correlations. For example: participating members, show a moderate correlation of the frequency they access the registry to executive summary reports accuracy at 0.485 (p<0.001), individual practice patterns accuracy 0.474 (p<0.001), and comparison to aggregate patterns 0.432 (p<0.001).   There was a statistically significant correlation between "frequency of access" and "are the data reports are easy to understand" (Spearman p=0.322, p<0.001). For those members who do not participate in the registry, but receive the reports there is a very strong correlation between those who believe the accuracy of the executive summary reports and ease of understanding the reports

(Spearman=0.771, p<0.001). For those that understood the reports, they believed that the reports provided accurate reflections of the aggregate practice.

There is a statistically significant difference in whether the registry meets its users' needs when comparing those members that participate in the registry and those who do not participate. While 49.2% of those participating affirm that the registry "often" meets their needs, 23.7% (n=9) of those not participating state that the registry "rarely" meets their needs (p=0.007).

3.4.3 Barriers to Registry Use

Start up costs and lack of uniformed industry standards were identified most often as major barriers by survey respondents (32.3% and 27.2%, respectively). Although different percentages are noted for users (33.9%, n=40) and non-users (26.1%, n=12), start up costs were not statistically significant; lack of uniformed industry standards was also not statistically significant with 29.4% (n=35) of users and 25.6% (n= 11) of non-users believing that it is a major barrier (p=0.644). However, maintenance costs barrier differences were statistically significant between users (28.3%, n=34) and non-users (24.4%)(p<0.019) (Figure 3-1). Two items were not identified as major or minor barriers to greater registry use: privacy and evidence of registry effectiveness; as 66.1% and 61.6% of the respondents respectively, marked "not a barrier". This is contrary to many who hypothesize that privacy concerns are primary obstacles in registry and general technology adoption. Additional barriers evaluated include lack of training and lack of time, with 78.5% of the physicians' stating lack of time as a contributing barrier to use (Table 3-3, Figure 3-2).

3.4.4 Technology Value and Timeliness

Respondents held strong opinions with respect to the value of Internet access, updating, and analysis of the registry. When queried about the value and usefulness of accessing the registry via the Internet 72.6% (n=127) of all STS member respondents state that Internet access would be "very valuable", with merely 1.1% (n=2) responding that Internet access would not be valuable. This pattern holds with responses concerning the ability of periodic updating (75.9% of all STS members, n=126) and analysis via the Internet (75.3% STS members, n=125). There was no statistically significance difference between the registry participants and non-user participants.

The members were asked about the frequency they use other technology tools in their medical practice. Of the STS registry participants, 30.0% (n=36) do not currently use electronic patient medical records, while 17.1% (n=20) currently do not use electronic billing services (Pearson Correlation 0.339, p<0.001). Electronic ordering of tests, procedures or drugs is routinely used by 51.8% (n=88) of both the users and nonuser registry respondents, while 28.8% (n=49) do not use this feature at all; yet, 73.3% (n=121) of the respondents obtain patient test results via electronic access (Pearson Correlation 0.365, p<0.001).

An inquiry into the frequency of use of email communication was designed in two questions: 1) email communication with patients and 2) email communication with other physicians for patient consultation. Email communication with patients is not a tool utilized by most of the user and nonuser groups, 57.1% (n=68) and 56% (n=28), respectively. Following a similar pattern, but utilized more frequently is email correspondence with another physician as only 38.7% (n=65) do not correspond via

email. A statistically significant correlation was noted between emailing with patients and emailing other physicians (Spearman 0.646; p<0.001).

Usage of electronic or computer-based decision support tools that provide real – time treatment recommendations or diagnostic tools based on data about specific patient populations and practice guidelines varied between registry users and non-users as 52% (n=26) of the non-users do not utilize this decision aid (Chi Square p=0.040). A secondary medical registry question revealed that 42.9% (n=21) of the non-STS registry users do not use any type of medical registry in their practice (p<0.001). The use of electronic billing systems minimally if at all affects the non-users preference towards other technology usage (Spearman 0.285, p=0.045); although a slightly higher correlation with other technologies utilized by the participating users group, overall billing technology has a low correlation (highest EMR at 0.360, p<0.001)(Table 3-4).

Non-users currently maintaining electronic medical records also appear to access patient test results via computers (Spearman Correlation 0.744, p<0.001). However, aside from an email correspondence correlation (0.561, p<0.001), the participating user members do not appear to permit other technologies influence their decision to participate in others. When questioned about their current technology usage and medical registry participation, most of the user group responses do not yield a statistical significance; except for low correlations with access to test results (Spearman 0.265, p=0.005) and current use of decision support tools (0.272, p=0.003). This is particularly remarkable with minimal correlation between medical registry participation and all of the other technologies questioned. Each technology used appears to be an independent decision of the use of other technologies in their medical practice.

81

3.4.5 Data Quality, Clinical Outcomes, Evidence-Based Medicine

Data Quality, Clinical Outcomes and Evidence Based Medicine practices and beliefs were evaluated based on a set of questions designed to reveal multiple decision making factors. The respondent was given three options, and if the respondent replied affirmatively to the first part, then a second question was prompted.

Once the respondents confirmed receipt of the data, a second question ascertained the usefulness of the information. As expected statistical significant differences were noted between users and non-users exist for all questions posed concerning the receipt of the data. However, both groups consistently maintain that the information received is useful (Table 3-4). Applying this data to decision making was addressed when only 32.1% (n=36) of the STS user participants receive clinical decision making information that aids in specific patient treatment decisions; however, 91.7% of those state that the information is helpful. If the physician utilized the information in their decision making process they ascribed that the information presented was helpful in reaching that decision. In addition only 57% receive information regarding adherence to evidenced based guidelines, yet 97% (n=58) finds this information useful. Evidenced based guidelines are pivotal in the current decision making realm as noted by the majority of the respondents using some form of EBM.

Evidence based guidelines are the basis for clinical improvement for both registry users (91.7%, n=110) and non-users (91.7%, n=44). Furthering assessing the influence of evidence –based guidelines, two additional questions inquired about the circumstances when the physician would use these evidence-based guidelines: 1) Patients with common conditions, and 2) patients with complex or chronic diseases, users and non-users alike

responded similarly with combined usage of 53.8% (n=92) and 46.7% (n=79) respectively, "often" follow the guidelines.

Very specific questions targeted whether the respondents knew if the STS national registry provided access to evidence based guidelines 38.3% (n=46/124) of those participating in the registry chose "Don't know". A follow- up question referred to the likelihood of using guideline access if provided, 39.7% (n=31/124) stated that at least "sometimes", while 51.3% (n=40/124) stated that, they would likely access the guidelines "often". Interestingly, 64% (n=16/50) of those non-users not participating stated that they would likely access the guideline information often.

3.4.6   Registry Satisfaction

Overall registry satisfaction was evaluated and correlated with all other survey questions. Of the STS member registry users, 71.8% (n=84/117) were either satisfied or very satisfied with the current registry in contrast to only 39% (n=16/41) of the Non-STS member registry users satisfied or very satisfied with their current registry (p<0.001). Overall registry satisfaction comparison of users and non-users are in (Figure 3-3). For registry participants, the number of procedures performed and number of years in practice slightly correlates to registry satisfaction (Spearman Correlation: 0.136, p=0.144, n=117) and (Spearman -0.043, p=0.646), respectively, with the number of years in practice correlating negatively with satisfaction although not statistically significant.

STS registry participant responses illustrate a Spearman Correlation of 0.696 with registry meetings its users needs and registry satisfaction (p<0.001). Additionally, overall registry satisfaction significantly correlates with other registry importance and frequency

of access questions of the registry providing an accurate view of practice patterns (Spearman 0.538, p<0.001), comparison of data (Spearman 0.504, p<0.001), and ease of understanding of data reports (Spearman 0.483, p<0.001).

One of the objectives of the survey was to evaluate the relationship between overall registry satisfaction and barriers to registry use. Through crosstabs including only those responses of the STS registry participants with medical registry satisfaction and lack of training barrier, the data reveals that 57.9% (n=11/19) of those dissatisfied with the registry also marked that lack of training was a minor barrier to registry use (Spearman 0.262, p<0.001)). Fifty-eight percent (58.3%, n=14/24) of those responding very satisfied with the registry marked that lack of training was not a barrier.

Evaluating this even further, when comparing those users participating in the adult cardiac surgery registry and those participating in both the Thoracic surgeons and the adult cardiac registry, lack of training was identified by 65.2%(n=15/23) of the dual participant respondents as a minor barrier, while 41% (n=34/83) of the cardiac only participants do not believe that lack of training is a barrier to greater use (Spearman p=0.037)

Utilizing a 5-point Likert scale, those satisfied with the registry and those dissatisfied with the registry viewed start-up costs and maintenance costs differently. Thirty-eight percent (37.7%, n=23/61) of those satisfied with the registry marked that start-up costs were not a barrier while 70.0 % (n=7/10) of those dissatisfied with the registry marked that start- up costs were a major barrier (Spearman .189, p=0.049). Similarly, 36.5% (n=23/63) of those satisfied with the registry did not consider maintenance cost barrier to use; while 60.0% (n=6/10) and 40.0% (n=4/10) of those

dissatisfied with the registry considered maintenance cost a major barrier or minor barrier respectively (Spearman 0.283 p=0.002).

Although not statistically significant, both the satisfied and dissatisfied with registry respondents, 66.7% (n=42/63) and 60% (n=6/10), respectively marked that privacy concerns were not a barrier to use of the registry (Spearman .158 p=0.091). Of those satisfied with the registry, 33.3% (n=21/63) of the respondents marked that lack of uniform standards within the industry, which includes redundant data entry and poor interface design was not a barrier to use. All respondents dissatisfied with the registry marked that lack of uniform standards was a minor or major barrier. For those neither satisfied nor dissatisfied, 57.1% (n=12/21) also marked that lack of uniform standards was a minor or major barrier (Spearman .292, p=0.002).

Seventy-five percent (n=9/12) of satisfied registry users marked that lack of convincing evidence about the effectiveness of registries (registry) to improve care was not a barrier to registry use while 66.7% (n=6/9) thought it was a minor barrier (Spearman 0.234, p=0.013)

Sixty-six percent (66.2% n=43/62) of those routinely receiving their practices clinical outcomes are satisfied with the STS registry (Spearman .339, p<0.001) and 75.4% of those satisfied with the registry also receive aggregate clinical outcomes (Spearman .236 p=0.003). Seventy percent (Spearman, p=0.009) of the user participants and 100% (Spearman p=0.119, n=9/9) of the nonuser participants dissatisfied with the registry do not receive clinical decision making information. Seventy-seven percent (77%, Spearman p<0.001, n=47/61) of the participating users satisfied with the registry receive specific diagnosis and surgery type information.

Sixty-three percent (62.5%, n=35/61) of those participating users receiving adherence to guideline information are satisfied with the registry, whereas 70% of those users dissatisfied do not receive guideline information (Spearman .412, p< 0.001).

3.4.7   Barriers to Registry Use

A separate analysis was conducted to determine if non STS member responses were similar to the member responses. When comparing the two separate analyses, the major differences noted were with the perception of maintenance costs. Maintenance costs (26.9%, n=59/219; users 18.6%, n=27/145; non-users 43.2%, n=32/74; Chi Square p<0.001) were identified most often as major barriers by survey respondents. However, these barriers were statistically significantly lower among those currently using the STS registry (23.8% and 18.6%) than with those not using the STS registry (45.6%, and 43.2%) (Chi Squares: p<0.001 and p<0.001). This was similar to the STS member responses, which identified start up and maintenance costs influences were statistically significant between the users and non users in both analyses.

Dwelling one step further to relate registry satisfaction with the costs, those satisfied with the registry and those dissatisfied with the registry viewed start-up costs and maintenance costs differently. Forty-one percent (41%, n=41) of those users satisfied with the registry indicated that start-up costs were not a barrier, while 66.7% (n=8) of those users dissatisfied with the registry marked that start-up costs were a major barrier (p=0.002). Of the nonuser group even 31.2% (n=10) of the satisfied group marked that start up costs were a major barrier with 75.4% (n=49/65) of the non-users marking that start up costs were at least a minor barrier (p=0.002). Similarly, 39.2% (n=40) of the user

group satisfied with the registry did not consider maintenance cost a major barrier to use; while 58.3% (n=7) of those dissatisfied with the registry considered maintenance cost a major barrier (p<0.001). Of the nonuser group, 36.4% (n=12/33) of those stratified with the registry considered maintenance cost a major barrier with 50% (n=7) of those dissatisfied considering maintenance costs a major barrier, 78.8% (n=52/66) considered it at least a minor barrier to use. No other barriers revealed significant differences indicating that the users of the registry were similar regardless of membership.

3.5   Discussion

Medical decision making practices are different between users and non-users; this research indicates that physicians who utilize a registry elicit different practice behaviors than those who do not participate. Additionally, it is evident that the physicians who use the registry also use the information obtained from the registry in their decision making. Other results with potential for significant impact in the adoption of technology, is that simply providing access to the registry, does not guarantee its use. Moreover although both groups follow evidenced based medicine (EBM) and practice guidelines, those participating in the registry are more apt to utilize EBM in their decision making than those who do not participate. The active design of the STS permits the users to receive quarterly updates as well as request more frequently analysis if needed. Even so, the majority of the physicians indicated that they would like to have "anytime" access via the Internet to view and analyze their own data.

Comparison of the two analyses yielded one significant difference, Non-STS Members and non-users stated that startup and maintenance costs were major barriers to

participation, while the users did not view the costs as major barriers. All other variables did not show a difference between the two analyses. This finding was independent of demographics of the respondents.

High registry satisfaction is noted with the registry users. However, there is little evidence to suggest that years in practice or number of procedures performed are related to registry use or satisfaction. Additionally, similar to Audet et al. (2004) whose study did not find statistical differences in the age of technology adopters the STS registry users demographics do not support the popular theory that "older" physicians are less likely to utilize technology as our results did not show a statistical difference of the registry users age or experience in either analysis situation.(Audet, Doty et al. 2004; Grossman and Reed 2006) Another method to cross check whether our respondents answers agree with the older "more experienced" physicians are laggard or slow adopters, was to correlate years of experience to frequency of registry access; this also was not statistically significant..

When assessing the quality of the reports derived from the registry, over half of its users, responded that the STS registry provides accurate practice reports and almost half agree that the STS registry reports are representative of their practice as well. This level of confidence in data accuracy is important as many purport that in order to encourage usage, the registry must have the requisite quality required by its user community (Davis 1989; Domino and Huskamp 2005). The data illustrates that the more confident the physician is in data accuracy, the more frequently they access the data or consult its derived reports.

In addition, a positive correlation suggests the easier the reports are to understand the more frequently the physician will access the registry. This ease of understanding strongly correlates with the registry meeting its users needs more often, which also goes hand in hand with the frequency one accesses the registry and confidence in the data quality. The ease of understanding reports is also important as the majority of both users and non-users report that lack of time at least a minor barrier affecting their registry use and frequency of access.

Of particular note was that both the users and non-users of the STS registry and more than half of all survey respondents replied lack of evidence about the effectiveness of the registry was not a barrier to their using the registry i.e. for those not using the registry other issues were the primary factors affecting their decision to not participate. This confidence in quality and ease of understanding is important as even the best IT system cannot affect practice unless the physicians are willing to use it (Millenson 1999; Domino and Huskamp 2005). While many agree that the reports generated from the data are accurate, the laggard amount of time before they receive the reports is of concern. As previous research has shown, physician's receiving feedback and peer (non-identifiable) comparisons with practice variations adhere to suggested guidelines and alter their practices more readily than those not receiving feedback or connected to peer networks.(Schmittdiel, Bodenheimer et al. 2005)

In respect to the registry providing access to evidence based guidelines, while a little more than a third did not know whether the registry provided access, over half stated that if this feature were available, they would utilize the asset "often". This is important, as the physicians have identified an area where the registry has future potential

contributing to increased usage; as over ninety percent of the respondents currently utilize evidenced based guidelines for clinical improvement. Moreover, according to the literature, higher adherence to guidelines should perpetuate better aggregate patient outcomes as recent studies indicate that those patients in practices with less variation by more adherence to guidelines, had lower mortality rates and better outcomes than those with less adherence and more variation(Richards, Emori et al. 2001).

Almost half of the STS registry users state that the registry does not permit early identification of areas needing improvement hence, missing an opportunity to affect practice patterns or correct problem areas in a more-timely manner. One potential advantage a registry has is the ability to extract and analyze data more frequently thus permitting more real time changes to effective practices.

This timeliness is addressed in the barriers section as the responders were asked about the importance of registry access via the Internet and the ability to analyze ones own data and compare to aggregate data via the Internet. There was an overwhelming very valuable response with a mere 1.4% stating that it would not be valuable; in addition to each asset standing alone there is a strong correlations between all three questions addressing the importance of the Internet.

The majority of the registry respondents participated in the Adult Cardiac portion of the STS registry with some members participating in two or more of the STS registries. This is not a surprise as the Adult Cardiac portion has been in existence much longer than the General Thoracic (2003) or Congenital Heart Surgery (2002) registries and maintains higher participation rates.(2008) However, this fact should not preclude one from looking for ways to speed up the adoption practice of the other two registries.

90

The overall response rate (71.3%) for members only and (65% all users) who utilize the STS registry is less than the response rate (80%) that Jacobs et al (2006) report in their workforce report of the Congenital Heart Surgery Practice and Manpower survey of their target group (Jacobs, Mavroudis et al. 2006). For this study, the response rate for the Congenital Heart Surgery Portion only resulted in an n=13; thus making it difficult to derive specific results of their practice preferences. This is certainly an area needing further evaluation. Both the General Thoracic Surgery and the Congenital Heart Surgery registries are working towards improving their members' participation rate with the admirable goal of 100 percent participation (2008). The General Thoracic Surgery Registry current membership is 90 sites comprising of more that 49,000 surgical procedures and The Congenital Heart Registry has expanded to 48 centers in 2006 from 16 centers in 2002 and currently has 63 participating sites with more than 71,000 surgical procedures (Laudun 2007; 2008).

Physician education should assist in not only improving participation, but also increasing satisfaction with the registry participants, as lack of knowledge and training are formidable challenges that must be overcome as noted by the STS users who participate in both the cardiac and thoracic registries.

Although much research has indicated that prohibitive costs remain a barrier to health technology adoption with maintenance costs being underestimated, this study indicates that startup or maintenance costs were barriers to use only by those not satisfied with the registry and non-users, and not with STS registry members (Poon, Jha et al. 2006; Randeree 2007). However, it should be noted that the majority of the STS registry users are from larger organizations and much of the literature suggests that the size of a

physicians' practice organization plays an important role in the physician's technology

adoption rates as many surmise that larger organizations have more financial resources to

support the technology and its maintenance costs. Poon et al studying health IT adoption

practices in two large markets (Boston and Denver) with the intent to distinguish whether

size of organization plays a role in adoption timing and level also concur that larger

markets and organizations adopt HIT earlier than their smaller counterparts such as stand

alone or small physician practices (Poon, Jha et al. 2006).

As most of the STS respondents replied that they use evidence based medicine in

their practice, these survey results also indicate that they would prefer EBM guidelines as

a part of the registry and that they would use this feature if available. Additionally, for

those respondents who use the registry, they use it for many reasons and are confident in

the quality of the data. The data is used for more than simple reports; it is used for

practice decision making.

3.6   Conclusions

While the STS national registry participation far exceeds many other available

registries, it still has 14% of its members rarely if ever accessing the registry for any

reason. This study has illuminated a few barriers stated by the physicians that hinder

more active participation in the registry as well as ascertained areas for future

development as identified by its physician users.

Returning to our original questions, according to our survey results, registries are

underutilized by most and those that utilize the registry also tend to practice evidence

based medicine. However, generalization limitations of the survey do not permit us to

make a conclusive statement that those following evidenced based medicine are more apt to utilize the registry. Numerous factors affect a physician's decision to utilize an available registry and the subsequent use of the gained information in their decision making process. The design and timing of the registry will also affect the physicians use.

For organizations preparing to initiate a medical registry, the advantages of Internet access was preferred by all respondents and may prompt more registry utilization in the decision making process, as evident from our research the participants accessing the information often use the information in their decision making process. In addition, barriers to registry use are viewed differently between the users and non-users and should be addressed separately. A limitation of this research is the unique sample of physicians limited to cardio thoracic surgeons, and in the future should be expanded to include other areas. Additionally, as the conference attendants' were cardiac or thoracic surgeons, these results may not be generalizable to all physicians as internal medicine physicians may be unique. Of note, is the continued use of a registry and practice patterns of the Children Oncology Group, which maintains high medical registry participation of its active registry. This group may also be unique as they have a very different population group, that of very ill children. For generalizability, more diverse physician groups including other specialists should be surveyed.

3.7　References

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TABLE 3-1: Factor: Demographics

Demographics	p-value
Number of procedures performed previous year	0.150
Experience	0.386
Hospital size	0.371
Hospital type	0.221
Geographic location	0.001*
(33% of users located in Midwest)	
* Significant at α=0.05	

TABLE 3-2: Factor: Frequency

How Frequently:	Users	Non-Users	p-value	Difference between users and non users
STS database access frequency	3.5	3.05	0.065	No
Frequency executive summary reports reflect your specialty practice and patient populations?	3.8	3.44	0.080	No
Frequency database permits early quality improvement areas	3.48	2.97	*0.023	Yes
Does the registry data provide an accurate view of your practice patterns?	3.74	3.32	0.055	No
Frequency data comparison to aggregate practice accurate?	3.85	3.18	*0.002	Yes
reports ease of understanding?	3.83	3.37	*0.024	Yes
Does the registry meet your needs?	3.68	3.11	*0.010	Yes
			* alpha= 0.05	
	**1-5 Likert scale 1=Never, 5=Always			

97

TABLE 3-3: Factor: Barriers to Database Usage

Barriers to Database Usage	Not a barrier	Minor barrier	Major Barrier	Users	Non Users	p- -value	Difference between Users and non users
High Start-up costs	31.7%	36.0%	32.3%	33.9% n=40	26.1% n=12	0.074	No
High Maintenance Costs	27.3%	46.1%	26.7%	28.3% n= 34	24.4% n= 11	*0.019	Yes
Lack of uniformed industry standard	28.4%	44.4%	27.2%	29.4% n= 35	25.6% n =11	0.644	No
Lack of time	21.5%	54.6%	23.9%	20.3% n= 24	24.4% n=11	0.663	No
Training or knowledge on use	34.5%	45.5%	20.0%	34.2% n=41	35.6 n=16	0.596	No
Privacy Concerns	66.1%	26.7%	7.3%	68.3% n= 82	60% n= 27	0.425	No
Lack of convincing evidence of registry effectiveness	61.6%	32.9%	5.5%	61.9% n =73	60.9% n= 28	0.516	No

TABLE 3-4: Factor: Technology Utilization

Do you currently use any of the following technology tools in your practice?	*Users*	*Non-Users*	*p-value*	*Total STS members*
a. Electronic billing of services	71.8% n=84/117	60% n=30/50	0.069	68.3% n=114/167
b. Electronic ordering of tests, procedures, or drugs	51.7% n=62/120	52% n=26/50	0.349	51.8% n=88/170
c. Electronic patient medical records	52.5% n=63/120	64% n=32/50	0.073	55.9% n=95/170
d. Electronic access to your patient's test results	72.6% n=85/117	75% n=36/48	0.77	73.3% n=121/165
e. Email with patients to communicate about care	16% n=19/119	20% n=10/50	0.661	17.2% n=29/169
f. Email other doctors to consult or communicate about your patients	26.3% n=31/118	38% n=19/50	0.287	29.8% n=50/168
g. Electronic or computer-based decision support tools that provide real-time treatment recommendations or diagnostic tools based data about your patients and practice guidelines	12.6% n=15/119	22% n=11/50	*0.04	15.4% n=26/169
h. Medical Registry	38.8% n=45/116	28.6% n=14/49	*0.00	35.8% n=59/165

TABLE 3-5: Registry Impact on Medical Decision making

Routinely receives data from the registry on any of the following aspects of your care	*Users*	*Non Users*	*p-value*
a) Your patient's clinical outcome:	**65.4%** (n=70/107)	**38.1%** (n=16/42)	*0.002
b) **Finds Information Useful*	97.1% (n=66/68***)	100% (n=16/16)	
a) Clinical decision making for a specific patient:	**32.1%** (n=36/112)	**14.6%** (n=6/41)	*0.023
b) **Finds Information Useful*	91.7% (n=33/36)	100% (n=16/16)	
a) The registries aggregate patient clinical outcomes:	**78.8%** (n=89/113)	**53.7%** (n=22/41)	*0.003
b) **Finds Information Useful*	98.8% (n=83/84***)	81.8% (n=18/22)	
a) The registries data by specific diagnosis or surgery type:	**75.2%** (n=85/113)	**52.4%** (n=22/42)	*0.006
b) **Finds Information Useful*	96.3% (n=78/81***)	95.2% (n=20/21***)	
a) Adherence to evidence-based guidelines:	**57%** (n=61/107)	**26.8%** (n=11/41)	*0.002
b) **Finds Information Useful*	96.7% (n=58/60***)	100% (n=10/10***)	

*Fisher's Exact Test ** Information Useful answered only by those responding Yes in part a
*** crosstabs of part a and b of each question resulted in some of the "n's" in part b less than the number of yes responses in "a" because of missing data

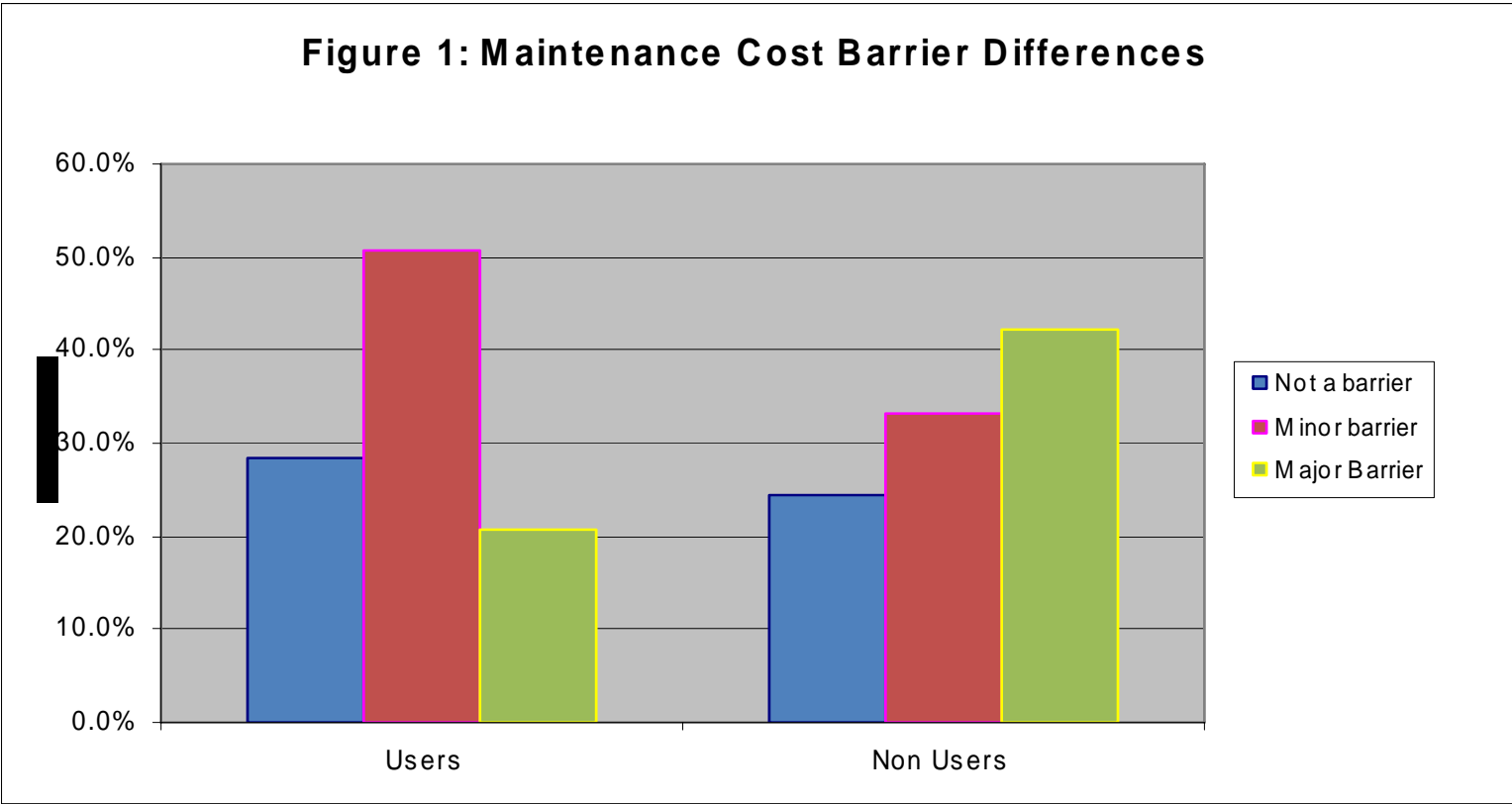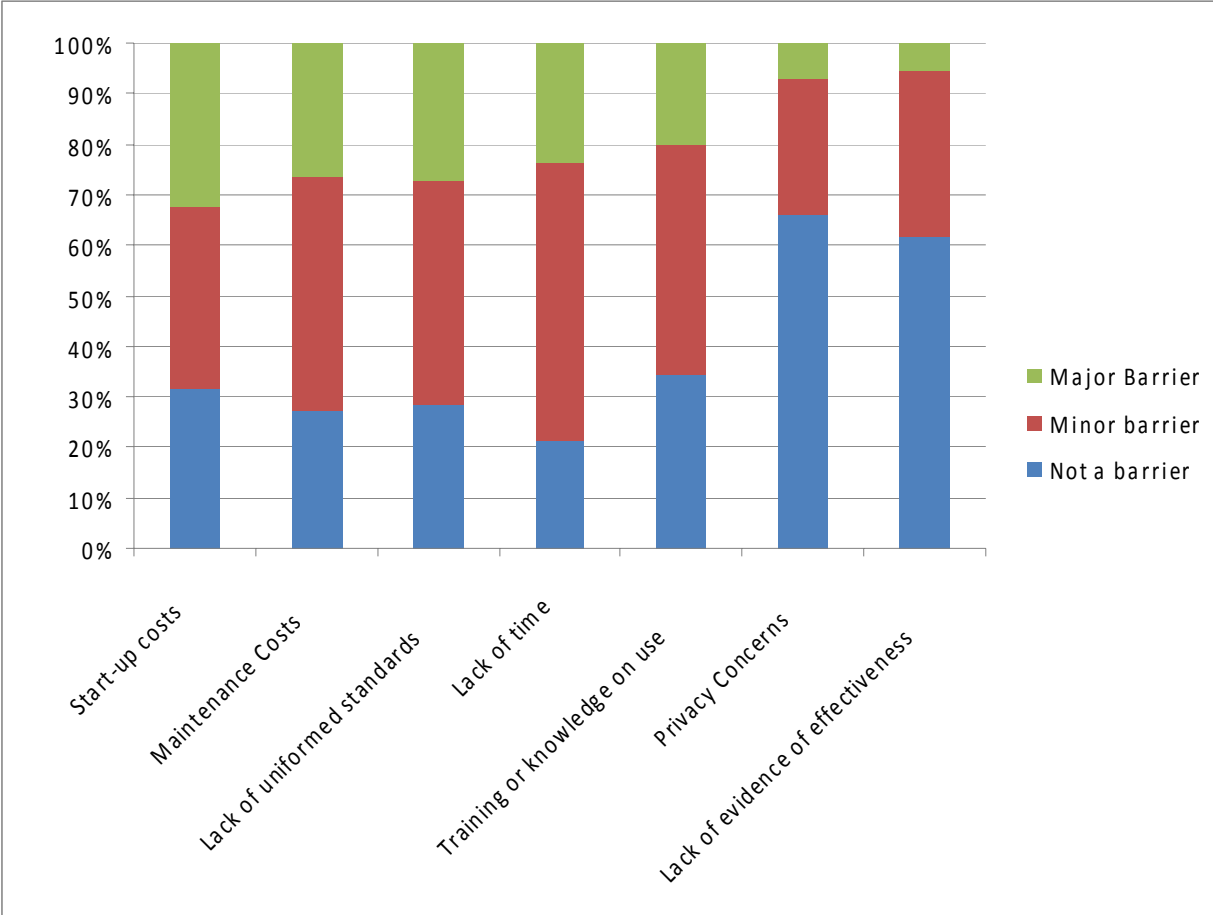**FIGURE 3-1: Comparison of Users vs. Non-Users with regard to Maintenance Cost as a Barrier**

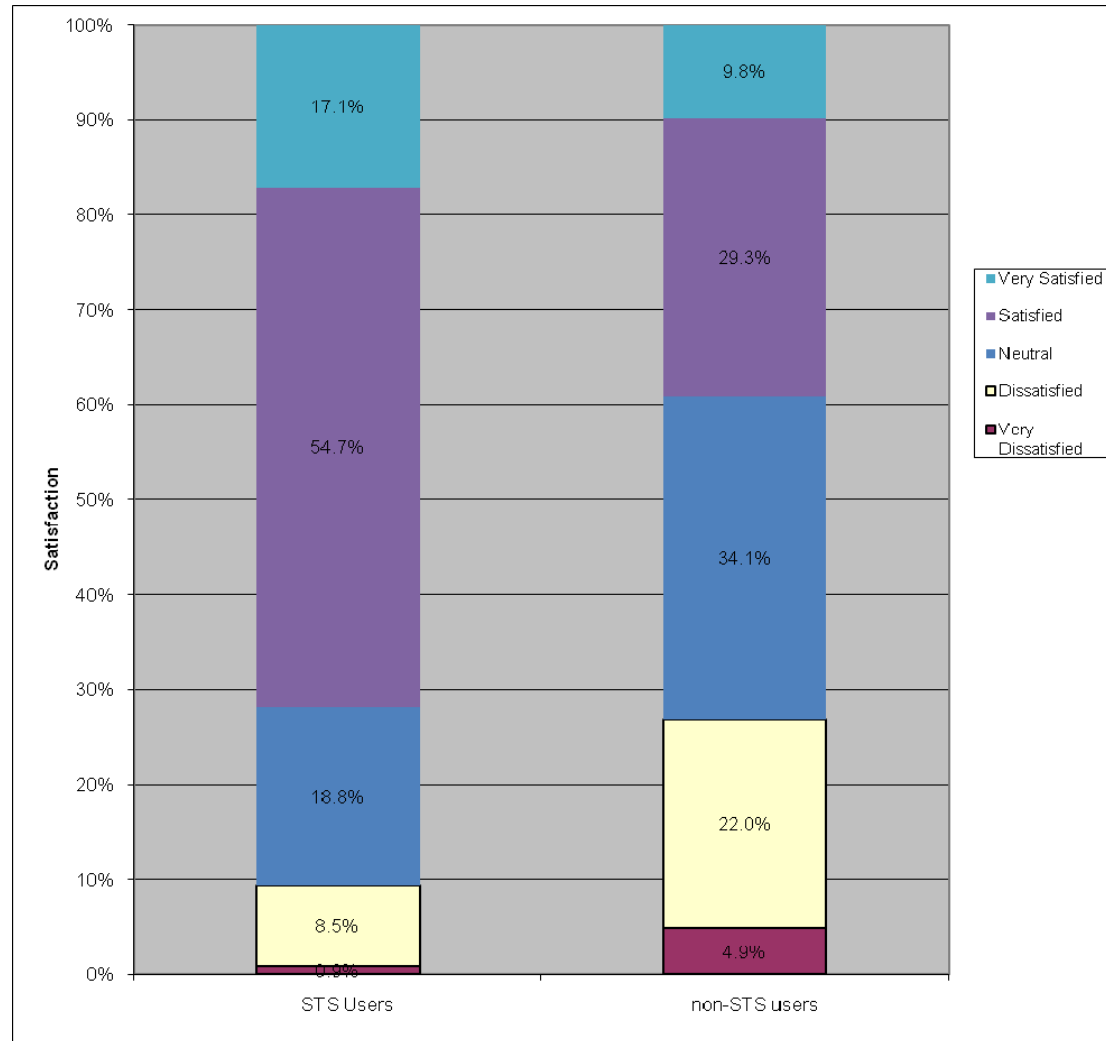**FIGURE 3-2: Comparison of Users vs. Non-Users Barriers to registry use**

FIGURE 3-3: Comparison STS Users and Non-users for Database Satisfaction

APPENDIX C:

SAMPLE SURVEY ADMINISTERS AT THE 2007 SOCIETY OF THORACIC SURGEONS NATIONAL DATABASE USERS

DEMOGRAPHICS

1. Are you a STS member or a Guest MD?
   - ☐ STS Member   ☐ Guest MD

2. What is your practice setting?
   - ☐ Academic Institution   ☐ HMO Network   ☐ Independent Hospital

3. What is the size of your hospital?
   - ☐ Under 250 beds   ☐ 250 – 500 beds   ☐ Over 500 beds

4. How many procedures have you performed in the last year?
   - ☐ <10   ☐ <25   ☐ <50   ☐ <75   ☐ <100   ☐ <150   ☐ <200   ☐ >200

5. In what geographic regions do you practice?
   - ☐ East   ☐ West   ☐ Midwest   ☐ Northeast   ☐ South

6. How many years have you been in practice?
   - ☐ <5 yrs   ☐ <10 yrs   ☐ <15 yrs   ☐ <20 yrs   ☐ <30 yrs   ☐ >30 yrs

7. Are you participating in the Society of Thoracic Surgeon's (STS) National Database?

   a. ☐ Yes (answer #7b)   ☐ No (answer #7c)

   b. IF **YES**, which one(s)   ○ Adult Cardiac   ○ Thoracic   ○ Congenital Heart Surgery

   If you participate in more than one STS registry, which of the registries is your primary registry?

   ○ Adult Cardiac   ○ Thoracic   ○ Congenital Heart Surgery

   c. IF **NO**, do you participate with any other registry?
   - ☐ Yes
     (please specify: _____)
     If yes, is this registry:
     - ☐ Mandatory
     - ☐ Voluntary
     - ☐ Don't Know
   - ☐ No, but plan to implement in the next year
   - ☐ No, and no plans to implement in the next year

(Please address the following questions based on your primary registry)

MEDICAL REGISTRY

8. How Frequently:	NEVER	RARELY	SOME-TIMES	OFTEN	ALWAYS
a. Do you or your staff access the medical registry?	☐	☐	☐	☐	☐
b. Do the executive summary reports reflect your specialty practice and patient populations?	☐	☐	☐	☐	☐
c. Does the data in the registry permit early identification of areas for improvement in quality of care?	☐	☐	☐	☐	☐
d. Does the registry data provide an accurate view of your practice patterns?	☐	☐	☐	☐	☐
e. Is the comparison of your data to the registries aggregate practice accurate?	☐	☐	☐	☐	☐
f. Are the data reports easy to understand?	☐	☐	☐	☐	☐
g. Does the registry meet your needs?	☐	☐	☐	☐	☐

9. Overall, how satisfied are you with the current medical registry?
   - ☐ Very satisfied   ☐ Satisfied   ☐ Neither satisfied nor dissatisfied   ☐ Dissatisfied   ☐ Very dissatisfied

9. How much of a BARRIER is each of the following to the greater use of the registry?	NOT A BARRIER	MINOR BARRIER	MAJOR BARRIER
a. You and/or your staff lack of training or knowledge on how to use the registry	☐	☐	☐
b. Start up costs are too high (equipment and training)	☐	☐	☐
c. Privacy concerns (clinical information and records not secured)	☐	☐	☐
d. Lack of uniform standards within the industry (multiple systems required, redundant data entry): Poor Interface design	☐	☐	☐
e. Lack of time	☐	☐	☐
f. Maintenance costs are too high	☐	☐	☐
g. Lack of convincing evidence about the effectiveness of registries to improve care	☐	☐	☐

10. Do you routinely receive data from the registry on any of the following aspects of your care?	YES	NO	DON'T KNOW
a. Your patient's clinical outcome:	☐	☐	☐
If YES, do you find this data useful?	☐	☐	☐
b. Clinical decision making for a specific patient:	☐	☐	☐
If YES, do you find this data useful?	☐	☐	☐
c. The registries aggregate patient clinical outcomes:	☐	☐	☐
If YES, do you find this data useful?	☐	☐	☐
d. The registries data by specific diagnosis or surgery type:	☐	☐	☐
If YES, do you find this data useful?	☐	☐	☐
e. Adherence to evidence-based guidelines:	☐	☐	☐
If YES, do you find this data useful?	☐	☐	☐

11. Do you use "evidence-based" guidelines as the basis for clinical improvement?
☐ Yes   ☐ No   ☐ Don't Know

12. How often do you use "evidence-based" treatment guidelines in the care of

    a.   Patients with common conditions

    ☐Never   ☐Rarely   ☐ Sometimes   ☐Often   ☐Always   ☐ No guideline available

    b.   Patients with complex or multiple chronic diseases or diagnosis

    ☐Never   ☐Rarely   ☐ Sometimes   ☐Often   ☐Always   ☐ No guideline available

13. Does the registry provide access to accepted "evidence-based" treatment guidelines?

    ☐ Yes (answer #14a)   ☐ No (answer #14b)   ☐ Don't Know (answer #14b)

    a.   **IF YES**: How often do you consult this feature?

        ☐ Never   ☐ Rarely   ☐ Sometimes   ☐ Often   ☐ Always

    b.   **IF NO**: How likely are you to use this feature if available?

        ☐ Never   ☐ Rarely   ☐ Sometimes   ☐ Often   ☐ Always

9. How valuable would it be to your practice if:	VERY VALUABLE	SOMEWHAT VALUABLE	NOT VALUABLE
a. The registry is accessible via the Internet.	☐	☐	☐
b. The registry permits periodic (quarterly) data collection updates	☐	☐	☐
c. The registry permits analysis of the data via the Internet	☐	☐	☐

10. Do you currently use any of the following technology tools in your practice?	YES USED, ROUTINELY	YES USED, OCCASIONALLY	NO PLANS TO USE WITHIN NEXT YEAR	NOT USED
a. Electronic billing of services	☐	☐	☐	☐
b. Electronic ordering of tests, procedures, or drugs	☐	☐	☐	☐
c. Electronic patient medical records	☐	☐	☐	☐
d. Electronic access to your patient's test results	☐	☐	☐	☐
e. Email with patients to communicate about care	☐	☐	☐	☐
f. Email other doctors to consult or communicate about your patients	☐	☐	☐	☐
g. Electronic or computer-based decision support tools that provide real-time treatment recommendations or diagnostic tools based data about your patients and practice guidelines	☐	☐	☐	☐
h. Medical Registry	☐	☐	☐	☐

11. From which of the following, if any, do you receive "Quality of Care" data about the care you provide to your patients. (Select All that Apply)

a. _____ Federal Centers for Medicare and Medicaid Services (CMS)
b. _____ Commercial Insurance Companies or health plans
c. _____ Employer Group (Leapfrog, business coalitions)
d. _____ Accreditation agencies (Joint commission, JAHCO, NCQA,)
e. _____ Medical Professional Societies
f. _____ Regulatory Agencies (States, board of registration)
g. _____ Internal sources
h. _____ Other (Please Specify: _____)

12. What is the primary reason that you **do** or **do not** use the STS registry?

_____
_____
_____
_____
_____
_____
_____
_____
_____

13. Any additional comments?

_____
_____
_____
_____
_____
_____
_____

_____*Thank*

you for helping in my dissertation research!

CHAPTER IV

MEDICAL DECISION MAKING:
IMPACT OF EDUCATIONAL BACKGROUND

4.1 Preface and Research Model

Chapters 2 and 3 investigated medical registries in general, and, in specific, the

influence of a medical registry in a physician's clinical decision making practice. These

chapters did not expand to include other factors, such as the educational background of

the decision making participants. This chapter delves into potential differences in medical

decision making depending on a participant's educational background. The functional

background differences in medical decision making were tested through a series of

medical scenarios provided to students in three different educational areas: undergraduate

junior and senior level engineers, graduate level nurses, and graduate level management

students. As shown in this chapter, educational background impacts decision making

(albeit in varying degrees) in the following areas: information pursuit, inclusion of

additional information, information source, experience, and availability of alternatives.
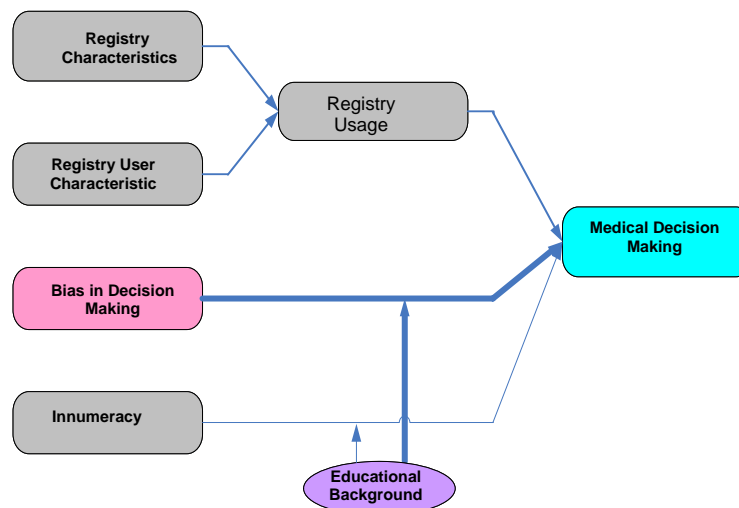
4.2   Introduction

Medical decision making has changed over the years, as healthcare providers and patients increasingly turn to novel information sources for making decisions compared to what was used in the past. For example, until about twenty-five years ago, most of the major medical decisions in United States were nearly always left exclusively in the hands of the physicians, with little participation by the patient (Quill and Brody 1996). More recently, shared decision making between patients and their health care providers (which includes physicians, physician assistants, nurse practitioners, and nurses) along with the inclusion of patient preferences in their care have been, in theory, embraced as models for good clinical practice (Ruland and Bakken 2001). Additionally, the increasing availability of statistical and other data via new communication technologies provided different methods of accessing information by providers and patients. With this increase, some patients have changed their behaviors and have become more inquisitive about their health care. The move towards increasing patient involvement has not been driven simply by a theoretical concern of respect for patient autonomy as there are empirical evidence that providing patients with information and involving them in decisions about their health care can result in beneficial psychological and physical outcomes(Ford, Schofield et al. 2003).

While prior research has recognized that individuals differ in what they value, how they make their decisions, and in their propensity to take risks(Hope 1996; Clemen and Reilly 2001), the ability to include these differences via standardized solutions are not always acceptable to patients(Rosen, Anell et al. 2001). Less studied are the influencing factors affecting patients and providers alike when faced with detailed

medical decision making information. These issues are escalated when there are high amounts of mathematical or statistical data presented, such as those that might be found in a medical registry.

While the use of data in medical decision making has been extensively studied, one overlooked area of research is that of educational background impacts decision making. Therefore, the objective of this chapter is to research how education background, namely training to become an engineer, a manager or a nurse, impacts medical decision making. Using various medical scenarios, we show that such background can significantly impact the resulting decisions.

4.3   Background

4.3.1   Diffusion of Information using Decision-Aid Technology

Diffusion of new medical knowledge and issues with its acceptance are not new obstacles in the medical profession (Coleman, Katz et al. 1966; Davis and Taylor-Vaisey 1997; Millenson 1999; National Cancer Institute 2000; Rich 2002; Brailer 2004). For example, it is known that depending on widely read or highly respected journals to disseminate new research to the practicing realm is not optimal, as a 2003 JAMA editorial openly admits that, except for the occasional special theme issue, translational research (defined frequently as bench-to-bedside (Woolf 2008)) is "rarely" reported in its issues (Fontanarosa and DeAngelis 2003); even though, both editors agree that physician awareness of new knowledge and developments are important and the exchange of information should be encouraged (Fontanarosa and DeAngelis 2003). Therefore, new approaches must be attempted.

One diffusion technology to assist in medical decision making that has been accessible by physicians for years, but with only limited accessibility by patients, is that of medical registries. Medical registries are databases, data repositories, or collections of patient medical information from multiple healthcare providers, potentially from multiple sites, used for tracking prevalence of conditions, evaluating outcomes from various treatment options, or assisting in selection of treatment options (Kibbe 1999; Institute of Medicine 2000; Miles 2000; Institute of Medicine 2001). Use of registries allows for better retro- and prospective information regarding appropriate treatments as, in theory, every provider and patient would participate in research if the registry was consulted or if the provider added a new "entry" (i.e. patient) to the registry. With ongoing access and timely evaluations of therapies, the time required for knowledge diffusion would decrease. As Berwick(2003) noted that "failing to use available science is costly and harmful" leading to underuse of good treatment options and overuse of less effective treatments. Such failure has been noted by many others also (Chassin, Galvin et al. 1998; Institute of Medicine 2000; Institute of Medicine 2001).

Unfortunately, even using registries or other information technologies will not suffice if providers and patients do not understand how to correctly interpret or use the medical data provided. Thus, those supplying information for medical decision making must understand the ways in which provider's and patient's background may impact such understanding. For completeness of understanding, before directly addressing this issue, we need to have a brief review the history of medical decision making.

4.3.2   Medical Decision Making

Prior to World War I, "the diffusion of new ideas and techniques occurred through rather simple processes when men lived in simple societies"(Coleman, Katz et al. 1966); when doctors consulted colleagues for informal advice or relied on their expertise to treat a new "illness". While this simple, yet time-consuming, process may have worked in the past, now new multiple modalities of communication provided by technological advances have dramatically increased the ability to disseminate information and to provide decision aids to providers and patients alike.

Communication technology for medical decision making now comes in a wide variety of forms, including surface post ("snail mail"), telephone calls, conference interactions, email, online medical libraries, and access medical registries of current clinical trials and treatment options. Although the *availability* of additional information has increased, this does not necessarily mean that the *utilization* of the additional information has increased or that such information is helpful in the decision making process.

Perhaps the best way to address the landscape of medical decision making is to describe four different situations of medical decision making from a provider's perspective. Each situation focuses on the physician and their decision making process.

Situation I: No External Investigation -- Dr. South is an experienced lung cancer radiologist. His first patient of the day is a patient with recently diagnosed lung cancer. His prior patients experienced success with a treatment plan consisting of a two-week intensive site-specific radiation therapy treatment; hence, Dr. South recommends the same plan for his new patient. He does not involve his patient, consult his colleagues, or a

use a registry; thus he is following the well know decision making error of the "law of small numbers" (Tversky and Kahneman 1971) as he proceeds to prescribe a similar treatment plan only because it worked for a few patients in the past. While Dr. South may be internally consistent, he may be at variance with his colleague's practice patterns (Kercsmar 2003; Rastogi, Shetty et al. 2006) or with the best available evidence-based medicine found in a registry.

Situation II: Informal External Data Gathering -- Dr. North and her colleague Dr. Northeast are working in different radiology practices in the same state. During the past month, Dr. North has also seen multiple cases of lung cancer in her adult non-smoking population. With moderate experience to draw upon and concerned, she consults with Dr. Northeast to see if he has experienced a similar increase at his practice, his current treatment of such patients, and other available treatment options. In this situation, Dr. North is using not only her experience and disease treatment knowledge, but is completing informal external data gathering by drawing upon peer's knowledge to guide her assumptions and treatment plans. Such a process is frequently accomplished through an informal process such as a telephone call (Coleman, Katz et al. 1966) or through email. While Dr. North involves other professionals, patient involvement is minimal. This process may require Dr. North to interpret statistical data, or assign risk levels for future communication to her patient as well as her communication with her colleagues.

Situation III: Formal External Data Gathering -- Dr. East, a researcher and practicing radiologist, has frequently prescribed a treatment plan consisting of two separate radiation regimens. He knows that physicians are required to enter the lung cancer diagnosis in the state cancer registry. These data are used for determining

incidence and prevalence rates, but the registry does not permit current data analysis or

trends (Center For Disease Control 2001) as the data is normally used primarily for

development of future educational plans or identifying at-risk populations. Dr. East also

conducts Medline searches for published literature and consults National Cancer

Institute's (NCIs) Surveillance, Epidemiology, and End Results Program (SEER) registry

for his patient population. SEER, the most frequently consulted cancer registry, provides

large population numbers and permits easy access to other cancer populations and

treatments for comparison. Although SEER is widely acceptable as a source for study

populations (National Cancer Institute; National Cancer Institute 2005), it is retrospective

in that patients are entered only after treatment results are known and thus does not affect

treatment plans. While Dr. East is performing his due diligence and gathering

information, his patient is also searching the Internet for information. When Dr. East and

his patient meet, both have large amounts of information, albeit, not all accurate or

applicable to the situation. Dr. East thus must be capable of interpreting the information,

as well as identifying potential factors leading his patient to inquire about certain

treatment options that are a higher risk or where an article provided identifies many side

effects regardless of probability of occurrence.

 Situation IV: Formal External Data Gathering For Active Treatment Selection --

Dr. West, also an active researcher and practitioner, has recently learned of a registry that

maintains both archival, passive treatment results and a list of all active treatment plans

and on-going lung cancer clinical trials for adult non-smokers. By entering her patient

data into this registry, she discovers the current standard of care for this type of patient

and uses the registry to select a specific treatment plan. However, one of the requirements

for using the registry is that she continuously monitor and up-load patient responses to the treatment so that the registry is maintained as a science-based real-time active repository of knowledge. While this is inconvenient, she feels that the value to the patient, and to her practice, is worth the additional time. Likewise, she feels that she will be using state-of-the-art rather than historical treatment plans. Dr. West's patient, a college graduate, has also researched the disease treatment options and wishes to participate in this treatment plan. Both Dr. West and the patient discuss the options, and agree upon a plan. However, like Dr. East, Dr. West must be capable of interpreting and communicating the information correctly, particularly with respect to numerical information.

Discussion of the Provider Situations -- While all situations presented involve patients, the level of involvement and utilization of outside resources varied. In situations 1 and 2, the physician basically decided upon a treatment plan without consulting the patient. In scenarios 3 and 4, the patient is more likely to have numerous treatment options presented them when meeting with the physician. Additionally, the use of external information varied in the situations and the use of such information might be an artifact of when the provider was trained. For example, one study indicated that how a medical student learns his or her "craft" in medical school and residency greatly affects their future practice patterns and decision making (Cox, Smith et al. 2005).

Thus, the first step in including the patient as part of the medical decision is the physician's decision with respect to the number of treatment options to present to or discuss with the patient. While multiple choices might not always be possible (Whitney, Holmes-Rovner et al. 2008), if they are, then the provider has the obligation to present

114

such alternatives to the patient. However, presenting multiple choices to the patient, because of how information may be incorrectly interpreted, may hinder both the physician and the patient in making the most informed decision (Buchanan 1995; Gurmankin, Baron et al. 2002; Damberg, Hiatt et al. 2003).

Providers often face the daunting task of deciphering what information to provide to their patients. "Providing information is a key part of clinical care, which influences patients satisfaction, compliance, recall and understanding" and failing to provide information may cause harm(Kinnersley, Edwards et al. 2008). Additionally, many providers feel that the Internet has changed the way they communicate with their patients(Damberg, Hiatt et al. 2003; Ferranti, Putnam et al. 2008; Whitney, Holmes-Rovner et al. 2008) as patients can come to the office armed with volumes of information, some of which is of questionable quality (Bastardi and Shafir 1998; Damberg, Hiatt et al. 2003). While patients collect such information, the physicians remain the primary source of information(Damberg, Hiatt et al. 2003) as it is believed that the patient will generally defer to the physician's recommendation but patients feel empowered by being informed (Kapp 1999; Gurmankin, Baron et al. 2002; Katz 2002; Whitney, Holmes-Rovner et al. 2008). This feeling, however may be impacted by the length of the provider-patient relationship and if the provider engages the patient in the decision making process(Adams, Smith et al. 2001; Damberg, Hiatt et al. 2003).

Providers are expected to be knowledgeable of the disease presented and provide treatment options. The availability of additional scholarly information has exploded (Whitney, Holmes-Rovner et al. 2008) and, with numerous decision support tools and registry access (Millenson 1999; Schmittdiel, Bodenheimer et al. 2005), the time to

receive such information has been reduced dramatically. Unfortunately, merely having

these tools available does not necessarily translate into their effective utilization

(Millenson 1999; Schmittdiel, Bodenheimer et al. 2005). Earlier research has indicated

that the majority of physicians (84%) state that they conduct their clinical improvement

process based on evidenced based medicine, however, few take full advantage of the

technology advances in their decision making with only 17% utilizing decision support

tools and 18% emailing patients(Ferranti, Putnam et al. 2008).

4.3.3   Shared Decision Making with Patient Involvement

While providers have multiple ways to access additional information, their

hesitancy to share this information may impact their relationship with patients. Katz

(2002) notes that "potential harm" is rendered when a physician does not permit the

patient to make their treatment choice and that physicians are irrevocably promoting

distrust between the physician and patient(Katz 2002). Jimison (1998) noted that patients

had four major reasons for wanting information: 1) for treatment compliance, 2) to veto

physician's decision 3) to enhance their decision making, and 4) for respect for their

wishes; three of these reasons may be directly applicable to medical treatment

options(Lidz, Meisel et al. 1983) and to the ultimate treatment decision. This list

highlights the necessity that both providers and the patient understand the information

communicated and presented.

Stevenson et al (2000) found that one of the major barriers that physicians

identified to more patient participation in decisions were the physician's beliefs

concerning their patients ability to comprehend the treatment explanations and potential

treatment options. This belief is not without merit as other research indicates that the presentation of information influence college educated healthy individuals when provided with choices of patient conditions and potential treatment options and various levels of risk(Buchanan 1995; Clemen and Reilly 2001; Gurmankin, Baron et al. 2002; Ubel 2005; Dilts and Ferranti 2008).

Interestingly, while the impact of education *level* has been well researched (Damberg, Hiatt et al. 2003), there has been little research concerning the nature of the *type* of education on individuals with similar education levels. We decided that it would be most effective to build upon existing research in medical decision making, and to explore it in the dimension of educational background. Specifically, we build upon previous research and instruments to investigate the four constructs of: 1) pursuit of additional information(Redelmeier, Shafir et al. 2001), 2) the comparative importance of testimonial versus other information sources (Ubel 2002), 3) experience bias(Chinander and Schweitzer 2003) and 4) availability of provider alternatives, rather than treatment alternatives as is typically evaluated in medical decision making. Each of these topics is discussed further in the survey instrument design aspect of the next section.

4.4   Methodology

This section is divided into two subsections: survey instrument design, and sample, sampling method, and statistical methods utilized in the research.

4.4.1 Survey Instrument Design

General construction – There were two survey instruments developed for this research, each with two parts. Part I, which was identical for both surveys, collected demographic information plus additional general viewpoint questions. These included the respondent's expectation of the influence of "experience" of the physician and pharmaceutical firm on their decision and their feeling as to the quality of information gleaned from the Internet. Responses used a 7 point Likert scale [1: Not at all or Poor to 7: Critical or Excellent]. The survey instrument was piloted in two classroom settings. The first setting, in a class of about 12 graduate students, resulted in the elimination of some questions and refinement of the survey, which was then subjected to a second pilot test with nearly 300 students before final administration to the targeted respondent groups.

Part II was composed of match-paired of hypothetical scenario questions, with one survey having a base scenario and the other having the scenario varied by the factor of interest. This structure was varied alternatively for each scenario, that is, Survey A had the base scenario for all the odd numbered scenarios, but had the varied factor of interest for the even numbered scenarios; and Survey B had the opposite: variation in the even numbered scenarios and base in the odd numbered scenarios. This way there was complete randomization by survey and scenario. Responses were the respondents self-reported likeliness of making a choice using a 7 point Likert scale [1: Extremely Unlikely to 7: Extremely Likely].

Constructs -- Four constructs were evaluated using scenarios, three for each of the initial three, and one for the last construct.

Pursuit of Additional Information: To evaluate the influence of information pursuit on the respondent's medical decisions, we extended scenarios from Redelmeier et al (2001). Their research indicated that the presentation of information impacts the decision of whether to use the information and the perceived importance placed on that information, i.e. if the information is readily available or presented at the initial reviewing, the information is perceived as *less important* than if the provider had to wait for or search extensively for the *same* information (Redelmeier, Shafir et al. 2001). Scenarios also addressed the influence "non-instrumental information", which is additional relevant information that should not change a decision, but merely provides additional reinforcing information. One final aspect investigated was the impact of including information such as side effects on the decision.

Importance of Source and Testimonial Influence: The actual and perceived quality of information may vary depending on the information source (Ubel 2002). As previous research suggests that including patient testimonials in decision aids can greatly influence treatment choices when presented with statistical data on treatment effectiveness, we choose to test testimonials via different modes of communication such as Internet or non-Internet, kind of Internet source, or information from another patient. Additionally, to examine how the amount of testimonials may affect treatment choice, participants were given a choice of 2 treatment options for the low and high risk medical conditions with varying numbers of testimonial support.

Provider experience bias: Expectation of experience influence was directly questioned in Part 1 of the surveys, however these beliefs evaluated in an indirect manner

in Part 2 by providing scenarios where the scenario change was degree of experience. These scenarios were loosely based on the studies conducted by Chinander et al.(2003).

Availability of alternative provider: Shared decision making is based on the availability of alternatives; however such alternatives typically revolve around treatment options. For this scenario, we decided to take a different slant at the question by asking about different alternative providers rather than different treatments. For example, what happens if there is no ability to ask for a second opinion if one lives in a rural or underserved area?

4.4.2   Sample, Sampling Method, and Statistical Methods

For two semesters, a random sample of students from a large academic university's School of Engineering, School of Nursing, and Graduate School of Management were surveyed. Specifically, the sample was composed of senior and graduate level engineering students ("engineers"), graduate nursing students ("nurses"), and graduate management school students ("managers"). The survey was administered in the beginning of each class in the classroom, an incentive was not provided. The participants were instructed that the survey questionnaire would require approximately 15 minutes to complete and participation was voluntary.

A full factor ANOVA design was used with the main effects of survey factor at two levels (Survey A or B), and educational group at three levels (engineers, managers, nurses). The interaction of survey and group was also analyzed. If no statistically significant interactions were discovered at $\alpha=0.05$, Tukey HSD post hoc contrast analyses were performed for statistically significant main effects.

4.5 Results

A total of 486 surveys were returned, a 99% return rate, with Survey A representing 240 subjects and Survey B with 246 subjects. Thirty-one percent (31.5%, n=153) were engineers, 42.4% (n=206) nurses, and 26.1% (n=127) managers. There were 282 (58%) female respondents and 204 (42%) male respondents. Nurses represented 68.4% (n=193) of the females and only 6.4% (n=13) of the male respondents. The mean age overall was 25.5 (SD 5.936), with engineers 20.5 (SD 1.045), nurses 27.5 (SD 7.019), and managers 28.4 (SD 2.936) (p<0.001). Therefore, engineers were younger than the other two groups, and nurses had proportionally more females than the other two groups (See Table 4-1). Thus caution should be used in interpreting the results as the results may be caused by factors other than only educational background. However, assuming that nurses are predominately female and that practicing engineering might be younger than managers is not unreasonable.

4.5.1 Background Questions

In addition to the demographic questions detailed about, Part I of the survey asked three overall questions with respect to impressions of experience and Internet quality. The first of these questions[1] is:

> *"Do you believe the years of experience a physician has should influence a patient's choice of taking a recommended treatment?"*

The mean of each group's responds are: nurses 4.05 (standard error SE 0.101); engineers 4.91, (SE 0.116); and managers 4.87 (SE 0.128). Thus while all groups

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[1] For ease, every question is included in the form it was asked in the manuscript.

consider physician experience as only modest importance, nurses consider physician

experience significantly less important than the other two groups (p<0.001).

> *"Do you believe that the number of years a pharmaceutical firm has manufactured a drug should influence a patient's choice of the drug?"*

The three groups do not consider a pharmaceutical firms manufacturing experience

important, (means and SE for nurses, engineers, and managers respectively were 3.90 (SE

0.123); 4.07 (SE 0.125); and 3.75 (SE 0.144). There is no statistical significant difference

between the groups (p=0.266).

The final background question was:

> *"How good a source of medical information is the Internet?"*

Engineers and managers were statistically more positive toward Internet information

quality than were nurses (p≤ 0.025). The means were, respectively: engineering 4.42 (SE

0.107), managers 4.54 (SE 0.110) and nurses 4.16 (SE 0.09).

4.5.2   Constructs

4.5.2.1 Construct 1: Receipt of Additional Information

The next three scenarios evaluate the first Construct, that of the influence of

additional information either the through the pursuit of the information or the addition of

extra information during the initial encounter. For ease in understanding, all ANOVA and

mean results are presented in Table 4-2, 4-3, and 4-4.

4.5.2.1.1   Scenario 1.1:
Suppose that your 68-year-old relative needs a kidney transplant as a result of renal failure.
> [2][*Survey A: Suppose that you were a suitable match. How likely are you to donate a kidney?]*

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[2] Wording without brackets were the same in both surveys. Wording after [Survey A… was the wording used in Survey A, and wording after [Survey B… was the wording in Survey B. Care was made have only the relevant intervention modified in only one of the surveys.

[Survey B: It is not known whether you are a suitable match, but you could be tested to determine if you are a suitable donor. How likely is it that you would take the test? If you indicated that it is likely (5 or greater) that you would take the test, how likely are you to donate a kidney if the test showed that you were a suitable match?]

This scenario is a variation of Redelmeier et al. (2001), where respondents have the ability to ask for additional information before making a decision to aid another.

There were no statistically significant interactions among the main effects (p=0.671). There were main effect differences by both survey (p<0.001) and group (p=0.009). With respect to acquiring additional information, all groups were more likely to donate if they opted to take the additional test and it proved that they would be a suitable donor (mean Survey A: 4.88, Survey B: 5.49). With respect to groups managers were least likely to donate (mean 4.92 SE 0.159) followed closely by engineers (mean 5.03 SE .127). Nurses were significantly more likely to donate than the other two groups (mean 5.41 SE 0.097).

4.5.2.1.2   Scenario 1.2
Your family has a history of high blood pressure and strokes and you are beginning to worry about your health.
> *[Survey A: You have read that if you are at risk of a stroke, it means that you would have to stop smoking, change your diet, curb alcohol (no more than one beer or one glass of wine a day), and get regular exercise. How likely is it that you would ask your doctor about your potential for high blood pressure? If you indicated that it is likely (5 or greater) that you would like to ask your doctor, please answer the following question: optimal blood pressure is at or below 120/80 ml/Hg. Your doctor tells you that your blood pressure is 150/91 ml/Hg and you are at risk for a stroke.]*
>
> *[Survey B: Your family has a history of high blood pressure and strokes and you are beginning to worry about your health. Optimal blood pressure is at or below 120/80 ml/Hg, but your blood pressure is 150/91 ml/Hg. Your doctor tells you that you are at risk of a stroke and should make lifestyle changes. You would have to stop smoking, change your diet, curb alcohol (no more than one beer or one glass of wine a day), and get regular exercise.]*

> *How likely is it that you would make the lifestyle changes?*

This scenario assesses willingness to make lifestyle changes based on initial risk factors and potential outcomes. There were significant interactions (p=0.014) so the results must be discussed jointly. Interestingly, while engineers and managers remained relatively the same between the two surveys (Engineers - mean 6.07, SE 0.16; 6.17 SE:0.15) (Managers - mean 6.05, SE 0.17; 6.08, SE 0.14). Nurses, on the other hand, changed from being very likely to make the lifestyle change when given limited information (mean 6.53 SE 0.07), but this number dropped significantly (mean 5.97 SE 0.12) when told what life style changes were required.

Scenario 1.2 differs from scenario 1.1 in that the decision of donating a kidney affects both the decision maker and another person, whereas scenario two implores lifestyle changes only by the decision maker and does not directly affect others health. A positive likelihood of donating a kidney or initiating a lifestyle change was noted for all groups in both scenarios. Yet when the decision was based on personal health, the nurses were less likely to change than when their decision involved another person.

4.5.2.1.3   Scenario 1.3

You have been diagnosed with thyroid cancer. The treatment options for thyroid cancer are 1) Partial thyroid removal surgery, which has a 60% cure rate or 2) Total thyroid removal surgery, which has an 85% cure rate. Of the total thyroid removal surgery patients, 2% will have side effects [Survey B added: such as chronic tiredness, tremors, rapid heart beat, or has their voice changed.] .
How likely are you to choose the total thyroid surgery?

This scenario evaluates the influence of listing multiple options and complexity of options in medical decision making. There were no statistically significant interactions (p=0.860), but there were significant difference between groups (p=0.015) and by survey (p<0.001). Nurses again were more willing to donate either with or without the listed side effects (mean 5.87 SE.81) than their engineering (mean 5.55 SE 0.96) or management

124

counterparts (mean 5.54 SE 0.16). And, consistent with other research, listing specific

side effects significantly impacted the choice likelihood (Survey A mean 5.92 versus

Survey B mean 5.45).

4.5.2.2   Construct 2: Impact of Information Source
These three scenarios compare 1) general Internet information versus medical site

specific Internet source, or 2) a medical library versus specific medical web pages, or 3)

general Internet versus a personal testimonial. The last scenario evaluates the influence of

the source as well as the influence of the volume of information received.

4.5.2.2.1   Scenario 2.1
Assume you wear glasses, but they are bothering you and are considering LASIK
(Laser in Situ Keratomileusis) surgery. Searching the Internet using Google, you
discover 332,000 "hits" on [Survey A side effects; Survey B advantages] and
31,500 "hits" on [Survey A advantages; Survey B side effects]. Searching
Medline, you discover 13 articles on [Survey A side effects; Survey B
advantages]and 637 articles on [Survey A advantages; Survey B side effects]. of
LASIK.
How likely are you to have LASIK surgery?

Survey B was reverse coded to ensure accuracy of information. No significant

interactions were found (p=.709), but there were significant group (p=.001) and survey

(p<.001) effects. Nurses are more trusting of Medline information than their counterparts

(mean 5.40 SE .129), and significantly less trusting of general Internet information than

their counterparts (mean 2.66 SE .140). Overall, however, all groups were significantly

more likely to accept a respected source (mean 5.08 SE .094) than a simple Google

search (mean 2.88 SE .100).

4.5.2.2.2   Scenario 2.2
You notice a strange growth on your arm. You are not too concerned, but you
spend half a day [Survey A looking it up in the medical library; Survey B on the
Internet looking it up on medical web pages and Medline.]. Everything you read
says there is nothing to be concerned about. However, when walking to class, a

125

fellow student sees it and remarks that they had something just like it and that it was malignant.

> *How likely are you to make a special appointment with your doctor about the growth?*

Interestingly, there were no statistically significant interactions or main effects with this scenario. While in the previous scenario, Medline was more trusted than the general Google Internet for information, this scenario showed no difference in personal testimony over a good literature medical source. The following scenario also evaluates Internet source, but also factors in volume of information obtained.

4.5.2.2.3 Scenario 2.3

You have been diagnosed with non-melanoma skin cancer. The treatment options for non-melanoma skin cancer are 1) Wide local excision, which has a 75% cure rate and 2) Narrow margin excision combined with adjuvant immunotherapy, which has a 50% cure rate.

You searched the Internet and found [Survey A 8 patients; Survey B: 2 patients] who were treated for non-melanoma skin cancer using wide local excision procedure. [Survey A 6; Survey B: 1] patients were completely cured, but [Survey A 2; Survey B: 1] required additional treatment.
You met [Survey A: 2 patients; Survey B:8 patients] patients who were treated for non-melanoma skin cancer using combination of narrow margin excision and adjuvant immunotherapy. [Survey A 1; Survey B: 6] patient was completely cured, but [Survey A: 1; Survey B:2] one required additional treatment.
How likely are you to get the wide local excision treatment?

No significant interactions were found (p=0.904), but there were significant group (p=0.026) and survey (p<0.001) effects. Survey A respondents (mean, 5.53 SE 0.077) were more likely to have the surgery than survey B respondents (4.78 SE 0.098) indicating a preference of personal testimony. Group differences were noted with nurses

again the outlier with mean=5.34 (SE 0.100), versus engineers (4.95 SE 0.116) and managers (5.07 SE 0.124).

This scenario similar to the previous scenario supports human interaction made a more positive impact than the Internet. Both survey responses indicate that additional information and higher percentage cure rate was chosen by all groups regardless of information source. However, with the personal testimonials factoring in, the likelihood became less for all groups, with managers less affected by the testimony.

All three scenarios addressing Construct 2: Influence of Information Source indicates that personal testimony may impact the decision maker's choice of treatment even in situations where the medical literature does not agree. However, such an impact is not universal, i.e., if information is from either a good medical source or a testimonial, decision makers are more likely to have the condition investigated.

4.5.2.3 Construct 3: Does the Experience of the Information Source Influence the Decision Maker's Decision?

Information source influence was evaluated through the lens of perception of importance of years of experience by both the physicians and medical device companies. Physician experience influence was assessed both in a direct question (previously discussed) and a medical scenario.

4.5.2.3.1   Scenario 3.1

You have of unexplained illness. You decide to visit Dr. Alpha and Dr. Beta, who practice together, for their opinions regarding your condition. Before visiting, you look up information regarding their experience. Dr. Alpha has been in practice for [Survey A: 25; Survey B: 5] years and Dr. Beta has been in practice for [Survey A: 5; Survey B: 25] years. They give different treatment recommendations for your condition.

>   *How likely are you to select [Survey A: Dr. Beta's; Survey B: Dr. Alpha's] recommendation?*

How likely is it that the amount of <u>experience</u> influenced your decision?

There were no statistical significant interaction (p=0.388) nor main effect differences by survey (p=0.118), but there were significant differences by group (p<.001), with nurses more likely (mean 4.29 SE 0.082) that engineers (mean 3.51 SE 0.104) or managers (mean 3.89 SE 0.113).

The follow up question is a direct question inquiring about the influence of the physicians experience on the respondent's decision. This question elicits statistical significant differences among the groups (p<0.001), but not with survey type (p=0.108) or group to survey interaction (p=0.193). Additionally, when asked directly, the nurses responded that experience was not a factor in their decision; this is contrary to their scenario results where they responded by choosing the less experienced physician more frequently.

4.5.2.3.2   Scenario 3.2

[<u>Survey A:</u> You have gone to your 60-year-old physician, who you have gone to all your life, for chronic back pain; <u>Survey B:</u> You have recently moved into a new town. Due to chronic back pain, you visit a 60-year-old physician.] She has suggested that you have lower back surgery. When searching the Internet for more information, you discover that surgery is not often done for low back pain because, in most cases, the cause of the pain cannot be helped by surgery (source: webMD.com).

How likely are you to follow the surgery recommendation?

There were no statistical significant interaction (p=.715) nor main effect differences by survey (p=.079) or group (p=.089). Surprisingly, all scores were low (under 3.25).

4.5.2.3.3   Scenario 3.3

To treat a condition, you need to purchase a specialized medical device. The device is made by two manufacturers. Company Gamma [Survey A: has been manufacturing the device for 15 years; Survey B: originally designed the device, processed it through the FDA approval process, and has been manufacturing it for 15 years.] and Company Delta has been manufacturing the FDA approved device for 3 years. The devices contain identical parts.

> *How likely are you to select Company [Survey A: Delta's' Survey B: Gamma] device?*

> *How likely is it that the amount of company experience influenced your decision?*

There were no statistical significant interaction (p=0.674) nor main effect differences by group (p=0.992), but there were significant differences by survey (p<0.001). Respondents were more likely to use a device from a firm that the more extensive level of experience with the device (mean 5.10 SE 0.079) than one that only had years of experience (mean 4.18 SE 0.094).

These results indicate that the more information provided as well as the experience of the manufacturer was a factor in the decision process, which contradicts the previous responses indicating that experience did not affect their decision making practice when the question was posed hypothetically without a medical scenario. Experience influence was slightly evident with medical devices; however, the experience of a sixty year old physician does not appear to be the primary influence in the respondent's decision making. The first scenario evaluating physician experience and the manufacturing experience scenario responses are close to neutral likelihood. In all of the above scenario constructs, an alternative option has been available for the respondents to select. The following scenario will address whether this alternative affects the decision makers choice.

4.5.2.4 Construct 4: Availability of an Alternative Provider

4.5.2.4.1   Scenario 4.1

You have been diagnosed with Irritable Bowel Syndrome. Your primary care physician has informed you that two well known gastroenterologists have recently started practice in a local hospital, Dr. Zeta [Survey A: and Dr. Phi.] When visiting Dr. Zeta's office you are given a waiver to sign informing you that Dr. Zeta has no malpractice insurance and that you promise not to sue for any reason. [Survey B: Upon calling, you discover that Dr. Phi has insurance and does not require a waiver.]

How likely are you to use Dr. Zeta's services?

There were no statistical significant interaction (p=0.795) nor main effect differences by group (p=.985), but there were significant differences by survey (p<0.001). Not surprisingly, none of the respondents like the options (overall mean 2.42), however they like the no-provider alternative less (mean 2.10 SE 0.089) than the provider alternative (mean 2.67 SE 0.102).

4.6   Results Summary

Pursuit of Additional Information (construct 1) revealed interesting results when the respondent's decisions involved other people such as donating a kidney, versus requiring a personal lifestyle change. This difference was particularly noticeable with the nurses' responses as they were the most likely to donate even prior to information pursuit, yet not as likely to enact personal lifestyle changes with information pursuit relating to their own health. Additionally, as the immediate risks are identified in donating a kidney, the risk levels of not making lifestyle changes may not be seen as an immediate consequence.

Construct 2, the impact of the information source was evident in two of the three scenarios; with differences in groups noted when given the choice between Google and Medline, Medline is the chosen. While Medline was preferred to Google, testimonials were preferred to Medline information or information obtained from a medical library or the general Internet. Construct 3, experience was viewed differently by the three groups in one of the three scenarios. Construct 4, availability of a provider alternative did not reveal differences among the three groups but did demonstrate the rejection of having limited provider choice Table 4-5.

4.7   Discussion

There are many factors to consider when assessing the influences in medical decision making. We assessed numerous influences; however, one caveat that must be made is that our sample population was students, who were asked to *assume* that they had received the various diagnoses, and not patients, who were *actually* required to make the decision.

Although few disagree that patients need to be involved in their medical decision making treatment choice; few agree on the best way to present the information. While some researchers advocate the use of numbers or probabilities citing that uncertainties communicated verbally are frequently interpreted differently among the patients with large variation as well as the propensity of vagueness leading to more variability (Gurmankin, Baron et al. 2002), other community members note that numbers are more difficult for patients to understand and words are easier to comprehend (Gurmankin, Baron et al. 2004).

The four constructs tested in this research illustrate that not only does additional information affect decisions, so do a wide variety of factors, including the key one for this research: educational background.

In the direct questions evaluating experience, the groups did not consider the physician's experience, or the pharmaceutical company's experience as major factor in their decision making. The nurses, the only medically related participants, did consider the physicians experience less relevant than their engineering and manager counterparts.

The influence of side effects or complexity of choices, both types of ways to provide additional information for assistance in medical decision making, and the high risk testimonial thyroid cancer scenario responses illustrate differences when the responses added side effects and advantages as well as percentages of "cure" rates. These results also indicate that when listing side effects, participants had a significant tendency to choose another option, despite the fact that the other option had a lower cure percentage rate (60% versus 85%), and that only 2% of "total excision patients" experienced the side effects. Although all groups showed a dampening effect on the treatment selection when listing side effects, nurses were still more likely to agree to total thyroid removal than the other two groups.

As many healthcare providers struggle with divulging the appropriate amount of information, as well as the legal accountability to inform their patients of all possible consequences, these results illustrate that exhaustive listings of potential outcomes may lead to *less* desirable choice selection, prompting patients to make choices based on misunderstood probabilities, instead of lifestyle preference, and physician recommendations. Physicians are increasingly challenged with providing sufficient

information in a manner that is easy to understand so that their patients can make informed decisions, but not so much that the "most appropriate" choice is lost because the patient does not understand or is afraid. Unfortunately, in today's litigious environment, and the ever- increasing access to various medical diagnoses and treatment options via the Internet, some with misinformed or incorrect information, this problem is not likely to disappear. Even so, in the scenario in which no alternative was available the sample population was reluctant to sign a malpractice waiver.

Rational thinking would suggest that participants should pick the alternative with the highest "cure" rate; however, similar to other research, our results indicate that this is not always the case. Although not statistically different, the mean scores indicate that while many choose the option with the highest cure rate, others did not. How is this so? Supporting previous research, our results indicate that indeed the inclusion of side effects can sway ones decision away from a higher cure rate to a lower cure rate. Awareness of this cognitive bias may lead to improved decision making in complex medical situations (Redelmeier, Shafir et al. 2001). For providers, it is important to note that when providing side effects a simple listing may need further explanation complete with severity of side effects as well as the expected time required for the side effects to resolve. Previous research suggests that the inclusion of testimonials with statistical data in decision aids can influence ones treatment choices, our results did not provide statistical significance that testimonials origin are as influential as previously thought. Nonetheless, those meeting patients were less likely to choose wide excision than those testimonials found on the Internet. However the number of testimonials may significantly influenced ones decision toward one treatment option or another (Ubel, Jepson et al. 2001; Ubel 2002;

Ubel 2002), is supported in our non-melanoma skin cancer scenario, where both surveys' respondents lean towards "wide excision treatment", the survey version with the greater number of wide excision testimonials choose wide excision statistically more frequently than the respondents in survey B ($p<0.001$), which had fewer respondents for wide excision. Additionally, the respondents with the higher in person testimonials for the lower percentage success rate narrow excision treatment had a lower propensity to have the wide excision treatment. Whether testimonials presented proportional or disproportional to the statistical information of particular treatment options can play a significant role in choosing the optimal option (Ubel, Jepson et al. 2001). Although not tested by Ubel or Redelmeier, group differences were not statistically significant, even though, the nurses were consistently more likely to choose wide excision than their engineering or management counterparts.

Information pursuit or the addition of more information does not always precipitate a change or event. It may elicit a "non-response", such as the case in scenario 1.2 where the more information pursued and obtained had a negative relationship to prompting a life style change. However, in the high risk scenario with participants contemplating two types of surgery for thyroid cancer, those receiving additional information in the form of side effects, were less likely to choose the more invasive surgery than those participants receiving fewer side effect details. This is important as physicians attempt to decide how much and what type of information to relay to their patients.

Providers must not only assess what level of information and type of information to provide to each patient but, as Damberg et al. (2003) noted, while patients consistently

demand high levels of information, their involvement in their decision making is not as predictable. Specifically, they cited studies showing that 69% of hospitalized cancer patients wanted to actively participate in their treatment regimen although older cancer patients preferred to take a less active role (Blanchard, Labrecque et al. 1988; Damberg, Hiatt et al. 2003).

The key characteristics of medical decisions include importance and certainty(Braddock, Edwards et al. 1999). While including the patient is desirable, noting the differences of people's personal values and importance of medical facts may not be congruous between the provider and the patient(Whitney, Holmes-Rovner et al. 2008). Part of the provider's responsibility includes assessing their patients and the level of involvement they wish in their treatment regime. However, before a provider can engage the patient in their treatment plan, the provider must be aware of the more recent and accurate options available. This timeliness is not only important for the provider in gathering information, but also for the patients in acquiring additional information from various information sources as some patients are very active in their treatment plan.

4.7.1   Medical Registry Role in Decision Making

While classic decision making theory does not involve the use of technology, technology's increasing availability may impact its role in the decision making process. One such technology is that of the medical registry. As evident from our research, the reliability of an information source and the correct amount of information shared with the patient is paramount to a good decision making process. A medical registry has the potential to provide trustworthy recent medical information to the physicians necessary to

assist in their decision making. Additionally, since the majority of the information about treatments and treatment successes (and failures) is accessed through one source, the physician can decide what options and amount of information should be reviewed, further investigated or factored into the decision. Additionally, a medical registry may address decision making through its use and ability to track and compile numerous treatment options, which may later reflect in best practices, evidenced based medicine and indirectly lessen practice variations.

As wide practice variation continues to flourish in the clinical community, medical registries provide a means to capture the various decision making patterns. Although uncertainty and "sunk costs" bias elements are components of decision costs, such as a provider choosing not to recommend or follow a new treatment because that provider has always followed a different treatment regime. Previous research has shown, providers receiving feedback and peer (non-identifiable) comparisons with practice variations adhere to suggested guidelines and alter their practices more readily than those not receiving feedback or connected to peer networks(Schmittdiel, Bodenheimer et al. 2005). A medical registry has the ability to provide this feedback and analysis of practice variations.

Schmittdiel et al (2005) results indicate that organizations with registries are apt to provide more feedback as well as have other Information Technologies, such as patient reminder systems. This feedback is an important aspect in a physician's performance as multiple studies have shown that feedback improves practice (Myers, Turner et al. 2004; Schmittdiel, Bodenheimer et al. 2005; Sender Liberman, Liberman et al. 2005).

Previous research indicates that physicians who access a registry frequently, use the obtained information in their decision making process (Ferranti, Putnam et al. 2008). In the past, physicians have relied on their own experience as their primary source of information for formulating a treatment plan and making decisions about treatment options, however, registries may provide them with additional information that they can share with their patients and formulate a specific patient specific treatment plan. As many factors influence both patients and physicians medical decision making tools, the use of a medical registry may assist both groups in obtaining more specific medical information, improve the quality of the information obtained, and therefore impact the quality of the decision made.

Returning to our four decision making situations:

In situation one, the primary medical decision maker is the physician, therefore the additional information or pursuit of information is often an overlooked step, where by the physician is relying on their own experience to make the decision and minimally involving the patient. While the physician views his experience as very important this was not always evident depending on the educational background of our respondents. In this situation, the physician may offer an alternative treatment, but likely will make a recommendation. The physician in situation 2, will utilize informal communication with colleagues as an information source to complement own experience. Again, in this scenario, the patient will most likely receive additional treatment options and information from outside sources, in which case the information source and types of additional information collected may negatively affect the decision process.

In situations 3 and 4, the physician and the patient are active participants in the process. While these two scenarios have the potential to have the best decision making process, it may also require the most patience and cooperation. As our research shows, the background of the decision makers may lead them to different conclusions, with each emphasizing a different area. In these situations, it is imperative that the physician can accurately communicate side effect probabilities, levels of success as well as other pertinent statistical information for the available alternatives. As physicians are charged with communicating these statistics and medical registries provide mostly quantitative information.

4.8   Conclusion

Medical decision making is a complex arduous process involving many intricate factors. This research has shown that one of those factors is the educational background of the decision making participants. Recognizing that the educational background of the providers is essential, and will not only assist in actual patient treatment decision making, but also in the education and training of providers. This is particularly important as this research indicates that the only group surveyed with medical experience, were most different from the other two groups i.e. the majority of the patient population. This finding illustrates the difficult task that providers have in presenting options to their patients as many follow different decision making rules. Although not currently utilized by the majority of physicians, a medical registry has the potential to assist the provider gain access to the most recent validated data and information of treatment options for patients most similar to their own; thus decreasing the amount of information requiring

speculation and improving the opportunity for the best treatment selection.

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TABLE 4-1: Background Information on Survey

Respondents	Survey			Gender			Age	
	A	**B**	**Total**	**Female**	**Male**	**Total**	**Mean**	**Std. Error of Mean**
Engineers n=	78	75	153	46	107	153	20.46	0.08
%	32.5%	30.5%	31.5%	16.3%	52.5%	31.5%		
Nurses n=	103	103	206	193	13	206	27.47	0.49
%	42.9%	41.9%	42.4%	68.4%	6.4%	42.4%		
Managers n=	59	68	127	43	84	127	28.39	0.26
%	24.6%	27.6%	26.1%	15.2%	41.2%	26.1%		
Total n=	240	246	486	282	204	486	25.5	0.27
%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%		***.000**

143

TABLE 4-2: ANOVA Results

Scenario	Survey Effect	Group Effect	Interaction Effect
1.1	**0.000**	**0.009**	0.671
1.2	0.184	0.324	**0.014**
1.3	**0.000**	**0.015**	0.860
2.1	**0.000**	**0.001**	0.709
2.2	0.120	0.582	0.188
2.3	**0.000**	**0.026**	0.904
3.1	0.388	**0.000**	0.118
3.2	0.079	0.089	0.715
3.3	**0.000**	0.992	0.674
4.1	**0.000**	0.895	0.795

TABLE 4-3: Scenario Mean Values

Scenario	Survey A	Survey B	Engineers	Nurses	Managers
1.1	4.88	5.49	5.03	5.41	4.92
1.2	Interaction Effect (See Table 4.4)				
1.3	5.92	5.45	5.55	5.87	5.54
2.1	5.08	2.88	3.96	4.03	3.9
2.2	No effect				
2.3	5.53	4.78	4.95	5.34	5.07
3.1			3.51	4.29	3.89
3.2	No effect				
3.3	4.18	5.10	4.65	4.74	4.68
4.1	2.10	2.67	2.39	2.42	2.46

TABLE 4-4: Scenario 1.2

Group	Survey A	B
Engineers	6.07	6.17
Nurses	6.53	5.97
Managers	6.05	6.08

TABLE 4-5: Scenario Results

Scenario	Survey Effect	Group Effect	Interaction Effect	Survey Difference	Comment
Additional Information					
1.1- Kidney Donation	**0.000**	**0.009**	0.671	Yes	Key Difference with Nurses (more likely)
1.2- Lifestyle Change	0.184	0.324	**0.014**	Interaction	Nurses went in different direction (less likely)
1.3- Thyroid Side Effects	**0.000**	**0.015**	0.860	Yes	Nurses different (more likely to have surgery)
Impact of Information Source					
2.1- Google vs.. Medline	**0.000**	**0.001**	0.709	Yes-Medline preferred	Nurses different (more trusting of Medline)
2.2- Medical Library vs. Webpage; testimonial	0.120	0.582	0.188	No	No difference
2.3- Internet vs.. Testimonial	**0.000**	**0.026**	0.904	Yes	Nurses different (more likely to follow higher cure percentage rate)
Experience					
3.1-MD experience	0.388	**0.000**	0.118	No	Nurses different (more likely to choose less experienced)
3.2- MD Experience (back pain)	0.079	0.089	0.715	No	No difference
3.3- Manufacturer Medical Device Experience	**0.000**	0.992	0.674	Yes more experienced chosen	More experience preferred
Availability of Alternatives					
4.1- Waiver	**0.000**	0.895	0.795	Yes	Difference on waiver

SAMPLE SURVEY ADMINISTERED TO ENGINEERS, GRADUATE LEVEL NURSES, AND GRADUATE LEVEL MANAGEMENT STUDENTS

1   Introduction

The objective of this survey is to investigate some of the factors involved when people make medical decisions. The survey contains two parts. The first collects background information. The second part provides a variety of health scenarios and asks for your opinion about how likely you would be to make a particular choice. Please do not put your name anywhere on the form because all of your answers will be kept confidential.

2   Part 1: Background Information & Calculations

1. What is your major/concentration(s)?

   _____
                    Year in Program: _____

2. What is your sex?:   Female: _____   Male: _____

3. What is your age?:   _____

4. Are you an international student? Yes_____   No _____;

5. Using the following scale, do you believe the years of experience of a physician should influence a patient's choice of taking a recommended treatment? (Please circle one number)

   Not at all [1…2…3…4…5…6…7] Critical to the Choice

6. Using the following scale, do you believe the number of years a pharmaceutical firm has manufactured a drug should influence a patient's choice of drug?

   Not at all [1…2…3…4…5…6…7] Critical to the Choice

7. Using the following scale, how good a source of medical information is the Internet?

   Poor [1…2…3…4…5…6…7] Excellent

Please fill in the blank with the correct number:

8. If there is a 1% chance that a stomach ulcer will reappear after a treatment, how many cases of reappearing ulcers will occur if exactly 1000 patients are treated?

   _____ Cases out of 1,000

9. A brain tumor operation has three equally probable outcomes. 1) the tumor is completely removed, 2) the tumor is not completely removed, or 3) the tumor is

completely removed, but the patient is paralyzed. If 1,200 operations are performed, how many patients will have no tumor remaining?

_____ *Patients out of 1,200*

10. If there is a 1 in 5 chance of prostate cancer remaining after a treatment, how many patients will still have prostate cancer if 1,000 undergo treatment?

_____ *Patients out of 1,000*

3   Part 2: Health Care Scenarios

In this section, there are a number of different scenarios. Please read each scenario and then circle the scale value that most closely fits your likeliness of making the choice. Use the following likelihood scale:

Likelihood Scale:
1   Extremely Unlikely
2   Very Unlikely
3   Unlikely
4   Indifferent
5   Likely
6   Very Likely
7   Extremely Likely

For example, if you are indifferent to the choice in the scenario you would circle 4. If, on the other hand it is extremely likely that you chose the option, you would circle 7.

Scenario 1

Suppose that your 68-year-old relative needs a kidney transplant as a result of renal failure. Suppose that you were a suitable match.
How likely are you to donate a kidney? (circle one)

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 2

Your family has a history of high blood pressure and strokes and you are beginning to worry about your health. You have read that if you are at risk of a stroke, it means that you would have to stop smoking, change your diet, curb alcohol (no more than one beer or one glass of wine a day), and get regular exercise.
How likely is it that you would ask your doctor about your potential for high blood pressure?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

If you indicated that it is likely (5 or greater) that you would like to ask your doctor, please answer the following question: optimal blood pressure is at or below 120/80 ml/Hg. Your doctor tells you that your blood pressure is 150/91 ml/Hg and

you are at risk for a stroke.   How likely is it that you would make the lifestyle changes?

Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

Scenario 3

Assume you wear glasses, but they are bothering you and are considering LASIK (Laser in Situ Keratomileusis) surgery. Searching the Internet using Google, you discover 332,000 "hits" on side effects and 31,500 "hits" on advantages. Searching Medline, you discover 13 articles on side effects and 637 articles on advantages of LASIK.
How likely are you to have LASIK surgery?

Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

Scenario 4

You have been diagnosed with thyroid cancer. The treatment options for thyroid cancer are 1) Partial thyroid removal surgery, which has a 60% cure rate or 2) Total thyroid removal surgery, which has an 85% cure rate. Of the total thyroid removal surgery patients, 2% will have side effects.
How likely are you to choose the total thyroid surgery?

Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

Scenario 5

You have been diagnosed with non-melanoma skin cancer. The treatment options for non-melanoma skin cancer are 1) Wide local excision, which has a 75% cure rate and 2) Narrow margin excision combined with adjuvant immunotherapy, which has a 50% cure rate.
- You searched the Internet and found 8 patients who were treated for non-melanoma skin cancer using wide local excision procedure. Six patients were completely cured, but two required additional treatment.
- You met 2 patients who were treated for non-melanoma skin cancer using combination of narrow margin excision and adjuvant immunotherapy. One patient was completely cured, but one required additional treatment.

How likely are you to get the wide local excision treatment?

Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

Scenario 6

You have of unexplained illness. You decide to visit Dr. Alpha and Dr. Beta, who practice together, for their opinions regarding your condition. Before visiting, you look up information regarding their experience. Dr. Alpha has been in practice for 25 years and Dr. Beta has been in practice for 5 years. They give different treatment recommendations for your condition.

How likely are you to select Dr. Beta's recommendation?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

How likely is it that the amount of experience influenced your decision?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 7

To treat a condition, you need to purchase a specialized medical device. The device is made by two manufacturers. Company Gamma has been manufacturing the device for 15 years and Company Delta has been manufacturing the FDA approved device for 3 years. The devices contain identical parts.

How likely are you to select Company Delta's device?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

How likely is it that the amount of company experience influenced your decision?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 8

You have gone to your 60-year-old physician, who you have gone to all your life, for chronic back pain. She has suggested that you have lower back surgery. When searching the Internet for more information, you discover that surgery is not often done for low back pain because, in most cases, the cause of the pain cannot be helped by surgery (source: webMD.com).

How likely are you to follow the surgery recommendation?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 9
You notice a strange growth on your arm. You are not too concerned, but you spend half a day looking it up in the medical library. Everything you read says there is nothing to be concerned about. However, when walking to class, a fellow student sees it and remarks that they had something just like it and that it was malignant.

How likely are you to make a special appointment with your doctor about the growth?

Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

Scenario 10
You have been diagnosed with Irritable Bowel Syndrome. Your primary care physician has informed you that two well known gastroenterologists have recently started practice in a local hospital, Dr. Zeta and Dr. Phi. When visiting Dr. Zeta's office you are given a waiver to sign informing you that Dr. Zeta has no malpractice insurance and that you promise not to sue for any reason. Upon calling, you discover that Dr. Phi has insurance and does not require a waiver.

How likely are you to use Dr. Zeta's services?
Extremely Unlikely [1…2…3…4…5…6…7] Extremely Likely

The Convergence of Major League Baseball and Medical Decision Making

Case one: Weekend Pitcher

Weekend pitcher Jim, is a fastball pitcher and because fastballs have retired the previous two batters, he throws all fastballs to Marc. Although, Marc is a fastball hitter, Jim is indifferent to Marc's preferences. Practicing the "law of small numbers" principles, Jim relies on his experience with the two previous batters.

Case 2: (Dugout: Peers)

Sam, a minor league baseball pitcher, is preparing for his first game against the Yankees; he consults with the other pitchers on his team for advice on pitching to the first batters. His teammates, who have previously pitched to Jeter, advise Sam to throw curve balls down and out to Jeter, who does not hit curve balls very well. Even though Sam has a better fastball than curve ball, the information provided by his teammates helps Sam to strike- out Jeter.

Case 3: (Coach: Game statistics)

Preparing for today's game, Major League Baseball, Manager Charlie Manual studies game statistics from the previous two days and finds that most of the Mets players are fastball hitters. Coach Manual relays this information to his pitchers. In addition, he provides today's pitcher, Lieber with more detailed information about the batters from his previous meetings with the Mets, offering detailed information on strike- outs, home

runs, and walks. He also has information on the Mets performance against other Phillies pitchers or from previous years playing that he shares with his team and coaching staff. As the game progresses, Coach Manual compiles additional batting statistics for his players as well as his pitching staff's performances against particular Mets batters. This knowledge assists Coach Manual and the pitching coach on when instructing the pitcher and catcher on how to pitch to the batters or make a pitching change during the upcoming innings or games.

Case 4: (Broadcast Booth)

Major League Baseball commentator, Joe Morgan proudly announces to the listening audience that Roger Clemens will only last one or two more innings as he has thrown 89 pitches and 40 are fastballs through four innings. Morgan is basing his assertion on data indicating that Clemens normal pitch count has never been above 100. Unbeknownst to the pitching staff, the broadcast booth announcers observe the umpire's strike zone has become very narrow. Using technology, the broadcast booth and viewers see after each pitch the strike zone and pitch location. While the Coaches or fielding players can relay this information at the end of an inning, the announcers are privy to the information earlier permitting them to "suggest" the pitch location and speed for each batter even during the current at bat between pitches. The broadcast booth uses current real-time data to help them relay information to the viewing public.

Applying the baseball analogy to medicine, assume that the physician could gain access to new treatment options for the upcoming "inning" pitchers instead of utilizing the preference of the last "batter's" hitting repertoire. In addition, that the physician could compare his batting average to his peers against the fastball, curve ball or sinking ball or

with certain batters. In fact, medical registries may provide that vehicle to access knowledge more quickly. More importantly, some medical registries permit "end of inning" analysis, rather than only post-game analysis. In addition, medical registries can assist in tracking practice variation for the providers.

Similar to case one's weekend pitcher, whose previous limited experience throwing fastballs led to strike- outs, and case two's minor league baseball's informal "consultations", physicians frequently rely on their previous limited successful treatment plans to treat an illness or informally consulted colleagues(Coleman, Katz et al. 1966; Fontanarosa and DeAngelis 2003; Schechter and Margolis 2005). Few physicians and managers have access to recent knowledge of the available treatments and their effectiveness. However, baseball managers and broadcast announcers use as much real-time data as possible in their respective positions. For instance, if an opposing team's pitcher is a late withdrawal, then Coach Manual makes changes based on the new pitcher and the broadcast booth is ready to announce the pitchers accuracy after the first pitch. However, most physicians similar to Dr. South and Dr. North do not access the most current data or utilize the new guidelines in their practice until much later(Fontanarosa and DeAngelis 2003). While some physicians may have started their own "mini-registry", most continue to rely on implementing "the law of small numbers" (Tversky and Kahneman 1971), to organize their treatment plan.

Presently, physicians and baseball managers alike have the ability to make decisions based on more recent data than their counterparts 20 years ago. A medical registry has the ability to compile and evaluate real-time data for the physician as well as permit the physician access to the most recent treatment options. Similar to the manager

changing pitchers from one batter to the next, the registry permits a physician the opportunity to alter the ongoing treatment based on the changing data available. In many instances, this access permits current patients to benefit from the most recent treatment options.

Medical Decision Making and baseball have evolved very similarly. During its initial inception, baseball teams played with much uncertainty. Not only, did the team members frequently change, but also, scores were often not reported for years. This uncertainty left others not privy to watching the game and the specific players, little information to base their opinions on the teams' and players' abilities in order to develop a strategy for playing against the team.

Moving forward a few decades, baseball became more organized and the once racially divided leagues were merged (Major League Baseball 2009) it was then that the players and coaches became more aware of the other league members abilities. In addition, teams also had the advantage of previous meetings recollection. However, even though prior knowledge was gleamed from previous years, real- time current season during the game information were not available. Decisions were frequently based on how a general player performed last season; for example, how a left-handed batter performed against a left –handed pitcher, not particular to the batter or the pitcher facing today.

Presently, Major League Baseball teams have the ability to track a particular player's statistics from game to game, from pitcher to pitcher, as well as from one at bat to the next. Concurrently, while tracking a particular batter, a manager can track his team's pitcher or the other teams pitcher's performance, "pitch count, type, tendencies, and velocity", not only is the manager aware of the pitcher's performance in his most

recent outing, but also, as the game progresses. This detailed real-time tracking permits the manager to instruct his batter to adjust to the pitching changes from one batter to the next; or if it his right-handed pitcher in place to face the next batter and the batter is left-handed, the manager may decide to substitute a left-handed pitcher. The manager may also be privy to statistics that match up his left-handed pitcher to the upcoming left-handed batter.

This real-time up to date information allows the managers and players to make decisions based on more timely data, which should lead to more informed and improved decision making. Instead of relying on past data that may reveal that a batter has a .210 batting average, but does not disclose that the batter had an injury during that time, the manager can utilize data that provides a picture of the batter's more recent performance, which may indicate a batting average of .300; consequently, the manager can make a pitching change based on more than distant past performances, leading to more informed decision making.

Applying the baseball analogy to medicine, assume that the physician could gain access to new treatment options for the upcoming "inning" pitchers instead of utilizing the preference of the last "batter's" hitting repertoire. And, that the physician could also compare his batting average to his peers against the fastball, curve ball or sinking ball or with certain batters. In fact, medical registries may provide that vehicle to access knowledge more quickly. More importantly, some medical registries permit "end of inning" analysis, rather than only post-game analysis. In addition, medical registries can assist in tracking practice variation for the providers.

Similar to baseball's formal beginnings, physicians (prior to1950's) informally consulted colleagues or had to rely on their own expertise to treat a new illness(Coleman, Katz et al. 1966). Few physicians as managers had access to recent knowledge of the available treatments and their effectiveness. While some physicians may have started their own "mini-registry", most relied on implementing "the law of small numbers" (Tversky and Kahneman 1971), to organize their treatment plan.

Jackie Robinson's entry into Major League Baseball, in 1947, and the subsequent demise of racially segregated baseball (Major League Baseball 2009) permitted managers the opportunity to evaluate players more often through either radio or watching the players in play. In addition, recognizing that game statistics such as "home runs", "at bats", and "strike outs" were important game statistics, these numbers were tracked. Similarly, in 1960's, Spratt, an oncologist, recognized the importance of tracking cancer patients and developed the first paper based registry(Spratt 1966). Medicine has always recognized the need to track incidence and prevalence rates, since "typhoid Mary"; and as such resulted in practice changes years later. As in baseball, even though physicians' had limited access to information concerning previous patients and their treatment, they still lacked real-time "game day" treatment options.

Similarly, as Jackie Robinson and (the hiring GM) were the "first adopters" /first to change practice, such as changing league expectations, with some teams immediately following suit, others did not adapt quite as quickly such as the Boston Red Sox and Cleveland Indians, which did not integrate until 1956, ten years later (Major League Baseball 2009). Medical practice change has met an equally daunting challenge when implementing a change in expectations or practice patterns. Although Spratt saw the need

for a cancer registry in 1966, other cancer groups did not initiate their registries until much later.

Presently, physicians and baseball managers alike have the ability to make decisions based on more recent data than their counterparts 20 years ago. A medical registry has the ability to compile and evaluate real-time data for the physician as well as permit the physician access to the most recent treatment options. Similar to the manager changing pitchers from one batter to the next, the registry permits a physician the opportunity to alter the ongoing treatment based on the changing data available. In many instances, this access permits current patients to benefit from the most recent treatment options. While physicians and baseball managers have more information at their disposal, consistent acceptable measures to determine their decision making practices, remain less agreeable.

The following section will address potential ways to measure physician decision making practice.

Measuring Physician Practice

Physician practices can be measured in a number of ways. This example measures two decision points of practice: 1) the time it takes from the creation of "new" knowledge to enter into general practice; and 2) if the new knowledge is in practice and there remains a high degree of practice variation, then is the entry or timing of new knowledge entry into practice relevant.

When assessing physician practice, these two elements are interrelated such as in our baseball analogy: how long it takes a batter to learn to hit a new "curve ball" pitch,

but is still not comfortable swinging at it, and how consistently does he recognize the new "curve ball" and try to hit it.

While bench to bedside, and practice variation both contribute to the primary gap of translating research results into practice, other factors also affect the breadth of the *GAP*. For example: Holland-Barkis et al (2005) study reveals that even when some physician's are aware of practice guidelines, adherence varies widely even within the same clinical setting, and especially when deciphering the differences in specialties, such as all obstetricians were aware of ACOG guidelines, but merely 76.3% of family practitioners knew of their specialty guidelines(Holland-Barkis, Forjuoh et al.). Furthermore, where guidelines are published also make a significant difference when assessing which physicians were aware of the guidelines(Holland-Barkis, Forjuoh et al.). Physician practice variation, "variation phenomenon", "is so robust and consistently documented that it may be one of the most universal characteristics of modern medicine"(Margo 2004). Other potential causes include 1) lack of information access, 2)the providers maintaining a wait and see attitude, i.e. they know the information, but are waiting to implement their own practice changes until others have documented success, 3) providers having no incentive to change their practice, 4)patient population uniqueness, and 5) the well documented practice inertia. A medical registry does not address all of the potential causes of the *gap* from new knowledge to entry to practice use, but may moderate some of the causes (See Table 1-1). Utilization of a medical registry is one way to assist physicians in their decision making. Patient advocates such as the Kantar Family foundation also support the creation of an outcomes database to assist patients in their medical decision making (Kantor Family Foundation 2009).

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CHAPTER V

MEDICAL DECISION MAKING:
IMPACT OF INNUMERACY

5.1 Preface and Research Model

Previous chapters have discussed medical registry and user characteristics, as well as the difference in decision making procedures per educational background. However, does this difference hold true when testing numeracy proficiency of the respondents? This chapter presents the results of a survey developed and administered to test innumeracy skills, particularly with regard to percentage calculations and probability interpretations. These mathematical skills were chosen particularly because much of the medical information is presented in this manner in a medical registry or on the Internet, as well as by many healthcare professionals when discussing treatment options to their patients. This chapter shows that numeracy proficiency varies based upon respondents' educational backgrounds. Even with highly educated individuals, numeracy literacy is problematic and educational background of both provider and patient impact medical decision making.
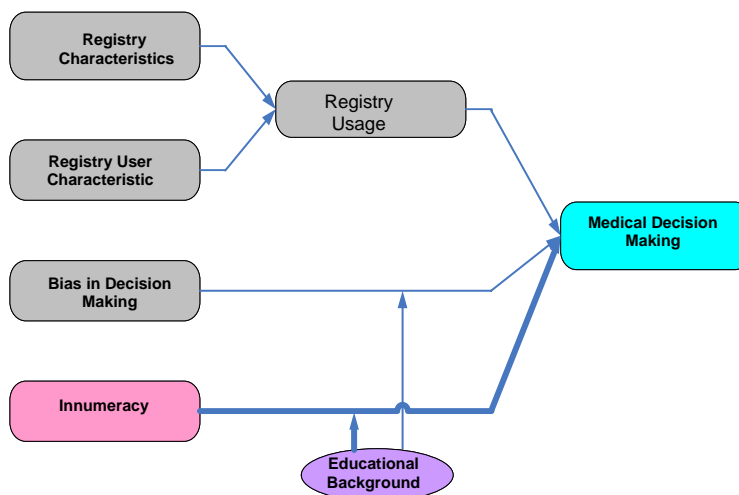
5.2   ABSTRACT

Background: Numeracy's influence on medical decision making continues to remain problematic, thus it is rarely evaluated particularly with respect to educational background. Patient involvement in decision making increase, the education and numeracy proficiency of the patient and provider become more critical.

Objective: To assess whether educational training impacts numeracy competency in medical decision scenarios.

Design: Building on postulates of innumeracy influence, three medical scenarios are tested. Two of the scenarios assessed familiarity with probabilities and one required respondents to convert a percentage to a proportion. All results were evaluated using chi-square (χ^2) statistics.

Setting/Sample: Random sample of three university students groups. 486 surveys were returned, 153 undergraduate engineering, 206 undergraduate and graduate nursing, and 127 graduate management students.

Results: Overall, 74% responded incorrectly to at least 1 scenario. Additionally, responses to 2 of the 3 scenarios revealed significant differences among groups (p<0.001) and p=0.006). Specifically, 7.3% of nurses responded incorrectly, while only 4.6% engineers and .8% of managers responded incorrectly in the probability scenario. One unique finding is that all groups "skimmed" one scenario, which led to missing

information necessary to compute correct responses. This detailed scenario resulted in a poor performance when evaluated using strict correct/incorrect measure (54.4%, 40.5%, and 37% incorrect responses by nurses, engineers, and managers respectively ($p<0.001$).

Conclusion: Numeracy proficiency varies in medical scenarios based upon educational major. Even with highly educated individuals, numeracy literacy is problematic and educational background of both provider and patient impact medical decision making.

5.3   Introduction

Numeracy's influence on shared medical decision making continues to remain problematic as it is frequently perceived to be either a non-factor or only a minor limitation of a research study, particularly when compared to the perceived importance of patient or physician's age, gender, or propensity for risk(Benowitz 2000; Institute of Medicine 2001; Berwick 2003; Lewis, Robinson et al. 2003). Thus, the importance of literacy in numerical meanings, or numeracy, is rarely evaluated before moving forward in assessing the influences of medical decision making. Historically, most major physician-patient healthcare decisions were made by physicians, with limited patient participation (Quill and Brody 1996). However, with direct-to-consumer advertising for pharmaceuticals (Toop and Mangin 2007; Evans and McCormack 2008), increase in privacy and safety issues (Institute of Medicine 2001; Rothstein and Talbott 2006), and dramatic rise in availability of patient-obtained medical information (Xie, Dilts et al. 2006), the current trend in medical decision making is to inform and involve patients intimately in their medical treatment plan. This is considered a top priority in the medical community to promote shared decision making (Lipkus, Samsa et al. 2001). However, do patients understand numeracy issues when presented for healthcare decisions and, of importance for this paper, does the educational background of patient impact the degree of numeracy?

Most medical decision recommendations are structured on the assumption that patients understand quantitative information (Schwartz, Woloshin et al. 1997). Ubel (Ubel 2002) cites a 1997 Schwartz et al. study of the public's ability to understand probabilities in medical scenarios -- where only one third of the respondents answered

three quantitative questions correctly -- as an obstacle in patient participation in medical decision making, particularly when decision alternatives are presented as probabilities or likelihoods. Merely presenting patients with numerical data does not guarantee that they understand the information provided or can correctly interpret the values, numbers, probabilities, or outcome likelihoods provided (Skinner, Kreuter et al. 1998; Ubel 2002; Gurmankin, Baron et al. 2004). As noted in Bramwell et al. (Bramwell, West et al. 2006) even those providing the statistics may not accurately interpret the results; they found an average 86% of incorrect responses provided by obstetricians, midwifes, pregnant women, and companions accompanying the pregnant women.

Part of the problem may lie with healthcare providers in disseminating such numeracy information because, as suggested by Weinfrut et al. (Weinfurt, DePuy et al. 2005) and Chao et al. (Chao, Studts et al. 2003) suggests, risk and benefit quantitative information can be confusing even for medically knowledgeable participants. Yet, this has not hindered the pharmaceutical industry or the national media in inundating the public with "health statistics" such as: 1 in 10 people develop a certain disease; that the "western diet" i.e., fried foods, salty snacks and meat, accounts for approximately 30% of heart attack risk worldwide.(American Heart 2008); or that individuals should buy a home defibrillator since "less than 1 in 20 people survive largely because a defibrillator was not available" (Philips 2005).

While there are numerous potential decision making issues with respect to numeracy, we focus on three primary areas: 1) informed consent, 2) patient knowledge, and 3) healthcare providers' numeracy proficiency, and communication. The following discussion encompasses influences and obstacles presented in all three areas.

5.3.1　Informed Consent and Numeracy

Informed Consent, as defined by the American Medical Association (AMA), is a process of "communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention" (American Medical Association 2008) evidenced by a patient signing a written consent form. It has been assumed in the past that merely signing the form was adequate proof of consent and understanding. However, more broad definitions also mention the physicians' ethical obligation to ensure that the patient understands what is being presented and is "competent" to participate in the decision making process (Wagner and Keany 2006). Numeracy becomes a significant issue when informed consent is required for a clinical trial, as potential risks and benefits are typically presented in numerical formats.

Need for additional patient knowledge has become more pronounced as treatment options per disease increase, as patients demand additional information to assist in their decision making (Damberg, Hiatt et al. 2003), and as HIPAA requirements specify that patients make decision about their medical records. With such growth, comes an increase in informed consent protocols and a subsequent need for improvement to the informed consent process (Kaufmann 1983; Varricchio and Jassak 1989; Jimison, Sher et al. 1998). Even though informed consent has many purposes and provides an excellent opportunity for physicians and patients to engage in an active dialog to verify comprehension; this dialog frequently does not occur due to such factors as time limitations (Braddock III, Edwards et al. 1999), patient anxiety (Faden and Beauchamp 1996; Jimison, Sher et al. 1998), or poor literacy skills (Taub and Baker 1983; Flory and Emanuel 2004). To further complicate matters, research shows that only half of the individuals receiving

health education information comprehend such information (Holt, Hollon et al. 1990; Doak, Doak et al. 1998; Jimison, Sher et al. 1998). For example, one study of cancer clinical trials consent forms showed that they contained 73% of passages written at a college level or above (Jimison, Sher et al. 1998) for populations where 20% are considered functionally illiterate (Jimison, Sher et al. 1998). So even when the physician attempts to communicate such risk and provide written explanations, comprehension remains an obstacle in many simplest situations (Ancker and Kaufman 2007; Peters, Hibbard et al. 2007).

Furthermore, as the lines blur between informed consent for treatment and informed consent for research, the complexity and amount of information communicated between the patient and physician becomes increasingly difficult. Examples of this include such obstacles as variable probabilities depending on placebo or "drug" that are used in a study, or the use of Bayesian probabilities for potential outcomes. Additionally, there is the possibility that neither the patient nor the physician will understand such statistically variable side effects or outcomes.

5.3.2   Patient-Obtained Medical Information and Numeracy

Jimison (1998) noted that patients had four major reasons for wanting information, 1) treatment compliance, 2) to veto physician's decision 3) to enhance their own decision making, and 4) respect for their wishes (Jimison, Sher et al. 1998); three of these reasons may be directly applicable to their medical treatment options (Lidz, Meisel et al. 1983) . Thus, this list highlights the necessity that both the physician and the patient understand the information communicated and presented.

A particular need for numeracy in medical decision making occurs in outcomes research. Such research addresses the nuances involved when there is no single treatment best for all patients and the physician is tasked with presenting multiple options (Wennberg, Barry et al. 1993; Damberg, Hiatt et al. 2003). Wennberg et al. (1993) (Wennberg, Barry et al. 1993) observe that "when the outcomes of a particular treatment are multiple and when more than one treatment option exists, an optimal treatment choice for individuals depends on the evaluations they give to the risks and benefits associated with alternative treatments with the outcomes that matter to them". While taking into account patient desire for information so that they can prioritize such issues as quality of life, many authors argue that this information is not easily accessed, organized or understandable to patients when they are trying to make their treatment choice (Damberg, Hiatt et al. 2003; Whitney 2003; Erickson 2004) or that access to such data leads to "rational" decision making in all cases (Ubel 2002). Others cite financial or administrative burdens that may bias rational decision making (Sanidas, Valassiadou et al. 2000; Damberg, Hiatt et al. 2003). Finally, some outcomes research proponents put forth that outcomes databases or registries such as "People like Me" may help reduce these obstacles (Damberg, Hiatt et al. 2003), others cite that patients in such registries may be the most ill, and consequently have worse outcomes than less severe cases, thus making treatments in the registry appear less effective (Mantel 1983).

Another issue is the increase in patient-obtained medical information (Bramwell, West et al. 2006), such information, gathered from Google or PubMed (for the more knowledgeable patient), may bias the patient to an inappropriate choice. The physician is then charged with parsing, addressing, and interpreting the large volume of

misinformation that the patient obtained from questionable information resources. One component of this information concerns numeracy as it often contains proportions, probabilities or frequencies to communicate the success of the treatments.

5.3.3 Healthcare Provider and Numeracy

Such the numeracy challenges do not only pertain to the patient side of the equation; deficient numeracy skills are also found in the healthcare professional (Merz, Druzdzel et al. 1991; Nelson, Reyna et al. 2008). Metz (Merz, Druzdzel et al. 1991) noted that physicians were inconsistent in qualitatively categorizing risk; and furthermore physicians find it challenging to work with odds ratios or decimals. Gramling et al. (Gramling, Irvin et al. 2004) found that 97% of physicians maintained higher confidence with qualitative verses quantitative formats for risk communication. Consistent with the theory of Reasoned Action and the theory of Self-Efficacy (Gramling, Irvin et al. 2004), these findings imply that the physicians are more inclined to communicate risk qualitatively as 93% of their respondents stated that qualitative risk was important to their practice; yet 76% also perceived quantitative risk as important; however, 84% perceived qualitative risk as more important than quantitative; hence, while they believe that quantitative risk is important, when required to present the risk to their patients, physicians communicated risk qualitatively more often than quantitatively. Furthermore, physicians indicated that only 36% felt they could effectively communicate numeric risk as compared to their 87% confidence in their ability communication of qualitative information (Gramling, Irvin et al. 2004). This factor is important as literature shows that

the method the physician chooses to present the information also presents inherence
biases (Ancker and Kaufman 2007).

Qualitative and quantitative dissemination methods continue to evolve as new and
innovative decision aids are created. Examples span from disease-specific patient chat
rooms and physician-only message boards to websites where personal diagnosis
information is entered for analysis. While some of these methods are a mixture of
quantitative and qualitative, many of these decision aids are based on numeracy
concepts(Lipkus, Samsa et al. 2001), such as the Canadian Cancer Society's decision aid
for breast surgery, which states probabilities such as 6 out of 100 (Canadian Cancer
Society 2001).

While the number of decision aids have prospered, mathematical computations
and probability understanding and proficiency that were once assumed have become a
question of concern, resulting in studies addressing the influence of numeracy on medical
decisions both by physicians as well as in physician-patient collaboration (Paulos 1990;
Black, Nease et al. 1995; Adelsward and Sachs 1996; Schwartz, Woloshin et al. 1997;
Lipkus, Samsa et al. 2001).

As shared decision making has increasingly been identified as a goal in risk
communication between doctors and patients (Lipkus, Samsa et al. 2001) particularly in
decisions with treatment options and medical interventions producing equitable outcomes
(Gafni and Whelan 1997; Frosch and Kaplan 1999; Lipkus, Samsa et al. 2001), lack of
numeracy comprehension or at least fear of numbers remains a valid stumbling block.

Much like numeracy itself, one little studied aspect of numeracy is the potential
impact that educational background may have on medical decision making. The question

of interest for our study is: does educational background impact numeracy skills? If this is the case, then education background of both the healthcare provider (in our case, senior level nursing students) and the patient (senior level engineering students and graduate management students) must be taken into account when designing medical decision making tools. In order to answer this question, we tested frequencies, probabilities and risk levels with students from three different discipline majors: engineering, nursing, and management. Our prior expectations is that engineers, with their heavy training in mathematics, would have better numeracy skills, followed by nurses, and management students least.

5.4   Methods

Building on postulates of innumeracy influence (Ubel 2002), we adapted three questions from Schwartz et al.(1997), placing them in three different hypothetical medical scenarios. Two of the questions assessed familiarity with probabilities and one question required respondents to convert a percentage to a proportion. When designing the survey questions, the numeracy definition utilized by Estrada (2004) were followed, namely: "Numeracy is defined as the ability to handle basic probability and numerical concepts" (Estrada, Martin-Hryniewicz et al. 2004). All results were evaluated using chi-square (χ^2) statistics, with alpha level of significance of .05.

5.4.1   Sample

A random sample of students from a private top 50 ranked university's School of Engineering ("engineers"), School of Nursing ("nurses"), and Graduate School of

175

Management ("managers") were surveyed. For all three groups, questionnaires were distributed as part of their respective classes and participants were given a two-minute verbal description of the study, which included disclosure of survey anonymity and voluntary participation. A total of 486 surveys were returned, of which 153 were undergraduate engineering students, 206 were undergraduate and graduate nursing students, and 127 were graduate management students. There were 282 female respondents and 204 male respondents. Overall, fifty eight percent of the respondents were female (n=282), with nurses comprised significantly more female respondents than the other majors (68%, n= 193; engineers 16.3%, n=46; managers 15.2%, n=43) (p<.001).

The mean age of all the groups was 25.5 (SE 0.27); with engineers younger 20.5 years old (SE 0.08) than the other two populations nurses 27.5 (SE 0.49), and managers 28.4 (SE 0.26) (p<0.001).

5.5   Results

Overall, 25.7% of respondents answered all questions correctly; meaning that 74% of the respondents incorrectly answering at least 1 question. This result does not take into account partial credit for question 3, which is discussed later.

The first question required calculating a number from a percent, in the scenario:

"If there is a 1% chance that a stomach ulcer will reappear after a treatment, how many cases of reappearing ulcers will occur if exactly 100 patients are treated?"

Table 5-1 illustrate the results, which indicate that 7.8% of nurses provided incorrect answers, with 5.9% and 5.5% of engineers and managers respectively with incorrect responses. These differences were not significant (p=0.696).

The second innumeracy question required respondents to evaluate three equal probable outcomes for a brain tumor operation:

> *A brain tumor operation has three equally probable outcomes. 1) The tumor is completely removed, 2) the tumor is completely removed, but the patient is paralyzed, or 3) the tumor is not completely removed. If 1,200 operations are performed, how many patients will have no tumor remaining?*

The first evaluation, a strict correct or incorrect result, showed 54.4%, 40.5%, and 37% incorrect responses by nurses, engineers, and managers respectively (p<0.001)(Table 5-2). Due to the complexity of the question, we further evaluated the answers by analyzing the answers that were correct, incorrect, or "nearly correct," defined by the fact that the question was misinterpreted or misread and, in post-survey debriefing sessions, the respondents indicated that they mis understood the phrasing of the question or overlooked the fact that option #3 included that there was no more tumor. This is an interesting result in itself as it showed that the phraseology of the question may have led the respondents to misinterpret the complete question and focus only on part of the question. Further investigation should be completed to see if this is a common phenomenon with patients and healthcare providers.

The "incorrect" responses dropped significantly in all three groups once partial credit was given for the "semi-correct" answer. Utilizing the new scoring format, engineers had 8.5% incorrect answers, 32% nearly correct and 59.5% correct, with nurses having 8.7%, 45.6%, and 41.7%, and managers 9.4%, 27.6%, and 63% of incorrect,

"nearly" correct, and correct answers respectively (Table 5-3). Overall, the percentages were: 8.8%, 36.6% and 52.9% (p<0.001).

The next probability question asked participants to compute:

If there is a 1 in 5 chance of prostate cancer remaining after treatment, how many patients will still have prostate cancer if 1000 undergo treatment?

Overall, Table 5-4 illustrate that 4.7% of the respondents provided incorrect answers, with 7.3% of nurses, 4.6% of engineers, and 0.8% of managers answering incorrectly (p=0.006).

5.6   Discussion

The results of this study support previous research findings that poor numeracy knowledge and lack of probability knowledge may result in misappropriate use of quantitative information. Surprisingly, even though our respondents were will above the norm in educational level, as all of our respondents had some college education (most with at least a junior level status), 25.7% experienced difficulty utilizing quantitative data.

Although few disagree that patients need to be involved in their medical decision making treatment choice; few agree on the best way to present the information. While some advocate the use of numbers or probabilities, often citing that uncertainties communicated verbally are frequently interpreted differently among the patients with large variation as well as the propensity of vagueness that leads to higher variability (Gurmankin, Baron et al. 2004), others note that numbers are more difficult for patients to understand and words are easier to comprehend (Gurmankin, Baron et al. 2004). And

as Huizinga et al (2008) found, the framing of information presentation affects the patient's ability to understand what is presented and "may impact health outcomes" (Huisinga, Elasy et al. 2008).

Our results concur with finding that show that numbers were difficult to compute and understand. Our numeracy results were not quite as positive as Gurmankin et al. (2004) as their sample "on average" answered 7 out of 9 questions correctly while ours "on average" only answered about 1 out of 4 (25.7%). These results are more similar to Lipkus et al. (2001) overall result of "on average, 18% and 32%" of participants providing correct answers and slightly higher than Schwartz et al. (1997) result of 16%.

Another finding is the difficulty that future nurses had with numeracy scenarios, where they were often statistically less likely to arrive at correct results than either future engineers or managers. As nurses are one of the major sources of medical information provided to patients, such a finding is troubling (Ernst 2008).

One surprising result of our study is the difficulty that all participants showed in their inability to successfully answer the mixed mode questions such as "completely removed, not completely removed, and completely removed but paralyzed", Acknowledging this deficit is especially important since many of the medical decision options are phrased in this manner; for example "partial removal of impinging disc with some remaining limitations, or complete removal of disc with higher probability of more serious side effects" (Ernst 2008), as well as because many available decision aids have scenarios phrased in this way (Canadian Cancer Society 2001).

5.7   Conclusion

With office visits mean time ranging between 14 and 17 minutes (Braddock III, Edwards et al. 1999), it is no surprise that physicians do not always provide complete explanations or confirm that patients understand completely treatment options and probabilities before a patient leaves the physician's office. Yet, patients continue to request for more information, frequently resorting to the Internet for more disease specific treatment options and potential outcomes statistics (Damberg, Hiatt et al. 2003). As other studies (Institute of Medicine 2001; Ancker and Kaufman 2007; Evans and McCormack 2008; Nelson, Reyna et al. 2008) have indicated, much of this information is at least partially presented in numeric format with percentages and probability interpretation knowledge required. Our findings confirm that even in highly educated populations, such information maybe misunderstood.

Consumer-driven healthcare is based on permitting patients to consider their own values or preferences for particular treatments or outcomes, rather than having a physician only provide generalized information of the options and outcomes (Dowding, Swanson et al. 2004). Although O'Connor et al (O'Connor, Stacey et al. 2003) results indicate that those patients using decision aids increase their knowledge; this may not translate to increased numeracy knowledge. Their study also found that patients who utilized decision aids with detailed descriptions of probabilities as well as other detailed information were more likely to have realistic risk and benefits expectations (Damberg, Hiatt et al. 2003; O'Connor, Stacey et al. 2003). Given our results, it would be interesting to understand the background of the patients in their study.

Edwards' (2001) systematic review suggests: "that probability estimates can be effective for improving outcomes, particularly if tailored to the individual" (Edwards and Elwyn 2001; Damberg, Hiatt et al. 2003). However, this assumes that the patient understands the numeracy estimates provided. Damberg et al. (2003) systematic review acknowledged the potential numeracy limitations, as it conceded that numeracy is difficult to understand (Edwards and Elwyn 2001; Kennelly and Bowling 2001; Lloyd 2001; Damberg, Hiatt et al. 2003). In this review, these same studies indicate that while, some prefer quantitative information, and many prefer qualitative risk presentation such as high or low. Our finding, supported by numerous education and psychology studies that people learn in different manners, further emphasizes the need to present the information in multiple ways, incorporating educational background, in order to best assure that the interpretations are correct.

Our results further underline the need to assess numeracy knowledge in both the patient and healthcare provider populations so that deficiencies in numeracy can appropriately address. Merely, eliminating numeric information from treatment explanations is not a plausible short term or long term option, especially given the increase in avenues for patients to obtain information.

Providing numeracy education and training for healthcare provider's (nurses and physicians) as well as patients will assist in reducing the innumeracy levels. Future research in decision tools should include the addition of qualitative factors to explain the more complex scenarios involving numeracy.

While there are numerous potential decision making issues with respect to numeracy, we focused on three primary areas: 1) informed consent, 2) patient knowledge,

and 3) healthcare providers' numeracy proficiency, and communication, and this research indicates that each of these areas are not independent of another. Although future research is needed to assess the interaction of these areas, it is a reasonable assumption that by ensuring that the informed consent adheres to the fifth grade level reading comprehension and more informed patients and improving healthcare providers' proficiencies in communication of statistics, both providers and patients will benefit.

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TABLE 5-1: Ulcer Results

Grouping	Incorrect		Correct	
	n	% of Total	n	% of Total
Engineers	9	5.9%	144	94.1%
Nurses *	16	7.8%	189	91.7%
Managers	7	5.5%	120	94.5%
Total	32	6.6%	453	93.2%

* 1 missing response from nursing sample

** No statistically significant differences among groups (Pearson Chi-Squared: p=0.696)

TABLE 5-2: Tumor Results – One Error

| | **Incorrect** | | **Correct** | |
Grouping	n	% of Total	n	% of Total
Engineers	62	40.5%	91	59.5%
Nurses *	112	54.4%	86	41.7%
Managers	47	37.0%	80	63.0%
Total	221	45.5%	257	52.9%

* 8 missing response from nursing sample

** Groups are statistically significant (Pearson Chi-Squared: p<0.001)

TABLE 5-3: Tumor Results – Two or more Errors

| | **Incorrect** | | **Nearly Correct** | | **Correct** | |
Grouping	n	% of Total	n	% of Total	n	% of Total
Engineers	13	8.5%	49	32.0%	91	59.5%
Nurses *	18	8.7%	94	1.0%	86	41.7%
Managers	12	9.4%	35	27.6%	80	63.0%
Total	43	45.5%	178	36.6%	257	52.9%

* 8 missing response from nursing sample

** Groups are statistically significant (Pearson Chi-Squared: p<0.001)

TABLE 5-4: Prostate Results

| Grouping | Incorrect | | Correct | |
	n	% of Total	n	% of Total
Engineers	7	4.6%	146	95.4%
Nurses *	15	7.3%	186	90.3%
Managers	1	0.8%	126	99.2%
Total	23	4.7%	458	94.2%

* 5 missing response from nursing sample

** Groups are statistically significant (Pearson Chi-Squared: p=0.006)

CHAPTER VI

CONCLUSIONS

6.1   General Conclusions

Medical registry use and the educational background of decision makers influence medical decision making. This research investigated medical decision making 1) by physicians who use medical registries and 2) the impact of the educational background of those participating in the medical decision making process. The research was divided into four main components:

1) a systematic review of registry literature, including its purpose, use of outcome measures, and factors discussed,

2) an evaluation of the differences between registry user and non-users in their decision making process,

3) an investigation of the potential influence on medical decisions of the decision makers educational background i.e. nurse, engineer or managers, and

4) an analysis of the mathematical skills of the decision makers with different educational backgrounds.

The research findings provide insight into factors related to medical decision making and the complexity of the process and the individuals making the decisions. Additionally, this research identifies the potential areas of future research to include more registry design impact and the use of registries for decision making in other professional organizations. These findings also reveal that the educational background of the decision maker needs

future study, especially when including general public access to a registry designed for a specific medical professional population.

6.2   Medical Registries: A Systematic Review of the Literature

Chapter 2 addressed proposition 1, in how the design of a medical registry may affect its use in decision making. The use of a medical registry may impact medical decision making in multiple ways, hence it is important to understand the purpose, design, and characteristics of the registry . This research discovered that most of the literature on registries concerned how to utilize the registry as a data source or sample population for research study. Three primary aspects for a registry, noted in the literature, were 1) data quality within the registry, 2) registry use and 3) registry design (i.e., how to build a registry).

The potential for the greatest impact in decision making with a registry is with the timeliness of the data, which is often driven by the registry design. The majority of medical registries discovered in the literature are passive, retrospective registries and, while they are an excellent resource for research populations, they do not provide real-time access for healthcare providers to use in selecting ongoing treatment options.

Medical registries have the greatest initial potential in rare disease or diagnosis, where providers do not see the repetitive symptoms or diagnosis sufficiently often to gain experience for quick diagnosis and treatment. This potential is most likely to occur with active registries. Prospective-observational based, also known as Real Time Science Based registries, are "active" registries that permit an ongoing timely evaluation of the

data permitting ongoing treatment evaluation and regimen changes, thus identifying key elements in the decision making process.

The ability of a medical registry to provide up-to-date information as well as aggregate data can provide the physician with more recent treatment options and their progress thereby positively affecting their patients. Additionally, medical registries may provide an alternative to multiple Internet searches by both physicians and patients.

6.3 Impact of Registry Use in Medical Decision Making: The Case of the Society of Thoracic Surgeons

In chapter 3, the registry characteristics identified in chapter 2, are incorporated into a survey designed to evaluate the decision making practices of registry users and non-users. The Society of Thoracic Surgeons provided the sample setting. The survey evaluated five major components: respondent demographics, medical registry use, decision making practices and the use of evidenced based medicine, and the use of other technologies in medical practice.

The research findings showed no difference in demographics such as years of experience and practice setting between those participating in the registry and those choosing not to participate. As one would expect, registry satisfaction differs based on the use of the registry with registry users more satisfied than the non-users. Additionally, neither group identified data quality or security as an issue encouraging or discouraging their use of the data provided or as a reason for not using the registry. Maintenance costs were noted as a significant barrier for those not using the registry, but not for those already participating.

Medical decision making was affected by those participating in the registry as they used the registry in direct patient care. While both groups overwhelmingly utilize evidenced base medicine and practice guidelines, the registry users responded more frequently to using such information. Additionally, not only did the registry user's trust the information provided by the registry reports, but they also utilized this information in their decision making process.

6.4   Medical Decision Making: Impact of Educational Background

In chapter 4, which studied the influence of educational background , found that the final decision choice was affected by the educational discipline of the decision maker (proposition 3). This research compared the medical decision making choices of three different educational groups: engineers, nurses, and managers. These findings illustrated that nurses were influenced more differently than their engineering and manager counterparts. For example, the pursuit of additional information was more influential in nurse's decision choices than engineers or managers.

All groups were influenced by the source of the data, although to varying degrees, again the nurses were most trusting of known medical sources such as Medline. However, personal testimonials were the preferred information source by all three groups. Physician experience was also viewed differently as nurses were more likely to select a younger physician. Such an experience gap was not discovered when viewing medical device companies. The findings also showed that even when an alternative provider option was available, the respondents were not likely to sign a malpractice waiver.

Similar to Cox et al. (2005), which studied pediatric physician education during medical school and residency and showed that how one was educated influenced their future practice, my research illustrates that the discipline of the education will influence current medical decision making.

6.5   Medical Decision Making: Impact of Innumeracy

Chapter 5 addresses proposition 4 and it shows that innumeracy is a factor when making decisions. The findings of this research indicate that future nurses have more difficulty interpreting numeracy scenarios, where they were often statistically less likely to arrive at correct results than either future engineers or managers. As nurses are one of the major sources of medical information provided to patients,(Ernst 2008) such a finding is troubling. One surprising result of my study is the difficulty that all participants showed in their inability to successfully answer the mixed mode questions such as "completely removed, not completely removed, and completely removed but paralyzed", Acknowledging this deficit is especially important since many of the medical decision options are phrased in this manner; for example "partial removal of impinging disc with some remaining limitations, or complete removal of disc with higher probability of more serious side effects" (Erstad 2008).

The findings of this research also highlight the importance of follow-up inquiry to ensure understanding of the information provided; as noted through the follow up process employed in this research to ascertain the extremely high percent (greater than 40%) of participants calculating an incorrect response. From this inquiry it was determined that the phrasing of the scenario may have led to a misunderstanding of the question, which

led to an incorrect response. The implications of this misunderstanding are particularly important as patients are becoming more active participants in the decision making process coupled with the poor mathematical skills found in even my highly educated sample, could lead to incorrect decision choices.

6.6   Overall Conclusions

Medical decision making is a complex process with many integral pieces. The use of a medical registry may positively affect one of those factors: timeliness of information. This time line is minimized with active registries, such as the one developed by the Society of Thoracic Surgeons. However, simply providing the information via the medical registry may not impact decision making. This research shows that medical decision making is different depending upon the use or non-use of a medical registry, with those using a registry utilizing it to gather information that factors into their decision making practice. The use of a medical registry may also assist in tracking and evaluating global health issues as well as specific disease conditions within specific geographic areas. However, as my additional findings show, a registry must be carefully designed as there are difference in how even objective data may be interpreted.

The medical decision making process is also influenced by the educational background of both patients and healthcare providers. My research has demonstrated that there are statistically significant differences in decisions made by individuals with different educational backgrounds even when presented with the same medical scenario. While most medical registries are only utilized by physicians, proponents of the current movement to develop patient-centered databases must be cautious in their assumptions of

the level of understanding capability of their users. This is particularly true with respect to numeracy proficiency, where this research showed that differences exist even within a highly educated sample.

Overall my research has discovered that active medical registries, while valuable for clinical practice, remain the least discussed registries in the literature. Also, providing information from a registry without understanding or acknowledging the education background of the user can be problematic particularly when numeracy skills are required.

6.6.1   Impacts on the Physician-Patient Relationship

Historically, most major physician-patient healthcare decisions were made by physicians, with limited patient participation (Quill and Brody 1996). However, with direct-to-consumer advertising for pharmaceuticals (Toop and Mangin 2007; Evans and McCormack 2008), increase in privacy and safety issues (Rothstein and Talbott 2006; HHS 2008), and dramatic rise in availability of patient-obtained medical information (Xie, Dilts et al. 2006), the current trend in medical decision making is to inform and involve patients intimately in their medical treatment plan. This is considered a top priority in the medical community to promote shared decision making (Lipkus, Samsa et al. 2001). The use of a medical registry may assist in this communication, but may also hinder the communication if the information is not clearly understood by those attempting to communicate the options or by the patients interpreting the physicians' or nurses presentation of available options. Physicians need to be cognizant that patients may not follow the same decision making rules when options involve different levels of

risk. Additionally, as patients are requesting more timely access to information, the use of a registry may provide this information or feedback more quickly than the current available options.

6.6.2 Limitations and Future Research

The results and findings from this research are only applicable in the context of their specific settings. Medical registries are available for multiple professional organizations for such diseases as childhood cancers, chronic diabetes, and oncology clinical trials; this setting was limited to adult cardiac, adult thoracic or pediatric cardiac surgeons. Future research should include other specialty groups including both those with active registry designs as well as passive registry design.

Another limitation is this research only focused on the registry designed for only medical professionals, not the patient target population. Registries are also being developed for the patient population to access such as the outcomes registry co-sponsored by the Kantor Family Foundation and AHRQ (Damberg, Hiatt et al. 2003). To determine more generalizability, future research should include those registries designed for patient use as well as those registries designed for physicians or medical experts, which are accessed by the general population.

This research also provided a unique setting for testing the impact of educational background . All of the respondents were from a top tier university at the upper levels of undergraduate programs or graduate school. Future research should also include other educational disciplines to determine whether the differences evident from this research such as that nurses may follow different decision making rules than engineers or

197

managers, are also evident among other disciplines involved in the medical field as well as others not in healthcare related studies. Additionally, future studies should include more patient populations to evaluate the key influences in their decision making process.

Mathematical skills were assumed to be above normal in the sampled population. However, this assumption should be met with some skepticism as the results indicated that even this higher educational group had difficulty with some basic statistical computations. Future research should not only include a lengthier questionnaire, but also include physicians and actual patients.

This brings up the final limitation: the setting of the decision making survey did not test patients who are participating in actual medical decision making. The setting provided medical scenarios to respondents who were presumed to be healthy. It is difficult to assess whether the decisions put forth during a scenario situation are the same as those when made under more stressful situations.

6.6.3   Uncovering Additional Factors

This research also discovered that, while previous research indicated that privacy of data was a key limiting factor for technology use, this was not the case here. Additionally, my research revealed that utilizing active registries to assess or track patient outcomes is an area that is yet to be fully realized. Outcomes research, as defined by AHRQ "*Outcomes research seeks to understand the end results of particular healthcare practices and interventions*."As my research has shown, the ties between outcomes and registries have yet to penetrate the scholarly literature, with less than 26% of the literature mentioning both items.

Moreover, this research revealed that the response to a direct question does not always elicit the same response when placed in the context of a medical scenario. This was particularly evident when investigating the importance of physician experience.

Another key component recognized is the propensity to skim readings rather than thoroughly read a given document. The ability to recognize this factor led to more refined and explainable responses to the survey.

The influence of a malpractice waiver was particularly evident as even when the availability of alternative provider choice was not an option, the majority of the respondents were not likely to sign the waiver, hence opting to not visit a physician rather than see one requiring a waiver.

An additional factor discovered was that the same decision rules may not apply if the medical decision involved others or only the individual responding.

6.6.4   Overall Impact on Researchers and Patients

The registry users use this information in their decision making process. The active registry design may provide an excellent learning opportunity for both the researcher and the practitioner for incorporating it into their decision making practice. For example, Pediatric residents are taught that the standard of care practice is that their leukemia patients will be entered into the registry, thus when they enter their own practice, they continue to learn the process learned in medical school and residency(Coleman, Katz et al. 1966; Robbins 1981). One pediatric study (Cox, Smith et al. 2005) indicates that when a physician is exposed to certain literature and learns a practice in medical school, it transcends into their future practice patterns. This practice is

different from other specialties where the registry often does not play a major role in the delivery of care.

The incorporation of teaching registry use in particular, active registries, which comprise chronic disease registries such as diabetes management, and continuous quality improvement registries, such as The Childrens Oncology Group, capture active clinical decision making and encourage continuous ongoing involvement, which may in turn assist in better decision making outcomes.

Additionally, the influence of numbers and the educational background may also be addressed during residency or medical school education. Moreover, for researchers, who frequently work with statistics, or the clinical physician attempting to present oncology clinical trial options, the recognition that similar competency levels do not exist for other specialties and care must be taken to assure that even discussing statistics with other professionals, the interpretation may be different. Finally, as medical registries has been shown to impact medical decisions, and as medical information is increasingly being requested by the general public, it is vital that an understanding of how the educational background of the public/patient may impact their view of the information provided and that other influences may lead one to follow different decision rules.

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