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## Understanding and Characterizing Shared Decision-Making and Behavioral Intent in Medical Uncertainty

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Dissertation

**Understanding and Characterizing Shared Decision-Making and Behavioral Intent in  
Medical Uncertainty**

By

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March 31, 2011

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Understanding and Characterizing Shared Decision-Making and Behavioral Intent in Medical  
Uncertainty

A

DISSERTATION

Presented to the Faculty of  
The University of Texas  
School of Biomedical Informatics  
at Houston  
in Partial Fulfillment  
of the Requirements

for the Degree of

Doctor of Philosophy

by

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by

Roxana Maria Maffei

2011

## **DEDICATION**

To

my parents, Mario and Natalia, for giving me every opportunity possible to pursue my goals, and  
for instilling in me the importance of hard work and education

my husband, Daniel, for his ongoing support and patience, for being my sounding board.

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## INTRODUCTION

*“The core predicament of medicine- the thing that makes being a patient so wrenching, being a doctor so difficult and being a part of a society that pays the bills they run up so vexing – is uncertainty. Medicine’s ground state is uncertainty. And wisdom – for both patients and doctors – is defined by how one copes with it.”*

- Atul Gawande, *Complications: A Surgeon’s Notes on an Imperfect Science*, 2002.

There is always some degree of medical uncertainty present when it comes to medical reasoning.<sup>1,2</sup> It appears in many facades during the medical consultation. Some of the scenarios in which this uncertainty appears include: the risk of occurrence of a disease; the probability that preventive, diagnostic, or therapeutic interventions will be effective for a given individual; the risk of adverse consequences from therapeutic interventions; and the long-term prognosis.<sup>1</sup> A recent summary of the state of medical knowledge reported that nearly half, 47% of all treatments for clinical prevention or treatment were of unknown effectiveness, and an additional 7% involved an uncertain tradeoff between benefits and harms.<sup>3</sup>

Shared decision-making (SDM) has been identified as an effective technique for managing uncertainty involving two or more parties.<sup>4</sup> Shared decision making between patient and physician involves both parties engaging in a communal dialogue regarding medical options and preferences before the actual decision and plan of action are made. Other techniques for managing uncertainty include meticulous history-taking & evaluation and establishing trust with patient.<sup>5</sup> However, from the available research regarding medical uncertainty, the most productive way to deal with this inevitable component of medical decisions is by practicing shared decision-making whenever possible.

Despite the identification of SDM as an effective technique, it is under circumstances of medical uncertainty, where even less shared decision-making is practiced between a physician and patient.<sup>4</sup> A recent survey conducted by the Foundation for Informed Decision Making claimed that 84% of physicians say that uncertain information was a barrier to shared decision-making.<sup>6</sup> Consequences of lack of shared decision-making in medically uncertain situations include: decreased satisfaction and confidence in the medical encounter; insufficient

understanding of the health issues discussed; inadequate coping skills regarding health problems/issues; patients living with undesirable consequences that are against lifestyle and/or personal values; and greater decisional conflict related to feeling informed.<sup>7-10</sup>

Since medical issues involving uncertainty are complex and may be difficult to communicate, especially if not provoked or directly engaged, a physician's intent is often to revert to nondisclosure or oversimplification.<sup>11-13</sup> Physicians may opt to oversimplify or avoid discussing these issues with patients.<sup>11-13</sup> Subsequently, patients may be left with incomplete or distorted accounts of the issues involved and decisions made regarding the medically uncertain health matter. Shared decision-making, under these particular circumstances of medical uncertainty can be regarded as an important and critical aspect to maximize patient education and safety.<sup>14</sup> Shared decision-making has also been shown to: improve psychological and well-being outcomes, as well as provide physicians with more insight into their patients' lives and their ability to tolerate effects of certain treatment options.<sup>14</sup>

Although shared decision-making has proven to be an optimal solution for medically uncertain situations, it has been observed that it is specifically in those medically uncertain situations that SDM is rarely practiced. How do we move away from this cycle of negative correlation between shared decision-making and medically uncertain situations? The communication and relation between patient and physician seen when SDM is practiced, calls for the need to understand and incorporate human behavioral elements in order to successfully achieve the benefits that SDM has to offer. Behavioral informatics (BI), an emerging discipline of informatics, may provide a solution to this issue of interest. Behavioral informatics aims to develop methodologies and tools for modeling and utilizing behavior, interactions, patterns, intent, behavior impacts, collective intelligence, and behavioral intelligence.<sup>15,16</sup> In particular, the construct of behavioral intent has successfully predicted behavioral action in other health situations.<sup>17,18</sup> Elements of behavioral intent including attitude, subjective norms, and external and internal factors positively correlate to behavioral action. It is the main component involved in the Theory of Reasoned Action, (TRA), which is the used as the behavioral basis factor for this dissertation.



Shared decision-making has yet to be explored using a behavioral informatics approach to determining the impact of behavioral intent under medically uncertain situations. The current lack of knowledge about the use of shared decision-making and behavioral intent in situations of medical uncertainty detracts from our ability to fully implement SDM in medical care.

To address this gap in knowledge of how to fully implement SDM in medical care when uncertainty is present, a theoretical framework has been constructed based on a behavioral informatics approach. The belief is that this framework will allow one to 1) better understand key elements involved in shared decision-making when a medical uncertainty is involved; 2) identify characteristics of human behavioral intent and determine its influence in patient/physician shared decision-making process; and 3) measure a patient's preference for information and active involvement in healthcare.

Specifically, the following aims are proposed:

- **Specific Aim #1:** Characterize shared decision-making elements observed during primary care encounters where medical uncertainty is involved.
  - A qualitative ethnographic study was conducted using content analysis of data collected during fieldwork and audio-recording of patients and physicians engaged in a medical encounter in a primary care setting where medical uncertainty was involved. This ethnographic study focused on describing the communication processes and identifying & characterizing the elements of shared decision-making observed during the medical encounter.
- **Specific Aim #2:** Characterize and assess behavioral intent of patients.
  - Subject from a similar patient population from aim #1 were recruited to conduct semi-structured interviews in order to characterize their behavioral intent based on elements such as attitude, subjective norms, and past health experiences & behavior.
- **Specific Aim #3:** Measure patient preference for information and active involvement in healthcare.

- A descriptive study was performed on subjects from aim 2 to determine the subject's information-seeking and behavioral involvement in their healthcare.

Three manuscripts are presented as a PhD dissertation for the study of patient behavior and shared decision-making in medically uncertain situations. The main purposes of this research was to understand the basic concepts involved in medical uncertainty; to identify and understand the most important elements found in shared decision-making; and to determine an individual's behavioral intent surrounding shared decision-making in the event of a medically uncertain situation. The first manuscript in this dissertation presented a background to the theoretical constructs involved in medical uncertainty, shared decision-making, and theory of reasoned action, and how they tie together to create a unique behavioral informatics framework. This framework served as a roadmap for this research. The second manuscript is a method paper aimed to identify shared decision-making elements present in primary care encounters. By identifying SDM elements in 101 medical encounters, we were able to understand which elements were the most useful and effective in participating in shared decision-making. The third manuscript involved a mix-method approach to understanding a patient's behavioral intent to practice shared decision-making in the event of a medical uncertain situation. Here, 25 subjects of a similar sample population from the 101 medical encounters discussed in the 2<sup>nd</sup> manuscript, participated in a semi-structured interview regarding medical uncertainty, and attitudes and subject norms in regards to shared decision-making. In addition, these subjects were also asked to complete a validated questionnaire regarding their information-seeking and healthcare behavioral involvement preference. The results of this study led to the creation of an informatics category framework.

Together, these three papers represent the intricacy of this dissertation research that involves medical uncertainty, medical decision-making, behavioral intent, and their implications to the study of informatics. This dissertation resulted in a clearer understanding of the concept of medical uncertainty, as well as the identification of the necessary SDM elements and behavioral attributes needed to participate in shared decision-making. The results of this research enabled the development of an informatics category framework which highlighted an individual's representation of medical uncertainty, and their behavioral intent to participate in medical

decision-making. The results revealed three main categories including: 1) an individual's representation of medical uncertainty, 2) how the individual copes with medical uncertainty, and 3) the individual's behavioral intent to seek information and participate in shared decision-making during times of medically uncertain situations. The pathways and interactions involved in this framework were observed to be consistent with previous research and literature relevant to the study of behavioral intent and decision-making. This framework should be incorporated in future studies in order to provide a comprehensive and systematic assessment of variables and processes associated with uncertainty and behavioral intent outcomes for shared decision-making. Finally, with future additional research, this framework has the potential to provide a basis for selectively testing and refining existing behavioral theories, thus improving their predictive potential with respect to decision-making in medically uncertain situations. Since the task of formulating such use is cumulative and progressive, this study proposes the informatics category framework as a first step towards further integration of individual representation, coping, and behavioral intent into the study and application of shared decision-making in medically uncertain situations.

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## **MANUSCRIPTS**

## **Applying Theoretical Constructs to Address Medical Uncertainty**

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## **Abstract**

Situations involving medical reasoning usually include some level of medical uncertainty. Despite the identification of shared decision-making (SDM) as an effective technique, it has been observed that the likelihood of physicians and patients engaging in shared decision making is lower in those situations where it is most needed; specifically in circumstances of medical uncertainty. Having identified shared decision making as an effective, yet often a neglected approach to resolving a lack of information exchange in situations involving medical uncertainty, the next step is to determine the way(s) in which SDM can be integrated and the supplemental processes that may facilitate its integration. SDM involves unique types of communication and relationships between patients and physicians. Therefore, it is necessary to further understand and incorporate human behavioral elements - in particular, behavioral intent - in order to successfully identify and realize the potential benefits of SDM. This paper discusses the background and potential interaction between the theories of shared decision-making, medical uncertainty, and behavioral intent.

## **Introduction**

Situations involving medical reasoning, such as medical consultations, usually involve some level of medical uncertainty. [1-3] Some topics which often involve medical uncertainty include: the risk associated with the occurrence (incidence) of a disease; the probability that preventive, diagnostic, or therapeutic interventions will be effective for a given individual's medical condition; the risk of adverse consequences from therapeutic interventions; and the long-



term prognosis. [1] A recent review regarding the state of medical knowledge revealed that nearly half (47%) of all treatments were of unknown effectiveness, and an additional 7% involved an uncertain tradeoff between benefits and harms. [4] In the context of these unknowns, shared decision-making (SDM) has been identified as an effective technique for managing uncertainty when two or more parties are involved. [5] Shared decision-making between patients and physicians involves both parties engaging in a communal dialogue regarding medical options and preferences before the actual decision or plan of action is made. [6-10] Other techniques for managing uncertainty include: meticulous history-taking and evaluation and establishing trust with patient.[11,12] However, from the available research regarding medical uncertainty, a productive way to deal with this inevitable component of medical decisions is by practicing shared decision-making, whenever possible. [1,2]

Despite the identification of SDM as an effective technique, it has been observed that the likelihood of physicians and patients engaging in shared decision making is lower in those situations where it is most needed: circumstances of medical uncertainty. [2,5,12,13] A recent survey conducted by the Foundation for Informed Decision Making reported that 84% of physicians claim that uncertain information was a barrier to shared decision-making. [14] Consequences of the lack of shared decision-making in medical uncertain situations include: [2] decreased satisfaction and confidence in the medical encounter; insufficient understanding of the health issues discussed; inadequate coping skills regarding health problems/issues; patients living with undesirable consequences that are against lifestyle and/or personal values; and greater decisional conflict related to feeling informed.[15-19] Since medical issues involving uncertainty are complex and may be difficult to communicate, especially if not provoked or directly

engaged, a physician's impulse is often to revert to nondisclosure or oversimplification. [2,20,12,13] For example, in a situation involving medical uncertainty, physicians may opt to oversimplify to avoid discussing difficult issues with patients.[ 2,20,12,13] Subsequently, patients may be left with incomplete or distorted accounts of the issues involved and the decisions made regarding the medically uncertain health matter. [21-23] Shared decision-making, under these particular circumstances of medical uncertainty can therefore be regarded as a critical approach to maximizing patient education and safety. [21-23] Shared decision-making has also been shown to improve psychological & well-being outcomes, and provide physicians with more insight into their patients' lives and their ability to tolerate effects of certain treatment options. [6-9]

Having identified shared decision making as an effective, yet, often neglected approach to resolving a lack of information exchange in situations involving medical uncertainty, the next step is to determine the way(s) in which SDM can be integrated and the supplemental processes that may facilitate its integration. SDM involves unique types of communication and relationships between patients and physicians. Therefore, it is necessary to further understand and incorporate human behavioral elements in order to successfully identify and realize the potential benefits of SDM. Behavioral informatics is an emerging discipline which aims to develop methodologies and tools for modeling and utilizing behavior, interactions, patterns, intent, behavior impacts, collective intelligence, and behavioral intelligence. [24,25] In particular, the construct of behavioral intent has successfully predicted behavioral action in other health situations.[26-33] Elements of behavioral intent including attitude, subjective norms, and external & internal factors, positively correlate to behavioral action. Shared decision-making has

yet to be explored using a behavioral informatics approach to determine the impact of behavioral intent in situations of medical uncertainty. The current lack of knowledge surrounding shared decision-making combined with behavioral intent in these situations detracts from our ability to fully implement SDM in medical care.

The practice and perceived benefits of SDM, especially when dealing with medical uncertainty, cannot move forward without the incorporation of human behavioral principles. To rectify this gap in our knowledge of SDM, we propose an innovative framework incorporating human behavior to increase the body of knowledge and potential benefits from SDM when a medical uncertainty is involved. This approach involves integration of the human behavior model which incorporates behavioral intent: the Theory of Reasoned Action (TRA). This theory focuses on the principle that intention predicts behavior. Further, the model states that a person's intentions are guided by two factors: the person's attitude towards the behavior, and the subjective norm. TRA has been proven to predict and explain a wide range of health behaviors and intentions. However, TRA has yet to be combined with the field of informatics to determine if the combination of information knowledge (informatics) and a person's intended action or behavior could facilitate increased decision making among physicians and patients.

This paper discusses the background and potential interaction between the theories of shared decision-making, medical uncertainty, and behavioral intent.

## Medical Uncertainty

Shared decision-making, which involves a communal dialogue between a patient and physician regarding medical options and preferences before the actual decision is made, has demonstrated that both parties have important roles to play in arriving at a course of action. [10] However, complications arise when the decision in question involves a medical uncertainty or lack of evidence-based knowledge on best practice. Uncertainty comes from many sources, including lack of scientific data as well as ambiguity in applying that data to a particular case. [34] Physicians can be uncertain about a number of clinical matters including the risk of occurrence of a disease; the probability that preventive, diagnostic, or therapeutic interventions will be effective for a given individual; the risk of adverse consequences from therapeutic interventions; and the long-term prognosis. [34] Other examples of decisions that are difficult or uncertain include the following:

- When there are major differences in outcomes
- Where conditions have more than one treatment alternative
- When a decision can result in a small chance of a grave outcome
- When there are tradeoffs between near and long-term outcomes [10, 35-37]

Since medical issues involving any type of uncertainty are complex and difficult to communicate, many physicians either revert to nondisclosure or oversimplification. [2,20, 63]. In either event, patients are left with an incomplete or distorted account of the issues involved and health decisions made regarding this medical uncertainty. It is often true that patients want to impart their own extra-medical values in the decision making process when medical factors alone do not seem to be decisive. [64] However, it is precisely in these situations that physicians find it harder to disclose all of the details related to the medical issue at hand, thereby

undermining true joint decision making.[20] Physicians can be insensitive to the reliability of information, or to the degree to which information allows an accurate judgment to be made and therefore over-weight low-relevance diagnostic information. [90] In addition, even in cases where patients are not particularly interested in assuming the role of decision-makers, they remain very interested in the details of their situation even if they are uncertain. [38] Shared decision-making, under these particular circumstances of uncertainty, can therefore be regarded as an important and critical aspect to maximize patient safety.

As examples of gaps in physician-patient communication, it has been reported that many physicians do not follow some cancer screening guidelines. [39] Many believe that the use of what they deem are ineffective procedures or where the evidence is unclear are a waste of scarce health resources, lead to harm or precipitate more expensive, unnecessary testing for those whose test are false positive. [65]

Even if physicians accept and become adept at handling uncertainty in the practice of medicine, it is still not clear whether they will become adept at revealing uncertainty to patients. Some are good at handling uncertainty in their practice and as such use a range of constructive strategies for dealing with uncertainty, including recognizing alternatives, collecting additional information, reevaluating decisions after time, and planning for contingencies. [2] It is still not clear how this translates into communication with patients.[2] In more stressful situations or ones in which there is a lack of community consensus of clinical circumstances, physicians exhibit confidence in their own recommendations, thereby preventing full consideration of alternatives. Also, most physicians are ill-equipped to effectively communicate prognostic information to patients in part due to a general discomfort with uncertainty and the possibility of error. [2]

Providers need support in order to deliver high-quality healthcare, particularly when medical uncertainty exists and effective patient/communication is critical. Specifically, providers need information, decision support tools, and training to effectively communicate with patients about complicated medical issues. [39] Being able to understand a specific patient's preference and behavioral attitude toward shared decision-making, would also lead to effective decision-making results.

Communicating uncertainty may also elicit different information-seeking behaviors. Some patients may respond to uncertainty by actively seeking information. The attempt to resolve uncertainty may help them cope with it, as knowledge about uncertainty can motivate patients to seek out and understand information about their healthcare. However, uncertainty may also lead to information avoidance and confusion if patients lack the appropriate resources to interpret available information in order to manage uncertainty. [66,67] That being said, uncertainty may not also have this negative effect. For example, when faced with uncertainty about a diagnosis or treatment, some patients may be able to maintain hope and optimism. In addition to influencing emotions during decision making, communicating uncertainty may influence patients' emotional responses following a decision.[66] Past research has showed that patients may experience 3 types of regret following treatment decisions: [67]

- outcomes regret: regret about a negative health outcome following a decision
- option regret: which is regret about the choice one made
- process regret: regret about the quality of the decision-making process

Perhaps communicating uncertainty could lead to increased satisfaction with the quality of the decision-making process, thereby reducing option or process regret following a decision.

Medical decisions are optimized and executed when knowledgeable patients function as partners with their caregivers. In regards to information seeking and preparedness, both physicians and patients place considerable emphasis on task-oriented behavior as constituting patients' communication competence during a medical interview. Being prepared for the appointment is highly valued by both patients and physicians. [20,38] From the physician's perspective, the communicatively competent patient is well prepared, gives prior thought to medical concerns, and educates himself about the illness. The patient comes to the appointment with an agenda and stays focused on it, while providing detailed information about his medical history, symptoms and other relevant issues. [38] At the same time, the patient seeks out information by asking questions about his diagnosis and treatment plan. From the patient's perspective, communication competence is displayed by providing information about one's medical problems, prepared with an agenda, and the ability/opportunity to ask questions. Although little research has focused on determining why training has positive effects on patient discourse and health outcomes, it is possible that these effects are likely due to patients being prepared to engage in an equal exchange in terms of awareness of their concerns and a formulation of a medical encounter agenda. [40]

## **Shared Decision-Making**

The process of medical care has always involved some type of decision making on the part of medical professionals. There are established models of decision making, namely 1) the ‘paternalism’ model and 2) the more recent ‘shared decision-making’ (SDM) model. For many decades, the dominant approach to making decisions about treatment in the medical encounter has been one of paternalism.[6-9] This model involves assumptions that the physician knows best, making decisions on behalf of patients without involving them, and feeling threatened when patients have access to alternative sources of medical information.[6-9] In recent years, paternalism has come under fire through the concept of patient autonomy, or a patient’s right to choose and refuse treatment. “Paternalism is considered inappropriate in a modern world where the standard for the client-professional relationship is more like a meeting between equals than like a father-child relationship”.[41] Physicians may say that they know best, but that alone does not necessarily translate to what may be best for the patient. [41] Shared decision-making has been shown to give best possible outcomes, even if it is psychological. [6-9] A patient feels comfortable since his thoughts, beliefs and lifestyle choices have been discussed. This alone has shown to improve patient outcomes. [6-9] Paternalistic decision-making is not as acceptable as it was in the past for these reasons. More often than not, medical paternalism tends to focus more on the patient’s care and outcomes rather than the patient’s needs and rights. “Current specialists, it is said, rarely know their patient well enough to make this assumption without serious risk of ignorant arrogance.”[41]



Decision making involving uncertain or undefined outcomes, patient values, and inclinations comprise important pieces of information. The inattention by healthcare workers to obtain this information can jeopardize the likelihood of achieving best possible outcomes. [42]

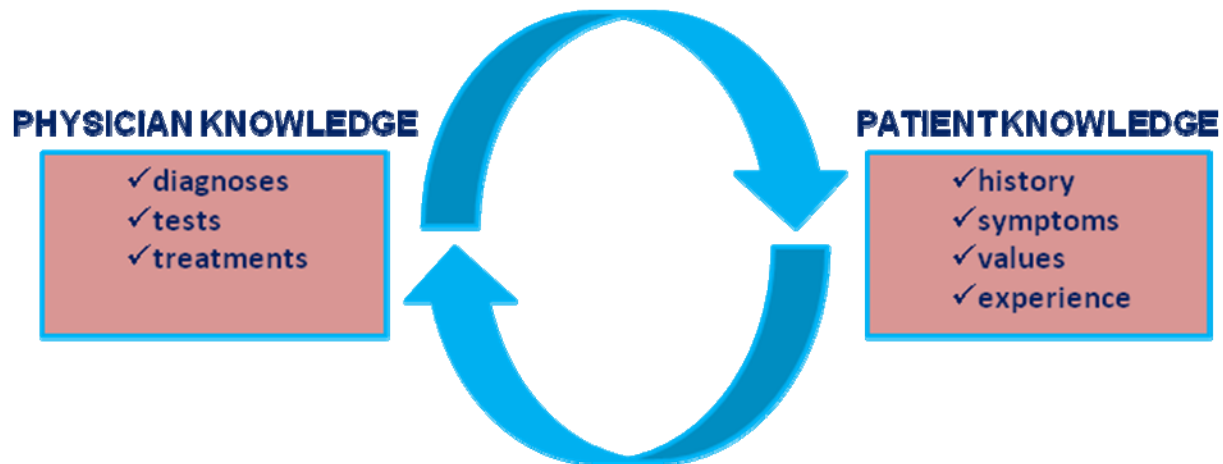


Figure 1: Physician & Patient Expert Knowledge cycle, Roter & Hall, 2006

Verbal communication is the core element from which the doctor-patient relationship is built and by which medical and therapeutic goals are achieved. Therefore, though physicians conduct tests and physical exams to achieve therapeutic goals, actual value of these medical activities is limited without the verbal and then written documentation that organizes history, symptoms, and experience. Together these components place the conversation and plan of care in a meaningful context for both physician and patient. [43] This is not seen nor practiced in paternalistic decision-making. [6-9]

In recent years aforementioned model has been challenged by many healthcare professionals who advocate more of this partnership relation between doctors and patients. [6,7] That ideal has evolved into one in which decision making power is shared based on mutual participation and respect, known as shared decision-making.[6-9] Shared decision-making

between patient and physician involves both parties in a communal dialogue regarding medical options and preferences before the actual decision and plan of action is made.[10] Shared decision-making offers substantial benefits to both patients and physicians in negotiating treatment decisions. Numerous studies have shown that increased patient involvement and participation leads to improved psychological and well-being outcomes.[44] Likewise, a handful of studies have increasingly connected patient involvement with improved treatment outcomes.[45] In addition, physicians also benefit from engaging in a shared decision-making process with their patients, since it improves physician-patient communication, as well as provides physicians with more insight into their patients' lives and their ability to tolerate the negative effects of certain treatment options. This information can enhance a physician's capacity to advise his or her patient on treatment choices.

Despite these potential benefits, shared decision-making is still not a common or widespread practice in the medical practice. [46, 47] The criticisms of shared decision-making can be divided into three categories: 1) inadequate time, expense and resources; 2) communication challenges; and 3) patient needs and expectations. [53] Each provides a distinct hurdle that the medical system would have to overcome in order to implement shared decision-making effectively. Research has found a wide range of negative consequences when shared decision-making is not practiced, and these challenges are amplified when a medical uncertainty is involved. [46-53]:

- Decreased satisfaction and confidence in the medical encounter
- Insufficient understanding of the health issues discussed

- Inadequate coping skills regarding health problems/issues
- Patients living with undesirable consequences that are against lifestyle and/or personal values
- Repetition of procedures and tests
- Greater decisional conflict related to feeling uninformed
- Less realistic expectations about outcomes and/or course of disease
- Lower agreement between values and actual choice

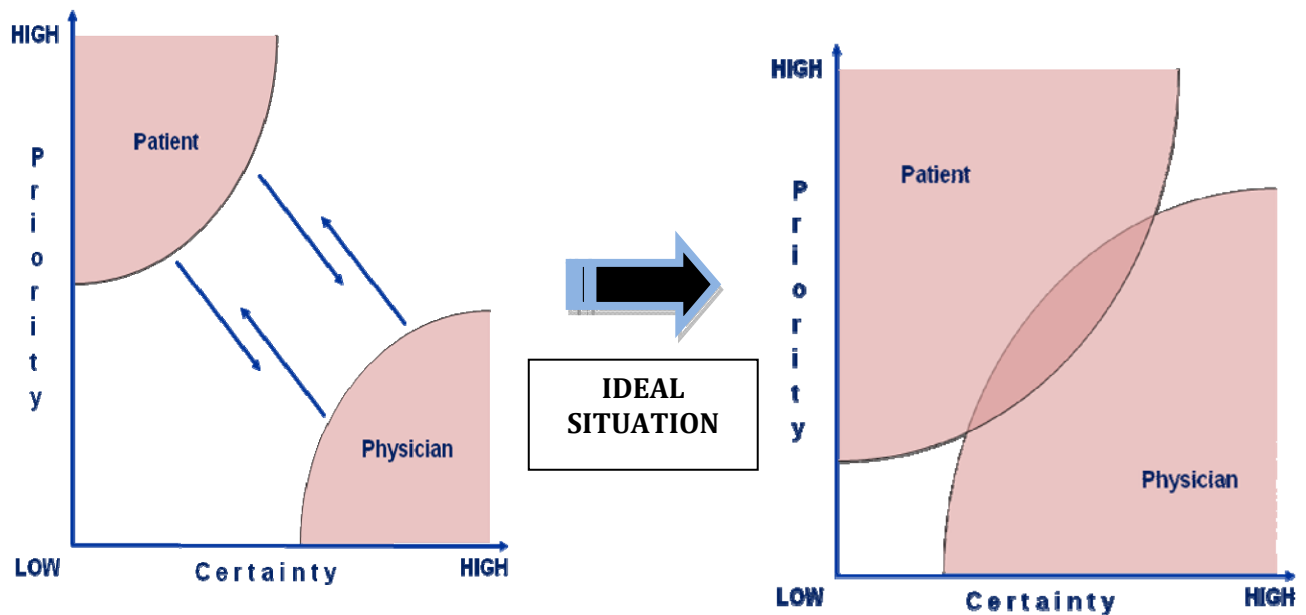


Figure 2: Ideal SDM situation when dealing with medical uncertainty

### Theory of Reasoned Action (TRA)

The Theory of Reasoned Action (TRA), focuses on individual motivational factors as determinants of the likelihood of performing a specific behavior. In other words, a person's behavioral intention (BI) depends on the person's attitude (A), about the behavior and subjective norms (SN). Therefore: **(BI = A + SN)**. In other words, if an individual aims to do a behavior

then it is likely that he will do it. [54, 58] A person's intentions are themselves guided by two things: the person's attitude towards the behavior and the subjective norm. [54, 55]

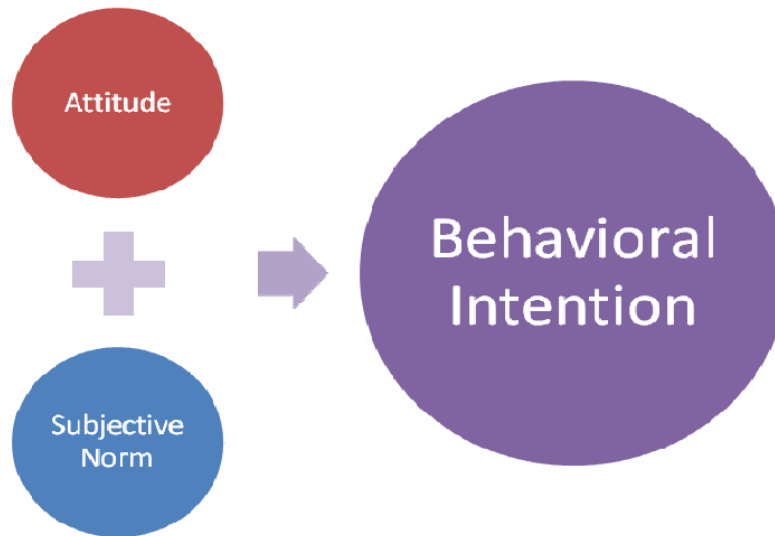


Figure 3: Theory of Reasoned Action (TRA), Ajzen & Fishbein 1980

The point of TRA is that intention predicts behavior (i.e., behavioral intentions predict use). This theory focuses on identifying the determinants of intentions – e.g. attitude, social influences and condition. [54, 55, 57, 58]

- **Behavioral intention** measures a person's relative strength of intention to perform a behavior.
- **Attitude** consists of beliefs about the consequences of performing the behavior multiplied by his or her valuation of these consequences.
- **Subjective norm** is a combination of perceived expectations from relevant individuals or groups along with expectations to comply with these expectations.

The theory distinguishes between *attitude toward an object* and *attitude toward a behavior with respect to that object*. [54-57, 59] An example of this distinction would be the attitude toward the

object of prostate cancer versus the behavior of seeking screening for prostate cancer. The attitude toward a behavior is a much better predictor of that behavior than attitude toward the target at which the behavior is directed. [60] Therefore, the attitude toward prostate cancer is expected to be a poor predictor of prostate cancer screening behavior, whereas attitude toward seeking prostate cancer screening is expected to be a good predictor. This theory provides a framework for identifying key behavioral and normative beliefs that affect an individual's behavior. By applying this framework, interventions are then designed to target and change these beliefs -or the value place upon them- in turn affecting attitude and subjective norm, leading to a change intention and behavior. [59] Simply stated, the reasoned action approach to the explanation and prediction of social behavior assumes that people's behavior follows reasonably from their beliefs about performing that behavior. [60] TRA helps predict behavior through intent. Examples of using this theory to predict a behavior regarding a particular act include:

<b>AIDS Preventative Behavior [83]</b>
<b>Mammography Participation [84]</b>
<b>Infant-feeding intentions &amp; behavior [85]</b>
<b>Coupon usage [43,86]</b>
<b>Condom use [87]</b>
<b>Testicular self-examination [88]</b>
<b>Prostate Cancer Screening Behavior [89,90]</b>

Table 1: TRA used in other medical behaviors

TRA has been successful in predicting the above health-related behaviors. Now this research will test to see if TRA is applicable to shared decision-making behavior in medically uncertain situations.

### **Uncertainty, Shared Decision-Making, and Informatics**

The responsibilities of informing and recommending treatments to patients lie with their providers, but the process of deciding on how to act on this information is shared. The goal is to enhance patient involvement and, on the basis of the available evidence, facilitate “evidence-based patients choice.” [17] One of the most critical factors in predicting positive patient outcomes is the concept of “finding common ground.” [18] In order for shared decision-making to be successfully applied and result in increased patient health outcomes and safety, communication practices between the patient and physician must be meaningful. [1] This requirement demonstrates why human behavior and human cognition are pertinent to both shared decision-making, and thereby informatics. Our understanding of informatics includes the following principles:

- Machines process *data*, not *information*
- Humans need *information*, not *data* in order to make educated *decisions*
- Data needs to be filtered so that only meaningful data will be processed as *information*,
- Information (filtered data) leads to *knowledge & wisdom* which support *meaningful decisions*

Health communication interventions could be developed to leverage the assumptions and knowledge contained in the informatics principles listed above in order to impact the respective

health belief/attitude models (meaning, justification, and action) within the various informatics principles to achieve a shared result or wisdom.

Still ubiquitous is the complex issue of how people respond to and process information. Shared decision-making - carried out under the conditions of medical uncertainty- involves the use of intuition. Although some sources of uncertainty can be reduced by close study and research of scientific facts and evidence-based practice, issues involving personal behavior and conceptual sources could remain. The breakdown of these issues can be rationalized with informatics. Both patients and physicians use, process, and manage data that result in actions and both are required for a result.

An approach to integrating their use of data to action is based on the principles of informatics outlined below:

**Patient:** data + meaning= **information** + justification = **knowledge** + action



= **wisdom**



**Doctor:** data + meaning= **information** + justification = **knowledge** + action

Below is the in-depth version of the proposed informatics framework, explaining both the patient's and physician's objective (i.e., informatics), and subjective (i.e., behavioral theory) motivation and understanding in order to achieve their respective results.

<b>Patient</b>	<b>OBJECTIVE</b>		
	<b>data</b> + meaning =	<b>information</b> + justification =	<b>knowledge</b> + action =
	<i>Example: medical terms</i>	<i>Example: belief about medical terms and relevance to them</i>	<i>Example: Willingness to act</i>
	<b>SUBJECTIVE</b>		
	<b>Attitude</b> (individual) +	<b>Subjective norm</b> (what others around you believe) =	<b>Behavioral Intention</b> + action =
	<i>Example: personal belief (what comes to mind when indiv hears specific medical term)</i>	<i>Example: familial belief (what comes to mind to those around you when they hear a specific medical term)</i>	<i>Example: Intention to act or not act (depending on positive or negative belief)</i>



= wisdom (evaluating understanding)



<b>Physician</b>	<b>OBJECTIVE</b>		
	<b>data</b> + meaning =	<b>information</b> + justification =	<b>knowledge</b> + action =
	<i>Example: Practice/screening recommendations</i>	<i>Example: Efficacy Belief model (relevance to patient)</i>	<i>Example: Willingness to act</i>
	<b>SUBJECTIVE</b>		
	<b>Attitude</b> (individual) +	<b>Subjective norm</b> (what others around you believe) =	<b>Behavioral Intention</b> + action =
	<i>Example: prescriptive norms (this is how it is going to be)</i>	<i>Example: cultural norms (this is how other physicians practice)</i>	<i>Example: Case-by-case (taking all into account via pt/md discussion)</i>

Figure 5: Proposed Informatics Framework



For the purpose of this informatics framework, the term “meaning” has factual understanding of data. “Justification” is the validation of information’s relevance for a decision. The term “action” means the willingness to act on that relevance, which leads to “wisdom”, or the desired end result.

## **Conclusion**

Shared decision-making involves a personal dialogue between two human beings. Beyond establishing a dialogue, additional emphasis must be placed on the components of human behavior, interaction, and communication in order to understand the ways by which we can incentivize the application of shared decision-making as well as realize its full benefits. By studying the human behavioral aspects of SDM in the context of medical uncertainty, we could attempt to discern whether or not adding a well defined and successful human behavioral theory will help resolve the lack of application of SDM. Planned future components of this research will involve identifying key elements of shared decision-making which appear in typical patient-physician relationships in the primary care setting. From our observations we anticipate creating a template for semi-structured patient interviews in order to categorize patient attitudes and behavioral intentions towards their physicians in scenarios of medical uncertainty.

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## **Identifying Shared Decision-Making Elements in Medical Encounters Dealing with Uncertainty**

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## **1. Abstract**

A recent summary of the state of medical knowledge in the U.S. reported that nearly half (47%) of all treatments were of unknown effectiveness, and an additional 7% involved an uncertain tradeoff between benefits and harms. Shared decision-making (SDM) was identified as an effective technique for managing uncertainty when two or more parties were involved. In order to understand which of the elements of SDM are used most frequently and effectively, it is necessary to identify these key elements, and understand how these elements related to each other and the SDM process. The elements identified through the course of the present research were selected from basic principles of the SDM model and the “Data, Information, Knowledge, Wisdom” (DIKW) Hierarchy. The goal of this ethnographic research was to identify which common elements of shared decision-making patients are most often observed applying in the medical encounter. The results of the present study facilitated the understanding of which elements patients were more likely to exhibit during a primary care medical encounter, as well as determining variables of interest leading to more successful shared decision-making practices between patients and their physicians.



## **2. Introduction**

A recent summary of the state of medical knowledge in the U.S. reported that nearly half (47%) of all clinical prevention or treatment were of unknown effectiveness, and an additional 7% involved an uncertain tradeoff between benefits and harms.[1,2] Uncertainty stems from many sources including a lack of scientific data as well as ambiguity in applying that data to a particular case; [4] the risk of occurrence of a disease; the probability that preventive, diagnostic, or therapeutic interventions will be effective for a given individual; the risk of adverse consequences from therapeutic interventions and the long-term prognosis. [5-7] Improved knowledge in identifying sources and resolution of medical uncertainty presents opportunities for enhancing patient outcomes.

Shared Decision-Making (SDM) has been identified as an effective technique for managing uncertainty when two or more parties are involved. [3] Despite the identification of SDM as an effective technique, it is under circumstances of medical uncertainty where even less shared decision-making is practiced between a physician and patient. [3,8-10]

Consequences of lack of shared decision-making in medically uncertain situations may include decreased satisfaction and confidence in the medical encounter; insufficient understanding of the health issues discussed; inadequate coping skills regarding health problems/issues; patients living with undesirable consequences that are against lifestyle and/or personal values; and greater decisional conflict related to feeling informed.[8, 11-15] In order to understand which of the elements of SDM are used most frequently and effectively, it is necessary first to: a) identify these key elements and b) understand the key elements associated with patient participation in shared decision-making with his physician.

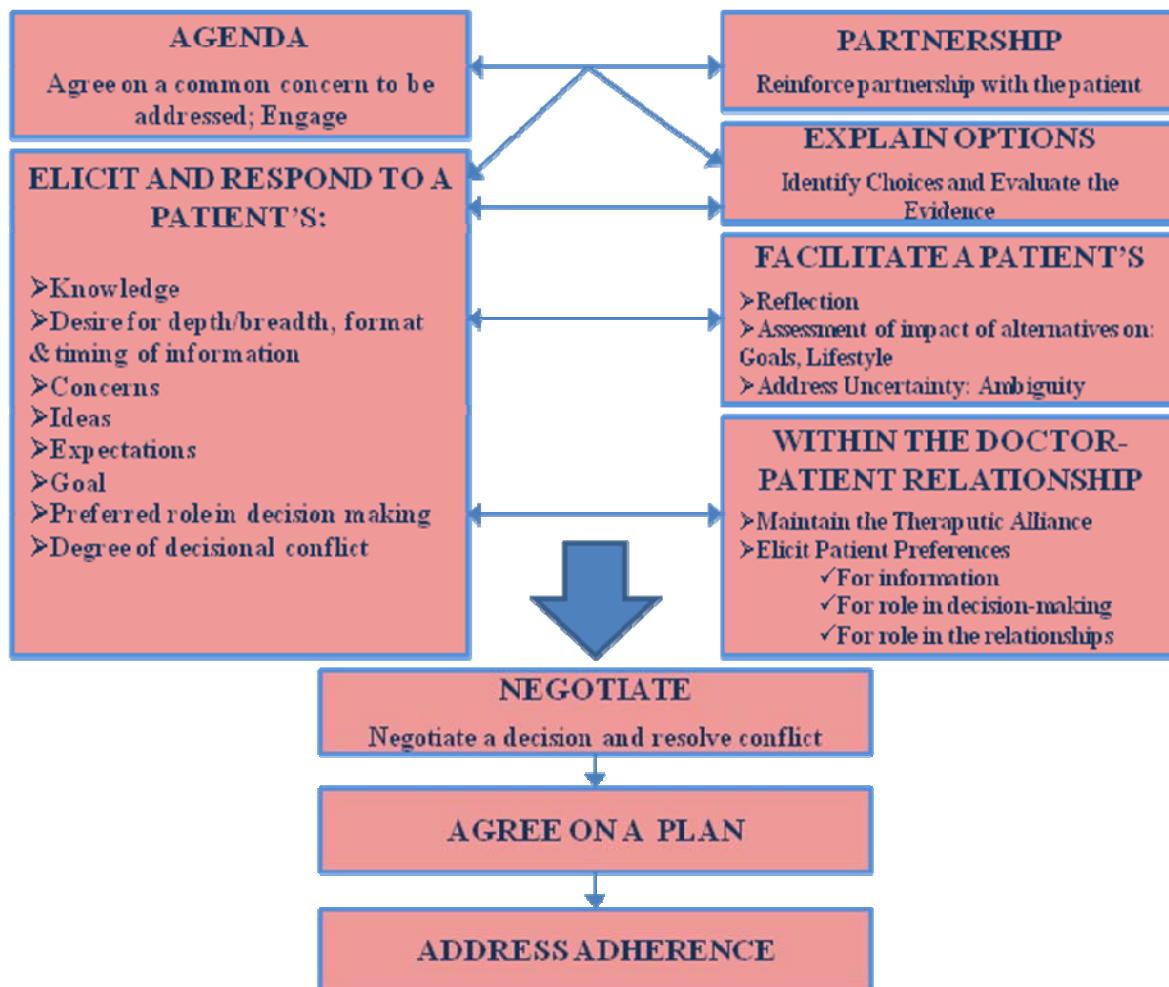
To achieve these objectives, an ethnographic study was conducted that included observing typical medical encounters in a primary care setting. Specifically, one hundred and one recorded primary care medical encounters of African American and Caucasian males between the ages of 45-75 were analyzed. This research provided an opportunity to observe, analyze and document shared decision-making elements and characteristics between patient and physician when dealing with a medical uncertainty in a primary care setting. Based on literature review and for the purpose of focusing the medical encounter analyses, a total of six elements were selected from the basic principles of the Shared Decision-Making Model and the Data, Information, Knowledge, Wisdom (DIKW) Hierarchy. These elements included: *partnership, support, respect, compromise, mutual agreement (from the SDM model), and information (from the DIKW model)*. For the present study, the goal was to identify which of the selected elements are most often exhibited by the patient in the medical encounter. The results of this ethnographic study could provide further insight into which type of patients are more likely to exhibit specific elements.

### **3. Background**

#### **3.1 Shared Decision-Making**

The foundation of this model implies that medical decisions are shared by doctors and patients. [16] In the shared decision-making model, patients and physicians are involved in a communal dialogue regarding medical options and preferences before the actual decision and plan of action is made. [16] The decision making power is shared based on mutual participation and respect. This model also emphasizes that although decisions should be made using the best possible evidence-based practice, it also needs to reflect the beliefs and preferences of the patient.[17] There are several steps involved in the Shared Decision-Making model, which contains many elements of human behavioral interaction: 1) state and definition of the clinical problem; 2) equipoise, or genuine uncertainty over which treatment route to take; 3) present options and information about the options; 4) enable patients to explore their concerns and queries; 5) make decisions; and 6) review arrangement.[17] If one or more of these steps are not followed, or if elements are not practiced, the process of Shared Decision-Making is undermined, leading to less than optimal patient outcomes. [4,18,19]

The SDM diagram below is a detailed example of the many characteristics and actions involved in this process.



[www.brown.edu/.../Mod2SharedDecMaking/.../Handout2SDMModel.doc](http://www.brown.edu/.../Mod2SharedDecMaking/.../Handout2SDMModel.doc)

Figure 1: SDM Diagram

From this SDM diagram and based on literature review, the researchers selected five specific elements (*Partnership, Respect, Support, Compromise, and Mutual Agreement*) below believed to accurately represent the intricacies that SDM has to offer. These five elements (represented in Figure 2 below) combined with one additional element (see section 3.2 DIKW hierarchy) represent the primary focus of the research interviews.

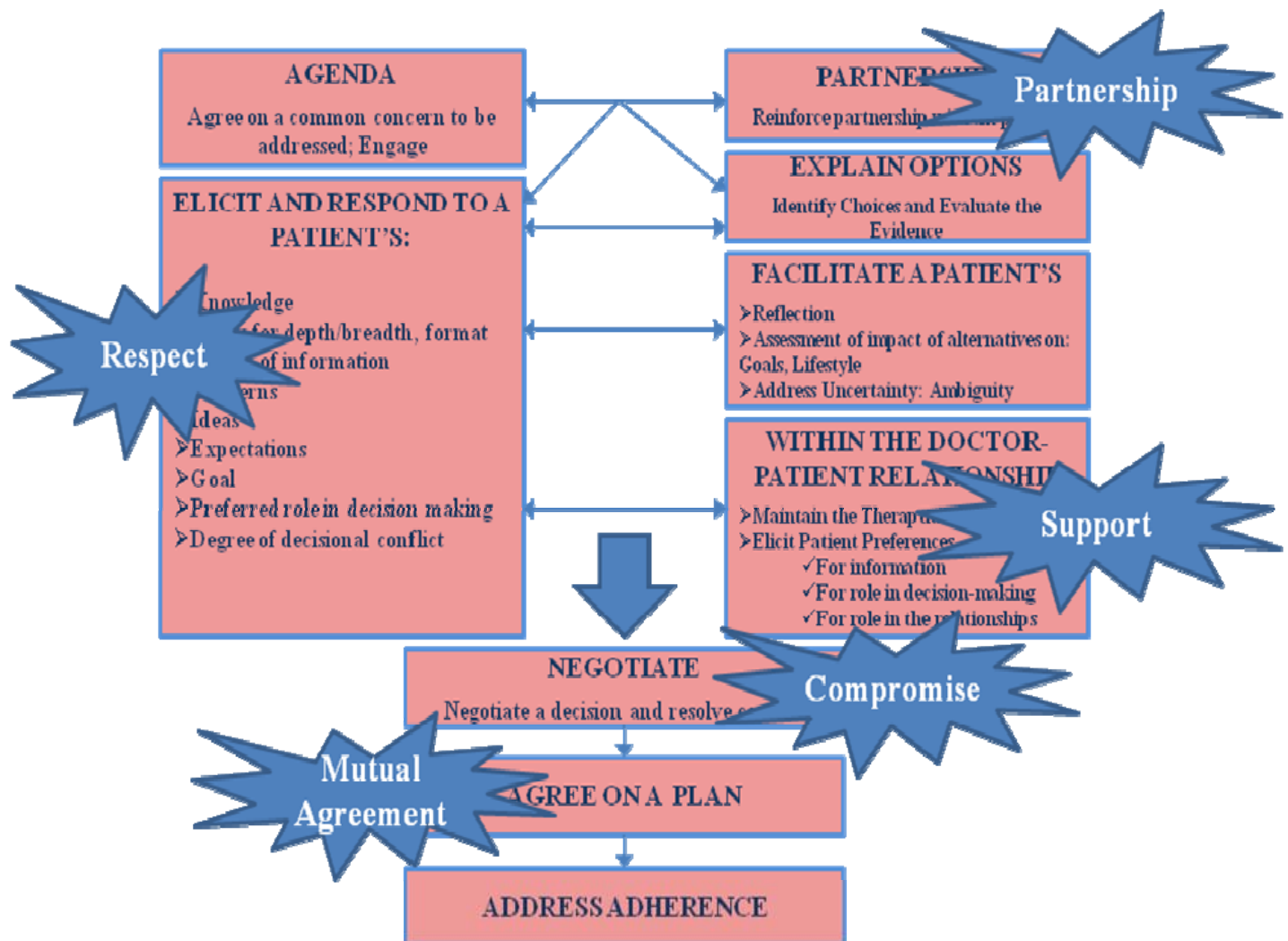
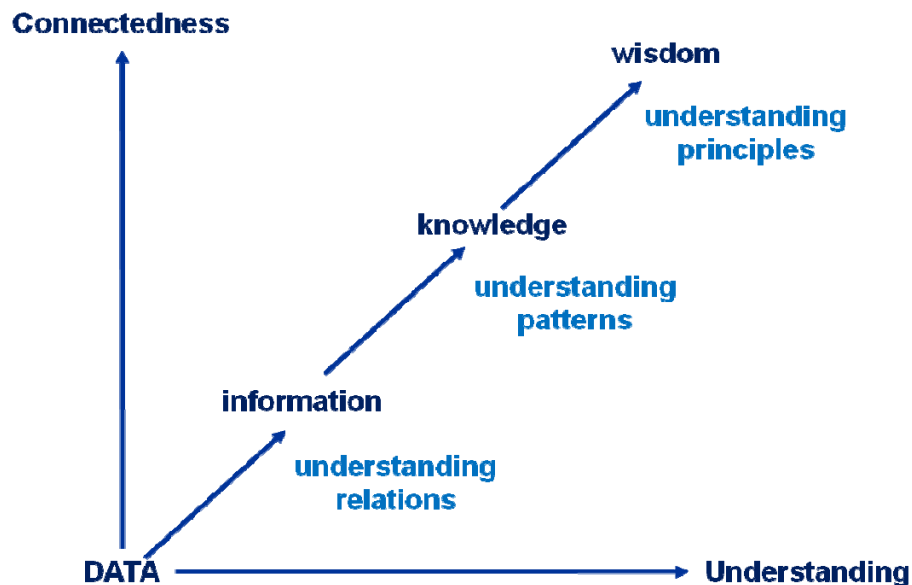


Figure 2: SDM Elements selected from Diagram

### 3.2 Data Information Knowledge Wisdom (DIKW) Hierarchy

*An ounce of information is worth a pound of data, an ounce of knowledge is worth a pound of information, an ounce of wisdom is worth a pound of knowledge. [20]*

Countless references to the DIKW hierarchy can be found in the popular literature. However, Russell Ackoff is generally given credit for making available the first academic publication.[20] The premise of the DIKW theory is that data begets information begets knowledge begets wisdom. [20-23] In addition, this hierarchy implies that there is more data than information, more information than knowledge, and more knowledge than wisdom. However, a review of recent literature regarding this hierarchy has found a lack of consensus. [21] The only identified consistent result is that knowledge is something more than information, and information is something more than data. [21]



(Bellinger, Castro, & Mills, 2004)

Figure 3: DIKW Hierarchy

The DIKW hierarchy explains that each of the DIKW elements serve as the basic unit of the subsequent element. Therefore, there are four levels in the understanding and decision-making hierarchy. The purpose of gathering data, information, and knowledge is to be able to make wise decisions. [22]

**Data:** Symbols that represent the properties of objects and events. These include basic, discrete objective facts. [20]

**Information:** Created by analyzing relationships and connections between the data. Data that is related to each other through a context such that it provides a useful story, linking the who, what, when, & where of a specific something.

**Knowledge:** Application of data and information. Information that has been understood, such that it explains the how and why about something, or provides insight & understanding into something.

**Wisdom:** Created through use of knowledge. Evaluated understanding, or accumulated scientific learning.

These definitions imply a relationship between data, information, knowledge, and wisdom which could be described as a “roll up” hierarchy of data leading to information leading to knowledge and finally leading to wisdom. [24] Ackoff also stated that the first three categories (data, information, and knowledge) relate to the past in so far as they deal with what has been or what is known. [22] Only the last category (wisdom) deals with the future because it

incorporates vision and design. From wisdom, people can create the future rather than just grasp the present and past. [24]

From this theory, *Information* was selected as the sixth element to be identified in the medical encounters. Since information is meaningful data, we believe that understanding the information exchange between a physician and patient during a medical encounter is pertinent to the practice of shared decision-making.

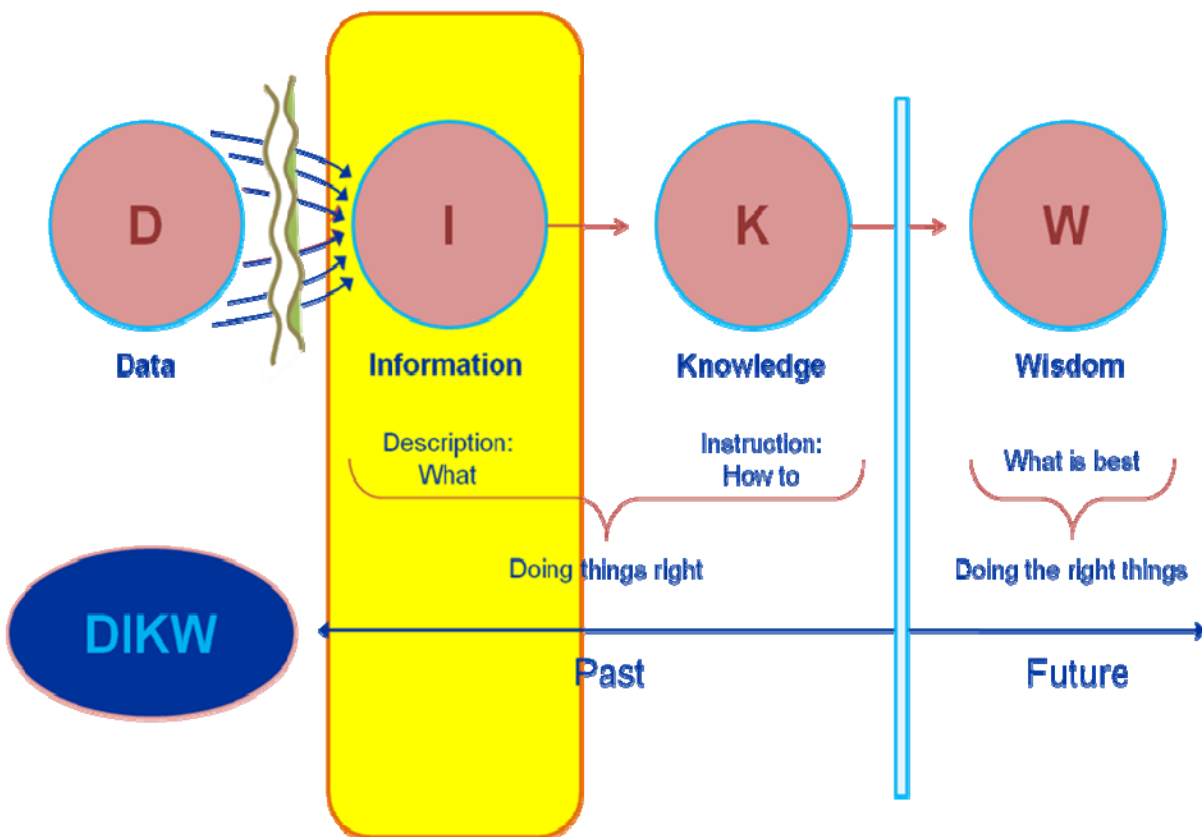


Figure 4: DIKW Element Selected from Diagram



#### 4. Methods & Research Design

Based on the literature review and the objectives of this project, the researcher identified six elements as the foci when reviewing and analyzing the medical encounters. Five elements are based on the principles of Shared Decision-Making, including *Partnership*, *Support*, *Respect*, *Compromise*, and *Mutual Agreement*. The final element, *Information*, is based in the principles of information science, in particular the DIKW hierarchy. In order to identify these elements in the medical consultations, the researcher established a standardized and constant definition for each.

***Partnership:*** A relationship where two people join together, usually involving close cooperation and having specified joint rights and responsibilities, based on similar principles.

***Support:*** To promote, defend, assist, corroborate, and uphold the interests of an individual or group.

***Information:*** Meaningful data. Understanding relationships to help answer the “who, what, where, when” questions.

***Respect:*** Consideration or esteem.

***Compromise:*** Settlement of differences by consent reached by mutual concessions; something intermediate between or blending qualities of two different things.

***Mutual Agreement:*** Harmony of opinion, action, or character; an arrangement or contract as to a course of action.

In order to identify and characterize these six elements, the researcher listened to the recordings and read the transcripts for each medical encounter. The researcher then documented the number of times that each of the various medical encounter elements were observed (i.e. number of encounters in which the element of *Support* was observed). In addition, the researcher identified the various combinations of decision making elements used in the medical encounter, and also counted their incidences. For example, the combination of *Mutual Agreement*, *Information*, and *Support* was found in seven different medical encounters.

The medical encounters chosen for analysis were from 101 recorded primary care medical consultations involving African American and Caucasian male patients between the ages of 45 and 75. These recordings were considered typical medical consultations (no intervention) between men and their primary care physician.

The analysis of each medical encounter required an average of thirty to sixty minutes, depending on the length of the consultation. The researcher listened to each recording and read each transcript in order to determine which element(s) were present in the encounter. When a patient presented with any of the six established elements in his medical encounter, the element was selected. At the end of each conversation, all elements were tallied and charted. In order to ensure the quality of this quantitative research, regular debriefing sessions were held to maintain the validity, reliability and consistency of the data analysis and interpretation. The research protocol was reviewed and approved by UTHHealth IRB to ensure the protection of human

subjects was properly addressed and complied with due federal guidelines in protection of confidentiality and privacy.

## 5. Results

One hundred and one medical encounters were analyzed. The average age of the men was 58, with a minimum age of 47 and a maximum age of 76. Sixty-three of the patients were African American, and 38 were Caucasian. The table listed below provides additional demographic markup regarding the varying levels of education and health issues associated with the patient subject population.

	Total		African American n = 63 (%)		Caucasian n = 38 (%)	
Average Age	58		58		57	
Education						
Grade 8 or less	3	2	(3.17)		1	(2.63)
Some High School	13	11	(17.46)		2	(5.26)
High School or GED	20	17	(26.98)		3	(7.89)
Post High School Training other than college (Vocational, technical, etc.)	7	4	(6.35)		3	(7.89)
Some College	25	18	(28.57)		7	(18.42)
College Graduate (Bachelor's Degree)	21	8	(12.70)		13	(34.21)
Graduate Degree (Masters or Doctorate)	12	3	(4.76)		9	(23.68)
Health Issues						
Heart Disease	14	9	(14.29)		5	(13.16)
Emphysema	2	2	(3.17)		0	(0.00)
Diabetes	33	25	(39.68)		8	(21.05)
Cancer	8	1	(1.59)		7	(18.42)

Table 1: Demographics

The graph below shows the frequency with which each element occurred as a percentage (%) of the 101 medical encounters. For example, the element of *Partnership* occurred in 7 of the 101 encounters and is represented on the graph as having a frequency of 7%.

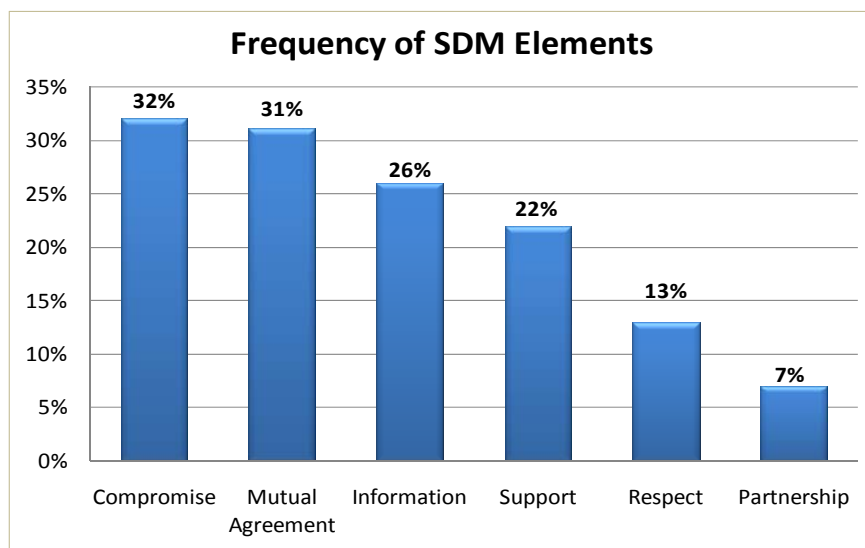


Figure 5: Frequency of SDM Elements

The graph below shows a distribution of patients who exhibited varying numbers (0-6) of the selected elements within a single medical encounter. For example, 39 of the 101 patients observed exhibited only one (1) of the selected SDM elements.

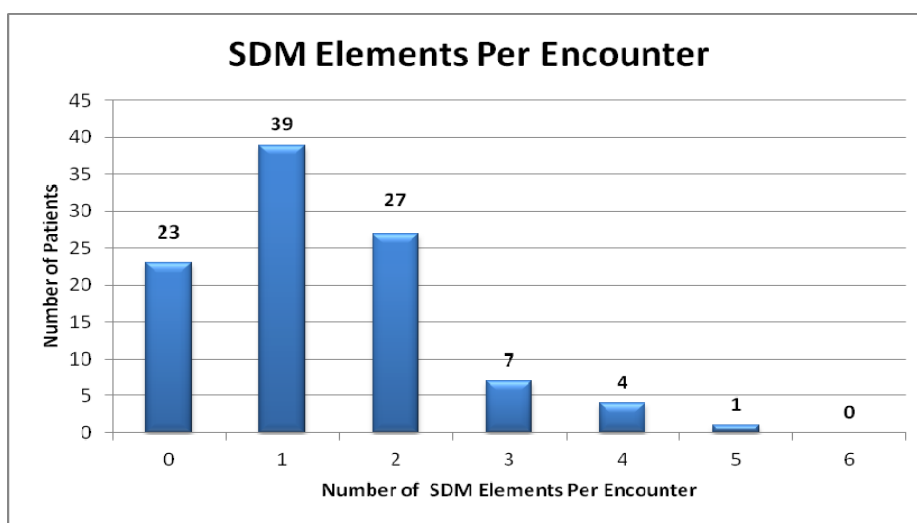


Figure 6: SDM Elements Per Encounter

The chart below lists the distribution of patients who exhibited varying numbers (0-6) of the selected elements within a single medical encounter. All combinations are listed below:

Combination of Elements Exhibited	Instances	Percent of Total
No Elements	23	23%
Compromise	9	9%
Compromise / Mutual Agreement	6	6%
Information	10	10%
Information / Compromise	3	3%
Information / Compromise / Mutual Agreement	1	1%
Information / Mutual Agreement	3	3%
Information / Respect	3	3%
Information / Respect / Compromise / Mutual Agreement	1	1%
Mutual Agreement	11	11%
Partnership	2	2%
Partnership / Compromise	2	2%
Partnership / Respect / Mutual Agreement	1	1%
Partnership / Support / Compromise / Mutual Agreement	1	1%
Partnership / Support / Respect / Compromise	1	1%
Respect	3	3%
Support	4	4%
Support / Compromise	2	2%
Support / Compromise / Mutual Agreement	3	3%
Support / Information	2	2%
Support / Information / Compromise	2	2%
Support / Information / Respect / Compromise / Mutual Agreement	1	1%
Support / Mutual Agreement	3	3%
Support / Respect	3	3%
Support / Respect / Compromise / Mutual Agreement	1	1%
<b>Total</b>	<b>101</b>	<b>100%</b>

Table 2: Combinations of Elements Exhibited

The results of identifying and understanding different types of SDM elements in this project showed that different combinations of elements led to different decision-making outcomes. For example, the encounters with the elements of *Support & Information*, and *Information & Respect*, the patients wanted to know all the options available to them, but at the end of the encounter, wanted the physician to make the ultimate decision. This supports the literature regarding the different types of decision-making styles that patients prefer. [26] In addition, patients that exhibited the elements of *Partnership & Compromise*, or *Partnership & Mutual Agreement*, preferred to make the ultimate decision jointly with their physician. Therefore by examining the particular elements, the healthcare provider can successfully determine the type of decision-making style that an individual patient prefers.

## 6. Discussion

### 6.1 Identifying the Elements

As part of the analysis of the transcripts, the researcher had to separate conversations and interactions associated with the process of making decisions from those conversations and interactions associated with general discussion and/or problem solving.

**Decision-making oriented** – A situation where the patient and physician discuss and agree upon the next steps for treatment of a medically uncertain situation.

**Not decision-making oriented** – A situation where the patient and physician discuss information unrelated to making a decision.

For the purposes of this paper, the researcher's goal was to identify shared decision-making elements exhibited by the patients. Since other research has focused on shared decision-making elements initiated or directed by physicians, this research focused on the elements initiated or directed by the patient. The following is an example of the element of ***Respect*** initiated by a patient: "Well, I value your opinion doc, would you recommend it anyway? What would you do?" -Patient #78. This varies from an observation of a physician-directed encounter: "I trust you can make the right decision, Mr. X". Other examples of shared decision-making elements observed in the medical encounters include:

***Partnership***: "So what's our plan of action here?" -Patient #30

***Support***: "I want to know if you can help me. What do you need to know from me?" – Patient #38

***Information***: "If there is something wrong [complications from cellulitis], I want to find out. Can you tell me all the issues about this?" –Patient #18

***Compromise***: "If I can avoid the insulin for now great, but if not, I will be fine with it." – Patient #24

***Mutual Agreement***: "I agree, I believe the lung function test is the way to go to figure this out." -Patient #40

## 6.2 Presence of Shared Decision-Making

In analyzing the medical encounters, twenty-three (23) encounters were identified as containing no shared decision-making elements. Upon further analysis of the encounters and the context of the statements, the situations were categorized into the following four scenarios:

*No uncertain situations were discussed.* These medical encounters consisted of medication refills, update on specific medical condition (diabetes, high blood pressure), annual blood test, and flu shot requests.

*Patients agreed with everything.* Some situations involved the physician making all of the decisions without much opportunity for discussion: Physician: “There is a lot of controversy with performing the DRE (digital rectal exam), but I’m going to do it anyway,” Patient #67: “Ok”. In other instances, as stated before, the patient did not want to participate in SDM. Patient #69: “Whatever you say doc, you are the boss.” Patient #19: “I will go with whatever you say.”

*Patients were adamant about their decisions.* On the other hand, although physicians were ready to have a discussion about certain medical issues, a few patients were not interested in having a discussion, as they had already made their decisions. Patient #43: “I understand, it’s your job to talk about it, but I am very against those [flu shots], remember a few years ago when everyone got sick from it? No, no, thank you.”

*The spouse is present in the medical consultation.* - When the wives of the patients were present, less shared decision-making occurred between the patient and physician. Instead, there was an increase in dialogue between the wife and physician. The wives typically answered the



questions, and made the ultimate decision on what route to take. The patient usually agreed with what spouse suggested/recommended.

### 6.3 Hierarchy of the Elements

There were instances when specific content in the conversations exhibited traits of more than one element. Background: A situation where a patient and physician are working to make a decision whether to pursue medication, therapy or surgery to address the patient's knee pain, Patient #46 statement: "Let's try the alternative, to see how that works." In this scenario it is reasonable to conclude that the patient is exhibiting: *partnership*, *support*, *respect*, or *compromise*. In listening to the recording of this particular medical encounter and reading the transcript, the context showed that partnership was the main SDM element elicited by the patient, with the remaining three serving as the supporting elements.



Figure 7: Example of Primary and Supporting Elements in a Medical Encounter

#### 6.4 Advanced element Analysis

As shown in the *SDM Elements Per Encounter* graph in the Results above, the element which occurred with the most frequency was *Compromise*. A potential explanation for this observation may be that since the test subjects were all ranging from middle aged to older males, and males at that age are known to exhibit more conservative and less communicative behavior, the element *Compromise* may be the least intimidating (relative to other elements) for the patient to engage in during the medical encounter.

The graph also indicates that *Partnership* was the element which occurred with the least frequency. Only 7% patients used the element of *Partnership* during their medical encounter. In this case, *Partnership* may represent the most intimidating element for the patient to engage in during a medical encounter. A possible explanation of *Partnership* as the most intimidating may be due to a patient's perception of the physician as having superior authority, knowledge and experience in the context of medical decision making.

Combining the observations regarding the *Compromise* and *Partnership* elements, it seems reasonable that additional research and analysis may support a correlation between the two. Based on this correlation, the additional research may support an approach for modifying patient perceptions of the physician to increase patient involvement in SDM behavior. While these are only preliminary hypotheses, it becomes easy to see how more advanced research across a more diverse population may result in significant advances in improving patient outcomes as a result of increasing SDM.

Using the frequency and distribution of the six SDM elements, the researcher incorporated these observations in both the creation of interview templates and in conducting patient interviews, focusing on the same patient population and targeting those perceptions, feelings and behaviors which are most pertinent to identifying methods for resolving the lack of SDM in situations of medical uncertainty.

### 6.5 Limitations

This study was limited to African American and Caucasian males between the ages of 45 and 75. As previous research has shown, sex, age, race, and education level all play a role in the degree of SDM participation by the patient. It is anticipated that the number of occurrences and combination of the observed elements may be different for other population groups. However, the methods conducted in this study are generalizable and can be successfully used with other population groups. In addition, by initially limiting this study to a certain group helps to assure validity and reliability of the results.

In addition, this was designed as a qualitative study and not intended to produce precise estimates of archetype prevalence or distribution of the elements. In addition, the researcher used an original method to characterize and identify SDM elements, and all conclusions from this study should be tested by further research.

## **7 Conclusion**

The objective of this research study was to increase understanding of patient/physician communication and decision-making styles. In order to accomplish this objective, this study

included observation of typical medical encounters. The results of this study successfully advanced an understanding of which elements patients were more likely to exhibit in SDM. In general, there was a positive correlation between the number of elements exhibited in a patient encounter and the completeness of the shared decision-making pathway exhibited in that encounter. In other words, those patients who exhibited more elements, as opposed to those exhibiting less elements, displayed higher levels of involvement in the encounter, greater understanding of problem/uncertain situation, higher number of questions/concerns, greater understanding of available options, and greater understanding/ownership of the final plan of action. Additionally, some elements were more prevalent than others, demonstrating that certain SDM characteristics are more frequently practiced by the sample population (male patients). The elements of compromise and mutual agreement had the highest prevalence, while the element of partnership had the lowest.

This study represents an innovative project that has the potential to help health professionals understand the most common elements male patients exhibit when communicating with their physicians. By identifying the SDM elements exhibited by a patient, the medical professional would be able to determine the decision making preferences of that patient and the best approach to optimizing communication in order to maximize the effectiveness of the patient encounter. Therefore, this study could ultimately be used to improve patient health outcomes by improving the communication between health professionals and patients in situations of medical uncertainty.

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## **Understanding Behavioral Intent to Participate in Shared Decision-Making in Medically Uncertain Situations**

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## **Abstract**

**Objective:** This article describes the process undertaken to identify and validate behavioral and normative beliefs and behavioral intent of men between the ages of 45-70 with regard to participating in shared decision-making in medically uncertain situations. This article also discusses the preliminary results of the aforementioned processes and explores potential future uses of this information which may facilitate greater understanding, efficiency and effectiveness of doctor-patient consultations.

**Design:** Qualitative Study using deductive content analysis

**Setting:** Individual semi-structure patient interviews were conducted until data saturation was reached. Researchers read the transcripts and developed a list of codes.

**Subjects:** 25 subjects drawn from the Philadelphia community.

**Measurements:** Qualitative indicators were developed to measure respondents' experiences and beliefs related to behavioral intent to participate in shared decision-making during medical uncertainty. Subjects were also asked to complete the Krantz Health Opinion Survey as a method of triangulation.

**Results:** Several factors were repeatedly described by respondents as being essential to participate in shared decision-making in medical uncertainty. These factors included past experience with medical uncertainty, an individual's personality, and the relationship between the patient and his physician.

**Conclusions:** The findings of this study led to the development of a category framework that helped understand an individual's needs and motivational factors in their intent to participate in shared decision-making. The three main categories include 1) an individual's representation of medically uncertainty, 2) how the individual copes with medical uncertainty, and 3) the individual's behavioral intent to seek information and participate in shared decision-making during times of medically uncertain situations.



## Introduction

Decisions are “the acts that turn information into action.” [1] The need to make accurate and effective health decisions is indisputable, regardless of whether the patient exhibits a medical condition which threatens his/her life or a psychological condition that may adversely affect his/her quality of life, and regardless of whether the research evidence is robust or lacking. Uncertainty nearly always enters the equation, as it is frequently a component of medical reasoning.[2-4] A summary of recent trends in medical reasoning and knowledge reported that nearly half (47%) of all treatments for clinical prevention or treatment were of unknown effectiveness and an additional 7% involved an uncertain tradeoff between benefits and harms.

Shared decision-making, (SDM) has been identified as an effective technique for managing uncertainty involving two or more parties. [5] Despite the identification of SDM as an effective technique, it is under circumstances of medical uncertainty where even less shared decision-making is practiced between a physician and patient. [5-8]

How do we move away from this cycle of negative correlation between shared decision-making and medically uncertain situations? The communication and relationships observed between patients and physicians when SDM is practiced requires a deeper understanding and incorporation of human behavioral elements in order to successfully achieve the benefits SDM has to offer.

There is substantial evidence that positive attitudes, subjective norms, and past experiences correlate with positive behavioral intent.[9-16] Based on this correlation, it can be deduced that the intent to engage in a behavior leads to the behavioral action. Behavior is defined as the action or reaction of an entity, human or otherwise, to situations or stimuli in its environment. [17] It is a key concept in understanding the driving forces and cause & effects of many issues. In particular, the construct of behavioral intent has successfully predicted behavioral action in other health situations.[9-16] However, behavioral intent has never been studied adequately to understand the behavioral action or preference for shared decision-making. The purpose of this ethnographic study was to understand the factors involved in a patient’s behavioral intent to participate in shared decision-making in the event of a medically uncertain situation.

## Background

### *Behavioral Intent*

Behavioral intent is the basis for the Theory of Reasoned Action (TRA). [18,19] This has “received considerable and, for the most part, justifiable attention within the field of consumer behavior...not only does the model appear to predict consumer intentions and behavior quite well, it also provides a relatively simple basis for identifying where and how to target consumers’ behavioral change attempts” [20] It has also been used to successfully predict and explain a wide range of health behaviors and intentions – and findings have been used to develop behavior change interventions. [21-25] A given patient and a given physician have a unique behavioral action model and approach to managing information that impacts a prevention practice or clinical intervention for a given patient. [18, 19] Behavioral intention is the most proximal determinant of behavior and its best predictor. [1, 14, 17, 26, 27] Individuals with stronger intentions to engage in a particular behavior are more likely to engage in that behavior than individuals with weaker intentions.

In order to understand and characterize the behavioral intent of the patients, elements from the TRA were used. The TRA, focuses on individual motivational factors as determinants of the likelihood of performing a specific behavior. In other words, a person's behavioral intention, (BI) depends on the person's attitude (A), about the behavior and subjective norms, (SN). As such, **BI = A + SN**. Therefore, if an individual aims to engage in a behavior then it is likely that he will do so. [18,28] A person's intentions are, themselves, guided by two things: the person's attitude towards the behavior and the subjective norm. [18,19]

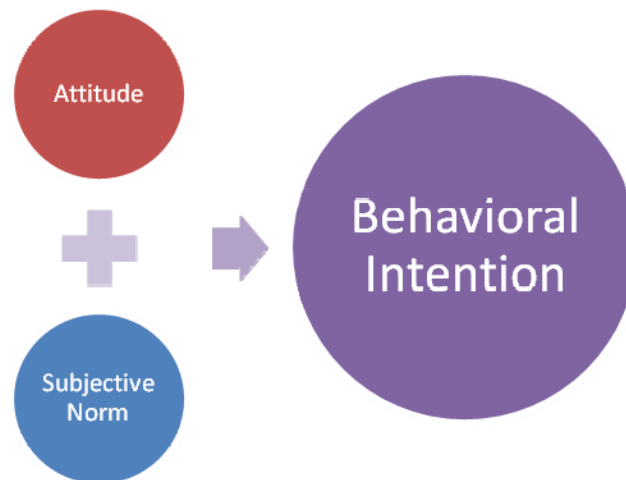


Figure 1: Theory of Reasoned Action, Ajzen& Fishbein 1980

The point of TRA is that intention predicts behavior (behavioral intentions predict use). This theory focuses on identifying the determinants of intentions – e.g. attitude, social influences and condition. [18, 19, 28, 29]

- **Behavioral intention** measures a person's relative strength of intention to perform a behavior.
- **Attitude** consists of beliefs about the consequences of performing the behavior multiplied by his or her valuation of these consequences.
- **Subjective norm** is a combination of perceived expectations from relevant individuals or groups along with expectations to comply with these expectations.

The theory distinguishes between *attitude toward an object* and *attitude toward a behavior with respect to that object*. [18,19,29-31]An example would be a patient's attitude toward the object of prostate cancer versus his behavior of seeking screening for prostate cancer. The attitude toward a behavior is a much better predictor of that behavior than the attitude toward the target at which the behavior is directed. [32] For example, the attitude toward prostate cancer is expected to be a poor predictor of prostate cancer screening behavior, whereas attitude toward seeking

prostate cancer screening is considered to be a better predictor. This theory provides a framework for identifying key behavioral and normative beliefs that affect an individual's behavior. Applying this theory, interventions can be designed to target and change these beliefs or the value placed upon them, in turn affecting attitude and subjective norm, and leading to a change intention and behavior. [31] Simply stated, a reasoned action approach to the explanation and prediction of social behavior assumes that people's behavior follows reasonably from their beliefs about performing that behavior. [32]

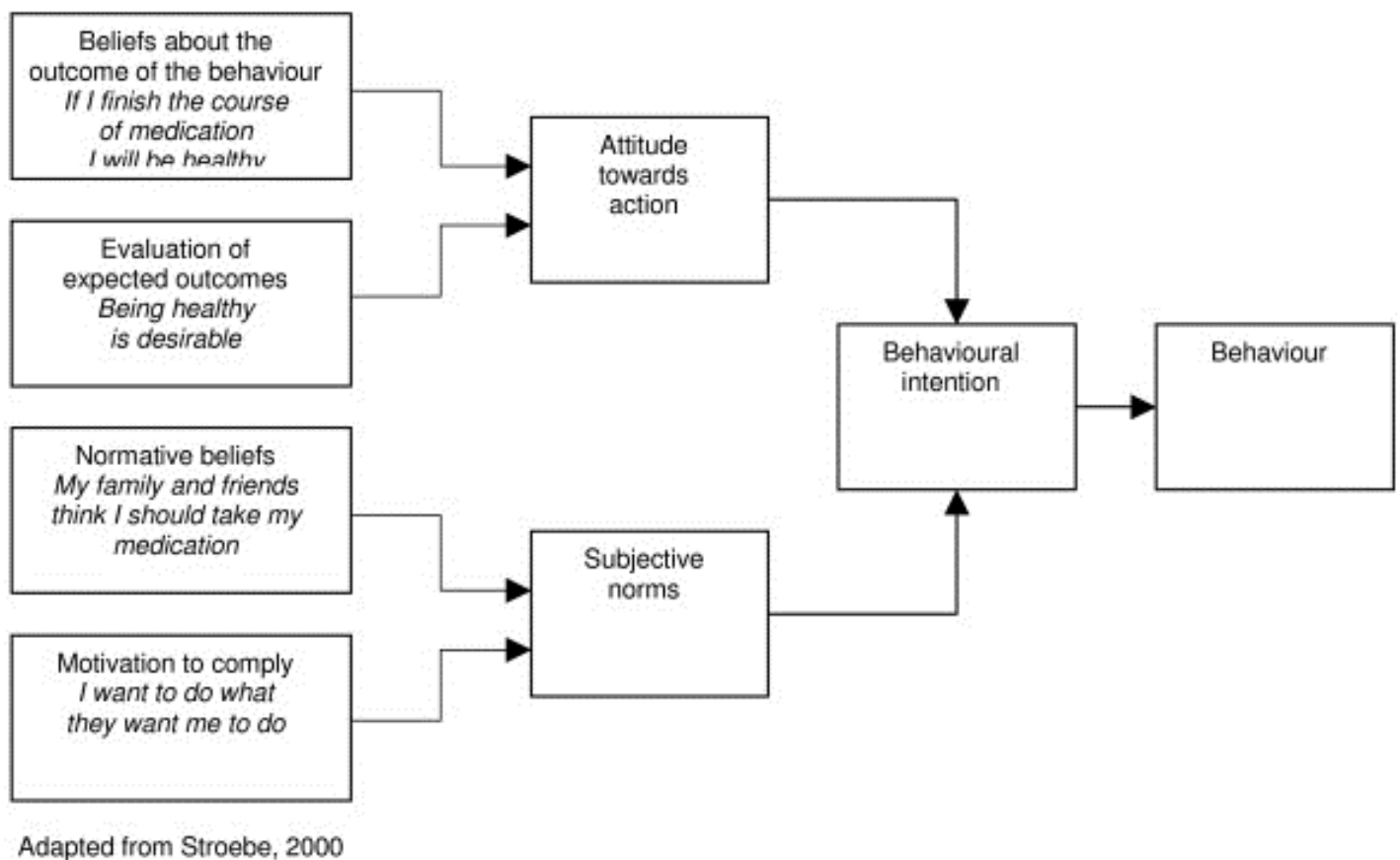


Figure 2: Application Example of Theory of Reasoned Action (TRA)

## **Methods**

### ***Research Design***

The research protocol for this study was reviewed and approved by The Institutional Review Boards for University of Texas and University of Pennsylvania to ensure the protection of human subjects was properly addressed and complied with due federal guidelines in protection of confidentiality and privacy. Subjects were informed that their participation was voluntary and that they had the right to withdraw from the study at any time, and that their interview would be audio-recorded. Subjects were informed that only first names would be use during the interviews in order to maintain confidentiality. No identifying information regarding subject participants was included in any transcripts.

### ***Interview content***

The content for the semi-structured interviews was developed from a) literature review of shared decision-making, medical uncertainty, and theory of reasoned action; and b) data analysis of a secondary retrospective ethnographic study involving medical encounters between men (ages 45-70) and their primary care physicians. The figure below shows the interview schedule for this project.

<b>Grand Tour</b>	<b>Probes</b>
<b>Socio-demographic characteristics</b>	<ul style="list-style-type: none"> <li>• Past medical history</li> <li>• Past preventive behavior</li> </ul>
<b>Cognitive/Psych factors</b>	<ul style="list-style-type: none"> <li>• Knowledge of screening, treatment, disease</li> <li>• Perceived susceptibility to a disease</li> <li>• Worry about having the disease</li> <li>• Interest in knowing diagnostic status</li> <li>• Belief in disease prevention &amp; curability</li> <li>• Belief in Salience and coherence of behavior</li> <li>• Belief in efficacy to detection and treatment</li> <li>• Concern about behavior-related discomfort</li> </ul>
<b>Social support and influence factors</b>	<ul style="list-style-type: none"> <li>• Family members</li> <li>• Friends</li> <li>• Healthcare professionals</li> <li>• Colleagues</li> </ul>
<b>Programmatic factors</b>	<ul style="list-style-type: none"> <li>• Characteristics of healthcare delivery system</li> </ul>
<b>SDM Elements</b>	<ul style="list-style-type: none"> <li>• Partnership</li> <li>• Support</li> <li>• Respect</li> <li>• Information</li> <li>• Compromise</li> <li>• Mutual Agreement</li> </ul>

Table 1: Interview Schedule

### ***Questionnaire – Krantz Health Opinion Survey (KHOS)***

Following the interview, a questionnaire based on Krantz et al. was given to measure preference for healthcare information and active involvement in healthcare. [33] Extensive testing was undertaken to establish the instruments' validity and reliability. [33] The instrument has two subscales, one measuring information preference (I-Scale) and the second measuring the degree of behavioral involvement (B-Scale). The I-Scale contains seven items measuring desire to ask questions and desire to be informed about medical decisions. The following is an example of a statement found on the I-Scale: "I usually don't ask the doctor or nurse many questions about what they're doing during a medical examination." The B-Scale contains nine statements that measure attitudes toward self-treatment and active behavioral involvement of patients with their care. An example of the B-Scale: Clinics and hospitals are good places to go for help, since it is best for medical experts to take responsibility for healthcare." The scale yields a total score, which is a composite of the two subscales. The binary, agree-disagree format was so designed that the high scores represent positive attitudes toward self-directed or informed treatment.[33]

The study included African-American and Caucasian men between the ages of 45 and 70 without any history of prostate cancer. A purposive sampling strategy was used to select participants from the University of Pennsylvania Medical Center meeting eligibility criteria.

### ***Setting***

#### ***Recruitment and Data Collection***

Recruitment: Patients were recruited via flyers placed around the University of Pennsylvania medical center. If interested, potential subjects were asked to call a number to schedule an time for an interview. Calls were then screened by the research coordinator who asked questions to ensure eligibility. Once eligibility was established, a date and time was arranged for the subject to come for the interview. A day before each interview, the research assistant would call the subject as a reminder of date, time and location.

Site selection: The University of Pennsylvania medical school campus was chosen as the site for the semi-structured interviews. A room in the Department of Epidemiology was reserved for the interviews.

### *Semi-Structured Interviews*

A semi-structured, open-ended interview guide developed by the investigator guided all the discussions. This interview was reviewed by four faculty members, three from the School of Biomedical Informatics at the University of Texas Health Science Center, and one from the department of Clinical Epidemiology and Biostatistics at the University of Pennsylvania School of Medicine, as well as two nursing research assistants. This process ensured that the questions being asked were structured in a manner that a) facilitated dialogue among subjects, b) did not lead subject responses, and c) maximized the likelihood that behavioral and normative beliefs could be elicited in regards to shared decision-making in medically uncertain situations.

Each interview was conducted by the research coordinator. The responsibilities of the research coordinator were to read consent forms to subjects at the beginning of the interviews; to ensure appropriate forms were distributed, signed, and collected; to take notes during the interviews; and to ensure that all notes and tapes were properly labeled at the end of each interview.

### *Transcription*

Since this project was the research coordinator's dissertation work, she was responsible for transcribing each interview verbatim. In order to ensure the quality of this quantitative research, regular debriefing sessions occurred throughout the project with the research coordinator and two nursing research assistants.

## **Data Analysis**

The semi-structured interviews were analyzed using a qualitative, deductive content analysis. Qualitative deductive content analysis is "a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying



themes or patterns. [34] This type of analysis is most often used to analyze interview transcripts in order to uncover or model people's information related to behaviors and thoughts. [35] The following steps were taken during the content analysis process.

#### *Step 1: Prepare the Data*

The content analysis began during early stages of the interview process in which the researcher alternated between data collection and concept development. This method helped to guide the data collection from the interviews toward sources that were useful for addressing the research question of understanding behavioral intent for shared decision-making in medically uncertain situations. [36] The interview data was transcribed into written text. For the sake of this project, the main questions from the interview guide were transcribed verbatim rather than summarily.

#### *Step 2: Define the Unit of Analysis*

Unit of analysis is the basic unit of text that is classified during the content analysis. Messages were unitized before they were coded. Defining the coding unit is one of the most fundamental and important decisions. [37] An individual theme is usually used as the unit for analysis rather than physical linguistic units, such as words or sentences. In this case, the theme used as the coding unit was a patient's behavioral intent (attitudes, subjective norms) to practice shared decision-making in medically uncertain situations.

#### *Step 3: Develop Categories and a Coding Scheme*

The categories and coding scheme was derived from three sources: the literature, the data, and the theory of reasoned action. For this study, a deductive reasoning approach was used since the theory of reasoned action was used as the basis for the inquiry. A deductive content analysis is used in cases where one wishes to re-test existing data or theories in a new context [38] Therefore, the initial list of coding categories was generated from this theory. However, this theory was modified during the course of the analysis as new categories emerged. [36] The next step was to develop a categorization matrix, followed by the development of a coding manual (to ensure coding consistency). Category names, their respective definitions and rules

for assigning codes were included in the manual. Any doubts or confusion regarding the definitions of categories, coding rules, or categorization were discussed and resolved in regular debriefing sessions. After the categorization matrix and coding manual were developed, all the data was reviewed for content and coded according to identified categories.

*Step 4: Code the Text*

*Step 5: Assess Coding Consistency*

Rechecking the consistency of the coding was performed at various times throughout the coding process, and was executed by the research coordinator and the two nursing research assistants.

*Step 6: Draw Conclusions from the Coded Data*

In this step, the properties and dimensions of the categories were explored to identify relationships between categories and uncover themes and patterns.

## Results

The data analysis began after the collection of data from the first subject and continued until saturation. Data saturation was considered to be attained when no new information related to the research question resulted from the subject interviews. Demographic data were summarized as descriptive statistics. A total of 25 men were interviewed, among them 16 (63%) were African American, and 9 (38%) were Caucasian males. The mean age of participants was 57. The table below shows the full demographic data of the participants.

	<b>African American n = 63 (%)</b>	<b>Caucasian n = 38 (%)</b>	<b>Total</b>
<b>Average Age</b>	16 (56.4)	9 (58.2)	57.1
<b>Marital Status</b>			
Single	2 (13)	1 (11)	3
Married	9 (56)	6 (67)	15
Divorced	3 (19)	1 (11)	4
Widowed	1 (6)	0 (0)	1
Civil Union	1 (6)	1 (11)	2
<b>Education</b>			
Some High School	1 (6)	0 (0)	1
High School or GED	8 (50)	1 (11)	9
Post High School Training other than college (Vocational, technical, etc.)	3 (9)	0 (0)	3
Some College	3 (19)	5 (56)	8
College Graduate (Bachelor's Degree)	1 (6)	3 (33)	4
Graduate Degree (Masters or Doctorate)	0 (0)	0 (0)	0
<b>Health Issues*</b>			
Hypertension	11 (69)	5 (56)	16
COPD	1 (6)	0 (0)	1
Heart Disease	0 (0)	2 (22)	2
Diabetes	8 (50)	1 (11)	9
None	2 (13)	4 (33)	6

Table 2: Subject Demographics

## ***Main Themes***

A few main themes were repeatedly mentioned by the subjects as being important in the intention to participate in shared decision-making in the event of a medical uncertainty: past experience, personality, and physician-patient relationship. As illustrated in the following paragraphs, these themes overlap but each emphasizes a distinct characteristic involved in decision-making participation in medically uncertain situations. These themes were used to ultimately construct the category framework as a way to provide a comprehensive, systematic exploration of variables and process associated with uncertainty and behavioral intent outcomes for shared decision-making.

### **Past experience with medical uncertainty**

*“Well, is anything really ever certain? I mean you can get all the information you want, and the doctor can tell you % that he's read or witnessed, but you never know. You know the saying ‘Man plans, and God laughs?’ Haha, it’s true.” - Subject 17*

*“Well after that it changed my outlook, I was more invested with everything that was going on. So yes, my intent would be more towards finding out what is going on in all future events.” - Subject 5.*

However, even though subjects with past experiences with medical uncertainty stated that their intent to participate increased after the experience, their decision-making preference did not experience a radical change. Rather, the patient gained a more realistic idea of how to handle information and decision-making in situations of medical uncertainty.

Subject 5 describes his past experience with medical uncertainty, exhibiting openness to shared-decision making:

*“I mean I will ask questions, and want my physician to give me all the choices and options, but I feel - it has actually calmed me down more in turns of understanding that some things cannot be predicted, it’s okay to get information from your family, internet, and doctor; be open with your*

*doctor; but I will still have him make the ultimate decision. I think that my participation in that extent is moving toward more of a shared decision-making aspect. I'm not going to go 180 and say now that I know best and I am the expert. But I feel calmer with uncertain situations that it's okay to ask questions, and then listen to what your doctor has to say."*

Subject 22 describes his lack of past experience, focusing on his anxiety and exhibits hyper-vigilance in his approach towards addressing the situation:

*"I've never been involved in a medical uncertain situation, that you say. I don't think I know anyone in my family that has as well. I think I would be a little freaked, so I'd get information from the internet, probably get a second and third opinion, and then make the ultimate the decision on my own. If it's uncertain, then the docs don't know what to do either. I might as well do it."*

The lack of past experiences with medically uncertain situations resulted in increased anxiety in respondents' answers, and an increased desire and intent to move toward a completely hyper-vigilant information seeking and decision-making behavior.

### Patient/Physician Relationship

Even subjects who had a trusting relationship with their physician stated that their intent to participate in SDM in an event of a medically uncertainty was not very likely. They indicated that they would prefer their physicians to tell them about the uncertainty and to let them know the options and concerns, but the final decision should be made by the physician.

Subject 12:

*"I don't expect he would ask for my opinion, but he'll explain it to me and ask if I have any questions."*

Subject 9:

*“I don’t want to say that participating in medical decisions is pointless and a waste of time. (hahah) but I don’t really do it much, because of my relationship with my doc. He’s great, and he knows everything about me already, and I trust his judgment.”*

Subject 3:

*“I do want to know choices and options, and my doc’s recommendations but then they make final decision. He’s the expert, after all. I know he is human and not perfect, but I trust him to look after my best interest.”*

On the other hand, subjects who did not have a close personal relationship with their physician stated that their intent to participate in SDM was very likely.

Subject 15:

*“My future intent is to be more proactive in my healthcare especially if there is some ambiguity. You have to learn how the system is. You have to push things along and follow through, unfortunately in medicine that is not there a lot of the time. Doctors have so many patients, but there is only one you – and you need to look after yourself, because to doctors, you are just another number.”*

Subject 19:

*“It’s not that I don’t trust my physician, but sometimes I think they are looking after their own pockets. I would just always want to protect myself, but asking and getting enough information as possible from doctors, but in the end make the final decision myself.”*

### ***Personality type***

Subjects also stated that their distinct personalities definitely influence how they felt about medical uncertainty, and that it also influenced their preference for information-seeking and behavioral intent to participate the shared decision-making process.

Subject 6:

*“When it comes to something that you cannot predict – it’s not necessarily that I am ok, it’s just such a difficult field that I’m a little bit more lenient when it comes to wanting to know everything upfront - they tell you “we have to open you up to see what we find”, ok there is nothing more we can do – so I’m okay with that standpoint.”*

Subject 24:

*“It has to do with your psych and personality as well. If you are an anxious person, the idea of uncertainty will drive you crazy. I feel that uncertainty is like death. It is the unknown. I think those that accept the concept of death and deterioration, can more easily accept the everyday concept and aspect of medical uncertainty.”*

Subject 8:

*“I’m a total hypochondriac, if I have a shoulder pain, I think its cancer. (haha). I guess uncertainty is another thing to worry about. “*

Subject 20:

*“Now, I would rather hear what the uncertainty is, and so it is what it is at that point. I’m not going to go crazy because I understand now that everyone will go through some medically uncertainty one time or another in their lives. You have people around you to support you (doctors, nurses, family) no one is trying to hurt you. You are all on the same side.”*

## Category Framework

A category framework was developed from the content analysis. The objective of this framework was to guide and generate research on individual's representation of medical uncertainty, and their behavioral intent to participate in medical decision-making. The emerging framework based on this study's content analysis can be seen in the figure below. There are three inter-linked elements in the framework that combine to describe and determine sources of individual differences in relation to behavioral intent to participate in shared decision-making in the event of a medically uncertain situation.

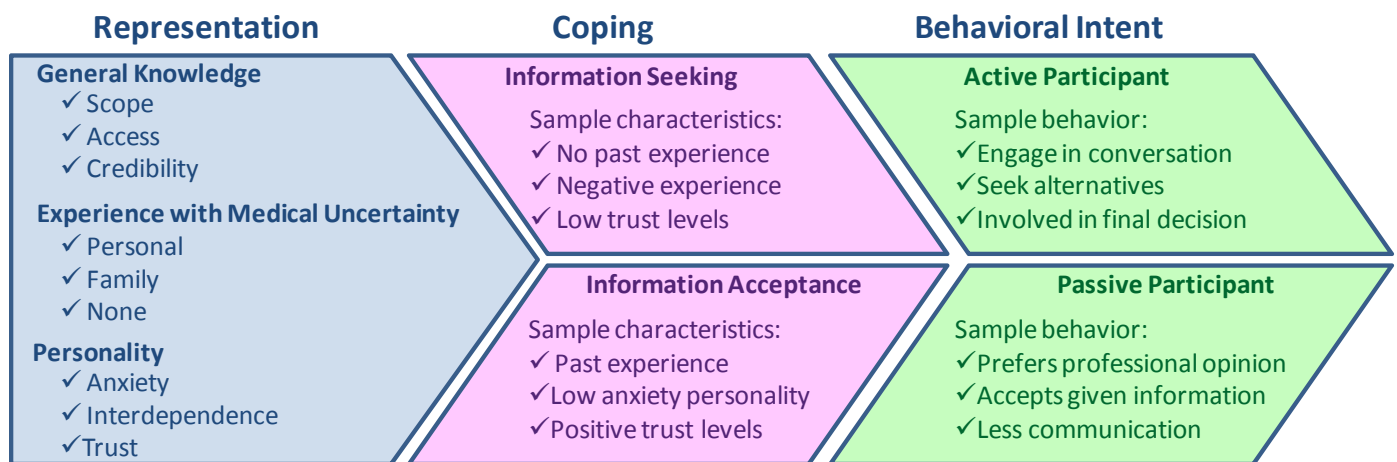


Figure 3: Category Framework

### Category A – Representation

In this first category, an individual labels medically uncertain situations using the factors of general knowledge, personal experience, and personality. General knowledge includes scope of knowledge compared to medical professional; access to information including internet, family, health professionals; and interpretation and trust of information. Personal experience includes past experiences with medical uncertainty, a family member's past experience with medical uncertainty, and individual's relationship with his physician. Personality includes anxiety,



hypochondriac, adoptive, low-stress, dependent, independent, and trusting personality. The three categories of general knowledge, personal experience and personality provide the structure from which individuals form opinions and conceptualize medical uncertainty.

### ***Category B – Coping***

Having addressed the structure patients use to represent uncertainty, the second category involved the methods in which the individual copes with the concept of medical uncertainty. An individual can have difficulty or can have no difficulty with coping. Those individuals who have difficulty coping are considered as being in the active Information Seeking group. This group is characterized by having negative past experience(s) with medical uncertainty, having no experience with medical uncertainty, and/or having a lack personal or trusting relationships with medical professionals. Meanwhile, those individuals who do not have difficulty coping with medical uncertainty are considered as being in the passive, Information Acceptance group. This group is characterized as having past experience with medical uncertainty, having close relationship(s) with their physician, and/or having a relaxed or low-stress personality.

### ***Category C – Behavioral Intent***

The final category within the framework is the behavioral intent to practice shared decision-making when medical uncertainty is involved. From this study, a positive correlation was identified between difficulty coping with uncertainty and positive intent to actively participate in SDM. The subjects in this group were those individuals without prior experience with medical uncertainty and without a strong or trusting relationship with their physicians. Further, the individuals in this group were more likely to actively seek information and medical alternatives and to be involved in the final medical decision. Conversely, the subjects who were better at coping with uncertainty were passive participants in the decision-making process. Categorization in this group does not necessarily indicate the level of desire to be involved. Rather, it was observed that subjects in this group were content with the information provided or otherwise available to them, and accepted their role as a passive participant, ultimately deferring final decisions to the healthcare professional.

### *Krantz Health Opinion Survey*

Scores from the KHOS Health Opinion Survey were split into high and low information seeking and high and low behavioral involvement groups with a median split and were treated as interval data. The KHOS-I scores for this sample ranged from 1 to 7 and the mean was 4.16 (Std Dev =1.67). The KHOS-I scores were divided into low and high information seeking groups with a median split. Likewise, the KHOS-B scores for this sample ranged from 1 to 5 and the mean was 2.64 (Std Dev = 1.35). The KHOS-B scores were also divided into low and high behavioral involvement groups. The low and high information and behavioral involvement groups were used to analyze the results of the questionnaire completed by the 25 subjects. Accordingly, the results listed below are divided into high or low information seeking and high or low behavioral involvement.

		Behavioral Involvement								
Information Seeking	Low	Low			High			Totals		
		Population	Count	% of Total	Population	Count	% of Total	Population	Count	% of Total
		Total Subjects	9	36%	Total Subjects	6	24%	Total Subjects	15	60.00%
		Black	8	50%	Black	1	6%	Black	9	56.25%
		White	1	11%	White	5	56%	White	6	66.67%
	High									
		Population	Count	% of Total	Population	Count	% of Total	Population	Count	% of Total
		Total Subjects	3	12%	Total Subjects	7	28%	Total Subjects	10	40.00%
		Black	2	13%	Black	5	20%	Black	7	43.75%
		White	1	11%	White	2	22%	White	3	33.33%
Totals										
	Population	Count	% of Total	Population	Count	% of Total	Population	Count		
	Total Subjects	12	48.00%	Total Subjects	13	52.00%	Total Subjects	25		
	Black	10	62.50%	Black	6	37.50%	Black	16		
	White	2	22.22%	White	7	77.78%	White	9		

Table 3: KHOS results

A total of 9 subjects (36%) of the sample population were categorized as low information seeking and low behavioral involvement. Of the sample population, 3 subjects (12%) were categorized as high information-seeking and low behavioral involvement. Six subjects (24%) were identified as low information-seeking and high behavioral involvement. Finally, 7 subjects (28%) of the subjects were high information seeking and high behavioral involvement.

### ***Triangulation and Measurement***

The concept of methodological triangulation is associated with the use of more than one method for data gathering and measurement practices. As Webb et al (1966) stated: “Once a proposition has been confirmed by two or more independent measurement processes, the uncertainty of its interpretation is greatly reduced.[39] The most persuasive evidence results from a triangulation of measurement processes. To extend this concept, this project used Denzin’s 1970 definition of between method triangulation, which involves contrasting research methods, semi-structured interviews and questionnaire in the case of this study.[40] In this application, triangulation is taken to include the combined use of qualitative research and quantitative research to determine how far they arrive at convergent findings. [40] For the purpose of this study, the multi-method approach was used to increase the completeness of the findings as compared to if the study had leveraged one of the methods alone. This triangulation method was also used to check the validity of the findings by cross-checking them with another method.

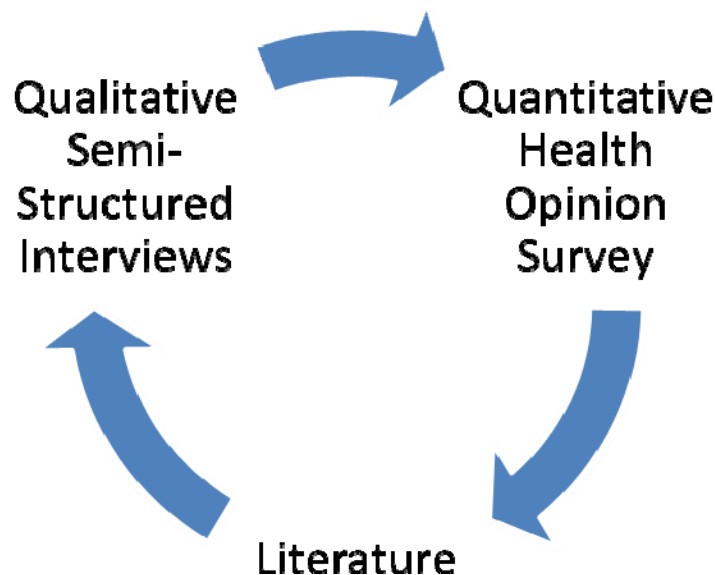


Figure 4: Triangulation Method

Of the entire sample population, only three subjects had interviews and questionnaire results which did not exhibit positive correlation, limiting the ability to identify their information seeking and behavioral preferences with respect to healthcare decisions. Although the “n” in this research may be considered small for computing a quantitative questionnaire data and establishing reliability, the three subjects had one major factor in common: none of them had personal or second-hand experience with medical uncertainty. It is reasonable to interpret this as suggesting that past experience (with medical uncertainty) alone will help with the consistency of predicting future behavioral intent to participate in shared decision-making in the event of an uncertain situation.

### ***Trustworthiness of the study***

The reliability of the study was also increased through a demonstrated link between the results and data. In addition to the use of triangulation, the credibility of the study was increased through planned regular debriefing sessions between the research coordinator and the two research assistances. To facilitate transferability and dependability, the research coordinator established clear description of the context, transparent selection criteria and characteristics of the participants, systematic data collection processes, and ongoing analysis documentation and archiving. [41]

## **Discussion**

Throughout this study, the core category of “coping or dealing with uncertainty” emerged as a primary characteristic, connecting and conveying the experiences of the subject’s efforts to understand uncertainty. Despite having information and social support, the subjects still had to cope with the idea of uncertainty before determining how to proceed with regard to shared decision-making. The core category of coping was enhanced defined by the three descriptive categories described in the framework: 1) representation of uncertainty, 2) coping, and 3) behavioral intent. This supports the literature that information-seeking has also been described as a model of coping, with coping being the link between information preference, desire for behavioral involvement, and information-seeking behavior in health related situations that involve risk. [42] Information-seeking can be used to support direct action and/or regulate

emotions in a stressful situation, such as situations of uncertainty. [43] In the Krantz survey, it was found that the level of preference is related to number of questions asked by patients in healthcare environments, as well as the general desire to be involved in health care decisions. Information is relayed to patients to guide appropriate coping. Knowledge of a patient's preference for information is very important as the healthcare professional identifies the manner in which he/she should interact with the patient during a medical consultation. Therefore, appropriately matching preference level with the amount and depth of information can enhance patient outcomes.

Another theme that emerged from the study was the difference in information-seeking behavior when medical uncertainty was involved. Some patients responded to uncertainty by actively seeking information, whether from their physicians, internet, or family members. This behavior was observed as a way of coping with the concept of uncertainty.

In addition, this study identified a correlation between the manner in which a subject represents the idea of uncertainty in his mind and his/her behavioral intent towards decision-making in the situations of medical uncertainty. These results suggest that, because of an individual's complex behavioral, cognitive and emotional responses to uncertainty, coping with the idea or representation of uncertainty has greater potential benefit than simply helping an individual understand it. [44-46]

Another interesting concept identified through this research involves the presentation of certain information in situations of medical uncertainty. There does not appear to be a consensus among healthcare professionals regarding optimal methods for communicating and understanding different types of uncertainty. The manner in which information is communicated and presented in times of medical uncertainty can affect how the uncertain situation/condition is perceived and responded to by individuals. However, healthcare professionals still have limited information regarding optimal methods for applying mechanisms to achieve these framing effects. There are many ways to present uncertainty – verbally, statistically, graphically, etc. Tailoring information to the individual patient may increase the perceived relevance of situational information, thus providing easier access to information and increasing the likelihood of patient participation in

decision-making processes. [46]

Finally, although one might expect that trust and positive relationships with their physician would be associated with a high intent to participate in shared decision-making, subjects in this study felt that their intent to participate in SDM was more likely when they had less trust in their physician. This finding is consistent with Kraetschmer et al [47] and Fraenkel & McGraw[48] studies. This study adds to the findings that patients having high levels of trust may believe that their physicians understand their values and know already what are best for them.

### **Study limitations**

Subjects were self-selected volunteers who responded to fliers. These people were likely to either have an interest or concern about medical decision-making and human behavior and therefore may have responded in varied, important, and unknown ways from other patients. In addition, the subjects in this study were African American and Caucasian males between the ages of 45 and 75. It is anticipated that the results may be different for other population groups. However, the methods conducted in this study are generalizable and can be successfully used with other population groups. Furthermore, by initially limiting this study to a certain group helps to assure validity and reliability of the results.

### **Conclusion**

This research study explored the fundamental understanding of how an individual processes, interprets, and responds to information regarding medical uncertainty and their behavioral intent to participate in decision-making. By administering a semi-structured interview to the subject population, the findings clarify behavioral intent of shared decision-making participation in situations involving medical uncertainty. The content analysis of these interviews led to the development of category framework regarding the individual's representation of medical uncertainty, and their behavioral intent to participate in medical decision-making. The results revealed three main categories including: 1) an individual's representation of medical uncertainty, 2) how the individual copes with medical uncertainty, and 3) the individual's behavioral intent to seek information and participate in shared decision-making during times of

medically uncertain situations. This category framework helped highlight pathways and interactions between the variables identified through the content analysis of the data obtained through the semi-structured interviews. These pathways and interactions were observed to be consistent with previous research and literature relevant to the study of behavioral intent and decision-making. This framework should be incorporated in future studies in order to provide a comprehensive and systematic exploration of variables and processes associated with uncertainty and behavioral intent outcomes for shared decision-making. Finally, with future additional research, this framework has the potential to provide a basis for selectively testing and refining existing behavioral theories, and improving their predictive potential with respect to decision-making in medically uncertain situations. Since the task of formulating such usage is cumulative and progressive, this study proposes the category framework as a first step towards further integration of individual representation, coping, and behavioral intent into the study and application of shared decision-making in medically uncertain situations. The results of this study contribute to, apply, and extend the field of behavioral informatics to assist medical practice and decision-making in situations of medical uncertainty.

## APPENDICES

### Appendix A – Subject demographics and KHOS scores

Subject	Age	Race (1)	Edu (2)	Marital Status (3)	KHOS- I Count	KHOS- B Count	KHOS Total	KHOS-I/ KHOS-B (4)
1	69	C	5	2	3	4	7	L/H
2	49	C	6	2	2	5	7	L/H
3	52	C	3	2	5	4	9	H/H
4	65	AA	4	2	6	5	11	H/H
5	63	AA	3	2	7	3	10	H/H
6	59	AA	3	3	3	3	6	L/H
7	53	AA	2	5	3	2	5	L/L
8	60	C	5	5	5	2	7	H/L
9	66	AA	6	2	2	2	4	L/L
10	50	AA	5	4	4	2	6	L/L
11	52	C	6	3	3	3	6	L/H
12	67	C	5	2	2	3	5	L/H
13	51	AA	4	2	5	2	7	H/L
14	50	AA	3	2	4	1	5	L/L
15	57	AA	5	2	4	1	5	L/L
16	55	AA	3	1	6	1	7	H/L
17	57	C	5	1	3	1	4	L/L
18	45	AA	4	1	4	1	5	L/L
19	47	AA	3	2	7	4	11	H/H
20	56	C	6	2	1	3	4	L/H
21	67	AA	3	3	3	1	4	L/L
22	59	AA	3	2	6	4	10	H/H
23	54	AA	5	3	4	1	5	L/L
24	62	AA	3	2	6	4	10	H/H
25	62	C	5	2	6	4	10	H/H



(1) C=Caucasian, AA= African American

(2) 2=some high school; 3 = high school or GED; 4= post high school, vocational/tech ; 5= some college ; 6= college grad/bachelors

(3) 1= single; 2 = married ; 3= divorced; 4 = widowed ; 5= civil union

(4) L = Low; H= High

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## RESEARCH SUMMARY

In general, information used in medically uncertain situations is not well described. More specifically, medically uncertain situations are problematic due to the fact that information may be missing, unused, or misunderstood. By researching and applying the methods & processes discussed in the three manuscripts, this dissertation research developed information understanding regarding the behavior of patients when dealing with shared decision-making in the context of medical uncertainty. This information understanding supports the generation of knowledge on how to improve human health. Further, this dissertation research developed an informatics category framework which provides pathways for understanding patient representations of medical uncertainty and their behavioral intent to participate in medical decision-making.

This research supports the basic definition of biomedical informatics by describing how human beings store, retrieve, discover, and process information by filtering out meaningless data. In the case of this research, this was achieved through the identification and assessment of SDM element combinations and understanding individual's behavioral intent. Meaning must be considered when dealing with concepts of a) SDM in medically uncertain situations; b) physician-patient communication; and c) human behavior. In this dissertation research, we studied the data plus its contextual meaning, as well the data's usage and effects with regard to the aforementioned concepts.

### Contributions to Informatics

*Knowledge contribution* – This research adds a new perspective on understanding decision-making and patient's behavioral intent with regard to medical uncertainty.

*Theoretical contribution* – This research creates an informatics framework combined with human behavioral disciplines to develop knowledge in the area of medical decision-making.

*Practical application* – This research presents potential strategies & interventions to influence change in patient and physician behaviors in the decision-making process.

In summary, presenting medical uncertainty is a challenging task for healthcare providers, but with the support of the informatics category framework developed by this research, providers would be better prepared to identify the type of information and decision making style most appropriate for a given patient. This, in turn, will increase patient satisfaction and improve health outcomes as a result of proper decision-making.

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