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

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Summary
Objective: This article describes the process undertaken to identify and validate behavioral and normative beliefs and behavioral intent based on the Theory of Reasoned Action (TRA) and applied to men between the ages of 45 and 70 in the context of their participation in shared decision-making (SDM) in medically uncertain situations. This article also discusses the preliminary results of the aforementioned processes and explores potential future uses of this information that may facilitate greater understanding, efficiency and effectiveness of clinician-patient consultations.

Materials and Methods: Twenty-five male subjects from the Philadelphia community participated in this study. Individual semi-structured patient interviews were conducted until data saturation was reached. Based on their review of the patient interview transcripts, researchers conducted a qualitative content analysis to identify prevalent themes and, subsequently, create a category framework. Qualitative indicators were used to evaluate respondents’ experiences, beliefs, and behavioral intent relative to participation in shared decision-making during medical uncertainty.

Results: Based on the themes uncovered through the content analysis, a category framework was developed to facilitate understanding and increase the accuracy of predictions related to an individual’s behavioral intent to participate in shared decision-making in medical uncertainty. The emerged themes included past experience with medical uncertainty, individual personality, and the relationship between the patient and his physician. The resulting three main framework categories include 1) an individual’s Foundation for the concept 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.

Discussion: The theme of Coping (with uncertainty) emerged as a particularly critical behavior/characteristic amongst the subjects. By understanding a subject’s disposition with regard to coping, researchers were better able to make connections between a subject’s prior experiences, their knowledge seeking activities, and their intent to participate in SDM. 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. In addition, the coping category reinforced the importance of information seeking behaviors and preferences for shared decision-making.

Conclusions: This study applies and extends the field of behavioral and health informatics to assist medical practice and decision-making in situations of medical uncertainty. More specifically, this study led to the development of a category framework that facilitates the identification of an individual’s needs and motivational factors with regard to their intent to participate in shared decision-making in situations of medical uncertainty.

1. Background and Significance

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 or psychological condition which threatens his life or adversely affect his quality of life, and regardless of whether the research evidence is strong or lacking. Uncertainty nearly always enters the equation, as it is frequently a component of medical reasoning [2–5]. Some topics which 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 [6]. A summary of recent trends in medical reasoning and knowledge reported that nearly half (47%) of all therapies for clinical prevention or treatments...

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were of unknown effectiveness and an additional 7% involved an uncertain tradeoff between benefits and harms [7].

Shared decision-making (SDM) has been identified as an effective technique for managing uncertainty involving two or more parties [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 [8]. 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, 9–11]. Even those patients that prefer not to participate in SDM, should still at least understand that it is an option and may alleviate some stress involved in medical uncertainty [12, 13].

How do we move away from this cycle of negative association 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 [14–21]. Based on this evidence, the intent to engage in a behavior leads to the behavioral action [14–21]. Behavior is defined as the action or reaction of an entity, human or otherwise, to situations or stimuli in its environment [22]. Behavior 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, including mammography participation and AIDS-preventative behavior [14–21]. However, behavioral intent has never been studied adequately to understand the behavioral action or preferences in the context of shared decision-making. In addition behavioral intent adds to the transdisciplinary scientific exchange and research that is needed in the field of informatics, and thereby SDM [23].

Therefore, the purpose of this 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.

1.1 Behavioral Intent

In order to understand and characterize the behavioral intent of the patients, elements from the Theory of Reasoned Action (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). Therefore, if an individual aims to engage in a behavior, it is likely that he will do so [8, 24].

Behavioral intent is the basis for the Theory of Reasoned Action (TRA) [24, 25]. This theory has 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 [26–30]. 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
2. Materials and Methods

In order 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, the researchers conducted a semi-structured, open-ended interview on 25 subjects from the Philadelphia area.

2.1 Inclusion Criteria

Researchers recruited African-American and Caucasian men between the ages of 45 and 70. The reason for the specific population sample was due to the fact that the researchers had more access to recruit this particular population at the University of Pennsylvania Medical Center.

2.2 Recruitment and Data Collection

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 the interview. Calls were then screened by the research coordinator who asked questions to verify eligibility. Once eligibility was established, a date and time was arranged for the interview. All interviews were conducted by the research coordinator between December 2010 and February 2011. All interviews were recorded and later transcribed.

2.3 Interview Content

The content for the semi-structured interview was developed from the literature review of shared decision-making, medical uncertainty, and theory of reasoned action. Table 1 shows the interview schedule for this project.

In order to initiate and set the tone for the interview discussion, the interviewer explained the concepts of medical uncertainty and shared decision-making. These concept descriptions were followed by reiterating to the subjects the purpose of the study: to identify and understand characteristics involved in the individual’s behavioral intent to participate (or not to participate) in shared decision-making when medical uncertainty is involved. The semi-structured interview was guided by the interview schedule, which provided a framework for issues that needed to be addressed and discussed, but also allowed for flexibility and elaboration on the individual’s personal beliefs and experiences. The majority of questions and specific paths of questioning were selected during the interview, allowing for the opportunity to probe for details and discuss issues. However, the initial question that was asked to all the subjects was: “After just hearing the definition of medical uncertainty, can you tell me if you have ever been involved or have experienced a medically uncertain situation?” Questions and discussions evolved based on the subject’s answer, while still using the interview schedule to guide and address research objectives. Appendix A shows a list of sample follow-up questions that were asked.

2.4 Data Analysis

The semi-structured interviews were analyzed using a qualitative, deductive content analysis, which 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 information related to behaviors and thoughts [35]. Deductive content analysis is used in cases where one wishes to re-test existing data or theories in a new context – in this case, applying the Theory of Reasoned Action in the context of shared decision-making in medically uncertain situations [36].

The content analysis for this study began during early stages of the interview process in which the researcher alternated between data collection and concept development. This method helped guide the data collection and concept development.
tion from the interviews toward sources that were useful for addressing the research question of understanding behavioral intent, as well uncovering the factors that influence behavioral intent for participating shared decision-making in medically uncertain situations.

The categories and coding scheme were derived from two sources: the literature – specifically, shared and medical decision-making, and the elements from the Theory of Reasoned Action – specifically, behavioral intent, attitudes and subjective norms. Furthermore, the unit of analysis used in this coding scheme was a patient’s behavioral intent (including attitudes, subjective norms) to practice shared decision-making in medically uncertain situations. Since these elements from the TRA were the basis, the initial list of coding categories was generated from this theory [24]. Therefore, the initial categories and codes included, attitudes about medical uncertainty and SDM, personality types, past experience, subjective norms of family, friends, and coworkers, to name a few. However, this theory was modified during the course of the analysis as new categories emerged during the interview process. In addition, category names, their respective definitions and rules for assigning codes were included in the coding manual. Appendix B provides an example of the category names, definition and rules based on a section of a subject’s interview. After the categorization matrix and coding manual were developed, all data was reviewed for content and coded according to identified categories. The properties and dimensions of the categories were explored to identify relationships between categories and uncover themes and patterns. Figure 2 is an example of one category matrix based on the interviews, coding, and emerging themes.

3. 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. The mean duration of the semi-structured interview was 37.2 minutes with a range of 21–55 minutes. The mean number of pages of the transcripts analyzed for the study was 7. Diggressions and off-topic conversations were not transcribed. 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. Table 2 shows the full demographic data of the participants.

3.1 Category Framework

From the subject interviews, the researchers identified common themes as key elements to the subjects’ intention to participate in shared decision-making in situations of medical uncertainty. These elements were utilized to construct the foundation for a category framework as a way to provide a comprehensive, systematic exploration of variables and processes associated with uncertainty and behavioral intent outcomes for shared decision-making. The objective of the category framework developed from the content analysis was to guide and generate research on an individual’s basis of medical uncertainty, and their behavioral intent to participate in shared decision-making. The three category framework factors (Foundation, Coping, and Intent) were derived from literature regarding the Theory of Reasoned Action and Shared Decision Making. As discussed in the methods section, the information from this literature was incorporated into the interview structure and also served as the basis for a deductive content analysis of this study’s interview data. The Foundation, Coping and Intent factors emerged as primary themes in the results of the deductive interview content analysis. The framework illustrated in the figure below highlights the three interlinked categories in this framework that combine to identify and describe sources of individual differences in relation to behavioral intent to participate in shared decision-making in the event of a medically uncertain situation. Figure 2 shows the category framework.

The following three sections provide a more detailed description of the primary framework categories developed through this study:

3.1.1 Category A – Foundation

The first category involves the individual’s Foundation for the concept/representation of medical uncertainty. The following three elements 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: general knowledge, past experience, and personality. These elements overlap but each emphasizes a distinct characteristic involved in decision-making participation in medically uncertain situations. These foundation themes are associated with the TRA’s factors involving at-
titude and subjective norms [24, 25, 33]. 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 [45, 46]. Personality examples include anxiety, hypochondriac, adoptive, low-stress, dependent, independent, and trusting personality. As mentioned above, the three elements of general knowledge, personal experience and personality provide the structure from which individuals form opinions and conceptualize medical uncertainty.

“I am 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 15

“Sure, I’ll hear the choices and options that my doc recommends, but then he makes the final decision. He is the expert, after all. I know he is human and not perfect, but I trust him to look after my best interest. My wife feels that same way, especially since a ‘medical uncertain’ event actually did happened to our son.” Subject 3

3.1.2 Category B – Coping Profile

The Foundation category identifies an individual’s basis for the concept/representation of uncertainty. The second category, Coping Profile, involves the methods in which the individual copes with the concept of medical uncertainty. We use the Lazarus & Folkman [12] definition of coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing.” An individual can have difficulty or can have no difficulty with coping. The individual is classified in one or the other category based on their responses and their personal foundation listed in Category A. Those individuals who have difficulty coping are considered as being in the active Information Seeking group. This conclusion was reached by assessing the individual’s responses from the semi-structured interviews. Individuals with difficulty coping were identified as having stated that the concept of medical uncertainty was a bit too much to cope with and their predicted intent would more likely be to get as much information as possible, e.g., internet searches, 2nd opinions, etc. This group is further characterized by having negative past experience(s) with medical uncertainty, having no experience with medical uncertainty, and having lack of personal or trusting relationships with medical professionals. Meanwhile, those individuals who were identified as having little to no 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.

“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.” Subject 20

“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 8

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Subject demographics. *COPD: chronic obstructive pulmonary disease</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>African American (n = 16 (63%))</td>
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<tr>
<td>Average Age</td>
<td>56.4</td>
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<tr>
<td>Marital Status</td>
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<td>2 (13)</td>
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<td>Married</td>
<td>9 (56)</td>
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<td>Divorced</td>
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<td>1 (6)</td>
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<tr>
<td>Education</td>
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<tr>
<td>High School or GED</td>
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<tr>
<td>Post High School Training other than college (Vocational, technical, etc.)</td>
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<td>Some College</td>
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<tr>
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<td>Diabetes</td>
<td>8 (50)</td>
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<tr>
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<td>2 (13)</td>
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“When it comes to something that you cannot predict—it’s not necessarily that I am okay, 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, okay there is nothing more we can do—so I’m okay with that standpoint.” Subject 6

3.1.3 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 relationship was identified between coping and intent to actively participate in SDM. The subjects identified as having difficulty coping 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 identified as having better abilities to cope 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 with difficulty coping were content with the information provided or otherwise available to them, accepted their role as a passive participant, and ultimately deferred final decisions to the healthcare professional.

Of the 25 subjects, 11 were observed to be information accepting participants, while 14 were information seeking. Additionally, all subjects identified as information seekers were also identified as active participants. Likewise, all information accepting patients were identified as passive participants. This result could be due to the small sample size or comparable sample characteristics (middle age-later age males from urban area). This breakdown is consistent with other studies that reveal an even split between patient preferences for active and passive roles [47, 48].

“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 decision on my own. If it’s uncertain, then the docs don’t know what to do either. I might as well do it.” Subject 22

“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 doctor. He’s great, and he knows everything about me already, and I trust his judgment.” Subject 9

“From my experience, I feel it has actually calmed me down more in turns of understanding that some things cannot be predicted… it’s okay to be open with your doctor…but I will still have him make the ultimate decision. 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 17

3.2 Study Validity

Various steps were taken to ensure the validity of this study. To facilitate transferability and dependability, the research coordinator established clear description of the context, transparent selection criteria, characteristics of the participants, systematic data collection processes, and ongoing analysis documentation and archiving. Credibility of the study was established through planned regular debriefing sessions between the research coordinator and the two research assistants. Since all three investigators independently coded the data, these sessions were held to ensure adherence to established, coding protocols, as well as to assess the consistency of the coding. In addition, any doubts or confusion regarding the definitions of categories, coding rules, or categorization were discussed and resolved in regular debriefing sessions. Although the construction of the category framework was created by the research coordinator, the research assistants were kept abreast on the development of the framework during these sessions.

4. Discussion

Using TRA for the development of this framework is consistent with the practice of applying existing theories or models outside of health informatics to adapt, modify and extend health and biomedical informatics research [37]. This study rein-
forced TRA, as the elements of subjective norms and attitudes were maintained as core elements of the Foundation category. Expanding upon TRA, this study identified Coping as an intermediary category which serves as a bridge between the Foundation (attitudes and subjective norms) and Behavioral Intent in the context of medical uncertainty. Throughout this study, the category of “coping or dealing with uncertainty” emerged as a primary characteristic, connecting the foundational and behavioral intent categories for understanding and dealing with medical 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. By recognizing this connection between the other categories, the coping category was established as a key to predicting behavioral intent from the observed foundational elements. Further, this framework also identified two distinct profiles (Information Seeking and Information Accepting) within the coping category which were observed to be related to two distinct profiles (ActiveParticipant and Passive Participant) within the behavioral intent category. From the interviews, it was observed that an individual’s specific disposition with respect to the foundational elements of general knowledge, personal experience and personality was associated with his/her coping profile. Thereby, the individual’s coping profile was observed as descriptive and predictive of their behavioral intent.

The concept of coping as a predictor of behavioral intent is supported by 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 [12, 39, 40]. Information-seeking can be used to support direct action and/or regulate emotions in a stressful situation. This framework helped to identify a new category of coping and two distinct profiles within that category (Information Seeking and Information Accepting). Through content analysis of the interviews led to the development of category framework regarding medical uncertainty and their behavioral intent to participate in decision-making. The results revealed three main categories including: 1) an individual’s Foundation for the 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 processes specific to situations and patients in order to optimize the effectiveness of communication, increase the likelihood of SDM, and maximize health outcomes. In this manner, this study and the resulting framework will contribute to informatics knowledge and facilitate the medical and healthcare goals of emphasizing personal decisions in regards to diagnosis and treatment of the individual [43].

4.1 Study Limitations

Subjects were self-selected volunteers who responded to fliers. These individuals were likely to either have an interest or concern about medical decision-making and human behavior and therefore may have responded in varied 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. Moreover, the methods conducted and described in this study are transferable and can be used with other population groups. Furthermore, by initially limiting this study to a certain population group helps to assure validity and reliability of the results. Future studies using other population samples would be of interest to conduct in order to determine how similar or different the category framework would appear.

5. 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 depiction of medical uncertainty, and their behavioral intent to participate in medical decision-making. The results revealed three main categories including: 1) an individual's Foundation for the 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 framework helped highlight a new category of coping and two distinct profiles within that category (Information Seeking and Information Accepting). Through content analysis of the
data resulting from the semi-structured interviews, this study also identified relationships between the two coping profiles and two distinct behavioral intent profiles (Active Participant and Passive Participant). These profiles and interactions were observed to be consistent with previous research and literature relevant to the study of medical decision-making [12, 13, 39–41]. This framework should be incorporated in future studies in order to provide a comprehensive and systematic exploration of variables and processes associated with uncertainty, behavioral intent, and ultimate behavior 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 foundation, coping, and behavioral intent into the study and application of shared decision-making in medically uncertain situations.

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References