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# Design of an Intelligent Patient Decision aid Based on Individual Decision-Making Styles and Information Need Preferences

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**Abstract**
An emerging trend in healthcare delivery is that of patient-centered medicine which includes empowering patients through shared decision-making in their medical care. The use of information technology is a key enabler for empowering patients and supporting patient-centered care. The patient decision aid is one tool for getting patients more involved in their care. However, existing patient decision aids make generalized assumptions about their users and fail to accommodate the variability of individual information needs and decision-making preferences known in the literature. In this paper, we investigate patient attributes that influence patient decision-making preferences and present a framework for the design of individualized patient decision aids. The proposed framework is instantiated in the context of end stage renal disease and was tested to evaluate its effectiveness.

**Keywords** Patient decision aids · Decision maker preferences · Information needs · Personalization

## 1 Introduction

Healthcare expenditure in the United States constitute a significant portion of the gross domestic product (GDP) and have continued to rise over the years (Kamal et al. 2020). However, the high healthcare expenditures have not translated to higher quality of care (Kurani et al. 2020). Physician accountability programs have offered patient-centered care as a mechanism for improving quality, maintaining costs, and balancing short- and long-term health management goals in ways that consider patients' interests (Boyd et al. 2005).

Patient-centered medicine is geared to deliver care on a more personalized level capable of improving patient satisfaction and quality of care without incurring additional costs (Sinaiko et al. 2019). The Institute of Medicine (IOM) (2001) defines patient-centered care as respecting and being responsive to individual patient needs, preferences, and values while using them as a guide for clinical decision-making. Patient-centered medicine obliges physicians to establish healing relationships that place client interests above everything else. Recent research indicates that patient-centeredness is critical to patient adoption of emerging mechanisms such as online medical consultations and the formation of interpersonal trust (Yang et al. 2021). In the absence of these healing relationships, patients often feel abandoned and misplaced by the demands and tensions of modern healthcare delivery methods (Vogus et al. 2020). Individually tailored information and shared deliberation processes are viewed as a necessary premise for establishing healing relationships during office visits.

*Patient decision aids* are instruments that assist patients in arriving at informed, value-based health care decisions (Feldman-Stewart et al. 2012) and serve as supplements rather than complete replacements of clinical consultations (Olling et al. 2019). Some of the predicted effects of patient decision aids are increased patient comfort, knowledge, and involvement in shared decision-making (Izquierdo et al. 2011; Thomson and Hoffman-Goetz 2007; Yu et al. 2019). When

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properly implemented, patient decision aids should stabilize treatment preferences, reduce decisional conflict, improve satisfaction rates, control levels of anxiety, and accelerate the speed clinical decision-making (Evans et al. 2007; Holmes-Rovner et al. 2007). Patient decision aids can assist patients in clarifying personal values, understanding treatment options, and deliberating possible outcomes (Elwyn et al. 2006; O'Connor et al. 2007; Zeballos-Palacios et al. 2019).

However, there are significant differences between the current and desired levels of personalization, clinical utilization, and ability to correct the overwhelming effect of human emotions and stressful context in current patient decision aids (O'Connor et al. 2007; Phillips-Wren et al. 2019). Current patient decision aids make generalized assumptions about their users and fail to accommodate the variability of individual information needs and decision-making preferences known in literature. In order to increase comfort, knowledge, participation in the decision-making process, and support for personal health related decisions, patient decision aids should be individualized for the end user (Dolan and Frisina 2002; Levine et al. 1992; Stacey et al. 2011). Individualization is especially important because patient decision aids are meant to support treatment selections lacking the medically apparent right or wrong answers (Harrison et al. 2009; Holmes-Rovner 2007; Levine et al. 1992; Vromans et al. 2019a).

Most current patient decision aids ignore personal information needs and individual desires for decision-making autonomy (Vromans et al. 2019b). They also lack the ability to minimize human bias caused by uncontrolled emotions and high levels of anxiety. An ideal patient decision aid should provide a means to control emotional bias and list information about treatment options in a manner that is meaningful to each patient. To achieve this objective, we present in this paper a patient decision aid framework that considers individual human characteristics such as preferences for decision-making autonomy and personal information needs. The framework has a strong basis in decision-making theory and accounts for the role of emotions in human decision-making. The framework includes a process model for providing a personalized treatment selection experience that is tailored for the patient and results in improved decision-making by lowering the levels of decisional conflict.

In the following sections, we begin with an overview of the literature on patient decision strategies and patient information needs that influence the design of patient decision aids followed by a discussion of the shortcomings in current patient decision aid designs. We then discuss the design science research approach used to develop a patient decision aid design framework followed by the description of the various framework components. We evaluate the framework with a user study in the context of end stage renal disease (ESRD) and present the results of the study.

## 2 Background

### 2.1 Decision Support in Healthcare

An abundance of data has led to the development of several new types of decision support systems in healthcare, including new data and text analytics based approaches (Guo et al. 2017; Huang et al. 2020; Piri et al. 2017), Bayesian models (Topuz et al. 2018), process discovery, case-based reasoning and optimization models (Mertens et al. 2020; Miller and Mansingh 2017) and artificial neural networks (Walczak and Velanovich 2018). However, most of the decision support models focus on clinicians as end users. Given the evolving practices of patient-centered and participatory decision-making in healthcare, there is also a need to build patient decision aids that are personalized to patient decision-making preferences.

The design features of a decision support system have significant impact on decision outcomes. Factors such as fit between information representation and cognitive style (Engin and Vetschera 2017), true personalization (Xiao and Benbasat 2018) and design of appropriate guidance design features (Morana et al. 2017) can significantly influence decision-making outcomes. Patient-centered healthcare, specifically, emphasizes the use of participatory decision-making, which is defined by the Institute of Medicine (2001) as shared decision making between a clinician and patient where the "decisions respect patients wants, needs and preferences and solicit patients' input on the education and support they need to make decisions and participate in their own care". While a large amount of research has been published on guidance features in the past several years, there is a limited amount of research on participative guidance systems (Morana et al. 2017).

### 2.2 Decision Strategies and Patient Decision Maker Types

Decision strategy, context, and information management are stated to be some of the fundamental components of decision support systems (Zhuang et al. 2012). Four main strategies assist users in reaching the vast majority of decisions: 1) "recommend for", 2) "recommend against", 3) factual information, and 4) "how-to" recommendation (Dalal and Bonaccio 2010; Zhuang et al. 2012). Highlighting the best alternative is also known as the "recommend for" or the inclusion decision strategy (Heller et al. 2002). A "Recommend for" decision strategy suits those seeking to delegate their decision-making autonomy, since it is the most direct approach to quickly orient passive decision makers. The next advice giving decision strategy focuses on recommending against a particular course of action and, thus, is called a "recommend against" or exclusion decision strategy (Dalal and Bonaccio 2010). A "Recommend against" decision strategy is a better fit for those seeking to share their decision-making autonomy, since it does not prescribe any one specific alternative but simply reveals the least fitting option (Zhuang et al. 2012). The third decision strategy is the provision of factual information, which refrains from any explicit recommendations. The factual information decision strategy suits those who value their autonomy and prefer an independent decision-making process (Dalal and Bonaccio 2010). The fourth strategy is "how-to" decision support, which also does not make any specific recommendations but instead facilitates the process through structure and presentation (Zhuang et al. 2012).

The vast majority of the existing patient decision aids assume that patients desire to be the primary decision makers; however, evidence reveals that only a minority of patients seek such autonomy (Deber et al. 1996; Scott and Lenert 2000). Anticipated decision-making preferences are usually matched for less than half of all patients, and patients' autonomous decision-making desires are matched even less frequently (Degner et al. 1997; Kasper et al. 2008). Patients whose treatment selections match with their goals and values exhibit more confidence and lower conflict with the resulting decisions (Sepucha et al. 2012). Therefore, decision aids that reflect a patients decision making preferences can increase the value of clinical care and lead to greater adoption of the decision aids.

There is an agreement in the literature that four main patient types lead to four patient-physician relationships and four decision-making preferences (Emanuel and Emanuel 1992; Green 1988; Scott and Lenert 2000). The four relationship models are paternalistic, informative (or informed), collaborative and deliberative. The correlation between the desired and actual decision-making preferences has the ability to predict patient regimen adherence (Hirsch et al. 2011). Sharing of the decision-making process should be driven by patient desires. Otherwise, it may cause undue anxiety and fail to achieve health care improvements (Elwyn et al. 1999). Matching decision-making strategies with individual preferences is now recommended as a more rational approach to decision aids rather than advocating an increased control for everyone regardless of their individual desires (Kasper et al. 2008). The Control Preference Scale (CPS) is an instrument that can be implemented to elucidate patient decision-making preferences (Kasper et al. 2011), and it is claimed to be one of the best ways of doing so in clinical settings (Kasper et al. 2008).

#### 2.2.1 Paternalistic Patient Model

The paternalistic model of patient-physician relationship assumes that doctors and their patients share common goals and personal values (Emanuel and Emanuel 1992). The paternalistic model vests physicians with performing professional problem solving as well as personal decision-making tasks, and patients are expected to be grateful for the decisions made on their behalf (Emanuel and Emanuel 1992; Scott and Lenert 2000). Emanuel and Emanuel (1992) state that the paternalistic model can be fully justified in cases of medical emergencies when losing time may cause irreversible patient harm. Even though the population preferring this completely passive role is not large, the paternalistic model has traditionally been the most prevalent type of consultation style (Elwyn et al. 1999). The paternalistic patient group can be significantly larger in select populations, since most patients exhibit a diminishing desire for decision-making involvement as the severity of illness increases. This patient type wishes to relinquish the process of treatment selection and prefers a "recommend for" decision strategy.

#### 2.2.2 Informed Patient Model

The informed model presumes a clear separation of medical facts and individual patient values. Patients who prefer this type of relationship fully recognize their beliefs and are capable of exercising independent decision-making (Scott and Lenert 2000). Physicians act as technical domain experts who provide patients with the facts necessary to operate autonomously (Emanuel and Emanuel 1992). Problem-solving and decision-making processes are separated and assigned to tasks performed by each of the parties. Physicians are relieved of the duty to clarify personal values, and patients are prepared to make personally suited treatment choices. The majority of patients do not seek complete decision-making autonomy, but neither do they want entirely passive paternalistic roles (Benbassat et al. 1998). The informed patient type prefers the provisioning of factual information as a decision-making strategy.

#### 2.2.3 Collaborative Patient Model

The collaborative model clearly separates medical facts from patient values while tasking the physicians to assist patients in elucidating and articulating their personal beliefs (Emanuel and Emanuel 1992). In this relationship model, doctors are not only technical domain experts but also personal counselors and advisers. Collaborative patients rely on their physicians for clarification of values. Green (1988) recommended that the collaborative model replace informed consent, which currently serves a legal rather than clinical purpose. Scott and Lenert (2000) stated that physicians of the collaborative patients should not dictate or judge personal values but help in elucidating patient beliefs and aligning the available treatment options with them. It is stated that 50–60% of all patients are of the collaborative type. The collaborative patient prefers to share the decision-making autonomy and compare the output of "recommendation for" and "recommendation against" decision strategies.

#### 2.2.4 Deliberative Patient Model

Physicians of deliberative patients influence their clients' beliefs by suggesting the best personal values for particular clinical situations (Emanuel and Emanuel 1992). Doctors rely on their domain knowledge together with prior experiences to explicate why some values are more admirable and worth pursuing than others. Deliberative relationships urge physicians to abandon objectivity and act as friends who attempt to correct mistaken patient views for their own best interests (Scott and Lenert 2000). In the end, both patients and their doctors need to believe that the chosen path is the best available alternative. It is stated that 10–20% of all patients are of the deliberative type. This group often includes female and highly educated individuals (Emanuel and Emanuel 1992; Scott and Lenert 2000). As with the collaborative patient type, deliberative patients prefer to share their decision-making autonomy and compare the output of the "recommend for" and "recommend against" decision strategies.

### 2.3 Information and Information Need

Health information seeking behavior is a key aspect that mediates the relationship between patient technology use and quality of life (Ghahramani and Wang 2020). However, it is important to understand that information has the capability to increase uncertainty or reduce it (Dervin and Nilan 1986). Cognitive psychology research shows that unrestricted information flows and material complexity may quickly overwhelm decision makers leading to systematic errors (Carrigan et al. 2004). It has been shown that patients become anxious when they are presented with an abundance of information too soon (Kaprowy 1991). Information needs tend to vary considerably among patients. Some patients may use information gathering as a coping mechanism and as a form of stress reduction. Others may be so overwhelmed that they admit hearing and comprehending only 25–50% of the relayed information (Kaprowy 1991). In one study, Ameling et al. (2012) found that patients are openly critical of the large amount of presented information even when decision aids are designed according to the widely accepted international standards. Researchers had to develop a complementary minimalist version of the material to address the stated concerns (Ameling et al. 2012).

The amount and type of information provided by patient decision aids should be preceded by the explicit elucidation of personal needs (Feldman-Stewart et al. 2012). Sharing of clinical decision-making processes often fails because it is not preceded by information sharing (Elwyn et al. 1999). Information need happens upon recognition of general inadequacy to meet a particular goal (Case 2002). Information need is a construct uncorrelated with decision-making preferences. Patients yearning for the maximum amount of information may simultaneously seek to delegate their decision-making autonomy (Degner et al. 1997). Patient desires for information are often described to be stronger than those for shared decision-making (Elwyn et al. 1999).

Patients show that they seek different kinds of information at different points of their disease trajectories. Varying degrees of psychological states and decision-making preferences have been shown to affect information needs (Ankem 2006; Cassileth et al. 1980). In a psychologically compromised state, patients may develop a conflict between information need and fear of bad news (Parker et al. 2007). To avoid the above issues and information overload, patients should be provided with the exact amount of information they desire, and research confirms that patients are capable of identifying the amount of information they need (Kaprowy 1991). Instruments such as the Information Styles Questionnaire, can be used in a clinical setting to elicit the desired level of informational detail (Cassileth et al. 1980).

### 2.4 Current State of IT-Enabled Patient Decision Aids

Several different patient decision aids have been developed to support patient decision-making for health screening and treatment decisions (Stacey et al. 2011). While several of the patient decision aids are not computerized or online, computerized and online patient decision aids for specific disease conditions such as colorectal cancer (Schroy et al. 2011) and type 2 diabetes (Ng et al. 2014) among others have been developed. However, a major limitation for developing computerized or internet-based patient decision aids is the lack of a framework that integrates the theoretical rationale from cognitive psychology, decision psychology with human-computer interaction and decision support technologies for the development of interactive and individualized patient decision aids (Hoffman et al. 2013). Interactive computer-based applications hold clear potential for effective information provisioning, correction of forecasting bias, and elucidation of individual preferences (Elwyn et al. 2011). However, this potential remains largely underexplored (Elwyn et al. 2011; Vromans et al. 2019a).

Even with the seemingly endless potential to individualize the decision-making process, there is a clear absence of a formal information technology framework, which can assist patient decision aid developers in designing new applications. Specifically, there are three major research gaps identified in literature related to the design of computerized patient decision aids that include (1) a lack of informational individualization (Feldman-Stewart et al. 2005; Stacey et al. 2011; Thomson et al. 2007), (2) a lack of individualization based on the decision-making preferences (Emanuel and Emanuel 1992; Green 1988; Scott and Lenert 2000), and 3) a lack of design based on accepted decision-making theory including human emotions (Elwyn et al. 2011; Hoffman et al. 2013). In order to address the above research gaps, we develop a framework for the design of intelligent patient decision aids using the design science research approach.

## 3 A Design Framework for Intelligent Patient Decision Aids

### 3.1 Research Approach and Framework Objectives

We followed the principles of design science (Hevner et al. 2004) and the design research process model (Peffers et al. 2008) to develop the framework. We utilize the design research methodology because of the stated objective to advance the fields of health care and information systems via a solution-oriented innovation of patient decision aids. We identified the problem by analyzing relevant literature and identifying the limitations of existing patient decision aids. Specifically, the problems identified relate to three main shortcomings of current patient decision aids and are related to providing better emotional support for human decision makers, personalization of individual information needs, and preferences for decision-making autonomy. The solution objective focuses on addressing the three identified research gaps. The design and development phase of the methodology involves the development of a patient decision aid framework that includes components aimed at achieving patients' emotional adaptation and personalizing the treatment selection process by satisfying the individual desires for decision-making autonomy and personal information needs. Patient decision aids created according to this framework are expected to yield higher quality decisions. The feasibility of the framework is demonstrated through the implementation of an end stage renal disease patient decision aid based on the proposed framework. In evaluation, we conducted a user study that compares the functionality of a traditional patient decision aid to that of the developed framework.

The proposed framework takes into account varying patient decision-making preferences and information requirements. In the context of the Morana et al. (2017) taxonomy of guidance features, this paper presents the design of decision aids that are participative in mode, suggestive and informative in terms of directivity and prospective in terms of timing. Table 1 lists the shortcomings of existing patient decision aids and the corresponding objectives of the proposed framework and needed application features. As seen in Table 1, the framework closes the gap of information needs personalization by satisfying information needs with an individually tailored end user experience. The information needs framework objective is aligned with the application feature called the Information Need Component. Similarly, lack of individualization based on the decision-making preferences is the deficiency addressed by the framework's strategy personalization. The Decision Strategy Component is the application component, which must be present to close the stated deficiency. The framework is made to be aware of the role of human emotions in the treatment selection process through the inclusion of an emotion aware decision-making theory. Thus, the application based on the framework must also contain the Emotional Adaptation Component, which reduces the negative effects of highly emotional states.

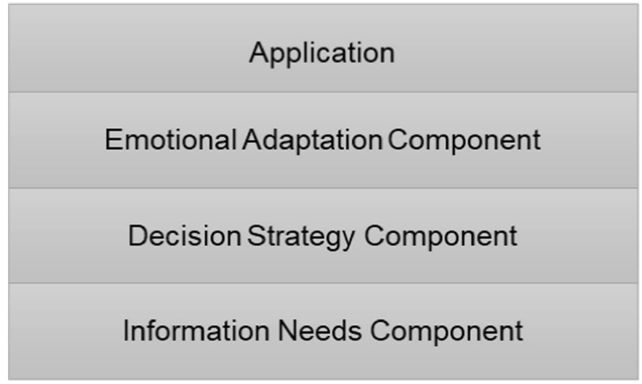



**Fig. 1** Framework components for patient decision aids

### 3.2 Framework Components

A high-level architecture diagram of the framework is shown in Fig. 1. It begins with the top layer Emotional Adaptation Component, which applies an accepted emotionally aware decision-making theory and attempts to de-bias the fragile emotional state of medical decision-making by incorporating an emotional adaptation exercise. The next layer is the Decision Strategy Component which is responsible for

**Table 1** Framework objectives

| Research gaps | Framework objectives | Application features |
|---|---|---|
| Lack of individualization based on patient information needs. | Personalization: Information needs are tailored individually. | Information Need Component |
| Lack of individualization based on patient decision-making preferences. | Personalization: Decision-making preferences are tailored individually. | Decision Strategy Component |
| Lack of design based on accepted theory, which includes the role of human emotions. | Explicit use of decision-making theory, which accounts for human emotions. | Emotional Adaptation Component |

eliciting patients' decision-making preferences and individualizing informational output with the help of the developed formulas and binary matrices. The next layer is the Information Need Component, which contains the formulas and binary matrices used to individualize the amount of presented information.

The underlying theoretical basis for inclusion of the above components in our framework is shown in Fig. 2. The existence of emotional forecasting bias motivates the development of the corresponding adaptation exercise. Variability in personal information needs, which cannot be predicted based on demographic or other contextual data, drives the development of the framework's informational personalization. Variability of individual desires for shared decision-making shape the development of the Decision Strategy Component, which assembles personal decision-making strategies based on the elicited individual decision-making preferences.

Figure 3 displays the high-level process model for personalizing the user experience based on a patient's informational needs and decision-making preferences. The process begins by eliciting individual desires for shared decision-making. Next, individual information needs are identified continuously, based on the patient's desire to review additional information. The patient's decision-making desires and information needs are used as input by the Decision Strategies Component and Information Need Component to present a personalized output for the patient to help in their decision-making.

## 3.3 Decision Strategy Component Implementation

Decision makers are paired with the application interface, which first presents general information about the disease, treatment options, and the Emotional Adaptation Component. The Decision Strategy Component uses a previously validated instrument to reveal personal desires for shared decision-making. The developed binary matrices are then applied to match the elucidated preferences for shared decision-making with the corresponding decision-making modules residing in the decision support repository.

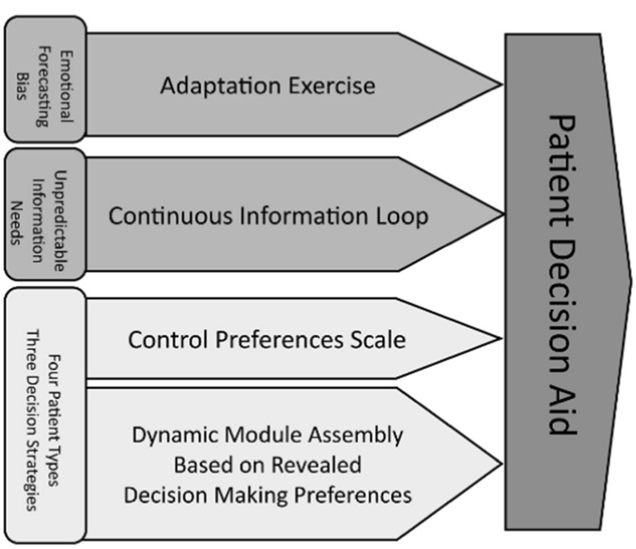



**Fig. 2** Theoretical underpinnings of patient decision aid framework

### 3.3.1 Control Preferences Profile (Coefficient x)

The Control Preferences Scale (CPS) is used to elucidate individual preferences for shared decision-making desires used by the decision strategy and workflow recommendation components. Patient Type coefficient x assists in recording the results of Control Preferences Scale in the Patient Type matrix. Coefficient x is the direct output of Control Preferences Scale in binary format, and it is used to record individual preferences for shared decision-making in the Patient Type (PT) matrix. Coefficient x can accept values of the following range: $\{x \in \mathbb{N} \,|\, 1 \leq x \leq n\}$, where n is the total number of decision maker types as measured by the CPS instrument. Lower coefficient values signify desires for reduced decision-making autonomy while larger coefficient values highlight the desires for more autonomous decision-making styles. For example, coefficient x = 1 represents a Paternalistic (passive) decision maker while x = n is the decision maker with the highest degree of desired autonomy.

### 3.3.2 Patient Type (PT) Matrix

The patient type (PT) matrix is a binary 1 x n matrix for n decision maker types, which are the output of the Control Preferences Scale. The matrix contains four variances of decision-making autonomy that include passive decision maker, collaborative decision maker, deliberative decision maker, and informative decision maker. Individual preferences for shared decision-making are recorded within the matrix by assigning the binary value 1 (one) in the component marked by the Patient Type coefficient x.

Each component of Patient Type Matrix (PT) is set by the following definition where *n* stands for the number of decision maker types.

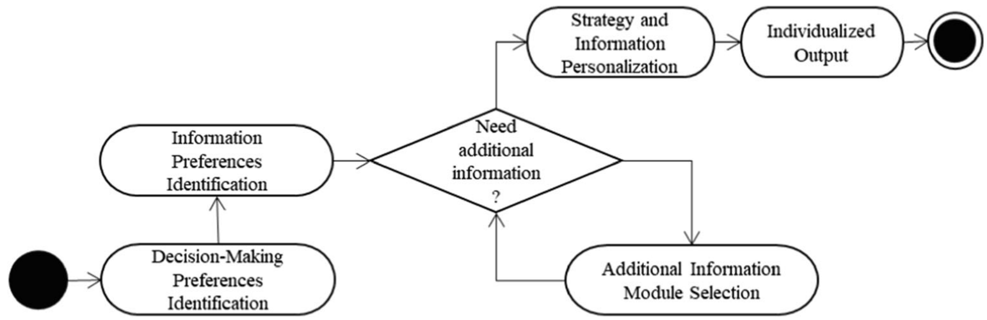
$$PT_{1\times n} = \begin{cases} 1, & \textit{if patient has a preference for decision making style } x \\ 0, & \textit{otherwise} \end{cases}$$

A sample patient type matrix (PT) is given in Table 2.

### 3.3.3 Strategy Type (ST) Matrix

The Strategy Type (ST) matrix represents the decision strategies available within the system. ST matrix uses the binary value one to match the decision maker types with the corresponding decision-making strategies. Each decision maker type is aligned with a single decision-making strategy by

**Fig. 3** Personalized user experience provisioning process




setting the binary value one to the corresponding component of the Strategy Type matrix.

Each component of Strategy Type (ST) matrix is set by

$$ST_{n\times m} = \begin{cases} 1, & \textit{if strategy module } y \textit{ is relevant for decision making preference } x \\ 0, & \textit{otherwise} \end{cases}$$

where $n$ stands for number of decision maker types and $m$ stands for number of decision strategies. In this study, the strategy type matrix is populated such that paternalistic (passive) decision makers are paired with the Recommend For decision strategy module, collaborative and deliberative decision makers are paired with the "Recommend For" and "Recommend Against" modules, and informative decision maker type is paired with the Factual Information module. A sample Strategy Type Matrix is provided in Table 3.

### 3.3.4 Strategy Output (SO) Vector

The personalized decision strategy for the patient is then revealed by the Strategy Output (SO) vector, which is achieved via multiplication of the PT and ST matrices.

$$SO_{1\times m} = PT_{1\times n} \times ST_{n\times m}$$

The SO Vector, which combines the framework's static logic described in the ST matrix and dynamic individual preferences recorded in the PT matrix, is a 1 x n matrix of binary information that acts as a set of software attributes that can be used by the decision aid software to filter decision support components and present a personalized decision strategy to the end user.

**Table 2** Sample Patient Type Matrix

| | Paternalistic | Collaborative | Deliberative | Informative |
|---|---|---|---|---|
| Decision Maker | 1 | 0 | 0 | 0 |

## 3.4 Information Need Component Implementation

The application begins by presenting decision makers with general information about the disease, treatment options, and Emotional Adaptation Component. Then, the Decision Strategy Component uses the Control Preferences Scale to reveal personal desires for shared decision-making. After forming the individual decision strategy by arriving at Strategy Output vector, the application must meet personal information needs.

### 3.4.1 Information Needs Profile (Coefficient Y)

Coefficient y represents the number of information modules decision makers elect to review. Coefficient y accepts the following values: $\{y \in \mathbb{N} \mid 1 \le y \le p\}$, and it is incremented by a value of 1 with every additional information module a decision maker wishes to examine. First information module is always presented, which sets the lowest value of coefficient to 1 (one). It is recommended to follow the content guidelines of the IPDAS Criteria (O'Connor et al. 2007) for the structure of the initial information module. Content section of the IPDAS Criteria document is considered the minimum amount of information needed for a successful process of treatment selection.

### 3.4.2 Information Selection (IS) Matrix

Coefficient y is used to record individual information need in the Information Selection (IS) matrix. The first component of the matrix is the minimum information to be provided to a patient that is necessary to arrive at a treatment selection. As the information need for the patient increases, we increment

**Table 3** Sample Strategy Type Matrix

| Decision Maker | Recommend For | Recommend For and Recommend Against | Factual Information |
|---|---|---|---|
| Paternalistic | 1 | 0 | 0 |
| Collaborative | 0 | 1 | 0 |
| Deliberative | 0 | 1 | 0 |
| Informative | 0 | 0 | 1 |

the value of coefficient y by 1 until y = $p$ is reached where $p$ represents the highest level of information need.

Information need is satisfied individually by allowing decision makers to elect additional information modules and, thus, directly manipulate the values of coefficient y. Information needs are recorded in the IS matrix by assigning the binary value 1 (one) to the corresponding level of patient information need. Each component of Information Selection Matrix (ISy) is defined as follows where there are $p$ possible levels of information needs.

$$IS_{1\times p} = \begin{cases} 1, & \textit{if patient has a preference for information module y} \\ 0, & \textit{otherwise} \end{cases}$$

A sample Information Selection Matrix is shown in Table 4.

### 3.4.3 Amount of Information (AI) Matrix

An Amount of Information (AI) matrix represents information modules available within the system. Information modules of the matrix are typically based on the extant literature where patients reveal their concerns about the type of information missing from their usual clinical consultations(Kaprowy 1991). Rows of the AI matrix represent the cumulative information range while columns list the corresponding information modules. A binary value one (1) marks relevant information modules while the value of zero (0) shows the information modules, which are not applicable to the corresponding amount of information. Each component of Amount of Information (AI) matrix is defined as follows where $p$ is the levels of information needs and $q$ stands for number of available information modules.

$$AI_{p\times q} = \begin{cases} 1, & \textit{if information modulex is relevant for information preference y} \\ 0, & \textit{otherwise} \end{cases}$$

Table 5 is an example representation of the Amount of Information matrix where binary value one (1) marks relevant information modules for a possible range of personal information needs. The remaining components of the AI matrix are set to their default binary values of zero (0).

### 3.4.4 Information Output Vector

The Information Output (IO) vector is the product of the Information Selection (IS) matrix and the Amount of Information (AI) matrix.

$$IO_{1\times q} = IS_{1\times p} \times AI_{p\times q}$$

The Information Output Matrix can then be used by the patient decision aid software to filter relevant information modules and present personalized output that satisfies the patients information needs.

## 3.5 Implementation of Patient Decision Aid for Dialysis Treatment Selection

In order to demonstrate the feasibility of the proposed framework and provide a prototype for evaluation of the framework, we developed a patient decision aid for End Stage Renal Disease (ESRD) based on our proposed framework. End stage renal disease is becoming a major health problem as the number of patients entering chronic renal programs continues to increase (Kaprowy 1991). In the United States alone, chronic kidney disease (CKD) affects as many as 20 million adults (Keith et al. 2004). Many of whom progress towards end stage renal disease, which is the last stage of chronic kidney disease

**Table 4** Example Information Selection Matrix

| | Minimum Information | Balanced Information | Maximum Information |
|---|---|---|---|
| Decision Maker | 1 | 0 | 0 |

**Table 5** Binary Representation of Amount of Information (AI) Matrix

| | IPDAS Criteria Content Section | Additional Module q-1 | Information Module q |
|---|---|---|---|
| Minimum Information | 1 | 0 | 0 |
| Balanced Information | 1 | 1 | 0 |
| Maximum Information | 1 | 1 | 1 |

when renal replacement therapy becomes a necessary life supporting treatment. There are several forms of renal replacement therapy two of which are considered medically equivalent: hemodialysis and peritoneal dialysis. Selecting between the two treatment options can be characterized as a process of personal value judgments, which should reflect individual patient desires and lifestyles (Wang and Chen 2012).

Literature reveals that ESRD patients have experienced difficulties in electing the most fitting treatment types because of the inability to share the process of treatment selection and a lack of desired decision supporting information (Christensen and Ehlers 2002; Kidachi et al. 2007). Unfitting treatment types have been shown to worsen patients' mental states, regimen adherence rate, quality of life, and subsequent expected medical outcomes (Feroze et al. 2010; Rahimi et al. 2008). Currently existing patient decision aids for dialysis treatment selection lack the capacity for emotional adaptation, facilitation of shared decision-making, and satisfaction of personal information needs. There are four existing online instruments, which attempt to facilitate the decision-making process of dialysis treatment selection. They include NHS Choices aid for dialysis, chronic kidney disease options grid, and DaVita dialysis treatment evaluator. However, none of them include emotional adaptation, personalized decision strategy or information personalization features.

### 3.6 Framework Validity

We establish formative validity of the proposed framework by identifying and using relevant theory in the design of the proposed artifact. A summary of the research objectives and their corresponding evaluation is given in Table 6.

## 4 Evaluation and Validation

In order to test the summative validity of the artifact, we implemented a patient decision aid based on the framework and conducted a user study to empirically test if the decision aid meets its objectives.

### 4.1 Decisional Conflict Scale

In order to evaluate the quality of decision-making as a result of using the patient decision aid, we used the Decisional Conflict Scale (DCS), which has been recommended by the Foundation for Informed Medical Decision Making as an effort to standardize decision quality measures (O'Connor 1993). Decisional Conflict Scale calculates one Total Score and several sub-scores used to quantify the quality of the decision-making process. Each of the sixteen Decisional Conflict Score questions are assigned a score in the range of zero through four. The value of Total Score is calculated as follows:

$$Total\ Score = \left( \frac{\sum_{q1}^{q16} 0 \leq q \leq 4}{16} \right) \times 25$$

**Table 6** Evaluation methods

| Objective | Formative Validity | Summative Validity |
|---|---|---|
| Explicit use of decision-making theory | Use of formal decision-making theory, which includes human emotions as recommended by Elwyn Glyn (Elwyn et al. 2011). | Collected data analyzed with independent samples T-test of the Decisional Conflict's mean values of 1) Total Score, 2) Uncertainty Subscore, 2) Informed Subscore, 3) Effective Decision Subscore. |
| Personalization: Information needs are tailored individually | Information baseline is defined by the IPDAS criteria (O'Connor et al. 2007). Explicit inquiry drives informational personalization (Benbassat et al. 1998). | |
| Personalization: Decision-making preferences are tailored individually | Control Preferences Scale (CPS) is used to reveal the desired level of decision-making autonomy (Kasper et al. 2008). Existing decision strategies are incorporated in the framework to match the desired levels of autonomy. | |
| Framework reliability | Mathematical verification of accuracy | Prototype implementation |

The Total Score is a numerical representation of personal decisional conflict. Low Total Score values depict a high-quality decision-making process (low levels of internal conflict) and high values indicate a potential problem.

The Uncertainty Subscore quantifies the degree of certainty a decision maker has after making a particular selection. Low scores (good) mean that a decision maker is certain about the choice while high scores (bad) depict uncertainty. The Uncertainty Subscore of the Decisional Conflict Scale is calculated as follows:

$$Uncertainty\ Subscore = \left(\frac{\sum_{q10}^{q12} 0 \le q \le 4}{3}\right) \times 25$$

The Informed Subscore reveals the feeling of being adequately informed. Low scores reveal informational sufficiency while high scores mean that the subject feels generally uninformed. The Informed Subscore is calculated as follows:

$$Informed\ Subscore = \left(\frac{\sum_{q1}^{q3} 0 \le q \le 4}{3}\right) \times 25$$

The Effective Decision Subscore is another subset of Decisional Conflict Scale. It represents the effectiveness of the decision-making process and is calculated using the following formula.

$$Effective\ Decision\ Subscore = \left(\frac{\sum_{q13}^{q16} 0 \le q \le 4}{3}\right) \times 25$$

Low Effective Decision Subscores mark decision-making ineffectiveness while the desirable high scores signify effectiveness.

## 4.2 Hypotheses

In order to test the utility of the proposed intelligent patient decision aid framework, we evaluate the performance of the implemented ESRD decision aid using the total and specific sub-scores of the decision conflict scale. The specific hypotheses are listed in Table 7.

## 4.3 User Study Protocol

### 4.3.1 Objectives

The objective of the user study is to evaluate the utility of the proposed framework. A group of 57 students from a midwestern university was asked to perform the tasks identical to those meant for future end stage renal disease patients. Although it would be ideal to test the framework with end stage renal disease patients, due to feasibility concerns, we were limited to testing the framework using healthy non-patients. However, we accounted for potential biases of the subjects by using an affective forecasting technique that has been successfully used in previous research and is further detailed in Section 4.3.3. Study data were collected, and artifact objectives were measured with the scores of Decisional Conflict Scale. Study design and process are described in the following sections.

**Table 7** Hypotheses to test the utility of the intelligent patient decision aid framework

| Hypotheses | Artifact Feature | Measurement |
|---|---|---|
| H1. Decision aids based on the proposed framework result in lower decisional conflict than non-individualized patient decision aids. | Emotional adaptation via an accepted decision-making theory. Personalization of decision-making process with the Strategy Output Vector and Information Output Vector. | Independent T-test analysis for Total Score of the Decisional Conflict Scale in experiment and control groups. |
| H2. Decision aids based on the framework better satisfy information needs. | Personalization of information need with the Information Selection Matrix. | Independent T-test analysis for Informed Subscore of the Decisional Conflict Scale in experiment and control groups. |
| H3. Decision aids based on the framework improve decision effectiveness. | Personalization of information need with the Information Selection Matrix and personalization of decision strategy with the Patient Type Matrix. | Independent T-test analysis for Effective Decision Subscore of the Decisional Conflict Scale in experiment and control groups. |
| H4. Decision aids based on the framework reduce decisional uncertainty. | Personalization of information need with Information Selection Matrix and personalization of decision strategy with Patient Type Matrix. | Independent T-test analysis for Uncertainty Subscore of the Decisional Conflict Scale in experiment and control groups. |
| H5. Decision aids based on the proposed framework satisfy the needs of more decision maker types than non-individualized patient decision aids. | Emotional adaptation via an accepted decision-making theory. Personalization of the decision-making process with the Strategy Output Vector and Information Output Vector. | The Total Score of the Decision Conflict Scale will be lower for the experimental group for a greater number of patient types than the control group. |

#### 4.3.2 Study Design and Participant Recruitment

We used a two-group posttest experimental design to evaluate the framework. Participants were randomly assignment to either control group or the treatment group conditions. Upon completion of the experimental tasks, we measured decision quality using the Decisional Conflict Scale. The participants in the treatment group were exposed to a patient decision aid system implemented using the proposed framework. The control group were exposed to an existing patient decision aid without personalization that consists of disease-specific treatment options and their alignment with personal values.

Potential participants were solicited via university email. More specifically, students studying Information Systems at Mid-Western University were asked to volunteer their time to help to evaluate the prototype. Participants are given an Universal Resource Locator (URL) link to the function randomly assigning them into either the experiment or control group. We used the JavaScript's Math.random() function to send participants to one of the two Uniform Resource Locators (URLs). The first URL is the patient decision aid designed according to the blueprint outlined in this work. This group is named the experiment group. The second URL is for the control group and includes a patient decision aid without personalization and implemented according to the IPDAS criteria checklist consisting of treatment options and their alignment with personal values.

#### 4.3.3 Accounting for Forecasting Bias of Healthy Non-Patients

In this study, we use healthy nonpatients to evaluate the patient decision aid. However, literature reveals that healthy individuals tend to predict that being on dialysis treatment would create an unpleasant mood the vast majority of the time, while actual dialysis patients commonly report positive mind states (Ubel et al. 2005). Human memories are known to contain accurate summaries of past emotional states (Buehler and McFarland 2001). Comparing future events to past experiences may reduce the intensity of forecasting bias by helping the decision makers recognize that emotional responses fade over time (Buehler and McFarland 2001; Ubel et al. 2005; Wilson et al. 2000). One study suggests that even greater reduction of forecasting bias is possible when the participants are asked to identify and list various coping mechanisms they would utilize to minimize the emotional impact of a challenging future event (Ubel et al. 2005). In this work, we adopt the instrument successfully applied by Ubel et al. (2005) to reduce forecasting bias. The instrument's questions are based on the theory of Affective Forecasting and can be interpreted similarly for a range of health-related conditions.

#### 4.3.4 User Study Process

The study was held using a web-based system. After the group assignment, participants were asked to sign a digital consent form and introduced to the basics of role playing. The scenario was explained, objectives were outlined, and participants were informed that the study would take 25–35 min of their time. They completed an adaptation exercise (Ubel et al. 2005) and use Control Preferences Scale to reveal decision-making preferences. Then, they reviewed available treatment options and perform individual selections. As the last step, participants are exposed to Decisional Conflict Scale which saves the anonymous and confidential answers on the web server.

#### 4.3.5 System Evaluation

Quantitative evaluation of the prototype's effectiveness is achieved with the statistical (Independent samples T test) comparison of the control and experiment groups. Decisional Conflict Scale values of Total Score, Uncertainty Subscore, Informed Subscore, and Effective Decision Subscore were compared. The study applies the 16-item version of Decisional Conflict Scale, which is used by the Foundation for Informed Medical Decision-making and IPDAS Collaboration and recommended for research purposes (O'Connor et al. 2007).

### 4.4 Study Results

The study used independent samples T-test analysis to compare the means of the experiment and control groups. The study applied an independent T-test to reveal whether Decisional Conflict Scale's Total Score, Effective Decision Subscore, Informed Subscore, and Uncertainty Subscore values were statistically different in control and experiment groups. Fifty-seven results were obtained via the solicitation email. The randomization function diverted 28 participants to be part of the control group while 29 students were randomly assigned to the experiment group. Summary of the results is presented in Table 8.

> ***Hypothesis H1: Decision aids based on the proposed framework result in lower overall decisional conflict than non-individualized patient decision aids.***

As seen in Table 8, the Total Score means of the experiment and control groups were 22.3 and 45.1, respectively. The difference in means between the two groups indicates a significant improvement in the decision-making quality for the experiment group. Independent samples T-test analysis, further corroborated the finding with the $P$ value of 0.000. Based on the $P$ value's we find support for the conclusion that decision aids based on the proposed framework are better as indicated by the significant improvement in the resulting overall

**Table 8** Summary of results for all decision maker types

| | | Number of Participants | Mean | *P* value | Mean Difference |
|---|---|---|---|---|---|
| Total Score | Control | 28 | 45.1 | .000 | 22.9 |
| | Experiment | 29 | 22.3 | | |
| Effective Decision Subscore | Control | 28 | 41.3 | .002 | 20.0 |
| | Experiment | 29 | 21.3 | | |
| Informed Subscore | Control | 28 | 40.8 | .006 | 22.7 |
| | Experiment | 29 | 18.1 | | |
| Uncertainty Subscore | Control | 28 | 56.3 | .006 | 20.9 |
| | Experiment | 29 | 35.3 | | |

decisional conflict measured by Total Score of Decisional Conflict Scale.

***Hypothesis H2: Decision aids based on the proposed framework better satisfy information needs.***

The Informed Subscore means of the experiment and control groups are 18.1 and 40.8, respectively. Informed Subscore of Decisional Conflict Scale reveals that the experiment group is better informed than the control group. The Independent samples T-test analysis produces *P* value of 0.006, which further confirms the findings. Based on the P value's we find support for the conclusion that the Informed Subscore of the experiment group is, indeed, lower than that of the control group. Therefore, decision aids based on the proposed framework satisfy individual information needs better. This conclusion is clearly indicated by the statistically significant improvement in the feeling of being well informed as measured by the Informed Subscore of Decisional Conflict Scale.

***Hypothesis H3: Decision aids based on the proposed framework improve decision effectiveness.***

The Effective Decision Subscore means of the experiment and control groups are 21.3 and 41.3 respectively. Lower scores of the experiment group represent higher decision-making efficiency. Participants of the experiment group exhibit higher decision effectiveness, as evident by the difference in means. Based on the *P* value of 0.002, we can conclude that decision aids based on the proposed framework improve the decision effectiveness as indicated by the statistically significant improvement in Decision Effectiveness Subscore of Decisional Conflict Scale.

***Hypothesis H4: Decision aids based on the proposed framework reduce decisional uncertainty.***

The Uncertainty Subscore means of the experiment and control groups are 35.3 and 56.3 respectively. Participants of the experiment group had a statistically significant reduction in their decisional uncertainty. The large and significant reduction in decisional uncertainty for the experimental group as opposed to the control group supports our claim that decision aids based on our proposed framework can reduce decisional uncertainty as indicated by the Uncertainty Subscore of Decisional Conflict Scale.

***Hypothesis H5: Decision aids based on the proposed framework satisfy the needs of more types of decision makers than non-individualized patient decision aids.***

Literature review reveals that current decision aids are designed for only one type of decision maker. Correspondingly, we expect that non-individualized patient decision aids will only satisfy the needs of one type of decision maker whereas the intelligent patient decision aids based on our framework will satisfy the needs of more types of decision makers as it adapts to their decision-making preferences and information needs. A statistical summary per decision maker type, as shown in Table 9, indicates that this decision maker type is of the Collaborative kind. The Mean Total Score values of Collaborative decision maker types for experiment and control groups were 24.9 and 25.8 respectively. The remaining decision maker types experience statistically significant improvements in the Total Score of Decisional Conflict Scale. Therefore, while the non-individualized patient decision aid can meet the needs of only the collaborative decision maker, the individualized patient decision aid is meets the needs of all the decision makers including the collaborative decision maker.

**Table 9** Summary of results per decision maker type

| | Group | Total Score | P Value |
|---|---|---|---|
| All Decision Maker Types | Control | 45.1 | |
| | Experiment | 22.3 | .000 |
| Informative Decision Maker | Control | 72.3 | |
| | Experiment | 15.6 | .000 |
| Collaborative Decision Maker | Control | 25.8 | |
| | Experiment | 24.9 | .873 |
| Paternalistic Decision Maker | Control | 76.6 | |
| | Experiment | 19.8 | .000 |

## 5 Discussion

The findings of this study contribute to the knowledgebase in two ways. First, the developed framework is reusable and can be implemented to serve a variety of medical conditions. It has been developed in a modular format, so that some of the components can be updated and replaced in line with our expanded understanding of patient decision aids and the roles they play in modern healthcare delivery systems. Second, the results of our evaluation confirm the benefits of personalization on the quality of patient decision-making. Our study adds to the knowledgebase of empirical studies on personalized patient decision aids, reinforces their validity, and can serve as a baseline for future studies on personalized patient decision aids with additional disease-specific instantiations.

The study results are also of importance to practitioners in two areas. It provides software developers for patient decision aids a ready to use framework for the design and implementation of future patient decision aids for a variety of conditions. The framework can server as a reference for general design principles of emotional adaptation, decision strategies, information needs assessment and corresponding personalization of recommendations. The study results are of utility to healthcare providers as well. Providers can consult the framework for a better understanding of patient decision aids and the technology's capacity to optimize patient-centered workflows, assign treatment selection responsibilities, and improve patient satisfaction and regimen adherence rates.

## 6 Conclusions

The computerized patient decision aids are a critical consumer facing health information technology and are an essential component of providing patient centered care and enabling patient empowerment through shared decision-making. Most patient decision aids available today are not individualized for patient specific information needs and decision-making preferences. A computerized patient decision aid that can deliver individualized user experiences for patients can increase the adoption of decision aids, increase patient satisfaction, and help realize the goal of higher patient involvement in their care.

The framework presented in this paper serves as a template for the design of computerized patient decision aids. The framework utilizes insights from cognitive and decision psychology and operationalizes them in the form of necessary components for developing computerized patient decision aids that optimize output according to the individual information and decision-making preferences. The instantiation of the artifact presented in this paper serves as a live example and an evaluation of the effectiveness of the underlying framework. We have further demonstrated the utility of the proposed framework by conducting a user study to measure the subjective decisional conflict of the participants after they arrive at treatment selections. Results of the Decisional Conflict Scale have helped to reveal that the proposed framework yields a higher quality of decision process marked by a statistically significant reduction of the resulting decisional conflict.

The contributions to research of this paper include a new design artifact for computerized patient decision aids in the form of a framework, and additions to the knowledgebase an experimental study confirming the benefits of personalized patient decision aids. The paper also contributes to practice by providing a readily implementable framework that can be used by health software developers for the design and implementation of new patient decision aids for different disease conditions.

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