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Deborah J. Bowen *Editors*

Handbook of Health Decision Science

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Introduction

In this *Handbook of Health Decision Science*, we take an inclusive view of this area of scientific inquiry, based on our many discussions together of the state of the science in health decision-making. We were struck not only by the rapid growth of evidence-based theory and research, but also by its central position in the unprecedented and large-scale developments in healthcare practice and policy more broadly, both nationally and globally. At the same time, we realized that there was no unifying resource available that provided a systematic and comprehensive overview of the field.

This handbook was borne out of these discussions and was specifically conceived to respond to recent changes and challenges in healthcare law, ever expanding healthcare options, and the proliferation of preventive, diagnostic, treatment and medical management options. These developments have resulted in a dramatic shift in how healthcare decisions get made, with greater and greater responsibility falling on individual patients and families to chart and navigate their own course through often muddy medical waters in accordance with their own needs, goals, and values. Yet, many individuals, families, providers, and systems are still ill-equipped to take on this responsibility to produce outcomes that are satisfactory for everyone.

Research has convincingly demonstrated that most people, especially after a diagnosis of an unexpected life-threatening disease, show deficits in processing information, understanding their options, and reaching a quality decision. On the provider side, clinicians often do not have the time or training to follow recommended shared-decision protocols, despite their understanding of the importance of such approaches to care. Furthermore, systems for various policy or financial reasons do not always support the latest evidence-based measures, thus creating an environment that is not conducive to optimal decision-making and health outcomes.

Health decision-making pervades every aspect of life, yet individuals rarely notice the myriad decisions that they and those around them make throughout a given day, week, or year. With regard to their health, individuals often focus on the "big" and highly salient decisions that confront them, such as whether to have surgery or radiation treatment for prostate cancer or whether to forgo chemotherapy after breast cancer treatment. However, even seemingly small daily decisions, such as choosing food for breakfast in the morning or engaging in a routine exercise regimen, can have a long-term consequential impact on their health and well-being.

Since Tversky's and Kaheneman's (1974) seminal paper on decision biases, decision-making research has exploded rapidly in a number of non-medical, as well as medical, domains. Initial research efforts focused on the nature and determinants of choice behavior in the economic arena but quickly expanded to other decision areas, including health decision-making. Over time, the field has become increasingly clear that individuals and families in the medical context want to be involved in decision-making about their health. This has been especially true for preference-sensitive decisions, those decisions that entail in equivalent options for disease management from a medical standpoint but result in different consequences for patients at the personal level, such as the nature of their post-treatment symptoms and/or their quality-of-life and function. A prime example of a preference-sensitive decision is the choice between different prostate cancer treatments (surgery, radiation, active surveillance) with similar effects on recurrence and mortality but different effects on quality of life.

These decisional dilemmas have largely originated from basic science and clinical advances which have produced an increasing number of efficacious regimens across the spectrum of disease prevention, detection, and treatment. Combined with developments in computing capabilities and bioinformatics these advances have created an increasing number of complex choices for providers, patients, and family members. For example, a woman deciding on hormone replacement therapy following breast cancer treatment needs to consider not only the potential benefits in preventing a breast cancer recurrence but also weigh the potential side effects and the increased cardiovascular and ovarian cancer risk. In addition, she may consider the costs and benefits of not taking any action and compare the pros and cons of action versus inaction on the implications for her daily activities, quality of life, and quantity of life.

While being adequately informed about the pros and cons of different options is a key component of the decision-making process, the other and arguably more important component is how individuals process the information they receive. Specifically, decisions are largely determined by how individuals cognitively and affectively react to the information, how they connect the incoming data with prior experiences, and the social and cultural context in which they are embedded. Together these factors help to explain a number of seemingly “irrational” decisions, such as why individuals do not choose to uptake evidence-based cancer prevention and screening regimens, including quitting smoking or obtaining colonoscopy to detect colon cancer or the Papanicolaou (PAP) smear to detect cervical cancer. Clearly, health insurance status, access to care and lack of information have been shown to be negatively associated with screening uptake. However, emotional factors such as worry about “finding cancer,” and cognitive factors such as inaccurate perceptions about the risk of disease or side effects of the procedure also significantly impact decisions about screening.

An additional challenge for individuals is that health decision-making usually occurs under conditions of uncertainty. Only rarely are all relevant data known and available. Consider the example of prostate cancer treatment decision-making. Patients diagnosed with prostate cancer not only have to cope with the emotional impact of a cancer diagnosis but also they have to deal with different treatment options with fairly equivalent outcomes, ranging from active surveillance, to different forms of radiation therapy, to different forms of surgical removal of the prostate. There is no clinical trial evidence base on which to draw to help guide choice of treatment; thus patients need to make treatment choices guided by estimations of future urinary and erectile functioning and their impact on quality of life. These estimates involve high levels of uncertainty but need to be factored into the decision-making process, which further compounds the anxiety-inducing nature of the process for many men.

It is now well-established that in cases of decision-making under uncertainty, most individuals resort to using heuristics or “cognitive shortcuts,” that are activated, often automatically, to reduce the degree of decisional complexity. Understanding how heuristics and biases influence health decision-making and become incorporated into the cognitive-affective processing system is a key focus of inquiry for researchers. Elucidating this area of research is also relevant to the issue of why some individuals often fail to act in their own best interest by taking what seems to be logical and simple precautions to protect themselves. There are many examples of such behaviors in the literature, such as the patient who is urged to adopt a low-fat diet after heart surgery but decides not to do so, or the lung cancer patient who continues to smoke.

Other factors that influence decision-making directly or indirectly are literacy and health literacy factors. Health literacy goes beyond an individual’s ability to read, write, or compute basic mathematical operations. Health literacy is commonly defined as the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” Low health literacy affects all aspects of health-related functioning and has clear implications for decision-making, ranging from difficulties adopting healthcare recommendations, medication intake instructions, and understanding public health warning messages. Improving communication methods to assess and address health literacy demands is an ongoing field of research and of utmost relevance for the decision-making literature.

The aim of the current volume is to provide the state-of-the-science information geared towards the researcher, clinician, policy maker, and student of the decision-making field. The handbook is divided into sections corresponding to key areas of inquiry. We start out with “Basics First” with chapters that are designed to provide a solid foundation on the building blocks of the decision literature, such as the Pieterse and Stiggelbout chapter on values, utilities, and preferences and the chapter on research methods by Kiviniemi and Ellis. The chapter by Beck discusses the literature on modeling medical decisions and that by Hesse introduces concepts of decision architecture. Finally, the last chapter in this section, by Hsu and Chiong, presents a needed overview of decision dysfunction focusing on a translational approach that combines basic studies with applied outcomes.

The introductory section of the handbook is followed by the section that examines decision-making at the individual level. The majority of research has focused on individual decision-making and various theoretical approaches to decision-making are represented here (see Brust-Renck et al., Leventhal et al., Peters et al., and Rothman et al.). The chapter by

Han and colleagues discusses the concepts of uncertainty and ambiguity, factors that have the capacity to influence decision-making at all levels. The last two chapters in this section discuss decision-making across the life span. Halpern Felsher and colleagues focus on adolescents and young adults, whereas Dr. Lockenhoff reviews the literature on age-related differences in decision-making.

This part of the handbook is followed by sections Decision-Making on the Interpersonal Level and Applied Decision-Making. At the interpersonal level, we examine decision-making in the family (Siminoff and Thompson) and shared decision-making between patient and providers (Rowland and Politi). This section concludes with a primer on the legal aspects of decision-making in a changed healthcare environment. Chapters 17–21 describe various aspects of applied decision-making. Ramachandran and colleagues discuss specific requirements for decision tools for healthcare professionals and Knight reviews how the Veteran's Affairs system has incorporated such tools into their web-based patient portal to improve patient and physician communication. Noar and colleagues synthesize the large field of tailored communications and Waters and colleagues provide a hands-on approach to communicating risk effectively. The chapter by Col and Springmann addresses the question about the effectiveness of decision aids.

The penultimate section deals with decision-making at organizational, state, and national levels. Greenup and Peppercorn provide a critical review of the shared decision-making approach in the clinical practice. This leads to a discussion of how the transformation of the healthcare system has led to an emphasis on evidence-based medicine and its influence on healthcare policy (Cheely and Zaas). This section closes with a concise description of how the healthcare delivery system has been transformed in recent years (Weiner).

The Handbook closes with two chapters that speculate on the future of decision-making that is already upon us. Graham and colleagues describe the transformation that social media has brought to health decision-making with its ubiquitous availability of information. Sanderson and Schadt discuss the promises and potential consequences of whole genome sequencing on individual decision-making.

This Handbook highlights progress in the discovery of how we make medical and health decisions in an ever more complex world. We believe that the chapters in this Handbook lay the groundwork for future research and the development of supportive decisional interventions. We hope that through this volume we have assembled a case for the field of decision-making that will resonate long after you have finished reading.

Reference

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Part I

Basics First

1

What Are Values, Utilities, and Preferences? A Clarification in the Context of Decision Making in Health Care, and an Exploration of Measurement Issues

Arwen H. Pieterse and Anne M. Stiggelbout

Introduction

Values are omnipresent in health-related decision-making—be it values of patients, professionals, policy-makers, or the general public. The term value is generally loosely described as something to strive for, something desirable or important, but in that respect may be just as meaningless as the term quality, another contemporaneous buzz word. Value is sometimes used in a quite specific sense, when meaning valuation, and thereby resembling the term *utility*, which is a synonym for a very specific form of value. Value is sometimes also used interchangeably with *preference*, causing further confusion. In this chapter, we will distinguish the various conceptions and misconceptions of these terms and illustrate the contexts in which the terms are, or should be used. We will further explain what the role values, utilities, and preferences play at different levels of decision-making in health care and describe the ways they can be assessed. We will conclude with key areas for future research.

Conceptualizing Values, Utilities and Preferences

Values

From a psychological perspective, various theoretical definitions of the concept of values exist. Schwartz and Bilsky (1987) identified five features common to many definitions. Values are (a) concepts or beliefs, (b) about desirable end states (i.e., terminal goals) or behaviors (i.e., instrumental goals), (c) that transcend specific situations, (d) guide the selection or evaluation of behaviors or events, and (e) are ordered by relative importance. Schwartz and Bilsky theorized that values stem from universal human requirements reflected in biologically based needs of the organism, social motives relating to social interactions, and social institutional demands for group welfare and survival. They further proposed that it is through cognitive development that individuals become able to represent these requirements consciously as goals or values. In other words, the value system is a meaning-producing super-ordinate cognitive structure, and this cognitive structure is affectively charged (Rohan 2000). An important empirical finding is that the *structure* of the human value system is universal and there are a finite number of universally important value *types* (e.g., power, hedonism, benevolence, and security). People differ rather in terms of their value *priorities* (Schwartz 1994).

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In health-related decision-making and the evaluation of health care delivery in particular, more specific definitions of values are usually considered, which generally depend on the levels of decision-making. Three levels are generally distinguished (Sutherland and Till 1993). The first is the health care or macro-level, where in the case of limited resources budget allocation choices have to be made among programs. The second, or meso-level, pertains to policy making at the patient group or hospital level, at which decisions have to be made for defined groups of patients with the same symptoms or disease, and for which evidence-based guidelines or protocols are to be developed. The third is the micro-level and applies to decision-making for an individual patient. The term value refers to different entities in these contexts, resulting in different elicitation processes. For each of these levels, we prefer to reserve the term "values" for abstract, trans-situational judgments.

Utilities

Utility is a summary measure of the extent to which each outcome of each choice option achieves each of our ultimate goals (Baron 2008, p. 233). Health state utilities play an important role in health care decision-making and health economics. The most important applications of utilities are in expected utility decision analysis, in which the expected utility for each possible strategy is calculated by combining the utilities for all possible resulting health states (outcomes) with the probabilities of these states occurring. The utility of a health state is a cardinal measure of the strength of an individual's preference for particular outcomes when faced with uncertainty (Torrance and Feeny 1989). This concept of utilities dates back to the 1940s when a normative model for decision-making under uncertainty, expected utility theory, was developed (Von Neumann and Morgenstern 1944). In most decisions in health care, outcomes may occur with a certain probability, and the decision problem is thus a problem of choice under uncertainty and expected utility theory applies. An important application of utilities is the QALY, or quality adjusted life year, in which each year spent in a health state is multiplied by its utility, and the thus adjusted life years are summed. QALYs are mostly used in cost-effectiveness ratios, based on expected utility decision analyses in which the numerator is expressed in costs (Dollars or Euros) and the denominator (effectiveness) in QALYs.

Preferences

There is no consistent definition of preferences in health care, but there is convergence in the notion that health care preferences can be defined as "statements made by individuals regarding the relative desirability of a range of health experiences, treatment options or health states" (Brennan and Strombom 1998, p. 259). Individual preferences exist as the relatively enduring consequences of values (Brennan and Strombom 1998). Differently from values, preferences are object-focused and relate to specific options, or attributes of options, in a specific decision context.

Health-related preferences have been described in relation to a variety of domains. In recent studies, the term has been used to describe, for example, choice among a set of treatment options (Alolabi et al. 2011), treatment aspects (Pfützner et al. 2012), or health professionals (Bishop et al. 2013); the desirability of procedural aspects of screening (Blom et al. 2012) or treatment (Vela et al. 2012); the desirability of sources (Gaglio et al. 2012), amount (Ter Hoeven et al. 2011), or kind of information (Ormond et al. 2009); and the desirability of participating in health-related decision-making (Davison and Breckon 2012). Patient preferences—and this is true for health care provider or significant others' preferences too—vary further widely with respect to stability and clarity (Street et al. 2012). Individual preferences can be quite steady but need not. Preferences can vary as a function of disease severity, can evolve as individuals learn new information or gain new experiences, or have had more opportunity to explore thoughts, feelings, and values relevant to the clinical situation. For example, Feldman-Stewart et al. (2004) found that 82 % of early stage prostate cancer patients who had already discussed their condition with their oncologist and who were thinking through their treatment options, changed which attributes affected their decision, and 72 % changed how much they valued the treatment options as a whole, as they were going through a patient decision aid (see section "Values Clarification Methods" on decision aids).

From Basic Values to Articulated Utilities and Preferences: A Constructive Process

Conceptualizations of values differ in the extent to which they are articulated (Fischhoff 1991). On the one end of the continuum, people are seen to hold *articulated* or well-differentiated, "complete" values that can be elicited if one asks the right question (Gregory et al. 1993). On the other end, people are seen to hold only *basic* values, that is, lack well-differentiated values for all but the most familiar issues, and that preferences need to be constructed (constructive preferences) from basic values at the time of decision-making (Payne et al. 1999). In this partial perspective, people could respond with values that are not at stake if they miss nuances of the question asked. Articulated values most often exist when decisions are personally familiar; with few consequences; implying no conflicting roles; and formulated in a familiar fashion (Fischhoff 1991, Table 3). Complex decisions in health care—such as allocation of resources or choice of treatment, often are new to decision makers; have more than a few consequences; and many of these consequences are not commensurable, such as trading treatment convenience (e.g., pills versus injections) for treatment effectiveness. Further, values may be conflicting because options on offer cannot achieve both the goals of, for example, lengthening life and improving quality of life (Epstein and Peters 2009). For health care decision-making, the basic values paradigm thus seems most appropriate. Utilities and preferences are usually being constructed as a function of the specific decision options and the context in which the utility or preference is being elicited (Payne et al. 1992).

Measurement of Utilities at the Macro- and Meso-Level

Utilities are mostly used at the macro- and meso-levels of health care decision-making, and the level determines whether they should be assessed from the general public or from patients. In cost-utility analyses from a societal perspective, i.e., for macro-level decision-making, Gold et al. (1996) have recommended the use of society's preferences, that is, from a representative sample of fully informed members of the general public. In guideline development, the meso-level, the use of utilities obtained from actual patients is preferred. Members of the public who are asked to imagine experiencing health states assign lower utilities to those states than the patients who are actually experiencing these states (Stiggelbout and De Vogel-Voogt 2008), which resonate with the disability paradox; many people with serious disabilities report that they experience a good or excellent quality of life (Albrecht and Devlieger 1999). At the micro-level, with an individual patient, utility assessment is seldom used and if used, it is done in a constructive way and meant to serve as values clarification (e.g., Unic et al. 1998, and section "Values Clarification Methods").

Approaches to Utility Measurement

We can distinguish two different approaches to measuring utilities. The **holistic** approach requires the participant to assign values to each possible health state, where a state represents a combination of many attributes. The **decomposed** approach enables the investigator to obtain values for all health states without requiring the judge to assign values to each one. It expresses the overall value as a decomposed function of the attributes. This approach can also be used specifically to obtain the utilities of the attributes per se, in health services research.

Holistic Approaches to Utility Measurement

Holistic valuations of health states encompass valuations of the quality of life of those states, and the valuations are therefore sometimes called *preference-based* measures of quality of life, as distinct from *descriptive* measures of quality of life, using questionnaires such as the SF-36. The methods can be used either to have participants value hypothetical health states, or to have patients rate their own health. In the former case, the health states are described in a scenario, generally framed in terms of physical, emotional, and social functioning. Several methods exist to assess utilities for health states holistically (Stiggelbout and De Haes 2001). The **Standard Gamble (SG)** has long been seen as the gold standard, since it adheres to the axioms of expected utility theory. It is based on the principle that a person will be willing to accept a risk in order to obtain good health, if he or she feels that the health state under evaluation is undesirable. The participant is offered the hypothetical choice between the sure outcome (the health state to be valued, for one's remaining life expectancy) and a gamble, with probability p of obtaining the best possible outcome, set at 1 (generally optimal health, for one's remaining life expectancy) and a probability $(1 - p)$ of the worst possible outcome, set at 0 (usually immediate death). By varying p, the value is obtained at which the participant feels the sure outcome and the gamble to be equivalent. The utility for the sure outcome, the health state to be valued, is equal to the value of p at this point of indifference $(U = p \text{ x } 1 + (1 - p) \text{ x } 0 = p)$. Thus, for example, a woman is asked to rate the state "rheumatoid arthritis". If she is indifferent to the choice between her remaining life in that state and a gamble with a probability of 0.90 that her remaining life will be in optimal health and a probability of 0.10 of immediate death, her utility for that health state is 0.90. The utility measured with a SG reflects not only the participants' preference for life in the health state, but also their attitude toward risk. The use of probabilities has proven to be a major drawback of the method, since participants have difficulties relating to probabilities. Moreover, they have been shown to transform probabilities; they tend to overweight small probabilities and underweight large probabilities (Tversky and Kahneman 1992). In most examples in health, small probabilities of bad outcomes (such as death) occur, which thus tend to be overweighted, leading to extremely risk averse answers, and too high utilities for the states under evaluation. Ceiling effects subsequently limit the ability of the SG to discriminate between health states. This has led researchers to use an alternative method, the time tradeoff method **(TTO)** (Wakker and Stiggelbout 1995).

In the **TTO,** a participant is asked to choose between her remaining life expectancy in the health state to be valued and a shorter life span in optimal health. In other words, she is asked whether she would be willing to trade years of her remaining life expectancy for an improved health. As an example, let us say a 65-year-old woman has a remaining life expectancy (according to national life tables) of 15 years. She is asked what length of time (X) in optimal health would be equivalent to 15 years in her state of rheumatoid arthritis, assuming that in each case death would follow immediately. The simplest and most common way to transform this optimal-health equivalent X into a utility (ranging from 0 to 1) is to divide X by 15. Thus, if she is willing to trade 3 years to obtain optimal health, her utility is 0.80 (12/15).

Both for the SG and TTO, elicitation becomes more complex when temporary states are to be valued (see, e.g., Jansen et al. 1998 for the details on the procedure).

In the TTO no uncertainty is involved, and it therefore does not adhere to expected utility theory, but in practice TTO-scores are generally considered utilities, since they are preference-based. This is in contrast with scores of the next method, the visual analogue scale.

A **Visual analogue scale (VAS)** is a rating scale, which can be self-administered, and therefore is often used to obtain valuations of health states in surveys. Participants are asked to rate the state by placing a mark on a 100-mm horizontal or vertical line, anchored by death (usually on the left or bottom) and optimal health (on the right or top). The preference is the number of millimeters from the "death" anchor to the mark, divided by 100. The VAS does not reflect any tradeoff that a participant is willing to make in order to obtain better health, neither in terms of risk nor in years of life. It can therefore not be considered a preference-based, or utility, method (Torrance et al. 2001). Transformations of VAS-scores have been proposed to approximate true SG- or TTO utilities (Torrance 1976; Torrance et al. 1996).

To obtain utilities for policy making, the researcher needs to choose from SG, TTO, and VAS. The SG used to be considered as the gold standard, but due to biases in the method, especially probability transformation, the TTO is most frequently used nowadays. Further, patients generally find it an easier and more acceptable method. Little is known about the biases that may operate in the TTO (see Bleichrodt 2002, for a clear explanation of the possible biases operating in the SG and TTO). As described above, a VAS score is not a utility, but nevertheless the VAS is frequently used to assess utilities, due to its ease of administration. SG and TTO are preferably administrated in an interview, to minimize inconsistent and incoherent responses, whereas a VAS can be administered in a questionnaire. The VAS is potentially influenced by basic psychological phenomena (Torrance et al. 2001), and its scores have been argued to be too low, since no tradeoff is involved. Therefore, transformations as described above are generally performed, although Abdellaoui et al. (2007) made a convincing case for an untransformed use of the VAS.

Decomposed Approaches to Utility Measurement

The decomposed methods to value treatments express the overall value as a decomposed function of the health state or treatment attributes. The best-known application of a decomposed method is that based on Multi-Attribute Utility theory (MAUT). Each attribute of a health state (or intervention) is given an importance weight. Next, participants score how well each health state (or treatment) does on each attribute. These scores are weighted by the importance of the attributes and then summed over the attributes to give an overall multiattribute score for each state (or treatment). For this summation, the theory specifies utility functions and the independence conditions under which they would be appropriate. For example, Chapman et al. (1999) provided a MAUT-model for metastatic prostate cancer. They predefined the five attributes such as pain, mood, sexual function, bladder and bowel function, and fatigue and energy to explain the state. Patients were asked to rate the relative importance of these attributes by dividing 100 points among them. Next, patients categorized their current level of health for each attribute. MAU-scores were computed by multiplying, for each attribute, the level by the attribute importance weight, and summing across the attributes.

Most decomposed methods assess valuations for health states or treatments and use regression models to infer the parameters of the attributes, assuming an additive linear process. In subsequent applications, the model thus estimated can be used to infer health state preferences from attributes. This approach has become widespread in the health state classification systems, which are used in cost-effectiveness analyses from a societal perspective, such as the EQ-5D (Dolan 1997) or the Health Utilities Index (Feeny et al. 1995), to generate utilities from the general public. Health state classification systems or health indexes are customarily composed of two components: a descriptive system and a formula for assigning a utility to the health states described by this system. The descriptive system consists of a set of attributes, and a health state is described by indicating the appropriate level of functioning on each attribute. For instance, in the EQ-5D the attributes are mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each attribute is divided into three levels of severity (no problem, some problems, and extreme problems). By combining one level from each of the five attributes, a total of 3^5, that is, 243 EQ-5D health states are defined. The formula for assigning utilities to these states is based on utilities that have been obtained in a sample from the general public, in part from direct measurement and in part from application of MAUT (as in the Health Utilities Index) or statistical inference (as in the EQ-5D), to fill in values not measured directly. Based on this formula (for the EQ-5D, e.g., see Dolan 1997), premeasured utilities from the general public are thus available for these systems (Russell et al. 1996). In a cost-effectiveness study it suffices to map the treatment outcomes (the health states) onto the descriptive system—using a patient questionnaire based on the descriptive system—and to use the scoring formula to obtain utilities from the general public for the health states indicated by the patients. In this way, standardization over studies is obtained. All researchers use the same utility set, and cost-effectiveness ratios are comparable.

Whereas the aim of these decomposed techniques is mostly to assess holistic valuations of health states or treatments via decomposition, other techniques, such as conjoint analysis and discrete choice experiments, aim to measure how treatment or health state attributes are valued per se.

Conjoint Analysis, developed to examine consumer preferences in marketing is increasingly used in health to assess attribute preferences. Similar to the decomposition techniques described above, participants judge hypothetical cases (health states or treatments) that are described in terms of combinations of attributes at particular levels. Statistical analysis reveals the attribute level utilities (Ryan and Farrar 2000). Most commonly, two cases or options (treatments or health states) are seen at a time (hence the name conjoint analysis) and a choice is made between them. *Adaptive* conjoint analysis cases are paired according to a set of stated attribute weights and responses to previous options—using special software (Pieterse et al. 2010). Analysis of the data is based on random utility theory. These methods have predominantly been used in health services research to assess correlates of preferences, such as sociodemographic characteristics of (potential) service users and to influence policy decision-making. The adaptive methods are finding their way in micro-level decision-making, to support values clarification, as described in the next section.

Measurement of Preferences at the Micro Level

Assessments of preference for specific options, rather than outcome states, are tailored to the clinical problem at hand and will reflect the real-life situation more than does the utility assessment. In health services research, at the meso-level, assessment of treatment preferences informs cut-offs in guidelines above or below which treatment is indicated. For example, patient preferences were incorporated in the decision to recommend chemotherapy at a benefit in overall 10-year survival of 5 % in the Dutch breast cancer treatment guidelines (Bontenbal et al. 2000). Alternatively, preferences can be assessed to define profiles of patients for whom a particular option is more germane than for others. At the micro or individual patient level, decisions about treatment and health care management ought to reflect individual patients' preferences (Kassirer 1994).

Treatment Tradeoff Method

The treatment or probability tradeoff method was developed to assess participants' strength of preference for one health management option relative to another, usually treatments. In this method, preferences for combined process-and-outcome paths are elicited in the following way. The patient is usually presented with two clinical options, for example, treatments A (e.g., no adjuvant treatment) and B (e.g., adjuvant chemotherapy), which are described with respect to (probabilities of) benefits (e.g., additional probability of 5-year survival) and side-effects (e.g., nausea, hair loss, and fatigue), and is asked to state a preference for an option. If treatment A is preferred, the interviewer systematically either increases the probability of benefit from treatment B, or reduces the probability of benefit from treatment A (and vice versa if treatment B is preferred at the outset). Which treatment aspects are altered and in which direction, is decided upon beforehand, according to the relevant clinical characteristics and the research question (Llewellyn-Thomas et al. 1996). The patient's willingness to accept side-effects of one treatment or forego benefits of the alternative treatment determines the patient's relative strength of preference. This general approach has been adapted to a variety of treatment decisions, including adjuvant chemotherapy in breast cancer (Levine et al. 1992), treatment of Lupus Nephritis (Fraenkel et al. 2002), and radiotherapy for rectal cancer (Pieterse et al. 2007). In all cases, preference strength is idiosyncratic to the original decision problem, that is, relative to the specific alternatives that were presented. The method can be used to support individual treatment decision-making and has been applied "at the bedside" using decision boards as visual aids (Levine et al. 1992).

Values Clarification Methods

At the micro-level, so-called patient decision aids have been developed to help individuals facing challenging health decisions make specific and deliberative choices (Stacey et al. 2011). As a part of these interventions, components referred to as "values clarification methods" (VCM) can be included to help elucidate individuals' health management preferences. The name is confusing as these interventions really are aimed at eliciting and clarifying *preferences*. VCM include any methods "that are intended to help patients evaluate the desirability of options or attributes of options within a specific decision context, in order to identify which option he/she prefers" (Fagerlin et al. 2013). These VCM can also be used to measure individual preferences (Fraenkel et al. 2006).

Many and very different types of VCM exist. In treatment-related decision-making, interventions described as VCM include balance scales (O'Connor et al. 1998); rating (Feldman-Stewart et al. 2006) or ranking (Sheridan et al. 2010) the importance of risks or benefits of options; indicating whether each piece of information pushes one toward or away from a given choice (Smith et al. 2010); or listing reasons (Abhyankar et al. 2011). They can also consist of having an open discussion about attributes of interest (Matheis-Kraft and Roberto 1997). Evidence on the effects of using VCM in the context of patient decision aids is still limited, but there are indications that it improves decision processes (Fagerlin et al. 2013).

There is a little evidence suggesting how patients actually clarify the personal importance they associate with different health management options, such as how they weigh pros and cons within a decision, and thus how best to support the process. Further, since preferences in health are deemed constructive, there is no way to measure "true" preferences since they are formed in the process of elicitation. From a cognitive psychological perspective, VCM should aim to facilitate one or more of the following processes: help optimize individuals' mental representations of the decision and the options; encourage individuals to consider all potentially appropriate options; delay the selection of an initially favored option; facilitate the retrieval of relevant values from memory; facilitate the comparison of options and their attributes; and offer time to decide (Pieterse et al. 2013). These recommendations were formulated based on commonalities between the four process theories of decision-making (differentiation and consolidation theory, image theory, parallel constraint satisfaction theory, fuzzy-trace theory), for which evidence has been gathered though mostly outside of the health care context.

Key Directions for Future Research

At the macro-level, most of the researches that are currently performed in utility assessment relate to the classification systems, such as the EQ-5D. This is likely because these have the most direct practical application in cost-utility analyses, which in turn are mandatory for reimbursement decisions in many health care systems around the world. The assessment of holistic utilities, for example using the TTO, is typically seen in purely scientific work, without direct practical application. The challenges for the EQ-5D mostly lie in improving the descriptive systems, for example, by adding levels to the attributes. A recurring issue is the actual content of the classification systems, and whether the traditional dimensions, generally based on the WHO definition of health and incorporating physical, psychological, and social functioning, should not be replaced by a capability approach or by dimensions of subjective well-being (Coast et al. 2008).

The elicitation of utilities is quite an abstract task, with which participants have been found to have difficulties (Edelaar-Peeters et al. 2014). Interviewer help is therefore generally needed, even though web-based administration would highly reduce costs. Future research should find ways to mimic the help that interviewers give as part of web-based administration.

Moreover, conventional approaches to the TTO are problematic when evaluating health states that are perceived to be worse than death. The TTO requires fundamentally different tradeoffs tasks for the valuation of states better and worse than death (Tilling et al. 2010). An alternative elicitation method, "lead time TTO" is currently under study as a way to possibly overcome the problem (Augustovski et al. 2013).

At the micro-level, research revolves around the evaluation of how effective the VCM are at clarifying preferences. A challenge at the micro-level for future research lies, therefore, in designing theory-based VCM and outcome measures—where the theory chosen should help in selecting outcome measures that the intervention is expected to affect (Pieterse et al. 2013).

Conclusion

Preferences refer to very different entities at the macro-, meso-, and micro-levels of health-related decision-making. At each of these levels, we recommend to save the term *value* for abstract, trans-situational judgments. The most adequate process of preference elicitation is a function of the goal of assessing individuals' health-related priorities and depends on the level of health care decision-making. Particularly at the level of the individual patient, more research is needed on the clarification of patient preferences.

Box 1. Definition of values, utilities and preferences in a health care decision context

Values

Abstract, trans-situational judgments about intermediate or terminal goals that guide the evaluation of states or selection of behaviors and are ordered by relative importance

Utilities

Summary measures of how health states realize our ultimate values or goals; should be measured in specific ways resulting in a number between 0 and 1 and are most often applied in expected utility decision analyses and in cost-utility analyses at the macro and meso-decision-making level

Preferences
Relative desirability of a range of specific health experiences, health management options, attributes of options, or health states, in a specific decision situation; the assessment of preferences can inform decision-making at the meso- and micro-level of decision-making

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Decision Architectures

2

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Introduction

At the core of many of the quality improvement initiatives spearheaded by the U.S. Institute of Medicine (IOM) was an assumption that medical communication and decision-making must be improved in order to achieve true population benefits from evidence-based medicine. Medicine is an information-intensive enterprise, argued the authors of the IOM report "*Crossing the Quality Chasm: A New Health System for the 21st Century*" (Institute of Medicine 2001). The only sustainable way to improve patient outcomes is to reengineer the *systemic architectures of medicine* to ensure that the right information is delivered to the right people in the right way to improve the quality of care (Reid et al. 2005; Hesse and Shneiderman 2007). This was the rationale underlying passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, which sought to improve patient care by delivering better cognitive and decision support to health care providers, patients, and family caregivers. It was also the rationale underlying many of the provisions of the Affordable Care Act of 2010, which sought to reengineer incentives within health care to emphasize prevention, patient engagement, continuity of care, and cost effectiveness (Hesse 2010; Stead and Lin 2009). The U.S. House Appropriations Committee added further reinforcement when it highlighted "health decision-making" as an important focus for ongoing research and development within the priorities of the National Institutes of Health (NIH) in 2011 (The Cancer Letter 2011; President's Council of Advisors on Science and Technology 2010).

Strains Within the System

The need for continued work in the area of supported decision-making sounds well and good, but what does it really mean to say that health systems researchers need to reengineer the systemic architectures of medicine? Isn't this what eight (+) years of advanced medical education in the classroom and residency programs, plus a plethora of up-to-date science articles in advanced medical journals, are supposed to accomplish? Aren't physicians and patients used to making effective decisions unassisted by decision aids or information technologies?

To be sure, training is an important and necessary part of medical judgment; but unaided decision-making is rapidly becoming insufficient in a world of information-intensive medicine. As hard as it may be to believe, the first Randomized Controlled Trial (RCT) in medicine was only

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