13

Improving Medical Decisions

Jorge Risco and Adam Kelly

Introduction

Physicians can make over one hundred decisions in a workday. For neurologists, this can range from increasing the dose of an antiepileptic medication, to more high-stakes decisions such as administering tissue plasminogen activator for acute stroke or initiating tube feeds in a patient with Amyotrophic Lateral Sclerosis (ALS). These decisions vary in risk, benefit and complexity. Caring for patients nearing the end of their life is a common yet special medical scenario. End of life decisions have important consequences on patients and their families. These decisions can be complex, require deep thought and careful balance with patient values. In these situations, what constitutes a good or bad decision? Can we say that one decision is better than another?

A medical decision is slowly molded by multiple factors. Developing a framework of the decision making process can be helpful. The process can be conceptualized in three main steps: (1) diagnosis, (2) option assessment and (3) shared decision making. Diagnosis is a step that involves gathering information surrounding the problem. Option assessment is a step where the risks and benefits of potential solutions are weighed against each other. Finally, once the problem and potential solutions have been studied, one engages with patients or surrogate decision makers in shared decision making. The potential solutions are shared with patients. They are taken in the context of patient values to arrive at a medical decision. These steps are often intertwined and do not occur in perfect sequence, but all three are required for an optimal decision-making process.

In this chapter, key concepts in the decision-making process will be further explored. These can be applied to most medical scenarios though areas of particular relevance to neuropalliative care will be highlighted.

Variations in Clinical Practice

Anecdotal experience and observational studies show significant variation in clinical practice across neurologic disorders, including palliative care aspects of these disorders. The underlying reasons are diverse. Variation can arise from different interpretation of available evidence; paucity of evidence; strong patient or family preferences; systematic over or under treatment of certain populations (racial groups, women); or financial incentives. Less patient-centered factors should be minimized to whatever degree possible.

J. Risco, MD (✉) · A. Kelly, MD
Department of Neurology, University of Rochester, Rochester, NY, USA
e-mail: Jorge_Risco@URMC.Rochester.edu; Adam_Kelly@URMC.Rochester.edu

C. J. Creutzfeldt et al. (eds.), *Neuropalliative Care*, https://doi.org/10.1007/978-3-319-93215-6_13

Diagnosis

The foundation of good decision making relies on understanding the problem. A physician must diagnose (a) the medical problem, (b) the problem from the patient's perspective and (c) the patient's preferences and values. Failing to understand the patient's perspective can lead to overuse or underuse of therapy [1]. An assessment of (d) patient capacity and (e) skilled doctor-patient communication are intrinsic to the process.

Medical Problem

The medical problem should be framed as clearly as possible. Misdiagnosis leads to unnecessary and harmful risks. One series assessing misdiagnosis in multiple sclerosis found that one third of patients had experienced unnecessary morbidity [2].

Understanding the medical problem leads to an understanding of the prognosis (see Chap. 12 "Prognostication"). There are two types of prognostic questions: how long? And how well? [3]. The medical options that we will offer our patients will be framed within this foundation. If "how long" and "how well" are not clear, we risk decisions for unrealistic or potentially harmful options. Failing to grasp the problem at hand or relying on incorrect information leads to poor decision making.

Patient Understanding

As we prepare to guide patients through a complex decision, a physician needs to understand the problem from the patient's perspective [4]. This insight allows us to anticipate and understand the choices they will make.

A starting point is asking what a patient knows about their medical problem. Numerous studies have demonstrated that patients recall and comprehend very little of what they are told by their physicians [5–7]. This communication gap between physicians and patients can have several reasons including poor patient health literacy; poor physician communication skills; a patient's emotional state; a patient's cognitive or communication impairment; or different belief systems [8]. A national assessment of health literacy found that one third of US adults had a basic or below basic level. These individuals were unable to use a prescription drug label to correctly take medications [9]. On the other hand, physicians often fail to disclose key information and rarely verify patient understanding [10–12]. The communication gap between physicians and their patients often goes undetected [13, 14]. Prior to embarking on important decision making, a patient must have a clear understanding of their disease and prognosis, and the clinician needs to have a clear understanding of the patient's perception. Disease misconceptions should be clarified.

Recognizing limited health literacy allows physicians to adjust their communication strategy. In some cases, limited health literacy may only become apparent after a lengthy interaction between a provider and a patient or surrogate. However, there are two questions that can more rapidly screen for lower literacy. They have sensitivities ranging from 54% to 83%, depending on the clinical setting [15]:

- How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
- How confident are you filling out medical forms by yourself?

While ensuring that patient or surrogate understanding has occurred is important in any medical scenario, it is of utmost importance in a palliative care setting. Not only are many of these decisions "high stakes" in nature (for example, goals of care decisions), but there are considerable knowledge gaps on the part of the public on the roles of palliative care specialists and hospice approaches [16, 17].

Values and Preferences

A patient's *values* are the aspects of life which they find important. They remain relatively stable over time, rarely changing with medical scenarios. They sit at the core of a patient's decision making process.

A *preference* is a choice that pertains to a specific medical scenario. It is the end result of a patient's decision making process. A preference is constructed from an individual's core values and is influenced by multiple factors: their understanding of disease, their understanding of medical options, physicians, the opinion of friends and family and the media (Fig. 13.1) [18]. A preference-sensitive condition has more than one clinically acceptable solution (for example medical vs. surgical management) and may therefore be guided by what matters most to the patient. A preference-sensitive treatment decision or recommendation aims to find the solution that is most in line with a patient's values and preferences.

Poorly constructed preferences do not reflect patient values. Consider the case of an 82 year old man with terminal cancer including brain metastases. He may value the ability to engage with friends and family over the duration of his life. He may elect to maintain a full code status not knowing that there is a low chance of subsequently achieving a successful resuscitation and an even lower chance that he will return to his prior functional state. In this case, the patient's preferences are not aligned with his values due to a poor understanding of his medical problem.

Because preferences are susceptible to undue influence, the more important question is: What does my patient value?

We *value* aspects of life differently. Some find accomplishment through work; others through connections with family and friends; others through creativity and art. The paths towards well-being are as diverse as we are.

Similarly, as health declines, we experience illness in many of ways. The predominant concerns of patients with Parkinson disease can vary from falls to unemployment. Understanding what a patient values about their health and illness is crucial.

As the complexity of medical problems increase, they demand a greater understanding of a patient's values. When selecting first-line therapy for episodic tension type headaches, a superficial expression of preference may suffice. On

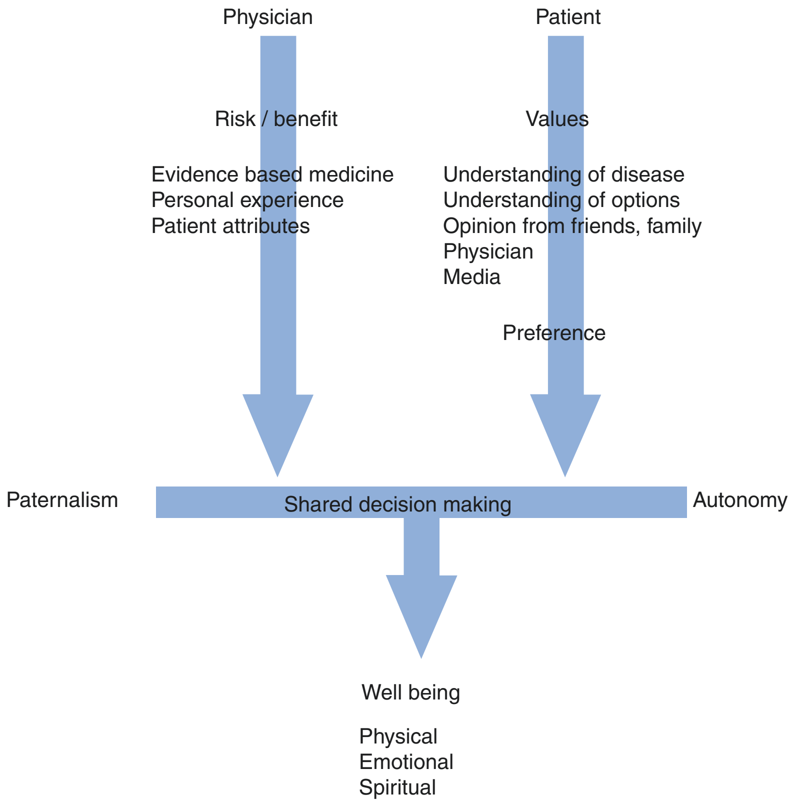

Fig. 13.1 Medical decision making overview. Physicians bring their expertise and patients bring their values. Participating in shared decisions is engaging in dialogue, where both perspectives are expressed. The overall objective of a medical decision is to promote patient well-being

the other extreme, physician assisted death or terminal extubation require a full understanding.

Impaired patient capacity is common in neurological illnesses and adds a layer of difficulty to medical decision making. This is particularly true in many disorders where neuropalliative care plays a key role, including severe stroke, neurodegenerative conditions, and brain tumors or metastases. Often, there are no written advanced directives to guide management. Even so, patients cannot anticipate an infinite number of medical scenarios and therefore judgement is required. We turn to the surrogate decision maker and ask "What would (the patient) have done?". The underlying question is "What does (the patient) value?". We construct a preference that pertains to the specific medical scenario from the patient's core values.

Eliciting patient values is not an easy task. The goal is determining: what elevates this individual's well-being? In other words, what brings him or her: relief, comfort, joy, meaning and purpose? It requires a great deal of introspection on the patient's behalf. This is triggered through interviewing with open ended questions. In more difficult cases, when capacity or introspection are limited, answers may be inferred from a patient's behaviors over the course of life.

The following questions can serve as starting points (Table 13.1). A follow up open question such as "why?" or "tell me more" allows for further exploration:

Table 13.1 Eliciting patient values

Health
What aspect of your health can we focus on maintaining?
What aspect of your current health is most important to you?
What is the most distressing symptom/deficit/barrier?
What do you think about the risks involved with therapy X?
What is important to you about therapy X?
What would be unacceptable?
Emotional/spiritual
What do you enjoy in life?
What are you proud of?
What makes you laugh?
What gives you peace of mind?
What makes you sad/angry?
What are you hoping for?
What do you fear?

Capacity

An assessment of the patient's ability to make decisions is an intrinsic aspect of medical decision making. Does a patient have capacity? This should be an early consideration, as it determines the need for surrogate decision making.

Patients with neurologic illness are at high risk of having impaired decision making capacity [19–21]. Neurologic diseases are often characterized by cognitive impairment, the main determinant of impaired capacity [22]. Capacity is impaired in over half of people with mild-to-moderate dementia and nearly all people with severe dementia [23]. Even mild cognitive impairment is associated with decreased performance in capacity evaluations [19, 24]. Similarly, capacity is acutely impaired in patients with severe acute brain injury and even among stroke survivors with excellent functional recovery, cognitive impairment is seen in over one half [20, 25].

Impaired capacity is also common near the end of life. In a US nationally representative cohort of subjects that required end of life decisions, 70% lacked capacity [26]. This proportion is likely higher for people with neurological illness.

There are four components that constitute capacity: understanding, expressing choice, appreciation and reasoning [27]. Expressing a choice is a patient's ability to clearly indicate a preferred treatment option. Understanding is the patient's ability to grasp the meaning of the information communicated by the physician. Appreciation is the patient's ability to acknowledge their medical condition and the consequences of treatment options. Reasoning is the patient's ability to engage in a rational thought process of manipulating the relevant information.

Capacity is implicitly assumed in healthy adults. The presence of cognitive impairment should raise concern for impaired capacity and prompt a more formal assessment. These components are generally assessed in a semi-structured interview with the use of open ended questions (Table 13.2). While standardized cognitive tests

Table 13.2 Assessing capacity

	Patient objective	Physician questions
Communicate choice	Indicate a choice	What is your decision?
Understand information	Repeat the information regarding their:	What have you been told regarding:
	Medical problem	Your medical problem?
	Treatment options	The treatment options?
		The risks and benefits of the treatment options?
Appreciate the situation and its consequences	Acknowledge the:	What do you believe:
	Medical problem	Is wrong with your health?
	Consequence of the treatment options	The treatment effects will be?
		Will happen if you are not treated?
Reason about treatment options	Compare the different treatment options	Why did you choose X over Y?

Adapted from Appelbaum [27]
The table reviews the four components of capacity, each component's objective and assessment questions

cannot substitute a capacity evaluation, low scores correlate well with impairment. In one study of Alzheimer's dementia, MMSE scores below 19 or above 23 were helpful in discriminating capacity [28].

Communication

The word doctor is derived from the latin word "*docēre*", which translates "to teach". Educating patients on their disease and therapeutic options is one of a physician's main responsibilities. Patients cannot make good decisions if they have incomplete or incorrect information. It becomes increasingly relevant when barriers exist, such as poor health care literacy or cognitive impairment from neurologic disease.

Effective communication can be considered as an intervention. When assessing capacity in patients with mild cognitive impairment, "understanding" is the most deficient consent ability [19, 29]. Understanding complex medical facts relies heavily on short term verbal memory, which is prominently affected in MCI and dementia. In elderly populations, promoting clear communication through educational interventions and disclosure forms improved decision making abilities [30, 31]. However, studies involving people with moderate to severe dementia are equivocal in the effect of the interventions [23].

While cognitive impairment is the main determinant of impaired capacity, aphasia is also a barrier to decision making [32]. Patients with aphasia may have capacity, yet their ability to fully participate in a dialogue regarding a proposed medical intervention is impaired [33]. Language pathologists can sometimes facilitate communication, allowing aphasic individuals to reveal their capacity, often in complex scenarios. Modified consent forms with simplified writing and pictographic representations can be used. Every exchange of information is followed by a series of questions to verify comprehension [34].

Several strategies have been recommended to improve communication with patients [15] and more are discussed in Chap. 11 "Communicating Effectively" and Chap. 12 "Prognostication".

- Slow Down. Communication can improve by slowing the rate of information. New information requires time to be processed and comprehended. If one component of the message is not understood, subsequent pieces of information may also be lost. Use pauses. Listen instead of speaking. Take additional time to deliver an important message.
- Use non-medical language. Use plain conversational language instead of complex medical terminology. Explain things as you would to a family member without a medical background. This creates the opportunity for dialogue with patients.

- Show or draw pictures. Images are remembered better than words or letters. Simple images, devoid of distracting details, are more effective forms of communication. They can support the written and spoken message.
- Limit the amount of information at each encounter. There is a limited amount of new information a patient can remember and process. If there is a complex message, this can be broken up into smaller pieces. Each encounter should have a set goal. Start by laying out the "big picture". Subsequent encounters can be used to fill in the details.
- Use planned redundancy. Repetition of information helps consolidate memory. Repetition can also occur after the patient visit, through the use of handouts. In follow up encounters, summarize prior information.
- Proactively plan meetings. In the ICU setting, the implementation of a communication strategy with the relatives of dying patients reduced the burden of bereavement [35]. The strategy included a proactive end of life conference and a brochure. It resulted in decreased post-traumatic related symptoms and symptoms of anxiety and depression three months after the patient's death.
- Use the "teach back" technique [36]. Teaching back is an effective method of verifying patient comprehension, and involves asking the patient to explain what they have learned. For example, you can say "When you get home, your spouse will ask you what the doctor said. What will you tell your spouse?". In doing so, a physician takes responsibility for adequate teaching. If a patient is unable to complete the task, we assume that our explanation was not adequate. This method should replace the common practice of asking patients: "Do you understand?". Despite poor comprehension, patients frequently answer "yes" to such questions. They may be embarrassed to admit the contrary.

Option Assessment

After diagnosing and communicating the problem, we need to find potential solutions. This includes (a) assessing benefits and risks of each option including a consideration of costs; (b) understanding and managing uncertainty including the use of time limited trials and default options; and (c) considering the biases associated with option assessment and ways to debias.

Assessing Benefits and Risks

Our actions will affect patients in good and bad ways. We generate viable therapeutic options with potential benefits in mind. Almost all therapy carries the risk of adverse events and these need to be considered as well.

Benefits and risks each have two attributes: impact and probability. The impact is the clinical importance of the effect. The probability is the chance of the effect occurring. For example, natalizumab is a disease modifying therapy used in the treatment of aggressive relapsing-remitting multiple sclerosis. It is highly effective and viewed as superior to first-line drugs. However, its use has been limited by the occurrence of progressive multifocal leukoencephalopathy (PML), an opportunistic encephalitis caused by the ubiquitous JC virus [37]. With therapy, the risk of developing this disease is less than 1:1000 in patients treated for 2 years or more. In this scenario, the impact of the therapy's risk is large, as PML is a devastating and potentially fatal neurologic disease. The probability of this occurring is low.

The impact and probability of both risks and benefits are determined in three different ways: Scientific evidence, clinical experience, and patient attributes.

The first is derived from evidence based medicine. Published articles report the probability that an effect will occur for a given study population. It can be expressed as a percentage, relative risk, relative risk reduction, absolute risk reduction, etc. The exact probability can never be known. The true probability lies somewhere in the neighborhood of a point estimate. This neighborhood is expressed as a confidence interval [38]. Research provides a probability for a large yet not necessarily diverse population; this raises questions about its applicability to a specific patient.

The second is derived from anecdotal, personal experience. Compared to other disciplines, neuropalliative care has a relative lack of evidence from large clinical trials. Providers may need to draw more from personal experience (themselves or others) for guidance. Estimating probability can also be derived from a physician's personal experience. This is particularly relevant for some procedural based therapies. For example, a physician may recognize that, at their institution, the rate of gastrointestinal hemorrhage from gastrostomy tube placements is higher among gastroenterologists than interventional radiologists (or the other way around).

The third are the attributes of the patient. A physician uses published articles and personal experience to make an estimate that applies to an average patient. The estimate, is then refined upwards or downwards depending on the attributes of the patient. Considerations such as age, sex, comorbidities and life expectancy are taken into account. We may think of these as being physician cognitive exercises, but patients and their surrogates also adjust their perception of treatment effects. Their estimate is influenced by media, personal experiences, stories, beliefs, culture and understanding of disease.

Considering Cost Historically, treatment-related costs were disregarded in the context of a specific medical decision. Health-care costs were evaluated by economists and policymakers from a societal perspective, but an individual physician preferred to remain agnostic. As insurance plans have increasing out-of-pocket expenses, a physician's acknowledgment of cost is important. Choosing a slightly less effective agent, which the patient can afford, is preferable over the option that is unaffordable (or one that is paid for at the expense of food or housing) [39]. However, overemphasizing cost in a physician's decision making process runs the risk of increasing health care inequalities between the rich and poor.

This analysis leads to an overall appreciation of a therapy's benefits and risks. There may be multiple viable therapeutic alternatives that need to be compared against each other. It is helpful to place these options in one of four quadrants (Fig. 13.2). Ideally, a therapy should provide high benefits with low risk, located in the bottom right quadrant. Mentally placing all options in this space can help summarize complex medical information.

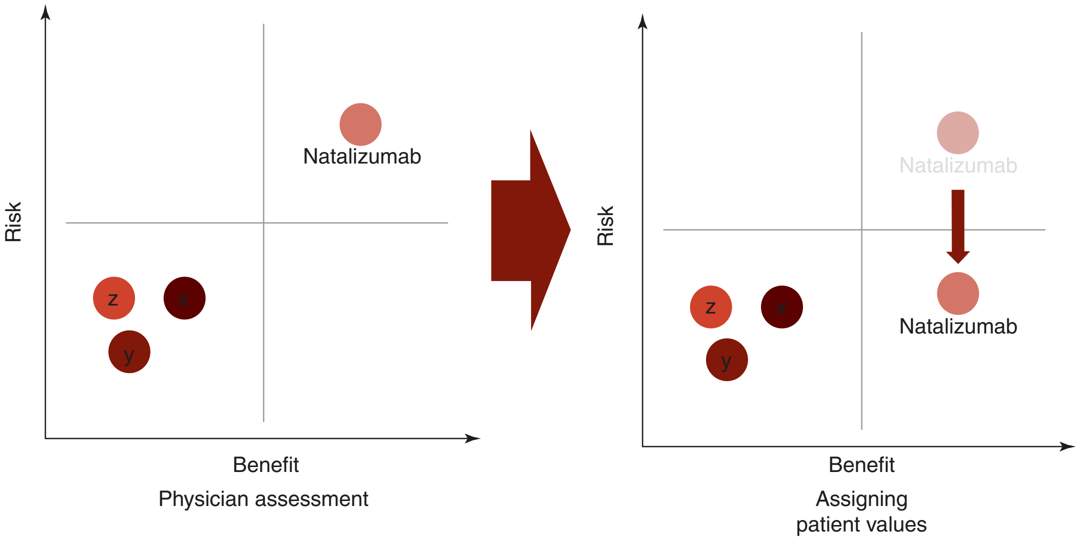

Fig. 13.2 Assigning patient values. In this example, therapies for multiple sclerosis are compared against each other. Ideally, a therapy should provide high benefits with low risk, located in the bottom right quadrant. In a physician's assessment, Natalizumab carries high benefits and high risk, with a 68% annualized relapse rate reduction and a 1:1000 risk of developing PML, respectively. In this case, a patient values disease remission over the risk of PML. Given the benefits, the patient's perception of PML risk is lower

Uncertainty

Uncertainty is an overarching component of clinical medicine though perhaps no specialty epitomizes this more than neurology. Examples include diagnostic uncertainty with atypical patient presentations or rare disorders, prognostic uncertainty in many settings (such as acute brain injuries like stroke or hypoxic-ischemic encephalopathy), and therapeutic uncertainty in scenarios without the support of high quality evidence [40]. Neurologists must develop skills to make decisions in the setting of uncertainty and to clearly communicate this concept in a productive fashion [3]. Some of the following strategies may be helpful in dealing with various types of uncertainty:

Diagnostic uncertainty Find out what diagnoses are most distressing to the patient and reassure that these are unlikely (if possible). "Although I can't tell you exactly what happened, I know you said you we're worried about a brain tumor – I think that is extremely unlikely based on your normal MRI scan."

Therapeutic uncertainty At present, many neurologic disorders lack clear evidence-based management strategies. Participating in a shared decision making process is critical in these settings, in order to review possible benefits and risks of various options. This should include a timeline of when therapeutic benefit will be reassessed.

Prognostic uncertainty Define a prognostic range, from the best to the worst case scenario. Frame this in the context of outcomes that are most important to the patient. "Some recovery of her language and right-sided weakness is possible, however I doubt that this is going to be to an extent where she can return to her prior state of independence." Take additional time to increase the prognostic precision if reasonable. If managed well, prognostic uncertainty can still lead to high quality decision making.

Time limited trials Acute brain injuries such as stroke, intracranial hemorrhage, and hypoxic-ischemic encephalopathy are distinct among neurologic disorders in that they can require life support (mechanical ventilation, artificial nutrition) while maintaining a highly variable prognosis in the short term (see Chap. 2 "Severe Acute Brain Injury"). In these settings, a time-limited trial of supportive measures can be helpful. A time-limited trial is an agreement between the patient and/or family and their clinicians to use certain medical therapies over a defined period to assess the patient's response according to agreed upon clinical outcomes that define relative successes or failures in view of the patient's goals [41]. First, although prognosis will not always be clarified over the course of a several day-long trial of interventions after acute brain injury, one can potentially begin to see some early signs of improvement that may predict a more optimistic prognosis. Conversely, progression of the initial injury or development of additional complications (venous thromboembolism, aspiration pneumonia, etc.) may lead the provider to downgrade a prognosis in a less favorable direction. Second, a time-limited trial often serves to give family members or other surrogate decision makers additional time to process the diagnosis, extent of injury, and expected impact on function (e.g., psychosocial time-limited trial). Disorders with a more slowly progressive course (e.g., dementia, ALS) allow for patients and families to prepare themselves for decisions on life-sustaining interventions; this lag time is not present in acute brain injuries. As a result, extra time may be necessary to reach a decision that is felt to be consistent with a patient's wishes.

While there is no one-size-fits-all approach to initiating a time-limited trial, some common elements can be identified. An initial meeting with key members of the decision making process should be considered, during which the nature of the disorder and active medical issues can be reviewed. Specifically, the key decisions that are anticipated (such as placement of a feeding tube or tracheostomy) should be explicitly stated. At that time, it is often helpful to place limits on further escalations of intensity of care, such as placing a DNR order or discussing withholding mechanical ventilation if it becomes necessary.

Finally, a timeframe to reconvene for another meeting, discuss prognosis, and make key decisions should be established; this time should be appropriate to the patient's overall clinical state as opposed to being an arbitrary duration.

Default options/smart defaults As described first in psychology and decision making research, a default option is the option that a decision maker will be provided if he/she chooses nothing [42]. Default options are used implicitly or explicitly in a number of different clinical settings; while often purported to be a way to increase workflow and efficiency, there are some unintended consequences of this form of decision making. Obtaining daily blood draws on patients who have been hospitalized for long periods of times, with resultant over-phlebotomy and both a burden on the patient (discomfort) and the healthcare system (cost), is one example [43].

From a palliative care standpoint, a common scenario involving this type of decision making is the choice of cardiopulmonary resuscitation (CPR) versus do-not-resuscitate (DNR) status. In almost all clinical settings, the default option is to proceed with CPR if a patient's (or their surrogate's) wishes are not queried. Yet prior research has shown that older adults are much more likely to proceed with DNR status if this is provided as a default option when resuscitation status is discussed [44]. Some authors' recommendations have gone so far as not offering CPR in situations where CPR might be considered inappropriate or futile [45]; at the very least, changing DNR to the default option in the case of patients with advanced neurologic dysfunction is likely to result in fewer unsuccessful resuscitation efforts with their resultant emotional burden.

Bias

Recognition of biases are vital to optimize medical decisions [46]. They can occur in both patients and physicians, at any stage of interaction. Some biases are personality traits, which reflect a person's confidence or natural response towards ambiguity and risk. The first step to overcome biases is becoming aware of their existence [47]. Among over forty types of clinical biases have been described, the following are examples that arise when assessing therapeutic options, particularly ones that are relevant to neuropalliative care. For readers wanting a more in-depth review of cognitive biases in medical decision-making, we refer them to several recent reviews [46, 48, 49].

Regret bias is the perception that harm by commission is worse than by omission. If a bad outcome occurs, the regret is greater if it resulted from treatment than from adopting a "watchful waiting approach". Physicians may experience an anticipated sense of regret, which may influence the decision towards inaction.

Framing bias is a tendency to draw different conclusions, depending on how information is presented. Physicians can transfer their preferences to patients. This occurs by using different connotations when communicating: presenting a favored option first, highlighting benefits, minimizing risk or using a different tone of voice. Physicians are also susceptible to this bias when interpreting medical information.

Alternative bias is the decisional conflict generated by increasing the number of options. This manifests as a tendency to change preference when also presented with an additional option that is asymmetrically dominated. In one scenario involving a patient with osteoarthritis, family physicians were less likely to prescribe a medication when deciding between two medications than when deciding about only one medication [50].

Ambiguity aversion is the tendency to avoid options for which missing information makes the probability seem "unknown". In a study of primary care physicians, overutilization of prostate cancer screening among healthy individuals was associated with aversion to ambiguity [51].

Risk tolerance is a measure of uncertainty that someone is willing to accept with respect to negative outcome. As expressed earlier in this segment, patient and physicians may have different set points.

De-Biasing. Cognitive psychologists have postulated a dual system of decision making. System 1 refers to a fast, automatic and unconscious process of decision making. System 2 is a slow, non-programmed and conscious process of decision making [52].

Clinical work involves repetitive activity, which can resort to system 1 thought. Overuse of this system likely causes cognitive biases [46]. Conversely, techniques that enhance system 2 could counteract these biases, thereby improving medical decisions. Reflective reasoning, checklists and decision analytics are strategies which induce physicians to pause and adopt more analytical thought [53, 54]. Advice can be drawn from these strategies, which pertain to variable medical scenarios:

- Decrease your reliance on memory. Review medical literature to confirm or broaden your diagnostic and therapeutic possibilities.
- Think about your thinking. Step back from the immediate problem to examine your thought process. Ask yourself: Was I comprehensive? Was my judgment affected by bias? Can this problem be seen from a different perspective?
- Assign weight. Complex medical problems have multiple variables and not all are relevant. Ask yourself: which variables are more important?
- Check your emotions. Recognize that altered mood states influence your thought process. If fatigue, hunger, sleep deprivation, anxiety are present, take steps to reduce their presence.
- Know your set point. Our form of practicing medicine can reflect personality traits. We have different set points of tolerance to risk and ambiguity. Ask yourself, where is *my* set point? Reflect on your overall practice as a physician. Compared to your peers, where do you stand? If you do stand towards one extreme, realizing this may help you adjust your practice towards more balanced decision making.

Shared Decision Making

We have diagnosed and 'understood' the problem. Through evidence based medicine, we have generated viable therapeutic options. The next step is engaging with patients to arrive at a decision.

Decision making roles between physicians and patients occur along a continuum [55, 56]. At the physician end of the continuum lies the paternalistic model. In this model, physicians assume what is in the patient's interest and the patient has a passive role, with limited participation in decision making [57]. At the other end of the continuum is a fully autonomous patient. Over the past few decades, there has been a shift from paternalism towards an emphasis on patient autonomy.

In 1988, the Picker Institute coined the term "Patient Centered Care". It is defined as health care that meets and responds to patients' wants, needs and preferences and where patients are autonomous and able to decide for themselves [58]. The model has become prevalent in modern medicine. No approach within medicine embodies this more than the palliative care approach, where goals revolve around maximizing quality of life and relieving suffering. Shared decision making is the core process of this model [59]. Shared decision making is often viewed as the middle ground along the decision making continuum. Both parties have different but equally valuable perspectives and roles. Physicians bring their expertise and patients bring their values. Participating in shared decisions is engaging in dialogue, where both perspectives are expressed [55]. Successful communication is critical to this process. The need to engage in shared decision making is greatest when a treatment plan has a high risk to benefit ratio; when the plan could conflict with patient values; and/or when there is no single best solution.

Two factors influence the balance between autonomy and paternalism: prognosis and the certainty of prognosis, and patient's decision making role preference [56]. For example, if the prognosis seems certain and one option promotes well-being over another, it is our duty to promote it. In doing so, the decision making balance may temporarily tilt towards paternalism. Similarly, if a family is making a decision about life sustaining treatment in an incapacitated patient, whose poor prognosis seems certain, the physician may ease the burden of a tragic choice by recommending limitation of life-sustaining treatment.

Most patients and families prefer a shared relationship with their physician. A sizable minority wish to retain full autonomy or contrarily, have a passive role [60, 61]. Despite its importance, physicians infrequently engage with patients in their preferred way. In one study assessing 1000 office visits, less than 10% of all decisions met the minimum standard for informed decision making [62]. Lack of time, resources and expertise may limit the incorporation of patient preferences [63].

Assigning Patient Value

Earlier in this chapter, the process of placing different medical options along a graph of benefits and risks was reviewed. These options should be further adjusted along this space by the patient's values (Fig. 13.2). For example, one multiple sclerosis study compared neurologist and patient perceptions of natalizumab therapy. Given the risk of PML, 49% of neurologists would stop treatment, while only 17% of patients would do so [64]. Certainly, a patient's values will not affect the probability of achieving a benefit or risk. With natalizumab, the risk of acquiring PML will remain 1:1000 and the annualized relapse rate reduction will remain 68% [65]. Conversely, the perceived impact of risks and benefits will change with patient values. In this case, patients were willing to accept higher risks in exchange for therapeutic benefits, valuing disease remission over the risk of PML.

Decision Aids

Decision aids are tools that enhance patient and family participation in the decision making process. They come in a variety of media (print material, video, interactive computer interfaces, etc.) and are developed with the goal of conveying complex medical information in an easily understandable and standardized way. Decision aids improve patient knowledge, decrease decisional conflict, improve risk perceptions and result in a more engaged role for patients [66]. Disease-specific decision aids present prognosis or treatment risks and benefits. Other decision aids, such as the Ottawa Personal Decision Guide, can be used to probe patient goals, concerns, and values [67].

Decision aid benefits have been shown in a variety of clinical settings and certain states in the US as well as the Center for Medicare and Medicaid services are increasingly requiring clinicians to use decision-aids in an attempt to enhance discussion about treatment options [68]. However, research in the neuro-palliative care setting is limited. Within this domain, a study of advanced dementia patients' surrogates found improved knowledge and decreased decisional conflict when deciding on artificial nutrition [69]. The neurological intensive care unit, where many decisions involve a trade-off between high-intensity interventions that can prolong survival in a disabled state versus a palliative approach, seems ripe for decision aid research.

Challenges

Shared decision making research has focused on cognitive and behavioral patient outcomes (satisfaction, decisional conflict, knowledge and adherence). However, research on health outcomes is limited, with most studies using patient-reported and un-validated instruments [70]. Furthermore, shared decision making has not improved physiological measures (e.g. hemoglobin A1c, blood pressure, lipid levels) [71, 72].

Studying shared decision making is inherently challenging. Engaging with patients is the final step of a complex process. Errors can occur at any preceding step: assessing diagnosis, prognosis, therapy risks/benefits, patient values, etc. Thus, a high quality shared decision between physicians and patients does not guarantee a high quality medical decision.

Despite the need for more research, there is an ethical imperative to advocate for shared decision making. It strengthens patient autonomy, a fundamental right.

The Objective

What constitutes a good decision? What constitutes a bad decision? Can we say that one decision is better than another?

In order to address these questions, we must reaffirm our purpose as health care providers. Medicine begins and ends with patients. Our purpose is to promote their well-being. This is meant in the broadest sense possible: physical, emotional and spiritual. Therefore, the success of our medical decisions should be measured in a patient's well-being.

Physical well-being is more than just the absence of disease. It includes lifestyle choices to ensure health, such as diet, exercise and sleep. Emotional well-being is what enables an individual to be able to function in society and meet the demands of everyday life. People with good emotional well-being can recover effectively from illness, change or misfortune. Spiritual well-being is what enables us to experience and integrate meaning and purpose in life. It is achieved through a person's connectedness with self, others, art, music, literature, nature, or a power greater than oneself. This focus on multiple domains of well-being is at the heart of palliative and neuropalliative care.

The concept of an ideal state of well-being is evolving and is open for continued debate. There may be many ideal states and many paths to these states. In addition, most aspects of well-being are difficult to quantify. As physicians with scientific training, emphasis is placed on objective quantitative outcomes: blood pressure, tumor size, seizure frequency, survival time, etc. We often fail to value subjectivity. The human experience is entirely subjective and therefore so is much of well-being: disease symptoms, mood and our sense of purpose in life. Subjectivity does not preclude differentiating better states of well-being from worse states of well-being.

How can we elevate well-being in the face of certain death? Imagine the following scenario: A 30 year-old man presents to the hospital with severe headache and nausea, and is found to have an acute intraparenchymal hemorrhage from metastatic melanoma. Clearly, symptomatic treatments for his headache and nausea should improve his well-being. Likewise, facilitating his wife's visit and playing his favorite Pink Floyd album while in the ICU, bring comfort and enhance his well-being. Unfortunately, his status suddenly decompensates, he becomes unconscious and he is intubated. He had expressed wishes for aggressive medical care, with the goal of surviving one week, until his child's birth. How long is it reasonable to continue life sustaining measures? While the most appropriate answer will be difficult to ascertain and will vary from patient to patient, it should always be framed with the goal of improving well-being.

Well-being should not be conflated with satisfaction. Satisfaction is seeking positive emotions while avoiding negative emotions. What would life be devoid of pain, anxiety or sadness? In many cases, we have to endure temporary displeasure to achieve higher states of well-being. An Olympic athlete cannot achieve a high state of physical prowess without enduring pain or forgoing sleep. A Buddhist monk cannot achieve a high level of spirituality without sacrificing hours of meditation and experiencing hunger. A child cannot develop immunity without coughing and sneezing from a cold.

Physicians should be cautious about overly emphasizing patient satisfaction. Patients typically bring expectations to medical encounters, often making specific requests. Satisfaction correlates with the extent to which physicians fulfill patient expectations [73–75]. In a US nationally representative sample, higher patient satisfaction was associated with higher health care expenditures and increased mortality [76]. When practicing patient centered care, we must recognize that a patient's requests are not always conducive to well-being. What they want may not be what they need.

Conclusion

On a broad scale, what can be done to improve medical decisions? First, there is a need to emphasize patient well being. Medical specialization leads to focused clinical problem solving.

Conversely, complex medical problems demand that we maintain a broad appreciation of the factors that enhance a patient's physical, emotional and spiritual well being. Second, there is a need for metrics to describe decision making quality in advanced neurologic illness. Third, there is a need to study implementation strategies. High quality decision making requires time. The additional time and the added value of applying shared decision making should be reflected in compensation strategies. These considerations are relevant in an era where physician burnout is prevalent, particularly among neurologists. Finally, there is a need to incorporate the teaching of shared decision making skills into the medical curricula for all providers, particularly neurology residents, fellows, and others that are highly engaged in the care of patients with neurologic disorders.

Take Home Messages

- Educating patients on their disease and therapeutic options is one of a physician's main responsibilities. Strategies to improve communication with patients include: slowing down, using non-medical language, using pictures, limiting information at each encounter, repeating information, proactively planning meetings and using the teach back technique.
- A patient's *values* are the aspects of life which they find important. A *preference* is a choice that pertains to a specific medical scenario. A preference is constructed from an individual's core values, is influenced by multiple factors.
- Therapeutic risks and benefits are determined in three different ways: Scientific evidence, clinical experience, and patient attributes. Therapeutic options should be further adjusted by incorporating patient values.
- Bias can occur in both patients and physicians, at any stage of interaction. The first step to overcome biases is becoming aware of their existence.
- Shared decision making is often viewed as the middle ground along the decision making continuum. Both parties have different but equally valuable perspectives and roles. Physicians bring their expertise and patients bring their values.
- The need to engage in shared decision making is greatest when a treatment plan has a high risk to benefit ratio; when the plan could conflict with patient values; and/or when there is no single best solution.
- The success of a medical decision should be measured in a patient's well-being: physical, emotional, and spiritual.

References

1. Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter. BMJ. 2012;345:e6572.
2. Solomon AJ, et al. The contemporary spectrum of multiple sclerosis misdiagnosis: a multicenter study. Neurology. 2016;87(13):1393–9.
3. Holloway RG, Gramling R, Kelly AG. Estimating and communicating prognosis in advanced neurologic disease. Neurology. 2013;80(8):764–72.
4. Epstein RM. The science of patient-centered care. J Fam Pract. 2000;49(9):805–7.
5. Crane JA. Patient comprehension of doctor-patient communication on discharge from the emergency department. J Emerg Med. 1997;15(1):1–7.
6. Roter DL. The outpatient medical encounter and elderly patients. Clin Geriatr Med. 2000;16(1):95–107.
7. Makaryus AN, Friedman EA. Patients' understanding of their treatment plans and diagnosis at discharge. Mayo Clin Proc. 2005;80(8):991–4.
8. Gramling R, et al. Determinants of patient-oncologist prognostic discordance in advanced cancer. JAMA Oncol. 2016;2(11):1421–6.
9. Kutner M, Greenberg E, Jin Y, Paulsen C. In: U.D.o. Education, editor. The health literacy of America's adults: results from the 2003 national assessment of adult literacy. Washington, DC: National Center for Education Statistics NCES; 2006. p. 2006–483.
10. Schillinger D, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. Arch Intern Med. 2003;163(1):83–90.
11. Tarn DM, et al. Physician communication when prescribing new medications. Arch Intern Med. 2006;166(17):1855–62.
12. Ha JF, Longnecker N. Doctor-patient communication: a review. Ochsner J. 2010;10(1):38–43.
13. Rogers ES, Wallace LS, Weiss BD. Misperceptions of medical understanding in low-literacy patients: implications for cancer prevention. Cancer Control. 2006;13(3):225–9.
14. Graham S, Brookey J. Do patients understand? Perm J. 2008;12(3):67–9.
15. Weiss BD. In: A.M.A.F.a.A.M. Association, editor. Health literacy and patient safety: help patients understand. 2nd ed. Chicago: American Medical Association Foundation and American Medical Association; 2007.

16. El-Jawahri A, et al. Qualitative study of patients' and caregivers' perceptions and information preferences about hospice. J Palliat Med. 2017;20(7):759–66.
17. McIlfatrick S, et al. Exploring public awareness and perceptions of palliative care: a qualitative study. Palliat Med. 2014;28(3):273–80.
18. Epstein RM, Peters E. Beyond information: exploring patients' preferences. JAMA. 2009;302(2):195–7.
19. Okonkwo O, et al. Medical decision-making capacity in patients with mild cognitive impairment. Neurology. 2007;69(15):1528–35.
20. Triebel KL, et al. Treatment consent capacity in patients with traumatic brain injury across a range of injury severity. Neurology. 2012;78(19):1472–8.
21. Karlawish J, et al. Cognitive impairment and PD patients' capacity to consent to research. Neurology. 2013;81(9):801–7.
22. Raymont V, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. Lancet. 2004;364(9443):1421–7.
23. Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. Am J Geriatr Psychiatry. 2002;10(2):151–65.
24. Abu Snineh M, Camicioli R, Miyasaki JM. Decisional capacity for advanced care directives in Parkinson's disease with cognitive concerns. Parkinsonism Relat Disord. 2017;39:77–9.
25. Kapoor A, et al. "Good outcome" isn't good enough: cognitive impairment, depressive symptoms, and social restrictions in physically recovered stroke patients. Stroke. 2017;48(6):1688–90.
26. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. N Engl J Med. 2010;362(13):1211–8.
27. Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. N Engl J Med. 2007;357(18):1834–40.
28. Karlawish JH, et al. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. Neurology. 2005;64(9):1514–9.
29. Martin RC, et al. Medical decision-making capacity in cognitively impaired Parkinson's disease patients without dementia. Mov Disord. 2008;23(13):1867–74.
30. Tymchuk AJ, Ouslander JG, Rader N. Informing the elderly. A comparison of four methods. J Am Geriatr Soc. 1986;34(11):818–22.
31. Krynski MD, Tymchuk AJ, Ouslander JG. How informed can consent be? New light on comprehension among elderly people making decisions about enteral tube feeding. Gerontologist. 1994;34(1):36–43.
32. Brady MC, Fredrick A, Williams B. People with aphasia: capacity to consent, research participation and intervention inequalities. Int J Stroke. 2013;8(3):193–6.
33. Stein J, Brady Wagner LC. Is informed consent a "yes or no" response? Enhancing the shared decision-making process for persons with aphasia. Top Stroke Rehabil. 2006;13(4):42–6.
34. Aura Kagan MDK. Informed consent in aphasia: myth or reality? Clin Aphasiology. 1995;23:65–75.
35. Lautrette A, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78.
36. Cegala DJ, Marinelli T, Post D. The effects of patient communication skills training on compliance. Arch Fam Med. 2000;9(1):57–64.
37. Major EO. Progressive multifocal leukoencephalopathy in patients on immunomodulatory therapies. Annu Rev Med. 2010;61:35–47.
38. Guyatt GH, Sackett DL, Cook DJ. Users' guides to the medical literature. II. How to use an article about therapy or prevention. B. What were the results and will they help me in caring for my patients? Evidence-Based Medicine Working Group. JAMA. 1994;271(1):59–63.
39. Berkowitz SA, Seligman HK, Choudhry NK. Treat or eat: food insecurity, cost-related medication underuse, and unmet needs. Am J Med. 2014;127(4):303–10. e3
40. Simpkin AL, Schwartzstein RM. Tolerating uncertainty – the next medical revolution? N Engl J Med. 2016;375(18):1713–5.
41. Quill TE, Holloway R. Time-limited trials near the end of life. JAMA. 2011;306(13):1483–4.
42. Thaler, RH, Sunstein CR, Balz JP. Choice Architecture. 2010. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1583509.
43. Hart J, Halpern SD. Default options in the ICU: widely used but insufficiently understood. Curr Opin Crit Care. 2014;20(6):662–7.
44. Halpern SD, et al. Default options in advance directives influence how patients set goals for end-of-life care. Health Aff (Millwood). 2013;32(2):408–17.
45. Blinderman CD, Krakauer EL, Solomon MZ. Time to revise the approach to determining cardiopulmonary resuscitation status. JAMA. 2012;307(9):917–8.
46. Saposnik G, et al. Cognitive biases associated with medical decisions: a systematic review. BMC Med Inform Decis Mak. 2016;16(1):138.
47. Bornstein BH, Emler AC. Rationality in medical decision making: a review of the literature on doctors' decision-making biases. J Eval Clin Pract. 2001;7(2):97–107.
48. Croskerry P. The importance of cognitive errors in diagnosis and strategies to minimize them. Acad Med. 2003;78(8):775–80.
49. Blumenthal-Barby JS, Krieger H. Cognitive biases and heuristics in medical decision making: a critical review using a systematic search strategy. Med Decis Mak. 2015;35(4):539–57.
50. Redelmeier DA, Shafir E. Medical decision making in situations that offer multiple alternatives. JAMA. 1995;273(4):302–5.
51. Sorum PC, et al. Why do primary care physicians in the United States and France order prostate-specific antigen tests for asymptomatic patients? Med Decis Mak. 2003;23(4):301–13.
52. Sloman SA. The empirical case for two systems of reasoning. Psychol Bull. 1996;119(1):3–22.

53. Mamede S, et al. Effect of availability bias and reflective reasoning on diagnostic accuracy among internal medicine residents. JAMA. 2010;304(11):1198–203.
54. van den Berge K, Mamede S. Cognitive diagnostic error in internal medicine. Eur J Intern Med. 2013;24(6):525–9.
55. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Educ Couns. 2006;60(3):301–12.
56. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. Chest. 2008;134(4):835–43.
57. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. JAMA. 1992;267(16):2221–6.
58. Hart JT. The autonomous patient: ending paternalism in medical care. J R Soc Med. 2002;95(12):623–4.
59. Barry MJ, Edgman-Levitan S. Shared decision making – pinnacle of patient-centered care. N Engl J Med. 2012;366(9):780–1.
60. Deber RB, et al. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. Health Expect. 2007;10(3):248–58.
61. Heyland DK, et al. The seriously ill hospitalized patient: preferred role in end-of-life decision making? J Crit Care. 2003;18(1):3–10.
62. Braddock CH 3rd, et al. Informed decision making in outpatient practice: time to get back to basics. JAMA. 1999;282(24):2313–20.
63. Shippee ND, et al. Patient and service user engagement in research: a systematic review and synthesized framework. Health Expect. 2015;18(5):1151–66.
64. Heesen C, et al. Risk perception in natalizumab-treated multiple sclerosis patients and their neurologists. Mult Scler. 2010;16(12):1507–12.
65. Polman CH, et al. A randomized, placebo-controlled trial of natalizumab for relapsing multiple sclerosis. N Engl J Med. 2006;354(9):899–910.
66. Stacey D, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014;1:CD001431.
67. O'Connor A. Ottawa personal decision guides. The Ottawa Hospital Research Institute. 2017. https://decisionaid.ohri.ca/decguide.html.
68. Spatz ES, Krumholz HM, Moulton BW. Prime time for shared decision making. JAMA. 2017;317(13):1309–10.
69. Hanson LC, et al. Improving decision-making for feeding options in advanced dementia: a randomized, controlled trial. J Am Geriatr Soc. 2011;59(11):2009–16.
70. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. Med Decis Mak. 2015;35(1):114–31.
71. Deinzer A, et al. Is a shared decision-making approach effective in improving hypertension management? J Clin Hypertens (Greenwich). 2009;11(5):266–70.
72. Heisler M, et al. Physicians' participatory decision-making and quality of diabetes care processes and outcomes: results from the triad study. Chronic Illn. 2009;5(3):165–76.
73. Kravitz RL, et al. Internal medicine patients' expectations for care during office visits. J Gen Intern Med. 1994;9(2):75–81.
74. Macfarlane J, et al. Influence of patients' expectations on antibiotic management of acute lower respiratory tract illness in general practice: questionnaire study. BMJ. 1997;315(7117):1211–4.
75. Marple RL, et al. Concerns and expectations in patients presenting with physical complaints. Frequency, physician perceptions and actions, and 2-week outcome. Arch Intern Med. 1997;157(13):1482–8.
76. Fenton JJ, et al. The cost of satisfaction: a national study of patient satisfaction, health care utilization, expenditures, and mortality. Arch Intern Med. 2012;172(5):405–11.