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## **Titration Guidance: A Model to Guide Physicians Assisting Patients and Families Facing Complex Decisions**

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### **Abstract**

Over the last century, developments in new medical treatments have led to an exponential increase in longevity, but as a consequence, patients may be left with chronic illness associated with long-term severe functional and cognitive disability. Patients and their families are often forced to make a difficult and complex choices between death and long-term debility, neither of which are acceptable outcomes. Traditional models of medical decision making, however, do not fully address how clinicians should best assist with these decisions. In this manuscript, we present a new paradigm which demonstrates how the role of the physician changes over time in response to the curved relationship between the predictability of a patient's outcome and the chance of returning to an acceptable quality of life. To translate this model into clinical practice, we present a five step model for physicians where they: 1) determine where the patient is on the curve; 2) identify the cognitive factors and preferences for outcomes which affect the patient/family's decision-making process; 3) reflect on their own reaction to the decision at hand; 4) acknowledge how these factors can be addressed in conversation; and 5) guide the patient/family in creation of plan of care. This model can help improve patient-physician communication and decision making so that complex and difficult decisions can be turned into ones that yield to medical expertise, good communication, and personal caring.

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Mr. G is an 86 year old man with a history of coronary artery disease and atrial fibrillation. He works as a chemical engineer and has been widowed for four years. He lives independently and has close relationships to his three children. After a night of dancing, he is at dinner with his partner when he has the sudden onset of right sided weakness and an expressive aphasia. At a large community hospital, he is diagnosed with a left middle-cerebral artery thrombosis and is administered thrombolytic medications. A week after the event he continues to have a dense, right-sided hemiparesis, expressive and receptive aphasia, and difficulty swallowing. Although delirious, he can still interact with his family intermittently, and by their description, he is "in there." Given his difficulty swallowing and high-risk for aspiration, Dr. R - Mr. G's physician for many years - asks the family if they want to place a feeding tube for artificial hydration or nutrition (AHN) or follow a comfort-based approach without further life-sustaining treatments. The family is conflicted: they feel they are being forced to choose between two unacceptable outcomes -- prolonged disability or death.

Over the last century, developments in public health and new medical therapies have led to an exponential increase in longevity. Treatments offered by modern medicine can now avert death,

but patients are often left with long-term severe functional and cognitive disability. Patients and their families are forced to make difficult and complex choices between death or severe debility. In this paper, we review why traditional models of medical decision making do not fully address these complex decisions and then present a new paradigm to assist with them.

## Existing Models of Medical Decision Making

### Paternalism

The model of paternalism guided medical decision making from the time of Hippocrates until the 1970's. In this paradigm patients are allowed to be passive and exempted from their responsibilities in making their own health care decisions,<sup>1</sup> as their illnesses are believed to make them incompetent to make choices.<sup>2</sup> Clinicians are charged with making all decisions for the patient,<sup>3</sup> including establishing priorities for care. In a primarily male-dominated, non-pluralistic society this model worked well – particularly given that there were few treatment options available to patients. Additionally, most patients had long relationships with their physicians and there existed an overall culture of inherent trust in authority figures. As medical care evolved, numerous problems with this model came to light. Input about desires for quality of life was not sought, and cultural and religious factors relating to health care were ignored. The model began to fall out of favor in the 1970s, partly due to an increasing distrust in medical authority figures and the increasing number and complexity of medical decisions.<sup>4</sup> For all of these reasons, the autonomy model was created.

### Autonomy

Under the autonomy model, clinicians are responsible for informing patients and their families of the salient issues in their care and the treatment options available, but the ultimate decision is made by patients<sup>5</sup> and after the landmark case of Karen Ann Quinlan,<sup>6</sup> by families. The difficulty with the autonomy model is that it presumes that physicians can translate their knowledge and experience in a manner which allows patients and families to grasp the implications and nuances of a particular decision. Patients are ill, families feel overwhelmed, and thus decisions become difficult if not impossible. Short of handing a patient or family member a textbook of medicine and infusing into them the physician's clinical experience, they can not be expected to make truly informed choices. As these limitations became apparent in the 1990's, the shared-decision making model was created.<sup>5, 7, 8</sup>

### Shared Decision Making

In shared-decision making, physicians work with patients and families to make health-care decisions.<sup>4, 5</sup> This model assumes that clinicians and patients can evaluate the options together in a systematic way, consider the benefits and burdens of each treatment, and arrive at clear and logical decisions.<sup>5</sup> Although seemingly combining the benefits of both paternalism and autonomy, it is rooted in the assumption that patients and families make decisions in a rational way based solely on the clinical evidence. While physicians often make decisions by applying the latest evidence-based medicine to clinical scenarios and assess the likelihood of potential outcomes, patients and their families do not proceed in this fashion.<sup>9</sup> The stress, prior experiences, and fears of future complications<sup>10</sup> may lead patients and families to make decisions that lead health care providers to label patients and families as “having unrealistic hopes,” “being in denial,” or “acting irrationally.”

## Titration Guidance: Matching the Physician's Role in Decision-Making to Likelihood of Patient Recovery

We propose a new model to assist clinicians in determining the degree of guidance they should provide in decision-making. Unlike previous models which describe a static role for physicians,

this paradigm demonstrates how their role changes over time in response to changes in patients' states of health. As shown in the Figure, there is a curved relationship between the predictability of a patient's outcome and the chance of returning to an acceptable quality of life. Our model is accompanied by a series of steps which help clinicians translate theory into improving clinical care.

### **Left of the Curve: Outcome Easily Predicted, High Probability of Recovery**

On the left of the curve, patients are healthy, and decisions are relatively straight forward because the chance of recovery is high. The role of physicians at this part of the curve is to provide information, as the choices are relatively straightforward with low risks.

### **Top of the Curve: Outcome Difficult to Predict, Indeterminate Probability of Recovery**

Patients and families need the most assistance from clinicians at the top of the curve, as these are the most complicated decisions. At this point, each question creates a seemingly endless series of subsequent additional choices and conundrums.

One way to guide patients and families at this point is to acknowledge that there are numerous factors which influence decision making. For example, uncontrolled physical symptoms,<sup>11</sup> depression,<sup>12, 13</sup> functional status,<sup>12</sup> anxiety,<sup>14</sup> lack of feeling in control about one's own health,<sup>15, 16</sup> and trust in physicians have all been shown to influence patients' desires to engage in decision making. The family/caregiver is particularly important because they can also suffer from emotional and physical strain,<sup>17-19</sup> all of which may influence their decision-making. Cultural, religious, and socio-economic issues play a role and may even be in conflict.

In addition to these concerns, an understanding of the cognitive and psychological processes which influence decision-making is key. One issue for patients and families at the peak of the curve is their concerns about future regret.<sup>10</sup> It has been postulated that the potential regret of having failed to “do everything” (i.e. refusing treatments or interventions) is so great that patients will choose treatments even if they are presented as having a small likelihood of benefit.<sup>20</sup> After one path is chosen, the family may always wonder what would have happened had they chosen an alternate path, leading to a state of indecision.

“Sunk costs” are another factor which clinicians must understand in communicating with patients and families. Adapted from economics,<sup>21</sup> this theory postulates that once patients have begun a certain treatment, they will continue with it (regardless of efficacy or future discomfort) to avoid the feeling that resources (including time) used until this point were not wasted.<sup>10</sup>

In addition to these psychological factors, physicians must consider patients' and families' preferences and values for acceptable outcomes. Decisions about interventions are ultimately a comparison of the benefits of a particular treatment weighed against its burdens. Acceptable outcomes vary based on the individual patient and family's benefit-burden analysis. The balancing of this equation may be influenced by past experiences with the healthcare system (either for themselves or others), and physicians may often need to inquire about these to better understand how they shape the decision making process.

Physicians must also examine the role their own emotions play in the guidance they provide. Concern for future regret also can affect physicians. When counseling families about stopping treatments, clinicians may wonder if there is just “one more thing” that can be done, a feeling that can both influence the way they counsel individuals as well as turn into an enduring sense of guilt after the patient dies.<sup>22</sup> Sunk costs may also affect physicians -- clinicians may feel that terminating therapies invalidates their original rationale. In terms of personal values, it is important to remember that an acceptable outcome for the patient may differ dramatically from what clinicians would want for themselves.<sup>23</sup>

Finally, physicians' reactions can have a concrete influence on the family. For example, unconscious emotions may alter the way that a physician frames a medical treatment or problem. Studies have shown that patients are more likely to choose treatments if the outcome is presented in terms of survival rather than mortality rates, even if the odds are the same.<sup>9, 24</sup>

For all of the reasons outlined above, decisions at the peak of the Titrating Guidance curve may be even more difficult for families and patients than they first appear. Suggested communication tools to be used at the top of the curve, including phrases to begin these conversations, are shown in Table 1.

### **Right of the Curve: Outcome is Easily Predicted; Chance of Return to Acceptable Quality of Life is Almost None**

Patients at the far right of the spectrum have advanced illness. There is little to no chance of recovery and choices often relate to desire for symptom control, maximizing quality of life, and location and nature of death. Patients and families must deal with balancing treatment options with personal values and preferences, and the process of making these decisions is complex and distressing. Because there are ultimately few paths down which the treatment plan can proceed, the role of the physician changes from guiding to reducing emotional and psychological stressors.

### **Employing the “Titrating Guidance” Model in Practice**

As outlined in Table 2, applying the guide to practice can be accomplished through a five-step process: 1) determine where the patient is on the curve; 2) identify the emotional and cognitive factors affecting patient/family decision-making (which may be articulated as values, preferences, and past health care experiences) and determine which factors need further exploration; 3) reflect on the physician's own reaction to the decision at hand, including personal preferences and values, acknowledging that they may differ from that of the patient; 4) determine how each of these factors can be addressed on the part of the patient/family as well as the physician; 5) guide patient/family in creation of plan of care. Steps 1–4 are done by the physician as preparation for step 5, which occurs as a conversation with patients and their families.

### **Left Portion of the Curve**

Returning to the case of Mr. G, consider the clinical scenario when he was first diagnosed with atrial fibrillation. At this point, Dr. R wanted to add warfarin to his medication regimen. First, Dr. R thinks about the Titrating Guidance curve and determines that because Mr. G is relatively healthy and data about the benefits and burdens of anticoagulation are robust, this conversation occurs on the left portion of the curve. Dr. R determines that it is unlikely that Mr. G will have a strong emotional reaction to the conversation, but he may have some concern for future regret – wondering about what the outcome might be if he chooses the other path. She remembers she needs to inquire about any previous experience Mr. G might have had with others who have made decisions about anticoagulation, and how the factors which influence his own benefit-burden analysis. In step three, Dr. R thinks about her own emotions. In her years of practice, she has had numerous patients on anticoagulation with only one case which she considers had a bad outcome. She also acknowledges that her own personal bias if she were faced with this decision herself would be to opt for anticoagulation, but acknowledges that Mr. G may have a bias towards not intervening. Fourth, Dr. R considers how she will address the issue of concern for future regret, and she decides to tell Mr. G about her one bad outcome. Finally, Dr. R has a conversation with Mr. G where she outlines the need for the treatment, and its benefits and burdens. Ultimately, Mr. G needs little guidance in making the decision,

and Dr. R respects and supports his choice regardless of whether it is in conflict with her recommendation or personal preferences she might have for her own care.

### Top Portion of the Curve

Dr. R employs a similar process in her approach to communication with Mr. G's family immediately after his stroke. First, she notes that the ultimate outcome can not readily be predicted, and it is unclear what his future quality of life will be. The family is being forced to make an extremely difficult decision – continue to support him in a physical state he would have found intolerable, or allow him to die. Questions arise such as: If they choose to start AHN, will Mr. G be able to go home or will he need to be transferred to a long-term care facility? If they choose to not provide AHN, will they be able to live with their guilt? Can a trial of AHN be provided but stopped later if Mr. G does not improve? For all of these reasons, Dr. R determines that the current decisions which need to be made place Mr. G and his family at the top of the curve.

In step two, Dr. R examines the emotional and cognitive factors affecting the family's ability to make decisions. They have a range of reactions to Mr. G's sudden illness, so their sadness, shock, and denial all play a role in their decision-making. In terms of cognitive factors, sunk costs should also be considered; the idea of not providing all life-sustaining treatments may leave the family wondering if they should have ever chosen to provide previous treatments (e.g. thrombolytics) in the first place. Concern for future regret is particularly high; if the comfort path is chosen and the family foregoes AHN, they may always wonder what would have happened if they chose an alternate path. Preferences for quality of life also affect their decision – is living in a state where he is alive but not able to communicate acceptable to Mr. G? Some patients would find a life of dependency on others unacceptable, whereas others would consider it inline with their religious and moral values.

A strategy often used to assist patients and families in these complicated decisions is that of a time-limited trial of AHN. In this scenario, Dr. R makes a judgment that she understands the family well enough to propose that a gastric tube be placed for a pre-specified length of time (e.g. one month). This will allow the family a better sense of the potential benefits and burdens of this treatment modality, as well as allowing for more time to see if his neurologic status improves. Of note, while withholding and withdrawing medical treatments are considered to be both legally and ethically equivalent,<sup>25</sup> patients and their families may often may not see them as such. When the end of the allotted time frame arrives, Dr. R plans another conversation about the outcomes observed by the family and the medical team.

In the third step, Dr. R examines her own emotions. She has been Mr. G's physician for many years, so she must acknowledge her own feelings of loss and grief. If the family chooses to forego further life-sustaining treatments, then Dr. R may be left wondering if there is just “one more thing” that could be done. This is a variation of concern for future regret, and it can turn into an enduring source of guilt for Dr. R if Mr. G dies. Dr. R must also acknowledge her personal preferences if one of her family members were in the same situation as Mr. G, and she must be sure that her own preferences do not color her conversation with the family.

Dr. R must also consider how her framing of the medical options will affect the decision the family makes. It is unlikely the family will agree to stopping treatments if she asks “Do you agree to withdraw care?”, but they might agree to the concept of reframing the goals of care<sup>26</sup> (e.g. “Let us focus now on assuring comfort and dignity in the time he has left instead of trying to prolong his life as long as we can.”). In both cases she is asking about moving from a life-sustaining treatment plan to a comfort-oriented approach to care, but the framing of the second scenario is more consistent with the values expressed by Mr. G's family.

For step four, Dr. R considers how she will handle each of these issues when counseling the family. To address the degree to which the family is struggling with sunk costs, she will ask, “Are you concerned that stopping life-sustaining treatments now invalidates decisions that you have previously made?” To address concern for future regret, Dr. R. might say, “It is important to consider whether you will be comfortable with these choices when you look back on them twenty years from now.” In terms of her own reactions, she could discuss the plan to stop AHN with Mr. G's neurologist, or even ask for a second opinion, to lessen her own concerns for future regret.

For the final step, Dr. R discusses with the family the benefits and burdens of AHN. To assist her with opening the conversation, Dr. R chose to use the informed recommendation tool as described in Table 1. She began the conversation with, “Given what you've told me about your father and his desire for both independence and quality of life, I don't think it makes sense to put in a feeding tube. Tell me your reactions to my recommendation.” Dr. R then moves on to address the family's concerns about future regret and sunk costs. Ultimately the family decided not to place a tube for AHN.

### Right Portion of the Curve

Several weeks later, it became clear that Mr. G could not eat enough to sustain himself. At this point, Dr. R re-examined where Mr. G was on the curve. She knows that recovery is unlikely, and so the decision now is whether the family will care for him at home or admit him to an inpatient hospice. The choices are well defined and regardless of what is selected, the ultimate outcome – death – is known. Dr. R thus determines that the current decision is on the rightmost portion of the curve.

Next, Dr. R determines both the emotional and cognitive factors which influence the family's decision making at this point. Sunk costs are not particularly applicable, and concern for future regret will only come into play if the family is not provided with the resources (both in terms of guidance and medications) to assure that his final days are comfortable. The family may have preferences based on past experiences with the care of other family members or their own personal beliefs about where Mr. G should die. Likewise, while Dr. R may have a strong emotional reaction to Mr. G's death, she realizes that because of the straightforward nature of the choices to be made, this is unlikely to influence the way she guides the family (step three). While she knows that if it were her father she would want him to die at home, she will work to keep her personal preferences from influencing her counseling of the family.

In step four, Dr. R realizes that her role changes from guiding decisions to primarily supporting the family. In speaking with the family and creating a plan of care (step five), she focuses on emotional counseling regarding the acceptance of imminent death rather than choosing biomedical interventions, and assures that treatments will be focused on palliation of symptoms. The family chooses to enroll Mr. G in home hospice. Dr. R continues to work closely with the family to assure they do not feel abandoned.

### Limitations

Our model has not been empirically tested and validated, although it is based on work by others about participation in medical decision making, and how communication about the process improves both satisfaction and outcomes.<sup>27–29</sup> In addition, while our model could be used by an interdisciplinary team, we have not explicitly outlined this process. Future research will be needed to test and validate the proposed model.

## Conclusion

As medicine advances, the possibilities it offers for sustaining life sometimes forces patients and their families to make choices that can seem difficult if not impossible. We have created a model for decision-making that recognizes how a physicians' role ought to change with the uncertainty of the desired outcome and the chance of restoring an acceptable quality of life. These difficult decisions can be turned into ones that yield to medical expertise, good communication, and personal caring.

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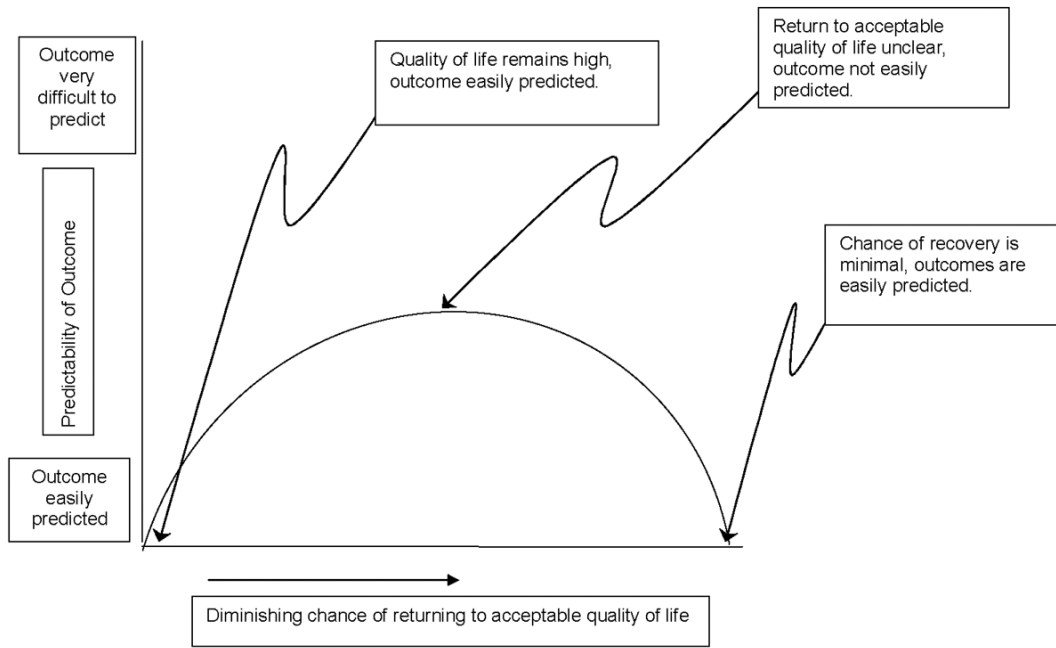
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This manuscript is dedicated to the memory of Isadore Elliott Goldberg.

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**Figure.** Conceptual model of relationship between ability to accurately predict outcome to diminishing chance of returning to an acceptable quality of life. As illness progresses, the role of the physician changes across the entire continuum, but for the sake of clarity only three points have been shown on the Figure.

**Table 1**

Examples of communication tools and phrases to aid physicians in discussions with patients and their families at the top of the Titrating Guidance curve. Which option is selected depends both on the physician's assessment of the patients/family dynamic as well as the clinician's comfort with using each style.

Communication Tools	Definition	Example
Articulating challenge for patient/family	Physician acknowledges difficulty of decision and also importance of careful thought	"This is a tough decision and in this sort of situation I think it is helpful to do the following..."
Values-based proposal	Physician makes a proposal about care plan based on values elicited from patient and/or family	"I'm hearing a couple of important values as we talk, which are... Tell me what you think about this proposal. What if we decided on a trial of a feeding tube, because..."
"What if?" scenarios	Physician projects into the future based on hypothetical decisions	"Let's think through what might happen if put in a feeding tube...Now let's think through what might happen if we do <b>not</b> put in a feeding tube?"
Informed recommendation	Physician makes a medical recommendation informed by patient/family values, & medical evidence related to efficacy of intervention	"Would it be helpful to hear a recommendation from me?...Here's how I put the situation together..."
Negotiate process for decision making	Physician helps family identify a process for thinking through the decision, and other resources	"I can see there are many different perspectives here. Would it be helpful to talk about a process your family could use to think this through?"

**Table 2**

Elements to be considered at three points in “Titrating Guidance” paradigm. Top row demonstrates point at which decision needs to be made, and leftmost column outlines each of the five steps to guide families in decision-making. The clinical questions take the case of Mr. G and extrapolate it to decisions that he might have made in the past and that his family might have to make in the future. QOL = Quality of Life

	<b>Outcome can be predicted, Chance of recovery to acceptable QOL is high</b>	<b>Outcome can not be predicted, Chance of recovery to acceptable QOL can not be determined</b>	<b>Outcome can be predicted, Chance of recovery to acceptable QOL is almost none</b>
Example of decision to be made	Should Mr. G begin anticoagulation therapy?	Should Mr. G's family consent to having a tube inserted for artificial hydration and nutrition [AHN]?	After stopping AHN, should Mr. G's family take him home or admit him to an inpatient hospice facility?
<i>Step One:</i> Determine Place on Curve	Left	Top	Right
<i>Step Two:</i> Elicit Patient / Family Emotional and Cognitive Reactions	No emotional response; no sunk costs, mild chance of concern for future regret	Strong emotional response; significant sunk costs and concern for future regret	Very strong emotional response, but to clinical situation – not decisions themselves
<i>Step Three:</i> Reflect on Physician Emotional and Cognitive Reactions	Little	Strong emotional response; significant sunk costs and concern for future regret	Very strong emotional response, but to clinical situation – not decisions themselves
<i>Step Four:</i> Acknowledge emotional/cognitive reactions, values, goals that may shape decision preferences	Briefly address concern for future regret	Directly address emotional and cognitive issues; physician must consider own reaction as well as influence of framing	Attempt to relieve physical, emotional, psychological, spiritual, and existential suffering (+/- refer to experts in other disciplines)
<i>Step Five:</i> Titrate physician role in decision making based on previous four steps + location on curve	Inform patient of options and discuss risks / benefits	Guide patients / families in discussion about desired outcomes and then tailor treatments to those goals	Few decisions in care plan, so role moves to supportive