Parental Personal Sense of Duty as a Foundation of Pediatric Medical Decision-making

Chris Feudtner, MD, PhD, MPH, Theodore Schall, MSW, MBE, Douglas Hill, PhD

We describe a model of parental (or more broadly, surrogate) decision-making that includes 5 aspects of decision-making that other models simplify or omit. First, we describe problem structuring recognizing that parents often face multiple potential problems or decisions with multiple potential solutions, rather than a single problem, and the initial challenge is deciding which of the problems to focus on. Second, we discuss sense-making recognizing that difficult decisions are not made in isolation but are often part of a confusing, labyrinthian situation in which disoriented parents must make a series of decisions over time in hopes of getting closer to 1 or more goals. Third, we describe path dependency recognizing that decisions influence what and how decisions are made later. Fourth, we discuss personal sense of duty recognizing that parents and other surrogate decision-makers have central personal roles, self-identities, and relationships with the patient, culminating in a personal sense of duty, such as what they perceive they should do to be in their own judgment a “good parent,” which substantially affects their decision-making. Fifth, we describe self-judgments recognizing that parents experience distress when they judge themselves as falling short of their duties or if they think others are judging them for falling short. Clinical practice, medical ethics, and research regarding decision support can all benefit by acknowledging and addressing these key aspects of medical decision-making.
The small, windowless room was down at the end of a hallway in the NICU. The pair of doctors entered ahead of us, followed by the bedside nurse, as the social worker held open the door for us to all file in. My partner and I knew all these people. They were nice, they had been taking care of my 4-month-old daughter for her entire life. We knew how sick she was, about the brain bleed that she had had that first week of life, and now how bad her lungs were. And we knew that we were going to talk about whether or not we should move ahead with a tracheostomy. But as we sat down, I kept wondering, as I had for weeks and weeks, how a parent could even begin to think about this kind of decision.

When we have to make decisions for others, perhaps as a parent deciding for a child or an adult child deciding for an aged parent, how do we approach not only the specific task of making a particular decision but also the encompassing task of being a surrogate decision-maker?1,2

We argue that the second task is far more important than we in the realms of medical ethics and medical decision-making have acknowledged. Our main thesis is that the specific decisions we make are fundamentally shaped by how we make sense of being in a relationship as a surrogate decision-maker (which is to say, by creating for ourselves our personal sense of duty to fulfill the role, complete with an individualized notion of the major responsibilities of being a good surrogate decision-maker, and even more specific operational rules of conduct that a good surrogate decision-maker follows). We believe that support for surrogate decision-makers is focused far too much on the details of medical intervention options and not nearly enough on assisting with the confusions, dilemmas, and self-recreations inherent in trying to formulate a guiding personal duty to serve in the role of surrogate decision-maker.

We support our claims with evidence drawn from studies of decision-making in the pediatric realm as well as more general behavioral research. Some of this evidence is from studies that we have conducted with parents of children with serious illness. We also ground our arguments in the lead author’s experience as a pediatrician providing pediatric complex and palliative care.

Our view is that decision-making plays out and evolves over time. We present the remainder of our hypothetical case in the form of a multiact play, complete with an epilogue, and after each part, we address specific assumptions embedded in how ethicists and decision-support advocates conceptualize what are, as we wish to emphasize, the separate but paired tasks of making shared medical decisions and making medical decisions for someone else. Although we focus our attention on the clinical situation in which the parent is the main decision-maker, many of the issues we address are also relevant to situations in which an older child is also involved in the decision-making process via assent or to situations in the realm of adult medical care when an incapacitated adult patient has a surrogate medical decision-maker, such as a spouse or an adult child.

**OBSCURED BY SIMPLICITY: THE ASSUMPTION OF A CLEAR AND SET PROBLEM STRUCTURE**

The attending described again the many problems with our daughter’s lungs and the various times we had already met to decide what to do along the way. She had a long agenda for the meeting; she wanted to talk about what a tracheostomy was as well as what going home someday on a ventilator might look like and go through the pros and cons of doing this. She also wanted to talk about what would happen if we did not move forward with the tracheostomy and instead focused on our daughter’s comfort, knowing that she would not live long that way. All I kept thinking was that there was no decision here; her bad lungs threatened her survival, and the tracheostomy was the only option.

In the half a century since the rise of informed consent in medical practice, the practice of clinicians sitting with patients or surrogate decision-makers and outlining the medical problem, followed by a description of treatment options and their advantages and disadvantages, has become a well-worn routine, even if done, as often as not, inconsistently or poorly.3–6 Embedded in this practice, however, is a key assumption that warrants attention.

The basic model of informed consent takes as a given, more or less, that there is a single medical problem with several possible solutions, and the decision confronting the patient or surrogate is chiefly which of the treatment options to choose. This “one-to-many” model (Fig 1A) structures the problematic situation, reducing the complexity of the overall situation. It is presumed in this basic model, and thereby is essentially used to dictate, what “the” decision is that has to be made. Importantly, although parents and clinicians often do not identify the same set of problems for a given patient,7,8 the problem at hand is typically selected by the clinician.

The shared decision-making framework largely assumes this basic one-to-many model, and in particular has been focused on the right side of the model, in which decision-makers choose among possible solutions. Clinicians are encouraged to work with the patient or surrogate to clarify values or preferences that would inform the evaluation of the potential solutions.9,10 Decision aids can help in this work.11 Depending on patients’ or surrogates’ preferences about decision-making, the clinician may also have a larger or smaller role in recommending a particular treatment option.12
The strength and the weakness of this basic model are both due to the simplification that this model imposes on the more complex reality of making high-stakes medical decisions for oneself or for a loved one. Let us examine 3 aspects of this simplification. First, most serious medical conditions present several potential problems to the patient or the surrogate (see Fig 1B). In a “many-to-many” model of decision-making, the solution-oriented right side of the model is balanced by the problem-defining left side; thus, in addition to the evaluation of potential solutions, an equal amount of effort needs to be devoted by the clinician and patient or surrogate into sorting through, evaluating, and prioritizing the various problems. Although it is not explicitly within the scope of the basic model of informed consent, good clinicians and advocates of shared decision-making have tackled this work with patients and surrogates as part of values and preferences clarification.\textsuperscript{9,10} Defining the problem may not only enhance the quality of subsequent decisions (judged within the informed consent standard) but also improve long-term outcomes by enhancing adherence to treatment plans or minimizing decisional regret.

Second, both the basic one-to-many model and our many-to-many model oversimplify the challenges of medical decision-making by depicting the making of “a” decision as a discrete act. This act may take hours or days to complete, but then once the decision has been made, formal ethical attention or decision support starts to fade. In ethics case discussions, the story of “what happened after the decision was made” is generally presented more or less as an informative coda. From the vantage of a patient with a serious illness or their surrogate decision-maker, however, decision-making is recurrent; most likely there were a string of decisions before any particular decision, and there will be more decisions to follow. Like someone cast suddenly into a labyrinth, walking in search of a path that leads them out, the surrogate decision-maker must choose again and again which way to turn (see Fig 2).

Third, in the setting of pediatric serious illness, the process of shared decision-making between parent and clinician often takes more time than suggested by the basic one-to-many model. In practice, we believe that most critical care or complex care clinicians already know this to be the case. Importantly, however, because the processes of problem-defining and of making several decisions in series, clinicians can devote the required time not just in 1 big meeting, but rather (and, in our judgement, more ideally) spread out over many interrelated conversations with parents.

\textbf{FIGURE 1}  
A, One-to-many model of medical decision-making. B, Many-to-many model of medical decision-making.

\textbf{FIGURE 2}  
Labyrinthian model of medical decision-making.

\textbf{INSIDE A LABYRINTH: THE ASSUMPTION OF A CLEAR APPROACH TO MEDICAL DECISION-MAKING}  
As the attending started to talk about the tracheostomy, I felt the now-too-familiar sense of uncertainty and dread that had swept over me in previous conversations about what to do. Hardy a week had gone by when we had not needed to meet to discuss some bad news and what could be done. How had we gotten to
this point? I knew we had come to a great hospital, but was this the best place for our daughter given how ill she had remained? Should we have pushed for a transfer to another hospital? Should we get a second opinion? Yet I had put my trust in these doctors, and they seemed really good. Everyone I talked to back home was supportive, but no one understood what we were going through. The day she was born so premature, our world had been turned upside down, and every week it seemed to flip over again. My head was spinning, but I needed to be strong and make a decision. But how could I live with myself if we did not go for the tracheostomy?

Is the fact that parents encounter repeated decision points in the care of their seriously ill children worthy of ethical attention? The metaphor of medical decision-making as an attempt to escape a labyrinth and move toward a desired goal may seem too untidy or farfetched, yet the labyrinth metaphor can be used to suggest aspects of an illness journey that the simpler models do not, such as the sense, reported by many parents confronting a medical crisis for their children for the first time, of complete disorientation with no clear, direct path to the goal and the recurrent and sequential nature of decision-making.

Indeed, in a variety of studies, parents have consistently described how confusing and overwhelming having an ill child in a hospital can be, not only emotionally, but also in the sense of not knowing or being able to comprehend what is going on.15–17 Devotees of a basic model of informed consent or decision support might respond to a parent or surrogate’s lack of comprehension by redoubling their efforts to explain what is going on with the child, from details of the medical condition to pros and cons of proposed treatments. Parents are often trying to find a path that will result either in their child’s full recovery or return to a previous baseline level of health but may have difficulty seeing whether each treatment decision is getting them closer to their goal or not. Consider a case in which a treatment results in unexpected negative side effects that must be addressed before the child’s recovery can proceed. Such developments may seem like wrong choices or dead ends that lead the parent and their child further into the labyrinth and away from their goal.

The metaphor of the labyrinth can also be used to capture the path dependency of medical decision-making (ie, past decisions influence present decisions). Over the course of time, decisions made earlier, such as what hospital to go to or what initial treatments to try, shape the way that parents approach later decisions as well as the decisions they have to make. When we have asked parents of children with serious illness about the biggest decision that they had made for their hospitalized child, many have said the decision to come to our hospital was the biggest decision, and now they were ready to be told what the best thing was to do. For these parents, the decision of who to trust shaped all subsequent decisions. If later the parents learn that their child might benefit from a specific treatment only offered at another institution, they may feel trapped by their past decision to go with the current hospital. Path dependence suggests that parents’ decisions (both what they must decide and how they make the decision) are predicated on the choices they made earlier. Reassessments and revisions of the medical plan, although based on the best information available at each decision point, may leave parents feeling more trapped and hopeless as they fail to make progress toward the goal of their child’s recovery.

Importantly, these feelings are not just about what is going on with the child, but also arise from thoughts that the parents have about the role that they themselves should play.18 None of the decision-making models discussed thus far adequately capture this pivotal aspect of medical decision-making by parents and other surrogates and their relationships with and responsibilities to the patient. As alluded to at the end of this vignette, the decisions that parents confront are not only about their child, but also themselves in how they will judge their own motives and actions and ultimately who they will choose to be.

FROM ROLES TO RULES: THE ASSUMPTION THAT SOCIAL RELATIONSHIPS ARE IRRELEVANT

When the attending had finished educating us about tracheostomies and home ventilators, she then shifted and engaged us in a conversation about how much our daughter had already suffered, and then she gently described to us what a compassionate extubation would be like. She and the social worker reassured us that we did not need to make any decision now, but they just wanted to start preparing us for this decision. Then my partner asked, “How have other parents made this type of decision? How will we know when too much is too much?”

In the basic models of informed consent and medical decision support (operating within the framework of either substituted judgment or the best interests standard), the values and preferences of the patient or surrogate are clarified so that they can be applied to the work of evaluating treatment options, mostly in terms of the short- and long-term potential health benefits and risks. This approach assumes not only that each parent (or surrogate) has a stable set of values and preferences that can be drawn out and applied to the decision but also
that these values and preferences are independent of the parents’ social roles or relationships with the patient and others. In other words, the same values could presumably be applied to a decision for a sick parent, spouse, or child. By contrast, we suggest that, far from being irrelevant, the relationships between the surrogate decision-maker and the patient are fundamental, morally and empirically, to the process of medical decision-making.

Individuals have well-developed roles that are central to their identities, such as professional role, spouse role, and parent role, and serve as a source of meaning, purpose, and structure.19,20 These roles are operationalized in day-to-day life by specific rules or duties (see Fig 3). For parents, the role of “parent” comes preloaded by social convention with a set of explicit heuristics (as well as some unstated rules) are the stuff with which parents form their personal sense of duty.

Over the past decade, along with colleagues, we have worked to better understand how parents of ill children perceive their personal sense of duty. Much of this work has been focused on improving our understanding of “good-parent beliefs,” which are beliefs that parents have about what they, as a parent, should be most focused on for their child.22 A range of potential good-parent beliefs have emerged (see Table 1), and the 2 consistent findings are that parents affirm a set of these beliefs strongly, and parents differ regarding which beliefs they hold most strongly.23,24 We have also advanced the notion of “explicit heuristics,” which are decision-making rules used to facilitate or shape the performance of different tasks that are bound up in the role of being a parent of a child with serious illness (see Table 2).25 Our argument here is that, for any given parent, a set of good-parent beliefs combined with a set of explicit heuristics (as well as some unstated rules) are the stuff with which parents form their personal sense of duty.

Although the parents’ sense of duty is often left unexplored, this sense of duty serves as an overarching framework when making decisions (see Fig 4). Responsibilities provide a focus and orientation when trying to comprehend the complex medical situation and sort through treatment.

TABLE 1 Examples of Good-Parent Beliefs

<table>
<thead>
<tr>
<th>Good-parent beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making sure my child feels loved</td>
</tr>
<tr>
<td>Focusing on my child’s health</td>
</tr>
<tr>
<td>Making informed medical care decisions</td>
</tr>
<tr>
<td>Advocating for my child with medical staff</td>
</tr>
<tr>
<td>Focusing on my child’s comfort</td>
</tr>
<tr>
<td>Focusing on my child’s quality of life</td>
</tr>
<tr>
<td>Putting my child’s needs above my own</td>
</tr>
<tr>
<td>when making medical care decisions</td>
</tr>
<tr>
<td>Staying at my child’s side</td>
</tr>
<tr>
<td>Keeping a positive outlook</td>
</tr>
<tr>
<td>Focusing on my child having as long a life as possible</td>
</tr>
<tr>
<td>Focusing on my child’s spiritual well-being</td>
</tr>
<tr>
<td>Keeping a realistic outlook</td>
</tr>
<tr>
<td>Doing right by my child</td>
</tr>
<tr>
<td>Maintaining faith</td>
</tr>
<tr>
<td>Having a legacy</td>
</tr>
<tr>
<td>Being a good life example</td>
</tr>
<tr>
<td>Letting the Lord lead</td>
</tr>
<tr>
<td>Making my child healthy</td>
</tr>
</tbody>
</table>


TABLE 2 Explicit Heuristics

<table>
<thead>
<tr>
<th>Purpose or Function</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>To depict or facilitate an understanding of complex situations</td>
<td>I just play it over and over again that your son is going to die; this is my child; everything works for the good; God is in control</td>
</tr>
<tr>
<td>To clarify, organize, and focus pertinent information and values</td>
<td>Take things day by day; that is not even a decision; distinction between quality of day versus quantity of time; I have to fight</td>
</tr>
<tr>
<td>To serve as a decision-making compass, highlighting primary rule(s) to follow when making a decision</td>
<td>We said we wanted them to do everything they can to keep our child alive; I do not want my child to be in pain; we just want her to be comfortable</td>
</tr>
<tr>
<td>To communicate about a complex topic with others, including clinicians or family members</td>
<td>There are no answers, there are never any answers, but he is sick; we have to think outside of the box</td>
</tr>
<tr>
<td>To justify a choice</td>
<td>It was best for him; it is not that we are giving up on her; we have done everything in our power</td>
</tr>
</tbody>
</table>

options, with rules (be they explicit or implicit) enabling judgments to be made about specific options. When parents undertake the task of weighing options in light of their preferences and values, we believe that much of this weighing occurs via the heuristics of rules that they have formulated on the basis of their role as a good parent. The search for a treatment to pursue is preceded by a search for and selection of a set of rules to follow. Falling short of their duties or fear that others will see them as falling short can have important consequences as we consider how parents, while engaging in problem-solving and decision-making activities, construct appraisals regarding not only their child but also themselves. Parents may struggle to honor and fulfill their personally identified duties while also engaging in the shared decision-making process; the seemingly firm dictates of some of the explicit heuristics, such as “we must not stop fighting,” are at odds with the cognitive flexibility that the shared decision-making process requires.

**WHISPERS IN THE DARK: THE ASSUMPTION OF DECISIONS WITHOUT SELF-JUDGMENTS**

They had all left the room. We had asked for time to be alone. They had been kind and empathetic; they really did care about our daughter and about us. They had answered all our questions. Although we knew we would never fully understand what either choice would entail, we felt that we had plenty of information. We sat in silence for awhile. I was so upset but so grateful that we were there together; I could not imagine doing this on my own. Then my partner said, “I don’t want to be selfish.” And I blurted out, “I’m going to feel so guilty, no matter what.”

We now come close to what feels like a third rail in the internal monologues that parents have with themselves not only about what to do but also about themselves. One of the authors has had the privilege over the years of talking with mothers and fathers about their deeply personal thoughts of love and grief, hopes and fears, and points of pride and recrimination. For these parents, not only does the well-being of their child depend on their decisions, their self-identity as a good parent is also on the line, with self-judgment lurking everywhere. To advance decision support, we need to appreciate the role that these inner deliberations have on the decision-making process and, in particular, parents’ fundamental moralistic judgments about good and bad. When individuals fall short of their desired self-identity, they experience depression and anxiety. Being a parent is often a core part of one’s identity once one has children, and when a child becomes sick, other goals and identities are often downgraded or dropped because caring for the sick child becomes the highest priority. Yet, parents of a suddenly ill child may have no clear idea of what a good parent should do in such circumstances and no actionable plan of how to go about being that good parent. This uncertainty about what they ought to do can bring down an avalanche of negative self-judgment. Parents may experience high levels of anticipated regret as they worry about the consequences of making the wrong decision and how that will affect their child. Furthermore, parents may feel that they have already failed regarding keeping their child safe, healthy, and free from harm. In the context of such inner-facing judgments, when presented with nondirectional information about the advantages and disadvantages of different treatment options, parents may decide on the basis of their rubric of what would constitute being a “good parent,” such as the belief that a good parent never gives up. Even when some parents are painfully aware that a decision may result in suffering for the child, they may lament that they are unable to see any other way to fulfill their duty.
In addition to self-judgment, individuals are usually aware of how others judge them and will strategically choose to present themselves so others will see them the way they see themselves.35–38 People, even when making hypothetical moral decisions, anticipate how others will perceive them (such as being ethically correct but uncaring) and may change their decisions accordingly.39 Parents, especially mothers, are used to being judged by others for their decisions and behaviors, even before the child is born.40

These social pressures do not go away when a child is hospitalized. In the context of serious illness, parents report the importance to them not only of being a good parent, but also that others recognize how hard they are working to be a good parent.26 Parents are aware that others may judge them for making the wrong decisions, not putting the child’s needs ahead of their own, or for being too antagonistic and difficult with staff. Parents report worrying about what clinicians will think of them if they make the “wrong” decision or argue too much.41–44

Parents continue to, and likely always will, grapple with this question of what constitutes being a good parent for an ill child. The issue then is whether a clinician has the concepts and skills to help parents address this question for themselves.

What are we, charged with our professional duty to support parental decision-making, to do with these judgments about good parents? To avoid the paternalistic judgments of previous generations, conversations about what a parent should do have largely been ruled out of bounds. A medical professional is on safe familiar ground when reviewing the pros and cons of different treatment options. Raising the issue of what good parents should do in a difficult situation seems to cross the line from an impartial professional to someone passing judgment. But even in the heyday of paternalism, the question of “what should I as a parent do?” was never the problem; the problem was providing prescriptive answers or keeping medical diagnoses secret and providing presumptuous answers to questions never asked. Parents may therefore play their cards close to their chest, not showing their full range of thoughts about what they should or should not do, their doubts and fears, and/or their negative self-judgments. They wait for the doctors to leave the room and converse quietly in private or keep entirely to themselves.

The medical decision-making process for parents (and more generally, for surrogate decision-makers) needs a broader conceptualization, such as the one we have offered in part here, if we are to adequately meet the needs of parents. Although we can suggest sets of questions that can be used to explore aspects of the decision-making process (Table 3), much work is needed to determine the most helpful and effective ways to support parents of children with serious illness as they engage in the more fully conceptualized process of making medical decisions.

<table>
<thead>
<tr>
<th>TABLE 3 Questions to Explore Different Aspects of Decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questions</strong></td>
</tr>
<tr>
<td>What do you think are the main problems for your child?</td>
</tr>
<tr>
<td>How about for you and your family, what are the main problems?</td>
</tr>
<tr>
<td>What worries you the most?</td>
</tr>
<tr>
<td>What are you hoping for?</td>
</tr>
<tr>
<td>Regarding your child’s situation, how do you think that we got to where we are now?</td>
</tr>
<tr>
<td>Do you think any of the decisions we have made thus far have been mistakes?</td>
</tr>
<tr>
<td>Do you have any regrets?</td>
</tr>
<tr>
<td>What do you feel you most need to do to be, in your own judgment, a good parent?</td>
</tr>
<tr>
<td>What do you think is most important for you to focus on?</td>
</tr>
<tr>
<td>How do you think you are doing?</td>
</tr>
<tr>
<td>How do you think we, the health care team, are getting along with you?</td>
</tr>
<tr>
<td>How could we help you better?</td>
</tr>
</tbody>
</table>

**REFERENCES**


38. Schlenker BR. Self-presentation: managing the impression of consistency when reality interferes


Parental Personal Sense of Duty as a Foundation of Pediatric Medical Decision-making
Chris Feudtner, Theodore Schall and Douglas Hill
Pediatrics 2018;142;S133
DOI: 10.1542/peds.2018-0516C

Updated Information & Services
including high resolution figures, can be found at:
http://pediatrics.aappublications.org/content/142/Supplement_3/S133

References
This article cites 40 articles, 4 of which you can access for free at:
http://pediatrics.aappublications.org/content/142/Supplement_3/S133
#BIBL

Permissions & Licensing
Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
http://www.aappublications.org/site/misc/Permissions.xhtml

Reprints
Information about ordering reprints can be found online:
http://www.aappublications.org/site/misc/reprints.xhtml
Parental Personal Sense of Duty as a Foundation of Pediatric Medical Decision-making
Chris Feudtner, Theodore Schall and Douglas Hill
*Pediatrics* 2018;142;S133
DOI: 10.1542/peds.2018-0516C

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/142/Supplement_3/S133