

Parental Explicit Heuristics in Decision-making for Children With Life-threatening Illnesses



WHAT'S KNOWN ON THIS SUBJECT: Heuristics are decision-making aids or shortcuts that ease the task of making a wide variety of decisions in diverse contexts. Little is known about the heuristics that parents of children with serious illness use when confronting difficult decisions.



WHAT THIS STUDY ADDS: Parents of children with life-threatening illnesses use several different types of heuristics, explicitly, in making sense of complex situations, making decisions, and communicating these decisions to others. Better understanding of these heuristics may improve communication and decision support.

abstract



OBJECTIVE: To identify and illustrate common explicit heuristics (decision-making aids or shortcuts expressed verbally as terse rules of thumb, aphorisms, maxims, or mantras and intended to convey a compelling truth or guiding principle) used by parents of children with life-threatening illnesses when confronting and making medical decisions.

METHODS: Prospective cross-sectional observational study of 69 parents of 46 children who participated in the Decision-making in Pediatric Palliative Care Study between 2006 and 2008 at the Children's Hospital of Philadelphia. Parents were guided individually through a semistructured in-depth interview about their experiences and thoughts regarding making medical decisions on behalf of their ill children, and the transcribed interviews were qualitatively analyzed.

RESULTS: All parents in our study employed explicit heuristics in interviews about decision-making for their children, with the number of identified explicit heuristics used by an individual parent ranging from tens to hundreds. The heuristics served 5 general functions: (1) to depict or facilitate understanding of a complex situation; (2) to clarify, organize, and focus pertinent information and values; (3) to serve as a decision-making compass; (4) to communicate with others about a complex topic; and (5) to justify a choice.

CONCLUSIONS: Explicit heuristics played an important role in decision-making and communication about decision-making in our population of parents. Recognizing explicit heuristics in parent interactions and understanding their content and functions can aid clinicians in their efforts to partner with parents in the decision-making process. *Pediatrics* 2013;131:e566–e572

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KEY WORDS

palliative care, chronic disease, decision-making, hospital care, medical ethics

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Explicit heuristics (noun): We offer the following definition – decision-making aids or shortcuts expressed verbally as terse rules of thumb, aphorisms, maxims, or mantras, and intended to convey a compelling truth or guiding principle.

Parents of children with life-threatening conditions are frequently called on to make decisions about matters of profound importance for their children. These decisions often arise amid complex clinical circumstances in which the parents encounter vast amounts of information and, paradoxically, an irreducible amount of uncertainty. When acting under these circumstances, parents often find that a broad range of information and values compete for the spotlight at the center of any given decision. Further increasing the difficulties that parents confront, the decision-making process also requires that they communicate and collaborate with an array of health care professionals and other family members, often needing to do so quickly while other responsibilities, such as parenting other children or job duties, compete for attention.^{1–6}

Contrasted with this complexity, the leading theories of decision-making are conspicuously lean and logical. These theories are dominated by the notion that people make decisions through a deliberative process aimed toward the rational maximization of expected utility. In practice, theories of medical decision-making further restrict the definition of utility to measurable clinical outcomes.¹ The model of informed consent exemplifies this framework, wherein a physician and patient discuss the patient's diagnosis and prognosis, along with the potential benefits and risks of treatment options, so the patient can make an informed choice.¹ Although valuable when addressing specific clinical problems in fixed and narrow terms, the model of informed consent and other forms of

deliberative decision-making may fail to provide adequate guidance for parents of children with life-threatening conditions.⁷ These models assume that the decision-maker understands the nature of the problem, has ample time to consider potential courses of action, can reasonably estimate the probability of occurrence for all outcomes for each course of action, can place a value on each of these diverse outcomes, and is able to execute the deliberation process in a step-wise manner. In the tumultuous lives of parents with gravely ill children or in similar circumstances of high risks and large amounts of uncertain information,^{8–11} these assumptions are off the mark. Consequently, theories of decision-making based on these assumptions do not do justice to the realities of parental decision-making and ultimately fail to facilitate the advancement of the child's best interests.

An alternative paradigm for studying how parents make decisions arises from the theory that people use heuristics to make effective decisions under conditions of uncertainty with a minimum of time, knowledge, and cognitive effort.^{12–18} Research regarding heuristics has focused mostly on unstated or implicit heuristics, patterns of thought that operate in a subconscious or subliminal manner so that decision-makers are typically unaware of their use. Yet we have noted in our clinical experience that parents of children with life-threatening illnesses often use patterns of language (aphorisms, mantras, or maxims) in conversations about decision-making. These sayings appear to function as explicit heuristics, as we define them, essentially uttered "rules of thumb" that are intended to embody compelling truths or guiding principles and which simplify the task of making and communicating about decisions.

Prototypical phrases that function as explicit heuristics might include "We will always choose the option that most improves her quality of life" and "We always said we would do anything to fight this disease." Explicit heuristics such as these help parents to make sense of the world, ease the process of assessing values and casting judgment about a course of action, and simplify the task of communicating with others.³

In this study, we sought to identify and illustrate the explicit heuristics that parents use, by utilizing a qualitative research approach nested in a prospective cohort study, with the aim of illustrating and elucidating the function that these phrases serve for parental decision-makers.

METHODS

Sample

The Children's Hospital of Philadelphia's institutional review board approved this study. Participants were parents of children receiving palliative care and who enrolled in a prospective cohort study conducted at the hospital. Parents were eligible to participate if their child was not able to make medical decisions owing to age or impaired cognitive capacity and if the parents spoke English. Parents were not eligible for the study if their child had died, was discharged, was too critically ill, or if the parent was emotionally unstable, as determined by the referring physician. In total, 73 parents of 50 patients (62.5% of all palliative care consults during the study period) consented to participate. Most parents participated in person, whereas 17 (23.3%) participated by telephone.

Data Collection

Parents participated in semistructured interviews, being asked open-ended

questions regarding the most significant elements of their child's illness and care, the most significant problems for their child, and their goals of care. Parents also were asked whether a religion, spirituality, or life philosophy influenced their experience, and how the words "trust" and "hope" applied to them. Interview audio recordings were transcribed. Parents were directly asked their age, gender, relationship to the patient, marital status, and education level, and the child's age, gender, race, insurance status, primary underlying disease, baseline level of cognitive function, and degree of involvement in medical decisions.

Data Analysis

In total, interviews with 69 parents of 46 children were included in this analysis; 4 interviews were not available owing to faulty recordings. Two researchers randomly selected 4 interviews and used an inductive approach to identify explicit heuristics. All phrases identified as explicit heuristics shared 2 core characteristics: (1) from the parent's perspective, the phrase expressed a pertinent truth or important aspect of the child's situation or the parent's situation, and (2) the phrase was commonly used in everyday lay language, frequently used in the interviews of several study participants, or repeatedly used by a study participant. The researchers' results were compared for cross-validation. The remaining interviews were randomized, split between the researchers, and read sequentially. Once thematic saturation was reached ($n = 24$), the reviewers coded the remaining transcripts ($n = 45$). The entire set of coded interviews was then analyzed qualitatively for broad categories and quantitatively for frequency of the appearance of each specific type of explicit heuristic.

RESULTS

Participants in this study represented a diverse group in terms of demographic and clinical characteristics of the pediatric patients (Table 1) and their parents (Table 2). All parents used phrases during the interview process identified as explicit heuristics. The number of explicit heuristics identified in a single interview ranged from <10 to >130 . This number typically correlated with the length of an interview, although some parents tended to use explicit heuristics more frequently than others. Among all the identified explicit heuristics, 12 categories were predominant (Table 3). In the interview conversations, parents used each of these categories of explicit heuristics in ways that served 5 core functions. Although the function that a particular explicit heuristic played depended on the context of the conversation and a given heuristic often seemed to function in >1 manner, Table 3 illustrates the most common ways in which categories of heuristics were used based on our observations.

The explicit heuristics were often cited by the parents when describing the major challenges of pediatric palliative care decision-making; namely, trying to understand a complex and stressful situation, one that has not only clinical but also social, spiritual, and existential dimensions; deciding how to decide, particularly in the face of risk and uncertainty; making a decision (and more often, many decisions, as the child's illness experience unfolded); and then living with these decisions. In these regards, the explicit heuristics appear to have helped the parents to choreograph the intrapersonal integration and the interpersonal communication of complex cognitive and emotional information. The heuristics also were cited when parents, in the process of decision-making, confronted how to best define their own role as parent

TABLE 1 Demographic and Clinical Characteristics of 46 Children

	No.	%
Age, y		
<1	11	23.9
1–4	14	30.4
5–9	11	23.9
10–17	9	19.6
18–24	1	2.2
Gender		
Female	24	52.2
Male	22	47.8
Location		
Not in hospital	10	21.7
Hospital ward	22	47.8
Hospital ICU	14	30.4
Race		
White	29	63
Black	10	21.8
Asian	1	2.2
>1 race specified	3	6.5
Not specified	3	6.5
Ethnicity		
Non-Hispanic	39	84.8
Hispanic	4	8.7
Not specified	3	6.5
CCC category		
Neuromuscular	14	30.4
Cardiovascular	1	2.2
Respiratory	2	4.3
Gastrointestinal	1	2.2
Metabolic	11	23.9
Congenital	8	17.4
Malignancy	9	19.6
Insurance		
Private	18	39.1
Medicaid	23	50
Low cost/limited/none	2	4.4
Not specified	3	6.5

CCC, complex chronic condition(s).

and decision-maker and work through their relationships with not only the child but also other members of the family. And lastly, some parents uttered various explicit heuristics repeatedly, scattered throughout the course of the conversation, almost as self-affirming maxims or self-reassuring mantras.

Viewed broadly, the explicit heuristics identified in this study performed 5 core functions.

1. To depict or facilitate understanding of complex situations: Explicit heuristics were often used to orient, make sense of, or give shape to a complex experience or situation. Depending on the context of

TABLE 2 Demographic Characteristics of 69 Parents

	No.	%
Gender		
Female	45	65.2
Male	24	34.8
Age, y		
21–34	22	32
35–38	19	27.5
39–66	19	27.5
Not specified	9	13
Relationship to child		
Mother	42	60.9
Father	23	33.3
Other	4	5.8
Race		
White	50	72.5
Black	9	13
Asian	1	1.5
>1 race	4	5.8
Not specified	5	7.3
Ethnicity		
Non-Hispanic	59	85.4
Hispanic	5	7.3
Not specified	5	7.3
Relationship to other parent		
Married or partnered	49	71
Widowed/separated/divorced	11	15.9
Single	6	8.7
Not specified	3	4.4
Education level		
High school	13	18.9
College	33	47.8
Graduate school	14	20.3
Not specified	9	13
Financial difficulties		
No	25	36.2
Yes	34	49.3
Not specified	10	14.5

the comment, this depiction or grounding may have been for the benefit of the health care providers or for the parents themselves. For example, 1 mother said: “I just play it over and over again that your son’s going to die, your son’s going to die.” This mantra established a frame of reference on which subsequent comments were built. The phrase “this is my child” was used repeatedly as a starting point for statements about a parent’s special interest, obligation, authority, or motivation to care for the child. Other heuristics were used to express how sense could be made out of a seemingly senseless

situation. These included “everything happens for a reason,” “everything works for the good,” and “God is in control.”

- To clarify, organize, and focus pertinent information and values: Explicit heuristics were used to create systems in which information could be filtered, labeled, organized, and evaluated. Some heuristics were used to help parents decide what to think about by setting the scope of attention (“take things day-by-day”), or to declare the presence or absence of a choice (“that’s not even a decision”). Other heuristics established values (such as comfort, happiness, quality of life) that were thought to be relevant to the decision-making process. Often, these heuristics were used to create conceptual, value-based scales by which several possible courses of action could be measured and compared. For example, commonly used phrases established a preference for “comfort” in relation to “pain and suffering” or “quality of days” in relation to “quantity of days.”
- To serve as a decision-making compass: Some heuristics were used to indicate a supreme value or a primary rule that all decisions should pursue. For example, 1 parent said: “We said that we wanted them to do everything they can to keep [our child] alive.” By indicating that maximal effort should be used to prolong life, this parent indicated that other values should be secondary. Other explicit heuristics were used to establish a supreme goal and appeared in the prototypical formulation “we just want _____,” as in: “we just want her to be comfortable.”
- To communicate with others about a complex topic: Parents must

communicate their child’s often-extensive health history and complex medical care, as well as the guiding principles of care, to others with speed and efficiency. One parent said, “Just trying to communicate everything that needed to be known about her to [the doctors] was impossible.” Parents used explicit heuristics as linguistic tools to distill complex thoughts and memories into short, exchangeable, and easily understood phrases. For example, 1 parent said, “There’s no answers. There’s never been answers. But he’s sick.” Another parent said, “We need to be able to relay to any doctor or any health care provider for [our child] that they have to think out of the box.” Parents also used the heuristic phrases mentioned above not only to talk themselves through a decision-making process but also to communicate to others their perspective about the child’s complex situation, to focus on key issues, and to provide a decision-making compass for the entire medical team to follow.

- To justify a choice: Parents often used an explicit heuristic to justify a course of action. This usage might be expected, given that explicit heuristics also were used to establish criteria and goals on which decisions should be based. Retrospectively attaching an explicit heuristic to a decision implied that the decision was justified by whatever value the explicit heuristic suggested. Parents illustrated the ways in which an explicit heuristic can be used to justify a choice with phrases such as “it was best for him,” “it’s not that we are giving up on her,” and “we’ve done everything in our power.”

TABLE 3 Predominant Explicit Heuristic Categories and 5 Primary Functions

Top 12 Categories ^a	5 Primary Functions ^b					
	N (%) of 69	Depict and Ground a Situation	Clarify and Focus	Decision-making Compass	Communicate About a Complex Topic	Justify a Choice
"I want my child to be comfortable."	29 (42.0)		✓	✓		✓
"I want my child to have quality of life."	27 (39.1)		✓	✓		✓
"I don't want my child to be in pain."	22 (31.9)		✓	✓		✓
"I want my child to have a normal life."	21 (30.4)		✓	✓		✓
"Everything happens for a reason."	20 (29.0)	✓			✓	
"I want the best for my child."	19 (27.5)			✓	✓	✓
"I don't want my child to suffer."	18 (26.1)		✓	✓		✓
"I want my child to have a longer life."	17 (24.6)		✓	✓		✓
"I have to be strong."	17 (24.6)	✓			✓	✓
"I have to fight."	15 (21.7)	✓		✓	✓	✓
"It's hard."	15 (21.7)	✓			✓	
"I want my child to be happy."	15 (21.7)		✓	✓		✓

^a As illustrated by a typical paradigmatic phrase.

^b A particular instance of an explicit heuristic may have a different primary function depending on the context in which it was used; the check marks indicate common functions for various categories of explicit heuristics.

DISCUSSION

Parents of children with life-threatening and life-shortening illnesses appear to use a wide variety of explicit heuristics. These explicit heuristics are used to address core decision-making tasks, including portraying the situation, detecting that a problem or dilemma exists, representing and framing the problem, deciding to engage or disengage the problem, conceiving of and evaluating possible courses of action, and choosing and committing to a course of action.¹ Our findings also support the notion that explicit heuristics ease the tasks of decision-making because they fit unfamiliar, complex, or novel information into familiar patterns of thought and language. By using common maxims and rules of thumb, parents can tackle the current challenges of decision-making by casting the daunting situation in terms and concepts that in the past have helped to make sense of other situations, solve problems, and communicate.

Importantly, several of the explicit heuristics that we identified are

analogous to implicit heuristics that have been described by psychologists. For instance, the explicit heuristics that in various ways either mobilize or manage emotions are akin to affective heuristics, in which people "base their judgments of an activity...not only on what they think about it but also on what they feel about it."¹⁵ Other explicit heuristics that emphasize the child's current dire clinical circumstance or a probable future outcome may be working with the anchoring-and-adjustment heuristic, which establishes a potentially new baseline that informs subsequent comparison of treatment options or judgments about what would be best¹² and are reframing the situation and the sense of what can be lost or gained.¹⁹ More generally, explicit heuristics appear to enable parents (in a manner similar to various implicit heuristics) to make decisions with greater efficiency than deliberative decision-making models, focused on risks and benefits, pros or cons, or maximizing expected utility.

Our data should be interpreted in the context of the strengths and limitations

of the study. On the 1 hand, the overall study's prospective cohort design scheduled the interviews so that they occurred when parents were in the midst of making medical and other decisions on behalf of their children, so that issues of recall bias were nullified. The interview transcripts were independently reviewed and coded by 2 members of the research team. On the other hand, our study was limited to English-speaking families who had already agreed to receive palliative care consults in a single children's hospital and who agreed to participate in the study regarding decision-making. These restrictions likely narrowed the range of explicit heuristics identified in this study. Additionally, because our semistructured interviews included specific questions about hopes, goals, and factors that influenced parents' decision-making, this study may have systematically elicited explicit heuristics related to these topics.

Even accounting for these limitations, we are intrigued by the ways in which explicit heuristics function as tools for communication and decision-making. Why do parents of children with life-threatening conditions use common phrases to communicate about a complex and difficult process? Why do some phrases become trusted rules of thumb? One potential answer is that all social interactions can be thought of (metaphorically) as role performances, in which individuals represent themselves as coherent characters to the others present through verbal and nonverbal cues.²⁰ These role performances are governed by what the individual perceives to be his or her "true" self, but also by the self that he or she desires to project to the audience and the self that he or she believes his audience expects or will accept.^{20,21} Role performances may be disrupted by external cues or

contradictory evidence beyond the individual's control; this disruption can result in shock, embarrassment, alienation, and confusion for the performer or the audience.^{20,22–24} Explicit heuristics can be thought of as terse elements of the scripts that parents use to manage a performance at home, in the emergency department, in the ICU, or during an interview. With a phrase, parents can cast themselves as fighters, believers, logicians, martyrs, or as difficult, pragmatic, or compassionate guardians, with all the behaviors and goals to match. This “role performance model” may explain why certain categories of explicit heuristics seemed to predominate: these phrases may be those that were learned, positively reinforced, or spared from elimination through multiple performances in various settings. Because there is an effort involved in changing roles^{20,25} and because there are negative consequences associated

with an unbelievable or inconsistent performance,^{22,23} the predominant explicit heuristics may be those that parents use to represent themselves in a coherent, consistent, adaptable, and acceptable way across the broadest range of scenarios.

Clinicians who care for children with life-threatening illnesses and their families can use our findings in 3 ways. First, clinicians may think of this study as a primer on explicit heuristics, their content, and the reasons for which they are used. We hope that this study will sensitize clinicians to listen carefully for the aphorisms, maxims, and mantras that parents use, and thereby enable clinicians to perceive more clearly the ways in which individual parents actually engage the process of making decisions. Second, clinicians may be able to partner more effectively with parents in a collaborative decision-making process by learning to discern

the goals and values that parents identify through explicit heuristics, exploring and clarifying these values, and weaving them into the decision process. Noting a particular explicit heuristic that a parent uses can serve as a stepping-stone to advance a conversation; for example: “I noticed you said you need to ‘keep fighting’; can you tell me more?” Third, clinicians can reflect on parents’ explicit heuristics to counsel parents in a manner that enhances their sense of self-efficacy to make effective decisions and maintain a coherent representation of themselves; for example: “You mentioned a minute ago that you need to stay strong, and I just wanted to say how strong you are being in taking care of your child.” Combined, the acts of noticing, inquiring, reflecting, and endorsing the explicit heuristics that parents use can provide forms of decision support that benefit them and their children.

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