The Rationality and Morality of Dying Children

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BY BARRY HOFFMASTER

There is more rationality in our lives than there is in our philosophy. There is more morality in our lives than there is in our philosophy. Those claims undoubtedly are startling, perhaps even incomprehensible, given that the Western philosophical tradition from Plato on is devoted to rationality, in morality and everywhere else. The narrowly circumscribed account of rationality in that philosophical tradition—formal reason—is, however, the source of both claims. The formal reason of philosophy is rule-governed reasoning, the kind of inferential reasoning used in logic and mathematics. This view percolates through ordinary understandings of rationality as well, exemplified by the familiar use of the expression, “That’s not logical,” to mean, “That’s not rational.”

Deducing theorems from axioms in logic or geometry is a paradigmatically rational activity, and this paradigm can easily be extended to other domains so that the application of moral principles or rules of law to the facts of cases likewise is a paradigmatically rational enterprise.

The applied ethics model of bioethics is grounded in formal reason, too, but, more importantly, the well-recognized failings of applied ethics—specifying the general terms in principles and resolving conflicts between principles—proceed from the narrowness of formal reason. Moreover, the philosophical assimilation of morality to a moral theory also is a correlative product of formal reason. The moral principles and rules applied to cases have to be rationally justified themselves, and formal reason pursues that rational justification by systematizing them into a theory. Inferential reasoning connects and organizes moral principles and rules into a

system, traditionally in the deductive, foundationalist model characteristic of Euclidean geometry and, more recently, in terms of their mutual, formal coherence or “fit.” Either way, the formality of both approaches creates the same difficulties. In sum, for formal reason, rationality is no more than inferential reasoning, and morality is no more than a rational moral theory. Therein lies the poverty of formal reason.

Formal reason hides the real nature and extent of the rationality and the morality in our lives because it denigrates, if not ignores, our experience and our creativity. Attending to both reveals the richness, the complexity, and the power of our rational intelligence and our morality. One wonderful example is the deliberation of women who are deciding whether to try to become pregnant after having received genetic counseling. By abandoning the constraints of formal reason, which would confine them to deducing least-risk and like decisions, these women ultimately achieve a more robust and critically insightful appraisal of themselves, their families, and their real options. Another wonderful example is found in Myra Bluebond-Langner’s work on how children with leukemia discover their diagnoses and how they orient their lives after they know they are dying. Children are, Bluebond-Langner studied used nonformal reason.

The findings of Bluebond-Langner’s study provide an exquisite foil to the abstract, constricted rationality and morality of philosophical theory.

In fact, Bluebond-Langner found that children acquired a vast amount of information, not only about the hospital, the people who work in it, and how it is run, but also about their disease, its treatment, its progression, and its prognosis. And she found their acquisition of all that information “even more remarkable because they learned in a situation in which the parents and the staff unconsciously conspired to keep them in painless ignorance” (p. 165). So how do these children “pick up quick”? They are eminently rational, but not in the manner formal reason prescribes or in a manner that formal reason can recognize or explain. Understanding their remarkable accomplishments requires an enhanced, broader conception of rationality.

Fortunately, such a conception of rationality—nonformal reason—has been developed by C.A. Hooker to vindicate the rationality of science, which also outstrips the resources of formal reason.

knew their prognosis. All knew that they were dying before death was imminent” (p. 165). Two mothers suspected as much, as an exchange between them reveals:

Mrs. Smith: It’s pretty hard to keep things from them, no matter how hard you try.

Mrs. Andrews: Have you told your son?

Mrs. Smith: He knows he has a blood disease, and, well, I don’t know. But they do pick up quick.

(p. 226)

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are real, practical illustrations of nonformal reason at work and of the social roles, practices, and institutions that comprise much of our morality. Understanding the import of her work is essential for philosophy and bioethics to engage effectively with our lives.

First, however, it will help to briefly consider why and how formal reason dominates, shapes, and ultimately vitiates the rationality of moral philosophy and bioethics, and how nonformal reason provides a more capacious alternative.

**Formal and Nonformal Reason**

Formal reason is deeply entrenched in Western philosophy and Western thought generally because it promises the certainty, objectivity, and universality that are taken to be the hallmarks of knowledge in any domain, whether it is logic, mathematics, science, or morality. In mathematics—long division, for example—there are universally correct answers. What is the source of this strong, right-answer objectivity and its correlative universality? As Harold Brown points out in his analysis of formal reason, which he calls “a classical model of rationality,” universality derives from necessity, and necessity derives from the application of rules:

> Rationality requires objectivity and universality, and only formal reason possesses the necessity that can produce objectivity and universality. In morality, conclusions about what ought to be done are rational because they are derived from the putatively “appropriate” and “universally applicable” principles and rules that comprise a moral theory. Given this philosophical background, it is no accident and no surprise that bioethics is widely taken to be “applied ethics.”

Two brief examples have to suffice to illustrate how thoroughly moral philosophy is embedded in formal reason. In *The Moral Point of View: A Rational Basis of Ethics*, Kurt Baier says that we determine “whether a given course of action is right or wrong by examining whether it has the weight of moral reasons behind or against it,” and we do that “by subsuming a given course of action under a given principle.” There is no more succinct, crisper, clearer statement of formal reason. In the first chapter of a textbook on professional ethics, the editor distinguishes morality from subjective matters of “mere taste” and “mere opinion” by affirming that “we can argue rationally about moral beliefs” and then explaining what “arguing rationally” means:

> Moral reasoning is a form of reasoning, that is, there is a structure of reasoning proper to moral decision making that takes the form of a logical argument. Particular moral judgments (e.g., “Beth should lie to protect her client” or “Beth would be wrong to lie to protect her client”) are derived as conclusions of moral arguments which include as their premises general moral principles and certain factual claims.

There is no more concise statement of the assumptions and approach of standard moral philosophy.

Deriving conclusions from moral principles or rules is simple in theory but rife with practical difficulties. In addition to the more obvious problems of the indeterminacy of general norms and conflicts between norms, there is the crucial but generally unrecognized problem of ascertaining the relevance of norms to particular situations. To adopt Baier’s language, how do we determine what Baier himself takes to be given—how do we decide whether a “given principle” is relevant to a “given course of action,” and indeed, how do we determine what the relevant description of a “given course of action” is? Answers to these crucial questions about establishing relevance, removing indeterminacy, and settling conflicts can be rational for formal reason only if they are derived from rules. But appealing to further rules at this point simply introduces a vicious regress. Thus, this essential work is best understood as occurring before and beyond that logical maneuver, but doing so vitiates the rationality imparted by formal reason. For formal reason, everything that precedes and structures the subsumption of “certain factual claims” under “general moral principles”—everything that goes into establishing the givens of the subsumption—must be nonrational because it is not rule-governed. The triumphal application of a “given principle” to a “given course of action” is in fact just the last step in a preceding complex process of analysis, deliberation, critical assessment, and judgment that is not rule-governed, and that last step cannot, in itself, be rationally redemptive.

That decidedly unpalatable conclusion—that much of morality is arbitrary or subjective—follows, however, only if rationality is reduced to and equated with formal reason. To constrain rationality to the application of rules is a mistake, one that Richard Wasserstrom, writing in the context of judicial decision-making, aptly labels “the irrationalist fallacy”:

> It is recognized quite correctly that the canons of formal logic have a decidedly limited applicability [in judicial decision-making]. It is inferred quite incorrectly from...
this that all the questions which cannot be settled by appealing to formal logic cannot be settled in any manner which could be called “reasonable” or “logical.” An appeal to formal logic is equated with an appeal to criteria of rationality or reasonableness, and it is concluded that because the courts cannot have used formal logic to select or formulate legal premises, the courts cannot have appealed to any rational or objective criteria when engaged in these undertakings. . . . It may not make much sense to describe the judicial decision process as a completely deductive one. But it makes even less sense to insist that for this reason courts could not (and should not) employ a procedure or a set of procedures that permits of some kind of reasoned justification for the judicial decisions reached by those courts.9

The irrationalist fallacy likewise is a fallacy in morality, and the challenge it raises—to account for the rationality of undertakings that do not involve the application of rules—is precisely the challenge that nonformal reason addresses. As a corrective to the mistake he identifies, Wasserman insightfully proposes a broader procedural basis for rationality, and as we will see, nonformal reason adopts that approach.

Bioethics as applied ethics displays all the problems with formal reason and thus suffers from the irrationality that ensues. Applied ethics flounders in dealing with real moral problems because it brings only a small set of free-floating, abstract principles—in bioethics, for instance, "do no harm" and "respect autonomy"—to sketchily characterized cases. It assumes that problems can be adequately constructed and well formed in its terms; that the relevant principles can be readily identified; that the applicable principles are sufficiently determinate and robust to be helpful; and that inevitable conflicts between principles can be plausibly resolved in a manner consistent with their role in deducing correct decisions for moral problems. Yet the principal challenges for analyzing and working through real moral problems are precisely to do those things: to bring structure and meaning to messy, amorphous, complex, and dynamic real situations, and to find creative means of proceeding when it seems clear that one, or more, or all of the relevant considerations must be compromised. Applied ethics lacks the critical resources required to meet those challenges: the powerful principles needed to frame problems properly and productively and to establish the relevance of substantive principles to those problems, the ancillary bridging principles needed to engage the general concepts of its substantive principles with the specifics of particular problems, and the often creative higher-order principles needed to settle conflicts between its substantive principles. The real work of moral decision-making must be done before and beyond the application of norms, yet that essential work cannot be rational when rationality is identified with the application of norms. The paradoxical upshot of assimilating rationality to formal reason is not to establish but to disestablish the rationality of a domain—in this case, bioethics—and that outcome is well appreciated and vigorously exploited by proponents of more extreme versions of postmodern and critical theory.

The recognized weaknesses of applied bioethics have prompted two responses, neither of which escapes the pitfalls of formal reason. One is the philosophical salvage operation of constructing a moral theory. The best example is Henry Richardson's theory of specification for resolving conflicts between norms.10 Richardson regards specification as a third way between the deductive application of norms, which is rational and objective but too hard, if not impossible, and the intuitive balancing of norms, which is easy but subjective and arbitrary. He is tempted by Aristotle's "prolean account of practical wisdom" and judgment but rejects it because "although judgment is essential, no theory of practical judgment is possible."11 Instead, he proposes a coheralistic approach to theory construction that "in effect carries the Rawlsian idea of 'wide reflective equi-

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considerations enable us to decide is that the one or the other must be chosen, they do not enable us to decide, definitively, which one. But then if we cannot decide between (A) and (B) by appeal to coherence, how can we rationally decide between them? Unless we are given a satisfactory answer to this question by proponents of reflective equilibrium methodology, and so far we have not been given a satisfactory answer, we shall, I think, be able to decide between (A) and (B) only arbitrarily, or else irrationally by appeal to prejudices, intuitions, or revelations.14

The irrationalist fallacy of formal reason frames both Richardson’s dichotomous construction of the problem—deductive application or irrational—and Haslett’s dichotomous criticism of his solution—definitive answer or irrational. The only real solution is the Aristotelian one Richardson disclaims. Judgment is beyond the purview of formal reason, yet judgment is essential and ineliminable. Nonformal reason is a theory about the rationality of judgment.

The second response imports methods such as casuistry and narratives into bioethics, but although these methodological enhancements provide helpful ways of improving our reasoning and our understanding of issues, they cannot escape the irrationalist fallacy because they, too, require judgment. Casuistry is argument by analogy, and determining what case to select as the paradigm from which to begin, what similarities between cases are relevant, what dissimilarities are relevant, whether the similarities or the dissimilarities are stronger, and how compelling the overall argument is all require judgment. With narratives, determining what stories to tell and not to tell, how to tell a story, how to interpret a story, and how to choose between warring stories all require judgment. What Tom Tomlinson finds “untenable” about narratives is “the idea that narrative provides a mode of ethical justification that is independent from or superior to appeals to moral principles”; the problem, as he sees it, is that “neither interpretation nor narrative coherence offers the tools needed for choosing from among all the interpretive and narrative possibilities.”15 Tomlinson’s apt criticism proceeds from formal reason but ignores formal reason’s own inability to provide the kind of ethical justification he seeks. Again, the alternative is to recognize the inevitability of judgment and to establish the rationality of judgment by developing a more commodious conception of rationality that, as Wasserstrom suggests, is procedurally oriented. Nonformal reason is that alternative.

Whereas formal reason confines rationality to rule-governed inferential procedures, nonformal reason takes a more comprehensive, systemic approach that locates rationality in the manifold processes from which judgments emanate and the institutional structures and contexts within which those processes operate. That fundamental shift is, in part, a response to the rampant idealization that suffuses formal reason and is so debilitating in practice. Formal reason strongly idealizes agents and the circumstances in which they make decisions by, for instance, projecting human beings to have limitless cognitive capacities and memories, to possess complete knowledge, to be thoroughly impartial and unbiased, and to be free of time constraints. Perhaps the most blatant example of this unbridled rationality is economic man, the homo economicus, who has been described, tongue-in-cheek, as being able to “think like Albert Einstein, store as much memory as IBM’s Big Blue, and exercise the willpower of Mahatma Gandhi.”16

Formal reason also strongly idealizes the deductivist standard of justification and correctness, for example, by requiring global consistency and deductive completeness in a system of logic and a moral theory. Yet real human beings have limited, fallible intellectual capacities and memories and limited knowledge and time, among their many other constraints.17 An appreciation of the actual nature of human beings and the circumstances in which they deliberate and decide leads to an understanding of reason as the capacity in virtue of which human beings, with their finite, fallible resources and abilities, nevertheless transcend their imperfections through a process that improves their judgments. This approach includes, reflexively, the capacity of reason to improve itself in concert with the development of our understanding and practical control of our world.18

Given the finitude and fallibility of human beings and the dynamic complexity of the world, the outcomes of the decision-making processes that human beings design and employ will be fallible and contextual. Contextuality entails a kind of relativity, of course—a relativity to context. But this kind of relativity yields only sensitive variety, not relativism—not arbitrariness and subjectivism—because outcomes are rational if they emanate from rational processes. Nonformal reason takes rationality to be a capacity, operating at both individual and collective levels, for initiating processes that replace ignorance with trustworthy information, reactivity and carelessness with systematic judgment, and prejudice and partiality with broad and insightful critical appraisal, and for reflexively applying these processes to the rational evaluation processes themselves. Formal reason has a useful role to play in these processes, but only as one resource among others.

The fallible, improvable, learnable tools utilized in the processes of nonformal reason are observation, constrained but creative construction, systematic critical appraisal, and both formal and informal reasoning procedures. Observation is concerned with obtaining reliable information about sensorily accessible features of the world relevant to moral decision-making (for example, a person’s experience of pain, emotional distress, and memory loss). Creative
Much of what the children learned about their situations and their surroundings came from careful, intense observation.

The Rational Knowledge of Dying Children

The children whom Bluebond-Langner studied were able to “pick up quick” not just because they were, like most children, curious and savvy, but also because they were, like most children, intelligent and rational. That explanation, of course, needs to be sustained by an account of rationality that, unlike formal reason, does not equate rationality with the application of rules. The rationality of these children resides not in what they learned but how they learned—that is, in the processes they devised and used to discover their diagnoses and prognoses. The four tools of nonformal reason are used by individuals and communal groupings of various kinds (ethics committees, research agencies, learned societies, collaborative and discussion groups, and public fora) to improve both the judgments made and the processes by which judgments are made, which in turn further improve the judgments themselves.

This sketch of nonformal reason is, of course, unsatisfyingly superficial and vague. The best way to understand nonformal reason, however, is through practical examples. The dying children whom Myra Bluebond-Langner studied were abundantly rational in the ways they went about discovering their diagnoses and prognoses. The remainder of the paper will explore how these children used the tools of nonformal reason to understand their clinical position and its implications and then describe how these children and their parents dealt morally with this knowledge and how nonformal reason, together with the human spirit, also can account for the rationality of that behavior.
it. The children's acute observation of course operated more widely. By watching the behavior of residents, interns, and medical students in the evening, for instance, the children were able to identify, with remarkable accuracy, romances between staff members (pp. 151-52). And they inferred the likely functions of rooms in the hospital from observations of the equipment in the rooms (p. 136).

The children displayed an uncanny perspicacity. They knew what to watch, how to sift from everything they watched the features of the world that were relevant to them, and, as we will see, how to critically assess their experiences and use them to refine and focus their subsequent observation. From the information they obtained from their persistent, dedicated watching, they created classifications and posited generalizations that they then used reasoning methods to test.

**Formal and informal reasoning methods.** The children employed familiar reasoning methods to understand their surroundings, what was happening to them, and what was likely to happen to them. To begin to comprehend who they were, they quickly differentiated themselves from children with other diseases:

All the children could distinguish between leukemic and nonleukemic patients. “They [the leukemic patients] come to Monday clinic.” “We [leukemic patients] all have the same blood disease. You know Greta, she comes [to the hospital] all the time. Well, she has a blood disease [sickle cell disease] too, but she goes to another clinic.” (p. 155)

Reasoning methods enabled them to explore, develop, and test the significance of their observations. They used induction and analogies to draw inferences from their observations; for example, a boy’s loss of hair indicated that he was on the drug vincristine because other boys had lost their hair after being put on vincristine (p. 103). Their reasoning often relied on assessments of other people’s behavior: “Alan . . . knew that things were not going well when, in spite of how good he felt, his mother would cry. ‘In my house, crying and bad things go together’” (p. 180). Similarly, they made comparisons with other people’s past behavior to get a sense of the seriousness of their illness:

The children put people’s behavior together with the tests and treatments they were receiving and concluded that they were really sick, “seriously ill,” “very, very sick.” “This is not like when I had my tonsils out”; or even “when I cut my head open.” “This” was somehow worse, as were they. (p. 173)

The children appreciated that arguments by analogy have two sides: the relevant similarities between the items being compared that support the analogy and the relevant dissimilarities between the items being compared that challenge the analogy. When a death occurred or was imminent, the children were concerned with establishing the cause of the death. Having done that, they compared the deceased to themselves. Children who only recently had discovered their prognosis emphasized their dissimilarities to the deceased.

But children who had known their prognosis for some time realized that their similarities to the deceased were more compelling (p. 189). In short, they had learned how to improve their informal reasoning.

At times the children used the deduction that typifies formal reason:

Only children who are dying do not have to go to school anymore.

All other children must go to school.

I do not have to go to school anymore.

Therefore, I am dying. (p. 190)

Deduction, as we will see in the section on systematic critical assessment, also is the logical basis of the hypothesis-testing the children did to evaluate the correctness of their inferences.

**Creative construction.** The creative construction of these children often took typically childish forms. They would congregate in places where they could talk privately, and they would devise strategies for eavesdropping on conversations. Older girls, for example, met in the women’s bathroom on the “adult” side of the clinic’s waiting room to talk about the disease, drugs, and what was happening to other children. When adults entered, they became silent and often dispersed. Aware of what was going on, boys gathered near the bathroom door, clutching a toy (p. 144). Because the children knew that information exchanged between adults was more valuable and more reliable than information adults conveyed to them, they surreptitiously sought that precious information. They would try to delay separations from their parents in the clinic’s waiting room so that they had more opportunities to overhear adult conversations; they would hide behind office doors; they would pretend to be asleep; they would turn down the volume on the TV; and they would ask people to be quiet when doctors assembled by the door of their room to talk to their parents. Sometimes they were more daring: one child planted a tape recorder in the doctors’ office, which served as a conference room.

But one of Bluebond-Langner’s central findings—that the children proceeded through a series of stages of awareness in learning about their diagnosis and prognosis—shows a more sophisticated use of creative construction. The children went through five stages in acquiring information: “it” is a serious illness; names of drugs and side effects; purposes of treatments and procedures; disease as a series of relapses and remissions (minus death); and disease as a series of relapses and remissions (plus death) (p. 166). At each stage the children
had to formulate a new definition or self-concept of themselves: as someone who is seriously ill, seriously ill but will get better, always ill but will get better, always ill and never will get better, and dying (terminally ill) (p. 169). To move from one stage to the next, the children had to have both information and experience. When new information was forthcoming, their existing information had to be sufficient to enable them to recognize its relevance and incorporate it into a set of premises from which they could reason to a conclusion:

Without the requisite information, the children could not integrate new information to come to a new conclusion. For example, if a child knew the names of all the drugs and their side effects, as well as the purposes of various treatments and procedures (stage 3), but did not know the disease was chronic (stage 4), the news of another’s death did not lead the child to conclude that the disease had a terminal prognosis. (p. 168)

Experience both yielded new information and linked information:

First, the children needed the disease experiences (e.g., nosebleeds, relapses, bone pain) to gather significant disease-related information. At any sign of illness, the children were taken to the clinic, where they could again meet their peers and discuss what was happening to them. Second, the disease experience enabled them to assimilate this information by relating what they saw and heard to their own experience. (p. 168)

Bluebond-Langner found that children could remain at one stage for an extended time and that “age and intellectual ability were not related to the speed or completeness with which the children passed through the stages” (p. 169). Some younger children with average intelligence knew more about their prognosis than some very intelligent, significantly older children who were still in their first remission and had made fewer clinic visits. The older children knew only that they had a serious illness. They needed more experience to proceed through the subsequent stages and realize that they were going to die (p. 169).

Creative construction is a third crucial component of this process because it gives the children the capacity to use their information and their experience to construct and evaluate new conceptions of themselves. Formal and informal reasoning methods enable them to abstract from the information they have acquired through observation, personal experience, and conversations. Then systematic critical assessment allows them to test and revise the self-concepts they create until those self-concepts match the information they possess and explain the experiences they have had.

Systematic critical assessment. The children conducted systematic critical assessment in two important, familiar ways: to assess the credibility of evidence and to test inferences drawn from that evidence. With respect to evidence, the children astutely realized that information is reliable only if it comes from trustworthy sources. So they tested people who served as their sources, including Bluebond-Langner:

Benjamin asked everyone he saw that day what happened to Maria [who had just died]. Later, when I asked him why he asked everyone, he said, “The ones who tell me are my friends. I knew Maria died. I saw the cart come for her. They told everyone to go in their rooms. I wanted to see if you were really my friend.” (p. 188, n. 27)

Their critical scrutiny included, not surprisingly, the hospital staff:

The staff’s refusal to answer questions directly, and parries such as, “Well, we’ll see” or “I don’t know,” eroded their credibility. “I asked three times when I could go home and they said, ‘I don’t know.’ They saw the tests. They told me that’s why [to see when I could go] I had to have them.” If the staff did not know, who would? In the chil-

Bluebond-Langner’s finding—that the children proceeded through stages of awareness in learning about their diagnosis and prognosis—shows a sophisticated use of creative construction.
observations and conversations and the self-concepts they developed at each stage by employing a rudimentary form of scientific hypothesis testing. Bluebond-Langner describes a prevalent practice:

The children tried out their newly acquired self-concept on everyone they saw. Children . . . would often exclaim, “I’m really pretty sick, you know,” and then offer as evidence the changes in people’s behavior towards them or the physical changes in themselves, especially the “wounds” suffered from procedures. . . . The children would begin by counting their needle pricks and pointing to them. (p. 173)

At stage 1, Bluebond-Langner reports, children used this strategy to begin every encounter, and it continued to be used in the succeeding four stages, albeit less frequently. The repetition at stage 1 probably was important because the children were testing a very different—and undoubtedly frightening—conception of themselves. The outcome of the testing was that “The children found confirmed in people’s reaction to their pronouncement the fact that they differed from other children” (p. 174).

The same testing procedure was used to resolve other uncertainties. When a child died or was close to dying, for example, “the children attempted to establish the cause of death either by asking a question or stating a hypothesis and assessing the other party’s reaction” (p. 189). In stage 3, after the first relapse made it clear that the disease was chronic, the children were, as Bluebond-Langner puts it, “left more and more to their own devices” (p. 181). They had to obtain the information they wanted from other children, and to do so, “They formulated hypotheses about the relationship between various symptoms and the drugs, procedures, or treatments employed, and checked them out with peers” (p. 181).

The testing procedure the children used is a version of orthodox scientific method: formulate a hypothesis, develop predictions from the hypothesis, and test the predictions to see whether they are confirmed or refuted. It is a drastically simplified and much less reliable version, but nevertheless an instance of a core strategy for generating knowledge in any natural realm.

The children’s testing of self-concepts introduces another informal reasoning method: fit or coherence. The progressive growth of knowledge and unfolding of the stages imposed constraints on how the children could respond to new information and experiences:

Once children reached stage 4 . . . they had fitted all of their acquired information into a pattern of relapses and remissions, of never getting well. And just as all other events could be fitted into the scheme, so too could the death of another child. It could not be seen in isolation, but was part of the same chain of events that they were. They realized that they shared with peers not only the same experiences, but also the same prognosis. (p. 184)

As they acquired more information, the children had to make judgments about how well that new information fit or cohered with their current overall understanding of their situation. When that new information was hard to reconcile with their prevailing understanding or exposed tensions or inconsistencies in that understanding, they had to make further judgments about how to create a new understanding that could accommodate it.

The criterion of fit also operated more specifically. A child’s first relapse was profoundly distressing because the preceding months of remission had lured the family into thinking they could lead “normal” lives. With a relapse, the old symptoms were back, and the same medical procedures were being performed. Jarred from their comforting respite, the family had to drastically revise their feelings and their understanding of the situation. In particular, the child had to create a new self-concept that fit the new evidence. People’s reactions were the same as they had been at the time of the initial diagnosis, except that now they were crying more and telling less. In addition, the child no longer was getting the drugs for headache and bone pain that had been prescribed during the remission.

As the children used the four tools of nonformal reason, their knowledge improved, and their capacity to use the tools to acquire knowledge improved. With respect to improving knowledge, for example, when the children immediately began to orient themselves as they stepped off the elevator on their first hospital visit, they quickly made a crude distinction between “us” and “them.” “Them” were those in uniform, and “us” were those not in uniform (p. 171). “Us” were the patients and families who took orders and spoke only when spoken to. “Them” came and went as they pleased and inflicted pain or delivered news that caused pain. Initially, the children were not aware of the criteria they used to make these distinctions. They recognized a multiplicity of differences, however, not just the obvious one between doctors and nurses, and they realized that the distinctions were not based solely on uniform. Over time they progressively refined the distinctions to develop an accurate understanding of the hospital staff and their functions.

With respect to their methods, the children were able to critically assess their observational and reasoning skills, adapt them to new circum-
The children appreciated how much they relied on observation and testing for information, and as they recognized changes in how people behaved toward them through the progression of their illness, they realized that their observational and testing strategies needed to be adapted and enhanced. In short, experience with the tools of nonformal reason, combined with application of the tools to the use of the tools, improves the tools, which is how nonformal reason reflexively improves itself.

This survey of how the children used the four tools highlights three important features of nonformal reason. First, the tools of nonformal reason do not function singly and independently; rather, they operate jointly, reciprocally, and reflexively, in ways that can improve their collective use. Second, the operation of nonformal reason is thoroughly grounded in experience. Watching others and reflecting on one’s own experiences are essential to acquiring and testing information and to the creative construction of self-concepts. Third, the operation of nonformal reason is robustly social. Talking, acting out together, and generally interacting and collaborating with others provide the children with crucial information, not just for judgments about themselves and their peers in various stages of the disease process, but also for testing information and improving their methods of observation, creative construction, and systematic critical assessment.

The magnitude of what these children do should not be underestimated. They suddenly found themselves in strange and frightening new circumstances, indeed in circumstances so unprecedentedly different that they had to radically rethink and reorder their environment, their place in that environment, and ultimately themselves. They could not rely on any of their old assumptions or rules, or any of their old methods; everything had to be relearned. They managed to do all that. How? Their challenge strongly paralleled that of scientists entering novel research environments, such as quantum mechanical or ape language learning environments, where any measurement can make a profound difference (though, it seems, for very different reasons). In such new envi-

They could not rely on any of their old assumptions or rules, or any of their old methods; everything had to be relearned.

environments, and hone them as experience and necessity dictated:

Astute observers, as time went on the children became more astute, more capable of drawing conclusions from people’s behavior. They knew the indices for various types of behavior and what they meant. These skills were sharpened as people began telling them less, acting out more, and slipping with greater regularity. (p. 173)

The children appreciated how much they relied on observation and testing for information, and as they recognized changes in how people behaved toward them through the progression of their illness, they realized that their observational and testing strategies needed to be adapted and enhanced. In short, experience with the tools of nonformal reason, combined with application of the tools to the use of the tools, improves the tools, which is how nonformal reason reflexively improves itself.

This survey of how the children used the four tools highlights three important features of nonformal reason. First, the tools of nonformal reason do not function singly and independently; rather, they operate jointly, reciprocally, and reflexively, in ways that can improve their collective use. Second, the operation of nonformal reason is thoroughly grounded in experience. Watching others and reflecting on one’s own experiences are essential to acquiring and testing information and to the creative construction of self-concepts. Third, the operation of nonformal reason is robustly social. Talking, acting out together, and generally interacting and collaborating with others provide the children with crucial information, not just for judgments about themselves and their peers in various stages of the disease process, but also for testing information and improving their methods of observation, creative construction, and systematic critical assessment.

The Rational Morality of Dying Children

Realizing that children with leukemia know they are dying and understanding how they know they are dying might seem to remove any residual moral responsibility to tell them that they are dying. Yet it could be argued that the children should be told, both to confirm what they know and to give them an opportunity to talk about death. That position is theoretically attractive, but the lived morality of these dying children defies its abstract appeal. Bluebond-Langner observed the children’s “consistent impenetrable silence in the face of ultimate separation and loss” and sought an explanation of this perplexing phenomenon (p. 198). The children are not silent because talking about death is taboo. Moreover, unlike adults who initially conceal a terminal illness but subsequently disclose that they are dying, the children’s silence is resolute. Why is secrecy so vital to them?

The practice of mutual pretense, which exists when each party knows the patient is dying but acts as if the patient were going to live, allows the
“I thought you would understand. You once told me you wanted to be a doctor.” He screamed back, “I’m not going to be anything,” as he threw an empty syringe at her. She said, “OK, OK,” but a nurse present asked, “What are you going to be?” “A ghost,” he replied, and turned over. (p. 194; emphasis in original)

Yet practicing mutual pretense is difficult for all parties and sometimes requires quick thinking:

When a seven-year-old boy’s Christmas presents arrived three weeks early and Santa came to visit him, suggesting that the boy would not live to Christmas, he turned to his choked-up family and the staff members around his bed, saying, “Santa has lots of children to see, he just came here first.” (p. 204)

What makes the extraordinary vigilance and effort that mutual pretense demands of everybody worth it?

In a society and a culture so thoroughly oriented to the future and so doggedly devoted to achievement, the prospect of death, in addition to the inherent fear and uncertainty it instills, erases a child’s identity and concomitant sense of worth. These children appreciate the hopes and expectations their parents harbor for them, and they know they never will fulfill those hopes and expectations. Adults go to work; children go to school. They no longer go to school or even do schoolwork. They will have no future achievements because they have no future. Childhood is about becoming, but there is nothing they will become. Those portentous losses give the children powerful motivation to hold on to as much as they can. Mutual pretense sustains their status as children so they still can be valued as children.

Because the roles of children and parents are symbiotic, mutual pretense likewise sustains the status of their parents so they still can be valued as parents. The loss of authority and control over their children, not just in the hospital but in general, is threatening and debilitating to parents. They feel ignorant: “Many parents thought that they did not know very much, too little to answer their own questions, not to mention the children’s” (p. 215). They feel overwhelmed and helpless: “The parents saw themselves as powerless before the disease, the doctors, the machines used for treatment, and, most important, their children. They felt that they could not care for their children on a day-to-day basis, let alone in the future” (p. 215). They lose some of the joys and pleasures of being parents. Mothers could not cuddle their children because being hugged or touched was painful (p. 215). Most importantly, the parents of dying children lose the three tasks that define parenthood: nurturing, protecting, and rearing (p. 229). By preserving the established social framework, mutual pretense retains order in a world roiled and disordered by disease and thereby affirms the identity and worth of the children and their parents. As Bluebond-Langner emphasizes, “the social order is a moral order” (p. 230).

The children’s pretense is indeed deeply caring, loving, and altruistic. Bluebond-Langner comments, “Ironically, these children came to see their own task in life as supporting others” (p. 232). An exchange with one child provides an unsurprisingly childish illustration:

**Myra:** Jeffrey, why do you always yell at your mother?

**Jeffrey:** Then she won’t miss me when I’m gone. (p. 126)

The children’s gift to their parents was, however, also the greatest gift they could give to themselves. The children realized that sustaining the hopes of adults secured their continued presence, which meant that they would not be left alone (pp. 228-29). Mutual pretense was a way of satisfying the deep human need to belong; everyone could retain their identity and membership in society, except those who did not practice mutual pretense; they were ostracized and abandoned. To put it another way, as long as individuals fulfill their obligations and responsibilities and do not violate the social order, they are granted continued membership in the society and all that comes with it—freedom from fear and abandonment. No one seemed to know this better than the terminally ill children; for they practiced mutual pretense unto death. (p. 232)

The basic roles, structures, and institutions of society are designed to meet that fundamental need, but at the price of fulfilling the accompanying social responsibilities. In this regard, the loving, caring altruism of the dying children was supplemented and supported by an exquisite appreciation of their vulnerability. For greater than the fear of dying is the fear of dying alone, without comfort, without solace, and without love. The children did not want to be abandoned when they most needed to belong. Arriving at a moral practice that is practically accessible in the circumstances yet meets the deepest needs of everyone involved is a model of constructive, creative ethical rationality at work; moreover, one that holds its own among the adult achievements of civilized culture and society that support thriving personal lives.

How, then, does the practice of mutual pretense emerge and, given the strenuous demands it imposes on all parties, persist? Conditions propitious to mutual pretense existed from the moment the children entered the hospital. The staff strove to withhold information from patients, to prevent leaks, and to cover up leaks. They also displayed an unwillingness to answer the children’s questions by leaving the room, reprimanding the children, and ignoring their questions (pp. 200-1). Parents were reluctant to volunteer information, explained little, and displayed their unwillingness...
to communicate through lengthy absences from the room, brief interactions with their children, and avoiding conversations about disease-related topics (p. 201). The children observed this behavior and used informal reasoning techniques such as argument by analogy and induction to recognize the significance of the behavior, to construct patterns, and to infer the implications for their behavior. Just as they would have countless times before in their family setting and in the hospital, they recognized and interpreted the nonverbal signals now being sent to them—that adults were not willing to acknowledge their reality and were withdrawing from them—and they responded to those signals by fitting themselves into the changed family and hospital milieux. As Bluebond-Langner notes, “When they realized they were dying and that people were no more willing to talk about their condition than they had ever been, the children started to practice mutual pretense” (p. 210). Engaging in mutual pretense was a straightforward extrapolation from and continuation of their experience with their parents and the hospital staff.

If the process by which children arrive at pretense explains only its general character as an intelligent adaptation, the process of continuing pretense reveals more. Pretense is not a simple single action (“deny I’m dying”) that is repeated. Rather, pretense is a whole complex, contextual, reciprocal pattern of relating that is needed to express denial and that must be continually assessed and re-constructed as circumstances change. How the children managed to maintain that pattern again displays their use of nonformal reason. The practice of mutual pretense involves following guidelines, for example, to avoid dangerous topics, to keep interactions brief, and to ignore breakdowns, and the children devised tactics accordingly. Children who had never cried about painful procedures began to refuse the procedures by crying in the way “normal” children do instead of protesting, “Well, I’m dying anyway,” or “It won’t do any good” (p. 204). A boy and staff member talked about past Christmas plans as if they were for an upcoming Christmas even though he was unlikely to celebrate it (p. 202). As did their parents, children adopted a “distancing” strategy to avoid or limit interactions with others. But because they were confined to their beds, the children could not stay out of a room or make excuses to leave, so they had to refuse to talk, pretend to be asleep, lash out or cry out continually, or speak inaudibly or superficially (pp. 206-7). Whereas the children formerly employed tactics for cultivating relationships, they now adopted tactics that would weaken and destroy relation-

**They recognized that adults were not willing to acknowledge their reality and were withdrawing from them, and they responded by fitting themselves into the changed milieux.**

ships to reduce the number of people with whom they arduously had to sustain the illusion that they were not dying.

Preserving mutual pretense is, as Bluebond-Langner describes it, a “delicately balanced drama” (p. 208). Preserving that precarious balance requires constant attentiveness and perceptiveness and the ability to make specific contextual judgments about competing demands. The children must be disciplined yet accommodating, committed yet flexible, strong yet sensitive, self-interested yet altruistic. Making good judgments involves the four tools of nonformal reason: scrupulous observation of their surroundings and the demeanor and reactions of others, as well as their own demeanor and reactions; sound inferences about what has happened in the past and why it happened, what is likely to happen now and what would be effective means to desired ends; creative responses to breakdowns and ways of preventing breakdowns; and unrelenting comprehensive critical assessment of particular aspects of the practice (asking themselves, for example, Why did I slip up there, and how can I avoid doing that again?) and the practice as a whole (Are people going along with me, or are they questioning and challenging me more?).

The success of the children—that “they practiced mutual pretense unto death”—testifies to their perspicacity. The children certainly were “willful” and “purposeful,” and their use of nonformal reason enabled them not only to act in the world created for them but to create their own world—
impending death of a child? That is a formal-reason question, particularly when asked without regard to the experiences of those involved in the practice and the diverse contexts within which the practice operates. Can the practice of mutual pretense be improved? Is there a better way to respond to the impending death of a child, perhaps a hybrid that preserves the identity-forming, worth-creating roles of dying children and their parents yet allows the children to talk about dying? Those are the questions of nonformal reason, which always is critically attuned and searching for improvement. If there is a better way, it will not come from an abstract moral principle or moral theory. It will come from experience honed by careful observation and systematic critical assessment of, and reasoning about mutual pretense, complemented with creative construction of novel alternatives. And ascertaining its superiority will be a matter of judgment. Above all, though, it will respect what the real rationality and morality of these children teach us.

The dying children with whom Bluebond-Langner worked were richly rational and heroically moral. They were understandably eager and determined to find out what was wrong with them, and they used the tools of nonformal reason to acquire the knowledge they sought. They had an impressively mature and sophisticated appreciation of the impact of their illness on their parents, and they used the tools of nonformal reason to find a way of preserving the identity, dignity, and worth of their parents and themselves. They displayed seemingly preternatural moral acumen, sensitivity, and fortitude in maintaining, in the direst of personal circumstances, the silence of protection. They knew that the process of dying is for the living, and they knew how to guard the living.

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References

3. References to Bluebond-Langner’s study are given in the text.
6. Ibid., 19.
11. Ibid., 290.
12. Ibid., 300.
13. Ibid.
18. The accounts of formal and nonformal reason in this and the next two paragraphs are adapted from Hooker, “Rationality as Effective Organisation of Interaction” and Reason, Regulation, and Realism.
19. A detailed account and defense of nonformal reason in moral life is provided in C.A. Hooker and C.B. Hoffmaster, Re-Reasoning Ethics (unpublished manuscript). For the philosophical basis of the account of rationality utilized there, see Hooker, “Rationality as Effective Organisation of Interaction” and Reason, Regulation, and Realism.
20. Bluebond-Langner was tested in other ways: “It . . . became apparent . . . that the children asked me to watch TV to test the relationship. As one eight-year-old boy said to me after I watched TV for one solid hour without a word, ‘All right. You’re OK. What do you want to know?’” (p. 247).
22. In this regard, nonformal reason provides direction for critically examining the research on truth-telling to dying children that has appeared since Bluebond-Langner’s study was published in 1978 and for designing future research.
23. Bluebond-Langner explains: “The funeral is for the living, and so is the dying. The way we are permitted to die, and the way that we permit others to die, is to enable the living to continue the process of their lives. The dying have to be fitted into this scheme of the living, there is no separate way for them” (p. 233).

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