Deception and the Death of Ilyusha: Truth and the Best Interest of a Dying Child in The Brothers Karamazov

abstract

For centuries, many physicians and parents assumed that it was ethically justifiable to lie to a dying child. The reasoning was clear: Because the lie would likely eliminate or prevent a concrete harm (the child’s fear), and the lie is about a harm that is unavoidable anyway, a lie appeared to be the morally desirable thing to do. Today, the ethical consensus has shifted. Many doctors and other health professionals now argue that we have an obligation to tell children the cold, hard truth. In this article, I argue that “the cold, hard truth” (assuming we can know it with certainty) might not always be in the best interest of the patient. To illustrate the point, I analyze an episode in Dostoevsky’s novel, The Brothers Karamazov, in which a child is dying, his father lies to him about it, and 2 doctors take very different approaches to the truth. Each of these individuals has a particular interest when it comes to the question of “the truth” about the death of Ilyusha. I use this story to ask whether it is ethically permissible to lie to a dying child and, if so, who has the moral authority to tell that lie. Pediatrics 2014;134:S87–S96
Deception and self-deception interestingly complicate the question of “best-interest.” On first glance, it might seem that maximum objectivity, the cold, hard truth, is the ideal perspective from which to evaluate the best interest of any patient, and especially perhaps the interests of a child, when the confusing, distorting lenses of strong emotions make it difficult for others to see it clearly. When a child is dying (the case we will focus on here) both parents and other family members can become particularly shortsighted. But it might not be the case that physicians are the best sources of objectivity. And “the cold, hard truth” (assuming we can know it with certainty) might not be in the best interest of the patient. Finally, deception and self-deception, particularly powerful forces when we are dealing with the death of children, further complicate our ability to know and tell the truth. Is a lie ever in the best interest of a sick or dying child? If so, who has the moral authority to tell that lie? It not, who has the moral authority to insist on the truth? Might we sometimes tell a lie while believing that it is the truth? Should we correct a child’s false belief when it is expressed for her own wellbeing? Should we reinforce it, thus lying to the child, or encouraging self-deception? And, finally, are there practical constraints that might impact the way we handle truthfulness in therapeutic contexts?

I will be using the case of the death of Ilyusha from Dostoevsky’s The Brothers Karamazov to look at some of the ways death, deception, and self-deception complicate the questions around “the best interests” of pediatric patients.

THE DEATH OF ILYUsha

Toward the end of Dostoevsky’s masterpiece The Brothers Karamazov the novelist kills one of his most affecting heroes: Ilyusha, the little boy who attacked Alyosha Karamazov earlier in the novel because of a terrible insult suffered by the boy’s father at the hands of Alyosha Karamazov’s brother. Ilyusha is in fact a kind of childish parallel to the Christ-like figure of Alyosha, and when he dies Dostoevsky confronts us with 1 of the themes of the novel: how can the world be a good place (good in the cosmic sense of the word) if innocent children can suffer and die for no apparent reason?

Ilyusha has not left his bed for 2 weeks. When a schoolboy friend visits him, the friend is in shock:

He could never have imagined that we would see such a wasted, yellow face, such huge, feverishly burning eyes, such thin little hands. He observed with mournful surprise that Ilyusha’s lips were so dry and that he was breathing so heavily and rapidly.

When his friend asks him how he’s doing, Ilyusha is unable to speak, but the friend smiles “ruefuly at him.”

Dostoevsky sets the stage of a child’s deathbed with all of the elements we in fact expect (allowing for a little artistic exaggeration): his father “never doubted for a moment that, in spite of his fears for Ilyusha, his boy would recover suddenly,” although of course he changes all of his habits (even quits drinking, and accepts charity) because he is “terrified at the thought that his boy might die”; the local physician Dr Herzenstube “came to see the patient punctually every second day, but his visits were of little help, though he kept dosing him with medicines”; an expert physician is called in at the last minute from Moscow, who looks “almost angry and disgusted” after his consultation, “I’m afraid I can’t do anything, I’m not God,” said the doctor in a casual, though his customary impressively tone of voice, “because the case is so obviously hopeless”; and Ilyusha himself is not entertaining any illusions about his situation: he even tells his father “Daddy, Daddy! Oh I’m so sorry for you Daddy!” and “when I die, get a good boy—another one—choose one yourself from all of them, a good one, call him Ilyusha and love him instead of me.” His father, who has just been told by the famous physician that Ilyusha’s case is hopeless, lies to his son and tells him, “My darling Ilyusha—the doctor said you—you’d be all right and—and we’ll be happy—the doctor.”

But when it comes to considering his own death, Ilyusha has a little story he tells himself, and a favor he asks his father: “Daddy, when they fill up my grave, crumble up a crust of bread on it so that the sparrows may fly down, and I shall hear and it will cheer me up not to be lying alone.” When Alyosha, who is in many ways the champion of truth in the novel, hears the story, he says to Ilyusha’s father, “That’s a very good thing—you must take some, often.”

So, a classic pediatric end-of-life scenario: a child who accepts the fact that he is dying, but entertains childish fantasies or self-deceptions about what death is (probably) like; a parent who cannot accept the death of the child, and when he does seem to accept it, nevertheless lies to his child about it; 1 physician who seems to be silent on the case, continuing to care for the child but neither holding out hope nor making the dreadful prognosis; and the great medical expert, who does in fact mention 1 possible cure (which is unlikely and extravagantly expensive, wholly beyond the poor family’s means) but who is mostly annoyed that he has been called in to consult on a case in which death is the obvious and imminent outcome.

Now the question, for my purposes here, concerns what the so-called “best interests” of the various involved parties might be vis a vis the truth of Ilyusha’s situation. The expert physician from Moscow represents the cold, hard truth. The local doctor, Dr Herzenstube (literally translated: “heart office”), seems to represent a kind of Hippocratic principle of “do no harm”; Ilyusha’s father is
lying both to himself and to his son; Ilyusha knows and accepts that he is dying but has a very different idea of what death is than do most of the adults around him. Each of these individuals has a particular interest when it comes to the question of “the truth” about the death of Ilyusha.

A doctor I know and respect is chief of pediatric palliative care at a major US hospital and, like many pediatricians and other health professionals who care for children, she constantly has to deal with the reality of dying children and the families of those dying children in the most concrete, everyday way. She gets angry when academics (even academics who are fellow physicians) talk about “telling the truth” versus “deception” in the context of family communication about the death of a child. She tells me that she tries to teach her students that the physician’s job is to learn how the family talks about death, to respect that, and to be a participant in the conversation they are having about the child’s death. It is not, on her account, the physician’s job to tell the child the “cold, hard truth” or to lie to the child. Good communication in real life (so my friend plausibly argues) doesn’t work that way, because every case is different. People have different religious and moral beliefs. On this account, it’s not even the physician’s job to guide the conversation. When a child is dying, the physician’s job is to care for the child and the family as best she can, and part of that care is learning to communicate effectively and therapeutically with them.

The case of Ilyusha is tough terrain, particularly when it comes to the question of whose interests count and why. Is it in the child’s best interest to know he is dying? Does the physician have a moral interest, as a professional, to tell her or his patient everything the patient ought to know? Does the physician have an interest in the truth, the patient, the family, the care of the patient and the family, or all of these (which interests often seem to be at odds with each other)? What about the interests of the parents, who very commonly cannot confront the imminent death of the child, especially if the parents don’t want the child to know that he is dying? To make our road rockier still, what we may or may not know in these crisis situations is heavily mitigated by what we want to believe, and sometimes such instrumental beliefs can turn out to be good things. “A lie” (alternatively a false belief, a pseudo) “can be a good thing, like a medicine,” Plato wrote in The Republic, where he nonetheless also very strongly identifies the good with the truth (so much so that he would banish poets like Dostoevsky from his ideal city-state entirely, because the poets, however talented and admirable in other ways, tell lies).

**DECEPTION AND SELF-DECEPTION INTRODUCED**

Traditionally, these are 2 particular instances in which most philosophers agree that a lie might at least not be morally blameworthy, or may even be morally praiseworthy: a lie to prevent the murder of another human being, and a lie to a dying child. Deception of patients by doctors or concerned family members was in fact standard practice until recently, and was usually morally justified on the grounds that the belief that one might get better at least did no harm, and might well contribute to the recovery of the patient. Doctors have publicly defended the moral obligation for physicians to lie to their patients as recently as Sandeep Jauhur’s February 22, 2014 article in The New York Times. Last year a study was published in Health Affairs that showed 1 in 10 doctors admitted to knowingly lying to a patient, and more than half “described a patient’s prognosis in a manner more positive than warranted.” Other doctors will admit to lying to demented patients for their own good, and recommend discreet silence as a healing art at times when a barrage of cold, hard truths might do harm. Optimistic lies about the prognosis of a sick and possibly dying child, we might reasonably suppose, are likely to be more common than those told to adults or the elderly. Naturally it’s easier to be honest about a greatly negative prognosis with an 80-year-old patient than it is to be honest with the distraught mother of an 8-year-old child.

Of course it does not follow from the fact that doctors are lying to their patients that they ought to be doing so. But it is also true that there is good evidence to suggest that positive false beliefs about the likelihood of recovery may improve the chances of recovery. David Dennet has called this “the Dumbo effect,” after the story of Dumbo and the magic feather he is given by the crows and Timothy the mouse that convinces him he can fly. The fact is that Dumbo can fly (and in some cases, a patient may recover) but he can’t do it until he believes that he can. The true belief that he can’t fly remains true until it is supplanted by a false belief, and then the belief-revision is accomplished so that a new true belief (and with it, the capacity that depends on that belief) is created and confirmed.

Now we should be careful to notice that here, that 1 false belief (the feather is magic) is being used to overcome another false belief (that Dumbo can’t fly). That case, when we are using 1 false belief to overcome another false belief, is very different than when we are using a false belief to supplant or influence a true belief (such as, the belief that you are going to die). If Dumbo really couldn’t fly, the “magic feather” false belief could only harm him; similarly, we might worry that a false belief about impending death could only harm a child, or the family of the child,
whose death was certain. But we shall see as the article progresses that the kinds of beliefs we are concerned with when it comes to the best interests of dying children and their families are more complex than simply “the child will live” or “the child will die.” Furthermore, what we are most interested in, for the moment, is the fact that beliefs are malleable, and that false beliefs can at least sometimes be instrumental goals.

Dumbo is told a lie, given an instrumentally useful false belief, that enables him to achieve something he otherwise could not (at least, not consciously: he managed it the night before when he was drunk, which is how he wound up in the tree in the first place). But these kinds of Dumbo or placebo effects may also operate when the agent is deceiving him or herself. That is, an agent may use self-selected false beliefs for instrumentally desirable ends. William James tells the story of a hiker contemplating the daunting task of leaping a mountain crevasse. The truth is that he doesn’t know whether he can make it, although it looks like too great of a jump. If he tells himself he’ll never make it, we all know what will happen. But if he insists, despite his doubts, that he can leap further than he’s ever leapt before, he at least (we all know this from personal experience) has a better chance of making the jump than he otherwise would. In the medical context of a prognosis from a physician, the physician may support or undermine the patient’s attempt at an instrumental self-deception about recovery: it is much easier to lie to oneself about one’s chances either with the help of a lie from a physician, with her evasive remarks, or with her discreet silence (we shall have more to say about the conversational techniques of physicians below). If a physician tells you that you are certainly dying and will die very soon, that communication may not only darken your final days but may hasten them as well. If the crows told Dumbo he was just stuck in the tree, he’d probably break his neck trying to climb down.

A leading expert on deception and self-deception, Dan Ariely, also tells 2 interesting stories about self-deception and deception in a medical context. He too suffered a terrible burn injury, with burns over 70% of his body. During the long, torturous process of his recovery, he was often told by his nurses and his doctors that he was “going to get better.” This was literally true. But, late in his recovery process, Ariely met a man who had burn damage similar to his own and yet was “fully recovered.” Ariely relates that he was horrified by what he saw (he considered the man to be terribly disfigured, even deformed) and he realized that throughout the process of his treatment he had been lying to himself about what the end result would be. His false belief was no doubt instrumental in helping him endure the process of the treatment itself. But his disillusionment when that self-deception was exposed was also extremely painful.

In a slightly less upsetting story, Ariely explains that, toward the end of his treatment, he had to undergo a horribly painful procedure involving pins being inserted into his fingers. He asked the nurses if it would be painful when the pins had to come out again a few weeks later. “No, no,” they told him, “That will come as a relief. This is the bad part.” It turns out that they were lying; the extraction of the pins was every bit as horrible as their insertion. Nevertheless, Ariely insists that he is grateful that the nurses lied to him, because he would have been incapable of enjoying the weeks between the 2 procedures.9 Of course we should also note that stories reported by people who have been lied to, such as Ariely’s, do not offer us the experimental control of the alternative scenario: that is, we don’t know (except in Ariely’s imagination, which may or may not be a reliable source of information) how Ariely might have reacted if he had been told the
truth. Often we in fact succeed in dealing with difficult truths better than we anticipate that we might.

**SELF-DECEPTION IN THE CONTEXT OF A DYING CHILD**

The case of Ilyusha’s father, who is deceiving himself about Ilyusha’s chances of recovery, is familiar and relatively noncontroversial. We expect people to react with denial in the face of the imminent deaths of the people they care most about; and, as is well known, that denial can carry over in complicated ways even after the sick person has actually died. But why it is relevant for our purposes is that it impacts the question of the best interest of the patient. In the most obvious sense it impacts the question of the best interest of the treatment of the patient: if a parent sincerely believes that a child may live when all of the experts have concluded that death is imminent and palliative care is the only appropriate action, that parent may demand expensive, time-consuming, and even painful treatments that are simply inappropriate. In such instances we can all agree that the objective opinion of the medical professional is both necessary and morally legitimate.

But the case of Ilyusha’s father is more nuanced than it might initially appear. Dr Herzenstube is administering only the simplest medicines, and presumably focusing on helping Ilyusha with his pain and his breathing; the famous physician from Moscow pronounces the case hopeless almost before he can step inside the door; and as soon as he can, he hastens back out again. Is it appropriate, we may ask, for Ilyusha’s father to reassure Ilyusha that he will live? Even once he himself has come to accept the inevitable, as he seems to do, after the visit from the cold, hard doctor from Moscow, is it appropriate for him to lie to Ilyusha? Could a lie to Ilyusha be in Ilyusha’s best interest? Or does the truth always better serve the interest of the dying child?

Interestingly, the recent literature on this subject is inconclusive. For centuries, as I remarked at the outset, it was supposed by most thinkers that a lie to a dying child was justified, was in the best interest of the child, for precisely the reasons Ariely advances in justifying the lie told to him by his nurses about the finger-pin procedure. Because the lie will likely eliminate a concrete harm (fear), and the lie is about a harm that is unavoidable anyway (in Ariely’s case, the pulling of the pins, in Ilyusha’s case, death), doesn’t the lie look like the morally desirable thing to do?

In the late twentieth century, thanks to works by Myra Bluebond-Langer and others, this view changed; we learned that very often children were well aware of their medical situations and that the lies that family members were telling them were actually preventing those children from dealing with their impending death in healthier, more psychologically valuable ways. And Dostoevsky seems to agree with Bluebond-Langer: in the case of Ilyusha, it is Ilyusha who lets his friends and family know that he understands that he is dying, and he is even put in the position of having to comfort his father (a common problem, as Bluebond-Langer has shown). So we might be tempted to argue that simply telling the truth to dying children is the desirable course of action, and serves the best interest of all parties involved. That said, even the most cynical among us will agree that at least sometimes a lie to a dying child may be of psychological benefit to the child; and, as we discussed above, almost everyone admits that where there is room for doubt about the outcome, it is at least potentially of benefit to the patient, and probably morally justified on those grounds.60 Most of us believe that giving hope, when there might be cause for hope, is a moral good, and that stealing or defeating hope is usually morally blameworthy.

When I discussed the case of Ilyusha with my friend Pat Barrodale (the nurse who lost her 2 children in a fire) she said, “Well, I can tell you what my own mentor told me: If anyone says they know the right thing to say in every circumstance, don’t believe them.” For Pat, as for the pediatric palliative care physician at Harvard, what some moral philosophers call a “particularist approach” is the ethically appropriate one: how best to handle each case will vary according to the facts of the case and the personalities of the various involved interests. What we should not miss, when we take this approach, is that the best interest standard is implicitly expanded beyond the superficially narrow (but in fact quite broad) “best interest” of the patient.

The fact is that we can’t really talk about the best interest of Ilyusha without at the same time talking about what is in the best interest of his father: their interests are too closely intertwined. Ilyusha’s father is his most important caregiver. If his father were to completely collapse, that would not be in Ilyusha’s best interest; and yet if his father were mulishly to insist that Ilyusha would recover despite Ilyusha’s insistence that he was going to die very soon, that would make his father incapable of entertaining Ilyusha’s dying wish that he place crumbs for the sparrows on his grave, and that, too, would conflict with Ilyusha’s best interest. For Ilyusha’s father to continue to deny the fact of his son’s death to Ilyusha would make genuine communication about Ilyusha’s death difficult or impossible (this is a common problem in the context of the death of a dying child), and that also looks like it is in conflict with Ilyusha’s best interest.
Ilyusha’s father goes through a process in dealing with how he discusses the fact of his son’s death with his son. At first he is in a state of sincere self-deception despite what is obvious to everyone around him, that Ilyusha is dying; Ilyusha’s father simply insists that Ilyusha will recover, he must recover. Ilyusha does not disagree with his father about this, although it seems clear that he himself understands that his father is wrong. But while there is still any room for doubt, few of us would deny Ilyusha’s father the consolation of continuing to hope, and we might even suppose that the hope maintained by Ilyusha’s father provides some consolation to Ilyusha. (None of us want hastily to be written off as dead by the people who love us.) It is in conversation with his son (while telling Ilyusha a lie that Ilyusha himself contradicts) that Ilyusha’s father revises his opinion, without ever going so far as to say to his son: yes, you are dying. What he does do is acknowledge the dying wish of his son, that he will place a crust of bread on his grave so that the sparrows can keep him company, and in doing so he implicitly acknowledges that Ilyusha is going to die, and that to continue to protest otherwise would be a source of harm rather than help to his son. (He does not grant Ilyusha his wish that he adopt another boy as his replacement, and we suspect that Ilyusha is seeking reassurance by making such a wish).

My point about the changing relationship that Ilyusha’s father has toward the truth of Ilyusha’s death is that it seems to be in concord with Ilyusha’s best interest. His father follows Ilyusha’s lead with respect to the truth of Ilyusha’s situation—a reversal of the normal parent-child relationship. Now we might worry that this places an undue burden on Ilyusha: should he really have to be the one who confronts his father with the fact of his impending death? But the point, of course, is that Ilyusha only needs to guide the conversation about his death with his father as far as he is comfortable doing so. What is most important in the dynamic between Ilyusha and his father, I think, is their ongoing communication, and the willingness of Ilyusha’s father to revise his opinions in light of what his son is asking him to believe and acknowledge. If Ilyusha were self-deceived about his own circumstances, it is true, his father would have done nothing to revise Ilyusha’s beliefs in favor of the truth, but that looks as though it would also be in Ilyusha’s best interest.

One possibility should give us pause: suppose the not-uncommon case in which the dying child wants to talk about death, but the parent is deep in self-deception about the truth of the matter, and the child is either afraid to broach the question or simply does not have the appropriate communicative resources to do so. In this respect Ilyusha’s case is not representative because he is very willing to discuss his death with his father once the subject has been introduced. In this instance it seems to me that a physician might have an appropriate role in suggesting to a self-deceived parent that, given the likely outcome, finding ways to approach a conversation with the child about his or her death could be in the child’s best interest. These techniques (for getting children to talk about things they already want to talk about, but are being silent about) are familiar to all parents and pediatricians: reading a book or watching a movie about a dying child, for example, is a nonconfrontational way to approach the question of how a child is feeling about impending death. Depending on the child, simply asking whether the child wants to talk about death may be appropriate.

The controversial and interesting point here is that self-deception about the death of the child (either by the parent or the child) is not necessarily a bad thing, and should not necessarily be confronted by “the truth.” Self-deception may be an essential component of a patient’s best interest, at least for a time, and especially, as we have said, when that patient’s best interest is realistically broadened to include the interests of closest caregivers. The good thing about self-deception (and why it is so important to all of our day-to-day lives) is that it allows us simultaneously to entertain contradictory beliefs, usually depending on the psychological needs we are presented with. Ilyusha’s father both knows that his son is going to die and believes that he may still live. He can at 1 level prepare for the death of his son and at another avoid confronting what the future will look like without having his son in his life. At a certain stage, Ilyusha also probably entertains the same contradictory belief-state: and he might be importantly bolstered in maintaining that state by observation of his father’s self-deception. Here self-deception is understood as a valuable stage in a transitional process. It’s a toe-dipping technique; it’s a way of getting accustomed to those very cold waters before actually taking the plunge (simply jumping into an ice-cold lake is a good way to get the air knocked out of your lungs and drown).

The manner in which Ilyusha’s 2 physicians handle the question of best interest and the truth is also illuminating: the expert from Moscow is made indignant by the case, which he recognizes is hopeless, while he also tries to save face for himself by blurt out an improbable cure that he knows the family cannot afford (here the “cold, hard truth” is used as a self-defense mechanism by the physician, who does not want to seem powerless); Herzenstube, by contrast, palliates and maintains a discreet silence, allowing the family to handle the matter in the way that seems best to them. A relatively
humble doctor in a small provincial town, we are not surprised to see him handling the death of Ilyusha in a case-by-case way, not offering hope, not pronouncing the case hopeless, and also not ending his modest course of treatment.

**SELF-INTEREST, “BEST INTEREST,” AND SELF-DECEPTION: MORE THOUGHTS ON THE ROLE OF THE MEDICAL PROFESSIONAL**

Self-deception commonly takes place, generally speaking, when we believe what we want to believe, rather than what is supported by the best evidence. It tends to be motivated by self-interest: when self-deception takes place in nonhuman animals, for example, it is generally used as a strategy for more effective bluffing in contexts of competition (either for food or mating opportunities). Self-deception is widely acknowledged to have evolutionary advantages, but those advantages tend to accrue to the individual practicing the self-deception. Accordingly, we might worry that self-deception tends to serve self-interest rather than best interest.

Certainly when it comes to the role of physicians in considering the best interests of patients, self-deception looks like it is straightforwardly bad. This is a fascinating fact, because I have suggested that lies by physicians may be candidates for moral goodness. In the case of Pat Barrodale’s daughters, the likely self-deception of a young physician gave her false hope that, 40 years and many patients of her own later, she insists caused her enduring psychological harm. Whether it is in denying the possibility of a patient’s recovery (a self-deception possible because of the limitations of a doctor’s abilities), insisting on the possibility of a patient’s recovery (a self-deception possible for many reasons, but obviously promoted by the hopes of the patient and the family), or encouraging the patient toward a radical or unnecessary form of treatment (a self-deception that again may have many causes), in every instance we want to say that we do not want self-deceived physicians. This is unfortunate for at least a couple of reasons. First, physicians are human beings, and like all human beings they need self-deception to flourish. Pediatricians who are regularly dealing with dying children may be in particular need of strategic self-deception because of the enormous daily psychological stress of the kind of work that they do. But it is crucial that these physicians be vigilant about self-deception, because the physician’s self-interest is not the same as the patient’s best interest.

An unfortunate if predictable and perhaps inevitable consequence of the vigilance against self-deception that must be maintained by a good physician is that self-deception can come to be viewed by physicians as a therapeutically or morally blameworthy thing. If I am in the habit of thinking self-deception is bad for me, I am likely to suppose that it is bad for other people, too. The confusion here, of course, is between my self-interest as physician and the patient’s self-interest with regard to the question of best interest. Although my self-deception serving my self-interest is probably never in the best interest of the patient, the patient’s self-deception servicing his or her own self-interest may well be, and it is important that I not allow a prejudice against self-deception generally to interfere with that good. As we have seen, especially because of the intimate connection between the best interests of children and their closest caregivers, self-deception by family members may also serve the best interest of the dying child. It is not to be endorsed as an intrinsic good. But it should be acknowledged and respected as a possible instrumental good.

The key here, as in the case of Ilyusha, is a respect for the particular circumstances and techniques of communication of the child and his or her closest caregivers. Communication in family context, especially in times of great stress, is a fascinating mix of truth, storytelling, reassurance, fantasy, historical re-creation, humor, deception, and self-deception (in fact it is now generally believed that communication evolved for the purposes of deception, not truth telling): it is the medical professional’s obligation to recognize that the best interest of her or his patient is to respect each family’s ways of talking and being together. To insert “the cold, hard truth” into that dynamic is a violent act; but it can be just as harmful to allow self-deception on the part of the physician, who could thus be wittingly or unwittingly drawn into the family narrative. It is widely recognized that self-deception is contagious.11 Listening to and communicating with a family about their situation while maintaining objectivity about the facts of their situation must be 1 of the most difficult tasks confronting a medical professional, particularly when that entire conversation is premised on the impending death of their child.

This is the physician’s challenge: both to keep a firm grasp on the truth of the situation, as best she can discern it, and not to impose that truth on the family in a way that might interfere with the best interest of the patient. This may mean that the physician simply treats in relative silence, like Dr Herzenstube. That granted, if directly asked by a caregiver for the cold, hard truth (as Ilyusha’s father does in fact ask the expert from Moscow) then the physician has the obligation to provide the facts as accurately as possible. I think the appropriate attitude for the physician is to recognize that the truth about the patient’s condition is neither intrinsically valuable nor always instrumentally
valuable, but a potential instrumental good and numbered among the goods that the patient may demand from the physician.

I am tabling for another day the question of whether a doctor should ever actively enable the self-deceptions of a patient or a patient’s family. It should be admitted that, if we suppose that a lie to a patient may sometimes be morally justified, enabling a patient’s self-deception (a more modest form of misleading than an out-and-out lie) ought also at times to be morally justified. Indeed, some thinkers would argue that maintaining silence while practicing medicine in the context of a family that is participating in a collective self-deception about the death of a child is itself enabling the self-deception. In this way Dr Herzenstube’s policy of quietly doing no harm might be seen as facilitating the self-deception of Ilyusha’s father and, if so, then I am committed to the claim that he did the morally praiseworthy thing.

**DIETRICH BONHOEFFER ON THE DEATH OF ILYUSHA: THE LIVING TRUTH AND THE CRUST OF BREAD**

We should begin by admitting that we do not know what the truth about death is. So as far as the question of, “What will happen when I die?” is concerned, the medical professional cannot speak with any more (or any less) authority than the rest of us. Given that fact, medical professionals are obligated to be respectful of a family’s stance on, or story about, this question, and to be silent if the family has a narrative that is at odds with the medical professional’s personal beliefs. This much seems uncontroversial.

But now recall the 2 dying requests that Ilyusha makes of his father. The first is that he should adopt another boy and raise him as Ilyusha, which his father simply and sensibly refuses to do. (Whether this was Ilyusha’s attempt to comfort his father or his attempt to comfort himself is unclear. Ilyusha does seem comforted when his father refuses to entertain the request.) The second request is that his father should regularly place crusts on his grave so that sparrows will come down to eat from the grave and Ilyusha will take comfort in their company.

Now, whatever is waiting for us in the afterlife (Socrates suggested it was either complete silence or great conversation), Ilyusha’s version of it seems especially unlikely. Whether he himself takes it entirely seriously is a fair question: it seems like the kind of fanciful storytelling that we often engage in when we are deceiving ourselves (“wouldn’t it be nice if...” or “it’s unbearable to think that, so an attractive alternative might be...”). What both of Ilyusha’s dying requests have in common is that he is clearly worried, and rightly so, that his father will be lonely after he dies. In fact, when they are carrying Ilyusha’s body in his coffin to his grave, his father goes into a temporary panic when for a moment it appears that he does not have the crust of bread for after the burial (the problem is quickly resolved). Now, whatever Ilyusha might believe about the afterlife, it seems particularly unlikely that Ilyusha’s father genuinely believes that his son will be able to hear the sparrows coming down to collect their bread crumbs. Nevertheless the crust of bread is a great comfort to him—as are the flowers so many people bring to the graves of the people they love. So what exactly is going on here? What kind of request is Ilyusha making, and what sort of belief structure is informing his father’s agreement to the request (where he absolutely would not agree to the first request) and his emotional commitment to it?

The philosopher Dietrich Bonhoeffer argued for a concept he called “the living truth.”12 According to Bonhoeffer, we very often mean something very different than the literal truth of what we say; and we are very often understood to mean something different than the literal truth of what we say. So, for example, suppose next month I ask my wife, “Do you think I’m getting fat?” and she says, “No, honey, you haven’t gained a pound.” We both know that literally she’s telling a lie: it’s January, and I always gain 5 or 10 pounds over the holidays. But “the living truth” of what she’s telling me is that she thinks I look fine, and I don’t need to worry about my weight. This is also, she knows, the real reason I’m asking the question: I am in fact asking her to lie to me, although I wouldn’t want her to lie even more and say, “You look too thin! You need to put on a few pounds! Let’s order pizza tonight!”

Many of the stories we tell each other, as with the stories in the Bible and many other foundational moral texts, Bonhoeffer argues, are not literally true—they are often in fact literally false. Nevertheless they may communicate a “living truth” that could not be communicated in a better way. Consider our most popular lie at this time of year: the story of Santa Claus. Simply explaining that giving is a good, virtuous, kind thing is only going to make so much headway with a 4-year-old (or a 6-year-old, or even probably a 9-year-old). But telling a story about a good-natured, funny fellow who picks 1 day a year to give gifts to everyone, after spending the whole year making those gifts: that teaches the 4-year-old child a living truth about generosity that the child otherwise might not understand. Consider 1 more example. When we make our marital vows—to love each other “until death do us part”—we are not really in a position to make any such promise. Half of all marriages end in divorce; many other marriages that last until death are unhappy ones.
And yet the vow contains a “living truth” about the nature of love, the intensity of our particular love for each other, and our intention to try our best to maintain that love.

Ilyusha’s story about the crust of bread is, I think, simply an example of 1 of Bonhoeffer’s “living truths.” Understood literally, even Ilyusha probably doesn’t believe it; understood metaphorically, he himself tells us the moral of its story: “It will cheer me up not to be lying alone.” Whatever other fears Ilyusha may have of death, 1 of them probably is the fear of living without his family or friends, and especially his father. More to the point, we already know that he is worried about his father suffering loneliness after he dies, and he is a subtle enough psychologist to understand that if his father is doing something to make him less lonely, it will in turn make his father feel less lonely. The inevitable separation that is marked by his death is what is bothering both of them more than the physical fact of his death, and so Ilyusha invents a little story (a literally false, living truth) that will soften both their current fear of the separation to come and the actual separation once it comes. He even gives his father an activity to perform, which probably helps both of them not only in its performance, but in the anticipation of its performance. When Ilyusha’s father tells Alyosha Karamazov about the crust of bread, Alyosha encourages him to bring a crust of bread often. Naturally, such stories are going to be particularly common and effective in the lives of children, when our belief structures are less rigidly tied to a fact-based way of looking at the world.

The reason I emphasize this story is I think it illustrates precisely the kind of self-deceptive belief, Ilyusha’s story is neither truth nor is it precisely falsehood: it occupies a funny place in our belief structure, more akin to fiction or to the rules of a game than to straightforward fact or bald-faced lie. But we are naïve if we suppose that makes the story trivial. If we examine the beliefs that constitute our relationships, that help us get out of bed in the mornings, that guided us into our careers, or that inform our hopes for the future, we will quickly find many narratives that are not very different than Ilyusha’s crust of bread story. Our values are not material things, we cannot point to them or grow them in a petri dish; they live in mental, verbal, emotional space; they are nurtured and sustained by the ways we talk about them, the stories we tell about them, the demands they place on ourselves and other people, the connections they form between us.

In closing, then, I’d like to suggest that the case of Ilyusha shows that we should be very careful about appeals to “the truth” when considering the best interest of dying children and their closest caregivers. In some instances even outright lies may be morally justifiable; in many instances, various states of self-deception may be natural and desirable. But this does not diminish the medical professional’s obligation to understand the facts of the patient’s (and the family’s) situation as best she can; on the contrary, it increases that obligation, because self-deception may tend to undermine the medical professional’s ability to see beyond her own self-interest to the best interest of her patient and family. When it comes to the best interest of a dying child, accordingly, the medical professional is thus the caretaker of the truth without necessarily being its spokesperson.

There is a practical objection we should consider: the situation represented by Dostoevsky does not at all resemble the typical situation of a dying child in today’s world. The typical dying child in the West, in the twenty-first century, will be in a hospital, and will have not 1 or 2 caretakers but teams of different caretakers, which may number in the dozens. These caretakers may have trouble enough simply agreeing on, knowing, and accurately representing the actual diagnosis of the child. How, then, could we realistically expect these caretakers to collaborate in the family’s wishes to present the truth (or even a falsehood) to the dying child as part of a particular narrative and in a particular way?

I think this objection actually serves to illustrate what might be the most important practical consequence of the argument of this article: namely, that especially in the case of a dying child, health care professionals have a duty to listen that trumps the duty to speak. It may well be that in ordinary therapeutic settings the health care professional should see herself primarily as a resource of care and good information. But when it comes to the context of a dying child, being a source of care may come into conflict (so I have tried to show) with being a source of “good information.” What I am saying here, in fact, is that raw information is not the same as good information, and surely the more caretakers involved in the therapeutic context, the more aware those caretakers will be that no 1 caretaker in particular is the authoritative voice for what information should be provided, when that information should be provided, and how it should be provided. This is not to suggest that caretakers in these contexts should be silent or should refuse to provide information. But it does suggest that, in the context of the care of a dying child, caretakers should be particularly attentive to the kinds of questions that are being asked, and circumspect about the kinds of unnecessary or idle
information they may be providing. For caretakers other than the primary physician or physicians, it could well be that a kind of “loose lips sink ships” rule might be useful to protect the best interests of dying children and their families.

One final note: I have focused my attention on Ilyusha’s case, for whom death is certain. An interesting consequence of my view is that when self-deception (and indeed, deception by the physician) may serve as instrumental to a patient’s recovery, the truth might be morally blameworthy, and falsehood morally demanded. This deeply counterintuitive view suggests that truth and falsehood may only be instrumental goals. In any event, my argument strongly rejects the notion that truth is intrinsically valuable; and indeed, should a physician or medical professional have to choose between the truth and the good of her or his patient, we suspect that the caretaker would justifiably choose the latter.

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