

# Narrative responsibility and moral dilemma: A case study of a family's decision about a brain-dead daughter

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**Abstract** A brain death case is presented and reinterpreted using the narrative approach. In the case, two Japanese parents face a dilemma about whether to respect their daughter's desire to donate organs even though, for them, it would mean literally killing their daughter. We argue that the ethical dilemma occurred because the parents were confronted with two conflicting narratives to which they felt a "narrative responsibility," namely, the responsibility that drives us to tell, retell, and coauthor the (often unfinished) narratives of loved ones. We suggest that moral dilemmas arise not only from conflicts between moral justifications but also from conflicts between narratives and human relationships.

**Keywords** Brain death in Japan · Organ donation · Narrative ethics · Moral dilemma · Narrative dilemma · Narrative responsibility

## Introduction

The narrative approach is helpful for analyzing and interpreting bioethical cases. The premise of this analysis is that narratives are important to each of us for all of us tell and listen to stories [1, p. 38]. Alasdair MacIntyre states that the human is "essentially a story-telling animal" [2, p. 201], implying that we organize and construct our experiences by telling our own stories and understand the experiences of others by listening to their stories. The narrative approach can also lead to deep

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insight into a bioethical case because narrative is naturally sensitive to the intimate and unique human situations that arise from any moral experience.

In this article, we will introduce the concept of “narrative responsibility” and reinterpret a moral dilemma from a narrative perspective. Narrative responsibility can be defined as our responsibility to tell, re-tell, and conclude the last chapter of the life narrative of a loved one. From the viewpoint of narrative responsibility, we will “think with,” walk with, and listen to the stories of two Japanese parents who lost their daughter to brain death. We will focus on their personal narrative responsibility toward their daughter’s two unfinished but competing narratives.

After the tragic death of their daughter in an accident, the parents insisted on telling her narrative not only to make sense of what they were going through (achieving narrative understanding) but also to bring an appropriate end to the last chapter of their daughter’s life narrative (fulfilling narrative responsibility). The problem for them was that there were two competing narratives of their daughter, each with a different ending. The first narrative was that of the brain-dead body. As the parents engaged in nonverbal dialogue with their daughter’s brain-dead body, they began sharing the undeniable reality that the daughter was still alive. They thus wished to fulfill their narrative responsibility by rejecting organ donation and closing the last chapter of the daughter’s life narrative as peacefully as possible.

The second narrative was the daughter’s narrative of coming back. This was a narrative that started when the daughter told her mother that she would come back via a recipient’s body after organ donation. Taking over from their daughter’s narrative of coming back, the parents wished to fulfill their narrative responsibility by agreeing to organ donation and closing their daughter’s life narrative. Doing so was necessary to ensure that the daughter would come back to them. The problem was that the two competing narratives placed the parents into a “narrative dilemma.” The parents suffered from a sense of moral failure because it was impossible for them to fulfill their responsibility to both narratives.

Many health care professionals tend to underestimate (or fail to perceive) how serious family members are about fulfilling their narrative responsibility to complete a loved one’s unreasonably terminated life narrative. We are thus eager to explore how, as a result, health care professionals can perceive and interpret a moral dilemma in a way that patients and their families do not. We hope that with a more appropriate understanding of “narrative dilemma,” health care workers can better support patients and family members who must make difficult and painful moral decisions.

## The case

A 17-year-old female was transported to a hospital following a traffic accident. She was diagnosed as clinically brain-dead. In Japan at the time, both a donor card and family consent were necessary for organ transplantation following a legal diagnosis of brain-death.<sup>1</sup> However, the girl had forged her mother’s signature on the donor

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<sup>1</sup> This case preceded the revision of the Japanese Organ Transplantation Law in 2009. In this revised law, only family consent is needed to allow for organ removal following a legal diagnosis of brain death.

card.<sup>2</sup> A year before the accident, she had said to her mother, “I have a donor card. If I become brain-dead and my organs are transplanted successfully, I will transform myself into the organs and I will come to meet you. I am not sure how the recipient will come to meet you. That person may ask you for directions or beg you for some money at a convenience store. In that case, please be kind because that person is me.” Even after the doctor explained brain death to the parents, they continued to believe that their daughter was still alive because her body was warm and her heart was beating. The mother wanted to respect her daughter’s decision to donate her organs. However, the mother believed that in order to do this, she would have to kill her daughter. The mother was unable to make a decision; she thought that this was a hell on earth. The father too experienced great hardship and was vomiting at home. In such cases, how can physicians and nurses support the family’s decision making and provide them with psychological care?

### The narrative of the brain-dead body

Some of the patient’s family members in Japan see their loved one’s brain-dead body as “the communicative body,” the body that is open to family members via non-verbal communication, such as touch, facial expression and breathing [3, pp. 48–52]. Kunio Yanagida’s striking phrase, “the brain-dead body that directly talks back,” is probably the best example of such non-verbal communication. In *Gisei (Sacrifice)*, Yanagida writes that he actually perceived his son’s brain-dead body talking to him:

When Kenichiro [the oldest son] and I [the author] talked to Yojiro, though he was brain-dead, his body talked back to us. This was truly a mysterious experience. This was probably a sense that can be understood only by members of a family who have shared happiness and sorrows with each other. Despite the scientific explanation that a brain-dead person is literally a dead person who has no consciousness or senses, I became quite sure that a beloved one’s brain-dead body means a lot to the family members who have shared a spiritual life with each other. [4, p. 129; authors’ translation]

A brain-dead person talking to his family may seem scientifically impossible. However, it appears to have happened to some bereaved families in Japan. For them, the brain-dead body continues the relationship between the dead and the living; the unconscious body still has a social role. Arthur Frank emphasizes that we communicate through our bodies because “the body itself is the message; humans commune through their bodies” [3, p. 50]. He suggests that for the family of a brain-dead person, his or her body transmits messages and provokes memories, emotions, and a sense of relationship. In responding to the messages sent by the brain-dead

<sup>2</sup> The donor card was still valid even though the daughter had forged her mother’s signature. According to the old transplantation law, organs could be removed from a donor who had been declared brain-dead under two conditions: (1) the donor had previously given written consent, and (2) the family did not overrule the donor’s decision.

body, the family takes on the role of retelling that person's narrative: the "narrative of the brain-dead body."

In reviewing the argument for a communicative brain-dead body, we shall revisit the case of the girl described above. According to the case description, the parents believed that their daughter was still alive because her body was warm and her heart was beating. After the daughter was diagnosed as clinically brain-dead, the parents visited her in the ICU. The mother described that experience:

As we were informed that her brain waves were gone and she became [clinically] brain-dead, we visited the ICU to see her right away. "You have tried hard enough, Mari. Rest in peace. I will carry you on my back so let's go home," said the father as he put his hand on Mari's heart. I pushed my cheek against her cheek and kissed and embraced her as usual. But Mari was too warm to be a dead person! Her skin was still red. I could see her blood circulating as I rubbed her hands. "Is this death? If it is, I can bring her back to life!" I truly thought I could do that. [5; authors' translation]

The daughter's body was not silent. Via its warmth, its color, and the rhythm of its heart, the daughter told her parents that she was still alive. The body in this case is indeed communicative and open to the parents. It evoked the parents' memories and emotions. The parents became the spokespersons for their daughter's body. They heard her voice, and in response, the mother told the "narrative of the brain-dead body."

However, this narrative appears to work against the parents giving consent to organ donation because harvesting her organs would have required them to end her life. This was unthinkable as long as their daughter's heart was still beating. Eventually, however, the parents did in fact agree to her organ donation. Their decision was based on another counteracting narrative: the daughter's narrative of coming back.

### **The daughter's narrative of coming back**

This case began with the description of a young woman who was clinically diagnosed as brain-dead after a traffic accident. We changed the tone of the case by including the distinctive narrative turn marked by the girl's statement, "I have a donor card." From this point on, the case ceased to be a typical bioethical case and became the mother's "narrative of recollection." The daughter is the original narrator, and the mother recollects and retells that story for her. About a year before her automobile accident, the daughter, Mari, learned that her mother's cancer had returned. Mari then began to tell her mother the "narrative of coming back."

At times, Mari looked down holding back her tears and then looked at me. She said, "please use my organs if people with serious diseases will be saved. After these people regain health following a successful transplant, I will enter into the heart, the liver, and the kidney, and I will come to see you. For the

sake of society and other people [I will donate my organs]; then I can come to see you. It is a solution that kills two birds with one stone, isn't it? Mother, I want you to live longer. Please don't feel sad because of my organ donation. I promise I will come back to see you." [6; authors' translation]

Upon agreeing to donate her daughter's organs, the mother requested that the doctors not remove the corneas. "I begged them not to take the corneas, her eyes, because Mari cannot find and enter into the recipients [without her eyes]. That was something we could not compromise on" [5; authors' translation]. Because the daughter's coming back was a reality for both parents, they finally agreed to donate the other organs.

Having seen the parents retell and coauthor their daughter's two narratives, some readers may wonder where such a strong sense of narrative responsibility originates. We believe that it originates from the fact that we tell not only our own narratives but also those of others. Nobody can tell a narrative alone; a narrative requires both a narrator and a listener. Only a story that is told is a true narrative. Yet in a deeper sense, the acceptance of ourselves as storytelling creatures means that we are entangled in a web of intimate and reciprocal relationships [7, 8] and that we are telling and listening to "self-other-stories" [3, p. 163]. In this sense, our most basic narrative responsibilities are to be honest when telling our own narratives and to listen genuinely to the narratives of others.

We all take on such narrative responsibility in our everyday lives. We often do so without consciously realizing it, but there are situations where we clearly and fully perceive its presence, such as when we lose a loved one to accident or illness. The more abruptly and brutally our loved one's life narrative is interrupted, the more we tend to perceive that his or her life narrative remains utterly unfinished. We are then driven by a narrative responsibility to conclude that the deceased had a coherent and meaningful life narrative and then to tell it to others. This strong sense of responsibility is why it is vital for health care professionals to understand the nature of narrative responsibility. Surviving family members may raise questions or make requests that appear to be irrational from a medical and scientific perspective, but these communications may be significant and meaningful for the family members and loved ones who tell and coauthor the narratives of the deceased.

We encourage health care professionals not to dismiss these requests and questions but to take them seriously and to consider whether these requests and questions make narrative sense. Health care professionals can then imagine how they might respond in a way that assists family members in fulfilling their narrative responsibilities.

In summary, what makes the case presented here unique is that the parents were compelled to tell the two different narratives of their daughter simply because they had to employ two competing means of telling those narratives. Since the daughter was no longer able to communicate, her parents had to (1) recall a "once-told" narrative of the daughter and (2) listen to their daughter's communicative body. The issue is not that there are two narratives for which the parents must be responsible but that the two narratives are in apparent conflict, giving rise to a painful narrative dilemma.

## Why is a narrative dilemma difficult to resolve?

In a narrative dilemma, it is the narratives, not the moral principles, that clash. In our case, the conflicting narratives have incompatible moral actions: the narrative of the brain-dead body provides the moral ground for the rejection of organ donation and the narrative of coming back provides the moral ground for consenting to that organ donation.

What makes the narrative dilemma difficult to resolve is “narrative responsibility,” a commitment to believing in a narrative(s) for as long as that narrative exists. The following excerpt shows that the father truly believed the daughter’s narrative of coming back and thus agreed to donate her organs.

The father said again and again that he decided to agree to the donation because Mari had said “I will come to see you, mother.” [The father said,] “That her soul possesses [the organs] sounds like an idea from a movie, but I believed in what she said. This must have been her ultimate desire or maybe it was her destiny.” [5; authors’ translation]

Although the parents chose to believe in the narrative of coming back, this did not mean that they gave up believing in the other narrative. As the following excerpt shows, these parents remained faithful to the narrative of the brain-dead body despite consenting to organ donation. According to the mother,

With the presence of a coordinator, the father signed the agreement in the small room right next to the ICU. His fingers holding the pen seemed to tremble. With a pale look, “I will sign it, all right?” said the father in the end. “I am so sorry,” I said silently to her [the daughter] then. All of us were thinking that we would carry the burden of agreeing to the donation for the rest of our lives. [5; authors’ translation]

The mother’s apology here and her intent to “carry the burden” deserves further examination. The “burden” that the parents decided to carry was, we think, the unique consequence of fulfilling their responsibility toward the narrative of the brain-dead body. According to the excerpt, the parents’ consent to organ donation implied that they had made a commitment to the narrative of their daughter’s coming back. At the same time, the mother’s comment, “all of us were thinking that we would carry the burden of agreeing to the donation for the rest of our lives,” indicates that they also felt responsible for the second narrative. We interpret this sense of “burden” as the enduring guilt of terminating the life of their daughter, who was still alive for them. Yet, this sense of burden needs further elaboration from a narrative perspective because it exemplifies a unique way in which family members can fulfill their narrative responsibility over an extended period of time.

What is, then, “the burden” that the parents decided to carry? What does it mean when they say they will carry it for the rest of their lives? From a narrative perspective, the “burden” can be interpreted as the guilt of failing to honor both narratives. By agreeing to organ donation, they believed that they fulfilled only half of their narrative responsibility—to just their daughter’s narrative of “coming back.” As pointed out before, the parents did not permit themselves to replace one narrative

with the other. The other half of their narrative responsibility was not overridden or argued away but simply left unfulfilled. That unfulfilled narrative responsibility, we presume, forced the parents to shoulder the burden of asking themselves again and again (or telling and retelling) whether their decision was the right one, knowing also that they would never have a completely satisfactory answer to that question.

### **An epilogue: retelling narratives**

This case ended in an unexpected way for these parents. After the first brain death test, the medical team found that their daughter's left eardrum was ruptured, so the team could not complete the test of brain stem reflexes. The medical team consulted the Ministry of Welfare and was ordered to terminate the whole legal process of brain death diagnosis and suspend organ donation. The girl's kidney was donated after she succumbed to cardiac arrest.

After the daughter's death, the mother looked back on the termination of organ donation and spoke to her daughter.

[The mother saw that] the flame of a candle on the Buddhist altar [for the daughter] was gently moving. "Mari, I know you are there. I am so sorry that the organ donation was aborted. It was really too bad. But you rejected the transplantation [from the state of brain death], didn't you? You did not want to see your father suffer anymore, did you? We did the right thing, didn't we? After all, your beloved Daddy finally came back to you, Mari." [5; authors' translation]

What we see here is that the mother reinterpreted the unanticipated termination of organ donation as an expression of her daughter's wish to reject organ donation. We insist that this act of reinterpretation is very meaningful for the mother from the narrative perspective because it allows the mother to bring closure to the daughter's life narrative.

We would especially like our readers to pay close attention to the mother's comment about the father finally coming back to his daughter. The comment might seem peculiar, but there is a narrative explanation. Ten months after Mari was born, her parents divorced, and the father remarried and began another family. While Mari was growing up, daughter and father rarely saw each other. The father was led to believe that Mari hated him, and she started rebelling against him. It was at the hospital that the father finally returned to his beloved daughter, now in brain death.

The mother told the father that Mari was in fact very proud of him. He was told that Mari misbehaved only in an attempt to get his attention; she wanted him to be angry with her so that she could believe that he cared about her. Then the father wept, and said, "Indeed, Mari has loved me, hasn't she? I have done nothing for her" [5; authors' translation]. When the father signed the consent form, he intended to carry the burden of his guilt for the rest of his life. What lies behind this mournful resolution is the father's profound regret that he had wronged his daughter and would have asked for forgiveness from her if he could.

The father and daughter were estranged even though they wanted to see each other. The irony is that the daughter's brain death appears to have reunited the

family. From the mother's comment, "After all, your beloved Daddy finally came back to you," we can assume that the mother was engaging in an act of reinterpreting and retelling. She reinterpreted Mari's brain death as the means by which she was finally reunited with her father, just as she had wanted. Her father finally had the opportunity to come back to his daughter with a genuine sense of contrition. Thus, hidden deep inside this case is another layer of narrative: the narrative of estrangement and reconciliation.

All narratives, including the mother's, are potentially interminable. The mother concludes the article by suggesting that her narrative continues: "Now, I am wishing and waiting for someone to approach me as Mari said. One day I sincerely believe someone will come" [5; authors' translation].

Also, as Walter M. Robinson points out, family stories are sometimes "messy and may be internally contradictory as well as self-serving" [9, p. 99]. Some may argue that the mother's reinterpretation and conclusion are too subjective and too arbitrary to be morally justified. The parents got what they wanted—the termination of organ donation—and they simply crafted their stories to meet that need. Yet, we believe that this case shows why such "messy" and "contradictory" narratives of patients and family members are valuable to health care professionals.

People often operate in morally different ways in the spheres of narrative responsibility than in those of formal ethical decision making. In the sphere of ethical decision making, deciding or making the "right choice" by using sound justification is given the highest importance. In contrast, in the sphere of narrative responsibility, what matters most is holding oneself responsible for multiple narratives. We believe that the sphere of ethical decision making is important because it allows health care professionals and ethicists to make and suggest practical and workable ethical decisions. Yet it is worthwhile also to put an emphasis on narrative responsibility for several reasons. Narrative responsibility illustrates that human relationships are integral to our moral system. We have seen in this case study that the parents' conflict was essentially relational. We have also seen that, for them at least, their relationship with their daughter was based not on aspects that could be reduced to objects of moral justification but on aspects that were worth being forever responsible for. Thus, the narrative approach is indispensable to our moral system; narratives are capable of depicting human relationships in vivid and rich ways—in ways that principles, rules, and theories are not capable of.

Lastly, we suggest that by relying only on the traditional, principles-based interpretation of a moral dilemma, health care professionals and ethicists can fail to grasp the ways in which different patients and their relatives may perceive and interpret a moral dilemma. The case here illustrates that narratives can conflict with each other, giving rise to a different type of moral dilemma and causing the parents to feel guilty about not fulfilling their responsibility to honor both narratives. We also hope that the idea of "narrative dilemma" can provide health care professionals and ethicists an alternative way of handling moral dilemmas as they support patients and family members who must make difficult and painful ethical decisions.<sup>3</sup>

<sup>3</sup> Additional related materials can be found at <http://www.lifestudies.org>.



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