

Modern Frankenstein?



The Science and Social Science of Organ Replacement

by

Susan M. Nava-Whitehead, Kerri W. Augusto, Korryna A. Finkelstein, Shianna Cruz, & Joel Clark
Becker College, Worcester, MA

Part I – An Unexpected Turn

At the age of 15, Ava Simons was living a dream. A gymnast since the age of three, she excelled at her sport and had been scouted by an elite coach from the US National Team. Although her parents' business prevented them from relocating, they allowed Ava to move across country, where she lived and trained with her teammates near the national training facility. Ava claimed a number of titles and medals, and by the age of 16, had a handful of professional endorsements, a near-guaranteed spot on the next US Olympic team, and minor celebrity status. Media attention highlighted Ava for two distinct personal attributes: her perfect smile, and her ability to “remain humble and grounded.”

“The former,” Ava was often quoted as saying, “comes from good genes. And the latter, from my faith.” Raised by parents who claimed to be Humanistic Jews, Ava had re-discovered her faith after relocating and rooming with an Orthodox teammate. She embraced these more conservative views and thanked God, each day, for her good fortune.

On the morning of her 16th birthday, Ava's life took an unexpected turn. During a routine practice, she found herself winded and in need of several breaks. Fatigue overwhelmed her, and her stomach began to cramp. The following day, the pads on her fingers and toes became inflamed and tender, and her palms appeared mottled with red blotches of color. Deciding she had a viral infection, Ava took two days off from practice. On the third day, she returned to the gym with the intention of easing back into her routine. But while attempting a simple warm-up on the floor, Ava collapsed and lost consciousness.

Ava awoke several hours later in a hospital bed, her mother and a cardiology resident by her side.

Question

1. Given these symptoms, brainstorm some possible causes for Ava's condition.

Susan Nava-Whitehead is a professor of science and education; Kerri Augusto is a professor of psychology; Korryna Finkelstein, Shianna Cruz, and Joel Clark were undergraduate students at Becker College when this case study was originally written.

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Part II – Available Options

The first thing Ava noticed were the tears streaking down her mother’s cheeks. “Welcome back,” her mother said.

The resident stepped forward and introduced herself. “You’re a lucky young woman,” she said. “Your coach got you here right away and we were able to intervene. But your situation is serious, Ava. You have a condition called endocarditis—an infection. You had a cardiac episode and a minor stroke.”

Ava tested her limbs and her voice, terrified of paralysis. “But I’m okay?”

“You were lucky,” the resident repeated. “But you aren’t out of the woods. We can fix the infection, but there’s significant damage, and you need a heart valve replacement to prevent additional problems.” Ava shook her head in protest.

“Without it,” her mother said, “you can have another stroke; a much more severe one.” She paused and a pleading look came into her eyes. “Ava, I know what you’re thinking. But this isn’t a choice. A stroke killed Grandma Rosen when I was your age. I lost my mother, and I’m not losing my daughter.”

The resident continued. “We’ve discussed your options with your mother and thoracic team. Your mother has decided to opt for the fastest route to getting you in and out of here. We will be replacing your valve with a porcine one.”

Ava felt the world slip out from under her. She shook her head and glared at her mother. “Porcine? Like pig? Mom, I’m not having a pig inside my body.” She turned to the resident. “I’m a vegetarian and it would be totally against my religion.” Her mother made a guttural sound of protest. “I know you don’t care about Judaism or my dietary choices,” Ava continued. “But you’ve let me live on my own for two years. You’ve trusted me to make my own choices. And I’m making this one too. I’m not doing this.” Again she turned to the resident. “Can’t I get on a waiting list for a human valve? Or get a plastic one or something?” The room began to spin and a monitor beeped.

“We are not waiting,” her mother interjected, an edge of unexpected anger lacing her words. “This is life and death, Ava. I’m still your mother. And you are only 16. You are having this surgery as soon as possible. The porcine valve is your best option. If you have another stroke we might not be as lucky....”

“Mrs. Simons,” the resident interjected, “nothing needs to be decided tonight. Ava needs to rest. Perhaps we can revisit this when the specialist comes in tomorrow morning.”

The next day, Ava’s mother arrived at noon. “I have a solution,” Ava said with a smile. “Coach Brian did some research on the Internet. He says doctors at Cornell are using 3D bioprinting to create human tissues. No waitlist. No pigs. He’s trying to see if there’s an open clinical trial.”

Her mother frowned. “I’m sorry Ava. This isn’t your coach’s choice or yours. We’re not going that way. I’ve already signed papers for the porcine valve. I know you don’t like it, but you are 16. I’m your mother, and this one has to be my decision.”

Ava’s face turned stony. “We thought you’d say that. In addition to calling Coach Brian, I called my attorney. He thinks he can get me declared a mature minor. The choice is mine.”

“Mature minor? We’ll see about that!” Her mother began to yell. “There is nothing mature about you right now. I let you move in with that team, gave it a chance. But clearly that was a mistake. You’ve been living a crazy life and the adults you live with are clearly incapable of giving informed advice. If you want to take this to court, we can. But you are wasting valuable time and money, Ava. You are being stubborn and ridiculous. I am your *mother*... .”

After a brief emotional exchange, Ava’s mother headed home to call her own attorney.

Question

1. Ava requires a heart valve replacement. List at least two available options and provide the pros and cons of each. Consider all stakeholders’ perspectives.

Major Theories of Child and Adolescent Development

Table 1. Piaget's Stages of Cognitive Development

<i>Stage</i>	<i>Description</i>
Sensorimotor	Differentiates self from objects. Recognizes self as agent of action and begins to act intentionally. Achieves object permanence (realizes that things continue to exist even when they are no longer present to the senses).
Preoperational	Learns to use language and to represent objects by images and words. Thinking is still egocentric (has difficulty taking the point of view of others). Classifies objects by a single feature (e.g., groups together all the circles regardless of their color).
Concrete Operational	Can think logically about objects and events. Achieves conservation of number and mass and weight. Classifies objects according to several features and can order them in series along a single dimension, such as height.
Formal Operational	Can think logically about abstract propositions and test hypotheses systematically. Becomes concerned with the hypothetical, the future and ideological problems.

Table 2. Kohlberg's Stages of Moral Development

<i>Stage</i>	<i>Description</i>
Obedience/Punishment	No difference between doing the right thing and avoiding punishment.
Self-Interest	Interest shifts to rewards rather than punishment—effort is made to secure greatest benefits for the self.
Conformity and Interpersonal Accord	The “good boy/girl” level. Effort is made to secure approval and maintain friendly relations with others.
Authority and Social Order	Orientation toward fixed rules. The purpose of morality is maintaining the social order. Interpersonal accord is expanded to include the entire society.
Social Contract	Mutual benefit, reciprocity. Morally right and legally right are not always the same. Utilitarian rules that make life better for everyone.
Universal Principles	Morality is based on the principles that transcend mutual benefit and achieve a higher level of “philosophical good.”

Table 3. Marcia's Theory of Identity Development

	<i>Low-Level CRISIS</i>	<i>High-Level CRISIS</i>
<i>Low level COMMITMENT</i>	<i>Diffusion</i> No clear identity; making no attempt to search for one; might be struggling.	<i>Moratorium</i> Vague or ill-formed commitments; still undergoing identity search or crisis
<i>High level COMMITMENT</i>	<i>Foreclosure</i> Blindly accepts identity and values given from childhood by family and others; committed to identity but has never searched or experienced crisis.	<i>Achievement</i> Clear sense of personal identity; well-defined personal values; strong ego; has experienced a search or crisis; strong commitment to personal identity.

A *crisis* refers to the adolescent's period of engagement in choosing among meaningful alternatives; searching for an identity. *Commitment* refers to the degree of personal investment the individual exhibits. Marcia believed a well-developed identity equated to: a strong sense of personal strengths, weaknesses and uniqueness; higher self-esteem; increased critical thinking; advanced moral reasoning; and lower levels of anxiety.

Table 4. Erikson's Theory of Psychosocial Development

<i>Basic Conflict</i>	<i>Important Events</i>	<i>Outcome</i>
Trust vs. Mistrust	Feeding	Develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust.
Autonomy vs. Shame and Doubt	Toilet Training	Develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy, failure results in feelings of shame and doubt.
Initiative vs. Guilt	Exploration	Begin asserting control over their environment. Success leads to a sense of purpose. Those who fail may exert over-control, resulting in disapproval from others and a resulting sense of guilt.
Industry vs. Inferiority	School	Begin learning to cope with social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority.
Identity vs. Role Confusion	Social Relationships	Success leads to an ability to stay true to oneself, while failure leads to role confusion.
Intimacy vs. Isolation	Relationships	Success leads to strong relationships while failure results in loneliness.
Generativity vs. Stagnation	Work and Parenthood	Begin nurturing things that will outlast them. Success leads to feeling useful and accomplished, while failure results in shallow involvement in the world.
Ego Integrity vs. Despair	Reflection on Life	Look back on life and feels a sense of worth and fulfillment. Success leads to feeling wise, while failure results in feeling bitter and filled with regret.

Part IV – Public Hearing

The court decides that any decisions about Ava’s treatment should be made by her mother. Although Ava is resigned to having the transplant, they soon learn that insurance will not fund the procedure, as it is considered an experimental surgery. Undeterred, Ava’s mother begins an online crowdfunding campaign to raise money to save Ava’s life.

One month after her initial collapse, Ava opens the newspaper and sees the following headline: “Xenobiotechnology: Frankenstein may be in your backyard.”

Though vague in details the article is enough to stimulate heated public debate around many moral and ethical issues surrounding Ava’s surgery. Over the next few weeks, picket lines form in front of the hospital where the surgery is expected to take place and strangers flock from all over the state to have their say in a public forum designed to maintain the flow of communication and reduce the risk of violence.

You will be assigned the role of a stakeholder in this case. Consider the questions involved in this case and construct a position consistent with your role. The instructor will serve as a moderator as you enact this public discussion.

Stakeholders

- Member of PETA (People for the Ethical Treatment of Animals)
- Local Chaplain
- Clinical Psychologist
- Public Health Employee
- Attorney with the American Civil Liberties Union
- Recipient of an UNOS (United Network for Organ Sharing) donor heart

Member of PETA

You are a resident of the local community and a member of PETA (People for the Ethical Treatment of Animals). You have come to this public forum to speak to the following two questions:

1. Is it ethical to kill an animal so that a human can benefit?
2. Are animal parts compatible with human bodies as is, or will this decision start us down a path of genetic modification? And if so, should we be concerned?

Discuss these issues among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.

Local Chaplain

You are a local Chaplain who has come to this forum to represent the voices of several religious groups in the local community, which includes Jehovah Witnesses, Christian Scientists, Jews, Muslims, and Christians. Chief among your concerns is:

1. Are there religious concerns and objections to be considered around the issue of xenotransplantation?

Discuss this issue among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.

Clinical Psychologist

You are a clinical psychologist living in the local community. You have come to this public forum to raise two important issues for discussion.

1. Is the rush to facilitate xenotransplantation procedures a valid attempt to save lives? Or is it another expression of our society's inability to accept death and dying as a part of life?
2. Might human recipients of animal donor body parts be at increased risk for developing body integrity identity disorder?

Discuss these issues among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.

Public Health Employee

You are a public health employee working in the local community. You have come to this public forum to raise three important issues for discussion.

1. Can disease be transferred from animals to humans when body parts are transplanted? And if so, what are the risks and legal ramifications if disease is transferred from the animal donor to the patient?
2. Can the health care team members be at risk? What about the community at large?
3. What are the benefits/risks of conducting clinical trials in our community? Who approved this trial?

Discuss these issues among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.

Attorney with the American Civil Liberties Union

You are an attorney working for the American Civil Liberties Union. You are concerned about the following questions:

1. What are the economic issues that need to be addressed?
2. How will organs be distributed? Who will receive animal versus human organs?

Discuss these issues among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.

Recipient of an UNOS (United Network for Organ Sharing) donor heart

You are a recipient of a donor heart. You waited several years to move up the UNOS (United Network for Organ Sharing) list, but ultimately had a successful transplant. You have come to this meeting with the following concerns:

1. How might xenotransplantation impact the current practices related to obtaining organs?
2. How might xenotransplantation impact the availability of organs for those who are in need?

Discuss these issues among your group. Use whatever resources you have available to educate yourselves on these issues and prepare to join a discussion with other members of the public forum.