The Case of Jahi McMath: Race, Culture, and Medical Decision-Making

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I have been following the very unfortunate case of Jahi McMath. McMath is a 13-year-old African-American child in California. She went into cardiac arrest and suffered irreparable brain damage after undergoing a tonsillectomy to relieve sleep apnea.5 Her story has frequently been in the news and has been portrayed as a battle between Children's Hospital Oakland, where her surgery was held, and her parents, who disagreed with the hospital's recommendation to discontinue all life-sustaining practices. This battle has both legal and medical components. Medical practitioners, children's rights advocates, right-to-life groups, legal experts, and bioethicists have all weighed in on the relevant issues that a case like Jahi McMath raises.

A review of the literature reveals one major yet forgotten issue in the McMath case: the intersection of race and medicine. Bioethicists are calling on the public to inform themselves about the concepts that are more or less common topics of discussion in bioethics, such as the medical and legal definitions of death, rather than relying on emotional responses. But bioethicists must also advocate using lessons about race and culture, and their relationship to decision-making in medicine, of which bioethicists are well aware.

After literature searches of bioethics and popular current news databases, this author did not find any articles that addressed a possible relationship between culture and decision-making in the McMath case. When ethnicity or race was mentioned, the words "African-American" or "black" were used only as terms to identify the ethnicity or race of McMath and her family. But besides medical and legal issues, the Jahi McMath case presents an interesting illustration of the intersection of medicine and the roles that race and culture play in making medical decisions, especially end-of-life decisions. Without assuming that all members of a particular race have the same relationship with medicine, we have to consider the historical relationship between racial minorities and medicine while also employing the basic standards of good patient-practitioner relationships. Medical practitioners have to understand how race and culture can influence medical decisions to understand why racial minority patients or their proxies make particular choices about healthcare. This idea seems to be lost in the way news outlets and bioethicists alike discuss the McMath case.

The contentious nature of Jahi McMath's case began after she was declared brain dead by physicians, which was followed by the recommendation to end life-sustaining procedures. Prompted by McMath's family, a federal judge issued an order prohibiting Children's Hospital Oakland from stopping life-sustaining procedures. After McMath's family and the hospital reached an agreement, McMath was released to the coroner, who then released her to the custody of her mother. McMath then entered a long-term care facility, where she remains as of June 2014.1,7

The McMath case also raises conceptual and metaphysical issues concerning the medical definition of death. Loss and irreparable functioning of the brain, including the brain stem, is a common and accepted medical and legal definition of death; however, as evidenced by this case, this definition can be difficult for individuals outside of the medical and legal community to accept. Medical experts, including neurologists, declared McMath dead. Subsequently, based on the empirical evidence, they declared that McMath could

not recover the bodily functions that were lost.3 Right-to-life groups and McMath's parents believe that McMath is not dead because her heart is still beating. And they believe that she still has the potential to recover.7

One reason why McMath's family believes that Jahi is not dead is because of their religion. As reported by the Los Angeles Times, "Plaintiffs are Christians with firm religious beliefs that as long as the heart is beating, Jahi is alive."7 After a county court judge ruled that life-supporting procedures can be stopped while allowing McMath's family to appeal the decision, Jahi's uncle, Omari Sealey, reportedly said that "prayers are more important than ever before."3 Nailah Winkfield, McMath's mother, wrote an open letter addressing her daughter's situation. In it she states that she believes McMath is alive because she is "warm" and she "responds to [her mother's] touch." Winkfield also states that she knows God will "spark her brain awake."7

Beyond the conceptual, medical, and legal aspects of the McMath case, culture and decision-making are also pertinent. Understanding patients' and their families' decision-making approach is important to the patient-physician relationship because it can foster dialogue between practitioners and the family. By making an effort to understand the reasoning behind certain medical decisions of patients and their families who are a part of a racial minority group, physicians can ensure that they do not feel alienated or ignored. One way to prevent alienation is to take into consideration the culture of both the patient and her family. For instance, members of the McMath family have identified themselves as followers of Christianity. It is very common for African-Americans to identify as Christian or followers of another religion. (The U.S. Religious Landscape Survey of 2008 reports that of the major racial groups, blacks, which could include individuals who do not identify as African- American, are most likely to report that they identify with a formal religion, with 85 percent of self-reported blacks identifying as Christian. The survey also reports that of the 12 percent of blacks who did not identify with a formal religion, two-thirds of these individuals still reported that religion is somewhat to very important in their lives, while only 1 percent of blacks identified themselves as atheist or agnostic.)8 Knowing this, as well as the likelihood that their African-American patients may be part of the 85 percent of blacks who identify as Christian, or the 12 percent who identify as somewhat religious, can give a medical practitioner a better understanding of her black patients.

It is common for Christians to turn to their faith in perilous times. This can mean that they leave major decisions about life and death in the hands of God, whom they believe to be an omnibenevolent, omnipotent being, rather than in the fallible hands of humans. Acknowledging this can shed light on why a Christian family such as McMath's would want to continue life support for Jahi. If physicians consider what influences a patient's decisions, such as religion, they may see an increased acceptance of their care recommendations. Patients may nevertheless reject recommendations because of cultural norms or past experiences, and it is possible that physicians' recommendations will be rejected because of a family's Christian beliefs.

Another reason why a practitioner's recommendations might not be accepted by minority patients is because of the damaged relationship between individuals in minority groups and the medical community.4 This is another perspective on the McMath case that seems to have been left out of articles yet is frequently discussed among bioethicists: the legacy of distrust and suspicion between the African-American community and medicine. Historical cases like the Tuskegee syphilis study along with eugenics and race-based medicine, which presumed that African-Americans were mentally and physically inferior to whites, have created a lasting sense of distrust of and alienation from medicine by many African-Americans.6 When interacting with African-American patients, medical practitioners cannot ignore

that remnants of and current instances of racial disparities in health care affect the modern relationship between African-Americans and their caregivers.

Perceived racism can also influence medical decision-making by African-Americans. Past transgressions by medical practitioners and instances of current unjust treatment can lead African-American patients to question the motives of their caregivers. For example, when a physician makes a decision for an African-American patient that she or her family does not agree with, such as an early discharge from a hospital or a failure to administer diagnostic tests that the patient requests, the patient or family might question whether the decision is rooted in prejudice. To remedy this, medical practitioners must communicate their care plans to and practice diligence with patients and their families. Medical practitioners can also begin to remedy concerns about prejudice by showing respect for patients' and their family's decisions. One way to do this is by trying to understand why patients and their families make particular medical choices.

The typical tools that medical practitioners use to create and maintain a healthy patient-physician relationship, such as information, education, consideration, listening, and respect, have to be employed with African-American patients and their families, just as they are used with other patients and their families. However, when interacting with African-American patients and their families, medical practitioners have to use these strategies while also remember the historically poor relationship African-Americans have had with medicine. For common concepts and ideals within bioethics such as these to be understood and accepted by the general public, it is important that the public be continually educated and informed about discussions within the field. Doing so can help the public better understand cases like McMath's and attendant controversy, real or perceived, as noted by bioethicists, and then examine issues without emotional charge.

Individuals in all racial groups want great care by competent practitioners. All people want to be heard, respected, and to have their religious and cultural beliefs acknowledged by their caregivers.2 When interacting with African-American patients, caregivers must also take into account the history of racism and medicines poor performance in that context. When we discuss Jahi McMath, case we too have to take this into consideration if we want to have a better understanding of her parents' decision-making process. The bioethics and medical communities may empathize with the tragedy the family is experiencing; however, we also know that McMath is medically and legally dead even if her family believes her to be alive based on spiritual conceptions of death. Still, the bioethics and medical community, and the general public, must strive to understand McMath's family and the historical and cultural context in which they have to make life-and-death decisions for Jahi.

REFERENCE NOTES

1 Debolt D, Bender KJ, Hurd R, "Jahi McMath: Brain-Dead Teen's Family Moves Her From Children's Hospital Oakland," San Jose Mercury News, January 5, 2014, http://www.mercurynews.com/breaking-news/ci_24852227/jahi-mcmath-leaves-childrens-hospital-oakland .

2 Duffy SA, Jackson FC, Schim SM, et al., "Racial/Ethnic Preferences, Sex Preferences, And Perceived Discrimination Related to End-of-Life Care," The American Geriatrics Society54, no.1 (January 2006): 150-7.

3 Elias, Paul, "Judge Rules Jahi McMath, 13-Year Old Declared Brain Dead Following Tonsillectomy, Can be Taken Off Life Support," Huffington Post, December, 24, 2013, http://www.huffingtonpost.com/2013/12/25/jahi-mcmath-life-support_n_4500292.html.

4 Klessig, J., "The Effect of Values And Culture on Life-Support Decisions," Western Journal of Medicine157. no.3 (September 1992): 316-22.

5 Morain, Dan, “Dan Morain: Jahi McMath Case is Rifled With Tragedy and Politics,” The Sacramento Bee, January 14, 2014, http://www.sacbee.com/2014/01/05/6045087/dan-morain-jahi-mcmath-case-is.html.
6 Munson, Ronald, Intervention And Reflection, ninth edition (Boston: Wadsworth, 2012).
7 Romney, Lee, “Jahi McMath Case Muddies an Already Agonizing Subject,” Los Angeles Times, January 6, 2014, http://www.latimes.com/local/la-me-brain-death-20140106,0,5643888.story#axzz2pkPc8QBl.
8 U.S. Religious Landscape Survey, “Religious Affiliation: Diverse And Dynamic,” Pew Research Center, February 2008, http://religions.pewforum.org/pdf/report-religious-landscape-study-full.pdf.