



PROJECT MUSE®

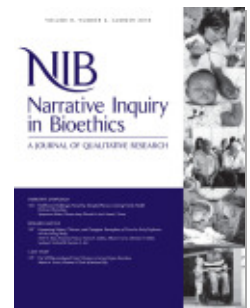
When Health History is a Matter of Life or Death

Cathy Heslin

Narrative Inquiry in Bioethics, Volume 8, Number 2, Summer 2018, pp. 113-116 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2018.0041>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/702873>

Perhaps DNA testing will get to the point where it is even more useful than family history for a majority of health care decisions. That possibility is very exciting for adoptees. But even without the benefit of any of that information, I already know that I have some medical concerns that are related to my being genetically different from my adopted family.

As an extremely fair-skinned person adopted into a family who loved to sunbathe in baby oil in the late 1970s and '80s, I got sunburned every summer as a child. I know that is a risk factor for skin cancer, so I monitor my skin regularly and if I see any significant changes, I head to the dermatologist. It doesn't matter if I have a family history of skin cancer. I already know that I have a major risk factor, and need to monitor my skin accordingly.

All people need to be the responsible drivers of their own health care, but it is especially important for adoptees to listen to their bodies, and advocate for themselves with their physicians. At the same time, it is crucial that physicians listen closely to their adopted patients, and respect the patient's autonomy and personal choices regarding their health care. Beneficence might look different for an adopted person.

It could be argued that physicians should be encouraged to do diagnostic tests on adopted persons that they would routinely do on those who have a family health history suggesting the test is warranted. And insurance companies should cover the tests. The fact that adoptees lack the benefit of a family health history might be enough to argue that justice demands this allowance. I acknowledge that there is a slim chance that insurance companies would cover some of these tests, and this recommendation might create a separate issue of justice in already constrained health care systems and specifically in resource poor settings. However, as we strive towards individualized, "precision medicine," and for the best health care possible, leveling the playing field as much as possible between the adoptee and the average person is a worthy goal for which to strive.

While there is not a simple answer to the existential question of the adoptee, adoptees should try to temper dichotomous thinking, and seek balance.

We must strive not to think either "I have every disease of which I hear" or "I am at low risk for everything because I don't know of any hereditary health problems." It is true that we adoptees are at a disadvantage as far as certain hereditary diseases go. But by adopting healthy lifestyle choices we actually can control a lot of our health outcomes, regardless of family history.

It is far better to know your family health history than not to know it. But regardless of what your family history says, it is best to incorporate healthy behaviors into your life, and be in the driver's seat of managing your own health, with a competent and caring physician acting as your navigator, confident and guide.

Author's note: This article was written in cooperation with my sister. All quotes attributed to her were from a conversation we had about this article on 11/10/2017.



When Health History is a Matter of Life or Death

Cathy Heslin

My mother called and asked me to come over one evening. It wasn't unusual, I was 27, and I visited regularly. She lived only a few miles from my apartment, so rather than going home after work, I went straight over to her place.

It was getting dark as I drove up to her Portland bungalow. I gave a quick knock and then let myself in. She was sitting by the fire and her husband got up and walked into the back office as I came in. I could hear muffled sobs coming from the kitchen.

"What's going on?" I asked.

"Come sit," she said.

My mother told me she had a brain aneurysm. She went on to explain that her sister was diagnosed first, and because first-degree relatives (parents, children, siblings) were at a higher risk for also developing an aneurysm, her doctor recommended

that the siblings get tested. Of the eight siblings, three of the sisters, one being my mother, were discovered to have an aneurysm. The three sisters were all going to undergo brain surgery within the next few weeks.

"You should get tested as well," she said.

I sat stunned and speechless.

While this would be a distressing family health crisis for anyone, it was particularly striking for me because the "mother" I am referring to is my birth-mother. We met nine years earlier when I turned 18, despite being in a closed adoption in a state with sealed records. After processing the shock of my birthmother facing a brain surgery, realizing that I was at risk of a potentially life-threatening condition threw me. It sunk in that I would never have known that aneurysms were something I had to be tested for unless I was in reunion. It felt as if I had been yanked back from stepping into oncoming traffic. There was no way I could have seen it coming.

My brother and I had known we were adopted since we were very young. While my parents were always open and supportive, I quickly learned that asking questions about where I came from was useless; they just didn't know.

It wasn't until I was a teenager and went to my first OBGYN appointment that I realized that being adopted left a gap in my knowledge that affected my ability to take care of my own health. When I went into the doctor's office, the OBGYN asked when my mother had her first period. I explained I didn't know, that I was adopted.

She read off the next question that was also about family history and I had to remind her, "I don't know."

"Right," she said, and flipped over the paper to the questions that I could answer. I hadn't realized before then that it might be something that was important for me to know.

Adults had always acted like the parents I was born to were irrelevant; that all that mattered was that I had parents who loved me and took care of me. But, how could they truly take care of me when they didn't know anything about me? They knew what I was like from the time I arrived in

their home, but nothing about my nationality, my heredity, or my genes. There was no way to know about predispositions in my family, tendencies that I should know about, of things to avoid. If those things didn't matter, why did doctors ask about them? I realized then that who I came from might be more important than anyone had ever admitted.

My parents had always told me they would help if I wanted to find out more about where I came from, that I just had to wait until I was legally an adult at eighteen. So, a month before my eighteenth birthday, I told them I wanted to search. My brother asked why I would want to.

My brother, also adopted, was eighteen months older than me and had no desire to find out anything about his own family. We came from different parents, we weren't siblings by blood. He half-joked that he had enough problems with our own adoptive parents, why would he want to deal with another set of parents?

Although I never said it out loud, I wondered if he was secretly worried about what he might find out. My brother was explosive, angry, erratic and prone to violent outbursts. He was smart, but did terribly in school. He didn't get along with other kids. My parents didn't know how to help him. I both feared and pitied him.

I couldn't tell him or anyone else what I hoped to learn by unearthing my roots, but health history was one good reason, so I stuck to that. My parents got me the number to the adoption agency and I set up an appointment to meet with them right after my eighteenth birthday. The agency explained I would be able to see my "non-identifying information," which would have any health information as well as nationality and some other things that would give me insight into where I came from.

The day I went to the adoption agency, I felt a nervous thrill as I took the papers from the social worker, sure I was about to discover the truth of my identity. As I scanned the information, my excitement faded to disappointment. The document revealed some of my heredity (a mix of Polish on my father's side and a British mash on my Mother's side of Irish, English, Scottish and Welsh), but the health information was no more than a couple

sentences noting that both the mother and father were healthy at the time of the adoption and their parents were alive. It may have mentioned cause of death of my grandparents on my mother's side, but that was pretty much all it contained. As far as discovering what were the health issues to look out for, I was no better off than I had been before I went to the office that morning.

However, the lack of insight was soon made insignificant because my birthmother had also reached out to the agency on my 18th birthday. The social worker explained I would be able to meet her if I chose to. New Jersey had sealed records at the time, so the only reason we were able to meet is because we both sought each other out. Had I contacted the agency but my birthmother hadn't, they were forbidden by law to give me any information on how to contact her.

I met my birthmother, Kate, a few weeks later. I learned the circumstances of my conception and relinquishment (an unplanned pregnancy at 18 after several indiscretions with a casual friend). She told me about her family and upbringing and what she knew about my father. I asked her what I should know about her family's health history.

"Nothing much," she said. "My grandmother died of a heart attack, I think. My grandfather died of old age, really. Otherwise, everyone in my family has been pretty healthy. We're lucky."

I didn't feel lucky, or reassured. Kate had no information on my father's health history since she didn't know him well and didn't keep in touch with him after she discovered she was pregnant. Once again, I felt as though I gained no information that was helpful or useful. I still wasn't sure what I was hoping for in reunion.

But, I stayed in touch with Kate after that initial reunion and, a decade later, I met my birthfather. With both of them in my life, the missing puzzle pieces finally fit to reveal the entire picture of who I was.

Learning my health history was a process that unfolded over time.

I learned that direct family members on both my mother and father's side had problems with alcohol. Since alcoholism in a close family member increases

a person's chances of also having addiction issues, I learned to keep a close watch over my relationship with alcohol.

My birthfather noticed during a visit once that my hands shook. I explained that it always concerned me, but that I asked my doctor and after some preliminary tests, they didn't think there was any underlying health issue. My birthfather said that his hands shook as well, as did his brother's. It was just something in our family, nothing I needed to worry about.

Another time, I discovered a lump in my breast and told Kate about it. She said that she had that happen once as well, but it was benign. When I went to have my mammogram, I was asked if anyone in my family had ever discovered lumps in their breasts. I was about to go on autopilot to reply that I didn't know, when instead I answered, "My mother! She had a lump, but it wasn't cancer." The technician nodded and made a note in my chart. I wondered if I came across as disproportionately excited about my mother having a lump in her breast, but I was just so pleased to actually have an answer.

There were other discoveries that were less obvious, but just as important to understanding how to manage my health. For example, many of my relatives were creative—either artists, musicians, or writers. I learned that channeling my stress into art helped me work through difficult emotions.

I have often wondered if things would have been different for my brother if he had decided to search for his birth family after all. He may have benefited by learning how they dealt with anger, or discovered that they too had a learning disorder and how they overcame it. He may have discovered that there were traits in his family that brought them together, and would make him feel less alone. We may have been able to find out that he had fetal alcohol syndrome, something I began to suspect after I first learned about the disease, but could never confirm whether it was true.

Instead, after years struggling with addiction, he took his life, hanging himself in his friend's garage. He was lost and alone and couldn't quite figure out how to make his life work in this world. So, instead,

he cast aside this life, and left a tremendous amount emotional damage in his wake.

I also learned that adoptees are four times more likely to attempt suicide than someone who isn't adopted. Doesn't it seem like that's the kind of health information that should be widely shared? Shouldn't adoptive parents know, so they can be vigilant? Shouldn't adoptees know, so when suicidal thoughts come up they can understand they're not alone, and go for help? Isn't that healthier than just pretending who your original parents were doesn't matter? Isn't that more ethical that saying adoption doesn't cause trauma?

My birthmother and her sisters survived brain surgery and are all doing well. Soon after Kate returned home, I went to my doctor to get an MRI. I didn't know whether my insurance would allow it. It was illogical, but I was so used to associating who I was to my adoptive family, even though we didn't share genetics, that I worried they might not consider my birthmother "family."

The MRI came back negative. I will have to get checked periodically, something I would have never known to do had I not been in reunion. After all, health history doesn't end at the birth of a child; it unfolds alongside life. And, in more ways than one, having access to that information can be a matter of life or death.



A Personal Reflection on the Medical History Questions facing Adopted Persons

Mark A. Cotleur

I think it is important that I preface my reflection with a comment on the term "parent." I want to be clear that when I use the term "adoptive parents" I do so only to make the distinction between my "biological parents" and my "adoptive parents." Simply put, my adopted parents *are* my parents. The other couple are the people who conceived and bore me. They are not my parents.

I am a person who has known from my earliest memories, that I was adopted, and, at the same time, I am also someone who is extremely grateful that I was adopted by very caring, selfless parents who raised me in a loving and nurturing home. Having the book, "The Chosen Baby" read often to my adopted sister and me, and hearing a recounting of the stories of the journey our parents went through to adopt us, I have always known I was adopted. It was part of our family lexicon, and I always felt special and "chosen" as a result.

I make this point because I think this is important to note that the fact that I was adopted has rarely surfaced to the point where I was actively aware of it. I rarely think about the fact that I am adopted—let alone refer to myself as an "adoptee" or "adopted person."

Interestingly enough, throughout my life, the topic has only surfaced in the context of discussing family medical history, which is why I am most interested in participating in this discussion.

I don't know how other adopted persons feel about honoring the privacy of their biological parents, but I can say that, part and parcel of my gratitude for the family who adopted me, I have a sense of gratitude that is equally profound for my biological parents because of the difficult decision they made to "offer me up" for adoption. As a parent myself who feels the strongest bond to my two daughters, I have to believe that there was a strong bond my biological parent felt as well. Yet, they knew the right decision for my future was adoption, so I truly believe that the word "offering" is the most appropriate word to describe their other-centered action. For this reason, I have always considered the privacy and anonymity of my biological parents to be truly sacrosanct. They made the difficult decision to pursue adoption on my behalf based, in part, on the understanding that their privacy would be honored. This promise of privacy is imperative for those making such a heart-wrenching decision and so I think that they have every right to expect this promise would be honored going forward.

I was adopted through Catholic Charities for the Diocese of Cleveland in Ohio. I was born in 1964 at St. Ann's Hospital and cared for by the Sisters