



Narrative Inquiry in Bioethics

A Journal of Qualitative Research

Call for Stories

Healthcare Challenges Faced by Adopted Persons Lacking Family Health History Information

Symposium Editors Thomas May, PhD, Richard Lee, PhD and James P. Evans, MD, PhD

Narrative Inquiry in Bioethics will publish a collection of personal stories from adopted individuals about their experiences navigating the U.S healthcare system while lacking family health history information from genetic relatives. We will approach the experiences of adopted persons in this context from a variety of perspectives: Has missing family health history caused concern about interpretation of symptoms? Have inherited disease conditions emerged that might have been detected earlier had it been known that this “runs in the family” of genetic relatives? Have you undergone unnecessary testing for symptoms or screening for conditions because you lacked reassuring family health history that would help assess the likelihood of an inherited disease? Has the lack of family health history from biological relatives caused you embarrassment or anxiety while undergoing a medical exam or treatment? Has missing family health history influenced your family planning or reproductive decision making?

We seek stories from adopted individuals who have first-hand experience engaging health services where better access to family health history would have been helpful.

We want true, personal stories in a form that is interesting and easy to read. **Please share this invitation and guide sheet with appropriate individuals.**

In writing your story, please consider these questions:

- How have your healthcare providers react to your not having family health history information?
- How do *you believe* better access to family health history would have helped your healthcare?
- Do you believe you were subjected to unnecessary testing or screening because you did not have family health history to help assess risk for inherited disease?
- Do you believe symptoms of an inherited condition were missed or misinterpreted because you did not have a family history to provide context for interpreting these symptoms?
- What obstacles or challenges have you face in you interactions with health providers because you lacked family health history?

You do not need to address each of these questions—write on the issues that you think are most important to share with others. **If you are not a writer, tell your story in your own words and our editorial staff will help you.**

If you are interested in submitting a story, we ask you to **first submit a 300-word proposal**—a short description of the story you want to tell. **Inquiries or proposals should be sent to the editorial office via email: narrativebioethics@gmail.com. We will give preference to story proposals received by January 15, 2018.**

We plan to publish 12 stories (4 – 10 double-spaced pages or 800 – 2000 words) on this topic. Some additional stories may be published as online-only supplemental material. We also publish 2 – 4 commentary articles that discuss the stories that are published in the journal. To see a finished symposium you may access *Narrative Inquiry in Bioethics* Volume 3.1 for free on [Project MUSE](#). For more information about the journal *Narrative Inquiry in Bioethics*, the guidelines for authors, and privacy policies, visit our webpage at: <http://www.nibjournal.org/authors/guidelines.html>

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