

Focus Group Attitudes and Opinions About the Potential Use of Genomic Sequencing as a Substitute for Genetic Medical Information for Adult Adoptees

This study was conducted by the MCW Program in Genomics and Ethics

Alison La Pean Kirschner, MS, CGC¹; Thomas May, PhD¹; Kaija Zusevics, MPH, PhD¹; Kimberly A. Strong, PhD¹; Harold Grotevant, PhD²; Samantha Wilson, PhD¹; Jessica Jeruzal, BA¹; Arthur Derse, MD, JD¹; Carmen Knight, BA³; Michael H. Farrell, MD¹

¹Medical College of Wisconsin, Milwaukee, WI; ²University of Massachusetts Amherst, Amherst, MA; ³Edgewood College, Madison, WI

Background

There are currently about **7.8 million adoptees in the U.S.** For many of these adoptees, genetic medical information is missing for at least one biological parent. The importance of genetic health information is well established in medical practice. There are considerable challenges posed to adoptees by a lack of access to genetic medical history, including failure to screen for conditions due to limited or no biological family history; delays in diagnosis of conditions for which biological medical history would facilitate early identification and interpretation of symptoms; and significant adoptive parental anxiety due to uncertainties about the etiology of certain conditions.

Genome Sequencing (GS) is the process of determining the complete DNA sequence of a person at a single time. GS offers the possibility of "filling the gap" of dispositional genetic information that would normally be available to individuals and healthcare providers through observation and family history. Eliciting attitudes and opinions about the use of GS as an alternative route to this important health information may contribute not only to the health and well-being of adoptees, but may also be relevant for other groups with missing genetic health information (e.g., individuals conceived via gamete donation or raised in single-parent households).

Purpose of this Study

This pilot study sought to explore opinions about the potential usefulness of GS as a means of "filling the gap" of genetic information for adults who were adopted (internationally or domestically) as infants/young children.

Methods

Focus Groups

- International and domestic adult adoptees were invited to participate in one of 4 focus groups held in the Milwaukee Metro Area
- U.S. distance participants were included via Skype

A facilitator provided background information about the study and about GS. Participants were invited to provide opinions and feedback about specific topics regarding access to genetic health history and perceptions of GS. Conversation was prompted by the facilitators with overarching questions in mind, while free-flowing discussion about related topics was encouraged.

In total, 17 adults participated in the focus group study representing 5 countries of origin and diverse adoption experiences (e.g., variable access to biological family).

Qualitative Analysis

Focus groups were audio recorded and transcribed. Data reduction and preliminary qualitative analysis were conducted using standard coding, memoing and content analysis methods aimed to reveal themes and questions surrounding the use of GS and its potential role as a substitute for genetic medical information in the context of adoption. All transcripts were analyzed using QSR NVivo 10.

Results

Focus group participants offered a range of opinions, attitudes, concerns, and questions about the potential use of genome sequencing within the adoption community. Below are preliminary quotes that illustrate emerging themes regarding adults' perceptions of the unique issues regarding the use of genomic sequencing to 'fill in' missing genetic medical information.

Narrative Burden & Not Knowing

- Lack of genetic medical information continued to engender a "narrative burden" for some participants.

"It comes up. Actually, I have three children...I'm always ask[ed]... 'What's your family history?' ...and I don't know my family history...so just mark them 'Don't know.' And every once in a while I'll get a nurse that will look at me, and say, 'Well, why don't you know?' So I get those [comments]...medically-wise I've...been hassled quite a bit."

- Importance of genetic medical history information varied based on whether or not participants perceived themselves to be "sick."

"...we [focus group participants] are all fortunate enough not to have any childhood medical histories [problems]. So it's [genetic medical information] not a big concern."

Increased Medical Information

- Participants acknowledged the potential GS might offer with regards to medical information but expressed ambivalence about access to increased health risk information.

"It's sort of like when someone asks if you want to go see a psychic...it's interesting enough where like, 'Yeah, that'd be kind of cool' but then when you're right by the door you're like 'Do I really want to know what they potentially may have to tell me and, if I do, how is that going to change how I live my life?'"

"I have had enough sad stuff in my life...I don't need clouds up ahead [i.e., genetic risk knowledge]."

"...my whole life I said 'I wish I had this, I wish I had this,' and now I'm sitting here and you're asking what [medical information] do you wish you had, I don't know."

Perceived Benefits & Risks

- Participants noted benefit of knowing genetic risk factors through GS.

"For me...the benefits would outweigh any negatives of having that [genetic risk] information....knowing if I had a high risk factor for some incurable disease or something..."

"It would be nice to know whether...my [biological] family has a disposition towards dying early or for various diseases."

- Participants noted concerns with regards to the impact of GS on future insurance coverage.

"Well, I've heard concerns about, for instance, getting tested if you're predisposed to breast cancer, heart disease, things like that. It actually going the opposite route where you're going to have a heck of a time getting insurance because they're not going to want you. You're going to cost them a fortune down the line."

Limitations of GS

- GS was considered of limited benefit in situations where there were great perceived differences between the biological and adoptive families.

"...being an international adoptee...our diet and our lifestyle are so different from anyone of my birth family. So I think even for me my risks are different..."

- Often results from GS were considered to have little potential influence on behavior.

"People already don't live healthy lifestyles even though they know all this knowledge ...so now if you know you're going to get an illness or whatever, are they really going to change their lifestyle to prevent it?"

- Some expressed a preference of a "clean slate" regarding limited genetic knowledge.

"I just really look at it as it's a clean slate and whatever happens, happens from here on out."

Impact on Reproductive Decision Making

- Increased interest in genetic information (and GS) was reported with regards to understanding any potential risks to future offspring.

"I've been in a few serious relationships and, you know, when you get far enough into one we start thinking about getting married and maybe having a family and things, that's when it really crosses my mind, [because] it would be really nice to know for my family's sake and for future spouse's sake, you know, if my kids should be looking out for anything."

"...For my kids I would like to have that [genetic risk information] or if they should need it for their kids...because I want them to know as much as possible..."

"I would like to know...I wouldn't want to pass anything along that was...fatal."

Impact on Identity

- Genetic information offered by GS was embedded within larger questions of identity.

"Some of us are less concerned with medical and more concerned with identity. I think we're all going to be identity seekers for the rest of our lives until we die."

- Beyond medical information, GS has potential to connect individuals to their genetic ethnic/cultural roots.

"...it would be a big deal if I could find out and if I ever did find out I was a full-blooded Korean because it ...would add a dimension to who I am I guess..."

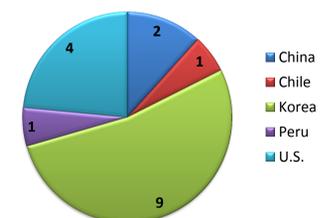
- Relative to the non-adopted population, GS could have greater impact on self-identity when used for adoptees.

"...even for people who have built their own sense of identity, this [genetic information offered via GS] could be something that...could potentially break down their identity and how they view themselves."

Participant Demographics

| Characteristics | n |
|------------------------------|----|
| Gender | |
| Male | 2 |
| Female | 15 |
| Age (years) | |
| 18-29 | 7 |
| 30-39 | 5 |
| 40-49 | 1 |
| 50-59 | 1 |
| Did not report | 3 |
| Type of Participation | |
| In-person | 14 |
| Distance (via Skype) | 3 |

Country of Origin



Conclusions

The use of GS is of potential value as a supplement when biological family medical history is unknown. However, unanticipated risks may emerge when GS is applied within special populations. Adult adoptees represent one such special population for whom the risks/benefits of GS may be unique. Participants noted myriad potential positive and negative impacts of the use of GS in understanding their own personal health risks. Additional research is needed to explore the unique application of GS within this population.

The knowledge gained from this study is being used to:

- Contribute to general scientific knowledge regarding adoptees' attitudes toward genomic sequencing
- Inform the development of a pilot implementation project
- Inform the future development of a prospective research proposal to explore the uptake and impact of GS on adult adoptees

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