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“We don’t know her history, her background”: Adoptive parents’ perspectives on whole genome sequencing results

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Abstract

Exome sequencing and whole genome sequencing (ES/WGS) can provide parents with a wide range of genetic information about their children, and adoptive parents may have unique issues to consider regarding possible access to this information. The few papers published on adoption and genetics have focused on targeted genetic testing of children in the pre-adoption context. There are no data on adoptive parent perspectives about pediatric ES/WGS, including their preferences about different kinds of results, and the potential benefits and risks of receiving results. To explore these issues, we conducted four exploratory focus groups with adoptive parents ($N=26$). The majority lacked information about their children’s biological family health history and ancestry, and many viewed WGS results as a way to fill in these gaps in knowledge. Some expressed concerns about protecting their children’s future privacy and autonomy, but at the same time stated that WGS results could possibly help them be proactive about their children’s health. A few parents expressed concerns about the risks of WGS in a pre-adoption context, specifically about decreasing a child’s chance of adoption. These results suggest that issues surrounding genetic information in the post-adoption and ES/WGS contexts need to be considered, as well as concerns about risks in the pre-adoption context. A critical challenge for ES/WGS in the context of adoption will be balancing *the right to know* different kinds of genetic information with *the right not to know*. Specific guidance for geneticists and genetic counselors may be needed to maximize benefits of WGS while minimizing harms and prohibiting misuse of the information in the adoption process.

Keywords

exome sequencing; whole genome sequencing; adoption; autonomy; return of results; ancestry; direct-to-consumer genetic testing

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CONFLICT OF INTEREST

Julia Crouch, Joon-Ho Yu, Aditi G. Shankar, and Holly K. Tabor declare that they have no conflict of interest.

INTRODUCTION

Pediatric exome sequencing and whole genome sequencing (ES/WGS) can provide parents with a wide range of genetic information about their children. Adopted children are among the diverse pediatric populations that may undergo ES/WGS. Adoptive parents likely share many of the same perspectives about potential benefits and risks of sequencing results as biological parents, but may also have some unique considerations. The scope of potential secondary results identified by ES/WGS may provide adoptive parents with the opportunity to learn desired, but previously unknown and possibly unexpected, information about their adopted children's family health history, disease risks, and ancestry.

Adopted children frequently have significantly different health conditions and risks than non-adopted children, which may result in adoptive parents needing or wanting more genetic information about their children. The 2003 National Survey of Children's Health revealed that adopted children are more likely than biological children to have special health care needs, moderate or severe health problems, developmental delay or physical impairment, learning disabilities and other mental health difficulties (Bramlett et al. 2007). This has led to an increased focus on characterizing those needs in the adoption context, as well as understanding how they affect the design and implementation of pre- and post-adoption services and supports for families, and how they impact health care needs and service delivery (Bramlett 2008). Such needs may also lead adoptive parents to pursue genetic testing and clinical ES/WGS for their adopted children for diagnostic and treatment purposes.

Adoption patterns and trends have been changing in recent decades in ways that may also influence ES/WGS usage. A 2009 United Nations report indicated that there are more than a quarter of a million adoptions per year worldwide, and that the United States of America (USA) accounts for more than half of all adoptions. The number of intercountry adoptions has been increasing over time, with the USA having more intercountry adoptions than any other country (UN Department of Economic and Social Affairs 2009).

Adoptions are also becoming more open today than in the past, with more frequent exchange of information between biological and adoptive parents. According to a recent report from the Evan B. Donaldson Adoption Institute, 55% of domestic infant adoptions in the USA are "fully disclosed," with ongoing contact between the birthparents and adoptive parents, 40% are "mediated," with a limited exchange of information, and 5% are "closed," with no exchange of identifying information (Siegel and Smith 2012). The trend toward more open adoption is accompanied by a growing desire by many adoptees for information about actionable genetic information that can be learned from family history (McCullough 1996).

Anecdotal evidence suggests that adoptees and/or their families may increasingly be using Direct-to-Consumer (DTC) genetic testing. Recent media reports describe adult adoptees using DTC genetic testing to identify biological relatives, including birth parents in some cases (Blackstone 2012; Swarns 2012). The DTC company 23andMe has over half a dozen blog stories in the last two years about adult adoptees using DTC genetic testing to learn about ancestry, identify biological relatives, and learn about unexpected disease risks

(23andMe Helps Man Find Family 2013; 23andMe's Tools Help Solve Ancestry Mystery 2013; Amy's Story 2013; An Unexpected Discovery 2013; Connecting With The Past 2013; Sisters Connect with 23andMe 2013; Stories From 23andMe: "Hey, Bro" 2011). The Mixed Roots Foundation, a non-profit supporting the adoptee community, has recently created a DTC genetic testing program called the Global Adoptee Genealogy Project (GAGP) that partners with 23andMe and Family Tree DNA to "help adoptees learn more about their own biological and cultural roots" (Global Adoptee Genealogy Project 2013).

In spite of the potentially increasing applications of genetic testing among pediatric adoptees and their families, few policy statements address pediatric genetic testing in the context of adoption. In 2000, the American College of Medical Genetics (ACMG) and the American Society of Human Genetics (ASHG) recommended that:

"[g]enetic testing of adopted children is unquestionably appropriate if it is consistent with preventive and diagnostic tests performed on all children of a similar age. Genetic testing that has no timely medical benefit to the child should be approached with great caution. Genetic testing that detects genetic variations within the normal range should be avoided." (ASHG/ACMG 2000)

At the time, this position was consistent with recommendations for genetic testing in all children (ASHG/ACMG 1995). These guidelines allowed for genetic testing that was in the short-term therapeutic or preventative best interest of a child, while protecting a child's right to an open future and autonomy over decision-making about genetic testing for adult-onset conditions.

This recommendation has been reinforced in the updated American Academy of Pediatrics (AAP)/ACMG policy statement from 2013 on genetic testing in children. The authors wrote: "The rationale for genetic testing of children in biological families should apply for adopted children and children awaiting placement for adoption" (Ross et al. 2013). However, the 2013 guidelines did not consider ES/WGS or the scope of potential incidental or secondary findings identified by ES/WGS, which may limit its application to some of the unique considerations in the adoption context. The National Society of Genetic Counselors (NSGC) recently released an updated statement on Genetic Testing and Adoption, in which they supported genome-wide testing for adopted adults, but encouraged deferring "this type of adult-predictive testing for children in the adoption process" (Genetic Testing and Adoption, 2014). The statement did not address how adult-onset results identified through ES/WGS in adopted children should be addressed.

In conjunction with the absence of policy guidance about genetic testing in adopted children, there is also an almost complete lack of data about adoptive parents' perspectives about genetic testing and possible results, including the possible scope of results from ES/WGS information. Without these data, it is unclear whether the needs and concerns of parents with adopted children differ from those with biological children, and therefore whether the same normative framework should apply. In order to investigate the specific perspectives of this population, we conducted focus groups with adoptive parents to characterize their perspectives about the benefits and risks of WGS results for their children. These exploratory data suggest directions for further research, areas for policy discussion and

development, and the development of tailored approaches to genetic counseling for adoptive parents considering ES/WGS for their children.

METHODS

Participants

We recruited adoptive parents in the Seattle, WA area through local pediatric clinics, adoptive parent email listserves and snowball sampling. Adoptive parents who were 18 years or older and fluent in English were eligible for this study. We conducted four, two-hour focus groups of 6-7 participants. Each group was led by a moderator (JC) along with one or two assistants (JY and HKT) and was audio-recorded and later transcribed. Participants received a \$40 grocery store gift card.

Materials and Procedures

A semi-structured focus group guide was developed and implemented that was adapted from a guide that was used in previous studies about parent attitudes about WGS and results (Yu et al. 2013). The guide addressed WGS, rather than ES, to allow comparability across focus groups. Further, we anticipate that WGS will be increasingly used in the near future, and inevitably supplant ES. Therefore, for the purposes of group discussion, WGS provides a hypothetical context sufficiently inclusive of the scope of ES and WGS results, benefits and risks, and interpretive challenges. Questions specific to adoption and adoption experiences were added to the guide. The focus group sessions began with introductory questions about participants' adopted children, including the amount and types of biological family history information they have about their children. The moderator then provided a brief 10-15 minute overview of genetics and inheritance and introduced four key concepts about WGS including: (1) the scope of results information that could be available; (2) that knowledge about variants will change over time such that in the future additional results could be available; (3) that the interpretation of results could change over time (e.g., the clinical utility of a variant or lack thereof could become evident); and (4) some results might be surprising or unanticipated. Participants were subsequently asked to consider what types of genetic results they would or would not want to receive, and why, for themselves and for their children, and how they might want to receive those results. The guide primarily framed WGS in the context of a genetic research study, but mentioned that this kind of analysis is increasingly becoming available in clinical care and may be available through direct to consumer testing in the future. Participants also completed a 16-item demographic questionnaire. The University of Washington Institutional Review Board approved this study and all participants provided written informed consent at the beginning of each focus group.

Data Analysis

Audio recordings of focus groups were transcribed and transcripts were uploaded into Atlas.ti (v7), a qualitative data management and analysis software program. We used a deductive approach to formulate initial codes based on our research questions and focus group guide. Additional themes and codes were developed following an inductive approach where new codes were allowed to emerge after initial review of the transcripts by two team

members (JC and HKT) and were added to our codebook. Content analysis was conducted to describe participants' views about WGS information (Hsieh and Shannon 2005). Two team members (JC and AGS) independently coded each focus group transcript. Coding differences were reconciled by consensus. Summaries of each code's output were created by three team members (JC, AGS, and HKT) and used to identify patterns in the data. Microsoft Excel was used to analyze the demographic data.

RESULTS

Twenty-six adoptive parents from the Seattle, WA, area participated in this series of four focus groups, which were numbered 14 through 17 as part of our larger study. Participants were predominantly female (73%), married (69%), self-reported as white (77%), and had a mean age of 49 years (range 35-66). Two of the participants were a couple; all other participants attended without a partner. The majority of parents (65%) had adopted at least one child internationally (IA), compared to 35% adopting domestically (DA). Focus group 16 had only IA parents, while the other three focus groups each had a mix of at IA and DA parents. The participants were highly educated, with 73% having an advanced degree, and 38% having household incomes of over \$10,000 per month (Table I). Our analysis identified five key themes: 1) absence of information about family medical history, 2) identifying existing and potential future medical concerns, 3) ancestry information, 4) WGS in the pre-adoptive context: risks, benefits and fairness, and 5) concerns about privacy and sharing information with adopted children (Table II). The fourth theme emerged in only two of the focus groups (15 and 17), while the rest of the themes emerged in all four focus group discussions.

Absence of information about family medical history

Most adoptive parents in this study described a lack of information about their children's biological family health history and a strong desire to obtain this information. Participants frequently contrasted the limited information available to adoptees with the "base knowledge" held by people who know their biological parents. A mother from focus group 15, who had adopted internationally, said, "I don't know anything at all about my son's biological background." (15-04, IA) Another mother said, "I've always known my family history...and I never really thought how important that would be, but now that I see her [my adopted daughter], I'm like 'Yeah, she needs to know'" (14-06, IA).

Several parents expressed concern that their adopted children's lack of family medical history information could result in potential health-related harms. For example, one mother said:

"[Adopted kids are] starting out at a level of ignorance, most of them, that you're not, if you're born into a family. We know that a couple of relatives had breast cancer or they had like in my case macular degeneration, or whatever it may be. You have kind of the base knowledge, and the adopted kids don't have that."
(15-06, IA)

Another parent described how knowing her own family history of heart disease saved her life because it allowed her doctor to proactively monitor her heart health and detect a pre-

symptomatic blockage in time to do a life-saving bypass surgery. She contrasted this experience with the unsettling fact that her adopted children “have no idea if they’re at high risk for anything” (14-05, IA).

Several participants have had some limited contact with their children’s biological parent(s), which allowed for varying degrees of collection of family health information. Many described being disappointed by the lack of relevant information even when they had some past or current contact with the biological parents. As one mother said: “You don’t really have a complete history even when you meet them, unless you want to stay in touch over the whole life span” (15-06, IA).

Many participants expressed a strong desire to fill in these gaps in family medical history. Some of the adoptive parents saw WGS as a potential means to achieve this goal and provide their children with the opportunity to access information about potential future health risks. One parent said: “I’ve always thought, ‘Well my son won’t have to worry about not knowing his family history because they’ll be able to map the whole genome and they’ll be able to look at it and see if he’s got any illnesses in his background, and so on’” (15-04, IA).

Identifying existing and potential future medical concerns

Many participants in this study expressed a hope that genetic information from WGS could help guide prevention, treatment and management of existing health concerns for their children. As one parent said, “If you’ve got a sick kid, I would consider it [WGS] would be a medical tool and it would be helpful and useful and worth doing probably” (15-06, IA). Five parents specifically described medical conditions that their children currently had in which genetic information would be, or might have been, useful. One parent described recent expensive ophthalmological testing for her son that she believed might have been avoided if they had access to genetic or family history information:

“She [the doctor] noticed that he had a long optic nerve, which can be a symptom of glaucoma, or it can be hereditary, and so we went to a specialist. It cost about \$500. I didn’t have insurance that would cover that, and they found out that it was indeed a genetic thing, but you know it would be nice to know stuff like that. She wouldn’t have sent him [for the testing] if she’d known there was a family background of this long optic nerve thingy.” (17-01, IA)

Another parent described wanting genetic information as an explanation for significant medical problems that her child had upon adoption, including cleft palate, hearing loss and velopharyngeal insufficiency. She said, “We don’t know her history, her background. We don’t know if she has this in her lineage” (17-02, IA). Still another parent expressed interest in potential pharmacogenomic results from WGS, in the context of her daughter’s existing medical conditions and her previous surgery for cleft lip palate, saying, “it would’ve been nice to know” in advance to try to avoid the adverse reaction to morphine that occurred (16-03, IA).

Many participants reported that they would want results related to their children’s future health, especially conditions for which they could “do something” to prevent or mitigate.

One mother said, “I would like to know if they’re at risk for depression, for some of the, you know, not just physical, but the things that are treatable...” (14-01, IA). Yet another parent said that she was only interested in actionable information: “I don’t need to know that she might get Alzheimer’s later on, and I don’t want to give her anxiety or whatever, and there’s no reason for her to know it now” (14-05, IA). In contrast, several participants described feeling conflicted about whether they would want to learn genetic results for their children that they couldn’t do anything about.

Ancestry information: “This is the kind of information adopted kids want”

Many of the participants described their lack of information about their children’s ancestry. Like family health information history, many participants articulated that this information was something their children have a right to know, if possible: “I think that’s where I’m coming from is I want to be able to give her, if she wants, the same information that I had available” (17-05, DA).

Several participants, especially parents of internationally adopted children, described receiving comments and questions from strangers about their children’s physical appearance and their apparent ancestry and/or country of origin. One parent said, “People have asked if she’s all sorts of different ethnic backgrounds. So it’s really interesting, I’d like to, if we ever have the opportunity, I’d love to check more into what might be in her background...” (16-03, IA). Another participant with an internationally adopted child described how comments from strangers about her daughter’s unique features, and her difference in appearance from her adopted parents, had provoked her daughter’s intense curiosity about her ancestry:

“Our daughter wants to do it [ancestry-related genetic testing] very badly... From the time she’s been a child, baby in the, people will stop her. Even today we’re in the store, somebody comes in and says, ‘You have the most beautiful eyes,’ and they’re very slightly almond, and she’s wondering, ‘Okay, where did I get those from?’” (14-05, IA)

Another mother also wanted to help her daughter respond to other people’s curiosity:

“She’s enough, you know, different-looking that she’s gonna get questions as she grows up, just innocent questions like, you know, ‘What’s your background?’... I always just thought it would be awful to have to say ‘I don’t know,’ and that just seemed brutal to me.” (17-07, DA)

Many participants described concerns about not being able to give their adopted children an origin story. They stated that being able to answer their children’s questions about their background was part of being a good parent, and they hoped that genetic ancestry information would help them provide some of these answers. One parent said, “[Genetic ancestry information is] one of the big questions that adopted kids have... So yeah, I think this is great, and this is the kind of information that adopted kids want, and there’s no negativity to it. It’s just there” (15-06, IA). Another parent said:

“I’d definitely want to know that [genetic ancestry information]. That’s one of the areas where I’m feeling most in the dark that she’s gonna ask me at some point,

yeah ‘Where am I, am I Irish ancestry?’ ... I want to know the answer so that I can be informed such that if she wants to know, I can be intelligent-sounding as dad...” (17-05, DA)

One mother described how many preschools spend the first week of school having students talk about “where they come from.” She said, “I’m not ready for all that for him to have all these questions, and so I mean I need to be prepared for it...” (14-03, DA).

Several adoptive parent participants, especially of internationally adopted children, viewed genetic ancestry information as providing a specific benefit to adopted children by helping to construct a positive narrative about identity and origin in what might otherwise be seen as a story of loss or absence. A mother of a child adopted from Ethiopia explained this motivation:

“...knowing what we do about her background, you know a lot of it is sad, and so it would be fun to have something that’s more fun to discuss and something to be proud of, you know ‘This is your genetic background.’ ...So to be able to have that like fun part of her story to share with her would be really great I think.” (16-05, IA)

A subset of participants mentioned specific discussions with other adoptive parents about the benefits of genetic ancestry testing, especially in domestic and international transracial adoptions. Three participants with domestically adopted children said that they and their children had already participated in genetic ancestry testing through DTC companies in order to try to learn something about their children’s background and to alleviate guilt and concerns about not being able to answer their children’s questions. One parent said:

“...when she grows older, like it’ll be horrible to not be able to answer that question, like, ‘What are you?’ and so to that end, we actually I just signed up for that 23andMe... It’s a giant genetic database, and they take certain marks...and supposedly can tell you where your ancestry [is]...” (17-07, DA)

Two parents described their experience of receiving their children’s ancestry results from DTC companies. One expressed surprise at the results: “I was surprised...We thought my son was French, because that’s what the birth mom put down, and he’s like from South America. His genes are all in South America” (14-04, DA). She went on to describe how the genetic information revealed that she and her daughter have similar ancestry: “And then my daughter, she’s Irish and I’m Irish, and I was like ‘That explains a lot!’” (14-04, DA).

Another participant described how direct-to-consumer ancestry information helped her to create a positive sense of identity for her transracially adopted child:

“...earlier we did this thing, and we took a cheek swab and mailed it to a company... She’s adopted domestically, but African-American, so this is a way to get beyond slavery... We found out she’s got these traits from originated probably in West Africa... So it’s like we’ve done some of it, a little bit, to get us [up to] snuff learning more about her background.” (15-01, DA)

Only two participants, both with internationally adopted children, mentioned any hesitation or concerns about learning genetic ancestry-related results about their children from WGS.

One parent explained that his 13-year-old daughter was not very interested in ancestry information, saying, “There hasn’t been this deep questioning...” (15-02, IA). Another participant expressed concern that the information might create uncertainty: “...well does that [genetic ancestry information] answer, does that open more doors, more questions that I can’t answer? So does that make it worse or better?” (17-02, IA).

WGS in the pre-adoption context: risks, benefits and fairness

While the focus group guide did not specifically address use of WGS in the pre-adoption period, several participants in two of the four focus groups spontaneously raised concerns about WGS potentially becoming part of the adoption process. Specifically, they said they were uncomfortable with the idea that people or adoption agencies might require a genetic profile before deciding to adopt. One parent said, “I could see this becoming a requirement, people won’t adopt a child, unless this test is run or accept a sperm or egg from a donor unless this is run, and that really gives me the creeps...” (15-06, IA). Another participant explained that she worried that WGS could violate adoptees’ rights by requiring the information to be obtained and made a part of their file like other pre-adoption information: “Providing or making them have the genome sequencing and put it as part of the dossier, I think that’s overstepping the boundaries of that, that child’s rights” (17-02, IA).

A few participants mentioned concerns about whether WGS information might somehow influence the decision of potential adoptive parents to adopt a child or reduce a child’s likelihood of being adopted. One parent acknowledged that genetic information might not be different than some other medical and family history information that prospective parents receive pre-adoption and might also influence adoption decisions: “I don’t know that it’s really any worse than the information we already get, and we can tell the race or the, you know, some of the diseases that they might have, sometimes” (17-01, IA). Another participant reflected on whether knowing about her daughter’s deafness and other conditions from WGS would have affected her decision to adopt, and decided that it would not have: “I think if someone had told me that my daughter would be hearing impaired and she had all these things, I don’t think it would have changed it [her decision to adopt]...” (17-02, IA).

Several other participants agreed that accessing any information at all about a child is a basic challenge of the adoption process that exists independent from possible access to genetic information. They conveyed that adoptive parents use a limited set of information to make decisions about the kind of child they want to have, or believe that they are equipped to raise. A discussion in one of the focus groups highlighted this issue. One participant said:

“An awkward part about adoption is you actually are forced to make decisions about these things that as a biological parent you don’t get the luxury of making a choice. As, as an adoptive parent, you can say, ‘This child was born with Down Syndrome. I’m choosing not to pursue this situation.’ Most biological parents aren’t gonna make that choice.” (17-07, DA)

Another focus group participant responded, arguing that adoptive parents should have a right to the same amount of genetic or family history information available to biological parents. She said, “You could argue that people have a lot more information about genetic

background of their birth children and that to make it fair for you know adoptive children from unknown areas, we should have some more information about that” (17-01, IA).

Concerns about privacy and sharing information with adopted children

Adoptive parents across all focus groups cited wanting to protect their children’s privacy if they underwent WGS. They specifically stated a desire to respect their adopted children’s developing and future autonomy by acting as custodians of genetic information and allowing their children to make choices about whether they would want genetic information in the future. Participants expressed concern about the unique privacy and autonomy concerns of adopted children, who may feel like their private information, as well as many life decisions and developments, are out of their control. An adoptive father echoed this perspective and concerns about his child’s future privacy:

“Maybe it’s special pleading from an adoptive parent, but it seems to me that adopted children already have a higher substantial invasion of their privacy just because of the whole situation they’ve gone through and will continue to go through. So that’s another reason to really look at the privacy issue...” (15-07, IA)

A mother talked about trying to balance her adopted son’s right to privacy in the future with her need to make decisions for him in the present:

“Let him make that decision [to get WGS results] because it seems like an invasion of his privacy in some ways because you can’t go back on that... He’s a, a minor right now and so I’m responsible for him, but I still think of him in the future and I want to respect his privacy as a person...” (15-04, IA)

Some participants wanted to defer disclosure of specific kinds of genetic information about adult-onset disease or reproductive risk until their children were adults in order to allow them to make their own decisions. One parent said, “...then when it’s her [daughter’s] turn, you know, and she’s the adult and she wants to take care of herself, then I think I feel like it’s her choice” (14-06, IA). Another mother said, “They need to know that it’s available, and I think for an adopted child it might be of more significance. They may truly want it, but then they, that’s their decision” (15-06, IA).

Several participants expressed concern about the potential psychological impact of sharing genetic risk information for their children. One adoptive parent said, “...even an older child may think they want the information, but would they really be able to handle it?” (17-07, DA). Another participant added, “Life is tough for kids. I mean they’re worried about the new zit on their nose. They have worries. You know life is tough at every stage. We have things. I wouldn’t want my child to add that [adult-onset risk results] to their baggage at all” (16-04, IA). One mother described how she would consider the personalities of her two adopted children in deciding whether to share results and which results to share:

“I’m having trouble with this because of the nature of my two children. So for my daughter, I feel like I’d like to learn everything. She’s interested in knowing who her birth mom is. She likes to know the worst of every situation, and you know she’d, she’d want the information... My son is more of the spontaneous, live life as it comes type, and for him I think I want to restrict it to, to conditions that I could

do something about...and let him decide when he's an adult what more information he wants..." (17-01, IA)

DISCUSSION

There is an ongoing debate about when and whether ES/WGS should be conducted in children, and what results should and should not be available to parents (Green et al. 2013; Knoppers et al. 2014; Ross et al. 2013). It is clear that one of the most likely applications of ES/WGS in the near future is for diagnostic purposes among children, including adopted children, with complex conditions. The existing pediatric genetic testing guidelines from AAP/ACMG emphasize testing children for pediatric-onset conditions, and restrict testing for adult-onset diseases or risks during childhood. The guideline authors argue that providing adult-onset genetic risk information might damage the child's right to an open future and future autonomy about whether or not they want to receive genetic risk information (Ross et al. 2013).

Our preliminary findings about the perspectives of adoptive parents on WGS testing of their children counter the assumption of recent guidelines that the benefits and risks of different kinds of genetic information are similar for adopted and non-adopted children. While our focus groups addressed only WGS, we believe the results about perceptions of benefits and risks are likely to be similar for ES as well as WGS. These exploratory results, from a group of highly educated, English speaking adoptive parents from the Seattle area, suggest that adopted children and their families may in fact have the potential to receive greater benefits from having access to a broader array of ES/WGS results than non-adopted children for three reasons. First, the potential for diagnostic and health care benefits may be greater because adopted children on average have more health conditions and challenges than non-adopted children. Second, the potential for ES/WGS information to fill in gaps in adopted children's family medical history increases opportunities for disease prevention, screening, and preparation for both childhood- and adult-onset disorders. Third, adopted children and their parents may derive greater benefit from ES/WGS information about ancestry because of its potential to provide information about the children's cultural background and possibly contribute to the construction of an origin story and sense of identity.

The adoptive parents in our study generally considered WGS results to be potentially beneficial and empowering, and they planned to use the results to serve their children's best interests, specifically their sense of identity and current and future health. They believed that the potential benefits of most WGS results, including results for adult-onset conditions and ancestry information, would generally outweigh possible harms.

Adoptive parents in our exploratory study expressed concerns similar to those raised by biological parents in our other focus groups; specifically, both sets of parents were concerned about respecting their children's current and future autonomy (Yu et al. 2013). Several adoptive parents mentioned that adopted children may be sensitive about their privacy and autonomy because their personal information has been shared with many people through the adoption process. A few participants expressed concerns about WGS information being misused if it was obtained prior to adoption by prospective parents to

avoid adoption of children with or at risk for specific health conditions. At the same time, these parents also acknowledged that some access to genetic information in the pre-adoption context might be useful to prospective adoptive parents, and similar to the kinds of information biological parents have about their children during pregnancy.

While our results need to be confirmed and further explored in other geographic, racial and socio-economic groups, our study suggests that a prohibition on sharing adult-onset ES/WGS results for adopted children with their parents may be unnecessarily restrictive and unjust. Specifically, prioritizing avoiding the potential harms of knowing genetic information and protecting the child's future autonomy over their genetic information fails to acknowledge and recognize the specific needs and concerns of adoptive families.

Adoptive parents in our study reported that having the ability to access genetic information from WGS would be in the best interests of their adopted children because it allows parents to decide whether and how to use this information to help their children learn about potential health risks and healthy preventive and/or preparation strategies, in the same way that biological parents would for conditions that run in their families. This position is similar to that reflected in the recent ACMG recommendations on return of incidental findings, but is in contrast to the AAP/ACMG guidelines on genetic testing in children and the recent NSGC statement on genetic testing and adoption (Genetic Testing and Adoption, 2014). These guidelines will need to be revisited in the future to fully consider the needs of adopted children and provide clear guidance for practitioners about the benefits and risks of sharing adult-onset ES/WGS results with adoptive parents.

If these perspectives are found to be widespread among adoptive parents, rather than prohibiting or limiting access to genetic information from ES/WGS of adopted children, clinicians and genetic counselors should explain to adoptive parents the benefits and risks of different kinds of secondary results, including possible psychological harms, social harms, limitations of genetic information, and rationale for deferring some decisions to adulthood. When provided with such guidance, adoptive parents can make informed decisions according to their own values about what is in the best interest of their child.

Practice Implications

Geneticists, genetic counselors, and pediatricians should be aware that adoptive parents may have a stronger interest in genetic risk information about adult-onset conditions than biological parents, due to the absence of family history and background information. There may be a greater potential benefit of this information for adoptive parents and children, and a greater relative benefit-risk ratio, compared to non-adoptive families. Adoptive parents need to balance these relative benefits and harms for their children, and where possible may choose to defer receiving certain genetic risk information until their children are old enough to participate in the decision.

Informed consent, results management, and results return policies and practices should take into consideration the specific context and needs of adoptive families in clinical, research, and DTC settings. This is especially true in the DTC context, because of the limited opportunities for professional genetic counseling for families. DTC companies should consider the specific needs and concerns of adoptive parents and adopted adults seeking out

genetic testing for a range of reasons, including ancestry testing, particularly as ES/WGS becomes available from these companies in the future. The companies should develop and test educational content targeted to adoptees and/or their families about the benefits, risks, and limitations of this genetic information for their informed consent, results, and promotional materials. The risks and limitations of attempting to use genetic information through DTC social networking to identify relatives should also be more clearly delineated to adoptees and adoptive parents.

Our exploratory data suggest that adoptive parents and adoptees may be likely to over-interpret the ability of ancestry data to provide nuanced information about a child's cultural background, or specific locations and origins of his or her biological parents. Therefore, one potential risk of WGS for adopted children is of providing false hope or incomplete data about this highly desired topic, which may lead to frustration and disappointment. Clinicians and genetic counselors, as well as DTC companies, should develop materials and approaches to advise and counsel adoptive parents, adoptees and families about the potential limitations of the use of genetic ancestry data for these purposes.

Further research should be conducted to explore the potential benefits and harms of sharing ES/WGS secondary results with prospective adoptive parents. In the absence of data, providers should take a conservative approach and only share information relevant to pediatric-onset diseases, in order to minimize possible stigma in the adoption placement process. Future policy development should consider specific kinds of secondary results that might be beneficial in optimizing placement, even for children who may have or be at risk for disease and disability.

In the future, ES/WGS may be offered to parents as part of the comprehensive health evaluation of newly adopted children. The AAP currently recommends a broad set of evaluations for newly adopted children, including diagnostic testing, age-appropriate screenings, and evaluations of current and future health and disease risks in order "to fully address all of their [adopted children's] health and developmental needs" (Jones et al. 2012). The AAP recommendation authors acknowledge that a complete medical history for an adopted child "is ideal but rarely available." Use of ES/WGS as part of the health evaluation of adopted children could allow for the identification of otherwise unknown but actionable pediatric-onset conditions, such as medullary thyroid cancer or pediatric-onset epilepsies, for which specific preventative or treatment actions can and should be taken. ES/WGS could also identify potential genetic risk factors for hereditary adult-onset conditions such as colon cancer, sudden cardiac death, or hypercholesterolemia.

Non-adopted children may be aware of such risk factors and conditions by knowing their family history, but without testing or screening, adoptive children may have no indication of such increased risks. While the number of adopted children identified with known pathogenic and/or actionable variants may be small, these results potentially could be beneficial either for direct short-term prevention or diagnostic screening, or for education and preparation for future disease risks. More in-depth consideration of use of ES/WGS in this context should be considered, and its potential benefits and harms should be explored and debated in greater detail.

Research Recommendations

There is a need for additional empirical studies on the attitudes of adopted parents and adoptees about learning various types of genetic information, including the range of information offered through ES/WGS about medical diagnoses, current and future medical risks, and ancestry. More data are needed about perceptions of the benefits and risks of different kinds of genetic information and the long-term health and psychological impact of adoptees receiving genetic information. More information is also needed about the potential benefits and risks of ES/WGS in the pre-adoption context. Such studies can further inform policy and tool development for the management of genomic information for this community. In addition, our findings should be confirmed and further explored in larger and more racially and socio-economically diverse groups of adoptive parents, adolescent and adult adoptees, as well as adoptees actually undergoing ES/WGS testing. The findings should also be validated in other regions of the country and with other kinds of adoptions, including family adoptions and adoptions from foster care.

Study Limitations

Our study has several important limitations. We recruited only English speaking adoptive parents in the Seattle area, the majority of whom were highly educated and had a high income level. More than half of our focus group participants had adopted their children internationally, and none of the participants had adopted relatives or described experiences adopting through the foster care system. Therefore, it is possible that their views do not reflect those of other adoptive parents and cannot be generalized to the larger population of all adoptive parents. Participants were asked to consider hypothetical WGS results, outside of the context of clinical care, and it is possible that perspectives might vary when considering real results or results in the context of diagnostic WGS. We did not discuss the challenges of the clinical diagnostic use of ES/WGS when DNA from biological parents is not available for comparison and interpretation. We did not ask participants specifically about WGS in the pre-adoption process, or about past or future use of DTC genetic testing, and therefore our results on those topics are limited to what arose spontaneously during the focus groups. While this study was focused on WGS, we believe that most of the questions addressed regarding potential benefits and risks of genomic testing are relevant to both ES and WGS.

Conclusions

Our focus groups with adoptive parents in the Seattle area suggest that adoptive parents are interested in WGS data for three main purposes: to fill in missing information about their children's family medical history, allowing for preparation and prevention, identify existing and potential future medical concerns, and learn about their adopted children's ancestry and background to help provide them with a positive origin story and connection to their culture. They expressed concerns about accessing information in a way that would protect their children's emerging and future autonomy, and ensuring that genetic information would not create stigma in the adoption context. As ES/WGS become more broadly used in diagnostic and clinical contexts clinicians, genetic counselors, and policy makers may need to develop specific guidelines and educational/counseling materials to help educate parents of adopted

children and adult adoptees about the potential benefits, harms, and limitations of ES/WGS results. Such materials could mitigate possible harms from misunderstanding and misinterpretation, while allowing adoptive parents and adoptees to make decisions about receiving results. The materials could also provide guidance about what kinds of actions to take in response to possible results, specifically in the context of adoption and a lack of detailed family history information. Special consideration should be paid to the use of clinical ES/WGS in the pre-adoption context, and which, if any, possible secondary results should be made available to adoption agencies or prospective adoptive parents.

INFORMED CONSENT

All procedures followed were in accordance with the ethical standards of the University of Washington Institutional Review Board and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants.

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Table 1

Participant characteristics

	<i>n</i>	% (of 26)
Gender		
Women	19	73.1%
Men	7	26.9%
Age		
Average	49	
Range	35-66	
Education		
Advanced Degree	19	73.1%
Bachelor's Degree	7	26.9%
Self-identified race		
White	20	76.9%
Asian	4	15.4%
Black or African American	1	3.8%
More than one race	1	3.8%
Self-identified ethnicity		
Not Hispanic/Latino	25	96.2%
Hispanic/Latino	1	3.8%
Marital Status		
Married/living with partner	19	73.1%
Divorced or separated	4	15.4%
Single, never married	3	11.5%
Religion		
Other	7	26.9%
Catholic	6	23.1%
Christian	6	23.1%
Jewish	4	15.4%
None	3	11.5%
Employment status		
Full-time	14	53.8%
Not working	6	23.1%
Part-time	5	19.2%
Working at home	1	3.8%
Household income per month		
less than \$4,000	1	3.8%
\$4,000-\$9,999	14	53.8%
\$10,000 or more	10	38.5%
Number of adopted children		
1 child	15	57.7%
2-4 children	8	42.3%

	<i>n</i>	% (of 26)
Any children adopted internationally?		
Yes	17	65.4%
No	9	34.6%

Table II

Themes that emerged from adoptive parents focus group discussions of WGS

1	Absence of information about family medical history
2	Identifying existing and potential future medical conditions
3	Ancestry information
4	WGS in the pre-adoption context: risks, benefits and fairness
5	Concerns about privacy and sharing information with adopted children

Note. Twenty-six parents participated in one of four focus groups.