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BACKGROUND



People with congenital heart disease (**CHD**) are living longer due to medical advances.

A better understanding of the social and ethical implications of living with CHD for adolescents and young adults (**AYAs**) is needed to inform clinical care, resources, and research.

RESEARCH AIM

The purpose of this qualitative study was to explore the social and ethical issues that AYAs with CHD and their parents report related to living with CHD.

METHOD

Participants were:

- AYAs between 15 to 21 years old with moderate to severe CHD
- parents of AYAs with CHD
- recruited via flyers, chart review, and a university study recruitment website
- asked to participate in a ~45 min. semi-structured interview and provided a \$50 gift card in study remuneration



During virtual interviews participants were asked questions about different aspects of living with CHD:

- social (e.g., impacts of having CHD on quality of life, dating, participation in activities and sharing information with friends) and
- ethical (e.g., interest in genetic testing, consent to data registries and health information sharing)

Interviews were audio-recorded, transcribed, & analyzed to identify themes.

PARTICIPANTS



6 AYAs with CHD

- 5 females, 1 male
- 3 adolescents (15-17 years)
- 3 young adults (18-21 years)
- 1 Hispanic/Latino
- 83% identified as White
- See cardiologist between 1-2 times per year

Average Interview Length

- AYAs: 43 minutes
- Parents: 52 minutes



5 Parents of AYAs with CHD

- 4 females, 1 male
 - Avg. age: 45 years (range: 41-49)
 - All identified as White, household income > \$75,000, and a 4-year college degree at minimum
- Characteristics of child with CHD:**
- Avg. age: 16 years (range: 15-20)
 - 3 females, 2 males

RESULTS



Social Implications: Most AYAs Limit Disclosure of CHD to Friends

Disclosure Not Necessary

{Interviewer} Do you share your CHD information with friends?

“No...See, for now, since it's not doing anything wrong, it's not causing me to have anything or anything wrong, then I feel like I shouldn't worry them about it. But if it does do something drastic, then and only then will I probably tell them anything about that.” – *Young adult*

Partial Disclosure

“I don't always tell a lot of my friends that I have it, especially when I was younger. As I get older, I mention it but I don't really talk about it a lot. I don't feel like they need to know... If I've known them long enough, yes. But, just meeting them or like not knowing them as well, I kind of don't like saying personal information with other people I don't really know that well.”

– *Young adult*

Positive Impact of Disclosure

“I just want people to know somewhat about my situation....they help me, because I've told them I have to be wary of what I'm doing...Like last year at school, my friend, [name], went to Fresh Market every day for lunch...he was always helpful of getting me across the street in time and just making sure I'm okay there, comfortable. He's a good guy.” – *Adolescent*



Ethical Considerations: Most AYAs and Parents Interested in Genetic Testing

Informs Family Planning

“I might want kids so I would really be interested in knowing if this is a possibility to pass it on, if I'm endangering anyone by doing this, if it's as big of a deal as what mine is like, so like if it escalates or anything like that it would just be really important to like stay in the loop and know what's going on.” – *Adolescent*

“Yes, I'm very interested in that because we have six children total. I would be interested to know, like from what we know, none of our other children have any CHDs...it would also be nice to know if when they have families of their own if this is something that we need to let them know about, if it's something that's a genetic thing. That they can at least be aware and be able to take the steps to find out if that's going to be an issue with their children.” – *Parent*



Ethical Considerations: Most AYAs and Parents Support Data Sharing for Research

Data Registries/ Research Benefits Others

“I think it's important to be able to use those studies and research in other places so that my body can also be used as tests and studies to help others too, because if I can help even just one other person that means a lot to me.”

– *Young adult*

“Oh, totally comfortable, yeah. Yes, I think that not only would help us in our generation but the future. Those born in the future, anything that would help families not go through some of what we went through.” – *Parent*

Importance of Consent/Privacy

“I would like to – I'd still want my permission if I were to give away something as important as that.”

In response to being asked about the importance of confidentiality:

“I think it's important because ...just knowing that it's just mine at the moment and I get to decide who gets to know this. I don't know. That's just important to me so like I think that everyone should decide whether or not it should be private.” – *Adolescent*

Ability to Opt-Out

“I think an opt out would be good instead of an opt in because then someone who has a really strong feeling about it could opt out or opt out of specific information shared. I personally wouldn't have a problem with it. But I understand some value their privacy more that way.”

– *Parent*

CONCLUSION

- Limited disclosure of CHD by AYAs to their social network may have positive (e.g., psychosocially protective to be perceived as “normal”) or negative consequences (e.g., encounter medical emergency and friend doesn't know to report CHD) that should be further explored.
- Most participants viewed genetic testing favorably and were supportive of their health information being used for data registries and research
 - Clinicians and researchers should be mindful of privacy concerns and obtaining appropriate consent.
- **Next Steps:** Conduct more interviews with parents (n=10) and AYAs (n=20) to gain more insight about ethical and social implications of living with CHD.

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