


Genetic testing for hereditary cancer
Challenges to ethical care


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Overview



- Genetic testing for hereditary cancer
- Research methodology and narrative accounts
- Equity and justice in health care

Hereditary Breast/Ovarian Cancer Genes: BRCA1 and BRCA2

- 56% to 87% risk of getting breast cancer by age 70
 - 16% to 44% risk of contracting ovarian cancer by age 70
 - associated with a 59% risk for pre- menopausal breast cancer
 - increased risk for second primaries
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Benefits of Genetic Testing

- BRCA1/2 mutation carriers can reduce their cancer risks by using available prevention strategies:
 - Increased surveillance (breast self exam, clinical exam, mammography)
 - Risk reduction surgery (prophylactic mastectomy or oophorectomy) / chemoprevention
 - Changes to life style
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Potential drawbacks

- Measures of prevention are imperfect
 - Benefits of mammography are not clear in younger women
 - Questions remains re. role modifying factors (hormonal, dietary, environmental, additional genes) may play in determining whether a given mutation gives rise to cancer
 - Psychological impact of genetic testing raises concern
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Study methodology



■ Qualitative study:

- 26 participants - pts and practitioners
- One-on-one interviews
- Interviews were taped and transcribed
- Analytic induction – common themes

Confidentiality: Participants' responses

“For myself personally the confidentiality thing wasn't even an issue. Like I, I don't really care.... I know some people really, it has to be still strictly confidential but you know ... my private life is pretty public”

Confidentiality: Participants' responses

“As long as I could get information, that was more important to me than the privacy part of it in a way. Like when most people in a small town know your mother has breast cancer for instance, or you know, all your close friends know that you have a family history so it's [privacy] not imperative to me.”

Confidentiality: Participants' responses

"I wasn't concerned with any type of privacy issues or anything like that. The lady who I did know that works at the hospital ...she's quite fine. ..very helpful and an incredible lady. Actually her husband was one of my son's hockey coaches. So, you know, the comfort level is, it was fine for me."

Confidentiality: Participants' perspectives

"It would probably be nice to know other people that are going through this, because I am actually isolated because of the confidentiality. I'm isolated because I don't know of anybody else that's doing it....[it] would probably make me feel better being in a room with people that were in a similar situation as I was. OR that had gone through this, that are around this area that I could talk to and say, what did you do? And how was this and what was your experience?"

Access costs



"To go down to Vancouver [is] an expensive proposition for us anyway. I mean [my sisters] are the only income in their households so to take time off work....there's no coverage and work situation wouldn't have covered it. So it would have been a loss of pay, plus the cost of going down."

Access costs – community support

"We have a little paper here called Coffee Talk Express, it's just kind of like a newsletter ... And there's fundraisers for so and so who has to go down for cancer treatment constantly up here. It's wonderful the community is supporting these people like that. We just lost a mother of four to cancer who had to constantly go down for treatments. You know, it devastated the community, devastated the children obviously."

Access Costs



"But gee you know, like what was the government thinking when they put the next closest cancer treatment center in [the Interior]. Why not Prince George, why not somewhere further North?...It's not like the government steps in and saying okay well we're not going to give you guys cancers centers, but we'll pay for your airfare to get there for your radiation. They don't step in and say THAT."

Social hardships

"[My husband] was able to come with me. You know cuz it wasn't, a matter of taking three days off work. He was able to come with me in an afternoon and um, which is great because he's my biggest support like, he was my biggest support through the cancer. Him and my kids."

Social hardships

"My dad had brain cancer and he passed away a few years ago... So anyways, he had to go down for surgery and radiation and that's not nice....especially cuz like my dad was, was like clinging, like leave me here at home....

We're all up here, he's down there. So mom went down with him, so she's the only support...Well any kind of surgery would be bad, but this is, like dealing with your BRAIN...

Being away from loved ones

... And there's a chance that the person won't be the same again. A very good chance that they won't be the same again and here he is way down there!

I get very angry about that. So we had to pay to go down there to be with him if we wanted to/if we COULD even. And I COULDN'T."

Leaving a familiar place

"I feel that I can deal with the cancer and there's a whole bunch of things that you CAN deal with, but when you're in familiar surroundings it makes it WAY, way better. The person that's going through this I think should be given that opportunity to be, have their treatment done in their home or as close to home as possible. But you're taking, it's like you're taking a farm person and plunking them right in the city. And that's the worst."

Reflections

- Do these findings relate to how you understand access and confidentiality in your practice?
 - Do these findings challenge you to think about access and confidentiality in a different way?
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Reflections

- Have you encountered difficulties with confidentiality in practice and if so, how do you deal with them?
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Wrap Up

- Context will shape how we see ethical issues or determine which ethical issues come up in genetic testing for hereditary cancer
 - Confidentiality is meant to protect people from unwanted disclosure, but what counts as unwanted disclosure may be interpreted differently, e.g. rural vs urban health care
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Wrap-Up

- Rural perspectives and contexts may be one in a number of approaches that can help enrich and diversify bioethics
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