Background

A consenting process is required prior to receiving genetic testing. In clinical settings, consenting is provided in-person by genetic counselors. In research settings, consenting is often provided via paper explanation. Both parents and adolescents need to understand and be adequately informed about expectations in research genetic testing during the consenting process, including limitations to testing, the possibility of secondary findings, and the risks/benefits of receiving positive/negative results. Both parents and adolescents have requested the return of results from research genomic testing, which is currently not required but yet remains an ethical obligation for researchers. Currently, there are not enough genetic counselors available to provide the information needed prior to consenting for both clinical and research purposes.

Methods

The video reviewed in this study was developed through pretests with qualitative focus groups, followed by video production.

Phase 1

Sample Characteristics

Three questionnaire items were added in phase two. Additional statements included:

- "Health insurance companies cannot deny me health insurance coverage based on genetic test results."
- "Insurance companies can deny me life, disability, or long-term care insurance based on genetic test results."

The third new item asked for specific video content causing confusion. On average, adolescents answered 7.53 questions correctly on the questionnaire.

Reactions to Genomic Testing

- Adolescents mentioned the video being too long or had a hard time recalling its content (n=1).
- Adolescents expressed confusion in understanding information when the voiceover expressed information differently than it was displayed on the screen (n=2).
- Adolescents interviewed were able to give examples of things they learned from the video, including specific facts about the genome (n=4) and the potential for denial of insurance (n=3).

Results: Phase 1

- There were significant differences in the number of correct parents and adolescents for over half of the questions, including:
  - Genomic test results for conditions I choose to receive will become part of my (child's) medical record. (n=13)
  - All gene variations that cause a specific condition will be examined on the genome. (n=14)
  - Other researchers may have access to my (my child's) genetic information. (n=15)
  - My (child's) doctor may recommend different screening. (n=16)
  - I (My child) could still develop the condition. (n=17)

Conclusions & Next Steps

- More attention in the genetic testing and consenting process needs to be focused on adolescents.
- Education of genetics and related concepts may need to be improved in the greater community, and specifically within minority and low-income populations.
- Adolescent interview responses suggested adolescents lack confidence with explaining genetic content and thus did not demonstrate substantial learning.
- Individuals may be encountering this information for the first time, and may need aid in understanding.

Future Research Suggestions

- Consider sectioning the video into essential/recommended and optional sections. This may lead to a shorter viewing experience that misses some information but would still highlight key areas for recall.
- Consider sectioning the video into chapters based on topic, without assigning importance levels.
- Incorporate repeated exposures and an assessment of knowledge 1) after viewing the video at test consent and 2) after viewing the video at receipt of results.

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