NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

Submission Id: 6132

Title

Patient Perspectives on Obtaining Information About Inherited Cancer Risk via an Online Assessment Tool.

Priority 1 (Research Category)

Cancer research (not screening)

Presenters

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Abstract

Context

Few affected by hereditary cancer syndromes know their cancer risk. Electronic risk assessment and communication may enhance screening and prevention, but patient perspectives are understudied.

Objective

The Family Study, a randomized comparative effectiveness-implementation trial, evaluated three methods of capturing family history and providing care for individuals at increased risk of hereditary/familial cancers: 1) routine care, 2) brief online risk assessment, and 3) full (3-generation pedigree) online risk assessment. Elevated-risk individuals in Arms 2/3 were referred to genetics/screening services.

Study design and analysis

Our approach was informed by the Theoretical Framework of Acceptability. After risk assessment, participants in arms 2/3 were randomly selected for semi-structured interviews. After thematic analysis, we compared outcomes by study arm.

Setting or dataset

The trial enrolled adult members of Kaiser Permanente Northern California. Sixty of 630 participants invited completed interviews. Qualitative researchers designed, conducted and led analysis. Patient co-investigators and clinicians were involved in all research steps.

Population studied

Interviewees were 62% female with a mean age of 54. Thirty-eight percent identified as non-Hispanic white. Forty-five percent were at average risk, 6% at moderate risk, and 45% at high risk. We interviewed 28 participants from arm 2 and 32 from arm 3.

Intervention/instrument

A semi-structured interview guide asked about completing the online risk assessment and reactions to its results.

Outcome measures

Participants' understanding of risk assessment results.

Results

Most participants' risk level matched their expectations, informed by prior knowledge. Participants generally understood that hereditary cancer risk differs from overall cancer risk. Perceived benefits included gaining knowledge of health risks and cancer prevention measures, and contributing to science. Perceived harms included unintended interpretation of results, uncertainty of results' accuracy or validity, lack of awareness of results or referrals to genetic services for those at elevated risk. Participants noted that opportunities for personal communication could mitigate against some harms of a fully online approach.

Conclusion

Participants generally experienced the interventions as intended, with few differences using brief vs. full pedigree assessment. Future analyses will explore variability by risk