PATHWAYS -- A FERTILITY PRESERVATION PATIENT DECISION AID WEBSITE FOR WOMEN WITH CANCER: DESIGN, DEVELOPMENT AND FIELD-TESTING

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Abstract Body

Purpose
Fertility preservation counseling is recommended for women at risk for cancer-related infertility; however, challenges persist in providing information and support during the brief and stressful time between diagnosis and treatment. To address these challenges, this study engaged cancer survivors, clinicians, and researchers in the development of Pathways: a fertility preservation patient decision aid website for women with cancer.

Method
The research team collaborated with a stakeholder advisory board (patients, patient advocate leaders, oncologists, reproductive endocrinologists, decision scientists, and an ethicist) to create an initial design based on previously-identified patient and clinician information and decision support needs. The team iteratively revised and optimized storyboards through internal and external clinical review (n = 21 reproductive endocrinologists and oncologists), as well as in-depth interviews with cancer survivors (n = 14). Field-testing of the initial website with female cancer survivors (n = 20, English-speaking, aged 18 to 45 years-old) assessed post-decision aid knowledge and usability and acceptability ratings.

Results
The Pathways website includes novel features including tailored information by cancer type, staged values clarification exercises, testimonials, financial/referral support links, and a printable personal summary. Women who viewed Pathways scored an average of 8.2 correct out of 13 (SD 1.6) on the Fertility Preservation Knowledge Scale. All women (100%) rated Pathways favorably for its usefulness, ease of use, visual attractiveness, ability to help patients make decisions, and likelihood that they would recommend it to other women. Most (>85%) said it was the right length, clear, navigable, had the right amount of information, and made them feel ready to talk with their doctor about their options.

Conclusion
The Pathways decision aid website is a useful and acceptable tool to help women with cancer learn about their fertility preservation options. Pathways may be an effective tool to help inform and clarify decision-making values and preferences in women at risk for cancer-related infertility.