



ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS' PERSPECTIVES ON GENETIC COUNSELING

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PURPOSE

To explore AYA survivors' perspectives on the utility of genetic counseling, including

- Levels of cancer worry and reproductive/fertility concerns
- Interest in genetic counseling and preferred timing of referrals
- Hereditary cancer risk knowledge

METHODS

- Online survey of self-identified pediatric or AYA cancer survivors >18 years old and one-year post cancer treatment distributed in winter 2021
- Included a vignette describing a genetic counseling session with an AYA cancer survivor

RESEARCH FINDINGS

REPRODUCTIVE CONCERNS

- All participants had moderate to high levels of reproductive concerns
- Participants who received genetic counseling in the past indicated:
 - Lower levels of concern regarding fertility potential
 - Greater acceptance of not having future children

CANCER WORRY AND REFERRAL TIMING

- **98%** of participants indicated fear of cancer recurrence (Cancer Worry Scale)
- **62%** indicated that referrals to genetic counseling should occur at the time of cancer diagnosis

HEREDITARY CANCER RISK KNOWLEDGE

- **72%** overestimated the extent of AYA cancer cases that are due to a genetic predisposition
- **44%** thought that it was likely or extremely likely that they inherited genes that contributed to their cancer development (8.5%-15% will actually have an underlying cancer predisposition syndrome)

IDENTIFIED THEMES

- Theme 1: Reproductive risk and family planning
- Theme 2: Future cancer risk informed decision making, and planning for self
- Theme 3: Effects on anxiety and worry

CONCLUSIONS

- There are significant misconceptions about hereditary cancer risk among the AYA cancer population
- Genetic counseling may address information and psychosocial needs of all AYA cancer survivors, not only those who would be offered genetic testing
- Referrals should occur at the time of diagnosis
- Genetic counseling could theoretically be implemented for all AYA cancer survivors

REFERENCES

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