Genomic Sequencing in Pediatric Oncology: Perspectives of Parents and Adolescents on Ethical Issues

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August 21, 2023

Abstract

Background As both tumor and germline sequencing become more common practice in children with cancer, it will be necessary to anticipate and address potential ethical issues. This study aimed to elicit the perspectives of adolescents with cancer, and parents of children with cancer, regarding tumor and germline genomic sequencing in pediatric oncology. Procedure Semi-structured interviews were conducted with adolescents/young adults with cancer, and parents/guardians of children with cancer. The interview guide included questions on potential benefits of genomic sequencing, heritable cancer predisposition conditions, impacts on family relationships, and secondary findings. Demographic information was also collected, and baseline genetics knowledge was assessed. Results Participants reported several ways they believed sequencing results could be valuable, including more targeted cancer therapy and knowledge regarding heritable variants. However, opinions varied on what information would be useful, with many participants reporting an interest only in those results which would directly impact cancer therapy. Multiple people expressed concerns about results that could be undesirable or even harmful, such as secondary findings unrelated to cancer. Several parents reported feeling guilty about their children having cancer, whether or not a genetic predisposition to cancer was found. Conclusions Patients and parents held a wide variety of opinions on the utility and proper implementation of genomic sequencing for cancer. Most participants saw potential benefits to such testing, but many participants felt they lacked the knowledge to make an adequately informed decision on results derived from complex scientific techniques, and reported. These findings will help inform the process of obtaining informed consent for genomic sequencing in children with cancer.

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