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Parents of children with cancer value sequencing results, even if non-actionable

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Parents of children newly diagnosed with cancer value the results of whole exome sequencing for a variety of reasons beyond clinical actionability, according to research presented at the American Society of Human Genetics (ASHG) 2016 Annual Meeting in Vancouver, B.C.

This study is part of a larger study on the introduction of genetic sequencing into pediatric cancer care at the Texas Children's Cancer Center in Houston. Janet Malek, PhD, Associate Professor of Medicine and Medical Ethics in the Center for Medical Ethics and Health Policy at Baylor College of Medicine, and colleagues interviewed the patients' parents, an ethnically and racially diverse group, on how they perceived the value of sequencing at three time points: upon agreeing to undergo sequencing (64 interviews), upon receiving the sequencing results a few months later (33 interviews), and one year after receiving results (25 interviews). All participating families received a germline report, which described the genomes of the child and both parents, including information on genes associated with cancer, genes associated with other diseases the child might have, other actionable findings, and variants of unknown significance. In addition, when tumor tissue was available, families received a tumor report describing the genetics of the tumor. Over 90 percent of families also chose to receive information about carrier status unrelated to the child's cancer.

"There is a general, ethical inclination to be reluctant to disclose sequencing information without clear clinical utility, especially when children are involved," said Dr. Malek, who presented the research.

"However, our study showed that parents find this information useful in a much broader way than clinicians might expect," she said.

For example, many parents cited psychological benefits to receiving the information. "Almost all of the parents we interviewed wanted to know where the cancer had come from," Dr. Malek explained. "They hoped that evidence of a genetic cause would show that they had not caused it through any action or negligence, relieving them of guilt; so in some sense, they hoped for a genetic explanation. But at the same time, they did not want to have been the one to pass this risk on to their child," she said.

Parents also cited pragmatic benefits that helped them and their families plan for the future. Parents of children with a genetic risk of cancer noted that this knowledge could help the children make reproductive decisions of their own. In a few cases, sequencing results prompted siblings and other family members to undergo genetic testing to assess their own risk of cancer or other diseases. If no genetic cause was found, parents felt reassurance for their other children's health, including that of future children.

"Throughout the process, I was surprised by how positive the parents were about sequencing, even if the results did not affect any medical decisions," Dr. Malek said. "Our findings raise questions about the assumptions we make by prioritizing clinical actionability when deciding whether to disclose genetic information. They also raise questions about health insurance companies' coverage of sequencing tests and physicians' decisions in recommending these tests to families."

The researchers hope to follow up this work with a quantitative, survey-based study comparing the various benefits of receiving sequencing information in a larger sample of parents. They also hope to more closely analyze the roles of guilt, regret, and parental responsibility in

how parents perceive the value of genetic sequencing.

More information: Dr. Malek will present her research on Thursday, October 20, 2016, from 11:15-11:30 a.m., in Ballroom B of the Vancouver Convention Centre, West Building.

Provided by American Society of Human Genetics