

“What’s in a name?” An assessment of knowledge about reproductive technology among young adults at risk for Huntington’s disease

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Huntington’s disease (HD) is an adult onset neurological condition characterized by cognitive decline, chorea, and emotional disturbances. Individuals who are gene positive or at risk for HD have numerous options for family planning, including the use of reproductive technology. Past research has assessed knowledge of preimplantation genetic diagnosis (PGD) and revealed a limited understanding in the general population and among individuals at risk for hereditary cancer syndromes. No study to date has measured awareness of various reproductive technologies among individuals who risk passing on HD. A survey which evaluated interest and awareness, as well as resources used to learn about reproductive technology was distributed to young adults through the Huntington’s Disease Youth Organization and National Youth Alliance. Among 34 participants who completed the survey, only 47.1% correctly identified amniocentesis/ CVS and 38.2% identified PGD. However, most participants demonstrated awareness that it is possible “To test a fetus for the HD mutation” and “To select an embryo that does not have the HD mutation”, without identifying the technology by name. Analysis revealed that age ($p= 0.01$), testing positive for HD ($p= 0.00049$), and discussing reproductive technologies with a genetic counselor ($p= 0.0072$) were associated with better knowledge of reproductive technology. Overall, 76.5% of participants expressed potential interest in using reproductive technology. Notably, only 30% of participants who expressed interest in this study discussed reproductive options when they met with a neurologist and/or genetic counselor. Participants endorsed discussing reproductive options most with family and friends. Given the high level of interest in utilizing reproductive technology and comfort talking with family and friends, coupled with the finding that speaking with a genetic counselor increases knowledge, future studies should explore how to make genetic counselors more accessible in the community. Future research should analyze how community-based education initiatives could improve comprehensive knowledge of reproductive technology.