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COVID-19 impact on genetic counseling for Huntington's Disease via telehealth

Wes Solem, Debra Roter, Leila Jamal

Huntington's disease (HD) is a severe, heritable, adult-onset neurological disorder that impairs mood, movement, cognition, and behavior, with a life expectancy of 15-20 years following onset of symptoms. HD is caused by a genetic variant of the *HTT* gene. Because the cause of HD has been isolated to a known genetic variant, predictive genetic testing is available for individuals at risk of HD. Historically, most counseling for Huntington's disease — particularly predictive genetic testing — has been provided in-person, to assess an at-risk individual's psychological readiness to undergo genetic testing and to monitor potential adverse reactions to test results. During the COVID-19 pandemic, many genetic counselors (GCs) were obligated to provide telegenetic counseling by phone or video conferencing despite the normative convention of in-person practice. Little is known about GCs' experiences of providing HD telegenetic counseling (HD-TGC). To address this gap, we conducted a retrospective mixed-methods study consisting of surveys and interviews with HD GCs. Our objectives were twofold: [1] To assess the nature and extent of HD-TGC services offered during COVID-19 restrictions; and [2] To assess GCs' attitudes toward the provision of these services as well as their perceptions of factors that favored or hindered its effectiveness. The online survey investigated both objectives and was completed by 49 GCs — 36 of whom had provided HD-TGC services during COVID restrictions, while the remaining 13 counselors provided HD genetic counseling only in-person. A sample of 16 GCs who provided HD-TGC services were interviewed to discuss their attitudes toward HD-TGC in deeper detail. Most responses from these GCs were favorable, regarding assessments of: [1] their comfort in providing HD-TGC, [2] the

perceived effectiveness and [3] quality of HD-TGC services, and [4] the potential for HD-TGC to be offered as an option to the HD community beyond the COVID-19 pandemic.