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Healthcare delivery via telehealth during the COVID-19 pandemic: The experience of a Huntington's disease clinic

The COVID-19 pandemic demanded a rapid adaptive response from health systems across the world. Video-based telemedicine was implemented through an unprecedented shift in healthcare delivery [1]. Chronic diseases affecting multiple domains, such as Huntington's disease (HD), represent a specific challenge. A previous study illustrated the potential of telehealth for HD, although focused on the administration of a rating scale through a research protocol [2]. How telehealth performs for HD clinical care has not been reported to date.

We transformed the clinical operations of our HD Center (described in [3]) to only video-based visits between April and June 2020, while a mixed model (in clinic visits and telehealth) was followed in March and July 2020. During pre-COVID clinics, a multidisciplinary team provided care. During COVID telemedicine visits with some providers were not synchronous and some, such as physical therapy, were very limited. Here, we focus on the clinical encounters with the neurologist, except for predictive testing visits, when a genetic counselor and a neurologist evaluated the patient in the same telehealth visit, including a psychiatrist when deemed necessary as in our in clinic protocol. Medical education was successfully incorporated into this model [4].

We measured the impact of telehealth on the number and type of encounters. Because we only offered telehealth between April and June 2020, the same months from the previous 3 years were used as a control metric. The average number of new and follow up encounters during those months in 2017–19 were 19.7 and 64, respectively, while in 2020 there were 9 (new) and 62 (follow ups) visits. When we added the telehealth encounters that took place during the mixed model periods (March and July 2020), the total number of video-encounters completed was 88 (9 new and 79 follow ups). As a control group for these 88 encounters, we included the last 88 consecutive in-clinic visits that took place before March 2020 (pre-COVID cohort, 19 new and 69 follow up). Thus, using both control groups, we observed a modest reduction in the new to follow up visit ratio, a consequence of a reduction in referrals. Lower healthcare utilization, beyond HD, has been observed during COVID.

Adoption of telehealth did not vary by age (mean ± SD, range: Pre-COVID 48.9 ± 14.1, 20–81; COVID 52.2 ± 14.3, 19–81; $p = 0.13$, T-test), but gender seemed to have an effect (43.2% women pre-COVID versus 59.1% during COVID, $p = 0.035$, χ^2). Using time from reported symptoms onset as a surrogate marker of disease severity (excluding at risk and premanifest subjects), there were no differences between groups (mean ± SD, range: Pre-COVID 8.5 + 4.5, 1–20 years; COVID: 7.8 + 4.8, 0–20 years; $p = 0.4$, T-test). We found no significant differences between diagnostic categories, including those with clinically manifest HD (66 pre-COVID versus 69 encounters in the COVID telehealth group), and premanifest mutation carriers or at risk subjects undergoing counseling or predictive testing (22 pre-COVID versus 19 COVID).

To indirectly address if telehealth encounters provide optimal neurological care, we recorded the number of actions taken by the neurologist during the 88 visits pre-COVID versus during COVID as a surrogate qualitative marker of care. As shown in Table 1, there were no differences on prescription management or referral patterns, suggesting a similar practice.

In summary, the COVID-19 pandemic handed us an unwanted opportunity to evaluate telehealth in clinical care. The data provided here illustrates its successful adaptation in a HD clinic. Despite maintaining a similar number of encounters as in previous years, we observed a modest reduction in new patient visits caused by a reduction in referrals. We found no changes in practice pattern between pre-COVID in clinic visits and COVID telehealth encounters and, as previously shown [5], telehealth was successfully used for predictive genetic testing in a multidisciplinary manner. Collectively, this data supports that telehealth can quantitatively meet clinical demand and likely deliver qualitatively adequate care for HD. Encounters that require a detailed full neurological exam or a physical therapy interventions, among others, will still require in clinic assessments and a hybrid model seems to most optimal moving forward. This is an uncontrolled and descriptive report, lacking scales to measure quality of care, and future controlled studies with standardized qualitative measures of care and satisfaction by patients and providers should expand on these observation. While the importance of a close doctor-patient interaction cannot be emulated with telehealth, its benefits are sufficient to maintain this approach to healthcare delivery in a hybrid model in the post-COVID era.

Table 1
Actions taken by the neurologist evaluating HD via in clinic visit (88 encounters pre-COVID) or telehealth (88 encounters during COVID).

	Pre-COVID	COVID
Predictive testing protocol		
Counseling, no testing	0	3
Genetic testing requested	6	4
Disclosure of genetic testing results	9	4
New medication prescribed		
Chorea	10	9
Other indication	4	7
Medication dose adjustment		
Chorea	16	23
Other indication	2	4
Referral to other provider	7	9
EKG requested for QT interval	3	3
Other	1	2
No Changes	37	23

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