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Tremor and Other Hyperkinetic Movements

Viewpoints

Telemedicine for Hyperkinetic Movement Disorders

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Abstract

Telemedicine is the use of electronic communication technology to facilitate healthcare between distant providers and patients. In addition to synchronous video conferencing, asynchronous video transfer has been used to support care for neurology patients.

There is a growing literature on using telemedicine in movement disorders, with the most common focus on Parkinson's disease. There is accumulating evidence for videoconferencing to diagnose and treat patients with hyperkinetic movement disorders and to support providers in remote underserviced areas. Cognitive testing has been shown to be feasible remotely. Genetic counseling and other counseling-based therapeutic interventions have also successfully performed in hyperkinetic movement disorders.

We use a problem-based approach to review the current evidence for the use of telemedicine in various hyperkinetic movement disorders. This Viewpoint attempts to identify possible telemedicine solutions as well as discussing unmet needs and future directions.

Keywords: Telemedicine, hyperkinetic movement disorders, tremor, videoconferencing

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Introduction

Technological advancements have expanded the application of information technology in the field of medicine, changing the landscape and enabling medical practice, research and education without the encumbrance of geographical barriers.[1] Telemedicine is the use of electronic information and communication technology to provide and support healthcare when distance separates participants. It is traditionally subdivided into synchronous and asynchronous telemedicine.[2] Synchronous telemedicine is defined as interactive video connections that transmit information in both directions at the same time. Asynchronous telemedicine is a term describing store-and-forward transmission of medical images and/or data because the data transfer takes place over a period of time, and typically in separate time frames. In asynchronous telemedicine,[3] the transmission typically does not take place simultaneously.

Telemedicine formally includes more than just videoconferencing. Anything that takes medicine out of the traditional consultation room and back into the patient's own home environment could rightly be regarded as a form of telemedicine.[4] Studies of real-time, interactive telemedicine technology using videoconferencing have been conducted in the field of neurological diseases.[5,6] There has also been an expanding use of telemedicine in movement disorders,[7,8] particularly where the combination of mobility limitations, timely follow-up for progressive disease, and the sparse distribution of movement disorder specialists create challenges in access to care.[9] In this regard, telemedicine can have a role in the diagnosis and treatment of movement disorders, replace or complement in-office evaluations, and promote education and training. However, the most common disadvantages reported in the literature with the use of telemedicine in movement disorders include lack of hands-on care, intimacy, and technical difficulties.[10]

Over the last few years, there has been a growing interest and number of publications about telemedicine in movement disorders, especially Parkinson's disease (PD). As of December 6, 2019, 72 out of 241 (29.8%) articles were published under the topic "Tremor OR Chorea OR Huntington's disease (HD) OR tics OR Dystonia AND telemedicine" compared to "PD AND Telemedicine" (personal data, source: Entrez PubMed), highlighting the need to increase the awareness of telemedicine relating to hyperkinetic movement disorders. In this article, we discuss the current and future prospects, challenges and strategies to overcome barriers for the practice of telemedicine in hyperkinetic movement disorders. Description of new technologies is beyond the scope of this review. Table 1 outlines major components of literature review cited.

Tremor

The problem

Tremor is the most prevalent movement disorder with estimates ranging from 0.4% to 6.3% in various populations.[11] Essential tremor, the most common disorder, affects approximately 4% of adults aged 40 years and older.[12] Accurately distinguishing between various tremor phenotypes (resting, kinetic, postural, intention, orthostatic) is important for diagnosis and treatment, which, in turn, is contingent upon correct assessment of the severity, loss of function, and disability. The challenge is assessment and treatment of large numbers of patients by a specialist, namely, providing effective accessible care for/to remote and/or elderly population.

The solution

Telemedicine for tremor enables remote diagnosis and follow up of various types of tremors. Synchronous videoconferencing has allowed assessment of tremor characteristics that can be objectively and reliably assessed using the modified version of the Unified Parkinson's Disease Rating Scale (UPDRS) in PD patients.[13,14] This includes measurement of postural, kinetic, and resting tremor components, which, in turn, allows for phenotypic/etiologic tremor distinctions. Tremor, just as all hyperkinetic movement disorders, can be observed in the same way as in in-person clinics. Spiral traditional testing can be viewed to recognize tremor patterns in both synchronous and asynchronous manners.[15] Tremor evaluation in synchronous visits is limited by the quality of the video, which relies on video resolution per frame and frame rate per second, among other variables. The adequate combination of hardware and software is therefore an important consideration and can be a limiting factor. Conversely, asynchronous video visit using digital cameras circumvents this problem and is a more readily available method.[14] Videotaped UPDRS motor examination is a useful means of diagnosing PD, although milder PD with shorter duration of symptoms may have higher false negative rates.[16] There has been no formal telemedicine validation of objective measures for essential tremor rating scales (Fahn–Tolosa--Marin Clinical Rating Scale for Tremor (FTM), and the Essential Tremor Rating Assessment Scale (TETRAS)).

Unmet needs and the future directions

Videoconferencing, both synchronous and asynchronous, is limited by the lack of quantitative measurable tremor data such as frequency, amplitude, and duration, which can further increase diagnostic granularity. Novel and more advanced digital sensors have come to the forefront to assess tremor, including the use of kinematics for clinical assessment and treatment. Digital sensors have been studied to optimize Botulinum toxin injections to alleviate tremor in PD and essential tremor.[17] The future technologies, such as Ultra-Wideband (UWB) radar technology, can provide objective measures of frequency and amplitude estimation of tremors, precluding the need for physical active markers or inertial sensors. Longitudinal variations of tremors are also not adequately captured. Concomitant use of wearable sensors can help overcome these limitations but the impact of data from digital devices on Quality of life (QOL) measures remains to be seen.[18] More studies are required to assess the impact of wearable monitoring in the evaluation and treatment of essential tremor.

Tic disorder

The problem

Transient tics are relatively common, affecting as many as 20% of school-age children and rarely require treatment. Tourette syndrome is a common neurodevelopmental disorder affecting up to 1% of the population. Comprehensive Behavioral Intervention for Tics (CBIT), an individual, outpatient therapy protocol, is shown to reduce tics in randomized controlled trials effectively. This program serves as the main treatment that requires regular visits that may not be available and challenge adherence and compliance.

The solution

Both synchronous and asynchronous behavioral therapies are effective. Synchronous CBIT was demonstrated to be effective for variable disorders, but was not studied systematically for tics.[19] Asynchronous telemedicine was found effective in a randomized controlled study of 10 weeks. Two methods were used: exposure and response prevention, and habit reversal training.[20] Patients and parents rated both interventions as highly acceptable, credible, and satisfactory. While both interventions resulted in reduced tic-related impairment, parent-rated tic severity, and improved QOL, only exposure and response prevention reduced tic severity. The therapeutic gains were maintained for up to 12 months after the end of the treatment. The average therapist support time was less than half an hour per participant per week. A similar randomized study using Tic Helper.com was completed; however, results are not yet reported.[19] We did not find studies comparing face-to-face CBIT to telemedicine.

Table 1. **Telemedicine for Hyperkinetic Movement Disorders Summary**

Authors	Movement Disorder	Aims	Methods	Main Findings
Schoffer et al.[14]	Tremor	Guidelines for filming digital camera video clips for the assessment of gait and movement disorders.	Blind comparison between video clips filmed with different quality settings.	Adequate quality video clips of movement disorder can be produced and transmitted for telemedicine purposes.
Abdolahi et al.[13]		Validation of a modified version of the motor UPDRS without rigidity and retropulsion pull testing.	Baseline and longitudinal reliability of the modified UPDRS compared to standard UPDRS.	A modified version of the motor UPDRS without rigidity and retropulsion pull testing is reliable and valid for remote assessments.
Louis et al.[16]		To study the accuracy of diagnosing PD by the videotaped UPDRS motor examination.	PD patients and controls examined by the UPDRS (in-person and videotaped examination).	The videotaped UPDRS motor examination is a useful means for diagnosing PD and provides an alternative approach for the diagnosis of PD in field studies.
van Uem et al.[18]		To evaluate HRQoL in PD patients wearing a wearable system for movements for 12 weeks in the home environment.	PD patients assigned to wearable sensors received daily feedback on the features tremor, dyskinesia/hypokinesia, and gait. HRQoL was assessed at baseline and after 4, 12, and 14 weeks, using the PDQ-39.	Overall perceived HRQoL does not deteriorate over a 12-week measurement period. Continuous assessment of PD symptoms in the domestic environment using wearables had a trend toward significant improvement in mobility domain of HRQoL.
Frich et al.[26]	Huntington's disease	To describe how health care services are organized and delivered in HD-clinics taking part in or eligible for the Enroll-HD study.	Of the 231 sites surveyed, videoconferencing and telemedicine were used by 23.6%.	By using telemedicine as part of a regional outreach program, the volume of patients serviced can be expanded.
Hawkins et al.[25]		To study whether tele-health testing improves access to HD predictive testing while maintaining quality of care and support.	There were no significant differences between the in-person-tested and tele-health-tested groups with respect to quality of care, information, counseling, and support.	Predictive testing for HD can be delivered by telemedicine while maintaining quality of care and support.
Bull et al.[24]		To determine the feasibility of conducting virtual visits directly into the homes of individuals with HD to assess the reliability of conducting remote versus in-person motor assessments, and to determine the test-retest reliability of conducting motor assessments remotely.	Participants were randomized to receive in-person and virtual visits via web-based videoconferencing. The level of agreement between remote and in-person assessments and a survey on interest in telemedicine were analyzed.	Virtual visits into the home are feasible and reliable for conducting motor assessments in HD.
Abdolahi et al.[23]	Cognitive assessment in movement disorders	To study the feasibility of conducting the Montreal Cognitive Assessment remotely in patients with movement disorders	Seventeen individuals (8 with PD, 9 with HD) were evaluated in-person and by videoconferencing.	Administration of the Montreal Cognitive Assessment remotely in a sample of movement disorder patients with mild cognitive impairment is feasible.
Fraint et al.[21]	Motor severity assessment	Determines reliability, feasibility, and satisfaction of telemedicine visits for evaluating cervical dystonia using the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) motor severity subscale.	Eighteen individuals with cervical dystonia were evaluated in-person and by videoconferencing.	Excellent agreement between clinical and telemedicine visit when assessing cervical dystonia motor severity with high feasibility and satisfaction.

Table 1 continued

Table 1. (*Continued*) **Telemedicine for Hyperkinetic Movement Disorders Summary**

Authors	Movement Disorder	Aims	Methods	Main Findings
Dekker et al.[48]	Myoclonus	To describe the phenomenology of a patient diagnosed with inspiratory myoclonus secondary to a post-anoxic encephalopathy.	Intermittent inspiratory myoclonus represents a rare disorder with a likely origin in the brainstem.	Rare movement disorders can be identified even in remote areas of the world where access to neurological care is limited by using teleconsultation.
Andrén et al.[50]	Tic disorder	To assess the impact of Internet asynchronous Behavior therapy (BT) on tic severity.	Ten-week protocol of Internet-delivered exposure and response prevention versus Internet-delivered habit reversal training.	Both reduced tic-related impairment, parent-rated tic severity, and improved quality of life, only exposure and response prevention resulted in reduced tic severity. Therapeutic gains were maintained up to 12 months after the end of the treatment.

Abbreviations: HD, Huntington's Disease; HRQOL, Health-Related Quality of Life; PD, Parkinson's Disease; PDQ-39, 39-Item Parkinson's Disease Questionnaire; UPDRS, Unified Parkinson's Disease Rating Scale.

Unmet needs and the future directions

Owing to the wide range of comorbidities, management often requires a multidisciplinary approach in Tourette's syndrome, including parents, teachers, psychiatrists, psychologists, and/or neurologists. Virtual multidisciplinary clinics that serve as a referral center may be useful in complex cases. The extent to which telemedicine facilitates multidisciplinary treatment needs to be further studied.

Dystonia

The problem

Dystonia presents at different ages and in many forms, with various phenotypical and etiological classifications. The index of suspicion of dystonia may be influenced by family history and medication history. Neurological examination techniques in telemedicine strongly determine diagnostic acumen. In asynchronous consultation, an appropriate selection of presented video fragments may depend on subtle variations in camera resolution, view angle, and lighting. Medication treatment response for various types of dystonia may be suboptimal, and many underserved areas have no access to deep brain stimulation (DBS) surgery, electromyography, and botulinum toxin treatment. Psychiatric comorbidity in dystonia may further complicate regular follow-up in patients with dystonia. This gap could possibly be narrowed by developments in telemedicine, lowering patient's threshold to access follow-up.

The solution

Depending on examination techniques and video quality, features of dystonia can be demonstrated relatively easily, leading to correct diagnosis. Telemedicine can be helpful in physiotherapy strategies. Precipitating movements in task-specific dystonia types such as writing can be shown, as well as relieving maneuvers such as a patient-specific geste antagonistique or sensory trick. A recent study ($n = 18$) has shown an excellent agreement between clinical and telemedicine visits when assessing cervical dystonia motor severity with high feasibility and satisfaction.[21] Without using the correct camera angles or lighting, however, telemedicine analysis may miss crucial dystonia features when they are very site- or task-specific. In another study,[22] a multilingual website and Skype™ videoconferences were produced for patients with oromandibular dystonia. Questions about the oromandibular dystonia clinical features (stereotyped pattern of muscle contraction, task-specificity, sensory ticks, the overflow phenomenon, and co-contraction) plus videos or images were included. With this information, the clinicians provided a provisional diagnosis, and confirmed when the patients were visited in the clinic. Approximately 1,000 patients with involuntary movements performed cyber-consultations. The Japanese version was the most frequently visited version (accounting for 23.8% visitors), followed by the English (17.6%), the Arabic (8.8%), the Italian (7.9%), the French (6.8%), and the Russian version (3.3%). According to Yoshida,[22] the use of free software might contribute to increasing awareness of oromandibular dystonia, diagnosis, and treatment.

Unmet needs and the future directions

Comparable to PD,[14] a generic dystonia tele-diagnostic video protocol could facilitate assessment by a third party. Telemedicine-guided treatment may comprise expert instructions about the muscles to target for botulinum toxin injection in specific types of dystonia. In contrast, medication-only strategies, often the only lower resource setting option, could be disappointing. Therefore, multidisciplinary management for patients with dystonia is not limited to neurology, physiotherapy, and occupational therapy, but may also require psychological intervention.

Huntington's disease

The problem

Access to subspecialist care in hyperkinetic movement disorders is often limited by the concentration of specialists in urban teaching centers. Patients with Huntington's disease may have difficulty travelling into urban centers for regular follow-up and may benefit from clinical contact in their city or home. Telemedicine is ideal for filling some of these care gaps such as timely follow-up and multidisciplinary support.

The solution

Tele-clinics for patients with Huntington's disease have been shown to be feasible, with some modification in examination technique. Written portions of the Montreal Cognitive Assessment (MOCA) have been captured by screen shot.[23] In a pilot study of 11 patients, Bull et al. were able to perform follow-up visits after the first in-person assessment.[24] Patients were seen at their homes via a provided web camera. Although there are technical limitations in assessing ocular movements, balance, and gait, most elements of physical examination are reliable. Telemedicine-based genetic counselling for Huntington's disease has been reported as well.[25] There was good patient satisfaction with this form of care. A survey of Enroll-Huntington's disease study clinics identified 23.6% of sites used telemedicine in some capacity.[26] This ranged from discussions with other clinical providers to patient visits or between-visit support. This was often used as part of a regional outreach program to expand the volume of patients serviced.

A practical example is from the Ontario Telemedicine Network, which is being operated through a secure Internet-based system since 2001 with an estimated volume of at least 600 movement disorders patient visits per year. Ontario, Canada, has approximately 14.3 million residents. At the Centre for Movement Disorders in Toronto, organized telemedicine visits are adjunct to regional outreach clinics or for patients with Huntington's disease for ongoing care after the initial face-to-face visit. The patient and family can discuss concerns as in a usual assessment. While certain elements of the examination are limited, assistance of the telemedicine coordinator can be used to better visualize the patient and to assist in obtaining relevant medical information and performing the examinations. Social workers of the Huntington's Society of Canada, who provide support and connect patients with local services across the province, may also be connected to visit remotely. Similar telemedicine assessments for patients in long-term care facilities allow for direct discussion with patients, their care providers, and their families. The ability to evaluate and make decision without the difficulties that arise from transporting a patient to another facility greatly improves the access to care. Using this existing infrastructure to provide long-distance care has allowed the Ontario Telemedicine Network to expand the geographic area of patients serviced without significant increase in cost. The multidisciplinary approach helps care to be coordinated. Although further study is required to provide evidence that telemedicine improves care in Huntington's disease patients, it has become a standard of practice at the Ontario Telemedicine Network site based on positive feedback from patients and families.

Unmet needs and the future directions

While there is experience in PD,[27,28] there is limited description of how telemedicine is used to evaluate other chorea beside Huntington's disease and to replace the regular clinical care. The efficacy of telemedicine in initial evaluation, diagnosis, and follow-up visit should be assessed as in similar movement disorders studies.

Parkinson's disease-related dyskinesias

The problem

Dyskinesias (excessive involuntary movements) represent a complication of dopaminergic treatment in patients with PD. The movement disorder is varied, unpredictable, and may not be present during clinical visits. No studies have been published relating to videoconferencing for the study of this motor complication.

The solution

One of the benefits of asynchronous telemedicine is that videos can be obtained for patients experiencing paroxysmal movement disorders at the time of event. Families and referring physicians can capture these events and forward them to the specialist physician. There were no studies assessing how videoconferencing adds to evaluation of dyskinesias.

Unmet needs and the future developments

Diaries are commonly used to track the severity of dyskinesias as a basis for optimizing the therapeutic management using either pharmacotherapy or DBS.[29] While diaries have been used in multiple clinical trials to demonstrate efficacy of approved therapeutics, these are limited in tracking the patient's motor state in daily life. As an alternative, several research groups have used one or more wearable sensors, typically accelerometers, to try and track objectively both presence and severity of dyskinesias.[30–36] Wearables are not always considered a part of telemedicine, although they are certainly an important part of tele-monitoring, and as such could be reckoned to be a part of the larger overarching concept of telemedicine. The studies were relatively small for a variable disorder using many different sensor locations.[30] It remains unclear which sensor location is most suitable, and, particularly, what is the added value of combining multiple sensors. Other alternatives are recording functional abilities from a simulated home environment either in a natural setting or under carefully controlled circumstances in the laboratory.[36] The field would benefit from an objective comparison of multiple sensor locations in studies with a much larger sample size, conducted in and around the patients' own homes (preferably with videotaped performance at home as objective reference), and including a larger variety of unscripted activities.

Pediatric hyperkinetic movement disorders

The problem

Pediatric movement disorders are an emerging field with a limited amount of specialists. Many specialists receive videos daily via WhatsApp from colleagues, patients, and friends consulting about diagnosis and treatment (unpublished data). Although instant messaging is trusted and widely used by the general public, most health systems do not recognize, reimburse, or document these consultations. Moreover, instant messaging raises questions of doctor-to-patient relationship, security, and other ethical concerns that are better addressed in a formal setting.[37,38] Another problem is that some parents are separated and have joint custody for a child. This may pose a problem in regular clinical management.

The solution

Telemedicine offers the opportunity to provide informal mentoring to other physicians from subspecialists that may be difficult to access. Pediatric tele-neurology is shown to be convenient, cost-effective, patient-centered with high adherence, compliance, and satisfaction.[39,40] We did not find existing studies regarding telemedicine for pediatric movement disorders in medical literature. Reviews mention potential opportunities, but telemedicine has not been widely implemented within the standard services.[1] This is surprising when taking into account the need for providing care to patients with accessibility and challenges who require specialist care. Gaps between needs and opportunities are more prominent in remote areas, as demonstrated in the cerebral palsy clinic in Queensland, Australia. The majority of children travel for long distances to consult a specialist (average distance of 836 km), and clinicians perceived healthcare services as inadequate in terms of accessibility for children with these movement disorders.[41] Moreover, videoconferencing allows both parents to participate in clinic for better management.

The future development and unmet needs

An accessible network of pediatric movement disorders may serve as the center of referral and consultation. Establishing such a service has legal and marketing barriers. We believe in the near future, and there will be a possibility of groups of specialists to provide direct consultation to hospitals and health maintenance organizations (HMO) similar to the telestroke model.[42]

Myoclonus

The problem

Myoclonus is a clinical sign characterized by brief, shock-like, involuntary movements caused by muscular contractions or inhibitions. Muscular contractions produce positive myoclonus, whereas muscular inhibitions produce negative myoclonus (i.e., asterixis).[43] Myoclonic movements have many possible etiologies, anatomic sources, and pathophysiologic features.[44]

The solution

For myoclonus, included in the group of paroxysmal movement disorders, asynchronous telemedicine could be of interest in order to capture the videos at the time of the event and later uploaded for consultation.

Telemedicine consultations have been considered for epileptic myoclonus. In one study,[45] the diagnosis of myoclonus pathologies was established by using tele-EEG examination and videos of the patient. There are few reports about telemedicine in non-epileptic myoclonus, which is described in telemedicine under hyperkinetic movement disorders in paragraph of "underserved areas."

The future development and unmet needs

As we have described for other hyperkinetic movement disorders, efficacy of telemedicine in initial evaluation, diagnosis, and follow-up visit should be assessed in myoclonus, as in studies on other similar movement disorders.

Telemedicine in hyperkinetic movement disorders in underserved areas

Telemedicine is a suitable modality for lower-income regions and is commonly used in academic teaching setting. Certain aspects of neurology, such as hyperkinetic movement disorders, lend themselves well to telemedicine consultation.

The problem

Lack of resources and certain sociocultural stigma around hyperkinetic movement disorders may contribute to delayed recognition and treatment. Eastern and central Africa have fewer neurologists (Tanzania presently has one practicing neurologist for about 10 million people),[46] and referrals more often come from non-neurologists. Local health professionals, however, have created makeshift telemedicine solutions. Most areas in need lack the bandwidth and continuous connectivity to perform synchronous telemedicine for hyperkinetic movement disorders.

The solution

Asynchronous telemedicine is widely used. Videos are easily sent through email and WhatsApp, although in many remote regions, bandwidth and Internet quality usually allow for short segments only. Short video segments may capture all of the characteristic features of a hyperkinetic movement disorder, which may be sufficient to make a diagnosis. Over the last 6 years, the International Parkinson's Disease and Movement Disorder Society has been sponsoring several telemedicine programs in underserved areas, including South America, Africa, and China. The Asynchronous Consultation in Movement Disorders (ACMD) is a specialized program conducted in Africa. The use of this store-and-forward technology has enabled referring sites with slower Internet speeds and variable electrical power to participate in ACMD. In 2018, 12 out of 51 clinical cases (43%) presented using the ACMD platform were related to dystonia, myoclonus, and dyskinesias, and none contained queries regarding PD,[47] likely the most commonly discussed movement disorder elsewhere. These observations highlight the difficulties of diagnosing hyperkinetic movement disorders in underserved areas. An example of a rare disorder, inspiratory myoclonus, was successfully diagnosed and was described in a previous edition of this journal.[48] Referrals often comprise conditions which are not commonly seen overseas. One good example is the case of a poly-mini-myoclonus in a survivor of East African trypanosomiasis with basal ganglia abnormalities on neuroimaging, or segmental tetanus mimicking focal dystonia. More training and consideration, including tele-education, could be considered to address specific needs of underserved areas.[49]

Unmet needs

The main challenge today in providing telemedicine is not technical but financial; these consultations are given in a voluntary manner. As demand increases, budget will be required.

The future directions

Expanding services and data collections from different populations in developing counties is needed. This requires expanding teaching, expert recruitment, and data collection format. Investing in telemedicine in developing countries will enable better services with lower cost than face-to-face consultations. As medicine is moving to big data for clinical practice, data collected from variable populations, especially combined with genetic testing, would contribute to improved global medical knowledge.

Summary

Telemedicine has the potential to improve care in patients with hyperkinetic movement disorders. The literature on telemedicine in movement disorders, as in other specialities, is currently developing, and is yet to prove the efficacy compared to face-to-face clinic in various populations and conditions. Although not many studies have been published in this area and more work needs to be done, the authors support expansion in the provision of clinical care and research.

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