Patients' post-judice of tele-neurology for movement disorders

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Background

The COVID-19 pandemic and ensuing public health emergency resulted in an unprecedented transition to so-called 'virtual' (telephone and video-call) healthcare for patients with movement disorders. In the acute phase of the pandemic, this proved invaluable, enabling continuity of care while limiting the potential for viral transmission. In recent months however, the situation has changed. Availability of effective vaccines and ongoing public health measures have brought COVID-19 disease under some degree of control, enabling lifting of most restrictions on everyday life and a semblance of return towards normality.

With face-to-face healthcare options available once more, a major unanswered question is what long-term role tele-neurology should play in the care of patients with movement disorders. Some have argued that it should become the new gold-standard, citing high levels of patient and physician satisfaction, convenience, as well as time and cost savings[1, 2]. Others are more skeptical, pointing to the limitations of virtual approaches including its negative impact on doctor-patient relationships, its likely inferior diagnostic ability (particularly for new patients), its potential to increase health inequalities and its remoteness and lack of touch and warmth [3-5].

In the UK, the NHS is moving towards a 'digital first' primary care system, where by default, all first interactions would take place online. Most other healthcare systems are similarly encouraging physicians, including those involved in the care of patients with movement disorder, to incorporate more remote healthcare visits into their clinical practice.[6] However, one needs to pause and reflect on whether this is in patients' best interest and if this is actually what they want. Indeed, despite

being the ones who will be principally impacted, patients' views on this issue (outside of formal studies) remain largely unknown. We therefore sought to ascertain their opinions of real world tele-neurological care for movement disorders, in order to help guide future healthcare planning in the field.

Study design

All consecutive patients having undergone a remote healthcare appointment (either by phone or video link) in our movement disorder clinic at the National Hospital for Neurology and Neurosurgery, Queen Square, London, between October 2020 and September 2021 were contacted and asked to complete, via an online web portal, a self-administered questionnaire about their experiences (supplementary material 1). Patients specifically requiring face-to-face intervention e.g. botulinum toxin injections, deep brain stimulation adjustments, were excluded. Four main aspects were assessed: patient clinical and demographic characteristics, ease of setup, perception of their telemedicine visit and preferences for future care. Opinions regarding telemedicine were assessed on a 5-point Likert-like scale ranging from strongly disagree to strongly agree. Correlations between demographic and clinical variables (age, sex, ethnicity, occupational status, income, educational achievement, travel time to clinic, diagnosis, appointment type) and preference for future care delivery (face-to-face Vs telemedicine) were assessed using Pearson correlation coefficient. A sub-analysis comparing attitudes patients undergoing new Vs follow-up appointments, and of patients undergoing phone Vs video reviews was also performed, using the Mann Whitney U test to assess for group differences in response patterns to individual questions. Patients were also invited to provide unstructured 'free-text' feedback about the positive and negative

aspects of their virtual visit. The study was approved by the National Hospital for Neurology and Neurosurgery service evaluation committee (ref: 32-202122-SE).

Study Outcomes

Of the 253 patients contacted, 214 (56% female) completed the survey. In 88% of cases, the clinical encounter had been conducted by telephone. Data from a broad range of age, ethnic, educational and income categories was captured (Figure 1). Parkinson's disease, dystonia and tremor were the most common movement disorder diagnoses (accounting for 34%, 20% and 15% of respondents, respectively), though other conditions including ataxia (9%) and tic disorders (1%) were also represented. Over 70% of patients had travel times >1 hour (one-way) to reach the clinic, and 28 % travelled > 2 hours. In most cases (86%), the appointment was a follow-up visit. Most patients had no difficulty with the set-up or communication process, and the majority (88%) had access to high-speed internet (figure 2). Most people did not consider telemedicine an intrusion of their privacy.

As with previous studies,[7-9] the majority of patients reported being 'satisfied' with the experience. Yet, only 20% of patients agreed or strongly agreed that the quality of remote care was as good as face-to-face, while less than 15% were confident that the physician could correctly diagnose their problem remotely (figure 2). Over 80% agreed or strongly agreed that it was easier to build a rapport with a doctor in-person, while nearly three quarters had more confidence in a doctor when seeing them face-to-face (figure 2). Only 2% of patients surveyed felt that telemedicine was better than face-to-face care, 14% considered them equivalent,

and the remainder (84%) regarded telemedicine as inferior to in-person care (figure 2). When asked if they now had the choice of how their future care should take place, 82% opted for face-to-face (figure 2).

None of the clinical or demographic variables correlated with preference for future method of care delivery, except for a very weak positive correlation between travel time to the clinic and preference for long-term remote healthcare provision ($r=0.19$, $p<0.01$). Sub- analyses comparing patients receiving a phone versus a video appointment, and those undergoing new versus follow-up appointments, identified no significant differences in perception of tele-neurology between these groups. (supplementary material 4 and 5).

Discussion and Conclusions

To our knowledge, this is the first large-scale, post-hoc study evaluating patients' perceptions of telemedicine for movement disorders in a real-life clinical setting. The studied population spanned a wide range of ages, ethnicities, income levels and movement disorder diagnoses and is therefore likely to be representative of the general movement disorder population. The results suggest that there is an overwhelming preference for a return to face-to-face care (figure 2, Supplementary material 2 and 3).

Several factors appeared to contribute to patients' dissatisfaction with telemedicine. The first is a concern about mis-diagnosis. Patients recognize the particular reliance

of movement disorder clinical practice on astute observation, and understand that despite the allure of convenience and time/cost savings, even video encounters carry significant potential for oversight. This impacts both their confidence in the diagnoses - “I didn't feel the doctor could really diagnose without actually seeing me”- and their ability to feel understood: “I could not demonstrate impairments of function”(patients’ ‘free text’ responses on these issues are comprehensively presented in supplementary material 2 and 3).

Many patients commented on the impact of telemedicine on effective communication and the doctor-patient relationship. As one patient put it, “It does not have the personal touch”, while others mentioned the lack of eye contact, facial expression and difficulties in discussing sensitive topics (supplementary material 2 and 3). The impact on non-verbal cues is indeed a critical drawback. Remote healthcare truncates, or sometimes completely abolishes non-verbal aspects of communication, which are vital in understanding patients’ attitudes, emotions and expectations[10]. Effective non-verbal communication is key to forming the strong therapeutic alliances which enable accurate diagnosis, development of shared treatment plans, counseling and compassion[11]. This becomes especially important when discussing sensitive issues or breaking bad news, where it is often not what is said, but how it is said, that matters[12]. The ethics behind addressing difficult questions – “will I get dementia”, “will I end up in a wheelchair”, “will Parkinson’s disease kill me”- over the phone or video, also remains a matter which the movement disorder community needs to reflect upon..

Remote healthcare alters doctor-patient relationships on many other levels. Patients tend to become more passive, while doctors focus narrowly on specific

problems rather than adopting a holistic approach to care[13, 14]. Physicians comment that phone consultations allow them to adopt a 'business-like' approach and 'take control' and lead the conversation[15]. As one physician in another survey put it, "I'm very much pigeon-holing the patient into where I want them to be"[15]. However, patients are not pigeons to be put into holes, and such approaches are likely drivers of their dissatisfaction.

Moreover, patients likely obtain less therapeutic benefit from remote interactions. No treatment is ever administered in a vacuum, and regardless of the intervention, accompanying rituals and contextual stimuli – the doctor's office, the stethoscope, the physical examination – which provide a sense of reassurance and confidence, are major determinants of treatment efficacy and patient outcomes[16]. Much medical healing power stems not from pharmacotherapies, but rather from the healing powers of the clinical consultation[17, 18]. As Walter A Brown eloquently put it, "the healing environment is a powerful antidote for illness"[16]. Clinician behavior is also critical, with diagnoses and treatment plans delivered with confidence achieving better outcomes [16, 19]. Regrettably, telemedicine reduces physicians' diagnostic certainty (especially in movement disorders, which relies heavily on eliciting confirmatory physical examination signs)[20], likely compromising both timely initiation of appropriate treatment, and its efficacy[21].

The findings of this study are at odds with the prevailing sentiment in much of the published academic literature, where the merits of 'virtual' care are frequently extolled. There are likely multiple reasons for this discrepancy. First, many studies of tele-neurology were conducted in a highly structured way, in pre-selected populations outside of 'real-world' clinical practice. As such the findings are poorly

generalizable to everyday clinical care. Second, outcome measures in these studies frequently focused on the non-specific metric of 'patient satisfaction', often inappropriately conflating this into a measure of quality of care[7]. Third, one must acknowledge that most of the articles on telemedicine during the COVID-19 era are likely biased by the fact that alternatives, particularly face-to-face clinic visits, were often not available, and telemedicine therefore constituted the only opportunity to talk with a doctor. Finally, non-response bias may be significant. It is well established that those satisfied with a process are more likely to complete surveys about it, whereas the dissatisfied tend to keep their disquiet to themselves[22, 23]. Many studies on telemedicine have had a 40-60% rate of non-responders/declined participation[9, 24-28], raising the possibility that the published results merely reflect the views of a satisfied, more vocal, minority.

Our patients did mention some positives of telemedicine visits. Similar to previous studies, these mainly related to time and cost saving, convenience (especially for those in employment) and avoidance of the risk of viral transmission (supplementary material 3). The weak positive correlation between travel time to the clinic and preference for virtual healthcare suggests that particularly for those travelling long distances, incorporation of telehealth into their clinical care may be desirable. Interestingly, most patients described themselves as satisfied with the experience, highlighting the crucial difference between satisfaction with a service, and a preference for it becoming the new normal. This also underscores the flawed reasoning behind basing long-term healthcare policy decisions on studies of patient 'satisfaction', as when given the choice, an overwhelming majority prefer to see the doctor in person.

There are limitations to this study, which must be acknowledged. First, the majority (88%) of encounters were conducted by telephone, and it is possible that patient satisfaction may have been higher if more had undergone video visits. In our sub-analysis comparing phone versus video encounters however, we found no major differences in patient perceptions (albeit that small numbers in the video arm may have limited our ability to detect this). Second, participants were not necessarily reviewed by the same physician during remote and in-person visits. This could have accounted for some of the differences in opinions between modalities. Finally, we acknowledge that while new patients also largely perceived telemedicine as inferior, the validity of this judgement may be limited by not having actually had a similar in-person appointment for comparison.

Telehealth is being widely promoted as a path towards better, more personal and cost-effective care for all; a panacea which will fix waiting lists and provide patients with a new model of care which they desire. Healthcare institutions, politicians and industry, all with significant vested interests, will likely continue to promote telemedicine as a method of chasing performance metrics, cutting waiting times and increasing throughput, meaning that doctors will spend increasing amounts of time in front of the computer rather than caring for living breathing patients[29]. Meanwhile, patients will be forced to accept a service which they don't want, and which on multiple levels, is likely inferior to an available alternative.

The proof of the pudding is in the eating, and with lifting of restrictions, patients are flocking back to clinics in their droves. Even during the COVID-19 lockdown, when movement disorder patients were offered a choice between face-to-face visits and remote consultations, over 70% chose to see the doctor in person[30]. It is also telling

that movement disorder neurologists have largely returned to providing face-to-face care, seemingly well aware that this is both what patients want, and need[31].Patients have spoken and their message is loud and clear. It is now up to physicians to advocate on their behalf, and resists any attempts by managers, politicians or other lobbyists to mandate widespread and indiscriminate adoption of a largely unwanted, often inferior care model.

Author roles

1. Research project: A. Conception, B. Organization, C. Execution

2. Statistical Analysis: A. Design, B. Execution, C. Review and Critique

3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique

IR 1A, 1B, 1C, 2C, 3B

EM 1A, 1B, 2A, 2C, 3A

IC 1B, 1C, 2C, 3B

AJL 1A, 2C, 3B

KPB 1A, 2C, 3B

EM 1A, 1B, 2A, 2B, 2C, 3A, 3B

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Ethical Compliance Statement

The study was approved by the National Hospital for Neurology and Neurosurgery service evaluation committee (ref: 32-202122-SE). Informed consent was obtained. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines

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Figure legends:

Figure 1: Demographic and clinical characteristics of respondents (n=214; male=94, female=120).

Figure 2: Patient perceptions of 'real-life' telemedicine in movement disorders.

Supplementary material legends:

Supplementary material 1: Questionnaire delivered to participants

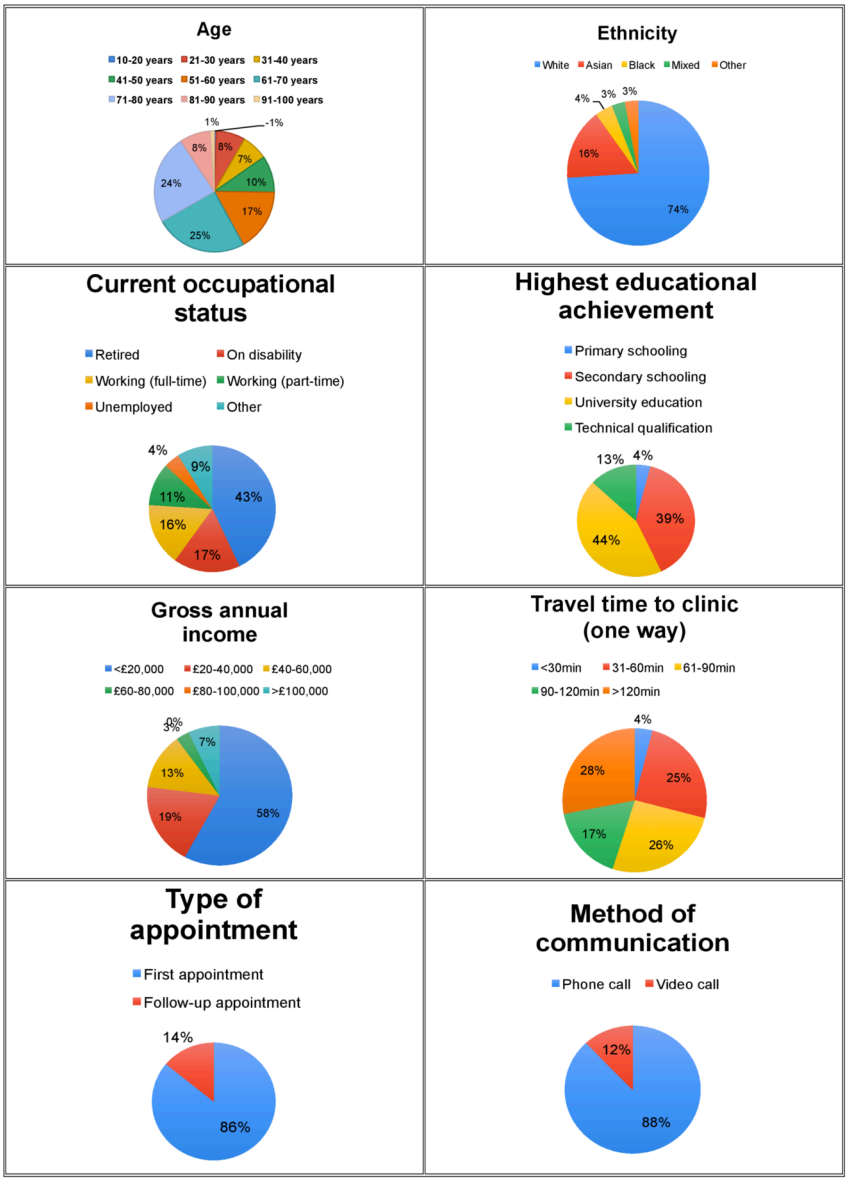
Supplementary material 2: 'free-text' patient responses about the most negative aspects of their telemedicine visit*

Supplementary material 3: 'free-text' patient responses about the most positive aspects of their telemedicine visit*

Supplementary material 4: Comparative perceptions of telemedicine and face-to-face visits in patients undergoing phone versus video appointments

Supplementary material 5: Comparative perceptions of telemedicine and face-to-face visits in patients undergoing new versus follow-up appointments

Figure 1: Demographic characteristics of respondents



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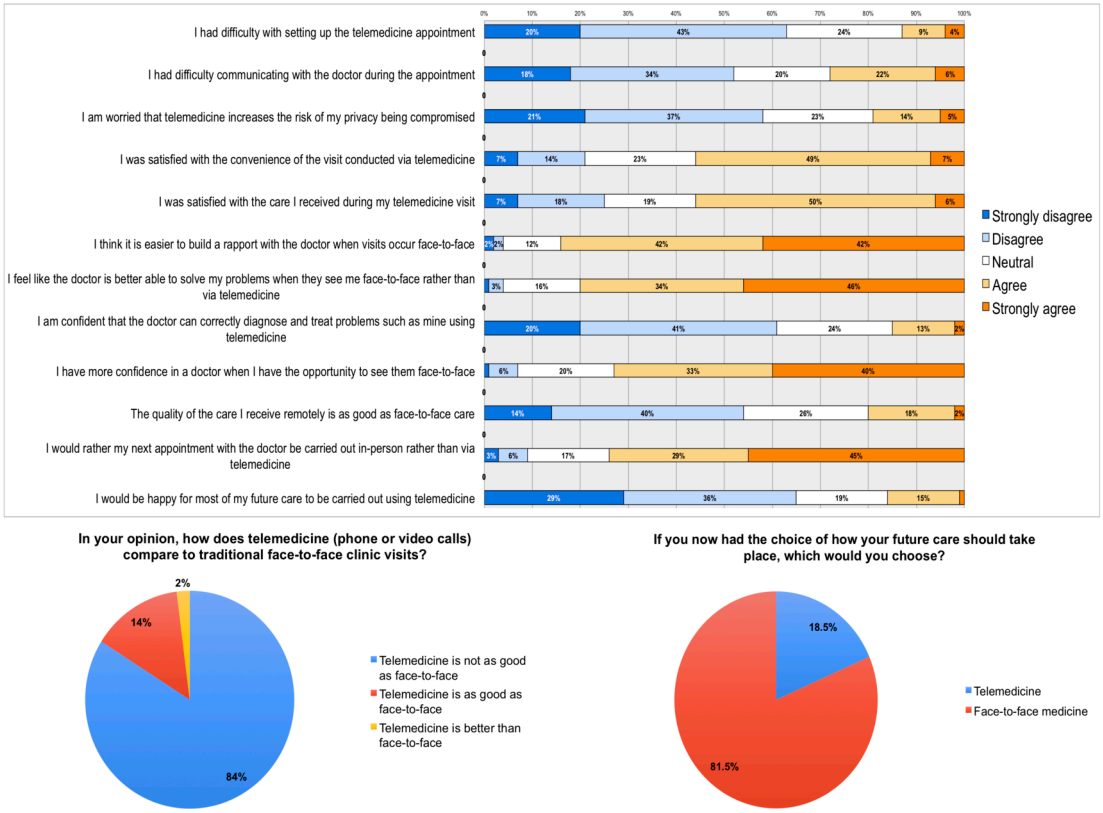

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