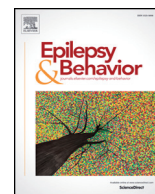




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Counseling of people with epilepsy via telemedicine: Experiences at a German tertiary epilepsy center during the COVID-19 pandemic

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ABSTRACT

Introduction: Driven by the challenges of alternative healthcare supply during the COVID-19 pandemic, acceptance and appreciation of telemedicine were assessed in a German tertiary epilepsy center.

Methods: Two hundred thirty-nine patients with epilepsy (53% female, 35% seizure-free, 97% on antiseizure medication) answered a structured audit on telemedical counseling as part of individual outpatients' care.

Results: Overall 82% of the participants were satisfied with the telemedical appointment. The telemedical appointment was rated equal to onsite appointments in means of time (91%), comprehensibility (94%), and opportunity to get answers to current questions (92%). It was evaluated as good as onsite appointments regarding comprehension of the disease (88%) and impact on following the physician's advice (82%). The participants considered immediate convenience and shortfall of travel expenses as advantages of telemedicine, whereas lack of personal contact and diagnostics (electroencephalogram [EEG] recordings, blood analysis) were seen as disadvantages. About 73% of the participants would appreciate the opportunity of future telemedical counseling, but the majority (75%) wished to have further appointments onsite.

Conclusions: Overall, people with epilepsy appear to be satisfied with telemedical counseling. However, patients greatly appreciate the medical services onsite and consider telemedicine as an add-on service rather than a substitute to visits onsite.

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1. Introduction

The COVID-19 pandemic led to dramatic changes in everyday living as well as clinical practice. Social distancing and the need of quarantine demanded quick and extensive changes in healthcare supply. So far, epilepsy itself is not estimated to be risk factor of COVID-19-related morbidity. Surely, some patients with epilepsy are at risk, e.g., those with tuberous sclerosis complex with lung affection or on everolimus medication, patients with autoimmune encephalitis on immunosuppressants, or patients with risk factors such as comorbid asthma or hypertension [1]. Therefore, exposure to places with increased risk of infection with SARS-CoV-2 should be avoided. In addition, many patients may be anxious and prefer not to see their physician even though symptoms may demand a visit. Moreover, patients living in assisted living institutions are presently not allowed to leave their facilities because of infection risk for their fellow housemates. Changing from face-to-face appointments onsite to remote telemedicine seems to be the most

advantageous way to care for patients with epilepsy without exposing them to higher risks in waiting rooms, emergency departments, and, not to forget that the majority of them are not fit to drive, to get them out of public transport.

The idea of telemedicine in epilepsy care was already suggested two decades ago [2], but up to now, it has rarely been used and was far from becoming standard. Particularly now with the rapid expansion of social media, the technology, and the tools for telemedicine at hand, a widespread implementation appears feasible. The COVID-19 pandemic overran most countries like no other illness in the past decades and led to dramatic changes in political, economic, and ethical domains with considerable restrictions of public life. This, in turn, made rapid modifications in healthcare pathways necessary, thereby boosting implementation of telemedical tools in the care of patients with chronic diseases such as epilepsy [3,4].

In this context, we modified our outpatient care within a few weeks from onsite appointments only to telemedical counseling (via phone or a commercial videoconference system) and onsite appointments if necessary for medical reasons. Telemedicine appointments started in the mid of March 2020 at our department. As patients with chronic diseases need special care and often develop a personal relationship with

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individual physicians, we assessed the acceptance and appreciation of telemedicine by patients usually seen in the outpatient setting.

2. Material and methods

2.1. Patients

Adult patients with any type of epilepsy aged 18 years or over who were counseled and treated by telemedicine between March 23 and May 8, 2020 were asked to participate in a structured audit. The audit was conducted by clinic staff, not by the treating physician, to avoid loyalty conflicts. The questions were answered by the patients themselves; for those with a mental disability, family members or caregivers who joined the visits answered the questions. For patients who are not native German speakers, family members or translators were asked to give answers. All patients were given the opportunity to ask further questions beyond the audit. Since the survey was part of quality measures that allow timely improvements of clinical care during the restrictions due to the COVID-19 pandemic, ethical approval was waived by the ethics committee of the Medical Faculty of the Rheinische Friedrich-Wilhelms University of Bonn.

2.2. Questionnaire

The audit was composed of five questions concerning general satisfaction with, advantages and disadvantages of telemedical appointment (TM appointment), as well as wishes toward further telemedical counseling and treatment. Two questions were ordinal, all others nominal. For patients who were previously seen in our outpatient department, six more questions (three nominal, three ordinal) were set to compare TM appointments to appointments onsite. An English version of the questionnaire is given in the supplemental material.

The following demographic data were obtained: age, sex, duration of epilepsy, epilepsy syndrome, seizure frequency, seizure freedom (yes/no), antiseizure medication (yes/no), number of previously prescribed antiseizure medications, highest level of education, native German speaker (yes/no), and time since the first visit to our department. Seizure frequency was raised on the basis of self-assessment using The Revised Seizure-based Outcome Classification System (Duke) with Analysis of Relationship to HRQOL (health-related quality of life) with three seizure categories (seizure-free, ≤ 10 seizures per years, > 10 seizures per year) according to Vickrey and colleagues [5]. This classification system was used as it strongly reflects the close relation to quality of life.

2.3. Statistical analysis

Statistics were done using SPSS IBM statistics calculator. Information on missing data were given where necessary. Models used are given in the context of the Results section. p-Values < 0.05 were regarded as statistically significant.

3. Results

A total of 345 appointments of TM appointments were carried out in the considered period. Two hundred fifty-five patients could be contacted afterwards. Five patients denied participating. Eleven patients were excluded from analysis as they did not suffer from seizures or epilepsy. Time between the appointment and the interview was short (2.4 ± 2.1 days, mean \pm standard deviation [SD]). Participants' characteristics of the remaining 239 patients reflect the population of a tertiary epilepsy center (Table 1). Six of the participants had first-ever visits, and 233 participants had follow-up visits.

Fifty-one (21%) of the TM appointments were performed using a video conference system and 188 (79%) by phone. Overall, 197 (82%) participants were satisfied with their TM appointment. Participants

Table 1
Participants' characteristics (n = 239).

| Feature | |
|--|-----------------------|
| Male/female | 113 (47%)/126 (53%) |
| Age (years), mean \pm SD/range | 41.5 \pm 17.2/18–93 |
| Age at onset of epilepsy (years), mean \pm SD/range | 21.0 \pm 17.1/0–75 |
| Duration of epilepsy (years), mean \pm SD/range ^a | 20.4 \pm 15.0/0–61 |
| Epilepsy type | |
| Focal | 174 (73%) |
| Generalized | 51 (21%) |
| Unknown | 28 (12%) |
| Additional psychogenic seizures | 9 (4%) |
| Seizure-free | 84 (35%) |
| Lower seizure frequency | 44 (18%) |
| Higher seizure frequency | 111 (46%) |
| Medical therapy | |
| On anticonvulsant medication | 232 (97%) |
| Exposition to ≥ 3 different anticonvulsants | 105 (44%) |
| Number of actual anticonvulsants mean \pm SD/range | 2.04 \pm 1.1/0–5 |
| Time of being treated at our department (years) mean \pm SD/range | 9.13 \pm 7.9/0–30 |
| Education | |
| Education < 10 years | 36 (151%) |
| Education > 10 years | 58 (24) |
| No education/school for persons with mental or physical disability (with mental disability = 38) | 39 (16%) |
| No information | 106 (44%) |
| Native German speaker | 206 (86%) |

^a Missing = 1.

considered no transport (71%), more comfort (64%), short waiting time (51%), and no travel expenses (41%) as advantages of TM appointments. Ability in better following the conversation (6%) and preparing for the appointment (12%) were considered less important. Furthermore, 19 participants (8%) stated spontaneously that TM appointments avoid or reduce the infection risk. Participants considered the lack of personal contact (44%) and of further diagnostics (45%) as disadvantages of TM appointments. Leaving habitual surrounding (7%), meeting other patients with epilepsy (9%), lack of immediate prescription (9%), as well as technical (10%) or cognitive problems (3%) were less important to them. Stepwise regression analysis did not find any predictor for general satisfaction with TM appointment (not shown).

The majority of participants would be willing to attend future TM appointment. However, they wished further appointments onsite (178 patients, 74%) as well (47% at least once a year, 26% on demand) (Fig. 1). Stepwise regression analysis revealed that younger age, not being native German speaker, and shorter duration of being patient at the department were positively associated with the willingness to attend future TM appointments, whereas longer duration of epilepsy was found to be a negative predictor for the wish of future TM appointments. This model, however, only explained 11% of the variance. Conversely, positive predictors for the wish for future appointments onsite were longer duration of epilepsy, taking antiseizure drugs, as well as longer duration of being a patient at our department. The proportion of explained variance in all regression analyses was low ($< 6\%$).

Eighty percent of all participants wished low frequent or on demand onsite appointments in the future, which was significantly associated with the willingness to have TM appointments in the future ($f = 35.04$, $p < 0.001$).

Questions on comparisons of TM appointment with previous appointments onsite in our department were answered by 229 participants (6 patients had their first-ever appointments, 4 denied answering). Satisfaction with TM appointment was rated as good as with appointments onsite by 80% of the patients. Regarding quality aspects, equivalence was attested concerning time given by the physician

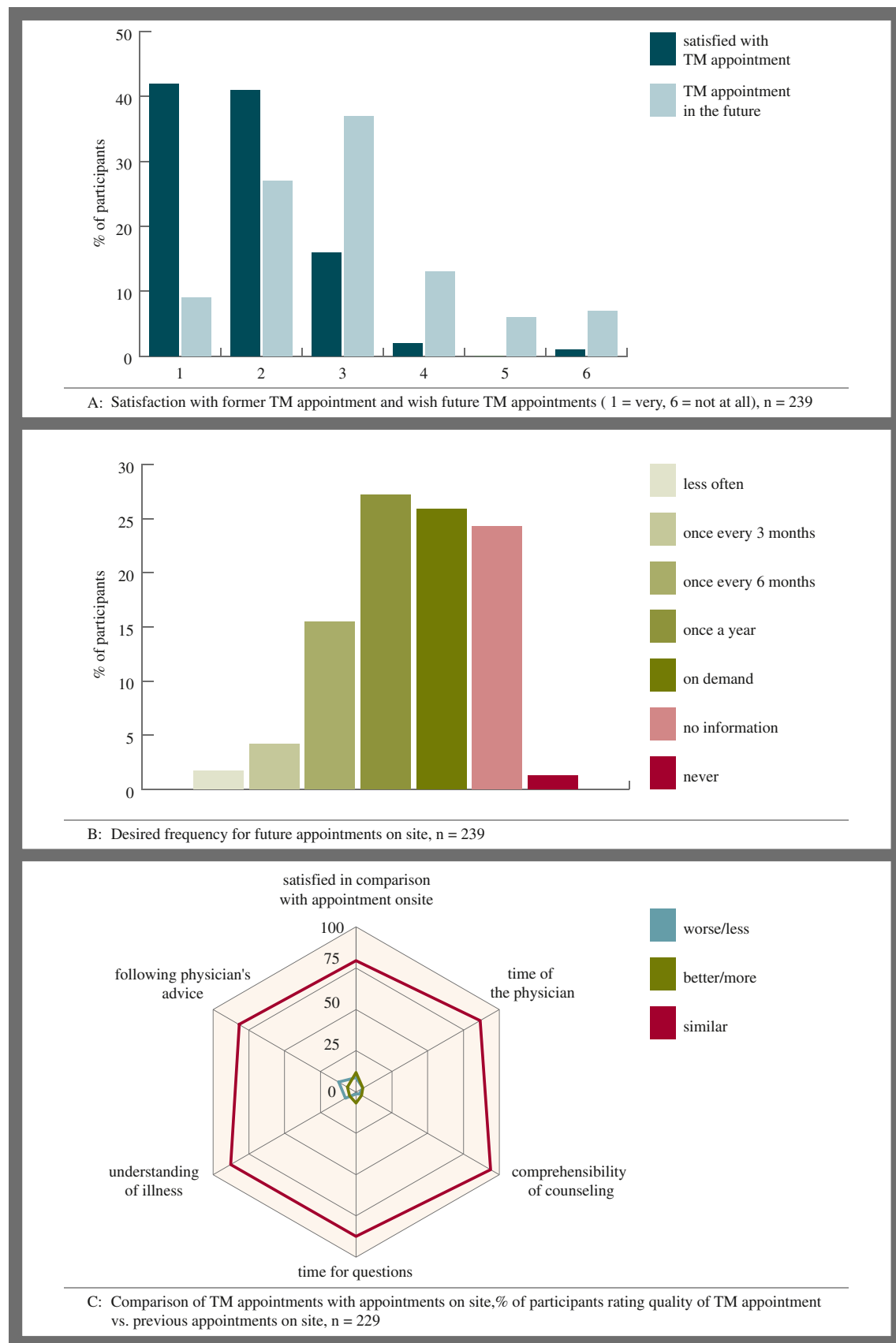


Fig. 1. A: Satisfaction with former TM appointment and wish future TM appointments (1 = very, 6 = not at all), n = 239. B: Desired frequency for future appointments onsite, n = 239. C: Comparison of TM appointments with appointments onsite, % of participants rating quality of TM appointment vs. previous appointments onsite, n = 229.

(91%), comprehensibility of counseling (91%), and opportunity to get answers to current questions (92%). About 88% of the participants stated that the TM appointment helped them as well as previous appointments onsite for the understanding of the illness, and 82% stated that they would follow the advice in the same way as if they had attended the appointment onsite (Fig. 1).

4. Discussion

During the last years, telemedicine in the management of chronic neurological diseases developed slowly and initially focused on settings where access to healthcare was limited by distance or poor resources. Time of implementation of telehealth varied dependent on the disease, the way was long and ponderous due to several limitations, e.g., tradition, privacy, legal aspects, and reimbursement [6,7]. Nevertheless, the benefits of telemedicine as a medical response to disasters were clearly documented before [8]. Hence, the COVID-19 pandemic catalyzed the implementation of previous ideas of telemedicine as it helps to support social distancing, to get patients out of crowded waiting areas and public transport, and to reduce required personal protection equipment. Furthermore, telemedicine helps to maintain appropriate care in times of limited healthcare access and supports chronically affected patients to cover their medical and psychological needs in times of social and medical crisis. Noninferiority of telemedicine to appointments onsite in epilepsy treatment (antiseizure medication adherence, seizure control, frequency of hospitalizations, and emergency room visits) was previously demonstrated [9,10], supporting the use of telehealth tools during the COVID-19 pandemic wherever possible [1].

In line with previous reports, the participants of our audit were mostly satisfied with the TM appointments [9,11]. Advantages were not only seen concerning financial aspects but also concerning time management and comfort. Quality aspects of telemedicine were addressed in previous controlled studies and showed no significant differences between patients treated remotely or onsite, respectively [9,11]. Additionally, our audit suggests that the majority of patients who have already had appointments via telemedicine and onsite rated the quality to be similar, and even the potential efficacy of treatment, at least from the patients' point of view (in terms of expected adherence), was estimated similar. Future studies to assess seizure control and long-term adherence in general (antiseizure medication, lifestyle issues, driving) in patients followed by TM appointments may be helpful to further improve patients' care.

Importantly, three quarters of the participants wished to have further appointments onsite, although overall satisfaction with TM appointments was high. Those participants who wished to have appointments on demand or less frequent appointments onsite were open for future TM appointments. It is tempting to speculate that the motivation for appointments onsite is bound more to emotional factors such as personal relationship and a sense of being part of an institution. Nevertheless, most participants wished both onsite and TM appointments with the latter being an additional option.

Our audit underscores that telemedical counseling is appreciated by patients with epilepsy, but rather as an additional option to onsite appointments than a substitute. However, the results must be interpreted in the context of the recent social conditions of lockdown and fears due to COVID-19 pandemic influencing patients' estimation.

Further studies on appreciation and valuation of counseling by telemedicine after lockdown due to COVID 19 pandemic will reveal if and how preferences might change afterwards and what lessons we have learned from this overwhelming experience in alternative healthcare supply.

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Declaration of competing interest

The authors declare that the audit was conducted in the absence of any financial or commercial interest that could be a potential conflict of interest. RvW has received fees as a speaker, consultant, or travel support by Cerbomed, Desitin, GW pharmaceuticals, Eisai, and UCB. SMH has received fees as a speaker, consultant, or travel support by Eisai, UCB, and Liva Nova. TB has received fees as a speaker and consultant by Eisai and UCB. CH has received grants from the EU, travel support by Desitin, honoraria for talks, counseling, and advisory boards by GW pharmaceuticals, Eisai, and UCB, as well as license fees by Eisai and UCB. RS has received fees as speaker or consultant from Bial, Cyberonics, Desitin, Eisai, LivaNova, Novartis, and UCB Pharma, and grants from Deutsche Forschungsgemeinschaft (DFG), Bundesministerium für Bildung und Forschung (BMBF), the Bundesministerium für Gesundheit (BMG), and Marga and Walter Boll Stiftung.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2020.107298>.

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