ORIGINAL ARTICLE

Experiences from an International Tele-Epilepsy Collaboration

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ABSTRACT: ***Objective:*** Our main objective was to use videoconferencing as a primary means to: a) assist in launching an epilepsy surgery program in Pakistan; 2) participate in case conferences on complex epilepsy patients in each country. ***Methods:*** Extensive testing using both point to point and bridged integrated service digital network (ISDN) and internet protocol (IP) connections was carried out using bandwidths of 384-768 kilobits per second (kbps). Videoconferences between sites were arranged two to three weeks in advance and connections were tested a day prior to the scheduled conference. Sharing of PowerPoint presentations, neuroimaging and video-EEG was available to all sites. Discussions centered on patients with medically refractory epilepsy. ***Results:*** Between July 2006 and June 2008, 17 sessions were booked. Five of these conferences bridged in specialists from West Virginia University. Most successful connections occurred using IP point to point calls or a bridge connecting end points through IP at 512 kbps. We conducted three surgeries for medically refractory temporal lobe epilepsy in Pakistan. At follow-up in January 2009, two patients have been seizure free and one had two breakthrough seizures after sudden unsupervised discontinuation of Levetiracetam. ***Conclusion:*** Our international tele-epilepsy collaboration has proven feasible and valuable to all participants. Our experience suggests considerable thought and preparation are needed before a teleconference to ensure its success. We provide a recipe to set-up similar telemedicine collaborations. Considerations include time zone differences, equipment type, interoperability between endpoints, connection capabilities, bandwidth availability, and backup plans for unsuccessful connections. Telemedicine can facilitate epilepsy care around the world, identifying with the concept of a "Global Health Village".

RÉSUMÉ: Expérience d'une collaboration internationale en télé-épilepsie. ***Objectif :*** Notre objectif principal était d'utiliser la vidéoconférence comme moyen d'aider à lancer un programme de chirurgie de l'épilepsie au Pakistan et de participer à des discussions de cas complexes de patients atteints d'épilepsie dans nos pays respectifs. ***Méthodes :*** Des tests extensifs au moyen de connexions de point à point et avec pont ont été effectués sur les bandes passantes de 384-768 kbps. Le moment des vidéoconférences entre les sites était fixé deux à trois semaines à l'avance et les connexions étaient vérifiées la veille de la conférence. Le partage de présentations PowerPoint, de neuroimagerie et de vidéo-EEG était disponible à tous les sites. Les discussions concernaient principalement des patients dont l'épilepsie était réfractaire au traitement médical. ***Résultats :*** Entre juillet 2006 et juin 2008, 17 sessions ont été organisées. Des spécialistes de la West Virginia University ont participé à cinq de ces conférences. Les meilleures connexions ont été celles faites par appel IP de point à point ou utilisant un pont reliant les extrémités par IP à 512 kbps. Nous avons procédé à trois chirurgies pour épilepsie temporale réfractaire au traitement médical au Pakistan. Un suivi fait chez ces patients en janvier 2009 a montré que deux patients n'avaient plus de crises et que l'autre avait eu deux crises suite à l'arrêt non surveillé du lévétiracétam. ***Conclusion :*** Cette collaboration internationale en télé-épilepsie s'est avérée réalisable et avantageuse pour tous les participants. Notre expérience indique qu'on doit la préparer avec soin afin d'assurer son succès. Nous recommandons une marche à suivre pour mettre sur pied de telles collaborations en télémédecine. On doit porter une attention particulière aux différents fuseaux horaires, au type d'équipement, à l'interopérabilité entre les sites, aux capacités de connexion, à la disponibilité de bandes passantes et prévoir des solutions de rechange si les connexions ne fonctionnent pas. La télémédecine peut faciliter le traitement de l'épilepsie à travers le monde, selon le concept d'un « village mondial de la santé ».

Can. J. Neurol. Sci. 2009; 36: 582-586

Telemedicine has taken great strides in the last ten years. It is no longer a novel concept and is routinely used by many primary and tertiary care centers for clinical care. The concept is quite simple. Two centers separated in space are connected through a telecommunication network. Although strictly speaking even a phone call between two physicians can be considered telemedicine, the term is generally applied to an interactive videoconference. Telemedicine has added a new dimension to global care and global collaborations.

We have successfully established telemedicine collaboration between the University of Alberta Hospital (UAH), Canada and Aga Khan University (AKU), Pakistan since June 2006. The main goal of this collaboration was to discuss medically challenging patients with epilepsy presenting to the two centers,

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Received January 27, 2009. Final Revisions Submitted April 30, 2009.
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and to provide support to the team at AKU to establish a level IV epilepsy surgery program. An epilepsy surgeon from University of West Virginia (WVU) joined our team in January 2008. Our collaboration culminated in three surgeries for temporal lobe epilepsy at AKU Pakistan in July 2008.

Through this article we would like to share our experiences with the rest of the community of epileptologists and neurologists, and will provide suggestions for those planning to embrace this technology. The article will summarize the technology, feasibility and applications of such a program in the care of epilepsy patients and provide basic guidelines for setting up such a program.

Epilepsy programs at AKU and University of Alberta

Aga Khan University is a major tertiary care private hospital in the city of Karachi, Pakistan. The epilepsy program is staffed with two US board certified neurologists with epilepsy fellowship training, a US certified EEG technologist, an epilepsy nurse and a US Board Certified neurosurgeon with experience in epilepsy surgery. It has a fully functional modern neurophysiology laboratory as well as video-EEG monitoring unit with two beds. Although AKU has been running a fully functional epilepsy clinic, the epilepsy surgery program is in its early stages of development.

The UAH is a tertiary care, level IV epilepsy center. It has two adult epileptologists, two pediatric epileptologists, a neuropsychologist, an epilepsy surgeon, several epilepsy nurses and fully staffed neurophysiology laboratory and VEEG monitoring units. The center has been fully functional for more than ten years and is a major referral center for Western Canada. Procedures are routinely performed for lesional and non-lesional epilepsy surgeries such as corpus callosotomies, intracranial EEG monitoring with depth and subdural electrodes, implantation of Vagus Nerve Stimulators, temporal, frontal and occipital lobectomies.

Major Goals for our telemedicine collaboration

1. Assist in launching of an epilepsy surgery program in Pakistan.
2. Ongoing case conferences about complex epilepsy patients in the two countries through video-conferencing.
3. Provision of an educational forum for neurology residents and fellows in Pakistan.

Our Model

Our collaboration started with telemedicine conferencing of complex patients, especially those who were potential candidates for epilepsy surgery. This program eventually focused on medically refractory temporal lobe epilepsy patients with lesions identified on the magnetic resonance imaging (MRI). The collaboration resulted in an epileptologist from Canada and an epilepsy surgeon from the US visiting AKU to assist in launching the surgery component of the epilepsy program.

Equipment

The telemedicine equipment available at AKU consists of a Polycom Picturetel 970 with internet protocol (IP) capabilities. At the UAH, Tandberg 6000 systems with both Integrated Service Digital Network (ISDN) and IP capabilities were used. Connections using both methods were attempted, with IP based connections at 384-512 kilobits per second (kbps) providing the best quality images.

The Clinical Need

Epilepsy is a chronic neurological condition with a crude prevalence rate of 9.98 per 1000 Pakistani population[1]. Based on published data in 1990, out of the two million Americans with epilepsy who were treated with antiepileptic drugs, approximately 20 percent continued to have seizures[2]. Although exact numbers are not available, we estimate that due to lack of a structured health care system and specialized care, the prevalence of medically refractory epilepsy in Pakistan far exceeds that in the US and Canada.

Aga Khan University is the major referral center for the city of Karachi, Pakistan. Karachi is considered the second most densely populated city of the world with an estimated population of 12,315,843. Based on 0.98% prevalence of epilepsy in Pakistan, Karachi has an estimated 120,695 patients with epilepsy, 20% (24,139) of whom are refractory to medical therapy and potential candidates for epilepsy surgery.

The work-up to determine the candidacy for epilepsy surgery is a staged process that requires several intermediate steps. At the centre in UAH, these include a thorough clinical history, detailed neurological examination, video-EEG (VEEG) monitoring, high resolution MRI of the brain with specific sequences tailored for the underlying lesion in consideration, neuropsychological testing, intra-carotid amytal testing (Wada test), and intracranial EEG and single photon emission computed tomography in select patients followed by a multidisciplinary case conference.

The most important objective of the collaboration between the two universities was to discuss patients from AKU in a multidisciplinary setting attended by experts from the two ends. Although most discussions pertained to surgical candidates, where UAH had relatively more experience, the discussions also included presentation on cases of rare diagnoses such as Lafora body disease, which is extremely rare in the Canadian clinics. The ongoing focus of this collaboration is to facilitate the epilepsy surgery program in Pakistan.

Challenges and accomplishments during the clinical conferences

Between July 2006 and July 2008, 17 teleconference dates were arranged, with the last five conferences also including connections with WVU. Of these, nine were successful encounters with quality video and audio present at both endpoints. Of the remaining eight scheduled, three were cancelled due to unforeseen circumstances unrelated to the video-conference connection, two were cancelled secondary to connection issues, two were cancelled after twenty minutes of successful connection due to connection instability, and one conference went ahead via audio link only. Connection stability and quality improved over our two years of experience. Table 1 summarizes the outcomes pertaining to our last eight discussions.

We discussed two to four cases during each session. All conferences were attended by an epileptologist and

https://doi.org/10.1017/S0317167100008076 Published online by Cambridge University Press

Table 1: Outcomes peertaining to the short-listed patients

NO.	Age	Gender	Duration of Epilepsy	Frequency	Semiology	MRI	EEG	Outcome of Telemedicine discussion
1	35	M	28 years	6-7/month	Temporal Lobe seizures	Right MTS	Right Temporal spikes	Right temporal lobectomy
2	19	F	16 years	3-6/month	Temporal lobe	Left MTS and lesion	Left temporal	Left selective amygdylohippocampectomy and lesionectomy
3	33	M	30 years	5-10/month	Temporal lobe seizures	Left MTS	Left Temporal spikes	Left selective amygdylohippocampectomy
4	60	M	6 years	2-4/month	Temporal lobe seizures	Bilateral MTS	Right temporal seizures	Surgery not offered as further investigations were needed
5	unknown	M	unknown	5-8/month	Temporal lobe	Questionable Right MTS	Left temporal slowing and sharp waves	Not selected for Surgery due to MRI not co-relating with the findings on EEG
6	35	M	20 years	1-2 every 2-3 months	Temporal lobe seizures	Left MTS	Bi temporal spikes and sharp waves	Not selected for Surgery due to non compliance with medication and MRI not co-relating with the findings on EEG
7	23	M	21 years	2-3 seizures/week	Frontal lobe seizures	Left parietal lesion	Left parietal lesion	Needs intracranial EEG recording
8	40	M	>20 Years	2-3/month	Temporal lobe	Normal	Right temporal spikes	Not selected for surgery based on a normal MRI

LEGEND: Three out of these eight patients underwent Temporal Lobectomy in July 2008.

neuropsychologist from Edmonton, with some also attended by additional epileptologists, epilepsy surgeon, nurses, clinical residents and fellows. From the Pakistani end, conferences were attended by two epileptologists along with clinical fellows and residents. Patients and their families also joined conferences in April and June 2008, to discuss risks and benefits of epilepsy surgery with the team in Canada and the Surgeon at WVU. When necessary, Urdu translation was provided by one of the epileptologists in Canada to the patients.

In retrospect, through our experience with telemedicine in an international context, we have gained valuable insight for development of future, similar programs. We learned the following aspects as important to consider when developing international telemedicine collaboration:

Different time zones: Organizing case conferences between the two sites proved difficult at times, given the 11-12 hour time zone difference (depending on daylight saving adjustments). Conferences were generally organized early in the morning for Canada (approximately 0730 MST) with a corresponding mid-evening attendance for the group in Pakistan. Once Virginia was included in the three-way conference their time zone also had to be taken into account.

Connections: Connecting sites through videoconferencing technology proved difficult for several reasons.

1. Use of ISDN lines – given the expense of using ISDN connections, the UAH agreed to test call quality by dialing AKU in Pakistan. Using three ISDN lines, repeat attempts to connect with Pakistan @ 384 kbps failed due to a couple of technological issues.

The first was determined to be a congestion problem within Pakistan itself and the lack of available bandwidth provided by the Telco used by the AKU. The partners in Karachi worked to resolve this issue with their Telco, yet once this was sorted out, a second issue arose in attempting a connection to the given telehealth conference facility. Through several test trials, we learned that the UAH was able to connect to a central technology room within the Aga Khan University campus, but were unable to establish the connection a little further to the telehealth conference room a kilometer or so from there. After thorough investigation, AKU learned the wiring from the central facility to the teleconference room was old and faulty and was going to take some time to replace. The connection between UAH and UWV was always smooth and of high quality.

2. *Audio and video quality:* Aside from some intermittent interruptions, the audio quality was mostly acceptable. The video for the power point presentation was good; however we had constant challenges in transmitting video EEG monitoring records. The most common problems were with freezing of the image frames at times, requiring redialing the connection. After switching to an IP connection at a broader bandwidth, this problem has significantly improved.

Over the last year we started transmitting our power-point presentations, MRI images and VEEG as FTP files. These were simultaneously run at the three sites during the teleconference. Although the power-point and for the most part MRI images were adequate we were unable to optimally review a synchronized VEEG recording.

https://doi.org/10.1017/S0317167100008076 Published online by Cambridge University Press

3. *Audio back-up:* After several attempts at holding conferences between the two groups, with some ending abruptly and short of completion, we decided to have in place an audio-line backup so that completion of the conference presentation could still proceed, albeit sub-optimally. Presentations and imaging were also forwarded to the remote group a day before the conference.

4. *Power outage in Pakistan:* On two occasions there was a power outage in Pakistan, leading to interruption of our conference. The power was immediately restored through a local generator and the conferences were able to proceed.

5. *Quality of case discussions:* All conferences that proceeded until the end lead to successful completion of the pertinent discussions. Through the telemedicine conferences, we were able to identify four medically refractory epilepsy patients for epilepsy surgery in anticipation of a visit by the North American team members to Pakistan in July 2008 (see Table 1). Discussion sessions were also held with the patients and their families to educate them about the risks and benefits of epilepsy surgery, as well as to share the experiences of medical professionals in Canada and US.

6. *Hardware/software compatibility:* In our case, some inter-compatibility issues arose with the two endpoints. Ideally, before purchasing equipment, users should ensure inter-operability between centers that are planning to form collaborations. Dated hardware/software can also pose a problem.

7. *Connecting through a bridge:* In our experience, difficulties also arose in our initial attempts to cross gateways on either side; overcoming the difficulties came about through a trial and error approach.

There can be many potential points of failure. When a connection fails, serious detective work is often needed to determine where the problem lies. Ultimately, we were able to establish a secure IP connection, and pass through the gateways. The successful connections occurred between AKU, in a different telehealth facility on the same campus that did not possess the old wiring encountered in the facility first utilized. Since June of 2007, all attempted connections have remained successful, with stable audio-video quality at 512 kbps and very little packet loss throughout each session.

8. *Medical staff familiar with the local culture:* It is very helpful to have a physician in the collaborative team who is familiar with the local culture and language of the other country. This is specifically useful when it comes to educating and counseling patients and their families.

9. *Data security and patient confidentiality:* All tele-conferences took place in secured medical facilities at each site and only treating members of the medical team had access to protected patient information. The University of Alberta Hospital employs advanced encryption standard (AES) 128 bit encryption for data security.

Table 2: Basics for establishing a telemedicine connection

Technical Aspects
1. A minimum standard of 384 kbps should be used to establish the audio-video connection, as lower bandwidths render poor quality images that are not worth the resources. Each site should check with their telco or network technicians to determine if these speeds are attainable and sustainable.
2. All sites should verify the compatibility between each Endpoint (equipment) manufacturer & software version.
3. Check connection capabilities of each Endpoint (IP1/ISDN2 & speeds).
4. Is there a firewall to go through? If a firewall is present, sites need to ensure that the site with the firewall opens ports or provides some means of traversing the firewall.
5. Ensure audio back-up.
6. Double check the connectivity of all sites prior to the conference.
Practical Aspects
1. Be aware of time differences.
2. Have contact information for technical operators at all sites on hand.
3. Exchange presentations ahead of time for backup in case of video failure.
4. Turn down cell phones and pagers to a vibration mode.
5. Avoid excess noise transmission by speaking one at a time and use voice activated screens when more than two sites are involved.

1.) IP = Internet Protocol, 2.) ISDN = Integrated Services Digital Network, 3.) kbps=kilobits per second

Visit to Pakistan

Two collaborators from North America (SNA and WB) visited Pakistan in July 2008 and reviewed the detailed clinical histories and investigations. Working along with the local team of epileptologists and neurosurgeons, the epilepsy surgery program was kickstarted with three successful surgeries for temporal lobe epilepsy. As of January 2009, two patients have been seizure free since their operations and one had two seizures in November 2008 when Levetiracetam was suddenly pulled off the market in Karachi.

While visiting Pakistan, the North American team further participated in informal and formal discussions with the residents, neurologists, neurosurgeons and technologists pertaining to establishing comprehensive epilepsy centers. Didactic lectures for patients and their families and an epilepsy mini-fellowship, similar to the Bowman Gray program, was organized by the local epileptologist.

Ongoing collaboration

Telemedicine collaborations have continued between Pakistan and Canada. We believe that in the initial start up of an epilepsy program there are advantages to "cherry pick" the best cases, those least difficult to evaluate and who have the best results from surgery. Based on this view, we are still focusing on

https://doi.org/10.1017/S0317167100008076 Published online by Cambridge University Press

lesional temporal lobe cases. As experience is gained by the Pakistani group, more complex cases can be tackled. Fortunately, the "cherry picked" cases (lesional temporal lobe epilepsy) comprise a substantial number of patients with medically intractable epilepsy in Pakistan. We, however, do plan to extend this collaboration to discuss non-lesional cases and those requiring intracranial monitoring. Our success will be defined by the number of medically refractory patients who are ultimately seizure free.

Discussion

Telemedicine through videoconferencing provides a unique opportunity to help set up comprehensive epilepsy programs around the world. The United States, Canada, Australia and some of the European countries have far more established level IV epilepsy programs than the rest of the world. Using telemedicine, there is an opportunity for connecting well established epilepsy centers with those in their initial or early development through a one-on-one partnership. The partnership between UAH, AKU and UVW is a story of success and can be used as a model to set up similar programs around the world.

The secret to success of any international collaboration is committed team members with a well defined objective. Ours was to start-up an epilepsy surgery program in Pakistan. Based on experience over the past two years, our setup for international teleconference has evolved. Our working machinery is very simple: Through email we decide on which of the two universities is going to present and forward the cases with the appropriate images in a power-point format. A day before the conference the two sites connect to ensure a smooth connection speed, optimal bandwidth and quality of audio-video transmission. On the day of the conference, the telemedicine coordinators on the two ends establish a connection 15 to 20 minutes before the starting time. All our recent connections have been IP based. The presentation is in a power point format with interactive discussions between the two groups. On-line review of video-EEG resolution has been a challenge with suboptimal resolution. The case discussion represents a conventional epilepsy surgery conference where a consensus regarding the medical vs. surgical management is made.

Thorough preparation before carrying out an actual conference can ensure its success. Table 2 summarizes some of the basics.

The literature has many reports on the use of international telemedicine in specialties such as neuroradiology[3] and pathology[4]. A model very similar to ours was used for cancer patients between the Sick Children's Hospital in Toronto, Canada and the King Hussein Cancer Center in Jordan[5]. The authors demonstrated a major impact in patient care with major changes in the management plan in 36% of the discussed cases.

Our project demonstrates that telemedicine collaboration for epilepsy care is a viable prospect and can be applied locally, nationally and internationally. On a local level, we found telemedicine to be feasible in terms of patient satisfaction and cost effectiveness[6]. During our international collaboration we came across additional challenges, as summarized in this article, but found ways to overcome most of the concerns.

One major concern often expressed about cross-border telemedicine is defining liabilities in the context of litigation. This is still untested water. Conceivably liability litigation can occur anywhere in the world. One would think that a civil judgment in a court in the developing world would be unlikely to impact an individual in the developed world. However, criminal judgment could possibly affect an individual in another country if there were extradition treaties in place. Brahams[7] very eloquently stated that, "unforeseen medico-legal implications of telemedicine will be revealed by litigation as it arises". The group from US and Canada obtained treating privileges at AKU before visiting Pakistan. The final treatment decisions were made by the patients in consultation with their local physicians who were all fully licensed and covered by liability insurance by their employers. Once cross-border telemedicine gets a wider acceptance and is viewed as an extension of the existing health care system the medico-legal aspects will be better defined.

In summary, telemedicine has a great potential for partnering epilepsy centers across the world. It is more practical and intuitively sustainable to create a one-on-one partnership. On similar lines, International League Against Epilepsy is attempting to create a similar model between North American centers and those in South and Central America. Telemedicine holds the promise to assist in creating a "Global Health Village" with easy access to appropriate epilepsy care around the world.

Acknowledgements

This project is funded through Regional Telemedicine Program, Alberta Health Services, University of Alberta, Department of Medicine Alternative Relationship Plan and an unrestricted educational grant from GSK – Pakistan. The authors thank all the technical and support staff for making this collaboration a reality, particularly to Clayton Knoll, Mubashir Ullah and Javed Desmukh for their unwavering technical support.

Conflicts of Interest

Carly Mann received salary support from Alberta Health Services Regional Telemedicine Program.

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