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Feasibiity and acceptability of tele-neurology services at a regional tertiary referral centre: a prospective study.

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FEASIBIITY AND ACCEPTABILITY OF TELE-NEUROLOGY SERVICES AT A REGIONAL TERTIARY REFERRAL CENTRE: A PROSPECTIVE STUDY.

By

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ABSTRACT

Background:

Neurological diseases are a leading cause of morbidity and mortality worldwide with a great burden lying in Sub-Saharan Africa. The paucity of neurologists in the region makes neurological care disproportionately inaccessible. Utility of tele-medicine is low cost, time efficient, convenient, reducing the carbon footprint and ultimately increasing health care access.

Objective:

We identified whether the concept of tele-neurology was feasible within our setup for patients with stable neurological diseases while establishing the cost effectiveness, efficiency, convenience and the carbon footprint burden.

Methods:

We conducted a prospective cross-sectional study. New patients were triaged by the neurologist based on guidelines from the Association of British Neurology to fit the tele-consultation profile or not. Follow-up patients were triaged by the nurse for the same. Recruited participants had a pre-tele-neurology questionnaire capturing their demographic data, email address, mobile number, time, travel distance and the cost of coming to clinic on a normal day sent electronically. The patients then underwent a tele-consult with a post tele- neurology survey sent thereafter. A prescription and lab request was emailed to the patient or an AKU outreach clinic near them.

Results:

From 219 enrolled patients, 66.7% (146/219) responded [74% (108/146) had both F2F and TNC]: age 40.9 (30.6-55.20 years; 63.0% (92/146) female ;2.7% (4/146) from neighboring countries; follow up period with neurologist (DSS) 6.8 (1.5-29.8) months. The most common presentations were headache [26.0% (38/146)], seizures [26.0% (38/146)] and neurodegenerative [15.1% (22/146) disorders.

For TNC >90%;(i) found it as comfortable as F2F (p=0.35) with no violation of their privacy; (ii)saved time [3.0 (2.0-4.0) hours], travel [11.0 (7.2-21.1) km] and cost [$10.5-20]; (iii)were

satisfied with their neurological concerns addressed; and (iv) would use TNC again. Conversely,15.1% (22/146) disagreed with TNC being as effective as F2F, including the neurologist not addressing their health problems satisfactorily (p=0.03). Our TNC service saved our patients $6,125, 1,143 hours and 25,506 km of travel, equating to 3.5 tons (21 trees) of carbon dioxide emissions.

Conclusion:

Our regionally unique study demonstrated that TNC service is an acceptable, efficient, effective and environmentally-friendly care delivery model in our resource poor setting.

LIST OF ABBREVIATIONS

AKUH	Aga Khan University Hospital
HIPAA	Health Insurance Portability and Accountability Act
DALY	Disease Adjusted Life Years
SSA	Sub-Saharan Africa
EEG	Electroencephalogram
EMG	Electromyography
WHO	World Health Organization
NIHSS	National Institute of Health Stroke Scale
tPA	Tissue plasminogen Activator
TNC	Tele-neurology consultation
F2F	Face to face consult
PI	Primary investigator
IERC	Institutional Ethics and Review Committee
ICT	Information communication technology

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I dedicate this work to my late mother, Rashida Yakub, who always believed in me and made the impossible possible.

DECLARATION

"I declare this dissertation does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university and that to the best of my knowledge it does not contain any material previously published or written by another person except where due reference has been made in the text".

(Signature of candidate)

9th September, 2022

Date

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CHAPTER 1: INTRODUCTION

1.1 Background

There is a severe shortage of neurology health care workers in low/low-middle income countries, especially in Africa. TNC, necessitated widely due to the COVID-19 pandemic, has been demonstrated to be effective in bridging neurology service gaps but there is little evidence of TNC's effectiveness in low- and middle-income countries.

Prevalence of neurological disorders.

Neurological disorders are among the leading causes of morbidity and mortality worldwide. A systemic analysis conducted between the years 1991-2016 identified neurological conditions as the leading cause of disease adjusted life years (DALYs) and second cause of mortality after cardiovascular associated deaths (1). Sub Saharan Africa (SSA) contains 12% of the world's population and two thirds of the global neurological disease burden (2). The World Health Organization (WHO) estimates that 12 out of 100 deaths globally are due to a neurological condition and the prevalence varies with the countries income status (2).

The spectrum of neurological disorders ranges from acute emergencies such as strokes to chronic debilitating conditions such as dementia, epilepsy, movement disorders, primary headache disorders among many others. Extrapolating this data to SSA, there is a great burden of neurological diseases with limitations in resources. For example, it is estimated that strokes cause 5.54 million deaths worldwide and two thirds occur in developing countries (3). Despite the staggering statistics, SSA lags in management of neurological disorders for various reasons as discussed below.

Factors contributing to the burden of neurological diseases.

The paucity of neurologists is a great contributor to morbidity and mortality from neurological conditions. It is estimated that the ratio of neurologist to the population in SSA is 1:3 million compared to European countries where the ratio is 1:20 thousand (3). The situation is compounded by the lack of physical resources including poor infrastructure. The number of neurological beds serving our population in SSA are 0.03 in 10 thousand. There is also a lack of nurses, specialized neurological services such as electroencephalogram (EEG), electromyography (EMG) and a

paucity in centers for neurological training as well (3). All this put together contributes to disease burden. A promising avenue of marshaling the few resources we have is the utilization of tele-medicine in bridging the discrepancy in health care provision.

About Tele-medicine

Tele-medicine is the delivery of health care services by means of electronic communication from a health care provider to a patient at a different location. It serves as a means of bringing specialist services to an underserved location. The WHO defines it as the use of ICT to exchange valid and critical medical information between a health care provider and a patient with distance being the critical factor (4). Tele-medicine is not a new concept, it's history dates back to as early as 1862 where the telegraph was used to order medical supplies during the American civil war (4).

The use of tele-medicine in neurology (tele-neurology) gained confidence in 1999 where the advent of "tele-stroke" emerged popularized by Levine and Gorman (5). This hub and spoke model has provided access to neurologists in hard to reach areas in the United Kingdom with tremendous results. In both acute and nonacute strokes, physical findings using the National Institutes of Health Stroke scale (NIHSS) were comparable when using either TNC or face to face physical examinations. This resulted in an increase in timely thrombolysis in acute strokes which is associated with better clinical outcomes. Interestingly, the outcomes of patients treated remotely were similar to in person evaluations (5). This concept has expanded to a wider scope of neurological conditions in the outpatient setup. TNC has been applied in the follow-up of movement disorders, epilepsy, multiple sclerosis, headaches, dementia among others (5). In the majority of cases, TNC was done after an initial face-face consultation.

The model of TNC can broadly be classified into asynchronous and synchronous methods. The former involves utilization of text without images such as mobile texts and emails. This model can be utilized in consultations that do not require an interactive examination. Synchronous tele-consultation on the other hand uses real time video conferencing, providing a two-way audio and video between the patient and the health care provider. Application of tele- neurology in the acute setup would require the availability of a tele-presenter to assist in elucidating signs and symptoms. In tele-stroke, the tele-presenter would be a general practitioner or a qualified nurse (5).

Tele-neurology around the globe

TNC has been compared to traditional ambulatory clinics in the management of several neurological conditions with non-inferiority of the former (6). The spectrum of conditions where TNC has been tried includes epilepsy, headaches, dementia, movement disorders, functional disorders and strokes in the acute setup (6).

Neurological conditions form a unique subset of diseases in that there can be limitation in mobility, restriction in the use of transportation in patients with epilepsy, cognitive functional decline and this can strain care givers. A study comparing patients with epilepsy attending Galveston clinic and Beaumont tele-medicine clinic found no statistical differences between the two in terms of emergency visits due to breakthrough seizures or compliance to medications (7). Both subset of patients demonstrated comparable seizure control and medication compliance. This demonstrates the utility of TNC in the management of such patients who have a great challenge and reliance on family members due to restrictions in transportation. Cost saving is also an important point in view of the chronicity of the disease and need for medications for seizure control (7).

Similarly, in the United States of America, rural areas such as New Mexico, Eastern Colorado, Western Texas have difficulty in accessing specialized neurological care due to distance and cost. TNC centers set up at community-based outpatient clinics allowed remote follow up of veterans over a period of two years. The results were remarkable with a 90% satisfaction rate and 92% of patients stating the service had saved them time and money (8). TNC has also been applied successfully in the follow-up of patients with primary headaches. Using the Headache Impact Test 6 which assesses the level of impairment in one's daily activity due to headaches and assessing the pain intensity with the visual analogue scale at 3 and 12 months; TNC was found to be as efficacious as traditional clinic visits when considering optimum headache control as well as identification of a secondary headache that would need further evaluation (9).

TNC studies have also been applied in the follow-up of patients with dementia in rural areas. The level of satisfaction was assessed by the Telehealth Satisfaction Scale (TeSS), a 10 item scale questionnaire, which was completed after the TNC with high satisfaction scores (10). Similarly, a preliminary study conducted in China to assess the level of satisfaction in participants partaking

in tele-health services demonstrated good outcomes when assessed using the tele-medicine satisfaction questionnaire (11).

Tele-neurology in Africa

The concept of tele-medicine is in its infancy in SSA (12). The slow adoption of this modality of health care in our region is due to economic, political and social instabilities. Indeed, the adoption of tele-medicine requires support in form of equipment and resource personnel which has financial implications. Thirty three countries in SSA have been ranked among the world's poorest countries directly translating to a slower uptake of new modalities of healthcare (12). The literacy level in Kenya and Africa as a region is at 70%, lagging behind the world's average of 90% literacy rate. This has implications in adoption of tele-medicine where complete understanding of what it entails is important in order to obtain consent. A study done in Kilifi County Hospital showed that participants were unable to understand what tele-medicine was even in the local dialect, reflecting how technology is evolving without people in the rural areas appreciating so (4). This can be a problem in adopting new modalities of health care such as tele-medicine. Some countries such as Ethiopia however have made tremendous progress in implementation of tele-medicine albeit still being in the early phases of development (13). What was evident from Ethiopia is that not only do we need technology for implementation of tele-medicine but there is also need for support from both governmental and non-governmental organizations (13).

Bringing this discussion to a local context, Kenya has had efforts of implementing tele-medicine with collaborations of major referral hospitals such as Kenyatta National Hospital (14). Tele-medicine has also been seen in underserved counties such as Lamu with collaborations with mobile companies such as Safaricom and Huawei to bring essential services closer in view of the paucity of medical practitioners due to political instability and safety concerns (15). Similar acceptability of TNC was demonstrated in the Disease Relief through Excellent and Advanced Means (DREAM) program operating in SSA since 2002 in multiple countries. It was noted that part of the problem in identifying neurological conditions within our communities was the lack of know-how on disease presentation and the lack of qualified personnel. This program empowered the local health care providers through trainings and subsequently had an asynchronous TNC system where the history, physical examination and laboratory findings would be sent via email to a neurologist in Europe to help with the diagnosis. Part of the outcome was satisfaction in the

patients receiving external input on their condition. It was noted that the most common neurological condition identified was epilepsy (16).

Despite the challenges we face as a country, great effort has been made in expanding the ICT sector, Kenya having the largest internet penetrance at 89.4% compared to the African average of 31.2% (4). In this context, TNC presents itself as a viable option in decentralizing health care. Currently there has been no other robust specialized tele-medicine service such as TNC and this is a void that can and ought to be filled to increase access to neurological services within the population.

Advantages and Disadvantages of tele-neurology.

TNC has been adopted in the West as a means of supplementing primary health care and expanding specialist services in hard-to reach areas. Many advantages as well as limitations to the adoption of this practice have been demonstrated as illustrated in the table below.

Table 1: Advantages and disadvantages of tele-neurology.

Advantages
• Increased practice outreach, development, and efficiency
• Decreased travel time and expenses for doctors and patients
• Expansion of educational opportunities and continuing medical education for physicians
• Individual and group education for patients about their neurologic disease
• Easy recruitment of patients into clinical trials
• Improvement of access to neurologic expertise for remote or underserviced areas
• Reduction in geographically disparity for neurologic care
• Decreased response time in stroke
• High patient and family satisfaction survey scores with their tele-neurology care
Disadvantages
• Disruption of traditional doctor-patient relationship
• Physician reluctance to adopt novel technology in practice
• Limitations to billing and reimbursement for time spent

• Additional costs for technology
• Licensing, credentialing issues for out-of-state physicians
• Concern for malpractice liability
• Performing complete neurologic examination solely via telehealth, particularly evaluating muscle tone and strength, sensation, reflexes and fundoscopic examination
• Obtaining neuro-diagnostic tests such as EEG, EMG, and neuroimaging in remote settings

Table adopted from the Report of the Telemedicine Work Group of the American Academy of Neurology (6).

Such successes in TNC have led to the service being advocated as standard of practice e.g. by the American Academy of Neurology Tele neurology Working Group (6). It offers huge benefits not only for patients, physicians and organizations but also the environment. In keeping with the Sustainable Development Goals and COP26 agenda, it is every healthcare worker's responsibility to promote environmentally conscious models of healthcare delivery.

The estimated greenhouse emission from health care facilities in Canada, United Kingdom, Australia and USA ranged from 4.5-10% (17). Pollution from healthcare facilities can take the form of medical wastes, unsustainable materials and anesthetics used in surgery; which are greenhouse gases; biofuels from the catering services as well as patient contribution from transportation to and fro the facilities. Studies have shown that the greatest contributor to global warming is carbon dioxide from motor vehicles (18). A head to head comparison of private cars and public means of transportation demonstrated an 88% higher carbon dioxide emissions in the former (18). The relevance of this is that TNC negates the need for transportation to and fro the hospital for routine checkups. This translates in a cumulative carbon foot reduction per patient. It has been demonstrated that the adoption of tele-medicine has a profound impact in reducing the carbon foot print by 40-70 times(21). Patients with chronic diseases whose next step of management largely depends on history, laboratory and radiological investigations and whom do not require routine physical examinations can safely be seen remotely via tele-medicine (20). Decarbonizing health care also goes hand in hand with the recently concluded COP26 agenda which focused on addressing health and climate change. Some of the resolutions included adopting tele-medicine as an alternative to health care delivery were possible and shifting from the use of

personal means of transport to public or active means e.g. walking, cycling which can be a challenging for patients with debilitating neurological conditions (22).

The world has also seen an upsurge in epidemics such as the H1N1 Influenza epidemic, the Ebola epidemic and the most recent COVID-19 pandemic. This has resulted in quarantines, frizzled transport systems with restriction in movements in an effort to contain the disease. This translates to less patients being able to come for routine follow up clinics. Tele-medicine has been shown to be an avenue to help curb disease epidemics and at the same time allow continuity of health care provision in a safer and convenient manner (23).

The Association of British Neurology guidelines which have been implemented to TNC services during the COVID-19 pandemic help triage of patients into low and high risk groups as illustrated in figure one below. Patients were assessed on phone by a neurologist for any danger symptoms and the duration of the same. Based on the symptomatology, patients were grouped into 2:

1. *Patients requiring urgent face to face consultation.*
2. *Patients who can be followed up later either physically or via TNC.*

To ensure continuous safety of patients given a later appointment date, doctors have implemented safety netting arrangements which entail empowering the patient with information about their condition and how to seek medical attention if any concern arises (24).

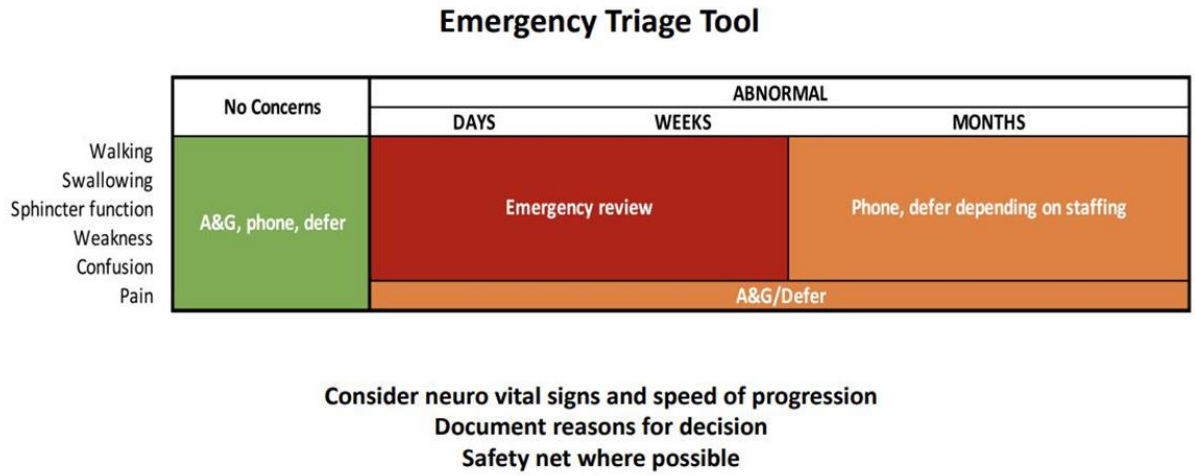


Figure 1: TNC emergency triage tool.

The idea of TNC has been slow to catch up in SSA despite the technological boom, due to various legal, political and infrastructural factors. Developing countries such as Tanzania have advocated for models to improve access, cost, support and ethical issues when it comes to TNC (25). The expansion of TNC services across the world has even led to standardized tools to measure patient satisfaction after engaging with such healthcare delivery with tremendous success. There is potential for TNC to pick up within our region (26). Some countries such as Zambia and Tanzania have already initiated pilot TNC studies with acceptable satisfaction rates from patients (27).

The questionnaire tool used in our study was adopted from a study done in Chile by Fredy Costanzo et al (26).It was a 23 question survey analyzing patient satisfaction with TNC. The survey was applied to 167 patients of the Hospital Las Higueras of Talcahuano (HHT), recruited between 2018 and 2019. The purpose was to conduct a pilot cross-sectional descriptive study to assess internal consistency (Cronbach alpha) and reliability (factorial analysis of main components). The survey showed an internal consistency of 0.88. Removing any of the items maintained its reliability in values over 0.8. All items showed point biserial correlations greater than 0.30. Overall, the survey constructed and evaluated in this study showed high internal consistency and reliability values. Using the above study, 15 relevant questions were adopted to be utilized in assessing patient satisfaction with TNC in our setup.

Indeed, as rosy as tele-medicine can look in bridging the discrepancy in health care provision, it does come with its own risks. Critics are more cautious, expressing concern about new or exacerbated risks to privacy and confidentiality, the limitations of electronically mediated interactions for physical examination and the potential for disruption of the patient-physician relationship. It has also been established that this mode of health care delivery is not for all patients and appropriate matching of patients is paramount. The limitations of this mode of health care delivery is limited by a patients' ability to access communication resources (28). All in all, a balance needs to be struck between the pros and cons of telemedicine and utilized with caution to maintain quality standard of health care provision and at the same time maintaining patient doctor confidentiality.

1.2 Justification

The burden of neurological diseases in SSA is immense with lack of resources in terms of the number of neurologists to offer specialized care, the number of hospital beds, infrastructural limitations and not to mention financial constraints amongst our population (2). Despite all these upheavals, it is important to find novel ways of offering specialized care to patients in a more convenient, cheaper and environment friendly way (6, 21). TNC has the potential in doing so and we do not have studies in Kenya to support this.

Based on audit data drawn from online patient lists, the neurology department at The Aga Khan University Hospital is well known to see a myriad of patients with neurological conditions in the outpatient clinic (29). These patients travel far, sometimes with relatives and care givers with difficulty to come to clinic due to disability and immobility. They have to sacrifice time and travel costs in order to see the neurologist for a disproportionately short clinic appointment. Using TNC, we will be able to extend neurology services to patients at the comfort of their homes and facilitate easier follow up of patients. We have also noted that most of our patients have access to a smartphone.

With the upsurge of the COVID-19 epidemic, this study allowed us to assess the feasibility of using TNC in the continuity of health care provision and at the same assist as an epidemiological measure in reducing contact between persons. The study aimed to demonstrate that not only is TNC applicable in normal circumstances, there is even more utility in times of pandemics to ensure health care sustenance. The study proposed a pilot TNC project which harnessed the patient's own telecommunication technology as a stepping stone in exploring the potential of this modality of health care delivery and assess how this impacts the patients' convenience, cost, time and disease outcome.

1.3 Research Questions

What is the patient satisfaction and benefits of introducing a TNC service at a tertiary hospital in Kenya?

1.4 Study Objectives

Primary Objective

a. To determine patient satisfaction in engaging with the proposed TNC service.

Secondary Objective:

a. To determine patient satisfaction in engaging prior F2F neurology consultation.
b. To determine the cost benefit of patients attending the TNC clinic.
c. To determine the travel time and waiting time at an ambulatory clinic.
d. To determine the carbon footprint burden while attending an ambulatory clinic.

CHAPTER 2: METHODOLOGY

2.1 Study Setting

The study was conducted at the Aga Khan University Hospital, Nairobi (AKUHN).

2.2 Study Design

This was a descriptive prospective cross-sectional study conducted between October 2020 to October 2021.

2.3 Study Population

The study population were patients seen at the neurology clinic at Aga Khan University hospital.

Inclusion Criteria

•Patients who were above the age of 18 years.

•Patients who had the cognitive capacity to consent. If the patient lacked capacity, they were recruited if they had a registered next of kin who could give a valid consent.

•Patients who were able to speak either English, Kiswahili or both.

Exclusion Criteria

•Patients who were not keen on having a tele-consultation.

2.4 Sample Size

Sample size was calculated based on the formula below, using the proportions formula. A study by Davis et al (2014) (30) showed that 90% of the patients were fully satisfied with their TNC visit.

$$N = \frac{z^2 P\,(1-P)}{d^2}$$

Where P was the assumed proportion of satisfaction, d was the precision rate and Z was the statistic corresponding to level of confidence. Based on the above formula and 95% level of confidence, with 90% satisfaction rate, and 5% precision rate, the minimum sample size required for our study

was 139 patients. After adjusting an attrition rate of 15%, the required sample size for this study was 159 patients.

2.5 Data Management

Patient recruitment:

There were 4 categories of patients arriving to the neurology clinic:

1. New patients on the PI's clinic list were contacted by the PI (DSS – neurologist) a day before their scheduled clinic appointment. The ABN triaging system was applied to decide whether those new patients were eligible to have a tele-consultation or a F2F. They were then categorized into the "tele" vs "F2F" arm.
2. As per departmental protocol, all follow-up patients were called a day before by the nurse and offered a teleconsultation service. They were also categorized into "tele" and "F2F".
3. There were patients who physically turned up to the clinic for F2F despite the above two measures. These were "walk-ins" sent from in-hospital and peripheral clinics and patients who could not be contacted as above.
4. All patients who turn up for F2F consultation (new, follow-ups, walk-ins, un-contactable at triage) were offered teleconsultation for the follow-up appointment.

TNC process:

On the day of the clinic, patients were contacted using the hospital line to confirm their attendance. Documentation occurred on the hospital sheets as usual. At the end of the consultation, the patient's email address was obtained to electronically send prescriptions, lab requests and radiology request forms. For prescriptions, patients had the option of obtaining medications via a home delivery service, an outreach pharmacy or the main hospital pharmacy. Lab request and radiology forms were sent electronically to the patients and samples were taken either at an outreach facility or the main hospital laboratory. Follow up visits were booked and patients' records were submitted to the administrative support for record purposes and filed together with the patients notes together and the email address of the patient.

The above steps captured all patients as per the patient flow figure 2 below:

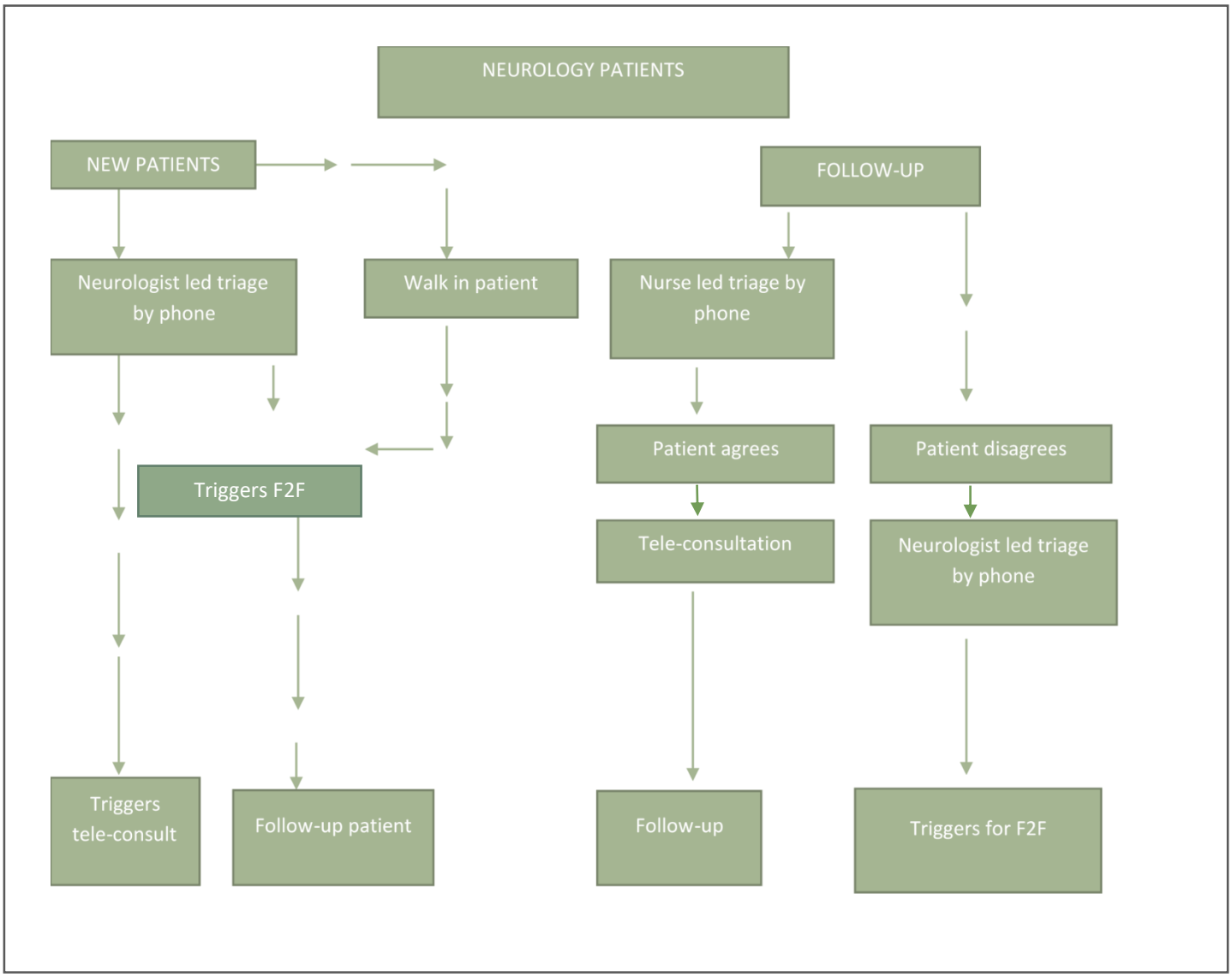


Figure 2: Patient recruitment flow chart

Participants recruited into the "tele" arm were consented to take part in the study. We electronically sent a demography questionnaire (Appendix 1) which also captured data for the secondary objectives. Patients who first had a F2F then a teleconsultation were consented in clinic by the PI, then had their demography and satisfaction questionnaires administered electronically for both F2F and then for the subsequent follow-up appointment. All patients who underwent the tele-consult had a post tele neurology survey (Appendix 2) sent electronically. This questionnaire was adapted with permission from authors of other tele neurology projects published in the literature (26).

The total cost and time spent utilizing TNC was calculated by averaging the data entered in the pre-questionnaire as illustrated in appendix 1.

2.6 Data Analysis

Based on the post tele neurology questionnaire, we identified the rate of satisfaction. These were presented as frequencies and percentages. The post questionnaire (15 questions) was based on a Likert scale with a maximum score of 75 points, and was graded in terms of satisfaction adapted from (26) .Very low (under or equal to 15 points), low (15 to 30 points), moderate (31 to 45 points), high (46 to 60 points), and very high (61 to 75 points).

From the questionnaire (illustrated in appendix 1), participants were also asked where they live, how much it costed and how long it took to attend the traditional ambulatory clinic. Based on their geo-location, the carbon footprint was calculated using https://www.carbonfootprint.com/measure.html. Using this information, the summation of the total distance covered, cost and time was done for the 146 study participants.

Continuous data were then summarized as median and interquartile ranges (IQR) whereas categorical data was summarized as frequencies and percentages.

2.7 Ethical Considerations

Ethical approval was sought from the Institutional Ethics and Review Committee (IERC) at the Aga Khan University, Nairobi prior to conducting the study. Confidentiality was maintained during conduction of the study. Patients were identified by their hospital numbers and not their names and further de-identified for analysis

CHAPTER 3: RESULTS

The study enrolled a total of 219 patients; 66.7% (146/219) met the eligibility criteria and consented to the study. Among the enrolled participants, 63.0% (92/146) were female and the median age was 40.9 (IQR: 30.6-55.2) years. Participants from neighboring countries accounted for 2.7% (4/146). The demographic characteristics are presented in Table 2. The median duration of follow-up by the neurologist (DSS) was 6.8 months (1.5-29.8). The median time taken by the participants to travel to the clinics was 3.0 hours (IQR: 2.0-4.0), with a median cost of 1000.0 Kenya Shillings (IQR: 500.0-2000.0) incurred. The median distance to the clinic was 11.0 km (IQR: 7.2-21.1). In summation, a total of $6,125, 1,143 hours and 20,812 km of travel was saved, equating to 3.5 tons (21 trees) of carbon dioxide emissions.

Most of the participants used their own means of transport to access the clinic, 30.1% (44/146) used taxis (Uber, little cab, public motor cycles) while the rest used public transport. The travel characteristics are presented in Table 3.

Table 2: Demographic characteristics of patients.

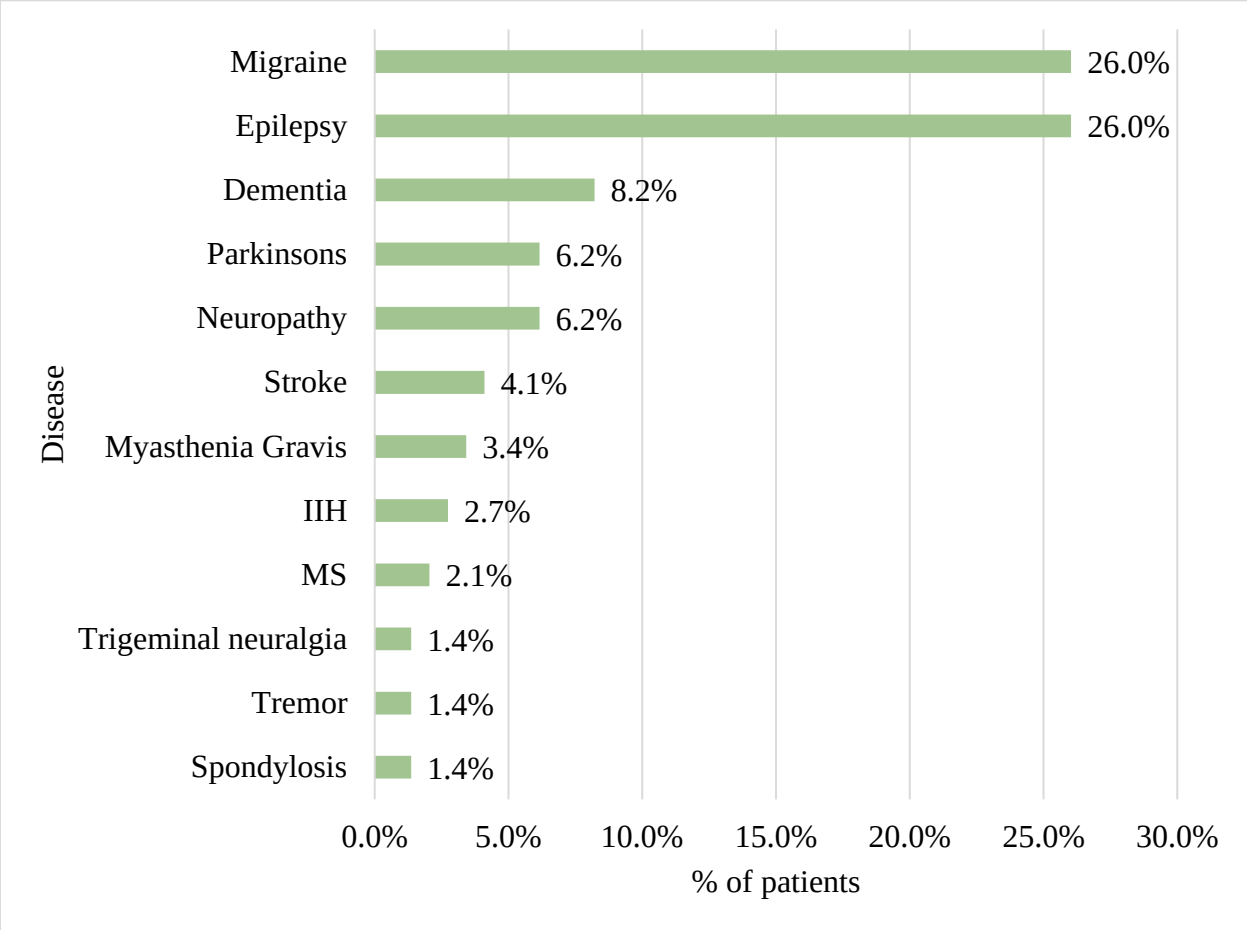
Demographic Characteristics (N = 146)	
Age (Years), median [IQR]	40.9 [30.6, 55.2]
Gender, n (%)	
Male	54 (37.0)
Female	92 (63.0)
County, n (%)	
Kenya	142 (97.3)
Out of Kenya	4 (2.7)

Table 3: Travel characteristics of patients.

Travel Characteristics (N = 146)	
Time Taken Out of Routine (Hours), median [IQR]	3.0 [2.0, 4.0]
Approximate Cost of Travel, median [IQR]	1000.0 [500, 2000]
Distance (km), median [IQR]	11.0 [7.2, 21.1]

Mode of Transport, n (%)	
Public Transport	14.0 (9.6)
Taxis (Uber, Little Cab, public motorcycles)	44.0 (30.1)
Own vehicle / Motorbike	88.0 (60.3)

The most common conditions seen by the neurologist were migraine headaches 26.0% (38/146), epilepsy 26.0% (38/146), dementia 8.2% (12/146) and neuropathy 6.2%. Other diseases are shown in the figure below:



* Other disorders included ataxia, bell's palsy, carpel tunnel syndrome, dystonia, functional disorders, motor neuron disease, other primary headaches, fibromyalgia and vertigo accounting for 0.7% each

Figure 3: Spectrum of Neurological Disorders.

Patients' satisfaction with ambulatory (traditional) neurology clinic.

Among the patients who attended the ambulatory clinic, 91.7% (99/146) were satisfied with the one-on-one care they received while 76.9% (83/146) felt more comfortable talking to their specialist physically. Majority of the patients [88.0% (95/146)] agreed that the specialist identified their health problems. However, 69.0% of the patients felt it took longer to see the neurologist physically.

Table 4: Characteristics of the traditional ambulatory clinic questionnaire.

Item	Disagree	Neutral	Agree
I am satisfied with the one on one care received	1 (0.9%)	8 (7.4%)	99 (91.7%)
I felt more comfortable talking to my specialist doctor physically	3 (2.8%)	22 (20.4%)	83 (76.9%)
My specialist doctor has identified my health problem	4 (3.7%)	9 (8.3%)	95 (88.0%)
The time to see a specialist physically is faster	69 (63.9%)	20 (18.5%)	19 (17.6%)

Satisfaction with the post TNC.

The study found a high level of satisfaction amongst patients within the TNC arm with 90.4% (132/146) agreeing that they were comfortable talking to their specialist just as F2F; (p=0.35). The patients agreed [91.8% (134/146)] that the audio clarity while talking during the consultation was satisfactory, 91.1% (133/146) concurred that TNC saved them time travelling to the hospital and 90.9% (130/146) felt that their personal information and privacy were protected after their consultation. Majority of the patients; 65.8% (96/146) agreed that a virtual consultation was as effective as an F2F. A group of patients; 57.5% (84/146) felt that the specialist doctor identified their health problems through TNC. This was the least number of patients compared to other items (Table 4). Conversely, 15.1% (22/146) did not agree with TNC being as effective as F2F adding that the neurologist did not identify all their health problems satisfactorily (p=0.03).

Table 5: Characteristics of the post TNC questionnaire.

Item	Disagree	Neutral	Agree
I am satisfied with the care received in tele-medicine (n=145)	8 (5.5%)	12 (8.3%)	125 (86.2%)
My family is satisfied with the care received in tele-medicine	8 (5.5%)	28 (19.2%)	110 (75.3%)
Tele-medicine helps me know my state of health	11 (7.5%)	27 (18.5%)	108 (74.0%)
I felt comfortable talking to my specialist doctor through a microphone	7 (4.8%)	7 (4.8%)	132 (90.4%)
Talking to my specialist was as effective as in person	22 (15.1%)	28 (19.2%)	96 (65.8%)
My specialist doctor has identified my health problem through tele-medicine	22 (15.1%)	40 (27.4%)	84 (57.5%)
The quality of sound were adequate to talk to my specialist doctor	4 (2.7%)	8 (5.5%)	134 (91.8%)
The time with a specialist is faster with tele medicine	6 (4.1%)	14 (9.6%)	126 (86.3%)
I prefer telemedicine because it is easier than to go to the hospital (n=145)	18 (12.4%)	22 (15.2%)	105 (72.4%)
Telemedicine saves me time travelling to hospital or a specialist clinic	8 (5.5%)	5 (3.4%)	133 (91.1%)
My specialist doctor was able to answer my questions through telemedicine (n=145)	4 (2.8%)	8 (5.5%)	133 (91.7%)
I find telemedicine an acceptable way to receive health-care services	13 (8.9%)	23 (15.8%)	110 (75.3%)
I will use telemedicine services again	6 (4.1%)	22 (15.1%)	118 (80.8%)
I trust that my personal information and privacy will be protected after my attention by tele medicine (n=143)	3 (2.1%)	10 (7.0%)	130 (90.9%)

Figure 4 shows the overall level of satisfaction with the TNC. Majority of the patients,56.2% demonstrated a high level of satisfactions, 36.9% had moderate level of satisfaction and 6.8% had

low level of satisfaction. There was no statistically significant difference in the level of satisfaction by the different age groups (table 5).

Figure 4: Level of satisfaction based on tele neurology clinic

Table 6: Mean satisfaction by age-groups

Age-group (years)	Mean (SD)	P-value
< 40	60.2 (10.2)	
40-60	62.0 (9.84)	0.144
> 60	64.6 (8.17)	

CHAPTER 4: DISCUSSION

The concept of tele-neurology is still in its infancy stages in sub Saharan Africa due to several barriers including financial, cultural and technological issues (30).A study done in Tanzania suggested models in addressing cost, access, support and ethical issues in order to support a more robust implementation of TNC (25). Despite these hurdles, the use of tele-neurology as a modality of health care delivery has definitely increased since the advent of COVID-19 pandemic worldwide; including Africa (27, 31). Developing countries like Zambia have initiated tele-neurology programs with acceptable patient satisfaction (27). The present study goes a step further to identify the economic and environmental implications tele-neurology has as well as assessing the patient satisfaction with this model of health care delivery.

The median age of patients who took part in our tele-neurology study was 40.9 years with a male to female ratio of 1:1.7. A study done in Norway demonstrated that women were more comfortable and keen on having a TNC as opposed to men (31). This age and gender distribution is comparable to studies done in Saudi Arabia, United States of America and Zambia (27, 32, 33). This is also explained by the age structure distribution in Kenya with a predominant younger population (34). The paucity of older patients partaking in the service could also be explained by the spectrum of neurological disorders they have suffered which were mainly neurodegenerative and previous debilitating strokes. The result of this is a failure to easily adopt new tech savvy health care models and patient reliance on family members. This has been demonstrated in other studies as well as a limitation in implementing tele-health in the geriatric population (35).

The spectrum of neurological diseases according to the global burden of disease include strokes, migraines and neurodegenerative disorders. These disorders are significant contributors to disease adjusted life years (DALYs) (36). The spectrum of disorders mirrors with the present study where the majority of the patients recruited suffered from migraine headaches and epilepsy. Previous studies done have demonstrated the effectiveness of tele neurology in the follow-up of these conditions with comparable efficacy in terms of seizure control and headache free days (7, 9). The prevalence of such disorders in this study also gives a reflection as to why there is an increased female to male distribution. Migraine disorders occur commonly in female patients with up to four time predilection especially during the child bearing ages connoting a hormonal influence (37).Interestingly the prevalence of patients who had previous strokes utilizing tele neurology was

4.11%.This contrasts with a study done in Zambia which demonstrated that patients who had suffered a stroke constituted a higher patient percentage (30.0%) participating in their tele neurology service. The disparity in this finding could also be explained by the older patient population recruited in Zambia for the study (mean age 50 ±20) (27).

Studies done in Kenya have identified the prevalence of strokes to be between 0.6% -7.1% with a higher prevalence in private hospitals likely due to earlier presentation (38). The lower uptake of TNC in stroke patients could be explained by the fact that most patients utilize physical rehabilitative services and their appointments with the neurologist are timed with their physiotherapy sessions. Tele-rehabilitation is a promising avenue that we have not explored that could probably increase the uptake of TNC in stroke survivors that has shown equal salutary effects compared with conventional face-to-face therapy (39). The median duration of follow-up with the neurologist in our study was 6.8 months.

The present study found a high level of satisfaction with the TNC services with an overall satisfaction rate of 82.0%. This finding is consistent with other studies done in Zambia, Chile and Norway (26,27,32). Interestingly, there was no statistical significant age related differences when it came to the level of satisfaction with TNC service. Conversely, around 15.1% did not agree that tele neurology was as effective as a face to face consultation. There are several factors that could have influenced this finding including cultural, technological difficulties e.g. connectivity issues and a preconception on traditional approaches on how health care is ought to be delivered. This has been demonstrated in other studies in Australia where primary barriers such as funding, equipment and preference for the traditional approach impaired telemedicine implementation. A preference to the traditional approach demonstrates probable lack of interest in ICT skill acquisition or difficulty acquiring the same (40).It is without say TNC services does remove the aspect of physical examination largely and this can influence the perception of a patient on whether they have actually had a meaningful review when done virtually. However studies have demonstrated utility and safety of tele medicine in follow-up of certain neurological conditions (41).

Policy related obstacles in paying for TNC services could also influence negativity towards the service. Currently, many insurance companies do not have policies that cater for tele-medical services and patients rely on out-of-pocket payment. This can negatively influence adoption of the service. These reimbursement challenges have also been noted in developed countries such as the USA (41).

Patients who had previously attended a traditional ambulatory clinical also demonstrated a high level of satisfaction. It was noted however, that a majority of patient who attended clinic physically felt that it took longer to see the specialist. The present study demonstrated that at least 3 hours was saved when engaging in TNC services. Indeed, TNC has been demonstrated to be a critical time saver even in acute emergencies such as strokes to influence timely thrombolysis and other intervention (5, 42).

The cost incurred by the patients when utilizing physical neurology consults was ksh.1000 ($10). This catered for transport costs to the hospital for the physical one on one consultation. There are limited studies to demonstrate the economic benefit of tele-medicine in general and few studies done have demonstrated cost effectiveness in fields such as tele-radiology but not tele-neurology (43). Our study sets the ground to have a more robust cost benefit analysis of TNC service however taking into consideration approximately 16% of Kenyan nationals are living below $1.90 a day, the cost saved is an important figure to take into account (44). Some of the transport costs saved include international patients from different countries in sub Saharan Africa e.g. Malawi, Tanzania who are on follow-up in Kenya. TNC not only has an economic benefit but also decentralizes health care within the region.

In keeping with the COP26 manifesto, it is prudent for the health sector to actively partake in environmentally friendly ways to deliver health care. Several developing countries have found ways in achieving this. As a developing country, the present study highlights that TNC is one of way of soldiering this agenda and in general tele-medicine has been shown to have a profound impact in reducing the carbon foot print by 40-70 times(21). Part of the major points of the COP26 agenda was restructuring urban centers and phasing out internal engine combustion and usage of private cars (22). Our study highlighted that the most common mode of transport was personal cars and motorbikes to come for a clinic appointment with a median distance covered of 11km in Kenya and 1,869km internationally. TNC on the other hands

flips the coin and enables patients to have consults remotely. Not only is this convenient for the patient but environmentally friendly. Indeed, studies have shown that the greatest contributor to global warming is carbon dioxide emissions from vehicles (17) . Using the carbon footprint analyzer and the data we collected from the current study, the total carbon emissions saved was 3.5 tons an equivalent to planting 21 trees to offset such a greenhouse emission. Our study is the first in SSA to take into consideration the environmental benefits TNC has as a model of health care delivery.

Limitations of the study.

Our study had multiple limitations. We were unable to fully execute physical examinations. This would require upscaling of human resources such as medical officers/qualified nursed as tele-presenters to upgrade to synchronous video enabled consultations. The patient selection was from one neurology clinic, and this could have contributed to a selection bias. Part of the exclusion criteria were patients who were not tech-savvy, and this possibly excluded a significant number of patients with neurological conditions. Another limitation was the inability for patients using insurance to be billed remotely, this forced them to come to hospital and clear the bill with the clinic at some point.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

The present study demonstrated that our regionally unique TNC is an acceptable, efficient, effective, and environmentally friendly care delivery model in our resource-poor setting. We recommend upscaling this service to the outreach clinics to increase the scope of TNC services in the hard-to-reach places of Kenya. Expanding the ICT capability to enable video assisted physical examinations will also aid in holistically managing our patients.

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APPENDICES

APPENDIX 1:

PRE-QUESTIONNAIRE

BIO DATA	
NAME	
AGE	
RESIDENCE	
MOBILE NUMBER	
EMAIL ADDRESS	
NEUROLOGICAL DISEASE	
DURATION OF DISEASE FOLLOWUP	
TAVEL TIME TO THE CLINIC	
COST OF TRAVEL	
TRAVEL DISTANCE	

Survey questionnaire for patients who have previously attended an ambulatory neurology clinic.

NO	QUESTION	Likert scale				
1.	I am satisfied with the one on one care received.					
2.	I felt more comfortable talking to my specialist doctor physically.					
3.	My specialist doctor has identified my health problem.					
4.	The time to see a specialist physically is faster.					

APPENDIX 2:

POST TELE-CONSULTATION QUESTIONNAIRE

NO.	QUESTION	LIKERT SCALE*				
1.	I am satisfied with the care received in tele-medicine					
2	My family is satisfied with the care received in tele-medicine					
3	Tele-medicine helps me know my state of health					
4	I felt comfortable talking to my specialist doctor through a microphone					
5	Talking to my specialist was as effective as in person					
6	Talking to my specialist was as effective as in person					
7	My specialist doctor has identified my health problem through tele-medicine					
8	The quality of sound were adequate to talk to my specialist doctor					
9	The time with a specialist is faster with tele medicine					
10	I prefer telemedicine because it is easier than to go to the hospital					
11	Telemedicine saves me time travelling to hospital or a specialist clinic					
12	My specialist doctor was able to answer my questions through telemedicine					
13	I find telemedicine an acceptable way to receive health-care services					
14	I will use telemedicine services again					
15	I trust that my personal information and privacy will be protected after my attention by tele medicine					

***Likert scale (Totally disagree, disagree, neutral, agree, totally agree)**

APPENDIX 3:

INFORMED CONSENT

Study Title: Applicability of tele-neurology in the follow-up of patients with neurological conditions.

Principal Investigator: Dr. Dilraj Sokhi

Co-Investigator: Dr.Fazal Yakub, Dr. Jasmit Shah

Informed consent

Introduction

My name is Dr. Fazal Yakub; a postgraduate student in the field of Internal Medicine at Aga Khan University Hospital, Nairobi. We are currently carrying out a research looking at the applicability of remote tele-consultations in the follow-up of patients with different neurological conditions. This study also comes at a time where the COVID19 pandemic has resulted in a limitation in face to face consultations. We therefore also wish to find out whether this study can be helpful in the follow up of patients in such times. Ultimately, we are looking at whether this mode of health care delivery can be rolled out to allow continuity of services in the field of neurology.

Purpose of this study: The aim of this study is to come up with a novel way to allow consistent clinic visits and at the same time assess the convenience in terms of cost, time and environmental benefit after assessing the carbon footprint burden when accessing traditional clinics.

Benefits of the study: The study will help establish whether tele neurology is a feasible model in the follow-up of patients with neurological conditions. This study will also enable us to know objectively whether this is something that can be rolled out in the long term.

Risks: This study will be involving new patients and patients who have been on follow-up by Consultant at the Neurology Clinic with stable neurological conditions. Follow up patients will be triaged by the clinic nurse and verbally consented for a tele neurology consultation.

New patients will be triaged by the neurologist and have a face to face consultation before being verbally consented for a follow up tele neurology consultation.

There are no direct risks or side effects in partaking in this study. Microsoft teams shall be used as one of the means of communication and has been ratified to be safe by the hospital security team.

Study participants will email the researches involved first for us to share the post tele-neurology questionnaire. This email will contain a code word in the subject head as an authentication code.

No medical information will be exchanged via email other than the questionnaire, lab requests or a prescription.

Voluntary participation: Participation in this study is entirely voluntary and you are free to withdraw your participation in this study at any time.

Confidentiality: The information obtained from this research will be confidential and only accessible to the researchers. Your information will only be identified using hospital identification numbers.

Conduct of Study and Follow up: Recruited participants will have a pre tele-neurology questionnaire sent electronically capturing demographic data, their email address, mobile number, the time, travel distance and the cost of coming to clinic on a normal day. The patients will then undergo a tele-consult and thereafter a post tele neurology survey capturing their level of satisfaction with the service will be sent electronically as well. An electronic prescription and lab request sent to them via email if need be.

Consent Agreement: I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked to have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant_____

Signature of Participant _____

Principal investigator

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APPENDIX 4:

Translated version informed consent form: -

UKUBALI WA TAARIFA

Kichwa cha Utafiti: Utekelezaji wa tele-neurology katika ufuatiliaji wa wagonjwa walio na hali ya neva.

Mchunguzi Mkuu: Dr. Dilraj Sokhi

Mpelelezi Mwenza: Dr Fazal Yakub, Dr Jasmit Shah

Idhini iliyojulishwa

Utangulizi: Majina yangu ni Dr Fazal Yakub; mwanafunzi wa uzamili katika uwanja wa Tiba ya Ndani katika Hospitali ya Chuo Kikuu cha Aga Khan, Nairobi. Tunafanya utafiti kuangalia matumizi ya mashauri ya mbali ya rununu katika ufuatiliaji wa wagonjwa walio na hali tofauti za neva.

Utafiti huu pia umekuja wakati ambapo janga la covid limesababisha upeo katika mashauriano ya ana kwa ana. Kwa hivyo pia tunataka kujua ikiwa utafiti huu unaweza kusaidia katika ufuatiliaji wa wagonjwa katika nyakati kama hizi. Mwishowe, tunaangalia ikiwa njia hii ya utoaji wa huduma ya afya inaweza kutumika kuruhusu mwendelezo wa huduma katika uwanja wa neva.

Kusudi la utafiti huu: Lengo la utafiti huu ni kuja na njia mpya ya kuruhusu uendelezaji wa matibabu bila kuja kliniki ana kwa ana. Pia tunapeleleza faida ya njia hii upande wa gharama, muda na faida kwa mazingira.

Faida za utafiti: Utafiti huu utasaidia kujua ikiwa teknolojia ya simu inaweza kutmika katika ufuatiliaji wa wagonjwa walio na hali ya neva. Utafiti huu pia utatuwezesha kujua kwa busara ikiwa hii ni jambo linaloweza kutumika baadaye.

Hatari: Utafiti huu utahusisha wagonjwa wapya na wagonjwa ambao wamekuwa wakifuatilia na Mshauri katika Kliniki ya Neurology.

Wagonjwa wanaofuatiliwa tangu zamani, watapigiwa simu an kuelezwa kuhusu utafiti huu na iwapo wangependelea kuhusika.

Wagonjwa wapya kwanza watamuona daktari mkuu ana kwa ana halafu wataelezwa kuhusu huu utafiti an iwapo wangependela kuhusika.

Hakuna hatari za moja kwa moja au athari za kushiriki katika utafiti huu. "Microsoft Teams" itatumika kama njia mojawapo ya mawasiliano na imeridhiwa kuwa salama na timu ya usalama wa hospitali.Washiriki wa utafiti watatuma barua pepe kwa watafiti. Barua pepe hii itakuwa na neno la msimbo kwenye kichwa cha somo kama nambari ya uthibitishaji.Hakuna habari ya matibabu itabadilishwa kupitia barua pepe zaidi ya dodoso, maombi ya maabara au dawa.

Kushiriki kwa hiari: Kushiriki katika utafiti huu ni kwa hiari kabisa na uko huru kuondoa ushiriki wako katika utafiti huu wakati wowote.

Usiri: Habari iliyopatikana kutoka kwa utafiti huu itakuwa ya siri na kupatikana tu kwa watafiti. Habari yako itatambuliwa tu kwa kutumia nambari za kitambulisho cha hospitali.

Maadili ya Utafiti na Kufuatilia: Washiriki walioajiriwa watakuwa na dodoso la mapema la tele-neurology lililotumwa kwa kukamata data ya idadi ya watu, anwani yao ya barua pepe, nambari ya rununu, wakati, umbali wa kusafiri na gharama ya kuja kliniki kwa siku ya kawaida.

Wagonjwa basi watafanyiwa ushauri wa simu na baada ya hapo uchunguzi wa baadae wa tele neurolojia wa kukamata kiwango chao cha kuridhika na huduma hiyo watatumwa kwa elektroniki pia. Maagizo ya elektroniki na maabara yaliyotumwa kwao kupitia barua pepe ikiwa inahitajika.

Mkataba wa idhini: Nimesoma habari iliyotangulia, au imesomwa kwangu. Nimepata nafasi ya kuuliza maswali juu yake na maswali yoyote ambayo nimeuliza ilijibiwe kwa kuridhika kwangu.

Ninakubali kwa hiari kushiriki kama mshiriki katika utafiti huu.

Chapisha Jina la Mshiriki_____

Saini ya Mshiriki _____

Mchunguzi mkuu

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