REPUBLIC OF MAURITIUS

MINISTRY OF HEALTH AND WELLNESS

In collaboration with

NEURAM

Investigating the impact of confinement due to the COVID 19 pandemic on Mauritius with Acquired Brain Injuries (ABI) and Spinal Cord Injuries (SCI)

Project Document for Ethics Committee

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1. Executive Summary

NEURAM in collaboration with the Ministry of Health and Wellness aims to investigate the psychosocial, emotional, cognitive, and functional deterioration of patients with neurological disability during confinement in Mauritius. This study will take place in a two-part survey where we collect data in a structured interview with patients and a close family member.

In the first section of the survey, data on demographic details, treatment before and during the lockdown, and their living situation will be conducted. The second section of the survey comprises a rated questionnaire assessing different aspects of patient functioning. A questionnaire from the quality of life before brain injury questionnaire (QOLIBRI) has been developed, which evaluates patients' subjective satisfaction with their functioning post-injury. The QOLIBRI is a 37 item questionnaire with six subscales (Gerin et al., 1991; Truelle et al., 2008). Each question has been reworded to ask whether, during the lockdown, each function addressed has not changed, become a little worse, or become a lot worse (e.g., During lockdown, my ability to concentrate did not change). The scoring system mirrors Deloche et al.'s (2000) development of the European Brain Injury Questionnaire (EBIQ). The EBIQ uses a three-point answer method. In scoring the questionnaire, we take the averages of patient scores in each of the six subscales are taken to assess which areas of functioning they perceive to have deteriorated the most. In addition, family members will be asked to take the survey on behalf of the patient. Subsequently correlation will be done for patient and family member scores as a test of validity.

2. Justification

There is little research pertaining to neurological disability resulting from spinal cord injury (SCI), acquired brain injury (ABI), or stroke patients in Mauritius. The study would like to begin assessing the quality of life of neurologically impaired patients in Mauritius and their available treatment.

As our lockdown is, for the most part, lifted, we would like to investigate the retrospective, subjective opinions of patients and their family members on the impact of lockdown. This research will allow NEURAM as well as Ministry of Health and Wellness to begin to formulate an understanding of what impacts patients of with neurological disability the most in Mauritius. We can subsequently mobilize relevant resources to aid these patients; this would allow us to tailor future treatment and educational programs to the needs of the people.

This study is an extension of the WFNR's survey, which aims to assess the impacts of lockdown on the treatment of patients with neurological disability (INSERT CITATION). The study will investigate whether patients feel they do not have access to treatment because they fear COVID-19 or because treatment resources have been allocated elsewhere.

3. Summary of Previous Studies

A few studies/ presentations address the issues. The webinar that is attached deals with the concerns about long covid. For instances:

1. *BMJ* 2020; 370 doi: https://doi.org/10.1136/bmj.m3489 (Published 07 September 2020) Cite this as: BMJ 2020;370:m3489

2. NHS England: https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/

3. World Federation of Neuro-rehabilitation WFNR
    a. International survey of Neurorehabilitation and how it has been affected by COVID-1 (https://jp.surveymonkey.com/r/S7W5KNZ)

The main objective of this survey is to learn about the experience of neurorehabilitation professionals who provide neurorehabilitation to victims of COVID-19 with neurological complications. The survey is not limited to the professionals who directly treat patients with Corona virus infection.

This survey addresses following three important issues:

- The experience of management of neurological manifestations of Corona virus infection, either directly caused by it or acquired due to complications of its treatment such as peroneal nerve palsy following prolonged bed confinement.
- **The effect on the rehabilitation of patients who suffer from usual neurological diseases such as stroke, spinal cord injury or brain injury** due to redeployment of medical resources during rapid spread of pandemic.
- **Neuropsychological impact of COVID-19** infection on patients and stress related effects on neurorehabilitation professionals

4. WHO
   https://www.euro.who.int/en/media-centre/events/events/2021/02/virtual-press-briefing-on-covid-19-understanding-long-covid-post-covid-conditions/understanding-and-managing-long-covid-requires-a-patient-led-approach
   Of relevance are the WHO conclusions:

   We need multidisciplinary, multispecialty approaches to assessment and management. We need to work with patients and their families to develop new care pathways, **including rehabilitation and online support tools**. We need to look at employment rights, sick pay policies and access to benefit packages for those affected. And we need much more research, again with patients fully involved in deciding what questions to ask and how to answer them.

4. Objectives of the study

4.1 Begin collating a database of patients with neurological disability

4.2 Understand the impact of confinement on access to treatment, whether it be out of fear of contracting COVID-19 or they were unable to access treatment ordinarily available. We will also assess what treatment was available before lockdown.

4.3 Understand the impact that this has had on family members and whether lockdown and lack of care have changed caregiving roles. We aim to understand how this has influenced relationships within the family unit.

4.4 Understand the impact of confinement on these patients in terms of cognitive, psychosocial, and emotional aspects of functioning. We will assess which areas of functioning deteriorate the most as a result of confinement.

4.5 Assess whether patterns of agreement between patients and family members on the deterioration of functioning follows patterns of overseas studies. For example, family members typically rate changes in emotion as more extreme than what patients do (Hendryx,. 1989).

5. Description of the study design

The study will require a minimum of 30 patients suffering from either ABI, SCI or stroke and a close family member. These patients must have lived with their injury and close family member during the 2021 lockdown. Therefore, the participant pool will include an equal number of patients with ABI, SCI, or stroke and close family members (see Deloche et al., 2000; Hendryx., 1989; Teasdale et al., 1997).

In part two of the survey, each question is scored either *1=no change, 2=became a little worse, or 3=became a lot worse.* When taking the averages of the scores per section, we obtain a measure of perceived deterioration during the lockdown. This design is in line with Deloche et al.'s (2000) scoring method on the European Brain Injury Questionnaire. Various studies assess the perception of functioning between patient and their family member as a measure of validity by correlating their scores (Deloche et al., 2000; Hendryx, 1989; Kinsella et al., 1988; Teasdale et al., 1997).

6. Research subjects

As NEURAM and Ministry of Health and Wellness aims to ultimately provide resources and essential neuro-rehabilitation services to patients with neurological deficits, our primary test subjects are patients living with ABI, SCI and stroke during the 2021 lockdown in Mauritius. These patients must have an acquired injury (i.e., must not be congenital defects or tumours). Head injuries, spinal injuries, accidents, stroke or toxicity induced injury are all acceptable.

As data collected are both retrospective and subjective, a close family member will also report their perception of the patients' deterioration in a separate interview. In doing so, we assess whether their opinions agree. Preferably, the family member interviewed will be the patient's primary caregiver. In section one of the survey, we evaluate whether the family members' duties have changed due to the lockdown or lack of access to other caregivers or resources. We also ask how this has impacted the relationship with the patient.

We intend to recruit subjects through local media outlets and news agencies. We hope that this recruitment approach will give us a diversified pool of participants from different demographic and socioeconomic backgrounds.

7. Criteria for inclusion or exclusion of potential subjects

ABI, SCI, and stroke patients

- Must have an acquired injury, not congenital or genetic deformation
- Must have a close family member
- Patients of other injury types are excluded from the study
- Patients who acquired injury less than one year before lockdown are excluded from the study

Family member

- Family member must preferably be the primary caregiver or someone who spends significant time with the patient
- We exclude family members residing outside of the home unit

8. Clinical and laboratory tests

Patients will participate in a structured interview where the researcher can ascertain answers regarding their living situations, treatment, and history of ABI, SCI, or stroke. In the second part of the interview, researchers will assess whether patients have experienced no change, slight deterioration, or considerable deterioration in different aspects of functioning. The interview should take no longer than 40 minutes.

We will subsequently interview a close family member to assess their opinions on the patients' deterioration. We will first ask the family member to confirm the living situation, neurological injury, and treatment history. Section two of the interview asks the family member to answer the same 37 questions but on behalf of the patient.

No clinical or laboratory tests beyond the interviews described will take place.

9. Potential benefits of the survey

The first section of the survey will explain what neurorehabilitation (NR) or other forms of treatment are mainly unavailable to patients of ABI, SCI, and stroke in Mauritius. There are few resources available to help family members and patients regardless of their socioeconomic background to adapt to the drastic changes resulting from a brain injury. Even to the wealthy who have the financial means to face ABI, SCI, or stroke, the expertise is not widely available.

The second section of the survey allows us to understand how lockdown impacts patients with ABI/stroke in various aspects of their functioning. Many patients suffering from ABI, SCI, and stroke become socially withdrawn; critical parts of neuropsychological rehabilitation involves helping these patients reintegrate into society (Wilson & Betteridge, 2019). With lockdown, brain injury patients often lose their social connections, which may be invaluable for their functioning (Denyse A. Kersel, Nigel V. Marsh, J, 2001; Gainotti, 1993; Morton & Wehman, 1995). Additionally, patients and their family members may feel particularly vulnerable due to the covid outbreak and not want to perform activities that are normal parts of their functioning. Small goal-oriented activities (such as going to the store independently) form essential aspects of neurorehabilitation (Wilson & Betteridge, 2019). Being afraid to go to the store or otherwise carry out these activities, patients may deteriorate in functioning as they no longer engage in activities that maintain and develop their functioning.

Additionally, sending away caregivers or therapists outside of the family (if typically employed) may deteriorate or halt patient functioning and have implications for family members as caregivers. Strained relationships between family members and patients affect the psychological wellbeing of both family members and patients (Braine, 2011; Hall et al., 1994; Knight et al., 1998).

10. Potential benefits to the country

This study may act as a starting point in building a neurorehabilitation program in Mauritius that could provide critical care to patients with neurological deficits and their families. We are expanding research of ABI, SCI and stroke victims on the island and developing a database from which we can one day draw to support them. In addition, we are assessing which needs of these patients and their families are not being met. Understanding these needs will allow us to, in line with NEURAM's goals, tailor the neurorehabilitation services we one day hope to provide to meet the needs of the Mauritian people. We will also begin to understand which demographics are the most affected by neurological disability and the leading causes of these kinds of disabilities on the island. In future, we could potentially focus educational campaigns (e.g., Headway's hat day) to target these causes of injury before they happen.

11. Plans to inform the subjects about the results

We are aware that many participants may not have access to computers or email. On sending the results for publishing, we will send participants a summary via text message or email and invite them to call us with any questions.

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13. Time schedule

We aim to have all data collected by the end of August. Following this we aim to finish writing the paper by October.

14. Sponsorship

None

15. Consent Form

16. Questionnaire