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**Determining the disability status of adult patients post general intensive care unit (ICU) discharge at the Aga Khan university hospital, Nairobi using the world health organization disability assessment schedule 2.0(WHODAS).**

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**AGA KHAN UNIVERSITY**

Postgraduate Medical Education Program

Medical College, East Africa

**DETERMINING THE DISABILITY STATUS OF ADULT PATIENTS POST GENERAL INTENSIVE CARE UNIT  
(ICU) DISCHARGE AT THE AGA KHAN UNIVERSITY HOSPITAL, NAIROBI USING THE WORLD HEALTH  
ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0(WHODAS).**

**BY**

**DR. KHADIJA AHMED**

A dissertation submitted in partial fulfillment of the requirement for the degree of

Master of Medicine

In Anesthesiology

NAIROBI, KENYA

31/05/2021

**DEPARTMENTAL DISSERTATIONS COMMITTEE APPROVAL**



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**Submitted to the Board of Graduate Studies**

In part fulfillment of the requirements for the degree of  
Master of Medicine  
In Anesthesiology

Members of the Dissertations Standard Committee appointed to vet the dissertation of

**KHADIJA HASSANNOOR AHMED**

Find it satisfactory and recommend that it be submitted for evaluation by external examiners



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Chair, Dissertations Standard Committee

31/05/2021

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Date

## **DEDICATION**

*Dedicated to my parents; Kaltuma Adow and HassanNoor Sheikh, they are my inspiration for this work.*

## ABSTRACT

**Background:** Critical care has evolved throughout the years since the polio outbreak when the first ICU was set up in the USA. There is an increasing number of survivors of critical illness. The survivors have been shown to have prolonged physical, cognitive and psychological impairments. There is no current information on the status of this patient post ICU in Africa.

**Objectives:** To measure the disability status of adult patients post general Intensive Care Unit (ICU) Discharge Using WHODAS 2.0. To determine the factors associated with the degree of disability.

**Methodology:** This was a cross-sectional analytical study. Patients admitted to AKUHN ICU, were on mechanical ventilation for more than 48 hours and survived to hospital discharge were called on the phone. Once they were found to be alive and consented for the study, the WHODAS 2.0 questionnaire was used. The level of disability was measured using the WHODAS 2.0 which has 12 items, where each item was scored between 0 and 4; and the total score was displayed as a percentage. Factors associated with the degree of disability were retrieved from the patients' files. Data analysis was done using SPSS version 2.0.

**Results:** 92 patients were enrolled into the study where 62.6% (n=57) were females. The disability status in our respondents was as follows; n=26(28.6%) of them had no disability, n=26(28.6%) mild disability and n=22(24.2%) had moderate disability, n=17(18.7%) of the patients reported severe disability while no participant had complete disability. Median age of 60 and length of ICU stay were found to be associated with moderate to severe disability. Other factors like; duration of mechanical ventilation, number of comorbid, use of muscle relaxant/steroids, admission diagnosis were not found to be statistically significant in relation to degree of disability.

**Conclusion:** In this study, 57.2% of patients had no disability to mild disability while 42.8% were found to have moderate to severe disability. Patients who were found to have moderate to severe disability had longer ICU stay and were in the older population.

**Keywords:** *Disability, critical care survivors, post ICU discharge, physical impairment, mechanical ventilation, quality of life.*

## **LIST OF ABBREVIATIONS**

<b>AKUH, N</b>	-	Aga Khan University Hospital, Nairobi
<b>APACHE</b>	-	Acute Physiology and Chronic Health Evaluation
<b>ICF</b>	-	International Classification of Functioning
<b>ICU</b>	-	Intensive Care Unit
<b>PICS</b>	-	Post Intensive Care Syndrome
<b>PTSD</b>	-	Post Traumatic Stress Disorder
<b>SAH</b>	-	Subarachnoid hemorrhage.
<b>WHO</b>	-	World Health Organization
<b>WHODAS</b>	-	World Health Organization Disability Assessment Score
<b>WHOQOL</b>	-	World Health Organization Quality of Life
<b>KIHME</b>	-	Kenya Institute of Health Metrics and Evaluations.
<b>POM</b>	-	Primary Outcome Measure.
<b>SOM</b>	-	Secondary Outcome Measure

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Thank you



## 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 have been made in the text.*



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(Signature of Candidate)

31/5/2020

Date

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## LIST OF DEFINITIONS

**Disability:** Is a physical or mental condition that limits a person's movements, senses, or activities.

**Critical illness:** An illness or injury that acutely impairs one or more vital organ systems such that there is a high probability of imminent or life threatening deterioration in the patient's condition.

**ICU:** Department in a hospital which provides intensive treatment medicine.

**Post Intensive Care Syndrome:** is a new or worsening impairment in cognition, mental health or physical function after critical illness.

**Mechanical ventilation:** Can be defined as the technique through which gas is moved towards and from the lungs through an external device connected directly to the patient.

**Discharge:** When a patient is allowed to leave the hospital after treatment.

**Impairment:** Is a state of diminishment or loss of function or ability.

# CHAPTER ONE: INTRODUCTION

## 1.1 Background of the Study

Intensive care is a branch of medicine that deals with critically ill with high morbidity and mortality rates(1). The practice has slowly evolved since the polio outbreak when they used the positive pressure ventilation in 1952 in Copenhagen, Denmark, to when they set-up a four-bed shock ward, as the first ICU in Los Angeles, California, USA(2). The evolution has increasingly focused on improving the inpatient-care as well as reducing the mortality rates in the ICU. This has led to a marked increase in the number of survivors. ICU discharge is the beginning of a long path towards recovery, requiring efforts from the patients, their families and healthcare systems.

Post ICU has been shown to have a lot of stress, physically and psychologically, which end up having effects on the quality of life patients may go back to. To create healthcare that is based on patient-centered outcomes for the survivors of critical illnesses, there has been a need to assess their post critical illness status in terms of, psychological well being , physical abilities and emotional status (3). The patient's physical status affects his/her family and the community in which he/she lives in. They may have survived critical illness, but may find it difficult to reintegrate and be productive in the society, economically and socially. This may lead to depression and anxiety, with an impact on the socio-economic status of the family.

The ability to serve as functional members in the community is an important consequence for all patients, after any critical ailment and it is a sign of being at the end of their journey in the critical illness. A patient's possibility of returning to their daily activities impacts on the contentment with their life, careers, family and overall health. Long term disablement of physical, mental and cognitive aspects affect most ICU survivors.(4) It is through this lens that we consider the use of the WHO Disability Assessment Schedule 2 (WHODAS) to assess disability status of ICU survivors and creating understanding between measuring of impairment and function and survival of critical illnesses.

## 1.2 Justification of the Study

Diagnosis is important as it aids in the management and monitoring of interventions. As much as we focus on what a patient has or had in ICU, we need to remember the impact, the critical illness has on the role of the patient at home, work/school and the social areas of a person's life. This is independent of the primary health problem since the study seeks to determine what the person can functionally do post-critical illness.

This is the functional status of the patient and has for a long time been ignored because our primary focus was on eliminating the disease process only and overlooking the impact it had on the patient. WHODAS 2.0 helps us in clearly defining the disability status of patients with chronic illnesses or post-illness. In Africa, no information has been published about the disability status of survivors of critical illness.

Disability is a major health issue and has led to more than half of premature mortality in the community according (5). People come to the hospital normally because they are not able to do what they used to do and not necessarily because of the disease they are suffering from. Although critical care services has reduced mortality over the years, the lives patients go back to are not the same and they may end up living with an increased burden in all aspects of life including social and economic aspects. Early identification of disability status is crucial so that timely and appropriate supportive measures can be given.

As critical caregivers, there is a need to move beyond merely reducing mortality and also focus on post ICU functionality, by assessing disability status so that we can set intervention strategies such as physiotherapy and occupational therapy clinics to improve on their overall health and well-being.

Existing studies from other parts of the world may not have the same economical, cultural and religious backgrounds as ours which affects support system of these patients post ICU discharge . Our financial and support structures may not be at par with the developed world. This study seeks to close the knowledge gap of post critical illness conditions, more so their disability status.

The results of this study will be first of its kind in the region and can help other researchers get a baseline in their future ICU follow-up studies. The factors found to have a strong association with



long- term severe disability will help in identifying patients who will be at risk during discharge as well.

### 1.3 Research Question

What is the disability status of adult patients, post ICU discharge in AKUHN using the WHODAS 2.0?

### 1.4 Primary Objectives

To determine the disability status of adult patients, post general Intensive Care Unit discharge at Aga Khan University Hospital using WHODAS 2.0.

### 1.5 Secondary Objective

To determine the factors associated with the degree of disability including:

- Age and gender
- Admission diagnosis
- Duration of mechanical ventilation
- Length of stay in ICU
- APACHE II score
- Number of co-morbidities
- Steroid use
- Muscle relaxants use

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Definition of Disability**

Disability is a physical or mental condition that curbs a person's movements, sensation, or activity(6). According to the World Health Organization (WHO), disabilities is a parasol term which covers functional limitations, and restrictions of activities (7). Thus, it's not just a health problem, it's a complex mechanism that shows the interaction between functional capacity of a person and the society in which they live in(8).

Worldwide, disability has become an important cornerstone for critical illness survivors. Patients suffer from what has come to be known as post-intensive care syndrome which entails impairment in patients' physical, cognitive and psychological aspects. Patients are thankful to their caregivers but report the painful need to getting back to their former lives, which has been hindered by their bodies being hurt or disfigured, hence loss of function. This has been shown to have an impact on quality of life, ongoing healthcare costs and economic impact on the family(9).

According to the Kenya Institute of Health Metrics and Evaluation, the causes of disability are; communicable diseases, maternal, neonatal and nutritional diseases followed by non-communicable diseases like diabetes(10). The country has generally been focusing on reducing the impact of these as most of other developing countries. This has left a gap in other areas like critical illness and its impact on contributing to the national disability status.

Disability can be classified into; physical like blindness, loss of a limb or intellectual like autism or acquired brain injury which can bring about loss of personality, slowness in activity, memory and concentration. The disability acquired from brain injury leads to a complete reorientation of a person's life, the roles they play at home, in society as well as his/her interaction with others compared to a disability in which a person was born with like blindness. Overall, these physical and mental impairment changes their quality of life in the long run.

### **2.3 Critical Care**

Critical care patients are patients whose conditions are a constant threat to life and require extensive multi-disciplinary care and constant monitoring, generally in intensive care units. For a long time, we have focused on minimizing mortality rates and this has been the primary outcome measure in ICUs'. Currently, the only study done by Lalani et al in Western Kenyan ICU, which

reported mortality rate at 53.6% (11). Although this was more than half their sample size, there was no other published data to compare within Kenya or East Africa. There are also no published studies showing any kind of follow up of critical illness survivors in Africa.

## 2.2 Post Intensive Care Syndrome

PICS is worsening health status that remain after a patient has been admitted in ICU due to critical illness. They may be present during the patient's ICU stay and can persist after return to home. They involve a patient's impairment in physical status, their thought process or feelings which affects the family and society around them. It can manifest as muscle weakness, new problems with thinking and judgement which is known as cognitive dysfunction or as other mental illness like PTSD and depression(12).

In a study done in multiple ICUs in the US, the mortality rates of ICU patients, of the years 1988/1989 and 2010/2012 were compared. They reported that the mortality rates were reduced from 17.3% to 12.4% (a 35% reduction in mortality rates)(13). The study showed that, although there was an improvement in mortality rates, there were many survivors who had severe illness on their admission. All these patients, as much as they survived, severe critical illness has had profound effects on their long term functional recovery which is known as post-intensive care syndrome. These patients have been shown to suffer from post-intensive care syndrome, which includes; long term physical, mental health and cognitive impairments. There is no current follow up of these patients in Kenya or in the region, so we tend to overlook the impact it has on their quality of life post-discharge.

A review done by Rawal G. et al on PICS showed that up to 30% of families or the carers have been undergoing anxiety, depression, stress and sadness due to patients's status post-ICU discharge(14). PICS has been acknowledged as a public health burden due to the associated functional and psychological disability, although the exact prevalence is not known since there is no data available in Africa so far unlike in the developed countries. In the analysis of the review, about 25% of patients may develop cognitive deficiencies, although it could be higher in our population. The psychological disorders associated with PICs may range from depression, anxiety, and PTSD with a reported incidence, ranging from 1-60%. The physical weakness which is a result of ICU acquired neuromuscular weakness, may occur in at least 25% critical illness survivor.

In a systematic review which assessed for patients at risk for developing ICU acquired weakness with subsequent long term physical weakness, found that it was mainly associated with patients who had sepsis and those who had prolonged mechanical ventilation(15). Other risk factors reported by several studies included multi-organ failure, hyperglycemia, higher Acute Physiological and Chronic health Evaluation score (APACHE) scores, duration of ICU stay (bed rest)(16).

Disability in ICU patients is mostly as a result of ICU acquired weakness. In Australia, in a five multi-center ICUs study which was done by Hodgson et al, aimed to measure key components of the WHO's International Classification of Functioning (ICF) concerning survivors of ICU by using a questionnaire administered to patients or their caregivers. In the study, they found that 25% of patients had no disability, 50% described mild disability and finally 25% had moderate to severe disability. No patients reported complete disability. Hodgson et al found that the prognosticators of increased level of disability were a history of mental illness, being divorced or separated, period of ventilation and discharge to rehabilitation centers instead of home. The study found that the severity of disability status was highest in areas of: movement, personal care and activities of their daily living. Greater levels of symptoms of depression and anxiety post ICU-discharge were seen in patients with higher levels of disability. There was a significant association between unemployment at the time of assessment and patient who had increased level of disability status(9). This study tried to assess most of the aspects of post-intensive care syndrome, however, this was done in a first world country, Australia, which is a first world country and a good support system for the disabled. This brings us to the question of; how our patients are doing with the post-intensive care life considering that, maybe, they were the breadwinners of their families and also the fact that we live in a third world country with different problems compared to a first world country. We also have depleted and poor healthcare system, completely different family and support structures and cultural beliefs. There is currently no data in Africa that has been published which shows any kind of follow of these cohort of patients.

### 2.3 Role of WHODAS 2.0 in Determining Disability Status

WHODAS 2.0 was originally developed for psychiatric patients, although, it has undergone a lot of developments to the current one now which reflects on the complete International classification of Functioning (ICF) for Disability and Health, and is able to measure the disability from both physical and mental chronic health status. WHODAS has been used to develop other measures for

Quality of Life like WHOQOL, which measures subjective well-being like what the person ‘feels’ compared to WHODAS 2.0 which assesses the functionality of an individual, what a person can do (17).

WHO designed this questionnaire to assess limitation of activities regardless of a person’s medical condition. It has items that cover six parts of common daily living activities: understanding and communicating with the world; ambulation; self-care; interacting with people; daily living activities; and participation in society in general (18). In each item, the responders estimate the degree of their disability during the previous 30 days, using a five-point Likert scale. The scores for each question ranges from 0 (no difficulty) to 4 (extreme difficulty/cannot do), providing a total range from 0 (no disability) to 48 (maximum disability) in the total score. The WHO-DAS 2.0 was evolved and tested across many cultures and found to be applicable both hospitals patients and in the community level(17).

In Africa, there was a study done in Ghana and Côte d'Ivoire assessing antepartum women with depression and anxiety and their impact on disability status using the WHODAS 2.0 12-item version, interviewer-administered with its translation. This study showed that we can use this version of the questionnaire and rely on it as a useful screening tool for disability in our set up with a translated version(19). Another study done in South Africa and the USA, comparing disability status of people living with HIV in those countries, the WHODAS 12-item version, self-reported questionnaire was administered (20). In our study, we plan to use the telephone interviewer-administered version because our patients come from East and Central Africa as referrals hence it would a difficult task and not cost-effective to call on people to come for interviews while the same information can be gotten via a phone call. Patient’s phone numbers are usually part of the information collected when a patient is admitted at AKUHN. Hence, it will be easy to retrieve this information from the record system.

A study done in Madagascar by White et al assessed for before and after disability status post-surgical interventions in which it was trying to show improvement in functionality using patient reported outcomes WHODAS 2.0(21). Hence why we can apply the questionnaire as a follow-up to our ICU-discharged patients.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Study Question**

What is the disability status of adult patients, post ICU discharge in AKUHN using the WHODAS 2.0?

### **3.2 Primary objective**

To determine the disability status of adult patients, post ICU discharge in AKUHN using the WHODAS 2.0.

### **3.3 Secondary Objective**

To determine the factors correlated with the degree of disability including:

- Age and gender
- Admission diagnosis
- Duration of mechanical ventilation
- Length of stay in ICU
- APACHE II score
- Number of co-morbidities
- Steroid use
- Muscle relaxants use

### **3.4 Study Design**

It was a cross-sectional analytical study.

### **3.5 Study Setting**

The study was conducted at The Aga Khan University Hospital, Nairobi through telephone interviews. The patients were recruited using the ICU database. Aga Khan University Hospital is a premier private tertiary healthcare facility and a teaching hospital located in Nairobi, Kenya. The ICU has 11 beds with most of the patients referred from in-hospital; from HDU or theaters.

However, there are some patients admitted as referrals from mainly East and Central African countries. It's completely an open ICU and several intensivists do daily rounds apart from the primary team.

Once the patients are discharged, they are taken to mainly HDU or the wards. Once the patient is discharged from the hospital, they are followed-up on a need basis at the primary team's discretion. The patient's records are kept safely in the hospital's records department where they can be retrieved when necessary with permission. The patient's contacts and next of kin are usually noted down as part of documentation during admission hence follow-ups and queries can be done whenever necessary.

### 3.6 Study Population

All adult patients admitted in ICU, between the period January 2017 and December 2018, had 48 hours of mechanical ventilation and survived to hospital discharge and alive at the time of assessment.

#### 3.6.1 Inclusion criteria

1. Adult patients aged 18 and above who were admitted to ICU from 1<sup>st</sup> January 2017 to 31<sup>st</sup> December 2018.
2. Patients who underwent mechanical ventilation of more than 48 hours and survived to hospital discharge.

#### 3.6.2 Exclusion criteria

1. Patients who had hypoxic brain injury; diagnosis done by a critical care consultant and a neurologist/neurosurgeon.
2. Patient's refusal to participate.
3. Not able to speak Kiswahili or English.

### 3.7 Sample Size Determination

All patients who met the inclusion criteria were recruited and the interview administered, once a verbal consent obtained from the patient or the caregiver.

### 3.8 Recruitment Process

Eligible patients were obtained from the hospital records system, for patients who were admitted between the period of 1<sup>st</sup> January 2017 and 31<sup>st</sup> December 2018. Patients were recruited from the hospital record system. Once they meet the inclusion criteria, they were called via the phone. The call was made by the primary investigator. If the patient was alive, the questionnaire was

administered once the verbal consent had been obtained via the phone from the patient or via proxy. If the patient was not alive/not reached, the next patient on the list was called until all the patients who met the inclusion criteria were called.

### 3.9 Data Collection Procedure

All patients admitted during that period were assessed for eligibility from the hospital record system. A master list containing the names, hospital numbers and phone numbers was generated for each patient. Each recruited patient was then assigned a study identification number. This was then entered into the questionnaire. Patient identifiers were not entered into the questionnaire.

Demographic data and data representing factors associated degree of disability was extracted from the patient's medical records by the principal investigator and a research assistant once the verbal consent was obtained during the phone call. These data included; name, age, sex, admission diagnosis, duration of ICU stay, number of comorbidities, medications used, use of muscle relaxants, use of any steroids and APACHE II scores. This data was then put into a data collection tool.

### 3.10 Data Management and Protection

The patient identifiable information was kept safely in an institutionally given laptop which is password protected in the custody of the principal investigator and assistant. A linking key to the patient's identifiable information in the original master list to the individuals' patient study was developed. The key and the master list was not stored in the same place to preserve confidentiality. Separate locks were used to store them. Hard copies of the filled out questionnaires was stored in a separate cupboard, locked and was accessible to only the primary investigator and the assistant. The study data was entered electronically to create a database on a password-protected laptop to which only the investigator and the assistant will have access to.

On the completion of the study, the data was to be handed over to AKU Faculty of Health Sciences as per Section 4.1.6 (f) of the faculty manual of research policies and procedures.

The data (both hard and soft copy) will stored for a period of up to 10 years after which it will be destroyed according to institutional policy.



### 3.11 Data analysis

The WHODAS has 12 items, each scored from 0 to 4 (total score of 48). The total was then displayed as a percentage. The level of disability was generated by categorizing the percentage score; categorized into no disability (0-5%), mild (6-24%), moderate (25-50%), and Severe (>50%). Continuous data for each patient's scores will be presented in a histogram form.

The association between the levels of disability and other factors was determined using the chi-square test and any variable with  $p\text{-value} < 0.05$  or clinically significant was a plausible candidate for the multivariate analysis. Statistical analysis was done using SPSS version 2.0.

### 3.12 Ethical Consideration

The proposal was submitted to the Aga Khan University Research Ethics Committee for approval. An over phone informed verbal consent was obtained and participation in the study was completely voluntary and anyone who wished to not participate was assured they not be victimized. For those who started the interview and at any moment during the interview, refused to continue with it, were not coerced and appropriate support was given, whether it was due to emotional trauma or not.

The patient identifiers such as names and hospital numbers was not entered into the questionnaires and the linking key to the patient identifiers to the master list generated was stored securely by the investigator. Separate locked cupboards were used for the master list containing patient identifiers and the key where access was limited to the investigator.

There was some risk of loss of confidentiality as the information got included some names, so that proper follow up was generated but the patient's autonomy was also put into consideration.

Patients who were found to have psychological or emotional distress from the interview were invited to meet with counselors at AKUHN for professional support and proper follow-up. The patients found to have a significant disability were referred to a physiotherapist or occupational therapist accordingly at AKUHN.

### 3.13 Expected application of the results.

Identifying patients with disabilities due to ICU admission would prompt us in making appropriate follow up in post ICU follow-up clinics and appropriate interventions carried out before the ongoing disability gets worse. Results of the study will be used to identify patients who will be

predicted to have severe long term disability using the risk factors association analysis and hence timely follow-ups and support can be established.

Health care providers can use the study as a baseline to follow up studies where different key interventions can be started as early as possible. Overall, the burden of post critical care on patients will eventually be lessened.

### 3.14 Dissemination of results.

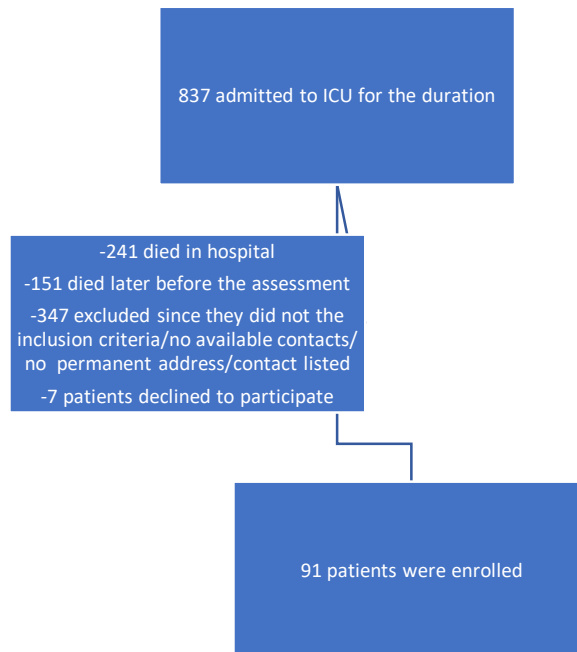
The findings of the study will be distributed to the AKUHN management, staff involved in the critical care services and the other members of the healthcare teams who encountered these patients in the course of their care.

The results will also be submitted to peer-reviewed journals for publications to add to the body of knowledge of the scientific research community.

## CHAPTER FOUR: STUDY RESULTS AND ANALYSIS

### 4.1. Patient enrollment

The total number of patients who were admitted to ICU between the period 2017 January- 2018 December were 837. 241 of them died in the hospital, 151 patients died later out of hospital at least three months to one year post discharge, 347 were excluded from the study because they had not the inclusion criteria (less than 18 years of age, admitted into ICU without mechanical ventilation during their stay, intubated and ventilated for less 48 hours, or could not be contacted), seven patients declined to participate even after meeting the inclusion criteria and only 91 patients could be enrolled into the study.



**Figure 1: Consort diagram**

### 4.2 Socio-Demographic characteristics

Demographic characteristics of the patients were as follows; majority of the patients were above 50 years old n=44 (48.4%). Patients with ages of 31-50 were 35.2% (n=32) and those 18-30 years were 16.5% (n=15). Among the 92 patients who responded, n=57(62.6%) of them were females. The average years of study was 15 years in school which was equivalent to a tertiary level of education.

Distribution of the patients by marital status was as follows; 20.9 % (n=19) of the respondents were never married and 62.6% (n=57) were still married at the time the study was conducted. Five patients (2.2%) were divorced, 8.8% (n=8) patients were widowed.

Majority of the patients were either self-employed 25.3% (n=23) or employed 25.3% (n=23). Eighteen (19.8%) of them were already retired while n=14(15.4%) was unemployed. Due to the design of the questionnaire, the patients' employment status before the ICU admission was not recorded.

**Table 1: Socio-demographic characteristics of the patients.**

<b>Characteristics</b>		
<b>Age (years): Median (IQR, Range)</b>	50 (35-65, 22-89)	
<b>Age (years)</b>	<b>Frequency(n-91)</b>	<b>Percent (%)</b>
18-30	15	16.5
31-50	32	35.2
>50	44	48.4
<b>Years of study in school: Median (IQR, Range)</b>	15 (12-16, 0-23)	
<b>Gender</b>		
Female	57	62.6
Male	34	37.4
<b>Marital status</b>		
Never married	19	20.9
Currently married	57	62.6
Separated	5	5.5
Divorced	2	2.2
Widowed	8	8.8
<b>Work status</b>		
Employed	23	25.3
Homemaker	4	4.4
Other	1	1.1
Retired	18	19.8

Self-employed	23	25.3
Stay at home	1	1.1
Student	4	4.4
Unemployed [H/R]	14	15.4
Unemployed [O/R]	1	1.1
Working	2	2.2

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#### 4.2 Disability status

The disability status in our sample population was as follows; n=26(28.6%) of them had no disability, n=26(28.6%) mild disability and n=22(24.2%) had moderate disability, n=17(18.7%) of the patients reported severe disability while no participant had complete disability.

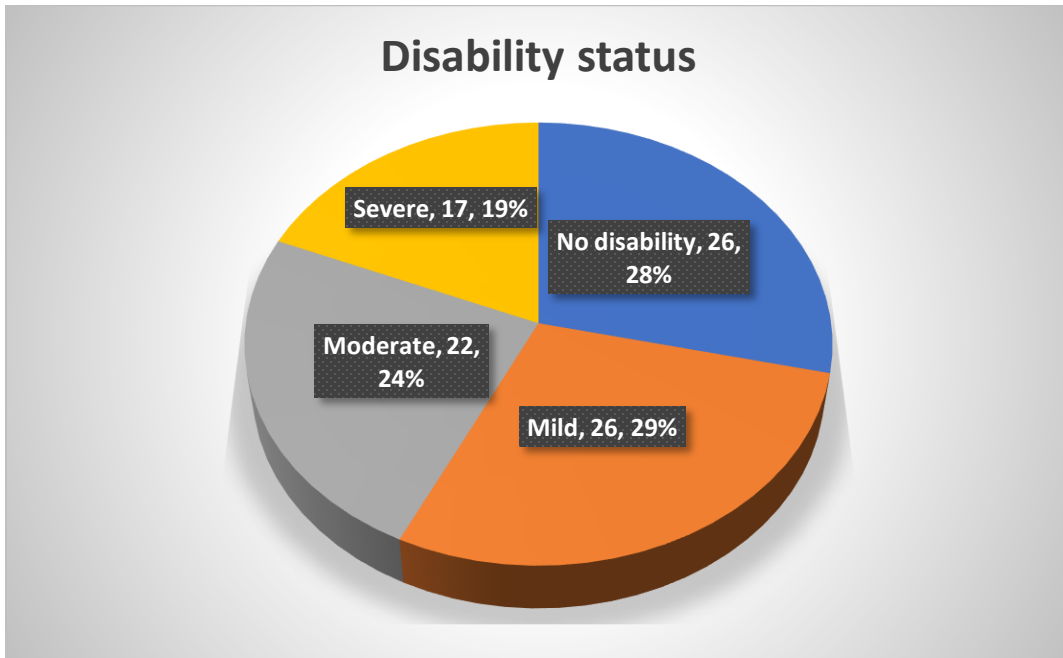
Addition of each respondents total score divided by 48, and converted to percent.

Disability: 0-5% No disability, 6-24% Mild, 25-50% Moderate, >50% Severe

**Table 2: Disability status**

<b>Disability</b>	<b>Frequency</b>	<b>Percent</b>
No disability (0-5%)	26	28.6
Mild (6-24%)	26	28.6
Moderate (25-50%)	22	24.2
Severe (>50%)	17	18.7

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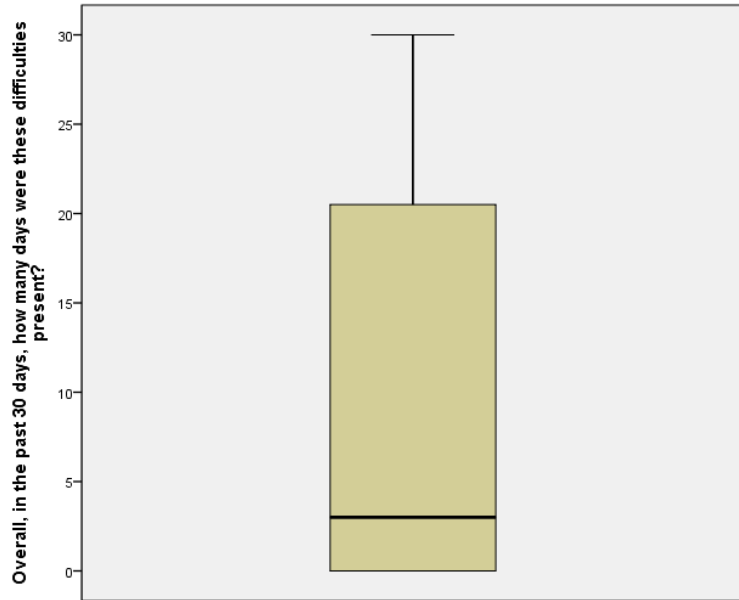
**Figure 2: Disability status**

The table below shows the average number of days in a month the patients had those difficulties present which was an average of 3 days while some had 2 days which they could not do their usual activities.

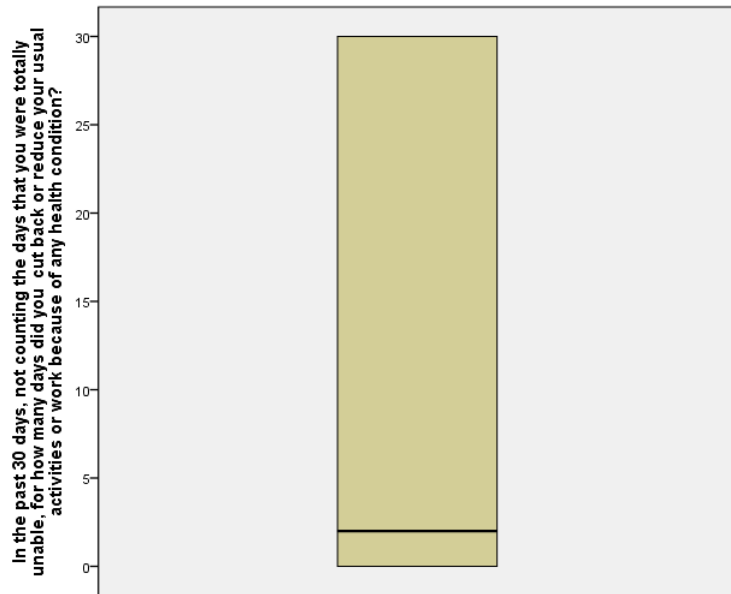
**Table 3: Average Number of Days disability was present**

	<b>Median (IQR, Range)</b>
In the last 30 days, overall, how many days were the difficulties present?	3 (0-21, 0-30)
In the last 30 days, how many were you not totally able to carry out your usual activities or work because of your health?	2 (0-30, 0-30)
In the last 30 days, not counting the days that you were totally unable, how many days did you have to cut back or reduce your usual activities or work because of any health condition?	2 (0-30, 0-30)

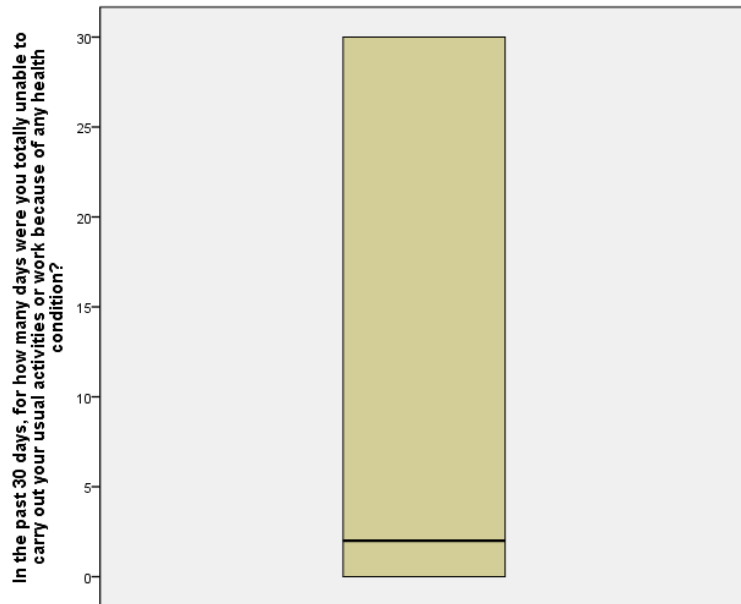
**Figure 3: average number of days difficulties were present in 30days**



**Figure 4: Average number of days the difficulties were present**



**Figure 5: Average number of days cut down from work**



**Figure 6: Average number of days unable to do usual daily activities.**

#### 4.3 Factors associated with Disability Status.

In the factors associated with disability status; only 58 patients' full records were found in the system and were analyzed where the median age for patients with disability was 60 years while the ones with no disability had a median age of 41. This was found to be statistically significant with a p value <0.001.

Disability according to gender distribution was as follows; n=24 of the females had disability, n=33 no disability while for the males n=15 had reported disability and n=19 had no disability.

According to the admission diagnosis; majority of the patients had neurological disease at 30.8% (n=28), followed by trauma/shock at 20.9% (n=19) and then which respiratory failure who had 18.7% (n=17). The others were found to be sepsis gastrointestinal disease and cariogenic.

The median duration of mechanical ventilation for patients with disability was 6.5 days while those with no disability had 4 days. This was however not statistically significant. On patients' length of ICU stay, the median was found to be at 9.5 days and the ones with no disability was 7.5 days. This was found to be statistically significant with a p-value of 0.035.

The APACHE score of patients with disability was at a median of 17 while the ones with no disability was at 15.5. In patients who were on steroids, the ones with disability were 39.3%



(n=11) while those with no disability were 43.3 (n=13). The ones who were never on any steroids, n=17 had disability while the other n=17 had no disability. Only one patient was found to have disability and was on muscle relaxant, n=5 had no disability with a history of muscle relaxant use in ICU. Twenty-seven patients had a disability with no use of muscle relaxant and n=25 patients had no disability and no use of muscle relaxant.

The number of patients who had disability together with comorbid were n=19 while n=16 had no disability with history of comorbidity. The ones with no chronic illness and had disability were n=9 while 14 had no chronic illness and no disability. The odds of having a disability with a chronic illness was higher at 1.8 than not having any comorbid. However, this was not statistically significant.

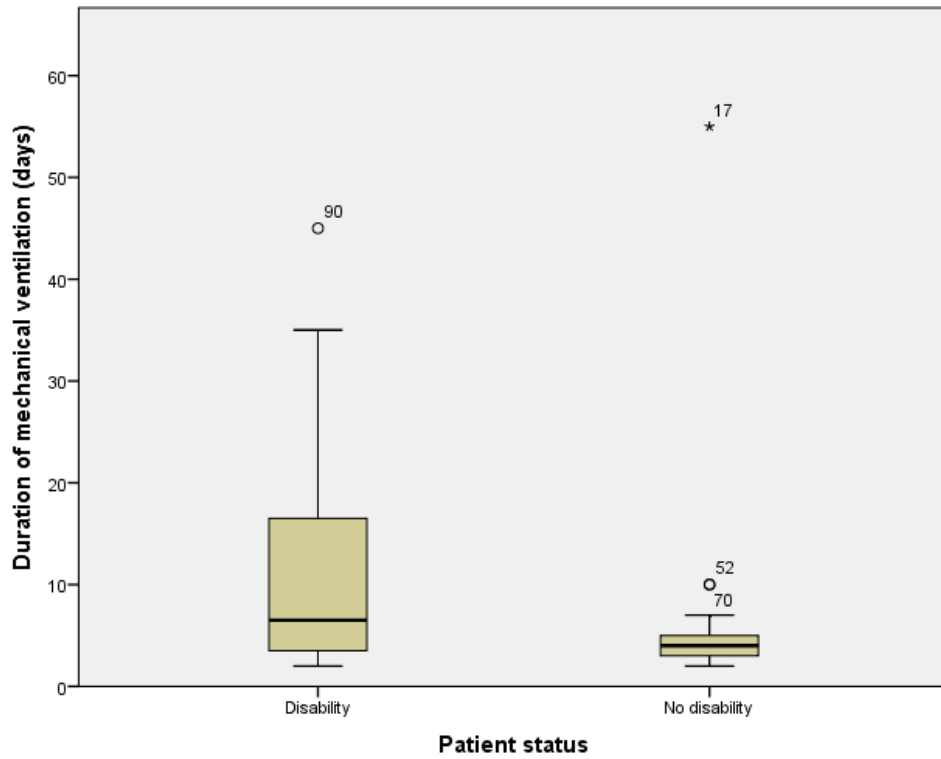
**Table 4: Factors associated with the degree of disability (Yes: Moderate/Severe, No: None/Mild)**

Factor	Disability		Total	OR (95% CI)	p-value
	Yes	No			
<b>Age: Median (IQR, Range)</b>	60 (49-80, 22-89)	41 (31-53, 22-72)			<0.001
<b>Gender (n,%)</b>					
Female	24 (61.5)	33 (63.5)	57 (62.6)	0.9 (0.4-2.2)	0.851
Male	15 (38.5)	19 (36.5)	34 (37.4)	Ref	
<b>Admission diagnosis: n, %</b>					
Neurological disease	10 (25.6)	18 (34.6)	28 (30.8)	Ref	
Cariogenic	5 (12.8)	2 (3.8)	7 (7.7)	0.8 (0.04-14.6)	0.880
Gastrointestinal disease	2 (5.1)	1 (1.9)	3 (3.3)	0.2 (0.04-1.4)	0.104
Respiratory failure	7 (17.9)	10 (19.2)	17 (18.7)	0.3 (0.04-1.9)	0.190
Sepsis	6 (15.4)	3 (5.8)	9 (9.9)	0.8 (0.1-6.8)	0.839
Trauma/Shock	8 (20.5)	11 (21.2)	19 (20.9)	0.3 (0.05-1.9)	0.197
Others	1 (2.6)	7 (13.5)	8 (8.8)	0.1 (0.004-0.8)	0.035
<b>Duration of mechanical ventilation: Median (IQR, Range)</b>					
	6.5 (3.5-16.5, 2-45)	4 (3-5, 2-55)			
<b>Length of ICU stay: Median (IQR, Range)</b>					
	9.5 (5.5-22, 5-60)	7.5 (5-8, 3-70)			

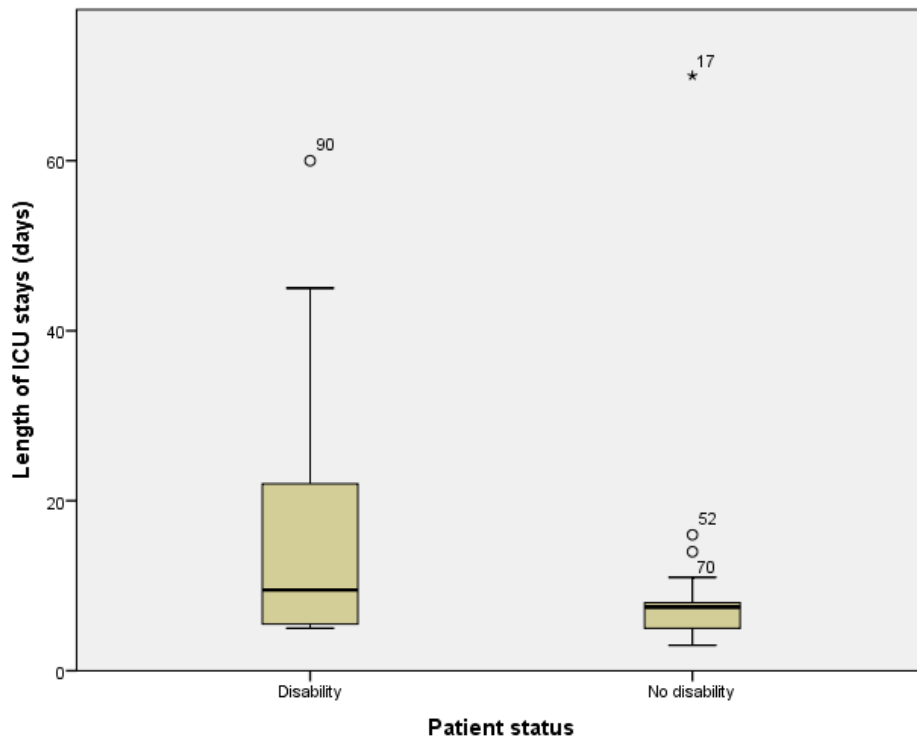
**Table 5: Factors associated with degree of disability- Comorbidity and APACHE II score**

	Disability	No disability	OR	p-value
<b>APACHE II Score: Median (IQR, Range)</b>	17 (15-21, 10-32)	15.5 (13-20, 7-35)		0.432
<b>Comorbidity</b>				
Yes	19 (67.9)	16 (53.3)	35 (60.3)	1.8 (0.6-5.4)
No	9 (32.1)	14 (46.7)	23 (39.7)	0.259

**Figure 7: Duration mechanical ventilation**



**Figure 8: Length of ICU stay**



**Table 6: Factors associated with Disability; steroid use and muscle relaxant**

<b>Steroid use: n, %</b>				<b>OR</b>	<b>P- VALUE</b>
Yes	11 (39.3)	13 (43.3)	24 (41.4)	0.8 (0.3-2.4)	0.754
No	17 (60.7)	17 (56.7)	34 (58.6)	Ref	
<b>Muscle relaxant: n, %</b>					
Yes	1 (3.6)	5 (16.7)	6 (10.3)	0.2 (0.02-1.7)	0.195
No	27 (96.4)	25 (83.3)	52 (89.7)	Ref	

## CHAPTER FIVE: DISCUSSION

### 3.1 Discussion

This was a retrospective study done on patients who were discharged from ICU, more than 6 months prior to the time of the study (2019 December-2020 March). It was carried out to determine the disability status post ICU discharge and factors associated with the degree of disability. Majority of our patients were found to be above 50 years of age while the rest were between the ages of 31-50 years. Most of our patients were married at the time of the assessment, the next group were the ones who reported that they had never married, although, this did not capture the number of patients who were not married but had living-in partners. Only seven of them reported to have been separated, 2 were officially divorced and the rest were widowed. Unfortunately, our data had not assessed on their pre-ICU admission marital status. However, our results, were with similar to a study done in the UK by Griffiths et al. where they were assessing the socio-economic impact of ICU admission, 97% of their patients reported no change in relationship status between six to twelve months follow-up of patients who were discharged from ICU(23). Marital status has not been shown to be a predictor for disability status in patients post ICU discharge. However, it has been found to be a predictor of functionality outcome in patients post cardiac surgery survivors(24).

Fifty percent of our cohort of patients were either still employed although at a different capacity or self-employed while 15% were unemployed. The patients reported that their job capacity/level had changed after discharge from ICU compared to before. This is similar to the study done by Griffith et al although, he was comparing before and after ICU admission employment status. He reported that 33% of their respondents had negative impact on their employment after their ICU discharge. An average of 2 days of the week, patients were found not being able to carry out their usual activities due to the presence of their disability. This is bound to impact on their total output at work and in life generally although we did not assess for before and after work status of our cohort of patients.

The national Kenyan disability status is approximately 10% according to the Global Disability Rights Now data. The findings from the study showed 28.6% of the patients had no disability, 28.6% with mild disability, 24.2% had moderate disability and 18.7% with severe disability (more

than 50% disabled). None of the patients were completely disabled (more than 95% disabled). This, certainly, adds to overall burden of disability in Kenya.

Comparing it with the study done by Hodgson et al, they found that 25% of patients reported no disability, 50% reported mild disability and 25% reported moderate to severe disability. In our study, our cohort had relatively higher, moderate to severe disability, 42.9% compared to the study above which was 25% for both moderate and severe disability rates. This was about 1.7 times more in our patients. This could be because some patients in that population were discharged to rehabilitation centers, unlike in our setup where the decision for rehabilitation was left to the primary physicians' discretion.

Age was found to be a predictor of presence of disability together with length of ICU stay in our study. Hodgson et al found that pre-admission history of anxiety and depression, separation or divorce or prolonged ventilation were factors affecting the degree of disability. In our study, duration on the vent did not show significant association with the presence of disability. However, the length of ICU stay was seen to have contributed to the presence of disability. This may be due to the prolonged duration of immobility in critical care despite being extubated while in ICU as evidenced by the prolonged ICU stay. The patients who were found to have disability were more of the elderly and this could be explained by the presence of other comorbidities, which is an independent factor; patients with comorbidities were more likely to have disability after ICU admission compared with patients with no comorbidities. This was however not statistically significant in our study. However according to the review done by Rawal G. et al, the conditions found to be strongly associated with ICU-acquired physical weakness were; prolonged mechanical ventilation, sepsis, multi-system organ failure and prolonged duration of the bed-restore deep sedation. They did not comment on length of ICU stay in ICU.

Other factors like severity of illness, steroid use or use of muscle relaxant which were not found to be associated with presence of disability or post ICU weakness compared to previous studies maybe due to high number of patient dropout due to death post ICU discharge, 158 and the seven patients who declined. According to Majer et al, people with disability in activities of daily living and ambulation, had a 10-year shorter life-span than non-disabled people. This could be due differences in lifestyle, socio-demographics, and major chronic diseases they had (25). This could

explain our high numbers of mortality post ICU discharge which could have been as a result of their post-ICU disability, together with the chronic illnesses.

## **CHAPTER SIX: LIMITATIONS**

Limitation of this study was that it was a cross-sectional which only captured the disability as a snapshot and does not report whether it was progressive in nature. It was not establishing whether the disability was a causality of the ICU admission or the primary disease progression since the study could not compare the before and after ICU disability status, due to recall bias. There was no comparing of pre and post ICU marital status of the patients, as we know psychological support may have changed the progression of the disability. We also excluded patients with hypoxic brain injury which may have increased our disability rates due the irreversible brain damage. The study could not enroll large numbers because many patients had died by the time of the study or due to lack of proper ICU admission criteria in our setup since majority of patients did not meet the inclusion criteria and the factors which contributed to the length of stay ICU could not be captured as this eventually affected the patients' overall disability status according to our study. It was also done among patients who had been admitted at AKUHN and this may be underestimating the burden of disability post ICU discharge in the country which could be higher since the patients in AKUHN hospital are from a different socio-demographic status.



## **CHAPTER SEVEN: CONCLUSIONS**

The disability status among patients who were discharged from AKUHN's ICU according to this study was 28.6% had no disability, 24.2% with mild disability and 42.8% with moderate to severe disabilities compared to a previous study done by Hodgson et al where their 25% of their patients had no disability and 50% mild disability and 25% were to have moderate to severe disability. In this study the factors found to be associated with presence of marked disability was increasing age and longer duration of ICU stay.

## **CHAPTER EIGHT: RECOMMENDATIONS**

We recommend closer follow-up of patients who were admitted to critical care with prolonged ICU stay, referral for physiotherapy and rehabilitation, as they are more prone to moderate to severe disability.

We also need to do a prospective study assessing the disability status pre and post admission, with proper follow up, to see if there is worsening disability with time. We also need to find out the psychological impact this amount of disability has on patients post ICU discharge. This would include patient reported outcomes of anxiety, depression and post-traumatic stress disorder according to their level of disability.

## REFERENCES

1. intensive care definition [Internet]. Available from: <https://medical-dictionary.thefreedictionary.com/critical+care>
2. Kelly FE, Fong AK, Hirsch N, Nolan JP. Intensive care medicine is 60 years old : the history and future of the intensive care unit. *Clin Med (Northfield Il)*. 2014;14(4):376–9.
3. Rosa RG, Ferreira GE, Wendt T, Robinson CC, Kochhann R, Berto P, et al. Effects of post-ICU follow-up on subject outcomes: a systematic review and metaanalysis. *J Crit Care* [Internet]. 2019;52:115–25. Available from: <https://doi.org/10.1016/j.jcrc.2019.04.014>
4. Denehy L, Hough CL. Critical illness , disability , and the road home. *Intensive Care Med*. 2017;43(12):1881–3.
5. Forman-hoffman VL, Ault KL, Anderson WL, Weiner JM, Stevens A, Campbell VA, et al. Disability Status , Mortality , and Leading Causes of Death in the United States Community Population. *Med Care*. 2015;53(4):346–54.
6. DEFINITION OF DISABILITY. In: WIKIPEDIA [Internet]. Available from: <https://en.wikipedia.org/wiki/Disability>
7. WHO disability definition [Internet]. Available from: <https://www.who.int/topics/disabilities/en/>
8. Dowdy DW, Eid MP, Sedrakyan A, Mendez-Tellez PA, Pronovost PJ, Herridge MS, et al. Quality of life in adult survivors of critical illness: A systematic review of the literature. *Intensive Care Med* [Internet]. 2005;31(5):611–20. Available from: <https://doi.org/10.1007/s00134-005-2592-6>
9. Hodgson CL, Udy AA, Bailey M, Barrett J, Bellomo R, Bucknall T, et al. The impact of disability in survivors of critical illness. *Intensive Care Med* [Internet]. 2017;43(7):992–1001. Available

from: <https://doi.org/10.1007/s00134-017-4830-0>

10. Top 10 causes of years lived with disability in 2017 and percent change,2007-2017,all ages,number [Internet]. 2017. Available from: [www.healthdata.org%3EKenya](http://www.healthdata.org%3EKenya)
11. Lalani HS, Waweru-Siika W, Mwogi T, Kituyi P, Egger JR, Park LP, et al. Intensive Care Outcomes and Mortality Prediction at a National Referral Hospital in Western Kenya. *Ann Am Thorac Soc* [Internet]. 2018 Nov 1 [cited 2019 May 18];15(11):1336–43. Available from: <https://www.atsjournals.org/doi/10.1513/AnnalsATS.201801-051OC>
12. Society of Critical Care Medicine. Post-intensive Care Syndrome (PICS). 2013.
13. Kuzniewicz MW, Vasilevskis EE, Lane R, Dean ML, Trivedi NG, Rennie DJ, et al. Variation in ICU Risk-Adjusted Mortality: impact of methods of assessment and potential confounders. *Chest* [Internet]. 2008;133(6):1319–27. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0012369208600689>
14. Rawal G, Yadav S, Kumar R. Post-intensive care syndrome : An overview. *J Intern Med*. 2017;(Jun):90–2.
15. Fan E, Cheek F, Chlan L, Gosselink R, Hart N, Herridge MS, et al. AMERICAN THORACIC SOCIETY An Official American Thoracic Society Clinical Practice Guideline : The Diagnosis of Intensive Care Unit – acquired Weakness in Adults. *Am J Respir Crit Care Med*. 2014;190(12):1437–46.
16. Hermans G, Berghe G Van Den. Clinical review : intensive care unit acquired weakness. *Crit Care* [Internet]. 2015;19(1):1–9. Available from: <http://dx.doi.org/10.1186/s13054-015-0993-7>
17. Üstün TB, Kostanjsek N, Chatterji S, Rehm J. Measuring Health and Disability Manual for WHO Disability Assessment Schedule. 2010.

18. Marx BP, Ph D, Wolf EJ, Ph D, Cornette MM, Ph D, et al. Using the WHODAS 2 . 0 to Assess Functioning Among Veterans Seeking Compensation for Posttraumatic Stress Disorder. *Psychiatr Serv*. 2015;1(66):1312–7.
19. Bindt C, Appiah-Poku J, Te Bonle M, Schoppen S, Feldt T, Barkmann C, et al. Antepartum depression and anxiety associated with disability in African women: cross-sectional results from the CDS study in Ghana and Côte d’Ivoire. *PLoS One* [Internet]. 2012 Oct 26;7(10):e48396. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/23110236>
20. Kietrys D, Myezwa H, Galantino M Lou, Parrott JS, Davis T, Levin T, et al. Functional Limitations and Disability in Persons Living with HIV in South Africa and United States: Similarities and Differences. *J Int Assoc Provid AIDS Care*. 2019;20(18):1–9.
21. White MC, Randall K, Alcorn D, Glasgow C, Shrime MG. Measurement of patient reported disability using WHODAS 2 . 0 before and after surgical intervention in Madagascar. 2018;18(1):1–7.
22. Daniel WW. *Biostatistics: A Foundation for Analysis in the Health Sciences*. 7th ed. New York: John Wiley & Sons; 13 p.
23. Griffiths J, Hatch RA, Bishop J, Morgan K, Jenkinson C, Cuthbertson BH, et al. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. *Crit Care* [Internet]. 2013 Jun 28;17(3):1–2. Available from: <https://pubmed.ncbi.nlm.nih.gov/23714692>
24. Maiga AW, Deppen SA, Pinkerman R, Grogan EL. Marital Status and Postoperative Functional Recovery. *JAMA Surg*. 2016;151(2):194–6.

25. Majer IM, Nusselder WJ, Mackenbach JP, Klijs B, van Baal PHM. Mortality risk associated with disability: a population-based record linkage study. *Am J Public Health* [Internet]. 2011/10/20. 2011 Dec;101(12):e9-15. Available from: <https://pubmed.ncbi.nlm.nih.gov/22021307>

## APPENDICES

### 7.1 Appendix I- Study Work Plan

	2019					2020		
MONTHS	February	March	April/May	July- September	October- December	January	February	March
Department Presentation – Concept								
Submission of Concept Note to Research Committee								
Proposal Development								
Submission to Ethics/Approval								
Data Collection								
Data Analysis								
Write Up								
Results Presentation								

## 7.2 Appendix II- Verbal Consent Form

Study Title: Determining the disability status of adult patients, post ICU discharge in AKUHN using the WHODAS 2.0.

Principal Investigator: Prof. Vitalis Mung'ayi

Co-Investigator: Dr. Khadija Ahmed

My name is Dr. Khadija Ahmed and I am studying for master's degree in Anesthesia at the Aga Khan University in Nairobi and, as part of my training, I am expected to conduct a research study. The research I am conducting is on disability status of patients post ICU discharge and the factors which contribute to its development while in ICU. I hope that from this study, guidelines will be created that will describe how to follow-up ICU patients post discharge from the hospital. The aim of all this will be to assess the quality of life of patients post discharge and how well they have integrated into their daily lives.

Today you will be participating in a phone interview, which should take approximately fifteen (15) minutes to complete. Your participation is completely voluntary. If you do not wish to participate, you may stop me at any time. Taking part in this study is completely voluntary, and if you do not agree to continue with the telephone call, it will not affect your care at our facility nor will it attract any penalty. Taking part in this study indicates your agreement to participate.

If you feel stressed as a result of the questions asked in this interview, we would like to invite you for a counseling session at the Aga Khan University Hospital where you will be attended to by professional counselors.

### **Benefits of the study:**

Participants who have been found to have marked disability will be referred to a physiotherapist and an occupational therapist at AKUHN or to one of their choice for proper follow-up and assessment.

### **Risks**

Some patients may be traumatized by this interview. Should you find this interview upsetting in any way, we will advise that you arrange to see the counselors at our hospital who will be able to offer you the professional help that you need to support you. The other risk associated with this study is loss of confidentiality.



### Confidentiality

Hard copies of the questionnaires will be stored in a locked cabinet and will not be accessed by anyone other than the principal investigator and his research assistant. Your responses will be completely confidential and neither your name nor your hospital number will be disclosed outside of the research team. We will keep your information private by omitting your name from this questionnaire, using study numbers in place of your name and hospital number. Any documents that may be used to link your responses in this questionnaire to you will be kept under lock and key in a cupboard accessed only by myself. Electronic copies of this form will be stored in a password-protected computer whose access is limited to my research assistant and I. Results from the study will be published in scientific journals to inform the scientific community of our findings and to guide further research. Nothing that could identify you will appear in the final report that we will write.

### Voluntary participation

Your participation in this study is voluntary. You are free to withdraw from the study at any time or refuse to participate without any consequences whatsoever. Any care you are currently receiving at AKUHN will continue as normal regardless of whether or not you agree to participate in this study. Feel free to ask any questions regarding the information given to you.

If you would like a copy of this consent for your records, please let me know and I will give you a copy via email, or physically when you visit the hospital. If you have any questions regarding the research, please contact me on 0722727901 or email me using [khadija.ahmed@aku.edu](mailto:khadija.ahmed@aku.edu).

If you have questions related to the ethics of this study please contact: The Secretariat, Ethics Review Committee, Aga Khan University, P.O. BOX 30270-00100, Nairobi. Telephone 020-3662148; Email: [research.supportea@aku.edu](mailto:research.supportea@aku.edu)

## **FOMU YA IDHINI**

UPAMBANUZI WA HALI YA ULEMAVU WA WAGONJWA AMBAO NI WATU WAZIMA BAADA YA KUTOLEWA KATIKA CHUMBA CHA WAGONJWA MAHUTUTI KATIKA HOSPITALI YA CHUO KIKUU CHA AGA KHAN NAIROBI.

MTAFITI MKUU: Prof. Vitalis Mung'ayi

MTAFITI: Dr. Khadija Ahmed

Jina langu ni Dkt. Khadija Ahmed, mwanafunzi wa uzamili wa Uganzi katika chuo kikuu cha Aga Khan mjini Nairobi na kama sehemu ya mafunzo yangu nahitajika kufanya utafiti. Ninachunguza hali ya ulemavu wa wagonjwa baada ya kutolewa katika chumba mahututi na vipengele vinavyochangia hali hiyo ya ulemavu wagonjwa hawa wakiwa kwenye chumba cha wagonjwa mahututi. Natumahi kwamba kutokana na utafiti huu miongozo ya jinsi ya kuwafuatilia wagonjwa hawa baada ya kuondoka hospitalini itabuniwa. Lengo la utafiti huu ni kutathmini ubora wa maisha ya wagonjwa hawa baada ya kutolewa hospitalini kwa kutumia kifaa kinachotathmini utendaji kwa kuwauliza kuhusu uwezo wao wa kufanya shughuli zao za kila siku.

Leo utashiriki katika mahojiano ya simu yatakayochukua takriban dakika kumi na tano kukamilika. Kushiriki kwako ni kwa hiari yako mwenyewe. Hata hivyo iwapo hutaki kushiriki katika mahojiano haya unaweza kuacha wakati wowote ule. Kushiriki katika utafiti huu ni kwa hiari yako hivyo kutokubali kuendelea na mazungumzo haya ya simu hakutaathiri uangalizi wako katika hospitali yetu wala hakutavutia adhabu yoyote ile. Kushiriki kwako kunategemea ukubalifu wako.

Iwapo unafedheheshwa na maswali ya usaili huu tunakualika kwa kipindi cha ushauri nasaha katika hospitali ya chuo kikuu cha Aga Khan utakakoshughulikiwa na washauri nasaha wetu.

### **Faida za utafiti**

Washiriki watakaopatikana kuwa na ulemavu dhahiri wataelekezwa kwa wataalamu wa tibamaungo na shughuli za matibabu katika hospitali ya chuo kikuu cha Aga Khan mjini Nairobi au hospitali nyingine waliochagua kwa kufuatiliwa na kutathminiwa.

### **Hatari**

Wagonjwa wengine huenda wakapata kiwewe kutokana na mahojiano haya. Iwapo mahojiano haya yanakufadhaisha kwa vyovyote vile, tunakushauri uwaone washauri nasaha katika hospitali yetu watakaokusaidia kitaaluma. Hatari nyingine inavyohusiana na utafiti huu ni kupotea kwa usiri.

### **Usiri**

Nakala za dodoso zitahifadhiwa katika kabati iliyofungwa isiyoweza kufikiwa na yeyote ila mtafiti mkuu na msaidizi wake. Majibu yenu yatawekwa siri na jina lako wala nambari yako ya usajili ya hospitalini haitafichuliwa kwa yeyote nje ya kundi la utafiti. Tutaweka maelezo yako siri kwa kutoweka jina lako katika dodoso hili kwa kutumia nambari nyingine tofauti. Stakabadhi zozote zinazoweza kukuhusisha na majibu katika dodoso hilo zitahifadhiwa na kufikiwa tu na mtafiti peke yake. Nakala tarakilishi nazo zitahifadhiwa kwenye kompyuta yenye nambari ya siri inayoweza kufikiwa nami mtafiti na msaidizi wangu pekee. Matokeo ya utafiti yatachapishwa katika jarida la kisayansi ili kuifahamisha jamii ya kisayansi na kutoa mwongozo wa tafiti zaidi. Hakuna chochote kinachoweza kukutambulisha kitatokea katika chapisho la mwisho tutakaloandika.

#### Kushiriki kwa hiari

Kushiriki kwako katika utafiti huu ni kwa hiari yako mwenyewe. Uko huru kujiondoa katika utafiti huu au kukataa kushiriki bila adhabu zozote. Uangalizi wowote unaopokea sasa katika hospitali ya chuo kikuu cha Aga Khan ya Nairobi utaendelea bila kuhitilafiwa ukishiriki au usiposhiriki katika utafiti huu. Jihisi huru kuuliza maswali yanayohusiana na maelezo uliyopewa.

Iwapo ungependa nakala ya idhini kwa minajili ya rekodi zako unaweza kunifahamisha nitakutumia nakala kwenye barua pepe au nikupe utakapotemebelea hospitali yetu. Iwapo una maswali kuhusiana na utafiti huu tafadhali nipigie simu 0722727901 au unitumie barua pepe kwenye anwani [khadija.ahmed@aku.edu](mailto:khadija.ahmed@aku.edu)

Iwapo una maswali kuhusiana na maadili ya utafiti huu basi wasiliana na sekretarieti ya kamati ya maadili ya chuo kikuu cha Aga Khan, S.L.P 30270-00100, Nairobi. Nambari za simu 020-3662148; Anwani ya barua pepe: [research.support@aku.edu](mailto:research.support@aku.edu)

7.3 Appendix III Script for Telephone Interview.

ENGLISH VERSION

**1. Begin the telephone interview by saying:** *“Hello, my name is (insert researcher’s name) from the Aga Khan University Hospital Nairobi. May I ask who I am speaking to?”* **(Wait for the person to confirm their name)**

**Respond by saying:** *“Thank you. Could you kindly confirm the language you are comfortable speaking in before we proceed?”* **(Confirms whether he/she prefers English or Kiswahili. If the respondent indicates that he/she is not comfortable with either, thank him/her for her time and politely end the interview).**

**2. For those who indicate their choice of language, proceed in either English or Kiswahili as appropriate and say,** *“I am calling regarding a research study that we are conducting at the Aga Khan Hospital in Nairobi. May I please speak to (insert patient’s name) \_\_\_\_\_?”*

**If the person answers no, end the call by saying,** *“That’s alright. Thank you for your time.”*

**If the response is that patient is not in, ask,** *‘Would it be alright if I called back later to speak to her?’* **If they say yes, note the time suggested and call back later. If they say no, end the call by saying,** *“That’s alright. Thank you for your time.”*

**3. If you are informed that the patient is deceased, say,** *‘I am very sorry for your loss. My sincere condolences. If you are willing, we would like to invite you to meet with our counselors at the Aga Khan Hospital who will be able to support you through this difficult time.’*

**4. If the person answers yes to the request for interview and you are able to speak to the patient say,** *“Hello. I got your telephone number from the medical records at the Aga Khan University Hospital Nairobi. Is this a good time to speak? I expect this telephone call to last about 20 minutes.’*

**If they are willing to speak but the time is not convenient, say,** *“May I call you later? What time would be better for you?”* **Note the time and call back later.**

**5. If the response to the request for interview is yes, explain the purpose of the research and gain verbal consent. Thereafter, begin the interview by saying,** *“I will now ask you a few questions. If you need clarification at any point, please stop me and ask.”*

A1	Record sex as observed	Female	1
		Male	2
A2	How old are you now?	_____years.	
A3	How many years in all did you spend <u>studying in the school, college or university</u>	_____ years	
A4	What is your current marital status? <b>(select the single best option)</b>	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Cohabiting	6
A5	Which describes your <u>main work status</u> best? <b>(select the single best option)</b>	Paid work	1
		Self-employed, such as own a business or farming	2
		Non-paid work, such as volunteer or charity	3
		Student	4
		Keeping house/ homemaker	5
		Retired	6
		Unemployed( health reasons)	7
		Unemployed ( other reasons)	8
		Other (specify)	9

In the past 30days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S1	<u>Standing for long periods</u> such as <u>30 minutes</u>	1	2	3	4	5
S2	Taking care of your <u>household responsibilities?</u>	1	2	3	4	5
S3	<u>Learning a new task</u> , for example learning how to get a new place?	1	2	3	4	5
S4	How much of a problem do you have in <u>joining community activities</u> (for example as festivities, religious or other activities) in the same way as everyone else.	1	2	3	4	5
S5	How much have you been emotionally affected by your health problems?	1	2	3	4	5

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S6	<u>Concentrating</u> on doing something for ten minutes?	1	2	3	4	5
S7	<u>Walking a long distance</u> such as a <u>kilometer</u> or equivalent?	1	2	3	4	5
S8	<u>Washing your whole body</u> ?	1	2	3	4	5
S9	Getting dressed?	1	2	3	4	5
S10	Dealing with people <u>you do not know</u> ?	1	2	3	4	5
S11	Maintaining a friendship?	1	2	3	4	5
S12	Your day-to-day work/school?	1	2	3	4	5

H1	Overall, in the past 30days, <u>how many days</u> were these difficulties present?	<b>Recording number of days_____</b>
H2	In the past 30days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition?	<b>Recording number of days_____</b>
H3	In the past 30days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	<b>Recording number of days_____</b>

This concludes our interview and thank you for your participation.

#### KISWAHILI-TRANSLATED VERSION

#### NAKALA YA MAHOJIANO YA SIMU

(KWA KISWAHILI)

**1. Anza mahojiano ya simu kwa kusema,** Halo jina langu ni (**jina la mtafiti**) kutoka hospitali ya chuo kikuu cha Aga Khan mjini Nairobi. Naomba kumfahamu ninayezungumza naye kwenye simu (**subiri mzungumziwa kuthibitisha jina lake**)

**Jibu kwa kusema,**” Asante, naomba uthibitisha ungependa tutumie lugha gani katika mahojiano haya kabla tuendelee. (**Mzungumziwa ambaye ni mshiriki atathibitisha ikiwa angependa kutumia Kiswahili/ Kiingereza, endeleza mahojiano kwa kusema,**” ninakupigia simu kuhusu utafiti tunaofanya katika hospitali ya Aga Khan mjini Nairobi. Naomba kuzungumza na (**weka jina la mgonjwa**)? Ikiwa mshiriki ataeleza kwamba hawezi kuwasiliana kutumia Kiswahili au kiingereza mshukuru kwa muda wake na kwa hesima uhitimisha mahojiano.)

**2. Kwa wale wenye uwezo wa kuchagua hivyo kuwasiliana kwa kiswahili au kiingereza, endeleza usaili kwa kiingereza/kiswahili faafu na useme,**” Ninakupigia simu kuhusu utafiti tunaofanya katika hospitali ya Aga Khan Nairobi. Naomba kuzungumza na (**weka jina la mgonjwa**)? Ikiwa mzungumzaji kwenye simu atajibu **La, hitimisho mazungumzo ya simu kwa kusema,**” Sawa, asante kwa muda wako.”



**Ikiwa jibu ni mgonjwa hayupo kwa wakati huo, uliza,”** Je, naweza kumpigia simu baadaye ili kuzungumza naye?” **Ikiwa jibu ni Ndio, nakili wakati uliopendekezwa na upige simu baadaye. Iwapo jibu ni la, hitimisha mazungumzo ya simu kwa kusema “sawa, asante kwa muda wako.”**

**3.Iwapo utafahamishwa kwamba mgonjwa alishaaga dunia basi sema,”** pole kwa msiba huo. Pokea risala zangu za rambirambi. Ikiwa una hiari, tungependa kukualika ukutane na washauri wetu katika hospitali ya Aga Khan Nairobi watakaoweza kukunasihwa wakati huu mgumu.”

**4.Ikiwa mzungumzaji ambaye ni mgonjwa atakubali ombi kwa ajili ya usaili na unaweza kuzungumza naye sema,”** Halo niliipata nambari yako ya kutoka kwenye rekodi yako kitabibu katika hospitali ya chuo kikuu cha Aga Khan Nairobi. Je, huu ni wakati mzuri wa kuzungumza? Natarajia mazungumzo haya ya simu yachukue dakika ishirini hivi.” **Ikiwa msailiwa yuko hiari kuzungumza ila wakati ule sio faafu sema,”** Naomba nikupigie baadaye, ni muda upi utakuwa sawa nawe”. **Nakili wakati na umpigie baadaye.**

**5.Iwapo kiitikio cha ombi la usaili ni ndio, eleza kusudi la utafiti na upate idhini zungumzi kisha uanze usaili kwa kusema,”** Sasa nitakuuliza maswali machache. Ikiwa unahitaji fafanuzi wakati wowote ule tafadhali nitishe na uniulize.

A1	Rekodi ya uana ilivyoonekana	Kike	1
		Mume	2
A2	Una umri wa miaka sasa?	Miaka .....	
A3	Je, umechukua miaka mingapi ukisema shuleni au chuoni?	Miaka.....	
A4	Hali yako kuhusiana na ndoa ni ipi?  (Chagua moja iliyo faafu)	Kutowahi kuolewa	1
		Umeolewa	2
		Mmetengana	3
		Mjane	4

		Uchumba	5
A5	Je, hali yako ya kazi inaweza kuelezwa vipi?	Umeajiriwa	1
		Umejiajiri	2
		Kazi hisani au hiari	3
		Mwanafunzi	4
		Mume/Mke wa nyumbani	5
		Umestaafu	6
		Hujaajiriwa (kwa sababu za kiafya)	7
		Hujaajiriwa (kwa sababu nyingine)	8
		Kingine chochote	9

	Katika siku thelathini umekuwa na ugumu kiasi gani katika	Haijakuwepo kabisa	Imekuwa kwa kiwango cha chini	Imekuwa kiasi	imezidi	Imezidi sana
S1	Kusimama kwa muda mrefu kama dakika 30 hivi?	1	2	3	4	5
S2	Kufanya kazi za nyumbani mwenyewe	1	2	3	4	5

S3	Kujifunza kazi mpya kama vile kujifunza jinsi ya kupata mahali papya	1	2	3	4	5
S4	Je, umekuwa na shida gani kujiunga na shughuli za kijamii (kwa mfano sherehe au shughuli nyingine) kwa njia sawa na mtu mwingine yeyote anavyoweza?	1	2	3	4	5
S5	Umeathirika kihisia kwa kiasi gani kutokana na hali yako ya kiafya?	1	2	3	4	5

Katika siku thelathini umekuwa na ugumu kiasi gani katika	Haijakuwepo kabisa	Imekuwa kwa kiwango cha chini	Imekuwa kiasi	Imezidi	Imezidi sana	
S6	Kumakinika kufanya kitu kwa dakika kumi	1	2	3	4	5
S7	Kutembea mwendo mrefu kama kilomita hivi	1	2	3	4	5
S8	Kuuosha mwili mzima	1	2	3	4	5
S9	Kuvaa	1	2	3	4	5
S10	Kujihusisha na watu usiowafahamu	1	2	3	4	5
S11	Kudumisha urafiki	1	2	3	4	5

S12	Kazi au masomo ya kila siku	1	2	3	4	5
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H1	Kwa jumla katika siku thelathini, magumu haya yalikuwa kwa siku ngapi?	Siku.....
H2	Katika siku thelathini zilizopita, ni kwa siku ngapi ulishindwa kabisa kufanya shughuli za kawaida au kazi kwa sababu za kiafya?	Siku.....
H3	Katika siku thelathini zilizopita, bila kuhesabu siku ambazo ulishindwa, ni siku ngapi ulizopunguza shughuli zako za kawaida au kazi kwa sababu za kiafya?	Siku.....

Mahojiano yamekamilika hapa. Asante kwa kushiriki kwako.

7.4 Data collection tool for secondary outcomes

Age

Gender

Admission diagnosis

Duration of mechanical ventilation

Length of ICU stay

APACHE II score

Number of co-morbidities

Steroid use

Muscle relaxants use

