

A SURVEY ON END OF LIFE CARE PRACTICES IN INTENSIVE CARE
UNITS OF THREE GOVERNMENT TEACHING HOSPITALS IN NAMIBIA

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE

DEGREE OF MASTER IN MEDICINE (ANAESTHESIOLOGY, CRITICAL
CARE AND PAIN MANAGEMENT)

OF

THE UNIVERSITY OF NAMIBIA

BY

LOINI TALISHI SHIVOLO

200505769

OCTOBER 2022

MAIN SUPERVISOR: DR KINGSLEY TOBI (UNAM)

Abstract

Background: End of life (EOL) care may be described as care provided for patients in the final hours or days of their life. More broadly it's defined as care for all patients with a terminal illness that is deemed progressive and incurable. It implies a focus on pain and symptom management which is distinct from the aggressive pursuit of investigation and therapies focused on cure. End of life care in the ICU however involves a substantial degree of emotional and psychological stress both for health care providers as well as the family members.

Significance of the study: The study aimed to evaluate the current practices of EOL care in a lifesaving department like the intensive care unit. It also intended to evaluate the knowledge of EOL care practices among ICU health professions and to identify gaps that would require improvement.

Methodology: This was a mixed study that used the sequential explanatory design. It had a quantitative study phase 1 and a qualitative study phase 2. The quantitative method looked at the experience of health care workers on EOL care as the dependent variable with relation to age, training background, gender, and years of employment and facility of employment. The qualitative method approach was used to assess the knowledge and attitudes of family members and health care providers on EOL care. This methodology was achieved through cross-sectional surveys and a series of questionnaire-based interviews.

Findings: About 59.7% of the respondents had never heard the term EOL care. In addition, less than half of them reported that the decision to offer EOL care to patients rested with the attending physicians. Furthermore, 50% of the study participants believed that family members do not take part in the decision to offer their patients EOL care.

Conclusion: EOL is an essential part of patient management. Not only for the patient but also focuses on family members and health care workers as it has an effect on their emotional, mental health, as well as physical health.

Recommendations: Improve communication between health care workers and family members and continuous medical education to be offered to health care workers on EOL care.

TABLE OF CONTENT

LIST OF TABLES	iii
LIST OF FIGURES	iv
ABBREVIATIONS	vi
ACKNOWLEDGEMENTS	vii
DEDICATION	ix
DECLARATIONS	x
1. 1 INTRODUCTION	1
1.1.1 Background	1
1.1.2 STATEMENT OF PROBLEM	2
1.2 RESEARCH QUESTIONS	4
1.3 SIGNIFICANCE OF THE STUDY	5
1.4 DELIMITATIONS	5
1.5 VALIDITY AND LIABILITY	6
2.1 LITERATURE REVIEW	6
2.1.1 Health care workers	8
2.1.2 Family members	9
2.2. RESEARCH METHODS	10
2.2.1 Study design	10
2.2.2 Study population and sample	10
2.3 PROCEDURE	12
2.3.1 DATA ENTRY	12
2.3.2 DATA ANALYSIS	13
3.1 FUNDING	13
3.2 RESEARCH ETHICS	13
3.3 RESULTS	14
3.4 DISCUSSION	28
3.5 LIMITATIONS	32
3.6 CONCLUSION	32
3.6 RECOMMENDATIONS	33
ANNEXURES 1	38

ANNEXURE 2.....	39
ANNEXURE 3.....	41
ANNEXURE 5.....	44
ANNEXURE 6.....	46
ANNEXURE 7.....	49
ANNEXURE 8.....	51
ANNEXURE 9.....	53
ANNEXURE 10.....	54
ANNEXURE 11.....	55

LIST OF TABLES

Table 1- Health care workers participants per hospital

Table 2- Grades and specialities of the health care workers

Table 3- Other professionals involved in EOL care decisions

Table 4- Why EOL care is important

Table 5- Need for psychological support for health care workers

Table 6- Demographics of family members

Table 7- Experience of relatives with patients admitted to ICU

Table 8- Health care workers communication with family

Table 9- Response by family members on their roles in their patient's management

Table 10- Suggestions on improving families' experiences

LIST OF FIGURES

Figure 1- Age range of the participants

Figure 2- Working experience in years

Figure 3- Training of health care workers on EOL care

Figure 4- Decision making on EOL care in the ICU

Figure 5- Participation of family members in decision making

Figure 6- Importance of EOL care towards patient care

Figure 7- Availability of standardised guidelines in ICU

Figure 8- Psychosocial support for health care workers

LIST OF ANNEXURES

Annexure 1: Questionnaire for Health care workers

Annexure 2: Interview guide for Health care workers

Annexure 3: Questionnaire for family members (English)

Annexure 4: Interview guide for family members (English)

Annexure 5: Information sheet and consent (English)

Annexure 6: Questionnaire and interview guide for family members (Oshiwambo)

Annexure 7: Information sheet and consent (Oshiwambo)

Annexure 8: Ethical approval letter from the Ministry of Health and Social services

Annexure 9: Approval letter from Windhoek Central Hospital

Annexure 10: Approval letter from Intermediate Hospital Oshakati

Annexure 11: Approval letter from Onandjokwe Intermediate Hospital Research committee

ABBREVIATIONS

ICU- Intensive care unit

WFSICCM- World Federation of Societies of Intensive and Critical Care Medicine

EOL- End of Life

WCH- Windhoek Central Hospital

IHO- Intermediate Hospital Oshakati

OIH- Onandjokwe Intermediate Hospital

UNAM- University of Namibia

MoHSS- Ministry of health and social services

NO- Nursing officer

MO- Medical officer

WHO – World Health Organization

ACKNOWLEDGEMENTS

Firstly, I glorify the Almighty God Jehovah for his sufficient grace towards me.

My husband, Mr Gideon N Hamutu deserves a special acknowledgement, for his love and for his spiritual, emotional and financial support during my journey to becoming a specialist.

My mother Hilma A Shivolo, my parents in law Mr and Mrs Hamutu, and my namesake Mrs Talitshi Loini Shivute, for their words of wisdom and, support when I was about to give up.

I would also like to thank my children, my siblings and my siblings in law, for their patience and full support.

My colleagues and friends Joana Wilbard, Ester Mvula, Delphina Joaquim, and Loide Amundaba, and Ndamono Ileka thank for offering me their homes and support when I travelled for interviews

Motor Vehicle Fund (MVA) for funding my MMED programme

My supervisor Dr Kingsley Ufuoma Tobi, for his kind support and great supervision throughout my study period.

My educators Prof A Rukewe, Dr J Mumba, Dr N Feris, Dr T Shivera, Dr L Nanyalo, Dr C Terblanche, Prof B Jenkins, Dr J Morgan, Prof T Roche and Prof G Dubowitz for sharing their knowledge with me

And lastly to all the health care workers of the intensive care units of Windhoek central hospital, Intermediate Hospital Oshakati and Onandjokwe Hospital for their willingness to participate in this study as well as the patients family members, for their strength and courage to answer emotional questions.

DEDICATION

I dedicate this publication to my late father Mr Josephat Jatheta Shivolo (1951-2013), who treasured my education and truly believed that I will make a great doctor.

To my husband Gideon Hamutu and our children, thank you for being the pillar of my strength and my reason to keep going. You are my greatest blessing.

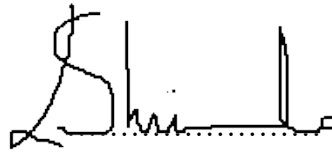
DECLARATIONS

I, Loini Talishi Shivolo, hereby declare that this study is my own work and is a true reflection of my research, and that this work, or any part thereof has not been submitted for a degree at any other institution.

No part of this thesis may be reproduced, stored in any retrieval system, or transmitted in any form, or by means (e.g. electronic, mechanical, photocopying, recording or otherwise) without the prior permission of the author, or The University of Namibia in that behalf.

I, Loini Talishi Shivolo, grant The University of Namibia the right to reproduce this thesis in whole or in part, in any manner or format, which The University of Namibia may deem fit.

Loini Talishi Shivolo



October 2022

Name of Student

Signature

Date

1. 1 INTRODUCTION

1.1.1 Background

The Intensive Care Unit (ICU) was first established in the late 1950s afterwards the speciality of critical care medicine began to develop.⁽¹⁾ A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine” (WFSICCM) defines intensive care, also known as critical care as “a multidisciplinary and inter-professional speciality dedicated to the comprehensive management of patients having, or at risk of developing acute life threatening organ dysfunction”. Furthermore, intensive care uses an array of technologies that provide support for failing organs systems particularly the lungs, cardiovascular system and kidneys.⁽²⁾ Thus, the main aim of intensive care is the maintenance of vital functions to reduce mortality and prevent morbidity in patients with a severe critical illness. But, despite the development of new technologies and the improvement of care, the death rate in the ICU still remains high, ranging between 20–35%, with variations according to geographical regions⁽³⁾.

Therefore, ICU clinicians need to remember that death is part of life, not an enemy to be defeated; that palliative care is part of ICU and requires physical, moral, psychological and interpersonal intensity surpassing most other clinical procedures.

⁽⁴⁾ Accordingly, the task force of the WFSICCM identifies End-of-Life (EOL) care in the ICU as a task objective in a series of task forces developed by the WFSICCM in 2014. Their objective was to develop a generic statement about current knowledge and to identify challenges relevant to the global community that may inform regional and local initiatives. They recognized the complexity of end of life care in ICU, which relates to withholding and withdrawing life sustaining treatment while

ensuring the alleviation of suffering, within different ethical and cultural environments.⁽⁵⁾

End of Life (EOL) care may be described as care provided for patients in the final hours or days of their life. More broadly it is caring for all patients with a terminal illness that is deemed progressive and incurable. It implies a focus on pain and symptom management which is distinct from the aggressive pursuit of investigation and therapies focused on cure. This type of care in the ICU involves a substantial degree of emotional and psychological stress both for the health care providers as well as the family members. This can cause a huge emotional turmoil on family members and health care providers, in many of whom there is a high prevalence of anxiety and depression with a high risk of post traumatic disorder⁽⁶⁾

This study aimed to evaluate EOL care practices in the ICUs of three accredited teaching hospitals in Namibia. In addition, it will help to identify challenges encountered during end of life care, as well as the attitude of ICU staff members and family members towards EOL in the ICU.

1.1.2 STATEMENT OF PROBLEM

Many countries have incorporated EOL care as an important aspect of their health care delivery system. It is usually offered in hospice centres or at home. However, due to the increase in ICU mortality, EOL care has been introduced as part of ICU management. Although EOL care decisions are difficult to make in ICU due to its definition, most countries in the world have established EOL care protocols in their ICUs. In Africa, countries such as Uganda, South Africa, Kenya and Zimbabwe have incorporated EOL care in their health system to improve patient care⁽⁷⁾. In Namibia however, there is a paucity of documented research on EOL care, which increased

the difficulty of decision making and management of EOL for the health care providers in ICU.

End of Life care is still new in clinical studies as such there is an evident gap of knowledge about EOL care in the ICUs. In our environment, for example, there are no studies done on EOL care in ICUs. Even though there is a study on palliative care in cancer patients, it was a hypothetical questionnaire for the general population on preferences of palliative care. The authors however emphasized the need for more research on the topic. ⁽⁸⁾

The process of dying in the ICU is complicated, and there are no adequate studies available on the obstacles that hamper the provision of EOL care. ⁽⁹⁾ It has nevertheless been well accepted that in some situations, conventional curative medical care should gradually be replaced by EOL care. However, according to many ICU healthcare professionals, such transition is the most problematic stage in providing EOL care. ⁽¹⁰⁾ The provision of standardised and suitable national guidelines on EOL management will go a long way to reduce the difficulty encountered by a health care worker in providing EOL care. In addition, it will also close the knowledge gap on EOL care among ICU professionals and improve the quality of intensive care. Furthermore, it will ensure that family members are offered adequate psychosocial and spiritual support, as well as the staff members.

1.1.3 STUDY OBJECTIVES

Primary Objective

To determine the knowledge and practice of health care workers on End of Life care in intensive care units.

Secondary Objectives

- 1) To investigate the attitude of doctors and nurses working in ICUs on end of life care.
- 2) To determine the attitude of family members of patients in ICU on end of life care.
- 3) To assess the need for standardised national guidelines on EOL care for health care professionals in ICU

1.2 RESEARCH QUESTIONS

1. Is End of life care incorporated in ICU as part of patient care?
2. What is the degree of knowledge on end of life care by health care workers?
3. What is the perception of the health care workers and family members on end of life care offered in ICU?

1.3 SIGNIFICANCE OF THE STUDY

The aim of the study was to evaluate the knowledge and practices of health care workers on EOL care in the intensive care unit. It was also intended to identify knowledge gaps on EOL care among family members of patients admitted to the ICU. The outcome of this survey would help to improve care for patients, family members as well as health care providers. The study would then come up with recommendations for the Critical Care Society and the Ministry of Health and Social Services for the formulation of protocols and policies on EOL care in Namibia. In addition, it will form a baseline for future research on EOL care in Namibia as part of Palliative care development in the country's health system.

1.4 DELIMITATIONS

The study was conducted only in the ICUs of three government hospitals in the country. This is because out of the five accredited government hospitals only three have ICUs. Although there are private hospitals with ICUs, they were excluded from the study due to the privacy policies and practices of such facilities. In the future, these facilities may be included in studies of this nature.

In addition, this study focused on health care workers and family members of the patients in the ICUs. A similar study with a focus on ICU patients could be carried out in the future.

1.5 VALIDITY AND LIABILITY

- A pilot study was conducted in all the three teaching hospitals chosen for the study in order to test the validity of the questions.

- The questions were evaluated by a statistician

- These questions were adapted from a study done in Uganda on the attitude of family members on end of life care in ICU and adjusted to suit our demographics ⁽⁶⁾

- Translations of the questionnaires to Oshiwambo was done by a professional translator, Anglo Premier translation and editing services

- Different methods of data collection were used, these included audio recording, structured questionnaires and noting down of answers by the investigator. This was to ensure the reliability of the data as it can be stored for future use.

2.1 LITERATURE REVIEW

A literature review was done in the United States of America (USA) which described palliative care as a rapidly growing inter-professional speciality that includes: effective management of distress from physical, psychological, and spiritual symptoms as well as timely and sensitive communication about appropriate goals of intensive care in relation to the patient's condition, prognosis, and values. It also includes alignment of treatment with patient preferences, attention to families' needs and concerns, planning for care transitions, and support for clinicians. ⁽¹¹⁾ In support of this, a prospective observational study of 22 European ICUs named ETHICUS 2

noted that it is universally acknowledged that dying patients should be treated compassionately. ⁽¹²⁾

The World Health Organization defines palliative care as an “approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. ⁽¹²⁾

However, there is no standard playbook for end-of-life care in the ICU. Care for dying patients tends to vary widely from one hospital to another, and is not clear whether patient’s preferences always drive the variation. ⁽¹³⁾

The traditional goals of intensive care are to reduce the morbidity and mortality associated with critical illness, maintain organ function, and restore health. Despite technological advances, the death rate in the ICU remains high. Death rates vary widely within and among countries and are influenced by many factors. Comparative international data are lacking, but an estimated one in five deaths in the United States occurs in a critical care bed. ⁽¹⁴⁾

A systematic review on EOL care in Sub-Saharan Africa noted it lacks the sound evidence base needed for the development of effective and, appropriate service provision. The authors emphasized that EOL care is an important public health concern predominantly due to the number of people it affects. However, out of 47 countries in Sub-Saharan Africa, only 26 render EOL care services. Countries such as Uganda, South Africa, Kenya and Zimbabwe have services that have reached a level of integration into their existing health system. ⁽¹⁵⁾ However, most of their published data is about palliative care in general rather than EOL care in ICUs.

A few studies done in Namibia on palliative care found that nearly two-thirds of the participants were of the opinion that improving quality of life was more important than prolonging life in the face of advanced illness. ⁽⁶⁾ Furthermore, they reported that there was a need to prioritize the education and empowerment of family members so that they can make informed decisions on behalf of their patients. In addition, training of health care workers in the area of communications and family meetings was highly recommended. This study was however limited as its focus was on a hypothetical study population than those with actual experience. However, recommendations were made that there is a need to study the actual (rather than the hypothetical) views of terminally ill patients.

2.1.1 Health care workers

A study conducted in Nigeria on the knowledge and attitude of health care workers on palliative care concluded that there was a gap in the knowledge of healthcare workers in the area of palliative care. This study was a cross-sectional questionnaire-based study carried out among healthcare workers in Ekiti State University Teaching Hospital, Ado-Ekiti, south-west Nigeria. The questionnaire had sections about definition of palliative care, its philosophy, communication issues, medications, and contexts about its practice. The authors, therefore, recommended that there is a need to include palliative care in both undergraduate and postgraduate study levels. ⁽¹⁶⁾ This will hopefully train health care workers on the practices of palliative and end of life care.

In a report which was produced as part of the Critical Futures initiative, looking to the future for critical care, it was noted that critical care teams frequently have to deal with the uncertainty of prognosis and outcome. They are often required to

simultaneously react to changing physiology with resuscitative measures, and consider palliative interventions and communicate (with empathy) rapidly changing situations to patients and families during very distressing times. Shared decision-making is regarded as best practice but lack of capacity often precludes this. If more information about patients' wishes and beliefs were available, ICU teams would be better positioned to make the best decisions. This will enable individualised care, thereby minimising confusion and conflict due to clear communications about advance care planning. Such an approach would also have an additional advantage of reducing stress, anxiety and burnout in those delivering care. ⁽¹⁷⁾

2.1.2 Family members

One of the major challenges for caring for critically ill patients is the inability to communicate directly with them. As a result of this, critical care physicians involve patients' family members in what is referred to as a "family meeting". ⁽¹⁸⁾ Needs of families are immense when their loved ones are critically ill. Stress, uncertainty and confusion all play a role. Patient centred care is a natural priority but family centred care also plays a role. As EOL care is being delivered, physicians are usually patient centred. It is therefore important to consider the needs of the caretakers as well and address them if possible. This will lead to total patient care because, at the end of it all, when the patient passes on, it is the family that remains in bereavement.

In developing quality EOL care, it is important to go step by step. Improvements can only be made if the perception of those that the quality is being provided is understood so that changes are tailored to the needs of the population. In that case, tools like questionnaires on quality improvement concerning EOL care can be developed. This will help to identify patient issues depending on the feedback

received from the patients' caretakers. In addition, this could be used in future for continued improvement. ⁽⁶⁾

2.2. RESEARCH METHODS

2.2.1 Study design

This was a mixed study that used the sequential explanatory design. It had quantitative study phase 1 and qualitative study phase 2. The quantitative method looked at the knowledge and practice of health care workers on EOL care as the dependent variable. This is in relation to age, training background, gender, and years of employment and facility of employment. And the qualitative method approach was used to assess the knowledge and attitudes of family members and health care providers on EOL care. This methodology was achieved through cross-sectional surveys and a series of interviews. ⁽⁶⁾

2.2.2 Study population and sample

The study population comprised of ICU health care providers and family members of patients in the ICU. The targeted population was all the staff members of the three ICUs chosen for the study. Windhoek Central Hospital (WCH) General ICU has three specialist consultants, six medical officers and 35 nurses while WCH cardiac ICU has five specialist consultants, nine medical officers and 26 nurses. Intermediate hospital Oshakati has two specialist consultants, three medical officers and 23 nurses. And lastly, Onandjokwe hospital has two medical officers and 16 nurses. The total population is 130 staff members of which 84 are nurses, 10 specialist consultants and 20 medical officers. Convenience sampling was used. This is a non-probability sampling method that is the most applicable and often used method for clinical and

qualitative research. It is popular because it is simple, cheap and not time consuming compared to other sampling strategies. ⁽¹⁹⁾ The convenience sample here was confined to the accessible population for the researcher, which in this study it was 65 health care workers.

The sample size for family members was determined using a purposive sampling method where characteristics such as being a close relative of a patient was a criterion to participate. More than two family members related to one patient participated if they both met the criteria and were willing to be part of the sample. The target sample was 20 family members as the study involved three hospitals in different regions of the country.

2.2.3 RESEARCH INSTRUMENTS

Data Collection

Data was collected using a sequential explanatory design; first through a cross-sectional survey using structured questionnaires in English for health care providers and in English and Oshiwambo for the family members. Individual interviews were conducted using open-ended questions which allowed room for probing. The questionnaire structure, as well as interview questions, were adapted from previous studies in other countries and modified to suit local demographics.

2.3 PROCEDURE

The study was conducted for over six months and not four months as estimated. It recruited doctors and nurses working in the ICUs of the three teaching hospitals. The hospitals identified were Windhoek Central Hospital (WCH), Intermediate Hospital Oshakati (IHO) and Onandjokwe Intermediate Hospital (OIH). The study's objectives and nature were explained to ICU staff members and family members who volunteered to participate orally and through an information sheet. Individual personal interviews were conducted upon appointment with staff members to capture individual experiences. The interviews were conducted by the principal investigator until reaching a saturation point. Consents were obtained from participants before participating.

Inclusion criteria: All doctors and nurses working in ICU including specialists from other departments e.g. internal medicine, orthopaedics, general surgery, obstetrics and gynaecology as a multidisciplinary approach in ICU.

Family members of patients who were receiving care in the ICU and, not necessarily the family members of those receiving EOL care only.

Exclusion criteria: Medical interns and students nurses rotating in ICU

2.3.1 DATA ENTRY

Data was entered on Microsoft excel transcribed from the audio recording and questionnaires by the principal investigator and the statistician. Data obtained in Oshiwambo language was translated by the principal investigator and transcribed to Microsoft excel thereafter.

2.3.2 DATA ANALYSIS

Qualitative data were analysed using a thematic analysis method. Themes and subthemes were identified from the data collected. Codes used included, decision makers, family involvement, the support offered, and quality of the management. The descriptive analysis method was used to analyse quantitative data to obtain a percentage using Microsoft excel.

3.1 FUNDING

Capital was used for travelling expenses, printing and copying of documents which were used in the research and, recording material for data collection, as well as translation of documents and fee for the statistician. All the fees were covered by the principal investigator.

3.2 RESEARCH ETHICS

Participation in the study was voluntary. There was no harm intended for the participants for taking part in the study.

No personal identifying information was used during data collection and neither staff members nor patient's family member's identities were revealed. Participants signed a consent form either by ink or thumbprint after being provided with a participant information sheet as well as a verbal explanation by the principal investigator. All information obtained was treated with strict confidentiality. Recorded interviews would be stored in the university's library for future references after study publication.

Ethical clearance certificates were obtained from the institutions ethic committees of the University of Namibia and Ministry of Health and Social Services and research

permission letters were obtained from Windhoek Central Hospital, Intermediate Hospital Oshakati and Onandjokwe Intermediate Hospital relevant bodies.

3.3 RESULTS

The study was done in three government teaching hospitals namely, Windhoek Central Hospital (WCH), (which has two ICU, an eight-bed main (general) ICU and a five-bed cardiac ICU) - Intermediate hospital Oshakati (IHO) which has a six-bed ICU and Onandjokwe intermediate hospital (OIH) which has a three-bed ICU. There is no intensivist available at OIH, unlike IHO which has two specialist doctors, WCH main ICU has three specialists and cardiac ICU has five specialists.

3.3.1 Health care workers

Demographic Characteristics

A total number of sixty-two (62) health care workers participated in this study. Fifty-four female (87.1%) and eight males (12.9%). Windhoek Central Hospital (WCH) has the majority of health care workers as it has two ICUs, cardiac and main ICU which accounted for 59.7% in total. Seven health care workers from Onandjokwe Intermediate Hospital (OIH) participated, representing 7% while 29.0 % which translated into 18 participants, were from Intermediate Hospital Oshakati (IHO) as illustrated in table 1.

Table 1- Health care workers participants per hospital

Health care workers per hospital		
Name of Hospital	Health care workers	Percentage
IHO	18	29.0%
OIH	7	11.3%
WCH	37	59.7%
Total	62	100%

Age of Health care workers who participated

The mean age in years of the health care workers who participated were 37.35 years. The highest number, 15 were between the ages of 25- 29 (24.2%) years followed by 35-39 (22.6%) years. Figure 1 illustrates the age in years of the health care workers.

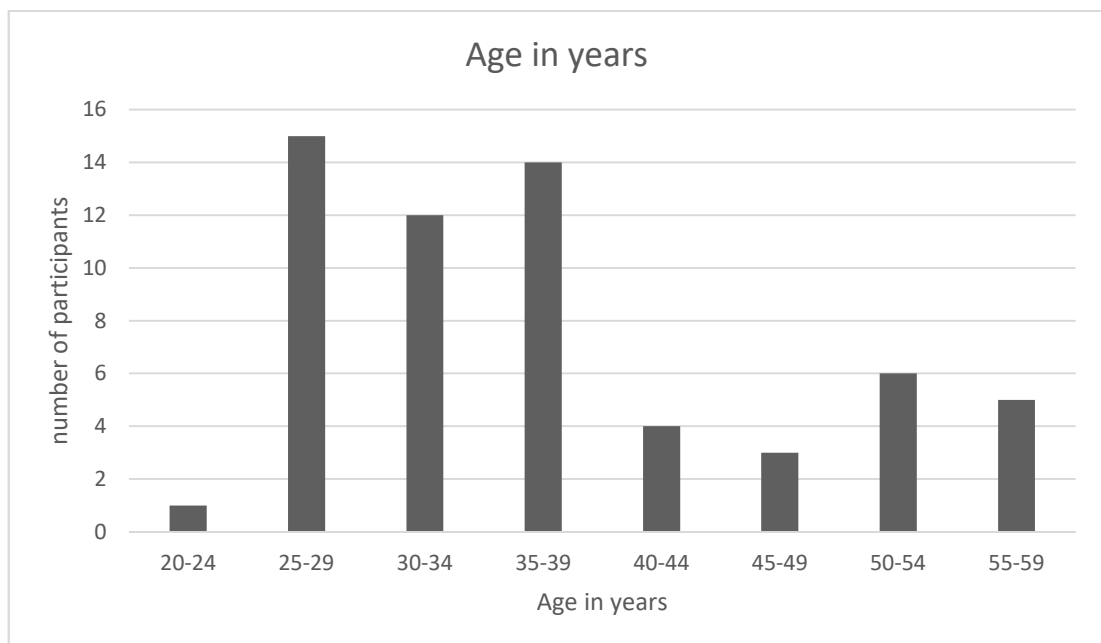


Figure 1: Age range of the participants

Grades and specialities of the health care workers

Table 2 shows the cadres of the health care workers that participated in this study.

Twenty-eight (45.2%) of the participants were registered nurses and only three medical specialists (4.8%) participated. Others were fifteen (24.2%) medical officers, eleven (17.7%) enrolled nurses and five (8.1%) senior registered nurses.

Table 2 Grades and specialities of the health care workers

Occupation	Number of participants	Percentage
Doctor Specialist	3	4.8%
Medical Officer	15	24.2%
Enrolled Nurse	11	17.7%
Registered Nurse	28	45.2%
Senior Registered nurse	5	8.1%
Total	62	100%

Years of employment

Most health care workers 36 out of 62, representing (58.1%) had less than 10 years of working experience and five (8.1%) participants had a working experience of between 30-39 years. The mean number of years of working experience was 11.11 years as illustrated in figure 2. This study showed (Figure 3.) that health care workers with more years of employment of above 20 years most had received training on EOL care. And, the health care workers with 10 years and less of employment had not been trained on EOL care in ICU.

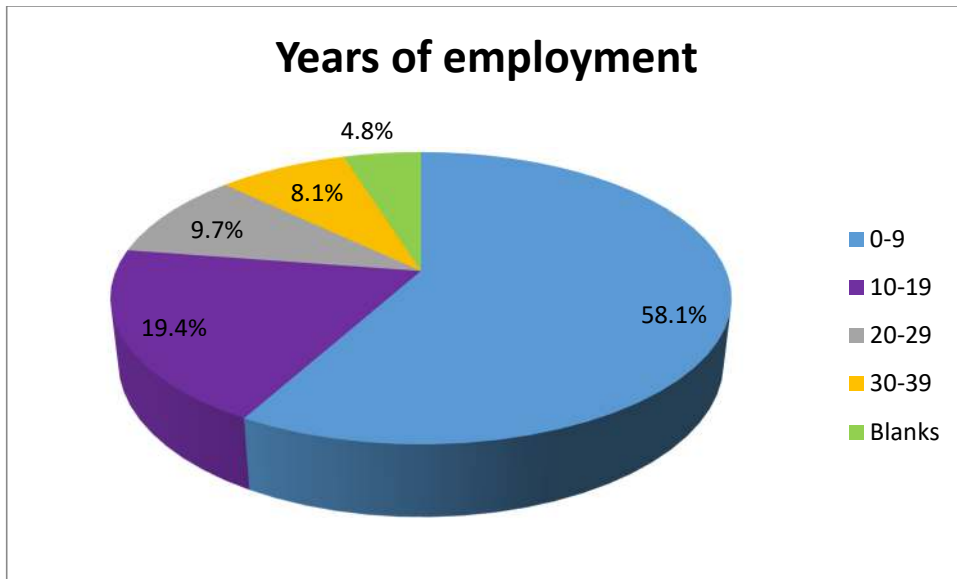


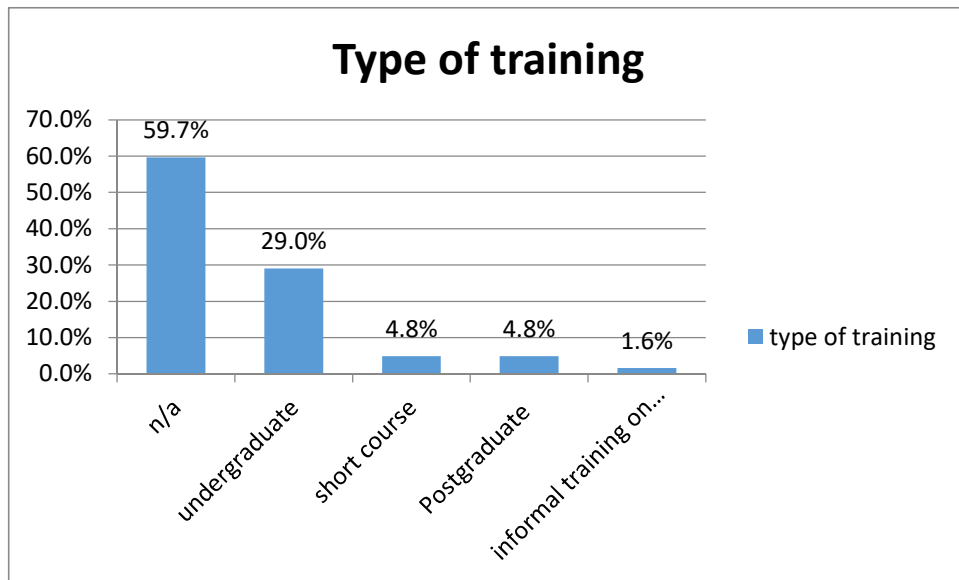
Figure 2: Working experience in years

Knowledge on end of life care

The majority of the participants, 37 of them which represented 59.7% reported that they had never heard of the term end of life care.

Out of those who knew about end of life care before, 17 participants (29.0%) heard about the term during their undergraduate training as a topic in one of their modules. About 4.8% got to know about the term during their postgraduate training while only one of the respondents learnt about it during ward rounds in his unit.

Figure 3: Training of health care workers on EOL care



Years of working experience to knowledge on EOL care

Health care workers that had less than 10 years of working experience did not receive training on EOL care. Compared to others who had 10 years or more years of experience noted that they received training on EOL care either during their postgraduate training, through a short course and some informally from ICU ward rounds.

Definition of EOL care

It was not clear what EOL meant to the participants. But, there were some opinions on what it may be although without certainty. There was often confusion with withholding and withdrawal of medications. Below were some of the definitions that participants gave to the term EOL care.

- “Care provided to a patient suffering physically, emotionally and psychologically.”
- “Not experienced it, thinking that it is when a patient is brain dead and a decision is made to give end of the life care.”
- “Not sure maybe it's palliative”
- “Process where there is not much to do for the patient, difficult situation not only for family members but also for health care workers, sometimes there is an attachment to the patient in ICU after a long stay.”
- “Care to give when someone is at end of life, terminal illness not to be treated.”.

Decision making

Some health care workers (40.3%) reported that the decision to offer end of life care in intensive care units is mostly done by attending doctors. However, on the other hand, 9.7% said it's a multidisciplinary team decision, involving doctors, nurses, and social workers. Of note, 1.6% did not believe that a decision to offer end of life care in the ICU should be made.

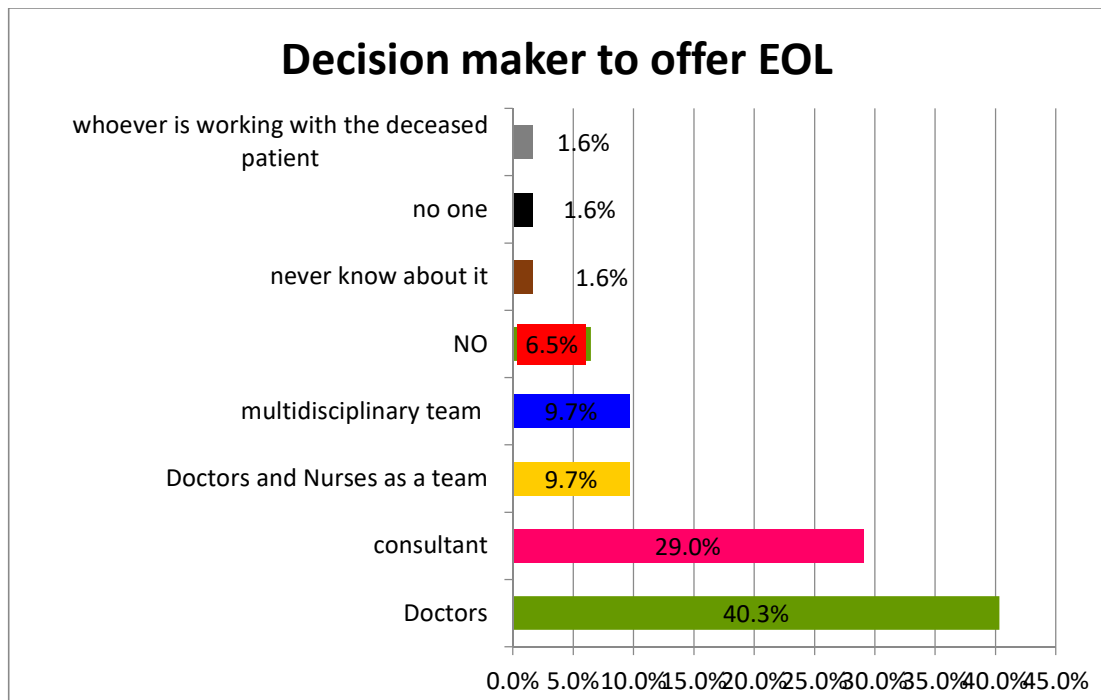


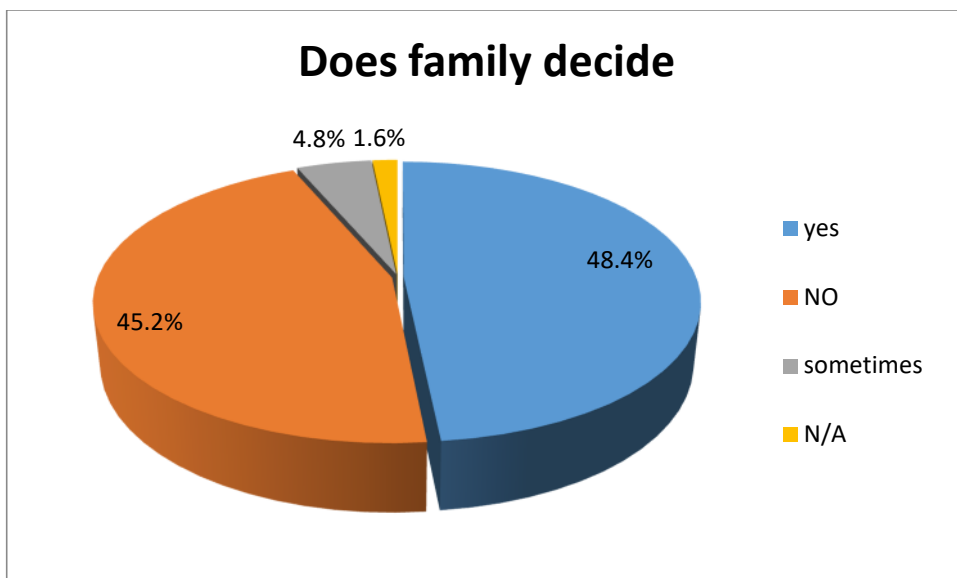
Figure 4: Decision making on EOL care in the ICU

Family involvement in decision making

About family involvement in decision making to offer EOL care, 50% of the study participants said that family members do not take part in the decision making.

Nevertheless, others such as social workers, spiritual leaders, physiotherapists, dieticians and medical superintendents were listed as parts of the decision to offer EOL care in ICUs. Among these, social workers were said to be more involved in taking EOL care decisions representing about 43.4%, followed by nursing officers 35.5%, as shown in table 3.

Figure 5: Participation of family members in decision making



<u>Profession</u>	<u>Percentage</u>
Social workers	43.4%
Nursing officers (NO)	35.5%
Medical superintendents and doctors	8.0%
Religious leaders	3.2%
Others	9.9%

Table 3: Other professionals involved in EOL care decisions

Importance of EOL care in ICU

Most health care workers (90.3%) believed that EOL care in the ICU was important for patient's care as it allows patients to die with dignity, respect patient's privacy,

pain relief, offer spiritual support and, as well as preparing the patient family for bereavement. On the other hand, 8.1% of the participants believed that it was not important as part of a patient’s care. Some of the reasons why 90.3% of the health care workers believed in the importance of EOL are illustrated in Table 4.

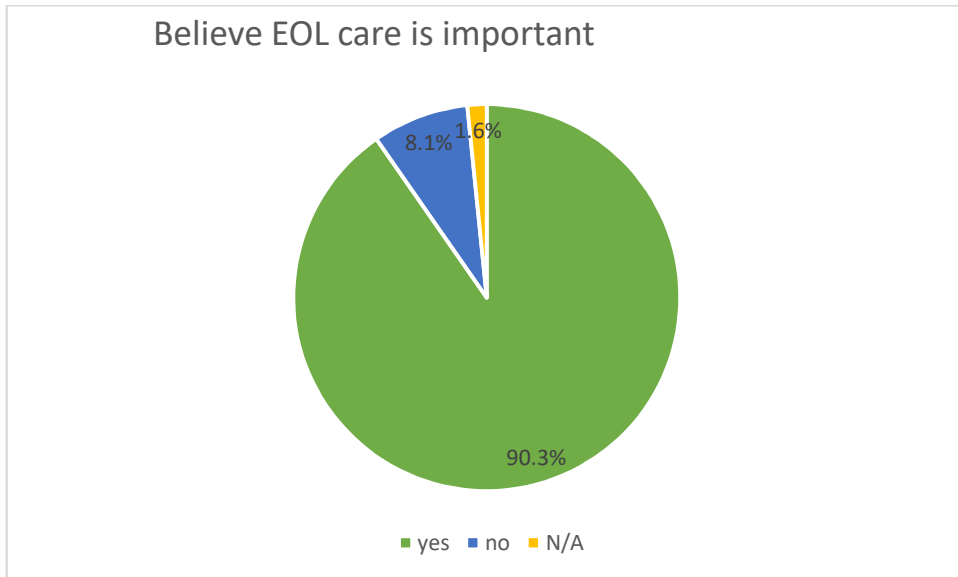


Figure 4: Importance of EOL care

Theme	Frequency	Percentage
human right	6	10%
Human dignity	14	23%
Planning	4	6%
N/A	9	15%
decision making	11	18%

Table 4: Why EOL care is important

Preparedness of the intensive care units to provide EOL care

Most of the respondents in this study (90.3%) said that there were no specific guidelines on EOL care in the ICU. But, 6.5% of the health care workers who noted the availability of such guidelines were not sure of what they were.

In terms of personnel and equipment available for providing EOL care in the ICUs, 37.1% of the participants believed that their ICUs were well equipped to provide EOL. On the other hand, 30.6% of the participants responded in the negative.

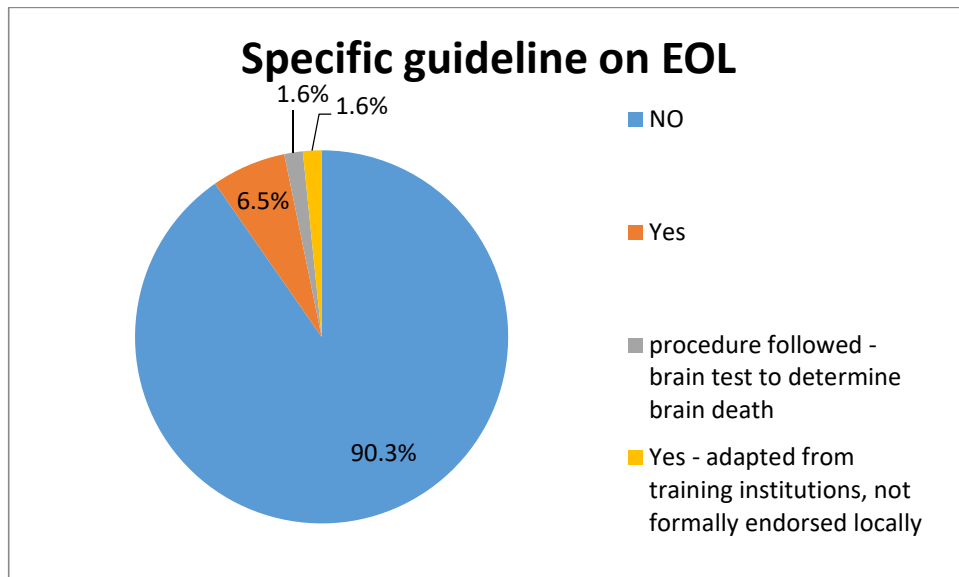


Figure 7: Availability of standardised guidelines in ICU

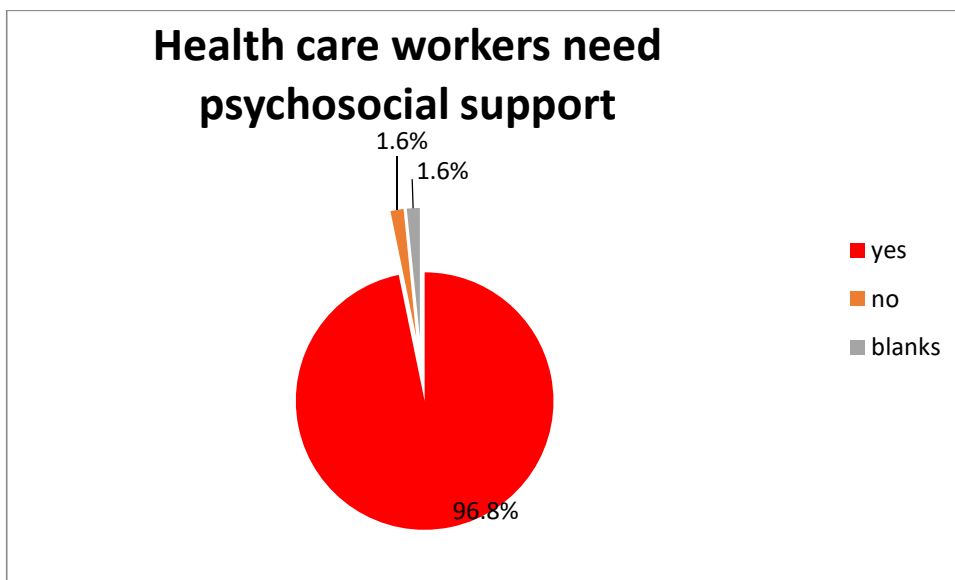
Psychosocial support to health care workers

The majority of the health workers interviewed (96.8%) believed that health care workers should receive some form of psychosocial support when caring for these patients on EOL care.

There were many reasons for this opinion part of which include the fact that offering

EOL care is emotionally taxing and traumatizing for the health care workers as reported by 32% and 13% of the respondents respectively.

Figure 8: Psychosocial support for health care workers



Theme	Frequency	Percentage
emotional	20	32%
Psychosocial/psychology	16	26%
traumatising	8	13%
Bond	4	6%
Mental	8	13%
Cope	4	6%
not easy decision	7	11%
Blanks	8	13%
Optional	1	2%

Table 5: Need for psychological support for health care workers

Demographics of family members

A total of five family members participated in the study, four were females and one male. Among these was a tailor, a nurse graduate, two were self-employed and one did not state occupation. One of the participants had a tertiary education level while

the others went until secondary school. Four of them were from town areas and only one of them was from the rural area. Their relationships with the patients were a mother, nieces, a nephew and a daughter. There were no relatives from the same family interviewed, each one of them were from different families with different patients admitted in ICU.

<u>Hospital</u>	<u>Age range</u>	<u>Occupation</u>	<u>Level of education</u>	<u>Relationship to patient</u>
IHO (4)	20-29 (1)	Self-employed(3)	Primary(2)	Mother(1)
WCH (1)	30-39(1)	Public servant(1)	Secondary(2)	Niece/nephew(2)
	40-49(3)	Others (1)	Tertiary(1)	Daughter(1)
				Uncle(1)

Table 6: Demographics of family members

Experience of having a family member in the ICU

Family members cited that their experience of having a loved one admitted to ICU was a difficult one. They did not expect their relative's condition to be as serious as to need an ICU admission. The outcome of the admission to the ICU was a major concern to most of them.

Family Members study number	Experience
F01	Hard to explain
F02	Very difficult
F03	Could not sleep
F04	Very hard
F05	Very hard and unexpected

Table 7: Experience of relatives with patients admitted to ICU

Communication from the health care workers

Up to 60% of the relatives expressed satisfaction for the care given to their loved ones in the ICU and they were also satisfied with the information they were provided concerning the condition of their loved ones.

However, other participants did not communicate with the health care workers at the time of data collection, but they said that the information about their patient was given to other family members that visited before.

Communication from health care workers	Family members
Satisfactory	3 (60%)
Not Satisfactory	2 (40%)

Table 8: Health care workers communication with family

Family role in the care of their loved one

The family members interviewed expressed their state of hopelessness as they were unable to take part in the care of their loved ones due to Covid-19 regulations.

Family members study number	Role in Patient Management
F01	Nothing
F02	None
F03	Nothing, Just pray
F04	No role
F05	Did nothing

Table 9: Response by family members on their roles in their patient's management

Family expectations

Some suggestions were made by the family members on how they expect health care workers can enhance their experience while having a relative in the intensive care.

These suggestions include:

“Continuous communication on the patient's condition”

“Allow the family to be close to the loved ones to make them feel that they are not alone and show them love and care”

“Culturally people have two families, maternal and paternal, allow all people to visit their relative”

“Doctors need to try and speak to the family members voluntarily and not relatives to request to see a doctor as it is not easy to ask because of fear that they are busy. At times you live far from the hospital and it’s not easy to come to see the doctor in the morning, suggestion to speak to relatives during visiting hours.”

“Allow family members to be close to their relatives even in the ICU on their last days.”

Suggestion	Frequency	Percentage
Improve communication	3	60%
Allow close family contact	2	40%

Table 10: Suggestions on improving families’ experiences

3.4 DISCUSSION

Health care workers

In this study, it was not demonstrated that the age and years of experience of the health care workers have an impact on their knowledge of EOL care. However, senior health care workers with more years of working experience had a better understanding of EOL care. Training on the subject also contributed to the knowledge gap among the staff members. In a study done in India among doctors in ICU on EOL care, lack of adequate training and information was reported to be the most frequent hindrances to EOL care. ⁽²⁰⁾

It was observed during this study that standard guidelines on EOL care were not available in the four ICUs studied. The practice of EOL in the units depended on the attending doctors and other health care workers. However, characteristics of the unit for example cardiac ICU compared to general ICUs could have an impact on EOL management. This finding suggests latent features of a unit, such as local culture and ethical climate, may have an important influence on EOL care delivery. ⁽²¹⁾

Although, there is limited literature examining variability in end of life decisions making and patterns of utilization for palliative consultation by type of ICU. ⁽²²⁾

On the definition of EOL care, most health care workers found it somehow difficult to provide a direct and certain definition. But, some had an idea of what it could be. It was often referred to as “caring for the patient who is dying”. As indicated in the literature, terminology confusion, however, has been slowing progress in quality end-of-life care in most ICUs. ⁽²³⁾ This ambiguity has led to some of the health care workers believing that EOL care is not part of ICU practices. This finding

underscores the need for training of health care personnel working in the ICU on the practice of EOL.

The decision to provide EOL care according to this study was principally made by attending doctors as indicated by 40.3% of the healthcare workers who participated in the questionnaire. It was clear that the family members do not participate in this process. Although, some studies done in other parts of the world had a different finding from the one observed from this study, as most critically ill patients are decisional impaired, family members and other surrogates must make end-of-life decisions for them. Ideally as per a substituted judgment standard. Physicians generally only make decisions for patients who lack families or other surrogates and who do not have advance directives. The decision however must be based on best practices and occasionally in consultation with other physicians or with review by a hospital ethics committee. ⁽²³⁾ At times there will be involvement of other personnel such as the social workers, religious leaders and the medical superintendents in decision making on case to case basis as reported by the participants. As 90% of the Namibian population is of Christian religion, at times family members request the involvement of religious leaders. In most hospitals in the country, social workers give psychosocial support as there are no clinical psychologists in the state facilities.

The health care workers in this study cited that EOL care is important towards patient care as it reduces prolonged suffering, prepares the family for bereavement and saves the hospital resources. In addition, it allows patients to die with dignity and pain free. In this study, the components of EOL were identified and agreed with the World Health Organization (WHO) which describes the goal of EOL care as maintaining and improving the quality of life of all patients and their families during any stage of life-threatening illness". EOL care aims to prevent and relieve suffering

by early identification, assessment, and treatment of physical and psychological symptoms, as well as emotional, and spiritual distress. ⁽³⁾

The emotional strain that comes with losing a patient in ICU and the burden of decision making on the health care workers made them appreciate that they need psychosocial support. Health care workers narrated that there is a need for them to receive psychosocial support as part of EOL practices. This emphasis was made because of the negative impact on the emotional, mental and physical wellbeing of the healthcare workers. While health care workers may have positive intentions to provide the highest quality care for patients facing death, they may also have fears related to death. This may negatively influence their attitudes about providing EOL care. Furthermore, caring for dying patients may lead to grief and perceptions of failure, which also evoke heightened anxiety about managing death situations in the work environment. ⁽²⁴⁾

Family members

It was discovered that the relatives who participated in the study did not have a clear understanding of EOL care. This was probably because their relatives were still alive although critical at the time of conducting this study. The experience of having their loved ones in the ICU was a difficult one as the patients were doing well before their admission and the illness they were admitted for were acute critical conditions.

The family meeting with the relatives by the attending health care providers was not adequate. The health care workers had met with the family members once or twice, while in some cases, there was no meeting at all. This may be due to many factors, one of such is time constraint. The ICU is a very busy ward both for the physicians and other caregivers. As a result of this, only very few clinicians working in the unit

have the time to conduct a thorough family meeting. ⁽¹⁹⁾ In another study, physician believe that families lack knowledge, have unrealistic expectations and experience grief emotions that cloud clear thinking could constrain open communication between them and families. ⁽²⁵⁾

However, some of the family members interviewed expressed satisfaction with the information given during the family meeting. Although they thought that it could be extended to a larger group of family members due to their culture. This was also related to their level of education. Education is one of the factors that determine a person ability to access information. The higher the level of education, the easier the ability to comprehend the information provided. ⁽²⁶⁾ In this study only one participant of the family members had a tertiary education level.

On the role of the family members in the patient's management during their stay in ICU, all the respondents did not seem to have any role. The main reasons patients' families did not contribute to their relatives' care in the ICU included lack of knowledge about how and the right time for participation in patient care (23.1%), not knowing how to treat patients (21.2%), financial incapacity (19.2 %), no difference when the family contributed (17.3%), and emotional trauma (9.6%). ⁽²⁶⁾ On the other hand, most ICU staff feel that families should not be involved in patient care because it can negatively affect the health services provided, adding to the family's suffering. ⁽²⁶⁾ However families of patients receiving EOL care should be an exception. In order to alleviate the anxiety level, involving the family in the nursing care process is vital. One theory that can be used to solve such problems is applying the Family care centre model. ⁽²⁷⁾ It is an effort at counselling and mentoring with the involvement of the family members of patients who have undergone hospitalization in ICU.

3.5 LIMITATIONS

Some of the limitations in this study include cultural, religious beliefs and stigma on End of life care especially from patient's relatives in the ICU

In addition, the sampling size of family members was limited due to the language barrier as interviews were conducted only in English and Oshiwambo as the principal investigator only speaks these two languages. Moreover, due to the Covid-19 pandemic, there were limited visits of patients by their relatives which also led to a small number of family members being interviewed. The other factor which affected the small sample of the family members was the emotional effect of the topic on the relatives as their patients were still alive although in critical conditions. Also, the limited number of beds at the hospitals making the number of patients to be less.

Another important limitation was the inadequate time for interviews with health care workers as the intensive care unit is a busy critical area especially for the specialist doctors who run different departments and in different hospitals.

3.6 CONCLUSION

EOL is an essential part of patient management. This is not only for the patient but also for family members and health care workers as it affects their emotional, mental health, as well as physical health. The knowledge gap on EOL care in the ICU among health care workers is due to factors such as years of working experience,

training received and the characteristics of the facility. The lack of training in the majority of the health care workers also contributed to the knowledge gap.

There is a need to improve communication between family members and health care workers. In our setting the poor communication is time related as the unit's workload is sometimes overwhelming to allow for sufficient time for family meetings.

In the end, psychosocial wellbeing is of importance both for the family members and the health care workers. But, there is negligence on this aspect for the health care providers, which can have a negative effect on their work life.

3.6 RECOMMENDATIONS

There is a need for continuous medical education on the subject of EOL for the health care workers working in the ICUs.

The establishment of clear standardised protocols on EOL care which include patient care, psychological and spiritual support for family members, family meetings and involvement of relatives in the nursing care of the patients for family members is hereby recommended.

Psychological support for health care workers by a psychologist or social worker is also highly recommended to help with the emotional strains that come with caring for a patient on EOL care. It will also help them to better prepare to offer EOL care for patients in the ICU. Such support should be available at any given time so that health care workers can feel free to participate in such exercise.

Further studies which will focus on family members' perceptions and attitudes on EOL care being offered in the ICUs is desirable.

Communication with family members is an essential part of EOL management, and it should begin from admission and throughout with the involvement of the social worker and religious support for all family members with patients who are at the end of life. Time and frequency for the family meeting should also increase.

REFERENCES

1. Vincent, J. Critical care – where have we been and where are we going? *Crit Care* **17**, S2 (2013). <https://doi.org/10.1186/cc11500>
2. Marshall JC, Bosco L, Adhikari NK, et al. What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *J Crit Care*. 2017;37:270-276. doi:10.1016/j.jcrc.2016.07.015
3. Mercadante, S., et al. Palliative care in intensive care units: why, where, what, who, when, how. *BMC Anesthesiol* **18**, 106 (2018).
4. Langley G, et al. South African critical care nurses' views on end - of - life decision – making and practices. *Nurs Crit Care*. 2014;19(1):9-17. Doi:10.1111/nicc.12026
5. Myburgh J, et al; Council of the World Federation of Societies of Intensive and Critical Care Medicine. End of life care in the intensive care unit: Report from the Task Force of World Federation of Societies of Intensive and Critical Care Medicine. *J Crit Care*, 34: 125-30. doi: 10.1016/j.jcrc.2016.04.017.
6. Nampawu, M.J. Attitudes of patients' family members toward end of life care provided in Ugandan intensive care units. (Unpublished master's dissertation.) Makerere University, Uganda. (2005)
7. Gysels, M., Pell, C., Straus, L. et al. End of life care in sub- Saharan Africa: a systematic review of the qualitative literature. *BMC Palliat Care* **10**, 6 (2022). <http://doi.org/10.1186/1472-684X-10-6>
8. Powell RA, Namisango E, Gikaara N, et al Public priorities and preferences for end –of-life care in Namibia. *Journal of pain and symptom management*. 2014 Mar 1;47(3):620-630.
9. Beckstrand, R.L., Lamoreaux, N., Luthy, K. E., and Macintosh J.L.B (2017) Critical Care nurses' perceptions on end of life care obstacles: comparative 17 year data, *Dimensions of Critical care nursing*, 36(2), 94-105
10. Coombs, M.A., Parker, R, and de Varies, K (2016). Managing risk during care transitions when approaching end of life: A qualitative study of patients' health care professionals' decision making, *Palliative Medicine* 1-8. DOI: 10.1177/026921631667347
11. Aslakson, R. A., Curtis, J. R., & Nelson, J. E. (2014). The changing role of palliative care in the ICU. *Critical care medicine*, 42(11), 2418–2428.

12. Connolly C, Miskolci O, Phelan D, Buggy DJ. End-of-life in the ICU: moving from ‘withdrawal of care’ to palliative care, patient-centred approach.
13. Colwell J End of life in the ICU. Retrieved from <https://acphospitalist.org/archives/2016/01/end-of-life-ICU.htm>
14. Cook, Deborah & Rucker, Graeme, Dying With Dignity in the Intensive Care Unit. *The New England journal of medicine*. 370. 2506-2514. 10.1056/NEJMra1208795 (2014)
15. Gysels, M., Pell, C., Straus, L *et al.* End of life care in sub-Saharan Africa: a systematic review of the qualitative literature. *MBC Palliat Care* **10**, 6 (211). <https://doi.org/10.1186/1472-684X-10-6>
16. Fadere, J. O., Obimakinde, A. M., *et al.* Healthcare workers knowledge and attitude towards palliative care in an emerging tertiary centre in South-west Nigeria. *Indian journal of palliative care*, 20(1), 1-5. <https://doi.org/10.4103/0973-1075.125547>
17. Cosgrove et al, Care at the end of life . Retrieved from <https://www.ficm.ac.uk/critical-futures-initiative/care-end-life> (2019)
18. Tobi, k. U., & Abhulimhen-Ihoya, B.I. THE NEED FOR FAMILY MEETING IN THE MANAGEMENT OF PATIENTS ADMITTED INTO THE INTENSIVE CARE UNIT: EXPERIENCE FROM A TEACHING HOSPITAL IN NIGERIA. *East African medical journal*, 91(3),77-82 (2014)
19. Stratton SJ. Population Research: Convenience Sampling Strategies. *Prehospital and Disaster Medicine* 2021;36:373–4.
20. Agrawal, K., Garg, R., & Bhatnagar, S. Knowledge and Awareness of End-of-life Care among Doctors Working in Intensive Care Units at a Tertiary Care Center: A Questionnaire-based Study. *Indian journal of critical care medicine : peer-reviewed, official publication of Indian Society of Critical Care Medicine*, 23(12), 568–573. <https://doi.org/10.5005/jp-journals-10071-23293> (2019)
21. Kruser JM, Aaby DA, Stevenson DG, et al. Assessment of Variability in End-of-Life Care Delivery in Intensive Care Units in the United States. *JAMA Netw Open*. 2019;2(12):e1917344. doi:10.1001/jamanetworkopen.2019.17344
22. Lee, J.D., Jennerich, A.L., Engelberg, R. A., Downey, L., Curtis, J. R., & Khandelwal, N. Type of Intensive Care Unit Matters: Variations in Palliative Care for Critically Ill Patients with Chronic, Life-Limiting Illness. *Journals of palliative medicine*, 24(6), 857-864 <https://doi.org/10.1089/jpm.2020.0412>

23. C. Connolly, O. Miskolci, D. Phelan, D. J. Buggy, End-of-life in the ICU: moving from ‘withdrawal of care’ to a palliative care, patient-centred approach, *BJA: British Journal of Anaesthesia*, Volume 117, Issue 2, August 2016, Pages 143–145, <https://doi.org/10.1093/bja/aew109>
24. John M. Luce **End-of-life decision making in the intensive care unit** *Am J Respir Crit Care Med*, 182 (1) (2010), pp. 6-11
25. Harasym, P.M., Afzaal, M., Brisbin, S. *et al.* Multidisciplinary supportive end of life care in long term care: an integrative approach to improving end of life. An integrative approach to improving end of life. *BMC Geriatr* **21**, 326 (2021). <https://doi.org/10.1186/s12877-021-02271-1>
26. Nia, H. S., Lehto, R. H., Ebadi, A., & Peyrovi, H. Death Anxiety among Nurses and Health Care Professionals: A Review Article. *International journal of community based nursing and midwifery*, 4(1), 2–10.(2016)
27. Hamzah, A., & Sukarni, A. H. (2017). Family care centre model could decrease anxiety level among family members of patients who have been undergoing in the Intensive Care Unit (ICU). *Open Journal of Nursing*, 7(1), 58–67.
28. Arofiati, Fitri & Primadani, Miranti & Ruhyana, Ruhyana. (2020). Role of family in the hospitalization of critical patients in the intensive care unit. *MEDISAINS*. 18. 4. 10.30595/medisains.v18i1.6482.

ANNEXURES 1: INTERVIEW GUIDE HEALTH CARE WORKERS

HOSPITAL _____

OCCUPATION _____

DESIGNATION _____

Gender:

Age:

Years of employment:

Phone number

1. Describe “end of life care” as you have experienced it in your work setting.
 - a. Have you ever heard of end of life care before? Received any training in this area?

 - b. Give an example of someone without mentioning their names, for which you provided end of life care, and describe that experience.

2. How is the decision made to provide end of life care (in your experience)
 - a. Describe who is involved in the decision making.
 - b. Describe the components of end of life care as you see them.

3. How do you perceive the experience of the patient’s families when their loved one is near death and receiving end of life care?

4. How can we as ICU practitioners enhance the experience of patients near death – and their families?

5. May I contact you for future interviews?

ANNEXURE 2: QUESTIONNAIRE FOR HEALTH CARE WORKERS

HOSPITAL _____

OCCUPATION _____

DESIGNATION _____

Gender:

Age:

Years of employment:

Phone number(s):

1. Have you received training on end of life care?
2. If yes, what kind of training i.e. undergraduate, specialization short course
3. In your unit, who makes the decision to offer end of life care to patients?
4. Are the family members involved in decision making?
5. Any other personnel apart from doctors and nurses in the ICU involved actively in end of life care in your unit. Kindly mention the professions involved.
6. Is there a specific guideline on end of life care management in your unit?
7. If yes, are there specific items that you may improve?
8. If not, will you recommend a standard guideline for end of life in ICU?
9. Do you believe end of life care is important towards patients care? Give a reason for your answer.
10. Is your unit equipped to offer end of life care to patients?
11. Give reason for your answer in question 10

12. Do you think the health care profession providing end of life care in ICU need psychosocial support?
13. Do you offer spiritual and psychosocial support to family members of a patient receiving end of life care?
14. Any other comments or recommendations?

ANNEXURE 3: QUESTIONNAIRE FOR FAMILY MEMBERS

STUDY NUMBER _____

HOSPITAL _____

REASON FOR ADMISSION _____

REFERRAL FROM _____

PHONE NUMBER(S) _____

1. Age (years): a) _____

2. Sex: a) male b) female

3. Occupation _____

4. Level of education a) never b) Primary c) Secondary d) Tertiary

5. Tribe _____

6. Preferred language(s) spoken _____

7. Religious affiliation _____

8. Relationship with the patient _____

9. Home base

i. a) urban b) rural

ii. Name of village / town _____

iii. distance from hospital _____

10. Please briefly describe the experience of having your family member or loved in the ICU recently.

11. What are your expectations?

12. In the future, is it ok if I contact you again concerning your experience in ICU?

- a) Yes
- b) No

ANNEXURE 4: INTERVIEW GUIDE FOR FAMILY MEMBERS

1. Can you tell me about your relative in the ICU? Without mentioning names, how you are related and patient characteristics
 - a. What is being done for your relative by the hospital staff and by whom?
 - b. How do/did you feel about the care provided for your relative especially near the end of life? (Follow up with “why”?)
 - c. What is your role in the ICU while your relative is here? How do you feel about this role? Is it consistent with what you expected? (Follow with “what did they expect?”)
 - d. What are your relatives’ main worries or concerns? Do you feel the hospital staffs were attentive to caring for them and alleviating symptoms?

2. Have you ever had this experience before? Perhaps another loved one in the ICU? (If yes, ask what happened to the other one)

3. Please tell us about the communication and information you received from the ICU doctors and nurses.
 - a. How many times did you meet with one of the health care team members and what information was provided?
 - b. What questions did you ask? How well did you understand what was/is happening to your relative?

3. At what point did you understand your loved one was unlikely to recover? Was the discussion of “end of life care” raised with you at that time?

4. What was your role in your family member’s care?

5. How did you respond when you heard your family member had passed away? May we ask why?

6. What were the most difficult things that you encountered during this time? What were the most helpful or most encouraging things you encountered?

7. What were some unexpected things that happened?

8. How can the ICU doctors and nurses be more helpful to you and other family members in the situation of having a loved one close to death in the ICU?

9. Should anything be changed to help patients and families in the ICU at the hospital in these situations?

ANNEXURE 5: Information sheet and consent

STUDY TITLE: A survey on End of Life Care in the intensive care units in Namibia

STUDY NUMBER: _____

Principle Investigator: Dr. Loini Talishi Shivolo

PART 1: INFORMATION SHEET.

INTRODUCTION: My name is Dr Loini Talishi Shivolo. I am pursuing a Master's degree in Anaesthesiology, Critical care and Pain Management at the University of Namibia, School of medicine DR Hage Giengob Campus. I am conducting a study to assess the practice, knowledge and attitude of healthcare workers and family members on end of life care in the intensive care units in Windhoek central hospital, Intermediate Hospital Oshakati and Onandjokwe Hospital as partial fulfilment for the award of a Master's degree of Medicine in Anaesthesiology, critical care and Pain Management.

PURPOSE OF THE STUDY: This study will generate valuable information on the care offered to the critically ill at end of life; compare that to international recommendations and probable changes to offer better service.

RIGHTS AS A RESEARCH VOLUNTEER: This form gives you information that will be discussed with you. Once you understand the study, agree to participate, you will be asked to sign this consent form. You will be given a copy of the form to keep. Your participation in this research is entirely voluntary and you may decide to withdraw from it at any time. Such a decision will not affect your access to medical care in any way or possible participation in future research studies.

PROCEDURE: This Will involve interviews, which will be audiotaped as well as a questionnaire that you will answer by writing. The study guide will either be in English or Oshiwambo

BENEFITS: There is no financial benefit; however since in this study you may be required to recall circumstances surrounding a patient's death or probability, it might affect you emotionally.

CONFIDENTIALITY: The information provided by you will remain confidential. Nobody except the principal investigator will have access to it. A study number known to you and the study personnel will be used instead of your name. The data may be seen by the Ethical review committee and may be published in (a) journal(s) and elsewhere without giving your name or disclosing your identity.

QUESTIONS: In case of questions or problems related to the study, you can ask now or contact:

Dr Loini Talishi Shivolo , Department of Anaesthesia, University of Namibia, mobile phone number +264-811666994 or email talishils27.ts@gmail.com, at any time during the study.

If you have any further questions concerning ethical issues or related to your rights while participating in this study, you may contact the School of Medicine Research and Ethics committee on telephone +264612065018.

PART II: STATEMENT OF CONSENT

I _____ have been informed about the study by

_____ its purpose and benefits. I understand that by signing this consent form I accept to participate voluntarily in the study and that I do not waive any of my legal rights; neither do I accept liability for anything

I am appending my signature/thumbprint as my indication of consent to participate in the study.

Signature/thumbprint of participant (Date)

Signature of Witness

ANNEXURE 6: Family interview guide, questionnaire, information sheet and consent in Oshiwambo

OMAPULO KAAKWANEZIMO

ONOMOLA YOMWIILONGI _____

OSHIPANGELO _____

ETOMPELO LYOKUTAAMBELWA

MOOMBETE _____

OSHIPANGELO HOKA WA ZI _____

ONOMOLA YONGODHI _____

1. Omimvo (oomvula): _____
2. Uukwashikekookantu: a) omulumentu b) omukiintu
3. Iilonga _____
4. Omuthika gwelongo: a) ine longwa b) onda hulila moprima c) onda hulila mosekundo d) onda hulila moshiputudhilo
5. Omuhoko _____
6. Elaka wa hogololola okupopya _____
7. Eitaalo lyoye olini _____
8. Omuvu ngono okwe ku pamba ngiini _____
9. Kegumbo openi
 - i. a) Omondoolopa b) Okomukunda
 - ii. Edhina lyomukunda/ondolopa _____
 - iii. Oshinano okuza poshipangelo _____
10. Hokolola paufupi kutya owa kala wu uvite ngiini pethimbo omupambele gwoye a kala moICU, omasiku ga zi ko.

11. Omayakulo geni wa li wa tegamena?

12. Monakuyiwa, otandi vulu ngaa okukupula kombinga yaashoka wushi nenge ontseyo yoye kombinga yoICU?

a) Eeno

b) Aawe

OMUSHOLONDONDO GWOMAPULO KAAKWANEZIMO

1. Oto vulu okulombwela ndje kombinga yomupambe gwoye ngoka e li moICU?
 - a. Owu shi kutya omupambe gwoye ota ungaungiwa naye ngiini moshipangelo?
 - b. Owa li wu shi uvitile ngiini kombinga yesiloshimpwiyu lyomupambe gwoye unene tuu pethimbo a li pokuhulitha? (Popya kutya “omolwashike”?)
 - c. Owa ningi po shike pethimbo omukwanezimo goye e li moICU? Shoka wa ningi po owu shi uvitile ngiini? Otashi tsu ngaa kumwe naashoka wa kala wa tegamena? (Popya kombinga yokutya “oshike wa li wa tegamena?”)
 - d. Omaipulo omanene ngoka aakwanezimo ya li ye na ogeni? Sho totala owu wete ngaa aaniilonga yomoshipangelo ya li yi itula mo mokukwathela osho wo mokuhwepopeka omandhindhiliko?
2. Shino owe shi tsakaneka ngaa nale? Ngiika komupambe gwoye gulwe ngoka a li moICU? (Ngele osho, pula shoka a li a ningilwa.)
3. Alikana tu lombwela kombinga yekwatathano nuyelele mboka wa pewa moICU, koondohotola osho wo kaapangi.
 - a. Lungapi wa li wa tsakanene nagumwe gomaaniilonga yuuhaku, nuyelele a li e ku pe owuni?
 - b. Omapulo geni wa li we ya pula? Okwa li wu shu uvite ko ngiini kombinga ya nkene omupambe gwoye a li ta pangwa?
3. Opo mpito yini wa li wa nongele kutya omuholike gwoye otashi vulika kaa aluke? Oonkundathana “dhesiloshimpwiyu lyomuntu e li momasiku ge gahugunina monkalamwenyo” odhe etwa po ngaa pungweye?
4. Maapambe yoye, oshike wa li wa ningi po okusila oshimpwiyu omuholike gwoye?
5. Owa ningi ngiini sho wa lombwelwa kutya omupambe gwoye okwa hulitha? Otatu vulu oku ku pula kutya omolwashike?
6. Onkalo dhini oondhigu ndhoka wa tsakaneka pethimbo ndika? Oshike sha li she ku kwathele unene nenge she ku kumike lela pethimbo ndyoka?
7. Inima yi ni mbyoka kaa wa li wa tegamena yi ningwe, ashike oya ningwa?
8. Oondohotola naapangi oye na okukukwathela ngiini pamwe naapambe yoye uuna muli monkalo ndjoka omuholike gweni e li pokuhulitha moICU?
9. Opu na shoka wa hala sha lundululwa, shi kwathele aakwanezimo yaavu ye li moICU osho wo aavu mboka ye li moICU ye li pokuhulitha?

ANNEXURE 7

OSHIPALANYOLO SHEHITULULOKONAKONO: Omapekapeko kombinga yiilonga, ontseyo osho wo omikalo dhaanilonga yuundjolowe osho wo aakwazimo kombinga yeloteko lyEsiloshimpwiyu lyopEhulilo lyOnkalamwenyo moICU, miipangelo itatu yi li moNamibia.

ONOMOLA YOMWIILONGI: _____

Omukonakoni Omunene: Omundohotola Loini Talishi Shivolo

OSHITOPOLWA 1: EPANDJA LYUUYELELE.

EFALOMO: Edhina lyandje ongame Omundohotola Loini Talishi Shivolo. Otandi ilongele uulongelewe woMasta mOkukotheka aavu, Esoloshimpwiyu lya kwata miiti osho wo Eloteko lyUuwehame moshiputudhilo shaUNAM, moshimpungu shuunamiti, moshitayi shomundohotola Hage Geingob. Otandi ningi omapekapeko gokutala iilonga, owino osho wo omikalo dhaniilonga yuundjolowe osho wo aakwanezimo kombinga yesiloshimpwiyu lyomuntu e li momasiku ge ga hugunina moICU, moshipangelo shaWindhoek Central, moshipangelo shaShakati osho wo moshipangelo shaNandjokwe ongoshitopolwa shokugwanitha po iipumbiwa yoku shi pondola muulongelwe woMasta mOkukotheka aavu, Esiloshimpwiyu lya kwata miiti osho wo Eloteko lyUuwehame – moshimpungu shiikwamiti.

ELALAKANO LYOMAPEKAPEKO: Eningo lyomapekapeko ngaka otali eta uuyeleele wa simana kombinga yesiloshimpwiyu hali gandjwa komuntu ngoka te ehama e li monkalo ombwinayi nokuli momasiku ge gahugunina mokukalamwenyo. Uuyeleele mboka owo nee tawu faathanithwa naashoka hashi ningilwa aavu ye li monkalo ya faathana muuyuni osho wo okugandja uuyeleele mboka tawu vulu okulongithwa ko ku gandjwe omayakulo ge li hwepo.

UUTHEMBA WOMWIIYAMBI GWOMAPEKAPEKO: Ofoloma ndjika otayi ku pe uuyeleele mboka tawu ka kundathanwa nangoye. Uuna wu uvako omapekapeko ngaka, e to zimine okukutha ombinga, oto ka pulwa wu shaine ofoloma ndjika yopaumwene. Oto ka pewa okopi yoye yofoloma ndjika. Ekuthombinga lyoye momapekapeko ngaka otali ningwa pakwiiyamba noto vulu okutinda nenge okuninguluka. Ngele owa tokola ngaaka, itashi imbi nande wu kale to pewa omayakulo gopaundjolowele nenge okukutha ombinga momapekapeko ngoka tashi vulika wu ka tsakaneeke monakuyiwa.

OMULANDU GOKUKONGA UUYELELE: Otagu kwatele mo omapulapulo, ngoka taga ka kala ga kwatwa ewi. Osho wo omapulo ngoka wu na okuyamukula pakushanga. Otaga kala mewiliko lyelaka lyOshiingilisa nenge mOshiwambo.

OMAUWANAWA: Kapu na ofuto, ashike molwashoka omapekapeko ngaka otashi vulika ga pule onkalo ndjoka tashi vulika tayi ku dhimbulukitha ekanitho lyomupambebe gwoye, nena otashi vulika shi ku uvithe nayi.

OSHIHOLEKWA: Uyelele mbuka wa gandja otawu kala oshiholekwa. Kapu na ngoka ta kala ewu shi kakele komukonakoni omunene. Onomola yomwiilongi ndjoka yi shiwike kungoye nokumwene, oyo tayi ka longithwa peha lyedhina lyoye. Uyelele mbuka otawu ka monika kokomitiye yokutala iinima mbyoka ya ningwa pamakankameno notashi vulika wu ka nyanyangidhwe moshifo nenge miifo yopaulongelwe nenge palwe ashike uukwatya woye itawu gandjwa.

OMAPULO: Kombinga yomapulo nenge yomaupyakadhi ge na sha nomapekapeko ngaka, oto vulu okupula ngashingeyi nenge muule wethimbo lyomapekapeko ngaka, nenge wu kwatathane na:

Omundohotola Loini Talishi Shivolo gwokwOshimpungu shEsitho lyaantu, moshiputudhilo shaUNAM, konomola yongodhi +264-811666994 nenge koemail talishils27.ts@gmail.com.

Ngele owu na omapulo ga gwedhwa po ge na sha nomakankameno guushili nenge ga pamba uuthemba woye pethimbo to kutha ombinga momapekapeko ngaka, oto vulu okukwatathana nOshimpungu shOmapekapeko gOpaunamiti nOkomitiye yomunashipundi gwOmakankameno konomola yOngodhi.

OSHIHOLEKWA 2: OMUKANDA GWEZIMINO

Ngame _____ onda tseyithilwa kombinga yomapekapeko ku _____ nelalakano lyago osho wo omauwanawa. Ondu uvite ko sho nda shaina ofoloma ndjika yeziminino, ondi itayela okukutha ombinga pakwiiyamba momapekapeko ngaka, ishewe inandi enda pambambo nande uuthemba wandje wopaveta, ngame ishewe inandi zimina okukalela po sha.

Otandi tula po eshaino lyandje/okustamba kwandje nomunwe, oku ulika kutya onda zimina okukutha ombinga momapekapeko ngaka.

Eshaino/okustamba nomunwe kwomukuthimbinga (Esiku)

Eshaino lyombangi

ANNEXURE 8: Ethical approval from the Ministry of Health and Social services



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2507
Fax: 061 - 222558
E-mail: itashipu87@gmail.com

OFFICE OF THE EXECUTIVE DIRECTOR

Ref: 17/3/3 LTS

Enquiries: Mr. A. Shipanga

Date: 04 February 2021

Dr. Loini Talishi Shivolo
PO Box 6191
Oshakati
Namibia

Dear Dr. Shivolo

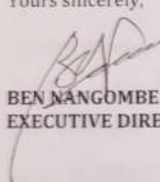
Re: A survey on end of life care in the intensive care units of three government teaching hospitals in Namibia.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
 - 3.1 The data to be collected must only be used for academic purpose;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;

17/3/3 LTS

- 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
 - 3.5 Preliminary findings to be submitted upon completion of the study;
 - 3.6 Final report to be submitted upon completion of the study;
 - 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

Yours sincerely,


BEN NANGOMBE
EXECUTIVE DIRECTOR



"Health for All"

ANNEXURE 9

Approval letter from Windhoek Central Hospital



Private Bag 13215 Windhoek Namibia	Harvey Street Windhoek Central Hospital	Tel. No: (061) 203 3024 Fax No: (061) 222886
Enquiries: Ms. S.lipinge Ref. 17/3 / 3		Date: 08 March 2021

OFFICE OF THE CHIEF MEDICAL SUPERINTENDENT

Dr.Loini Talishi Shivolo
P.O.BOX 6191
Oshakati

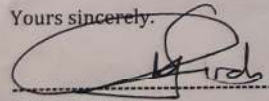
Dear Dr.Shivolo

SUBJECT: PERMISSION TO CONDUCT A SURVEY ON THE END OF LIFE CARE IN THE INTENSIVE CARE UNIT AT WINDHOEK CENTRAL HOSPITAL.

1. Reference is made to your application to conduct the above-mentioned study.
2. This letter serves to inform you that permission has been granted for you to do a survey on the above mentioned subject as you have requested and does not include any remuneration.
3. Patient/Client's information should be kept confidential at all times.
4. Preliminary findings copy to be submitted to Customer care office, Windhoek Central Hospital upon completion of the study.

Thank you.

Yours sincerely,


DR.D.I.UIRAB
CHIEF MEDICAL SUPERINTENDENT



ANNEXURE 10: Approval letter from Intermediate Hospital Oshakati



9 - 0/0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 5501

Tel: + 264 65 2233000

OSHAKATI

INTERMEDIATE HOSPITAL OSHAKATI

Fax: + 264 65 224564

Enq: Ms. S.P. Mwandangi

Tel:+264 65 223 1247

03 May 2021

TO: DR .Loini T .Shivolo
P. O. Box 6171
Oshakati
Cell: +264 -

Dear DR Shivolo


RE: AUTHORIZATION TO CONDUCT A RESEARCH STUDY

This is to inform you that your request to conduct a research study in Oshakati Intermediate Hospital has been approved.

Kindly be informed that confidentiality of the patient information seen during your research must be observed. In case of breach of confidentiality, you will be charged by the Nursing Council of Namibia Regulation Act.

We wish you all the best during your research.

Yours sincerely


DR. A. KIBANDWA
ACTING CHIEF MEDICAL OFFICER
INTERMEDIATE HOSPITAL OSHAKATI



ANNEXURE 11: Approval letter from Onandjokwe Intermediate Hospital
Research committee



ONANDJOKWE RESEARCH AND ETHICS COMMITTEE (OREC)

APPROVAL NOTICE

Ethics Reference #: OREC/0543/21

Name of applicant: Loini T Shivolo

Date: 26/05/2021

Re : A SURVEY ON END OF LIFE CARE IN THE INTENSIVE CARE UNITS OF THREE GOVERNMENT TEACHING HOSPITALS IN NAMIBIA .

Dear Loini T Shivolo

The New Application received on 20th May 2021, was reviewed by some members of Onandjokwe research and Ethics Committee via Expedited review procedures on 24-05-2021 and was approved.

Please note the following information about your approved research protocol:

1. The data to be collected must only be used for operational purposes
2. Preliminary findings to be submitted upon completion of the study
3. Final report to be submitted upon completion of study.
4. Separate permission should be sought from the ministry of Health and social services for the publication of the findings.

Yours sincerely

DR .A.Munyika

Chair Person OREC



DR.F.STRATO

Secretary OREC

Tel: +264 65 280 400 Private Bag 2016
Fax: +264 65 240 688 Ondangwa
E-mail: onandjokweresearch@gmail.com Namibia