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QUALITY PALLIATIVE CARE IN HUMANITARIAN
CRISES IN LOW- AND MIDDLE-INCOME
COUNTRY CONTEXT

Farzana Khan



THE UNIVERSITY
of EDINBURGH

Thesis submitted for the degree of Doctor of Philosophy

The University of Edinburgh

2023

Declaration

I confirm that this thesis is presented for Doctor of Philosophy of Population Health Sciences.

I also declare that,

I. The thesis has been composed by me

II. It is solely the result of my work

III. This work has not been submitted for any other degree or professional qualification

Dated: September 11, 2023

Farzana Khan

Abstract:

Introduction:

Providing quality palliative care within challenging humanitarian settings is a critical and complex endeavor, which has been overlooked and poorly invested in. This thesis seeks to understand the multifaceted dimensions of palliative care delivery within such contexts, shedding light on challenges, exploring strategies, and uncovering the transformative journeys of healthcare workers. It was carried out during the COVID-19 pandemic providing additional complexity, but adding to its value, as global shocks are likely to increase rather than decrease.

While palliative care has been identified as an essential health service under Universal Health Coverage (SDG3), the literature addressing its need and delivery especially in areas of conflict and fragility remains limited. Surprisingly, the quality of palliative care within such settings had not been hitherto assessed.

This thesis specifically seeks to make visible the intricacies of delivering palliative care within a specific humanitarian environment with the case studies focused on the experience of the Rohingya Community living in Cox's Bazar, Bangladesh.

Aims & Objectives:

The overarching aim of the thesis is to identify the nature of palliative care in humanitarian settings and assess the quality of such services using the World Health Organization's established quality of care domains as a metric. It explores whether new quality indicators have emerged from complex humanitarian situations, particularly in the context of the COVID-19 pandemic. It sets out to address gaps in knowledge related to patient needs, care quality, compassion within palliative care, and healthcare worker preparedness in humanitarian crises in order to provide a comprehensive understanding of the challenges and advantages of delivering high-quality palliative care within constrained healthcare settings, with specific emphasis on the pandemic's implications.

Methods:

Employing an exploratory convergent mixed-methods case study approach, the thesis utilized individual semi-structured interviews, participant observation,

field notes and documentary analysis for data collection. Ethical approval was obtained. Ethical integrity was maintained through adherence to the 'Quality Framework for Mixed Methods Research'. The initial scoping review assessed existing knowledge on palliative care in fragile, conflict, and violence-affected (FCV) environments. Ethnographic observations and semi-structured interviews explored the experiences of healthcare workers delivering palliative care during the COVID-19 pandemic.

Results:

Findings emanated from diverse data sources. Fifty interviews, 23 event episodes with 256 hours of participant observations were conducted, 30 field notes and 22 documents were also included. In conflict-affected environments, the emphasis on palliative care quality indicators underscores the importance of prioritizing people-centeredness, effectiveness, timeliness, and equity. Reflective analysis of a cross-sectional survey involving 311 participants provided specific context, helped to reveal longitudinal perspective to the studies related to patients and their caregivers challenges among the Rohingya refugees and provided insights into their palliative care needs, and their access to essential medical supplies.

The theoretical model, titled "The Journey Towards Engagement in Palliative Care," offered a framework for comprehending how FHCWs embarked on the process of caring for patients with incurable conditions and how this involvement evolved into a profound emotional and social commitment. It was proposed that this commitment, which was multifaceted and centered on alleviating suffering while promoting high-quality care, could be best characterized as compassion.

Semi-structured interviews unveiled healthcare workers' pandemic journey, culminating in the "Navigating Self-Preparedness Through Pandemic" theory. This theory specifically addresses care integration evolved with FHCWs' understanding of the pandemic, personal growth, and commitment to their roles. It shifted from a focus on physical health to a holistic approach considering emotional, psychological, and social dimensions of care. The emotional journey and self-preparedness facilitated compassionate and effective care responsive to pandemic challenges in a humanitarian setting.

Discussion:

The first among the two exploratory cases examined the quality of palliative care practices and compassion carried out by frontline healthcare workers (FHCWs) operating in a limited humanitarian palliative care setting, partly during the pandemic. Participant observations highlighted healthcare workers' adaptability and compassionate communication.

The focus of the second study was on examining the self-preparedness of FHCWs for providing quality care during the pandemic in Rohingya refugee camps. This was achieved through the application of constructivist grounded theory and mixed methods to comprehend palliative care provision in Cox's Bazar both before and during the pandemic, with a specific emphasis on exploring the challenges encountered by health workers in the face of health system shocks.

Through comprehensive data analysis and synthesis, the thesis presents recommendations for strengthening palliative care in humanitarian settings and pandemic responses. By adding self-preparedness as a quality indicator, the research can inform clinical leaders, educators, humanitarians, and policymakers, and offers novel insights into care quality within limited palliative care provision in refugee camps.

The study's recommendations include identifying patient, caregiver, and healthcare provider needs through allocating time and space to understand challenges, engaging with the need for self-preparedness, fostering compassionate connections, and advocating for all stakeholders. The research underscores the importance of understanding diverse patient needs, integrating compassion, and incorporating palliative care principles into healthcare practice. It reveals the interconnectedness of physical, emotional, and psychosocial aspects within care delivery. Healthcare workers' resilience shone amidst adversity, showcasing palliative care as a symbol of compassion and strength. The findings of the thesis show the importance of enhanced palliative care quality, and reiterate its pivotal role in providing compassionate healthcare, even amid challenging scenarios. The study provides a roadmap for enhancing palliative care provision, advocating a human-centric approach that acknowledges the unseen dedication of healthcare providers.

Conclusion:

The multidimensional findings and the theory generated from them offer a holistic perspective of palliative care within humanitarian settings. They underscore the significance of people-centeredness, effective interventions, equitable access, and compassion's transformative power. The findings while emerging from a specific context and at a specific time appear to have global significance resonating with WHO policy and the need to elevate palliative care delivery in challenging environments.

Word Count: 82,000

Lay Summary

Imagine going through a serious illness in a tough situation, such as during the COVID-19 pandemic when things are already hard. Now, think about being in a place where getting the help you need is even tougher, for example in a humanitarian crisis. That is what I wanted to explore for my PhD study. My goal was to understand how to give the best care to people facing difficult times, especially in places where humanitarian help is really important. This includes the amazing frontline healthcare workers who work tirelessly to take care of those in need, even when things are incredibly challenging. A humanitarian crisis happens when a big problem affects a lot of people, when families have to leave their homes because of dangerous situations including war or natural disasters.

My study specifically looks at the Rohingya refugees. They had to leave their homes in Myanmar because of violence and persecution. They have fled to neighboring Bangladesh, where they do not have basic things such as proper homesteads and medical care. One of the types of care that few refugees anywhere have is palliative care, which aims to make life better for people with serious illnesses. My aim was to understand how to make this kind of care work well in places where things are tough. I talked to patients, caregivers, and healthcare workers, and I also studied existing research. My findings showed that good care should focus on what each person needs – both emotionally and physically. Getting the right treatment at the right time is incredibly important too. I realized that being kind, communicating openly, and working together as a team are key aspects of providing excellent care.

In my research, I also saw how healthcare workers managed during the pandemic. These remarkable individuals learned how to take care of others while also taking care of themselves. They showed incredible strength and dedication, even when things were really challenging. Overall, my research helps us know how to provide quality care even in tough situations. It highlights the importance of understanding people's needs, providing the right treatment, and showing compassion. Although I looked at specific situations, what I've learned can benefit everyone, no matter what challenges they face. My findings offer important insights for policymakers, healthcare workers, and researchers, so that even during difficult times, everyone can receive the best care possible.

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Abbreviations:

CHWs = Community Health Workers

CINAHL Plus = Cumulative Index to Nursing and Allied Health Literature Plus

COPD = Chronic Obstructive Pulmonary Disease

COVID-19 = Coronavirus Disease 2019

CXB = Cox's Bazar

EMBASE = Excerpta Medica Database

ENTREQ = Enhancing Transparency in Reporting the synthesis of Qualitative research

EP HUM = Essential Package of Palliative Care for Humanitarian Emergencies and Crises

ETC = Ebola Treatment Centres

EVD = Ebola Virus Disease

FCV = Fragile, conflict-affected and violence

FHCWs = Frontline Healthcare Workers

FKRF = Fasiuddin Khan Research Foundation

GOC = Goals of Care

GRAMMS = Guidelines for Reporting of Articles in Mixed Methods Studies

HBC = Home-Based Care

HCTs = Health Coordination Teams

HCWs = Healthcare workers

HIV/AIDS = Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

IAHPC = International Association for Palliative Care

IRB = Institutional Review Board

IOM = Institute of Medicine

IRC = International Red Cross

JRP = Joint Response Plan

LMICs = Low- and middle-income countries

MeSH = Medical Subject Headings

MSF = Médecins Sans Frontières

NCD = Non communicable Disease

NGO = Non Governmental Organization

OCHA = Office for the Coordination of Humanitarian Affairs

OECD = Organization for Economic Co-operation and Development

PC = Palliative Care

PCAs = Palliative care assistants

PCC = Population, Concept and Context Framework

PCI = Palliative care intervention

PHC = Primary Health Care

PhD = Doctor of Philosophy

PPE = Personal protective equipment

PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews

PsychINFO = Psychological Information Database

PubMed = Publications On Medline

QOL = Quality of life

RETREAT = Review question-Epistemology-Time-Resources-Expertise-Audience and purpose-Type of Data

RRRC = Refugee, relief and repatriation commissioner

SARI-ITCs = Severe Acute Respiratory Infection Treatment Centers

SDGs = Sustainable Development Goals

UHC = Universal Health Coverage

UNICEF = United Nations International Children's Emergency Fund

UN-IOM = United Nations - International Organization for Migration

UoE = University of Edinburgh

WFP = World Food Programme

WHA = World Health Assembly

WHO = World Health Organization

Contributions to Science:

1. PUBLICATIONS AND PRESENTATIONS RELEVANT TO THE WORK OF THESIS

1.1 PEER-REVIEWED PUBLICATIONS:

Khan F, Azad TB, Bhuyian S, Karim H and Grant L (2023) Exploring the self-preparedness of frontline healthcare workers in a low- and middle-income country from a humanitarian context during the COVID-19 pandemic: A constructivist grounded theory study. *Front. Public Health* 11:1043050. doi: 10.3389/fpubh.2023.1043050

Doherty M, Power L, Petrova M, Gunn S, Powell R, Coghlan R, Grant L, Sutton B and **Khan F**. Illness-related suffering and need for palliative care in Rohingya refugees and caregivers in Bangladesh: A cross-sectional study. *PLoS Med*, 2020; 17(3):e1003011

Doherty M, **Khan F**. The Need for Palliative Care in Complex Humanitarian Emergencies: Experiences from Rohingya Settlements in Bangladesh. *Indian J Palliat Care*. 2018;24(2):228-82.

Doherty M, **Khan F**, Biswas F, Khanom M, Rahman R, et al. Symptom prevalence in patients with advanced, incurable illness in Bangladesh. *Indian J Palliat Care* 2017; 2017;23:413-8.

Khan F, Ahmad N, Iqbal M, Kamal AM. Physicians knowledge and attitude of opioid availability, accessibility and use in pain management in Bangladesh. *Bangladesh Medical Research Council Bulletin*, 2014; 40 (1): 18-24.

Ahmad NU, **Khan F**, Quadir SS, Rahman M, Laskar MH, Rahman AKM : Conceptual Prevalence in Palliative Care amongst the Physicians of Bangabandhu Sheikh Mujib Medical University : A Comparison between the Post Graduate Trainees and the Trainers: *Journal of BSA*, 2009; 22(1): 26-31.

Khan F, Ahmad NU, Anwar M. Palliative Care is a Human Right: *Journal of The Bangladesh Society of Anaesthesiologists*, 2008; 21(2): 76-79.

1.2 BOOKS AND BOOK CHAPTERS

Editor, Bangladesh national palliative care training modules for Physicians (in English)

Editor, Bangladesh national palliative care training modules for Nurses and Paramedics (in Bangla)

Co-author: *Child Refugee and Migrant Health: A Clinical Manual for Health Professionals*. ISBN 978-3-030-74905-7 ISBN 978-3-030-74906-4 (eBook) <https://doi.org/10.1007/978-3-030-74906-4> © Springer Nature Switzerland AG 2021

Co-author: *A Field Manual for Palliative Care in Humanitarian Crises*. Oxford University Press (Published: 09 December 2019)

Author: First original Bangla book on Palliative Care - “আসুন, প্যালিয়েটিভ কেয়ারকে জানি”

Let's Get to Know Palliative Care Asian Color Printer (Published 2018). ISBN No. 978-984-34-5252-8

1.3 INVITED SPEAKER IN INTERNATIONAL CONFERENCE, WORKSHOP, ROUNDTABLE, WEBINAR, MASTERCLASS AND PRESENTATIONS:

Khan F. (2023) (May 10 – May 20) - Advisory Team Member from the Global Health Academy, University of Edinburgh to Support Project SUNITA Research Team in Nepal.

Khan F. (2023) (March 24) – Masterclass in Palliative Medicine, Global Fellowship Program organized by Pallium India Trust. Presentation titled by ‘Humanitarian Crisis and The South-Asian Realities.’

Khan F. (2023) (March 2) – Organized by School of Social and Political Science, University of Edinburgh for participants of Masters students of UoE in ‘Refugees, Health and Humanitarian Action’ Course. Presentation titled, ‘Why palliative care is essential in humanitarian settings?’

Khan F. (2022) (November 3) – Global Health Academy Workshop by the University of Edinburgh on higher education in palliative care for humanitarian and primary palliative care in LMIC settings.

Khan F. (2022) (October 27) – Global Health Academy Conference by the University of Edinburgh. Presentation titled, ‘Embedding Palliative Care Education for Practitioners Working in Rohingya Refugee Camps in Bangladesh.’

Khan F. (2022) (19-27th September) – International organization for migration, Cox’s Bazar. Advanced training in palliative care.

Khan F. (2022) (June 8) – Yale University Global Health Day hosted by Yale Department of Emergency Medicine. Presentation titled, ‘Palliative care in low- and middle-income country humanitarian settings.’

Khan F. (2022) (May 23 – May 25) – Improving respiratory health in Asia: A showcase of RESPIRE research and lessons from Bangladesh, India, Malaysia and Pakistan. Annual Scientific Meeting.

Khan F. (2022) (May 5 to May 7) – Poster titled, ‘Symptom burden on COPD in Humanitarian Settings’. IPCRG; Malaga, Spain.

Khan F. (2022) (April 1) – SPEAKER CUGH Conference 2022, Healthy People, Healthy Planet, Social Justice. Presentation titled: ‘Why palliative care is needed in emergency response and humanitarian situations?’

Khan F. (2022) (February 16) - School of Social and Political Science, University of Edinburgh organized lectures for Masters students of UoE in 'Refugees, Health and Humanitarian Action' Course. Presentation titled, 'Palliative care in refugee settings.'

Khan F. (2021) (November 12) – 4th Slovenian Congress of Palliative Care, "Together on the right path." Presentation titled, 'Experience of Provision of Palliative Care to Forcibly Displaced Rohingya Refugees.'

Khan F. (2021) (June 10) - Global Refugee Health Research Network, University of Edinburgh, in collaboration with the Centre for Research in Protracted Crisis, University of Scotland and the Higher Population Council, Jordan is organising a webinar on 'The Lives of Refugee Women living in Protracted Crisis'. Presentation titled, 'Lives of Refugee Women in Protracted Crisis.'

Khan F. (2021) (April 28) – Civil Society Organizations (CSOs) Dialogue with WHO Director General Dr. Tedros. Presentation titled, 'Civil Society Initiatives Can Help To Integrate Palliative Care Services and Essential Palliative Care Medicines To Relieve Suffering During Emergencies, Including COVID-19.'

Khan F. (2020) (June 4) – SPEAKER- CHATHAM House organized a webinar: Virtual Roundtable on Palliative Care during Covid-19. Presentation titled:

Khan F. (2020), ISCG Health Sector, CXB. Presentation titled 'Palliative care_a pilot program in Cox's Bazar and refugee camps

Khan F. (2020) (February 13) TELE-LECTURE – McMaster University, Canada organized lectures for MPH Students of McMaster University. Presentation titled, 'Rohingya Refugee Health.'

Khan F. (2020) (February 3-7) - European Palliative Care Academy - Leadership Course 2019-21, Second Course Week at the Cicely Saunders Institute, Kings College London, UK.

Khan F. (2020) Cox's Bazar General Hospital. 'Pulmonary rhabilitation through palliative care'.

Khan F. (2019) SPEAKER – Multi-morbidity and Palliative Care in Fragile Settings. Edinburgh University, UK, October 3, 2019.

Khan F. (2019) TRAINEE – European Palliative Care Academy - Leadership Course 2019-21, First Course Week at the University Hospital of Cologne, Center for Palliative Medicine, Cologne, Germany, September, 23-27, 2019.

Khan F. (2019) POSTER – Sufferings due to respiratory diseases in Rohingya Refugee Camps. Annual Scientific Meeting organized by the NIHR Global health research unit on respiratory health (RESPIRE) and hosted by the university of Malaya, Kuala Lumpur, Malaysia, 10-12 September, 2019.

1.4 ACTIVITIES RELATED TO PALLIATIVE CARE IN THE ROHINGYA CAMPS

A short video on palliative care in humanitarian settings by The New Humanitarian.
<https://www.thenewhumanitarian.org/video/2019/04/22/healer-rohingya-camps-local-response-reaches-untreated-refugees>



(video at thenewhumanitarian.org web page)

2. Newspaper article on FKRF work in Rohingya Camps. The new humanitarian (2018): Geneva. Available at: (<https://www.thenewhumanitarian.org/feature/2018/03/28/caring-chronically-ill-bangladesh-s-rohingya-camps>)

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CHAPTER 1: OVERVIEW OF THESIS AND BACKGROUND

Quality Palliative Care in Humanitarian Settings: the Challenges of Designing and Delivering Services in a Syndemic

1.1 SECTION 1: STRUCTURE OF THE THESIS

Chapter 1: Overview of Thesis and Introduction to Palliative Care in Humanitarian Settings

I've divided this chapter into two sections. In the first section, I outline the comprehensive structure of my entire thesis. The second section provides the research's context, summarizing the current state of knowledge in the field and emphasizing persisting research inquiries. Specifically, I focus on the triple crises of delivery: the challenges of palliative care service delivery in humanitarian settings, within a fragile health system, and in the context of COVID-19. I also provide a broad overview of why palliative care is crucial in an already challenging context and how the delivery became even more complex in fragile settings during the COVID-19 pandemic. I conclude this chapter by presenting the aims, objectives, and research questions of my thesis.

Chapter 2: Literature Review – A Scoping Review

In Chapter two, I conducted an analysis of the existing literature through a scoping review for my PhD study. This scoping analysis helped me identify a gap in quality indicators in palliative care research within humanitarian contexts, which then led to the development of my research focus.

Chapter 3: Specific Context: Palliative Care Needs Assessment of Rohingya Refugees living in the Cox's bazar Refugee Camps

In this chapter, I provide contextual or foundational information, offering a valuable longitudinal perspective to my studies. I aim to establish a baseline of fundamental themes and challenges that existed before the onset of the COVID-19 pandemic, while also presenting a distinctive viewpoint from the perspective of patients and their caregivers.

I delve into a brief review of the historical background of Rohingyas in Myanmar, shedding light on the crucial aspects of the context in Cox's Bazar. I meticulously examine the category labeled 'situation analysis,' which involves navigating palliative care provision in Cox's Bazar both before and during the pandemic. Additionally, I provide insights into the national palliative care status of Bangladesh, aiming to clarify the position of palliative care in Rohingya refugee camps.

Furthermore, I offer a reflective analysis of the 2018 needs assessment study. The study revealed that refugees with serious illnesses expressed significantly lower satisfaction with their overall health, encompassing physical, psychological, and environmental well-being, compared to healthy refugees in the camps. These disparities were primarily influenced by factors such as experiencing pain or other physical symptoms, having someone to care for them, or caregivers, and the types of diseases they were coping with. I meticulously explore these findings in relation to the emerging criteria for quality indicators.

Chapter 4: Methodology

In Chapter four, I lay out the methodological procedures I've chosen for my study. I begin by presenting the ontological and epistemological perspectives that underpin my research. I then introduce the study's design, explaining my decision to use a case study approach and reviewing the theoretical contexts that have informed my project. I chose four methods of data collection for my study. Using a multimethod approach, I integrated semistructured interviews, participant observation, field notes, and document analysis, all in accordance with the principles of grounded theory methodology. Through a reflexive account, this chapter also delves into my personal role in the research process and how I've grappled with my own identity and perspective while shaping the project. I reflect on my sense of professional identity and my expectations for the research, considering how they relate to these methodological choices.

Chapter 5: Compassion of Health Care Workers on Palliative Care Provision in Rohingya Refugee Camps.

In Chapter 5, I delve into another study involving health workers, specifically focusing on their understanding of their roles within the framework of palliative care quality indicators. This chapter goes into detail regarding how compassion influences the palliative care profession, impacting the development of health

professionals' identities and the delivery of services within a humanitarian context.

Chapter 6: Self-preparedness of Frontline Health Care Workers Providing Care During the Pandemic

In Chapter 6, I delve into the study titled 'Navigating Self Preparedness of Frontline Health Care Workers through the Pandemic.' This study focuses on frontline healthcare workers during the COVID-19 pandemic, utilizing a 'paradigm' framework to gain insights into how healthcare workers shape their roles concerning themselves, their patients, and families, as well as their professional identity within the contemporary humanitarian healthcare system. The analysis within this chapter sheds light on the factors influencing health professionals' identity construction, particularly the conflicting ideologies that underlie health practices within the humanitarian context. Considering the evolving needs of patients and health professionals due to the COVID-19 pandemic, we closely examine the responses of frontline healthcare workers (FHCWs). This examination primarily centers on how they engage in self-preparedness measures to protect themselves against COVID-19 while simultaneously providing care to Rohingya refugees in healthcare clinics and through home-based care.

Chapter 7: Discussion

Chapter 7 integrates the categories developed in chapters 5, and 6. To explore how the needs of palliative care, how health professionals construct their professional identity in the contemporary humanitarian settings and compassion of palliative care professionals discussion and how the findings of the case study relate to quality care. This chapter finally concludes the thesis by addressing the research questions, summarizing and reflecting on the research. Implications of the research findings for the health professionals practice, education and wider policy are considered.

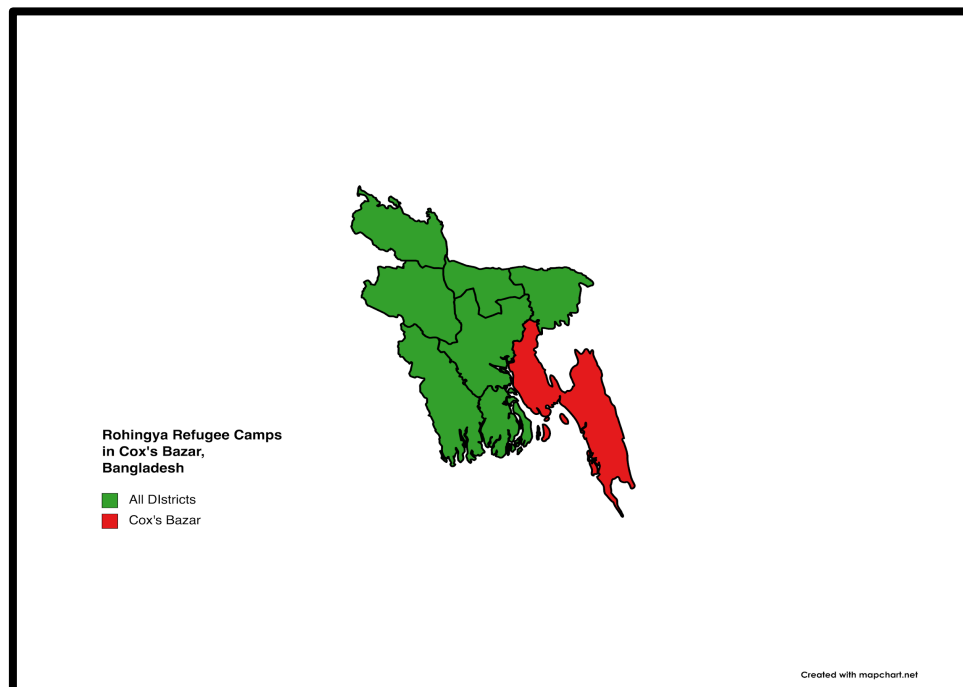
1.2 SECTION 2: PALLIATIVE CARE IN HUMANITARIAN SETTINGS: THE CHALLENGES OF DESIGNING AND DELIVERING SERVICES IN A SYNDEMIC:

1.2.1 Introduction:

This doctoral research aims to identify the key indicators of quality palliative care in the context of humanitarian settings during the COVID-19 pandemic. The study was conducted in Cox's Bazar, Bangladesh, where the Rohingya

refugee community has been displaced. It explores the lived experiences of individuals with complex and life-limiting illnesses, who have been marginalized due to their displacement. Additionally, the research provides an in-depth analysis of the perceptions of frontline healthcare workers involved in delivering care in humanitarian settings. The findings of this study hold the potential to guide the development and integration of effective strategies for delivering high-quality palliative care services within humanitarian contexts.

Figure 1.1: Cox’s Bazar, Bangladesh, the location where Rohingya refugees sought safety and shelter



(This Map presented here was generated using Mapchart.net.)

1.2.2 Setting the Scene:

The COVID-19 pandemic marked a profound transformative period on a global scale during which I conducted my doctoral research. My research efforts were centered in Cox’s Bazar, a region that serves as the home for the displaced Rohingya community from Myanmar. Before the COVID-19 outbreak, I collaborated with the Fasiuddin Khan Research Foundation (FKRF) to initiate palliative care services for the Rohingya community in their homes and community areas within the refugee camps.¹ The FKRF is a local non-governmental organization with a mission commitment to assisting individuals facing life-threatening and severe illnesses, acknowledging the ongoing

necessity for palliative care. It recognizes the persistent requirement for palliative care in vulnerable environments such as urban slums and refugee camps, and focuses its efforts on providing support in these settings.²

Amid the global focus on COVID-19, I found myself facing the consequences of another crisis caused by conflict and displacement. Within the community I directly observed a triple crisis marked by the neglect of those living with life-limiting illnesses, inadequate and vulnerable healthcare infrastructure, and the significant changes brought about by the COVID-19 pandemic on the type and effectiveness of care provided. The COVID-19 pandemic has magnified pre-existing challenges, including the scarcity of adequately trained healthcare personnel, while simultaneously introducing new issues such as shortages of personal protective equipment (PPE) and oxygen. These challenges have further burdened the already stretched healthcare workforce in camp settings and hospitals globally. The evolving and unpredictable nature of the refugee crisis, coupled with its immense humanitarian significance and vast magnitude, presented a research journey filled with unforeseen twists and turns. This path was characterized by numerous personal transformations and profound introspective moments, as I delved into the intricacies of the crisis.

Figure 1.2: Rohigya refugee camps in Kutupalong, Ukhia, Cox’s Bazar



(I captured this photo personally in August 2018)

1.2.3 Humanitarian Crises:

An estimated 2 billion people live in fragile, conflict-affected and violence (FCV) settings, and by 2030 nearly 50% of poor people worldwide will be living in such situations.³ Same report identified that 86% of countries that provide refuge to refugees fall into the low and middle-income classification. These countries encounter their own unique development challenges, which further complicates the issue at hand. In the Global Humanitarian Report (2019) released by the UN Office for the Coordination of Humanitarian Affairs (OCHA), a significant revelation was made. The report identified a population of 132 million individuals in urgent need of critical humanitarian assistance to save lives.⁴ This signifies that approximately 1 in every 57 people across the globe found themselves in a situation of crisis.

Humanitarian crises is defined as a multifaceted “crises in countries, regions, or societies where there is a total or considerable breakdown of authority resulting from internal or external conflict and which requires a multisectoral, international response that goes beyond the mandate or capacity of any single agency.”⁵ Complex humanitarian emergencies occur in areas where there is a significant breakdown of governing authority caused by internal or external conflicts. A comprehensive and international response is necessary to address these emergencies effectively that surpasses the capabilities and scope of any individual agency. Unlike disasters caused by single events like earthquakes, humanitarian emergencies and crises typically stem from a combination of diverse factors, including natural disasters, human actions, environmental issues, political unrest, and economic challenges.

1.2.4 Key Principles of Humanitarian Action: Framework for Humanitarian Response:

The humanitarian principles play a vital role in guiding and shaping humanitarian action. These principles encompass fundamental values and guidelines, including humanity, impartiality, neutrality, independence, and voluntary service (Table 1.1).⁶ The term "Humanitarian" refers to actions and initiatives that aim to promote human welfare, such as providing aid and support to individuals facing adversity. It also encompasses individuals and organizations committed to advocating for humanitarian causes.

While "saving lives" is a crucial objective of humanitarian action, it is not the sole purpose. The broader aim of humanitarian action is to alleviate suffering, uphold human dignity, and protect the rights of individuals affected by various

crises, including natural disasters, armed conflicts, and emergencies. Additionally, humanitarian organizations endeavor to prevent future crises and promote recovery and sustainable development within affected communities. The primary focus is on delivering immediate assistance, protection, and essential services like food, shelter, and medical care to those in need.

Table 1.1: Humanitarian principles with explanations

Principles	Explained
Humanity	The principle of humanity dictates that in humanitarian actions, the foremost priority should be given to the well-being and needs of individuals affected by a crisis. It emphasizes the imperative to prevent and alleviate suffering through dedicated efforts.
Impartiality	The principle of impartiality in humanitarian action mandates that aid should be allocated solely based on the level of need, without any form of discrimination based on factors such as race, ethnicity, religion, or political affiliation. It emphasizes the importance of prioritizing assistance to those individuals or communities who are most vulnerable and require immediate support. The aim is to ensure fairness and equity in the distribution of humanitarian aid, focusing on addressing the needs of the affected population without any biased preferences or exclusions.
Neutrality	The principle of neutrality in humanitarian action emphasizes the importance of remaining impartial and avoiding involvement in conflicts or political agendas. Humanitarian organizations are committed to providing aid based solely on the needs of affected individuals, without any form of discrimination or bias. This ensures that assistance is delivered in a fair and unbiased manner, prioritizing the well-being and protection of those affected by crises.
Independence	In order to maintain integrity and ensure effective humanitarian action, organizations must maintain independence from political, economic, and military influences. They must have the autonomy to make decisions and allocate resources based solely on the needs and well-being of the individuals they serve.
Voluntary service	Humanitarian action must always be voluntary, respecting the autonomy and dignity of individuals and communities. It is crucial that aid is not imposed upon those receiving it, but rather offered in a manner that allows for informed decision-making. Individuals and communities affected by crises should have the freedom to accept or decline assistance based on their own needs, priorities,

	and cultural considerations. By upholding the principle of voluntarism, humanitarian organizations promote the empowerment and agency of those they aim to support, fostering a more respectful and participatory approach to humanitarian assistance.
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The Health Emergency, Preparedness and Response division of the World Health Organization (WHO) is entrusted with the primary role of spearheading WHO's endeavors in readiness and response to health emergencies and disasters, encompassing those arising from natural phenomena or human activities.⁷ This entails furnishing countries and partners with technical guidance, fostering coordination, and extending support. Additionally, the division assumes a leadership role in formulating global policies and plans pertaining to health emergency and disaster risk management. WHO collaborates closely with various organizations and agencies, including the World Food Programme (WFP), the United Nations International Children's Emergency Fund (UNICEF), and the International Red Cross (IRC), to ensure a synchronized and harmonized approach in addressing emergencies and disasters.

1.2.5 Palliative Care:

During the 67th World Health Assembly (WHA) in 2014, the Resolution WHA 67.19, which was titled “Strengthening of palliative care as a component of comprehensive care throughout the life course”, was adopted, signifying a significant milestone.⁸ This resolution entrusted the World Health Organization (WHO) with the responsibility of collaborating with international experts and partner organizations to provide practical guidance to countries in implementing palliative care programs. The primary objective of this resolution was to promote the seamless integration of palliative care as an integral component of healthcare services across diverse healthcare settings.

A crucial element emphasized within this resolution is the integration of palliative care and symptom relief during humanitarian emergencies and other crises. This directive acknowledges the importance of ensuring access to palliative care and effective symptom management, even in challenging circumstances such as the global COVID-19 pandemic. By prioritizing the integration of palliative care within emergency response frameworks, the resolution seeks to address the specific needs and alleviate the suffering of

individuals facing humanitarian crises, including those induced by any pandemic.

Palliative care encompasses three dimensions: it is a service, a system, and a specialty dedicated to providing comprehensive care to individuals of all ages who are dealing with a serious illness. This includes conditions such as heart failure, chronic obstructive pulmonary disease, various forms of cancer, dementia, neuromuscular diseases, and other debilitating ailments. Palliative care involves an interdisciplinary team of healthcare professionals who collaborate to offer active, holistic support. Through this therapeutic process, healthcare providers are able to compassionately and empathetically address the multifaceted suffering experienced by patients and their families, instilling a sense of hope.

The core principles of palliative care focus on effectively managing symptoms and enhancing the quality of life for individuals living with life-limiting illnesses. Palliative care should be accessible at any stage of the disease process, alongside curative treatments, and is not contingent upon reaching the end stages of the illness. Ensuring that all patients receiving palliative care receive exceptional care is a collective responsibility of the entire healthcare team, rather than solely relying on a single specialist. Early identification and assessment of the quality of palliative care provided can offer valuable insights for improvement opportunities.

The World Health Organization (WHO) has released two important resources to support the expansion of quality palliative care worldwide. The first resource provides a set of actionable indicators for assessing and monitoring the provision of palliative care services in different countries.⁸ These indicators go beyond the consumption of opioid analgesics to provide a comprehensive view of palliative care development. The second resource focuses on improving the quality of palliative care services, offering guidance to policymakers and practitioners on various aspects of quality, including effectiveness, safety, and people-centeredness.⁹ Both resources are crucial in advancing palliative care as an integral part of Universal Health Coverage (UHC), alongside other important WHO resources. By utilizing these resources, countries can enhance their palliative care programs and bridge the existing gap in palliative care provision globally, ensuring that no one is left without access to quality palliative care.

1.2.6 Defining Palliative Care:

According to the World Health Organization (WHO), palliative care is defined as the comprehensive approach to preventing and alleviating the suffering experienced by adult and pediatric patients, as well as their families, who are confronted with the challenges associated with life-threatening illnesses. These challenges encompass not only the physical aspects but also the psychological, social, and spiritual dimensions of patient suffering, as well as the psychological, social, and spiritual impact on family members.

Defining palliative care presents challenges, as there is no universally accepted single definition. However, the World Health Organization (WHO) provides a commonly shared understanding of the fundamental concepts and defining elements. The global palliative care community often refers to the WHO's (2002) definition of palliative care.¹⁰

Palliative care is

“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

Nine overarching dimensions that characterize palliative care accompany this definition:

- Provides effective relief from pain and alleviates other distressing symptoms
- Acknowledges and respects the natural process of dying as a normal part of life
- Does not aim to hasten or postpone death, maintaining a neutral stance
- Integrates comprehensive care that addresses the psychological and spiritual aspects of patient well-being
- Establishes a support system to enable patients to live actively and meaningfully until the end of life
- Extends support to the family, assisting them in coping with the patient's illness and their own bereavement
- Adopts a collaborative team approach to address the diverse needs of patients and their families, including bereavement counseling, when necessary
- Enhances overall quality of life and may positively impact the course of the illness

- Is applicable early in the disease trajectory, alongside other therapies aimed at prolonging life, such as chemotherapy or radiation therapy, and includes investigations to better understand and manage distressing clinical complications.

WHO also has a separate definition for paediatric palliative care:¹¹

“Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.”

This also aims for four dimensions:

- It begins right from the time of diagnosis of the illness, and continues throughout the disease trajectory, death and bereavement.
- It evaluates and alleviates physical, psychological, social and spiritual distress.
- It involves an interdisciplinary team with an inclusive approach of using available community resources
- It can be provided at home, hospital, in community health centers – wherever the patient stays

1.2.7 Redefining Palliative Care:

In 2017, The Lancet Commission Report on Palliative Care and Pain Relief presented a groundbreaking study on palliative care.¹² According to this report, an estimated 60 million individuals, including 5.3 million children, require palliative care annually as they navigate their medical conditions. Among them, approximately 25.6 million individuals require palliative care specifically towards the end of life. The Commission defined palliative care as an indispensable element of comprehensive care for individuals with complex chronic or acute, life-threatening, or life-limiting health conditions.

To address this need, the report proposed an "essential package" of cost-effective and accessible interventions capable of delivering effective palliative care and alleviating suffering associated with severe illness across diverse settings. Furthermore, the Global Atlas of Palliative Care reported a total of 56 million deaths in 2016 across 195 countries, with 73.4% of these deaths attributed to non-communicable diseases.¹³

Within an evolving world, the Commission initiated a transformative movement to redefine palliative care. This redefinition extends the scope beyond

individuals with serious or life-limiting illnesses to encompass those with chronic conditions or disabilities. It emphasizes the importance of expanding access to palliative care and delivering it at earlier stages of the illness trajectory. Redefining palliative care also involves embracing integrative approaches, such as integrating alternative therapies and addressing patients' emotional, spiritual, and social needs. This comprehensive approach aims to enhance the overall quality of care and support provided to individuals throughout their healthcare journey.

In 2019, the International Association for Palliative Care (IAHPC), in collaboration with a diverse group of palliative care experts, practitioners, and caregivers from 88 countries, developed an updated consensus-based definition of palliative care.¹⁴ While not universally accepted, their suggested definition is as follows:

"Palliative care is the active holistic care provided to individuals of all ages who experience serious health-related suffering due to severe illness, particularly those nearing the end of life. Its objective is to enhance the quality of life for patients, their families, and their caregivers."

Palliative care encompasses the following key elements:

- It encompasses preventive measures, early identification, comprehensive assessment, and evidence-based management of physical issues, including pain, distressing symptoms, psychological distress, spiritual distress, and social needs.
- Palliative care provides crucial support to enable patients to experience a meaningful life until the end of their journey by promoting effective communication and assisting them and their families in establishing care goals.
- It is a comprehensive approach applicable throughout the entire duration of an illness, adapting to the specific needs of each patient.
- Palliative care is delivered in conjunction with disease-modifying therapies as necessary, ensuring a holistic and integrated approach to patient care.
- Notably, palliative care holds the potential to positively impact the course of illness, enhancing patients' overall well-being.
- Significantly, the fundamental principle of palliative care is to neither hasten nor postpone death, thereby acknowledging and respecting the

inherent value of life while recognizing dying as an intrinsic and natural process.

- Palliative care extends its support to the patient's family and caregivers during the illness and in their bereavement process.
- It is delivered with a deep understanding and respect for the cultural values and beliefs of both the patient and their family.
- Palliative care is applicable across diverse healthcare settings, encompassing various places of residence and healthcare institutions, and is relevant at all levels of care, ranging from primary to tertiary.
- While basic palliative care training equips professionals to provide palliative care, complex cases may necessitate specialist palliative care and the involvement of a multidisciplinary team.

The redefinition of palliative care has posed a significant challenge, requiring a delicate balance between two contrasting perspectives. On one hand, there is the belief that palliative care encompasses the relief of all forms of suffering, while on the other hand, it is seen as solely addressing the needs of individuals with a limited remaining lifespan, typically those expected to pass away within a few days or weeks. Personally, I find myself adopting a middle-ground stance on this matter.

In my opinion, it is crucial to incorporate the phrase "life-threatening and life-limiting conditions" within the definition of palliative care to ensure the application of established philosophies and guidelines that have evolved over time. This inclusive approach recognizes that many patients with incurable diseases experience severe suffering and require palliative care as their primary support option. Simultaneously, it acknowledges the importance of addressing practical, non-medical sources of suffering, such as the lack of access to basic necessities like food, shelter, water, and sanitation. These aspects must be given due consideration and prioritized alongside, and sometimes even prior to, the implementation of healthcare interventions.

By embracing this balanced perspective, palliative care can fulfill its role in providing comprehensive support and alleviating suffering for individuals with life-threatening and life-limiting conditions. It acknowledges the practical realities faced by patients and seeks to address their holistic needs, ensuring that both medical and non-medical aspects are appropriately addressed.

1.2.8 Palliative Care and Universal Health Coverage:

Palliative care plays a crucial role in achieving the objective of universal health coverage (UHC).¹⁵ The 2018 WHO, World Bank, and Organization for Economic Co-operation and Development (OECD) report emphasizes the importance of delivering quality health services for universal health coverage. It provides recommendations for governments, health systems, citizens, patients, and health workers. While these recommendations are generally applicable to fragile, conflict-affected, and vulnerable settings, adjustments are needed to accommodate challenges such as lack of functioning national governments or suitable governance structures in those settings.

The 2018 Astana Declaration on Primary Health Care (PHC) emphasized the importance of enhancing palliative care within the PHC system.¹⁶ It urged the provision of comprehensive healthcare services throughout people's lives, encompassing preventive, promotive, curative, rehabilitative, and palliative care. The Declaration advocated for the integration of healthcare services, particularly in primary care, and emphasized the significance of essential public health functions.

UHC aims to ensure that all individuals in need of health services, including promotion, prevention, treatment, rehabilitation, and palliation, are able to access them without facing excessive financial burdens. The core principles of UHC revolve around equity, ensuring that even rural areas and the most disadvantaged populations have equal access to the necessary healthcare services. UHC also emphasizes the importance of providing high-quality healthcare services while reducing the financial risks associated with healthcare expenses.

When palliative care is effectively and equitably delivered, it has a profound impact. It alleviates suffering, improves the quality of life for individuals with serious illnesses, enhances health outcomes, and mitigates the financial shocks that can arise from medical expenses. By addressing the holistic needs of patients and ensuring that they receive comprehensive care, palliative care contributes to achieving UHC goals and promotes a more equitable and compassionate healthcare system.

1.2.9 Palliative Care and Health Insurance Coverage:

A substantial body of evidence supports the provision of palliative care across diverse settings, such as hospitals, hospices, and community-based care, making it suitable for individuals of all ages and at any phase of illness. To achieve universal access to palliative care, integration of these services into the broader healthcare system is crucial. Moreover, there is a growing body of evidence highlighting the importance of incorporating palliative care within health insurance coverage. By ensuring that palliative care services are included in health insurance plans, discrimination can be minimized, and individuals are protected from financial hardship caused by out-of-pocket expenses for essential healthcare services. This approach also safeguards vulnerable families from experiencing long-term negative consequences that may impact future generations. By promoting the integration of palliative care into healthcare systems and providing coverage through health insurance, we can strive to eliminate barriers to access and guarantee equitable and sustainable palliative care services for all individuals and their families.

1.2.10 Palliative Care and Scarcity of Trained Healthcare Professionals:

The advancement of palliative care has faced significant challenges worldwide, particularly in low and middle-income countries, due to a shortage of adequately trained healthcare professionals specialized in palliative care. In countries where there is a general scarcity of healthcare professionals, it has been particularly challenging to prioritize investment in palliative care training and incorporate comprehensive palliative care education into existing curricula. Consequently, many healthcare practitioners find themselves caring for patients with severe pain and life-limiting illnesses without possessing the necessary skills and knowledge to deliver optimal care.

This scarcity of trained professionals has hindered the provision of high-quality palliative care, depriving patients of the best possible support and symptom management. It underscores the urgent need for increased investment in palliative care education and training opportunities to equip healthcare practitioners with the expertise needed to address the complex needs of individuals with life-limiting conditions. By enhancing the availability of training in palliative care approach, healthcare professionals will be better prepared to provide comprehensive and compassionate palliative care to those who need it most.

1.2.11 Health Care Quality Improvement:

According to Deming (2018), the essence of quality lies in a product or service's ability to effectively meet the needs of individuals and sustain a strong and lasting presence in the market.¹⁷ Avedis Donabedian, widely recognized as the pioneer in conceptualizing quality in healthcare, established a comprehensive framework consisting of three key components: structure, process, and outcome.¹⁸ This framework serves as a foundational approach to define and evaluate quality healthcare. In Donabedian's framework, structure encompasses the tangible and organizational attributes of a healthcare setting, encompassing factors like facilities and staffing. Process, on the other hand, pertains to the specific procedures and practices employed in delivering care, including diagnostic testing and treatment plans. Outcome reflects the ultimate results of healthcare, encompassing aspects like patient recovery and satisfaction. Donabedian emphasizes that enhancing the quality of healthcare necessitates addressing all three elements, recognizing their interconnectedness and significance.

In 1990, the Institute of Medicine (IOM) established a definition of healthcare quality that has remained influential and frequently cited. According to the IOM, healthcare quality refers to the extent to which health services, both for individuals and populations, enhance the probability of achieving desired health outcomes while aligning with current professional knowledge.¹⁹

The World Health Organization (WHO) has adapted and expanded upon this definition, encompassing a broader perspective of quality healthcare. WHO defines quality health care as the extent to which healthcare services, provided to individuals and populations, enhance desired health outcomes and align with the needs of patients while being consistent with current professional knowledge. Quality health care is characterized by effectiveness, safety, patient-centeredness, timeliness, efficiency, and equity.²⁰ Additionally, WHO emphasizes that quality health care should uphold the rights and dignity of patients and be responsive to the cultural and social diversity of the population it serves.

In my thesis, I focus on and expand upon the following attributes of quality healthcare:

- **Effectiveness:** The provision of healthcare services based on scientific knowledge and the application of evidence-based practices to ensure appropriate and optimal care.

- **Safety:** Prioritizing patient well-being by delivering care that is intended to prevent harm and minimize risks associated with medical interventions.
- **People-Centredness:** Recognizing the individuality of patients by considering their preferences, needs, and values, and promoting respect, dignity, and involvement in their care.
- **Timeliness:** Minimizing waiting times and avoiding unnecessary delays in delivering care to both patients and healthcare providers, thus enhancing access and responsiveness.
- **Equity:** Ensuring that the quality of care remains consistent regardless of personal characteristics such as gender, age, ethnicity, geographical location, socioeconomic status, language, or political affiliation.
- **Integration:** Establishing coordination mechanisms that facilitate seamless and continuous care across different healthcare services, including promotion, prevention, treatment, rehabilitation, and palliative care.
- **Efficiency:** Optimizing resource utilization to maximize benefits and minimize waste, encompassing equipment, supplies, ideas, and energy, with a focus on achieving optimal outcomes with available resources.

These attributes serve as the foundation for my thesis, where I delve into their significance and implications in the context of quality healthcare. Quality healthcare should cover the entire lifespan and spans across generations, addressing various stages of life and health needs. It encompasses a wide spectrum of care, including preventive, promotive, curative, rehabilitation, and palliative care. These services can be provided at multiple levels of care, ranging from the primary level, which includes self-care, home-based care, and community care, to the secondary and tertiary levels of care, which involve specialized and advanced medical interventions. The provision of quality healthcare also involves seamless coordination and appropriate referrals between different levels of care to ensure comprehensive and continuous support for individuals' health and well-being. Healthcare organizations hold the responsibility for ensuring the delivery of quality care to their service users.²¹ Within these organizations, healthcare professionals play a crucial role in recognizing their individual responsibilities in providing high-quality care and actively sharing good practices to enhance the overall quality of care provided.

The absence of access to safe, effective, and trusted healthcare poses a significant risk of exacerbating health outcomes.²² The World Health Organization (WHO) has highlighted that ensuring access to quality care could

potentially prevent 2.5 million deaths from cardiovascular disease, 1 million newborn deaths, and half of all maternal deaths annually. However, numerous healthcare settings lack even the most basic infrastructure, such as access to clean water in health facilities.

In low- and middle-income countries, inadequate quality of care is responsible for an estimated 5.7 million to 8.4 million deaths each year. Recognizing the urgent need for improvement, three global reports in 2018 emphasized the importance of enhancing the quality of care as countries strive to achieve universal health coverage. There is a growing body of literature recognizing the imperative to enhance the quality of care in fragile, conflict-affected, and vulnerable (FCV) settings.^{23,24}

The World Health Organization (WHO) has emphasized the significance of delivering quality care in such settings through their 'Quality Improvement Program'²⁵ This entails ensuring that individuals have access to essential health services, including primary care, maternal and child health services, and mental health care, even in the midst of conflict or other crises. WHO also underscores the importance of safeguarding health workers and facilities from attacks and providing support to health systems that have been adversely affected by conflict. Collaborating with governments, local organizations, and other partners, WHO strives to bolster the provision of health services in FCV settings and advocate for the protection of the right to health for all individuals. Despite global efforts to strengthen health systems and improve the quality of health services, the variability of quality care persists, particularly in addressing the unique challenges of FCV settings. A comprehensive review conducted in 2018 shed light on the uncertainty surrounding the quality of care and the moral distress experienced by healthcare professionals as a result of inadequate guidance and support.²⁶

1. 2.12 Palliative Care in Humanitarian Settings:

Within fragile, conflict-affected, and violence-prone settings, access to healthcare is severely restricted and resources are scarce, resulting in substandard quality of care due to external pressures and inequitable distribution. However, it is in these challenging contexts that we witness a heightened degree of suffering, with patients enduring severe pain and many living with untreated life-limiting illnesses. Achieving the necessary level of care that aligns with the quality indicators established by the WHO becomes even

more intricate in such circumstances. Adequate access to care is particularly crucial for patients facing heightened levels of suffering and those in the active dying process.²⁷⁻²⁸

The term "fragile, conflict-affected, and vulnerable (FCV) settings" refers to a diverse range of circumstances marked by crises arising from multiple factors. While a universally agreed-upon global definition is lacking, these settings typically encompass situations characterized by humanitarian crises, protracted emergencies, sustained disruption to critical public services or governance (such as challenges of a political or economic nature, conflict, or natural disasters), or armed conflicts.

Fragile, conflict-affected, and vulnerable settings are particularly susceptible to significant public health emergencies, which can intensify the strain on essential services.²⁹ These emergencies include infectious disease outbreaks and natural disasters. It is worth noting that more than 70% of major infectious disease epidemics transpire within such fragile, conflict-affected, and vulnerable settings.

Palliative care was almost non-existent in humanitarian crises until the last few years. Three technical resources have been developed from 2018-2021 to enhance the delivery of quality services in fragile, conflict-affected, and vulnerable settings. These resources include publications like the Sphere handbook,³⁰ Classification and minimum standards for foreign medical teams in sudden onset disasters.³¹ Additionally, clinical guidelines adapted to humanitarian contexts, coordination standards, and information management standards have been developed. There is also a growing effort among individual organizations to implement quality improvement interventions within healthcare programs in challenging environments.

This guide represents the fourth installment in the series of World Health Organization (WHO) guidance documents focused on palliative care. It highlights the crucial importance of integrating palliative care and pain relief into the response to various types of humanitarian emergencies and crises, both from a medical and ethical standpoint.

The guide presents an expanded understanding of palliative care tailored to meet the specific needs of individuals affected by such emergencies and crises. Additionally, it introduces the concept of an Essential Package of Palliative Care for Humanitarian Emergencies and Crises (EP Hum) as a proposed framework. These resources and initiatives aim to improve service delivery and ensure quality care in complex and demanding situations.

In 2018, the World Health Organization (WHO) revised a set of triage categories for humanitarian emergencies and crises, advocating for the inclusion of palliative care within the triage process.⁵ The purpose of triage is to ensure that the most critically ill patients receive the medical attention they need as quickly as possible. It also helps to ensure that the limited resources available in an emergency department are used most efficiently. Triage is a critical part of emergency medicine, and is used in many other settings, including mass casualty incidents, natural disasters, and even in primary care clinics.

Triage is not just about allocating resources, but also about making difficult decisions. In mass casualty incidents, the number of patients and the severity of their injuries may far exceed the available resources. In these situations, triage is used to determine which patients are most likely to survive with medical treatment, and which patients are unlikely to survive despite treatment

Table 1.2: Recommended Triage Categories in Humanitarian Emergencies and Crises.

Category	Colour code	Description
1a. Immediate	Red	Survival possible with immediate treatment. Palliative care should be integrated with life-sustaining treatment as much as possible.
2a. Expectant	Blue	Survival not possible given the care that is available Palliative care is require
	Yellow	Not in immediate danger of death, but treatment needed soon. Palliative care and/or symptom relief may nevertheless be needed immediately.
3. Minimal	Green	Will need medical care at some point, after patients with more critical conditions have been treated. Symptom relief may be needed.

(Source: Adapted from WHO, 2018)⁵

1.2.13 Quality in Humanitarian Palliative Care:

In the context of fragile, conflict-affected, and vulnerable settings, the success and long-term sustainability of well-intentioned quality initiatives are highly unlikely. This factor becomes a crucial aspect to consider, given the immense challenges that these settings encounter. Quality is a fundamental aspect of palliative care, as it guarantees that patients and their families receive optimal care and support during challenging circumstances. Quality palliative care encompasses addressing the comprehensive needs of patients and their families, encompassing the physical, emotional, spiritual, and practical dimensions.

By offering clear and accurate information about the illness and treatment alternatives, quality palliative care enhances patients' quality of life and alleviates their suffering. Moreover, it can contribute to the reduction of healthcare costs by minimizing the necessity for hospitalization and intensive medical interventions.

A culture of quality does not have a singular definition, but when it comes to health service providers, it has been characterized as follows: “a working environment which is open and participative, where ideas and good practices are shared, where education and research are valued and where blame is used exceptionally.” A culture of quality in health service providers involves strong leadership, openness, transparency, and accountability. It emphasizes teamwork, continuous learning, and meaningful engagement of the workforce, service users, and communities. It empowers individuals while recognizing complex system aligns professional and organizational values, and values compassionate care. It also ensures coherence between quality efforts and service organization and planning.

The WHO's "Quality Health Services: A Planning Guide" is an essential document that expands on the national quality policy and strategy approach.³² It presents a range of vital activities and foundational prerequisites for ensuring quality health services at various levels of the healthcare system. The guide emphasizes the interconnectedness of initiatives to improve healthcare facilities, provide subnational support, and establish a clear national direction. The insufficient availability of quality palliative care services in FCV settings is a pressing concern, and there remains a scarcity of evidence regarding

effective strategies for integrating and sustaining quality palliative care in such contexts.

Further research is warranted to document the significance of quality palliative care in enhancing FCV settings and to better understand and address the challenges associated with their implementation and adoption. This research will contribute to the identification of valuable insights and evidence-based practices that can strengthen palliative care services in FCV settings, ultimately improving the well-being of individuals in these settings.

1.2.14 Designing and Delivering Palliative Care in Humanitarian Settings:

Just as quality care relies on many different factors so too does the provision of quality palliative care.³³ These factors encompass the availability of healthcare services, appropriate allocation of resources, access to training opportunities for healthcare professionals, consideration of cultural aspects, the skills and competency of healthcare professionals, as well as effective supervision and monitoring of care.³⁴ Together, these elements contribute to ensuring the delivery of high-quality palliative care.³⁵

Table 1.3: Implementation strategies recognized by the World Health Organization (WHO) for the advancement of quality palliative care:

Topic	Explained
Building capacity	The training of healthcare professionals in palliative care principles, skills, and knowledge plays a pivotal role in fostering the advancement of quality palliative care.
Developing guidelines and protocols	The establishment of guidelines and protocols for palliative care in humanitarian settings serves as a crucial step in ensuring the consistent and effective delivery of care.
Incorporating palliative care into existing healthcare systems	The integration of palliative care into existing healthcare systems is essential, emphasizing its incorporation within the broader healthcare framework rather than its isolation as a standalone service.

Addressing cultural and social factors	Palliative care in low- and middle-income countries (LMICs) should encompass an understanding of the cultural and social factors that influence the delivery of care. By considering these factors, palliative care can be tailored to effectively address the unique needs and preferences of individuals within specific cultural and social contexts.
Using technology to improve access	The utilization of telemedicine and other technological advancements can play a crucial role in enhancing access to palliative care in remote and underserved regions. These innovative approaches have the potential to bridge geographical barriers, allowing individuals in distant areas to benefit from palliative care services, thus improving overall accessibility and expanding the reach of care.
Community engagement	The provision of palliative care should be carried out in collaboration with communities, employing a community-based approach that engages local healthcare workers, traditional healers, and community leaders. This inclusive approach fosters a sense of ownership and involvement within the community, ensuring that palliative care services are culturally sensitive, responsive to local needs, and effectively integrated into the existing healthcare framework.
Multi-disciplinary care team	The adoption of a team-based approach, involving diverse healthcare providers with specialized expertise, can ensure the delivery of comprehensive care to patients. By leveraging the collective knowledge and skills of various healthcare professionals, this collaborative approach enhances the coordination of care, promotes interdisciplinary collaboration, and enables a holistic approach to palliative care that addresses the multifaceted needs of patients.
Research and evaluation	Research and evaluation play a vital role in comprehending the effectiveness of palliative care in low- and middle-income countries (LMICs) and identifying areas that require improvement. By conducting rigorous studies and assessments, valuable insights can be gained regarding the impact and outcomes of palliative care interventions. This knowledge not only informs evidence-based practices but also facilitates the identification of strategies to enhance the quality and accessibility of palliative care services in LMICs.

1.2.15 Compassionate Care:

This PhD research aims to bring together three fundamental components: palliative services, the unique requirements of patients in humanitarian settings, and the concept of compassion. The primary objective is to investigate the possibility and approaches for providing quality palliative care within humanitarian contexts. Delivering care in such settings necessitates a profound understanding of the cultural and socio-economic factors at play, as well as the ability to adapt to dynamic conditions and promptly respond to the needs of those affected by the crisis. It also requires a strong commitment to serving others and a willingness to work in challenging and potentially hazardous environments.³⁶

Compassion holds significant recognition as a vital element within the realm of palliative care, encompassing the values of kindness, empathy, and understanding towards individuals. It entails acknowledging the person or community beyond the illness or outbreak. Within the context of a humanitarian camp, compassion serves as both a means to deliver palliative care and an outcome of it. Demonstrating compassion can assist individuals in navigating their challenging circumstances, enhancing their overall well-being. Furthermore, it aids frontline staff in operating effectively within demanding conditions.

An intersection of quality healthcare, palliative care, and healthcare in disaster and emergency situations emerges through the concept of compassion. Remarkably, the World Health Organization (WHO) has formulated a theory of compassion that serves as the cornerstone and indicator of quality care. A noteworthy contribution to this understanding is a WHO Learning Brief titled "The role of compassion in maintaining quality essential health services during the COVID-19 pandemic."³⁷⁻³⁹

The World Health Organization (WHO) has released a collection of Learning Briefs through its Quality Care Unit. These briefs aim to assist global programs in translating theory into practical actions by providing valuable insights and lessons learned. The Learning Briefs consolidate essential knowledge and experiences from various countries, focusing on strategies to ensure the continuity of vital health services and the recovery of health systems amidst the challenges posed by the COVID-19 pandemic and its aftermath.

Providing appropriate care for individuals with life-limiting illnesses in humanitarian settings is inherently complex. However, the challenges intensify when considering the additional complexities posed by a pandemic. Undertaking this PhD research amidst the backdrop of the COVID-19 pandemic has offered valuable insights into the adaptability of systems and the strategies required to ensure the resilience and sustainability of care in the future.

1.2.16 Navigating the Complexities of a Syndemic:

The COVID-19 pandemic exerted immense pressure on health systems worldwide. In humanitarian settings, this crisis imposed additional layers of challenges onto already fragile systems, which were grappling with the intricate management of multiple shocks. A syndemic theory refers to the simultaneous occurrence and interaction of two or more epidemics or pandemics within a population, leading to heightened adverse health outcomes.⁴⁰ Syndemic theory suggests that the co-occurrence of multiple epidemics, their meaningful interactions, and shared underlying factors are essential in understanding disease emergence. These factors encompass structural, social, cultural, ecological, and economic dynamics. This concept emphasizes the importance of considering biological, social, and psychological processes within specific contexts to fully grasp the complexity of epidemics.

Clinicians may hold divergent viewpoints on whether it is within their expertise to address broader issues beyond the clinical encounter. However, existing literature supports the notion that acknowledging the impact of structural and contextual factors on psychological distress, safety concerns, fear, and fragmented care for chronic conditions is well within the realm of clinical care. The syndemic example of Mexican immigrant women in the Chicago area revealed the interconnectedness of violence, migration, diabetes, depression, and abuse. Through a mixed-methods study, it was found that experiences of violence and fear related to immigration policy contributed to psychological distress and had adverse effects on chronic illness, particularly diabetes.⁴¹

Providing services in humanitarian settings amid a syndemic, such as COVID-19 pandemic, poses numerous challenges. These challenges encompass complexities in coordination, security concerns, constrained resources, logistical and infrastructural limitations, inadequate data collection and analysis, vulnerability, stigma, and structural issues. Effectively addressing syndemic challenges necessitates adopting a comprehensive approach that recognizes

the interconnected nature of diverse health issues and considers the social determinants of health. ⁴²

Table 1.4: Challenges in humanitarian settings during a syndemic:

Topic	Explained
Complexity	Syndemics involve multiple health problems that interact and exacerbate one another, making it difficult to understand and address the underlying causes.
Security	Providing services in areas affected by conflict or insecurity can put humanitarian workers at risk.
Limited resources	Humanitarian organizations often have limited resources, making it difficult to respond to the increased needs caused by a syndemic.
Access to healthcare	Syndemics often disproportionately impact marginalized communities, who may have limited access to healthcare and other services.
Logistics and infrastructure	Delivering services in disaster-stricken or war-torn areas can be challenging due to lack of infrastructure and limited access to transportation.
Addressing structural issues	A syndemic highlights and amplifies structural issues such as poverty, discrimination, and inequality, which require systemic change to address.
Lack of coordination	Multiple sectors, organizations and actors are involved in a syndemic response, which can be challenging to coordinate and align. Different organizations and agencies may be working on different aspects of the syndemics, leading to a lack of coordination and potentially inefficient use of resources.
Mental health	People affected by a syndemic may experience increased levels of stress, anxiety, and depression, which can be challenging for humanitarian organizations to address.
Vulnerability	Populations affected by syndemics are often marginalized and vulnerable, which can make it difficult to reach and provide services to them.
Stigma	People affected by syndemics may face stigma and discrimination, which can make it difficult to access services and discourage them from seeking help.

Limited data collection and analysis	Accurate data collection and analysis are key to understanding and responding to the impact of a syndemic, but can be challenging in humanitarian settings. Data on the prevalence and impact of syndemics is often limited, making it difficult to understand the scope of the problem and plan effective interventions.
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Examining the dynamics of challenges in the syndemic created by COVID-19 in the Rohingya camps sheds light on the stakes in structural and contextual factors in their fragmented care and epistemic dimensions. By understanding the hidden health consequences of these social factors, we are better able to understand not only the dynamics of humanitarian response, but also the alternative futures that are obscured in the Rohingya camps and elsewhere. Recognizing the Need for Palliative Care During the Pandemic

During the 73rd World Health Assembly in May 2020, a significant resolution, WHA73.1, was passed, urging the inclusion of palliative care as an essential component of care for patients affected by COVID-19. Recognizing the critical need for compassionate and supportive care during the pandemic, Member States collectively emphasized the importance of palliative care provision for individuals facing the challenges of the virus.⁴³

As an advocacy focal point of the International Association of Hospice Palliative Care (IAHPC), I actively participated in the process held in Geneva. In this capacity, I engaged in discussions, negotiations, and collaborative efforts to highlight the significance of palliative care within the broader context of COVID-19 management, including humanitarian contexts. By advocating for the integration of palliative care principles into the global response to the pandemic, we aimed to ensure that individuals with COVID-19 had access to holistic, person-centered care that addressed their physical, psychological, and social needs.

In response to the resolution passed at the World Health Assembly, the World Health Organization (WHO) swiftly acknowledged the importance of palliative care in the care continuum for COVID-19 patients. The WHO issued recommendations that emphasized the availability of palliative care services within healthcare facilities specifically designated for COVID-19 patients. These recommendations underscored the essential components necessary for

effective palliative care delivery, including the provision of appropriate medications, specialized equipment, skilled human resources, and robust social support systems.

1.2.17 The Rohingya Community in Cox's Bazar:

The Rohingya community, an ethnic group adhering to the Muslim faith, primarily resides in the western region of Myanmar's Rakhine state, which is predominantly influenced by Buddhism.⁴⁴ Unfortunately, the Rohingya population has been subjected to persistent persecution and violence within Myanmar for an extended period of time.⁴⁵ Consequently, a substantial number of Rohingya individuals have sought refuge in the neighboring country of Bangladesh over the past five decades. The decision to flee their homeland is a direct consequence of the prolonged experience of government-sponsored discrimination, detention, violence, and torture endured by the Rohingya community.⁴⁶ The situation further intensified in August 2017 when an armed conflict erupted in Myanmar's Rakhine state, engulfing the Rohingya population in a state of turmoil. As a result, an overwhelming influx of over 750,000 Rohingya individuals sought sanctuary in Cox's Bazar, a coastal district located in the southeastern region of Bangladesh.⁴⁷

The arrival of a substantial Rohingya population has engendered multifaceted socio-cultural, economic, and political repercussions for Bangladesh, with notable implications for the country's health and development sectors, as well as the local host community. The management of basic needs, healthcare, well-being, employment, education, and social cohesion for these traumatized populations has posed significant challenges. Recognizing the urgent need, the Government of Bangladesh designated 5,000 acres of land to construct temporary shelters to accommodate the influx of refugees.

Additionally, the government has undertaken measures such as food provision, deployment of mobile medical teams, and large-scale immunization campaigns. However, it is important to highlight that despite these efforts, the provision of palliative care services remain entirely absent in the refugee camps, representing a crucial gap in the comprehensive healthcare support being provided.

The primary emphasis has been placed on the provision of immediate emergency care services, while other crucial aspects have received comparatively limited attention. Phillips (2015) underscored the presence of overcrowded conditions, inadequate access to safe drinking water, the absence of basic sanitation facilities, and unhygienic environments within the refugee camps.⁴⁸ These conditions have significantly elevated the vulnerability of the Rohingya community to the persistent threat of communicable diseases.

Furthermore, the Rohingya community, alongside the wider population residing in Cox's Bazar district, located on the southeastern coast of Bangladesh, confronts emerging threats stemming from major tropical cyclones, floods, and landslides.⁴⁹ These adverse weather events, intensified by the impacts of climate change, have significantly disrupted the infrastructure of the refugee camps. As a result, there has been an alarming increase in the displacement of refugees. Moreover, the persistently rising temperatures and shifts in rainfall patterns have profound effects on food security and access to clean water, exacerbating the already dire humanitarian crisis faced by the Rohingya refugees.⁵⁰

The Rohingya community has been denied authorization to construct permanent structures that are resilient to cyclones, consequently compelling them to reside in densely populated temporary makeshift shelters constructed from plastic sheets, tarpaulins, and bamboo. The absence of sturdy housing arrangements increases their vulnerability to the destructive forces of cyclones. Additionally, the extensive loss of vegetation across approximately 573 hectares of land within the refugee camp area has detrimental effects on climate mitigation efforts, further exacerbating the environmental challenges faced by the Rohingya community.

1.2.18 Impact of COVID-19 on Rohingya Community:

The Rohingya community, in their efforts to establish camps, cleared natural forests and social forestry plantations that served as vital habitats and corridors for the critically endangered wild Asian elephant (*Elephas maximus*) in Bangladesh. The refugees extensively collected timber and fuelwood from the forests for construction and cooking purposes, resulting in the destruction of approximately 2,000 hectares of forested land. Consequently, *Elephas maximus*, in search of food and natural movement routes, ventured into the camps, leading to the destruction of settlements and triggering severe human-

elephant conflicts. Tragically, this conflict resulted in the loss of 13 refugee lives and left nearly 50 people injured.^{51,52}

Growing concerns have arisen regarding the protection and welfare of the Rohingya community. Of particular worry are the vulnerable populations of women and children who lack adequate support systems, educational opportunities, and face low levels of literacy. The prevalent issues of overcrowding, limited access to safe drinking water and sanitation facilities, and scarcity of WASH (Water, Sanitation, and Hygiene) resources further compound the challenges. Additionally, there has been an alarming increase in mental health problems within the community.

Amidst these numerous challenges, individuals with chronic and life-limiting illnesses are experiencing limited support, leading to their unfortunate demise without proper care and assistance. With the emergence of the COVID-19 pandemic, humanitarian activities in the camps experienced significant obstacles, resulting in a noticeable deceleration. In order to evaluate the impact of COVID-19 on the camps, Haque (2020) conducted a report that provided insights into previously inaccessible aspects for international researchers.⁵³ The report's findings indicated that the Rohingya population encountered heightened isolation and increased vulnerability, mirroring the challenges faced by individuals worldwide during this period.⁵⁴ It is important to mention that, as a Bangladeshi researcher working from Dhaka and frequently commuting to Cox's Bazar, I personally faced restrictions due to the implemented shutdown measures, which prevented me from visiting the camps.

1.2.19 COVID-19 Guidelines for Rohingya Refugee Camps

Despite the existence of comprehensive guidelines such as the WHO Emergency and Disaster Risk Management Framework, there is often a lack of consideration for the practical obstacles encountered by humanitarian workers in the field. Together with a team of researchers and clinicians, I actively contributed to the development of COVID-19 palliative care guidelines specifically tailored for Rohingya refugee camps within the Cox's Bazar health sector.

The unique challenges and vulnerabilities faced by individuals residing in these camps necessitated the formulation of comprehensive and contextually

relevant guidelines to mitigate the impact of the pandemic. These guidelines emphasized the importance of early detection, prompt isolation, and effective contact tracing to minimize the spread of the virus. Additionally, we emphasized the need for adequate palliative care training and provision of personal protective equipment (PPE) to healthcare workers operating within these challenging environments.

Recognizing the unique social and cultural contexts of Rohingya refugee camps, our guidelines aimed to safeguard the health and well-being of vulnerable populations, ensuring equitable access to healthcare services in the face of the pandemic. These guidelines served as a critical tool for healthcare providers and humanitarian actors, guiding their actions and interventions to mitigate the impact of COVID-19 within refugee camp settings.

Through a collaborative partnership between FKRF and the United Nations-International Organization for Migration (UN-IOM), a significant initiative was undertaken to integrate palliative care into the comprehensive COVID-19 response. Utilizing the existing palliative care team, the dedicated members were reassigned to provide vital assistance in the COVID-19 response while concurrently ensuring the provision of ongoing support to non-COVID-19 patients.

In response to the Cox's Bazar health sector's request, UN-IOM and FKRF extended support by developing a comprehensive guidance document for palliative care in Home-Based Care (HBC). Furthermore, in July 2020, a concise training session was conducted, centered on this guidance and encompassing respiratory positioning techniques and breathing exercises.

This preparatory initiative was aimed at anticipating the possibility of implementing Home-Based Care (HBC) as a contingency measure in the event that Severe Acute Respiratory Infection Treatment Centers (SARI-ITCs) reached a surge capacity of 75% occupancy. Additional training sessions were conducted, specifically designed for the Camp Coordinators, with the objective of equipping them to serve as an additional layer of support and the primary point of contact for palliative care (PC) within the Health Coordination Teams (HCTs).

The objective was to raise awareness among healthcare workers (HCWs) in SARI-ITCs about the palliative approach to care, with a specific focus on end-of-life care for patients who may not survive. Additionally, the aim was to empower and equip Health Coordination Teams (HCTs) with the necessary tools to fulfill the following objectives: identifying patients who would benefit from a palliative care approach, providing pharmacological and non-pharmacological interventions for symptom management and comprehensive care for patients and their families, initiating Goals of Care (GoC) discussions at appropriate times and with effective communication strategies involving patients, families, and other HCT members, as well as emphasizing the importance of team support and self-care.

The majority of individuals who can benefit from palliative care receive a palliative approach to care with fundamental symptom management. However, for those with more challenging symptoms or complex issues, the involvement of HCWs with additional training in palliative care becomes essential to provide the necessary support.

1.2.20 Online Training Sessions:

As part of this endeavor, I initiated online training sessions for the palliative care team working in Rohingya refugee camps, specifically focused on the challenges posed by the pandemic. These training sessions served as a platform for sharing current research papers, fostering discussions, and providing a space for personal problem-solving and debriefing.

Recognizing the importance of staying up-to-date with the latest research and evidence-based practices, I facilitated the dissemination of relevant COVID-19 research papers and also studies pertaining to palliative care during the pandemic. By sharing this valuable knowledge with the team, I aimed to enhance their understanding of the unique considerations and strategies in delivering palliative care in the context of the ongoing global crisis.

Moreover, the training sessions provided an opportunity for the team to engage in meaningful discussions, exchange insights, and share experiences related to the challenges encountered in their palliative care practice during the pandemic. These discussions allowed team members to openly address

personal problems and concerns, fostering a sense of support and friendship within the group.

Incorporating elements of debriefing, the sessions provided a valuable platform for team members to reflect on their experiences, process their emotions, and seek guidance or advice from their peers. This debriefing aspect aimed to mitigate the emotional toll and potential burnout experienced by palliative care providers during these challenging times. By conducting online training sessions that combined research sharing, discussions, and debriefing, I aimed to provide a supportive and enriching environment for the palliative care team. These sessions not only facilitated continuous professional development but also fostered a sense of solidarity and well-being among the team members as they navigated the complexities of delivering palliative care amidst the pandemic.

1.3 Aims, Objectives and Research Questions:

1.3.1 Aim:

The overarching aim of this PhD thesis is to gain a comprehensive understanding of the challenges and benefits associated with the implementation of high-quality palliative care services in humanitarian healthcare settings. Given that the research was conducted within the context of the COVID-19 pandemic, an additional aim is to explore the effects and impacts of this global external shock on palliative care.

1.3.2 Research Objectives:

The specific objectives are as follows:

- To review existing knowledge on palliative care and assess the quality of palliative care in humanitarian settings, while identifying knowledge gaps and service deficiencies.
- To assess the palliative care needs within a specific humanitarian setting by conducting a reflective analysis of the Rohingya population's needs for palliative care in the Refugee Camps of Cox's Bazar.
- To explore the beliefs, assumptions, and perceptions of healthcare workers involved in providing care, including the demonstration of compassion, in the context of a pandemic, and to understand the importance of these factors for the quality of palliative care in

humanitarian settings. Ethnographic observations were conducted to capture the perspectives of healthcare professionals.

- To investigate how healthcare workers navigate self-preparedness during a pandemic and examine how this contributes to the quality of palliative care. Semi-structured interviews were conducted to explore the performance and behavior of healthcare professionals in the humanitarian palliative care environment.
- To analyze how the research findings contribute to defining and developing quality standards in palliative care within humanitarian settings.

1.3.3 Research Questions:

Question 1: What does the published literature tell us of the quality markers of palliative care within humanitarian settings?

Question 2: What do we know about the specific palliative care needs of the Rohingya community living in Cox's Bazar?

Question 3: How do frontline healthcare workers perceive and describe the aspects of quality palliative care and compassion in humanitarian settings?

Question 4: What factors influence the nature of care provided and how does care integrate and depend on the feelings healthcare workers have towards themselves and others?

This thesis will undertake a comprehensive examination of the syndemic encompassing conflict, fragility, and system-level shocks, with a primary focus on identifying the optimal strategies and methodologies for delivering high-quality palliative care within such challenging contexts.

CHAPTER 2: SCOPING REVIEW

Quality of Care in Palliative Care Interventions: A Scoping Review of Humanitarian Settings in Low and Middle Income Countries

2.1 Introduction:

The understanding of quality of care in palliative care interventions in fragile, conflict-affected, and vulnerable (FCV) settings is currently limited. The objective of this scoping review is to draw together existing knowledge on the quality of palliative care and identify the factors that facilitate or hinder the provision of high-quality palliative care interventions in such settings. The findings of this review will serve as a valuable resource for key stakeholders in humanitarian healthcare, setting out evidence of which has the potential to support the integration and prioritisation of quality palliative care within their response efforts.

2.2 Specific Objectives:

The specific objectives of the scoping review are to:

- Identify the literature on palliative care in humanitarian and conflict settings in low and middle-income countries, focusing on the types and sources of this literature.
- Map the identified literature to the quality domains of care as defined by the World Health Organization (WHO), in order to understand how palliative care in humanitarian settings aligns with these domains.
- Curate operational recommendations based on the findings of the review, providing practical guidance for improving the quality of palliative care in humanitarian and conflict settings.
- These objectives aim to enhance our understanding of the existing literature, assess its alignment with quality domains, and provide actionable recommendations to promote better palliative care in these challenging settings.

2.3 Methodology:

To ensure comprehensive and transparent reporting, this scoping review followed a structured framework consisting of six key steps, as outlined by Arksey and O'Malley,⁵⁵ with additional recommendations from Levac et al.⁵⁶

and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist by Tricco et al.⁵⁷

These steps are:

- Formulating the research question: The research question was carefully crafted to provide a broad yet well-defined scope, considering the preliminary nature of the research area.
- Conducting a comprehensive search: A systematic search strategy was employed, including electronic databases, reference lists and hand searches, to maximize the retrieval of relevant studies.
- Study selection: Inclusion and exclusion criteria were clearly defined to guide the selection of studies that met the research objectives.
- Data charting: A structured data extraction form was developed to capture relevant information from the selected studies, ensuring consistency and completeness.
- Collating, summarizing, and reporting results: The extracted data were organized and summarized to provide a comprehensive overview of the literature, focusing on key themes and findings.
- The sixth step that is recommended– that of expert consultation where insights and validation from experts is sought, was not used.

By following this framework, the review aimed to adhere to best practices in scoping review methodology and provide a comprehensive and reliable synthesis of the available literature on palliative care in humanitarian and conflict settings.

2.3.1 Step 1: Identifying the Research Question

The main research question addressed in this scoping review is: "What is currently known about the quality of care provided by palliative care interventions in humanitarian settings in low- and middle-income countries?" The focus on quality of care as a metric was driven by the need to fill the existing knowledge gap regarding the nature of care delivered to patients with palliative needs in vulnerable humanitarian settings.

2.3.2 Step 2: Identifying Relevant Studies

To identify relevant studies, a two-step strategy was employed. Initially, a preliminary search was conducted on PubMed to gain familiarity with the

emerging themes and the extent of the available literature. This preliminary search helped in refining the search terms. The initial search terms encompassed the main concepts related to the research question, including Palliative care, Quality of Care, Humanitarian, and Low and Middle Income Countries (LMICs). Subsequently, the search terms were revised based on expert consultations with researchers specializing in humanitarian palliative care, incorporating their suggestions and key terms into the final search strategy.

The search term strategy for Medline via Ovid is provided in Table 2.1. The strategy involved a combination of both free text terms and subject indexing terms, including Medical Subject Headings (Mesh) terms. Boolean operators such as 'AND' and 'OR' were used to separate and combine the keywords effectively during the search. The final search strategy was initially tested on Medline via Ovid and then adapted for six additional electronic databases to identify relevant peer-reviewed literature: EMBASE, PsycINFO, Scopus, PubMed, CINAHL Plus, and Academic Search Complete. Grey literature was excluded as the focus was on research-based publications.

The search was limited to English-language literature published between January 2008 and 2021. This time frame was chosen based on previous review findings on palliative care indicating that the majority of relevant studies were conducted after 2008. A 12-year period was deemed sufficient to capture a comprehensive range of literature relevant to our research topic. Additionally, a "snowball approach" was employed, which involved manually examining the reference lists of selected studies to identify any additional articles that could be included.

2.3.3 Step 3: Selecting the Studies

The initial screening process involved reviewing the titles, followed by reading the abstracts of potentially relevant articles. Inclusion and exclusion criteria were established based on the Population, Concept, and Context (PCC) Framework⁵⁸ to guide the selection of studies.

Table 2.1: Search terms for my scoping review

Search Term 1: Palliative Care Key Words	A N D Search Term 2: Quality of Care Key Words	A N D Search Term 3: Humanitarian Settings Key Words	A N D Search Term 4: Low and Middle Income Countries
Palliat* Palliative Medicine Palliative Nursing Hospic* Terminal illness* End of life care Dying Death Bereavement Palliative support Supportive care Faith-based Care End stage Advance directive Terminal Care Terminally ill	Quality of health care Quality Quality of care Effective Equitable Integrated Efficient Safe Patient-centred Family-centred People-centred Timely	Humanitarian Disaster Ethnic cleansing Refugees Conflict Fragile disease* outbreak* or pandemic* or epidemic* or syndemic* Warfare and armed conflicts	Afghanistan or Africa or Afrique noire or Armenia or Algeria or Argentina or Albania or American Samoa or Angola or Azerbaijan or Bangladesh or Bhutan or Bolivia or Belarus or Belize or Bosnia or Benin or Burkina Faso or Burundi or Botswana or Brazil or Bulgaria or Cabo Verde or Cape Verde or Cambodia or Cameroon or Congo or Cote D Ivoire or Central African Republic or Chad or China or Colombia or Costa Rica or Cuba or Comoros or Congo or Dominica or Democratic Peoples Republic of Korea or Dominican Republic or Djibouti or Egypt or el Salvador or Eritrea or Ethiopia or Equatorial Guinea or Ecuador or Fiji or Gambia or Guinea or Guinea-Bissau or Gaza or Gabon or Ghana or Guatemala or Georgia or Grenada or Guyana or Haiti or Herzegovina or Honduras or India or Iran or Iraq or Indonesia or ivory coast or Jamaica or Jordan or Kazakhstan or Kosovo or Kenya or Kiribati or Kyrgyz or Kyrgyzstan or Liberia or Lebanon or Libya or Lao or Laos or Lesotho or Mauritania or Macedonia or Malaysia or Maldives Madagascar or Malawi or Mali or Mozambique or mocambique or Marshall Islands or Mauritius or Mexico or Montenegro or Micronesia or Moldova or Mongolia or Morocco or Myanmar or Namibia or Nepal or Niger or Nicaragua or Nigeria or North Korea or Papua New Guinea or Palestin or Philippines or Principe or Palau or Panama or Paraguay or Peru or Romania or Russia or Russian or Rwanda or Samoa or Sao Tome or Serbia or South Africa or Senegal or Sierra Leone or St Solomon Islands or Sri Lanka or Sudan or Sub-Saharan Africa or Sahara or Somalia or Suriname or Swaziland or Syria or Syrian Arab Republic or Tajikistan or Timor or Tokelau or Tonga or Tunisia or Thailand or Tanzania or Togo or Turkey or Turkmenistan or Ukraine or Uganda or Uzbekistan or Vanuatu or Venezuela or Vietnam or West Bank or Yemen or Zambia Zimbabwe or low-) and middle-income countr*) or LMIC).

The criteria included: 1) inclusion of patients with chronic or life-limiting conditions (Population); 2) description of their care and support needs (Concept); and 3) inclusion of patients residing in humanitarian settings (Context). Humanitarian settings were defined according to the criteria outlined in the Sphere Standards and the income classifications from the World Bank's 2021 report.⁵⁹ These settings encompassed populations affected by various circumstances such as war, terrorist attacks, political violence, armed conflict, natural disasters, pandemics or epidemics, and individuals living as refugees or internally displaced persons in camps or non-camp settings. Post-conflict or post-disaster settings, such as more than five years after the formal end of an armed conflict or signing of a peace agreement, were excluded from the review.

The focus of this review was on humanitarian palliative care services provided to populations affected by incurable diseases in the context of a humanitarian crisis. Humanitarian palliative care services encompassed care provided by trained providers in various settings, including public, non-governmental organization (NGO), and private facilities within humanitarian settings. The primary outcome of interest was how these studies defined, described, and measured quality domains in palliative care. The definition of palliative care provided by the World Health Organization (WHO) in 2002 was adopted for consistency. Studies that did not specifically address the quality of care in palliative care interventions were excluded from the review.

The study selection process is depicted in the PRISMA flowchart (Figure 2.1). Duplicate articles were removed, and titles and/or abstracts were screened to identify relevant studies addressing the research questions. Full texts of the selected studies were then assessed against the inclusion and exclusion criteria outlined in Table 2.2. To ensure consistency, operational definitions were developed based on these criteria, as summarized in Table 2.3. Using EndNote X9 software, all citations were imported and duplicates were removed. The review included empirical studies that examined the quality of palliative care interventions for individuals with serious diseases living in humanitarian crisis situations. There were no restrictions based on the age of the study population, and only peer-reviewed studies published in English were included.

Table 2.2: Inclusion and Exclusion criteria based on the Population, Concept and Context (PCC) framework

Criteria	Inclusion	Exclusion
<p>Population</p> <p>Patients of any age group with incurable diseases</p>	<p>Studies were included if they:</p> <p># Describe the perspectives of palliative care provision for patients of any age group diagnosed with incurable conditions.</p> <p># Description may be provided by Patients, Caregivers, Health/Social/Spiritual care professionals, Health administrators</p> <p>Incurable condition was defined as 'conditions that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies.^a</p>	<p>Studies were excluded if they</p> <p># Focus exclusively on:</p> <p>Acute conditions or Non-humanitarian group</p>
<p>Concept</p> <p>Quality of care and support</p>	<p>Studies were included if they:</p> <p># Discuss quality of care and support of patients of any age group diagnosed by any incurable conditions. This was defined as 'tasks or challenges faced by patients with incurable conditions in their daily lives that are related to their physical, mental, social or spiritual condition, and for which they need/want palliative care assistance or support.' OR</p> <p># Describe the lived experience of patients with incurable conditions needing palliative care</p> <p># Describe care seeking behaviors of patients with incurable conditions needing palliative care</p> <p># The primary outcome of interest was mentioned as domains of quality of care. This could include delivery strategies or any information on facilitators and/or barriers to quality of palliative care provision.</p>	<p>Focus exclusively on:</p> <p># The prevalence/incidence of an incurable/chronic condition OR</p> <p># Disease diagnosis/ aetiology/ clinical management OR</p> <p># Development, evaluation or assessment of interventions, services or clinical tools OR</p> <p># Determinants of health such as income, social status, education level, employment, genetics, gender, race, biomarkers. OR</p> <p># Review Papers, Editorials, Commentaries, UN guides and Reports, Advocacy papers, Letters to the editor, Book chapters, Book reviews,</p> <p>Protocol papers OR</p> <p># Any other language</p>

	# Peer-reviewed studies containing original data from palliative care programs on the quality care # English language only	
Context Living in humanitarian crises	Studies were included if they: # Are based in a broad range of humanitarian crises (war, armed conflict, famine, natural disaster, or emergencies) in a low or middle income country, as defined by the World Bank	Focus exclusively on: # Patients experiences in care and residential homes OR # other settings such as prison. OR # Non-humanitarian setting. OR # High-income countries # Any other language

^a“Incurable conditions can include: “physical and mental health conditions, complex symptoms like pain or other serious health related sufferings”

Table 2.3: Operational Definitions used for inclusion and exclusion of articles

Palliative Care	WHO (2002) Definition: Palliative care is 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.
Quality of care	WHO adapted definition of Quality of Care “the extent to which health care services provided to individuals and patient populations improve desired health outcomes.”
Humanitarian Settings	Areas affected by a broad range of emergencies, including natural disasters, armed conflicts including wars, and technological and industrial disasters
Low and middle-income countries (LMIC)	World Bank Classification of countries (2021) in accordance with estimations of Gross National Income

Table 2.4: Extracted Data on Quality of Care Domains

Quality of Care domains ^a Definitions ^{a, b}	Framing questions to examine quality in FCV settings ^a	Key observations ^b
<p>People-centred</p> <p>Providing care that responds to individual preferences, needs and values</p>	<ul style="list-style-type: none"> • How have the health needs of people and communities changed since the onset of fragility/conflict/vulnerability? • Are data collected on the experience of care from the patient and family perspective? • Are data collected from the community to understand their perception of health needs and the quality of care provided? <p>Are communities involved in the planning and management of health services (including those provided by NGOs/ the humanitarian sector)</p> <ul style="list-style-type: none"> • Are health services provided in a manner sensitive to age, gender, physical ability and culture as well as those living with conditions associated with stigma? 	<p>Health care: Dignified, Compassionate, Appropriate, Accessible, Relevant.</p> <p>Perceptions on health needs, Coping mechanisms, Barriers to health care, Health seeking behaviour, Patients know their rights, Health care satisfaction.</p>
<p>Timely</p> <p>Reducing waiting times and harmful delays for both those who receive care and those who give care</p>	<ul style="list-style-type: none"> • What factors are preventing patients from receiving care without potentially harmful delay? • Do timeliness incorporate access to the right setting and set of skills at the right time? • What is the capacity for health workers to respond to peaks in demand in a timely manner? • For health emergencies, such as outbreaks, are systems in place to ensure rapid response where required? 	<p>Time taken to access health care, Patient flow, Patient waiting times; Timely clinical decision-making and management; Referral mechanisms are in place and functional; Patient perceptions on time taken to seek, access, and receive care; Complaints and feedback, Health information and data, Public health decision-making: timely without delay Monitoring: joint integrated indicators.</p>
<p>Effective</p> <p>Providing evidence-based health care services to those who need them</p>	<ul style="list-style-type: none"> • What information is available on whether care for common conditions meets required standards? • Are quality improvement methods regularly applied to improve the effectiveness of care? • Are health workers and facilities ready to provide 	<p>Performance of clinical care: Standard guidelines and protocols; Advice given by health care staff: Per standard guidelines, given by staff with requisite communication skills fully understandable to patient; Patient discharge plan: Patients discharged in a timely manner</p>

	<p>effective care with the changing health needs in this setting?</p> <ul style="list-style-type: none"> • Are appropriate clinical standards, guidelines and protocols in place? 	<p>with information to ensure a smooth transition; Health information: is complete, timely and analyzed. Audits: Frequently conducted with feedback; Availability of services: Is as defined in the essential package of health services (EPHS) including referral mechanisms. Availability of essential medicines; Availability of essential devices and consumables. Availability of context relevant clinical standards, guidelines, and protocols</p> <p>Availability of health care staff: With adequate number, skills mix, with appropriate diverse languages, ethnicities, at least 50% female</p> <p>Training and supervision of health care staff:</p>
<p>Safe</p> <p>Avoiding harm to people for whom the care is intended</p>	<ul style="list-style-type: none"> • Do health services have protocols and resources to prevent harm to patients and staff • Do facilities have adequate provisions for water, sanitation and hygiene and infection prevention and control • Do communities feel they will be able to reach the health care facility safely? • Do communities trust that they will be safe if they attend health services? • Are health facilities and providers known to be at risk from attack? 	<p>Safe access, Safe infrastructure and design, Safety and security: Lighting, safe paths, lockable toilets, etc.; Disaster preparedness and risk mitigation: plans and SOPs in place. Safe movement of patients, Patient rights upheld: Informed consent, Data protection, Consultations held in private rooms or areas; Patient is safe from violence, harm, from healthcare workers; Staff are safe: Occupational health, immunizations, security. Safe medication practices; General Infection Prevention Control (IPC) interventions; Safe treatment protocols: utilised and followed.</p>
<p>Equitable</p> <p>Providing health care that does not vary according to gender, age, ethnicity, disability,</p>	<ul style="list-style-type: none"> • What barriers exist that prevent certain people from accessing the services they need? • Are there certain population groups or geographical areas that lack access to services? • Are services equally available to populations on all sides of the conflict or political divide, 	<p>Equitable access; Equitable service availability and service delivery mechanisms; Communication done is in languages, easily understood, respectful and culturally appropriate. Monitoring to understand: Equitable utilization, discrimination within healthcare settings by health care providers</p>

religion, sexual orientation, linguistic or political affiliation etc.	and to all those injured in conflict?	Data disaggregated by: Age, gender, diversity. Other characteristics if necessary, relevant to context and if safe
Integrated Health care is coordinated across levels and providers and makes available the full range of health services throughout the life course.	<ul style="list-style-type: none"> • Are mechanisms in place to ensure coordination among all health providers? • Is provision made for care across the continuum of promotive, preventive, curative, rehabilitative and palliative services? • What is needed for effective referral and transfer of patients? • Are there mechanisms to ensure coordination between different sectors to support patients? 	Referral system: Mapped, well planned; Referral pathways available and standardized protocol in place; Mapping of actors and services performed: Across all levels of care. Across different sectors; Regular Monitoring; Primary Health Care: Key for coordinating with networks. Providing mutual support.
Efficient Maximizing the benefit of available resources and avoiding waste.	<ul style="list-style-type: none"> • Are services provided to patients driven by medical need without underutilization or overutilization • Are there mechanisms in place for funding organizations (domestic and donor) to assess value for money on their health services investments? • Do those delivering health care work together to maximize synergies and minimize waste? 	Evidence based health care: Rational use of antibiotics, medicines, lab tests etc.; Logistics and stock management: including medicines, devices, and equipment; Health information: Analyzed by appropriate staff; Collaboration between providers to synergize programming; Building in existing guidelines in country; Cost effective: value for money, focused interventions with high impact; Governance mechanisms: exist to review efficiency.

Note: (a) WHO Quality of Care Action b) Global Health Cluster)

2.3.4 Step 4: Extracting Data

To extract the data, I mapped information from each study onto a customized extraction form developed using Microsoft Excel 2011 software. The categories included in the extraction form were: first author, date of publication, country of origin, aim of the publication, study design, setting, sample size, participants, description of the study, outcome measures, and key findings. Table 2.4 shows

the definitions of extracted domains, the framing questions and key observation for the review.

Regarding the quality appraisal of the included studies, Arksey & O'Malley guidelines did not require a formal quality assessment. The main criterion for inclusion was that the studies had undergone peer review. The objective of this scoping review was to provide an overview of the existing literature in a field that has been underreported in the past. The research question focused on identifying the processes indicating the quality of care rather than the outcomes of the studies conducted in LMIC humanitarian contexts.

Data extraction involved mapping the information related to quality of care domains. The domains of quality of care considered were people-centered, timely, safe, effective, efficient, equitable, and integration, as defined in Table 2.4. In addition, data were also extracted for author, year, and study project intervention showing in Table 2.6. Additionally, data on facilitators and/or barriers to quality palliative care were extracted. These data were obtained from the results sections of the included studies, including data extracts and the authors' discussions of their study's findings. Quotes from the papers, along with their corresponding page numbers, were extracted and organized in Table 2.7.

2.3.5 Step 5: Collating, summarizing and reporting the results

The data from the selected articles underwent analysis using two main strategies. Firstly, a descriptive numerical summary was conducted to highlight the key characteristics of the studies. Secondly, a qualitative thematic synthesis was performed, following the RETREAT⁶⁰ criteria to guide the selection of the qualitative synthesis method that aligns with the review's aims and characteristics. The thematic analysis of the findings followed the approach outlined by Thomas and Harden.⁶¹ Quotes from the articles were carefully read and coded line by line using free codes, contributing to the development of a comprehensive code bank.

These codes played a crucial role in generating descriptive themes and analytical themes. The codes were primarily developed deductively, drawing on the Global Health Cluster and WHO Quality of Care Framework Questionnaires to organize and analyze the data. This framework was chosen for its

comprehensive coverage of quality of care, applicability to humanitarian settings in low- and middle-income countries (LMICs), and adaptability to palliative care. During data extraction, particular attention was given to the framework's domains of quality of palliative care in fragile, conflict-affected, and violent (FCV) settings. Any discussions related to facilitators and/or barriers to the quality of palliative care interventions were extracted verbatim from the included papers as quotes. The reporting of the study adhered to the ENTREQ⁶² statement, while the PRISMA Extension for Scoping Reviews (PRISMA-SCR) guided the approach employed for data synthesis.

2.4 Results:

From the initial database search, a total of 3,816 articles were identified (Figure 1). After removing duplicates and screening the titles, 225 studies were deemed eligible. Following abstract screening, 43 articles remained. Finally, through a thorough review, seven peer-reviewed empirical research studies were found to meet the criteria. Additionally, two more studies were discovered through reverse citation and reference list searches. Data extraction was performed on these nine papers. The identification process is visually presented in Figure 2.1, while the characteristics of the studies can be found in Table 4. A summary of the included studies is provided in Table 2.5.

2.4.1 Description of Included Studies:

The studies included in this review focused on FCV settings in West Africa (n=1), Bangladesh (n=1), Jordan (n=4), and multiple countries (n=3).

The sample sizes of these studies varied, ranging from 12 to 1550 participants. Among the included studies, 67% (n=6) were identified as qualitative studies, 22% (n=2) as quantitative studies, and 11% (n=1) as case study designs. Over 50% of the studies were published between 2019 and 2021. It is worth noting that all the studies reported sub-domains related to people-centred quality of care.

Figure 2.1: PRISMA Flow Diagram

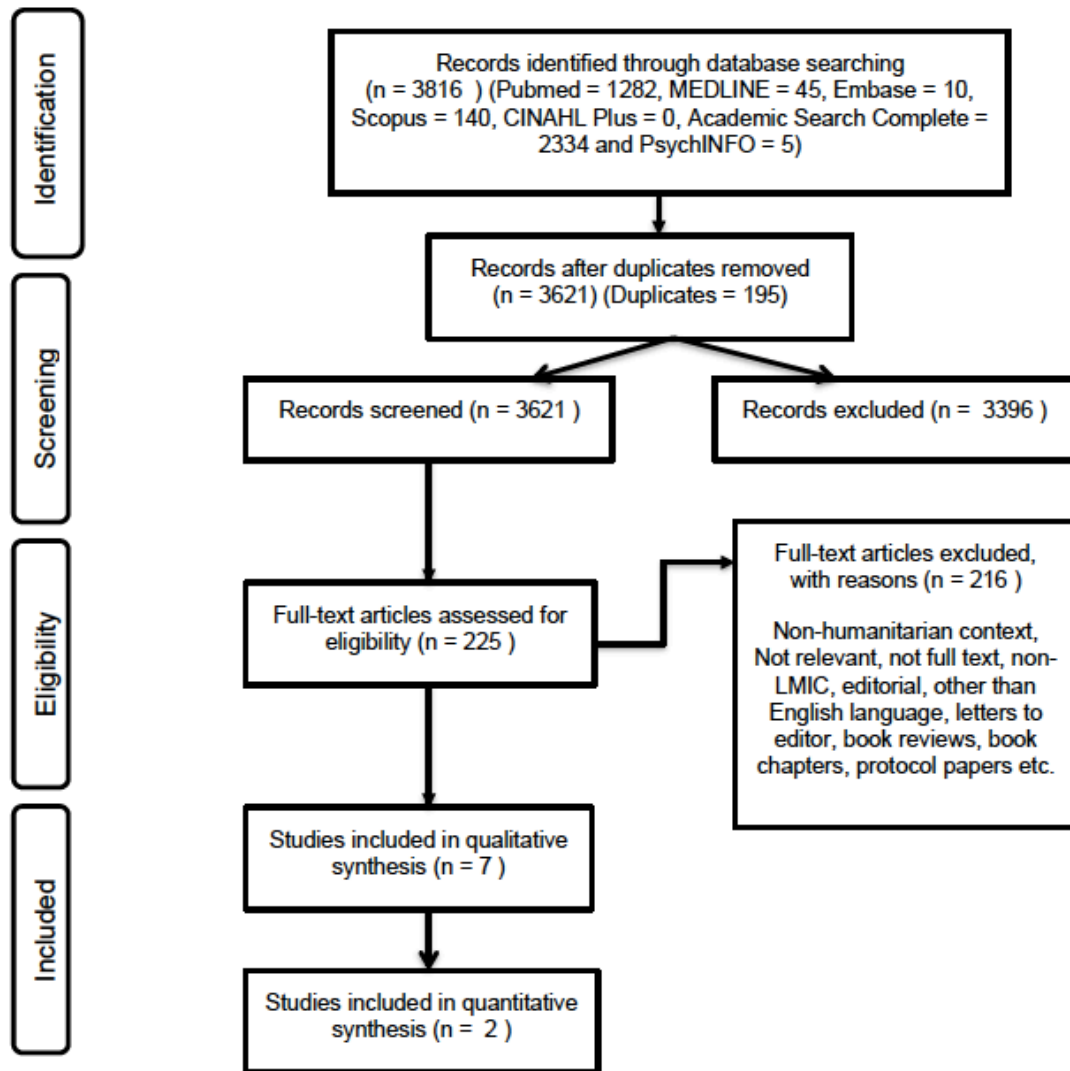


Table 2.5: Characteristics of included studies

Study Characteristics	No. of studies (n = 9)
Year	
2008-2015 [9]	1
2016-2018 [6 - 8]	3
2019-2021 [1 - 5]	5
Study Type	
Cross-sectional [4, 9]	2
Qualitative [2, 3, 5-8]	6
Case study [1]	1

WHO Region	
African [1, 6]	2
South-East Asia [3]	1
Eastern Mediterranean [5, 9]	2
Multiple Regions [2, 4, 7, 8]	4
Setting	
Public Health Emergency [1]	1
Acute Refugee Context [3]	1
Protracted Refugee Context [6, 9]	2
Natural disaster [4]	1
Key Informants from Multiple Organizations [2, 5, 7, 8]	4
Population Type	
Refugees [1, 3, 9]	3
Policy makers, Health care providers, host community members [2, 4, 6, 8]	4
Health care providers, Donors, NGOs [5]	1
Health care workers [7]	1

Table 2.6: Summary of included studies:

Author and Year Country Method	Settings Sample size Participants	Aim	Results
Nouvet et al, 2021 ¹⁶ West Africa Qualitative Case Study	Guinean Ebola treatment centres (ETC) 15 Participants	To describe experiences and expectations of patients, their family members, health professionals, spiritual care providers related to end-of-life palliative care for patients infected with Ebola virus disease (EVD).	Participants' accounts emphasized that healthcare delivery in humanitarian emergencies must remain respectful of patient preferences but also local and contextual values and norms. One key culturally valued experience was "dying in honor". This involves accompaniment to facilitate a peaceful death, passing on final messages to family members, prayer, and particular practices to enact respect for the bodies of the deceased.
Guo et al, 2021 ¹⁷ Jordan	Jordan hospitals 29 Participants	To describe the needs and experiences of adult refugees in Jordan with advanced cancer and	The experiences identified information lack: Refugees often experienced unmet psychosocial needs. However, psychosocial support was reported either absent or limited. Lack of information and poor communication between healthcare providers and

Qualitative study		informal caregivers.	patients caused significant distress due to uncertainty. Being away from the home country cut patients and caregivers off from their wider social support network, which added increased anxiety and responsibilities to caregivers.
Hunt et al, 2020 ¹⁸ Multi-country Qualitative study	Humanitarian care settings 24 Participants	To describe humanitarian policy-makers' and health care professionals' experiences and perceptions of palliative care during humanitarian crises.	Participants linked major obstacles to the life-saving ethos of humanitarian organizations, priority setting of scarce resources, institutional and donor funding, unavailability of guidance and expertise in palliative care, difficulty in access to medication, and cultural specificity around death and dying. They recounted other obstacles related to continuity of care, particularly after project closure, equity, security concerns, and terminology.
Doherty et al, 2020 ¹⁹ Bangladesh Cross-sectional study	Rohingya Refugee Camps, Cox's Bazar 155 Participants	To describe the illness-related suffering and need for palliative care in Rohingya refugees and caregivers in Bangladesh.	Many individuals with serious health problems experienced significant pain (62%, n = 96), the pain treatments prescribed were largely ineffective (70%, n = 58), and effective pain treatments were rarely available. Caregivers most commonly assisted with bathing (n = 117, 94%), administering medications (n = 99, 80%), and feeding (n = 98, 79%). Despite having limited training or money, caregivers provided many hours per day of care, which caused sadness, worry, and discrimination.
Marzouk et al, 2019 ²⁰ Jordan Qualitative	Jordan 12	To describe the clinical, ethical and policy decision-making experiences of health actors working within the current refugee cancer care system; the impact of refugee cancer care health policies	The study identified that central challenges for policy makers and health providers were the lack of quality cancer prevalence data to inform programming and care delivery for this refugee population, and insufficient health resource allocation to support services. In addition, limited access to international funding for the host country, the absence of long-term funding schemes, and barriers to coordination between institutions and frontline clinicians were seen as key barriers.
Schneider et	Humanitarian	To describe how	The findings identified lack of opioids as

al, 2018 ²¹	settings	expatriate health workers react to and cope with the dilemma on assignment with humanitarian emergency	a main reason for inadequate pain control and palliative care. Some expatriate health workers are not familiar with advanced pain control and palliative care. Expatriate health workers can feel frustrated and helpless in such situations. Training for expatriate health workers should be improved. Humanitarian organizations should strengthen their capacity to provide pain control and palliative care by developing and applying adapted guidelines.
Multi-country	15 Participants		
Qualitative study			
Hunt et al, 2018 ²²	Humanitarian settings	To describe moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crises context.	The findings illuminated experiences responding to patients who are dying or likely to die, and how these connect with the values of humanitarian health professionals, sometimes resulting in dissonance between values and actions. They also point to the need to make more space for palliative, alongside curative, approaches to care in situations of humanitarian crises, ideally by further integrating them.
Multi-country	23 Participants		
Qualitative study			
Pinheiro et al, 2018 ²³	Syrian Refugee Camps	To describe the role of palliative care in addressing the health needs of Syrian refugees in Jordan	This study found that patients in refugee camps and communities would benefit from receiving palliative care services that are often either unavailable or inaccessible. Training humanitarian teams and primary care providers to implement pain management, psychosocial support services and address emotional, spiritual, and psychological conditions could ameliorate many of the problems faced by this vulnerable group.
Jordan	23 Participants		
Qualitative study			
Doocy et al, 2015 ²⁴	Non-camp settings in Jordan	To describe the prevalence and care-seeking for chronic diseases among Syrian refugees in Jordan	Among adults, hypertension prevalence was the highest 9.7%, followed by arthritis 6.8%, diabetes 5.3%, chronic respiratory diseases 3.1% and cardiovascular disease 3.7%. Of the 1363 NCD cases, 84.7% received care in Jordan; of the five NCDs assessed, arthritis cases had the lowest rates of care seeking at 65%.
Jordan	1363 patients with NCD diagnosis		
Cross-sectional survey			

The data collected for this review were analyzed and grouped into four overarching themes and eight sub-themes, which serve as both facilitators and barriers to delivering quality care in FCV settings. These themes have been categorized as follows:

- (A) Emphasizing People-Centred Palliative Care in Humanitarian Settings,
- (B) Ensuring Effective and Efficient Palliative Care,
- (C) Implementing Timely and Safe Palliative Care, and
- (D) Promoting Equitable and Integrated Palliative Care.

Table 2.7: Themes, sub-themes and supporting quotes identified in the review.

Theme	Sub-theme	Example
(A) Considering People-centred Palliative Care	1. Recognizing dignified, compassionate, appropriate, accessible and relevant palliative care in humanitarian settings	“You know, all those who are sick want to be treated for their sickness. That is why one goes to the hospital. But in the case of Ebola, it’s more than that. First, there is the solitude. You are not used to living sick when you fall ill. Members of the family line up to visit you [normally]. And in the ETC, it is different. No one comes, and no one touches anyone. I would want to see my parents, my children, every day by my side. But it was impossible, according to the doctors. That is what made me cry.” (p.8) ⁶³
	2. Meeting health care to their specific needs and culture	“If I have diabetes I can access services; if I have cancer I can’t access any services. This is type of discrimination. If I have a cancer, it is not my fault I am refugees, and if I have diabetes it is not my fault, so services should be available for everything.” (p.11) ⁶⁴
	3. Coping mechanisms and health seeking behavior	“I wish they would tell me everything and not keep anything from me. Because when you don’t know anything about yourself, you’re always afraid and you keep thinking. The doctor talks to my husband and son. They are more informed about my illness. Sometimes when the doctors tell them things and they keep it a secret from me, I feel scared.”(p.921) ⁶⁵
	4. Moral distress of	“Yes, it was heavy...[S]ome of the things I did, they didn’t actually cause any problems while I was there, but when I came [home], I couldn’t sleep. It affected my sleep, my eating, even going to walk. I couldn’t have a shower for some time so it was heavy when I came

	health care staff	back...I had to receive – I got support psychotherapy, for I think up to 6 months or 8 months...”(p.9)
(B) Having Effective and Efficient Palliative Care	5. Performance of clinical care, skilled health care staff, guidelines and essential medicines 6. Performance of Psychosocial and Spiritual Care	“I was in so much pain and no one would listen to me, they would just give me the painkiller. There was that night where I saw death with my own eyes, I was vomiting a lot, and I told them about it, and they told me to wait for my doctor to come, that was at 2AM and I had to wait till 7AM, I died a million times.” (p.920) “When the indicators are so in the red, we do palliative care, and we need to accompany the patient up to their final breath...we have to maintain the mask of the human being. To keep, how can I say this in proper French? To humanize a person. Because even if I know they have to die, I need to accompany them. They need to die in all gentleness. That is what we call well planned palliative care.” (p.9)
(C) Adopting Timely and Safe Palliative Care	7. Setting Priority and Making timely and safe clinical decision (n =8)	“If you have 50,000 dinars, would you spend this on vaccinating 10,000 children or will you spend this on one case of cancer? Clearly. . . you will spend it on vaccinating 10,000 children because this is going to save more lives, prevent more infections.” (p.12)
(D) Keeping Equitable and Integrated Palliative Care	8. Ensuring Equitable Access and integrated Palliative Care	“When it is winter, all NGOs distribute blankets, so when you go to a house of refugee, he has 5000 blankets and nothing to eat. Some NGOs can provide health care. . . another cash, some take care of cancer, just they have to cooperate with each other and to be more active.” (p.11)

2.4.2 Identified Themes

Theme 1 – Considering People-Centered Palliative Care in Humanitarian Settings

Sub-theme 1: Recognizing Dignified, Compassionate, Appropriate, Accessible and Relevant Palliative Care in humanitarian settings (n=9)

Person-centeredness emerged as one of the most significant domains of quality care. Every study included in the review recognized the significance of people-centered care, prioritizing the dignity of individuals receiving or in need of care, rather than solely focusing on disease or pain thresholds. Nevertheless, the papers exhibited variations in both the definition and execution of people-centeredness. Nouvet et al.¹⁴¹ highlighted the challenges of meeting the specific needs of patients and ensuring the alleviation of suffering while protecting their dignity. They emphasized the importance of facilitating patient-family connections in Ebola Treatment Centers as a means of alleviating psychological distress. Participants consistently stressed the need for humanitarian health professionals to prioritize the dignity of dying patients. Upholding dignity was viewed as a response to the individuals' humanity, demonstrating respect and compassion. The attitude of health professionals towards patients and their families was explicitly described in this paper. Nouvet et al.¹⁴¹ discussed how patients were brought to the perimeter fence to interact with family members and how isolated patients were supported in communicating with their families using cellphones, tablets, or video messages.

In a study conducted by Doherty et al.⁶⁶ in Bangladesh, it was found that caregivers played a significant role in providing care for ill individuals, despite experiencing negative impacts on their own physical and emotional well-being. The patients required various medical interventions, including medications, medical equipment, visits to healthcare facilities, and basic care. However, accessing these interventions was challenging due to barriers such as financial difficulties, unavailable treatments or medications, and insufficient support for caregivers.

According to the study conducted by Hunt et al.,²⁷ the provision of palliative care in humanitarian settings should prioritize the expressed needs of individuals, adopting a people-centric approach. The study emphasized the importance of addressing not only physical issues such as nausea or delirium but also spiritual needs and caregiver concerns. It recommended that dying patients should feel accompanied and not abandoned, with active presence to

acknowledge shared humanity. The study also highlighted the significance of upholding dignity beyond death, including supporting family members in their bereavement process.

In another study by Hunt et al.,⁶⁷ the attendance of health professionals at memorials and funeral services was described as a way to honor patients who had passed away. The study further identified specific challenges in low- and middle-income country (LMIC) contexts, where the pre-existing healthcare system may lack access to opioids and palliative care. Any political instability in these contexts could disrupt health centers, leading to the unavailability of palliative interventions.

In a study conducted in Jordan by Marzouk et al.,⁶⁴ refugees who couldn't afford cancer treatment received support from a compassionate pooling fund, which relied on small donations. Schneider et al.⁶⁸ also highlighted the emotional impact on humanitarian providers when confronted with unmet needs for palliative care. Compassion was described as vital for health professionals, often involving strong emotional involvement during the initial stages of engagement. The study also found that some humanitarian workers related the patients' pain to their own personal experiences of pain and disease, leading to increased attention to ensuring adequate pain management. Many recognized that in a humanitarian crisis, patients themselves might have experienced the loss of family members, intensifying feelings of isolation during their own dying process.

Guo et al.⁶⁵ in their investigation, explored how patients with advanced cancer experienced symptoms and discomfort while also facing severe financial hardships due to healthcare expenses. They recommended that healthcare providers adopt a person-centered approach when developing and evaluating complex interventions for refugees with advanced cancer. This approach entails respecting the diverse beliefs, values, and unique experiences of refugees and addressing their multidimensional needs. The studies underscored the significance of maintaining the dignity of patients and their families in healthcare settings, recognizing their humanity and demonstrating compassionate care. Strategies such as facilitating patient-family communication and fostering emotional connections were highlighted as important approaches to upholding dignity and providing people-centered care.

The study conducted by Hunt et al.⁶⁷ shed light on various actions to alleviate suffering in humanitarian settings. The authors emphasized that addressing suffering went beyond simply providing analgesics, as it also involved acts such as providing water, offering shade, and ensuring companionship for severely injured patients who were not receiving life-saving care. The study participants also highlighted recognizing the presence or absence of family as crucial. The failure to engage in these acts was seen as a failure to uphold humanitarian values. Participants in the study expressed concerns that suffering, particularly among those who were dying, was often inadequately addressed. They argued that when curative care was not available or appropriate, palliative care should be provided, and that it was the responsibility of humanitarian health professionals to address symptoms and alleviate pain. Failing to do so was seen as an injustice.

The study recounted instances where dying patients were neglected or overlooked during crises, even before their actual passing, which dismayed healthcare professionals. Nurses shared the importance of demonstrating compassion, even in the face of overwhelming patient numbers, by offering physical comfort such as holding a child, sitting with someone, or providing gentle touch. Participants consistently emphasized that such acts of human connection were vital for preserving the dignity of dying patients. A key aspect of respecting the humanity of dying patients and upholding their dignity was ensuring that they did not feel abandoned. Leaving a dying person without any care or companionship was viewed as both an injustice and a violation of their dignity.

The narratives presented in the studies reflect the significant sense of responsibility experienced by humanitarian workers. In instances where palliative care was effectively provided in a humanitarian setting, this burden of responsibility was either lifted or felt lighter for the workers. However, many studies indicated that few participants could recount examples of palliative care being executed well. Nevertheless, in the few instances where such care was described positively, it was seen as a source of profound satisfaction for the providers.

Participants shared strategies that helped them cope with the weight of responsibility. They emphasized the importance of sharing this burden with trusted colleagues through open discussions and collaborative teamwork. Building strong relationships within the team and developing shared plans for

addressing palliative care needs were deemed crucial. Additionally, organizational strategies such as providing support and opportunities for debriefing were recognized as valuable in easing the weight of responsibility carried by the workers. These studies shed light on the challenges faced by both caregivers and patients in accessing necessary care and support. They emphasize the importance of considering the individual circumstances and specific needs of refugees when designing interventions, aiming to provide equitable and person-centered care in the face of complex healthcare and financial challenges.

Sub-theme 2: Meeting Health Care to Their Specific Needs and Culture (n=8)

Hunt et al.⁶⁷ findings emphasized that palliative care interventions don't necessarily require high costs, extensive resources, or specialized providers. Simple acts such as active listening, providing spiritual care, offering a comforting touch, sitting by the bedside, or keeping the patient comfortable were identified as essential ways to address suffering and show compassion. Individuals without training in palliative care approach, including community workers and lay caregivers, can carry out these interventions. By incorporating these efforts into healthcare teams, palliative care can be improved beyond the limitations of available resources.

The study highlighted the significance of dignity-promoting actions, with human touch being particularly impactful. From the initial contact with patients until after their passing, upholding dignity was seen as crucial. Through acts of care, addressing suffering, preserving privacy, and respecting cultural traditions, participants believed that the unique identities and worth of each dying individual could be acknowledged and honored. On the other hand, Guo et al.⁶⁵ reported that some participants felt that healthcare staff focused solely on the disease and neglected other aspects of care, such as psychosocial and spiritual support. While most participants believed that clinicians should attend to all aspects of the patient's well-being (physical, psychological, social, and spiritual), appropriate psychological and social support was either absent or limited. Additionally, many patients expressed a desire to know their condition, but caregivers often hesitated to disclose the truth in order to protect them.

Hunt et al.²⁷ emphasized the significance of preserving culturally valued and culturally acceptable end-of-life practices, as highlighted by a majority of

participants. They recognized that the concept of dignity and a dignified death varies across different cultures, which can pose challenges for health professionals, particularly those from outside the local context working in humanitarian settings. The cultural dimensions surrounding death and dying led many participants to suggest that local health professionals are best suited to lead palliative care initiatives. They also emphasized the importance of collaborating with local religious leaders, providing examples of successful partnerships. The study, which drew on data from an African physician responding to a humanitarian crisis in a neighboring country, underscored the need for community-based practitioners to take the lead in palliative care efforts, particularly during times of crisis. It recommended that international NGOs play a limited role in providing oversight and support while empowering local practitioners to guide and control the delivery of palliative care.

Several studies have highlighted the importance of effective communication in palliative care, as it is closely linked to improved psychological well-being, treatment adherence, and overall quality of life and patient satisfaction, particularly for individuals with conditions like cancer. The patient-centered approach to palliative care emphasizes the need for open, honest, and sensitive communication that takes into account the patient's beliefs, capabilities, and preferences.

Pinheiro et al.⁶³ identified certain physicians who were described as lacking sensitivity when delivering poor prognoses to patients, especially in crisis situations. On the other hand, some physicians were found to be unclear and hesitant in fully disclosing the patient's disease status. This variability in communication approaches could be attributed to localized cultural traditions, such as in the Middle Eastern context, where the disclosure of illness is typically directed towards a family member rather than the patient directly. However, this cultural practice poses challenges, particularly in situations of conflict or separation, where the patient may not have access to family members for information and support.

Another important finding from the literature on palliative care in humanitarian settings is that these services can play a crucial role in addressing issues related to the overall quality of care. The literature revealed that many individuals interviewed encountered difficulties in communicating with their healthcare providers. To enhance the quality of care, it is essential to have in-depth discussions about prognoses that respect the principle of relational

autonomy, which involves including families in the decision-making process. This approach exemplifies culturally responsive palliative care, as it acknowledges the importance of cultural values and beliefs in providing comprehensive and compassionate care.

In their study on infection control during the Ebola outbreak, Hunt et al.⁶⁷ documented that traditional practices of washing the deceased were prohibited to prevent the spread of the virus. However, healthcare professionals made efforts to accommodate cultural practices by allowing family members to view the deceased from a distance, even if the body remained inside a sealed bag. Additionally, some healthcare professionals paid particular attention to ensuring that the deceased received an appropriate funeral process, considering it as a way to honor and respect each individual. These actions demonstrated a commitment to cultural sensitivity and the recognition of the importance of preserving dignity and honoring cultural practices, even in challenging circumstances.

Pinheiro et al.⁶³ also highlighted the significance of shared linguistic and cultural traditions between Jordanians and Syrians, which fostered a sense of cohesion and connection within the host and refugee community. In the camps, neighbors often provided care and support to individuals grappling with illness and feelings of isolation. Due to the ongoing conflict in Syria, displaced Syrians have found themselves living in close proximity to tens of thousands of others who share similar circumstances. This living arrangement has facilitated the dissemination of information about available healthcare services within the camps and opportunities for external assistance, leading to personalized and culturally adapted care. Many Syrian refugees had established relationships with their neighbors, enabling them to access food and financial support for expensive medical treatments when needed. However, it was not uncommon for refugees to experience feelings of isolation and anxiety about the well-being of their family and friends who remained in Syria.

Schneider et al.⁶⁸ highlighted the challenges faced in delivering culturally responsive palliative care, acknowledging that culture plays a significant role in shaping medical practices and perceptions. The study participants observed how cultural factors influenced the communication of diagnoses and prognoses to patients and their families. They noted that local staff often preferred an indirect approach when sharing related information. Misunderstandings arose within the multicultural medical team regarding decisions on therapeutic

withdrawal. Divergent understandings between expatriates and local staff were common, encompassing varying interpretations of palliative care, the appropriate timing to initiate it, and the methods and timing of communication with patients and/or their families.

Sub-theme 3: Coping Mechanisms and Health seeking Behaviour (n=8)

Another aspect of people-centered care was the recognition and respect for patients' coping mechanisms and their health-seeking behaviors. Several papers emphasized that while individuals sought care for chronic health conditions, their coping mechanisms were often compromised due to the psychological impact of the crisis. This posed a significant risk, as individuals with severe health-related suffering could be overwhelmed by the existing humanitarian challenges they faced. The review, based on eight studies, revealed that although most patients were well-informed about their condition, the majority expressed dissatisfaction with the lack of guidance on coping strategies, particularly when they felt lost and abandoned. Both patients and their caregivers expressed a need for additional support from healthcare and public services, which they believed were insufficiently attentive. Some studies indicated that patients were unaware of their diagnosis, but had suspicions about the severity of their illness. In many cases, family members were aware of the diagnosis but chose not to inform the patient. Patients who were aware of their condition appeared to fare better overall.

In their study conducted in Jordan, Guo et al.⁶⁵ found that numerous patients expressed dissatisfaction with the lack of communication from healthcare providers and family regarding their diagnosis, prognosis, and care plan. This lack of information caused significant distress due to the uncertainty it created. Maintaining connections with family was particularly crucial for individuals with palliative needs, as highlighted by Hunt et al.⁶⁷ as this connection could help alleviate psychological distress. However, during crises, the loss of family members intensified the cycle of grief and distress, resulting in a compounded sense of isolation. The studies suggested that training and education could play a crucial role in changing healthcare practices to prioritize effective communication and address the psychological needs of patients.

According to Pinheiro et al.⁶³ refugees heavily relied on their faith as a coping mechanism for various challenges. The majority of individuals expressed that their faith provided them with patience and strength to endure adversity, as they

believed their situation was part of God's plan. Faith also played a role in promoting adherence to treatment regimens. During particularly challenging periods of illness, individuals turned to practices such as reading the Quran to alleviate pain or distressing thoughts. However, without supportive relationships, refugees often had to face difficulties related to their health and displacement on their own. Mental health issues were seen as exacerbating physical ailments, which sometimes affected refugees' determination to seek healthcare or follow prescribed treatments.

Marzouk et al.⁶⁴ reported that funding posed a significant barrier to both seeking care and coping. In a cross-sectional study conducted by Doocy et al.⁶⁹ in Jordan, the inability to afford care were identified as the primary reason for not seeking care across various chronic conditions. The proportions of individuals who did not seek care due to cost were as follows: hypertension (65.3%, CI: 61.0–77.3), cardiovascular disease (64.3%, CI: 44.7–80.1), diabetes (51.7%, CI: 33.9–69.2), chronic respiratory disease (50%, CI: 30.8–69.2), and arthritis (62.9%, CI: 51.8–72.7). The study also found that household head education level, geographic region of residence in Jordan, and specific health condition were significantly associated with the likelihood of seeking care. Interestingly, there was an inverse relationship between care-seeking and household head educational attainment: households where the head had completed more than secondary education had 89% lower odds of seeking care (CI: 22–98) compared to those with no education, while households where the head completed primary school had 88% lower odds of seeking care (CI: 13–98) compared to those with no education. No significant differences in care-seeking rates were observed between households where the head completed preparatory education and those with no education.

Sub-theme 4: Moral Distress of Health Care Staff (n=5)

The moral distress experienced by humanitarian staff was multifaceted. Health workers in humanitarian settings, including those in conflict-affected and fragile environments, came from diverse backgrounds. Several studies focused on volunteers from high-income countries, some of who were new to humanitarian work and were deeply affected by the experiences of death and dying. Others had prior experience working with organizations like Médecins Sans Frontières (MSF) in their home countries and had transitioned to become expatriates. Some had participated in multiple missions and had gained field experience. The term "moral distress" was employed to capture the complex emotions of frustration, concern, or sadness that arose when health workers recognized the morally right or optimal course of action but were limited by circumstances or

resources in fulfilling their moral obligations. This was particularly evident when workers identified individuals in need of palliative care but were unable to provide the necessary support. Marzouk et al.⁶⁴ reported that the inability to effectively manage pain was particularly challenging for medical teams, especially when they were aware of available pain control measures. Expatriate health workers strongly expressed their negative emotions, indicating the significance of their experiences. All healthcare providers conveyed feelings of helplessness and powerlessness in the face of the described challenges.

These emotions often compelled individuals to take personal initiatives to address the gaps in care, leading to a shared sense of personal and moral distress. For example, nurses and doctors would informally follow up with patients who could not access healthcare facilities in their home settings, and they would make exceptions by conducting lab tests while actively seeking alternative solutions. These efforts to personally address the gaps in care generated a collective sense of moral distress among healthcare providers.

Theme 2 - Having Effective and Efficient Palliative Care

Sub-theme 5: Clinical Care, Skilled Health Care Staff, Guidelines and Essential Medicines (n=9)

Across all the studies reviewed, a recurring theme highlighted that inadequate pain management posed a significant barrier to the delivery of effective palliative care in humanitarian settings. The findings of this review indicated that a majority of patients described in the studies experienced varying degrees of pain, ranging from moderate to severe. Although most of them received painkillers, they reported little relief from their pain. Their expressed needs encompassed a range of desires, including home visits, stronger pain medications, physiotherapy, and advice from specialists. Additionally, many resorted to self-medication with alternative pain remedies. The majority of patients also reported experiencing breathing difficulties, loss of appetite and weight, digestive issues, and severe nausea, often attributed to medication side effects (such as chemotherapy) or pains. While some patients confirmed receiving medical treatment to address these problems, most relied on self-adaptation strategies (such as adjusting body positions or modifying their diet) or simply accepting their situation without hope for improvement.

Pain emerged as a predominant and critical concern, as its presence hindered the effective addressing of other needs. When an individual experiences pain,

it becomes challenging to provide comprehensive care. Within this framework, active involvement and collaboration between patients and their families played a vital role not only in the planning of own care and support but also in the design and delivery of palliative care services.

Hunt et al.⁶⁷ reported that the available healthcare in the studied context demonstrated limited effectiveness due to several factors. Firstly, there was a notable absence of policies, guidelines, and evidence-based healthcare practices, which contributed to a lack of standardized care. Furthermore, there was a deficiency or insufficiency of expertise within the humanitarian team, further impeding the delivery of optimal care. The absence of clear guidance and clinical protocols resulted in uncertainty among workers regarding appropriate courses of action, leading to inconsistencies within and between teams. Additionally, legal restrictions, as well as fears or perceptions of addiction among certain health professionals, acted as barriers preventing the prescription of opioids to individuals experiencing pain. Regrettably, collaboration with other healthcare services was largely nonexistent, further limiting the comprehensive care that could be provided.

Insufficient availability of pain medications, particularly opioids, posed a notable obstacle. Participants universally recognized the necessity of accessing opioids for effective pain management. However, many emphasized the importance of extending palliative care approaches beyond mere medication provision, acknowledging that opioids alone were inadequate for meeting the needs of patients in humanitarian crises. Individuals expressed frustration regarding the inadequacy of pain medication provided between appointments, as it failed to sufficiently address the frequency and severity of pain episodes experienced.

According to Schneider et al.,⁶⁸ the primary barrier identified by many participants was the unavailability of opioids, which hindered the provision of advanced pain control. Instead, they were often compelled to rely on tramadol or basic analgesic medications. Various factors contributed to the unavailability, including temporary stock-outs resulting from logistical challenges, restrictive legal regulations concerning opioid importation into the assigned country, or internal limitations on opioid prescription. Some local health professionals, despite having access to opioids, chose not to utilize them, possibly due to limited experience with these medications. Expatriate health workers experienced frustration and helplessness as they were aware of the potential alleviation opioids could provide to patients' pain, yet lacked the necessary

means. In most cases, the unavailability of opioid medications prevented the delivery of adequate care, rather than a lack of expertise.

Numerous studies put forth recommendations for future preparedness in terms of skilled human resources and evidence-based guidance. One proposed strategy involves mandating or providing incentives for primary care physicians and humanitarian aid teams to undergo palliative care training, thereby enhancing the palliative care capabilities of generalists operating in communities and refugee camps. Addressing healthcare staff shortages is crucial, as dying patients often lack the presence of healthcare professionals, a practice deemed necessary from both clinical best practices and religious care perspectives. Schneider et al.⁶⁸ emphasized the importance of pain management training at various levels and the need to improve awareness in this domain. The recognition of teamwork and organizational aspects was highlighted as integral components of effective and efficient palliative care.

Furthermore, the studies identified the significant role of human presence in medical care. Although not a substitute for pain relief, the presence of compassionate individuals can offer solace to patients. This perspective underscores the evolution of non-pharmaceutical strategies to cope with the lack of therapeutic options, expanding the understanding of the role of healthcare professionals to encompass behavioral and psychological components.

Sub-theme 6: Psychosocial and Spiritual Care (n=8)

The studies documented the experiences of healthcare providers and policymakers, highlighting their frustration, emotional distress, and burnout resulting from the inability to fulfill their professional and personal duty of care due to resource limitations. Conversely, other studies demonstrated that even a modest trial initiative of palliative care yielded notable outcomes, with individuals expressing high levels of satisfaction with their care and reporting improvements in their overall condition.

This comprehensive review revealed that across various humanitarian and fragile settings, patients consistently expressed the need for psychological support and treatment for anxiety. Many patients reported a lack of information regarding available support services, and they faced challenges accessing

social and financial assistance, such as obtaining essential supplies like diapers, catheters, caregivers, or transportation to medical referral centers. Moreover, a significant majority of patients expressed concerns about their family members and their future, apprehensive about becoming a burden on loved ones. Interestingly, even simple interventions had the potential to make a meaningful difference. Some studies highlighted that increased social interaction, whether through volunteer home visits, peer support, or technology-based interactions, could enhance patients' ability to enjoy life. The opportunity to leave their bed or home, even briefly, was also mentioned as a source of relief. Additionally, many patients found solace in their faith, finding comfort in attending religious services, receiving communion, and having religious leaders visit them.

In Doocy et al.⁶⁹ study, several case studies were presented, highlighting the challenges faced by patients in humanitarian settings. For instance, an elderly man with cancer expressed his frustration with doctors at the tertiary facility located outside the camp, as they neglected to inquire about or address his health condition. While his family remained in Syria, his neighbors in the camp took care of him. This patient emphasized that the visits from the palliative care provider were the only moments of happiness he experienced at the camp. He eagerly anticipated the spiritual therapy component of these sessions, which involved engaging in exercises such as reflecting on peaceful and joyful memories, reciting the Quran passages, and identifying meaningful outcomes derived from hardship.

Pinheiro et al.⁶³ presented compelling data revealing the expressed needs of chronically disabled patients in camp settings. These individuals emphasized the potential benefits of increased access to psychological services and physiotherapy sessions. Many war-wounded Syrians expressed their dissatisfaction with the limited degree of strength and mobility regained through infrequent and brief physiotherapy sessions. Notably, several refugees felt a deep sense of gratitude for their own circumstances upon witnessing the hardships faced by others. Guiding fellow refugees provided them with a sense of purpose and self-worth, fostering a shared experience of solidarity in suffering. The experience was particularly challenging for young individuals disabled by war, as immobilization during hospitalization led to feelings of boredom and despair about their perceived bleak future. During this period, interviewees reported a lack of motivation to move, socialize, or eat. However, the repeated encouragement offered by healthcare workers, friends, and family

played a significant role in gradually reducing their withdrawal and fostering a more positive outlook.

Theme 3 - Adopting Timely and Safe Palliative Care

Sub-theme 7: Setting Priority, Making Timely and Safe Clinical Decisions (n=7)

In stable conditions, palliative care interventions are already characterized by their complexity. However, in times of instability and crisis, these interventions become even more intricate. The challenge lies in ensuring that timely interventions are implemented, supported by strategies that prioritize safety. According to Hunt et al.,⁶⁷ it is crucial to establish priorities when allocating limited humanitarian resources at various levels. Triage decisions play a vital role in this process, as without proper prioritization, it becomes difficult to make timely and safe decisions.

In their study, Doherty et al.³⁴ found that a large proportion of individuals in Rohingya refugee camps were enduring considerable pain and physical symptoms, with limited access to the required medical treatments for alleviating their suffering. The authors emphasized the pressing need for timely assessments of palliative care needs during humanitarian crises. They underscored the importance of using these assessments to establish priorities for palliative care and to inform the development of effective interventions in such settings. Furthermore, they highlighted the necessity of addressing barriers to accessing vital medications, supplies, and medical care, with a specific focus on improving the availability of opioids. Efforts to integrate palliative care into humanitarian contexts should aim to overcome these barriers and ensure that individuals receive the necessary support and relief they require.

A noteworthy and unusual observation was that in certain situations where making timely interventions seemed impossible, healthcare staff exhibited heightened compassion towards patients. This was particularly evident in chronic or protracted crisis scenarios, especially when formal care settings were unable to admit patients. Some participants shared instances of working informally and voluntarily, without remuneration, to educate and empower patients' family members in providing care for their loved ones. The findings of the review emphasize that the feasibility of ensuring patient safety largely relies on the specific context and the ability to customize care delivery according to

the unique needs of the facility, its staff, and its residents. These findings align with the existing literature on emergency palliative care. Marzouk et al.⁶⁴ highlighted one of the primary challenges in developing cancer care policies in Jordan, which was the limited availability of data on cancer prevalence among Syrian refugees and the existing healthcare services in the country. This scarcity of data was perceived as an obstacle to evidence-based strategic planning and advocacy for increased funding to support these patients.

Theme 4 – Keeping Equitable and Integrated Palliative Care

Sub-theme 8: Ensuring Equitable Access and Integrated Palliative Care (n=8)

The findings of Pinheiro et al.⁶³ highlight the importance of equitable access and quality in palliative care delivery for refugees. The fragmented nature of care provided by different organizations and healthcare providers hinders the effectiveness of service delivery and compromises equitable access to care. This is particularly evident in cases where patients receive multiple diagnoses or conflicting recommendations, leading to feelings of overwhelm and confusion. The lack of clear and consistent communication further exacerbates these challenges, resulting in misunderstandings about medication purpose, frequency, and duration.

To address these issues, Pinheiro et al.⁶³ propose a shift towards delivering palliative care in group therapy formats, recognizing the communal mindset prevalent among Middle Eastern refugees. Engaging refugees through group therapy programs, promoting mentorship initiatives, and avoiding stigmatization of mental health needs of individuals can better address the psychosocial addressed in an equitable manner. Furthermore, the extensive psychosocial support provided by friends, neighbors, family members, and palliative care providers in refugee camps fosters solidarity, gratitude, self-belief, and faith, creating a supportive environment that encourages equitable access to care and enhances overall well-being.

In the context of limited services and support for terminally ill patients, the lack of equitable access to palliative care can result in inadequate symptom management, feelings of abandonment among patients, and increased burden on family members who may struggle to provide care. This not only exacerbates patients' anxiety but also leads to financial and social challenges for their families. However, an experimental palliative care initiative focusing specifically

on cancer patients demonstrated that the nature of the approach, rather than the availability of additional resources, played a significant role in addressing patients' physical, psychological, and spiritual suffering. This emphasizes the importance of equitable access to comprehensive palliative care that considers the holistic needs of patients, irrespective of the availability of extensive resources.

The global burden of non-communicable diseases (NCDs) is on the rise, with approximately 80% of worldwide deaths attributed to these conditions. NCDs pose a significant and growing challenge in humanitarian responses, particularly in urban refugee populations. This issue is particularly pronounced in middle-income countries affected by conflict, as these populations tend to have higher NCD burdens due to factors such as aging and require long-term, resource-intensive treatment. In such settings, the international community and host country governments face multiple interconnected challenges in meeting the healthcare needs of refugees.

The management of non-communicable diseases (NCDs) poses a financial burden on donor agencies, depleting the already limited resources allocated for refugee healthcare. Furthermore, patients with advanced NCDs often experience prolonged periods of deterioration, requiring palliative care for extended durations. In addressing this challenge, Pinheiro et al.⁶³ highlight the case of the mobile medical unit in Za'atari camp, which serves as a model for integrating palliative care into existing healthcare services. This integrated approach aims to effectively manage the complex illness profiles of refugees by providing connected services that address their palliative care needs. By implementing such models, there is a greater potential for equitable access to comprehensive healthcare services, including palliative care, for refugees affected by NCDs.

2.5 Discussion

This scoping review, encompassing nine studies, presents a comprehensive analysis of the evidence on the quality of palliative care in humanitarian settings in low- and middle-income countries (LMICs). It is the first study to specifically address this topic. The review explores eight domains of quality of care for palliative care provision and identifies eight sub-themes that emerged from the analysis of the included research studies. These sub-themes represent

potential factors that can either facilitate or hinder the delivery of high-quality palliative care interventions. The findings are categorized into four overarching themes. The review synthesizes the experiences of 1630 individuals who participated as patients, caregivers, family members, healthcare providers, and health sector administrative personnel, providing a comprehensive overview of the topic.

The principles of humanitarianism explicitly emphasize the prevention and alleviation of human suffering. However, within the humanitarian healthcare setting, there are often unmet needs that require individuals to be referred to providers with specific technical expertise and mandates. This practical challenge serves as a significant barrier in humanitarian fields. In 2018, the World Health Organization (WHO) recommended a revision of the standard triage categorization in humanitarian emergencies, highlighting the importance of palliative care for patients with limited life expectancy.⁵

The WHO further emphasized the integration of palliative care and symptom management across all triage categories to the extent possible. The suggested approach includes triage, assessment, diagnosis, rational prescribing practices, treatment, and advice that recognize and address the important palliative care needs of individuals.

The findings have several implications for future research. Firstly, there is a need to broaden the definition of quality to encompass the impact of palliative care in crisis settings. This expanded perspective will provide a more comprehensive understanding of the effectiveness and outcomes of palliative care interventions. Secondly, it is crucial to develop and validate specific quality measures that are suitable for assessing palliative care in crisis settings. These measures should capture the unique challenges and circumstances faced in such contexts. Thirdly, future research should incorporate more diverse and rigorous study designs to strengthen the evidence base for palliative care in humanitarian settings. This will enhance the reliability and generalizability of findings. Additionally, healthcare providers should prioritize coordination and collaboration between different services, levels of care, sectors, and the community. This integrated approach will optimize the delivery of palliative care and ensure comprehensive support for individuals in crisis setting.

The review findings have emphasized the significance of addressing suffering as a fundamental aspect of providing quality care in humanitarian settings, particularly for individuals approaching the end of life. Several key factors were identified as facilitating the delivery of such care in humanitarian projects. These include a people-centered approach, establishing strong partnerships with local organizations, having clear guidance and supportive leadership, and ensuring access to essential resources such as opioids and other necessary medications. Conversely, barriers to effective care included limited availability of pain medications, particularly opioids, as well as inadequate access to vital equipment and supplies like adult diapers and catheters.

Insufficient attention to the needs of individuals and their unique experiences, as well as inadequate pain management and psychosocial and spiritual care, were common indicators of poor people-centered quality. Disregard for diverse beliefs, values, and cultural backgrounds further exacerbated the situation. This lack of understanding regarding the multidimensional needs of refugees placed a heavy emotional burden on healthcare professionals and undermined their resilience. The shortage of skilled palliative care staff and the presence of skeptical or unsupportive individuals within the healthcare workforce were additional barriers to quality care. The absence of clear organizational policies and clinical guidelines for palliative care further reinforced these obstacles. The studies also revealed systemic issues, with a growing recognition of a broader pattern of neglecting suffering. Effective communication and meaningful interactions with patients and families regarding their treatment, care plans, and psychosocial support were identified as crucial coping mechanisms but were often overlooked.

Advocacy emerged as a valuable and constructive approach to address obstacles and limitations. Various individuals, including healthcare professionals, family members, and community members, played crucial roles as advocates. Advocacy efforts could take place at different levels, including within the healthcare team, within the organization, and even on an international scale. Furthermore, the review indicated that palliative care services had the potential to tackle concerns related to the overall quality of care. By incorporating palliative care principles, improvements could be made in the perceived quality of care provided.

The challenges associated with delivering quality palliative care in humanitarian settings are evident. Fragile and conflict-affected environments present

complex obstacles that require careful consideration when striving for improvement. To gain a comprehensive understanding of effective approaches to enhance quality of care, more research is necessary. This includes exploring the individual impact of various quality domains and examining their interconnectedness. Additionally, there is a need for systematic reporting on quality domains to provide valuable insights for the development of high-quality palliative care interventions in the future.

Previous research has provided limited documentation on the potential for improving palliative care in fragile, conflict, and violence-affected (FCV) settings through the enhancement of quality of care. A significant finding of this review is the recognition that quality palliative care interventions should not only focus on improving palliative care knowledge but also encompass broader skills such as supporting teamwork.

The review has identified several factors associated with the quality of palliative care initiatives in FCV settings, primarily at the multinational organizational level, but with potential implications at the local level as well. Initiating change requires actions such as legislating for the right to quality health care for vulnerable populations, providing palliative care education for staff and caregivers, implementing robust regulations and standards, and establishing mechanisms for addressing grievances. To achieve fully integrated, high-quality palliative care in FCV settings, it is crucial to establish minimum standards for palliative care among the staff, develop appropriate frameworks and guidance, and adopt a multilevel approach.

2.6 Strengths and limitations:

This review exhibits several strengths, incorporating two established frameworks for conducting scoping reviews and adhering to the PRISMA-ScR guidelines for transparent reporting. A comprehensive and systematic search strategy was employed to identify relevant published studies. The methodological steps outlined in the Arksey and O'Malley framework were followed, while also incorporating method enhancements suggested by Levac et al. These enhancements included ensuring a clear scope for the review, utilizing the research question to guide decision-making, and adopting an iterative approach to study selection and data charting. Another notable strength was the inclusion of various study designs, allowing for the extraction of data from intervention studies employing both quantitative and qualitative methodologies. The incorporation of qualitative studies significantly contributed

to the understanding of facilitators and barriers related to the quality of palliative care provision in FCV settings, as it provided insights from the study authors and themes derived from data collection.

Despite not being a systematic review, this study successfully achieved its goal of providing a comprehensive overview of the research area, prioritizing breadth over depth of understanding. The inclusion of methodological guidance from papers on scoping review reporting standards has enhanced the methodological rigor of the review, adding a level of integrity to the findings.

One limitation of this review is that the data on quality of care palliative care interventions primarily come from short-term funded research, which may limit the generalizability of the findings. Additionally, relying on outcome measures based on staff perceptions may not necessarily translate into actual changes in practice. Another limitation is that the review only included studies published in English between 2008 and 2021, potentially missing relevant studies published in other languages or before or after the specified timeframe. As a result, it is possible that not all available

2.7 Conclusion:

In recent years, there has been an increasing focus on the quality of care provided in overall health systems within humanitarian settings. However, when it comes to palliative care, there remains a significant gap in studies that examine quality measures both at the point of care and within the broader health system. It is crucial to understand the specific health needs of individuals, families, and communities affected by humanitarian crises, taking into account their cultural background, preferences, and health knowledge in order to effectively meet those needs.

Several barriers to quality palliative care were commonly mentioned in the literature. These include the predominant life-saving focus of many humanitarian organizations, the challenge of setting priorities amidst limited resources, the availability of guidance and expertise in palliative care, access to essential medications, cultural considerations surrounding death and dying, ensuring continuity of care for refugees with chronic conditions, promoting equity, addressing security concerns, and addressing the moral distress experienced by healthcare providers.

The findings from this review shed light on key barriers and opportunities for delivering quality palliative care in fragile and conflict-affected settings. It emphasizes the importance of intentionally integrating palliative care capacity within humanitarian healthcare, adapting to structural changes and local cultural practices, and addressing the psychosocial and spiritual aspects of care. By addressing these factors, there is a greater potential to improve the quality of palliative care provision in humanitarian settings.

The review brings attention to a significant gap in the existing research literature when it comes to assessing the quality of palliative care in humanitarian settings. It is crucial to address this gap through further research that focuses on developing effective measurement strategies, accountability mechanisms, and robust evidence regarding various domains of quality of care in humanitarian contexts.

Special attention should be given to the formulation of specific frameworks that provide guidance to stakeholders on how to overcome the challenges associated with delivering high-quality palliative care during humanitarian crises. Urgent action is needed to fill these knowledge gaps and enhance the provision of quality palliative care in humanitarian settings.

CHAPTER 3: SPECIFIC CONTEXT

Understanding the Unique Palliative Care Needs of the Forcibly Displaced Rohingya Community in Cox's Bazar.

3.1 Introduction:

In this chapter, I provide contextual or foundational information, offering a valuable longitudinal perspective to my studies. I aim to establish a baseline of fundamental themes and challenges that existed before the onset of the COVID-19 pandemic, while also presenting a distinctive viewpoint from the perspective of patients and their caregivers.

Furthermore, I delve into the first research question that guided my study: What are specific palliative care needs of individuals residing in humanitarian settings, particularly in Cox's Bazar? I offer a reflective analysis of findings from my 2017 study, which represents the first comprehensive examination of the palliative care and Quality of Life (QOL) needs of refugees. This study played a crucial role in a broader situation analysis, contributing significantly to the understanding of palliative care provision in Cox's Bazar both before and during the pandemic.

3.2 Background

I was the senior investigator of a preliminary research study conducted in Bangladesh in 2017 that was the first formal assessment of palliative care needs in the world in an unfolding humanitarian crisis. It used a resource light method of assessing palliative care needs, which was easily implemented with limited resources early in a humanitarian crisis. Valuable data was collected on the burden of serious illness-related suffering, focusing on physical, social, and emotional suffering, and the availability of the essential package components.

Findings from this study highlighted that the main focus of the humanitarian agencies was on preventing and treating acute and curative disease. However, the thousands of adults and children who were facing chronic and/or life-threatening diseases did not receive the care they need. Those with HIV, cancer, diabetes and other non-communicable diseases remained unseen and their needs largely unmet, leading to pain and suffering for patients and their families.

The study confirmed what was indicated in the literature - that there is limited palliative care and where palliative care in humanitarian crises is available it often has little focus or research investment. This study noted that data from a palliative care needs assessment would allow for a better understanding of who and how many would benefit from palliative care in refugee camps and would build evidence about how to implement effective programs. It would also allow for monitoring of progress towards reducing the burden of preventable pain and suffering in humanitarian crises.

This study resulted in a published article in peer-reviewed journal the PLOS.⁶⁶

3.3 Aim

This chapter will describe the findings of this 2017 study and extend previous published analysis by reflecting on the implication of these findings in developing further work.

3.4 Context of the Study

During the period of the study the majority of the Rohingya community were housed in makeshift accommodations with little access to essential resources such as clean water, food and sanitation. I oversaw all of the research and supervised those conducting the interviews with patients and caregivers among Rohingya refugees living in the main refugee settlement areas of Kutupalong, Jamtoli, Tengkhali, and Balukhali in the Cox's Bazar District of Bangladesh. Retail pharmacy representatives in the refugee camp area, the nearest town center (5.5 km from the entrance to Kutupalong refugee camp), and the nearest government health complex (7.0 km from the Kutupalong camp entrance) were also interviewed. There were many NGO medical clinics (with basic outpatient facilities) and hospitals (inpatient and outpatient facilities) located within the Rohingya settlements or in close proximity, where basic and advanced-level medical and surgical care was available. In addition to NGO services, those from the refugee community had the choice to visit Bangladesh government health facilities, with the nearest primary-level government facility 7.0 km from the Kutupalong camp and a tertiary facility 37 km away.

Data was collected from 311 individuals, including 156 persons living with serious health problems and 155 caregivers during November 2017. The key informants interviewed were individuals with serious health problems and their

caregivers. In determining which of the patients with serious health problems to include, this study used WHO guidelines for palliative care in humanitarian settings, which indicates that palliative care is appropriate for those with serious health problems, including life-limiting conditions as well as non-life-limiting conditions, such as trauma, burns, paraplegia, quadriplegia, brain injuries, and congenital anomalies where significant suffering may occur. The study was dependent on Community Health Workers (CHWs) who were based in the local communities, offering basic health care. A set of interviewers from the local community was trained. Coordinators were selected to ensure that all CHWs who recruited informants, and the informants themselves, received all necessary information of the study, methods, limitations, their role and the possible outcome of the research. Participants were identified at the community level. Interviewers spoke to individuals in the refugee camp community and went from house to house to identify individuals requiring palliative care or symptom relief and their caregivers. Once identified, these individuals were approached about their interest to learn about the study; if individuals expressed interest, then the interviewer explained the goals and process of the study, responded to any questions, and then asked if the individual would be willing to participate. For individuals whose diagnosis was uncertain, interviewers reviewed the cases with study coordinators and myself to determine if the individual should be included as having a serious health problem, prior to conducting the interview. Patients who had significant impairments in movement, muscle tone, and/or balance were categorized as having a significant physical disability, and the breadth of this category was due to a lack of clarity from individuals about their exact diagnosis or the cause of their disability and a lack of access to diagnostic healthcare services. For children (0–17 years), a parent or the primary adult caregiver was approached for consent and completed the interview as a source of proxy information. Participants were identified through convenience sampling, and the maximum number of eligible participants that could be consented and interviewed during the data collection period determined sample size. For all pharmacies that could be identified in the defined locations for the study, interviewers interviewed a pharmacy representative about the availability of essential palliative care medications and supplies.

3.5 Design and Content of Interviews

The interview guide for the study was developed through a literature review that identified key themes from previous assessments of palliative care in low and middle-income countries (LMICs) and from the Sphere Handbook.^{107,108} Six of the study authors, including myself, and 3 additional individuals with expertise in humanitarian medicine, palliative care, and non-communicable diseases

provided feedback on the validity and comprehensibility of draft interview questions and this contributed to a pilot interview guide which was tested with 10 Rohingya interviewers from the refugee camps and 20 Rohingya individuals (11 with serious health problems and 9 caregivers). Modifications were incorporated to improve the clarity of questions and response options to reflect the specificities of the Rohingya refugees' experiences and culture.

Helpfully for the development of quality palliative care questions about medications and supply items included in the essential package were included for pharmacies. Demographic information about individuals' age, sex, household size, education, and occupation were collected. All those interviewed were asked about serious health problems and requested to report on the characteristics of their pain and other symptoms, including severity, and treatments and their efficacy. They were also asked about their needs for medications and medical supplies, as well as their basic needs for items such as food, shelter, and money. Recent healthcare experiences and the barriers to accessing care, medicines, and medical supplies were documented.

Ten Rohingya-speaking interviewers of Rohingya ethnicity were identified through a partnership with a local health non-governmental organization (NGO) working in the refugee camps (OBAT Helpers) and trained to conduct structured interviews for this study. They had completed secondary school and were fluent in both written and spoken English and in the Rohingya language (spoken only, as there is no widely accepted written form of Rohingya). Nine of the interviewers had been living in the refugee camps for more than 5 years, having arrived during previous waves of refugee movement from Myanmar.

Interviewer training was conducted in English and consisted of 2 days of theoretical and practical in-person training that included didactic teaching and practical examples related to research ethics and informed consent, the goals of the study, and key concepts related to the study (palliative care, serious health problems, cancer, HIV/AIDS, medications, medical equipment, and symptoms). During the training, the interviewers reviewed each question in the interview guide with the trainers, discussed the meaning of the question and the response options, and provided suggestions about cultural or other adaptations that would improve the clarity of the interview guide. Interviewers then agreed upon a single translation of each interview question into Rohingya, after group discussion. During the practical portion of the training, interviewers conducted practice interviews in pairs, with observation and coaching by

trainers, who provided feedback about interview technique and clarified the interview guide questions and response options. During the final phase of training, interviewers conducted interviews in the refugee camps, under the same conditions as those in the actual study, with observation by the 2 trainers, to ensure fidelity to the interview guide. The interviews were conducted over a 5-day period (November 20–24, 2017) immediately following training. Interviews typically took 30–45 minutes.

3.6 Findings:

The study found that the majority of ill individuals were experiencing significant pain and other physical symptoms and were unable to access the medical treatments necessary to relieve their suffering. Most of the identified needs were actually commensurate with the local health system functioning. Five actions emerged from the data as vital to the identification of palliative care needs of patients and caregivers in humanitarian settings. These were grouped in five themes:

- Symptom prevalence and inadequate treatment
- Lack of essential medications and medical equipment
- Lack of opioids
- Barriers to access medical interventions
- Caregiver burnout

Table 3.1: Socio-demographic data of individuals with serious health problems (n = 156).

Characteristic	Prior to leaving Myanmar		Current	
	n	Percent or mean; range (SD)	n	Percent or mean; range (SD)
Sex				
Male			82	52.6%
Female			73	46.8%
Missing data			1	0.6%
Age (years)				

0-4			8	5.1%
5-17			15	9.6%
18-49			58	37.2%
>50			68	43.6%
Missing data			7	4.5%
Highest level of education completed				
None			87	55.8%
Primary			54	34.6%
Secondary			11	7.1%
Post-secondary (college)			2	1.3%
Missing data			2	1.3%
Primary serious health problem				
Significant physical disability ^a			100	64.1%
Treatment resistant tuberculosis			32	20.5%
Cancer			15	9.6%
HIV infection			3	1.9%
Burns			2	1.3%
Diabetes			1	0.6%
Chronic respiratory disease			1	0.6%
Kidney disease			1	0.6%
Intellectual disability			1	0.6%
Number of individuals living in household ^b			150	5.3; 1-19 (2.4)
Number of children (0–18 years of age) the individual has ^c			109	1.7; 0-8 (1.9)
Occupation				
Homemaker	40	25.6%	21	13.5%

Farmer	34	21.8%	2	1.3%
Unemployed	31	19.9%	70	44.9%
Self-employed	7	4.5%	0	0.0%
Missing data	7	4.5%	7	4.5%
Other ^d	5	3.2%	2	1.3%
Public sector worker	2	1.3%	0	0.0%
Unable to work due to illness	4	2.6%	29	18.6%
Teacher	2	1.3%	2	1.3%
Student	1	0.6%	0	0.0%
Child<18 years old (therefore no occupation)	23	14.7%	23	14.7%

^aIncludes individuals with cerebral vascular accident, spinal cord injury, cerebral palsy, and undiagnosed conditions resulting in similar impairments. ^bMissing data for 6 patients. ^cIncludes individuals <18 years of age, and individuals 18 years of age if they are married. ^dIncludes carpenter, tailor, shopkeeper, and unspecified responses.

3.6.1 Symptom Prevalence and Inadequate Treatment

Pain due to serious illness within the last 3 days was reported by 110 patients (70.5%) and was frequently self-rated as being of moderate (n = 48, 30.8%) or severe intensity (n = 48, 30.8%). 83 patients (53.2%) reported receiving medication for their pain. Nearly half (n = 51, 46.4%) of those who received treatment for pain could not recall the name of the medication. The most frequent medications reported were paracetamol (n = 19, 17.3%) and non-steroidal anti-inflammatories (n = 9, 8.2%). Only 1 patient (0.9%) reported receiving an opioid pain medication, oxycodone. In addition to pain, individuals with serious illnesses reported an average of 3.8 (SD 2.2, range 0–9) other symptoms that were causing them physical discomfort. When asked about their greatest needs, patients most frequently reported medications (97.4%, n = 152), money (94.2%, n = 147), and food (76.9%, n = 120).

This study identified that a significant proportion of Rohingya patients (70%) reported pain, and just less than one quarter (21%) received no medications to treat their pain. However, the study recognized the absence of comparable studies from humanitarian settings, but several studies from regional countries such as India report similar pain prevalence rates of 71%–100% in patients with serious health problems at the time of initial assessment.^{66,109,110} In this study,

those who received treatment frequently reported limited improvement, with 70% reporting moderate or severe pain despite treatment. This may be because the most common pain treatments were paracetamol and non-steroidal anti-inflammatories, which are recommended only for mild pain.¹¹¹ Additionally, many of the reported treatments for pain were not analgesics. The findings support the Lancet Commission conclusion that pain contributes significantly to the burden of serious illness-related suffering worldwide.

3.6.2 Lack of Essential Medications and Medical Equipment

This study found that sixty-one patients (39.1%) reported needing medications, including paracetamol (n = 21, 34.4%), antibiotics (n = 16, 26.2%), medications for chronic diseases (n = 16, 26.2%), and medications for gastro-esophageal reflux (n = 14, 23.0%). Only 52.5% (n = 32) of these patients were able to access their medications at the time of the interview. Eighty-two patients (52.6%) reported needing at least 1 medical supply item, and 72.0% (n = 59) of these patients were unable to access needed equipment. The most commonly needed items were urinary catheters (n = 29, 35.4%), adult diapers (n = 21, 25.6%), and oxygen (n = 21, 25.6%).

Shopkeepers at 17 pharmacies were interviewed about the availability of essential palliative care medications and supplies. Morphine was not available in any pharmacy, and only 1 pharmacy (5.9%) had any suitable oral opioids available, in the form of oxymorphone tablets.

3.6.3 Lack of Opioids

This study found very little use or pharmacy availability of oral morphine, which is widely accepted as essential for achieving adequate pain control in humanitarian settings.¹¹² Despite morphine and other opioids being included on the Bangladesh Essential Drug List, morphine has not been practically available outside of the capital city of Dhaka.¹¹³ The International Narcotics Control Board reports that only 18 kg of morphine was consumed in Bangladesh in 2017, which previous studies have estimated represents less than 1% of the anticipated national opioid requirement.^{114,115}

Overly restrictive opioid policies are a common barrier to opioid availability in LMICs; however, several LMICs, including Uganda and Mongolia, provide examples of an appropriately balanced approach to opioid control, which provides for medical needs while addressing the risk of nonmedical use.¹¹⁶ Applying these lessons to humanitarian situations may improve morphine

availability in these settings. This study did not collect data directly from healthcare professionals.

3.6.4 Significant Barriers in Accessing Medical Interventions

This study identified the patterns of care and challenges in Rohingya refugee camps. Sixty percent of individuals (n = 93, 59.6%) reported visiting a health facility in the past month. Of those patients, 53.7% (n = 50) reported visiting an NGO hospital, 18.3% (n = 17) a health clinic, and 9.7% (n = 9) a government primary-level health facility. Forty-three percent (n = 40) of patients who visited a healthcare facility sought medical care for concerns related to their serious health problem, and 29.0% (n = 27) visited specifically for pain relief. More than half (59.1%, n = 55) of those who visited a healthcare facility reported that their visit was unsuccessful at treating their presenting problem. Commonly identified barriers and challenges to accessing healthcare included lack of money (n = 65, 60.2%), lack of treatment availability at the health facility (n = 14, 13.0%), and difficulty getting to the healthcare facility (n = 11, 10.2%).

The medical interventions that patients required, included medications, medical equipment, visits to health facilities, and basic care. The study identified significant barriers to accessing these interventions, including financial problems, unavailable treatments or medications, and a lack of support for caregivers. Humanitarian health facilities generally provide free medicines, but patients are usually given only 1–2 weeks' supply, which creates significant barriers to continuing treatment for individuals with a chronic condition who require medications indefinitely. Even if medications are free, the costs for transportation to health facilities and lost wages may be a significant financial burden for patients, and these factors may have contributed to the significant number of patients who reported being unable to obtain necessary medical interventions in this study. Role of healthcare in pain management has been frustrating. Many patients had sought healthcare for pain relief, yet few had received adequate pain relief. The drugs that were prescribed for the type and severity of pain the patient had been experiencing, mostly did not work. Barriers to accessing medical care included facilities not having the necessary treatment for the individual's complaint or facilities providing poor quality of treatment. Many physicians are not comfortable writing opioid prescriptions, since they are not accustomed to working with opioids.

3.6.5 Caregiver Burnout

The most frequent activities performed by caregivers included bathing (n = 117, 94.4%), administering medications (n = 99, 79.8%), and feeding the ill individual (n = 98, 79.0%). Only 11.3% (n = 14) reported having received training on how to provide care. Caregivers commonly reported having sleep difficulties (87.1%, n = 108), lack of appetite (58.1%, n = 72), and lack of pleasure in life (53.2%, n = 66) due to their caregiving role. When asked about their greatest needs, caregivers commonly reported money (88.7%, n = 110), food (74.2%, n = 92), and someone to help them (65.3%, n = 81).

Family caregivers provided many hours of assistance daily, most often helping with bathing, feeding, and administering medicines, while also providing emotional support. Very few caregivers had received any training in their role. A basic palliative care training manual for caregivers has been published in Bangladesh, and efforts are underway to adapt this training to humanitarian situations. Previous studies have demonstrated the feasibility of training for family caregivers, showing reductions in caregiver burnout by providing skills to cope with the emotional stress of caregiving.¹¹⁷

3.7 My Reflections:

Palliative care helps patients and families to live full and meaningful lives despite the challenges of illness and disease. This study made apparent what the majority of health workers knew that time pressure, inaccessibility, lack of trained healthcare workers, short-term appointment of health care workers in camps, low pay for the community health care workers, low priority of palliative care by the government and health sectors, were contributing factors to provision of palliative care in humanitarian context.

The findings from this study helped shaped the study presented in chapter Five.

3.7.1 Wider Perspectives

Quality palliative care in humanitarian settings is essential. Palliative care focuses on providing relief from the symptoms, pain, and stress of serious illness, and can improve the quality of life for individuals and families affected by crisis or conflict. In humanitarian settings, where resources may be limited and access to healthcare can be difficult, palliative care can be especially important in addressing the needs of vulnerable populations, such as those affected by chronic or terminal illness, injury, or displacement.

There is still a clear lack of understanding among stakeholders about how to utilize palliative care for the terminally ill, non-cancerous patients and aged refugees. There remains an urgent need for a holistic approach to patient-centered care also encompassing their families needs. Palliative care recognizes the burden and challenge of managing a chronic disease or severe illness and focuses on reducing physical and emotional suffering to improve quality of life.

Palliative care is complex, but it is essential in low- and middle-income countries (LMICs) humanitarian settings because it addresses the physical, psychological, social, and spiritual needs of individuals and families facing life-limiting illnesses or injuries. It can help to alleviate pain and other symptoms, improve quality of life, and provide emotional and practical support to patients and their families. Furthermore, palliative care can also help to reduce the burden on overstretched healthcare systems by improving the efficiency of care and reducing the need for costly and unnecessary interventions. Additionally, Palliative Care should be integrated with the primary healthcare system, which will support continuity of care, early identification and management of symptoms, and improve health outcomes. It may be challenging for humanitarian palliative care providers to address all those complex issues of life-limiting illnesses, with no or insufficient pre-training on palliative care. It is not only a disease related issue, but significant day-to-day practical struggles.

Trained palliative care staff can deliver basic community-based palliative care. As per WHO guidelines, with 10 days training community health workers can deliver palliative care supervised by medical and nursing staff. A comprehensive systematic exploration of these complex issues is required to inform the design and delivery of a better quality service provision and care. To provide a sustainable, cost-effective service by health professionals, long-term planning is required. Establishing minimum standards for palliative care service requires an evidence-base for the health sector plan.

A patient-centred orientation is vital for quality care - our focus should be on values, hope for the future, goals of care and what is important to the patient and family.¹¹⁸ Much work is needed to educate providers and incorporate guidelines in humanitarian palliative care practice. Further research is needed

so that this vulnerable population will benefit from early, and targeted, interventions to ameliorate their situation and prevent further risks.

3.7.2 Challenges of Undertaking Research

In response to the global COVID-19 pandemic, I had to adapt my research approach for the two studies conducted for this thesis, transitioning from in-person interviews to conducting them online. The limitations imposed by lockdowns, physical distancing measures, and travel restrictions necessitated this adjustment. Despite the challenges posed by this shift, the online interviews provided a profound opportunity for connection and understanding.

Engaging with frontline humanitarian healthcare workers through these interviews was a transformative experience. Their stories and experiences resonated deeply with me, offering insights into their unwavering commitment and the sacrifices they make in the face of humanitarian crises. The exchange of knowledge and the co-creation of understanding during these interviews left an indelible impression on my heart and mind. The wisdom shared by these dedicated individuals has not only informed my research but has also influenced my personal journey. Their stories have compelled me to reevaluate my own path forward, reinforcing my commitment to making a positive impact in the field of humanitarian healthcare.

3.7.3 Context Influencing Research Design

The onset of the COVID-19 pandemic necessitated a shift in the approach of this study, which originally aimed to investigate the delivery of essential palliative care services in Cox's Bazar with a focus on quality care provision. The global health crisis introduced new challenges that required an adaptable research approach to address the changing landscape of care delivery. Particularly, the vulnerable populations already facing hardships were further impacted, demanding a responsive and flexible research strategy.

The initial plan of conducting in-depth interviews with patients to gain insights into their perspectives and perceptions regarding palliative care needs had to be revised due to the constraints imposed by the pandemic. Consequently, I redirected my focus towards analyzing and leveraging the findings from a previous study conducted in 2017, in which I served as the principal investigator. By examining the results of this earlier study, I aimed to

contextualize and comprehend the current needs and challenges surrounding palliative care in the context of the ongoing pandemic.

This shift in research direction allowed for a valuable exploration of the present circumstances while building upon the foundation of past findings. It facilitated an examination of the impact of the pandemic on the provision of quality care and the identification of specific challenges and adaptations necessary for delivering palliative care services in Cox's Bazar during this unprecedented and evolving time.

CHAPTER 4: METHODOLOGY

Unraveling Methodological Insights: Exploring High-Quality Palliative Care Delivery in Cox's Bazar through a Case Study Approach.

4.1 Introduction:

In this chapter, I provide a thorough examination of the methodologies employed in my PhD study, focusing on the delivery of high-quality palliative care in Cox's Bazar. I begin by discussing the rationale behind adopting a case study approach, which allows for an in-depth exploration of the subject matter. I then present an overview of the various methods used for data collection and analysis. This includes a critical examination of the epistemological and ontological considerations that guided my research. By discussing these philosophical underpinnings, I aim to enhance our understanding of the complexities involved in delivering palliative care in this specific context. Furthermore, I share a personal reflection on my professional identity and the expectations I had for this research endeavor. This introspection highlights the personal motivations and perspectives that influenced my approach to the study.

Ethical considerations play a significant role in any research project, and I outline the rigorous steps taken to ensure the integrity and trustworthiness of the research process. I discuss the ethical dilemmas encountered during the study and the measures implemented to protect the rights and well-being of the participants. By delving into these methodological aspects, this chapter establishes a solid foundation for the subsequent chapters of the thesis. It sets the stage for a comprehensive exploration of the provision of quality palliative care in Cox's Bazar, ensuring that the research is grounded in sound methodology and ethical principles.

4.2 Reflective Narrative:

My journey to the Rohingya camps started with a simple invitation to participate in a two-day medical camping event for the Forcibly Displaced Myanmar Nationals (FDMNs). At first, my intention was to show support and respect for these vulnerable refugees, but little did I know that this experience would profoundly change me. As I immersed myself in the camp and engaged with the community, a transformation began to unfold within me. I felt a deep sense of connection and empathy towards the individuals living in such challenging

conditions. It was no longer enough for me to passively observe or provide temporary relief. I knew I had to do more.

With this newfound passion, I dedicated myself to conducting research and utilizing my skills to improve the quality of life for those in need of palliative care within the refugee camps. The experiences and stories I encountered during that time ignited a fire within me, and I made a conscious decision to make a meaningful impact in their lives. This turning point marked a shift in my perspective and priorities. It became clear to me that I had a responsibility to leverage my knowledge and expertise to address the unique healthcare needs of the Rohingya community. Their resilience and strength inspired me to push forward, seeking innovative solutions and advocating for better care.

In this journey, I have come to realize that making a difference goes beyond providing immediate aid. It involves long-term commitment, research, and collaborative efforts. My goal is to bring about sustainable change and empower these individuals to live with dignity, even in the face of adversity. I am grateful for the opportunity to be part of their lives and to contribute to their well-being. This journey has not only impacted the lives of those I serve but has also profoundly transformed me as a person. It has reinforced my belief in the power of compassion, resilience, and the pursuit of social justice.

When I embarked on this research journey in November 2019, I observed a significant gap in the academic literature regarding palliative care in humanitarian settings. At that time, only researchers to address the issues surrounding serious diseases in such contexts had conducted a limited number of studies. Recognizing the importance of this topic, I aimed to extend the existing research and fill the knowledge gap by conducting a comprehensive study on quality palliative care in humanitarian settings. By building upon previous work, my research contributes to a more nuanced understanding of this crucial area of study.

During my time working in refugee camps, I encountered individuals who had endured unimaginable suffering. Interacting with these refugees taught me a valuable lesson – that each person is more than their disease or current circumstances. This realization sparked a strong desire within me to delve deeper into the quality of palliative care provided in humanitarian settings. As a compassionate healthcare provider, I understood the importance of recognizing

the humanity of each individual and making a genuine effort to understand their unique experiences.

Building upon my previous research experience, I recognized the need to approach this profound research journey with careful reflection. Over the course of two years working in the refugee camps, my colleagues and I provided support to individuals living with incurable diseases and serious health-related challenges in various ways, including raising awareness, delivering home care, providing information guidance, offering advocacy support, and establishing day-care services, among others. Although I participated in the JRP 2018 and was awarded, unfortunately, we did not receive any funding to expand our pilot service into a larger-scale initiative. Despite this limitation, I consistently advocated for the needs of patients and caregivers in the healthcare sector meetings.

Throughout this journey, I have been fortunate to have the support of influential leaders in the global palliative care community. Their guidance and encouragement have been invaluable in shaping my approach and strengthening my commitment to improving the quality of palliative care in humanitarian settings.

With the emergence of COVID-19 as a global pandemic, I faced the necessity of conducting my second and third studies online. The challenging circumstances brought about by lockdowns, physical distancing measures, and movement restrictions compelled me to adapt from conducting face-to-face interviews to online interviews for my research. Although this shift presented its own set of challenges, I was profoundly moved by the experiences shared by frontline humanitarian healthcare workers during these interviews. The exchange of words and the co-creation of knowledge opened my heart and transformed my perspective.

Through these encounters, I gained a deeper understanding of the dedication and sacrifices made by those working tirelessly on the frontlines of humanitarian crises. This experience has left an indelible mark on me, and I will forever carry with me the lessons learned from their stories. The collective wisdom we shared during these interviews has not only shaped my research but has also compelled me to reevaluate my path forward.

As I bring this work to completion, I am driven by a renewed motivation to contribute to positive change in the realm of global humanitarian crises. I am committed to utilizing the insights gained from this research to advocate for and implement meaningful improvements in the lives of those affected by such crises.

4.3 Context influencing research design and methodological choices:

While my intention initially had been to examine the provision of quality care in the delivery of essential palliative care services in Cox's Bazar, the unfolding global health crisis brought about by the pandemic necessitated a shift in approach to adapt to the changing context of care delivery. The challenges faced by the most vulnerable populations were further exacerbated during this time, requiring a responsive and adaptive research approach. My original design for conducting in-depth interviews with patients to gain insights into their perceptions and perspectives on palliative care needs had to be reconsidered due to the pandemic. As a result, I had to pivot and draw upon the study conducted in 2017, in which I served as the principal investigator. By analyzing the findings of that previous study, I aimed to contextualize and understand the current needs and challenges related to palliative care in the midst of the pandemic.

This shift in research direction allowed for a valuable examination of the ongoing situation and the ability to bridge the gap between past and present findings. It provided an opportunity to explore the impact of the pandemic on the provision of quality care and to identify the specific challenges and adaptations required in delivering palliative care services in Cox's Bazar during this unprecedented time.

Designing for intellectual and clinical care contribution to the existing evidence-base for palliative care:

In recent years, palliative care interventions have started to gain attention in humanitarian settings, although their presence has historically been lacking. However, the literature on the need for and delivery of palliative care in these settings remains limited. Despite efforts to integrate palliative care services into humanitarian contexts, there has been a lack of assessment of the quality of such care until now.

The research questions were formulated with the aim of understanding the nature of palliative care provision and investigating how the established quality domains of health, as defined by the World Health Organization (WHO), align with palliative care services. Additionally, in the complex and challenging circumstances of humanitarian crises, particularly compounded by the ongoing pandemic, the study sought to identify any additional quality indicators that may emerge. The focus was on examining both the facilitators and barriers to delivering quality palliative care, considering the scarcity and constraints of existing services in the Rohingya refugee camps.

By exploring these research questions, the study aimed to shed light on the current state of palliative care in humanitarian settings, assess its alignment with established quality domains, and identify factors that influence the provision of high-quality care. This research contributes to a deeper understanding of the challenges and opportunities in improving the quality of palliative care services in these complex and resource-constrained environments.

In addition to addressing the needs of the Rohingya community, my research also involved conducting two preliminary investigations focused on understanding the challenges faced by healthcare workers on the frontline in Cox's Bazar. Specifically, the first cohort of palliative care professionals in the Rohingya camps was studied to gain insights into the complex dynamics of providing healthcare in an environment with limited resources. The aim was to develop a more comprehensive and theoretically informed understanding of the experiences of individuals who lacked adequate healthcare.

These investigations delved into the relationships among healthcare professionals, with a specific focus on their roles and the strategies they employed to provide palliative care in the face of the substantial changes induced by the COVID-19 pandemic. The objective was to gain valuable insights into the distinctive perspectives and experiences of these healthcare workers within the context of palliative care delivery. This research aimed to enhance our understanding of the complexities and dynamics involved in delivering high-quality healthcare during times of crisis and transformation, thereby contributing to the overall knowledge base in this field.

Healthcare settings serve as dynamic environments that require constant adaptation and evolution to keep up with new knowledge, technologies, and expectations. Within these settings, critical decisions with life-and-death implications are made on a daily basis. As a leader in palliative care and responsible for service improvement, I am immersed in a policy discourse that highlights the significance of change. The aim is to inform clinical leaders, educators, and policymakers by offering a fresh perspective on how quality of care is manifested within the limited palliative care provision in refugee camps. This study contributes to the ongoing debate on the feasibility of palliative care in humanitarian settings.

By employing a triangulation approach, incorporating data from different perspectives including healthcare workers and patients, a more comprehensive and nuanced understanding of this emerging area of specialist practice is achieved. This approach enriches the evidence base and provides valuable insights to guide future practices and interventions.⁷⁰

4.4 Research Questions:

Question 1: What does the published literature tell us of the quality markers of palliative care within humanitarian settings?

Question 2: What do we know about the specific palliative care needs of the Rohingya community living in Cox's Bazar?

Question 3: How do frontline healthcare workers perceive and describe the aspects of quality palliative care and compassion in humanitarian settings?

Question 4: What factors influence the nature of care provided and how does care integrate and depend on the feelings healthcare workers have towards themselves and others?

4.5 Supporting the Studies:

To address the four research questions, I employed a combination of methods that allowed for a comprehensive exploration of palliative care within humanitarian settings and specifically among the Rohingya community in Cox's Bazar.

In Chapter 2 of my work, I conducted a thorough scoping review and document analysis, which served as the foundation for answering research question 1. This literature review provided valuable insights into the quality markers of

palliative care within humanitarian settings, offering a theoretical framework for my research.

Building upon my previous study from 2017, Chapter 3 of my work presents a reflective analysis which addresses research question 2. This chapter delves into the specific palliative care needs of the Rohingya community in Cox's Bazar. By examining the provision of palliative care in this context, I aim to establish a contextual framework to understand and navigate this field.

In Chapter 5 of my thesis, I explore the perceptions and descriptions of frontline healthcare workers regarding the elements of quality palliative care and compassion in humanitarian settings. Through in-depth interviews and qualitative analysis, I set out to gain insights into how healthcare workers perceive and articulate the components of effective palliative care within this unique setting.

Chapter 6 of my PhD thesis centres on examining the self-perception of health workers in humanitarian settings and their level of preparedness during the challenging circumstances of the COVID-19 pandemic. I explore the factors that influence the nature of care provided and how the feelings of healthcare workers towards themselves and others impact the care they deliver. This chapter aims to shed light on the integration of care and the importance of self-care for frontline healthcare workers in humanitarian settings.

By employing these various methods in my thesis, I aim to provide a comprehensive understanding of the complexity of palliative care Rohingya community in Cox's Bazar. These findings will contribute to the existing knowledge base and inform the development of effective and compassionate care in similar contexts.

4.6 Theoretical Framework:

In this study, I adopted a paradigmatic stance that combined pragmatism and social constructivism. A researcher's paradigm reflects their worldview and the set of propositions that shape their perception of the world. It guides the researcher in determining what is important, legitimate, and reasonable in their systematic inquiry process.⁷¹ Differences among the three perspectives of

pragmatism, social constructivism, and quantitative approaches lie in the extent to which qualitative and quantitative methods can. Pragmatists advocate for the integration of methods within a single study, recognizing the value of both qualitative and quantitative approaches. On the other hand, Sieber (1973) suggests that researchers should utilize the strengths of both techniques to gain a deeper understanding of social phenomena.⁷³ Creswell and Plano Clark (2007) discuss three stances or worldviews in the mixed methods literature.⁷⁴ The first is the belief that pragmatism is the most fitting paradigm for mixed methods research. The second is a dialectical perspective that acknowledges the use of multiple paradigms in mixed methods research, as long as researchers are transparent about their choices. The third stance recognizes that worldviews can vary depending on the type of mixed methods design employed.

By adopting a pragmatic and social constructivist paradigm, I aimed to bring together the strengths of qualitative and quantitative methods in this study, allowing for a comprehensive exploration of the research questions at hand. This approach provided a solid foundation for understanding the complex nature of social phenomena within the context of this research.

My choice of methodology in this study was influenced by my epistemology (theory of knowledge) and ontology (nature of reality). I recognized the importance of understanding my own perspective on how knowledge is obtained and the nature of reality, as it would shape every aspect of my research process. Questions such as how I can come to know reality, the relationship between the knower and the known, and the principles and assumptions guiding the process of knowledge attainment were pivotal.⁷⁵

The epistemological position I held as a researcher had a profound impact on various aspects of my study, including the choice of subject, the development of research questions, the theoretical framework, and the selected methodology and methods. Additionally, my own conscious and unconscious questions, assumptions, and beliefs played a role in shaping the truths I sought in my study and influenced my personal perspectives.^{76,77}

Considering the complexity of my research questions and the nature of my roles as both a clinician and a researcher, I embraced a mixed-methods approach that combined qualitative and quantitative approaches.⁷⁸ From a philosophical

standpoint, I approached the concept of truth through the lens of "what works," evaluating the feasibility of employing both qualitative and quantitative methods in my study. Aligning my philosophical stance with the mixed methods research tradition of pragmatism and constructivism became crucial at this stage of my methodological and philosophical journey. Pragmatism emphasizes that knowledge is derived from experience, and human actions are based on past experiences and what individuals have learned. On the other hand, constructivism asserts that knowledge and meaningful reality are constructed through human practices and interactions within a social context.⁷⁹ Both philosophical underpinnings played a significant role in shaping my study, allowing for a comprehensive exploration of the research questions while considering practical solutions as a clinician and deeper understanding as a researcher.

4.6.1 Pragmatism

Pragmatism has been a guiding philosophy in mixed methods research, emphasizing the integration of methods within a single study.⁸⁰ As a pragmatist, I believe in utilizing the strengths of both qualitative and quantitative approaches to gain a comprehensive understanding of social phenomena, acknowledging that each approach has inherent strengths and weaknesses.

Embracing a pragmatist worldview, I find that the choice of paradigm is guided by the research problem itself. This approach enables me to tailor the selection of methods to address specific research questions effectively.^{81,82} The pragmatic worldview places emphasis on the consequences of research, prioritizing practicality and usefulness while incorporating multiple methods of data collection. Personally, I resonate with the values of pragmatism, as it aligns seamlessly with my commitment to discovering practical and effective solutions to clinical problems.⁸³

In adopting a pragmatist worldview, the choice of paradigm is driven by the research problem itself, allowing the selection of methods to be tailored to address specific research questions.^{81,82} The pragmatic worldview focuses on the consequences of research, prioritizing practicality and usefulness, as well as employing multiple methods of data collection. I resonate with the values of pragmatism, as it aligns with my commitment to finding practical and effective solutions to clinical and community related problems.⁸³

4.6.2 Constructivism

As a researcher, I adopt the constructivist perspective, which asserts that the world is actively constructed rather than simply discovered. Following Guba and Lincoln's (1994) framework, my approach to constructivism involves a relativist ontology, a transactional epistemology, and a hermeneutic dialectical methodology.⁸⁴ These foundational principles have significantly influenced the evolution of grounded theory. The focus is to delve into the participant's perspective, giving prominence to their subjective experiences rather than quantifying behaviors and attitudes.⁸⁵

However, it is important to acknowledge that critics of the constructivist paradigm raise concerns about potential threats to validity and argue that it lacks scientific value. They contend that it can be perceived as overly subjective and lacking in rigour.⁸⁸ Nevertheless, I believe that exploring the complexity of the human experience requires a more fluid, contextual, and relational understanding. This necessitates an interpretative approach that seeks to comprehend the intricacies of human thought, speech, and action.

On the contrary, I adhere to the positivist paradigm, which posits that reality is stable, and objective knowledge can be acquired through rigorous methodologies. I believe in the perspective that says meaning is not assigned but rather uncovered through scientific measures and objectivity. While constructivists attribute subjective meaning to objects in their world, my inclination as a positivist emphasizes the significance of objective measures and scientific rigor.

Several authors stress the significance of choosing a research method that effectively addresses the research question.⁸⁶ In alignment with this perspective, the aim of my study was to explore the viewpoints of healthcare professionals regarding palliative care and the self-preparedness and needs of patients with serious diseases within the context of humanitarian crises. To accomplish this, immersing myself in the culture of healthcare professionals involved in caring for patients in humanitarian settings was essential. My goal was to comprehend how the culture was shaped and how behaviors and experiences influenced the provision of palliative care for both healthcare professionals and patients, aiming for a comprehensive understanding. Therefore, I deemed the constructivist paradigm most appropriate for this type of inquiry.

4.6.3 Dialectical Pluralism

According to Johnson (2012), I find dialectical pluralism to offer a valuable perspective by taking a pluralist stance ontologically and employing a dialectical approach to learn from diverse viewpoints.¹³⁹ This metaparadigm framework resonates with me as it embraces multiple paradigms, theories, disciplines, and perspectives, recognizing the richness that comes from combining different ideas and values. In my view, dialectical pluralism aligns well with mixed methods research, as it allows for the integration of various approaches and adds a "metavoices" to social science research and practice.¹³⁹ As an individual engaged in the field of mixed methods research, I emphasize the importance of incorporating dialectical pluralism to foster a more comprehensive and inclusive understanding of complex phenomena. By embracing dialectical pluralism, I believe researchers can navigate the complexities of diverse perspectives, enabling a more holistic approach to research inquiry.

4.7 Research Design and Methodology:

I followed the definition of methodology by Hammells' (2006)⁸⁷, which stated:

"A specific philosophical and ethical approach to developing knowledge, a theory of how research should, or ought, to proceed given the nature of the issue it seeks to address, and an analytic approach to the political issues involved in the process."

This helped me to understand the importance of underpinning philosophical and theoretical assumptions, which are able to provide a bridge between my theory (ideas) and method (doing). The research design and methodology of this study were developed by carefully aligning my philosophical and theoretical assumptions with the chosen research method. This alignment aimed to establish a coherent connection between my ideas and the actions taken in the study. By considering my ontological and epistemological beliefs about the nature of reality and knowledge, I sought to determine the most suitable approach for acquiring the desired understanding of the world.

The process involved questioning which research approach would be the most effective in achieving the study's objectives. Guided by different paradigms, I evaluated various methodologies and selected the most appropriate one to address my specific research questions. Through this thoughtful consideration and alignment of philosophical and theoretical perspectives, the chosen research design and methodology were carefully selected to ensure a robust and effective approach to investigate the research objectives.

4.7.1 Utilizing the Case Study approach:

Considering the focus of this research on a specific complex humanitarian setting, I made the decision to utilize an exploratory, in-depth case study design. As defined by Creswell (2007),⁷⁴ a case study involves the exploration of a bounded system or a specific case, over a period of time, through extensive data collection that encompasses multiple sources of information rich in contextual details. The aim is to understand the intricacies and complexities of a single case within its significant circumstances.

The case study method allows for a thorough investigation of a contemporary phenomenon, delving deeply into its real-world context.⁸⁸ This method aligns with the goal of gaining a comprehensive understanding of the quality of palliative care in a humanitarian setting, particularly in light of limited prior research in this area. Additionally, it enables an examination of the impact of the COVID-19 pandemic on palliative care practices.

Trochim (2001) defines a case study as an intensive study focused on a specific individual or context. This definition resonates with my research approach, as I am delving deeply into the quality of palliative care service provision within humanitarian settings.⁸⁹ According to Yin (2008), conducting a case study requires certain qualities and skills from the researcher.⁹⁰ They should possess knowledge about the phenomenon being investigated, remain open to new and unexpected issues during data collection, ask insightful questions, be an attentive listener, and demonstrate adaptability and flexibility. In the case of my research on palliative care provision, these attributes are essential for a comprehensive understanding of the contemporary phenomenon within the real-life context of refugee camps, where multiple sources of information are involved and the complexity of the situation is acknowledged.

I opted for a case study design because it is well-suited for exploratory work and allows for the development of detailed knowledge about a single case. This approach focuses on specific situations and aims to thoroughly investigate and address particular issues, enabling me to conduct an extensive examination of the phenomenon of interest, which in this case is quality palliative care provision.

4.7.2 Mixed Methods Research:

Mixed methods research is a valuable approach that involves the combination and integration of both qualitative and quantitative research traditions. In the context of investigating the quality of palliative care provision in humanitarian settings, it was essential to utilize both methodologies to gain a comprehensive understanding from the viewpoints of healthcare professionals and patients. By leveraging the strengths and addressing the limitations of each methodology, the aim was to ensure that the research questions were effectively answered and that the results of the study were robust and well-supported.

Mixed methods research is not only a research design, but also encompasses philosophical assumptions and methods of inquiry. This methodology involves the integration of philosophical assumptions that guide the data collection and analysis processes, as well as the combination of qualitative and quantitative approaches throughout various stages of the research. Mixed methods research as a method focuses on the gathering, examination, and blending of both qualitative and quantitative data within a single study or a series of studies. The underlying principle is that the use of both quantitative and qualitative approaches together leads to a more comprehensive understanding of research problems compared to using either approach alone.

In mixed research, there are three primary types: quantitatively driven mixed research (QUAN + qual), qualitatively driven mixed research (QUAL + quan), and interactive mixed research where the researcher or research team combines insights from qualitative and quantitative epistemologies to create a more comprehensive whole.⁹¹ The research I conducted falls under the qualitatively driven mixed research category or (QUAL + quan). Quantitative data were collected to provide a broad overview of the research problem, while simultaneously, qualitative data were gathered and analyzed. The integration of data from both approaches allowed for an enriched description of the cases under study.

The utilization of a mixed-methods design allowed me to tackle more intricate research questions and gather a diverse and robust set of evidence, surpassing the capabilities of any single method alone. Inspired by Creswell (2002), I adopted a case study design with a core mixed methods convergent design, as depicted in Figure 4.1.⁹² The convergent design involves the separate collection and analysis of qualitative and quantitative data in parallel, prior to their

integration. This mixed methods research approach, which combines and integrates both quantitative and qualitative data, aims to foster a more comprehensive understanding. It is commonly employed in health and social sciences to explore complex phenomena. In social science research that investigates human behavior, the integration of quantitative and qualitative data enhances the depth and rigor of the findings by leveraging multiple complementary data sources. By employing various methods of data collection and analysis to effectively address the research questions at hand, this approach aligns with a pragmatic philosophy that is tailored to the specific research context.

In my research, I employed a mixed-method approach that acknowledges the ever-changing nature of the study. The design, delivery, and evaluation of the research were conducted concurrently, allowing for a comprehensive understanding of the phenomenon under investigation. To ensure data triangulation and address potential ethical and data reliability issues, I incorporated multiple sources of data. This approach enhances the robustness and credibility of the findings.

4.7.3 Constructivist Grounded Theory Approach:

Throughout this study, I had the opportunity to observe daily medical practices in various healthcare facilities and community care settings, including patients' homes within the Rohingya camps. This involved closely observing the communication between doctors, nurses, patients, and caregivers in different contexts such as outpatient departments, inpatient rounds, medication rounds, triage areas, project management roles of doctors, multidisciplinary team meetings, hand-over meetings, and health sector meetings. My aim was to delve into the complexities of social interaction within humanitarian settings and to gain insights into the underlying beliefs, values, and attitudes of patients, their relatives, and the healthcare staff responsible for their care.

In this study, my epistemological stance as a researcher was grounded in constructivism, which recognizes that individuals in the study actively construct their own knowledge. I believe that the participants within their specific social context, in a complex and socially mediated environment, individually construct knowledge, learning, and service delivery.⁹⁸ This perspective aligns with the constructivist approach, where knowledge is seen as a product of the interaction between the individual and their social environment.

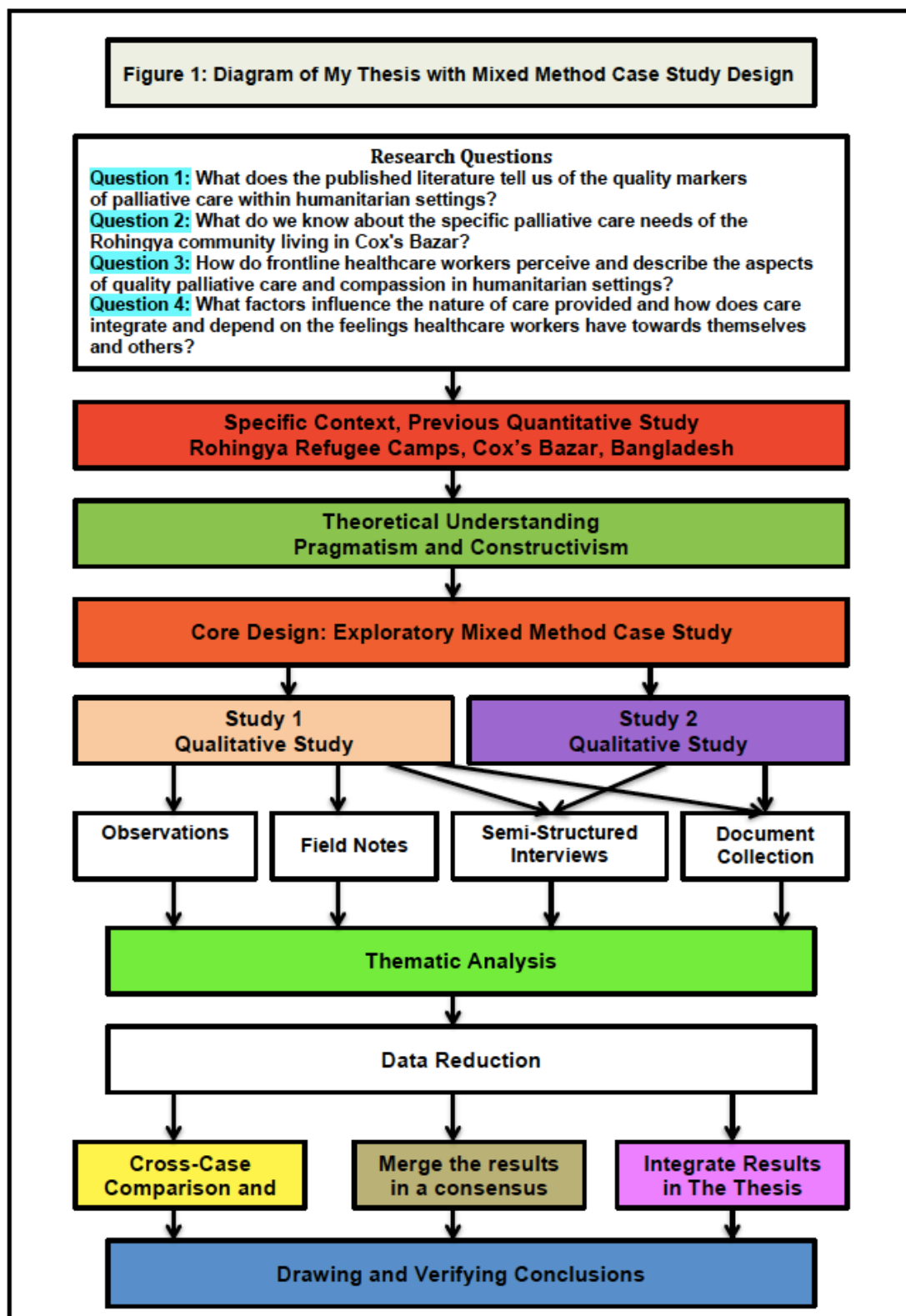
Using the constructivist grounded theory method; I aimed to develop an original theory that emerged from the data collected during the study. This approach allowed me to explore the rich experiences and perspectives of the participants, and to uncover the underlying patterns and themes that shape their interactions and practices in the humanitarian setting. By embracing the constructivist framework, I sought to understand the intricate dynamics of knowledge construction, learning, and service delivery within this unique context. Further details of the data collection and analysis procedures are contained in chapter 5.

4.8 Data Collection:

Case Study 1: Moving on to Chapter 5, my study titled "Uncovering the Challenges and Opportunities: Healthcare Workers' Perspectives on Palliative Care and compassion in Humanitarian Settings" utilized an ethnographic and grounded theory approach. The research involved participant observations, informal conversations, and interviews to gain a comprehensive understanding of the topic. I interviewed a total of 20 health professionals working in palliative care, including 2 physicians, 10 nurses, and 8 palliative care assistants. Their perspectives shed light on the challenges and opportunities associated with providing palliative care in humanitarian settings.

Case Study 2: In Chapter 6 of my research, titled "Exploring the self-preparedness of frontline healthcare workers in a low- and middle-income country from a humanitarian context during the COVID-19 pandemic: A constructivist grounded theory study," I adopted a constructivist grounded theory approach.

Figure 4.1: Overview of the thesis mixed methods case study design



The study further draws on the theoretical framework of symbolic interactionism, which highlights the importance of social interaction and the theoretical frameworks of symbolic interactionism and social constructionism.⁹³

To gather data, I conducted semi-structured interviews with frontline healthcare workers. These interviews provided valuable insights into the self-preparedness of healthcare workers and their experiences in a low- and middle-income country during the COVID-19 pandemic. The constructivist grounded theory methodology allowed for a deep exploration of the participants' perspectives and the construction of meaningful knowledge in this humanitarian context.

4.8.1 Ethnographic Observations:

In my study, I chose to employ ethnographic methods as they allowed me to explore a wide range of issues in a timely and sensitive manner. Ethnography provided me with a deep understanding of the phenomena under investigation by focusing on in-depth information and observing a small number of participants in their natural setting, rather than in a controlled and predetermined environment.

By adopting an ethnographic approach, I had the opportunity to immerse myself in the daily lives of the participants, spending a prolonged period of time "in the field" to observe their practices and gather valuable data. This involved both formal and informal interactions, such as formal interviews and casual conversations, which allowed me to collect a comprehensive dataset.⁹⁴

My goal was to provide an in-depth interpretation of the collected data, with a particular emphasis on understanding the meaning, function, and outcomes of the observed behaviors. This involved analyzing the data in a holistic manner, considering the social context and cultural nuances that influenced the participants' actions. By employing ethnographic methods, I was able to delve into the social phenomena under study, shedding light on the intricacies of daily life within the research setting. This approach facilitated a deep exploration of the research topic and provided valuable insights into the experiences and perspectives of the participants.

4.8.2 Interviews:

Alongside the ethnographical approach for Study 1, I also carried out Semi-structured Interviews. The ethics committee's decision to suspend face-to-face research interviews during the pandemic led to a shift to online interviews.

Three individuals from the FKRF assisted me in conducting these interviews: the project manager, psychologist, and field manager. Each of them brought valuable prior experience in the realm of research interviews. I interviewed frontline health professionals like doctors, nurses and community health care workers to better understand their views on providing palliative care and compassion in humanitarian settings. In my research, I utilized a semi-structured questionnaire to gather data and insights from participants. The questionnaire consisted of various questions related to palliative care, including its definition, the target recipients, and the exclusion criteria. I also inquired about the participants' previous experience working with incurable patients and their confidence in assessing and managing the care of patients receiving palliative care. Additionally, I asked about training needs, the positive aspects and challenges of palliative care work, teamwork dynamics, the impact of the palliative care service on their lives, memorable moments, and self-care strategies. The semi-structured nature of the questionnaire allowed for flexibility and the opportunity to delve deeper into participants' experiences and perspectives.

Interviews were recorded, transcribed and translated, with the translation used for analysis. To analyze the individual interviews, I first used Merriam's (1988) approach by developing categories that states, "developing categories involves looking for recurring regularities in the data" (p. 133).⁹⁵ I coded all transcribed interviews and used in vivo and initial codes to begin coding the data. In vivo codes are direct quotes from the participants that help better preserve their perspectives.⁹⁶

I also used initial coding to help synthesize information that might not have been as powerful as a direct quote. Once these codes were developed for each interview, I began to create categories. Therefore, I compared each of the codes per interview to one another and determined which codes could be subsumed into a category.

This also reduced the original number of codes to a smaller subset. Once categories for each individual interview were created, I incorporated Yin's (2014) pattern matching approach.⁹⁷ Pattern matching allows to group summaries or codes into smaller categories or themes. These codes typically identify an emergent theme or explanation in greater detail. I analyzed the categories from all interviews and found concordance of data by matching

similar categories across all participant interviews and developed patterns. These patterns became the overarching themes of the study.

4.8.3 Field Notes and Reflective Journal:

During the period from January to March 2020, I collected data through participant observation and informal conversations. My background as a specialist palliative care physician and lead implementer of these interventions proved beneficial in establishing rapport and smoothly integrating with the teams. I conducted observations during training sessions, meetings, and while providing supervision during clinical activities, particularly with patients who presented challenges and were difficult to manage, as well as adherence to clinical protocols.

To ensure accuracy and avoid memory bias, I occasionally recorded field notes using my mobile phone. Later, I transcribed these notes in more detail onto a Microsoft Word document. Informal conversations played a vital role in clarifying certain aspects that I had observed in specific situations. To gain a better understanding of the professionals' intentions, I posed questions such as, "What do you think you convey when you give the patient/family your direct contact number?"

Throughout the process, I maintained a reflexive journal to reflect on my observations and track analytic concepts. Additionally, I engaged in discussions with the research team at least twice a week. These discussions took place through informal conversations with the health professionals I observed.

Throughout my involvement, I acknowledged my dual roles as both a passive observer and an active intervener. It was an ethnographic experience for me, as I had trained a team of health professionals and now had the opportunity to observe them within their natural palliative care setting, specifically in ten Primary Health Centers (PHCs). This allowed me to gain a comprehensive understanding of the recently launched palliative care services and observe the behaviors of these professionals as they interacted with patients and their families.

My primary focus during these observations was to identify areas where care could be improved. I was constantly seeking opportunities to enhance the delivery of palliative care services. Additionally, these observations helped me

raise awareness about the potential benefits of palliative care within the Rohingya health sector. By implementing the Palliative Care Intervention (PCI), I aimed to support the staff in their activities and contribute to the overall improvement of patient care.

To ensure accuracy and capture the essence of the observations, I diligently recorded my thoughts, experiences, ideas, and personal reactions. These reflections encompassed my interactions with patients, health providers, and their families within the PHCs. Understanding the significance of field notes in ethnographic research, I made a conscious effort to maintain detailed descriptions of the observations, using the language and context of the informants without interpretation or simplification. This approach allowed me to vividly depict the rich context in which these observations took place.

4.8.4: Documentary Analysis:

Document analysis is a systematic method for evaluating both printed and electronic materials, including computer-based and Internet-transmitted content. Similar to other qualitative research analytical approaches, document analysis involves examining and interpreting data to extract meaning, gain understanding, and develop empirical knowledge.¹²⁸ I have used multiple documents in my study: Background papers, books, maps, newspapers (clippings and articles), reports, survey data and internet articles.

4.9 Recruitment and Participants:

In this study, I employed a constructivist grounded theory approach to gain a deep understanding of the experiences and perspectives of frontline health professionals working in the Rohingya refugee camps in Bangladesh during COVID-19 pandemic. The aim was to explore their insights on various aspects of healthcare delivery in this challenging setting.

To gather data, we conducted in-depth interviews with community healthcare workers (CHWs) who were actively working in the primary health centers within the Rohingya camps in Cox's Bazar. We specifically focused on frontline healthcare providers directly involved in patient care, excluding those only in managerial or training roles. Additionally, we excluded individuals who expressed unwillingness to participate in the study.

The sampling methods utilized in this study were purposive and snowball sampling. Initially, participants were selected using convenience sampling, considering their availability and willingness to be part of the study. Subsequently, snowball sampling was employed, where participants already included in the study referred us to other potential participants who met the criteria.⁹⁹

By using this combination of sampling methods, we aimed to capture a diverse range of perspectives and experiences from frontline healthcare professionals actively engaged in delivering care within the Rohingya camps. This approach allowed us to explore the nuanced insights and gather rich data that contribute to a comprehensive understanding of the healthcare challenges and practices in this humanitarian context.

4.10 Data Analysis:

The case study approach proved valuable in gaining a comprehensive understanding of the facilitators, obstacles, and deficiencies within the humanitarian palliative care setting. Both within-case and cross-case analyses were conducted to identify commonalities and variations in terms of resources and functions. The analysis incorporated multiple data sources, including transcribed interviews, translations, and survey findings. The overall approach can be summarized as follows:

4.10.1 Thematic Analysis:

Following the interviews and data collection, a thematic analysis was conducted, drawing on the approach outlined by Braun and Clarke (2006).¹⁰⁰ Key aspects of the case study analysis included utilizing multiple sources of evidence, establishing a case study database, and ensuring a clear chain of evidence. This comprehensive approach significantly enhanced the quality of the analysis, increasing the reliability and credibility of the resulting insights. By examining the information in this manner, significant themes and patterns were able to emerge, providing valuable insights into the research topic.

The themes and sub-themes were derived from the interviews conducted as part of the within-case and cross-case analysis of all the interviews from studies 1 and 2. To ensure data triangulation, various data sets were utilized, including online interviews, audio recordings, field notes, and member checking.¹⁰¹ This

comprehensive approach allowed for a thorough examination of the data, ensuring a robust and comprehensive analysis of the research findings.

4.11 Ethical Considerations:

The research study received ethical approval from The University of Edinburgh (UoE). To ensure data security, all interviews were recorded using an audio recorder, and all data, including transcriptions and data analysis procedures, were stored on UoE's server. As a security measure, recordings were promptly deleted from the recorder once transferred to the server. Access to this information was strictly limited to the primary and secondary investigators involved in the study.

Respecting autonomy or the principle of respect for persons is a fundamental consideration in research ethics. It emphasizes the importance of allowing participants to make their own informed choices about participation. In accordance with UoE's guidelines, participants were asked to provide their assent before participating in the study, ensuring their voluntary involvement and respect for their autonomy.

The principle of beneficence emphasizes the importance of minimizing risks and maximizing potential benefits for research participants. In my research design, I carefully considered potential risks, including the possibility of mental discomfort, especially during online interviews. It was my ethical responsibility to take necessary precautions and make every effort to anticipate and prevent any participant discomfort or harm throughout the entire study process. By prioritizing participant well-being, I aimed to ensure their safety and minimize any negative effects that could arise from their involvement in the study.

To ensure research integrity in the conduct of human subject research, the following steps were taken:

1. An Institutional Review Board (IRB) and Ethical Application were submitted to and approved by the University of Edinburgh.
2. Clear communication was established with the participants regarding the objectives and purpose of the research study.
3. Prior to the initiation of the study, written informed consent was obtained from all participants to ensure their voluntary participation and understanding of the research procedures and potential risks involved.

To ensure accurate representation of participants' views and promote ethical practices, a summary of the research findings was shared with selected participants. However, obtaining feedback from displaced persons who took part in the study posed challenges due to follow-up difficulties, pre-literacy limitations, and limited access to information technology. Zwi et al. (2006) have highlighted the complexities of sharing findings with crisis-affected participants and recommend exploring short-term reciprocal benefits, as providing feedback at a later stage may not be feasible.¹⁰² In this study, participants primarily benefited from gaining information about where, how, and why to access care in their specific setting. It is crucial to consider ethical considerations when engaging with displaced populations, as they are vulnerable and may lack the power and capacity to protect their own interests.¹⁰³

4.12 Trustworthiness in mixed-methods research:

In recent years, the topic of trustworthiness in mixed-method research has gained considerable attention and continues to be a subject of discussion and debate.¹⁰⁴ Teddlie and Tashakkori (2003) have identified 35 different types of validity that are applied in both qualitative and quantitative research, highlighting the complexity of the subject.⁷⁰ Despite the growing use of mixed methods in social and behavioral research, there is a lack of systematic literature addressing the quality of inferences in such studies. It is argued that terms like rigor and validity are often associated with the positivistic paradigm of quantitative research and may not align with the constructivist or interpretivist paradigm. While various quality criteria have been proposed, a consensus on their adequacy has yet to be reached.

In this study, I will adopt the 'Quality Framework for Mixed Methods Research' developed by Tashakkori and Teddlie (2008),¹⁴² which has been further expanded by O'Cathain (2010).¹⁰⁵ This comprehensive framework encompasses eight domains: Planning quality, Design quality, Data quality, Interpretive rigour, Inference transferability, Reporting quality, Synthesizability, and Utility.

These domains are organized within five stages of a research project: Planning, Undertaking, Interpreting, Disseminating, and Application in the real world. In the following sections, I will outline how I have addressed each of these domains in my study.

Domain 1: Planning Quality

The first domain of the Quality Framework for Mixed Methods Research focuses on the planning of the study. In this thesis, careful attention has been given to the foundational elements, rationale transparency, planning transparency, and feasibility. The Planning quality domain has been successfully addressed by incorporating the Organizing for Quality framework as the underlying element and conceptual theoretical foundation throughout all phases of the study. The aim and research questions of the thesis were developed based on identified gaps in knowledge regarding palliative care quality in humanitarian settings. Rationale transparency was achieved by conducting a thorough review of the literature, which emphasized the significance and validity of using mixed methods research in this specific area. By extensively examining existing studies and theories, the rationale for employing a mixed methods approach in the present study was clearly justified and supported. This ensured transparency in the reasoning behind the chosen research methodology and contributed to the overall credibility of the study.

Feasibility has been a crucial consideration, particularly in the context of limited resources. The study has taken into account the realities of timelines and available resources, while also accounting for the impact of the COVID-19 pandemic. The ethics committee's decision to suspend face-to-face research interviews due to the pandemic has posed significant challenges to meeting the time-bound completion date for the PhD.

Domain 2: Design Quality

Design quality is a critical aspect of the research process, and it encompasses various elements that contribute to its overall strength. The four relevant design quality criteria are Design transparency, Design suitability, Design strength, and Design rigour. To address the criterion of design transparency, the thesis provides a comprehensive description of the Mixed Methods Case Study Design, as outlined in this chapter. The sub-studies within the thesis have employed designs that align with the aim and research questions. Study 1 adopts a quantitative approach, Study 1 utilizes a qualitative approach with a semi-structured questionnaire, ethnographic observations, and field notes, while study 2 focuses on qualitative methods. These design choices align with the stated paradigmatic mixing legitimation and contribute to the transparency of the research design. The design suitability criterion considers whether the

chosen design is appropriate for addressing the research questions, ensuring a cohesive alignment between the design and the objectives of the study. The design strength criterion emphasizes optimizing the breadth and depth of the research, acknowledging both the weaknesses and strengths of the chosen design and taking measures to minimize any potential limitations. Finally, the design rigour criterion emphasizes implementing the design faithfully throughout the study, ensuring that the research stays true to its intended design and follows established protocols to maintain the rigor of the research process.

The design and methods employed in this PhD study were carefully crafted to align with the research questions and facilitate meaningful findings. The study design demonstrated its strength in study 1 and study 2, as it effectively addressed by integrating open-ended qualitative questions. This approach allowed for a more comprehensive exploration and understanding of the research questions. By analyzing previous quantitative and current qualitative data collection methods, the study design enhanced the depth and richness of the findings, providing a more holistic perspective on the research topic. This approach is consistent with the philosophical framework of pragmatism, which underpins this thesis. The inclusion of triangulation of methods in the study further enhances design quality by compensating for any potential methodological weaknesses in one study with the strengths of another.

The mixed-methods research design employed in this study contributes to the overall validity of the findings by incorporating multiple data sources that address the same research questions and concepts. This is particularly significant as quantitative data sources ensure anonymity, while some qualitative data is collected through face-to-face interactions.

Domain 3: Data Quality

Data quality was addressed through various domains, including data transparency, data rigor or design fidelity, sampling adequacy, analytic adequacy, and analytic integration rigor. Data transparency was achieved by providing detailed descriptions of the data collection process, recruitment, participants, setting, and analysis methods employed in each sub-study.

The research team adhered to the ethical guidelines of the University of Edinburgh, ensuring data rigor and maintaining consistency throughout the data collection process. No changes were made during data collection, further

enhancing the integrity of the study. Sampling adequacy was ensured by carefully considering the sampling techniques and sample sizes within the study's specific context. Analytic adequacy was achieved by employing appropriate data analysis techniques, which are comprehensively described for each sub-study.

Domain 4: Interpretive rigor

Interpretive rigor is essential in ensuring the credibility and trustworthiness of the conclusions drawn from mixed methods studies. This study addresses interpretive rigor through the examination of eight elements: interpretive transparency, interpretive consistency, theoretical consistency, interpretive agreement, interpretive distinctiveness, interpretive efficacy, interpretive bias reduction, and interpretive correspondence. To achieve interpretive transparency, the study clearly indicates which findings are associated with each specific method employed. The qualitative and quantitative components of the study are reported separately, allowing for a clear understanding of the relationship between the findings and the methods used.

Interpretive consistency is upheld through rigorous discussions among the research team regarding the inferences drawn from the results of each analysis. This process ensures that the interpretations align with the findings and are consistent across the study. Theoretical consistency is achieved by ensuring that the inferences drawn from the findings align with existing knowledge and theories in the field. The research team critically evaluates the compatibility of the conclusions with current knowledge, thereby enhancing the theoretical consistency of the study.

To foster interpretive agreement, the results are presented to a select group of participants who have the opportunity to provide feedback and respond to the findings. This member check process promotes consensus and agreement on the interpretations among researchers, healthcare professionals, and other stakeholders, thereby enhancing the interpretive agreement of the study. By addressing these elements of interpretive rigor, the study establishes a robust foundation for the authenticity and trustworthiness of its conclusions.

Domain 5: Inference transferability

To enhance the transferability of the study's conclusions, several factors were considered. Ecological transferability was addressed by examining the applicability of the findings to different ecological settings beyond the study context. Considering whether the conclusions could be generalized to other populations with similar characteristics assessed population transferability. Temporal transferability was taken into account by evaluating the continued relevance and validity of the findings over time. Aligning the study conclusions with existing theories or theoretical frameworks in the field ensured theoretical transferability.

The study also demonstrated interpretive rigor in its analysis and interpretation of the data. Interpretive transparency was achieved by clearly linking specific findings to their corresponding research methods. Interpretive consistency was upheld by ensuring that the inferences drawn from the findings were consistent and aligned with the empirical evidence. Theoretical consistency was maintained by ensuring that the conclusions were in line with current knowledge and theories.

Interpretive agreement was fostered through engaging other researchers, healthcare professionals, and stakeholders in the analysis and interpretation process. This allowed for a validation of the conclusions and enhanced the credibility of the study. Interpretive distinctiveness was achieved by providing unique and well-supported conclusions that went beyond alternative explanations. Overall, the study demonstrated a comprehensive approach to enhance the external validity and interpretive rigor of its findings. By providing detailed descriptions of the sampling strategy and sample characteristics, the study establishes a foundation for assessing the generalizability of the findings. Additionally, the careful consideration of inference transferability and the application of interpretive rigor contribute to the credibility, trustworthiness, and applicability of the study's conclusions.

Domain 6: Reporting quality

Reporting quality was given due consideration, taking into account report availability, reporting transparency, and the knowledge gained from the study. The thesis was executed according to the planned timeline, although there were delays in the dissemination of the results. The extended data collection period in sub-study II was influenced by the emerging pandemic situation.

However, these delays did not impact the completion of the thesis. On the contrary, they provided an opportunity for further exploration through inductive analysis in sub-study III. As a result, Paper III was written and seamlessly incorporated into the thesis, despite not being initially included in the original project plan from 2019. To ensure reporting transparency, the study adhered to guidelines for accurate reporting of mixed methods studies, such as the Guidelines for Reporting of Articles in Mixed Methods Studies (GRAMMS).¹⁰⁶ The thesis provides clear descriptions and justifications for the mixed methods design, demonstrating transparency in both the qualitative and quantitative components. The integration of results was meticulously carried out for each sub-study and the thesis as a whole, enabling a comprehensive presentation of the findings.

The study places significant emphasis on reporting quality, ensuring the availability of the thesis, addressing any dissemination delays caused by the pandemic, maintaining transparency through adherence to reporting guidelines, and effectively integrating the results across different sub-studies. These measures contribute to the overall strength, transparency, and accessibility of the research findings.

Domain 7: Synthesizability

Synthesizability is a crucial domain that focuses on how the synthesized evidence from the study can be applied and translated to the intended context. In this thesis, "The quality framework" for assessing quality in mixed methods research has been thoroughly tested. The study incorporates detailed descriptions of triangulation methods, in-depth discussions, comprehensive presentation of research findings, and active involvement of stakeholders at every stage of the mixed methods study. These elements collectively establish a solid foundation for effectively translating the knowledge gained from this study back to the context of low- and middle-income countries (LMICs) and the humanitarian palliative care setting.

Domain 8: Utility

The domain of utility focuses on how research findings are utilized by stakeholders and policymakers. Assessing the utility of a study can be challenging in practice, as it may be difficult to directly associate specific actions with specific studies. Some studies may have an immediate impact and receive wide dissemination due to their newsworthiness, while others may quietly

contribute to the growing evidence base on a specific issue. In the case of this study, the utility of the findings would rely on ongoing efforts to disseminate the research through publications, advocacy, and innovative approaches. These efforts aim to bring about changes in the culture of palliative care in humanitarian crises. Scholars in the field of mixed methods research have proposed the development of a utilization quality audit as a means to evaluate the effectiveness and impact of research utilization.

By employing various dissemination strategies and actively engaging with stakeholders, this study seeks to maximize its utility and ensure that the research findings are effectively utilized to bring about meaningful changes in the field of palliative care in humanitarian contexts.

CHAPTER 5: STUDY 1

How do frontline healthcare workers perceive and describe the various aspects of quality palliative care and compassion in humanitarian settings?

5.1 Introduction:

Chapter five introduces the first of the two studies that investigates palliative care in humanitarian environments. This study examines the quality of palliative care practices carried out by frontline healthcare workers (FHCWs) operating in a limited humanitarian palliative care setting. Furthermore, it seeks to uncover specific services that revolve around compassion. The central research question this study addresses is, "How do frontline healthcare workers perceive and describe the various aspects of quality palliative care and compassion in humanitarian settings?"

To conduct this study, an ethnographic case study approach was employed. In addition, a series of in-depth interviews with key informants provided valuable data. The study also employed the constructivist grounded theory method for analysis to develop an original theory.

5.2 Background:

Ensuring quality of care is a universal commitment recognized by the Sustainable Development Goals (SDGs) 3.¹⁵ This goal acknowledges that quality is a crucial component of achieving universal health coverage (UHC). Target 3.8 of the SDGs urges countries to attain UHC, encompassing financial risk protection and access to five essential health care services of high quality.²⁴ In low- and middle-income countries (LMICs), poor quality care is responsible for 60% of deaths caused by health condition-related issues, while the remaining 40% of deaths arise from the failure to utilize the healthcare system.²²

The impact of inadequate quality care is significant, with approximately 15% of total deaths in LMICs each year directly attributed to it. Moreover, the lack of quality care in LMICs leads to substantial economic losses, estimated at US\$1.4-1.6 trillion annually, due to lost productivity. It is worth noting that around 2 billion individuals reside in fragile contexts, which face considerable challenges in delivering essential health services of high quality.³

Palliative care plays a crucial role in preventing and alleviating suffering while enhancing the quality of life for individuals living with chronic and incurable illnesses. It recognizes and addresses the physical, psychological, social, and spiritual needs of patients, extending its support to bereavement if required. This approach is centered around the patient rather than being solely focused on the disease itself. Palliative care can be delivered through interdisciplinary teams utilizing various methods, including hospital inpatient care, outpatient care, home-based care, and hospice services. In the context of inpatient care, the palliative care programs ensure continuity of care for patients once they are discharged from the hospital. These programmes involve interdisciplinary teams dedicated to anticipating, preventing, and reducing suffering for patients with serious illnesses and their families. Assessments and treatments encompass not only physical aspects but also address emotional, existential, and spiritual distress. Effective communication regarding disease progression, prognosis, and the potential benefits and burdens of different treatments remains a key aspect of palliative care. Equally important is the process of eliciting and documenting patient goals, values, and preferences, allowing for personalized care and decision-making. In the midst of a humanitarian crisis, individuals with pre-existing chronic or life-threatening illnesses often find themselves systematically de-prioritized within the healthcare response.

While there is an increasing recognition of the significance of palliative care among humanitarian actors, it has yet to be fully integrated into humanitarian health programmes. As a result, healthcare workers often lack the necessary knowledge and skills to effectively address the everyday suffering and distress experienced by those affected. The intentional and consistent incorporation of palliative care into humanitarian responses represents a groundbreaking approach to addressing the palliative care needs within such crises. Traditionally, the primary focus has been on saving lives, leaving uncertainty regarding the role of compassion in the provision of palliative care for those who suffer in these contexts.

This study aims to explore the quality of palliative care practices provided by frontline healthcare workers (FHCWs) operating in a limited humanitarian PC setting. It sets out to uncover their experiences and the challenges they face during their transition into delivering palliative care. Outpatient consultations were conducted from primary health complexes, and though it was during the pandemic, health care staff still sought to provide home-based care to those who had suffered from being forcibly displaced.

The nascent palliative care programmes established in Cox's Bazar was instrumental in ensuring continuity of care for patients. These programmes offer ongoing support to patients following their discharge from the hospital. As noted in Chapter 1 in health systems that are not under significant stress, palliative care is most effectively provided by interdisciplinary teams dedicated to anticipating, preventing, and alleviating suffering for individuals with serious illnesses and their families.

Essential elements of good care include effective communication regarding disease progression, prognosis, and the potential benefits and burdens of various treatment options. Additionally, it is crucial to elicit and document patient goals, values, and preferences. However, the challenging question arises: "What can practically be achieved in a complex humanitarian situation?" To shed light on this issue, the present study aimed to gain insights from frontline practitioners on whether and how quality palliative care could effectively prevent and alleviate suffering while enhancing the quality of life for individuals living with chronic and incurable illnesses in a humanitarian setting.

5.2.1 Quality of Care as a Metric

This study marks a significant milestone as it introduces the concept of using quality of care as a metric to assess the existing gap in the provision of palliative care to patients in humanitarian settings. In 1990, the Institute of Medicine (IOM) defined quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge".¹⁹ The World Health Organization (WHO) subsequently adapted this definition to emphasize that quality is determined by the extent to which healthcare services enhance desired health outcomes for individuals and patient populations.⁹

For the purpose of this study, the adopted definition of quality aligns with that of the WHO. By utilizing this framework, the researchers aim to evaluate the level of quality in the care currently provided to patients in need of palliative care within humanitarian settings. This approach enables a comprehensive assessment of the extent to which healthcare services in these contexts contribute to improved health outcomes.

5.2.2 Domains of Quality

Chapter 2 of the publication discusses the World Health Organization's (WHO) establishment of seven interrelated domains ¹¹⁹ that define the concept of Quality of Care, as presented in Box 1. To provide a people-centered service

in humanitarian contexts, it is crucial to understand the unique needs of the affected community and determine the most effective way to meet those needs through healthcare services. Timely access to appropriate skills and supplies is essential for addressing these needs. Equitable access to healthcare must be ensured both among the affected populations and between displaced individuals and their host communities. The delivery of effective care relies on evidence-based practices that promote positive health outcomes across various healthcare settings. Furthermore, safe care requires the availability of fundamental elements, such as water, sanitation, hygiene, infection prevention control, and harm reduction measures for patients, families, and healthcare workers. Integrated care plays a vital role in coordinating services across different health system environments, including new and local contexts. Lastly, efficient care aims to minimize wastage and optimize the utilization of available resources to achieve the maximum benefit. These domains collectively contribute to the comprehensive understanding and implementation of Quality of Care within humanitarian settings.

Table 5.1: Quality of Care in Humanitarian Settings

<p>People centred responding to an individual’s preference, needs and values</p> <p>Safe avoiding harm to people for whom the care is intended</p> <p>Equitable care does not vary according to age, sex, gender, race, ethnicity, geographical location, religion, socio economic status, disability, sexual orientation, linguistic or political affiliation etc.</p> <p>Effective providing evidence-based health care services to those who need them</p> <p>Timely reducing waiting times and harmful delays for both those who receive and those who give care</p> <p>Integrated such that care is coordinated across levels and providers (as well as between sectors) and makes available the full range of health services throughout the life course</p> <p>Efficient Maximizing the benefit of available resources and avoiding waste</p>
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Source: adapted from Quality of Care in fragile, conflict affected and vulnerable settings: taking action. WHO (2020)¹¹⁹

5.2.3 Quality Care in Health Settings:

Developing a culture of quality is a gradual process that relies on accepting evidence-based good practices over time. It entails cultivating a working environment that is open, participative, and encourages the sharing of ideas and best practices. In such a culture, education and research are valued, and

blame is sparingly used. However, the challenges faced in delivering healthcare services in humanitarian settings often disrupt the processes of learning, accountability, improvement, and the establishment of a culture of quality, data, and governance systems.

Ensuring an adequate number of healthcare workers and the ability to replace them as needed is vital for delivering quality care. However, the scarcity of healthcare workers often presents a significant barrier to quality care provision in FCV settings.²⁹ Additionally, healthcare staff may face extreme moral distress in these challenging conditions.⁶⁷ Despite these obstacles, FCV settings may possess valuable assets and opportunities for building a culture of quality. Motivated healthcare workers who have chosen to remain in the humanitarian field can contribute significantly to delivering quality care.¹²⁰ External organizations with diverse experiences and expertise can also collaborate with local organizations to support the development of a culture of quality. Various organizations involved in service delivery within FCV settings can work together towards a shared purpose, guided by common goals centered on providing compassionate care.

5.2.4 Challenges to Quality of Care

Humanitarian settings often face multiple challenges when it comes to delivering quality of care. These challenges can be attributed to various human and system factors. Human factors commonly include a lack of knowledge among healthcare providers, resulting in uncertainty about the appropriate course of action. Non-compliance with guidelines and standards, human errors such as misdiagnoses or medication mistakes, communication failures among providers or with patients, and situations where patients and families struggle to comprehend their medical status or have difficulty adhering to treatment plans are also prevalent barriers.

System issues further contribute to the challenges faced in delivering quality care. Governance and the lack of accountability for the quality of care can undermine efforts to ensure consistent standards. Unstable resourcing, safety deficiencies, inadequate health management information systems leading to information gaps, and fragmented care across different levels, resulting in poor referrals and a lack of follow-up, are additional barriers posed by the system.

Addressing these challenges requires comprehensive approaches that encompass both human and system factors. Education and training to enhance healthcare providers' knowledge and adherence to guidelines, improving communication channels, promoting patient and family engagement, strengthening governance and accountability mechanisms, ensuring stable resources, enhancing safety protocols, implementing robust health management information systems, and fostering integrated care are all essential steps toward overcoming these barriers and improving the quality of care in humanitarian settings.

5.3 Aim:

The objective of this study was to examine the quality of care and the presence of compassion in limited palliative care practices, as perceived by frontline healthcare workers (FHCWs) in a humanitarian setting within a low- and middle-income country (LMIC).

5.4 Methodology:

5.4.1 Research Design

In my qualitative study, I employed an ethnographic approach to delve into the topic at hand. I conducted a thematic analysis of diverse data sources, including informal conversations, field notes, direct and reflective observations, and in-depth interviews with key informants, namely doctors, nurses, and palliative care assistants. Throughout this study, I adhered to an interpretivist tradition, which prioritizes direct observation and the participants' interpretations of their own learning experiences and service delivery. My aim was to obtain a profound understanding of the subject matter through the perspectives of the participants themselves.

For more information on the research design and theoretical underpinning, please refer to Chapter 3 of this study.

5.4.2 Research Context:

Palliative Care Intervention (PCI)

As part of an interdisciplinary collaborative multi-country partnership, I took part in developing a pilot palliative care intervention (PCI) aimed at addressing death, dying, disability, and palliative care (PC) concerns within the Rohingya

and local host population in Cox's Bazar. To ensure the intervention was contextually appropriate, we employed a strategy tailored to the specific needs of the community. The PCI consisted of two primary components:

1. Facilitation of integrated care for individuals with chronic diseases: We focused on enhancing the coordination and delivery of care for people with conditions such as cancer, disability, diabetes, hypertension, and other non-communicable diseases. The aim was to ensure that individuals received comprehensive support that accounted for their unique health challenges.

2. Training and support for health professionals: Recognizing the vital role of healthcare providers in caring for individuals with incurable diseases, we provided training and ongoing support to enhance their knowledge and skills. This included equipping them with the necessary tools and resources to deliver high-quality palliative care services. Through this intervention, we aimed to address the pressing palliative care needs of the Rohingya and local host population, fostering a more integrated and compassionate approach to care for those facing life-limiting conditions.

Intervention component 1: facilitation of integrated care of 'Palliative Care Intervention (PCI):

In fragile health systems where palliative care is lacking, individuals with incurable illnesses often experience immense pain, suffering, and overwhelming financial burdens. The profound impact of a palliative care team lies in their ability to treat patients with dignity and work towards alleviating suffering in its various forms - physical, psychological, social, and spiritual.

To promote comprehensive care that meets the diverse needs of individuals with chronic illnesses, we facilitated integrated care that involved collaboration among healthcare professionals from various disciplines. Our dynamic core team consisted of two doctors, ten nurses, two physiotherapists, one social worker, and twenty palliative care assistants. Under the supervision of a project manager, who was also a medical doctor, this team led the provision of services. As a palliative care specialist, I played a crucial role in guiding the team's efforts.

Since palliative care is centered around the needs of patients and their families rather than focusing solely on the disease, our palliative care intervention (PCI) emphasized individualized care. Our dedicated palliative care staff identified patients eligible to receive the PCI services. The services offered included outpatient consultations six days a week, limited inpatient care available in

select Primary Health Centers (PHCs), and homecare services accessible across all PHCs. To effectively manage the palliative care setup, each team of nurses was supported by up to three palliative care assistants (PCAs). While one nurse oversaw medical care provided by doctors, they also acted as a liaison between patients, families, doctors, the project management team, and PCAs. Additionally, doctors and physiotherapists visited each PHC twice a week to ensure regular and comprehensive care. By implementing this intervention in ten primary health centers within the Rohingya refugee camps, we aimed to make a meaningful difference in the lives of individuals suffering from incurable illnesses. Our focus was on delivering patient and family-centered care, providing support, and improving their quality of life during challenging times.

Intervention component 2: Training and Support for Health Professionals

As part of our efforts in addressing the lack of palliative care within fragile health systems, we witnessed the immense challenges faced by individuals with incurable illnesses. They endured tremendous pain, suffering, and financial burdens that often overwhelmed them. Recognizing the transformative impact that a palliative care team can have, we dedicated ourselves to treating patients with dignity and alleviating their suffering in all its forms - physical, psychological, social, and spiritual.

To ensure comprehensive care that met the diverse needs of individuals with chronic illnesses, we facilitated integrated care by collaborating with healthcare professionals from various disciplines. Our dedicated core team comprised two doctors, ten nurses, two physiotherapists, one social worker, and twenty palliative care assistants. Under the guidance of a project manager, who also happened to be a medical doctor, our team spearheaded the provision of services. As a specialist in palliative care, my role was pivotal in guiding and directing the team's efforts.

Emphasizing the patient and their family's needs, our palliative care intervention (PCI) placed a strong emphasis on personalized care. Our committed palliative care staff carefully identified eligible patients to receive the PCI services we offered. This included outpatient consultations available six days a week, limited inpatient care in select Primary Health Centers (PHCs), and homecare services accessible across all PHCs.

To effectively manage the palliative care setup, we ensured that each team of nurses had the support of up to three palliative care assistants (PCAs). While one nurse oversaw the medical care provided by doctors, they also acted as a vital link between patients, families, doctors, our project management team, and the PCAs. Additionally, our doctors and physiotherapists visited each PHC twice a week, guaranteeing regular and comprehensive care. Implementing this intervention in ten primary health centers within the Rohingya refugee camps, our aim was to make a substantial impact on the lives of individuals suffering from incurable illnesses. Our unwavering focus was on delivering patient and family-centered care, providing support, and ultimately improving their quality of life during these challenging circumstances.

5.5 Data Collection

5.5.1 Key Informant Interview Data

After receiving approval from the Usher Ethics Medical Review Committee of the University of Edinburgh, I recruited twenty participants for my study. These participants were purposively selected from the pool of health professionals involved in the pilot palliative care intervention project in Rohingya camps. Due to travel restrictions imposed during the early phases of the Covid-19 pandemic, I conducted online interviews using Microsoft Teams between May and June 2020. It is important to note that the responses I gathered reflect this specific period marked by the pandemic.

The research question driving my study focused on how frontline healthcare workers, operating within this unique humanitarian context perceived and described quality palliative care and compassionate care. I aimed to gain insights into their understanding of palliative care by examining their descriptions of who should and should not receive such care. Through in-depth semi-structured interviews, I explored the participants' perspectives on specific activities or behaviors within palliative care that they perceived as indicative of high-quality care. Additionally, I investigated the significance of compassion in the professional relationships between frontline healthcare workers and their patients.

Moreover, my objective was to develop a propositional grounded theory that would contribute to the existing understanding of how frontline healthcare workers engage in the delivery of high-quality and compassionate palliative care within humanitarian settings. By generating original insights from this

study, I aimed to shed light on the intricate dynamics and challenges faced by healthcare professionals in providing palliative care in such contexts.

I trained a group of research assistants with diverse backgrounds in medicine, nursing, communication, pharmacology, and psychology to conduct the interviews for this study. The interviews varied in length, ranging from 34 to 71 minutes, with an average duration of 50 minutes. Due to the constraints posed by the circumstances, all interviews were conducted online. To guide the interviews, we utilized a semi-structured interview schedule (refer to Figure 1) that focused on exploring health professionals' perceptions of palliative care, their perspectives on the impact of the palliative care intervention on patients and their families, as well as the personal impact the role had on the health workers themselves. The questions were designed to be open-ended, allowing participants to provide detailed responses and offer examples whenever possible.

During the interviews, audio recordings were made, and the research assistants transcribed each interview verbatim. To ensure accuracy, I personally cross-checked each transcript against the original recordings before proceeding with the analysis. Participation in the study was entirely voluntary, and participants had the freedom to withdraw from the study at any time without any obligations. I ensured that participants received a detailed participant information sheet, which contained comprehensive information to help him or her make an informed decision about their participation in the study. The information sheet covered all the necessary details, ensuring that participants had a clear understanding of the study's purpose, procedures, potential risks and benefits, confidentiality measures, and their rights as participants. This ensured that participants had the necessary information to make an informed decision about whether or not to take part in the study. All participants who were approached to take part in the research willingly agreed to participate and provided signed informed consent.

Table 5.2: Semi-structured Interview Questionnaire

What is Palliative Care?
Who should receive PC?
Who should not receive PC?
Do you have any previous experience to work with incurable patients?
Do you believe that you have the knowledge and skills to assess and manage the care of a patient receiving PC?
If the participant mentions 'training needs' – ask about which specific components of training he/she believes would help to prepare more for providing PC
What are the best parts of PC work?
What are the challenges?
Any comments about teamwork?
Does the PC service make any difference in your life?
Any memorable moment/s you had during this work period?
What are the strategies that you follow for your self-care?

5.5.2 Direct Observation:

Throughout the implementation of the palliative care intervention in the Rohingya refugee camps in Cox's Bazar, I diligently maintained a research journal to document my experiences. This journal served as a valuable tool for recording my observations, reflections, and insights gained during the project. As emphasized by several authors in the field of qualitative methodology, one of the key strengths of this research approach is the ability to obtain firsthand information by spending significant time directly observing and engaging with the participants.¹²¹ By immersing myself in the field, I was able to establish a deeper connection with the participants and gain a more nuanced understanding of their experiences and the impact of the palliative care intervention.

My research journal played a crucial role in capturing these firsthand observations, allowing me to document the context, interactions, and unique insights that emerged throughout the implementation process. It served as a rich source of information, complementing the data collected through interviews

and other research methods. By regularly recording my experiences and reflections, I was able to enhance the authenticity and depth of the research findings, drawing upon the valuable insights gained from my direct involvement and close engagement with the participants in the Rohingya refugee camps.

For details in field notes and reflective journal please refer to chapter 3. Data Analysis

During the ethnographic data analysis, I engaged in an in-depth interpretation of the data, with a focus on understanding the meaning, function, and outcomes of the observed behavior. I approached the analysis using a constructivist grounded theory approach, which aimed to allow the data to guide the development of theory, rather than imposing preconceived ideas or theories onto the data. This approach emphasized letting the data speak for itself.

To conduct the analysis, I employed thematic analysis of various data sources, including field notes, reflective journals, and interview transcripts. I approached the analysis through the lens of the research question, seeking to identify and explore emerging themes and patterns. It is important to note that no predefined codes were used, and the analysis was conducted inductively, allowing the themes and codes to emerge from the data itself.

Before starting the analysis we transcribed the audio recordings, ensuring accurate representation of the interviews. Additionally, I ensured that the handwritten diary field notes were typed and the original handwritten versions were destroyed for confidentiality purposes. The typed memos, organized chronologically with dates and narratives, were securely stored in password-protected files dedicated to each type of data, following recommended practices. These memos served as a way to describe and synthesize the data at a higher level, capturing key thoughts and potential findings from the study. Overall, the data analysis process aimed to uncover rich insights and develop a deep understanding of the research topic through an iterative and reflexive exploration of the collected data.

I manually analyzed the data using thematic analysis, which involved coding the data to identify meaningful units of information. Each code represented a section of information that carried significance within the data. I carefully assigned these codes to paragraphs or lines of the data, ensuring that every

piece of data received equal attention and consideration. To maintain validity and rigor in the analysis process, I followed a systematic approach to coding. Key themes were not derived from a limited number of examples, but rather, were based on a comprehensive examination of the data. I focused on identifying areas of good practice or strategies that could facilitate care discussions.

Once the key themes were established, I reviewed the codes under each theme and grouped them into smaller subthemes. This allowed for a more detailed analysis and exploration of the data. Subthemes were then tabulated according to whether the codes originated from the interviews, the reflective journal, or both. This approach enabled me to triangulate the data. By doing so, I was able to develop a comprehensive understanding of the themes within the context of care.

5.5.3: Documentary Analysis

The documents used in my analysis were actively collected from diverse sources. This collection facilitated a comprehensive understanding of how forced displacement impacts community life, particularly among populations with specific needs such as those requiring palliative care, older individuals, and those with mental health and psychosocial needs, especially during a pandemic.¹²⁹ Document analysis served as a complementary data collection procedure, supporting triangulation and theory building.

In my grounded theory research, similar to other qualitative methodologies, I take on the role of the primary instrument for both data collection and analysis. This means that I depend on a blend of skills, intuition, and an interpretive lens to filter and analyze the data. As a clinician, researcher, project implementer and analyst, I systematically extract and analyze data from documents as part of theoretical sampling.

5.6 Strategies for Trustworthiness:

To ensure the trustworthiness of this study, I employed a range of criteria and checks, including credibility, transferability, validity, triangulation, researcher's reflexivity, member checks, peer review, data saturation, maximum variation, audit trail, and rich thick descriptions (as outlined in Table 5.3). Credibility, as suggested by Patton (2002), relies on two key factors: rigorous methods and the credibility of the researcher.⁸⁸

In this study, I have diligently followed and described rigorous methods, employing robust research techniques. Additionally, the researchers involved in this study have established credibility in their respective fields. Triangulation at the data source level was implemented, which involved comparing perspectives from different points of view. To achieve this, I conducted interviews with various frontline health professionals, including doctors, nurses, and community health workers. By gathering insights from diverse perspectives, I aimed to enhance the credibility and comprehensiveness of the findings.

Furthermore, data analysis involved the collaboration of multiple authors, facilitating investigator triangulation. This approach ensured that the interpretation of the data was not solely reliant on one individual's perspective but benefited from the collective insights and discussions among the research team. By employing these rigorous methods and incorporating triangulation at both the data source and investigator levels, I sought to enhance the trustworthiness of the study.

Table 5.3: Criteria Used for Trustworthiness

Criteria	Definition	Definition and Sources
Audit trail	Audit trails are simply records kept of how qualitative studies are conducted. The audit trail should include all field notes and any other records kept of what the inquirer does, sees, hears, thinks, etc.	I kept a detailed account of the raw data including field notes and documents; data reduction and analysis notes; data reconstruction and synthesis products including category, themes, findings, conclusions, connections to literature and integration of concepts, relationships, and interpretations; process notes – research methodology notes, trustworthy notes; materials related to intentions and dispositions – personal, reflexive notes and expectations; Instrument development information – pilot work, interview schedules, and observation formats and decision points in the overall study (Carcary, 2020). ¹²²

<p>Conformability</p>	<p>The control of bias in qualitative projects/have something to do with objectivity.</p> <p>In my research, conformability refers to the extent of neutrality in the research finding as shaped by the interest as the researcher and participants' interest. In this study, allowing member checking, especially rechecking the data during the process of data collection assured conformability. I welcomed the participants to review my interpretations comparing it to their responses. One of the greatest benefits of member checking is that participants are able to verify information right from the data collection process to data analysis process.</p>	<p>Degree to which the study findings are derived from participant responses rather than researcher motivations or biases.</p>
<p>Data saturation</p>	<p>Adequate data collected to ensure commonality .</p>	<p>Adequate data was collected that made it unlikely that new information would emerge that would enhance to or change findings.</p>
<p>Maximum variation</p>	<p>Purposefully seeking variation or diversity in sample selection to allow for a greater range of application of the findings</p>	<p>I sought purposeful diversity in sample selection, aiming for maximum variation in FHCWs and richness of the complexity of the case, to allow for a greater range of application of the findings.</p>
<p>Member checks</p>	<p>Taking data and tentative interpretations back to the participants to ask if they are plausible.</p>	<p>Takes data and tentative interpretations back to the participants to ask if they are plausible. I took the data and tentative interpretations back to the participants for review after the data collection and first stage of analysis was complete</p>

Peer review	Discussions with colleagues regarding the process of the study, the congruency of the emerging findings with the raw data and tentative interpretations.	Holds discussions with colleagues regarding the process of the study, the congruency of the emerging findings with the raw data and tentative interpretations. I took expert opinions regarding the process of the study and the congruency of emerging findings from three researchers, other than my two supervisors
Reflexivity	Critical self-reflection by the researcher that may affect the investigation.	I undertook critical self-reflection and explained constructivist-learning theory through the theoretical lens, discussed researcher positionality and reflexivity statements.
Transferability	Findings may be transferred to another setting, context or group – detailed description of the context in which the research was performed and how this shaped the findings.	I provided a detailed and rich description of data collection methods, study setting, participants and recruitment, and data collection, and a description of participant demographics. This enables others to judge the applicability of study findings to different contexts, times, and populations
Triangulation	Using multiple sources of data or data collection methods to confirm emerging findings. ⁹⁵	I used multiple sources of data or data collection methods to confirm emerging findings. ⁹⁵ This included used interviews, observations, informal conversations, and reflections.
Validity	The concept of validity was formulated by Kelley ¹²³ who stated that a test is valid if it measures what it claims to measure.	I implemented several validation strategies, by undergoing prolonged engagement and persistent observation. ⁹⁹ Rapport was built with key informants as well as an understanding of palliative care provision.
Rich, thick descriptions	Providing descriptions to contextualize the study to allow for transferability of findings.)	Rich description of the contextual lens, site and context of the study; vignettes and testimonies are used to illustrate the uniqueness and complexity of the case

5.7 Findings:

5.7.1 Characteristics of fieldwork:

I personally engaged in 256 hours of participant observation, collaborating closely with a group of 20 palliative care professionals. This cohort consisted of 2 physicians, 10 nurses, and 8 palliative care assistants. The observations occurred from January to June 2020 and revolved around the operations of palliative care teams within ten primary healthcare centers situated in the Rohingya camps of Cox's Bazar. Table 5.4 shows a summary table of data collection types and numbers used in this study. I utilized multiple documents to grasp both manifest and substantive content, without specifically seeking deeper meanings embedded in language and text (Table 5.5). For an in-depth exploration of the participants' demographic information, refer to Table 5.6. Additionally, Table 5.6 provides an elaboration of participant observation events and settings.

Table 5.4: Summary Table of Data Collection Types and Numbers:

Data Collection Methods	Number of Episodes
Interviews	20 interviews
Documentary analysis	10 documents
Direct Observation	256 hours
Direct Observation Events	23 events

Table 5.5: Documents Included in The Study:

Document number	Document type	Source
Doc 1	Neglected Suffering: The unmet need for palliative care in Cox's Bazaar.	Reliefweb.int
Doc 2	Rohingya Palliative Care Needs Analysis	Health Sector, CXB
Doc 3	Assessment report of IOM about mental health and psychosocial needs of displaced refugees in Cox's Bazar.	Health Sector, CXB

Doc 4	Social Impact assessment of Rohingya refugees	Health Sector, CXB
Doc 5	Rapid needs assessment of older people in FDMN camps	HelpAge international
Doc 6	Multisector Needs Assessment 2018 – preliminary findings	Health Sector, CXB
Doc 7	Training Programme	FKRF
Doc 8	Health sector bulletin	
Doc 9	Mental health & psychosocial services	Health Sector, CXB
Doc 10	Integrating palliative care & symptom relief into responses to humanitarian emergencies & crises: A WHO guide. World Health Organization (2018)	WHO Publications
Doc 11	Maps of Rohingya camps	Health Sector, CXB
Doc 12	18 Newspaper Clippings, internet articles on report of Rohingya refugees	Daily Star, Dhaka Tribune, BBC News, wildlife-biodiversity, PeaceRep, Prothom Alo

Table 5.6: Demographic Data of Interviewed Participants

Participant No.	Gender	Age (Years)	Role	Experience in Rohingya Camps (Months)
P1	Male	28	Physician	12
P2	Female	25	Physician	12
P3	Female	23	Nurse	9
P4	Female	26	Nurse	5
P5	Male	25	Nurse	4
P6	Female	23	Nurse	17
P7	Female	23	Nurse	3

P8	Male	27	Nurse	5
P9	Female	22	Nurse	18
P10	Female	26	Nurse	7
P11	Female	23	Nurse	7
P12	Female	37	Nurse	33
P13	Male	20	PCA	24
P14	Male	24	PCA	24
P15	Male	44	PCA	6
P16	Male	23	PCA	19
P17	Female	21	PCA	5
P18	Male	19	PCA	15
P19	Female	27	PCA	12
P20	Female	34	PCA	26

Table 5.7: Details of Participant Observation Details:

Event Number	Events (January to March 2020)	Number of Hours	Setting
PO1	Project Meeting	6	FKRF office, CXB
PO2	Training program (5 Days)	20	FKRF office, CXB
PO3	Clinical duty observation	20	Kutupalong: extension 2W/D4
PO4	Home Visit with team	6	Kutupalong: extension 2W/D4
PO5	Clinical duty observation	18	Camp 3: Madhuchara PHC
PO6	Home Visit with team	8	Camp 3: Madhuchara PHC
PO7	Clinical duty observation	16	Camp 24: Leda PHC
PO8	Home Visit with team	4	Camp 24: Leda PHC
PO9	Clinical duty observation	16	Camp 9: BMS Burmapara Makeshift
PO10	Home Visit with team	2	Camp 9: BMS Burmapara Makeshift

PO11	Clinical duty observation	15	Camp 15: BDRCS/DGHS PHC
PO12	Home Visit with team	2	Camp 15: BDRCS/DGHS PHC
PO13	Clinical duty observation	16	Camp 11BDRCS/DGHS PHC
PO14	Home Visit with team	6	Camp 11BDRCS/DGHS PHC
PO15	Clinical duty observation	15	Camp 13 BDRCS/DGHS PHC
PO16	Home Visit with team	2	Camp 13 BDRCS/DGHS PHC
PO17	Clinical duty observation	15	Camp 19: IOM funded RTMI
PO18	Home Visit with team	3	Camp 19: IOM funded RTMI
PO19	Clinical duty observation	26	Ukhia Health Complex
PO20	Home Visit with team	6	Ukhia Health Complex
PO21	Clinical duty observation	12	Teknaf Health Complex
PO22	Home Visit with team	4	Teknaf Health Complex
PO23	Training programme, (mid-month and end-month)	18	FKRF office, CXB
Total: 23		Total: 256	

5.7.2 Identified Themes:

Theme 1: People-Centered Care

Two sub-themes: Know the whole person and Practice Compassion

The initial theme represented the FHCWs' perceptions about palliative care, a new area of practice for most participants. They identified palliative care improves patients' well-being and is people-centered. Their description of people centred can be understood through two sub-themes: "Knowing the whole person" and "Practicing compassion."

It was acknowledged that humanitarian settings present complex challenges, and the needs and preferences of the majority in these communities often go unmet. New healthcare providers often lack pre-existing relationships with the

community. Therefore, it is crucial to make sustained efforts to understand the community's needs and ensure that services are centered on the individuals they serve.

Know the whole person:

As the FHCWs gained experience, their attention shifted towards developing a deeper understanding of their patients. It was evident that FHCWs demonstrated genuine interest in their patients, taking the time to engage with them without any sense of urgency. A doctor's self-realization further highlighted this aspect:

“Previously, I used to believe that prescribing medications was the most crucial aspect of patient care. I had never considered the possibility of providing comprehensive care by establishing a close connection with the patient. However, my perspective has completely changed now. I have come to realize that unless I delve into the underlying factors affecting a patient's mental well-being and social circumstances, simply prescribing medicines won't be effective. Effective communication plays a transformative role in this process. I have learned the importance of dedicating sufficient time to patients, actively listening to them without passing judgment. This realization has truly transformed my approach to patient care.” (P2)

The degree and type of loss one undergoes play a crucial role in shaping the experience of suffering. Suffering is a multifaceted concept, with its manifestations and perception varying uniquely from person to person.¹²⁴ Recognizing suffering can be challenging since its meaning and the losses associated with it are subjective and vary from person to person. To truly understand the significance of a loss, it is essential to suspend our own perspective. This calls for health workers to be attentive to the needs of others and to acknowledge the importance of considering the whole person, beyond their illness or immediate concerns

Practice Compassion:

Most participants recognized that it takes compassion, time and courage to create equality in a relationship between FHCWs and patient cultivate compassion. As stated by Aristoteles (2004, 86:6–13), suffering in humanitarian settings can encompass various aspects such as death, physical injuries, disorders, old age, diseases, food deficiency, repeated disasters, and even

feelings of isolation.¹²⁵ To truly grasp the gravity of health-related suffering, it is crucial to comprehend the significance of the loss from the perspective of the individual experiencing it. Loss, being a deeply personal experience, carries subjective meanings. Therefore, it is imperative to provide the sufferer with the necessary time and attention to gain a better understanding of their unique circumstances and concerns.

Individualized approaches aimed at addressing the small but significant aspects that contribute to patients' well-being were identified as a crucial aspect of FHCWs' practice. This approach involves understanding and responding to patients' unique needs in subtle and meaningful ways. One PCA shared a touching example, recounting how during a conversation with a patient, she discovered the patient's longing for cakes and biscuits. In a subsequent home visit, the PCA brought along those treats, witnessing the joy and gratitude that lit up the patient's eyes (P17). FHCWs took pleasure in spreading the message of palliative care, nurturing its growth within humanitarian settings.

Many of these acts were spontaneous and driven by the genuine desire to make a positive impact. A nurse reflected on his own experiences:

“Palliative care is a new care, unknown to everyone work here. So, I did one awareness session for all kinds of staff including volunteers, to make them understood what palliative care means. That helped a lot. The volunteers of other NGOs mainly work in the fields. Now they refer people with incurable diseases into our facilities.” (P9)

Despite their limited exposure to palliative care, FHCWs wholeheartedly embraced the opportunity to learn and practice comprehensive care. They recognized the significance of their newfound knowledge in addressing the needs and challenges faced by their patients. One nurse vividly recalled the importance of creating a safe space for patients to express their emotions and share their experiences during consultations (P5). FHCWs took pride in their enhanced expertise, comparing it to their previous approaches in healthcare.

A nurse shared her perspective, highlighting the exceptional nature of palliative care compared to her previous experiences. In the past, a patient with COPD and breathlessness would have immediately received nebulization in her private clinic. However, in palliative care, a more thorough approach is taken. A detailed patient history is obtained, breathing exercise techniques are taught, and medication is prescribed with careful monitoring of the patient's progress.

Regular follow-ups are conducted, and if a patient misses an appointment, PCAs are sent to their home to provide necessary care. FHCWs expressed their dedication to delivering home care services, emphasizing the holistic approach of palliative care. (P9)

Another care worker shared his perspective stating, "As someone involved in implementing an innovative program like palliative care, I've come to realize that acceptance takes time. It's a reality that I've learned through experience. In the initial stages, we faced numerous questions from everyone, such as what palliative care is and why it is needed. But thankfully, we have overcome those challenges. When our staff members went to a camp, they were not provided with proper arrangements like chairs and tables, and they were not warmly welcomed by the existing personnel already working in those facilities."(P27)

Along with all the team members, I had the opportunity to visit each of the camps personally. It was important for us to engage with the camp in-charges and establish connections. Additionally, I attended multiple meetings at the Civil Surgeon's office, the Refugee Repatriation Relief Commissioner's (RRRC) Office, and the Health sector secretariat lead for the WHO.

During these visits and meetings, I made sure to document the progress in my field notes. I noted, *"Things are changing slowly, and we are in a better situation now. The message about our palliative care team's presence and effectiveness has been spread from the highest authorities to the grassroots level. I feel immensely grateful to the dedicated PC professionals whose positive attitudes have played a vital role in establishing a therapeutic relationship with patients and families, built on trust and the gift of dedicated time."* (Excerpt from My journal, June 2020)

Theme 2: Time and Space for Realizing the seriousness and significance of Peoples' suffering

Three sub-themes: Understanding what palliative care required of the health professional, The value of Communication and The unique contribution of the teamwork.

The second theme that emerged from the data highlighted the importance of allocating sufficient time and creating a supportive environment to acknowledge the gravity of serious health-related suffering. Within this theme, three sub-themes were identified: "Understanding the requirements of palliative care for

health professionals," "The significance of effective communication," and "The unique contributions of the team."

It is crucial to recognize that delivering effective care is fundamental in achieving positive health outcomes across all healthcare settings. However, in contexts affected by forced displacement and violence, such as FCV settings, the evolving health needs necessitate a deeper and more nuanced understanding of the diverse skills, resources, and guidelines compared to more stable settings. Additionally, the capacity of healthcare providers to meet evidence-based standards of care may be more limited in such challenging circumstances.

Understanding what palliative care required of the health professional:

The first sub-theme that emerged was centered on health professionals' understanding of what palliative care required from them. It went beyond providing clinical services based on their medical knowledge to address the needs of patients with terminal illnesses. The sub-theme also highlighted the importance of compassion in integrating different perspectives. FHCWs demonstrated compassion through their passionate daily activities, which involved understanding, caring, empathy, and actively listening to their patients.¹²⁶

Initially, the FHCWs perceived their work in palliative care as similar to what they had learned in their foundation training. However, as they became more involved in delivering care to those with terminal illnesses, they experienced a transformation in their capabilities and a greater sense of satisfaction in their roles. When asked about how their definition of palliative care had evolved and if their current work aligned with their initial expectations, the FHCWs expressed that their focus was not on curing the disease but on improving the quality of life for individuals diagnosed with serious illnesses throughout their journey until the end of life (P1).

The FHCWs recognized the significance of providing holistic care that extended beyond medical interventions, emphasizing the importance of addressing patients' emotional, psychological, and social needs. This shift in perspective underscored their commitment to enhancing the overall well-being of patients under their care. Among the healthcare professionals, nurses who had

additional responsibilities such as counseling, administrative tasks, and paperwork expressed a sense of confidence and satisfaction in their role. One nurse shared her perspective, stating, *"Nursing in palliative care is about alleviating the suffering of patients and their family members. It involves providing comprehensive support to patients with incurable chronic diseases, addressing their physical, mental, spiritual, and social needs. It goes beyond medication and encompasses various steps to ensure holistic care."* (P7)

At the onset, certain palliative care assistants found it challenging to comprehend and adapt to the new terminologies associated with their new role. One PCA, who had prior experience as a community health worker organizer, shared their perspective on this transition:

"Having previously worked in the health sector, I have provided counseling to various types of patients. However, the concept of palliative care was entirely new to me. I had counseled patients with cancer, diabetes, blood pressure, and liver jaundice, knowing that their conditions were incurable. But I was unaware that these patients would fall under the umbrella of palliative care. This realization came as a surprise to me." (P13)

As PCAs gained more experience and confidence in their work, they began to recognize the significance of their role. One PCA expressed her understanding of palliative care, stating, *"We provide palliative care to individuals living with serious diseases such as hypertension, cancer, diabetes, and COPD"* (P16). They acknowledged a fundamental shift in their approach, transitioning from a mechanistic focus on delivering services to a deeper understanding of the purpose and meaning behind their care.

Some of the FHCWs shared the challenges they faced in delivering palliative care in humanitarian settings. They emphasized the importance of increasing awareness about palliative care in the camps to make it more effective. One doctor reflected on his experience, saying, *"During my MBBS course, I was only introduced to the term 'palliative care'. However, working here has revealed the immense depth and breadth that lies within this concept"* (P2). There was a clear consensus among the FHCWs that it was crucial for others to understand and acknowledge the significance of palliative care in these settings.

The value of Communication:

"In my journey as a healthcare professional, I have come to realize the immense value of effective communication," expressed one doctor. "It goes beyond just exchanging information; it plays a vital role in our professional development. By actively listening and empathizing with patients, we can establish a strong therapeutic relationship and provide holistic care. It is through effective communication that we can truly understand their needs, address their concerns, and ensure their well-being" (P4). The sentiment was echoed by FHCWs at all levels, highlighting the significance of communication in their practice and its impact on patient outcomes.

"Patients are given our undivided attention as we introduce ourselves by name and engage in meaningful conversations," explained the doctor. "We understand the importance of active listening and ensure that patients feel heard and understood. Our approach involves discussing the prescription with the patient, followed by the nurse reiterating the information and addressing any missed details. These unique methods of care are exclusive to the palliative care team, and at the end of the day, our patients feel a sense of pride in experiencing this novel approach" (P2). These personalized interactions and thorough communication contribute to the overall satisfaction and well-being of the patients we serve.

Participants expressed the importance of receiving additional training to enhance their counseling skills and provide more effective support to patients. They emphasized the need to learn evidence-based communication techniques, especially in paying attention to introductory details, in order to prevent communication underuse or misuse. A nurse shared her perspective, stating, *"Delivering palliative care presents its challenges, but ensuring consistent and effective communication throughout a patient's journey and providing them with optimal support is equally challenging. However, the positive outcomes make it all worthwhile" (P5). The recognition of the impact of communication on patient care reinforces the participants' commitment to improving their communication skills through training and professional development. Nurses also highlighted the significance of effective communication in their practice. One nurse specifically emphasized the impact that good communication can have on patient care and outcomes:*

"The ultimate goal of communication is to prioritize the well-being of the patient. When we actively listen to patients without interrupting, it creates a remarkable outcome by fostering a sense of trust between them and us. They feel

comfortable sharing their deepest secrets with us and are more inclined to follow our guidance and recommendations" (Participant 4).

The researchers noted that there was a notable impact on service provision when FHCWs established effective communication with patients and their families. The field notes provided examples of how professionals would introduce themselves to patients, mentioning their own names, which was not a common practice in that cultural context. One excerpt from the field notes states:

[Within the Rohingya camps, the challenging conditions of overcrowding and high patient turnover were evident. However, amidst these circumstances, the efforts of doctors, nurses, and palliative care assistants to patiently explain prescriptions, medication schedules, and non-pharmacological methods to patients were greatly appreciated by both patients and their families. Many expressed gratitude, mentioning that they had never experienced such effective communication in their previous encounters with healthcare professionals.] (My Journal, field note: March 2020)

This sub-theme emphasizes the enthusiasm of FHCWs to adopt a mindset of continuous learning and advancement, particularly in enhancing their communication skills. Our observations revealed that compassion played a vital role in fostering effective communication within the FHCWs-patient relationship, thereby contributing to the delivery of high-quality care.

The unique contribution of the teamwork:

Teamwork emerged as a crucial asset for the FHCWs, providing them with valuable support and enabling them to leverage their individual strengths. As time went on, each team member developed a deeper understanding of their respective roles and responsibilities, further strengthening their relationships. One member highlighted the unwavering integrity that characterized their teamwork,

"We work as a cohesive team, comprising doctors, nurses, physiotherapists, and palliative care assistants (PCAs), to provide care for patients with incurable conditions. Continuous skill improvement is an integral part of our work, and we have dedicated time within our schedule for this purpose. During monthly group meetings, we engage in various discussions to enhance our knowledge and skills. Even during lockdown, our team leads arranged online training sessions

via Zoom. Additionally, we occasionally conduct classes to educate nurses and PCAs, fostering a better understanding among our team members." (P1)

The researchers noted that patients and their families consistently expressed their appreciation and provided positive feedback, which served as a source of motivation for FHCWs in their work. Each group of participants had their own compelling success stories that deeply resonated with them on a professional level. One extract from the field note journal exemplifies this sentiment:

The PC team took on the case of a middle-aged woman with stage 4 breast cancer and a severe wound. Compounded by the patient's anxiety, it was unfortunate that her family had abandoned her, leaving only one son to care for her. In response, the team made a compassionate decision: each team member would take turns visiting her at home every other day.

This dedication and commitment by the team is commendable. Their message to the patient is clear and assertive:

[We are here to alleviate your pain and suffering." Additionally, the team ensures ongoing support by regularly following up with the patient at home, ensuring her symptoms are well managed and preventing any further distress. This case exemplifies the team's unwavering commitment to providing comprehensive care and support.] (My journal: February 2020)

Theme 3: Greater Value of Noticing Serious Health-related Sufferings

Two sub-themes: "Importance of investing in simple measures" and "Palliative care has changed me"

The third theme that emerged from the data focused on the FHCWs' recognition of the heightened importance of noticing and addressing serious health-related sufferings in their daily work. Within this theme, two sub-themes were identified: "Importance of investing in simple measures" and "Palliative care has changed me."

Importance of investing in simple measures:

The first sub-theme, "Importance of investing in simple measures," highlighted the FHCWs' understanding of the significance of implementing simple interventions that could greatly impact patients' well-being. They recognized

that even small actions, such as providing emotional support, engaging in effective communication, and addressing basic needs, could make a significant difference in alleviating suffering and improving the quality of care. During the discussions on their experiences as palliative care workers, participants reflected on their personal and professional growth. They expressed surprise at the resilience demonstrated by individuals facing challenging circumstances, which in turn taught them to acknowledge their own limitations as FHCWs. A nurse shared her perspective:

"In my previous job settings, when a patient passed away, the family would often direct blame towards the clinicians for various reasons. However, in palliative care, the situation is completely different. The families express their gratitude and offer prayers for the palliative care team. Experiencing this shift in perception brings me a unique and fulfilling sense of happiness that I had never experienced before." (P7)

They recognized the universal vulnerability to serious suffering, acknowledging that it can affect anyone as an inherent part of the human experience. While compassionate behavior may not eliminate suffering entirely, it can serve as a response to alleviate its impact. One doctor shared personal experiences of finding deeper significance in seemingly simple measures:

"Simple measures can make a significant difference. I used to assume that patients were already knowledgeable about everything they needed to do. However, I have come to realize that it is our responsibility to provide thorough counseling to each patient. Teaching them how to perform breathing exercises, demonstrating the correct way to use an inhaler, and guiding them through proper inhalation and exhalation techniques require adequate time and attention. For a patient with COPD who will rely on an inhaler for the rest of their life, those few minutes of training mean a great deal. If I fail to provide proper instruction, they may continue using the inhaler incorrectly for years. I have encountered patients who have been holding their inhaler tubes upside down for an extended period. Now I understand that nobody took the time to explain to them that this is not the correct way to hold the inhaler." (P1)

[As part of the monthly discussion meetings with nurses, it became evident that their previous experiences working with various organizations in Rohingya camps involved caring for patients with serious illnesses. However, they acknowledged that the lack of palliative care knowledge hindered their ability to provide comprehensive care. They felt that their role was limited to merely following doctors' prescriptions and monitoring medication intake. However, with the acquired skills and knowledge in palliative care, they now believed that

they were truly making a difference in the lives of their patients.] (FK Journal, nurses' discussion in monthly meeting: January 2020)

Palliative care has changed me:

The second sub-theme, "Palliative care has changed me," underscored the transformative effect of practicing palliative care on the FHCWs themselves. Through their involvement in palliative care, they experienced personal growth and a shift in their perspectives. They developed a deeper appreciation for the value of empathy, compassion, and holistic care. This transformation had a profound impact on their professional approach and interactions with patients and families.

Overall, this theme emphasized the FHCWs' recognition of the greater value of noticing and addressing serious health-related sufferings in their daily practices. It highlighted the importance of investing in simple yet impactful measures and revealed the transformative power of palliative care on the FHCWs themselves. By actively engaging in compassionate care and understanding the unique needs of each individual, FHCWs were able to make a meaningful difference in the lives of their patients.

In fragile, conflict-affected, and vulnerable (FCV) settings, there are specific challenges in establishing the essential components of safe care. These settings often lack access to clean water, adequate sanitation and hygiene facilities, and proper infection prevention and control measures. As a result, the risks of harm to patients, their families, and healthcare workers are amplified in these environments.

The FHCWs shared a profound realization that fate can unexpectedly affect them, just as it has impacted their patients. This newfound understanding fostered a deep sense of compassion within them. As they continued to gain experience in palliative care, the FHCWs began to perceive their role as more than just a profession. They saw it as a calling that served a greater purpose, not only in aiding patients but also in nurturing their own humanity. An experienced nurse eloquently expressed this sentiment:

"Palliative care has transformed me in ways I never anticipated. Previously, my focus was solely on my duties and personal needs. However, now I recognize the profound impact my presence and care can have on my patients. Even during lockdowns, I go beyond my duty to check on my patients at home and

ensure their well-being. This experience has deepened my love for humanity and strengthened my commitment to providing compassionate care." (P8)

A doctor reflected on her personal growth in empathy within her professional practice. She shared, *"In the past, I used to be impatient and reluctant to truly listen to patients. I would interrupt their conversations and only focus on what I deemed necessary. However, now I have learned to allow the patients to express themselves fully. I give them the space to share their thoughts, and at the end of their narrative, I ask questions to gain the necessary information."* (P2)

Another FHCW described her newfound courage, saying, *"Since I started working in palliative care, my fear has dissipated. Courage has taken its place. It is an ability I have developed through this experience."* (P20)

Another FHCW, who had achieved a level of alignment between their professional and personal life, shared a heartfelt reflection:

["In the beginning, I faced pressure from my family to discontinue my work in this field. They expressed concerns about the emotional toll and potential risks associated with caring for patients with serious illnesses. However, I took the opportunity to explain to them that anyone, including ourselves, can be affected by such diseases at any point in life. It was a moment of realization for all of us. My mother, who holds strong religious beliefs, became my biggest supporter. She reassured me, saying, 'Son, you are doing noble work. Just ensure that whatever you do, you do it with sincerity and from your heart.' This profound understanding and support from my mother strengthened my resolve. I firmly believe that when we provide support to patients with love and compassion, both the patient and the healthcare professional find peace. Love is at the core of everything we do. I couldn't ask for anything more as I have received countless prayers and love from patients and their families."] (My Field notes, after talking with nurse P7]

The Rohingya camps are located in the hilly terrain of Cox's Bazar, which poses challenges for health workers who must travel long distances, often covering at least 35 kilometers. With limited availability of transportation in most parts of the area, they have no choice but to walk and navigate through hills. Despite the difficulties, these dedicated health workers acknowledge that providing compassionate care requires them to make sacrifices. However, within this theme, a concern emerged regarding the need for additional logistical support to facilitate their work effectively.

Theme 4: Authentically Connected with Patients & Families

Three sub-themes: “Shared responsibility,” “Co-construction,” and “Authentic connection.”

The fourth theme encapsulated the genuine connection between FHCWs and patients and families, revealing three sub-themes: "Shared responsibility," "Co-construction," and "Authentic connection."

Shared responsibility:

FHCWs constructed their narrative around the impact of their compassionate actions on their own support experiences. One nurse shared, "We have provided our personal telephone numbers to patients and family members. If I receive a call at night or midnight, I don't consider it a burden. We are here to solve their problems. No one should hesitate to reach out to palliative care, even outside of working hours. Palliative care should offer support 24/7. From my experience, I know that no one calls me without a serious problem" (P5). These two comments highlight the commitment of sharing personal telephone numbers with patients and families and the understanding that out-of-hours calls signify serious issues. This insight reveals the significance that FHCWs attributed to their support experiences based on their sense of responsibility. Their willingness to be open and available at all times, whether on duty or not, reflects their dedication to care. As a result, patients and families reported positive experiences in a context where support for incurable sufferings is often perceived as lacking. The FHCWs made deliberate decisions driven by compassion.

Ensuring equitable care that authentically connects with patients and families is of utmost importance. However, in FCV settings, various barriers such as logistical, geographical, social, cultural, and financial obstacles, along with the marginalization of certain populations and attacks on civilians, can further impede access for some communities. To address this, it is crucial to prioritize strategies that promote equitable access to healthcare among affected populations and bridge the gap between displaced and host populations. Despite these challenges, health workers have shown resilience by their unwavering presence and intentional availability. They have actively overcome these barriers, making themselves visible and accessible to ensure that all individuals receive the care they need.

Co-construction:

While community leaders were generally seen as the supportive allies of health workers, the narratives of FHCWs facing challenging situations, such as out-of-hour calls or healthcare services in the camps, highlighted their significant reliance on majhis (spokespersons of the Rohingya community) and the informational support provided by these leaders. Collaboration between different communities played a crucial role. The support received from majhis emerged as a vital factor in establishing an authentic connection and improving health outcomes. FHCWs, irrespective of their level and work setting, found their experiences most meaningful when they could co-construct solutions with other community leaders, which proved beneficial for their patients. A nurse recounted an incident, stating, *"During the lockdown, one of my patients ran out of morphine. At 3 am, I received a phone call from the Majhi (Rohingyan community leader) informing me about the increased pain experienced by my patient."* The health workers emphasized the significance of community Majhis in their work. It was observed that within the camps, telephone usage after 10 pm was restricted, but majhis were granted permission to use their phones.

Some FHCWs shared their experiences of going above and beyond to ensure that patients had access to the essential medications they needed. One health worker recalled an incident where they received a distressing call in the middle of the night about a patient in severe pain. Despite the family members' attempts to find morphine at a nearby hospital, it was unavailable. The health workers persisted in their search and the next day, they were able to visit the patient's home and provide the necessary medications (P11). During their regular team meetings, participants openly discussed various instances and the emotions they felt, which left a lasting impact on them professionally.

The health workers faced challenges within a healthcare system that primarily focused on delivering physical care and lacked provisions for palliative care. The existing hospital systems were not designed to address the psychological, social, and spiritual dimensions of human needs. This lack of awareness was particularly evident among local nurses who were unfamiliar with these aspects. However, nurses recognized the importance of training, both in theory and practice, to enhance their understanding of palliative care and improve their ability to fulfill their duties effectively. By prioritizing training, their comprehension of palliative care expanded, enabling them to provide comprehensive care to patients.

Nurses also acknowledged that limitations on support from community leaders could impede patients' access to already limited healthcare options, such as pain management, and could result in unbearable suffering. This created an environment where authentic connection between healthcare providers and patients was negatively affected. The choices available to patients were not only constrained by the availability of services but also by the accessibility and pathways to those services. Therefore, the involvement of community leaders as active participants and co-providers in the palliative care journey was crucial in supporting seriously ill patients. Nurses discussed the challenges they faced in providing integrated care, as the rapidly changing local health system introduced multiple new providers, which posed obstacles to the delivery of comprehensive palliative care.

They also acknowledged that in FCV settings, there is often a scarcity of domestic resources, and health service delivery relies on multiple donors who prioritize maximum return on investment. This underscores the importance of efficient services that minimize waste. Co-constructing services together was seen as essential to avoid waste and ensure that appropriate care is provided in a timely manner. However, achieving this required an awareness of the needs of the population and a compassionate approach that went beyond a task-oriented perspective of patients, emphasizing the importance of a sense of "togetherness" in the provision of care.

Authentic-connection:

The overall significance of authentic connection was evident in how FHCWs perceived and valued empathy and compassion in their daily interactions. Among the participants, particularly young female healthcare workers who had chosen to work in humanitarian care, actively sought to cultivate authentic relationships. This served as a vital source of motivation and dedication to their profession. One nurse shared her experience, saying,

"I had a patient with bladder cancer. I visited his home every 4 to 5 days to care for him. Sometimes, he experienced severe pain and was bedridden, but whenever he saw me, he would sit up on his bed out of gratitude. It brought me great comfort. After about a month, I removed his catheter at his home. The next day, I was working at the primary healthcare center when my colleague informed me that someone was looking for me. I went outside and saw that the patient had come. I held his hand, took him to the counseling room, and asked about his problems. He said, 'I just came to see you, I don't have any problem.' In that moment, I felt immensely grateful for palliative care. I realized that if I

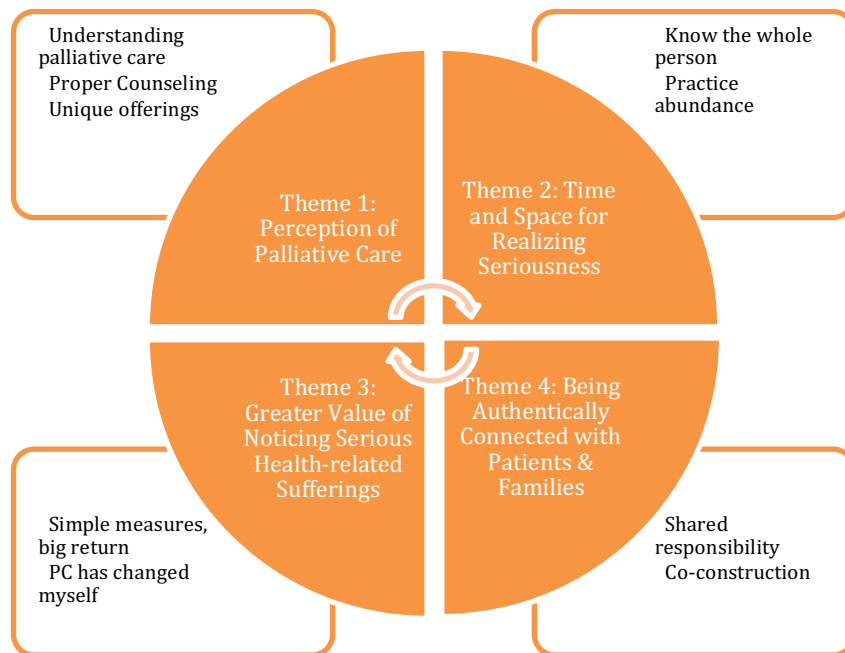
hadn't known how to provide palliative care, I wouldn't have been able to alleviate this patient's suffering, even if only temporarily" (P6).

These conversations highlighted how compassion, described by neuroscientists as a mirroring process, contributes to fostering authentic relationships within the professional care boundary, as it imbues life with meaning throughout the process. The caring attitude of FHCWs, especially the nurses, holds great significance. During a conversation with a patient's son at the primary healthcare center, one nurse introduced herself as part of the palliative care team. She engaged with sensitivity, emphasizing the positive aspects of her role. She highlighted that as nurses, they provide care for individuals with serious illnesses through palliative care, which may not cure the diseases but can help patients live comfortably for many years despite their illnesses. In response, the son expressed his lack of knowledge about palliative care but acknowledged the nurse's dedication, stating, "I don't know what palliative care is, but it's true that you do so much more than other medical services in the camps" (My journal: May 2020).

5.8 Development of theory from the generated data:

As I sought to generate a theory that would help to provide understanding of the data I was conscious of the need to address the distinction between inductive and deductive enquiry within grounded theory. Bulmer (1979) views induction as the key process with the researcher moving from the data to empirical generalization and on to theory.¹²⁷

Figure 5.1: Understanding the Journey Toward Engagement in Humanitarian Palliative Care: A theoretical model



Theory in qualitative research is also seen as an organized coherent and systematic arrangement of concepts to define and explain some phenomenon.¹²⁸ The aim of this study was to inductively produce a substantive theory generated from the data, which would begin to offer a form of explanation about the engagement of FHCWs with quality humanitarian palliative care.

As I engaged in the research process, the literature review served as a valuable guide for developing a theoretical framework. It provided me with insights and helped generate a list of topics to explore during the semi-structured interviews. However, it was through the interviews themselves that the true depth and intensity of the experiences emerged.

The interview data brought a sense of action and interaction, both within oneself and with the community that added a profound dimension to the research. It allowed me to delve into the lived experiences of the participants, gaining a deeper understanding of their perspectives and the dynamics at play. The interviews became a rich source of information, bringing the research to life and shaping the narrative of the study.

To summarize, the initiation of palliative care practices in daily clinical interactions with patients and families revealed seven central messages that can be grouped into four central themes. These themes are:

- Theme 1: People-Centered Care, which encompasses two sub-themes: understanding the whole person and practicing compassion.
- Theme 2: Time and Space for Realizing the Seriousness, which includes three sub-themes: comprehending the requirements of palliative care for healthcare professionals, recognizing the value of effective communication, and appreciating the unique contribution of the healthcare team.
- Theme 3: Greater Value of Noticing Serious Health-Related Sufferings, which consists of two sub-themes: the importance of investing in simple measures and the transformative impact of palliative care.
- Theme 4: Authentically Connected with Patients & Families, which is further divided into three sub-themes: shared responsibility, co-construction, and authentic connection.

These themes and sub-themes are represented in the theoretical model, highlighting the interrelationships and dynamics among them. The model provides a comprehensive framework for understanding the core aspects of palliative care practices and their impact on patients and healthcare providers.

The objective of this study was to gain insight into the stages of engagement in palliative care for health professionals operating in a humanitarian environment. The theoretical model, titled "The Journey Toward Engagement in Palliative Care," offers a framework for comprehending how FHCWs embark on the process of caring for patients with incurable conditions and how this involvement evolves into a profound emotional and social commitment. I propose that this commitment, which is multifaceted and centered on alleviating suffering while promoting high-quality care, can be best characterized as compassion.

5.8.1 An analysis of theory formation:

"The Journey toward Engagement in Humanitarian Palliative Care" theory can be categorized as a substantive theory because it is developed for a specific domain, offering an explanation for a defined issue within that field¹²⁹ Moreover,
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the theory is firmly rooted in empirical data, aligning with the principles of grounded theory. By adopting the flexible approach of constructivist grounded theory, the theory acknowledges the researcher's position, perspectives, privileges, and interactions as integral components of the research process. ⁹⁴

"The Journey Toward Engagement in PC" theory is a dynamic social process characterized by progressive movement and can be understood as a series of phases. These phases exhibit temporal sequences with discernible beginnings, endings, and significant milestones in between. The theory recognizes that these temporal sequences are interconnected, forming a process that unfolds across stages and evolves over time, incorporating changes and transformations. Moreover, it represents the participants' transition as they embark on the journey of palliative care, aiming to alleviate the suffering experienced by their patients.

The theory consists of four distinct phases, each with its corresponding categories and underlying concepts. These phases and categories are structured as follows:

- Phase 1: Perception of Palliative Care
 - Category 1.1: Understanding the nature of palliative care
- Phase 2: Providing Time and Space for Realizing Seriousness of Serious Health-Related Sufferings
 - Category 2.1: Recognizing the significance of patients' suffering
 - Category 2.2: Allotting adequate time and space for addressing suffering
- Phase 3: Appreciating Greater Values of Noticing Sufferings
 - Category 3.1: Emphasizing the importance of simple measures
 - Category 3.2: Personal transformation through engagement in palliative care
- Phase 4: Being Authentically Connected with Patients & Families Through Compassion
 - Category 4.1: Shared responsibility in caregiving
 - Category 4.2: Co-construction of care

Category 4.3: Cultivating authentic connections with patients and families through compassion

Each phase and category within the theory represents a distinct process, and they can each stand alone with their own set of concepts. These concepts form the foundation of the analysis and serve as the building blocks of the theory. They allow for the framing of key characteristics of individuals' experiences and enable the communication of a meaningful representation grounded in their everyday terms. Furthermore, the concepts facilitate the construction of relationships among the various components of the theory.

The four-stage process involved the health workers acquiring the knowledge and passion to learn about palliative care, recognizing the previously overlooked suffering of others, appreciating the impact of their actions in alleviating suffering for patients and their families, and experiencing a profound personal transformation. This transformation enabled them to connect more effectively with those experiencing suffering and respond in ways that fostered holistic care in humanitarian settings.

CHAPTER 6: STUDY 2

Self-Preparedness of Frontline Healthcare Workers for Quality Care Provision

6.1 Introduction:

Chapter six examines the third research question: “What are the processes of self-preparedness of FHCWs for quality care provision during the pandemic in Rohingya refugee camps?” Constructivist grounded theory and mixed methods were used in order to develop a better understanding of how to navigate palliative care provision in Cox’s Bazar before and during the pandemic. The research was able to explore the complexity of challenges that health workers faced as they sought to cope with shocks in health systems.

6.2 Background:

Our attention in the previous studies has been on patient experience and patient care. This study will turn its attention to care of health professionals - this is an important end in itself and also impacts the quality of healthcare that is provided to patients. Poor-quality care is one of the most challenging global health problems, particularly in light of the overwhelming COVID-19 pandemic. The World Health Organization (WHO) estimated 180000 deaths of health care workers due to COVID-19 pandemic impact between January 2020 and May 2021. The Lancet Global Health Commission on High-Quality Health Systems noted that poor-quality care impacts 60% of deaths from conditions amenable to health care.²² Evidence shows that an inter-professional team who are self-prepared with versatile competencies has been the key to deliver high quality care, which can prevent preventable deaths.²¹ Healthcare professionals are responsible for their self-preparedness in providing high-quality care, and sharing good practice. Health workers insufficient skills and capacities of provision of high-quality care remain as significant barriers.¹³

The impact of these identified issues are not known for humanitarian settings, where an estimated 2 billion people live and by 2030 nearly 50% of world’s poor people will be living there.¹³⁰ The challenges of such settings present significant risks to service access and quality that need to be addressed.

At the time of this study almost no research had examined how frontline healthcare workers (FHCWs) were looking after themselves and whether and how this affected their ability to deliver high-quality care provision in humanitarian context. This study sought to address this gap by understanding what knowledge exists about self-preparedness amongst FHCWs working in a refugee camp, particular needs of healthcare workers and how did they value self-preparedness during the early period of pandemic with probable human-to-human transmission. This research was an opportunity to contribute to the COVID-19 Research Roadmap of WHO to provide essential information on FHCW's perceived knowledge and behaviour on self-preparedness in a pandemic. The study aimed to develop a substantive theoretical framework that shapes the processes and factors for engaging in self-preparedness, considering a fundamental question: 'What are the processes of self-preparedness of FHCWs for quality care provision during pandemic in Rohingya refugee camps?'

6.3 The aim of this research:

To (i) explore factors influencing the ability to engage in self-preparedness from the unique experience of Frontline Health Care Workers (FHCWs) working in Rohingya Refugee Camps; during COVID-19 (ii) use this evidence-base to develop a substantive theoretical framework that explains the process of frontline healthcare workers (FHCWs) engagement in self-preparedness for self-protective measures in humanitarian settings.

6.4 Objectives of this study:

1. To build an evidence base from this case study in Cox's Bazar that can inform governments and health sectors in their development and implementation of realistic and socially, culturally sensitive strategies to protect and support well-prepared frontline healthcare workers.
2. To identify specific challenges to self-preparedness by examining how frontline healthcare workers in Rohingya Refugee Camps address self-preparedness in this particular setting.

6.5 Methodology:

6.5.1 Study Design:

I used a constructivist grounded theory method, rooted in a set of complementary theories and systems including interpretivist paradigm, relativist ontology, subjectivist epistemology and symbolic interactionism. My aim was to reconstruct the reality for FHCWs of their daily management of their condition (Table 3.1).

6.5.2 Settings and Participants

Thirty practicing frontline doctors, nurses and community health workers (CHWs) employed in primary health centres of Rohingya camps, Cox's Bazar were interviewed. FHCWs not directly providing patient care were excluded. Participants were selected initially using convenience sampling.⁷⁷ Later snowball sampling was used to identify potential participants.¹³¹

6.5.3 Ethical Considerations:

Ethical approvals were obtained through The University of Edinburgh and the Bangladesh Child Health Research Institute. Working permission to carry out the research in the Rohingya camps were granted by the Civil Surgeon's Office, Cox's Bazar (CXB) and the Refugee, relief and Repatriation Commissioners' (RRRC) Office, CXB. The issues of anonymity and confidentiality were addressed in a variety of ways throughout this study. To maintain confidentiality, research assistants using code number transcribed audio-recorded interviews. The research setting (including the hospitals and primary health-care facilities, non-governmental organizations) was all described in general terms without disclosing their identity.

6.5.4 Informed Consent:

I contacted potential participants through phone calls to gain their consent to participate in the study, explaining the purpose of the study during initial contact before sending 'participant information sheet' through email to enable potential participants to make an informed choice. The interview date, time and mode were discussed when participants agreed. The Study Information sheet contained information details of the aim, design of the study. Contact information of an independent Clinician was also given to help participants acquire further information if they needed, or discuss issues.

The method of consenting was verbal. Before starting the interview, the interviewer read out the consent form to the participant. Any research team member could receive the informed consent from participants. Participants were given one week to consider participation before consenting. Each of the participants was paid 20 GBP (in BDT conversions) in compensation for their time. Participants were fully informed that their participation was on a voluntary basis and that they could withdraw a participant. They understood they could decline to answer any questions or refuse to be audio recorded during the interview. The primary reason for withdrawal was to be documented in the participant's case report form.

Issues of anonymity and confidentiality were addressed in a variety of ways throughout this study. To maintain confidentiality, audio-recorded interviews were transcribed and translated by research assistants using code number. The research setting (including the hospitals and health-care facilities, non-governmental organizations) were all given general descriptions without naming. Electronic files were kept in a password-protected office computer to ensure security of the collected data. The dataset will be retained securely in University of Edinburgh's data repositories for five years from date of completion of the study for university requirements and then will be securely destroyed.

6.5.5 Data Collection and Analysis:

Data were collected through individual online semi-structured interviews using Microsoft Teams. Interviews were digitally audio-recorded, transcribed verbatim and checked for accuracy by myself. I analyzed data with independent contributions from all authors. Data analysis followed iterative strategies in grounded theory with a focus on processes, paying specific attention to time and context with simultaneous collection and analysis of data, manual coding, comparative analysis (within cases and across cases), theoretical sampling to refine theoretical ideas, memo writing and the integration of theoretical frameworks into developing grounded theory.¹³²⁻¹³⁴ (Coding involved 1) an initial phase (Open Coding) line-by-line coding, 2) a focused (Axial Coding) and 3) Selective coding (Theoretical Coding).¹³⁵ I examined each transcript line by line to gain a closer look at what participants had said and to identify implicit concerns and explicit statements. Each interviewer wrote memos immediately after the completion of interviews.

6.6 Quality of the Study

In light of the methodology underpinning this research, this study used four criteria - credibility, originality, resonance and usefulness - proposed by Charmaz (2006)⁹⁴ to evaluate the interpretive sufficiency of the developed theoretical model for this study, being mindful about that 'philosophical underpinnings or theoretical orientations and special purposes for qualitative inquiry will generate different criteria for judging quality and credibility', a diversity of quality criteria is warranted.⁸⁸

6.6.1 Credibility:

Credibility is the criterion to evaluate whether the findings of qualitative research represent a credible and believable interpretation of the data drawn from the perspectives of the participants in the research.¹³⁶

Credibility of the study and of emerging findings was established in five ways.

(1) Constant comparison: By means of constant comparison, the credibility of emergent findings in terms of meanings and concepts was constantly checked through a coding process.

(2) Theoretical sampling: Theoretical sampling methods enhanced the credibility of the study through self-correction.¹³⁷ It identifies gaps from the developed categories, follows the theoretical hints for further sampling and finally saturates these categories (Strauss and Corbin, 1998).¹³⁴

For example, in light of the developed categories 'Pandemic Learning: realizing seriousness', 'field workers' 'self care' and 'CHWs realizations', the study recruited CHW supervisor participants, which has added an additional perspective on the CHWs experience and the context where field care took place. This additional data source also provided richer and more comprehensive data to achieve deeper insight into the contextual factors that influence FHCWs self-preparedness construction. The work narratives and FHCWs' reflections provided deep insight into the FHCWs' interpretations of their self-preparedness construction. Using more than one data resource or method in the study is referred to as triangulation, which helps to enhance the strength of inference in qualitative research (Bryman, 2008)¹³⁶

(3) Member checking and Respondent validation (Bryman, 2008)¹³⁶ were used to support the trustworthiness of the data. These were conducted in different ways and at different stages of the study. During the data analysis, three transcriptions of the interviews were sent back to the FHCW participants for feedback and further clarification. When the theoretical model was developed,

a summary of the findings was sent back to three FHCW participants to gain feedback about whether the developed theoretical model had reflected the reality they experienced.

(4) Independent audit: The analysis was discussed with the research team throughout the research. These discussions added great insights and offered different views to the development of the theoretical categories and final theoretical model.

(5) Research team position: Strauss and Corbin (1998)¹³⁴ have recommended that the GT researcher be expected to possess qualities including 'appropriateness, credibility, intuitiveness, receptivity and sensitivity'. As discussed in methodology section, the research team members position based in refugee camps and the knowledge gained from their experiences of working and research in refugee camps were found to increase these qualities for the team as researchers to undertake GT. In the meantime, in order to retain openness to the data, research memos were used to help the team reflect on their background assumptions and their interactions with the data.

6.6.2 Originality:

Originality includes new insights of the categories, new conceptual frameworks, and the social and theoretical significance of the research. Originality in this study was evaluated by a return to the literature to compare the research findings with the existing knowledge in the field at the latter stage of the research, which is presented in the discussions.

6.6.3 Resonance:

Resonance asks how well the developed theoretical model can 'speak specifically for the population from which it was derived and to apply back to them' (Strauss and Corbin, 1998)¹³⁴ Resonance was tested by presenting the questions and the ongoing findings to the local community, and doing more formal presentations at several conferences and health sector meetings.

6.6.4 Usefulness:

To evaluate the usefulness of the final findings, the practical significance of the research and the recommendations for further studies are addressed in chapter 7.

6.7 Results:

Individual online semi-structured interviews were conducted to collect data from May 1 to June 30, 2020. Due to travel restrictions, the interviews took place online instead of in-person. As a result, the responses capture insights from the initial stages of the COVID-19 pandemic. The interviews were recorded digitally, transcribed verbatim, and personally checked for accuracy by me.

Thirty practicing frontline doctors, nurses and CHWs currently employed in primary health centres of Rohingya camps, Cox's Bazar were interviewed, (10 from each group). Table 6.1 summarizes the data collection types and number of episodes. Table 6.2 lists the documents used in this research and table 6.3 shows the individual demographics. A theoretical framework was developed based on the data collected from interviews.

Table 6.1: Summary of Data Collected

Data Collection Methods	Number of Episodes
Semi-structured Interviews	30 interviews
Documentary analysis	12 documents

Table 6.2: Documents used in this research:

Document number	Document type	Source
Doc 1	Joint Multi-sector Needs Assessment – Refugee and Host communities Health Rohingya Camps - 2021	Health Sector, CXB
Doc 2	Quality of care in fragile, conflict-affected and vulnerable settings: taking action. (World Health Organization, 2020)	WHO Publications
Doc 3	Quality of care in fragile, conflict-affected and vulnerable settings: tools and resources compendium. (World Health Organization; 2020)	WHO Publications
Doc 4	Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice.	WHO Publications

Doc 5	Working paper on the use of essential packages of health services in protracted emergencies. (Global Health Cluster and WHO, 2018)	WHO Publications
Doc 6	Mental health and noncommunicable diseases situation assessment report, Rohingya Camps, CXB	Health Sector, CXB
Doc 7	Training Programme	FKRF
Doc 8	Health sector bulletin	Health Sector, CXB
Doc 9	Rohingya refugee camps during COVID-19	Health Sector, CXB
Doc 10	Situation report	Health Sector, CXB
Doc 11	Integration of NCD care in emergency response and preparedness (WHO, 2018)	WHO Publications
Doc 12	National guideline for Hypertension	Government Publication

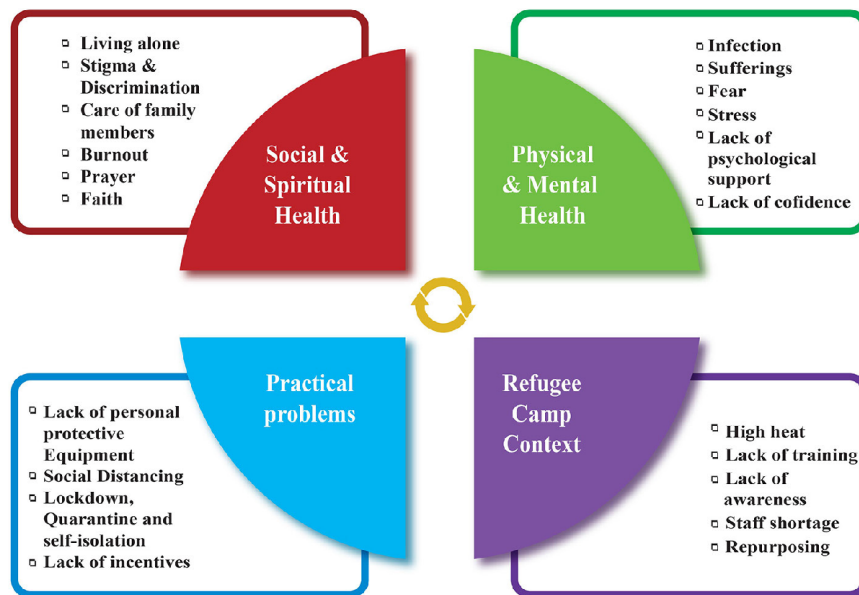
Table 6.3: Individual Demographics

Participants	Years of Experience	Gender	Age (Years)	Job Role	Workplace (Camp Number)
0101	5 months	Male	29	Medical Officer	3
0102	1.5 years	Male	29	Medical Officer	8W
0103	11 months	Male	28	Clinic Manager	21
0104	3 years	Female	28	Medical Officer	3
0105	11 months	Male	27	Medical Officer	19
0106	1.5 years	Male	27	Clinic Supervisor	20 Extension
0107	1.1 year	Male	29	Medical Officer	16
0108	2.6 year	Male	29	Clinic Supervisor	All
0109	1.5 months	Male	29	Clinic Supervisor	24

0110	1.2 years	Male	28	Medical Officer	13
0201	7 months	Female	24	Nurse	24
0202	10 months	Male	26	Nurse Supervisor	12
0203	2.6 years	Male	26	Nurse	12
0204	1.1 year	Female	24	Nurse	9
0205	2 months	Male	26	Nurse	3
0206	6.5 months	Male	22	Nurse	12
0207	2 years	Male	25	Nurse	4
0208	3 years	Female	22	Nurse	9
0209	2.8 years	Female	25	Nurse Lead	5 A
0210	2 years	Female	26	Nurse lead	12
0301	2.8 years	Male	25	Community Health Supervisor	26
0302	1.11 years	Male	27	Community Health Supervisor	1E
0303	3 months	Male	34	Community Health Supervisor	18
0304	2.5 Years	Male	22	Community Health Worker (CHW)	30
0305	4 months	Female	20	CHW	1E
0306	7 months	Female	21	CHW	1E
0307	7 months	Female	20	CHW	3
0308	7 months	Female	25	CHW	4
0309	1.2 years	Female	20	CHW	3
0310	3 years	Female	19	CHW	18

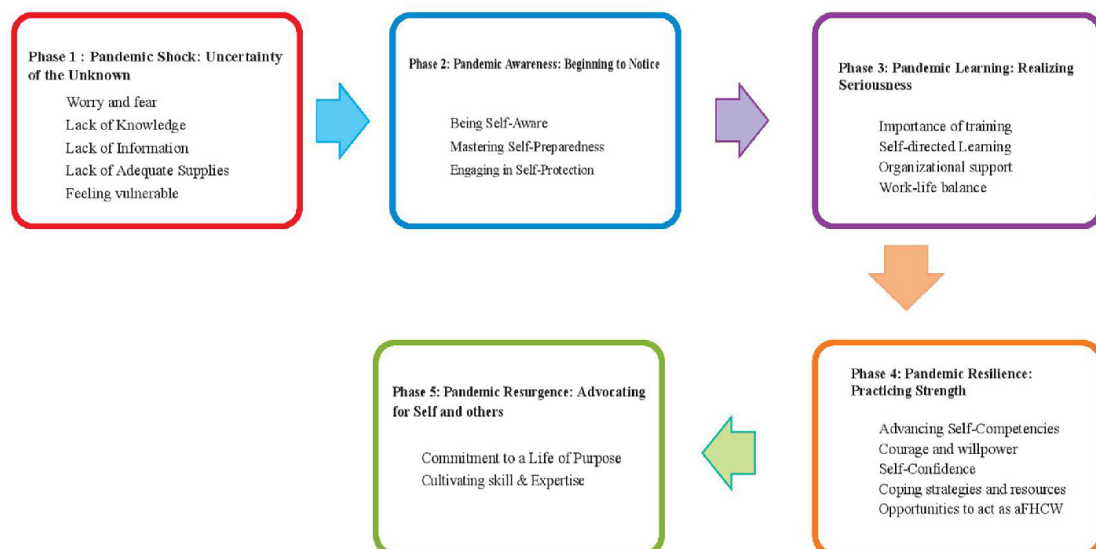
The FHCWs spoke of how the pandemic exacerbated what was already a challenging situation of working in a humanitarian crisis (Figure 6.1).

Figure 6.1: Multidimensional Barriers related to COVID-19 that affected FHCWs



However, it was clear from the data emerging that their own perspectives about coping and the support they gained from their families was a source of strength that reduced their stress levels and helped them regain control of their situation. Five theoretical phases were formulated (Figure 6.2): (a) Pandemic Shock; (b) Pandemic Awareness; (c) Pandemic Learning; (d) Pandemic Resilience and (e) Pandemic Resurgence.

Figure 6.2: Theoretical Phases



From these phases the emergent-grounded theory of ‘Navigating Self-Preparedness Through Pandemic’ was developed. The theoretical framework established a realistic and socially, culturally sensitive COVID-19 strategy to protect and support well-prepared FHCWs. Self-preparedness was comprised of 5 phases: (a) Pandemic Shock; (b) Pandemic Awareness; (c) Pandemic Learning; (d) Pandemic Resilience and (e) Pandemic Resurgence. From these phases the emergent-grounded theory of ‘Navigating Self-Preparedness Through Pandemic’ was developed. The theoretical framework established a realistic and socially, culturally sensitive COVID-19 strategy to protect and support FHCWs (Figure 6.3).

Figure 6.3: Constructed Theory

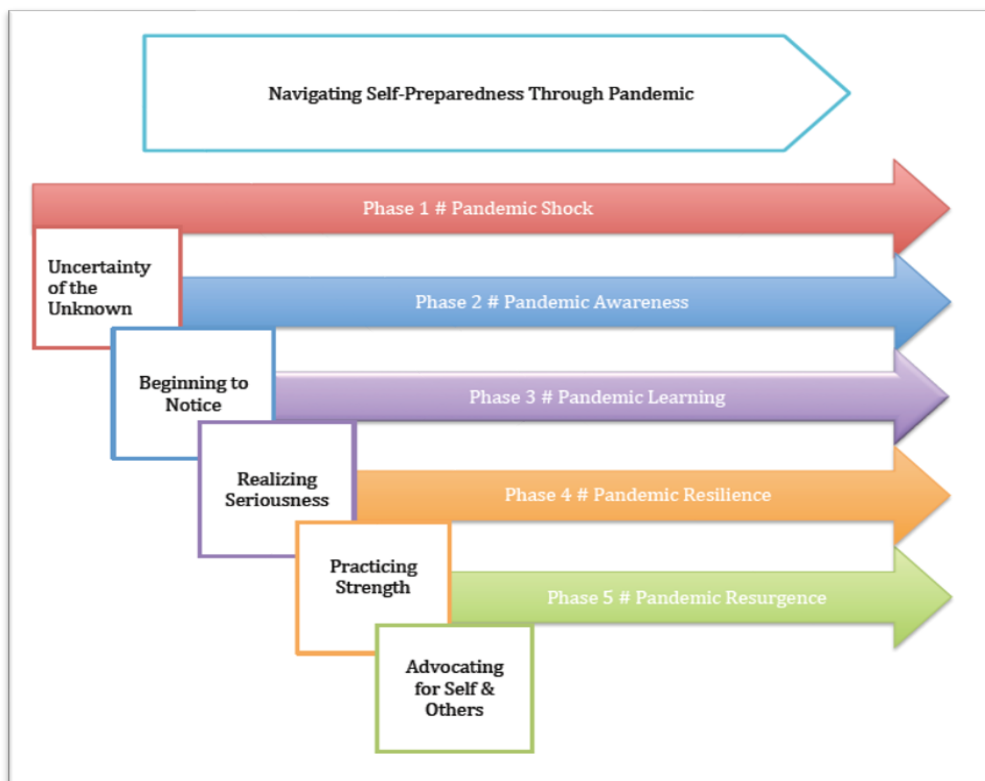


Table 6.4: Representative Quotes from participants

Representative Quotes	
Phase 1: Pandemic Shock: Uncertainty of the Unknown	
(-) Uncertainty	<i>"Somehow it seems that we are waiting for our turns to become COVID-19 positive and then get cured by the grace of the Almighty" (P5)</i>
(-) Anxiety	<i>"Actually we are working on the frontline, we are all living with this anxiety" (P16)</i>
(-) Fear	<i>"Now what will happen to me? Am I going to die? Moreover, I'd need to be in isolation area, there would be no one there. That means you have to survive there alone." (P19)</i>
(-) Separation from family	<i>"For the last four months, I could not go to Dhaka to see my parents." (P3)</i>
(-) Lack of adequate supply	<i>" For the first 15 days, we didn't have any PPE" (P15)</i>
(-) Feeling vulnerable	<i>"My wife (also a doctor) was pregnant. It was an early pregnancy, only 4 weeks. Suddenly she had started fever, vomiting and jaundice. I thought it was viral hepatitis and we desperately needed to check. There was no testing facility in camps. It was lockdown everywhere. I had to take her in Cox's Bazar that's 35 km away for testing with an auto rickshaw." (P6)</i>
(-) Stigmatization and discrimination	<i>"Needed overnight staying at a colleague's house in CXB, his landlord forbade him to allow us to stay" (P6)</i> <i>"House owners have stopped to let their houses to the clinicians, fearing they are sources of COVID-19" (P14)</i>
Phase 2: Pandemic Awareness: Beginning to Notice	
(-) Context realization	<i>"It's like a crisis within a crisis" (P9)</i>
(-) Lack of knowledge	<i>"I know less about the disease and situation management." (P 14)</i>
(-) Asymptomatic cases	<i>"As a frontline worker, since I've been in touch with a lot of patients, even after having protection, I feel worried that I may get infected anytime." (P11)</i>
(-) Limited testing facilities	<i>"Since testing facilities are still very limited in our country and we are not able to bring everyone under testing" (P7)</i>
(-) Lack of awareness	<i>"Everyone wears a mask but doesn't know how to wear it and how to remove it. Many people wear masks that are so dirty. People are wearing gloves but tearing parts of fingers, since it is</i>

	<i>difficult to press the mobile. We need to be more cautious about hygiene and correct use.” (P22)</i>
(-) Physical weakness	<i>“I’m having a lot of physical problems. I feel weaker than before because now I’m wearing this heavy PPE during duties in a hot climate in Rohingya refugee camps. I’m having a continuous headache. I’m dehydrated. I’m having problems with my BP; my BP is getting low due to dehydration.” (P4)</i>
(-) Stigma at community	<i>“When the camp dwellers saw us wearing PPE, they got scared and avoided us. They used to hide their symptoms” (P29)</i>
(+) Organizational support	<i>“The organization where I work has some good practice and organizes monthly or fortnightly sessions where COVID-19 related issues are explained” (P1)</i>
(-) Staff shortage	<i>“We are not just working with COVID now, general patients, the elderly, and children are also getting treatments. In that case, it would have been better if the number of health workers could be increased in this situation.” (P8)</i>
Phase 3. Pandemic Learning: Realizing Seriousness	
(+) Create awareness	<i>“We need to raise more and more public awareness. Repeated counseling, more publicity in the media about what to do and how to do it, are urgently needed.” (P13)</i>
(-) Lack of training	<i>“Although I’m working in this Coronavirus pandemic situation I haven’t received any training yet.” (P11)</i>
(-) Everyday challenges	<i>“In fact, the extremely hot weather in Rohingya camps is very difficult for a health worker to wear this. One who has worn it will understand how difficult it is to keep wearing it. And the most important thing is that you can do easily the donning part, but the real difficult thing is at doffing. After work, as it is very hot here, when we go out to work, we are in a panic mood. So, then we try to remove these from our body quickly. As a result, we are more likely to be infected with this doffing.” (P2)</i>
(-) Frustrating reality	<i>“We are wandering around, not believing anything. I’m not wearing a mask; I’m sneezing and coughing, not bothering about cough etiquette. People rushed home without accepting anything during Eid holidays. People are attending wedding parties.” (P17)</i>
(-) Heavy workload	<i>I work with 12000 people (among the total population of 44000) in my camp. I have to go to camp daily and search for symptoms, that are divided into yellow, red & green, in them. I have to cross mark in the tally sheet. I submitted 28th report last week” (P28)</i>
(-) New realities	<i>“When we go to the camp through the vehicle, we sit at a distance, when we reach the workplace there is chlorine solution mixed. We wash our hands, we wash our legs, we have to go through thermal screening.” (P26)</i>

(-) Isolation Centre	<i>"We visit patients at the isolation centre after wearing PPE. At the end we do 'doffing'. We have an observer who tells us the steps to follow, at the end we place our gumboots into chlorine wash." (P27)</i>
(-) Burnout	<i>"And actually, returning home from outside is now a hazard. Previously, returning home was a joy and relief. And now when I get back home, the first thing is to think about my hygiene and my sanitation. Wash my hand, and shower, sanitize all my stuffs that I'd taken outside." (P10)</i>
Phase 4: Pandemic Resilience: Practicing Strength	
(+) Coping strategies	<i>"I do breathing exercise sometimes. When I am anxious, I take 3 deep breaths and release slowly. Apart from this, I try to feel every part of my body closing my eyes, which I've learnt from a psychosocial training. I try to do this when I am very stressed, which gives me a bit of relief." (P6)</i>
(+) Self-directed learning	<i>"I completed training from my personal initiative such as I've completed online courses offered by the World Health Organization. I try to keep myself up to date reading journal papers." (P11)</i>
(+) Family support	<i>"I got a lot of support from my family. I talk to my parents everyday over telephone. That gives me mental comfort." (P8)</i>
(+) Monitoring awareness	<i>"As a health worker to prevent coronavirus infection, my opinion is that now the only way to prevent it is for everyone to be aware of themselves to protect themselves. As a health worker, I need to make others aware of this." (P15)</i>
(+) Communication in camps	<i>"In the beginning, the camps were very crowded. We told them not to visit another house. If someone was getting married then not to join the party. Don't gather and gossip in the store. Because if you keep yourself safe, your family will be safe." (P21)</i>
(+) Self-confidence	<i>"Now I am fully prepared, now we have proper supply of everything. And we're keeping a distance of three meters, everyone is wearing a mask, moreover no one has any plans to visit other places for now."(P13)</i>
(+) Faith and self-responsibility	<i>"When I go to work, my actual protection is PPE, which covered my head to toe, which we call coverall, N-95 mask, goggles and face shield. Outside the work area I usually use masks and goggles that I've bought on my own. So far, I'm healthy. By the grace of the Almighty, I'd say those are protecting me." (P12)</i>
(+) New normal	<i>"After returning from outside I go straight to the bathroom and dip clothes in soapy water. After cleaning these, I take a bath and then come in contact with others." (P25)</i>

<p>(+) Courage and willpower</p>	<p><i>"Since I am a nurse, we have to fight as front liners. We should not be afraid. We will have to continue to face this situation today and tomorrow. If everyone walks behind, it will not be possible to face the problem." (P20)</i></p>
<p>(+) No absenteeism</p>	<p><i>"Since we are working as a front liner we are getting infected. I have not been able to go to work for last 14 days as my COVID test was positive. Those who came in contact with me were also kept in quarantine. This was not intentional. Everyone tries to work with self-protection responsibility as much as possible. Besides actual reasons, no one remains absent in workplaces." (P10)</i></p>
<p>(+) Resilience</p>	<p><i>"Many of my colleagues often get upset while working. I try to counsel them. I describe the reality of the situation with what we are working and also that we have to continue the work. So we should take care of our physical and mental conditions. Because if we are not healthy ourselves then how would we provide proper services to the patients? This is why we have to stay healthy." (P11)</i></p>
<p>(+) Opportunities to act as a FHCW</p>	<p><i>"I'm not worried when I am on duty. Actually, I say it from the context; the highest numbers of health care workers in Bangladesh getting infected are who work at Non-COVID units. The reason behind this is when we work in COVID unit we maintain 100% protection. But those who are working in Non-COVID units, they do not get proper PPE or ignore the use of PPE. There are so many who comes to Non-COVID unit for the treatment who hide their symptoms so that they are at much more vulnerable situations." (P16)</i></p>
<p>Phase 5: Pandemic Resurgence: Advocating for self and others</p>	
<p>(+) Commitment to a life of purpose</p>	<p><i>"We have taken the Hippocratic Oath right, as our patients would be our first priority" (P5)</i></p>
<p>(+) Prayers</p>	<p><i>"The biggest learning from this corona time is we can control ourselves. The situation in the country and abroad are going deadly. In this case, if I keep myself panicked, I cannot provide my service properly. As a physician I get many phone calls from people with COVID-19 symptoms, all of which I try to attend. I feel like, thanks to the Almighty, that HE has given me the capability to help others. I pray to maintain this and gear myself up psychologically." (P1)</i></p>
<p>(+) Cultivating skill and expertise</p>	<p><i>"Now we know how to prevent it, if we are on pause, the prevention will be also at pause. So we need to arrange more training and let people know and help them to understand through counseling and inform everyone how to stay safe from it, there will be a change of situation into 'less fear and more courage' will happen then." (P9)</i></p>

(+) Adapting to change	<i>“As a health professional and human being, in both cases I see myself in a vulnerable group. Because I am going to the forefront everyday but at the same time I see myself again as a powerful source that I have got a chance to fight this pandemic, when the world needs more people to come forward and help each other and at least I have some medical knowledge which would make a difference here.” (P5)</i>
(+) Personal insecurities turns into professional identities	<i>“And in the time of crisis for a life - a human life, I can make a difference that also makes me feel content and satisfied. So even though I'm vulnerable, feeling stressed and I'm happy being in a position where I can give my support and care.” (P7)</i>

Self-preparedness in inter-professional frontline health teams during the pandemic included managing self and managing others, coping with ambiguity and uncertainty, communication, critical reasoning, continuing own education, identifying and analyzing problems, and practicing empathy. This ‘self-preparedness’ led to a sense of self that was fundamentally different from that before pandemic. This was evidenced among the citations of the participants (Table 6.4).

6.8 Identified Themes

Phase 1: Pandemic Shock: Uncertainty of the Unknown

The first phase that emerged from the categorized data was pandemic shock with the theme of uncertainty of the unknown. FHCWs described their early pandemic experiences with terms referring to the shock of a totally unknown situation and a lack of understanding the disease. Six concepts emerged in phase 1: “Worry and fear” “Lack of Knowledge” “Lack of Information” “Lack of Adequate Supplies” “Stigma & Discrimination” and “Feeling Vulnerable.”

Everyone expressed a fear of what could happen next and the need to find out from others, and from the emerging evidence, what the disease progression looked like and what risks were attached. Many of the FHCWs spoke of how they thought they were becoming COVID-19 positive, with fears of uncertainty. For example, one participant shared her earliest feelings towards the uncertainty:

“Somehow it seems that we are waiting for our turns to become COVID-19 positive and then get cured by the grace of the Almighty.”

Working in humanitarian setting during pandemic was characterized by lack of knowledge, information and uncertainty around supplies on COVID-19, which caused a great deal of distress. The lack of PPE was concerning for participants, especially when they were unsure whether they would have enough masks or gloves. FHCWs experienced vulnerability by many negative physical, social, and emotional responses in the earlier stages. Most of them were young and staying alone in the camps without any of their family members nearby.

Phase 2: Pandemic Awareness: Beginning to Notice

The second phase was that of pandemic awareness, with a theme of 'Beginning to notice' emerging. The three concepts identified in this phase were "Being self-aware" "Mastering self-preparedness", and "Engaging in Self-Protection with responsibility". Many FHCWs started noticing what was going on around them. It was not just about doing things mechanically, but a conscious choice of learning, because they understood the need to prepare them to confront the pandemic. The COVID-19 pandemic was both physically and emotionally taxing for the humanitarian workers. Participants highlighted that community people saw them as high risk, and that added some more negativity in their already difficult lifestyles.

For example, one participant added:

"It's like a crisis within a crisis"

Participants said it was important to notice and trying to understand from both personal as well as professional perspectives because that led them to understand their inner feelings and intention. Many FHCWs believed that to be successfully confronting COVID-19 everyone needs to engage in self-protection and behave responsibly.

Other participants stated that self-awareness matured as pandemic awareness matured. They had learned from their own experiences of living with and navigating each day with versatile information through workplaces, newspapers and media. They had also learned seeing people dying and suffering throughout the world. Self-awareness enabled individuals to be more inventive and intentional in the structuring of their daily lives. For some, that involved generating their own set of personal values, beliefs and behaviour. Others found comfort in pursuing religious involvement. Participants spoke about

there not being one specific event or activity that changed perceptions, but rather a combination of the ongoing pandemic and witnessing others struggling with the endlessness of it that brought about change. When the pandemic began all of the health messaging was focused on the emergency nature of the pandemic. The shift in seeing that the emergency wasn't like many other humanitarian emergencies – where there was a short burst of intensity with a long periods of either stagnation or slow recovery, but that this emergency had no end in sight, and was all encompassing infiltrating into every aspect of life changed the attitude of FHCW. It helped then to take stock and notice their strength and weaknesses.

Phase 3. Pandemic Learning: Realizing Seriousness

“I know less about the disease and situation management”

The theme underpinning this phase of pandemic learning was 'Realizing Seriousness' which had four sub themes: “Importance of training” “Self-directed Learning” “Organizational support” and “Work-life balance”. In this phase, most participants were still learning about COVID-19 and did not feel confident making self or patient management decisions.

FHCWs spoke of the importance of educating the entire group of FHCWs and creating public awareness about what might happen during a disaster because of the unavailability of resources, or resources being extremely limited because of devastation during an emergency. More needs to be done in the customizing and design of training and education of FHCWs that can be shown to lead to effective implementation of self-preparation practices for pandemic.

They emphasized that learning enhances self-esteem and confidence. Learning is also a social process of construction of shared meanings and beliefs, which is a result of social interactions that are necessary for individuals to interpret and give meanings to their experiences. In the reality of the Rohingya refugee camp situation, FHCWs needed to pick and adopt and get habituated with all kinds of self-protective measures, which they did through their own learning. Taking responsibility for own education was one part of the process of engaging in self-protection with responsibility.

Many participants spoke of how protection should not just be for the workplaces and the need to change peoples' perspectives. There was a strong message

among all FHCWs that they must wear PPE all the time to break the cycle of getting in contact with an infected patient. But it was difficult. There were challenges receiving PPE - though this was resolved as time went on.

They knew that many patients who were infected had none or very subtle symptoms, and some exhibited atypical symptoms. They were aware that such patients greatly endangered the health of staff even though clinical areas caring for patients with and without COVID-19 were separated from each other. Wearing PPE was challenging. There was a strong message among all FHCWs that they must wear PPE all the time to break the cycle of getting in contact with an infected patient. But it was difficult.

As doctors stated: "In fact, the weather in Rohingya camps is very difficult for a health worker to wear this. One who has worn it will understand how difficult it is to keep wearing it. And the most important thing is that you can do easily the donning part, but the real difficult thing is at doffing. After work, as it is very hot here, when we go out to work, we are in a panic mood. So, then we try to remove these from our body quickly. As a result, we are more likely to be infected with this doffing".

There were challenges receiving PPE - though this was resolved as time went on and orders of PPE increased. Nurses explained, *"Now I am fully prepared, at first our PPE did not arrive in time, anything did not arrive for about 15 days, then I was a little scared but now it is happening that we have proper supply of everything. And we're keeping a distance of three meters as much as we can, everyone is wearing a mask, moreover no one has any plans to visit other places for now"*.

Nurses spoke of how PPE was not just for the health sector and the need to change peoples' perspectives: *"When I go to work, my actual protection is PPE, which covered my head to toe, which we call coverall, N-95 mask, goggles and face shield. Outside the work area I usually use masks and goggles that I buy on my own. So far, I'm healthy. By the grace of the Almighty, I'd say those are protecting me"*.

FHCWs spoke of the importance of educating the entire group of FHCWs of the real-time possibility of what might happen during a disaster because of the unavailability of resources, or resources being extremely limited because of

devastation during an emergency. This finding suggests that more needs to be done in the customizing and design of training and education of FHCWs that can be shown to lead to effective implementation of self-preparation practices for pandemic.

Another important area was mental preparedness, which was just as important as physical preparedness. Many of the FHCWs spoke of how they thought they were becoming COVID-19 positive, with fears of *“now what will happen to me? Am I going to die? Moreover, I’d need to be in isolation area, there would be no one there. That means you have to survive there alone”*. As a result, everyone expressed a fear of what could happen next and the need to find out from others and from the emerging evidence of what the disease progression looked like and what risks were attached. In this situation of a pandemic in a humanitarian crisis it is important for everyone to be mentally strong and this strength comes from a number of areas, with access to knowledge essential.

Phase 4: Pandemic Resilience: Practicing Strength

“We have taken the Hippocratic Oath right, as our patients would be our first priority”

The fourth phase was that of pandemic resilience, captured through the themes of “Advancing Self-Competencies,” “Courage and willpower,” “Self-Confidence,” “Coping strategies and resources,” and “Opportunities to act as a FHCW.”

These appeared to be fundamentally influencing the professional self-preparation construction and resilience in FHCWs. These themes came together to constitute the contextual category under pandemic resilience, that of ‘Practicing Strength’.

We know from disaster theory that more preparedness leads to increased resilience. And in order to access the knowledge held by individuals it is important for that knowledge to be shared. Sharing of knowledge is the basis of collaboration. This was evidenced among the participants. Being able to work in a formal defined role as an FHCW appears to be essential to the development of resilience.

Resilience is about the idea that the participants recognized the suffering and concerned about the continuation of the activities forward. The FHCWs were no longer the one with fear of uncertainty. Because of self-competencies and self-confidence a bond was established which helped to look towards opportunities within the pandemic and struggles. One participant described the situation as:

“If everyone walks behind, it will not be possible to face the pandemic.”

The participants discussed different coping strategies and resources to support resilience: “breathing exercise, communication with family & friends, debriefing at workplace, family support, listening to music, meditation, physical exercise, and work/life balance. In addition, the FHCW’s beliefs about what was important in life changed, with many saying that they no longer worried about ‘getting COVID positive’. These appeared to be fundamentally influencing the professional self-preparation construction and resilience in FHCWs.

Nurse participants stated that their self-preparation in the current refugee care system was embodied in the title ‘nurse’, resulting in self-preparation being strongly attached to the health sector model. Nurses recognized that being identified as a nurse also brought with it a range of advantages in relation to being government nurses. This was also the case for Doctors but less for Community Health Workers.

Phase 5: Pandemic Resurgence: Advocating for Self and Others

In final phase 5, nearly all participants took the lead in their self-management and developed an understanding of the multifaceted impact of COVID-19. Participants shared numerous strategies when advocating for self and others. A few resonating comments were ‘commitment to a life of purpose,’ “prayers” “adapting to change” and “cultivating skill & expertise” for self-preparedness. Participant 1 discussed the theme “Advocating for self and others” as an important rationale to engage in self-preparedness, that also meant being sensitive at all times to the risks of the pandemic.

“People feel helpless of being infected with COVID-19, so to serve them as well as protecting ourselves, being fully aware about self-preparedness is our commitment.”

Participants identified that they need to continue training and counseling for prevention and staying safe from covid-19. The participants reported that they

felt vulnerable and powerful, stress and personal satisfaction at the same time. The ultimate success was the subtheme “Personal insecurities turns into professional identities.”

“We’ve been battling this pandemic for more than a year now. And even though we’ve made certain adjustments, maintaining this way of life is still challenging. We need to take extra care every day to protect our loved ones and ourselves. It exhausts you physically and mentally. But, we must continue since it is our duty and responsibility as healthcare professionals. No matter what, we have to keep both our patients and ourselves safe.”

6.9 Discussion:

In the midst of this anticipation of the future pandemic and its impact, the pandemic that would not go away easily, there was the development of an understanding of the many patient related problems from the pandemic. FHCWs saw immense suffering and they understood that patients and their families were struggling in ways unimaginable. FHCWs spoke of their care both as a professional duty and a source of personal satisfaction. Participants’ perception of self-competence in their role appeared to be fundamental to their professional competence development and their decisions to be practically orientated towards taking protection.

Advocating for self also meant being aware of the country and community tensions that colleagues were experiencing. Another participant shared: *“I’m not worried when I am on duty. Actually, I say it from the context; the highest number of health care workers in Bangladesh getting infected is from a non-COVID health service worker. The reason behind this is when we work in COVID unit we maintain 100% protection. But those who are working in Non-COVID they do not get proper PPE or ignore the use of PPE. There are so many who comes to Non-COVID unit for the treatment they hide their symptoms so that they are much more vulnerable. As I am working inside the COVID unit I am maintaining 100% PPE. Considering all of these I don’t think I will be infected.”* Advocating for self and others also meant being sensitive at all times to the risks of the pandemic.

6.10: Conclusion:

The conclusion of the study highlights the evolution of care integration with FHCWs’ understanding of the pandemic, personal growth, and commitment to

their roles. This evolution signifies a shift from a singular focus on physical health to a holistic approach that considers emotional, psychological, and social dimensions of care. The emotional journey and self-preparedness emerge as facilitators of compassionate and effective care, demonstrating responsiveness to pandemic challenges within a humanitarian setting.

CHAPTER 7: DISCUSSION

Beyond Boundaries: Uniting Methodology, Findings, and Vision for Progressive Palliative Care in Humanitarian Scenarios

7.1 Introduction:

As I arrive at the final juncture of this profound exploration into palliative care within humanitarian settings, I find myself at the confluence of methodology, findings, and their broader implications. This chapter serves as a reflective culmination of my journey, where the intricacies of my chosen methodology intersect with the richness of my findings, offering profound insights into the realm of palliative care for vulnerable populations.

In the pages that follow, I will navigate the landscape of my research endeavor, unraveling the tapestry of discoveries that emerged through my investigation. I will pause to contemplate the methodology that guided my path, shedding light on the choices and considerations that underpinned my approach. As I delve into the synthesis of findings, I will uncover the common threads that connect my research with previous studies, discerning where my insights harmonize, diverge, and contribute to the evolving discourse surrounding compassionate palliative care within complex contexts.

However, this journey doesn't conclude with the act of discovery. The implications drawn from my findings extend far beyond academia's boundaries. Through reflective introspection, I will chart the course for future research, outline policy recommendations aimed at dismantling barriers to equitable care, and pave the way for enhanced service provision. Furthermore, I will contemplate how the lessons I've gleaned can enrich the educational landscape, nurturing the growth of future caregivers who can adeptly navigate the intricacies of palliative care within the intricate web of crisis settings.

As I address the research questions that ignited my journey, I invite you to accompany me through this chapter. Here, at the intersection of reflection and revelation, I unveil not just the findings, but the resounding echoes that carry forth the essence of compassionate care into the very heart of challenging environments.

7.2 Answering Research Questions

In this segment, I will present responses to the research inquiries posed earlier.

Table 7.1: Research Questions

Research Questions: Question 1: What does the published literature tell us of the quality markers of palliative care within humanitarian settings Question 2: What do we know about the specific palliative care needs of the Rohingya community living in Cox's Bazar? Question 3: How do frontline healthcare workers perceive and describe the aspects of quality palliative care and compassion in humanitarian settings? Question 4: What factors influence the nature of care provided and how does care integrate and depend on the feelings healthcare workers have towards themselves and others?
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Question 1: What does the published literature tell us of the quality markers of palliative care within humanitarian settings?

Answer to question 1:

The scoping review in this study illuminates key quality markers crucial for delivering compassionate and effective palliative care in Fragile, Conflict, and Violence (FCV) settings. Prioritizing People-Centered Palliative Care, the dissertation highlights core values like respect and compassion, addressing cultural sensitivity, coping mechanisms, and alleviating moral distress among healthcare providers. Clinical aspects focus on Having Effective and Efficient Palliative Care, emphasizing pain management, skilled staff, guideline adherence, and addressing resource constraints. Timely assessments and safe clinical decisions are underscored amid instability, advocating for equity and integration in palliative care delivery. The dissertation promotes an inclusive approach, integrating palliative care into existing services for a comprehensive and humane response to complex needs in FCV settings. Overall, it presents a transformative, holistic model that transcends medical intervention, providing valuable insights for high-quality palliative care in challenging contexts.

Question 2: What do we know about the specific palliative care needs of

the Rohingya community living in Cox's Bazar?

Answer to question 2:

The dissertation effectively addresses the research question on the specific palliative care needs of the Rohingya community in Cox's Bazar. It reveals alarming statistics, such as 70.5% of patients experiencing severe pain, and highlights communication gaps in treatment. The study emphasizes the scarcity of essential medications and medical supplies, impacting pain control. Additionally, the absence of oral morphine, a crucial part of palliative care, is noted. The conclusion underscores the urgent need for a comprehensive approach, involving collaboration among humanitarian organizations, governments, and healthcare providers to bridge the identified gaps and provide dignified care for Rohingya individuals facing serious illnesses in challenging camp settings.

Question 3: How do frontline healthcare workers perceive and describe the aspects of quality palliative care and compassion in humanitarian settings?

Answer to question 3:

The study explores how frontline healthcare workers (FHCWs) perceive and deliver quality palliative care in humanitarian settings, highlighting their evolving commitment in challenging contexts. Initially viewing palliative care as novel, FHCWs transition to a comprehensive understanding, focusing on effective communication and personalized interactions for holistic patient care. Effective teamwork, regular gatherings, and ongoing education play pivotal roles in alleviating patient distress. Despite limited exposure, FHCWs embrace learning opportunities, recognizing the transformative impact on both patients and themselves. The research underscores the reciprocal impact, fostering personal development and empathy among FHCWs, leading to a transformation in their perspectives and a broader commitment to humanity's necessities. The partnership between FHCWs and community leaders proves pivotal in overcoming obstacles and enhancing healthcare accessibility, emphasizing genuine bonds rooted in empathy and compassion. Overall, the study showcases FHCWs' dedication to easing suffering, fostering significant bonds, and positively influencing the well-being of patients and families in humanitarian settings.

Question 4: What factors influence the nature of care provided and how does care integrate and depend on the feelings healthcare workers have

towards themselves and others?

Answer to question 4:

The study delves into the central aspect of how frontline healthcare workers (FHCWs) respond to the COVID-19 pandemic, emphasizing the integration of care and its dependence on their feelings. The journey through the phases of 'Navigating Self-Preparedness Through Pandemic' reveals the significant role emotions played in shaping the nature of care provided by FHCWs.

The emotional experiences of FHCWs, including fear, vulnerability, commitment, responsibility, courage, and a sense of purpose, were interwoven with their actions and approach to care throughout each phase. Care integration refers to how FHCWs' self-preparedness during the pandemic became intertwined with their provision of care to affected communities. The study's theoretical framework underscores the dynamic relationship between FHCWs' emotional responses and their care provision.

In the first phase, Pandemic Shock, uncertainties and fears shaped cautious interactions with patients, focusing more on the physical aspects of health. As awareness grew in the second phase, Pandemic Awareness, FHCWs transitioned to intentional care, considering both the physical and emotional well-being of patients. The third phase, Pandemic Learning, emphasized the importance of education and self-improvement, leading to more comprehensive care that addressed medical and emotional needs. In the fourth phase, Pandemic Resilience, emotional strength enabled a holistic approach to patient care, incorporating empathetic and compassionate interactions. The final phase, Pandemic Resurgence, saw FHCWs taking a proactive role in promoting preventive measures and providing education rooted in a sense of responsibility, dedication, and advocacy.

7.3: Summary of Findings

This study has explored a comprehensive understanding of delivering quality palliative care in challenging humanitarian settings, particularly amid the COVID-19 pandemic. It sheds light on intricate dynamics, urgencies, and possibilities associated with addressing the palliative care needs of vulnerable populations. Chapter 1 emphasizes indicators of quality care, addressing the triple crisis of neglecting life-limiting illnesses, vulnerabilities in healthcare infrastructure, and evolving care dynamics due to the pandemic. By aligning humanitarian principles with global commitments, it establishes connections between palliative care and Universal Health Coverage (UHC) principles for inclusive healthcare during crises. Chapter 2 introduced a scoping review to

systematically navigate the palliative care landscape within FCV settings in low- and middle-income countries. Employing rigorous methodologies, the study provides insights into care requirements, contextual settings, and delineates palliative care quality domains. Synthesized themes of people-centered care, effectiveness, timeliness, and equity offer a roadmap for navigating complexities in FCV settings, ensuring compassionate and effective care in adversity. Chapter 3 contributes contextual and foundational information, providing a valuable longitudinal perspective. It establishes a baseline of fundamental themes and challenges predating the COVID-19 pandemic, offering a distinctive viewpoint from the perspective of Rohingya refugee patients and caregivers. Emphasizing the prevalence of physical symptoms, medication scarcity, and the unsung heroism of caregivers, it proposes solutions for improved access and comprehensive training. Dedicated to the methodological journey, the chapter 4 aligns philosophical beliefs with practical research methods. The chosen exploratory, in-depth case study design within a mixed method framework reflects a thoughtful methodology capturing the depth and breadth of the research question, offering a valuable guide for future endeavors. In chapter 5, the compassionate journey of Frontline Health Care Workers (FHCWs) is unraveled, providing insights into their stages of involvement in palliative care. The resulting theoretical model, "The Journey Toward Engagement in Palliative Care," comprehensively frames how FHCWs navigate complexities and evolve into emotionally committed caregivers. Themes of people-centered care, effective interventions, timely responses, and equitable access underscore the dedication of FHCWs, prompting calls for policy changes and training programs. Chapter 6 navigates the challenges posed by the COVID-19 pandemic, the dissertation unfolds a nuanced journey of coping and resilience among FHCWs. The emergent-grounded theory of "Navigating Self-Preparedness Through Pandemic" encapsulates the evolution of FHCWs' resilience and transformation, offering insights applicable globally.

In addition to the comprehensive overview, an insightful exploration examines whether self-preparedness can measure healthcare quality, especially in the COVID-19 context. Focused on FHCWs, the study delineates distinct phases of their emotional journey and explores how these phases shape care provision. Emphasizing the evolution of care integration towards a holistic approach that considers emotional, psychological, and social dimensions, the emotional journey and self-preparedness emerge as facilitators of compassionate and effective care, demonstrating responsiveness to pandemic challenges within a humanitarian setting. Throughout these chapters, the study has elucidated the core processes or categories shaping and characterizing the research. Self-preparedness, viewed as a proactive measure individuals undertake to ready themselves for abnormal situations and emergencies, is proposed in this study as a quality indicator. Self-preparedness can serve as a measure of healthcare quality, particularly in the context of the COVID-19

pandemic. Focused on FHCWs, the study delineates distinct phases of their emotional journey and how these phases shape the provision of care. The emotional journey of FHCWs unfolds across five phases. This recommendation aligns with the fundamental principles detailed in Table 7.2 and the whole process has been described in a summary Table 7.3.

Table 7.2: Fundamental Principles of Self-Preparedness:

Quality of Care domains Definitions	Framing questions to examine quality in FCV settings	Key observations
<p>Self-Preparedness</p> <p>Proactive readiness of frontline healthcare workers for uncertainty and prompt response to emerging healthcare needs.</p>	<ul style="list-style-type: none"> - How has the healthcare facility prepared for changes in health needs during the pandemic in FCV settings? - What proactive measures address uncertainties, lack of knowledge, and shortages of supplies? - How do frontline healthcare workers cope with fear, vulnerability, and the need for self-protection? - What strategies ensure mental and emotional preparedness alongside physical preparedness? 	<p>Self-preparedness reflects the ability to navigate uncertainties, fears, and lack of knowledge during early pandemic phases. </p> <p>Importance of self-awareness, mastering self-preparedness, and engaging in self-protection with responsibility; Learning and adapting to the seriousness of the pandemic, emphasizing training, self-directed learning, and organizational support; Challenges in obtaining and using personal protective equipment (PPE), highlighting the need for effective training and availability of resources; Advancing self-competencies, courage, willpower, and coping strategies contribute to the resilience of FHCWs during the pandemic; Advocating for self and others becomes a crucial aspect of self-preparedness, including commitment, prayers, adapting to change, and cultivating expertise.</p>

Table 7.3: Summary Table of Self-preparedness:

<p>1. Phase 1: Pandemic Shock - Uncertainty of the Unknown:</p> <ul style="list-style-type: none">- FHCWs experience initial shock and uncertainty.- Emotions: Worry, fear, lack of knowledge.- Care Integration: Cautious interactions, limited engagement, emphasis on physical health.
<p>2. Phase 2: Pandemic Awareness - Beginning to Notice:</p> <ul style="list-style-type: none">- FHCWs become more aware of the pandemic's impact.- Emotions: Sense of duty and commitment.- Care Integration: Transition to intentional care, consideration of emotional well-being alongside physical health.
<p>3. Phase 3: Pandemic Learning - Realizing Seriousness:</p> <ul style="list-style-type: none">- FHCWs recognize the seriousness of the pandemic and focus on self-preparedness.- Emotions: Drive for self-improvement.- Care Integration: Comprehensive care, addressing both medical and emotional needs, providing information.
<p>4. Phase 4: Pandemic Resilience - Practicing Strength:</p> <ul style="list-style-type: none">- FHCWs develop resilience and coping strategies.- Emotions: Courage, self-confidence, determination.- Care Integration: Holistic patient care, empathetic interactions, addressing emotional needs.
<p>5. Phase 5: Pandemic Resurgence - Advocating for Self and Others:</p> <ul style="list-style-type: none">- FHCWs advocate for themselves and their communities.- Emotions: Commitment, adaptability, sense of purpose.- Care Integration: Proactive role in promoting preventive measures, education, care rooted in responsibility and advocacy.

7.4 Reflections on Methods including Strengths and Weaknesses

In this section, I will provide reflections on the methods utilized in this research, highlighting both their strengths and weaknesses.

Strengths of the Study:

Choosing the case study method to investigate the quality of palliative care within a humanitarian context allowed me to fill a gap in existing literature. This decision aligns seamlessly with an approach well suited for exploring complex phenomena, leading to valuable insights that enhance a research area often overlooked. I specifically employed this approach in my doctoral study. By adhering to a comprehensive framework and following these steps, I methodologically explored the landscape of palliative care in humanitarian

settings within low- and middle-income countries. This approach enhances my review's credibility, transparency, and potential impact on healthcare policy and practice. The methodological rigor ensures that my review process aligns with best practices and contributes valuable insights to the field of palliative care in challenging contexts.

During the period from January to March 2020, I collected data through participant observation and informal conversations. My background as a specialist palliative care physician and lead implementer of these interventions proved beneficial in establishing rapport and smoothly integrating with the teams. I conducted observations during training sessions, meetings, and while providing supervision during clinical activities, particularly with patients who presented challenges and were difficult to manage, as well as adherence to clinical protocols. In my study, I looked at information from different times and different groups of people in healthcare and emergencies. This helped set a base for future research. This way, I could see patterns, changes, and ongoing problems. It helps me share useful ideas to improve how we give good care in changing situations. One good thing about using different sources of information is that it helps make sure my results are reliable. For example, I talked to healthcare workers, looked at survey answers from patients and caregivers, and used data from local pharmacies. This way, I could double-check and make sure my findings are accurate and trustworthy. Following is an example, at Figure 7.1, of an entry from my reflective journal to showcase a researcher's thoughtful reflection on moments of bias during data collection, the steps taken to address it, and the realization of the ongoing effort required to maintain objectivity. The reflective journal serves as a tool for self-awareness and continuous improvement in research practices.

Limitations of the study:

The scoping review ultimately incorporated a modest number of studies (specifically, nine peer-reviewed empirical research studies) due to the rigorous application of inclusion criteria. While this stringent selection process upholds quality standards, it may inadvertently curtail the generalizability of the findings. The review's emphasis on peer-reviewed studies raises the possibility of introducing publication bias, wherein studies with positive outcomes are more likely to be included. Additionally, the review's inclusion criteria led to the consideration of studies published within a specific time frame (between 2008 and 2021), potentially excluding older studies that could

Figure 7.1: Excerpt of reflective journey entry in my journal

Reflective Journal Entry	Date: 8.7.2020
Research Stage: Data Collection - Interviews with Participants; Reflection on Potential Bias:	
<p>During today's interviews with participants from the refugee camp, I found myself subtly favoring responses that aligned with my initial assumptions about the challenges faced by FHCWs in providing palliative care. As I reviewed my notes, I realized that I had unintentionally probed for answers that confirmed my preconceived notions about the lack of PPEs & other resources and difficulties in communication. Upon recognizing this bias, I paused to reflect on the importance of remaining open-minded and neutral in my interactions with participants. I reminded myself that my goal is to capture the authentic experiences and perspectives of the participants, rather than seeking confirmation of my own beliefs.</p>	
<p>To address this bias, I took a step back during subsequent interviews and focused on asking open-ended questions that allowed participants to share their views freely. I also made a conscious effort to avoid leading questions that could inadvertently steer responses in a particular direction. As I transcribed the interview recordings, I paid close attention to moments when my biases might have influenced the way I interpreted participants' responses. I challenged myself to consider alternative explanations and interpretations for their statements.</p>	
<p>Reflecting on this experience, I realize the importance of continuous self-awareness and vigilance against bias throughout the research process. Maintaining an open dialogue with my research supervisor and seeking input from peers during data analysis will be essential to ensure the validity and integrity of the study's findings. By documenting this reflection in my journal, I aim to hold myself accountable for addressing bias and maintaining the rigor of the research. This experience serves as a reminder of the challenges inherent in remaining objective and the ongoing effort required to uphold the principles of ethical research.</p>	
Action Steps:	
<ol style="list-style-type: none">1. Review interview questions to ensure they are neutral and unbiased.2. Seek input from research supervisor during data analysis to validate interpretations.3. Engage in regular self-reflection to monitor potential bias throughout the research process.	
Overall Takeaway:	
<p>Today's experience highlighted the need for constant self-monitoring and critical reflection to prevent bias from influencing the research outcomes. It reinforced the importance of maintaining an unbiased stance to capture the diversity of perspectives and experiences within the refugee camp.</p>	

offer historical context or valuable insights. The exclusion of grey literature in the review may result in overlooking valuable reports, policy documents, and other sources that could contribute additional perspectives. Furthermore, the review's restriction to studies published in English may overlook relevant research conducted in other languages.

While my various roles may enhance the depth of my study, they also pose the risk of introducing researcher bias, where pre-existing beliefs and interpretations might unintentionally influence both data collection and analysis. To mitigate this concern, I implemented several precautionary measures to

bolster the study's objectivity and validity. Initially, during the data collection phase, reflexivity emerged as a crucial tool. I diligently maintained a reflective journal, documenting personal beliefs, assumptions, and potential biases that could impact the research process. This introspective practice facilitated ongoing self-awareness and critical examination of my subjectivity as a researcher.

Throughout my involvement, I acknowledged my dual roles as both a passive observer and an active intervener. It was an ethnographic experience for me, as I had trained a team of health professionals and now had the opportunity to observe them within their natural palliative care setting, specifically in ten Primary Health Centers (PHCs). This allowed me to gain a comprehensive understanding of the recently launched palliative care services and observe the behaviors of these professionals as they interacted with patients and their families.

My primary focus during these observations was to identify areas where care could be improved. I was constantly seeking opportunities to enhance the delivery of palliative care services. Additionally, these observations helped me raise awareness about the potential benefits of palliative care within the Rohingya health sector. By implementing the Palliative Care Intervention (PCI), I aimed to support the staff in their activities and contribute to the overall improvement of patient care.

In the analysis phase, I established a rigorous coding process to enhance reliability. To minimize bias, I, along with another researcher, collaboratively performed coding. Regular discussions were conducted to reconcile any discrepancies in coding decisions. This approach fostered a more comprehensive and balanced interpretation of the data.

Additionally, I utilized the practice of member checking as a mechanism to validate findings with participants. This involved sharing preliminary findings with participants and seeking their feedback to ensure accurate representation of their perspectives. By involving participants in the interpretation process, I aimed to mitigate potential distortions that could arise from my individual perspective as a researcher.

In my study, I used purposive and snowball sampling methods. At first, I chose participants based on their availability and willingness to join the study, using convenience sampling. Later on, I used snowball sampling, where participants who were already part of the study referred us to other potential participants who met the criteria.

I also carried out Semi-structured Interviews. The ethics committee's decision to suspend face-to-face research interviews during the pandemic led to a shift to online interviews. Three individuals from the FKRF assisted me in conducting these interviews: the project manager, psychologist, and field manager. Each of them brought valuable prior experience in the realm of research interviews.

In my study, tackling the resource-intensive nature of the case study design was essential, particularly in the context of the constraints imposed by the COVID-19 pandemic. To effectively manage resource constraints exacerbated by the pandemic, I adopted a strategic approach. For instance, I carefully selected a representative sample size within the chosen humanitarian setting, considering the challenges of remote data collection and limited on-site access due to pandemic-related restrictions. This approach balanced the depth of information required with the available resources and the constraints posed by the pandemic.

Additionally, I leveraged technology to optimize data collection while adhering to pandemic-related safety protocols. Conducting remote interviews and utilizing online survey platforms allowed me to gather data from a wider range of participants without the need for extensive travel or in-person interactions, thus minimizing the health risks associated with the pandemic. This approach not only conserved resources but also ensured the safety and well-being of both the research team and the participants. However, it's important to acknowledge that while these strategies helped mitigate resource constraints and pandemic-related challenges, they might have impacted the depth of data collection in some aspects. The focus on remote methods, driven by pandemic circumstances, may have limited the scope for observing certain contextual nuances that could have been captured through traditional on-site interactions.

In the case of the qualitative data collection, I relied on semi-structured interviews conducted remotely due to the constraints posed by the COVID-19 pandemic. While this approach allowed for continued data collection, it also introduced the limitation of potential technological barriers that participants

might have faced. Ensuring participants' access to appropriate technology and a stable internet connection was a challenge that needed careful consideration to avoid excluding certain segments of the population from the study.

Another limitation that arose due to the COVID-19 pandemic was my inability to conduct in-person observations within the humanitarian setting under study. This restriction prevented me from directly observing the nuances of palliative care interactions, body language, and contextual factors that could have provided deeper insights. Although I explored alternative methods, such as virtual tours or video recordings, they couldn't fully replicate the experiential understanding that in-person observations offer.

An additional limitation tied to the COVID-19 pandemic was the altered landscape of participant recruitment. The restrictions on travel and physical gatherings hindered my ability to engage with potential participants from the humanitarian setting. As a result, the pool of participants might have been limited to those who could be reached virtually, potentially excluding individuals with limited digital access or different communication preferences.

Another crucial consideration is the potential for social desirability bias in the data I collected. Given the sensitive nature of the topic—quality palliative care in a humanitarian setting—I recognize that participants might have been inclined to present their experiences and perspectives in a more favorable light, possibly conforming to what they believe I, as the researcher, expect. This bias could impact the accuracy and authenticity of the data, potentially leading to an overrepresentation of positive experiences and an underrepresentation of challenges.

Another aspect that requires consideration is the potential impact of "interviewer effect," my presence as the researcher during the data collection process. In the qualitative interviews conducted as part of this study, my presence could inadvertently have influenced participants' responses. There's a possibility that participants felt compelled to provide answers that align with social norms or politically correct views, particularly when discussing sensitive topics like quality palliative care in humanitarian settings.

To mitigate this potential influence, I took a proactive approach. I incorporated three additional interviewers into the interview process. This not only diversified

the interaction dynamic but also assisted in building rapport and trust with participants. These precautions were intended to create an environment where participants felt comfortable sharing candid insights, thereby enhancing the credibility and validity of the collected data.

Another potential consideration involves the risk of response bias in the quantitative survey conducted as part of my research. Due to the sensitive nature of palliative care discussions and the context of my study being within a complex humanitarian setting, participants might have been more likely to provide socially desirable responses. This could have led to an overestimation of positive perceptions or practices related to palliative care quality. To mitigate this, I have employed anonymity assurances to encourage participants to provide more candid and truthful responses.

Another potential limitation to consider is the possibility of selection bias in the qualitative phase of the study. Since participants for the qualitative interviews were purposefully selected based on their involvement in palliative care provision within the humanitarian setting, there's a chance that those with more positive experiences or a higher level of engagement might have been more willing to participate. This could lead to an overrepresentation of success stories or positive perspectives, while potentially neglecting voices of those who faced challenges or had different viewpoints.

7.5 Findings in Comparison to Previous Studies: Highlighting Similarities and Differences

Within the realm of palliative care within humanitarian settings, a collection of studies forms a tapestry of diverse insights, each contributing distinct threads to the comprehension of fundamental principles and challenges. The complexity of palliative care interventions is acknowledged even in stable environments, but this complexity intensifies during periods of instability and crisis. These collective studies emphasize the intricate nature of palliative care interventions amidst instability, underscoring the significance of prompt interventions, the hurdles tied to medication and treatment accessibility, the transformative impact on healthcare providers, and the importance of holistic care. A common thread among them is the need for a nuanced grasp of palliative care in varying contexts and the imperative to disseminate education and awareness about its practices. While their angles of approach may differ, these studies collectively foster an all-encompassing comprehension of the intricate process of delivering palliative care under trying circumstances.

My doctoral study, in conjunction with the work of Nouvet et al.¹⁴¹ sets the stage by revealing profound parallels that underscore the fundamental tenets of palliative care in these contexts. Schneider et al.'s⁶⁸ explorations further enhance the narrative by highlighting the roles of cultural sensitivity and collaboration as indispensable facets of effective palliative care provisioning.

The insights drawn from Guo et al.⁶⁵ research further enrich the discourse by aligning with shared perspectives and insights, emphasizing recurrent themes surfacing from their analyses. These themes, despite the diversity inherent in these studies, stand as unifying elements that construct a seamless narrative, offering a panoramic view of palliative care and offering a nuanced glimpse into the lives of healthcare providers.

Collectively, these studies lay bare the challenges healthcare providers grapple with, exposing the emotional weight they carry. Yet, within these struggles, they also unveil the transformative potential that practicing palliative care holds. This realization transcends professional boundaries, instilling personal growth and fresh outlooks into the lives of healthcare providers. Amidst this tapestry, these studies recognize the interconnectedness of contextual factors.

Although each study is distinct in focus, the shared themes that interweave them create a fabric of coherence. This fabric binds the intricate dynamics healthcare providers face as they navigate the sensitive terrain of providing palliative care to patients dealing with severe illnesses. Within this intricately woven tale, the essence of palliative care within humanitarian contexts emerges, furnishing insights that resonate universally across disciplines and cultures.

7.5.1 Comparative Findings Within the Realm of Scoping Review:

In the realm of palliative care within humanitarian settings, a profound transformation is taking place as researchers and healthcare providers delve into the intricacies of delivering compassionate and holistic care to patients facing serious illnesses. A convergence of studies conducted by various researchers sheds light on key themes that bridge diverse contexts and underline shared principles in palliative care within these challenging environments. Exploring these shared insights and their implications for healthcare providers and patients alike reveals the following collective points of comparison, similarities, and differences:

1. Setting and Population: The studies offer perspectives from diverse geographical settings. While Marzouk et al.⁶⁴ and Schneider et al. omit specific locations, Pinheiro et al.⁶³ delve into palliative care among Middle Eastern

refugees, and my doctoral study delves into healthcare workers' experiences in FCV environments, particularly among Rohingya refugees. Each study sheds light on distinct dimensions. While Hunt et al.⁶⁷ and Schneider et al.⁶⁸ underscore cultural sensitivity, Hunt et al.²⁷ specifically highlight the significance of upholding dignity and adhering to culturally accepted practices. In contrast, Schneider et al. explore culture's role in cross-cultural communication. An overarching insight is the intricate interplay of culture and context in palliative care. Both Hunt et al.⁶⁷ and my doctoral study reveal the profound impact of context on palliative care delivery. Cultural sensitivity and awareness emerge as pivotal, underlining the need to adapt care approaches to align with patients' cultural perspectives on death, dignity, and communication about severe illnesses. The complexity of context, encompassing resource constraints and humanitarian intricacies, underscores the necessity for nuanced and flexible care strategies.

2. Awareness Creation: All studies underscore the importance of increasing awareness about palliative care. Hunt et al.⁶⁷ and my study highlight the need for nuanced approaches and challenges in adhering to evidence-based care standards in FCV settings. Marzouk et al.⁶⁴ discuss challenges linked to cancer care policies and data scarcity in Jordan, emphasizing evidence-based planning and advocacy.

3. Compassion, Human Connection and Patient-Centered Holistic Care Provision: Central to the ethos of palliative care is the foundational role played by compassion and human connection. The bedrock of effective care delivery rests upon adept communication and the establishment of meaningful connections that foster not only trust and understanding but also enable tailored interventions to address the multifaceted needs of patients. A comprehensive approach to palliative care acknowledges the intricate dimensions of patients, spanning the physical, psychological, emotional, and spiritual realms. Collectively, the studies underscore scenarios wherein healthcare practitioners exhibit an elevated sense of compassion towards patients, particularly in situations where formal healthcare settings prove insufficient to accommodate them. These instances serve as poignant examples of the transformative potential that engagement in palliative care exerts upon healthcare providers, engendering empathy and consequently, a profound reframing of their perceptual outlook.

Patient-centered care stands as a prevailing emphasis woven throughout these studies, transcending their diverse contexts. This concept traverses the boundaries of mere medical interventions, extending its reach to encompass a profound comprehension of the multifaceted needs inherent to each individual patient. This shared commitment is articulated through various lenses, exemplified by the holistic well-being focus in Guo et al.⁶⁵ the exploration of

authentic connections in my doctoral study, and the exploration of communication dynamics in Pinheiro et al.⁶³ investigation. At its core, the resounding message resurfaces – quality palliative care hinges upon the discernment of each patient's distinctive circumstances and requisites, going beyond the confines of medical protocols.

In essence, while both the Hunt et al.⁶⁷ study and my research delve into the realm of palliative care, they diverge in their primary foci, participant roles, emphasis on dignity preservation, and perspectives explored. The Hunt et al.⁶⁷ study is anchored in the realm of cost-effective interventions and the engagement of non-specialized individuals, amplifying a grassroots approach. Conversely, my research immerses itself in the experiences of healthcare professionals operating within FCV settings, where the challenges and complexities of palliative care provision are acutely pronounced. Notably, the study underscores the indispensability of training in palliative care approach within challenging contexts and underscores the importance of adapting to the evolving healthcare demands unique to these environments. Significantly, the study elevates the value of teamwork and the multifaceted contributions made by each member of the care team, wherein effective communication emerges as a pivotal conduit for delivering high-quality palliative care amidst adversity.

4. Communication as a Bridge to Compassionate Care: The pivotal role of effective communication looms large within the realm of palliative care, underscoring its significance as a central pillar. This salient attribute is evident through the insights drawn from Guo et al.'s⁶⁵ study and the findings derived from my own doctoral research.

These investigations collectively underscore the paramount importance of clear and compassionate communication among healthcare providers, patients, and their families. By delving into the challenges and distress stemming from inadequate communication, these studies illuminate the consequences of heightened uncertainty and feelings of isolation. It is pertinent to note that the scope of communication goes beyond the mere transmission of medical information, encompassing the broader dimensions of emotional support, shared decision-making, and the establishment of a foundation of trust.

Guo et al.⁶⁵ dissect communication challenges through the lens of patients and their families, elucidating disparities and dissatisfaction that may arise during interactions with healthcare providers and within familial dynamics. Conversely, my doctoral study delves into the orchestrated efforts and resounding impact of efficacious communication from the perspective of healthcare practitioners. This juxtaposition exemplifies the multifaceted nature of effective communication, underlining its relevance both in patient-provider interactions and within the broader ambit of healthcare delivery. While Guo et al.⁶⁵

encapsulate the theme of dissatisfaction, my study accentuates the pivotal role that effective communication assumes in the foreground of healthcare workers' experiences within the palliative care domain.

Of particular note is the focal point of my research, which revolves around the identification of simple yet potent and cost-effective palliative care interventions aimed at alleviating suffering and extending compassionate gestures. Central to this narrative is the understanding that actions geared toward preserving dignity and fostering human connection hold profound value within the realm of palliative care provision. Participants within my study converge upon the conviction that upholding dignity remains indispensable throughout a patient's journey. Additionally, the research underscores the role of individuals without specialized medical training, such as community workers and lay caregivers. These figures, through their roles, serve as conduits for delivering fundamental interventions. The emphasis here is placed upon unassuming acts such as active listening, the provision of spiritual care, and the tender offering of comforting gestures, all of which serve to enhance the quality of palliative care, even within the constraints imposed by resource limitations.

5. Pain Management Challenges: A Universal Struggle: A recurring motif traversing through multiple studies is the persistent and formidable challenges confronted by healthcare providers in their pursuit of ensuring adequate pain control for patients grappling with severe illnesses. The investigations undertaken by Marzouk et al.,⁶⁴ Schneider et al.,⁶⁸ and my doctoral research converge upon a shared apprehension – the constraints and hindrances encircling the accessibility of opioids and efficacious pain management methodologies. This theme underscores the intricate nature of pain management, which extends beyond geographical confines, underscoring the exigency for an all-encompassing strategy that caters to the multifarious patient needs.

Particularly noteworthy, Schneider et al.⁶⁸ exploration spotlights the specific impediment of opioid scarcity, thereby accentuating its direct implication in hindering effective pain management. This focused analysis serves to illuminate the tangible consequences stemming from constrained access to pivotal medications, profoundly influencing both patient experiences and the challenges encountered by healthcare providers. The synthesis of these insights underscores the multifaceted dimensions of pain management as a complex quandary necessitating an all-encompassing and nuanced approach.

Doherty et al.⁶⁶ and Marzouk et al.,⁶⁴ conducted prior to the pandemic, and my study conducted during the pandemic, echo the shared concern of restricted access to medical interventions. The studies highlight the urgent need to surmount barriers obstructing essential medications and supplies in

humanitarian contexts. In the context of Schneider et al.,⁶⁸ the study accentuates the emotional repercussions and challenges faced by healthcare providers due to the complex landscape of pain management. It specifically underscores the impact of opioid unavailability on pain control and healthcare providers' emotions, portraying a stark picture of the intricate interplay between medical accessibility and care provision.

6. Professional Perspective: Pinheiro et al.'s⁶³ investigation and my doctoral study are primarily rooted in the exploration of the challenges faced by refugees and the consequential impact of care on their well-being. The collective discourse underscores the pivotal role of healthcare providers' perspectives, their collaborative engagement with community leaders, and the establishment of genuine connections. In the context of my doctoral study, an in-depth analysis of healthcare workers' experiences in delivering palliative care unveils a tapestry of shared responsibilities and the cultivation of authentic connections. This illumination into the domain of palliative care delivery within challenging contexts elucidates the coalescence of efforts between providers, community leaders, and patients.

Both Pinheiro et al.'s⁶³ research and my doctoral study advocate for the implementation of palliative care through innovative avenues, such as group therapy, which lends itself to the communal mindset often prevalent among refugees. This emphasis on communal approaches underscores the significance of shared responsibilities and the collaborative co-construction of care solutions, involving community leaders and patients alike. This collaborative ethos resonates through both investigations, shedding light on the interdependence necessary to navigate complex care scenarios within refugee populations.

While Pinheiro et al.⁶³ and my doctoral study converge in their advocacy for collaborative care and innovative delivery methods, Schneider et al.⁶⁸ and my doctoral study veer into distinct trajectories. Schneider et al.'s⁶⁸ emphasis orbits around cultural considerations and the challenges entailed within specific contextual dimensions. In contrast, my doctoral study delves into the experiences of frontline healthcare workers stationed in humanitarian settings. This divergence leads to a focal point on the imperative of specialized skills and effective communication in delivering palliative care in these demanding environments. The two perspectives, while distinct, contribute complementary facets to the overarching understanding of palliative care provision within humanitarian contexts.

7. Prioritization and Timely Interventions: Hunt et al.⁶⁷ highlight the importance of establishing priorities and making timely decisions while allocating limited humanitarian resources. Doherty et al.⁶⁶ stress the need for

timely assessments of palliative care needs during crises to inform effective interventions and prioritize care.

8. The Emotional Toll on Healthcare Providers: The realm of delivering palliative care uniformly subjects healthcare providers to emotional strain. In unison, Marzouk et al.,⁶⁴ Schneider et al.,⁶⁸ and my PhD study underscore the emotional toll that healthcare providers shoulder when confronted with intricate cases and arduous circumstances. Across these studies, healthcare providers uniformly voice a chorus of emotions encompassing helplessness, frustration, and powerlessness as they grapple with the intricacies and challenges inherent in their caregiving responsibilities. This collective acknowledgement of the emotional dimension intertwined with caregiving accentuates the exigency for robust support systems tailored to healthcare providers, safeguarding their well-being as they navigate the emotionally charged terrain inherent in their roles.

9. Faith, Spirituality, and Coping Mechanisms: The profound impact of faith and spirituality emerges consistently as a pivotal coping mechanism in the fabric of various studies. These studies illuminate how faith and spirituality infuse emotional strength, fortitude, and adherence to treatment regimens, yielding a resilient response to adversity. This recognition underscores the profound metamorphosis that compassionate care elicits in healthcare providers, catalyzing personal growth and transformation. From Guo et al.⁶⁵ to Pinheiro et al.,⁶³ the indelible influence of faith on bolstering emotional resilience, endurance, and commitment to treatment regimens reverberates with clarity.

Equally significant is my doctoral study, which accentuates how spirituality emerges as a wellspring of solace and tenacity for patients navigating the labyrinth of challenging circumstances. This acknowledgment emphasizes the imperative of an all-encompassing care paradigm that transcends mere physical needs, embracing the intricacies of emotional and spiritual dimensions. Pinheiro et al.⁶³ unravel the role of faith and spirituality as resilient strategies among refugees, while Marzouk et al.⁶⁴ highlight the hurdles posed by financial constraints in seeking care and grappling with adversity.

10. Bridging Barriers and Achieving Equitable Access: The clarion call for equitable access to palliative care resounds across these studies, resonating particularly for marginalized populations grappling with crises. Pinheiro et al.⁶³ spotlight the fragmented nature of care that undermines the realization of equitable access, while my doctoral study delves into the multifaceted barriers stemming from geographical, social, and cultural complexities within fragile and conflict-ridden contexts. The recognition of these formidable barriers underscores the imperative for concerted endeavors aimed at ensuring that the

tenets of palliative care remain within reach of all individuals, irrespective of their circumstances.

11. The Significance of Psychosocial Support: Psychosocial support emerges as a cornerstone of effective palliative care. Both Pinheiro et al.⁶³ and my PhD study underscore the importance of psychosocial support in enhancing overall well-being. The studies highlight the positive impacts of comprehensive psychosocial support, ranging from fostering solidarity and self-belief among refugees to the supportive role of friends, neighbors, family members, and palliative care providers in complex settings.

12. Collaborative Partnership for Enhanced Care Delivery: The imperative of collaborating with local stakeholders underscores the foundation of effective palliative care provision. The integration of local perspectives ensures the cultural relevance and community acceptance of care practices. Throughout the studies, the resounding significance of community engagement in palliative care is consistently emphasized. Pinheiro et al.⁶³ introduce innovative strategies like group therapy to address psychosocial needs, echoing the communal mindset prevalent among refugees. In my doctoral study, the spotlight is cast on the profound value of collaboration between healthcare workers and community leaders, such as majhis, as they collaboratively forge solutions to cater to patients' intricate needs. It's a shared acknowledgment that the realm of palliative care extends beyond the confines of clinical settings, converging the support and insights of the broader community to offer a truly holistic and impactful care approach. While Hunt et al.'s⁶⁷ study centers on identifying pragmatic and cost-effective interventions to alleviate suffering and convey compassion, emphasizing the involvement of non-specialized individuals like community workers and lay caregivers, Guo et al.'s⁶⁵ study echoes the pursuit of uncovering uncomplicated yet impactful palliative care interventions. The study underscores gestures that safeguard dignity along every step of the patient's journey, emphasizing the role of compassionate actions.

7.5.2: Comparative Findings to Wider Literature:

Relating this work to the wider literature of transportation engineering adds an interesting dimension. The concept of self-preparedness is applied here to a different context - emergency evacuations in train stations.¹⁴² The paper stresses the importance of passengers' knowledge on evacuation procedures and their preparedness to face potential emergency situations. The consideration of cultural differences in evacuation characteristics is particularly insightful, emphasizing the impact of socioeconomic, population, and cultural factors on passengers' behaviors and responses during emergencies.

While this thesis focuses on the healthcare sector, the broader concept of self-preparedness is universal and crisis response plans are highly applicable across various domains. The critique of public discourse neglecting personal situational awareness and self-preparedness in the event of an attack is a gap that my research can contribute to filling. My research on healthcare quality and self-preparedness in the context of COVID-19 among FHCWs is complemented by the insights from the transportation engineering literature, creating a comprehensive understanding of the role of self-preparedness across different domains and contexts. This interdisciplinary approach enriches the overall understanding of how individuals prepare and respond to emergencies, whether in healthcare settings or public transportation hubs.¹⁴²

Historically, disasters prompted evacuations in major train stations, emphasizing the need for providing information on evacuation procedures. Delays in the evacuation process may occur if passengers lack knowledge and preparedness, impacting survival chances. Access to the evacuation route alone is insufficient; self-preparedness is crucial. Individuals engage in self-preparedness as a proactive measure, reducing the impact of incidents during emergencies. This involves 'know-how' and 'know-who' actions, such as understanding evacuation plans and knowing whom to seek help from. The importance of self-preparedness aligns with the call for awareness and implementation of security measures.¹⁴³

The published literature indicates that health care workers experience many challenges in a pandemic situation due to a lack of education and training to manage disease outbreaks.¹⁴⁴ This highlights the necessity for the assessment of FHCWs preparedness, provision of education and training for FHCWs related to epidemic or pandemic disaster management as well as the prevention of the spread of infection and reduction of mortality rates due to them. Several gaps were identified in another study regarding preparedness among HCWs. In particular, almost a third of the participants reported the inability to identify the signs and symptoms of COVID-19, and more than half lacked the skills needed to manage and prioritize COVID-19 patients. Additionally, almost 50% of respondents were unsure or did not know to whom and to where COVID-19 cases should be reported. Similarly, the majority of HCWs did not participate in educational activities and emergency planning for COVID-19.¹⁴⁵

Disaster preparedness at a conceptual level typically entails the coordination of meetings, formulation of written communication or standard operating procedures, training of staff, volunteers, and community members, conducting simulated drills and exercises, and guaranteeing the presence of operational emergency equipment.¹⁴⁶ Disaster preparedness among nurses was viewed as having adequate knowledge and skills, and a high level of perception on the nurse's role in a disaster situation as well as their level of preparedness and management skills required to deal with a disaster effectively. The published literature from low and middle-income countries in this regard revealed and

emphasizes mostly first aid care, pharmacological needs, assess the condition of victims.

7.6 Research Implications:

Research in humanitarian settings, particularly in FCV contexts, should prioritize several key areas. Firstly, there is a need to delve into the impact of shared responsibility and co-construction on patient-centered care. Understanding the dynamics of these relationships can contribute to the development of more effective care models tailored to the unique challenges of FCV settings. Additionally, research should focus on identifying and documenting specific communication techniques that prove effective in promoting patient-centered care, empathy, and trust in these contexts. Investigating the direct impact of effective communication on patient outcomes, including satisfaction, quality of life, and overall well-being, is crucial for shaping palliative care strategies in FCV populations. Moreover, exploring the impact of compassionate care on patients' well-being and the overall healthcare environment can establish a link between empathy and positive health outcomes, adding to the evidence base for compassionate care in FCV contexts. Further research is needed to understand the prevalence and impact of symptoms in humanitarian settings, especially among non-cancer patients and aged refugees, utilizing cross-sectional studies, longitudinal research, and comparative analyses with other refugee populations. Additionally, exploring barriers to accessing medications and medical equipment, including supply chain issues, cost factors, and regulatory challenges, is essential. Investigating the underlying reasons for the lack of opioid availability, including regulatory barriers, stigmatization, and healthcare provider attitudes, is crucial for improving pain management in FCV settings. In-depth research should be conducted to understand multifaceted barriers to accessing medical interventions, considering financial, logistical, and systemic challenges. Lastly, exploring the specific needs of caregivers and assessing the effectiveness of caregiver training programs in reducing burnout should be a focus to improve overall patient care in FCV contexts.

7.7 Policy Implications:

Policies in FCV settings should adopt a multifaceted approach to enhance healthcare delivery and palliative care. Communication skills training for healthcare professionals are crucial and should be integrated into education and training programs to ensure effective and empathetic communication. Cultural sensitivity should be a focal point in policymaking to promote awareness and understanding of diverse communication styles within FCV settings. Community involvement, incorporating leaders and spokespeople, is essential for culturally sensitive and community-driven healthcare planning.

The integration of palliative care into FCV healthcare systems should be prioritized, recognizing its potential to alleviate suffering and enhance the quality of life for those with serious illnesses. Equitable access to palliative care services, particularly for marginalized populations, should be a policy priority, addressing barriers like geographical, cultural, and financial obstacles. Continuous education and training for healthcare professionals in palliative care should be emphasized in policies to ensure comprehensive understanding and effective implementation. Humanitarian organizations and governments, including guidelines and protocols for assessment and treatment in FCV settings, should develop pain and symptom management policies. Ensuring a steady supply of essential medications and medical equipment requires collaborative efforts to address regulatory obstacles. Governments and relevant authorities should review and revise opioid policies, balancing medical needs with the risk of nonmedical use, with advocacy efforts to increase opioid availability in humanitarian settings. Collaborative initiatives are essential to address barriers to healthcare access, including financial support mechanisms for transportation and treatment costs. Recognizing the vital role of caregivers, humanitarian organizations should provide training and support programs to help them cope with the emotional and physical demands of caregiving.

7.8 Service Provision Implications:

In FCV settings, transforming health services necessitates a holistic care approach, considering not only the medical aspects but also the psychological, emotional, and social well-being of patients. Embracing patient-centered care is crucial, urging healthcare providers to dedicate time to understand individual needs and preferences through effective communication and active listening. Palliative care training programs for healthcare professionals should include communication skills development, fostering stronger therapeutic relationships. Promoting interdisciplinary collaboration is vital, ensuring various healthcare team members effectively contribute to holistic patient care. Active engagement with community leaders facilitates co-construction of solutions, aligning healthcare services with community needs. Establishing collaborations with community organizations aids in disseminating information about palliative care and creates a supportive environment. Equipping health facilities in humanitarian contexts with essential medications and training healthcare workers in symptom management are crucial for effective palliative care. Training healthcare professionals in appropriate opioid prescribing practices and implementing monitoring mechanisms ensure responsible administration. Strategies to reduce wait times, increase treatment availability, and provide patient-centered care, including telemedicine and mobile clinics, should be implemented. Caregiver training programs and collaboration with mental health professionals enhances their capacity while maintaining well-being. Integrating palliative care into the broader healthcare system involves training community health workers and ensuring continuity of care through referrals when needed.

7.9 Implications in Wider Settings:

Being self-prepared is a proactive measure that individuals across various sectors should undertake to ready themselves for unforeseen situations and emergencies. Enhancing healthcare education is essential for improving palliative care not only in humanitarian settings, as suggested by this research. The curriculum should integrate palliative care education, emphasizing compassion, patient-centered care, and interdisciplinary teamwork. Communication skills are paramount, and healthcare education curricula should include components fostering self-awareness, self-preparedness, empathy, and active listening. Role-playing exercises and simulation scenarios are effective tools for teaching effective and empathetic communication. Cultural competency training is crucial, helping healthcare professionals navigate diverse communication styles and cultural nuances when interacting with patients. Educational programs should cover palliative care principles, symptom management, effective communication, and caregiver support, addressing the unique challenges of resource-limited environments. Additionally, emphasizing patient-centered care in healthcare education is vital, highlighting the importance of understanding patients' needs and co-creating solutions with them.

7.10 Final Reflections:

As a pragmatist, in the course of my research journey, I delved into the intricate world of palliative care within humanitarian settings, employing a variety of methodologies to uncover insights and shed light on the challenges and opportunities that lie within. The increasing attention on the quality of healthcare in humanitarian settings has highlighted a concerning gap in the realm of palliative care. As discussions focus largely on immediate life-saving interventions, the provision of dignified and effective palliative care has been marginalized. This omission is particularly disheartening given the already challenging circumstances of those in fragile and conflict-affected environments. The literature has illuminated various barriers that contribute to this gap, ranging from resource limitations and cultural sensitivities to organizational priorities.

The intersection of culture, individual preferences, and health needs is a crucial consideration often overlooked in humanitarian efforts. Each community has distinct views on death, dying, and care, which must be understood and respected for effective palliative care. A blanket approach to healthcare without cultural sensitivity can exacerbate the challenges faced by individuals already dealing with traumatic experiences. This realization underscores the necessity

of integrating palliative care within the broader healthcare structure, taking into account the specific needs of each population.

This chapter, encapsulating the summary of findings, reflections on methodology, and the implications of the research, provides a panoramic view of the path traversed. As I reflect on the meticulous methodological choices that guided this exploration and how these methods intertwined with the lived experiences of participants, it becomes evident that research is not a mere academic exercise. It is an expedition into the intricate tapestry of human lives, challenging preconceived notions and fostering a deep appreciation for the nuances that shape the reality of palliative care in humanitarian contexts.

The alignment and divergence of my findings with previous studies stand as a testament to the dynamic nature of research. The insights gleaned from these investigations have the potential to reshape perspectives, influence policies, and elevate the quality of care provided to vulnerable populations. The implications for research, policy, service provision, teaching, and learning are not isolated compartments but interconnected threads that together weave a fabric of change.

Ultimately, this research journey reaffirms the significance of compassionate care as a driving force in healthcare. It is a call to action that transcends disciplines, boundaries, and challenges. It beckons researchers, practitioners, policymakers, educators, and society as a whole to come together, honor the dignity of those facing adversity, and collectively elevate the standard of care in palliative settings.

The chapters preceding this conclusion have delved into the intricacies, findings, and implications; now, as I step beyond this chapter, I am reminded that the essence of compassionate care continues to unfold, evolve, and inspire.

7.11 Concluding Remarks:

In summary, this research delineates the transformative journey of care integration among Frontline Healthcare Workers (FHCWs) during the pandemic in a humanitarian setting. The evolution of their understanding, personal growth, and commitment to holistic care, considering emotional, psychological, and social dimensions, stands out. The emotional journey and self-preparedness emerge as crucial factors facilitating compassionate and effective care in response to pandemic challenges. The study underscores the universal significance of compassionate care, calling for collective efforts to elevate palliative care standards. The findings highlight the adaptability and responsiveness of FHCWs to pandemic challenges, positioning emotional

journeys and self-preparedness as critical facilitators. The study introduces self-preparedness as a proactive quality indicator, emphasizing the ongoing need for adaptability in healthcare practices during crises.

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LIST OF APPENDICES:

Appendix 1: Ethics approval from ACCORD, University of Edinburgh



THE UNIVERSITY of EDINBURGH

Research Governance

The University of Edinburgh
Queen's Medical Research Institute
47 Little France Crescent
Edinburgh EH16 4TJ
United Kingdom

Tel +44 (0) 131 242 9100

resgov@accord.scot

08th May 2020

Dear Professor Sheikh,

Study Title: RESPIRE – Exploring Personal Preparedness and Self-Protective Measures Against COVID-19 Pandemic: A Qualitative Study Protocol of Frontline Health Care Workers in Cox's Bazar, Bangladesh (AC20068)

The University of Edinburgh agrees in principle to act as Sponsor for this project.

Sponsorship is subject to you receiving a favourable ethical opinion from an authorised ethics committee in the countries involved in the study.

Our Sponsor review has determined the project to be low risk and we confirm that a UK based ethical opinion is not required.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any substantial amendments are reviewed and authorised by the Sponsor prior to submission for applicable approvals.

Yours sincerely,


Jo-Anne Robertson

Research Governance Coordinator
University of Edinburgh
The Queen's Medical Research Institute
47 Little France Crescent
Edinburgh, EH16 4TJ

Appendix 2: Local ethics approval

Page one of Local Ethics Approval

বাংলাদেশ শিশু স্বাস্থ্য ইনস্টিটিউট
ঢাকা শিশু হাসপাতাল, শের-ই-বাংলানগর, ঢাকা - ১২০৭।
টেলিফোন : (০২)-৯১১৩০৪৮, (০২)-৫৮১৫১৫৬৯।
পিএবিএক্স : (০২)-৯১০৪২১১-২০; এক্সট : ৪০৯, ৪১১।
ই-মেইল : info.bich@gmail.com ওয়েবসাইট : www.bich.gov.bd



Bangladesh Institute of Child Health
Dhaka Shishu (Children) Hospital, Sher-e-Bangla Nagar, Dhaka - 1207.
Telephone : (02)-9113048, (02)-58151569
PABX : (02)-9104211-20; Ext : 409, 411
e-mail: info.bich@gmail.com website: www.bich.gov.bd

No.: BICH-ERC-01-01-2020 Date: 4-6-2020

To
✓ Prof. Samir K. Saha, PhD
Executive Director, Child Health Research Foundation &
Professor of Microbiology, Bangladesh Institute of Child Health

Subject: Ethical clearance for the study entitled, "Exploring Personal Preparedness and Self- Protective Measures Against COVID-19 Pandemic: A Qualitative Study Protocol of Frontline Health Care Workers in Cox's Bazar, Bangladesh."

Dear Prof. Saha,


Thank you for requesting ethical approval of the research protocol "Exploring Personal Preparedness and Self- Protective Measures Against COVID-19 Pandemic: A Qualitative Study Protocol of Frontline Health Care Workers in Cox's Bazar, Bangladesh." Date: 01.05.2020. The proposal was thoroughly reviewed by the Ethical Review Committee of Bangladesh Institute of Child Health on 3.5.20 at 11.30., at an online meeting using ZOOM. All the members agreed that the proposal is very relevant and useful for the current situation. It is my pleasure to inform you that the committee reviewed the following documents and satisfied with the study design and implementation plan.

A. Study protocol
B. Study form
C. Consent form

Thus, the committee approve the study protocol and other relevant documents for field implementation with the following conditions:

1. As the principal investigator, the ultimate responsibility for scientific and ethical conduct including the protection of the rights and welfare of study participants vest upon you. Responsibility of the principal investigator will cover:
 - a. Ensuring the integrity and ethical conduct of other investigators and staffs directly involved in this project.
 - b. Obtain prior approval from the ERC for any modification in the approved research protocol and the consent form.
 - c. Strictly adhering to the criteria mentioned in the research protocol while enrolling the participants for this study.

বাংলাদেশ শিশু স্বাস্থ্য ইনস্টিটিউট
ঢাকা শিশু হাসপাতাল, শের-ই-বাংলা নগর, ঢাকা - ১২০৭।
টেলিফোন : (০২)-৯১০৪২১১-২০; এক্সট : ৪০৯, ৪১১
পিএবিএক্স : (০২)-৯১০৪২১১-২০; এক্সট : ৪০৯, ৪১১
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e-mail: info.bich@gmail.com website: www.bich.gov.bd

০৭. Arrangement of training of study team on taking informed consent to ensure that consents are taken.

- From the participant without any influence
- Only for the issues narrated on this approved protocol.
- With the declaration of the participants that their participation is absolutely voluntary and giving consent or not giving consent will not have any impact on their working status.
- Limiting the data collection and/or intervention to submitted questionnaires.

- For any deviation from the approved protocol, ERC may withdraw the approval. In such case the PI has to comply with the instruction of ERC.
- ERC would like to have the final report submitted at the conclusion of the protocol within three months of its completion.
- The protocol is approved for one year from the date of starting enrollment. Any further extension will need to be obtained before expiration of this endorsement.
- The ERC should be immediately notified if the protocol is discontinued before the expected date of completion.

I wish you success in running the above-mentioned study.

Prof. Mohammed Hanif 04/06/2020
Prof. Mohammed Hanif, FRCP
Convener
Ethical Review Committee
Bangladesh Institute of Child Health

Copy to:

- Academic Director
Bangladesh Institute of Child Health
- Director
Dhaka Shishu Hospital


Appendix 3: Local Government permission to conduct the study in refugee camps



Appendix 4. Patient Information Sheet (PIS) and Informed Consent Form (English)

Page one of PIS and Informed consent Form

Self-Preparedness HCWs COVID-19 Pandemic
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Participant Information Sheet

Exploring Personal Preparedness And Self-Protective Measures Against COVID-19 Pandemic: A Qualitative Study Protocol of Frontline Health Care Workers in Cox's Bazar, Bangladesh

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The recent Lancet editorial outlines healthcare workers (HCWs) safety concerns when they are providing services in the current high-alert situation of COVID-19 pandemic. China's National Health Commission estimated that 3300 Chinese HCWs were infected by COVID-19 as of early March 2020. In Italy, 1 in 5 responding HCWs have been infected, with a rising number of HCWs dying. There are particular needs exemplified by working in refugee settings of intense humanitarian crises. There is currently no global information on how COVID-19 will impact on refugee settings. The lack of research or theory relating to low and middle-income country FHCWs' perceived behaviour, particularly their understanding of self-preparation and of the protective measures in a pandemic, has led us to propose this rapid appraisal research project.

The aim of this study is to build an evidence base that can inform governments and health sectors in their development and implementation of realistic and socially, culturally sensitive COVID-19

An NIHR Global Health Research Unit on Respiratory Health (RESPIRE) at the University of Edinburgh project.

www.ed.ac.uk/nihr/respire

This research was commissioned by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.



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Self-Preparedness HCWs COVID-19 Pandemic
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strategies to protect and support well-prepared frontline FHCWs. The research project will also actively contribute to the COVID-19 Research Roadmap of World Health Organisation and is an opportunity to provide essential information on FHCWs' perceived knowledge and behaviour on self-preparation in a pandemic.

We are inviting a total 30 participants from each of three professional categories (doctors, nurses and community health workers) who have been working as frontline health workers in different primary health centres of Rohingya camps in Cox's Bazar, Bangladesh to participate in this study.

Why have I been invited to take part?

You have been asked to take part as you have been involved or positioned to be involved in implementing national COVID-19 pandemic guidelines in your care setting. We are interviewing approximately 30 individuals distributed across the thirty-five Rohingya camps, who can bring a range of thoughts and feelings while facing or anticipating these situations.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, we will let you know the details of study and you will need to give your verbal consent. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your legal rights.

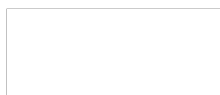
What will happen if I take part?

If you volunteer to participate in this study, we will ask you to participate in a semi-structured interview conducted by one of the research team members that will last approximately 45 - 60 minutes. The interview will be conducted via your preferred technology: MS team, Skype or telephone. We would like to digitally record this interview, with your permission. You can indicate your preference regarding recording of your interview at the end of this document. Only one interview will be conducted with each participant to explore their existing ideas and personal preparation regarding self-protective measures in COVID-19 or other influenza pandemic. You will be asked to share your thoughts on COVID-19 influenza symptoms, sources of infection, ways to avoid infection, pandemic preparedness national and international guidelines or framework, self-anxiety.

What are the possible benefits of taking part?

This project will give you 20 GBP (in BDT conversions) in compensation for your time. Also, information learned from this study may help support the development and implementation of HCWs personal preparation strategies for COVID-19, and future public health emergencies.

What are the possible disadvantages of taking part?



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The study is focused on personal preparedness of HCWs in a pandemic situation. Reflecting on this topic may be disconcerting. Please feel free to refuse participation in the study if you anticipate it will be too disconcerting for you, or, alternatively, feel free to interrupt your participation at any point. You can do so with no consequence, or judgment from the interviewer and study team: we understand.

What if there are any problems?

If you have a concern about any aspect of this study please contact Farzana Khan at 8801717311522 who will do their best to answer your questions.

What will happen if I don't want to carry on with the study

You can ask for the withdrawal of your participation at any time without any consequence, in which case the information you have shared will not be deleted.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If participants withdraw from the study, we will keep the information about them that we have already obtained. To safeguard their rights, we will use the minimum personally-identifiable information possible.

What happens when the study is finished?

Read the 'Privacy Notice' in Page 5 of this document to get the answers relevant to the following questions.

- What will happen to data?

We will use information from you in order to undertake this study.

- How long will it be retained?

Data will be retained for 5 years after the study has finished.

- Where will data be retained?

Non-identifiable data from this project will be stored in a research data repository at the University of Edinburgh to allow knowledge sharing and learnings about this study. Identifiable data will be kept with the local research team.

- How we plan to use data for future studies?

All audio recordings will be stored securely on a password protected computer at the FKRF office. The paper copies will be stored separately in a locked cabinet, only accessible by the researchers. This information will be held securely for 5 years, according to the University of Edinburgh Data protection rules. This data may be used for

Page four of PIS and Informed consent Form English



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knowledge sharing and learnings of the study.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

What will happen to the results of the study?

This study will be written up as publication, conference presentation. A report will be available on the RESPIRE website and through newsletter to describe the types of knowledge and the requirements necessary for the changes needed for health workers.

You will not be identifiable in any published results.

Who is organising and funding the research?

This study has been organised by Principal Investigators Dr. Farzana Khan (Fasiuddin Khan Research Foundation) and Prof. Liz Grant (University of Edinburgh) and sponsored by the University of Edinburgh.

The study is being funded by UK National Institute for Health Research (NIHR) Global Health Research Unit on Respiratory Health (RESPIRE), using UK Aid from the UK Government.

Who has reviewed the study?

The study proposal has been reviewed by RESPIRE Unit Management Committee and local ethics committee, Bangladesh Institute of Child Health.

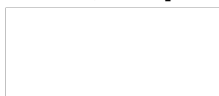
Researcher Contact Details

If you have any further questions about the study please contact Farzana Khan on +8801717311522 or email on: farzanakhan04@yahoo.com

Independent Contact Details

If you would like to discuss this study with someone independent of the study please contact

Rowsan Ara, Nursing Instructor, Shaheed Tajuddin Ahmad Nursing College, Gazipur



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Tel No: +880 1914186882, email: ssnrowsan@yahoo.com

Complaints

If you wish to make a complaint about the study please contact:

Barrister Shafiqul Kabir Khan, Legal Adviser, Fasiuddin Khan Research Foundation
Tel No: +880 1715004173, email: lawpartners007@gmail.com



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Privacy Notice

The University of Edinburgh is the sponsor for this study based in Bangladesh. The Sponsor has overall responsibility for the running of the study. To follow the United Kingdom's data protection regulations we must inform you of how we will use and store your personal data.

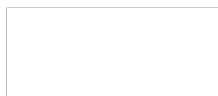
As a university, we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

We will use information from you in order to undertake this study. The sponsor will keep non-identifiable information about you for 5 years after the study has finished.

The University of Edinburgh will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Non-identifiable data from this project may be stored in a research data repository at the University of Edinburgh to allow knowledge sharing and learnings about this study. The University of Edinburgh provides its researchers (and their collaborators) two services for sharing and archiving of data which will be used for your information. There is an open access repository for anonymised data, which means that all non-identifiable data is freely available. For sensitive information a secure repository is used which can only be accessed by approved researchers who have undergone a rigorous application and review process.



Participant ID:		Centre ID (if applicable)	
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VERBAL CONSENT FORM

Exploring Personal Preparedness And Self-Protective Measures Against COVID-19 Pandemic: A Qualitative Study Protocol of Frontline Health Care Workers in Cox's Bazar, Bangladesh

Please **initial** box

1. I confirm that I have read and understand the information sheet (7 May 2020 and Version Number 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.
3. I understand that relevant sections of my data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh), or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. Yes No
4.
5. I agree to my interview being audio recorded. Yes No
6. I agree to my anonymised data being used in future studies. Yes No
7. I agree to take part in the above study.


Name of Person Giving Consent Date Signature

Name of Person Receiving Consent Date Signature

1x original – into Site File; 1x copy – to Participant

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www.ed.ac.uk/usher/respire

This research was commissioned by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.



Appendix 5: Patient Information Sheet (PIS) and Informed Consent Form (Bangla)

Page one of PIS and Informed Consent Form Bangla

Self-Preparedness HCWs COVID-19 Pandemic
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অংশগ্রহণকারীর তথ্য

কোভিড -১৯ মহামারীর বিরুদ্ধে ব্যক্তিগত প্রস্তুতি এবং আত্মরক্ষা পদক্ষেপ বিশ্লেষণঃ কক্সবাজার ,বাংলাদেশে সম্মুখে কর্মরত স্বাস্থ্যসেবা কর্মীদের উপর একটি গুণগত গবেষণা পদ্ধতি

আপনাকে একটি গবেষণায় অংশ নিতে আমন্ত্রণ জানানো হচ্ছে। অংশ নেবেন কি নেবেন না এই সিদ্ধান্ত নেওয়ার আগে, এটা বুঝা গুরুত্বপূর্ণ যে, এই গবেষণাটি কেন করা হচ্ছে এবং এর সাথে কি কি সম্পর্কমুক্ত। নিম্নলিখিত তথ্যটি মনোযোগ সহকারে পড়তে সময় নিন। আপনি চাইলে অন্যদের সাথে এই বিষয় সম্পর্কে কথা বলতে পারেন। যদি কোন কিছু বোধগম্য না হয় আমাদের সাথে যোগাযোগ করতে পারেন। কোন কিছু পরিষ্কার না হলে বা আপনার আরও কোন তথ্য জানার থাকলে আমাদের সাথে যোগাযোগ করতে পারেন। আপনি সময় নিয়ে জানান অংশগ্রহণ করতে চান কি চান না

গবেষণার উদ্দেশ্য কি?

সাম্প্রতিক ল্যানসেট সম্পাদকীয় স্বাস্থ্যসেবা কর্মীদের (সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের) সুরক্ষার উদ্দেশ্যে রূপরেখা তুলে ধরেছে যখন তারা কোভিড -১৯ মহামারীর বর্তমান উচ্চ-সতর্ক পরিস্থিতিতে পরিষেবা প্রদান করছে। চীনের জাতীয় স্বাস্থ্য কমিশন অনুমান করেছে যে ২০২০ সালের মার্চ মাসের গোড়ার দিকে ৩৩০০ চাইনিজ সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মী COVID-19 দ্বারা আক্রান্ত হয়েছিল। ইতালিতে, ৫ জনে ১ জন সাড়া প্রদানকারী সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মী সংক্রামিত হয়েছেন, ক্রমবর্ধমান এইচসিডাব্লিউ(সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মী) মারা যাচ্ছেন। তীব্র মানবিক সংকটগুলিতে উদ্বাস্ত পরিবেশে কাজ করার মাধ্যমে বিশেষ প্রয়োজনগুলির উদাহরণ তৈরি

An NIHR Global Health Research Unit on Respiratory Health (RESPIRE) at the University of Edinburgh project.
www.ed.ac.uk/usher/respire

This research was commissioned by the National Institute of Health Research using Official Development Assistance (ODA) funding. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.





হয়েছে। COVID-19 কীভাবে শরণার্থী পরিবেশে প্রভাব ফেলছে সে সম্পর্কে বর্তমানে কোনও বৈশ্বিক তথ্য নেই। স্বল্প ও মধ্যম আয়ের দেশে এই সম্পর্কিত গবেষণা বা তত্ত্বের অভাব রয়েছে। সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের'র অনুভূত আচরণ, বিশেষত তাদের স্ব-প্রস্তুতি এবং মহামারী সংক্রান্ত প্রতিরক্ষামূলক ব্যবস্থা সম্পর্কে তাদের নিজস্ব-ধারণা, আমাদের এই দ্রুত মূল্যায়ন গবেষণা প্রকল্পটির প্রস্তাব করতে পরিচালিত করেছে।

এই অধ্যয়নের উদ্দেশ্য হল একটি প্রমাণ ভিত্তি তৈরি করা যা সরকার এবং স্বাস্থ্য খাতে তাদের উন্নত এবং বাস্তবিক ও সামাজিক, সাংস্কৃতিকভাবে সংবেদনশীল COVID-19 কৌশলগুলি সু-প্রস্তুত করা সামনের সারির সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের সুরক্ষা এবং ভালভাবে প্রস্তুতির জন্য। গবেষণা প্রকল্পটি বিশ্ব স্বাস্থ্য সংস্থার COVID-19 গবেষণা রোডম্যাপে সক্রিয়ভাবে অবদান রাখবে এবং একটি মহামারীতে স্ব-প্রস্তুতির বিষয়ে সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের উপলব্ধি জ্ঞান এবং আচরণ সম্পর্কিত প্রয়োজনীয় তথ্য সরবরাহ করার সুযোগ তৈরি করবে।

আমরা এই গবেষণায় অংশ নেওয়ার জন্য বাংলাদেশের কক্সবাজারের রোহিঙ্গা শিবিরের বিভিন্ন প্রাথমিক স্বাস্থ্যকেন্দ্রে সম্মুখ সারির স্বাস্থ্যকর্মী হিসাবে কর্মরত তিনটি পেশাদার বিভাগের (ডাক্তার, নার্স এবং কমিউনিটি হেলথ ওয়ার্কাস) প্রত্যেকটি থেকে মোট ৩০ জন অংশগ্রহণকারীকে আমন্ত্রণ জানাচ্ছি।

আমাকে কেন অংশ নিতে আমন্ত্রণ জানানো হয়েছে?

আপনি জাতীয় COVID-19 মহামারী নিবেদিকা বাস্তবায়নে সেবা দান পরিবেশের সাথে জড়িত বা অবস্থান করার কারণে আপনাকে অংশ নিতে বলা হয়েছে। আমরা পঁচিশটি রোহিঙ্গা শিবির জুড়ে বিভক্ত হয়ে প্রায় ৩০ জন ব্যক্তির সাক্ষাৎকার নিচ্ছি, যাহারা আনয়ন করতে পারে দারুণ চিন্তা এবং অনুভূতির সীমারেখা যখন তারা উল্লেখিত আবস্থার মুখোমুখি বা প্রত্যক্ষজ্ঞান হয়।

আমার কি অংশ নিতে হবে?

না, এটা একান্ত আপনার সিদ্ধান্ত অংশ গ্রহণ করবেন কি করবেন না। আপনি যদি অংশগ্রহণের সিদ্ধান্ত নিতে সম্মত হন, আমরা আপনাকে গবেষণার বিষয়ে বিস্তারিত বলব এবং আপনাকে মৌখিক সম্মতি দিতে হবে। আপনি যদি অংশগ্রহণের সিদ্ধান্ত নিতে সম্মত হন তাহলেও আপনি আপনার নিজেসব সারিয়ে নেওয়ার ক্ষেত্রে স্বাধীন যে কোন কারণ দর্শানো ব্যতীত। অংশ না নেওয়ার সিদ্ধান্ত নেওয়া বা অধ্যয়ন থেকে সরে আসা আপনার আইনি অধিকারকে প্রভাবিত করবে না।

আমি অংশ নিলে কি হবে?

আপনি যদি এই গবেষণায় স্বেচ্ছাসেবক হিসেবে অংশ নিতে চান, আমরা আপনাকে গবেষণা দলের সদস্যদের দ্বারা পরিচালিত একটি অর্ধ-কাঠামোগত সাক্ষাৎকারে অংশ নিতে বলব যা প্রায় ৪৫ থেকে ৬০ মিনিট অবধি চলবে। সাক্ষাৎকারটি আপনার পছন্দসই প্রযুক্তি দ্বারা পরিচালিত হবেঃ এম এস টীম, স্কাইপ অথবা টেলিফোন। আমরা আপনার অনুমতি নিয়ে ডিজিটালি এই সাক্ষাৎকারটি রেকর্ড করতে চাই। আপনি এই নথির শেষে আপনার সাক্ষাৎকারের রেকর্ডিং সম্পর্কিত আপনার পছন্দটি নির্দেশ করতে পারেন। COVID-19 বা অন্যান্য ইনফ্লুয়েঞ্জা মহামারীতে স্ব-প্রতিরক্ষামূলক ব্যবস্থা সম্পর্কে তাদের বিদ্যমান ধারণা এবং ব্যক্তিগত প্রস্তুতিগুলি অন্বেষণ করতে প্রতিটি অংশগ্রহণকারীর সাথে কেবল একটি সাক্ষাৎকার নেওয়া হবে। আপনাকে COVID-19 ইনফ্লুয়েঞ্জা উপসর্গ, সংক্রমণের উৎস, সংক্রমণ এড়ানোর উপায়, মহামারীর



সময়কালে প্রস্তুতি এবং আন্তর্জাতিক নির্দেশিকা বা কাঠামো, আন্ত-উদ্বেগ/ উৎকর্ষা সম্পর্কে আপনার মতামত জানাতে বলা হবে।

অংশ গ্রহণের সম্ভাব্য সুবিধা কী কী?

এই প্রকল্পটি আপনাকে আপনার সময়ের সম্মানী হিসাবে ২০ জিবিপি (বাংলা টাকায় রূপান্তর করে) দেবে। এছাড়াও, এই গবেষণা থেকে জেনে নেওয়া তথ্য COVID-19, এবং ভবিষ্যতে জনস্বাস্থ্য জরুরী অবস্থার জন্য সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের ব্যক্তিগত প্রস্তুতি কৌশলগুলির উন্নয়ন এবং বাস্তবায়নে সহায়তা করতে পারে।

অংশ গ্রহণের সম্ভাব্য অসুবিধাগুলি কী কী?

এই গবেষণাটি মহামারী পরিস্থিতিতে এইচ সি ডাবলুদের/ সম্মুখে সেবাদানকারী স্বাস্থ্য কর্মীদের ব্যক্তিগত প্রস্তুতির উপর গুরুত্ব আরোপ করে। এই বিষয়টির প্রতিফলন অস্বস্তিকর হতে পারে। আপনি এই গবেষণায় অংশগ্রহণ থেকে বিরত থাকতে পারেন যদি অনুমান করেন যে এটি আপনার পক্ষে খুব অস্বস্তিকর হবে, অথবা, বিকল্পভাবে, যে কোনও মুহুর্তে আপনার অংশগ্রহণ বাতিল করতে পারেন। আপনি যেকোনো পরিস্থিতিতে বা সাক্ষাতকারকারী এবং গবেষণাকারী দলের সিদ্ধান্ত ছাড়াই এটি করতে পারেন: আমরা বুঝতে পারি।

যদি কোন সমস্যা হয়?

আপনার যদি এই গবেষণার কোন বিষয়ে উদ্বেগ থাকে, দয়া করে ফারজানা খান এর সাথে যোগাযোগ করতে পারেন। +৮৮০১৭১৭৩১১৫২২ যিনি তাদের সেরাটা করবেন আপনার প্রশ্নের উত্তর দিতে

আমি যদি গবেষণাটি চালিয়ে যেতে না চাই তবে কী হবে

আপনি যে কোনও সময় কোনও কারণ ছাড়াই আপনার অংশগ্রহণ প্রত্যাহারের জন্য বলতে পারেন, সেক্ষেত্রে আপনি যে তথ্য দিয়েছেন সেগুলি মুছে ফেলা হবে না।

তথ্যে প্রবেশযোগ্যতা, পরিবর্তন বা সরানোর ক্ষেত্রে আপনার অধিকার সীমাবদ্ধ, কারণ আমাদের গবেষণাকে নির্ভরযোগ্য ও নির্ভুল হওয়ার জন্য নির্দিষ্ট উপায়ে আপনার তথ্য পরিচালনা করতে হবে।

যদি অংশগ্রহণকারীরা গবেষণা থেকে সরে আসেন, আমরা তাদের সম্পর্কে যে তথ্য ইতিমধ্যে পেয়েছি তা রাখব। তাদের অধিকার সুরক্ষার জন্য, আমরা সর্বনিম্ন ব্যক্তিগতভাবে সনাক্তযোগ্য তথ্য ব্যবহার করব।

গবেষণা শেষ হলে কী হয়?



নিম্নলিখিত প্রশ্নের সাথে সম্পর্কিত উত্তরগুলি পেতে এই নথির ৫ নং পৃষ্ঠায় 'গোপনীয়তা বিজ্ঞপ্তি' পড়ুন।)

- তথ্য দিয়ে কি হবে?

এই গবেষণা করার জন্য আমরা আপনার কাছ থেকে গৃহীত তথ্য ব্যবহার করব।)

- এটা কতদিন পর্যন্ত থাকবে?

গবেষণা সমাপ্ত হওয়ার পরে তথ্য ৫ বছরের জন্য রাখা হবে।

- তথ্য কোথায় রাখা হবে?

এই প্রকল্পের অ-সনাক্তযোগ্য তথ্য এডিনবরা বিশ্ববিদ্যালয়ের একটি গবেষণা তথ্য ভাণ্ডারে সংরক্ষণ করা হবে যেন গবেষণালব্ধ জ্ঞান বণ্টন এবং শেখার জন্য। সনাক্তযোগ্য তথ্য স্থানীয় গবেষণা দলের কাছে সংরক্ষিত থাকবে

- আমরা কীভাবে ভবিষ্যতের গবেষণার জন্য ডাটা ব্যবহার করার পরিকল্পনা করি?

সমস্ত অডিও রেকর্ডিং এফ কে আর এফ অফিসে একটি পাসওয়ার্ড সুরক্ষিত কম্পিউটারে নিরাপদে সংরক্ষণ করা হবে। কাগজের অনুলিপিগুলি একটি তালাবন্ধ আলমারিতে পৃথকভাবে সংরক্ষণ করা হবে, যা কিনা কেবল গবেষকদের দ্বারা প্রবেশযোগ্য। এডিনবরা বিশ্ববিদ্যালয় তথ্য সুরক্ষা বিধি অনুসারে এই তথ্যটি ৫ বছরের জন্য নিরাপদে রাখা হবে। এই তথ্য সম্ভবত ব্যবহৃত হতে পারে জ্ঞান বণ্টন এবং গবেষণালব্ধ ফলাফলের জন্য

আমার অংশ গ্রহণ কি গোপন রাখা হবে?

গবেষণার সময় আমরা যে সমস্ত তথ্য সংগ্রহ করি তা গোপনীয় রাখা হবে এবং এমন কঠোর আইন রয়েছে যা প্রতিটি পর্যায়ে আপনার গোপনীয়তা রক্ষা করে।

অধ্যয়নের ফলাফল কী হবে?

এই গবেষণাটি প্রকাশনা, সম্মেলনের উপস্থাপনা হিসাবে লেখা হবে। স্বাস্থ্যকর্মীদের জন্য প্রয়োজনীয় পরিবর্তনের জন্য জ্ঞানের ধরণ এবং প্রয়োজনীয় আবশ্যিক শর্তসমূহ বর্ণনা করার জন্য একটি প্রতিবেদন RESPIRE ওয়েবসাইটে এবং নিউজলেটারের মাধ্যমে পাওয়া যাবে।)

আপনাকে কোন ফলাফলে সনাক্ত করা যাবে না

কে গবেষণা পরিচালনা করছে এবং অর্থায়ন করছে?

এই গবেষণাটি প্রধান তদন্তকারী ডঃ ফারজানা খান (ফসিউদ্দিন খান রিসার্চ ফাউন্ডেশন) এবং অধ্যাপক লিজ গ্রান্ট (এডিনবরা বিশ্ববিদ্যালয়) এবং এডিনবরা বিশ্ববিদ্যালয়ের অর্থায়নে পরিচালনা করেছেন।)

গবেষণাটি ইউকে ন্যাশনাল ইনস্টিটিউট ফর হেলথ রিসার্চ (এনআইএইচআর) গ্লোবাল হেলথ রিসার্চ ইউনিট অন রেসপিরেটরি হেলথ (রেসপায়ার) দ্বারা যুক্ত করা হচ্ছে, ইউকে সরকারের ইউকে এইডকে ব্যবহার করে।)



গবেষণাটি কে পর্যালোচনা করেছেন?

গবেষণার প্রস্তাবটি গবেষণা কেন্দ্রীয় ব্যবস্থাপনা কমিটি এবং স্থানীয় শিশু নীতি কমিটি, বাংলাদেশ শিশু স্বাস্থ্য ইনস্টিটিউট পর্যালোচনা করেছে।

গবেষকের সাথে যোগাযোগের তথ্য

গবেষণা সম্পর্কে আপনার যদি আরও কিছু প্রশ্ন থাকে তবে দয়া করে ফারজানা খানের সাথে যোগাযোগ করুন।
মোবাইলঃ +৮৮০১৭১৭৩১১৫২২ ইমেইলঃ farzanakhan04@yahoo.com)

স্বতন্ত্র যোগাযোগের বিস্তারিত

আপনি যদি অধ্যয়ন থেকে স্বতন্ত্র কারও সাথে এই অধ্যয়নটি নিয়ে আলোচনা করতে চান তবে যোগাযোগ করুন
রোসন আরা, নার্সিং ইনস্ট্রাক্টর, শহীদ তাজউদ্দীন আহমদ নার্সিং কলেজ, গাজীপুর)

মোবাইলঃ +৮৮০১৯১৪১৮৬৬৮২ ইমেইলঃ ssnrowsan@yahoo.com

অভিযোগ

আপনি যদি গবেষণা সম্পর্কে কোন অভিযোগ করতে চান তবে যোগাযোগ করুন:

ব্যারিস্টার শফিকুল কবির খান, আইনী উপদেষ্টা, ফাসিউদ্দিন খান রিসার্চ ফাউন্ডেশন
মোবাইলঃ: +৮৮০১৭১৫০০৪১৭৩ ইমেইলঃ: lawpartners007@gmail.com



গোপনীয়তা বিজ্ঞপ্তি

এডিনবরা বিশ্ববিদ্যালয় বাংলাদেশ ভিত্তিক এই গবেষণাটির অর্থায়ন করছে। গবেষণা পরিচালনার জন্য দাতাসংস্থা সামগ্রিক দায়িত্বে রয়েছে যুক্তরাজ্যের তথ্য সুরক্ষা বিধিমালা অনুসরণ করতে আমরা আপনাকে অবশ্যই অবগত করব যে আমরা কীভাবে আপনার ব্যক্তিগত তথ্য ব্যবহার করব এবং সংরক্ষণ করব।

একটি বিশ্ববিদ্যালয় হিসাবে, আমরা স্বাস্থ্য, যত্ন এবং পরিষেবাগুলিকে উন্নত করতে ব্যক্তিগতভাবে সনাক্তযোগ্য তথ্য ব্যবহার করি গবেষণা পরিচালনার মাধ্যমে। একটি সরকারী অর্থায়নে পরিচালিত সংস্থা হিসাবে, যখন আমরা গবেষণায় অংশ নিতে রাজি হয়েছি এমন ব্যক্তিদের থেকে ব্যক্তিগতভাবে সনাক্তযোগ্য তথ্য ব্যবহার করি তখন তা নিশ্চিত করতে হয় যে এটি জনস্বার্থে হচ্ছে। এর অর্থ হল আপনি যখন কোনও গবেষণায় অংশ নিতে রাজি হন, আমরা গবেষণা অধ্যয়ন পরিচালনা ও বিশ্লেষণের জন্য প্রয়োজনীয় উপায়ে আপনার তথ্য ব্যবহার করব।

এই অধ্যয়ন করার জন্য আমরা আপনার কাছ থেকে নেওয়া তথ্য ব্যবহার করব। অধ্যয়ন শেষ হওয়ার পরেও দাতা আপনার সম্পর্কে ৫ বছর ধরে আপনার অ-সনাক্তযোগ্য তথ্য রাখবে।

এডিনবরা বিশ্ববিদ্যালয় এই গবেষণার জন্য তথ্য নিয়ন্ত্রণকারী হিসাবে কাজ করবে। এর অর্থ হল যে তারা আপনার তথ্য দেখাশুনা এবং এটি সঠিকভাবে ব্যবহার করার জন্য দায়বদ্ধ।

আপনার অধিকার সীমাবদ্ধ তথ্য পরিবর্তন বা সরানোয়, কারণ আমাদের গবেষণাকে নির্ভরযোগ্য ও নির্ভুল হওয়ার জন্য নির্দিষ্ট উপায়ে আপনার তথ্য পরিচালনা করতে হবে। আপনি যদি গবেষণা থেকে সরে আসেন তবে আমরা ইতিমধ্যে আপনার কাছ থেকে প্রাপ্ত তথ্যগুলি আমাদের কাছে রাখব। আপনার অধিকার রক্ষার জন্য, আমরা সর্বনিম্ন ব্যক্তিগতভাবে সনাক্তযোগ্য তথ্য ব্যবহার করব।

এই প্রকল্পের অ-সনাক্তযোগ্য তথ্য এডিনবরা বিশ্ববিদ্যালয়ের একটি গবেষণা তথ্য ভাণ্ডারে সংরক্ষণ করা হবে যেন গবেষণালব্ধ জ্ঞান ভাগাভাগি এবং শেখার জন্য। এডিনবরা বিশ্ববিদ্যালয় তার গবেষকদের (এবং তাদের সহযোগীদের) দুটি সেবা প্রধান করে তথ্য ভাগ করে নেওয়ার এবং সংরক্ষণের জন্য যা কিনা ব্যবহৃত হবে আপনার প্রদত্ত তথ্যের জন্য। যেখানে বেনামে যুক্ত তথ্যের জন্য একটি প্রবেশযোগ্য সংরক্ষণাগার রয়েছে, যার অর্থ হচ্ছে সমস্ত অ-সনাক্তযোগ্য তথ্য উন্মুক্ত। সংবেদনশীল তথ্যের জন্য একটি সুরক্ষিত ভাণ্ডার ব্যবহার করা হয় যা কেবল অনুমোদিত গবেষকরা ব্যবহার করতে পারবেন যারা কঠোর প্রয়োগ এবং পর্যালোচনা প্রক্রিয়ার মধ্য দিয়ে যাবে

Participant ID:		Centre ID (if applicable)	
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মৌখিক সম্মতি পত্র

কোভিড -১৯ মহামারীর বিরুদ্ধে ব্যক্তিগত প্রস্তুতি এবং আত্মরক্ষা পদক্ষেপ বিশ্লেষণায়ণঃ
কক্সবাজার, বাংলাদেশে সম্মুখে কর্মরত স্বাস্থ্যসেবা কর্মীদের উপর একটি গুণগত গবেষণা
পদ্ধতি

খালিঘরে আপনার প্রাথমিক স্বাক্ষর দিন)	
১। আমি নিশ্চিত করছি যে আমি উপরের গবেষণার জন্য তথ্য পত্রটি (৭ মে ২০২০ এবং সংস্করণ নম্বর ১) পড়েছি এবং বুঝতে পেরেছি। আমি তথ্যগুলি বিবেচনা করার, প্রশ্ন জিজ্ঞাসা করার এবং এই প্রশ্নের সন্তোষজনকভাবে উত্তর দেওয়ার সুযোগ পেয়েছি।)	<input type="checkbox"/>
২। আমি বুঝতে পারি যে আমার অংশগ্রহণ স্বৈচ্ছাসেবী এবং আমি কোনও কারণ ছাড়াই এবং আমার আইনী অধিকারকে ক্ষতিগ্রস্ত না করে যে কোনও সময় নিজে থেকে প্রত্যাহার করতে স্বাধীন।)	<input type="checkbox"/>
৩। আমি বুঝতে পেরেছি যে অধ্যয়নের সময় সংগৃহীত আমার তথ্যগুলির প্রাসঙ্গিক বিভাগগুলি দাতা (এডিংবরা বিশ্ববিদ্যালয়) বা নিয়ন্ত্রক কর্তৃপক্ষের কাছ থেকে নেওয়া যেতে পারে যেখানে এটি এই গবেষণায় অংশ নেওয়ার ক্ষেত্রে প্রাসঙ্গিক। আমি এই ব্যক্তিদের আমার তথ্য প্রবেশ করার অনুমতি দিচ্ছি।)	হ্যাঁ <input type="checkbox"/> না <input type="checkbox"/>
৪। আমি আমার সাক্ষাৎকারটি অডিও রেকর্ড করতে সম্মত আছি।	হ্যাঁ <input type="checkbox"/> না <input type="checkbox"/>
৫। আমি সম্মত আছি যে আমার তথ্য বেনামে ভবিষ্যতের গবেষণায় ব্যবহৃত হবে।	হ্যাঁ <input type="checkbox"/> না <input type="checkbox"/>
৬। আমি উপরিউক্ত গবেষণায় অংশ নিতে সম্মত আছি।	<input type="checkbox"/>

অনুমতি প্রদানকারী ব্যক্তির নাম

তারিখ

তারিখ

অনুমতি গ্রহণকারী ব্যক্তির নাম

তারিখ

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1x original – into Site File; 1x copy – to Participant

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