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**Research Proposal**

**Palliative care in Pakistan: A scoping review and expert consultation on current approaches, barriers to care, and culturally appropriate interventions**

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## Abstract

According to the World Health Organization (WHO), non-communicable or chronic diseases are responsible for 74% of all deaths globally. In Pakistan, they are responsible for 58% of all deaths, a figure expected to only rise due to limited resources and planning. Due to the long-term and complex nature of chronic disease, often, catering to only the biomedical aspect of the disease is not enough. This is where the model of Palliative Care becomes essential: it is an approach that improves the quality of life of patients dealing with chronic or life-threatening illnesses by managing symptoms such as anxiety, depression, stress, pain or discomfort.

Additionally, palliative care facilitates communication with family members and connects patients to support groups as needed. It approaches health in a **holistic way**, by the consideration of social and emotional factors. Unfortunately, in Pakistan, palliative care is close to not existing at all. Palliative care education is not included in the medical curriculum, there is decreased public awareness, and access to essential pain management resources, such as opioids, is severely restricted. This observation highlights the importance of this research study, *Palliative Care in Pakistan: A scoping review and expert consultation on current approaches, barriers to care, and culturally appropriate interventions*. The methodology will be a true scoping review, inclusive of the expert consultation step.

## Introduction

As a Pakistani who grew up in the United Arab Emirates, a diverse country home to over 200 nationalities, I encountered different and at times, conflicting ideas of death and what it means to be diagnosed with a life-threatening or life-limiting illness. Religious and cultural norms play a crucial role in shaping these ideologies. For instance, death is an avoided subject in Pakistani society due to the cultural belief it brings negativity. Optimism is stressed and this sociological phenomenon influences end-of-life decisions such as not opting for advance care planning or overtreatment at the end-of-life.<sup>7</sup>

Consequently, I believe it is imperative for palliative care interventions to be culturally appropriate and to accommodate regional variation. I hope the findings of this study lead to increased awareness and informed policy decisions in shaping a better palliative care system for Pakistanis in the future. These goals are more technical and closely tied to the substance of this study; in addition to these, I hope to pursue and accomplish a few personal goals. Some of these include instilling confidence in Pakistani civilians that they have a right to demand diverse models of care which better suit their needs. In the long term, public discourse and infrastructure development are tangible impacts I would like to see.

## Research Questions & Objectives

The objectives of this study are as follows:

- (i) to examine existing approaches to palliative care in Pakistan, both in home-based care and primary health care
- (ii) to identify structural and cultural barriers of access to palliative care
- (iii) to suggest culturally appropriate interventions to optimize the model of palliative care in Pakistan.

## Background

According to the WHO, palliative care is “*an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*”<sup>1</sup> Due to the long-term nature of chronic diseases, the majority of adults in need of palliative care are those with chronic or noncommunicable diseases (NCDs).<sup>1</sup> NCDs account for almost 70% of deaths globally and in Pakistan, they are responsible for 58% of all deaths.<sup>2</sup> NCD cases in Pakistan are projected to rise in the near future, aggravated by limited facilities and resources.<sup>2</sup> Additionally, Pakistan has an ageing population increasingly affected by NCDs.<sup>3</sup> Establishing effective palliative care services is essential for Pakistan to reduce future disease burden and to address an ageing population.

The most recent global classification of palliative care provision categorized Pakistan to Group 3a, *isolated palliative care provision*, characterized by “the development of palliative care activism that is still patchy in scope and not well supported; sources of funding that are often heavily donor dependent; limited availability of morphine; and a small number of palliative care services that are limited in relation to the size of the population.”<sup>4</sup> This categorization points to the lacking status of palliative care in Pakistan and necessitates immediate improvement, requiring greater research and investment to guide the development of effective palliative care services.

## Methodology

Due to the scarce amount of literature available on palliative care in Pakistan, a scoping review methodology is best suited for this project. A scoping review examines the extent, range and nature of research activity and helps identify research gaps in existing literature.<sup>5,6</sup> The scoping review approach is both feasible and flexible and will allow the researcher to identify key sources of evidence from which the palliative care system in Pakistan can be strengthened.

The scoping review will be based on the six-phase methodology set out by Arksey and O'Malley (2005) and expanded and refined by Levac et al. (2010). Given the relevance of experiential evidence to the project objectives, phase six (consultation with experts) will constitute a distinct component of the study.

## **1. Scoping Review**

Relevant databases will be searched using a search strategy consisting of a mix of subject headings and free-text keywords developed in consultation with a university librarian. Boolean operators will be used where possible. Articles will be analyzed via a conceptual mapping of evidence regarding palliative care, publication type, research question aim, methodology, and key findings.

The following is a detailed breakdown of the stages of a scoping review:

1. Identifying the research question
2. Identifying relevant studies:
  - a. Developing a search strategy which includes defining inclusion/exclusion criteria (i.e., which databases will be included, language, date of publication)
  - b. Running database searches and exporting to screen search results
3. Screen searching results to identify studies for full text review
4. Developing a data-charting form to extract data from each study
5. Collating, summarizing and reporting results – involves a numerical analysis of the nature and extent of studies using tables and charts
6. Conducting expert consultations to enhance findings gathered from the literature

## **2. Expert Consultations**

Expert consultations will be conducted for dual purposes, including consultation (phase six of the scoping review) and supplementing findings from the scoping review to address the broader objectives of this study. Expert consultations are an important approach for generating experiential evidence and can be used as a form of data triangulation to strengthen the value of the scoping review findings. Qualitative interviews can contribute insightful perspectives from key stakeholders and experts with the opportunity to use anonymized quotes to create powerful narratives for explaining the findings and ultimately informing the rationale for palliative care development in Pakistan.

## **Research Location**

I will be residing at Chestnut Residence (89 Chestnut St, Toronto, ON M5G 2J1) located on the University of Toronto St. George Campus for the duration of the research period. This ensures that I can stay in close contact with both my research supervisor and the university librarian.

## Timeline

PRE-RESEARCH PERIOD (April 15 <sup>th</sup> – June 15 <sup>th</sup> )		
	<i>Purpose</i>	<i>Duration</i>
<b>April</b>	Initial meetings with the university librarian to learn about best practices when conducting a scoping review.	April 15 <sup>th</sup> – April 22 <sup>nd</sup> (1 week)
	Working through search strategy resources: learning about Boolean operators, different types of databases, and different formats of academic publications.	April 22 <sup>nd</sup> – April 30 <sup>th</sup> (1 week)
<b>May</b>	Will develop search strategy and export results to Excel after deduplicating through Zotero. This Master File of research articles will be prepared before the research period begins to allow for time to change search strategy if exported results are unsatisfactory. Check-in meetings with the university librarian to track progress and clarify any doubts.	May 1 <sup>st</sup> – May 31 <sup>st</sup> (4 weeks)
	Will shortlist experts to contact for the consultations in an excel sheet using the following format: <i>Name / Found Through / Relevance / Organization / Email Address</i>  The process of identification includes both looking at hospital websites and looking at authors of relevant journal articles; publicly available contact information will be synthesized	May 15 <sup>th</sup> – May 30 <sup>th</sup> (2 weeks)
RESEARCH PERIOD (June 16 <sup>th</sup> – July 27 <sup>th</sup> )		
	<i>Purpose</i>	<i>Duration</i>
<b>June</b>	Screen search results to identify relevant studies for analysis [Title/Abstract screening based on inclusion and exclusion criteria, checking PDF availability]	June 16 <sup>th</sup> – June 23 <sup>rd</sup> (1 week)
	Full text review for final inclusion [No further details since this step is contingent on the results the search strategy produces] Will track research articles using Microsoft Excel and Word	June 23 <sup>rd</sup> – July 14 <sup>th</sup> (3 weeks)
<b>July</b>	Develop a data-charting form to extract data from each study; draft a preliminary scoping review report by collating, summarizing and reporting results	July 14 <sup>th</sup> – July 21 <sup>st</sup> (1 week)
	***Conduct expert consultations The sixth and final step of a true scoping review.	July 21 <sup>st</sup> – July 27 <sup>th</sup> (1 week)

POST-RESEARCH PERIOD (August 1 <sup>st</sup> – September 1 <sup>st</sup> )		
	<i>Purpose</i>	<i>Duration</i>
<b>August</b>	Put together all final deliverables and submit them no later than September 1 <sup>st</sup> .	August 1 <sup>st</sup> – September 1 <sup>st</sup> (4 weeks)

**\*\*\*Note: Expert Consultations**

- Will start reaching out to experts as soon as REB approval is granted
- An initial email will be sent out introducing the research project; if there is no response, a maximum of 2 follow-up emails will be sent
  - Email will be the primary way via which I will coordinate/schedule interviews
- The consultations will be conducted virtually via Zoom/Teams - they are expected to be an hour in length and the goal is to conduct 5 consultations
- The expert consultation is an **optional step** in the scoping review protocol – in the case I am unable to contact any experts, the research can still proceed and be completed

**Resources & Support Needed**

U of T Library Resources will be used.  
 Meeting Frequency with the Supervisor: on an as-needed basis, expected to be weekly or bi-weekly at the very least.

**Potential Impact**

This research focuses on the interdisciplinary aspects of palliative care in Pakistan. The study integrates insights from sociology, health policy, and epidemiology to analyze palliative care in Pakistan. It is especially relevant globally as it not only provides indispensable perspectives on what barriers lower income countries face to accessing facets of healthcare, but it also spotlights how interconnected culture and health decisions can be. With a specific focus on Pakistan, this research contributes to a global discourse on shared regional challenges. Moreover, it highlights the importance of developing appropriate health policies that address both biomedical causes of disease and the social determinants of health that contribute to disease.

Palliative care aims to alleviate suffering by addressing issues beyond physical symptoms — this study contributes to the advancement of health being viewed as a constituent of multiple factors, many of which are beyond the control of an individual.

Additionally, this research addresses a critical gap in the existing literature, shedding light on palliative care in Pakistan and highlighting future directions for improvement. The primary outcome is producing a list of recommendations for culturally appropriate interventions by analyzing the cultural

context of life-threatening illnesses and barriers of access to palliative care. The report will be a valuable resource for policymakers and healthcare professionals as it will offer tailored insights and recommendations based on Pakistan's specific circumstances. Throughout this research, I aim to enhance my capabilities as a principal investigator and refine my skills in scoping review methodology. Beyond academic contribution, I hope to raise public awareness and foster discourse on palliative care provision in Pakistan— I hope to empower Pakistani citizens with the knowledge that they have the right to and deserve full access to such care.

## References

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