



“One life is
too short to
do good...so
do good all
your life”
(Volunteer@IPM,
Kozhikode)

Insights from the Churchill
Fellowship in Palliative Care,
2024

Rekha Vijayshankar, Queen's
Nurse

My Motivation....

LIVED EXPERIENCE OF
CAREGIVING

PROFESSIONAL
LEADERSHIP EXPERIENCE
SUPPORTING RESOURCE-
POOR COMMUNITIES

LANCET COMMISSION ON
THE VALUE OF DEATH
REPORT (2022)

MARIE CURIE DYING IN
POVERTY REPORTS (2022,
2024)



What research has told us about Palliative Care in the UK...

PALLIATIVE CARE IS INEQUITABLE- DISPROPORTIONATE PENALTIES ON RESOURCE-POOR MINORITISED AND MARGINALISED COMMUNITIES

TERMINAL ILLNESS SUBSTANTIALLY INCREASES THE RISK OF POVERTY

THERE ARE PERVASIVE STRUCTURAL INEQUALITIES AND ERODING SOCIAL INFRASTRUCTURES IN THE UK TODAY

THERE IS HIGH CAREGIVER BURDEN AND INADEQUATE BEREAVEMENT SUPPORT



What my UK study with resource poor Minoritised communities told me....

FIRST EVER PUBLIC
HEALTH FRAMEWORK-
BASED PALLIATIVE CARE
ENGAGEMENT WITH
MINORITISED
COMMUNITIES IN THE UK

PERVASIVE
INSTITUTIONAL
MISTRUST

RESOURCE POVERTY
INFORMS DEATH
ILLITERACY AND LOW
LEVELS OF CARE
PLANNING FOR THE
END-OF-LIFE

HIGH CAREGIVER
BURDEN (SOCIAL
ISOLATION, INTRA-
CULTURAL STIGMA) AND
GENDERED CAREGIVING
EXPECTATION OF
WOMEN

FEELINGS OF SYSTEMIC
IRRELEVANCE AND
LANGUAGE BARRIERS
PENALISE CARE
PLANNING
ENGAGEMENT

THE IMPORTANCE OF
TRADITIONAL ETHNO-
CULTURAL RELIGIOUS
AND SPIRITUAL
FRAMEWORKS

A DEATH PHOBIA
FUELLED BY MODERN
MEDICINE'S CURATIVE
PROWESS

Aim of the Fellowship Study

AIM

- Building community capacity in Care Planning, Death Literacy and Grief Literacy
- Supporting resource poor communities Support each other

SITES VISITED

- INSTITUTE OF PALLIATIVE MEDICINE, KOZHIKODE, INDIA
- SANJEEVAN PALLIATIVE CARE, SRI AUROBINDO SOCIETY, PUDUCHERI, INDIA

RATIONALE FOR VISITING INDIA

TO EXPLORE
COMMUNITY LED
MODELS OF PALLIATIVE
CARE FOR RESOURCE
POOR INDIVIDUALS AND
CAREGIVERS

ETHNO-CULTURAL
ALIGNMENT WITH
MINORITISED
POPULATIONS IN THE UK

KEY INSIGHTS LEARNED

A deeply **embedded** sense
of social responsibility
in health and care of the
frail and those with chronic
life limiting illnesses

Cultural frameworks
that encourage filial piety,
altruism

ADEQUATE Care
for all model
Versus Gold
Standard care for a
few

MODEL OF PALLIATIVE CARE DELIVERY

COMMUNITY LED

- De-centralized care – community/locality led
- Community financed
- Community care provided by nurses, doctors, allied therapists and social workers
- Provision of pain relief medications, dressings, catheters, mobility aids, and other equipment
- Psycho-social support

SOCIALLY ACCOUNTABLE

- Strong culture of family and community ownership of illness, death and dying
- Cultural philosophies and spiritual frameworks which provide a mechanism for integrating death and loss in everyday living

THE RESOURCE-POOR PALLIATIVE PATIENTS AND THEIR FAMILY CAREGIVERS I MET VALUE....

RELATIONSHIPS

KINDNESS IN WORDS
AND ACTION

FINDING JOY IN THE
PRESENT MOMENT

RELIGIOUS AND
SPIRITUAL FRAMEWORKS
TO UNDERSTAND,
INTEGRATE DEATH AND
DYING

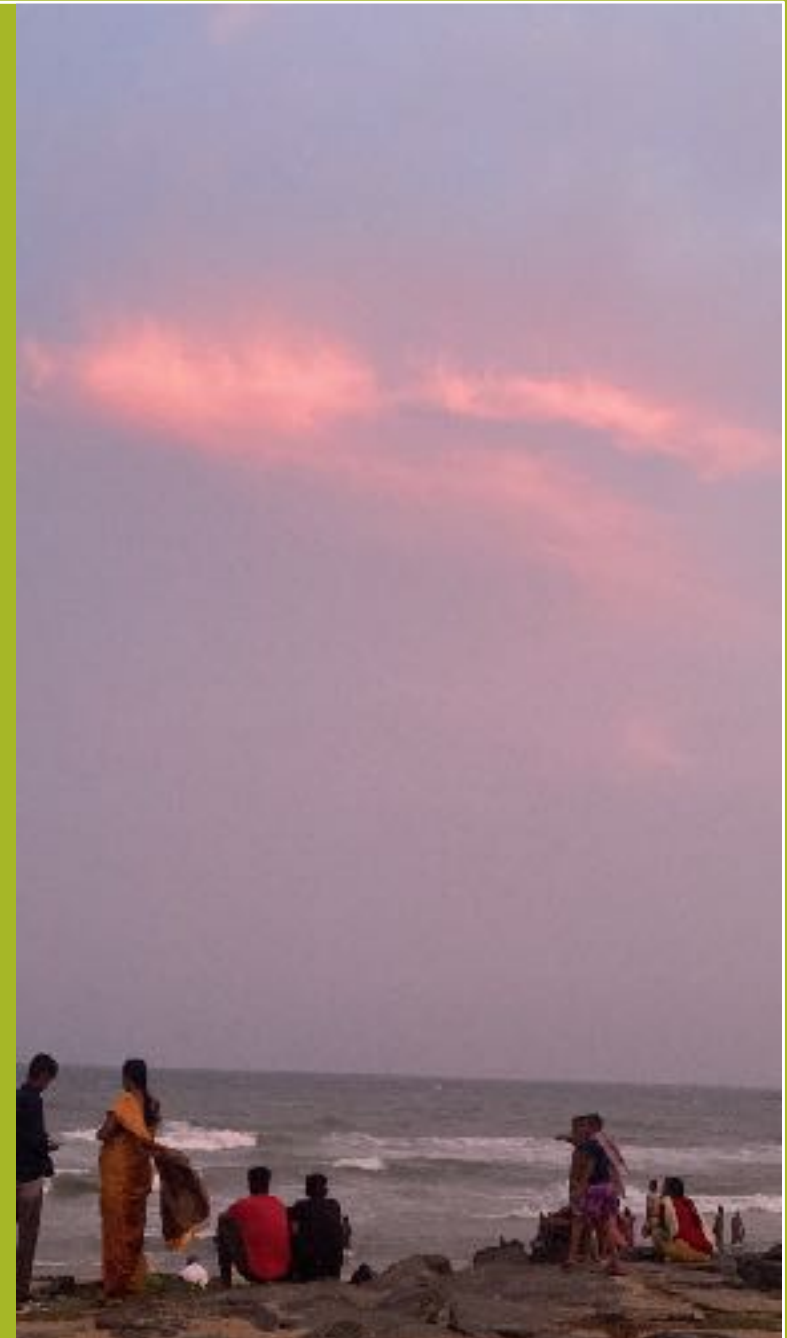
HEALTH AND
EDUCATION ARE
PRIORITIES

COMMUNITY
CAMRADERIE AND
SUPPORT

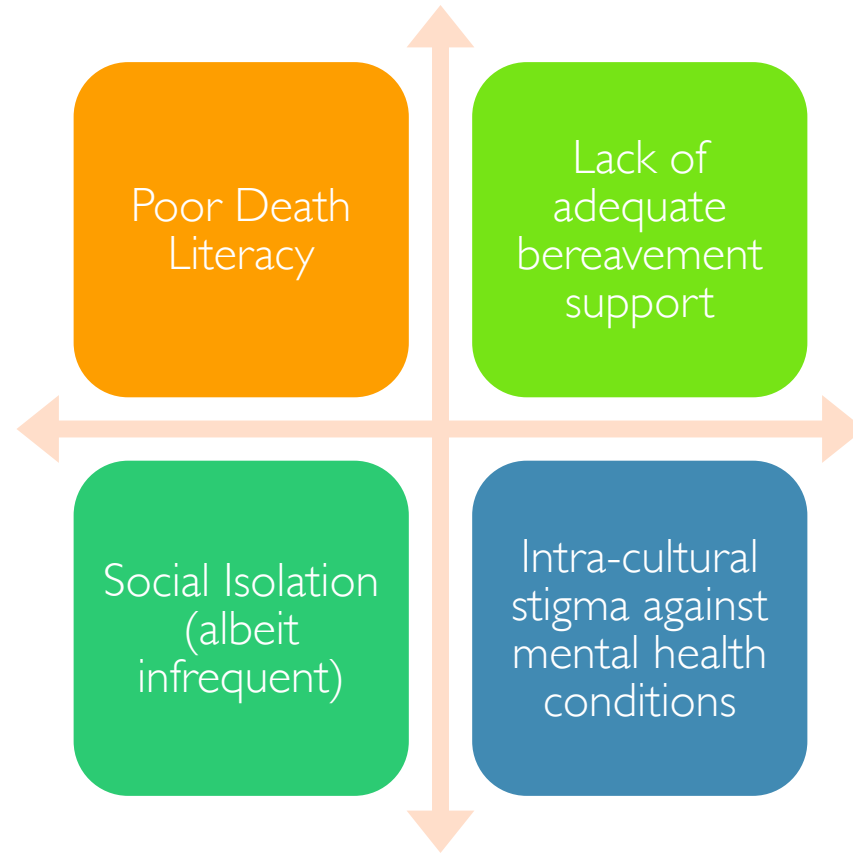
LOCAL CULTURE AND
TRADITIONS

OPENNESS TO LEARNING
AND CONTINUOUS
IMPROVEMENT

SIMPLICITY AND
AUTHENTICITY



DIFFERENT CONTINENTS.....yet some common themes to the UK observed...



So, what is this learning going to do for the UK ?



NEIGHBOURHOOD NETWORKS

A PEER SUPPORT MODEL FOR
BRINGING DEATH AND
DYING BACK TO RESOURCE
POOR MINORITISED
COMMUNITIES IN THE UK

Our Vision



Building **Community Capacity** for **bringing Death and Dying back to families**, and to communities

Our Goal

A **social change movement** to make End of life care that is **ADEQUATE FOR ALL**

The Neighbourhood Networks Model

How will this be achieved?

Three key strands inform the implementation of this vision and goal



Death as Regeneration

Exploring Purpose and Value of
Death

Aligned with Natural Cycles



Building Death Literacy

Building Awareness of Palliative
Care Symptoms and Systems

Building Awareness of Care
Planning



Building loss and grief literacy

Building understanding of loss
and grief

Building community capacity for
death and grief informed local
peer support

Phase I: Building Neighbourhood Network in Croydon (2025)

- **Description:**

Community led co-design of indoor biophilic productive space as backdrop for conversational workshops on death purpose as regeneration, death literacy and building neighbourhood peer support

- **Affiliates:**

Elsie Wagg Award from the National Garden Scheme, Local Minority Ethnic charities and Marie Curie (Impact Assessment)

- **Time Scale:**

March 2025-Feb 2026

- **Resources:**

Elsie Wagg Award fund (£5k maximum)

Session Planning and facilitation – Rekha V

MC UCL Research team (Oct-Dec 25, 12 hours in total)

Report Writing – (Jan-Feb '26- Rekha V)

Phase 2: Capacity building community-based organisations and volunteers, in their engagement with resource poor minoritised communities (2026 onwards)

Description:

Sharing knowledge of making difficult conversations and care planning

Methods:

Seminars and workshop facilitation

Audience:

Community-based organisations and Marie Curie Volunteers and Companions

- *Audiences thus far:*
- *Pan London Hospices,*
- *NiHR,*
- *PHPCI conference,*
- *Palliative Care Congress UK*
- *Pancreatic Cancer, UK*
- *Go Beyond UK*
- *Sri Aurobindo Society, India*
- *Indira Gandhi Medical College, India*
- *SoulFree, India*
- *, Butterfly Palliative Care, India*
- *Dhaka Medical College, Bangladesh*

Going forward

- IMPACT ASSESSMENT AS A RESEARCH PROJECT (2025-2026)
- RESULTS DISSEMINATED IN ACADEMIC PEER-REVIEWED JOURNALS, CONFERENCES ARTICLES AND ON NEIGHBOURHOOD NETWORK WEBSITE
- WEBSITE CREATION
- EXTENDING THE SCOPE OF THE PROJECT TO OTHER AREAS OF HIGH DEPRIVATION IN THE UK
- APPLYING FOR CPD ACCREDITATION OF NEIGHBOURHOOD NETWORK COURSE FACILITATION
- A BOOK ON THE STORIES OF HUMANITY AND COURAGE I WITNESSED DURING MY CHURCHILL FELLOWSHIP

CELEBRATING THE CHURCHILL FELLOWSHIP JOURNEY.....



ADEQUATE CARE FOR ALL – A COMMUNITY LED PALLIATIVE CARE MODEL IN SOUTH INDIA





All together...they build a
more beautiful world...

