

**CPCE-SHAPE**  
**Health Conference**  
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*Interdisciplinary Story as End-of-Life Healing:  
Palliative Care Film / Literature*



# Keywords:

*End-of-Life; Film; Literature; Palliative  
Care; Storytelling*

## Thankyou:

(C1) The Road Home - (Anne SMYTH, *University of New England*)

(C3) A Study on the Association between Poverty, Demographics,  
Family Support, and Cancer Care in Jharkhand, India (Imteyaz  
AHMAD, Padmaja GADIRAJU, Punam SINGH, Ranjit Kumar  
DEHURY, C. VANLALHRUAI, *University of Hyderabad*; Parthsarathi  
DEHURY, *AIPH University*)

# Introduction

- **Singapore's Aging Population**
  - Fastest aging population globally
  - Population aged over 65 will triple in 25 years
  - "Surging demand for palliative care" with limited information available (Ho, 2016, p. 1)
- **Government Initiative:**
  - Enhances Singapore's palliative care policy (ranked 20th of 80 countries)
  - Translates key findings into a cinematic story with the power to change minds
- **Project Outputs: *Ashes and Sighs***
  - Interdisciplinary research
  - Screenplay
  - 22-minute film targeting palliative caregivers
  - Distillation workshops

# Introduction

- **Intersection of Disciplines**

- Film, psychology, compassion and palliative care
- Represents life vs. death: 'dance macabre between Eros and Thanatos' (Rezaire, 2015, p. 193)

- **Palliative Care Needs in Singapore**

- Lien Foundation emphasizes greater capacity-building
- 'Compassionate Duty' and Chochinov's 'Dignity Model' resist the shame of mortality (Chan et al., 2012, p. 286)

- **Cinematic Expression**

- Protagonist/antagonist and life/death binary at the research epicentre
- Compassion obstructs death's triumph
- Film tagline: "Death be not Proud" (John Donne, 1609)

# Background of Research

- ❖ Assoc Prof Andy Ho's work through ARTISAN and MCAT
- ❖ Project ARTISAN: Aspiration and Resilience Through Intergenerational Storytelling and Art-based Narratives
- ❖ MCAT: Mindful-compassion art therapy for dementia care (MCAT-DC)
- ❖ Chochinov's 'Dignity Model'
- ❖ Evidenced recent TEDx talk through NTU.

# Background

- Ho's research encouraged End-of-Life (EoL) patients to reflect
- tell deep yet intangible stories, providing a powerful medium to make the intangible tangible.
- Generated genuine bonds to heal suffering for both EoL patients and caregivers.
- Andy Ho & PI discussed efficacy of mass communication for MCAT and EoL periodically, filmic representations of EoL and palliative care.

# Background

- Not piggyback on Ho's research => extend prior case studies cantered on life/death.
- Investigated policymaking for the elderly, indicated as a priority by Singapore's Ministry of Culture, Community and Youth (MCCY).
- Applied Chochinov's 'Dignity Model', offering life-affirming resistance to shame of mortality.
- Combining data analysis, psychology, film theory: life/death binary formed epicentre
- Compassion obstructs triumph of death
- Caregivers/medical professionals vanquished terror of mortality => Singapore affirmed life.

# Background

- Film's power placed research in effective context: gap in scholarship in SG
- Interpreting unique data reflected universality of caregiver stress to global marketplace.
- Collaborators Angela Frattarola and Michelle Chiang analyze and interpret material for academic contribution and edit softer insights of contributors from lay community.
- PI dramatized experience of death: scholarly publications
- Methodology to reflect scholarly outcomes

# Timetable

PROJECT DURATION	
Start Date	January 2022
End Date	December 2024
Duration of Project (mths):	30



# PROJECT DELIVERABLES AND DESIRED OUTCOMES

## Outcomes

1. Impactful short film as ‘proof of concept’ for a feature-length film on palliative care - real world issues, distributed globally
2. Template publication - literature of caregivers as ‘proof of concept’ for book-length publication on palliative care
3. Academic Publication: 2x co-authored interdisciplinary
4. NTU & Publicly accessible film/literature workshop

# The Team

## CO-INVESTIGATOR:

- Dr Angela Frattarola

Language and Communication Centre,  
SOH

## COLLABORATORS

- ❖ Assoc. Prof Andy Ho (Dr Death)

Psychology, School of Social  
Sciences & LKC Medicine

- ❖ Asst. Prof Hui Ling Michelle  
Chiang

Literature, SOH

- ❖ Dr Mansha Khemlani & Dr James

Palliative Care, Khoo Tech Puat  
Hospital



# Literature Review

- **ARTISAN & MCAT**
- **Hauntology**
  - Anxiety and fear of mourning; mourners vital for future societies (Fisher, 2003, p. 3/4)
- **Kinaesthetic Filmmaking**
  - 'Move with sensation' during voluntary body motions (Dowd, 2006)
- **Chochinov's 'Dignity Model'**
  - Dignified and redemptive end-of-life (EoL) care
- **Emergent Themes**
  - Enduring pain, moral transcendence, spiritual surrender, transgenerational unity (Ho & Chan, 2010)

# Literature Review

- ❖ Importance of palliative care: Choo, Ho, Dutta, Tan etc.
- ❖ Michael Chekhov (1953; 1985), Janet Murray (1997)
- ❖ Todorov, Joseph Cambell, Aristotle and Goethe
- ❖ *The Poetics* and *The Hero with a Thousand Faces* (1949).
- ❖ Colin Counsell's (1996) *Signs of Performance*
- ❖ Edna Lim's (2018) publication *Celluloid Singapore*

# The Research



- Choo, Ho, Dutta, Tan etc.
- Chochinov
- Cicily Saunders – Hospice Movement
- In-Depth Interviews
- email me:
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# Methodological Steps

- ❖ Library Research
- ❖ Ho/Datta/Chochinov/Saunders
- ❖ HK research
- ❖ Funnel
- ❖ Analytical
- ❖ In-Depth Interviews
- ❖ Practice-Led application

# Methodological Steps

## ❖ *1. Literature Review*

- **Objective:** Review literature on caregiver challenges in palliative care.
- **Steps:**
  - Identify key databases and journals.
  - Use search terms: "palliative care," "caregiver challenges," etc.
  - Focus on works by Andy Ho.
  - Summarize findings for an overview of Singapore's palliative care.

# Methodological Steps

## ❖ *Hypothesis Formation*

- **Objective:** Conjecture from academic literature to form insights:
  - Asian culture protects loved ones through Filial Piety
  - Learning to share important for Asian culture
- **Steps:**
  - Analyze literature for common themes.
  - Develop hypotheses on caregivers' emotional needs and denial.
  - Create research questions.

# Methodological Steps

## ❖ *Ethics Review*

- **Objective:** Ensured compliance with ethical standards.
- **Steps:**
  - Prepare an ethics application for NTU IRB.
  - Informed consent, confidentiality, participants' well-being.

# Methodological Steps

## ❖ *4. Data Collection and Processing*

- **Data Collection:**

- Methods: Observational, experimental, simulation, derived/compiled.

- **Data Quality Assurance:**

- Steps: Internal peer review data.

- **Data Organization:**

- Standardized folder structures and naming conventions.

# Methodological Steps

## ❖ *5. Interviews and Workshops*

- **In-Depth Interviews:**

- Recruit diverse participants, conduct semi-structured interviews.
- Compensate participants, record interviews, use outlines for consistency.

- **Workshops:**

- Transferring data to rhetorical visual information

# Methodological Steps

## ❖ *6. Handling Sensitive Data*

- **De-Identifying Data:**

- Remove identifiable information, use pseudonyms.

- **Access Restrictions:**

- Store data securely, restrict access, maintain access logs.

# Methodological Steps

## ❖ *7. Best Practices for Data Management*

### • **Before Data Collection:**

- Define standards, assign responsibility, design storage systems.

### • **During Data Collection:**

- Document changes, ensure completeness, identify outliers.

### • **After Data Collection:**

- Verify and clean data, maintain structured folders.

# Methodological Steps

## ❖ *8. Data Analysis and Scriptwriting*

- **Data Analysis:**

- Analyze data to inform screenplay, collaborate with editors.

- **Asian Medical Film Festival Proposal:**

- Develop proposal focusing on educational impact and global growth.

# Methodological Steps

## ❖ *10. Sharing Final Research Data*

- **Objective:** Plan data sharing while maintaining confidentiality.
- **Steps:**
  - De-identify data, share securely, deposit in reputable repositories.

## ❖ *11. Integrating Prior Research*

- **Objective:** Validate findings with existing studies.

# IRB Questions

- ❖ Research Question:

- ❖ How can cinema and literature convey vital information about end-of-life care that would not be possible in other rhetorical forms?

- ❖ These questions are designed in two parts:

1. For caregivers either currently engaged in nursing a loved one or dealing with grief after the recent passing of a loved one.
2. For caregivers or GP who attend a test screening of the draft edit film *Ashes and Sighs*

# IRB Questions

## ❖ Participants

### ❖ Sought 10—12 interviewees who:

- Singaporean
- Have lost loved one (a parent or daughter/son)
- Have given/are giving end-of-life care (for parent or daughter/son)
- Parents who have lost a significant family member
- People who have lost parents

# IRB Qs: caregivers – semi-structured

1. What was your caregiving experience like?
  - a. Can you tell us about what was most challenging? rewarding?
2. What is the one thing you wish someone would have told you before the caregiving process began?
  - a. What do you wish you knew about palliative care and associated support in Singapore before you began the process of caring for your loved ones?
3. What do you think a dignified death would look like? – [add def of what a dignified death is –or other wording that could simplify]  
Do you think that your loved one had a dignified end of life experience?
4. How do you think your cultural values and beliefs affected your caregiving and grieving process?
5. Did you discuss your feeling with anyone? If so, how did you find the experience of discussing your feelings?
6. What was the most challenging part of the entire process of caring and grieving for your loved one?
7. Have you ever watched a film about death, grieving or caregiving? If so, what did you think of them? Did you find anything particularly enlightening or lacking?

# IRB Questions: Test Audience

1. Were you engaged in the film?
2. How did you feel about the film?
3. Did you follow the story?
4. How did you find the length?
5. Did the film seem 'slow' to you?
6. Were you moved?
7. Did you feel empathy, or care about the characters?

# IRB Questions: palliative care/death

1. Did you identify with the characters? The caregiver? The dying?
2. Did any part of the film make you feel uncomfortable? What exactly made you feel this way and can you tell us more about it?
3. Did you learn anything about end-of-life or palliative care from this film? If so, can you specify what?
4. How likely are you to seek further information on Palliative Care in Singapore?
5. What struck you as 'new' in your understanding of death, dying and dignified care?

# The Film



- ❖ Draft #1
- ❖ Re-drafting (now)
- ❖ Locations sourced
- ❖ Casting
- ❖ Shooting July
- ❖ Post-Production

# Challenges

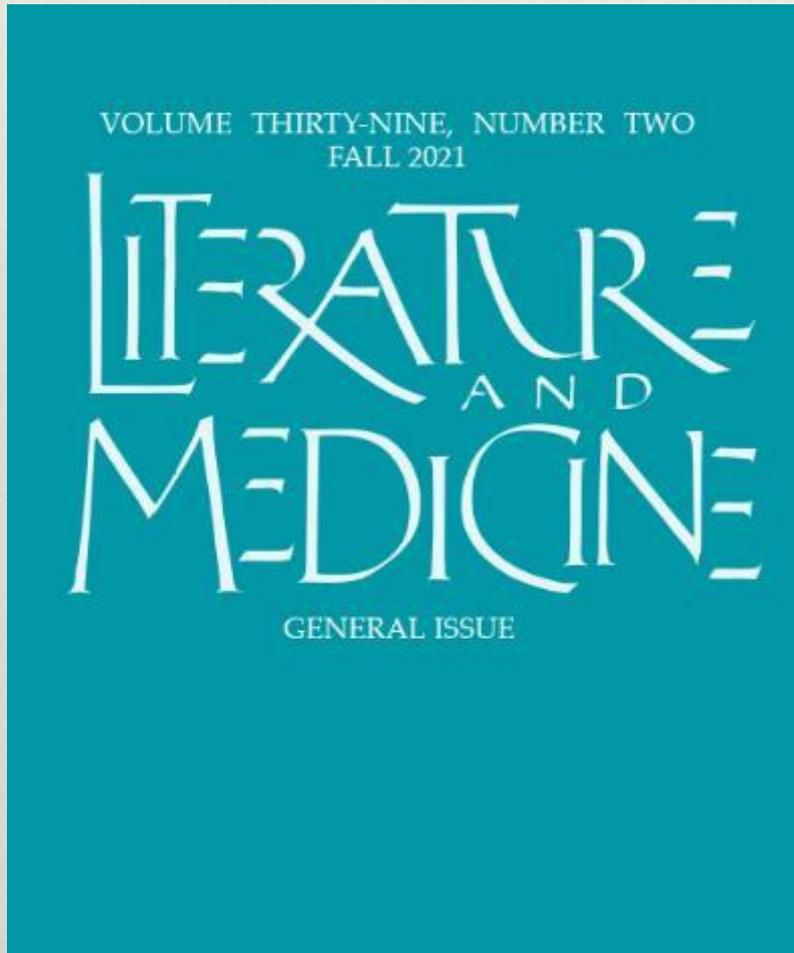
- Budget: changes required  
– scrubbing & reports
- 3.5k for interviews.
- Film production related
- IRB/Ethics
- Data management
- COVID



# Pathway to Impact & Users

2. Southeast Asian culture: Asian cultures revere family loyalty, especially in Singapore, Hong Kong, and Taiwan. No training videos on learning empathy were in use within the Singaporean hospital network.
3. Local policy: The project aimed to effect local policy for advanced care planning from a psychologically empowering perspective.
4. Emotional rhetoric of the film: Agencies and caregivers informed more efficiently through powerful media such as film and literature.
5. Academic dissemination: The project aimed to publish and conference material in phases, allowing access to the inner lives of real patients and caregivers.
6. International impact: The project extended overseas connections to enhance research for international impact.

# The Research Target Journals:



- ❖ *Literature and Medicine* by Johns Hopkins UP
- ❖ *Medical Humanities* by BMJ
- ❖ *Palliative Medicine*
- ❖ *BMC Palliative Care*
- ❖ *Screen; The Cinema Journal; Cinema Papers; Senses of Cinema; The New Review of Film and Television Studies;*
- ❖ *Nature; Nature / Human Behaviour*
- ❖ *Situations: Cultural Theory in an Asian Context (Scopus)*

# Findings

- **Emotional Engagement:**
  - All but one participant opened up emotionally
  - Shared tears with the researcher, highlighting the importance of the empathy model
- **Validation of Ho's Findings:**
  - Confirmed & Qualified Ho's findings - sample size was too small for definitive conclusions
- **Screenplay Development:**
  - Effective distillation into a short film screenplay
  - Readings: met with positive responses, especially from Asian participants

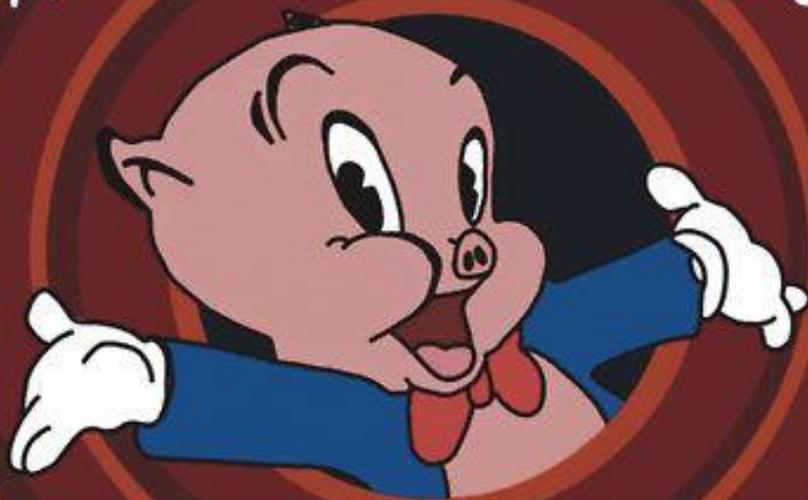
# Findings

- **Screening Opportunities and Funding:**
- Screening opportunities within NTU courses
  - Medical Humanities
  - LKC School of Medicine
  - Education in Psychological First Aid
  - Andy Ho's classes in Psychology
  - Michelle Chiang in Medical Humanities

# . Further Implications

- KK Luke in reading psychological signage influenced by Gilles Deleuze's micro-movements for
- Tanya Tierney – humanitarian training for doctors & medical students
- Potential model for disability films and science-based films in microbiology

*That's all Folks!*



kalilak