Decolonising Palliative Care: Learning from Research Beyond the Global West

An International Observatory on End of Life Care Research Webinar, held on the 10th January 2024

Reflections on the Controversies and Future Directions of ACP: Perspectives from Indonesia
Dr Diah Martina

Dignity in palliative care: patients' & family caregivers' perspective from Lebanon
Dr Silva Dakessian Sailian

Applicability of Westernised palliative care models in the African context: Insights from COMPASS-Ghana
Dr Yakubu Salifu

Click any of the images above to jump to the presentation.
Reflections on the Controversies and Future Directions of ACP: Perspectives from Indonesia

Diah Martina

Decolonising Palliative Care: Learning from Research Beyond the Global West
• Advance care planning (ACP) enables individuals to reflect upon the meanings and consequences of serious illness scenarios, to identify their values, goals and preferences for future medical care and treatment, to discuss these with family and healthcare providers, and to record and review these preferences if appropriate.
Over three decades of research have shown that ACP **DOES NOT** result in patients receiving the care they desire at the end of life, nor improving patient’s quality of life.

**Discussion that emerged:**
- Which ACP?
- Have we measured the “right” outcomes?
Reflection on the ongoing debates and our studies:


Including our collaborative works in Asia

3. Martina D, Segelov E (Editorial for Special Series of Cancer Care in Asia Pacific). Improving equity across cancer care continuum in Asia Pacific. 2023 (accepted for publication in JCO Global Oncology)
5. Martina D, Witjaksono M, Putranto R. Advance care planning in Indonesia: Current State and Future Prospects. 2023 (invited submission in ZIFQJournal as part of Special Series of Advance Care Planning-International 2023)
a giant farewell party disguised as a giant wedding banquet
The lie that everybody agreed upon

Lulu Wang
“There's a Chinese joke.
Two people go get a physical examination.
One of them is healthy,
and the other one has a terminal illness.
The hospital gets the results mixed up.
The healthy person got to know he had terminal prognosis and vice versa.
Eventually the healthy person ends up dying
while the sick person ends up living”

“We should give Nai Nai joy, not worry”
Billi [Wang], you moved to the West long time ago
You think one’s life belongs to oneself
But that’s the difference between the East and the West
In the East, a person’s life is part of a whole
Family. Society.

It’s our duty to carry
this emotional burden for her
Audiences:

“You reminded me of my real grandma”

“You reminded me of my family”
ACP in Different Contexts

Western context
- patient autonomy
- truth-telling
- control over dying

Asian context
- collectivism
- medical paternalism
- high-context culture

Self-determination
(The philosophy of ACP)

Indonesia: strong religiosity →
faith-based decision making

Mori M, Morita T. Pall Med. 2020
Various beliefs about ACP

Knowledge
- Advantages
- Implications
- Effectiveness

Beliefs
- Prognosis
- ACP
- Family/HCP’s support
- Alignment with religious beliefs

Complexities
- Socioeconomic situation
- Healthcare system

Willingness to engage in ACP (who, when, how)

Reflections
Reflection-1: Family and collectiveness in ACP

HCPs’ low engagement and late initiation in ACP was partly due to their fear of conflicts with family members and its legal consequences.

SR of HCPs in Asia (2020)¹

Reflection-1: Family and collectiveness in ACP

Patients’ perspectives:

- SR in Asia (2020)\(^1\)\(^2\) and qualitative studies in Indonesia\(^3\)-\(^5\) → family’s support and involvement in ACP was considered crucial by patients.

Survey among 1,030 cancer survivors:

- Willing to discuss ACP: 67%
- Medical therapy in the end of life: 90%
- Healthcare proxy: 66%
- What matters in the end of life: 94%
- Resuscitation: 50%
- With family members: 94%

References:
Patients wished to involve family members in ACP if it benefits family members but may be concerned about engaging them in a potentially emotionally laden process.

Engaging with family members during ACP may indirectly motivate individuals to have ACP discussions.
Family involvement may enable ACP

1. Instrumental support
2. Emotional support
3. Family members better prepared for realising patients' wishes

Providing support to the family is at least as important as the patient to facilitate patient’s engagement in ACP

Strategy to tackle cultural dilemma of breaking bad news

Table 1  Case scenario applying the ARCHES framework to a conversation with a patient’s family

<table>
<thead>
<tr>
<th>Case scenario applying the ARCHES framework</th>
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<tbody>
<tr>
<td>An 80-year-old woman is diagnosed with advanced pancreatic cancer. There are no options for curative treatment. Before these findings are discussed with the patient, her sons approach the medical team. They are aware that she is likely to have a serious illness. They insist that she should not be told the diagnosis. They are concerned it would be too distressing for her and would hasten her death.</td>
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<table>
<thead>
<tr>
<th>A</th>
<th>Acknowledge the request</th>
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<tbody>
<tr>
<td>“We understand that you have asked us not to tell your mother about her diagnosis. We would like to talk with you about this and to understand your perspective.”</td>
<td></td>
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<thead>
<tr>
<th>R</th>
<th>Build the relationship</th>
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<tbody>
<tr>
<td>“When you ask us not to tell her her diagnosis, what is on your mind? Are there particular things that you are worried about? What is she like as a person? What things do you feel are most important to her?”</td>
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<tr>
<th>C</th>
<th>Find common ground</th>
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<tbody>
<tr>
<td>“We can appreciate from what you have said that she is an anxious person. Your priorities are for her to be as comfortable as possible and not to be put under mental distress. These are goals that we share with you.”</td>
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<tr>
<th>H</th>
<th>Honour the patient’s preference and outline harm of non-disclosure of information</th>
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<tr>
<td>“Many families ask us not to tell patients about their diagnoses. As in your case, it is because they love their relative and are worried about them. However, we need to recognise that most patients want to know their diagnosis. We need to honour her choice if she would like to know. When patients understand what is happening, they feel better, physically and mentally. They feel more connected with their family. They are able to be involved in choices about their care. If we try to hide a diagnosis, the patient often feels alienated and will eventually find out the diagnosis in an unsupported way.”</td>
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<th>E</th>
<th>Provide emotional support and respond to concerns</th>
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<tr>
<td>“When we break bad news, we take care to do it sensitively. Your mother can always choose not to know her diagnosis and we will check we have her permission before starting the conversation. We will do it gently and in stages, giving her the opportunity to ask questions and to have her feelings and perspective heard.”</td>
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<th>S</th>
<th>Devise a supportive solution</th>
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<tr>
<td>“Now that we’ve discussed the situation, we need to make a plan of what we do next. We feel that it is important that we now tell her what is going on. What are your thoughts?” (Outcome 1)</td>
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</tbody>
</table>
| “We are glad to hear that you appreciate our need to tell her her diagnosis if she would like to hear it. Our usual approach is to give her the option with a family member if she would like this.”
Reflection-2: The complexities of “planning”

Belief in God’s authority of life

Belief in obligation towards preserving life

Preference for meaningful conversation

Limited readiness to engage in EoL related conversation

Difficulties on seeing the relevance of future planning

Shifting the focus of ACP:
creating plan in-advance → creating understanding of values

Beliefs in God’s predestination & ACP

• The desire to be in control of one's life may not be a universally shared interest → especially among devout people
• Reasons for unwillingness to engage in ACP discussion:
  1. The desire to surrender to God’s will
  2. The desire to focus on here and now

Also → creating alignment is key!

We are praying for miracle

Only God knows

It’s in God’s hands

Importance of Alignment!

- In order to engage ACP effectively, we need to be able to create alignment between ACP values and individuals’ values (including their religious values).

- Use patients’ language (e.g., “watch and see what God would do”; “mudharat” to explain the concept of futile treatment).

- Acquiring broad knowledge about religious values is part of sensitive communication skills → helps with creating alignment.

Byrne-Martelli S, Rosenberg LB. J Pall Med, 2022
Rimer K. ACP in Asia. 2023 (in press)
Martina, D, et al. BMC Pall Care, 2022.
Rethinking Focus: ACP and Documentation

Survey to Indonesian cancer survivors:

Wish to document

- Medical therapy in the end of life: 42%
- Healthcare proxy: 50%
- What matters in the end of life: 50%
- Resuscitation: 34%

ACP that focuses on formalizing and documenting the planning fails to achieve goal-concordant care.

Conversation and communication represented the most valuable component of the ACP experience.

Information provision as ACP prerequisites

Patients tend to avoid ‘harmful’ information and information that is irrelevant to their religious beliefs.

What information you wish to receive if you were diagnosed with a life-limiting illness?

- The name of the disease, 74%
- The severity of the disease, 61%
- The curability of the disease, 81%
- Progression over time, 66%
- Life expectancy; 37%

I don’t want any information, 6%

Martina, D, et al. JCO Global Oncology no. 9 (2023) e2300003
Sensitive communication of bad news: Indonesian perspectives

Implicit
Positive terms
Metaphor

“It should be like that, not too vulgar, though afterwards, the patient must still know about her condition”

(Family)

Implicit
Empathetic
Mediated

“We would not use the term ‘refusal of resuscitation’ rather than ‘allow natural death’ when asking them to sign the DNR form”

(Physician)

Use of Metaphors

1 Imagine it a bit like a scary fairground ride – it might be scary in places, but it will eventually stop and you can get off. Be strong, be brave and we will be here to hold your hand if you need it.
“Metaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe and slippers. At the very least, they are a relief from medical terminology”

(Anatole Broyard)
We propose rethinking the role of culture in ACP: Barrier → Asset

“What are commonly understood as barriers to ACP may in fact not be. *We propose reframing stereotypical barriers to ACP, such as religion and spirituality, or family, as cultural assets that should be engaged to enhance ACP*”

Sanders JJ, et al. 2019. Palliative & Supportive Care, 17(3), 306-313
Take home message

• Rethink ACP Operationalization:

1. **Beyond future planning** ➔ preparing for decision making (current-future)
2. **Beyond individual patient** ➔ facilitate mutual understanding between patient - families
3. **Beyond health care issues** ➔ promoting meaningful conversation
Take home message

• Rethink ACP approach:

Cultural diversities: barriers → assets we should embrace:
  1. An approach that upholds social harmony
  2. An approach that considers patients’ preferences for medical information
  3. Individualization based on patients’ preferences for communication style and belief systems
I chose to become healthcare professional because...

- Defeat the illness
- Add years to live
- Reduce healthcare cost
- Avoid legal prosecution
- Reduce the burden of healthcare service
- Rationalize healthcare utilities
COMMUNICATING AND CONNECTING

ACP should focus on creating connection, between patients and their family members, patients and their healthcare professionals, and most importantly between patients with themselves.
At the end of the day,
We learn that we can’t change one’s beliefs
Nor can we break into one’s family system
We learn that there is often no single truth
And that we need to listen more from both sides
While drawing connection into their realities
Advance Care Planning in the Asia Pacific

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This book is a paean to the multifaceted nature of ACP as well as a timely update regarding the current landscape of ACP implementation and practice across the Asia Pacific region.

A portion of the proceeds will be donated to APHN

20% off Promo code WSACP20
Dignity in palliative care: patients’ & family caregivers’ perspective from Lebanon

Silva Dakessian Sailian PhD, MPH, RN
Assistant Professor, Hariri School of Nursing,
American University of Beirut
Context in Lebanon

- Beirut Uprising Nov. 2019
- Covid-19 Pandemic
- Beirut Port Blast 2020
- Economic Crash & devaluation of the LL
- Today, War in the south of Lebanon

Beirut
Palliative Care in Lebanon

- Palliative care in Lebanon is underdeveloped, echoing the situation found in many of the LMIC palliative care.
- Categorised as a group 3a country (Lynch et al., 2013).
- Three home-based palliative care services with only six teaching-hospitals that cater for palliative care needs from a total of 167 hospitals (Daher, 2021; WHO, 2000).
- < 15 physicians are registered in the Ministry of Public Health as palliative care specialists in a country where the rate of physician is two per 1000 citizen (Daher, 2021; World Bank, 2018).
Dignity in Palliative Care

- Safeguarding patient dignity is an overarching tenet in palliative care.

- **Dignity** is ‘the quality or state of being worthy, honoured, or esteemed’ (Merriam-Webster online, 2018).

- Patients with life threatening conditions and serious illnesses often feel loss of dignity due to the heavy burden of the disease and its effect on normalcy of life.
  - Loss of dignity could lead to demoralization, hopelessness and sometimes the wish to hasten death. (Chochinov 2006).

- What is the meaning of dignity in illness?
Can the western literature of dignity be applied to the Middle Eastern setting?
Research Question

How is dignity interpreted and maintained by patients with palliative care needs and their family caregivers in the Lebanese context.

A) Explore the interpretations of the concept of patient dignity in palliative care as perceived by patients and family caregivers.

B) Examine how patient dignity is experienced while receiving health services from patients’ and family caregivers’ perspective.

C) Assess how family caregivers perceive and preserve the dignity of their relatives with palliative needs during illness and while receiving health care services.

D) Critically assess and compare the findings of the research in relation to Chochinov’s Dignity Model.
A qualitative interview study

fourteen patients with palliative needs and fifteen family caregivers recruited to understand how dignity is interpreted and preserved in illness.

The data were analysed inductively using reflexive thematic analysis.

The findings from the two groups of participants were compared against each other and with the Chochinov Model of dignity.
The Findings

Four overlapping themes among the participant groups
Theme 1: Faith

‘I have my faith you know’

Participants found a safe refuge of their dignity through their faith in God and practice of religious practices.

God is perceived as the omnipotent presence, the source of life and good and controller of events, the one who ‘listens to the sufferers.

‘No no, I have taken my illnesses as regular things, and first of all I have my faith you know. Whatever will happen will happen, what can I do...’
**Theme 2: Support of Family & Children**

- Being surrounded by family members and children is considered a loving shield, protective against physical and psychological threats to dignity.
- Children are regarded as the legacy of the participants to whom they pass on their values, ‘wisdom’, and stories.
- The family’s presence feeds into the patient’s identity, social status, worth, and dignity.
- In contrast, a husband, or a wife who is distant, non-caring or not involved in the care reduces dignity and is even a source of distress.
- Visitors, extended family members’ presence enhance patient dignity.

‘thank God, I have my children, they work, and they are employees, so they preserve my dignity.’
Theme 3: Physical, Social & Mental Wellbeing

Maintaining physical energy to carry on activities of daily living; symptom control is a shaper of dignity.

Preserving physical appearance (body parts, intact body, hair) & fitness

Stigma of illness/gossip/taboo/death anxiety. Find cure to find normalcy.

Maintaining memory and the ability to converse

Hmmm... I will tell you that for me the worst thing was my hair loss and the use of a wig. This was a topic that was very difficult for me to accept. ’
Theme 4: Compassionate & Accessible Care

‘The physician kissed me on the forehead and told nothing is wrong with me’

• Kind communication; Clear & honest explanations.
• Compassionate presence during hospitalizations. Competent care.
• Accessible and affordable services and available medications for all patients regardless of social or economic rank. (not discriminated against)

‘In Lebanon, it is not available, even the person who is insured, we stand in long queues “tawabeer” in front of the national security building to request our medications’
Chochinov Model amended considering the findings

New themes surfaced
- Faith/centrality of God in anchoring dignity
- Presence and dependence on family/children’s support
- Preserving Outer Appearance
- Equitable and affordable care

Different Emphasis
- Autonomy - collective
- Burden to others
- Aftermath concerns

Illness related issues
- Symptom Distress
  - Physical distress *
  - Psychological distress
- Level of Dependence
  - Cognitive acuity
  - Functional capacity
- Outer appearance
  - Stigma of disease
  - Death anxiety

Dignity-conserving repertoire
- Dignity Conserving Perspectives
  - Continuity of self
  - Role preservation *
  - Maintenance of pride
  - Hopefulness
  - Autonomy/control *
  - Generativity/legacy *
  - Acceptance
  - Resilience/fighting spirit *
- Dignity conserving practices
  - Finding spiritual comfort
  - Living in the moment
  - Maintaining normalcy

Social dignity Inventory
- Privacy boundaries *
- Social Support *
- Care Tenor
- Burden to others
- Aftermath concerns
- Equitable & affordable care
Implications

1. In palliative care No ‘one size fits all’. Need for openness for other ways of making meaning. Dignity is subjective

2. Take account of the socio-cultural, geopolitical context- unequal access and limited resources and adapt western interventions and advancements accordingly

3. Respect and humility to cultural values, tradition, and priorities- faith, family ties

4. Integrate patient’s cultural needs into the local practice, education and policy
Thank you
References


Applicability of Westernised palliative care models in the African context: Insights from COMPASS-Ghana

10/01/2024

Dr Yakubu Salifu, FHEA
What is the goal of Palliative Care?

- 40 million people need of palliative care; 14% receive it
- 78% of people needing palliative care live in low- and middle-income countries (WHO, 2020)
Research influencing ‘local’ practice

A clinical nurse

Academic

Care delivery, what works what doesn’t

Lack of research that has explored the Ghanaian context
Moving beyond Western-centric perspectives.

• Home-based palliative care usually unsupported by health staff
• Cultural Response-masculinity and Stigma
• Delivering palliative care in resource-poor settings

*Greater focus on home-based palliative care as an alternative to institutionalised palliative care*’ (Yu, et al., 2015)
Understanding what works, and for whom

Resource Disparities
Cultural Nuances:
Healthcare Infrastructure
Funding/Economic Factors
Population Demographics

Is it a rabbit or a duck?
Hospice Africa Uganda (HAU)

- Founded in 1993
- Dr. Anne Merriman - a British
- Africa is diverse
‘Best practice’ is context specific

- Healthcare infrastructure,
- Access - culture, geography
- Capacity - skilled health personal
- Funding (GDP spent on health overall, and palliative care specifically)

No Longer a Luxury But a Necessity (Higginson & Foley, 2009)
How accessible is the care?

[Image description: Three scenes depicting individuals in challenging environments, possibly related to healthcare delivery in remote or rural areas, with a Lancaster University logo.
Funding: Ad hoc support system

NHIS
- Subscription
- Extensive exemption
- Under funded
Heath staff Capacity

Original Article

‘My wife is my doctor at home’: A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting

Yakubu Salifu1, Kathryn Almack2 and Glenys Caswell3

Abstract
Background: Family caregiving is common globally, but when a family member needs palliative and end-of-life care, this requires knowledge and expertise in dealing with symptoms, medication, and treatment side effects. Caring for a family member with advanced prostate cancer in the home presents practical and emotional challenges, especially in resource-poor contexts, where there are increasing palliative cases without adequate palliative care institutions.

Aim: The study explored palliative and end-of-life care experiences of family caregivers and patients living at home in a resource-poor context in Ghana.

Design: This is a qualitative study using thematic analysis of face-to-face interviews at two-time points.

Participants: Men living with advanced prostate cancer (n = 23), family caregivers (n = 23), healthcare professionals (n = 12).

Findings: Men with advanced prostate cancer face complex issues, including lack of access to professional care and a lack of resources for homecare. Family caregivers do not have easy access to professional support; they often have limited knowledge of disease progression. Patients have inadequate access to medication and other practical resources for homecare. Caregivers may be overburdened and perform the role of the patient’s ‘doctor’ at home-assessing patient’s symptoms, administering drugs, and providing hands-on care.

Conclusion: Home-based care is promoted as an ideal and cost-effective model of care, particularly in Westernised palliative care models. However, in resource-poor contexts, there are significant challenges associated with the implementation of this model. This study revealed the scale of challenges family caregivers, who lack basic training on aspects of caring, face in providing home care unsupported by healthcare professionals.

Keywords
Family caregiver, Ghana, homecare, qualitative research, long-term care, palliative care, advanced prostate cancer
Culture and Beliefs

Not man enough
‘No balls’
‘Erectile dysfunction’
‘From head to tail’

‘Out of the frying pan into the fire’: a qualitative study of the impact on masculinity for men living with advanced prostate cancer

Yakubu Salifu, Kathryn Almack and Glenys Caswell

Abstract

Background: Studies have highlighted how advanced prostate cancer causes biographical disruption and presents challenges to masculine identities for men. This article draws on a wider study that focused on the experiences of men living with advanced prostate cancer and their caregivers. Although men’s experience of advanced illness is not overlooked in the literature, only a small body of work has taken an in-depth look at men’s experiences with advanced prostate cancer and their caregivers in a non-Westernised cultural and social context.

Objective: To explore how advanced prostate cancer impacts on men’s masculine identity from the perspective of patients and their caregivers.

Methods: A qualitative study of men living with advanced prostate cancer (n=23) and family caregivers (n=23) in Ghana. We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) as the reporting guideline.

Results: The findings from this study highlight profound challenges for most men to their masculine identities, from both the treatment and the symptoms of advanced prostate cancer within a non-Westernised, patriarchal society. Four main themes were developed. These were the impact on masculinity in terms of: (1) physical changes, (2) sexual ability, (3) socio-economic roles and (4) expressing emotions. Changes in physical appearance, feeling belittled, having no active sexual life and the inability and protecter of the family made some men describe their situation as one of moving out of the ‘frying pan into the fire’.

Conclusion: This study revealed the impact of advanced prostate cancer on masculine identity. These narratives add a new dimension to what is already known about the impacts on men’s masculine identities when dealing with advanced prostate cancer. This knowledge can help improve the care provided to men with advanced prostate cancer with emphasis on the cultures, beliefs and aspirations of these men and their caregivers.

Keywords: advanced prostate cancer, African/Black men, culture, intersectionality, masculinity, men’s health, physical appearance, sexual life, social construction
Compass-Ghana's Approach

- The development of a whole system approach.

- live to life as well as possible and to die with dignity, compassion and comfort.

- Ghana has some high expectations – universal health care by 2030, 80% signed up to the NHIA (Health Insurance) programme by 2030.
COMPASS-Ghana, a new dawn?
Call to improve healthcare provision for people with cancer in Ghana

4 February 2023 00:31

Lancaster researcher launches charity in Ghana to provide palliative and end-of-life care

20 Feb 2023

Successful Ghana trip to promote palliative care

3 May 2023 02:34

We acknowledge the immense dedication of healthcare professionals in Ghana, who are working tirelessly to provide compassionate palliative care despite resource limitations.

Dr Yakubu Safiu

Engaging the stakeholders
Impact and Success Stories: Hubs

COMPASS-Ghana (COMPASSionate Palliative Services)
Bringing Compassionate Palliative Care to Ashanti: Our £50,000 Mission

Join us in raising £50,000 for palliative care in Ghana. Every contribution matters. Support our mission today.
In our learning, unlearning and relearning, we need each other

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Come study with us at Lancaster University

Find out more: https://www.lancaster.ac.uk/study/postgraduate/postgraduate-courses/palliative-care-phd/2024/

Part-time, international, distance learning programme.