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

RSCM

UNIVERSITAS INDONESIA

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

Diah Martina

Decolonising Palliative Care: Learning from Research Beyond the Global West

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

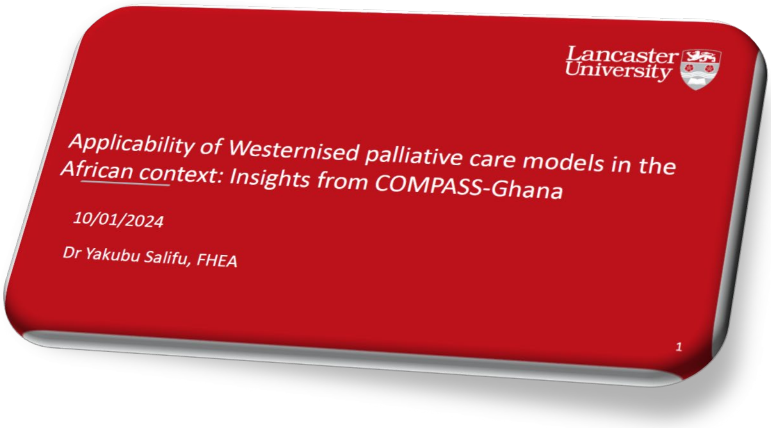
Dr Diah Martina

Dignity in palliative care: patients' & family caregivers' perspective from Lebanon

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

Dignity in palliative care: patients' & family caregivers' perspective from Lebanon

Dr Silva Dakessian Sailian



Lancaster University

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

10/01/2024

Dr Yakubu Salifu, FHEA

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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.

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

Diah Martina

Decolonising Palliative Care: Learning from Research Beyond the Global West

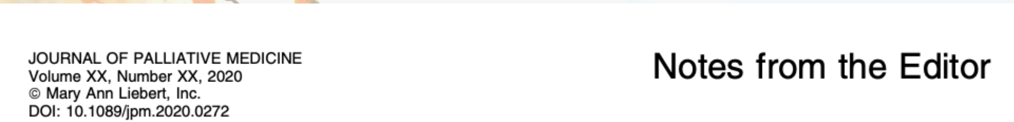
Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

Judith A C Rietjens, Rebecca L Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Droger, Agnes van der Heide, Daren K Heyland, Dirk Houttekier, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Jox, Ida J Korfage, on behalf of the European Association for Palliative Care

- 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.

Rietjens JAC, 2017. Lancet Oncol 2017; 18: e543–51

Controversies:
ACP and goal-concordant care



JOURNAL OF PALLIATIVE MEDICINE
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DOI: 10.1089/jpm.2020.0272

Notes from the Editor

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?

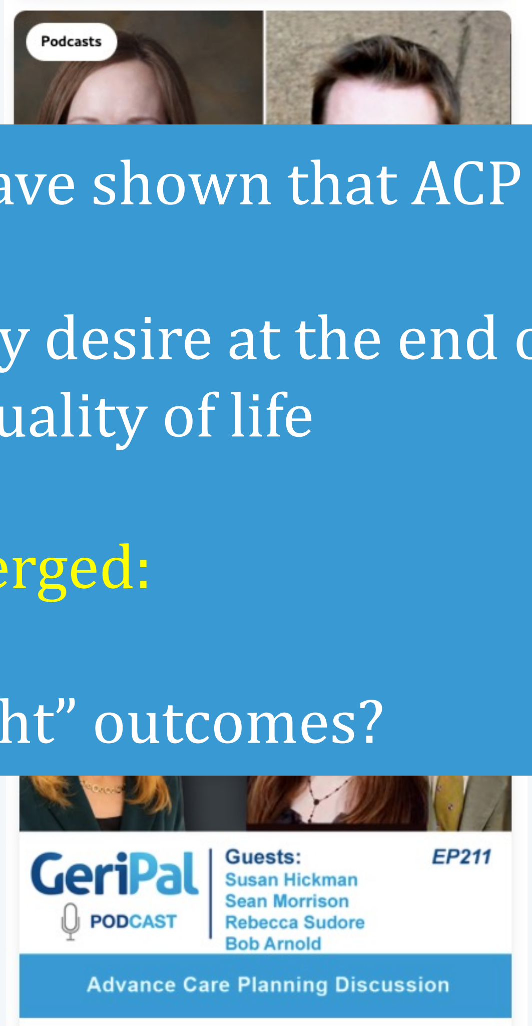
This Issue | Views 1,873 | Citations 14 | Altmetric 67

Comment & Response

February 15, 2022

Controversies About Advance Care Planning

Rebecca L. Sudore, MD[1]; Susan E. Hickman, PhD[2]; Anne M. Walling, MD, PhD[3]

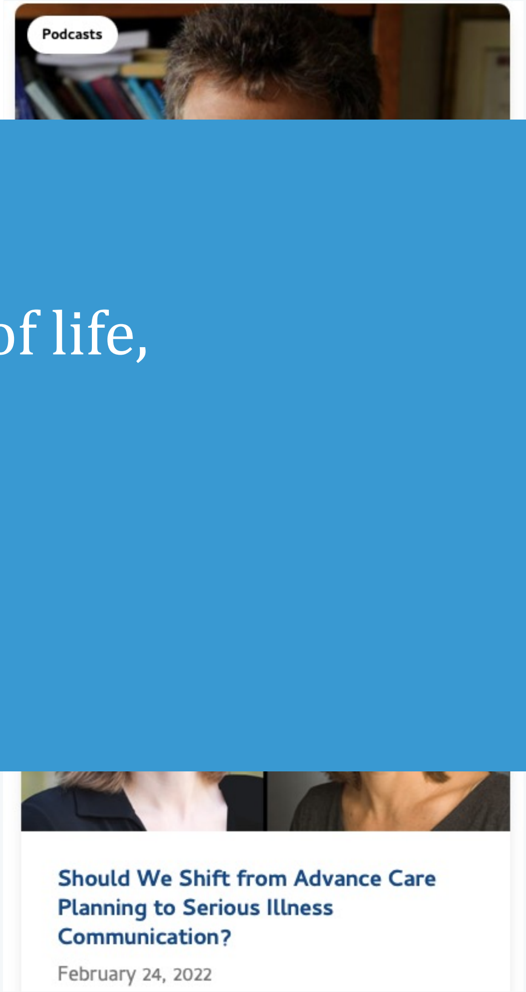


GeriPal PODCAST

Guests:
Susan Hickman
Sean Morrison
Rebecca Sudore
Bob Arnold

EP211

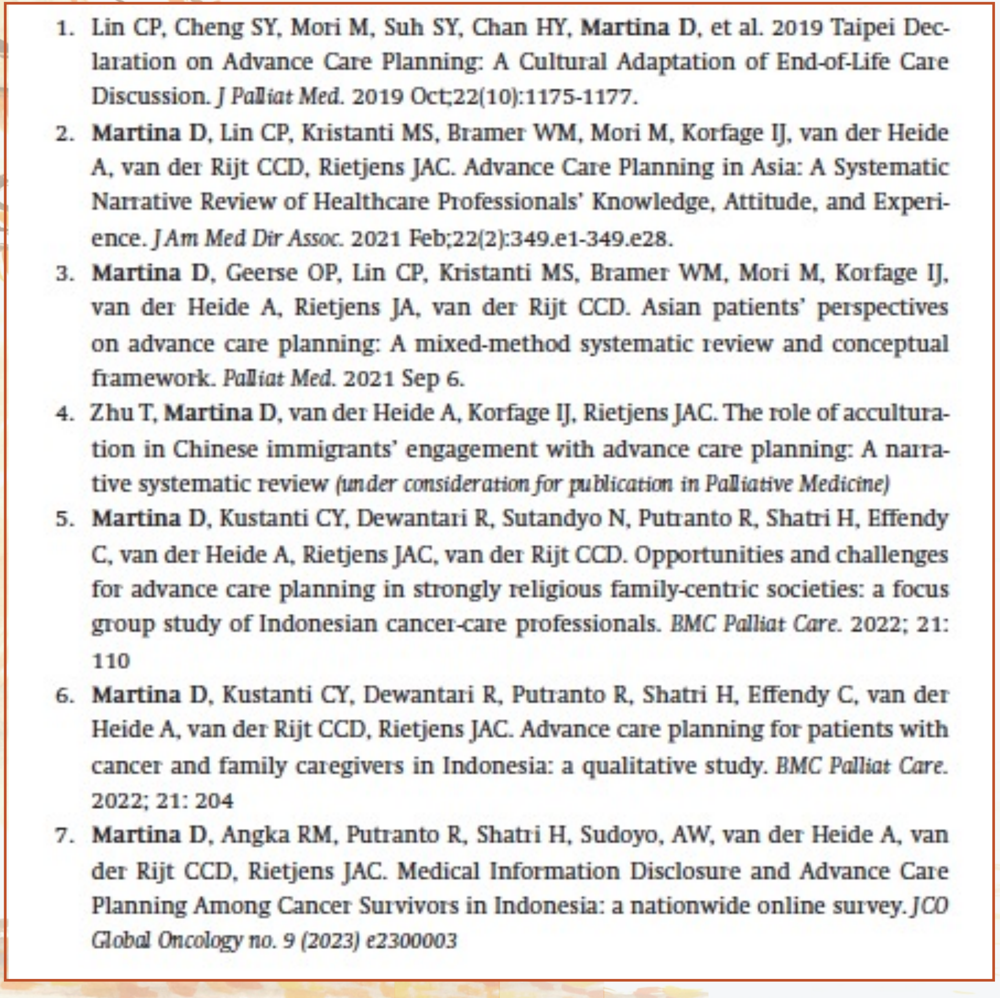
Advance Care Planning Discussion



Should We Shift from Advance Care Planning to Serious Illness Communication?

February 24, 2022

Reflection on the ongoing debates and our studies:



1. Lin CP, Cheng SY, Mori M, Suh SY, Chan HY, **Martina D**, et al. 2019 Taipei Declaration on Advance Care Planning: A Cultural Adaptation of End-of-Life Care Discussion. *J Palliat Med.* 2019 Oct;22(10):1175-1177.
2. **Martina D**, Lin CP, Kristanti MS, Bramer WM, Mori M, Korfage IJ, van der Heide A, van der Rijt CCD, Rietjens JAC. Advance Care Planning in Asia: A Systematic Narrative Review of Healthcare Professionals' Knowledge, Attitude, and Experience. *J Am Med Dir Assoc.* 2021 Feb;22(2):349.e1-349.e28.
3. **Martina D**, Geerse OP, Lin CP, Kristanti MS, Bramer WM, Mori M, Korfage IJ, van der Heide A, Rietjens JA, van der Rijt CCD. Asian patients' perspectives on advance care planning: A mixed-method systematic review and conceptual framework. *Palliat Med.* 2021 Sep 6.
4. Zhu T, **Martina D**, van der Heide A, Korfage IJ, Rietjens JAC. The role of acculturation in Chinese immigrants' engagement with advance care planning: A narrative systematic review *(under consideration for publication in Palliative Medicine)*
5. **Martina D**, Kustanti CY, Dewantari R, Sutandyo N, Putranto R, Shatri H, Effendy C, van der Heide A, Rietjens JAC, van der Rijt CCD. Opportunities and challenges for advance care planning in strongly religious family-centric societies: a focus group study of Indonesian cancer-care professionals. *BMC Palliat Care.* 2022; 21: 110
6. **Martina D**, Kustanti CY, Dewantari R, Putranto R, Shatri H, Effendy C, van der Heide A, van der Rijt CCD, Rietjens JAC. Advance care planning for patients with cancer and family caregivers in Indonesia: a qualitative study. *BMC Palliat Care.* 2022; 21: 204
7. **Martina D**, Angka RM, Putranto R, Shatri H, Sudoyo, AW, van der Heide A, van der Rijt CCD, Rietjens JAC. Medical Information Disclosure and Advance Care Planning Among Cancer Survivors in Indonesia: a nationwide online survey. *JCO Global Oncology no. 9 (2023) e2300003*

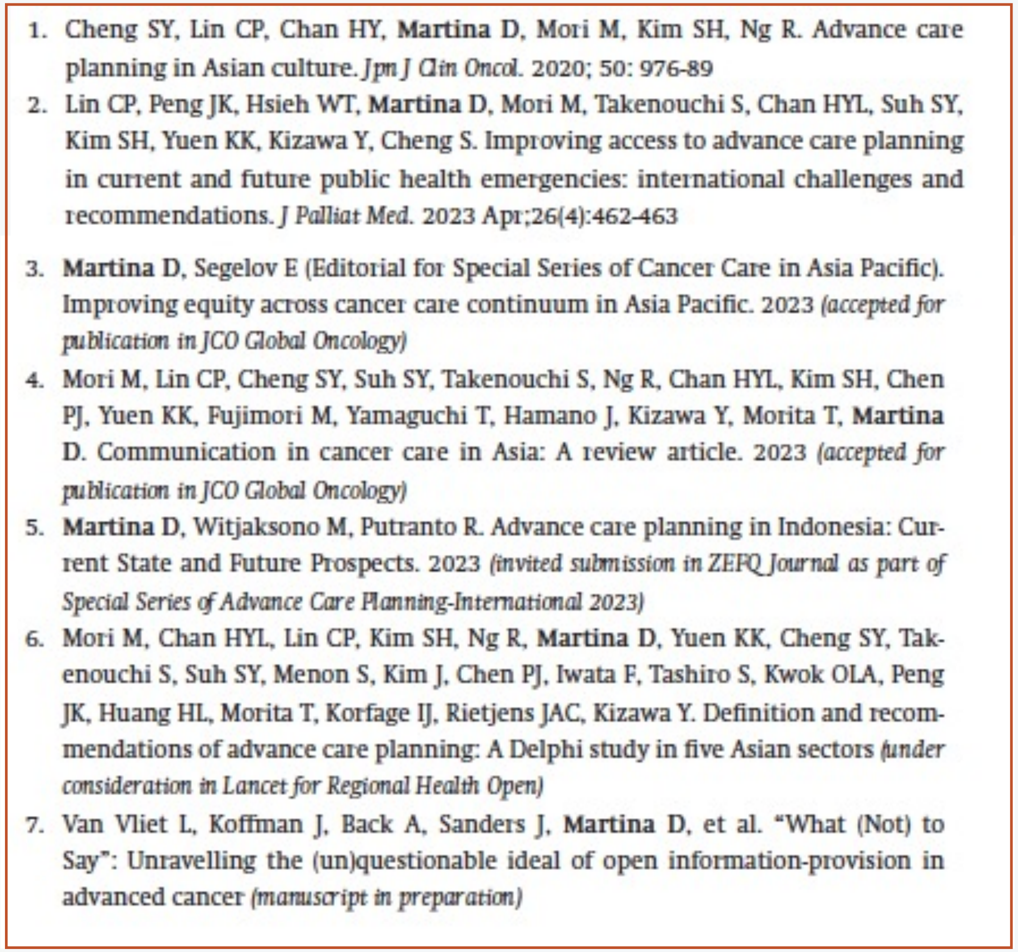
Expert panel meeting

Reviews

Online survey

Qualitative interviews

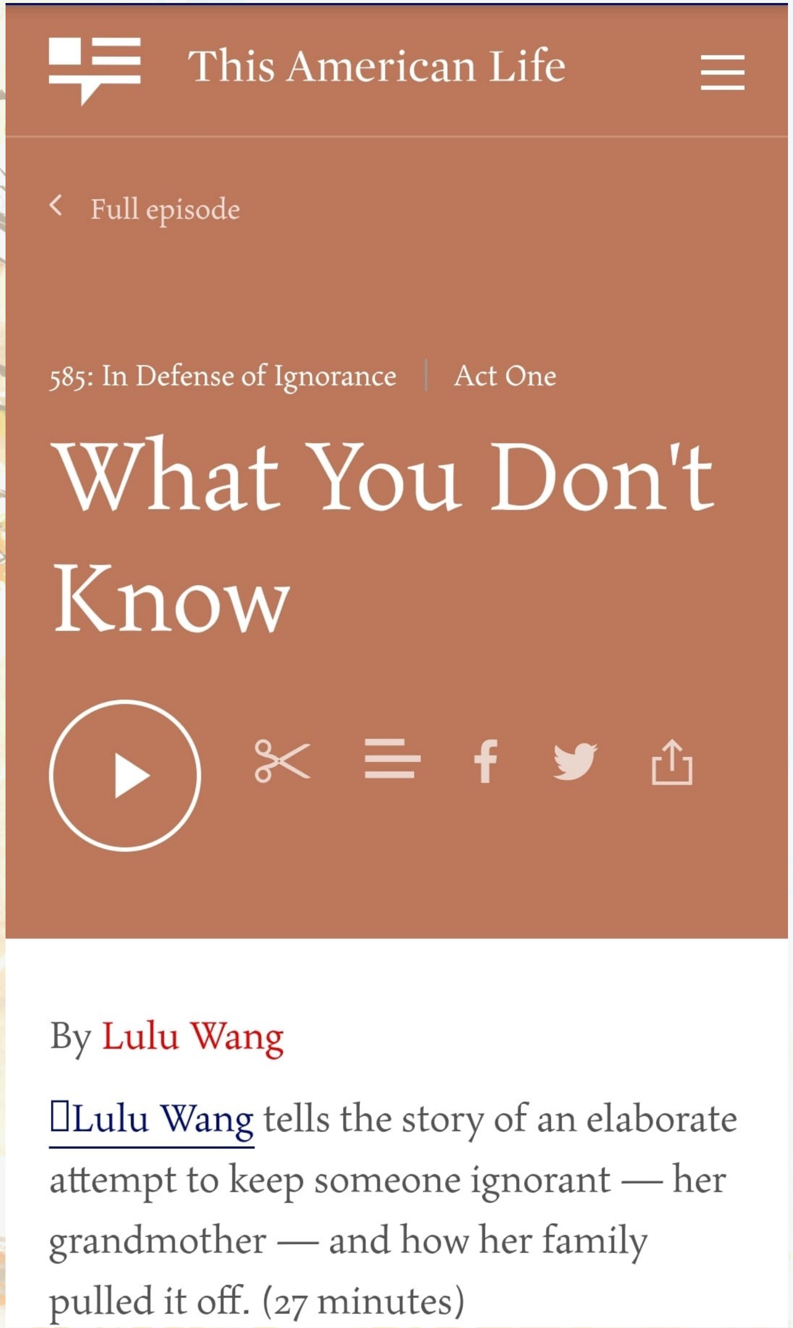
Including our collaborative works in Asia



1. Cheng SY, Lin CP, Chan HY, **Martina D**, Mori M, Kim SH, Ng R. Advance care planning in Asian culture. *Jpn J Clin Oncol*. 2020; 50: 976-89
2. Lin CP, Peng JK, Hsieh WT, **Martina D**, Mori M, Takenouchi S, Chan HYL, Suh SY, Kim SH, Yuen KK, Kizawa Y, Cheng S. Improving access to advance care planning in current and future public health emergencies: international challenges and recommendations. *J Palliat Med*. 2023 Apr;26(4):462-463
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)*
4. Mori M, Lin CP, Cheng SY, Suh SY, Takenouchi S, Ng R, Chan HYL, Kim SH, Chen PJ, Yuen KK, Fujimori M, Yamaguchi T, Hamano J, Kizawa Y, Morita T, **Martina D**. Communication in cancer care in Asia: A review article. 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 ZEFQ Journal as part of Special Series of Advance Care Planning-International 2023)*
6. Mori M, Chan HYL, Lin CP, Kim SH, Ng R, **Martina D**, Yuen KK, Cheng SY, Takenouchi S, Suh SY, Menon S, Kim J, Chen PJ, Iwata F, Tashiro S, Kwok OLA, Peng JK, Huang HL, Morita T, Korfage IJ, Rietjens JAC, Kizawa Y. Definition and recommendations of advance care planning: A Delphi study in five Asian sectors *(under consideration in Lancet for Regional Health Open)*
7. Van Vliet L, Koffman J, Back A, Sanders J, **Martina D**, et al. "What (Not) to Say": Unravelling the (un)questionable ideal of open information-provision in advanced cancer *(manuscript in preparation)*

a giant farewell party disguised as a giant wedding banquet
The lie that everybody agreed upon

Lulu Wang



585: In Defense of Ignorance | Act One

What You Don't Know

By Lulu Wang

Lulu Wang tells the story of an elaborate attempt to keep someone ignorant — her grandmother — and how her family pulled it off. (27 minutes)

"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

© Vemaps.com

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

Self-determination

(The philosophy of ACP)

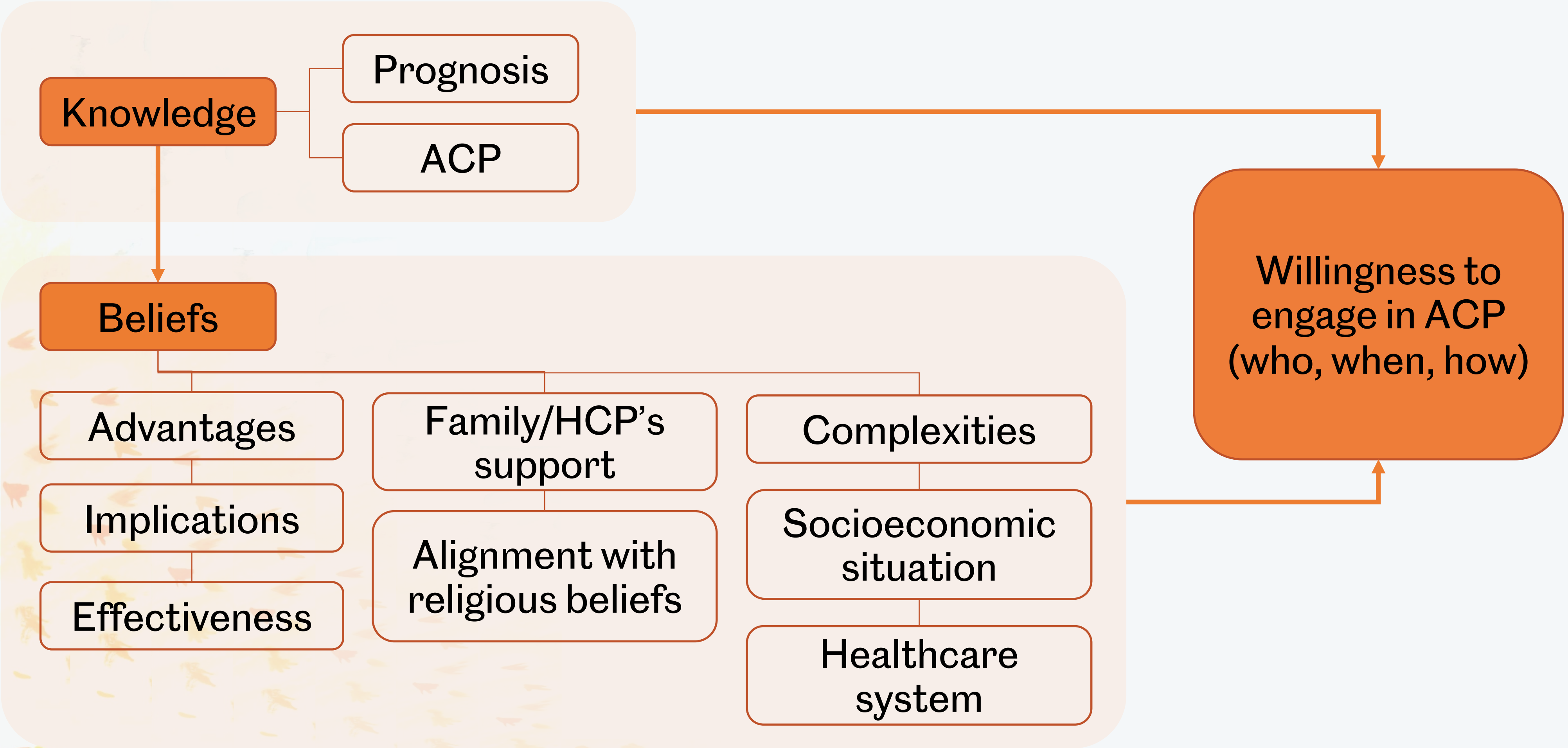
Asian context

- collectivism
- medical paternalism
- high-context culture

Indonesia: strong religiosity → faith-based decision making

Mori M, Morita T. Pall Med. 2020
Houska A, Loučka M. J Pain Symptom Manage. 2019, 57(4):835–845
Martina, D, et al. Pall Med, 2021: p. 02692163211042530

Various beliefs about ACP



Knowledge

Prognosis

ACP

Beliefs

Advantages

Implications

Effectiveness

Family/HCP's support

Alignment with religious beliefs

Complexities

Socioeconomic situation

Healthcare system

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

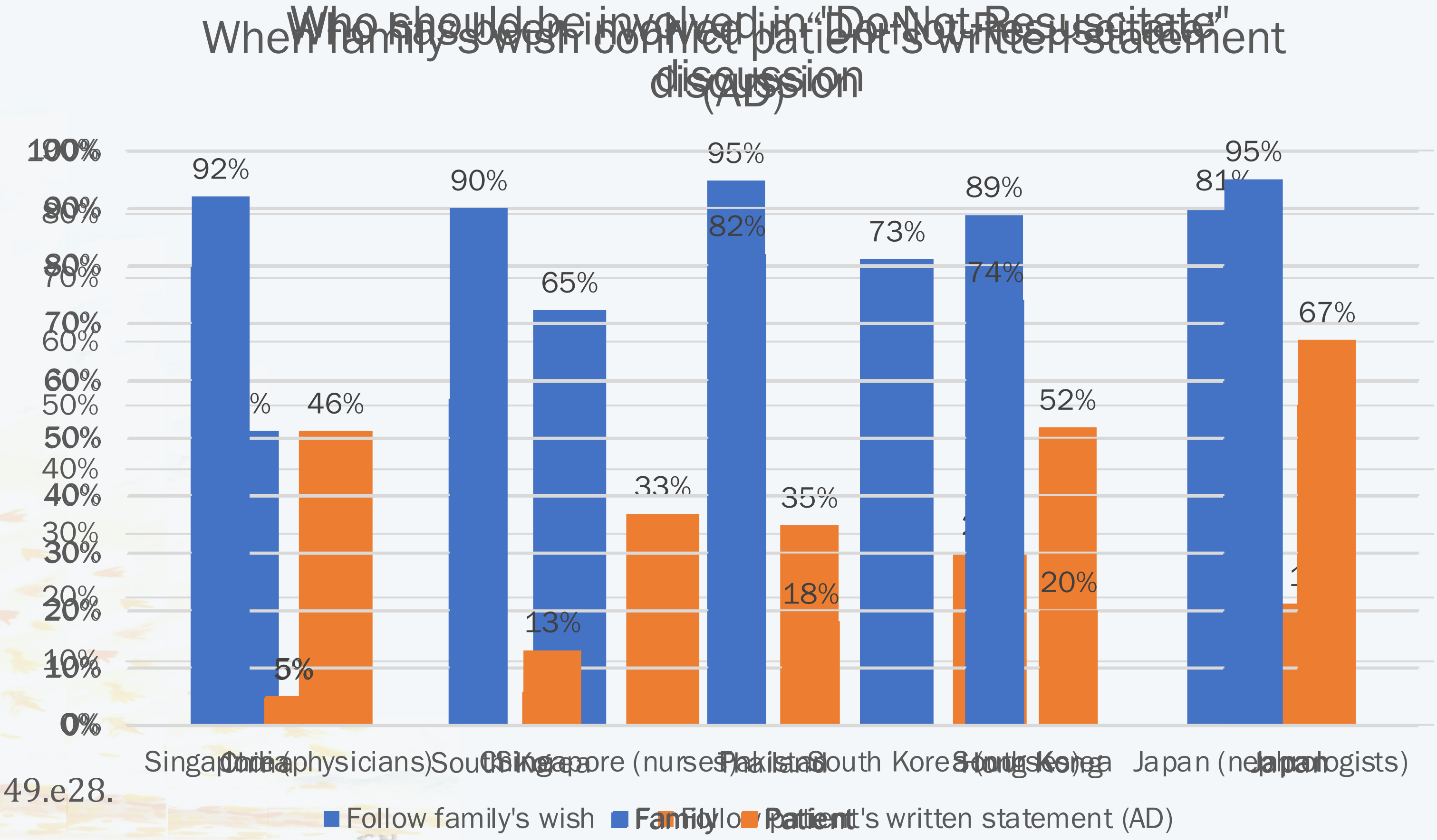
Martina, D, et al. Pall Med, 2021: p. 02692163211042530

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]

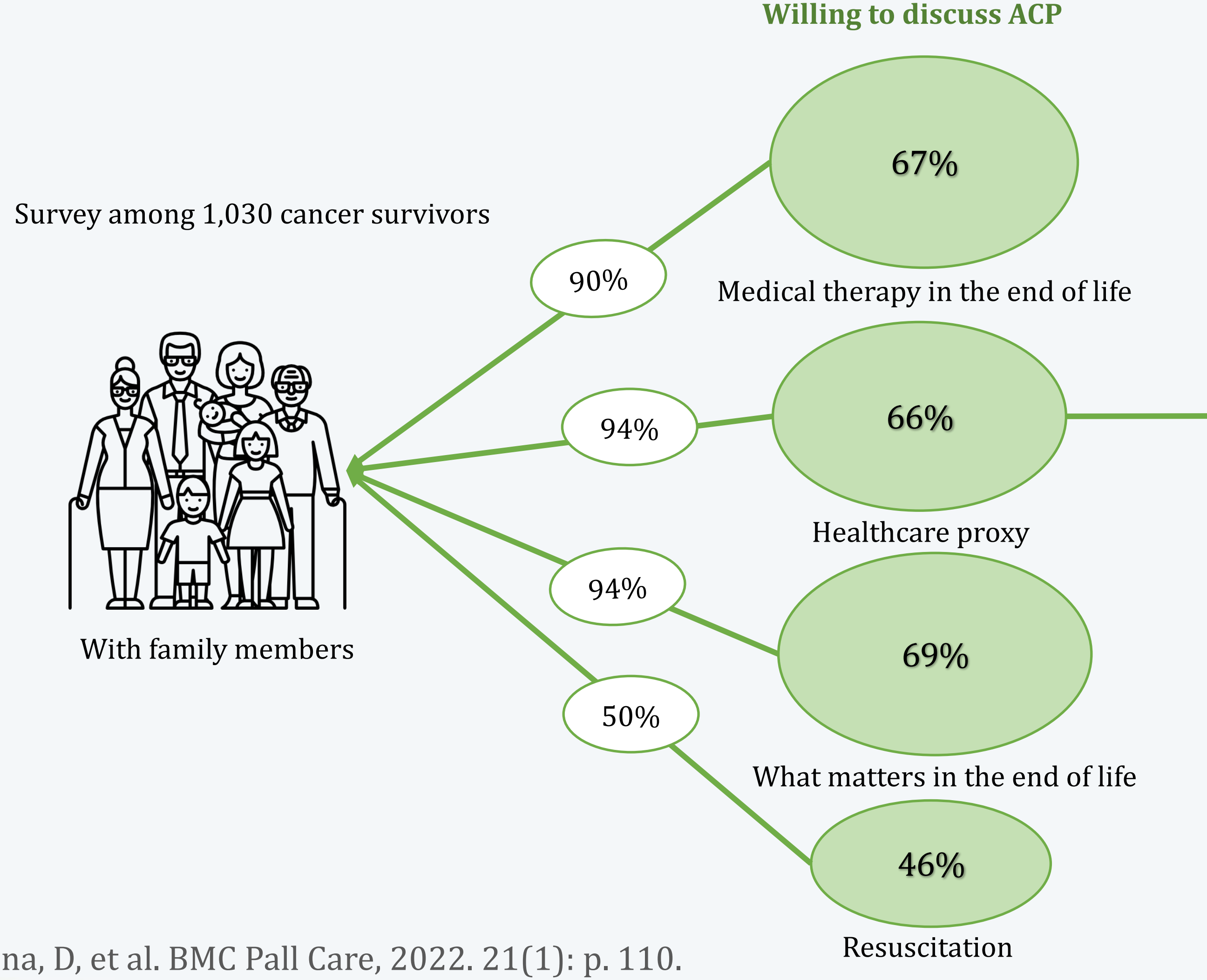


Martina, D, et al. JAMDA, 2021. **22**(2): p. 349.e1-349.e28.

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



Willing to discuss ACP

Survey among 1,030 cancer survivors

With family members

90%

67%

Medical therapy in the end of life

94%

66%

Healthcare proxy

94%

69%

What matters in the end of life

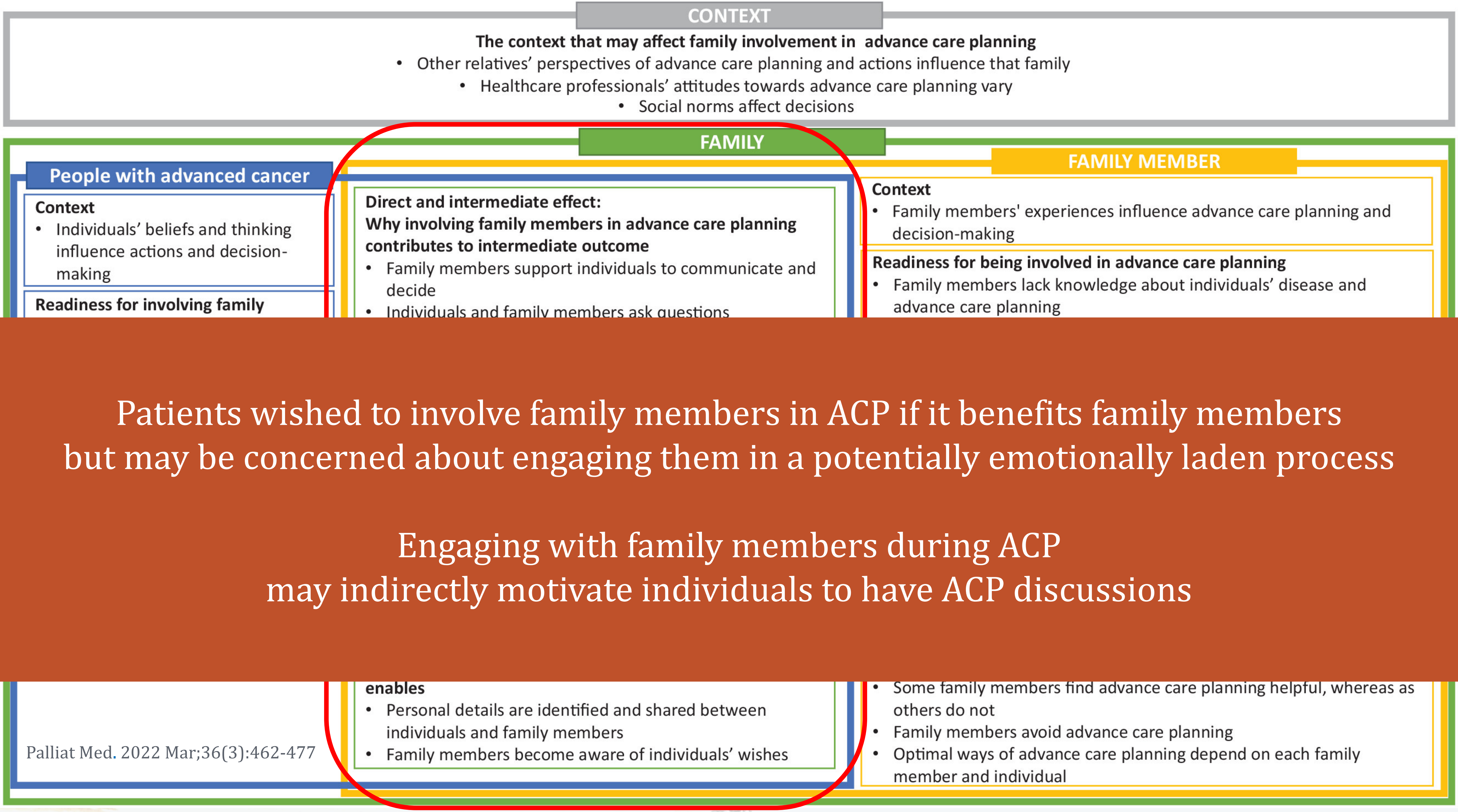
50%

46%

Resuscitation

---

1. Martina, D, et al. Pall Med, 2021: p. 02692163211042530.
2. Martina, D, et al. JAMDA, 2021. **22**(2): p. 349.e1-349.e28.
3. Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 110.
4. Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204.
5. Martina, D, et al. JCO Glob Oncol, 2023. 9: e2300003



CONTEXT

The context that may affect family involvement in advance care planning

- Other relatives' perspectives of advance care planning and actions influence that family
- Healthcare professionals' attitudes towards advance care planning vary
- Social norms affect decisions

FAMILY

People with advanced cancer

Context

- Individuals' beliefs and thinking influence actions and decision-making

Readiness for involving family

Direct and intermediate effect:
Why involving family members in advance care planning contributes to intermediate outcome

- Family members support individuals to communicate and decide
- Individuals and family members ask questions

enables

- Personal details are identified and shared between individuals and family members
- Family members become aware of individuals' wishes

FAMILY MEMBER

Context

- Family members' experiences influence advance care planning and decision-making

Readiness for being involved in advance care planning

- Family members lack knowledge about individuals' disease and advance care planning
- Some family members find advance care planning helpful, whereas as others do not
- Family members avoid advance care planning
- Optimal ways of advance care planning depend on each family member and individual

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

Palliat Med. 2022 Mar;36(3):462-477

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

Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 110.
Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204
Kishino M et al. Palliat Med. 2023 Oct;37(9):1434-46

Strategy to tackle cultural dillema of breaking bad news

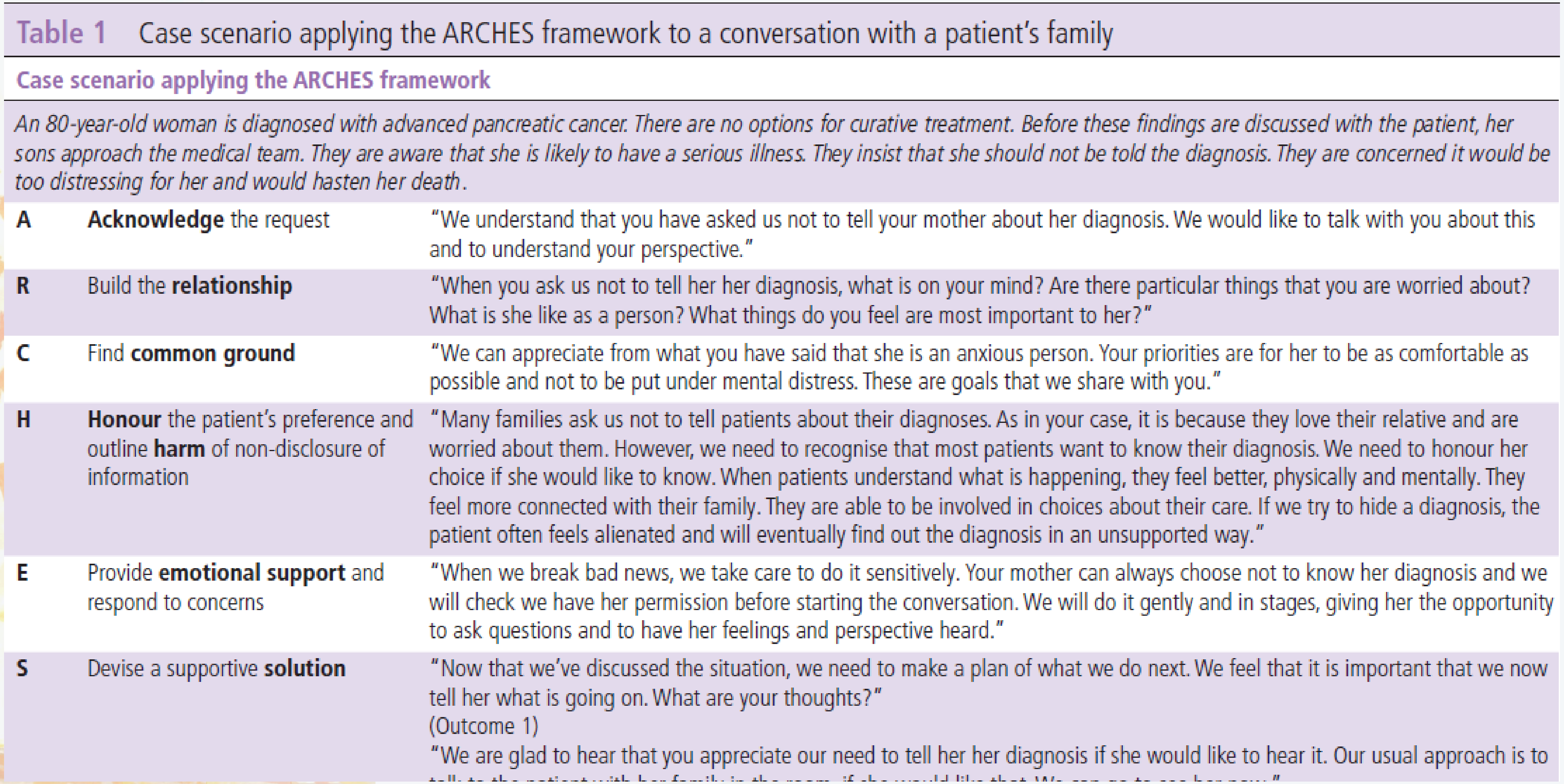


Table 1 Case scenario applying the ARCHES framework to a conversation with a patient's family

Case scenario applying the ARCHES framework		
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.		
A	**Acknowledge** the request	"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."
R	Build the **relationship**	"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?"
C	Find **common ground**	"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."
H	**Honour** the patient's preference and outline **harm** of non-disclosure of information	"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."
E	Provide **emotional support** and respond to concerns	"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."
S	Devise a supportive **solution**	"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) "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

BMJ Supportive & Palliative Care 2021;**11:**128-132

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

Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204.

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

Only God knows

We are praying for miracle

It’s in God’s hands

Also → creating alignment is key!

1. Martina, D, et al. Pall Med, 2021: p. 02692163211042530.
2. Martina, D, et al. JAMDA, 2021. **22**(2): p. 349.e1-349.e28.
3. Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 110.
4. Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204.
5. Martina, D, et al. JCO Glob Oncol, 2023. 9: e2300003

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

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

Ann Intern Med, 2010. 153(4): p. 256-61
J Am Geriatr Soc, 2021. 69(1): p. 234-244.

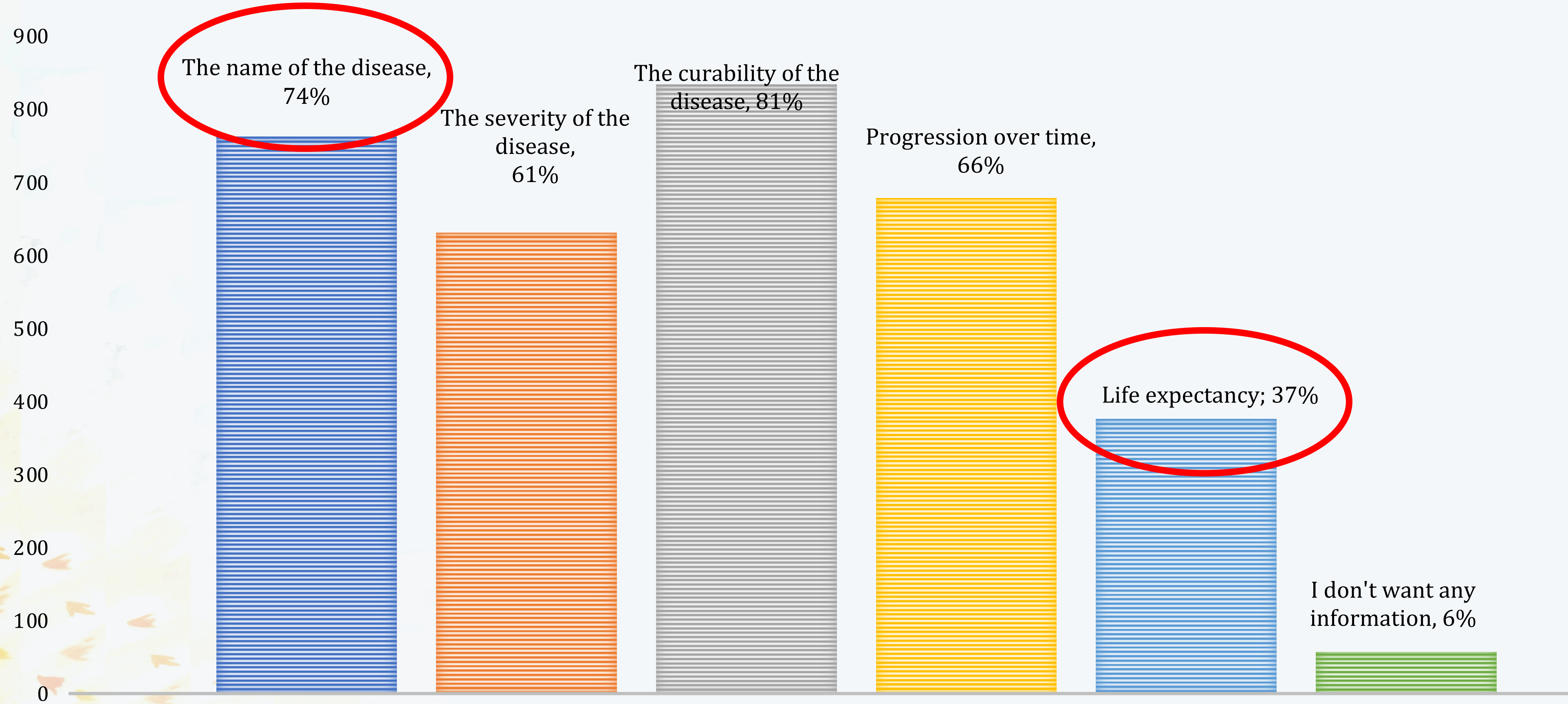
Survey to Indonesian cancer survivors :

	Wish to document
Medical therapy in the end of life	42%
Healthcare proxy	50%
What matters in the end of life	50%
Resuscitation	34%

Martina, D, et al. JCO Global Oncology no. 9 (2023) e2300003

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?

Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204
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

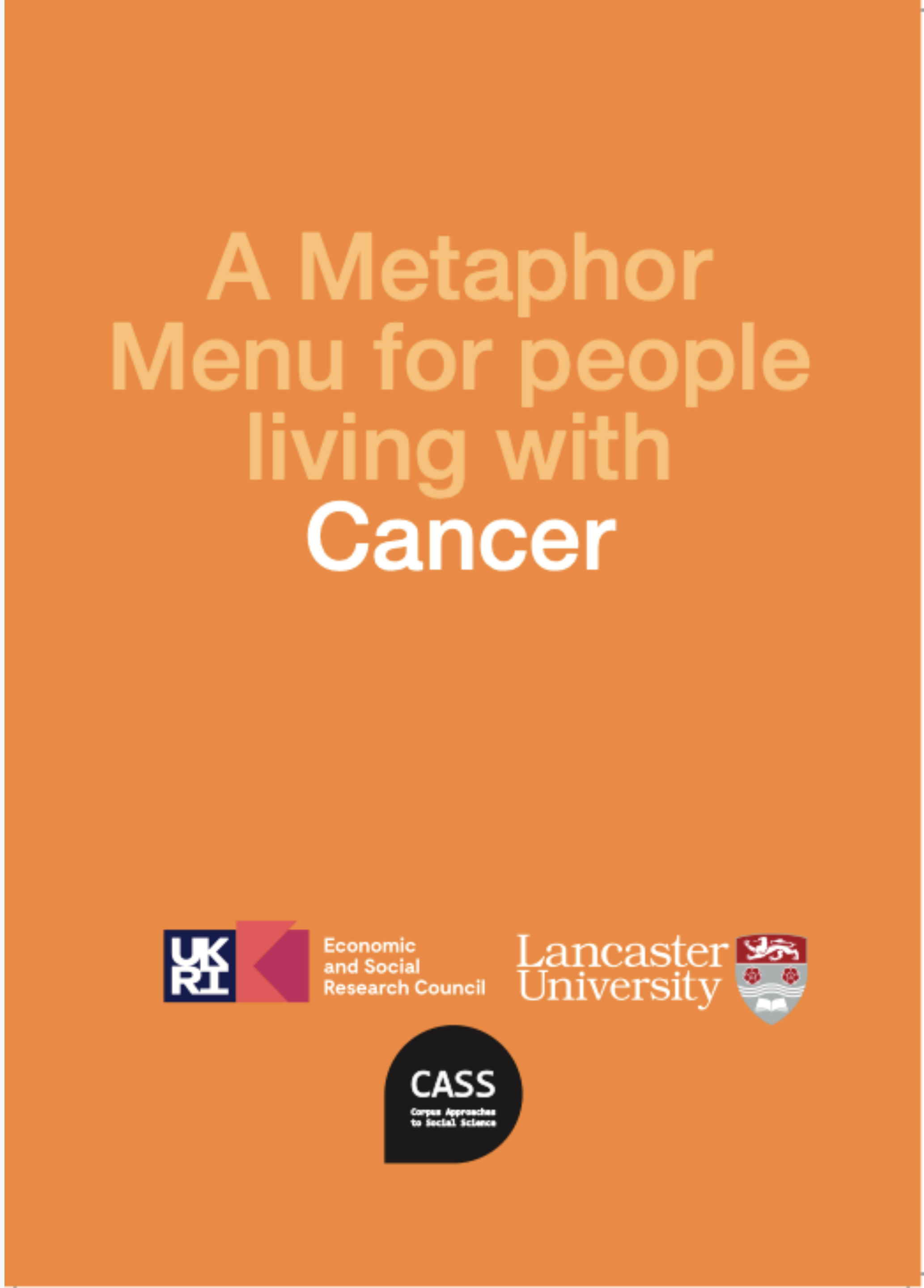
“We would not use the term ‘refusal of resuscitation’ rather than ‘allow natural death’ when asking them to sign the DNR form”

(Physician)

Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 110.
Martina, D, et al. BMC Pall Care, 2022. 21(1): p. 204.

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.



A Metaphor Menu for people living with Cancer

UKRI Economic and Social Research Council

Lancaster University

CASS
Corpus Approaches to Social Science


The Oncologist®

Medical Ethics

Serious Illness Conversations: Paving the Road with Metaphors

DAVID HUI, DONNA S. ZHUKOVSKY, EDUARDO BRUERA
Department of Palliative Care, Rehabilitation and Integrative Medicine, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Advance care planning • Communication • Hospice care • Metaphor • Neoplasms • Palliative care

> *“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)*

TheOncologist 2018;23:730–733

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 ilness

Add years to live

Reduce the burden of healthcare service

Reduce healthcare cost

Avoid legal prosecution

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

@DiahMartina2

Diah Martina

diah.martina@gmail.com

Thank you

Advance Care Planning in the Asia Pacific

Edited by

Raymond Han Lip Ng
Woodlands Health, Singapore

Diah Martina
Universitas Indonesia, Indonesia

Cheng-Pei Lin
National Yang Ming Chiao Tung University, Taiwan

Masanori Mori
Seirei Mikatahara General Hospital, Japan

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

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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

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?

Illness related issues

Symptom Distress
- Physical distress
- Psychological distress

Level of Dependence
- Cognitive acuity
- Functional capacity

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
- Living in the moment
- Maintaining normalcy
- Finding spiritual comfort

Social dignity Inventory

- Privacy boundaries
- Social Support
- Care Tenor
- Burden to others
- Aftermath concerns

Chochinov Model of Dignity (2002)

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.

Study Design

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’

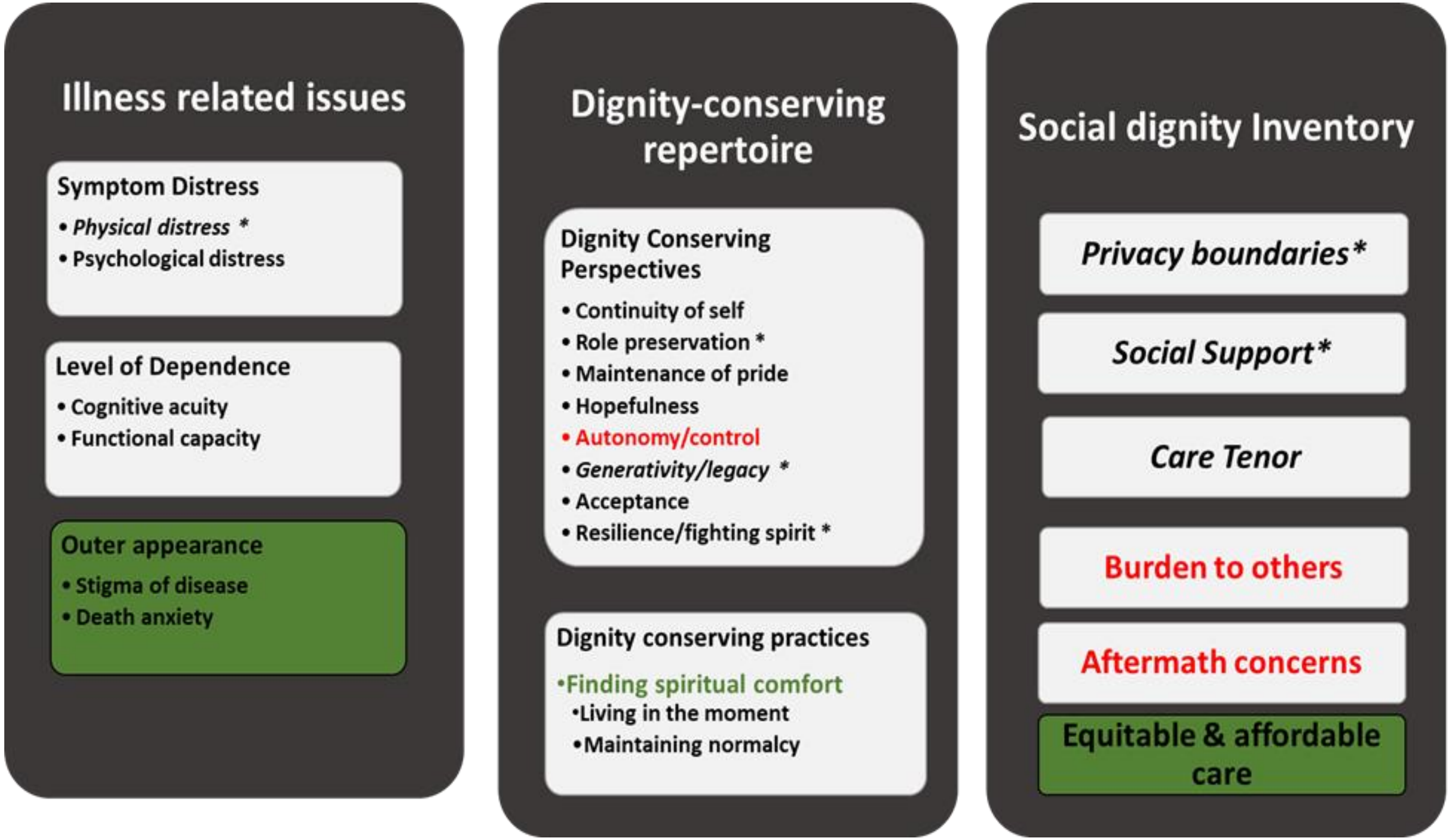
Chochinov Model *amended* considering the findings

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

- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic Analysis. In P. Liamputtong (Ed.), Handbook of Research Methods in Health Social Sciences (pp. 843-860). Springer Singapore. https://doi.org/10.1007/978-981-10-5251-4_103
- Chochinov, Hack, McClement, Kristjanson, & Harlos. (2002). Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*, *54*. https://doi.org/10.1016/S0277-9536(01)00084-3
- Daher, M. (2021, July, 2021). *State of Palliative Care in Lebanon* [Interview].
- Dakessian Sailian, S., Salifu, Y., Saad, R., & Preston, N. (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. BMC Palliative Care, 20(1), 112. https://doi.org/10.1186/s12904-021-00791-6
- Lynch, T. P., Connor, S. P., & Clark, D. P. (2013). Mapping Levels of Palliative Care Development: A Global Update. J Pain Symptom Manage, 45(6), 1094-1106. https://doi.org/10.1016/j.jpainsymman.2012.05.011
- Soueidan, Osman H, & F, E.-J. (2018). K2P Policy Brief: Integrating Palliative Care into the Health System in Lebanon. (Knowledge to Policy (K2P) Center, Issue.

Lancaster University

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

July 22, 2019, by sleatherland

Graduation blog – Dr Yakubu Salifu

This month we’re celebrating the achievements of our new School of Health Sciences graduates! In our latest blog post , Dr Yakubu Salifu shares an insight into his research…

Dr Yakubu Salifu is Doctor of Philosophy in Nursing (Palliative Care) and his PhD explored the Home-Based Supportive and Palliative Care for Men Living with Advanced Prostate cancer in Ghana. His PhD was supervised by Professor Kathryn Almack and Dr Glenys Caswell.

‘This is a novel study providing a substantial contribution to new knowledge. Being a qualitative study, with mixed data sources, one of its greatest strengths is the range of issues uncovered

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

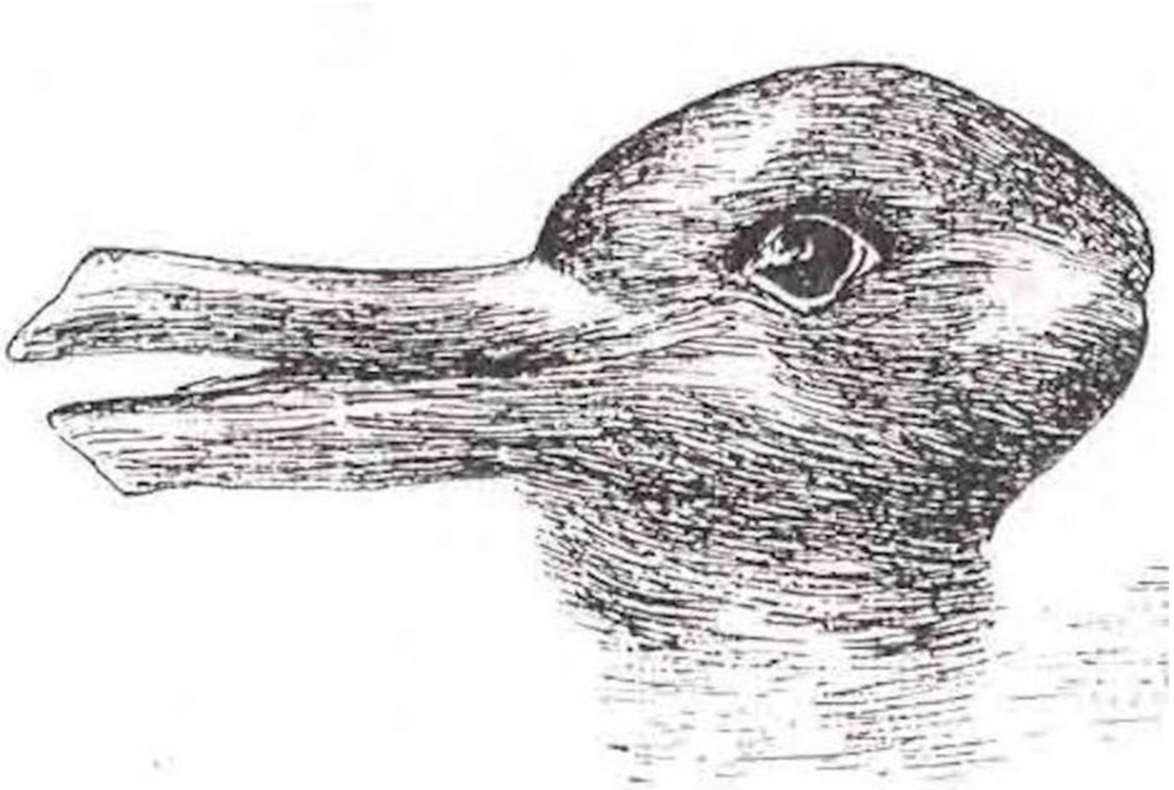
Resource Disparities

Cultural Nuances:

Healthcare Infrastructure

Funding/Economic Factors

Population Demographics



Is it a rabbit or a duck?

Hospice Africa Uganda (HAU)

Lancaster University

- 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?

Funding: Ad hoc support system

JOSEPHINE YOUNGE

NEEDS A CANCER SURGERY

TARGET: USD $ 3000.00

Josephine Younge is a 22 year old Nurse who had her SHS and college education at Archbishop Porter Girls and Sekondi Nursing and Midwifery training college respectively, is battling with a rare type of cancer called *pseudopapillary tumor* of the pancrease.

The surgery involved costs ***USD 3000.00***

Please touch a life with any amount via the following outlets :

STANDARD CHARTERED BANK
0101100460900
- Addai Grace

MTN MOMO
+233 (0)247828702
(Josephine Younge)

MAY GOD THE GOOD LORD BLESS YOU

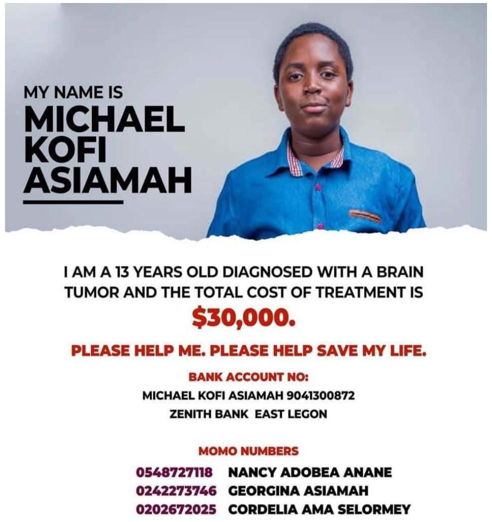
thank you

THANK YOU FOR SAVING THE LIFE OF GOLDA ADDO

You have helped us to raise GHC70,000 in less than 24 hours for Golda's metastatic carcinoma!

PLEASE continue to send in your donations, as we build a buffer fund for Golda to enable her have further treatment and rehabilitation after this round of surgeries and radio-/chemotherapy. We are hopeful that this first round of treatment will be all Golda needs, but if it isn't, your continuing donations will make all the difference.

MOMO NUMBERS:	NETWORKS: MTN
0541817725	ACCOUNT NAME: SHE AID (Golda's NGO)
0244828322	ACCOUNT NAME: GOLDA NAA ADAKU ADDO
054719999	ACCOUNT NAME: EBO GYEBI



MY NAME IS
MICHAEL KOFI ASIAMAH

I AM A 13 YEARS OLD DIAGNOSED WITH A BRAIN TUMOR AND THE TOTAL COST OF TREATMENT IS

$30,000.

PLEASE HELP ME. PLEASE HELP SAVE MY LIFE.

BANK ACCOUNT NO:
MICHAEL KOFI ASIAMAH 9041300872
ZENITH BANK EAST LEGON

MOMO NUMBERS

0548727118	NANCY ADOBEA ANANE
0242273746	GEORGINA ASIAMAH
0202672025	CORDELIA AMA SELORMEY

Pls my brother needs your help. Pls donate any amount don't worry how small it is. Pls help save his life. God bless you for donating 🙏

[illegible] diagnosed with mild kidney damage(Stage 3 Kidney Disease). In such short time it has progressed into End Stage Renal Disease(ESRD, Stage 5); the final stage of kidney injury . He is currently on twice weekly haemodialysis.
He is indebted so far to family, friends, prayer warriors, and others who in one way or the other have joined in support and in fundraising so far.

Kidneys function are to remove toxins and waste products from the body and balance the body's fluids.
ESRD is is a medical condition in which a one's kidneys stops functioning on a permanent basis leading to the need for a regular course of long-term dialysis or a kidney transplant to continue living.
Hemodialysis is procedure where a dialysis machine and a special filter called an artificial kidney, or a dialyzer,are used to clean your blood. To get your blood into the dialyzer, the doctor needs to make an access, or entrance, into your blood vessels. This is done with minor surgery
A kidney transplant is a surgical procedure performed when a person whose kidneys no longer function properly is replaced with a healthy kidney from a living or deceased donor.

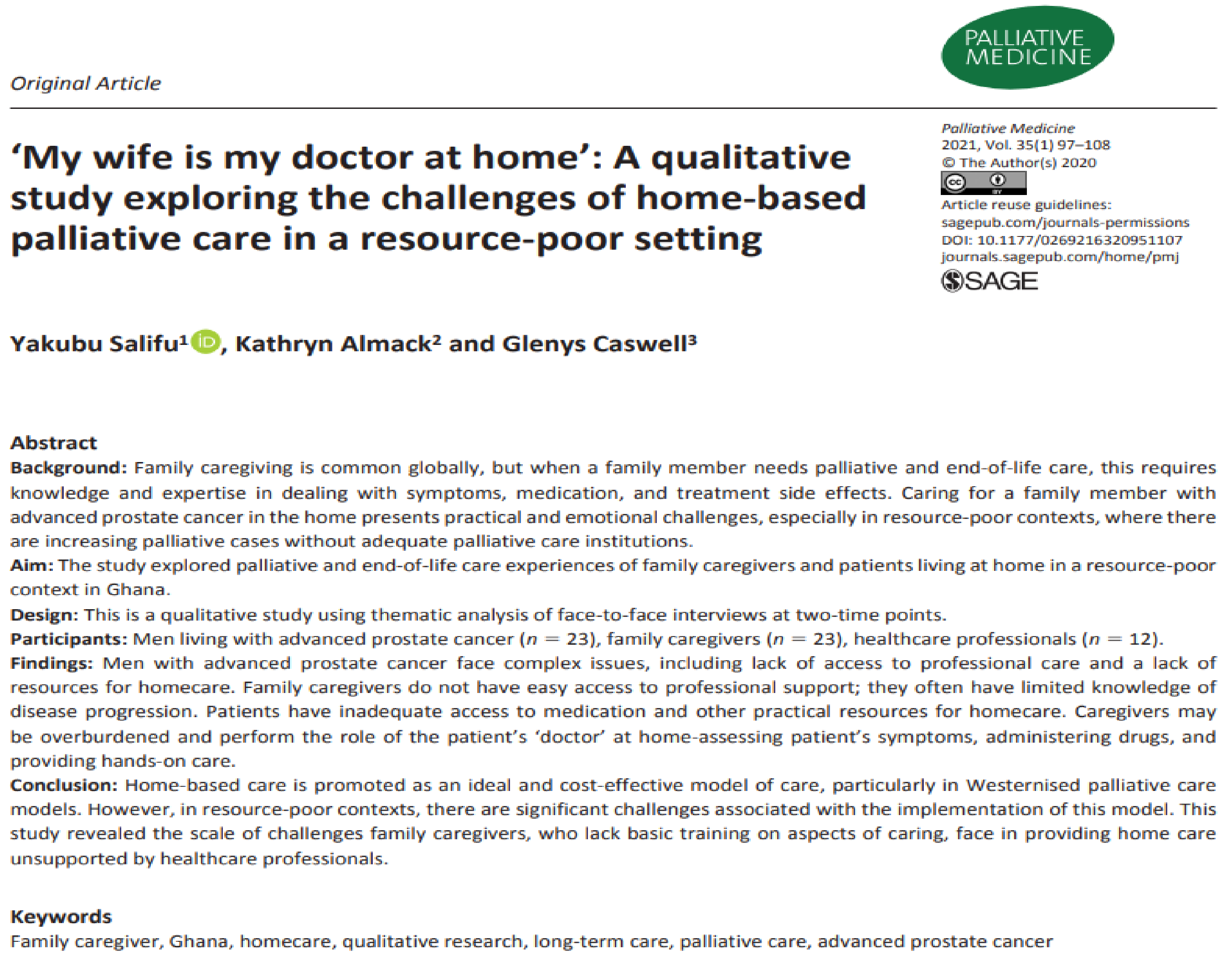
Momo
0243112774
Abigail OKRAH

COMPASS GHANA

NHIS

- Subscription
- Extensive exemption
- Under funded

Heath staff Capacity



Original Article

Palliative Medicine
2021, Vol. 35(1) 97–108

DOI: 10.1177/0269216320951107
journals.sagepub.com/home/pmj

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

Yakubu Salifu[1], Kathryn Almack[2] and Glenys Caswell[3]

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’

Palliative Care & Social Practice

Original Research

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

Palliative Care & Social Practice

2023, Vol. 17: 1–14

DOI: 10.1177/26323524231176829

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.

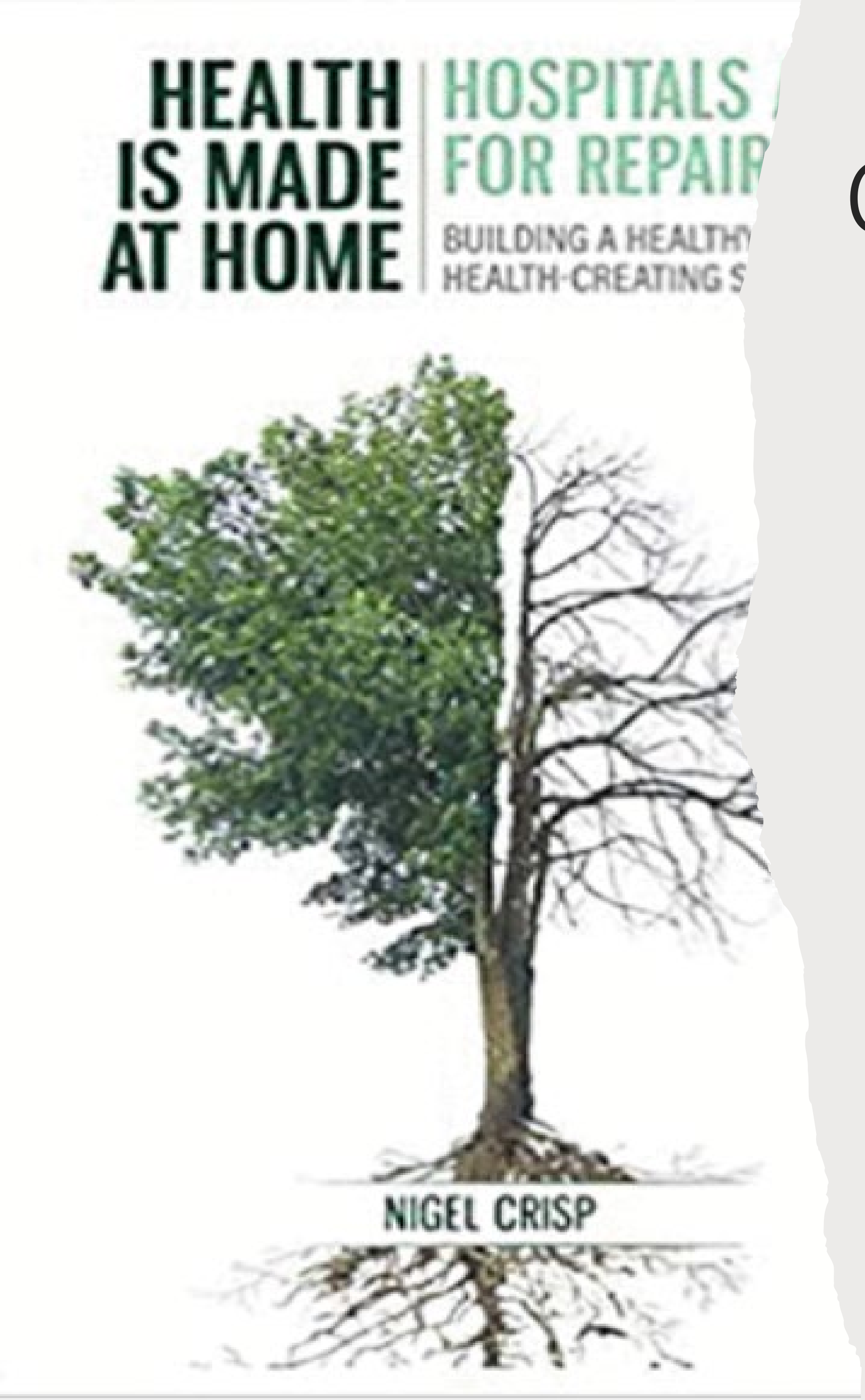
Results: The findings from this study highlight profound challenges for most men to their masculine identities, from both the treatment and the symptoms of advanced prostate cancer within a non-Westernised, patriarchal society. Four main themes were developed. These were the impact on masculinity in 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 to continue acting as provider and protector 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

Correspondence to:
Yakubu Salifu
Lecturer in Palliative Care, International Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, University of Lancaster, Lancaster, LA1 4AT, UK.
y.salifu@lancaster.ac.uk

Kathryn Almack
Professor of Family Lives and Care, Centre for Future Societies Research Communities,

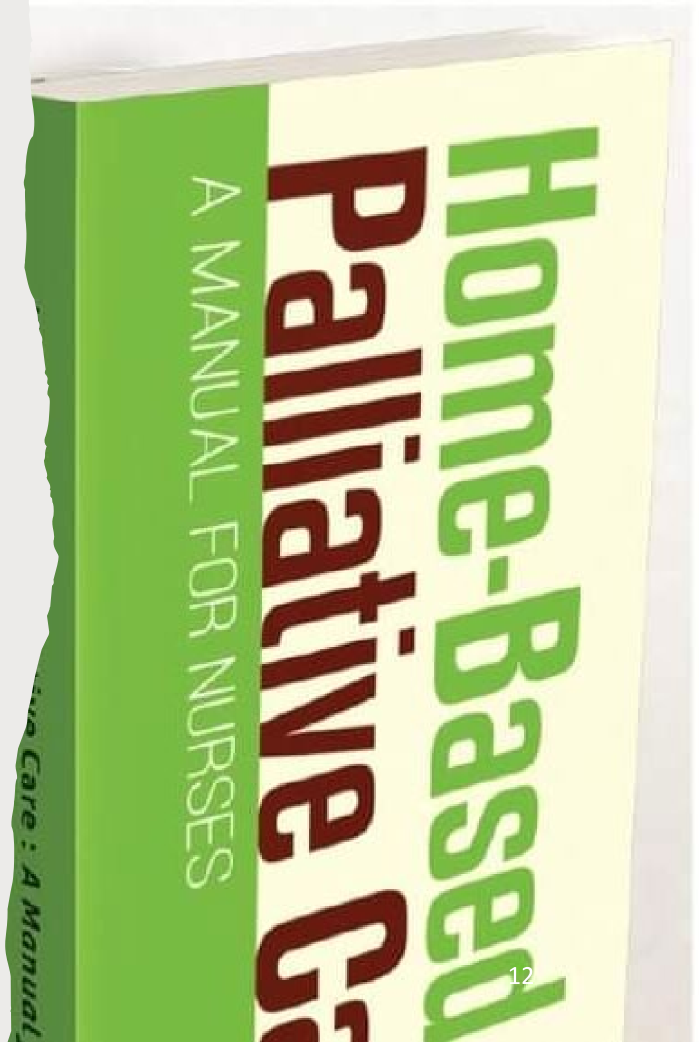


Compass-Ghana's Approach

- 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?

ster
sity

Compassionate Palliative Services

Call to improve healthcare provision for people with cancer in Ghana

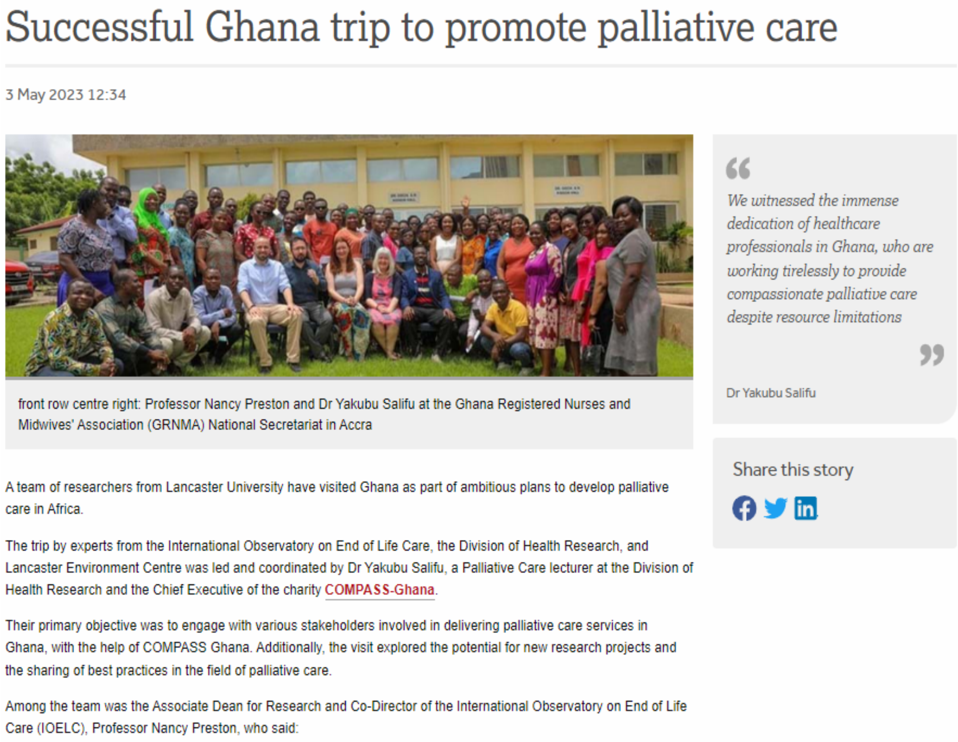
4 February 2020 00:01

Dr Yakubu Salifu (left) at the launch of Nursing Now

Lancaster University researcher **Dr Yakubu Salifu** says cancer patients in Ghana should get better access to palliative care.

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 12:34

front row centre right: Professor Nancy Preston and Dr Yakubu Salifu at the Ghana Registered Nurses and Midwives' Association (GRNMA) National Secretariat in Accra

> *We witnessed the immense dedication of healthcare professionals in Ghana, who are working tirelessly to provide compassionate palliative care despite resource limitations*
>
> Dr Yakubu Salifu

A team of researchers from Lancaster University have visited Ghana as part of ambitious plans to develop palliative care in Africa.

The trip by experts from the International Observatory on End of Life Care, the Division of Health Research, and Lancaster Environment Centre was led and coordinated by Dr Yakubu Salifu, a Palliative Care lecturer at the Division of Health Research and the Chief Executive of the charity COMPASS-Ghana.

Their primary objective was to engage with various stakeholders involved in delivering palliative care services in Ghana, with the help of COMPASS Ghana. Additionally, the visit explored the potential for new research projects and the sharing of best practices in the field of palliative care.

Among the team was the Associate Dean for Research and Co-Director of the International Observatory on End of Life Care (IOELC), Professor Nancy Preston, who said:

Engaging the stakeholders

Impact and Success Stories: Hubs

COMPASS-GHANA (COMPASSIONATE PALLIATIVE SERVICES)

Bringing Compassionate Palliative Care to Ashanti: Our £50,000 Mission

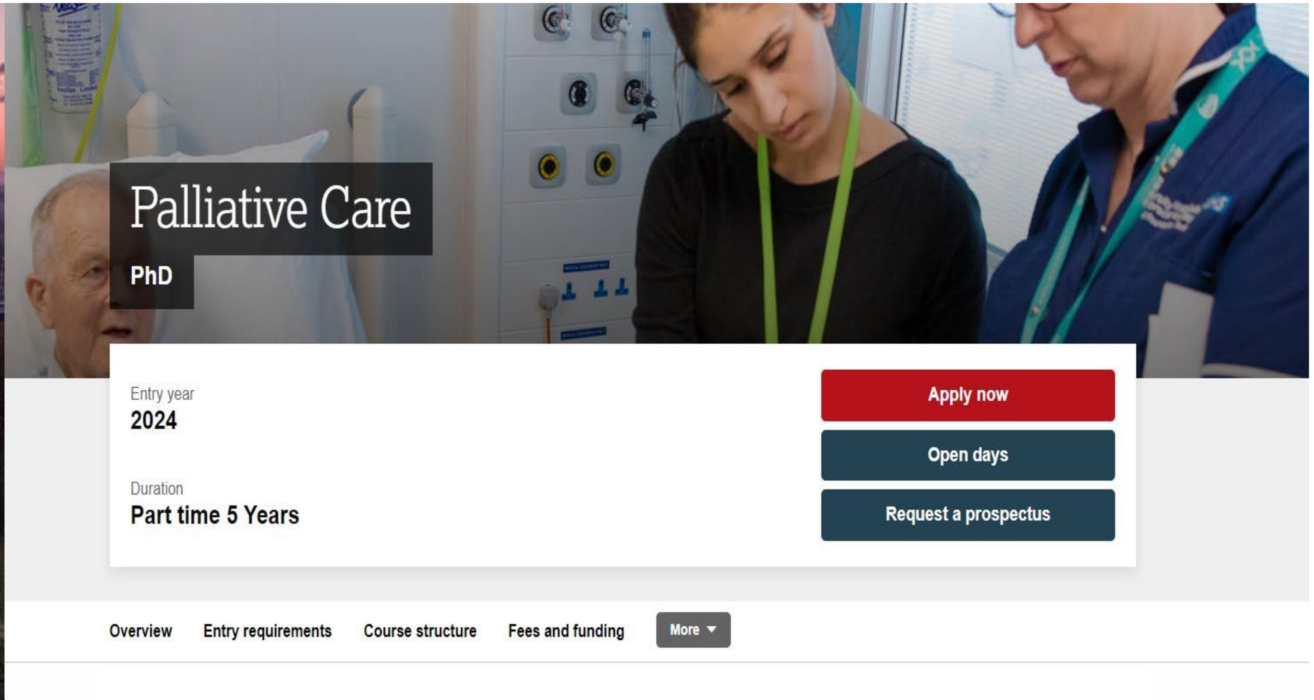
Join us in raising £50,000 for palliative care in Ghana. Every contribution matters. Support our mission today.

In our learning, unlearning and relearning, we need each other

✉ y.salifu@lancaster.ac.uk

𝕏 @Salid32Salifu

Come study with us at Lancaster University



Palliative Care

PhD

Entry year
2024

Duration
Part time 5 Years

Part-time, international, distance learning programme.

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