

A Palliative Care Journey in Kenya

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Living Room International

Kenya Demographics

- Population of Kenya is estimated to be 52.5 million.
- Leading causes of death are :
 - infectious disease
 - cardiovascular disease
 - cancer

- It is estimated that the annual incidence of cancer is about 37,000 new cases with an annual mortality of 28,000 cases. The leading cancers in women are breast and cervical and in men, prostate and esophageal.
- Seventy to 80% of patients are diagnosed in late stages because of lack of awareness, inadequate diagnostic and treatment facilities, high cost, and high poverty index.

History of Palliative Care in Kenya

- The Nairobi Hospice began providing home care in 1990
- Kenya Hospice & Palliative Care Association (KEHPCA) was founded in 2005 as a nonprofit nongovernmental organization representing health care institutions providing palliative care and individual health care professionals with an interest in palliative care.
- In 2007, 14 institutions providing palliative care to a population of more than 40 million.
- In 2021, 70 institutions providing palliative care, including hospices for home care, inpatient units in government hospitals, private hospitals, faith-based institutions, and community-based centers.

Living Room is a healthcare organization in Kenya.

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We provide dignity and quality of life to people in Kenya affected by life-threatening illnesses through holistic care and education.



Our values:



Vision

Create a community of compassion that honors life and offers hope for some of the world's most vulnerable adults and children in need of hospice care.



Our values:



Mission

To extend quality physical, psychological, and spiritual care to patients and their families.



Mission Goals:



Provide Patient Care

We increase access & affordability of palliative care services to adults and children in Kenya.



Build Relationships

We strengthen our services and effectiveness of our reach through local relationships and international partnerships.



Systemic Transformation

We demonstrate a model of compassionate care as well as education & research in effort to be a catalyst for systemic healthcare change in Eastern Africa.



Financial Sustainability

We develop income generating businesses that are aligned with Living Room's mission to increase financial sustainability in our communities.

LIVING ROOM

Our Facilities & Services:



Living Room Hospital

Eldoret, Kenya

49 BED INPATIENT HOSPITAL
OUTPATIENT CLINIC
PHYSIOTHERAPY
LABORATORY SERVICES
PHARMACY SERVICES
PSYCHOLOGICAL COUNSELING
CHAPLAIN CARE



Kimbilio Hospice

Kipkaren, Kenya

INPATIENT HOSPICE
OUTPATIENT PALLIATIVE CARE
PAIN AND SYMPTOM MANAGEMENT
COMMUNITY BASED CARE PROGRAM
PHYSIOTHERAPY



Kimbilio Funeral Home

Kipkaren, Kenya

BEREAVEMENT & FAMILY COUNSELING

POSTMORTEM SERVICES

TRANSPORT SERVICES & FUNERAL PRODUCTS









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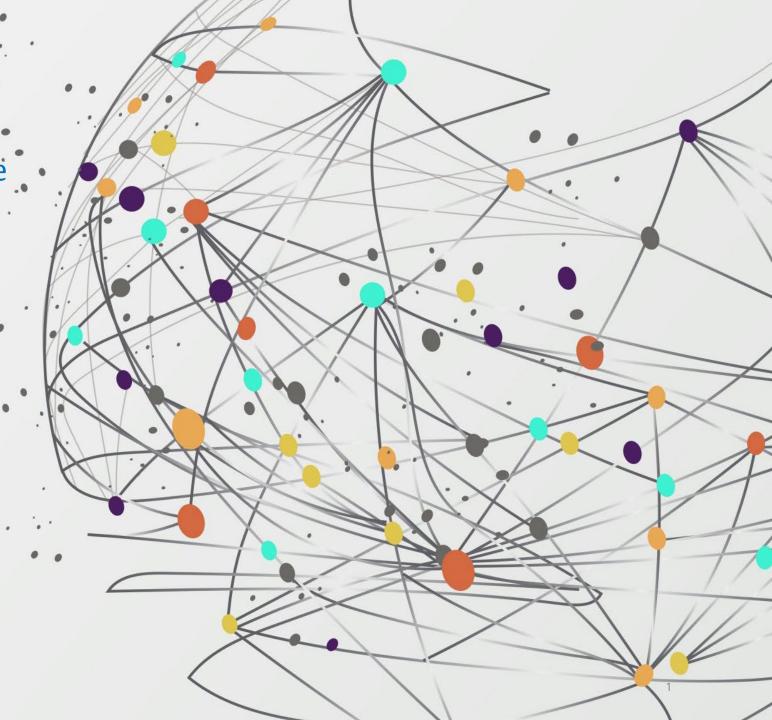


Honoring Life. Offering Hope. Optimizing the global palliative nursing workforce to alleviate serious health-related suffering

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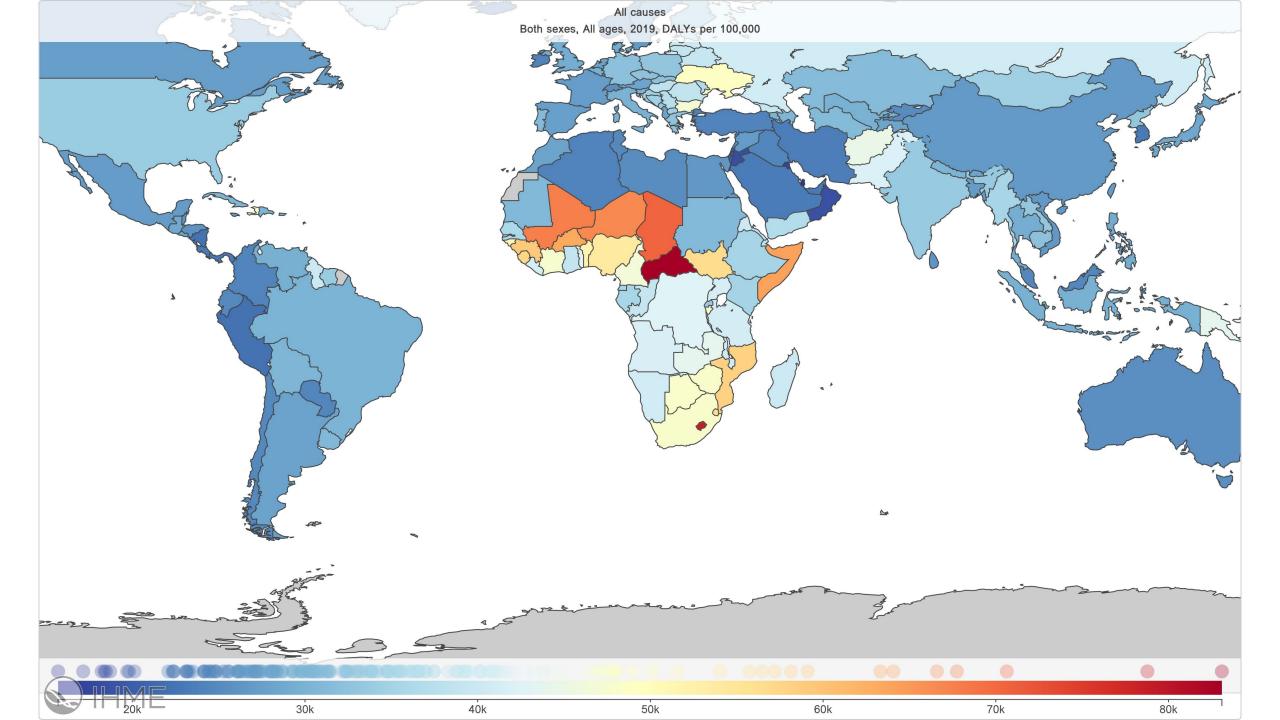
Palliative care needs in Sub-Saharan Africa

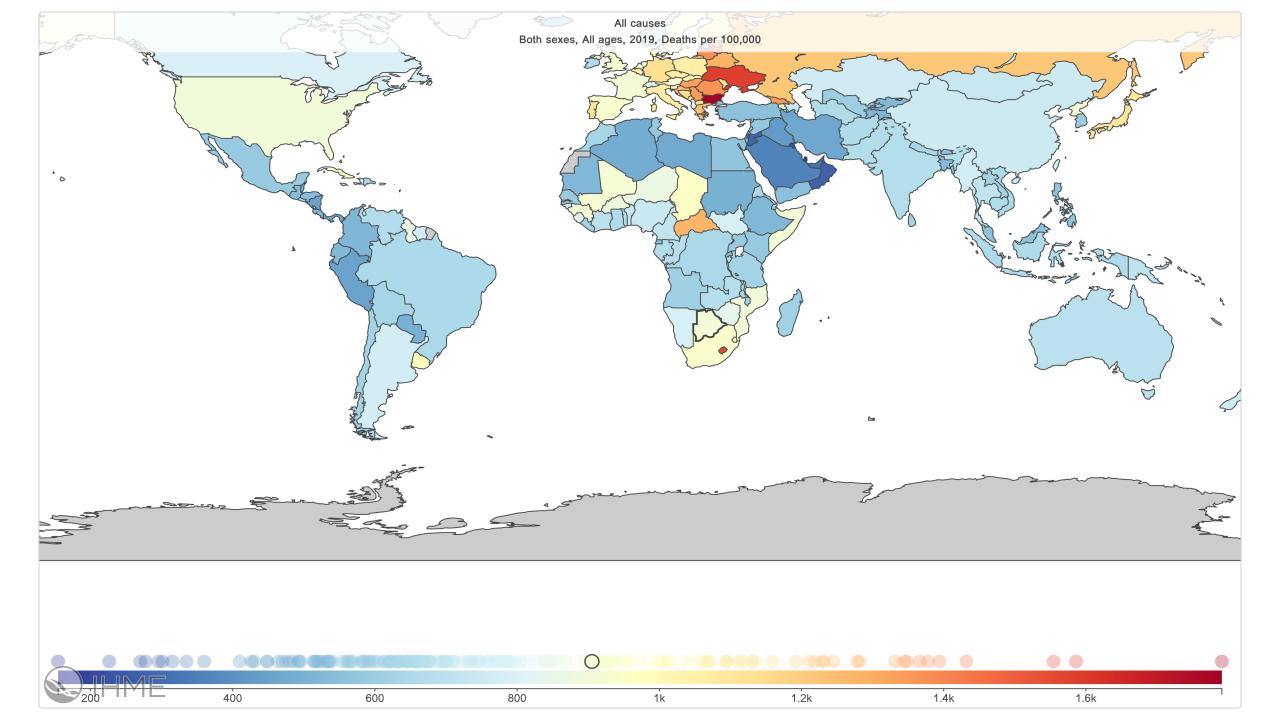
Persistently unmet needs

High deaths

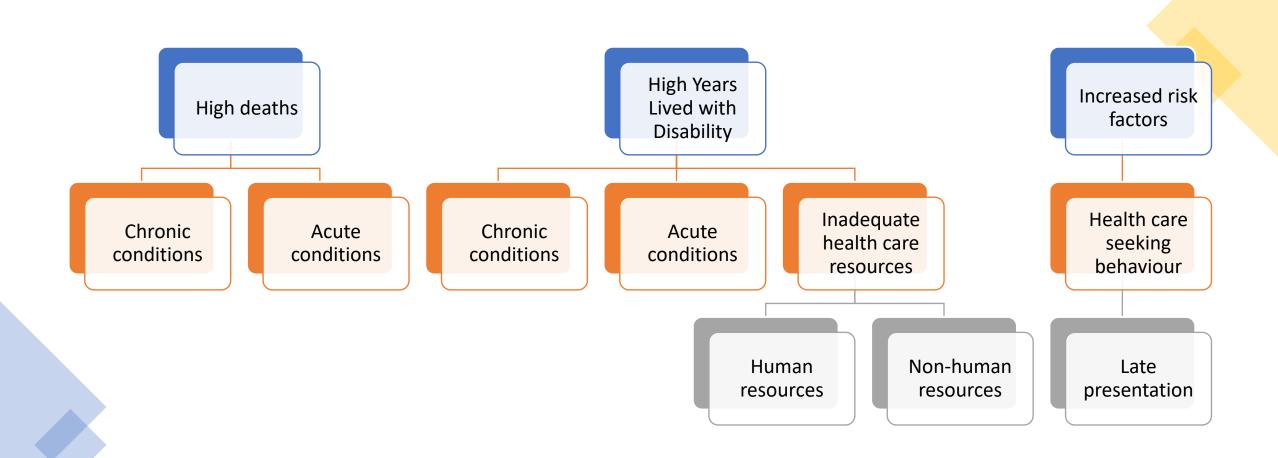
High Years Lived with Disability

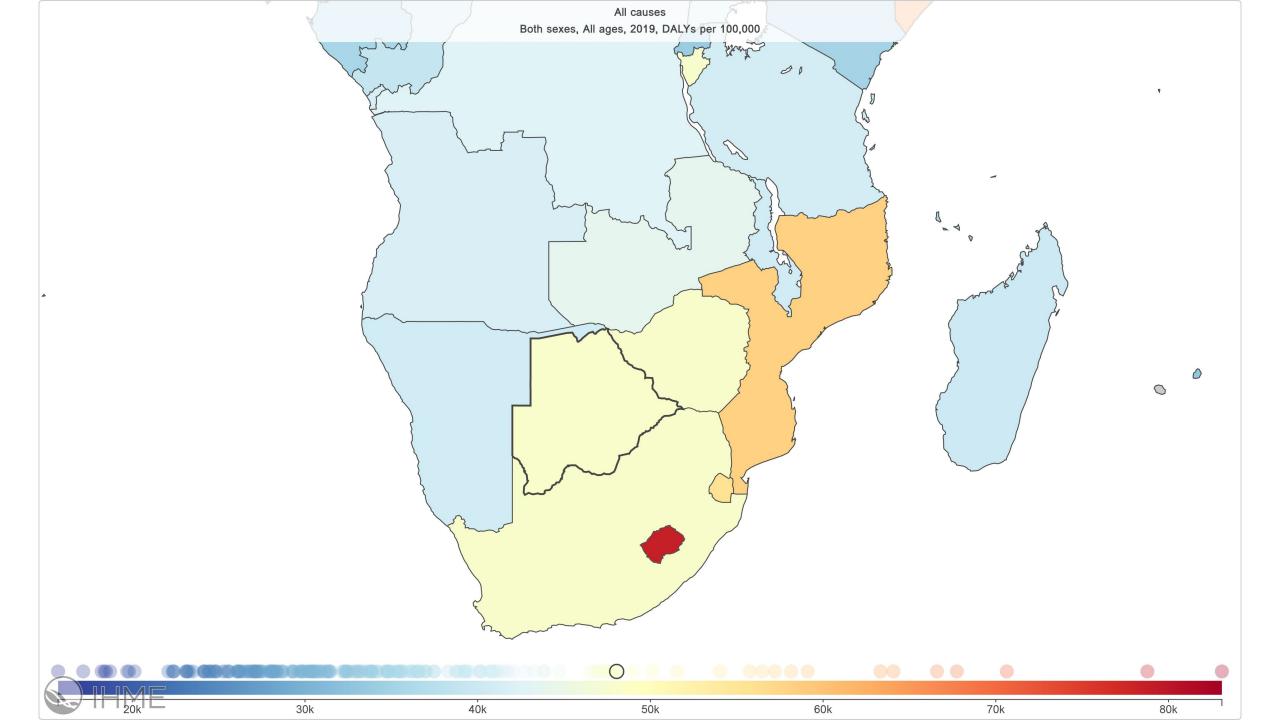
High risk factors





Palliative care needs in Botswana





2019 rank

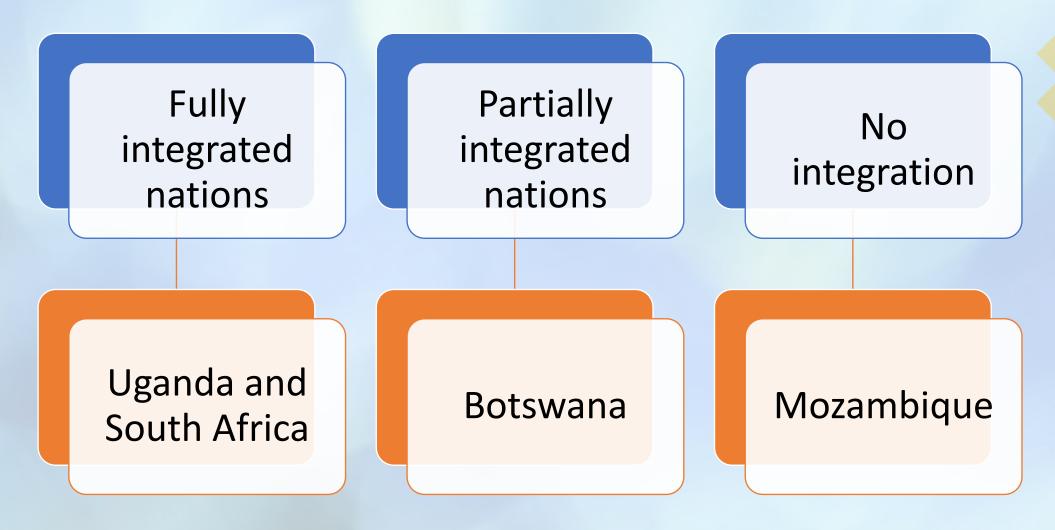
_	1 HIV/AIDS & STIs
_	2 Respiratory infections & TB
_	3 Cardiovascular diseases
-	4 Maternal & neonatal
_	5 Neoplasms
_	6 Other non-communicable
/	7 Diabetes & CKD
/	8 Self-harm & violence
/	9 Mental disorders
_	10 Transport injuries
-	11 Unintentional inj
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`	12 Enteric infections
`	12 Enteric infections
	12 Enteric infections 13 Digestive diseases
	12 Enteric infections 13 Digestive diseases 14 Musculoskeletal disorders
	12 Enteric infections 13 Digestive diseases 14 Musculoskeletal disorders 15 Neurological disorders
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	12 Enteric infections 13 Digestive diseases 14 Musculoskeletal disorders 15 Neurological disorders 16 Chronic respiratory 17 Nutritional deficiencies
	12 Enteric infections 13 Digestive diseases 14 Musculoskeletal disorders 15 Neurological disorders 16 Chronic respiratory 17 Nutritional deficiencies 18 Other infectious
	12 Enteric infections 13 Digestive diseases 14 Musculoskeletal disorders 15 Neurological disorders 16 Chronic respiratory 17 Nutritional deficiencies 18 Other infectious 19 Sense organ diseases

Communicable, maternal, neonatal, and nutritional diseases

Non-communicable diseases

Injuries

Progress of Palliative care in Sub-Saharan Africa



(LaVigne et al, 2018)

Progress of Palliative care in Botswana

- One of 74 countries worldwide considered to have "isolated palliative care provision
- Significant movement at national level in response to HIV/AIDS pandemic
- Community based model
 - Community members with minimum skills
- Policies to address Palliative care
- Partnerships
 - NGOs
 - Research
 - Training institutions

Challenges facing palliative care in the continent

Human resource for palliative care

Knowledge, attitudes and practices

Palliative care qualified members

Equipment and materials

Acceptance as alternative to health care system

Acceptance by community

Acceptance by health

professionals

Research and evidence-based care

Minimal evidence to support palliative care models in Africa

pportunities

Pivoting on the available resources

- Nurses
- Community
- Partnerships

Research

- Models
- Evidence on practices

Awareness

- Community awareness
- Health care providers education and awareness

ortunities

Non-human resources

Medications and supplies

Training

Health care workers

Benchmarking

 Integrated countries used to bench marking for other sub-Saharan African countries



Educational needs of Japanese nurses and exemplars of nursing leadership in the region

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About Myself

An Educator

An associate professor at the Kyoto University Graduate School of Medicine Department of Fundamental Nursing in Kyoto, Japan

A Researcher

- Advance Care Planning (ACP)/decision-making support models for patients with serious illness and citizens
- Ethics education and training programs for healthcare professionals
- Clinical ethics consultations
- Research ethics

A Nurse

Med-Oncology, Palliative/end-of-life care, Hospice care



Contents

OVERVIEW OF TODAY'S TOPICS

Educational needs of Japanese nurses
Palliative care education in Japan
Serious Illness Care Program
Strategies to understand what matters
Leadership in the region





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260 million

Persons aged 65 years or over in Eastern and South-Eastern Asia

GLOBAL PERSPECTIVE

The largest increase is projected to occur in Asia, growing from 260 million in 2019 to 573 million persons aged 65 years or over in 2050.

UN World Population Ageing 2019, https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf

The Need for Decision-Making Support in EOL care



One of the most important tasks is to improve the quality of end-of-life (EOL) care by supporting decision-making on medical treatment and care that respects the wishes and best interests of the patient.

"Delivering person-centered integrated care and primary health services responsive to older people."

WHO The Decade of Healthy Ageing (2021–2030)





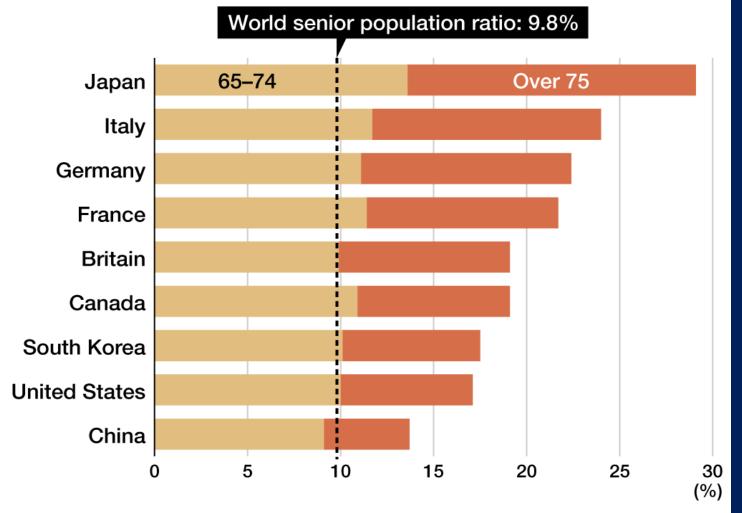
Japan has the highest senior population ratio in the world

Population 65 & over:

29.1%

36.3 million people

Senior Population Ratios in Selected Countries



Created by *Nippon.com* based on data from the Statistics Bureau, Ministry of Internal Affairs and Communications. Japan's value is based on population estimates as of September 15, 2022. Values for other countries are based on future estimates for July 1, 2022, from the United Nations' 2022 revision of *World Population Prospects*.

End-of-Life Nurse Education Consortium-Japan reached 60,428 Japanese nurses

- The ELNEC-Japan Project started in 2004.
- Trained 3,124 nurse educators, who in turn provided education to 60,428 nurses.













Challenges

of providing palliative/EOL care in Japan

Lack of knowledge and skills in advance care planning (ACP)

Basic education on palliative/EOL care is provided for nurses, but lacking training on ACP. (Kanoh et al., 2018)

Fear of causing pts psychological burden and conflicts w/ family members

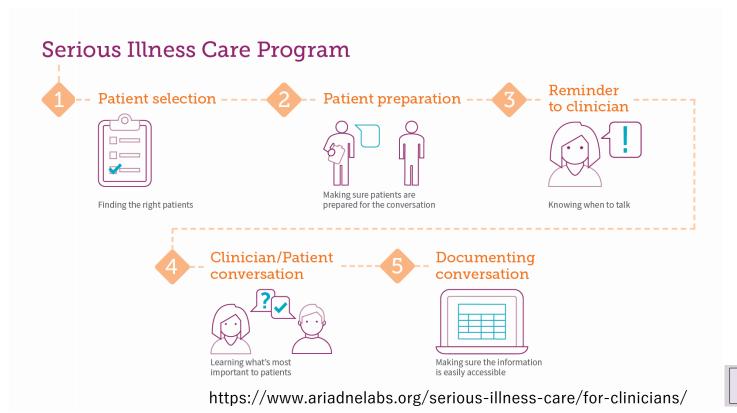
Do not have the skills to deal with the patients' emotions that arise from imagining what it would be like if their condition deteriorated. (Tarumi et al., 2016)

Difficult to elicit patients' values

Patients' values are strongly influenced by culturally shared concepts of "self." (Mori et al., 2020)

Serious Illness Care Program ARIADNE

Clinical Workflow Diagram



Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

"What is your understanding now of where you are with your illness?"

"How much information about what is likely to be ahead with your illness would you like from me?"

"I want to share with you my understanding of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."

)R

Time: "I wish we were not in this situation, but I am worried that time may be as short as _____ (express as a range, e.g. days to weeks, weeks to months, months to a year)."

OR

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

"What are your most important goals if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"

"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

"How much does your family know about your priorities and wishes?"

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this

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Qualitative Study

(Takenouchi et al., 2021)



Feature Article

Strategies to Understand What Matters to Advanced Cancer Patients in Advance Care Planning: A Qualitative Study Using the Lifeline Interview Method

Sayaka Takenouchi, PhD, MPH, RN O Ai Chikada, PhD, RN O Masanori Mori, MD O Keiko Tamura, PhD, RN O Kazuko Nin, PhD, RN

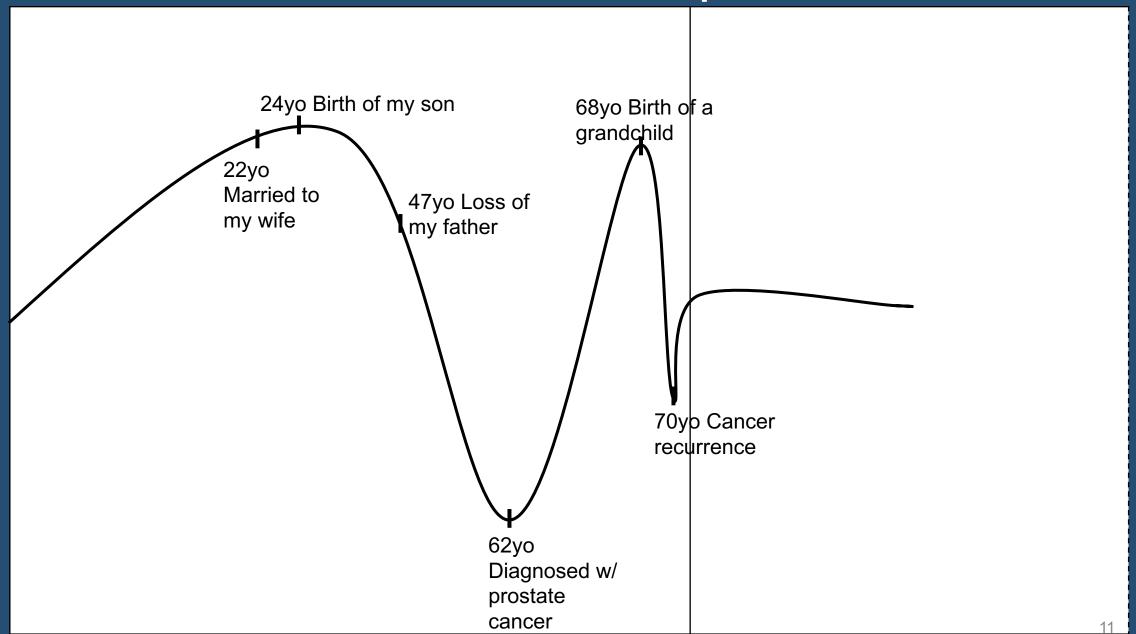
Little is known about how health care providers should conduct advance care planning to identify the values of East Asian patients who have serious illnesses. This study aims to explore whether and how patients from an East Asian culture and with advanced cancer express their values and priorities when nurses utilize the lifeline interview method to enable patients to reflect on their life trajectories and if it can bridge advance care planning discussions. Data obtained from individual, semistructured interviews of 11 patients with advanced lung cancer were analyzed using qualitative content analysis. Seven main

elicit patients' values and priorities. Moreover, it bridges advance care planning discussions to reflect on what matters to patients in future palliative care.

KEY WORDS

Asians, advance care planning, advanced lung cancer, lifeline interviews, palliative care

The Life-Line Interview Method: An example of a life-line



A model for ACP support through





A Research initiative



Dr. Tomoko Izawa, RN, OCNS



Dr. Yu Uneno MD, Field Operation and Quality



Sayako Ouchi, RN, OCNS



Prof. Shigemi Matsumoto MD, Quality Management



collaboration between physicians and nurses:

Takako Kuroda, RN, OCNS



Dr. Ai Chikada RN, In-House Operation



MD, Senior Management



MD, Consultant

The process of facilitating ACP: MD-Nurse collaboration model

Understand the purpose of ACP & identify values/priorities

2 Understand the medical condition and prognosis



3 Identify a surrogate decisionmaker & designate



5 Discuss future treatment/care priorities with HCPs (& family)

Review appropriateness of ACP

Introduce purpose of ACP

Ask permission of ACP

Assist life-review & explore values

Assess understanding & prognosis

Ask for a surrogate decision-maker

Ask if SDM has been delegated

Ask if SDM can join conversation

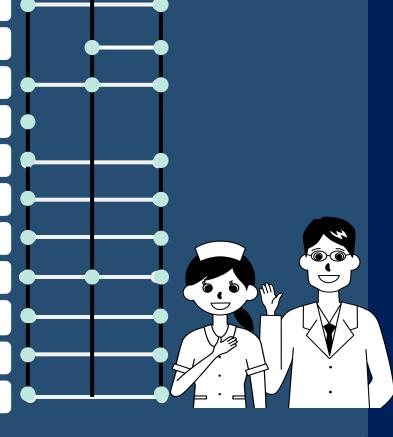
Explain treatment/care options

Facilitate shared decision-making

Make a recommendation & affirm commitment

Assist express wishes to physicians

Communicate with key HCPs



Nurse

Coordinate Listening/

Active

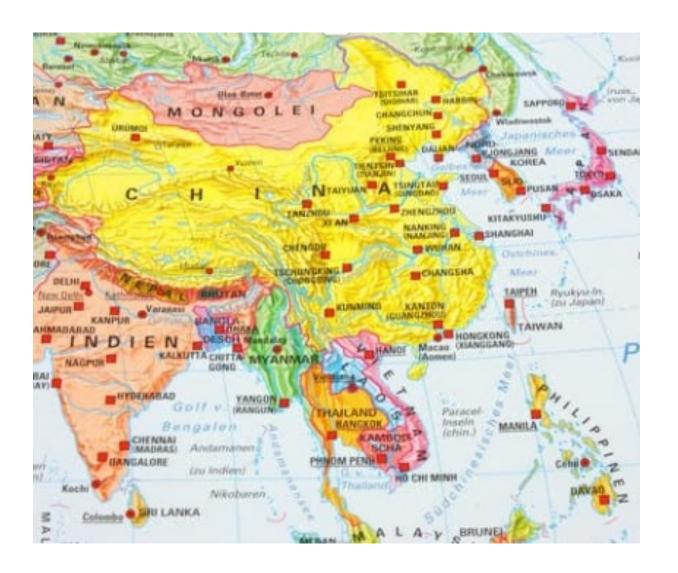
empathy

MD

KYOTO UNIVERSITY







Leadership in the region

 ELNEC International Mentorship Program

Matching nursing leaders from advanced palliative care countries with young Asian palliative care practitioners.

ACP Int'l Webinar
 Offering opportunities for nurses to learn on advance care planning through the Asia Pacific Hospice Network (APHN).

Thank you for listening!

Email: takenouchi.sayaka.6u@kyoto-u.ac.jp

HP: https://sites.google.com/view/nursing-ethics-kyoto-univ/home





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