Strategies for Overcoming Challenges of ACP in Japan

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Hello! こんにちは

About
Myself

An Educator

A Researcher

- Advance Care Planning (ACP)/decision-making support models for patients with serious illness
- 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

- Cultural challenges in ACP
- RN-MD collaborative SICP-based ACP
- Practical Strategies for Effective ACP

Culture

- Culture, unlike civilization, is rooted in what is unique to a people, and thus primordial.
- A certain way of life or form of thinking that has been practiced by a people since ancient times and which has remained despite historical developments and changes in their way of life.

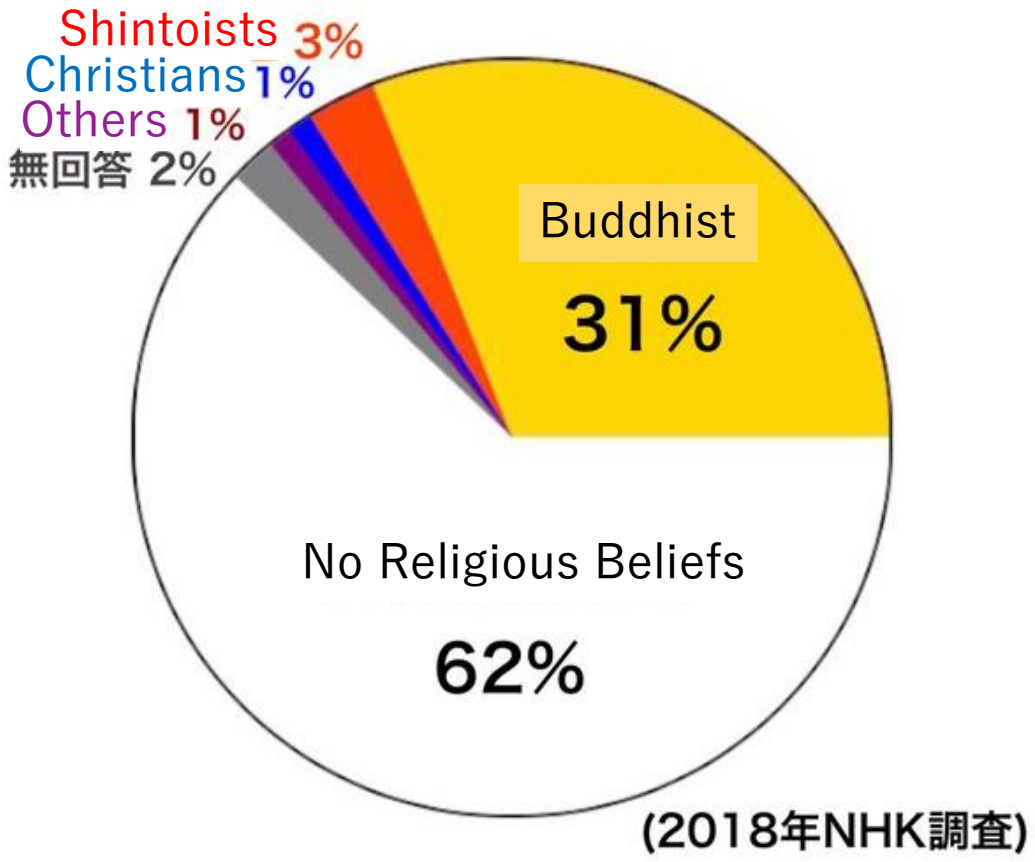
Tetsuro Watsuji, 風土 人間学的考察 (Climate, an Anthropological Consideration), 1980

Hot & humid climate natured receptive & patient personality

Spiritual, but not Religious

Japanese View of Life & Death
Diminishing Religious Consciousness

- Sense of disconnection between life and death
- Fear of death
- Sense of immortality
- Acceptance, endurance, and giving up



“家族”　Family

Japanese value Family, Community Bonds, Harmony, and Cooperation

国土交通省 https://www.mlit.go.jp/hakusyo/mlit/h30/hakusho/r01/pdf/np101300.pdf

How engaged are Japanese people in discussing/preparing for the end-of-life?

Survey data from the Ministry of Health, Labour and Welfare, Japan. 2023

ACP conversation

1.5% have had detailed discussions.

28% have had conversations to some extent.

Preparing advance directives (AD)

70% agreed that written AD should be prepared.

8% actually had AD prepared. (2018)

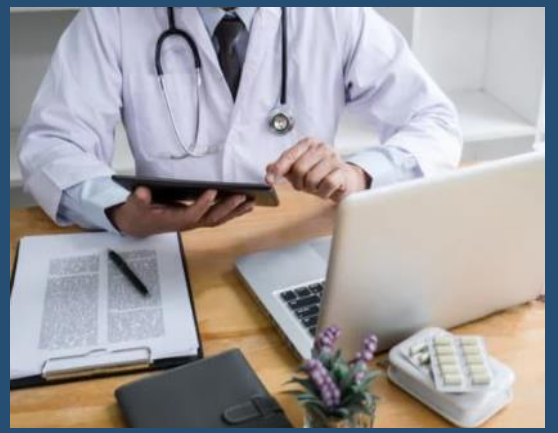
Why don’t Japanese people talk?

1. No chance to talk

People think they could talk about the ACP if they had the chance, but they don't think now is the time.

2. Procrastinating

Usually, the reason people talk about ACP is when they get sick or when a family member gets sick or dies.



3. Waiting for support

They want to receive information and support about ACP and AD from their health care providers.

Sense of disconnection b/w life & death, fear of death, sense of immortality

Words from an advanced lung cancer patient who exemplifies Japanese culture

- *“I want it to happen in the course of nature.”*

- *“I have a general idea of what kind of treatment/care I want in the future. But I can’t tell the doctor because he is working so hard to treat me...”*

- *“I’m trying to stay positive and not to think about it. When the time comes, it will work itself out.”*

Cultural Challenges in ACP Implementation:

- Family-Centered Decision-Making
- Implicit Communication
- Death denying society

Barriers to ACP for patients

1. Difficult to understand the purpose and significance of ACP
2. Difficult to imagine the future
   Hopes and requests are vague and lack detail. e.g., “natural death.”
3. Difficulty with care planning
   e.g., age, health literacy, capacity
4. Change mind when condition changed
   e.g., Opt for intubation with pharyngeal cancer
5. Family members showed negative attitudes toward ACP discussions

Challenges

for Japanese HCPs to Provide Optimal ACP Support

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

HCPs do not have enough 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 in ACP/Goals of Care Discussions (GoCD)

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

Culture-Sensitive Strategies for Effective ACP in Japan

Value harmony in family relations

Self-determination is not always valued and sometimes discouraged. Every patient, even if not explicitly stated, always has a unique priority in her/his mind.

It is important to allow patients to reflect on what matter to them and help them prepare for their future discussions.

Facilitate family-involvement in ACP

It is especially essential for HCPs in Japan to facilitate end-of-life discussions since family-centered decision-making and non/partial-disclosure remain the cultural norm.

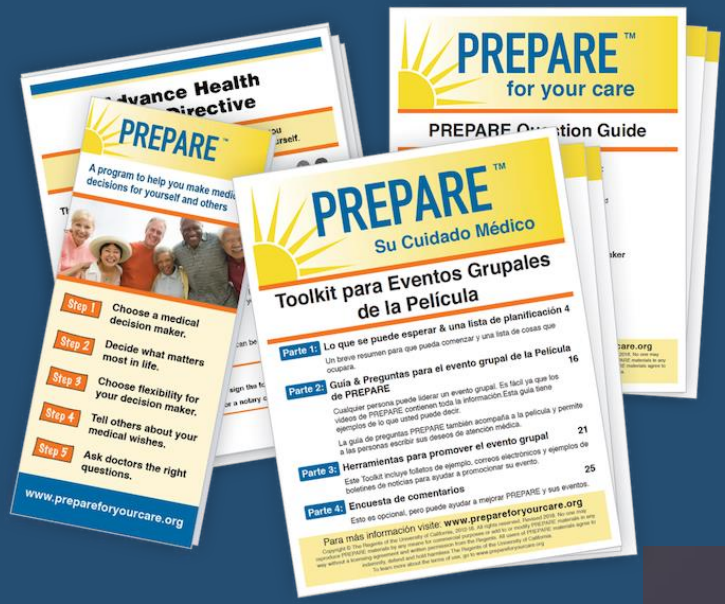
Mori M, et al. Palliat Med. 2020

Pursuing quality palliative care that improves and maintains patients' QOL

Patients may not express their wishes or distress clearly.

Conversation Guides/Programs

- **Can help HCPs to have meaningful conversations**
  ⇒HCPs can be trained to communicate better



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Serious Illness Care Program

Respecting Choices®
PERSON-CENTERED CARE

VITAL talk

To improve patients' Well-being…

Nurse-Physician Collaborative SCIP-based ACP Intervention: Feasibility RCT in Advanced Cancer Patients

(Takenouchi S, et al. EAPC 2024, Barcelona, Spain)

Dr. Tomoko Izawa, RN, OCNS

Sayako Ouchi, RN, OCNS

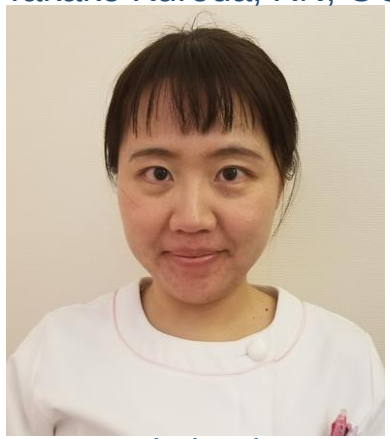
Takako Kuroda, RN, OCNS

Akari Ohara, RN, PHN

A. Prof. Ryuji Uozumi, PhD

Dr. Yu Uneno
MD, Field Operation and Quality

Prof. Shigemi Matsumoto
MD, Quality Management



Dr. Ai Chikada
RN, In-House Operation

Dr. Masanori Mori
MD, Senior Management

Prof. Yoshiyuki Kizawa
MD, Consultant

Objectives of our study

To assess the feasibility and effectiveness of a culturally adapted SICP-based nurse-physician collaborative Advance Care Planning (ACP) intervention tailored for Japanese patients confronting advanced cancer.

Method: HCPs training & interventions

- Oncology nurses are extensively trained and closely collaborate with physicians, conducting structured discussions with intervention group patients.
- The interventions targeted trust-building, understanding patient values, and facilitating SICP-based ACP.

Method: Cultural adaptation

- Included a Japanese cultural component in SICP training for HCPs to supplement consideration for Japanese patients
- Ensured that the same HCPs were continuously involved in discussions with patients to build trust
- Included the Life-line Interview Method (LIM) in the intervention to explore patients' values and explore what it means to live with their illness
- Created a Japanese translation of the SICG and changed the wording to fit the Japanese context

Cultural adaptation:

Providing patients with the opportunity to reflect on their important life events, explore their values, and express them

(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

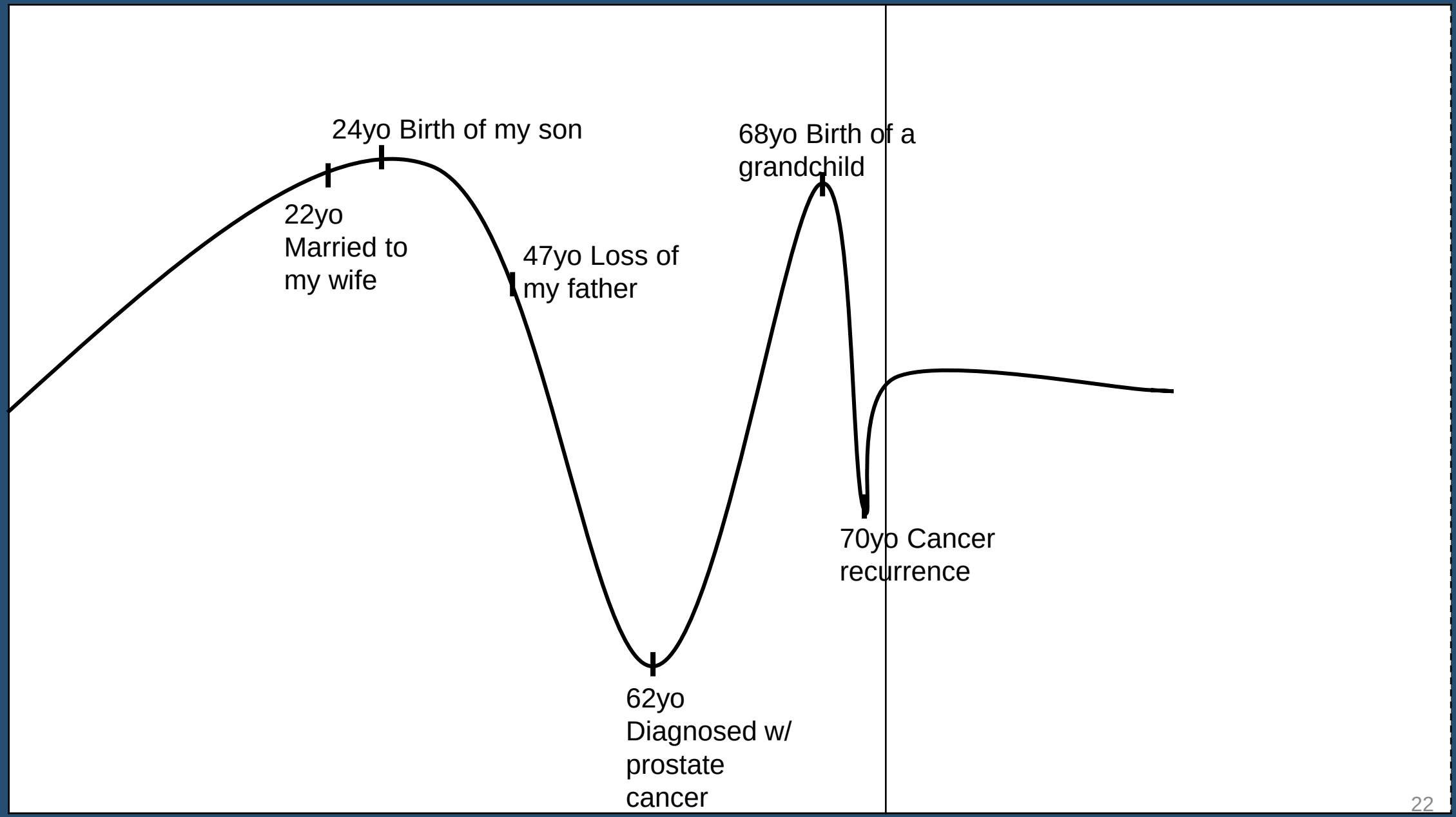
Sayaka Takenouchi, PhD, MPH, RN ❍ Ai Chikada, PhD, RN ❍ Masanori Mori, MD ❍ Keiko Tamura, PhD, RN ❍ Kazuko Nin, PhD, RN

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

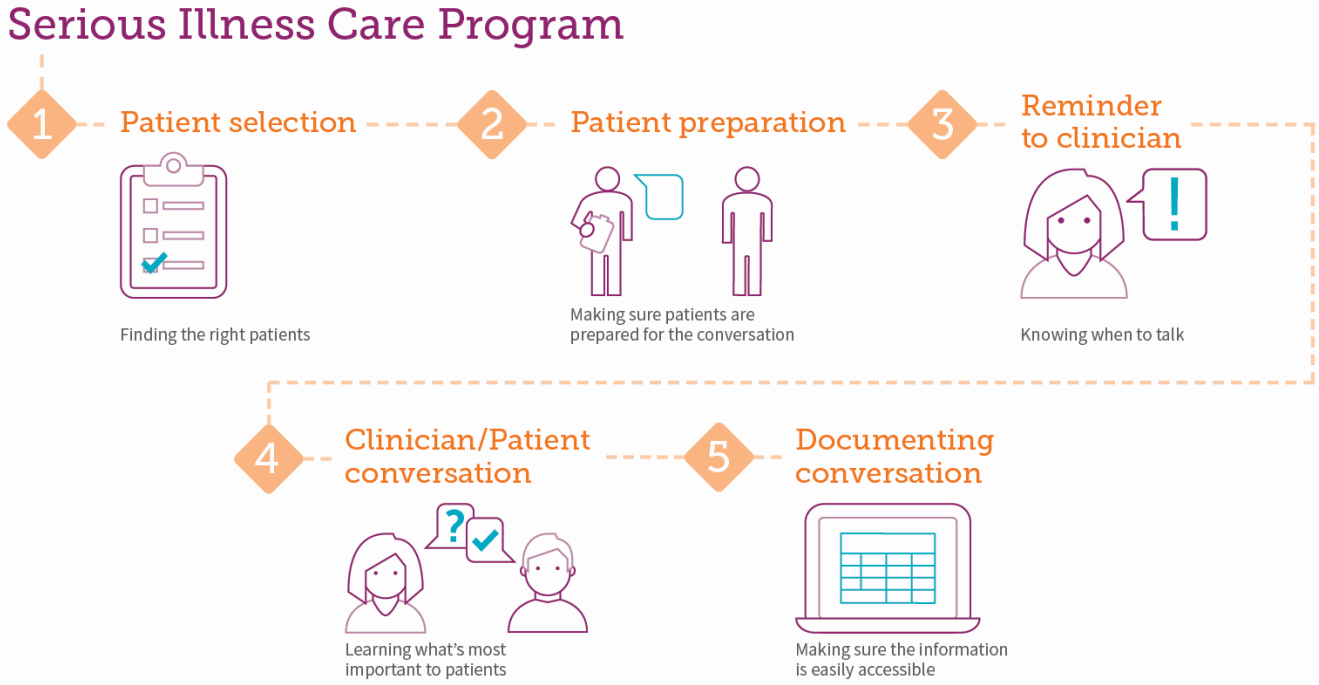


Method: patient participants & data collection

- Patient participants
  - Patients initiating first-line palliative chemotherapy within 6 weeks
- Data Collection
  - Primary endpoints achieving a 70% completion rate and evaluating spiritual well-being (FACIT-Sp) at 6 months.
  - Secondary endpoints comprised assessments of anxiety (GAD-7), depression (PHQ-9), quality of life (QOL) (CoQoLo), and ACP progress (ACP Engagement Scale) at 6 months.

Trained clinicians w/ Serious Illness Care Program (SICP)

Clinical Workflow Diagram



https://www.ariadnelabs.org/serious-illness-care/for-clinicians/

PATIENT-TESTED LANGUAGE

SET UP

"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?**"

ASSESS

"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?"

SHARE

"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."

OR

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."

EXPLORE

"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?"

CLOSE

"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

Insert health system logo here

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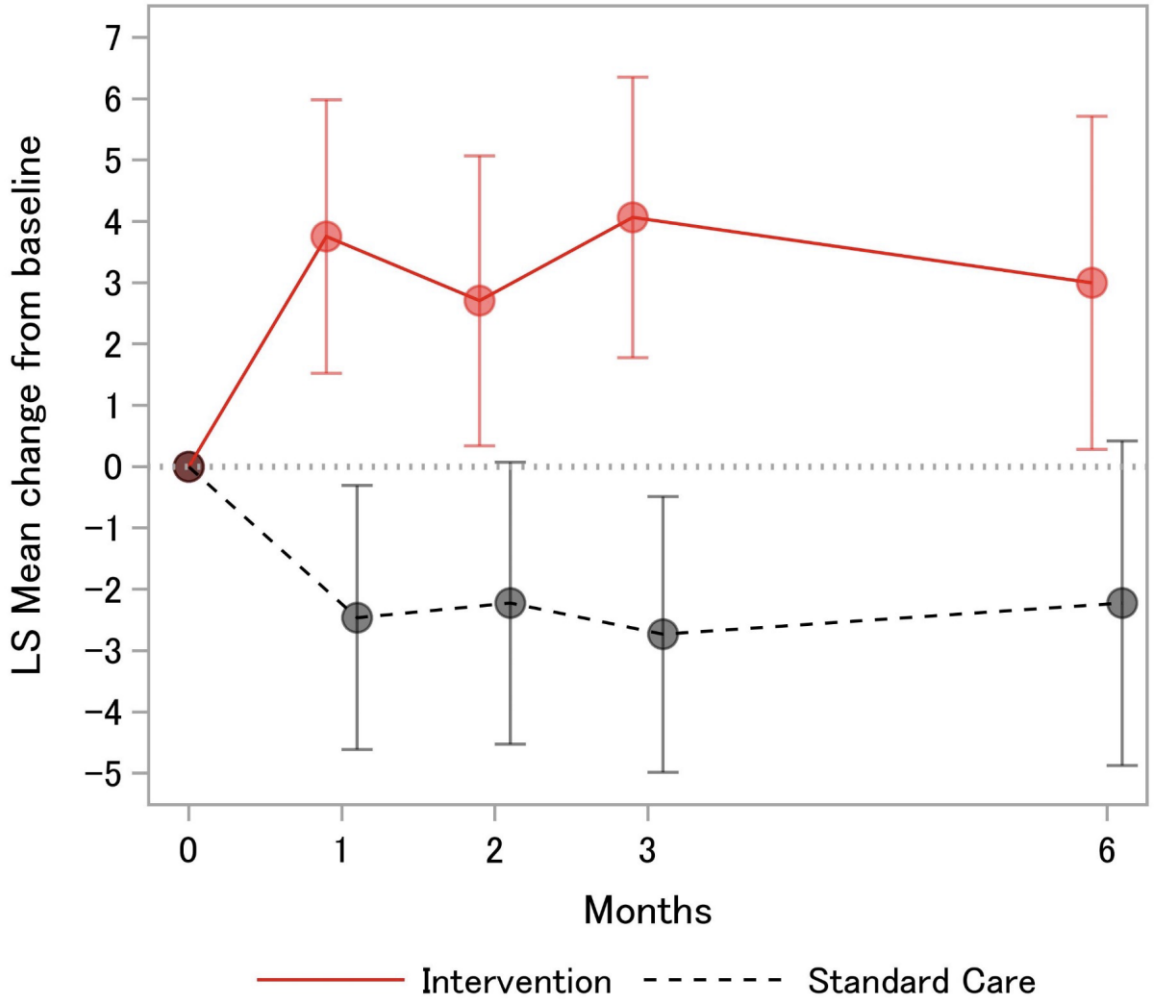
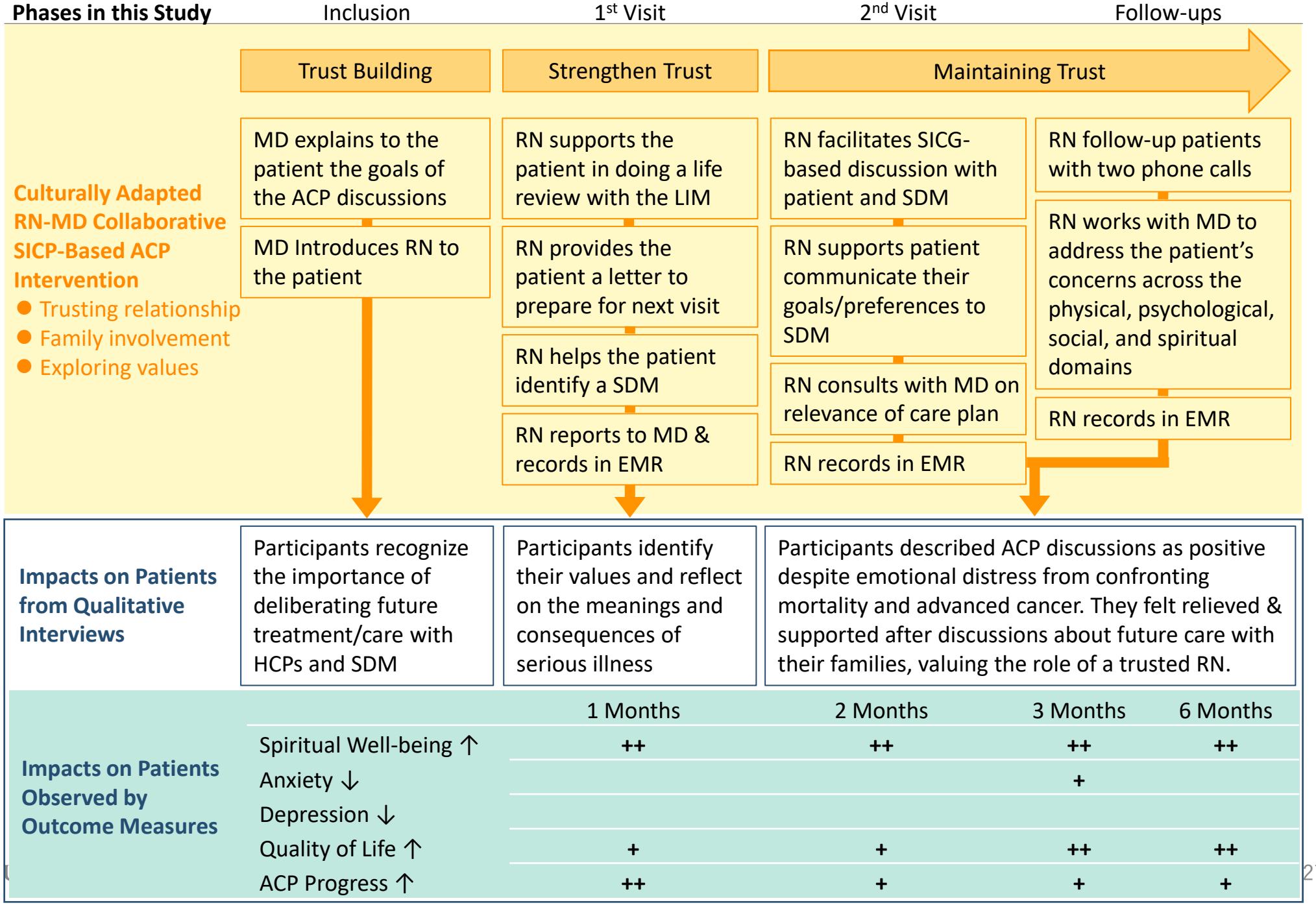
Results

- 41 patients (67.2%) completed the 6-month follow-up and did not meet the targeted completion rate.
- The least-squares mean change from baseline in spiritual well-being at 6 months was 3.00 in the intervention group and -2.22 in the standard care group (difference, 5.22 points; 95% confidence interval [CI], 1.38 to 9.06; p = .009).
- Similar superiority of the intervention was observed in QOL and ACP progress.

Results: Improvements in spiritual well-being




Phases in this Study
Inclusion
1st Visit
2nd Visit
Follow-ups
Trust Building
Strengthen Trust
Maintaining Trust
Culturally Adapted RN-MD Collaborative SICP-Based ACP Intervention
Trusting relationship
Family involvement
Exploring values
MD explains to the patient the goals of the ACP discussions
MD Introduces RN to the patient
RN supports the patient in doing a life review with the LIM
RN provides the patient a letter to prepare for next visit
RN helps the patient identify a SDM
RN reports to MD & records in EMR
RN facilitates SICG-based discussion with patient and SDM
RN supports patient communicate their goals/preferences to SDM
RN consults with MD on relevance of care plan
RN records in EMR
RN follow-up patients with two phone calls
RN works with MD to address the patient's concerns across the physical, psychological, social, and spiritual domains
RN records in EMR
Impacts on Patients from Qualitative Interviews
Participants recognize the importance of deliberating future treatment/care with HCPs and SDM
Participants identify their values and reflect on the meanings and consequences of serious illness
Participants described ACP discussions as positive despite emotional distress from confronting mortality and advanced cancer. They felt relieved & supported after discussions about future care with their families, valuing the role of a trusted RN.
Impacts on Patients Observed by Outcome Measures
1 Months
2 Months
3 Months
6 Months
Spiritual Well-being ↑ ++ ++ ++ ++
Anxiety ↓ +
Depression ↓
Quality of Life ↑ + + ++ ++
ACP Progress ↑ ++ + + +

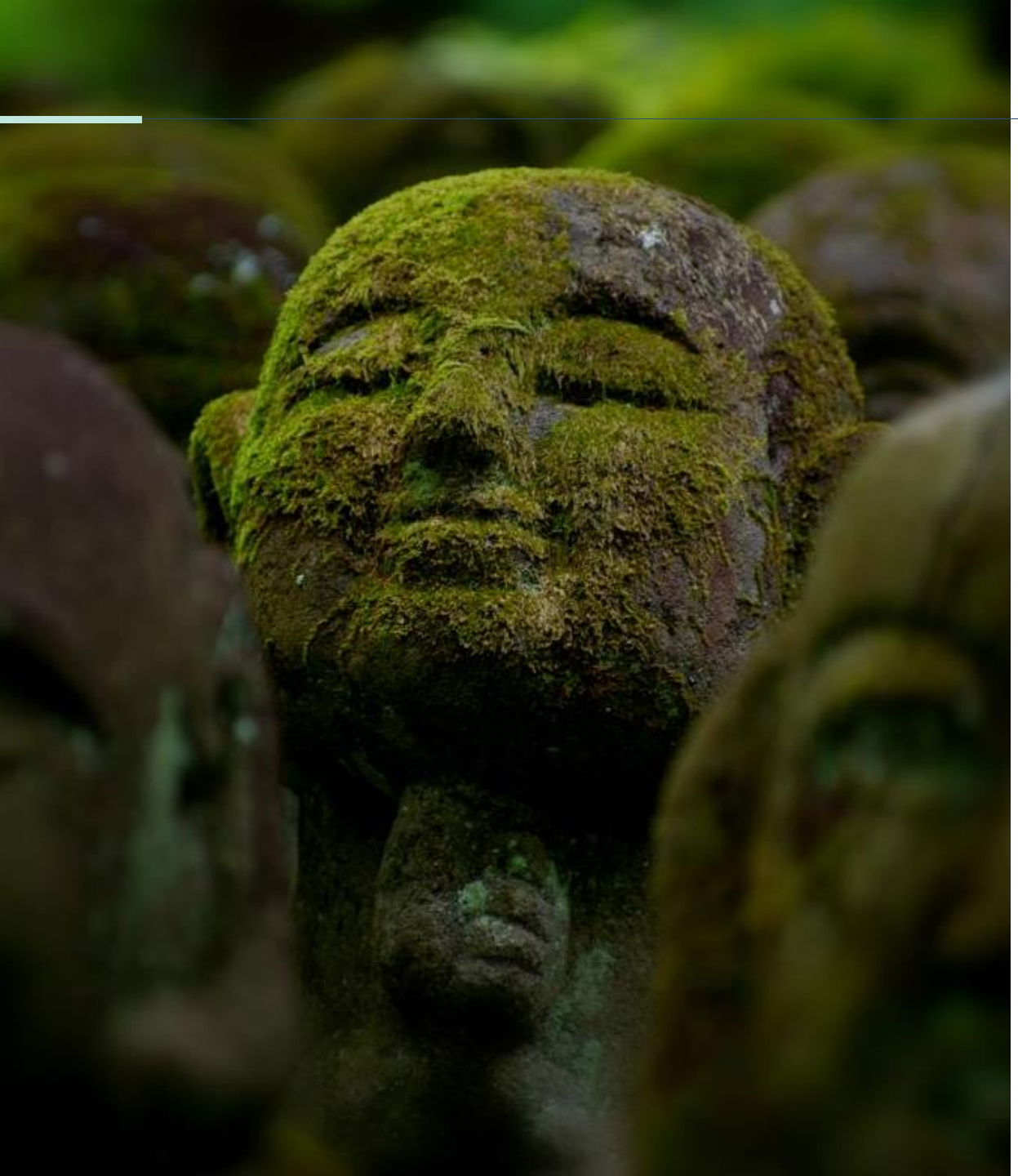
Lessons learned

- **UNDERSTAND PTS' VALUE THROUGH YOUR DAILY PRACTICE**

  Help patients verbalize what matters to them by building trusting relationships through active listening and compassion.

- **START MULTI-PROFESSIONAL COLLABORATION!**

  Multi-professional support in the same direction in each setting ensures the patient's wishes are respected, and the family's peace of mind is assured.



Summary

Through quality ACP that is culturally sensitive and fosters bonding, HCPs can support patients in living their own lives.

Start by exploring what matters most to the patient.

Thank you for listening!

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

ありがとう

Thank you

謝謝您

Gracias

Vielen Dank

Photography by Burt Glinn (1925-2008) Source : Magnum Photos

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