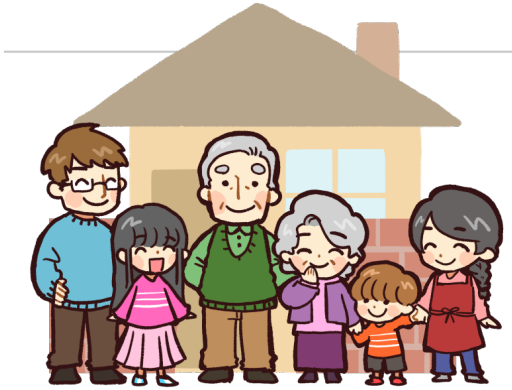

ATTITUDES TOWARD END-OF-LIFE AMONG JAPANESE OLDER ADULTS:

AN OVERVIEW OF THE EMPIRICAL FINDINGS AND THE PRACTICAL TOOL

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BACKGROUND

- In recent years, many older adults have faced decision-making regarding end-of-life (EOL), such as medical treatment choices and funeral/burial preplanning.
  - Advanced directives (ADs) and advance care planning (ACP) have gained social interest.

CURRENT SITUATION IN JAPAN

- Older adult population accounted for 29.1% of the total population in Japan, and more than one in 10 people in Japan are now aged 80 or older.
- Those aged over 65 are expected to account for almost 37.1% of the population by 2050, according to the National Institute of Population and Social Security Research (2023).

- No legislation on EOL medical issues, such as forgoing life-sustaining treatment (LST) or ADs.
- In 2007, the Ministry of Health, Labour and Welfare (MHLW) developed the first guideline on the decision-making process for terminal medical treatments.
- The guideline was revised in 2018 and emphasized ACP, but the completion rate for ADs has remained low.

Ozeki-Hayashi, R., et al. (2023). Guideline-Based Approach to End-of-Life Care Decisions in Japan: Practice, Regulation and the Place of Advance Directives. In D. Cheung & M. Dunn (Eds.), Advance Directives Across Asia: A Comparative Socio-legal Analysis (pp. 243-261). Cambridge: Cambridge University Press.

- Nearly 90% of Japanese had yet to write out any ADs.
- **85.0% of older adults did not have anything in writing**, despite agreeing that this would be a good idea.
  - WHY?

Ministry of Health, Labour and Welfare (2018). Report of the awareness survey on end-of-life medical treatment. https://www.mhlw.go.jp/toukei/list/dl/saisyuiryo_a_h29.pdf. (In Japanese)

WHY JAPANESE OLDER ADULTS DO NOT WRITE ADS?

1. Lack of EOL literacy.
2. Avoidance of death.
    - Usually, talking about death should be avoided in the public space in Japan. It may cause Bad Karma, "*Engi ga Warui*."
3. Many older adults fear putting burdens and worries on family members.

Shimada, C., et al. (2015). Communication with important others regarding their preferences for end-of-life care. Nippon Ronen Igakkai Zasshi, 52, 79-85.(In Japanese)

- The hesitation toward practical decision-making in Japanese clinical settings **should also be understood from Japanese socio-cultural contexts of dependency (Omakase) and Confucian culture**.
  - Confucian basis of the Japanese culture means the cultural norm that **authorities (e.g., physicians) know better** than the lay individual but also that the **family is responsible for supporting** the patient throughout treatment.

Nakazawa, E., et al. (2019). Why Can't Japanese People Decide?-Withdrawal of Ventilatory Support in End-of-Life Scenarios and Their Indecisiveness. Asian bioethics review, 11(4), 343–347.

- Compared to other ethnic groups, Japanese older adults tend to rely on the decision-making of their family members.

- **Their primary concern is the burdensomeness of their family, and to avoid it, they wish not to receive life-sustaining treatment** (Bito et al., 2007; Matsui et al., 2016).

Bito, S., et al. (2007). Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups. Bioethics, 21(5), 251–262.
Matsui, M., et al. (2008). Comparison of end-of-life preferences between Japanese elders in the United States and Japan. Journal of transcultural nursing : official journal of the Transcultural Nursing Society, 19(2), 167–174.

WHO IS RESPONSIBLE FOR EOL DECISION-MAKING?

- A family member or guardian reported that the physicians had seen the patient's living will and acted following the patient's preference as written in the living will.
- However, **over a third of the physicians have not seen the living will**.

Masuda, Y., et al.(2003). Physicians's reports on the impact of living wills at the end of life in Japan. Journal of medical ethics, 29(4), 248–252.

- Because they are concerned with **many potential limitations of living wills** (e.g., the vagueness of living wills, inadequate communication about how to interpret them, and the differences of patient and family expectations).

- A limited number of patients wrote living wills.

- **Japanese physicians tend to precede family consent** over individual autonomy (Terunuma & Mathis, 2021).

Terunuma, Y., & Mathis, B. J. (2021). Cultural sensitivity in brain death determination: a necessity in end-of-life decisions in Japan. BMC medical ethics, 22(1), 58.

- A literature review of the research on the family member's decision-making indicated…

1. Family members try to understand older adults' wishes and assume their EOL preferences through life stories.

2. However, family members struggle to estimate the older adult's wishes, and further, their EOL decision-making usually contains worries and uncertainties even after their decisions are made.

- **ACP is needed!**

Kato, M., & Takeda, K. (2016). Literature Review of Research on the Family of Decision Making at the End of Life of the Elderly. Journal of Japan Society of Nursing Research, 40(4), 685-694. (in Japanese)

THE DIFFICULT SITUATION OF EOL DECISION-MAKING IN JAPAN

- Most **medical practitioners and patient families fear police investigations**.
  - Physicians were arrested on suspicion of murdering patients.
- Thus, they choose the option of continuing life-prolonging treatment, even if they believe it to be meaningless and want to terminate it (Nakazawa et al., 2019).

Nakazawa, E., et al. (2019). Why Can't Japanese People Decide?-Withdrawal of Ventilatory Support in End-of-Life Scenarios and Their Indecisiveness. Asian bioethics review, 11(4), 343–347.

HEALTH CARE, FINANCIAL, AND FUNERAL DECISIONS

- Besides medical treatment, individuals and their families must resolve many other issues, such as financial arrangements, funeral preplanning, and other practical concerns (e.g., solitary death).
- However, such aspects of EOL planning have generally been considered separately from healthcare decisions such as ADs and ACP.
- Factors such as health care, financial, and funeral decisions are interrelated in EOL planning (Kelly et al., 2013). Thus, it makes more sense to examine all these EOL activities together.

Kelly, C. M., et al. (2013). End-of-life planning activities: An integrated process. Death Studies, 37(6), 529–551.

SHUKATSU IN JAPAN

- EOL activities, commonly known as *Shukatsu* (終活),

  encompass not only decision-making regarding medical treatments but also preplanning for one's funeral and burial and writing an "ending note" (written record of one's EOL planning).

- According to the Japan Ministry of Economy, Trade and Industry (2012), almost 70% of those aged 60 years and older know about an ending note, but only 3.2% have actually prepared one.

- The literature review (Kawashima, 2016) suggests that…

1. *Shukatsu* among Japanese older adults is promoted by fears and anxieties related to solitary death, family care burdens, and funeral arrangements.

2. The studies of ADs and ACP mainly recruited older patients, but the preferences of community-dwelling older adults need to be sufficiently examined.

Kawashima, D. (2016). Death in late adulthood. In D. Kawashima & M. Kondo (Eds.), *Introduction to Psychology of Death and Life* (pp.175-188). Tokyo: Shinyosya Publishing. (In Japanese)

BRIEF CONCLUSION OF THE PREVIOUS FINDINGS

- Considering the previous findings and social situations surrounding EOL in Japan, we should explore the factors that promote EOL preplanning and examine how to facilitate it.
  - Based on the public health model, three factors of EOL, i.e., health care, financial, and funeral decisions, should be examined.
  - EOL among community-dwelling older adults should be more examined.

EMPIRICAL EXAMINATIONS OF EOL AMONG JAPANESE OLDER ADULTS

- We conducted several studies examining EOL activities and attitudes among community-dwelling Japanese older adults.

1. Explorative study of EOL activities among Japanese older adults
2. Scale development of EOL attitudes
3. Cross-cultural comparisons of EOL attitudes between Japanese and American older adults
4. Making a practical tool (Life-Ending Work: LEW)
5. Evaluation of the effectiveness of the LEW

STUDY 1
EXPLORATIVE STUDY OF EOL ACTIVITIES AMONG JAPANESE OLDER ADULTS

- Participants were 123 community-dwelling older adults (mean age = 72.54) who attended Shukatsu seminars in Western Japan from 2016 to 2017.

- We found that **older adults with a higher fear of death reported difficulty communicating with family members** about funeral arrangements and EOL care (Tanaka et al., 2021).

Tanaka, M., Takahashi, M., & Kawashima, D. (2021). End-of-life activities among community-dwelling older adults in Japan. Omega, 83(3), 601-610.

STUDY2
SCALE DEVELOPMENT OF EOL ATTITUDES

- We developed a new scale that measures attitudes toward EOL among Japanese older adults (Tujimoto et al., 2021).
- We recruited 167 community-dwelling older adults who registered with the Silver Human Resources Center in mid-land Japan in 2018.
- After eliminating incomplete questionnaires, 166 (mean age = 72.54) were included in the analysis.

Tujimoto, T., Kawashima, D., & Tanaka, M. (2021). Development and validation of a scale for measuring end-of-life attitudes among older adults. Journal of health and welfare statistics, 68(7), 1-7. (In Japanese)

ATTITUDES TOWARD EOL

- This scale captures the attitudes of writing their wishes (ADs) and communicating with close relatives (ACP) about EOL.

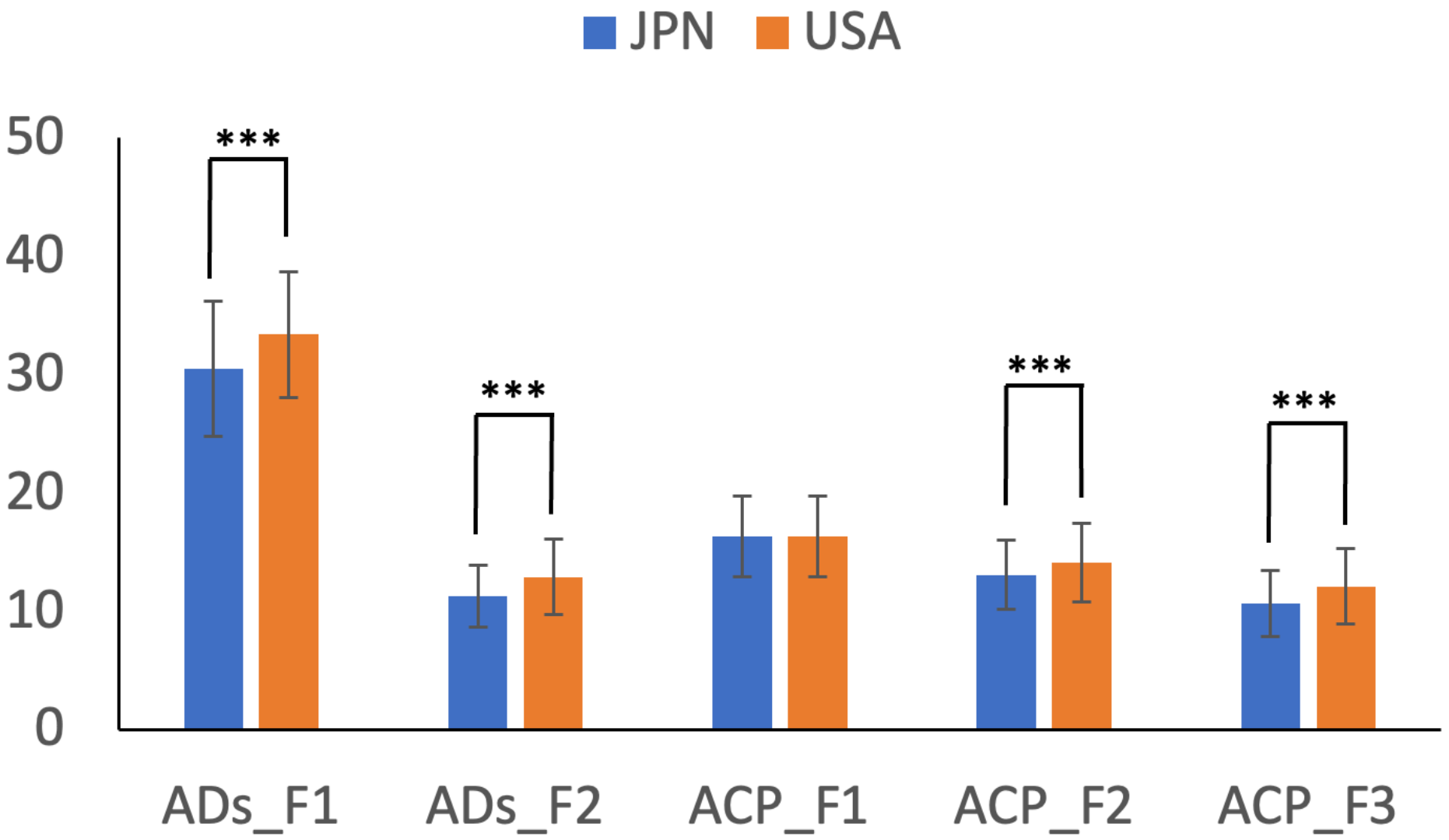
1. The scale of ADs comprises two subscales: Preference of care, procedure, and death ritual (9 items) and Meaning of life (ADs) (4 items)

2. The scale of ACP includes three subscales: Preference of procedure and death ritual (5 items), Preference of care (4 items), and Meaning of life (ACP) (4 items).

STUDY3
CROSS-CULTURAL COMPARISONS OF EOL BETWEEN JAPANESE AND AMERICAN OLDER ADULTS

- Japanese sample: We used the data from Study 2.
- American participants: 97 questionnaires were returned, with a response rate of 45.40%. After eliminating incomplete questionnaires, 81 (mean age = 73.64) were included in the analysis.
  - The survey was conducted for community-dwelling American older adults who are residents of Chicago city in 2018.

Tanaka, M., Kawashima, D., Tujimoto, T., & Takahashi, M. (In preparation). Comparison of Attitude toward End of Life between Community-Dwelling Older Adults in the United States and Japan.



Notes. ADs_F1, Preference of care, procedure, and death ritual; ADs_F2, Meaning of life (AD); ACP_F1, Preference of procedure and death ritual; ACP_F2, Preference of care; ACP_F3, Meaning of life (ACP)

- Most aspects of ADs and ACP were negatively related to worse interpersonal relationships (i.e., perceived burdensomeness and thwarted belongingness) in both samples.
  - Significant correlations were found between Meaning of life (ACP) and interpersonal relationships among Japanese older adults.
- ACP was positively related to the approach acceptance of death only among Japanese older adults.

TENTATIVE CONCLUSIONS OF OUR EMPIRICAL STUDIES

- Regardless of the social interests in *Shukatsu*, Japanese older adults do not actually engage in it.
- **We should consider death attitudes and interpersonal relationships among Japanese older adults to promote EOL preplanning … but How?**

STUDY4
DEVELOPING LIFE-ENDING WORK (LEW)

- Based on the empirical findings and theoretical framework, we have developed the Life-Ending Work, a Sugoroku game about end-of-life preplanning.

- **This game aims to promote older adults' thinking about their EOL wishes and communication with those around them.**

THEORETICAL FRAMEWORK: NARRATIVE THANATOLOGY

- This work takes **Narrative Thanatology** (Kawashima, 2011) as its theoretical perspective.
- Narrative thanatology emphasizes the reconstruction of meaning through interactions with sociocultural contexts and significant others during development throughout the lifespan.
- From this perspective, older adults who engage in their EOL issues are viewed as individuals who attempt to reconstruct meaning through recounting their own experiences and communicating with others.

Kawashima, D. (2011). Meanings of Death and the Relationship with Religion through Lifespan Development: Toward Narrative Thanatology. Kyoto: Nakanishiya Publishing. (In Japanese)

ERIKSON'S PSYCHOSOCIAL DEVELOPMENT: EGO-INTEGRITY AND GENERATIVITY

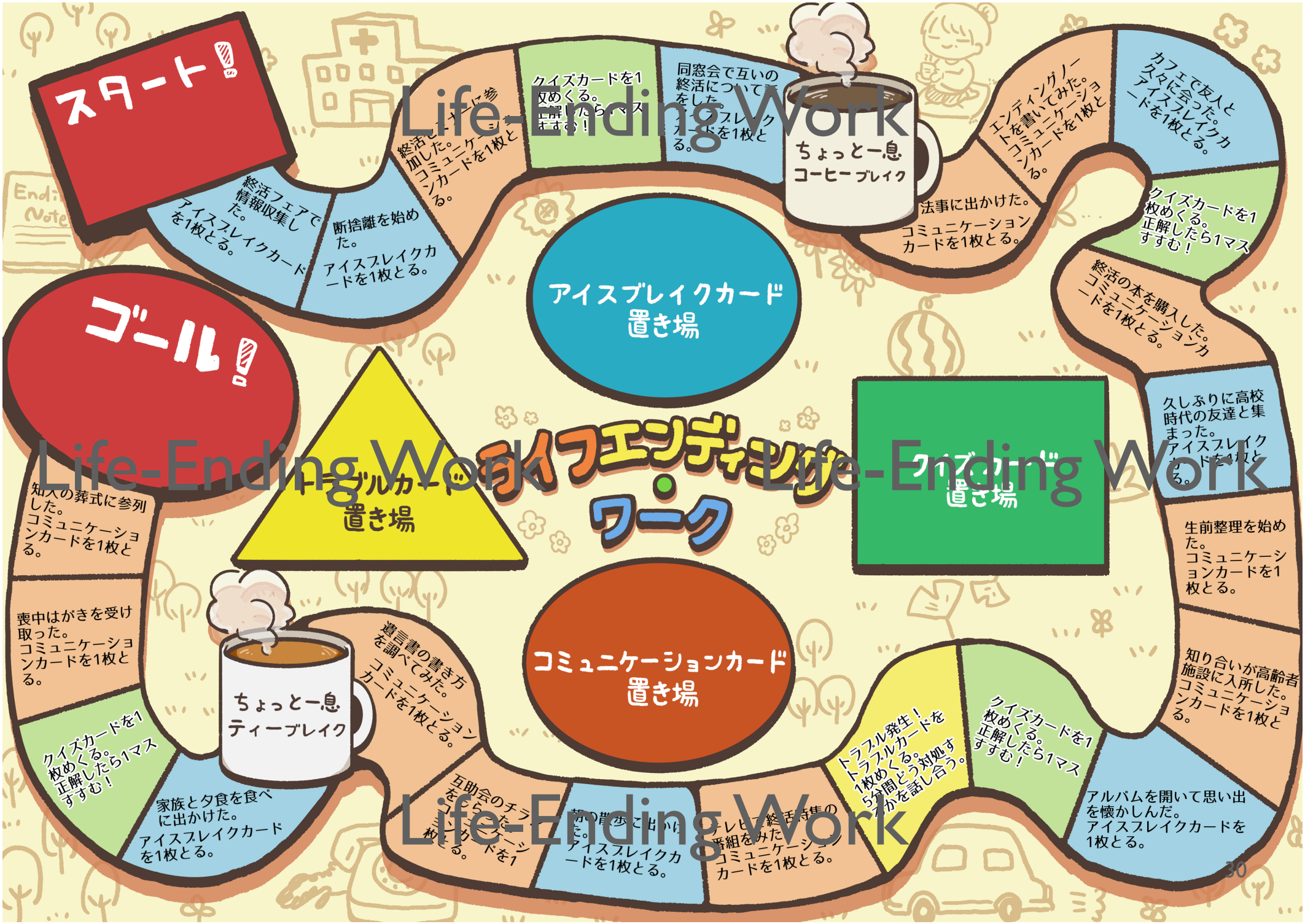
- **Ego-Integrity** refers to a person's ability to reflect on life with a sense of accomplishment and fulfillment (Erikson et al., 1986).
  - Those who feel a sense of integrity will attain wisdom, even when confronting death. Empirical studies revealed that ego integrity related positively to death acceptance and negatively to death anxiety (e.g., van der Kaap-Deeder et al., 2020)
  - Life-review therapy can facilitate the ego-integrity.
- **Generativity** is crucial in confronting death and maintaining a sense of dignity (cf. generative script: Chochinov, 2002).

THREE COMPONENTS OF LEW

1. Preference of EOL care (e.g., medical treatment, legal arrangement): medico-legal aspect
2. Preference of death ritual, inheritance: socio-cultural aspect
3. Meaning of life: developmental aspect

COMPONENTS

- Pieces (max. 7)
- Dice
- Sugoroku map
- Booklet, including ending note
- Cards (4 types of cards)


スタート!
ゴール!
アイスブレイクカード置き場
トラブルカード置き場
クイズカード置き場
コミュニケーションカード置き場
ちょっと一息 コーヒーブレイク
ちょっと一息 ティーブレイク
ライフエンディング・ワーク
Life-Ending Work
カフェで友人とダメに会った。アイスブレイクカードを1枚とる。
クイズカードを1枚めくる。正解したら1マスすすむ!
終活の本を購入した。コミュニケーションカードを1枚とる。
久しぶりに高校時代の友達と集まった。アイスブレイクカードを1枚とる。
生前整理を始めた。コミュニケーションカードを1枚とる。
知り合いが高齢者施設に入所した。コミュニケーションカードを1枚とる。
アルバムを開いて思い出を懐かしんだ。アイスブレイクカードを1枚とる。
クイズカードを1枚めくる。正解したら1マスすすむ!
トラブル発生!トラブルカードを1枚めくる。5分間どう対処するかを話し合う。
テレビで終活特集の番組をみた。コミュニケーションカードを1枚とる。
旅の散歩に出かけた。アイスブレイクカードを1枚とる。
互助会のチラシをもらった。コミュニケーションカードを1枚とる。
遺言書の書き方を調べてみた。コミュニケーションカードを1枚とる。
クイズカードを1枚めくる。正解したら1マスすすむ!
家族と夕食を食べに出かけた。アイスブレイクカードを1枚とる。
クイズカードを1枚めくる。正解したら1マスすすむ!
喪中はがきを受け取った。コミュニケーションカードを1枚とる。
知人の葬式に参列した。コミュニケーションカードを1枚とる。
終活フェアで情報収集した。アイスブレイクカードを1枚とる。
断捨離を始めた。アイスブレイクカードを1枚とる。
終活セミナーに参加した。コミュニケーションカードを1枚とる。
クイズカードを1枚めくる。正解したら1マスすすむ!
同窓会で互いの終活についてを話した。アイスブレイクカードを1枚とる。
法事に出かけた。コミュニケーションカードを1枚とる。
エンディングノートを書いてみた。コミュニケーションカードを1枚とる。

FOUR TYPES OF CARDS

- Communication cards
- Ice Break Cards
  - The communication cards and ice break cards are used to answer the questions written on them, and the person who draws the card answers the questions.

EXAMPLES COMMUNICATION CARDS

- Would you like to know the name of your disease and your life expectancy? Would you not? Please tell us what you think and why.
- What are your preferences for your cemetery?
- Where would you like to spend your last days?
- Tell us about the most inspiring time in your life.

EXAMPLES
ICE BREAK CARDS

- What brings you joy on a daily basis?
- Which song do you feel a deep connection with?
- What was your childhood nickname?
- What is your go-to stress management technique?

QUIZ CARD

- The person who draws a quiz card reads the quiz out loud, and everyone gives their own answers.
- The quiz is all true or false questions.
- The person who draws the quiz card will ask everyone, "Who thinks this is true?"

EXAMPLES
QUIZ CARDS

- In Japan, dementia is the leading cause of long-term care.
  - Who thinks this is true?
- Once life-prolonging treatment has begun, no one can stop or change it, even if the patient wants to.
  - Who thinks this is true?

TROUBLE CARD

- Trouble cards are used to discuss the card topic for 5 minutes.
- Participants discuss the troubles on the card by thinking, “What should I do to avoid this situation?”
- When participants reach a conclusion, they can end the discussion even before the time is up.
- After the discussion, open the booklet and read the experts' advice together.

EXAMPLES
TROUBLE CARDS

- After his death, the bank refused to allow his wife to withdraw the deposit. What should we do to avoid this situation?
- He made a lifetime gift to avoid estate taxes, which caused a family dispute. What should we do to avoid this situation?

HOW TO PLAY

1. Turn each card face down. Then, place the card on the field in the center of the map.

2. Decide on one's piece of the board and place it at the starting point.

3. After deciding on each turn, roll the dice to reach the goal!

RULES FOR PLAYING LEW

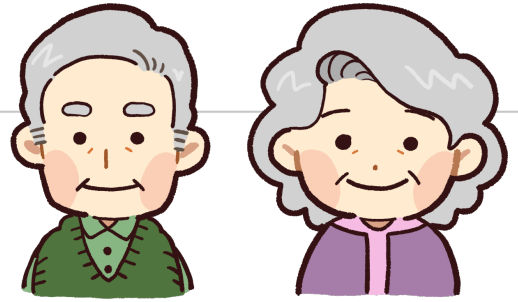
1. Please listen without interrupting when someone is speaking.

2. Do not criticize or ridicule others' opinions or ideas out of hand.

3. Please talk again about your thoughts and opinions, even if you draw a similar card or share the same opinion as another person.

4. If you do not want to talk, you can“pass.” Please work on it as you are comfortable with.

APPROPRIATE/ INAPPROPRIATE PARTICIPANTS



- The main target of LEW is (relatively) healthy older adults and their family members. Severely flailed older adults may not be suited.
- The secondary target is practitioners in EOL care settings, including medical staff, formal caregivers, and religious practitioners.

PROMISING EFFECTIVENESS OF THE LEW

1. LEW is designed to promote EOL preplanning, encouraging older adults to think and talk about their wishes with their close relatives.

2. Using this game, older adults and other people, including family members and medical staff, could communicate the issues of death and dying comfortably and safely.

3. Professionals can also reflect on their own EOL attitudes through this game.

STUDY5
EFFECTIVENESS OF LEW: RCT

- We recruited 41 community-dwelling older adults (mean age = 73.51) who registered with the Silver Human Resources Center in mid-land Japan during 2022. Participants were allocated to two groups: experimental and control groups.

- Participants who were allocated to the exp. group played LEW and answered the questionnaire at three time points, i.e., pre, post, and 1 month later. The control group only received the EOL booklet (Ending note).

- The booklet distribution is a very common practice in EOL seminars and administrative efforts in Japan.

- Participants in both groups were encouraged to write their wishes (Figure 1).
- The control group showed a decreased willingness to talk with those close to them.
- The control group indicated a temporarily increased fear of death; the fear of death could be eased in the LEW group (Figure 2).

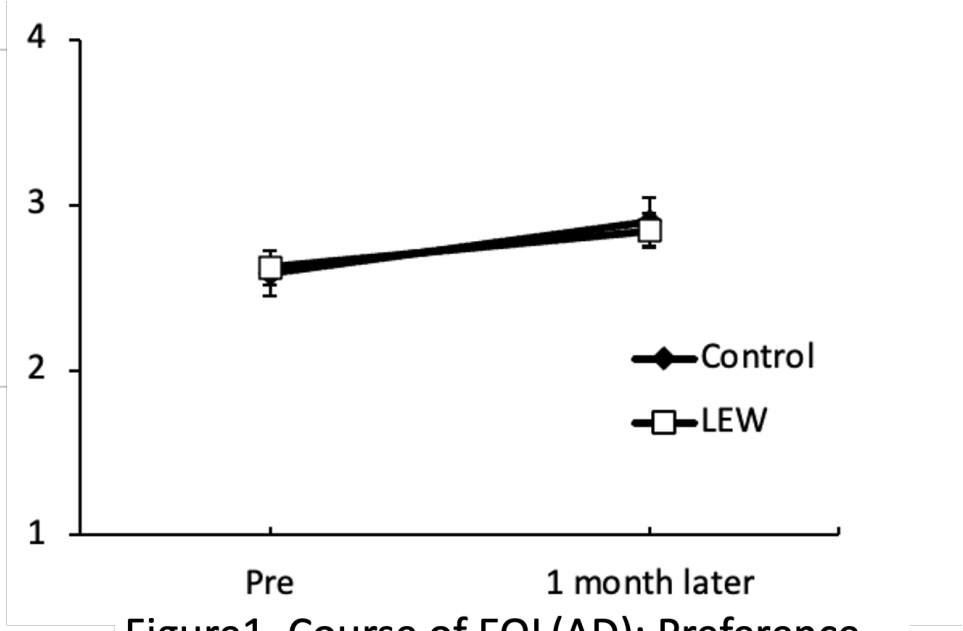


Figure1. Course of EOL(AD): Preference of care, procedure, and ritual

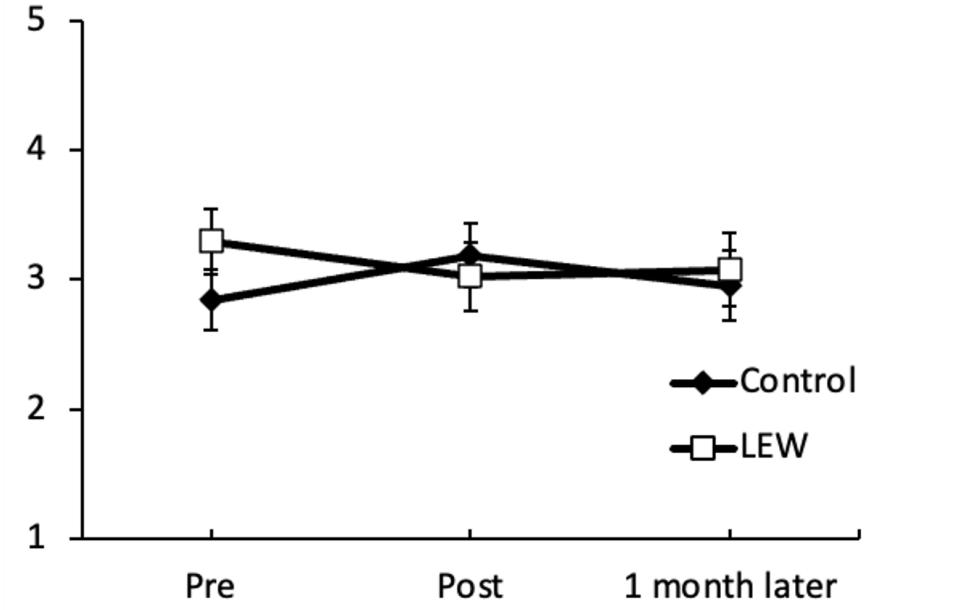


Figure2. Course of DARS: Fear of Separation

Note. The control group only received the EOL booklet.

LIMITATIONS AND FUTURE DIRECTIONS

- A limited number of related studies in Japan
- The effectiveness of LEW should be demonstrated after accumulating further empirical findings.
- Lack of consideration toward the differences between relatively healthy older adults and institutional/ hospitalized older adults.

THANK YOU FOR LISTENING!

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- If you have any questions, please contact daisuke1102@hotmail.com