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Community Nurses' Perspective on Barriers to Effective Utilization of Advance Care Planning for Terminal Care of The Elderly in The Home Environment in Japan: A Systematic Review and Synthesis of Qualitative Studies

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ABSTRACT Advance care planning (ACP) allows individuals to plan the health care which dignifies their personal values at the terminal phase of their illnesses. The Japanese government previously endorsed the concept of ACP in the guideline on end-of-life care and community nurses in Japan could play an increased role to improve its utilization by patients. The current study aimed to identify challenges surrounding ACP practice in the home environment in Japan from the community nurses' perspectives. Semi-structured interview was performed on eleven community nurses working in metropolitan areas in Japan. Qualitative data was collected and analyzed using Braun & Clarke's six-step framework of thematic analysis (2006). Five themes were identified as barriers to effective ACP utilization: complexity surrounding family power, informed consent and discussion, cultural influence, longer life versus better life, and absence of frameworks and guidelines. The first three themes were further subdivided into subthemes: imbalance in family power and family guilt, inadequate information for decision-making and 'no one talk about it', and traditional ways of thinking and taboo surrounding talking about death, respectively. The identified issues surrounding the current ACP practice in Japan were interconnected and reflective of the social, cultural, legal, and ethical aspects of life and care in Japan. This study highlighted the importance of respecting patients' preferences in care, which should be additionally protected by establishing clear policy and legal frameworks on ACP.

INDEX TERMS: advance care planning, community health nursing, culture, Japan, terminal care

I. INTRODUCTION

Advanced Care Planning (ACP) is a process of preparing future health and personal care for a time when one is not competent to make or communicate his/her decision and it captures a person's values, beliefs, and life goals [1]. Japan has the highest proportion of elderly people in the world [2] and Japanese elders appear receptive to ACP according to a study where community-residing elders were asked to fill questionnaires about preferred timing and methods of receiving information on ACP [3]. Yet its practice remains low and less than 30% of clinicians and nurses reported to use ACP with their patients [4]. Low uptake of ACP in Japan may partly relate to cultural values, beliefs, and expectations around end-of-life held by Japanese patients and their family [5].

In Australia, ACP is supported by its government. Advance Care Planning Australia, a national program funded by the Australian Government jointly released a policy statement with Palliative Care Australia in 2018 recommending ACP reform [6]. ACP is recognised by both statutory and common laws in Australia and all its states and territories have legislation related to ACP. In South Australia, Advance Care Directives Act 2013 [7] outlines the process for documenting the preference for future health care and personal matters, and appointing a substitute decision-maker for when one can no longer make a decision, with the emphases on the financial, medical and legal aspects of the procedure. South Australia has the highest prevalence of advance care directive completion at 40% [8].

In contrast to Australia, Japan currently lacks legal framework and process documentation for ACP and its implementation. This is despite Japanese Ministry of Health, Labour and Welfare promoted ACP and patient-centred decision-making for end-of-life matters in the guideline released more than a decade ago [9 Labour and Welfare, 2007]. The guideline has been more recently updated highlighting the importance of ACP and its documentation as well as recognising community care workers as a part of the multidisciplinary health care team to support patients in the community [10 Labour and Welfare, 2018]. The lack of legislative framework and the clarity in ACP execution process means that all of patients, the family and health care professionals struggle when considering the most suitable way to practice ACP [11].

For a large proportion of Japanese people, home is a preference place to receive end-of-life care [12]. With ongoing aging of its population and the government's recent reform to reduce hospital beds, the number of patients dying at either home or residential facilities is increasing [13, 14]. Community nurses consequently play a significant role in provision of end-of-life care for patients at these locations [14]. Together with clinicians, community nurses are in the position to trigger discussion of ACP with patients and the family and this was acknowledged in the recent national guideline [10 Labour and Welfare, 2018]. This study aimed to improve the understanding in the current practice of ACP in the home environment in Japan and barriers to its maximal utilisation from community nurses' perspective. The author used qualitative research, interpretive description methodology. To find out community nurse's experiences deeply.

II. METHODS

This research employed a qualitative descriptive method to analyse data collected through interview of community registered nurses in Japan. All participants were recruited using the poster displayed at hospital notice boards in metropolitan Japan. Those with more than ten years of nursing experience were interviewed to ensure they have a deep understanding of patient care. Semi-structured interview was developed focusing on the community nurses' knowledge of ACP, their use of ACP and experience when applying ACP to patients in the community setting. Following questions were asked;

1. How long have you been working a community registered nurse?
2. Tell me what you know about ACP?
3. What ACP model do you use? If you do not use any, do you still discuss ACP with your patients and/or their family and how do you do this?
4. Tell me of when you have used ACP and what the experience was like?
5. Have you had any issues when discussing ACP with your patients and/or their family?

Participants were individually interviewed face to face to explore the more intimate and personal aspects of their caring experiences. Interviews were conducted in Japanese and audio and voice recorded. The recordings were transcribed into Japanese then translated into English. During transcription and translation, a care was taken to respect the participants' right to privacy and confidentiality, and pseudo names were used to refer to each participant. Transcripts were analysed following Braun and Clarke's six-step framework of thematic analysis [15] and each piece of texts that specifically addressed the research questions were manually coded. The themes and potential subthemes were then categorised, analysed, reviewed, and named. Ethics approval had been obtained from the Flinders University Social and Behavioural Research Ethics Committee (Project number 8297) prior to commencement of the study.

III. RESULTS

Eleven community nurses were interviewed (Table 1). They had an average of 26 years' (range 20-35) experience working as registered nurses and 7 years (range 5-14) as community nurses, indicating a broad range of nursing experience. Nine of them were familiar with ACP, and 1 had attended a seminar on ACP. Participants were all employed by different community-based hospitals which had been established for more than 10 years. The five main themes were identified in the interviews, as well as six sub-themes. The main themes were complexity surrounding family power, informed consent and discussion, cultural influence, longer life versus better life, and absence of frameworks and guidelines. The first three themes had subthemes. Findings for each theme and subtheme are presented with use of quotations from the interview transcripts below.

A. THEME 1: COMPLEXITY SURROUNDING FAMILY POWER

All participants in this study expressed concerns regarding an imbalance of power between patients and their family when it comes to decision-making over health care. Patients often felt that they had no say in their care as the family had already made decisions on their behalf. The family frequently held the power and authority over individual patients as decision-makers and the role was commonly accompanied by a sense of guilt by them. This theme is subdivided into imbalance in family power and family guilt.

1. SUBTHEME 1.1: IMBALANCE IN FAMILY POWER

ACP was often implemented based on the wish of the family rather than that of patients and sometimes preferred care and goals of the care by the two parties contradicted from each other. Clinicians commonly consulted the family before patients for decisions related to their care and participants found this frustrating and confusing. Participants stressed the importance of timely patient involvement in discussion around their care. Following quotations illustrate the magnitude of decision-making authority the family may have over patients' choice of end-of-life care and it can be impossible to oppose them even if it results in dismissal of patients' wishes.

"In Japan, we cannot ignore the family's decision even when the decision they make for the patient is different from the

patient's preference. We need to support the family's feelings towards the patient because they have more power than the patient. In Japan the family always comes first." (Saki)

"When the patient said, 'I want to die', the family kept continuing medical treatment." (Hisako)

"The family does not want to regret the death of the patient, so they ask the doctor for life-extending treatment. It does not matter how much the patient suffers or wishes against it." (Mayumi)

"The decision is made by the family without being questioned and the patient always follows their opinion." (Asami)

2. SUBTHEME 1.2: FAMILY GUILT

Participants expressed the burden of responsibility and the sense of guilt experienced by the family for making decisions on patients' behalf. One participant thought that she could have alleviated the family's sense of remorse by providing the care which followed the patient's wishes. Participants also described the family can be conscientious of being judged by the public on the care they provide, especially if patients die at home with limited active treatment.

"The family said that they wished they could have done it a better way. (Patient's) deterioration was so sudden the family was not prepared. So, the family was confused and panicked." (Yoko)

"Regrets and concerns always manifest around someone's death. With many cases, there is no perfect death." (Hisako)

"I often find that I have done my job well when I attend the funeral through the family's response, when they thank me. I can only reflect on my nursing care through the family's impression of how good the quality of life was for the patient during the community-based care." (Keiko)

"The family always worry about how neighbours think of them letting the patient die at home without life-prolonging medical intervention." (Yoshi)

B. THEME 2: INFORMED CONSENT AND DISCUSSION

In Japan, it is common for clinicians to discuss patients' medical conditions with their family first. In some instances, the information was never or only partially provided to patients regardless of their mental capacity. Without adequately being informed and discussed on their illnesses, patients cannot make meaningful contribution to ACP. This theme is sub-divided into inadequate information for decision-making and 'No one talks about it'.

1. SUBTHEME 2.1: INADEQUATE INFORMATION FOR DECISION-MAKING

Participants in this study expressed frustration when clinicians do not give enough information to patients and the family. Patients and the family can be hesitant to ask clinicians for clarification and more information and this could make decision-making around the care difficult, especially at the time of medical crisis such as cardiac or respiratory failure where a decision needs to be made immediately with little input from patients.

"Part of the problem with informed consent is that medical information is not always directly delivered to the patient. The patient doesn't know what's going on and the family have to make a decision instead. This is huge stress for them." (Naomi)

Participants also recognised that honest disclosure is stressful for clinicians as much as for patients and the family. Clinicians may make the choice to tell either the patient or the family, depending on their relationship with them. At other times the family may sway clinicians from disclosing medical information with patients.

"The patient does not know the diagnosis and the prognosis until the terminal stage of his disease. The family thinks it is better to hide the information away because of the concern that it is impossible for the patient to cope if he finds it out." (Yoshi)

SUBTHEME 2.2: 'NO ONE TALKS ABOUT IT'

Participants emphasised the general lack of communication about end-of-life between health care professionals, patients and the family. Communication is a very important element of nursing care, however, when the end-of-life is approaching, few people talk about prognosis and death.

"Doctors never talk clearly about someone's prognosis; some of them consider patients are not ready to listen to bad news. They are afraid of the family's reaction as well. Time goes by, and they lose the chance to talk about it. On reflection, there are consequences when people are fearful of taking responsibility. I felt I was blamed for this." (Saki)

"There is no opportunity for patients to discuss with doctors about eventual end to the care; no one talks about it. Doctors don't initiate the conversation, and because of that, patients stay suffering, and their pain is not managed at all." (Naomi)

"With any treatment, the positives and negatives for the future should be clearly explained to the patient" (Hisako)

In Japan, patients and the family are commonly reluctant to express an opinion to the doctor. Doctors try to keep conversation opportunities to a minimum, even though it is their job to give medical information to the patient.

"The Medical Doctors Association has a positive attitude to ACP in Japan. They say it's important to discuss patients' preferences at an early stage, but the guidelines are unclear and vague. ACP can be a good trigger for clear conversation." (Chisato)

C. THEME 3: CULTURAL INFLUENCE

Participants were aware of cultural influence when introducing ACP to patients in the community and described how ACP had been accepted or not accepted in Japan. This theme is sub-divided into traditional ways of thinking and taboo surrounding talking about death.

1. SUBTHEME 3.1: TRADITIONAL WAYS OF THINKING

Traditional ways of thinking affect the delivery of care to patients in the community. Even experienced community nurses found that the traditional Japanese ways of thinking

influenced their professional practice, for example, in the display of feelings. It is rare for Japanese people to openly disclose their feelings in public as the expectation is that feelings should be kept hidden.

“The problem is we don’t talk much about anything verbally, maybe it’s the culture of Japanese. We expect to recognise each other’s feelings without talking about them, and underneath we are seeking assurance for acceptance.” (Yoshi)

“I know the word ACP, but I am not sure if Japanese elders can express their thoughts and if they get opportunities to do that? (Saki).

2. SUBTHEME 3.2: TABOO SURROUNDING TALKING ABOUT DEATH

Not talking about death and dying was noted as a significant barrier to quality care and made implementation of ACP very difficult.

“It is a taboo to talk about someone’s death in Japan, so it’s difficult to initiate the conversation on what to do if anything happens to one ...” (Chisato)

“Historically, talking about dying and death is a taboo in Japan.” (Denko)

D. THEME 4: LONGER LIFE VS BETTER LIFE

Prolonging a person’s life does not necessarily improve its quality. Participants felt they had a responsibility and a role to play in assisting patients to consider quantity against quality of life. Elderly patients, in particular, may not be asked about their preference in treatment or share this with family or health care professionals because they are worried about being a burden. Instead, it is frequently assumed patients will follow either clinicians or the family’s decision.

“The patient is alive just breathing, unconscious without any quality of life, the treatment is for prolonging life ... I cannot see it. So many bedridden patients.” (Mayumi)

“Patients over 80 years old usually do not express their wish in their treatment. They rely on doctors’ or the family’s plan. They may have had no chance to talk about it. Nobody asks them.” (Mayumi)

Whether to advocate quality of life at the end-of-life and therefore ACP as a health carer may be influenced by the nurse’s personal experience.

“One of my patients had terminal cancer at 56 years old. He wanted to know about the prognosis, how long he could be himself and the effects of the treatment on him. He was prepared to have a good end to his life. He had a beautiful birthday party with his partner, and he spent valuable time with his children.” (Hisako)

E. THEME 5: ABSENCE OF FRAMEWORKS AND GUIDELINES

The participants were positive about using ACP overall, however, they had difficulty identifying documentation which could guide them through use of ACP.

“There are no forms, no definition and no framework about ACP, so at each hospital, its implementation is varied among health professionals.” (Saki)

“ACP has been introduced by the the government who suddenly recommended the use of ACP, but there is no specific guidelines.” (Keiko)

IV. DISCUSSION

The current study identified complexity surrounding family power related to health care decision-making. Japanese family holds great power in decision-making around ACP and end-of-life care in general ascribable to cultural traditions and expectations. It was apparent from the results Japanese family dynamics is different from that in Western family and this difference has been acknowledged to complicate the implementation of ACP in Japan [16]. Hamano [17] previously pointed out the importance of considering the power relationships and conflicts between patients, the family and clinicians in preparation for ACP.

The results of the study pointed out psychological burden placed on the family during ACP, which does not only stem from the sense of responsibility. Japan is often described as having a *sham-based-culture* where shame is used to achieve social control [18]. It is also known for its unique cultural concept *sekentei*, which refers to people’s concerns about public perception of their behaviour and being socially acceptable [19]. Withdrawal from active treatment, for example, is considered bad for *sekentei* [20] and the family can be highly susceptible to the feeling of shame and guilt during ACP especially if patients’ wishes in care contradict from what the society considers appropriate.

Attainment of true informed consent from patients and the family in Japan is challenging when considering advanced care directive, a formalised advance care plan. ‘Informed consent’ in Japanese has slightly different meaning to that in English [21]. ‘Setsumei to doi’, the translation of informed consent in Japanese can be obtained without patients’ knowledge in their diagnoses as clinicians are not legally mandated to share this information with them [22]. Practice of informed consent differs between Japan and western countries such as Australia and United States where honest disclosure of diagnosis and prognosis is an important aspect of informed consent involved in ACP and it reflects their cultural differences [21]. In United States there is a focus on upholding the principle of patient autonomy during informed consent, while in Japan clinicians play paternalism and family authority takes precedence to an individual patient’s needs and wishes [21].

In Japan, there is a great reliance on others to assume the role for decision-making regarding lifestyle and health care. In this traditional practice called *omakase*, patients entrust their family and clinicians with health care decisions including those relevant to end-of-life care, assuming others would make the most appropriate and beneficial calls for them [23]. This custom unfortunately encourages delay in adequate consultation between patients, the family and health care professionals, thereby complicating decision making around end-of-life care [24]. Additionally, this over-reliance on others for health care decisions may result in lower quality health care practices that do not align with patients’ wishes.

Another factor influencing ACP practice in Japan is the traditional communication style of its people. Japanese society encourages non-verbal and indirect communication styles and its people are often expected to be intuitive about others' needs making much of their communication implicit [25]. This characteristics can be difficult for non-Japanese to understand, who tend to be direct, especially in professional contexts [26]. Following the original introduction of if its concept, the Japanese Government now uses the terminology 'Jinsei kaigi' to promote ACP [27 Labour and Welfare, 2018] . It translates into 'a meeting for life' and refers to discussion surrounding the meaning of life and wishes in medical care. This campaign has led to some health care professionals to initiate honest conversation with their patients about future care, a key to the successful implementation of ACP. The process of change, however, is slow.

The results of this study flagged the lack of framework and specific guideline to assist its users to practice ACP in Japan. Community registered nurses were generally positive about using ACP, however, absence of policy documents, guidelines and legal frameworks impowers ACP practiced in Japan and hinders its uptake. Such documentations and legal frameworks should be developed by the Japanese Government and relevant professional organisations urgently so that both patients and the family can prepare more appropriately for a time where one cannot make decisions for himself/herself, frequently near the end-of-life. ACP is presently practiced in an unstructured, unstandardised and legally unsupported manner and it cannot sufficiently protect patients' dignity and minimise suffering for both patients and the family when difficult decision-making around health and personal care is needed. Based on the findings of this study, authors recommend following measures to take place.

1. Establish policy document and guideline in Japanese on ACP that can be used in practice
2. Define ACP in the Japanese language such as 'shuumatsuki jizenn shiji' to enhance familiarisation of the concept by Japanese people
3. Improve public health literacy on the topic by public lectures, media announcements and publication
4. Arrange ACP trainings for health care professionals that include assertive professional communication skills development
5. Expand the research on quality of life from health perspectives in the Japanese context using both qualitative and quantitative measures.

This study has some limitations. The sample size was small and only community nurses from metropolitan Japan were interviewed. Future research should include broader range of health care professionals. The study builds on the role of community nurses in ACP implementation and adds to better understanding in the ACP currently practiced in the home environment in Japan and barriers to maximising its potentials to alleviate suffering by patients and the family.

V. CONCLUSION

The current study identified five themes to describe issues surrounding the current practice of ACP in Japan from

community nurses' perspectives. All the themes were interconnected and reflective of the social, cultural, legal and ethical aspects of life and care in Japan. Japanese culture was identified to greatly influence family power dynamics in health care related decision-making as well as communication between patients, the family and clinicians, including the manner informed consent is performed in Japan. This study highlighted the importance of respecting patients' preferences in care, which should be additionally protected by establishing clear policy and legal frameworks on ACP.

A conclusion section is not required. Although a conclusion may review the main points of the paper, do not replicate the abstract as the conclusion. A conclusion might elaborate on the importance of the work or suggest applications and extensions.

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APPENDIX

Table 1 Demographic data

Pseudo Name	Registered nurse experience (yrs)	Community nurse experience (yrs)	Knowledge of ACP	Attendance of an ACP seminar
M	28	5	no	no
N	21	10	yes	yes
S	27	8	yes	no
T	35	5	yes	no
Y	22	5	yes	no
K	34	14	yes	no
Y	20	5	yes	no
A	21	5	yes	no
H	30	6	yes	no
C	24	8	yes	no
D	28	5	no	no