

標題

Experts' perspectives and practices in end-of-life care: A qualitative study on bioethics and human rights regarding older patients' autonomy

終末期ケアにおける専門家の視座と実践：
高齢者の自律性を取り巻くバイオエシックスと人権に関する質的研究

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患者中心 (patient-centered) 高齢患者 (older patients) 終末期ケア (end-of-life care)

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要旨

生命医学倫理の基盤である患者の自律性は、主にインフォームド・コンセントや臓器提供に焦点が当てられてきた。終末期ケアは世界中で実践されているが、専門家や医療従事者が高齢患者の自律性をどのように認識して実践しているのか、特に生命倫理の原則や人権との関係性への研究は少ない。本研究では、終末期ケアの専門家が患者の自律性をどのように認識し実践しているのかを明らかにし、それを尊重・実現するため、また、保健政策・制度・枠組の中で終末期ケアの専門家がいかに課題解決の能力を向上することができるのか、その示唆を探求することとする。研究参加者 (N=54) はアジア圏 (n=42) : 日本・韓国、および欧州 (n=12) : 英国・スイス・イタリア・ノルウェー、計6ヶ国の終末期ケアの専門家とし、職種は主に管理職にある医療従事者 (医師、看護師、ソーシャルワーカー、臨床倫理士、臨床心理士、栄養士、理学療法士)、学識者および宗教指導者とした。研究方法は半構造化面接法を用い、高齢患者の自律性に関する視座と実践を問うた。データに密着した分析により独自の理

論を生成する、質的研究法の一つであるグラウンデッド・セオリーを用い、研究をデザインし、データの収集及び分析を行い、終末期ケアの専門家による視座と実践を説明するカテゴリー及びサブカテゴリーを構築した。さらに、本研究手法の基礎をなすシンボリック相互作用 (symbolic interactions) を検討することにより、一定の条件下における研究参加者の実践の理由や過程を検証した。データ分析から、患者が高齢であっても自律性を尊重すべきと全研究参加者が認識しており、それは信条や宗教に関係なく、地域や国、人種を越えてみられた。一方、高齢患者の自律性に関するケア実践においては三つの優先傾向が明らかになった。①患者の自律性優先：ケアを通じて患者の自律性を優先。終末期ケアの専門家は「患者中心のケア」を実践することにより、患者の自律性を優先していた。患者や家族あるいは終末期の多職種連携ケアチーム・メンバーとしばしば「積極的な相互作用によるチームアプローチ」を用い、「家族の意見は補助的要素」と捉えていた。②家族の意向優先：患者の自律性より家族の意向を優先。この傾向は、主に「終末期ケアにおける家族の役割」または「社会・文化制度」の影響を受けていた。このような傾向は、時折「終末期ケアの実践に関する専門家の懸念」（患者本人が終末期の意思決定から取り残されている等）を引き起こした。③優先順位の転換：優先順位の転換：患者の死が近づくに伴い、主に「患者の状態」、「家族の状況」、または「専門家の決断」により、終末期ケア医療専門家は優先順位を①から②に、あるいはその逆に転換していた。「可能な限りの最善のアウトカム」は、専門家の高齢者に対する終末期ケアにおいて①～③のいずれかを実践することで達成する目標（コア・カテゴリー）として抽出された。これは、患者の生活の質 (Quality of Life: QOL)、死の質 (Quality of Death/Dying: QODD)、および望ましい死 (good death) を含有していると解釈することができる。本質的研究は、終末期ケアという現代における地球規模の課題をバイオエシックスと人権の観点から検討し、専門家は患者の自律性の尊重を重要な原則であると認識していることを同定した。現行の医療政策および医療制度の下、終末期ケアの専門家は①～③の実践により、「可能な限りの最善のアウトカム」を目指していることが示された。一方、三つの優先傾向で提示されたように認識と実践に違いがみられ、患者の自律性の実践は死期が近づく高齢患者を取り巻く特定の条件や状況に影響を受け決定されていた。これらの多様性は地理的、文化的、社会的状況を越えて確認され、終末期ケアにおける公平性（サービス・医薬品の利用可能性、アクセス可能性、質の平等）および教育と研修の標準化をさらに検討する必要性が示唆された。患者の自律性を推進するための現行の取り組み（緩和ケアの拡大、アドバンスケアプランニングの推進、介護者のケア、終末期ケアの標準化等）は継続されるべきである。このような取り組みは終末期ケアの専門家の指針を確立し、一般の人々の意識を高めることにより、患者の QOL と QODD をより良くする包括的なアプローチとしての役割を果たす。人権保護と生命医学倫理の基盤である患者の自律性の尊重によって強化されたこれらの戦略は、患者や家族の希望、意向、状態に応じた終末期ケアの基盤となる。「誰一人取り残さない」とする国連

の持続可能な開発目標における世界的な約束に鑑みても、あらゆる年齢の終末期患者の人間の尊厳は維持されるべきである。

Abstract

Introduction Patient autonomy is a cornerstone of biomedical ethics. Studies have been conducted on patient autonomy, chiefly focusing on informed consent and organ donations. Although end-of-life care is practiced throughout the world, there have been few studies on how end-of-life care experts perceived and practice autonomy of older patients, particularly in the relationship with the principles of biomedical ethics and human rights. This study aims to identify the perceptions and practices of end-of-life care experts regarding patient autonomy, and to explore how to respect and realize it, as well as to improve their ability to solve issues within the framework of health systems and policies.

Methods The research participants were end-of-life care experts (N=54) affiliated with institutions in 6 countries: Asia (n=42); Japan and Korea, and Europe (n=12); UK, Switzerland, Italy, and Norway. Their occupations were healthcare professionals in management positions (physicians, nurses, medical social workers, clinical ethicists, clinical psychologists, nutritionists, and physical therapists), leading academicians in the subject, and religious leaders. We used semi-structured interviews to inquire about the perceptions and practices of the research participants regarding autonomy of older patients in end-of-life care. Employing a grounded theory (a qualitative research method that generates theories from a grounded-on-data analysis), we designed the study, collected and analyzed data, and developed categories and subcategories that explain perceptions and practices of end-of-life care experts. We also examined symbolic interactions, a foundation of grounded theory, among the research participants in reasoning and processing their practices under certain conditions.

Results & Discussion All research participants perceived that patient autonomy should be respected for capacitated people, even in their old age, regardless of creed or religion, and across regions, countries, and races. On the other hand, we identified three tendencies (categories) in the practice of patient autonomy in end-of-life care for older patients: (1) Patient Autonomy Priority: Healthcare professionals generally prioritized patient autonomy by providing ‘patient-centered care.’ They often used a ‘team approach to active interactions’ with patients, their family, and with other team members to respect patient autonomy in end-of-life care. They mainly considered ‘family input as supporting components.’ (2) Family Preference Priority: Healthcare professionals prioritized family preference over patient autonomy. It was mainly due to ‘family roles in end-of-life care’ and/or reflection of ‘social and cultural systems.’ These practices sometimes caused ‘healthcare professionals’ concern on the clinical practice,’ e.g., patients left behind in decision-making processes regarding their end of life. (3) Shifting Priorities: Healthcare professionals shifted priorities from (1) to (2) or vice versa, primarily due to ‘patient conditions,’ ‘family situations,’ and/or ‘expert decisions’ as the patient’s death nears. ‘The best possible outcome’ (core category) was extracted as the target at which healthcare

professionals aimed by practicing (1), (2), or (3) in end-of-life care for older patients. It implied the quality of life (QOL), quality of death/dying (QODD), and a good death of the patient.

Conclusion This qualitative study examined the contemporary global issue of end-of-life care from bioethics and human rights angles. It identified that respect for patient autonomy was perceived as an important principle among the end-of-life care experts. ‘The best possible outcome’ was extracted as the target (core category) at which healthcare professionals aimed to deliver under the existing healthcare systems and policies. Yet, we observed some discrepancies between perception and clinical practices on patient autonomy, as summarized as priorities (1)-(3), which were influenced and determined by certain conditions and circumstances surrounding the old patient who was approaching death. The identified variations across geographical, cultural, and social settings suggested a further consideration of fairness (e.g., equal availability, accessibility, and quality) and standardization of education and professional training in end-of-life care. All the endeavors currently undertaken (e.g., expansion of palliative care, promotion of advance care planning, care for carers, standardization of end-of-life care) to support patient autonomy should continue. These endeavors can serve as a comprehensive approach to improve the QOL and QODD of the patient by establishing a guide for end-of-life care experts and raising awareness of the general public. These strategies become a foundation for supporting end-of-life care in accordance with the patient/family wishes, preferences, and conditions reinforced by human rights protection and respecting patient autonomy, a core principle in biomedical ethics. Aligning with the global promise, “Leaving no one left behind” of the United Nations Sustainable Development Goals, human dignity should be respected and maintained for all people including older adults at end of life.

1. Introduction

The global population is aging. People aged over 60 are outnumbering children ≤ 5 years old and will nearly double from 12 % to 22 % between 2015 and 2050. All countries face major challenges to ensure its preparedness in health and social systems to address this demographic shift (Sallnow et al., 2022; World Health Organization 2018). Japan is the number one ‘super-aged’ society in the world with the older population (≥ 65 years old) of 36.3 million accounting for 29.1 % of its total population in 2022 (Statistics Bureau of Japan, 2022). It is expected to reach 33.3% by 2036 (National Institute of Population and Social Security Research, 2017) and an estimate of 1.5 million deaths per year will occur from 2025. Japan will become an ‘aged society with a high volume of deaths’ (*korei-tashi-shakai*) (Ministry of Health, Labour and Welfare, 2016). This implies an immediate threat to individuals, communities, society, and the country. The government of Japan has been addressing various countermeasures including Long-Term Care Insurance, which was launched in 2000 as a “socialization of care for the frail elderly” (Campbell and Ikegami, 2000).

End-of-life care is one of the areas facing such shift. An interchangeably used term, palliative care, is an approach that improves the quality of life of patients and their families facing problem associated with life-threatening illness, through the prevention and relief of suffering by means of “early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual” (World Health Organization, 2020). Palliative care can be provided at any life stage of the patient. Both end-of-life and palliative care are generally provided by multidisciplinary (interdisciplinary) teams, which often consist of healthcare professionals including physicians, nurses, medical social workers, clinical ethicists, clinical psychologists, nutritionists, rehabilitation specialists, and often religious leaders (e.g., ministers or monks). Their professional educations and trainings vary in depth and length while the shared goal is to treat and/or care for patients by aiming to achieve a good quality of life and/or good quality of death/dying.

One foundation in medical and nursing care is bioethics. In 2019, biomedical ethics marked its 40th year. Respect for patient autonomy is one of the fundamental principles in it (Beauchamp and Childress, 2019a). In Japan, for instance, a bioethics perspective has been studied primarily in the settings of informed consent (e.g., invasive treatments) and organ donation (Hoshino, 1995). The invocation of patient autonomy, which is the value of the informed consent doctrine, has been called for patients at end-of-life in particular (p182) (Machino, 2013).

Another essential component in end-of-life and palliative care is human rights. Palliative care is a basic human right (Health and Human Rights Resource Guide, N.D.). Essential elements of a human rights-based approach to end-of-life and palliative care include availability, accessibility, acceptability, and quality of healthcare, health services, and medicine; universality (non-discrimination); and accountability of the government and healthcare providers. The essential

elements often include participation and inclusion of the stakeholders (United Nations Economic and Social Council, 2000; World Health Organization, 2002). Although bioethics and human rights are essential in examining justice in medical and nursing care, two were traditionally examined separately. This study is unique in the way in which it attempts to address both bioethics and human rights in terms of end-of-life care for older adults in aging societies.

Autonomy of older adults (≥ 65 years old) is, however, sometimes regarded as ambiguous when considering end-of-life decisions. An existing study displayed a clear example: A Japanese 83-year-old female patient with advanced lung cancer was referred to the hospital's ethics committee. A Japanese hospital staff who was trained in the United States was concerned that a patient's decision-making autonomy was violated. When the patient was asked if she wanted to make the decision on her treatment, she clearly said, "No, you ask my son and my husband" (p322) (Braun et al., 2000).

However, justice in palliative care has been little studied. Since 1983, only 296 (average < 8 per year) articles have been published on the subject, as of February 22, 2023, in PubMed database (containing more than 35 million worldwide citations and abstract in biomedical literature) located at the U.S. National Institute of Health.

The quality of death is gaining attention in the healthcare field and a number of researchers suggest a definition based upon qualitative or quantitative studies (Munn et al., 2007; Emanuel and Emanuel, 1999; Singer et al., 1999; Patrick et al., 2001; Pierson et al., 2002, Schwartz et al., 2003). However, an agreed-upon definition of quality of death has been elusive. Moreover, although the experts of various related areas have published individual monographs, articles, and/or reports on the subject of end-of-life care, they have not been aggregated as a collective perspective based upon their expertise with a whole some of hundreds of thousands of patients' deaths and dying experiences. Such study of international comparison is even scarcer.

Given the information above, we developed the following research questions regarding end-of-life care;

- 1) How do the experts perceive patient autonomy, a core principle in bioethics, for older adults (≥ 65 years old) in end-of-life care?
- 2) How do health care professionals practice patient autonomy and reason in clinical settings? and
- 3) What are necessary measures for healthcare professionals to respect patient autonomy as a core principle of biomedical ethics and fundamental human rights in end-of-life care for capacitated older adults?

2. Methods

(1) Data Collection and Analysis

In our qualitative research, we employed grounded theory for data collection, analysis, and developing a theory (Corbin and Strauss, 2015; Strauss and Corbin, 1994, 1997). Grounded theory aims to develop a theory, which is grounded on the collected data. Its strength is to explore little studied phenomena, complicated issues, and fluid situations. It is widely used in human service sectors (medical, nursing, and health) and in sociology. Researchers conduct constant comparison, generate categories from the data, validate the data interpretation, and construct a theory, which ought to be grounded on data that is systematically gathered and analyzed through the research process (Corbin and Strauss, 2015; Strauss and Corbin, 1994, 1997).

In this study, we attempted to find patterns through analytical procedures by using theoretical comparison in a grounded theory approach that examines emerging categories that explain phenomena. The initial stage of this process was performed parallel to data collection to assist theoretical sampling (Corbin and Strauss, 2015; Strauss and Corbin, 1997). By the constant comparison method (Corbin and Strauss, 2015) of similarities and differences of various cases, we examined the relationships of categories and subcategories that indicate the core phenomena explained by the research participants.

A conceptual foundation of grounded theory is symbolic interactions (Blumer, 1969; Chamberlain-Salaun et al., 2013; Corbin and Strauss, 2015), which are regarded as relevant in end-of-life studies especially because “meaning and the concepts of action, interaction, self, and perspectives are themes” (Chamberlain-Salaun et al., 2013). Symbolic interactions are based on assumptions; a symbolic representation (the external world) and the interior worlds are created and recreated through interaction, meanings (symbols) are aspects of interaction and are related to others within systems of meanings, actions are embedded in interactions, etc. (Blumer, 1969; Chamberlain-Salaun et al., 2013; Corbin and Strauss, 2015). In this study, to understand perceptions and actions/interactions of the research participants, following the grounded theory’s analytical process (Corbin and Strauss, 2015; Strauss and Corbin, 1994, 1997), we generated categories (e.g., priorities in end-of-life care) and subcategories (e.g., conditions/consequences under each category) from the data by examining conditions (reasons and backgrounds) for the taken actions/interactions that caused a consequence in a particular phenomenon (e.g., respecting patient autonomy in end-of-life care).

(2) Enhancing Trustworthiness and Validity of Data Analysis

To avoid one-sidedness of participant representation, maximum variation sampling (Quinn, 2014) was used in recruiting the participants of this study. Specifically, we recruited research participants from different countries, locations (urban/remote), cultures (East/West and Christianity/Buddhism), and care-settings (hospital/hospice/home) to compare and contrast

backgrounds and conditions of the practices. To raise trustworthiness of the data analysis, we conducted triangulation (Maxwell, 2013; Patton and Schwandt, 2015) that “reflects an attempt to secure an in-depth tool or strategy of validation” (Flick, 2007) by collecting information from a diverse range of individuals and settings, as well as multiple professionals from the same multidisciplinary team that provide end-of-life care. By a constant comparison that also displays variations of the phenomena, we explored discrepant cases and negative cases (Corbin and Strauss, 2015; Maxwell, 2013, Quinn, 2014) to increase the depth and range of the analysis, rather than excluding them. We also referred to a checklist for qualitative study (Tong et al., 2007), which is often used in healthcare journals including the *British Medical Journal*.

(3) Interviews

We conducted semi-structured interviews (September 2018-December 2022) with end-of-life care experts, mostly at managerial levels; healthcare professionals (physicians, nurses, social workers, pharmacists, clinical ethicists, clinical psychologists, nutritionist, and physiotherapist), academicians, and religious leaders. Inclusion criteria were; experts in end-of-life care who generally held a managerial position, who were able to respond to the semi-structured interview questions in either Japanese or English and consented to participate in the study. We used an interview guide when conducting semi-structured interviews (e.g., regarding quality of life (QOL) and quality of death/dying (QODD) in end-of-life care, and a good death). The mode of interview was face-to-face or online in accordance with the research participant’s preference. The median duration of interview was 86 (60-190) minutes. All the interview audio was recorded and transcribed. Interviewers (authors) took memo upon interviewee’s permission. The geographical regions and six countries of the studied institutions were; Asia (Japan and South Korea) and Europe (the United Kingdom, Switzerland, Italy, and Norway). In Asia, we included South Korea for its implementation of the “Act on hospice and palliative care and decisions on life-sustaining treatment for patients at the end of life (Act No. 14013)” in 2016. In Europe, we included the United Kingdom where the first modern hospice (St. Christopher’s) was established, as well as other countries with similar cultural and social settings.

(4) Ethics Statement

This study was approved by the research ethics committee at Saitama Prefectural University in Japan (No.30050). We conducted informed consent with each research participant. The research participants’ names and institutions are anonymized to protect their privacy.

3. Results and Discussion

In this particular study, as part of an ongoing larger study, we first explored aforementioned research questions (1) and (2) by focusing on biomedical ethics and fundamental human rights in end-of-life care for capacitated older adults. We found a shared perception on patient autonomy among the end-of-life care experts. However, we observed a variation in clinical practices in which we categorized into three tendencies ('Patient Autonomy Priority,' 'Family's Preference Priority,' and 'Shifting Priorities') as shown in the below section. Given the gap between the perception and clinical practice, we further investigated our research question (3) to understand necessary measures to respect patient autonomy, a core principle of biomedical ethics and fundamental human rights in end-of-life care, for capacitated older adults, which will be discussed below.

(1) The Research Participants

The research participants of this study (N=54) were affiliated with institutions in Asia (n=42) and Europe (n=12). The breakdown of the countries is; Japan (n=40), South Korea (n=2), the UK (n=7), Switzerland (n=3), Norway (n=1), and Italy (n=1). We targeted professionals in management/leadership positions in the subject. Their primary professions were; physicians (n=17), nurses (n=9), social workers (n=7), pharmacists (n=2), clinical psychologists (n=2), physiotherapist (n=1), ethicist (n=2), nutritionist (n=1), academicians (n=6), and religious leaders (n=7). Some had a cross-professional appointment, e.g., nurse and bioethicist or religious leader and academician.

(2) Respect for Patient Autonomy

All the research participants (N=54) stated that patient autonomy should be respected if the patient is capable of decision-making even if he/she is ≥ 65 years old. Such perception was found across the geographical areas (regions and countries) and races, regardless of their creed and religious beliefs.

(2-1) Shared Perception

The research participants in this study emphasized that the principle of respect for patient autonomy has penetrated the modern medical education as an important principle of biomedical ethics in the countries studied in this research.

“After the change of the recent training guidelines, resident doctors (in departments of internal medicine) should take medical ethics courses while at the medical school.”

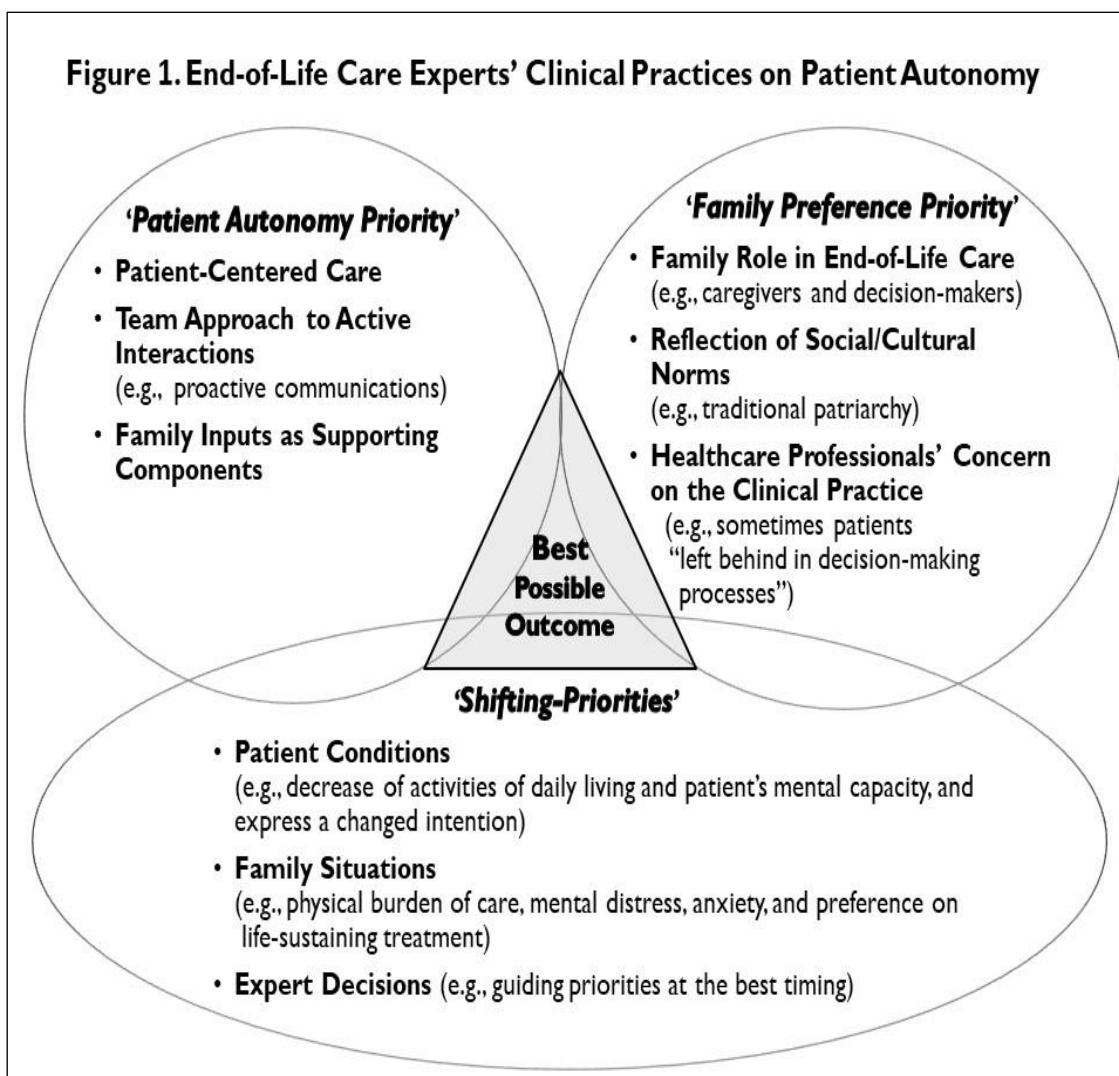
[Physician, university hospital, South Korea]

“All my interns understand patient autonomy because they study at a medical school today.

Thirty-some years ago (when I was a medical student), schools did not teach us. We learned it as we practiced medicine.” [Physician, hospice care unit, Japan]

(2-2) Variations in Clinical Practices

In clinical practices, however, we found three variations (categories) of priority in which healthcare professionals acted and interacted regarding patient autonomy for older adults in end-of-life care. From our data analysis (generating categories), three tendencies were revealed (Figure 1).



(2-2-1) 'Patient Autonomy Priority'

Our analysis found that a certain number of healthcare professionals in this study generally prioritized patient autonomy throughout end-of-life care. Such a tendency was shared and practiced by a number of research participants even if the patient was ≥ 65 years old.

Patient-Centered Care

The healthcare professionals in this study emphasized a ‘patient-centered care’ by placing patient autonomy as a core approach.

“We believe that patients should be informed first in case they have a capacity (to understand). If there is a risk (in patient’s choice or an action), the multidisciplinary team discuss it with the patient and sometimes with the family. Our basis is to respect patient dignity and rights.” [Physiotherapist, hospice, the United Kingdom]

“Respecting autonomy means giving people what they want. I think we have to find a way to be respectful of patients’ autonomy.” [Academician, university, Japan]

Team Approach to Active Interactions

To understand patient needs and preferences, healthcare professionals actively listen to patients at bedside.

“When I listen to my patients with all my heart and soul, there are moments that I precisely fit with my patient mentally and grasp the patients’ sufferings quite clearly.” [Nurse, hospice, Japan]

Multidisciplinary teams attempt to capture patient values which are carried throughout their life. They often interacted with patient’s deep suffering.

“I am among a few who are not medical staff (in a multidisciplinary team). I intentionally don’t wear a uniform. That way, patients can talk to me freely about non-medical issues, such as existential suffering, ‘Why is this happening to me?’” [Chaplain, hospice, the United Kingdom]

Non-medical and/or allied medical staff in a hospice multidisciplinary team also played important roles across the countries studied in this research.

“Patients might not express their real concerns to us. Sometimes, our cleaning volunteers hear important messages (from the patients) and share them with us. It helps us to figure out how to treat the patients in accordance with their needs and values.” [Physician, hospice, Japan]

At another hospital, a multidisciplinary team in the palliative care unit looks for multiple methods to relieve a patient’s physical pain.

“A female patient in her 60s had cancer. She was financially distressed and could not buy effective drugs to relieve her pain, [but] she refused to apply for a public subsidy. She said, ‘I haven’t descended that low yet.’ In addition, she preferred to dress herself up and wear makeup nicely. At first, we thought that this patient should buy medicine rather than be fashionable. But we noticed what the patient values most depends on the individual.” [Nurse, outpatient department, Japan]

As an example, in a survey conducted in Japan, 65.1% of physicians, 61.3% of nurses, and 55.7% of care workers answered that they have “sufficient discussions” or “some discussions” with their patients (p82). Regarding the topics discussed, 85.2% of physicians, 84.9% of nurses, and 68.5% of care workers cited “symptoms at the final stages of life and details and intentions of treatment to be provided.” It was followed by “Information on facilities and services for the final stage of life” and “Patients’ concerns and intentions,” cited by over a half of each group (p83) (Ministry of Health, Labour and Welfare, 2018).

To address the various issues in the diversified medical and social care of the older and their families, there is an increasing need for "multidisciplinary care" (Arai et al., 2012). The World Health Organization defines collaborative practice as “multiple health workers from different professional backgrounds working together with patients, families, caregivers and communities to deliver the highest quality of care” (WHO, 2010). The Basic Plan to Promote Cancer Control in Japan, revised in 2018, emphasized the need for comprehensive care that approaches both treatment and patient lives by promoting team medicine (Foundation for Promotion of Cancer Research, 2021). The healthcare professionals are expected to be advisers to their patients, and better communication is needed to improve mutual intelligibility among patients, families, and healthcare professionals (Aita, 2020). There has been an increasing interest in developing assessment methods for collaborative practice, including a measurement tool to quantify the quality of communication and cooperation among healthcare providers in a region (Morita et al., 2013) and the Multidisciplinary Coordination Ability Scale (Iioka, et.al., 2023) that assesses seamless healthcare, including collaboration with the community and hospitals.

Family Inputs as Supporting Components

The hospice multidisciplinary team that placed importance on ‘Patient Autonomy Priority’ interacted with the patient family mainly to achieve the ‘best possible outcome’ by respecting patient autonomy and self-determination of the patient.

“We supported a patient’s wish to keep eating solid food. There was a high risk of aspiration that could cause him death. We explained the risk to him. He said, ‘I will be more than happy to die of it (than using a feeding tube).’ We spoke with his family, and they agreed.” [Buddhist monk, hospice, Japan]

The end-of-life experts also often interacted with the family members as a part of bereavement care for the patient and family. The lengths and types of bereavement care varied largely among institutions in this study. Some offered it “as long as the family wants” [social worker, hospice, the United Kingdom], while many others regarded it to be completed after the first anniversary of the patient’s death.

(2-2-2) ‘Family Preference Priority’

In some cases, the end-of-life experts were aware that patients were not in the position to express their opinion within the family dynamics.

“When we ask the patient a preference of care at a meeting (with the patient and family), I sometimes observe that the patient casts a glance at the family’s facial expression before speaking up.” [Nurse, hospital, Japan]

Some research participants in this study interacted with family members first and sought their preference whether they wanted the patient to know the truth about situations of his/her disease.

“It is customary that we speak with the family first (without the patient presence). In many cases, family is much concerned to tell the true conditions (of the disease) to an old patient who may be deeply shocked and will mentally never recover.” [Nurse, palliative care unit, Japan]

Family Roles in End-of-Life Care

‘Family’s Preference Priority’ was largely influenced by the condition that family members play multiple roles in end-of-life care; caregiver to the patient, advocate of the patient, defender for the patient, providers of patient information to healthcare professionals, and (formal or informal) decision-makers for the patient. When the patient returns home, the family members become the primary caregivers. They often express anxiety on home care to end-of-life experts.

“After we alleviated the (patient) symptoms ... the patients are happy if they can return home ... if they wish (to spend the rest of their time at home). But families have a strong sense of anxiety if the patient’s conditions get worse.” [Nurse, public hospital, Japan]

Sharing end-of-life wishes and preferences with family members and healthcare providers, including emergency services, is useful when the patient is incapable of making decisions.

“We sometimes need to spend time contacting the family members (who are) designated as a proxy multiple times when the patient become unconscious, instead of being with the patient at the bedside.” [Physician, hospital, South Korea]

Regarding priorities and efficiency in end-of-life care, the burden of data entry and the difficulty of system operation (Leniz et al., 2020) are also pointed out, as well as an insufficient evidence from prospective studies to clarify the effectiveness of the existing system (Chu, 2022). There is a movement to develop a similar system in Japan (Miura, 2023), and new findings from these countries and beyond are awaited.

Reflection of Social and Cultural Systems

The tendency in this study that healthcare professionals primarily communicate with family members was more prevalent in the regions or countries that practices traditional patriarchy, a social and cultural system, in which elderly child (often the first son) hold primary power in the household and/or clan in leadership, moral authority, control of property, etc. On the subject of respect for autonomy, a three-condition theory is explained in a widely used textbook, *Principles of Biomedical Ethics*; (i) intentionality (intentional or nonintentional), (ii) with

understanding, and (iii) without controlling influences that determine their action (pp102-103) (Beauchamp and Childress, 2019b). Our findings, along with others, suggests that the third condition above might be particularly challenging for older patients who are capable of making decisions, likely due to cultural, social, and family dynamics surrounding the patient at end of life.

A study in the United States, for example, found that fewer respondents in certain ethnic groups (n=200 each group of age \geq 65 years old) believed that the patient should be told of a terminal prognosis; 35% Korean Americans, 48% Mexican Americans, 63% African Americans, and 69% European Americans. There was a tendency in the first two groups of the study to believe that the family should make decisions about the use of life sustaining treatment (Blackhall et al., 1995). It connotes that such attitudes vary among social and cultural norms even within the same country.

Healthcare Professionals' Concern on the Clinical Practice

Some healthcare professionals in this study expressed concerns of not prioritizing patient autonomy in their clinical practice, especially when the older patient is competent in making decisions.

“Patients are sometimes seem to be left behind in decision-making processes in end-of-life care. We should listen and record patient narratives frequently from the time they are capable to express (their values and preferences). Their narratives can be re-written when the situations (surrounding the patient) change.” [Clinical ethicist, university hospital, Japan]

These claims were made by multiple research participants in this study, particularly when referring to acute hospital staff.

We also observed discrepant cases, which might be understood as short in respect for patients or whole person's care.

“Sometimes (it appears as if) doctors only see blood vessels and organs of the patients, instead of living persons.” [Nurse, public hospital, Japan]

A veteran physician who leads palliative care in his country spoke with despair:

“A young doctor responded to me, ‘I only look at physical aspects (of patients),’ when I asked if he would care for a total pain of patients after receiving a palliative care training.” [Physician, hospice care unit, Japan]

A healthcare professional in a multidisciplinary team at a hospital stated:

“We should first ask patient and obtain consent from the patient because the body belongs to the patient even though the family's request is based on their thoughtfulness for the patient.” [Pharmacist, hospital, Japan]

It is noteworthy that healthcare professionals who act with a manner of ‘Family-Priority’ in this study generally respect patient dignity. As an example, they perform post-mortem procedures

(referred to as an ‘angel care’ in Japanese) including cleaning the patient body, putting on clean clothing that the patient liked, and applying slight make up on the face to make it lively. Several healthcare professionals in this study also indicated that they pay effort to attend patients’ funerals. All of which are considered to be a manifestation of respect for patients and their families.

The above cases, however, imply a necessity of clarification and standardization of patient autonomy in clinical practice in end-of-life care because physicians should recognize the ethical, emotional, and economic cost and ensure patients’ wishes, rather than focusing on keeping patients alive (p758) (Sutherland, 2019).

(2-2-3) ‘Shifting-Priorities’

In some cases, healthcare professionals in this study shifted priorities from ‘patient autonomy priority’ to ‘family’s preference priority’ or vice versa, primarily due to the following conditions: ‘patient condition,’ ‘family situations,’ and/or ‘expert decision.’

Patient Conditions

Older patients sometimes directly request healthcare professionals to communicate with their family as their illness advances.

“Please ask my wife, an old patient of mine said when I asked his preferred place (for the rest of his life). His mind was clear and making all the decisions up to this point. I don’t think the (Japanese) older generations are ready for autonomy” [Physician, palliative care unit, Japan]

In a book, a prominent Japanese doctor in medical science and anatomy wrote: “If I become ill, my wife will be the one who struggles the most. I should not stick to my opinion. I have no other choice but to leave it to others” (p92) (Yoro, 2016).

“My parishioners (*danka*) often come to the temple for consultation - how to write a succession of property, for instance. What old people say is *for* my children and *for* my grandchildren. They want to do something *for* others, even when they think about their own death.” [Buddhist monk, temple, Japan]

What it indicates here is that patients assume (*omon pakaru*) their family members’ feelings and preference and give up their own values and wishes even at the end of life.

Family Situations

Often, family members express their concern or anxiety in caring for a patient at home, which places the family members as the primary caregiver. A hospice nurse explains:

“Whether the patient (at the terminal stage of illness) should be sent home depends on the patient's wishes and the family's ability to care, as written in the textbook. The rest

is the duration (of how long the patient stays home). It is decided by these three (conditions). No matter how severe the illness is ... and even if the patient is using a ventilator, the family can look after the patient (if it is) for one day. The duration (also) determines whether home care is possible (at end of life).” [Nurse, hospice, Japan]

Understanding the general inclinations of the family members toward the patient’s end of life, a physician noted:

“I just know that families don’t want to bring the patient home at end of life. It’s better for the patient, too, to stay at the hospital (than going home).” [Physician, university hospital, South Korea]

Regarding family situations, their burden of care for the patient and pressures from other members of family/relatives were mentioned by the research participants in this study, although none of them indicated that a family requested to withhold/withdraw a life-sustaining treatment.

Expert Decisions

While providing end-of-life care, healthcare professionals (multidisciplinary team) of this study step into family business, if necessary, especially when family members attempt to shift the priority against the patient’s will.

“There was an occasion when a son spoke on behalf of his mother (patient) about a do-not-resuscitate order. We wanted to honour the patient’s decision (not to be resuscitated). We separately spoke with each to confirm her opinion.” [Physician, nursing home, Norway]

In other cases, healthcare professionals modify the conflicting priorities between the patient and family members with their expertise.

“Reconciling the opinions between the patient and the family, (we) inquire (healthcare facilities) where recuperation is possible. ... When there is no bed available, they have to wait for a month or so. There are quite a few patients whose conditions deteriorate and pass away (at our hospital) while waiting (for the bed at another facility).” [Nurse, hospital’s palliative care unit, Japan]

When family members do not know the priority while caring for the patient, the end-of-life care experts guide them under a certain condition.

“We offer the best possible care. ... Still, a number of patients die (in a hospital). When my patient was unconscious, his family member was outside the room and making calls to other family members. ...Family members often don't know. But because we see many patients, we know when they are approaching death. I said, ‘He (the patient) needs your presence now’ and let her to be with him at the last moment.” [Physician, hospital, Switzerland]

This research participant attempts to be at the bedside especially when no one was with the patient because “presence” or “being there” was important to dying patients, regardless of their consciousness, as many others in the study indicated.

Separately, we also found that the members of the same end-of-life care multidisciplinary team diversely approached patient autonomy under different leadership styles.

“With Dr. A’s patients, we communicate frequently among the team members. Dr. A seeks our opinion, too. And Dr. B has his own established ways of delivering care to his patients. We basically follow Dr. B’s protocols for his patients.” [Social worker, hospital, Japan]

“We are aware how Dr. A and Dr. B practice differently. Both are great doctors. Each has pros and cons.” [Nurse, hospital, Japan]

(2–3) ‘Best Possible Outcome’ in End-of-Life Care

We identified the ‘best possible outcome’ as the target aimed by the end-of-life care experts to achieve by priorities (1), (2), or (3) for older patients. ‘Best possible outcome’ was the central theme (core category) in this study that can be interpreted as a symbol (Blumer, 1969; Chamberlain-Salaun et al., 2013; Corbin and Strauss 2015) or a representation of the meanings in what they do. It was overtly or covertly shared among them when acting or interacting with the patient, family, and/or peers under conditions and premises in end-of-life care for older patients, e.g., ‘patient-centered care,’ ‘family role in end-of-life care,’ ‘patient conditions,’ and ‘with expert decisions’ (Figure 1).

To achieve the ‘best possible outcome,’ the end-of-life care experts often consider (*omon pakaru*) patient’s points of view. Among the Asian research participants in this study, such considerations sometimes did not accompany direct inquiries to the patients. In many cases, it is an underlying action/interaction based on a tacit agreement among stakeholders (e.g., patients, family members, and end-of-life care experts) to realize the ‘best possible outcome’ for older patients at end of life.

Sometimes the ‘best possible outcome’ even includes the patient best interest. In general, a concept of patient best interest is used for incapacitated patients who are unable to make decisions (American Medical Association 2023; Beauchamp and Childress 2019b; Fang and Tanaka 2022; Rhodes, 2020). In this study, however, the research participants attempted to assume and consider patient’s points of view (*omon pakaru*) even the patient was capable of making decisions, presumably due to the conditions and interactions particularly in aforementioned (2) and (3) priorities. The relationship between the ‘best possible outcome’ found in this study and patient best interest regarding patient autonomy requires further research

because the size of this study is rather small.

‘Best possible outcome’ in our finding implied the quality of life (QOD), quality of death and dying (QODD), and a good death. The definition a good death has been attempted by different groups and professions in various societies (Meier et al., 2016). Yet, no single agreed-upon definition of a good death has been established. One of the most referred definitions of good death is “free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Institute of Medicine, 1997). It should be also noted, however, that “there is no definitive supposition about ‘what death is supposed to be’...whether at home, facility, or hospital, with a family or alone, one should not judge which deaths are better. Experts and others should not impose their values (on patient deaths) upon others,” as a clinical psychologist stated (p100) (Kurokawa, 2016).

In a global assessment of the quality of death and dying, “managed pain and discomfort” (11.5%) was ranked as the most important indicator. “Clear and timely information” (9.3%) was ranked as the fourth, which was higher than “contact with family” (5.5%). (p422) (Finkelstein et al., 2022).

In our study, hospice care providers (physicians, nurses, psychologists, medical social workers, pharmacists) mentioned ‘minimal suffering’ as a key for a good death. To manage/control the physical pain and other symptoms, physicians prescribe and inject medicine, including opioids. Pharmacists prepare the medicine and nurses often provide hands-on care e.g., body part massage, to alleviate pain. By providing multi-layered end-of-life care through (1)-(3) priorities indicated above, the end-of-life care experts attempt to bring about the ‘best possible outcome’ for the patient.

(2–4) Plausible Reasons behind ‘Family Priority’ and ‘Shifting-Priorities’

Medical science is universal while healthcare reflects social and cultural contexts, as well as ethical considerations accordance with societal and cultural norms. Regarding the attitudes and actions in both ‘Family-Priority’ and ‘Shifting-Priorities’ in this study, it can be interpreted that healthcare professionals attempt nonmaleficence (do no harm; one of principles in biomedical ethics) to the patient whose physical, psychological, social, and/or spiritual state is already burdened by the disease at end of life, regardless of his/her decision-making capacity.

One aspect of healthcare professionals’ view on nonmaleficence is not to disturb family order or harmony (*wa*) at the patient end of life, as a study in Asia also identified (Morita et al., 2015; 2020), for example. It is often expressed by how they support patient maintaining or restoring family relationships as unfinished business towards his/her death. Patient autonomy can be inconsequential or sometimes harmful to family harmony if the values and preferences of patient and family disagree. It is recommended to provide end-of-life care, e.g., palliative care, in a culturally acceptable manner (Morita et al., 2015). To avoid such consequences, an

alternative approach, such as relational autonomy by respecting patient autonomy with interactions and involvement with family and healthcare professionals, has been proposed in various countries and cultures (Gómez-Vírveda et al., 2020; Morita et al., 2015). Some researchers observe the transformation in this area: “[T]he focus has shifted to a ‘joint decision-making between patients and healthcare professionals.’ Patients convey their own values to healthcare professionals, consider treatment options based upon their values jointly with healthcare professionals and jointly set the purpose of the medical practice. The role of a physician is not only a messenger as a professional of knowledge and techniques but also an advisor for the patient in a broader sense” (p488) (Aita, 2013). The key to co-determination is a good communication (Roter, 2000). It would reduce the current practices where some healthcare providers attempt to aggressively treat patients (Sineshaw et al., 2019) until it becomes too late to realize a good death.

In case of disagreements or disputes at end-of-life care, ethics consultations with healthcare professionals and ethicists, as a collaborative process, can be beneficial from bioethical and human rights perspectives. The aforementioned case of an 83-year-old female patient in the previous study was brought to an ethics consultation (Braun et al., 2000). However, in some countries examined in this study, availability and accessibility of ethics consultation at end-of-life care facilities were still limited.

“There are very few clinical ethicists in Japan. Not only the low number but also little connection among us across the nation is yet-to-be solved issue.” [Clinical ethicist, hospital, Japan]

As supportive evidence in a Japanese national survey, 55.1% physicians, 59.7% nurses, and 70.1% caregivers responded that there was no in-house ethics committee where they can seek for ethical consultations (p88) (Ministry of Health, Labour and Welfare, 2020).

(3) Endeavors to Support Patient Autonomy

(3-1) Expansion of Palliative Care

Palliative Care as a Basic Human Right

Palliative care is explicitly recognized under the human right to health (Radbruch et al., 2013). A human rights-based approach to health requires government to respect, protect and fulfil human rights by assuring availability, accessibility, acceptability, and quality of healthcare services and medicine; participation of the stakeholders; and government accountability (World Health Organization, 2002). Although human rights approaches to palliative care have been developed over the past decade in the international community (Ezer et al., 2018), a wide access to palliative care is still underway in many countries (Knaul et al., 2018), including the ones studied in this article.

A certain level of palliative care must be available at the place where patients spend their end of life (home, palliative care units, hospitals, nursing homes, etc.). Nevertheless, from a lens of human rights-based approach, some health disparities (inequalities) in availability and accessibility to hospice/palliative care exist. As an example, there are 409 hospice service (including palliative care) providers in Japan. However, only 8.4% cancer patients used a hospice in 2011 (Hospice Palliative Care Japan, 2018). In addition, Hospice/Palliative Care Units (PCUs) in Japan mainly accept patients with cancer and acquired immunodeficiency syndrome (AIDS) who require palliation of pain, while noncancer patients who require ventilator or haemodialysis tends to be excluded (Kizawa, et.al, 2021). It also causes inequalities between the patients who are eligible and ineligible to be admitted to these units. To address such issues, the Japanese government promotes ubiquitous care by increasing the number of designated cancer centers and hospitals (Ministry of Health, Labour, and Welfare, 2019; Yamaguchi, 2013). The 436 designated cancer centers and hospitals are required to provide annual staff trainings (Ministry of Health, Labour, and Welfare, 2019; The National Cancer Center Japan, 2019). However, senior staff in this study who train junior staff reported the training requirement to be a “heavy burden,” in addition to other certification requirements and daily practices.

(3-2) Promotion of Advance Care Planning

Advance care planning has been promoted in multiple countries. One method is to record patient value/preferences and utilize them for end-of-life care, as often discussed in the subjects of advance care planning and/or in a do-not-resuscitate order (Breault, 2011). The Ministry of Health, Labour and Welfare of Japan presented the concept of advance care planning and its necessity to the public in 2018. Participation of the patient in decision making is essential to improve the quality of end-of-life care. Decision making training has been conducted mainly for healthcare professionals (Okada et al., 2021; Goto et al., 2022). “The Japan Vision: Health Care 2035” aims to establish a system for individuals to design their own life (Ministry of Health, Labour and Welfare, 2015).

A Japanese survey revealed the general public’s attitudes regarding advance care planning; 59.3% of respondents reported having thought about end-of-life care, however, only 39.5% indicated that they had actually discussed it with family members and healthcare professionals (Ministry of Health Labour and Welfare, 2018). There is a difference between intentions and actions regarding advance care planning. It is because advance directives are not legally binding in Japan and communications regarding end-of-life care among family members are lacking (Nakazato et al., 2018). In addition, discrepancies between physicians’ practices and their perceptions exist in advance care planning and some physicians do not regard patients’ advance directives as important (Nakazawa, et al., 2014).

To promote advance care planning, it is necessary to address effective ways to provide support to patients from healthcare professionals by recognizing individual values and building

consensus among family members at an early stage. For example, our separate new study implies six factors related to the general public's experience of having discussions about end-of-life care; not to avoid discussions, having a primary care physician, the experience of thinking about death, recognition of the need for discussion, selection of proxy decision-makers, and designation of written end-of-life care. To enhance patient autonomy in end-of-life care, it is important to create opportunities for assertive discussions with family members and healthcare professionals (Yamaguchi et al., 2023). In addition, it is desirable to promote both the development of a culture of advance care planning discussion that includes patients and their families and the use of information and communication technology for efficiency and effectiveness the digital age.

(3-3) Care for Carers

Healthcare professionals are also concerned about their own physical and mental effects of providing end-of-life care. During the COVID-19 pandemic, the impact of the spread of an infectious disease with no end in sight exhausted healthcare professionals in end-of-life care settings (Ferreira et al., 2021; Kotera et al., 2022). Healthcare professionals also need to be under a system that allows them to safely implement care. As part of this process, self-care plays an important role in helping healthcare professionals cope with frequent exposure to death and dying (Sansó, et.al, 2015). One of our research participants in Europe was planning to initiate selfcare education at medical school. Some Japanese research participants in this study, too, organized meetings and consultations for healthcare professionals in their regions and communities to alleviate mental distress to prevent a burnout syndrome. Such remedies to care for carers are important examples in sustainable provision of end-of-life care, especially in aging societies.

(3-4) Standards of End-of-Life Care

The Leadership Alliance for the Care of Dying People (LACDP), for instance, has drawn up five properties focus on: recognising that someone is dying; communicating sensitively with them and their family; involving them in decisions; supporting them and their family; and creating an individual plan of care that includes adequate nutrition and hydration (Anderson, 2014). These priorities of care are intended to ensure that the dying person is at the center of the care plan. Since 2014, no new proposals have been found to replace this guidance, however, it is an indicator that contributes to improving the quality of care for physicians (Redman, 2017) and nurses (Thorpe et al., 2021). Recently, Electronic Palliative Care Co-ordination Systems (EpaCCs), information sharing systems for end-of-life care, have been developed and are in operation to involve the person in decision-making (Petrova et al., 2018).

(3-5) Inclusive Education and Training on End-of-Life Care

Generally, multidisciplinary team members have different background in education and training accordance with their profession and field. Hospice care provision in Japan largely depends on the primary physician's decisions under the Medical Practitioners Act in Japan, whereas nurses

and social workers often oversee and coordinate the multidisciplinary team and patient/family at hospice programs in the United States (Sase and Eddy, 2016). It is often nurses who provide direct care for patients at end of life. For example, the End-of-Life Nursing Education Consortium (ELNEC) in the United States, established by the American Association of Colleges of Nursing (AACN) and City of Hope National Medical Center in 2000, developed a systematic educational program for nurses who provide end-of-life care and palliative care (Ferrell et al., 2015). ELNEC-Japan's core trainer program was launched in 2009 (Takenouchi et al., 2011). In addition, the Specialized Palliative Care Education for Nurses Program (SPACE-N) implemented by the Hospice Palliative Care Japan aims to train nurses who are willing and able to take a leadership role in the field of specialized palliative care (https://www.hpcj.org/med/aboutspace_n.html). SPACE-N aims to train nurses who can take a leadership role in providing specialized palliative care and who are willing and able to improve the quality of specialized palliative care, and to improve the core competencies needed to support cancer patients and their families as they face suffering and death (Arahata, 2021).

The Japanese Society for Palliative Medicine has published six guidelines and one clinical evidence since 2010 (<https://www.jspm.ne.jp/english/committees/guidelines/index.html>). Among them, there are guidelines based on physical palliation such as cancer pain management and palliative sedation therapy, yet, there are no guidelines on holistic patient care in end-of-life. Along with the ongoing palliative care training for physicians (PEACE project) and nurses (ELNEC-Japan), education and training for paramedics must also be advanced. It helps accomplish efficient and effective collaboration of the interdisciplinary team in the hospice/palliative care, as mentioned in other countries (Lord, 2012). Multidisciplinary end-of-life educational intervention programs increased confidence in collaboration among health and social care professionals (Fukui et.al., 2019).

In this study, some medical social workers expressed their views that their specialized skills and capacity are not well used in hospice care. One wished a change of policy that allows medical social workers to attend the specialized trainings on paid holidays, similar to physicians and nurses. Pharmacists in multidisciplinary teams said that their expert recommendations are sometimes not welcomed nor accepted by primary physicians in palliative care. Japan is expected to enter an 'aged society with a high volume of deaths' (*korei-tashi-shakai*) (Ministry of Health, Labour and Welfare, 2016). In such situations, end-of-life care education is necessary for all care providers at hospitals and in communities. As the global population ages, it is also applicable to other countries and regions.

(3-6) Health Policy Development regarding Palliative Care

One example of a policy movement regarding palliative care and hospice is the Palliative Care and Hospice Education Training Act (PCHETA), which was reintroduced to the United States congress in 2022. It aims to "promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine." It is primarily to

require; the U.S. Department of Health and Human Services to take actions relating to palliative-care training, including operating the Palliative Care and Hospice Education Center, supporting individuals who are pursuing an advanced degree in palliative care or related fields, and awarding grants to nursing programs to train individuals in providing palliative care, the Agency for Healthcare Research and Quality to provide for a national education and awareness campaign to inform patients, families, and healthcare professionals about the benefits of palliative care, and the National Institutes of Health to expand national research programs in palliative care (U.S. Senate, 2022). The direction of the Act is yet to be seen.

(4) Limitation of the study

The results of this study cannot be generalized externally while they show strong generalization internally among the research participants in given settings. Cultural variations may not be fully captured due to the limited number of research participants and countries. Regarding the tendencies of healthcare professionals on respect for patient autonomy, their clinical practices in this study do not necessarily represent their professional communities that vary in age, genders, educational background, etc. Our study was designed prior to the COVID-19 pandemic. Therefore, the data may represent more general tendencies of the studied subject.

4. Conclusion

This qualitative study examined the contemporary global issue of end-of-life care from bioethics and human rights angles. Respect for patient autonomy was perceived as an important principle among end-of-life care experts. It exhibited an example in which *Principles of Biomedical Ethics* notes: “Respect for autonomy has nothing to do with American individualism, as we think is now globally recognized” (p11) (Beauchamp and Childress, 2019b). ‘The best possible outcome’ was extracted as a symbol (representation of an idea of taken actions/interactions) in which healthcare professionals aimed to deliver under the existing healthcare policies and health systems. Yet, we observed some discrepancies between perception and clinical practices as summarized as three tendencies: (1) ‘Patient Autonomy Priority,’ (2) ‘Family Preference-Priority,’ and (3) ‘Shifting-Priorities.’ These priorities were influenced and determined by certain conditions and circumstances surrounding the old patient who was approaching death, such as ‘family role in end-of-life care,’ ‘patient conditions,’ and ‘expert decisions.’ The identified variations across geographical, cultural, and social settings suggested a further consideration of fairness (e.g., equal availability, accessibility, and quality) and standardization of education and professional training in end-of-life care.

All the endeavors currently undertaken (expansion of palliative care, promotion of advance care planning, care for carers, standardization of end-of-life care, inclusive education and training, and health policy development on palliative care) to support patient autonomy should

continue. These endeavors can serve as a comprehensive approach to improve the quality of life (QOL) and quality of death and dying (QODD) of the patient by establishing a guide for end-of-life care experts and raising awareness of the general public. These strategies can support end-of-life care in accordance with the patient/family wishes, preferences, and conditions reinforced by human rights protection and respecting patient autonomy, a core principle in biomedical ethics. Aligning with the global promise, “Leaving no one left behind” of the United Nations Sustainable Development Goals (UN Sustainable Development Goal Group, 2023), human dignity should be respected and maintained for all people including older adults at end of life.

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