



## ORIGINAL ARTICLE

## EPIDEMIOLOGY, CLINICAL PRACTICE AND HEALTH

# International review of national-level guidelines on end-of-life care with focus on the withholding and withdrawing of artificial nutrition and hydration

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**Aim:** The purpose of the present study was to collate examples of end-of-life care guidelines from various countries, examine their contents, and gain an overall picture of how end-of-life care guidance is offered to physicians and care providers internationally.

**Methods:** In this study, eight researchers worked independently to source and examine national-level end-of-life care guidelines from different countries and regions. Data collected by each researcher were gathered into a unified table. The items in the table included basic information (publisher, year, URL etc.) and more specific items, such as the presence/absence of legal information and family's role in decision-making. These data were then used to identify trends, and examine the mechanics and delivery of guidance on this topic.

**Results:** A total of 54 guidelines were included in the study. All the guidelines were published between 2000 and 2016, and 60% ( $n = 33$ ) were published after 2012. The length of the guidelines varied from two to 487 pages (median 38 pages), and had different target audiences – both lay and professional. A total of 38 (70%) of the guidelines included information about the relevant laws and legal issues, 47 (87%) offered advice on withholding and withdrawing treatment, 46 (85%) discussed the family's role in decision-making and 46 (85%) emphasized the teamwork aspect of care.

**Conclusions:** The present findings show that end-of-life care guidelines are generally made reactively in response to the trend toward patient-centered care, and that to create effective guidelines and implement them requires multilevel cooperation between governmental bodies, healthcare teams, and patients and their families. *Geriatr Gerontol Int* 2019; ●●: ●●–●●.

**Keywords:** artificial nutrition and hydration, decision-making, end-of-life care, guidelines, withholding and withdrawing treatment.

## Introduction

For physicians and care providers alike, decisions about appropriate treatment and care for patients approaching the end of life (EOL) are often very difficult. Such decisions can be fraught with ethical dilemmas and conflicting opinions. As laws regarding EOL care can change over time and advances in medical care are made, guidelines can serve as a source of distilled knowledge for physicians and caregivers to make the right decisions, in accordance with the law, that also incorporate the most current research into best clinical practice. However, guidelines for EOL care, perhaps more so than other clinical guidelines, also have to factor in psychosocial, cultural and religious issues; they have to take into account the hopes and opinions of the patients and (particularly in the Japanese context) their families.<sup>1</sup>

In Japan's super-aged society, there is a growing demand for high-quality, evidence-based elderly and EOL care, and clear, consistent guidelines to meet that demand. Internationally, Japan has been ranked as the 14th best country for palliative care in the world, although much work is still required in generating guidelines suited to specific scenarios in EOL care.<sup>2</sup> To work toward that end, our research team compiled examples of EOL guidelines from various countries to obtain an overall picture of how EOL guidance is offered to physicians and care providers. By doing so, we hoped to identify international guideline trends and effective communication strategies within them that might be adapted for future Japanese publications.

Medically, some life-sustaining treatments at the end stages of terminal diseases and natural life processes, such as artificial nutrition and hydration (ANH), have been deemed unnecessary,<sup>3</sup> but moral, religious and cultural attitudes towards sickness and death have shifted these objective decisions to highly subjective decisions.<sup>4</sup> Governmental, quasi-governmental and professional agencies have therefore had to craft enormous amounts of guidelines that try to encompass these medical, legislative, cultural and religious expectations, and satisfy them all. As a result, confusion can ensue when concrete answers are required over best medical practice in a given situation. This report is not a detailed analysis of the laws and legal advice surrounding this issue, but more so an examination of the mechanics and delivery of guidance on this topic. This study can be taken an initial step in navigating various regulations from an international perspective and give a greater insight into how guidelines for ethically contentious issues are planned, constructed and disseminated. Although some systematic literature reviews of international medical guidelines have been published, to the best of our knowledge, this is the first to focus on EOL guidance and to cover such a large number of countries.<sup>5</sup>

## Methods

In the present study, our international team sourced and examined guidelines with each researcher focusing on particular

countries or regions according to their research interests. The majority of the guidelines that were collected were in the English, Japanese and Spanish languages. EOL care has many different challenges, and there are a plethora of guidelines relevant to meeting those challenges. Thus, we chose to focus our investigation on how guidelines deal with the topic of ANH. This is one of the most ethically contentious issues and is of particular importance in Japan, as many older adults receive ANH, even when it is perhaps not in their best interests.<sup>6,7</sup> Therefore, an Internet search strategy, using Google search engine, was devised using the terms, “guidelines,” “percutaneous endoscopic gastrostomy (PEG)” and “end of life.” Criteria for the inclusion of guidelines were: national-level guidelines from government departments, associations, societies, institutions, charities and so on. No limitations were placed on year of publication. The guidelines were about EOL care in general, specifically about provision of nutrition and hydration, and/or exclusively on the issue or withholding and withdrawal of treatment.

After collecting the guidelines, the researchers then tabularized their findings. The items in the table consisted of: country, guideline name, publisher/association, year of publication and URL (for accessing and referencing the guidelines); the number of pages and the guideline’s general focus (for gaining an overall idea of the scope, purpose and level of detail of the guideline); and the pages relevant to ANH, legal background, criteria for withholding/withdrawing ANH and the family role in EOL decision-making (for addressing the researchers’ particular topics of interest). The sourcing and data-gathering period ran from November 2016 to December 2016, after which the data from each researcher were collated into a single unified table.

## Results

A total of 54 guidelines were collected from 17 countries/regions: Australia ( $n = 2$ ), Canada ( $n = 2$ ), Europe ( $n = 2$ ), Germany ( $n = 1$ ), Hong Kong ( $n = 1$ ), India ( $n = 3$ ), Ireland ( $n = 3$ ), Japan ( $n = 6$ ), the Netherlands ( $n = 1$ ), New Zealand ( $n = 1$ ), Norway ( $n = 2$ ), Singapore ( $n = 1$ ), South Africa ( $n = 1$ ), Spain ( $n = 2$ ), Switzerland ( $n = 1$ ), the UK ( $n = 16$ ) and the USA ( $n = 9$ ). Tables 1–5 show the guidelines collected in this study by region: Europe (excluding the UK; Table 1), Asia (Table 2), Australasia and South Africa (Table 3), the UK (Table 4) and North America (Table 5).

The guidelines were published between 2000 and 2016, and 59% of the documents ( $n = 32$ ) were published in 2012 or later. The length of the guidelines varied greatly: the longest being 487 pages and the shortest document being just two pages in length. The median number of pages was 38, as just nine of the guidelines were of 100 pages or more, whereas 41% ( $n = 22$ ) were 25 pages or under in length.

We discovered guidelines that differed by intended audiences; although most guidelines were designed for clinicians and healthcare professionals, others were aimed at patients, their families or their caregivers. Some documents, such as the Council of Europe’s *Guide on the Decision-Making Process Regarding Medical Treatment in EOL Situations*, target healthcare professionals, patients and patients’ families.<sup>8</sup>

With regard to explaining the relevant legal aspects of EOL care, we found that the guidelines take three basic approaches: (i) they offer comprehensive explanations ( $n = 18$ ; 33%); (ii) they state the bare minimum or indicate that they are in line with relevant legislation ( $n = 20$ ; 37%); or (iii) they make no mention of

**Table 1** Guidelines from Europe included in the present study (excluding the UK)

Country	Guideline	Publisher/association	Year	No. pages	Legal	ANH	Family
Europe	Guide on the Decision-making Process Regarding Medical Treatment in End-of-life Situations	Council of Europe	2014	34	○	○	○
Europe	ESPEN Guidelines on Nutrition in Cancer Patients	The European Society for Clinical Nutrition and Metabolism	2016	38	○		
Germany	Evidenced-based Guideline: Palliative Care for Patients with Incurable Cancer	German Guideline Program in Oncology (GGPO) by the German Association for Palliative Medicine	2015	98	○	○	○
Ireland	Palliative Care for the Person with Dementia: Guidance Document 7: Ethical Decision Making	The Irish Hospice Foundation	2015	74	○	○	○
Ireland	Care for the Person with Dementia: Management of hydration and nutrition	The Irish Hospice Foundation	2016	56	○	○	○
Ireland	Guide to Professional Conduct and Ethics for Registered Medical Practitioner	Irish Medical Council	2009	64	○	○	○
Netherlands	Caring for People Who Consciously Choose Not to Eat and Drink so as to Hasten the End of Life	Royal Dutch Medical Association (KNMG)	2014	51	○	○	○
Norway	Decision-making Processes in the Limitation of Life Prolonging Treatment	Norwegian Directorate of Health	2013	40	○	○	○
Norway	Guidelines for Palliative Sedation at the End of Life 2014	Norwegian Medical Association	2014	2		○	○
Spain	Assistance guide: Amyotrophic Lateral Sclerosis: Guide for Shared Action for the Care of Persons Affected by Lateral Amyotrophic Sclerosis in the SSPA Plan of Attention to Persons Affected by Rare Diseases in Andalusia	Servicio Andaluz de Salud. Consejería de Salud y Bienestar Social. Junta de Andalucía	2012	200	○	○	○
Spain	Document of aid to the decision making in the management of patients with advanced dementia	Sociedad Andaluza de Medicina Interna (SADEMI)	2008	81	○	○	○
Switzerland	End of Life Care	Swiss Academy of Medical Sciences	2013	20	○	○	○

○ indicates that the guideline includes information on the topic. ANH, withholding/withdrawal of artificial nutrition and hydration; Family, family’s role in decision-making; Legal, legal background.

**Table 2** Guidelines from Asia included in the present study

Country	Guideline	Publisher/association	Year	No. pages	Legal	ANH	Family
Hong Kong	Palliative Care: Setting the Scene for the future; A position paper of Hong Kong College of Physicians	Subcommittee in Palliative Medicine, HKCP	2008	31			
India	Limiting Life-prolonging Interventions and Providing Palliative Care Towards the End-of-life in Indian Intensive Care Units	Indian Society of Critical Care Medicine (ISCCM)	2005	12		○	○
India	Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement	Indian Society of Critical Care Medicine (ISCCM)	2012	16	○	○	○
India	End of Life Care Policy for the Dying: Consensus Position Statement of Indian Association of Palliative Care	Indian Association of Palliative Care (IAPC)	2014	11	○		○
Japan	Decision-making in the Care of the Elderly Focusing on Indications for Artificial Hydration and Nutrition (AHN) (in Japanese)	The Japan Geriatrics Society	2012	24	○	○	○
Japan	Guideline of Parenteral and Enteral Nutrition (in Japanese)	Japanese Society for Parenteral and Enteral Nutrition	2010	487			○
Japan	Guideline of Decision-making Process in End-of-life care (in Japanese)	Ministry of Health, Labor and Welfare	2007	3			○
Japan	Guidelines on terminal medical care in emergency/intensive care: Recommendations from 3 academic societies (in Japanese)	Japanese Association of Acute Medicine, The Japanese Society of Intensive Care Medicine, The Japanese Circulation Society	2014	4		○	○
Japan	Guidelines for Gastrointestinal Endoscopy (in Japanese)	The Japan Gastroenterological Endoscopy Society	2006	344		○	○
Japan	Guidelines on the Decision-making Process for End-of-life Medical Care (in Japanese)	Ministry of Health, Labor and Welfare	2006	2		○	○
Singapore	National Guidelines for Palliative Care and Interpretation Guide	Singapore Hospice Council	2015	75	○		

○ indicates that the guideline includes information on the topic. ANH, withholding/withdrawal of artificial nutrition and hydration; Family, family's role in decision-making; Legal, legal background.

legal issues at all ( $n = 15$ ; 28%). Thus, legal issues are present in the majority of the publications ( $n = 38$ ; 70%), underlining the importance of its inclusion. The two European guidelines obviously could not give legal information, as the laws of the individual European states vary. Similarly, national-level guidelines from the USA did not go into detail about EOL legal issues that would be determined by its member states. We also discovered that, of the six Japanese guidelines analyzed in the present study, only one of them makes mention of the law.

Most of the guidelines ( $n = 46$ ; 85%) offered advice on the withholding and withdrawal of treatment. Our analysis of key concepts within the advice on withholding and withdrawal of treatment showed that of the 46 guidelines that dealt with this topic, 42 (91%) of them emphasized the need to respect patients' wishes and advanced healthcare directives, including the patient's right to refuse treatment. Connected to this issue, 28 (61%) of the

guidelines stressed the need to discuss/communicate/explain decisions over withholding/withdrawal of treatment with the patient and their family. Other key concepts include: the need for a multi-disciplinary team in the decision-making process ( $n = 25$ ; 54%); importance of knowing when to withhold/withdraw treatment ( $n = 22$ ; 48%); importance of acting in the patient's best interests ( $n = 20$ ; 43%); and 21 (45%) observe that ANH should generally not be offered or is of little benefit in EOL situations. Concepts that appear with less frequency include: ANH is a medical treatment ( $n = 14$ ; 30%); the goal of care should be patient comfort/quality of life ( $n = 13$ ; 28%) or relief from distress ( $n = 12$ ; 26%); and that it is important to respect a patient's cultural/religious background ( $n = 11$ ; 24%).

The majority of guidelines gave guidance on the role of patients' families in decision-making ( $n = 46$ ; 85%), and placed emphasis on the teamwork aspect of EOL care ( $n = 46$ ; 85%). The guidelines

**Table 3** Guidelines from Australasia and South Africa included in the present study

Country	Guideline	Publisher/association	Year	No. pages	Legal	ANH	Family
Australia	Good Medical Practice: a Guide of Conduct for Doctors in Australia	Medical Board of Australia	2014	25	○	○	○
Australia	National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care	Australian Commission on Safety and Quality in Health Care	2015	42	○	○	○
New Zealand	Good Medical Practice	Medical Council of New Zealand	2016	38	○		○
South Africa	Guidelines for the Withholding and Withdrawing of Treatment	Health Professions Council of South Africa	2008	14	○	○	○

○ indicates that the guideline includes information on the topic. ANH, withholding/withdrawal of artificial nutrition and hydration; Family, family's role in decision-making; Legal, legal background.

**Table 4** Guidelines from the UK included in the present study

Country	Guideline	Publisher/Association	Year	No. of pages	Legal	ANH	Family
UK	Advance Decisions and Proxy Decision-Making in Medical Treatment and Research: Guidance from the BMA's Medical Ethics Department	British Medical Association	2007	13	○	○	○
UK	Prolonged Disorders of Consciousness: National Clinical Guidelines	Royal College of Physicians	2013	132	○	○	○
UK	Serious Medical Treatment Decisions: Best Practice Guidance for IMCAs: PEG Feeds	Action for Advocacy	2011	15	○	○	○
UK	Ethics and Clinically Assisted Nutrition or Hydration Approaching the End of Life (Decision Tree)	British Association for Parenteral and Enteral Nutrition (BAPEN)	2012	4	○	○	○
UK	Nutrition and Hydration in End of Life Care	Royal College of Nursing	2015	6		○	○
UK	Nutritional Advice in Common Clinical Situations	British Geriatrics Society	2009	Online	○	○	
UK	Nutrition Support for Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition	National Institute for Health and Care Excellence (NICE)	2006	48	○	○	
UK	Nutrition Support for Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition	National Institute for Health and Care Excellence (NICE); National Collaborating Centre for Acute Care	2006	175	○	○	○
UK	NICE Pathways: Nutrition Support in Adults Overview	National Institute for Health and Care Excellence (NICE)	2016	8	○	○	
UK	Reference Guide to Consent for Examination or Treatment: Second Edition	Department of Health (UK Government)	2009	43	○	○	○
UK	Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision Making	General Medical Council (GMC)	2000 Withdrawn 2010	22	○	○	○
UK	Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making: 3rd Edition	British Medical Association (BMA)	2007	123	○	○	
UK	Treatment and Care Towards the End of Life: Good Practice in Decision Making	General Medical Council (GMC)	2010	91	○	○	○
UK	Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life	Royal College of Physicians and British Society of Gastroenterology	2010	100	○	○	○
UK	Care of Dying Adults in the Last Days of Life	National Institute for Health and Care Excellence (NICE)	2015	26			○
UK	End-of-life Decisions: Views of the BMA	British Medical Association	2009	6	○	○	○

○ indicates that the guideline includes information on the topic. ANH, withholding/withdrawal of artificial nutrition and hydration; Family, family's role in decision-making; Legal, legal background.

used terms, such as “multidisciplinary,” “interdisciplinary,” “care team” and “interprofessional,” to describe the healthcare “teams” responsible for EOL decision-making and healthcare provision. Another noteworthy similarity across almost a third ( $n = 17$ ; 32%) of the guidelines in our collection was the inclusion of decision trees, flowcharts and other visual ways of conveying information to help facilitate the decision-making process (this was not part of the original analysis, but something that occurred while reviewing of the guidelines).

## Discussion

We collected 54 EOL guidelines and analyzed them based on a number of viewpoints, including country, year, length and certain aspects of the content, such as the inclusion of legal issues and advice on the withdrawal and withholding of treatment. Although

the guidelines collected by our team is not an exhaustive list of the EOL or ANH guidelines available worldwide, we believe they represent a good cross-section of the examples of guidance available on this topic. Through our examination of the documents, we identified a number of trends. These trends tend to follow a definite shift over the past 20 years from medical-centered toward a patient-centered approach to healthcare in which patient autonomy and communication between the patient and healthcare professionals is increasingly important.<sup>9</sup> It is hoped that the trends identified here can form the basis for a number of suggestions toward creating better guidelines for the Japanese context, and our review lays the groundwork for future cross-cultural comparisons of EOL guidelines.

The majority of guidelines were published after 2012. The release of the Economist's Quality of Death Index in 2010, which ranked EOL care across the world, might account for the increased production of guidelines after that date.<sup>10</sup> Indeed, the

**Table 5** Guidelines from North America included in the present study

Country	Guideline	Publisher/association	Year	No. pages	Legal	ANH	Family
Canada	A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice Revised and Condensed Edition: 2013	Canadian Hospice Palliative Care Association	2013	30		○	○
Canada	A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice	Canadian Hospice Palliative Care Association	2002	118		○	○
USA	End of Life: Helping with Comfort and Care	U.S. Department of Human Health and Services National Institute on Aging	2016	76		○	○
USA	Health Care Guideline: Palliative Care for Adults	Institute for Clinical Systems Improvement	2013	82		○	○
USA	The IAHP Manual of Palliative Care: Third Edition	International Association for Hospice & Palliative Care	2013	113		○	○
USA	HPNA Position Statement: Artificial Nutrition and Hydration in Advanced Illness	Hospice and Palliative Nurses Association	2011	8		○	○
USA	NHPC Information Pamphlet: Artificial Nutrition (Food) and Hydration (Fluids) at the End of Life	National Hospice and Palliative Care Organization	2015	2		○	
USA	Academy of Nutrition and Dietetics Practice Paper: Ethical and Legal Issues in Feeding and Hydration	Academy of Nutrition and Dietetics	2013	15		○	○
USA	Clinical Practice Guidelines for Quality Palliative Care: Third Edition	National Consensus Project for Quality Palliative Care	2013	74		○	○
USA	Health Care Guideline: Palliative Care for Adults	Institute for Clinical Systems Improvement	2013	82		○	○
USA	AMA Code of Medical Ethics, Chapter 5: Opinions on Caring for Patients at the End of Life	American Medical Association	2016	9		○	○

○ indicates that the guideline includes information on the topic. ANH, withholding/withdrawal of artificial nutrition and hydration; Family, family's role in decision-making; Legal, legal background.

Quality of Death Index was a particularly influential study; the 2015 Quality of Death Index stated that the 2010 study “garnered much attention and sparked a series of policy debates over the provision of palliative and end-of-life care around the world.”<sup>2</sup> As a general principle, however, the relatively recent publication date for these guidelines probably indicates that the making and revision of guidelines is perhaps not a proactive process, but rather a reactive process that attempts to address public concerns arising from current ethical issues. Within the past 20 years, public consciousness has shifted to a point where palliative and EOL issues are being increasingly discussed publicly; the scrapping of the UK's Liverpool Care Pathway being a prime example.<sup>11</sup> Feedback from end users, such as physicians, caregivers and healthcare providers, might, therefore, be invaluable when crafting and fine-tuning these reactive guidelines in order to directly address critical points that are raised in legal and medical circles. Proactive guidelines, in contrast, might be too generic to precisely identify solutions or guidance on issues that have yet to be identified as important.

As a means of simplifying complexity, shorter and concise guidelines that offer quick, easily accessible information can save crucial time under dire clinical circumstances. However, both long and short guidelines are necessary. To show the importance of both, the National Institute for Health and Care Excellence (NICE)-commissioned guideline, *Nutrition Support in Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition*, consists of 175 pages of detailed guidance to physicians.<sup>12</sup> In contrast, their supplementary, *NICE Pathways: Nutrition Support in Adults: Overview*, summarizes all of the key points from the 175-page edition into just eight pages.<sup>13</sup> Both types of documents play a role in assisting the physician at different times, and at different levels of depth and detail, thereby facilitating decision-making.

Multiple guidelines are needed to educate and inform different audiences; EOL care decisions are made not only by clinicians and healthcare workers, but also by patients and their families, who might act as “gatekeepers” to dying patients.<sup>14</sup> As Loudon *et al.* showed, organizations are increasingly creating guidelines for patients.<sup>15</sup> Guidelines can help to close the opinion-gap between interested parties. It is important, therefore, that guidelines aimed at lay and professional readers are not contradictory – although they will inevitably vary in length, style, content and level of complexity.

Although specific legal guidelines could not be clearly issued at a national (USA) or international (EU) level because of variability between legal rights and statutes within the smaller units of organization (states or member countries, respectively), wherever possible, guidelines for healthcare professionals should include explanations of the relevant law. Physicians need to know that medical decisions made for the good of the patient are also within the bounds of the law. A noteworthy finding is that of the six Japanese guidelines analyzed in the present study, only one of them, *Decision-Making in the Care of the Elderly Focusing on Indications for Artificial Hydration and Nutrition (AHN)*, published by the Japan Geriatrics Society, makes mention of the law.<sup>16</sup> For comparison, of the 15 guidelines from the UK, just two made no mention of the law, but even so, their concordance with the law is implicit throughout. In the document from the Japan Geriatrics Society, Appendix 2 is a statement of approval for the guideline given by 29 legal experts, whose names and affiliations are listed. Although this statement is perhaps somewhat reassuring for the physician, it does not actually stipulate what the laws actually are.

This omission from most of the Japanese guidelines that were included in the present study could perhaps indicate a general ambiguity over the legal framework undergirding decision-making, patient rights, treatment and care at the end of life in Japanese

law. A 2014 publication by Makino *et al.* addressing ethical and legal perspectives on EOL care in Japanese intensive care units states that, despite the development of EOL guidelines by the Japanese government and medical societies, “some physicians practicing in Japan remain concerned about the adverse legal ramifications believing that guidelines offer no legal protection concerning decisions to withdraw or withhold care.”<sup>17</sup> Ambiguity over the legal status around ethically contentious issues, such as withholding or withdrawing treatment, could arguably lead to compromised quality of care for the patient and would likely lead to professional danger for the physician. Traditional Japanese culture, like its neighbors China and Korea, has been influenced by Confucianism, and has emphasized filial piety and familial harmony, which has, as Matsumura *et al.* have documented, had an impact on EOL practices, such as non-disclosure of fatal diagnoses (especially cancer) to the patient and the family’s pre-eminence in decision-making.<sup>18</sup> However, as Japanese society evolves with the influence of globalization, legal issues are arguably of increasing importance to Japanese physicians as they react to greater social demand for transparency within healthcare.<sup>19</sup>

One example of a guideline that explains national-level laws is the *Reference guide to consent for examination or treatment: Second edition* published by the Department of Health.<sup>20</sup> This document sets out in a very clear and concise manner the relevant English law surrounding this issue, and has a section devoted to withdrawing and withholding life-sustaining treatment. Such government-provided guidelines equip physicians and healthcare providers with a better understanding of the law, as it relates to such issues and eliminates ambiguity. Likewise, guidelines should always be evidence-based and include appropriate references to peer-reviewed studies, especially when dealing with complex and ethically-charged issues within the EOL framework. This is particularly important for the issue of withholding and/or withdrawal of treatment.

The present analysis showed that most of the guidelines addressed the difficult topic of withholding and/or withdrawal of treatment. Indeed, three of the guidelines were specifically focused on this issue, such as *Guidelines for the Withholding and Withdrawing of Treatment*, from the Health Professions Council of South Africa (2008).<sup>21</sup> Guidance varied in depth and content, but as shown in the results section, there were some key concepts that were present in many of the guidelines. By far the most important concept common to the majority of guidelines is the need to respect the patient’s wishes and advanced healthcare directives, and hence the need for advanced care planning to help mitigate potential difficult treatment decisions. Some guidelines state that the physician has a duty to understand when treatment (including ANH) should be withheld or withdrawn. The Irish Medical Council’s *Guide to Professional Conduct and Ethics for Registered Medical Practitioner*, for example, states: “There is no obligation on you to start or continue a treatment, or artificial nutrition and hydration, that is futile or disproportionately burdensome, even if such treatment may prolong life.”<sup>22</sup> This advice is usually tempered by stressing the need for physicians to communicate, explain and discuss decisions about treatment with the patient, their family and those within their circle of care. To quote from the same Irish guideline: “You should take care to communicate effectively and sensitively with patients and their families so that they have a clear understanding of what can and cannot be achieved.”<sup>22</sup> Many of the guidelines emphasize that clinical decisions need to be in the patient’s best interests, that physicians have a duty not to harm patients or burden them with unnecessary treatments or tests, and that the goal of care should be on comfort, relief from distress and quality of life.

The vast majority of guidelines in the present review pointed to the important role that multidisciplinary healthcare teams play in decision-making and care for patients approaching the end of life, including decisions of withholding and withdrawing treatment. This highlights the point that the responsibility for decision-making in difficult clinical situations should not lie directly with any individual alone – physician, family member or

even patient – but rather that it should be a collaborative, communicative process. Interestingly, Matsumura *et al.*, in their study of how Japanese culture impacts EOL care, discovered that Japanese people had a preference for a “group decision-making model.”<sup>18</sup> Thus, Japanese guidelines might leverage this cultural preference to improve EOL decision-making by extending the “group” beyond the traditional family unit to include the healthcare team.

In the Canadian Hospice Palliative Care Association’s guideline *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice Revised and Condensed Edition* (2013), they describe how the “professional team comes together with family members, friends and other caregivers to form a circle of care around the person and family.”<sup>23</sup> With regard to the family’s role in decision-making, this idea of the family being part of the care team and the importance of communication with the family is common to most guidelines. That does not imply, however, that the family has equal rights as the patient or professional healthcare team to make EOL decisions. The guidelines place the patient’s wishes at the top of the decision-making hierarchy, while the family are considered proxy decision-makers according to the patient’s wishes, as seen in this simple statement in the Australian Commission on Safety and Quality in Health Care’s *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (2015): “End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient’s expressed wishes and/or jurisdictional legislation.”<sup>24</sup> However, this same guideline encourages that when considering the care plan for patients in the dying phase, that it “must be specifically revised to meet the unique needs of the patient, family and carers.”<sup>24</sup> This distinction between EOL care plan and EOL decision-making is useful; it can help to involve the family in what we could refer to as “second-order decisions,” in which they are directly involved (e.g. place of care), from “first-order decisions,” which are the patient’s to decide (e.g. treatment).

The principle of collaboration also applies to the creation of guidelines, as NICE Chair Professor David Haslam explains, “the way that NICE develops guidelines is first of all to use the evidence as best we can, not just someone’s whim or opinion, we try and do everything in as transparent and open a way as we can, we use both experts whether clinicians or others and patients and the public to come up with our guidance.”<sup>25</sup> Bossaert *et al.* echoed this idea stating that: “Future guidelines may benefit from involvement of all stakeholders: members of the public, patients, survivors and the society as active partners in understanding and implementing the ethical principles.”<sup>9</sup> This could be a key concept for developing culturally sensitive, as well as medically, legally and ethically sound guidelines for Japan.

There were a number of limitations to our study. First, our Internet search criteria by design were not hyperspecific, but attempted to gather a large sampling of international documents. With regard to non-English language publications, our search method might have overlooked documents whose keywords or metasearch terms were not known to us. Finally, our guidelines were limited to those available on the Internet; printed publications (especially older publications) might not have been available in digital format. However, our broad sampling of guidelines from multiple countries will serve as a basis for future, more detailed searches that focus on individual countries as required.

In the present report, we set out to partially catalog EOL guidance in an international setting. Through initial analysis of dozens of guidelines, we saw several clear patterns. The length of the guidelines varied greatly, but the trend was toward guidelines <25 pages in length. Target audience also varied, highlighting the need for EOL guidance for both medical professionals and lay audiences. We saw that guidelines are being generated reactively based on issues raised by caregivers and patients within the context of modern thought about death and terminal illness. We saw that many guidelines included the relevant national laws and legal

issues, whereas, interestingly, the Japanese guidelines tended not to. Many guidelines also included guidance on the ethically difficult issues of withholding and withdrawing of treatment, and the role of the patients' families in decision-making. We also saw that flowcharts are commonly used to help facilitate decision-making. Finally, the guidelines almost unanimously underline the importance of a multidisciplinary, corporate approach to clinical decision-making. Taken together, the present findings showed that, like the decision-making process, a multidisciplinary approach, drawing together the expertise of professionals and drawing from the experiences of patients, is an effective model for the creation of culturally and medically appropriate, patient-centered guidelines. As a patient approaches the end of their life, such guidelines can be invaluable sources of distilled knowledge for facilitating good decision-making and good communication between healthcare teams, patients and families at this most difficult time.

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## Disclosure

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