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IAGG/IAGG GARN International Survey of End-of-Life Care in Nursing Homes

Cara L. Wallace PhD, LMSW [a], Daniel Swagerty MD, MPH [b], Mario Barbagallo MD, PhD [c], Bruno Vellas MD, PhD [d], Heung Bong Cha PhD [e], Iva Holmerova MD, PhD [f], Birong Dong MD [g], Raymond Koopmans MD, PhD [h], Alfonso J. Cruz-Jentoft MD, PhD [i], Luis Miguel Gutierrez Robledo MD [j], Juan Cuadros Moreno MD [j], Ramzi Hajjar MD [k], Jean Woo MD [l], Hidenori Arai MD, PhD [m], Jiro Okochi MD [n], Renuka Visvanathan PhD, FRACP, MBBS [o], Samia A. Abdul-Rahman MD [p], Ashish Goel MD [q], Andrea Moser MD, MSc [r], Yves Rolland MD, PhD [d], Angela M. Abbatecola MD, PhD [s], Marcello Russo MD [s], John E. Morley MB, BCh [t,*]

[a] *School of Social Work, College for Public Health and Social Justice, Saint Louis University, St. Louis, MO*
[b] *Landon Center on Aging, University of Kansas School of Medicine, Kansas City, KS*
[c] *Clinical Section, Department of Internal Medicine, University of Palermo, Palermo, Italy*
[d] *Gerontopole, Toulouse University Hospital—CHU, Toulouse, France*
[e] *International Association on Gerontology and Geriatrics (IAGG), Seoul, South Korea*
[f] *International Relations, Faculty of Humanities, Charles University, Prague, Czech Republic*
[g] *The Center of Gerontology and Geriatrics, West China Medical School/West China Hospital, Sichuan University, Sichuan, China*
[h] *Department of Primary and Community Care, Radboud University Medical Center, and Joachin en Anna, Center for Specialized Geriatric Care, Nijmegen, the Netherlands*
[i] *Servicio de Geriatría, Hospital Universitario Ramón y Cajal (IRYCIS), Madrid, Spain*
[j] *Instituto Nacional de Geriatría, Institutos Nacionales de Salud de México, San Jerónimo Lídice, Mexico*
[k] *Geriatric Medicine and Palliative Care, American University of Beirut Medical Center, Beirut, Lebanon*
[l] *Chinese University of Hong Kong, Hong Kong, China*
[m] *Deputy Director, National Center for Geriatrics and Gerontology, Obu, Japan*
[n] *Tatsumanosato Geriatric Health Services Facility, Daito, Japan*
[o] *Adelaide Geriatrics and Training with Research in Aged Care (GTRAC) Centre, University of Adelaide and the Aged and Extended Care Services, Queen Elizabeth Hospital, Adelaide, Australia*
[p] *Founding member of the Egyptian Society of Geriatrics and Gerontology, Geriatrics and Gerontology Department, Faculty of Medicine, Ain Shams University, Cairo, Egypt*
[q] *Department of Medicine, UCMS and GTB Hospital, Delhi, India*
[r] *Jewish Home for the Aged, Baycrest, Toronto, Canada*
[s] *Azienda Sanitaria Locale (ASL) di Frosinone, Frosinone, Italy*
[t] *Division of Geriatric Medicine, Saint Louis University School of Medicine, St. Louis, MO*

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A B S T R A C T

This article reports the findings of a survey on end-of-life (EOL) care in nursing homes of 18 long-term care experts across 15 countries. The experts were chosen as a convenience-based sample of known experts in each country. The survey was administered in 2016 and included both open-ended responses for defining hospice care, palliative care, and "end of life," and a series of questions related to the following areas—attitudes toward EOL care, current practice and EOL interventions, structure of care, and routine barriers. Overall experts strongly agreed that hospice and palliative care should be available in long-term care facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears the experts felt that in most countries the reality fell short of what they believed would be ideal care. As a result, experts call for increased training, communication, and access to specialized EOL services within the nursing home.

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* Address correspondence to John E. Morley, MB, BCh, Division of Geriatric Medicine, 1402 S Grand Blvd, M238, St Louis, MO 63104.
E-mail address: morley@slu.edu (J.E. Morley).

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Globally about 18% of older adults (age 65 years and older) die in residential facilities, with that percentage doubling for adults older than 75 years, and doubling again for adults older than 85 years.[1] With changing family structures, older adults are more likely to require long-term care (LTC) assistance through the end of their lives.[2] As such, nursing homes must be prepared to provide high-level end-of-life (EOL) care to residents. The World Health Organization has recommended that palliative care be implemented across all health care services,[3] and in a position paper on a global agenda for nursing home research and care, the International Association of Gerontology and Geriatrics (IAGG) more specifically recommends that palliative and hospice care programs be introduced in all nursing homes.[4] In different parts of the world, the acceptance of the discussion of impending death varies enormously, making the development of standardized EOL care programs in some countries difficult.[4] For this reason, we enlisted opinions of LTC experts across 15 countries to assess current worldwide practices and challenges in providing palliative and EOL care in nursing home settings.

Methods

Similar to the methods described in a prior IAGG consensus paper on research priorities in nursing homes,[5] this study surveyed 18 LTC experts across 15 countries in a 2-step process. The researchers were chosen as a convenience-based sample of known experts in each country. In the first step, identified experts responded to a questionnaire about their perception of the status of EOL care in nursing homes within their country. The first section of the questionnaire included open-ended responses for defining hospice care, palliative care, and "end of life." The next section included a series of statements on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree," along with 3 questions addressing the following: the structure of EOL care in nursing homes; used interventions in caring for patients at the EOL; and barriers to providing EOL care. The survey was developed and reviewed by the first author and a small focus group of the identified experts after a review of relevant literature.[6–11] The survey allowed space for additional comments to expand on nonqualitative responses.

After compiling all of the responses and results, each expert reviewed the results to provide further context to current practices and barriers within their area as it related to the collective international context. The countries represented were Australia, Canada, China, Czech Republic, Egypt, France, Hong Kong, India, Italy (2), Japan, Lebanon, Mexico (2), Netherlands, Spain, and the United States (2). An overview of how countries defined hospice, palliative, and end-of-life care is presented, followed by results organized in the following areas: attitudes toward EOL care, current practice and EOL interventions, structure of care, and routine barriers.

Results

Defining EOL, Hospice, and Palliative Care

Internationally there is often little to no distinction between hospice and palliative care,[12] which some experts sampled for this survey reinforced in their given definitions (France, Lebanon, Japan, and Spain). Others either used "palliative care" as part of their hospice definition (Canada, Czech Republic, and Italy) or provided a palliative care definition more closely aligned with others' overarching hospice definition (Mexico, Lebanon, Italy, Canada, Spain, Hong Kong) making the distinction further unclear. Respondents as a whole generally defined hospice as holistic, interdisciplinary care for terminally ill individuals. Descriptions of this care included focus on quality-of-life, comfort, psychosocial concerns, and physical problems. However, the time frame for when patients were identified as appropriate for hospice care greatly varied from "end-stage" to a few weeks, during the last month, or within 3 or 6 months of death. An additional difference in how LTC experts defined hospice was related to the setting of care. Five countries—one-third of the overall sample—identified hospice as a physical place or within institutions. Only 2 (United States and Italy) distinctly defined hospice as services provided both within facilities and patients' own homes. Experts in Egypt and India reported that hospice services there were very limited.

In defining palliative care, 5 countries (Australia, Egypt, Japan, Mexico, and Netherlands) directly reported resembling the World Health Organization's[13] definition of palliative care:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para. 1).

Though others did not explicitly cite the World Health Organization definition, descriptions were closely aligned (Czech Republic, France, USA, and India). The focus of palliative care is on both the patient and the family and is administered with an interdisciplinary team approach. Other important aspects include the idea that dying is a normal process within living and that although palliative care is not meant to hasten or postpone death, care can be given alongside life-prolonging treatments such as chemotherapy.[13] Remaining responding experts (Lebanon, Italy, Canada, Spain, and Hong Kong) differed from this definition by defining palliative care as appropriate only once the patient is no longer responding to curative treatment or only during final, terminal phases at the end. Mexico reported that although this is the approach taken within governmental policy, some others follow the World Health Organization definition.

Similar to the differences in timing for hospice care, definitions for "end of life" also varied. Though experts in Czech-Republic and Japan defined it as "terminal stages," most of the others connected EOL to different amounts of time. Some categorized EOL as imminent death (Lebanon and Mexico) or within days or weeks (Australia, India, and Italy), whereas others identified it as within 3 months (Netherlands), 6 months or less (Canada and Spain), or between 6 and 12 months (Hong Kong). France and Mexico reported not using the phrase "end-of-life" but instead using terminal period (preagonic or agonic periods) or terminality (within 6 months) respectively. Across all 3

Table 1
Attitudes Toward EOL Care in Nursing Homes by International LTC Experts

	Strongly Disagree, %	Disagree, %	Neutral, %	Agree, %	Strongly Agree, %
Residents in facilities should receive hospice at the end of life instead of receiving "care as usual."	0	6.67	0	40	53.33
Facility staff should receive specialized training on palliative and end-of-life care.	0	0	0	13.33	86.67
All facility residents should be encouraged to document wishes for end-of-life care and copies of those wishes should be kept on file in the resident's chart.	6.25	0	6.25	6.25	81.25
All facility residents should be asked about resuscitation preferences and these preferences should be kept on file in the resident's chart.	0	0	6.25	12.5	81.25

Table 2
Current EOL Practice Among International Nursing Homes

	Strongly Disagree, %	Disagree, %	Neutral, %	Agree, %	Strongly Agree, %
Hospice care is an important component of care in nursing homes.	0	13.33	6.67	40	40
In my country, hospice care is readily available in nursing homes.	26.67	26.67	6.67	20	20
In my country, training on palliative and end-of-life care is readily available to nursing home facilities.	25	37.5	18.75	12.5	6.25
Facility residents are often sent to the hospital for symptom management during their last month of life (some of which die in the hospital).	6.25	25	0	31.25	37.5
Facilities in my country routinely document residents' wishes for end-of-life care within their facility charts.	43.75	12.5	18.75	25	0
Facilities in my country routinely document residents' resuscitation preferences in their facility charts.	37.5	18.75	6.25	25	12.5

definitions, multiple countries mention the role of policy, funding, or insurance (or lack thereof) in defining each of the terms.

Attitudes, Current Practice, and Interventions

Attitudes toward EOL care in nursing homes by internationally recognized experts in LTC are overwhelmingly positive. All of the responding experts agreed, or strongly agreed, that all facility staff should receive specialized training on palliative and EOL care (Table 1). The majority of experts also agreed that facility residents should receive hospice at the EOL instead of "care as usual" (93.33%) and that they should be encouraged to document EOL care wishes (87.5%) and resuscitation preferences (93.75%) in charts located at the facility. Though beliefs about EOL care by experts are overwhelmingly positive, Table 2 demonstrates that current practices are not yet aligned with these positive attitudes about EOL care. For example, 62.5% of experts reported that training on palliative and EOL care is not available to nursing homes and only 40% agree that hospice care is even readily available in this setting. More than half of the surveyed experts (56.25%) reported that resuscitation preferences and EOL care wishes are not routinely documented in facility charts, and 68.75% agree that residents are often sent to the hospital within the last month of life for symptom management.

Table 3 outlines various EOL interventions and the total number of countries where experts report those interventions are used. It should be noted that multiple experts reported that the use of these interventions greatly varies across nursing homes throughout the country. Pain management (86.7%), oxygen and respiratory therapy (93.3%), and antipsychotics (73.3%) are the most widely used interventions at the EOL in nursing homes internationally. Experts reported that the following interventions are regularly used in around half of the countries included in the survey: availability of a private room at the EOL (46.7%), appropriate room for family members (46.7%), intravenous therapy/feeding (53.5%), and emotional support (46.7%) or spiritual support (53.3%) by nursing home staff. In 40% of the countries, experts report restraints are still commonly used interventions. The use of emotional (26.7%) and spiritual support (20%) provided by hospices were less common interventions used internationally within this setting. An expert in only one country, the Netherlands, identified euthanasia as a used intervention, though several others noted that legislation related to medical assistance in dying or death with dignity were in process or available in select areas.

Structure of Care

Table 4 outlines common structures for providing EOL care in nursing homes. More than half of the countries included report that nursing homes do not have access to palliative care (66.7%) or have a lack of access to hospice care (60%) for their residents. Alternatively, 53.3% of experts report that some nursing homes provide palliative care as part of their services. Based on the wide variation of what nursing homes provide across an individual country, several experts noted both of these responses (lack of access and palliative care as a part of services) within the same country. Only 1 in 5 countries surveyed report that nursing homes contract with local agencies to offer either hospice (20%) or palliative care (20%).

Barriers

International LTC experts in nearly every surveyed country (93.3%) agree that a lack of training about EOL matters remains an ongoing barrier to providing quality EOL care in nursing homes. Poor

Table 3
Used EOL Interventions in NHs by Country

	Countries	Total	Percent
Antipsychotics	Australia, Canada, China, Czech Republic (often), India, Italy, Lebanon, Mexico, Netherlands, Spain, USA	11	73.3
Emotional support visit specific to EOL care (by NH staff/employee)	Australia, Canada, France, Japan, Netherlands, Spain, USA	7	46.7
Emotional support (by hospice)	France, Italy, Japan, USA	4	26.7
Spiritual/pastoral care (by NH staff/employee)	Australia, Canada, Czech Republic (some), France, Italy, Japan, Netherlands, USA	8	53.3
Spiritual/pastoral care (by hospice)	Czech Republic (some), Italy, USA	3	20
Restraints	China, Czech Republic, India, Lebanon, Mexico, Spain	6	40
Private room during final days of life	Australia, Czech Republic (some), Italy, Japan, Netherlands, Spain, USA	7	46.7
Enough room for family to be with the patient during final days	Australia, Egypt, France, Hong Kong, Italy, Netherlands, USA	7	46.7
Pain management	Australia, Canada, Egypt, France, Hong Kong, India, Italy, Japan, Lebanon, Mexico, Netherlands, Spain, USA	13	86.7
Oxygen and respiratory therapy	Australia, Canada, China, Egypt, France, Hong Kong, India, Italy, Japan, Lebanon, Mexico, Netherlands, Spain, USA	14	93.3
Intravenous therapy/ feeding	China, Egypt, France, Hong Kong, India, Italy, Japan, Lebanon	8	53.3
Euthanasia	Netherlands	1	6.7
Physician-assisted suicide	None	0	0

NH, nursing home.

Table 4
International Structure of EOL Care in NHs by Country

	Countries	Total	Percent
NHs contract with local agencies to offer hospice care	France, Italy, USA	3	20
NHs have a hospice care provider housed within their facility	Italy	1	6.7
Contract with local agencies to offer palliative care	Australia, France, Italy	3	20
Offer palliative care as part of their services	Australia, Canada, France, Italy, Japan, Netherlands, Spain, USA	8	53.3
Do not have access to hospice services for their residents	China, Czech Republic, Egypt, Hong Kong, India, Italy, Lebanon, Mexico, Spain	9	60
Do not have access to palliative care services for their residents	Australia, China, Czech Republic, Egypt, Hong Kong, India, Italy, Lebanon, Mexico, Spain	10	66.7

NHs, nursing homes.

continuity of care (80%), low staff-to-patient ratios (80%), lack of documentation of advance directives (73.3%), staff turnovers (66.7%), and poor communication during transfers of care (73.3%) or changes in condition (66.7%) were other widespread barriers. More than half of the represented countries (60%) identified unclear prognoses as a barrier, and more than 1 in 3 countries (40%) reported challenges in accessing appropriate pain- and symptom-relieving drugs. Table 5 provides a full list of identified barriers.

Discussion

Although recommendations are that palliative care should be available to everyone with advanced illness, including those in nursing facilities,[14] 10 of the 15 countries represented in this survey reported not having access for their nursing home residents. Similarly, the Worldwide Hospice Palliative Care Alliance reported that there are no hospice and palliative care services in 42% of the world and that in an additional 32% of countries where services do exist, only a small percentage of the population have access.[15] The current survey results further demonstrated this inconsistency in access through experts' comments surrounding great variation of services in nursing homes across any given country.

Overall, experts strongly agreed that hospice and palliative care should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears that the experts felt that in most countries the reality fell short of what they believed would be ideal care. This disconnect between reality and ideal was exemplified by the lower reported use of emotional and spiritual support (20%-53% of countries surveyed) in comparison to higher rates of antipsychotics (73.3% of countries) and ongoing use of restraints as an appropriate intervention (40% of countries). Recent research suggests higher rates of antipsychotics and restraints continue,[16,17] though quality care calls for less of both interventions.[18,19] LTC experts report ongoing international disparity in EOL care in nursing homes internationally, highlighting prevalent barriers and inconsistent standards. Further discrepancies about what defines hospice care in comparison to palliative care limits some international comparison. Yet, overwhelmingly attitudes about the importance of hospice and palliative care are positive, with experts calling for increased training, communication, and access to specialized EOL services within the nursing home.

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Table 5
Barriers to EOL Care in NHs by Country

	Countries	Total	Percent
Lack of training for staff on EOL care matters	Australia, Canada, China, Czech Republic, Egypt, France, Hong Kong, India, Italy, Japan, Lebanon, Mexico, Spain, USA	14	93.3
High staff turnover	Australia, Canada, Czech Republic, Egypt, Hong Kong, Japan, Mexico, Netherlands, Spain, USA	10	66.7
Poor communication among staff	China, Czech Republic, Hong Kong, India, Mexico, USA	6	40
Poor communication with other providers during transfers or transitions in care	Australia, Canada, China, Czech Republic, Egypt, Hong Kong, India, Japan, Mexico, Spain, USA	11	73.3
Poor communication with family about changes in patient's symptoms or care	Australia, China, Czech Republic, Egypt, Hong Kong, India, Japan, Lebanon, Mexico, USA	10	66.7
Poor continuity of care	Australia, China, Czech Republic, Egypt, Hong Kong, India, Italy, Japan, Mexico, Netherlands, Spain, USA	12	80
Lack of documentation of advance care directives/wishes for EOL care	Canada, China, Czech Republic, Egypt, France, Hong Kong, India, Japan, Lebanon, Mexico, Spain	11	73.3
Lack of knowledge about patients' cultural traditions/preferences at the EOL	China, Czech Republic, Egypt, Hong Kong, Italy, Mexico, USA	7	46.7
Lack of knowledge about patients' religious/spiritual traditions/ preferences at the EOL	Czech Republic, Egypt, Hong Kong, Italy, Mexico, USA	6	40
Negative cultural attitudes toward hospice care	China, Hong Kong, Japan, Lebanon, USA	5	33.3
High caseloads of staff to patients	Australia, Canada, China, Czech Republic, Egypt, Hong Kong, India, Japan, Mexico, Netherlands, Spain, USA	12	80
Unclear prognoses	Australia, Canada, Czech Republic, Egypt, France, Hong Kong, India, Spain, USA	9	60
Payment/policy restrictions (ie, inability to access rehabilitation treatments alongside hospice care)	Canada, China, Czech Republic, Egypt, Japan, Lebanon, USA	7	46.7
Poor facility perceptions about available EOL services	China, France, Hong Kong, India, Japan, Lebanon, Mexico, USA	8	53.3
Patient/family expectations about care	Canada, China, Czech Republic, India, Japan, Lebanon, Spain, USA	8	53.3
Access to appropriate pain and symptom relieving drugs	Czech Republic, France, Italy, Japan, Lebanon, Mexico	6	40

NH, nursing home.

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