



# Complexity in the context of palliative care: a systematic review

Hironori Ohinata<sup>1,2^</sup>, Maho Aoyama<sup>1^</sup>, Mitsunori Miyashita<sup>1^</sup>

<sup>1</sup>Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Sendai, Japan; <sup>2</sup>Department of Nursing, International University of Health and Welfare, Narita, Japan

*Contributions:* (I) Conception and design: H Ohinata, M Miyashita; (II) Administrative support: M Miyashita; (III) Provision of study materials: H Ohinata, M Miyashita; (IV) Collection and assembly of data: H Ohinata, M Miyashita; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

*Correspondence to:* Hironori Ohinata, RN. Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, 2-1 Seiryō-machi, Aoba-ku, Sendai 980-8575, Japan. Email: hinata@iuhw.ac.jp.

**Background:** People receiving palliative care have complex, wide-ranging, and changing needs, not just physical distress, but also psychosocial, practical, and spiritual. Influences on complexity in palliative care are different among healthcare providers and may depend on diverse aspects of the patient's condition, time, and environment. Therefore, this study aimed to integrate and describe the perspective of complexity in palliative care.

**Methods:** We used an integrative review, which is a method of compiling, summarizing, and analyzing existing insights from previous studies. We conducted an electronic literature search in MEDLINE (Ovid), PsycINFO (EBSCOhost), Web of Science Core Collection, and CINAHL (EBSCOhost), examining literature from May 1972 to September 2020 and updated in December 2020. Subsequently, synthesis without meta-analysis of the findings was completed.

**Results:** We identified 32 peer-reviewed articles published in English. The included literature mainly originated in Europe and the United States. The research methods included quantitative studies (n=13), qualitative studies (n=12), case studies (n=3), and reviews (n=4). We identified 29 that influenced complexity in palliative care, 25 perceptions of the patient, including background and physical, psychological, social, and spiritual; two perceptions in the healthcare setting; and two perceptions in the socio-cultural setting. Above all, the perceptions of complexity in palliative care included younger age, prognosis, and spirituality. In addition, we added the identified perceptions of complexity with references to the complexity model in palliative care.

**Conclusions:** Although this review was limited in its search strategy and some data sources may have been overlooked, it still provided perceptions that influenced complexity in palliative care. These complex influencing perceptions are necessary for patients to receive appropriate palliative care at the right time and for health care providers to conduct a multi-disciplinary team approach. Furthermore, longitudinal prospective data are needed to examine the changes and relationships among complexity over time.

**Keywords:** Complex; complexity; palliative care; palliative medicine; integrative review

Submitted May 19, 2022. Accepted for publication Sep 03, 2022.

doi: 10.21037/apm-22-623

View this article at: <https://dx.doi.org/10.21037/apm-22-623>

<sup>^</sup> ORCID: Hironori Ohinata, 0000-0002-7963-9346; Maho Aoyama, 0000-0002-6094-0788; Mitsunori Miyashita, 0000-0002-7637-0409.

## Introduction

People receiving palliative care have complex, wide-ranging, and changing needs, including not only physical distress, but also psychosocial, practical, and spiritual difficulties (1). Several conceptual models have been proposed that consider these complexities of palliative care (2-4). For example, Pask *et al.* used Bronfenbrenner's ecological systems theory to report the physical, psychological, social, and spiritual domains in addition to the social perspective on care, how patients related to their families and professionals, and how services respond to their care needs (2). Hodiament *et al.* also used complex adaptive systems to show that complexity in palliative care consists of three subsystems: patient system (physical, psycho-spiritual, and socio-cultural); social system (characteristics of relatives, roles, relations); team system (structural characteristic, characteristics of team-members, relations); and environmental factors (3).

In addition, complexity in palliative care tools has been created and measured (5). For example, The Australian National Subacute and Non-acute Patient Classification (ANSNAP) and The Hexagon of Complexity (HexCom) (6,7). ANSNAP is an Australian casemix classification, consisting of nine items, including the Phase of Illness, the Resource Utilisation Groups-Activities of Daily Living (RUG-ADL), and the Palliative Care Problem Severity Score (6). HexCom assesses the complexity of a patient's condition in terms of six domains (clinical, psychological, social, and family, spiritual, ethical, and death-related) and resources (7). These measures of palliative care complexity might distinguish the patients who would benefit most from palliative care (3).

On the other hand, the applicability of these models and tools for palliative care complexity is limited (5). Pask *et al.* have shown that complexity in palliative care changes with the severity of illness and time (2). Furthermore, healthcare providers' perspectives on complexity in palliative care differ regarding the degree to which it is perceived as actually complex (4). For example, complexity is not merely the patient's complex symptoms, but also the degree of dissonance and engagement with healthcare between patients, family, and healthcare providers (2). In addition, inexperienced healthcare providers have difficulty recognizing the complexity of patients in palliative care. If healthcare providers can recognize the factors of complexity in palliative care, they can provide timely, appropriate, individualized, and coordinated care (8,9). Therefore, it is important to summarize what influences complexity

in palliative care. In this study, we aimed to integrate and consider the influences on complexity in the context of palliative care. We present the following article in accordance with the PRISMA reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-623/rc>).

## Methods

### Design

We used an integrative review, which is a method of compiling, summarizing, and analyzing existing insights of studies "to consider the influences on complexity in the context of palliative care" (10).

### Search strategy

We conducted first an electronic literature search in MEDLINE (Ovid), PsycINFO (EBSCOhost), Web of Science Core Collection, and CINAHL (EBSCOhost), examining literature from May 1972 to September 2020 (11). We also used Google Scholar to complement our search for eligible articles. Complexity was an abstract term, and many noncompliant references were detected; hence, a comprehensive and systematic search strategy was developed in consultation with the librarian. The keywords and subject heading terms were "palliative care" and "complexity" (Table 1). Publications were included in this review if the following inclusion criteria were met: (I) considering influences on complexity in the context of palliative care; (II) published in peer-reviewed journals; (III) studies published up to December 31, 2020; and (IV) published in English. We excluded publications from poster sessions, conference proceedings, gray literature, protocols, reports, and letters. We only included peer-reviewed journals listed in scientific databases to help increase the quality in our review.

Titles and abstracts were initially screened by the author (HO) to identify potentially eligible papers, and any areas of uncertainty were resolved by co-author (MM). The full manuscripts of potentially eligible papers were screened by two of the authors (HO, MM), who subsequently reached a consensus after discussing uncertainties regarding any article's eligibility. Moreover, the third author (MA) was consulted if consensus was not reached, and a definitive list of eligible studies was agreed upon. No additional hand-searching was conducted, but references of the included papers were also screened for any other relevant papers.

**Table 1** Search terms used for integrative review

Palliative care
MH “Palliative Care”
MH “Terminal Care”
TI “Hospice” OR AB “Hospice”
TI “palliative care” OR AB “palliative care”
TI “terminal care” OR AB “terminal care”
TI “supportive care” OR AB “supportive care”
TI “end of life care” OR AB “end of life care”
S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
Complexity
TW “complexity”
TW “complexities”
TW “complex need”
TW “complex needs”
TW “complex patient”
TW “complex patients”
TW “complex symptom”
TW “complex symptoms”
S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
S8 AND S17

### Data extraction

We reviewed the data to be extracted according to the Joanna Briggs Institute Reviewer’s Manual (12). The author prepared the extraction form and the co-author checked it. We descriptively extracted data based on the country, study design, methods, type of institution, population, the aim of the study, key findings, and influences on the complexity of palliative care. These data were integrated and mapped using tables. The classification of factors that influence the complexity of palliative care needs was classified by the author (HO) and validated by the co-author (MM). Any disagreements that arose in the classification process were resolved through third-party discussions. Furthermore, we used an inductive approach and identified themes of complexity in palliative care.

### Charting the data

We created a form describing the characteristics of each

article for charting the data. Two authors (HO, MM) extracted and summarized the data for author/publication date, country, study design, methods, type of institution, population (sample size), the aim of the study, key findings, and influences on the complexity of palliative care.

We refrained from applying a quantitative score to assess the quality of the studies, given the diversity of research methods. Assessing the quality of the study not be appropriate for reviews including different types of studies (10).

## Results

From 1,615 initial records, we screened 73 papers according to eligibility, of which 32 were included in the full review (*Figure 1*). A summary of the characteristics of these 32 studies is presented in *Table 2*.

### Research population

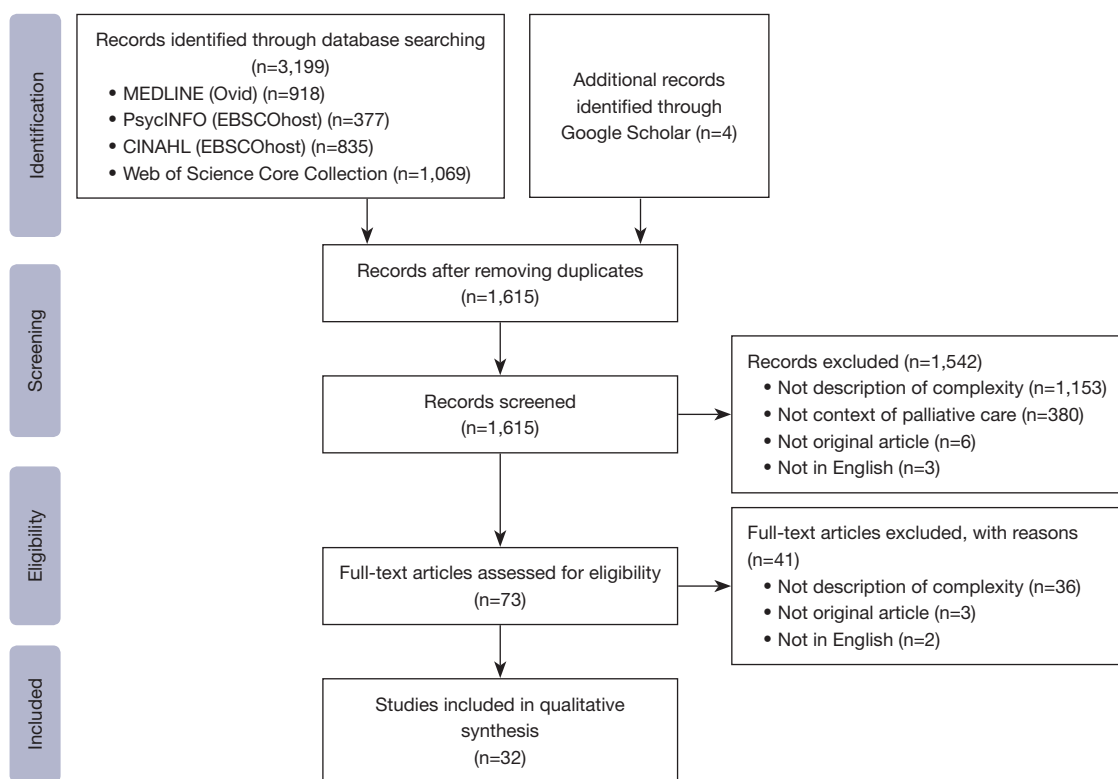
The year of publication, country, study methods, type of institution, and population of the 32 studies included in our review are summarized in *Table 3*. Thirteen of the studies were conducted in medical settings such as palliative care units or hospices (2,4,14,15,20,22,26,28,31,33,37-39), nine were conducted by academic societies or professional teams (7,18,19,23,27,29,30,35,40), and two were conducted over the telephone or at health centers for people living in specific areas (25,32). Other publications were reviews or case studies that did not specify the facility where they were conducted. Eighteen studies were conducted with patients; eleven on adult (14,16,22,23,27,29,30,37,39) and pediatric (13,22,31) cancer patients and seven on non-cancer patients with dementia and neurological diseases (some of the participants included cancer patients) (7,15,32,33,35,38,40). Other studies included a mixed population of healthcare providers, such as doctors and nurses, and family members of the patients, such as daughters and sons (2-4,13,20).

### Perceptions of complexity in palliative care

The factors influencing complexity in palliative care are shown in *Table 4*.

### Factors influencing complexity in patients

All 32 studies reported the factors influencing complexity in patients. In the background domain of complexity, the factors were sex (35,40), race (30,38), language (2,3), age (2,23,25,28,30,34,37-39), living situation (2,4,25,32),



**Figure 1** PRISMA flow diagram for the integrative review process. PRISMA, Preferred Reporting Items for Systematic reviews and Meta-Analyses.

family burden (2,22,25,28,29,32,34), resources (2,13,14, 18-21,26,39), treatment (4,15,16,31,36,40), decision-making (2,17,18,21,26,40), communication (2,4,26,39), prognosis (4,20,23,24,26,28,34), disease (2,4,7,25,28,31,32,35,38-40), and comorbidities/multimorbidity (4,22,23,25,26,28,30, 31,33,34,37,38). The factor of age influenced the decrease or increase of complexity in palliative care. Pediatric patients showed greater complexity and more frequently the inability to accept their illness (3). In adult patients, older age was reported to decrease complexity and increase likelihood of acceptance of disease progression and deterioration (2,39). However, older patients have been shown to have increased complexity due to an increased number of comorbidities (28). For example, patients with multimorbidity included progressive diseases such as cancer and heart failure, and psychological disorders such as dementia and schizophrenia (2,4,7,15,31,38). In different studies, multimorbidity ranged from two to five or more diseases, with therapeutic complexity including difficulty managing disease and polypharmacy (4,22,23,25, 26,28,30,31,33,34,37,38). Furthermore, factors influencing

complexity included disease stage, treatment preferences, and polypharmacy in addition to symptoms (15,19).

In the physical domain of complexity, the factors were physical function (19,22,26,33,34,36,37,39,40), pain (2,4,17,19,22,23,27,29,32,37,40), treatment for pain (16), symptoms (excluding pain) (4,19,22,26,40), and symptom burden (17,21,34,36,37,39). Decline in physical function was consistently reported in all relevant studies (19,22,26,33,34,36,37,39,40). The most reported symptom was pain, along with various other factors such as nausea, dyspnea, fatigue, and appetite (2,4,17,19,22,23, 26,27,29,32,37,40). Pain included factors such as numeric rating scale >5 pain, refractory pain, and uncontrolled pain (4,23). In addition, Hemming and Maher reported that different mechanisms for different types of pain and the ineffectiveness of analgesics are factors influencing complexity (16).

In the psychological domain of complexity, the factors were anxiety (23,35,40), depression (23,40), and mental health (20,22,23,34-36,38). Anxiety and depression were reported to be factors influencing complexity in their degree

Table 2 Summary of literature reviewed

Authors/ publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Morrissey [1997]	UK	Case study			Nurse (n not reported)	To recognize the complexity of the situation and the ethical issues involved for nurses caring for terminally ill patients	Nurses who care for terminally ill patients fail to recognize the complexity of the situation and the ethical issues involved. Assisting patients to achieve an 'appropriate death' requires communication and collaboration among patients, family members, and professional caregivers
Bottoff <i>et al.</i> [1998]	Colombia	Qualitative	Interview (grounded theory)	Two palliative care units	Patients (n=10), nurses (n=12)	To explore and describe patients' experiences of making choices related to their personal and nursing care routines on a palliative care unit	Patient choices related to their personal care and nursing routines in the palliative care unit appeared to be superficially uncomplicated on the surface, but the context of unfamiliarity, uncertainty, and unpredictability in palliative care increased the underlying complexity of decision making
Cowan <i>et al.</i> [2002]	USA	Quantitative	Retrospective study (medical record survey)	Palliative medical center	Inpatient and outpatient (n=210; non-cancer, n=175; non-cancer, n=35)	To report the medical complexity of cancer and noncancer patients receiving palliative medicine	The medical complexity of cancer and non-cancer patients is that they have five symptoms, including pain, weakness, and shortness of breath. Cancer patients were twice as likely to have more than five symptoms. The most common nursing problems were ambulation or fall risk and skin integrity
Hemming and Maher [2005]	UK	Review	Literature		End-stage cancer patients (n not reported)	To discuss some of the difficulties in cancer pain management to raise awareness of the enormous challenge it presents	Pain is enmeshed in a complex web of physiological, psychological, and social factors that affect its severity. Awareness of the breadth of the issues may help focus nurses' minds on the patient in every encounter
Hinds <i>et al.</i> [2005]	USA	Case Study			Children and adolescents dying cancer (n not reported)	To describe the complexities in end-of-life care of children and adolescents in end of life care of children and adolescents dying cancer-related deaths	The complexities in end-of-life care of children and adolescents include the intense emotional and physical suffering of patients and their family members during times of acute treatment decision making, the potential for differing priorities among family members, and even among clinicians when trying to manage patient symptoms and suffering, and the existence of conflicting parent goals in their desire to be a "good parent" to their very ill child
Pastrana <i>et al.</i> [2010]	Germany	Qualitative	Focus group interview (thematic analysis)	The German association of palliative medicine	Different regions in Germany and different disciplines (sociology, medicine, theology, psychology, social work, nursing) (n=9)	To investigate important dimensions and indicators for assessment and evaluation of palliative care	The important dimensions and indicators for assessment and evaluation of palliative care included 16 items, including quality-of-life, needs assessment of patients and relatives, resource assessment, surveillance of the decision-making process, as well as multi-spiritual well-being. The high number of relevant items showed the complexity of the agreement on a unique set of outcome criteria working for years in the field of palliative care
Johnson <i>et al.</i> [2011]	Australia	Qualitative	Semi-structured telephone interviews (thematic analysis)	General practitioners and cancer specialists from around Australia	The multidisciplinary expert advisory group in Australia (n=40)	To describe doctors' perceptions of barriers to referring patients for specialist palliative care, and to identify triggers and facilitators for the referral	The factors that doctors used to refer patients to palliative care were the presence of symptoms, their complexity, intensity, comorbidities, ability to successfully manage those symptoms, the stage of the disease, and the treatment plan. Routine use of objective measures of unmet and complex needs may help identify people who are likely to most benefit from palliative care and optimize access, regardless of timing, stage of disease, and treatment orientation

Table 2 (continued)

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Authors/ publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Quinn and Bailey (20) [2011]	Ireland	Qualitative	Semi-structured audio-recorded focus group interview (thematic analysis)	Palliative care center in the Republic of Ireland	Community palliative care clinical nurse specialists who had experience in caring for children with palliative care needs during the previous 2 years (n=7)	To determine if the needs of the patients in the community are being met	The provision of community pediatric palliative care by community palliative care specialist nurses is complex. The study demonstrated that a background of issues relating to accessing the patient and family, the complexity of the community palliative care specialist nurses' role, and the pressures that such work incurs
Reid et al. (21) [2011]	USA	Case Study			Case of difficulty with palliative sedation (n=6)	To present cases in the borderland between proportionate palliative sedation and palliative sedation to unconsciousness to better understand their application and distinctions in real practice	In palliative sedation to unconsciousness, when a patient loses capacity, families and other surrogates often struggle to understand and interpret a legacy of conflicting and complex goals of care mixed with their own opinions and desires for their loved one. Knowing how to identify these circumstances, and how to approach these interventions of last resort are critical skills for practitioners who take care of patients at the end of life
Gaertner et al. (22) [2012]	Germany	Quantitative	Routine electronic patient data (retrospective study)	Palliative medicine of the university hospital	Palliative care patients (n=1,451); the palliative care consultation service (n=850) and the palliative care unit (n=601)	To aid institutional planning, this study aimed at gathering patient data to distinguish assignments of a concomitantly run palliative care unit and palliative care consultation service at a large hospital and academic medical center	Patients admitted to the palliative care unit had a significantly worse performance status (OR =1.48), were significantly more likely to suffer from severe complexity of symptoms and psychosocial problems (OR =2.05), and were significantly much more likely to die during hospital stay (OR =11.03)
Tuca- Rodriguez et al. (23) [2012]	Spain	Quantitative	A multi-center observational two-phase study (phase I: an observational survey and phase II: a cohort study)	Palliative care hospital support teams in Spain	Phase I: palliative care hospital support teams (n=60), phase II: advanced cancer patients (n=364)	To describe the structure, characteristics of patients, and basic clinical outcomes in cancer patients receiving care from palliative care hospital support teams in Spain	In the characteristics of cancer patients receiving care from palliative care hospital support teams, 76% were classified as moderate- or high-complexity. The level of clinical complexity was determined by the team using several parameters including difficult status (refractory physical or psychosocial symptoms), decision difficulty, uncertainty (prognostic, therapeutic), or foreseeable need for intensive supportive palliative care. Overall, 64% of the patients were male, and the most common primary site was lung (26%). The main symptoms were pain (68%), anorexia (72%), asthenia (78%), insomnia (50%). The hospital support team's care was focused on the preterminal phase of cancer patients of moderate-high complexity
Watts (24) [2012]	UK	Review	Literature			To discuss the intricacies of the decision-making process about initiating end- of-life care pathways	The complexity of the end-of-life decision-making process cannot be overcome. Healthcare providers need to recognize subtle changes in the condition of the patient and respond appropriately by marking the transition to terminal care, dealing with ambiguity, reaching professional consensus, and engaging the patient and family
McVey et al. (25) [2014]	Australia	Qualitative	Interview (thematic analysis)	A rural location and a metropolitan location	The high-level care residents (n=21)/ persons responsible (n=72)	To identify knowledge gaps, barriers and unmet care need to inform future strategies for enhancing the quality of care for older people	Themes emerging in the care of older people with declining health and increasingly complex care needs living in residential aged care facilities were (I) meanings staff attribute to a 'palliative approach'; (II) shared ethos of care; (III) challenges experienced by staff incorporating this approach. The findings illuminate aged care staff experiences of providing care to high-level care residents

Table 2 (continued)

Table 2 (continued)

Authors/ publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Axelsson <i>et al.</i> (26) [2015]	Sweden	Qualitative	Interview (thematic analysis)	Two in university hospitals and one, a dialysis satellite	The medical record of a deceased hemodialysis patient (n=14); spouses (n=10), daughters (n=2), son and sister (n=1); 3–13 months after the death of the patient	To describe end of life for patients treated with maintenance hemodialysis as narrated by their close relatives	In end-of-life patients with maintenance hemodialysis, care needs and existential issues are increasingly complex. The identification of organizational factors to facilitate continuity and whole-person care to meet these patients' specific care needs with their complex symptom burdens and comorbidities is needed
Hackett <i>et al.</i> (27) [2016]	UK	Qualitative	Interviews and audio diaries (grounded theory strategies)	Oncology outpatients' clinics within a tertiary cancer center and a hospice palliative care service	Experiencing pain, living at home, over the age of 25 years, with advanced cancer (24 patients and 18 carers)	To explore patients' and carers' experiences of advanced cancer pain and the processes that they engage in to manage pain	Three distinct patterns of pain were discerned in patients' accounts, distinguishable in terms of complexity, severity, transiency, and degree of perceived control over pain. The complex and dynamic nature of pain and how it was understood shaped help-seeking and pain management
Oliveira <i>et al.</i> (28) [2016]	Canada	Qualitative	Interview (interpretive phenomenology)	Two medical units	Registered nurses (n=10)	To describe nurses' experiences providing end-of-life care and to identify factors that support and hinder end-of-life care in this context	Seven themes were generated from the analysis: caring in complexity, caught in a tangled web, bearing witness to suffering, weaving a way to get there: struggling through the process, creating comfort for the patient, working through the dying process with the family, and finding a way through the web. The findings contribute to an understanding of the experiences of nurses in providing end-of-life care on a medical unit including perceived facilitators and barriers
Pidgeon <i>et al.</i> (29) [2016]	Australia	Quantitative	Cross-sectional survey	Participating in the Palliative Care Outcomes Collaboration in Australia (n=115)	The patient received care from the palliative care services for a minimum of 3 days (n=1,800)	To explore patients' levels of pain and other symptoms while receiving care from palliative care services	One-quarter of patients at the end of life with complex symptoms and needs reported severe pain, 20% reported severe 'other symptoms', 20% reported severe patient anxiety, 45% reported severe family anxiety, 66% experienced depressed feelings and 19% reported severe problems with self-worth. Patients receiving care have physical and psychosocial concerns that are often complex and rated as 'severe'
Phongtankuel <i>et al.</i> (30) [2017]	USA	Quantitative	Retrospective cohort study	Centers for Medicare and Medicaid Services	Patients enrolled in the Medicare hospice (n=3,347)	To develop and validate a model predictive of hospitalization after enrollment into home hospice using pre-hospice admission risk factors	Reasons for hospitalization among home hospice patients are complex. Seven variables were associated with hospitalization: age 18–55 years old (adjusted OR =2.94, 95% CI: 2.41–3.59), Black race (adjusted OR =2.13, 95% CI: 1.93–2.34), East region (adjusted OR =1.97, 95% CI: 1.73–2.24), a non-cancer diagnosis (adjusted OR =1.32, 95% CI: 1.21–1.45), 4 or more chronic conditions [adjusted OR =8.11, 95% CI: 7.19–9.14], 2 or more prior hospice enrollments (adjusted OR =1.75, 95% CI: 1.35–2.26), and enrollment in a not-for-profit hospice (adjusted OR =2.01, 95% CI: 1.86–2.18). Patients who are younger, belong to a minority group, and have a greater number of chronic conditions are at increased odds of hospitalization

Table 2 (continued)

Table 2 (continued)

Authors/ publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Thrane et al. (31) [2017]	USA	Quantitative	Retrospective chart review (retrospective study)	Children's hospital	The ages of 2 and 16 years when they received the referral to palliative care (n=256)	To describe types of illnesses, the timing of referral, and time to death following referral to palliative care	Survival experience did not differ significantly based on gender, age, race, or religion; however, survival did vary based on referring diagnosis, particularly cancer. Results reflect earlier referral to palliative care for most children and highlight the medical complexity especially for children with congenital and genetic diagnoses
Carduff et al. (4) [2018]	UK	Qualitative	Semi-structured interviews (thematic analysis)	Primary care, specialist palliative care, the acute medical unit	Professionals including doctors, nurses, and allied health professionals (n=34)	To describe how health professionals, from three distinct settings in the United Kingdom, understand the complex need in palliative care	The interaction between diverse multi-dimensional aspects of need, existing co-morbidities, intractable symptoms, and complicated social and psychological issues increased perceived complexity. Poor communication between patients and their clinicians contributed to complexity. Complexity in the context of palliative care can be inherent to the patient or perceived by health professionals
de Veer et al. (32) [2018]	The Netherlands	Qualitative	Interviews (inductively analysis)	Shelters for the homeless	People experiencing homelessness in the palliative phase (n=19)	To give insight into the extent to which people experiencing homelessness have access to good palliative care	Three key themes were: 'late access', 'capricious trajectory' and 'complex care'. 'Complex care' refers to the complexity of their care about with pain and symptom control, psychosocial and spiritual aspects, and the social network. Education in palliative care of outreach professionals, training staff in shelters in the provision of palliative care and building a network of palliative care specialists for people experiencing homelessness
Santos et al. (33) [2018]	Brazil	Quantitative	Hospital records (retrospective descriptive study)	Patients hospitalized in the Palliative Care Unit	Patients to the palliative care unit (n=2,486)	To analyze the complexity of nursing care with use of the Perruca scale in a Palliative Care Unit	Of the patients admitted to the palliative care unit, 910 patients (58%) were classified as minimal or intermediate care. As semi-intensive and intensive care were classified 658 (42%) patients, of whom 64% died and only 36% were discharged. The Perruca scale is a tool to identify patients with a greater need for care and the possible prognosis for hospitalized patients
Martin- Rosello et al. (34) [2018]	Spain	Review	Literature			To present the state of the art of the role of complexity in specialist palliative care provision	Recent findings although studies related to complexity in palliative care are still limited, interesting reviews on complexity frameworks in co-morbidity conditions and palliative care are growing more present in current literature. They identify multi-dimensional issues, resource utilization, and the relationship between them as fundamental aspects of complexity constructs, helping to define and understand complexity, and to therefore design validated tools to support healthcare professionals identifying the most complex patients
Mateo-Ortega et al. (35) [2018]	Spain	Quantitative	Single group pretest (prospective multicenter study)	Specialized psychosocial care team (n=29)	Diagnosis of advanced and/or terminal illness and patients treated by specialized psychosocial care team (n=8,333)	To determine whether specific psychosocial interventions can ease discomfort in PC patients, particularly in those with high levels of pain or emotional distress	Patients were classified as complex, when presented with high levels of anxiety, mood, suffering (or perception of time as slow), and distress (or unease, or discomfort), or noncomplex. After successive psychosocial interventions, the level of suffering in complex patients decreased until close to parity with noncomplex patients, suggesting that patients with major complexity could benefit most from specific psychosocial treatment
Pask et al. (2) [2018]	UK	Qualitative	Depth qualitative interviews (framework analysis)	Six UK centers (hospital, hospice, and community)	Patients, family, professionals, managers, and senior leads (n=65)	To explore palliative care stakeholders' views on what makes a patient more or less complex and insights on capturing complexity at patient-level	Participants provided an understanding of complexity, which extended far beyond the commonly used physical, psychological, social, and spiritual domains. Complexity included how patients interact with family/professionals, how services respond to needs, and societal perspectives on care. The dynamic nature of illness and needs overtime was also profoundly influential

Table 2 (continued)



Table 2 (continued)

Authors/ publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Burt <i>et al.</i> [2018] (36)	USA	Review	Literature			To explore the idea of complexity-based palliative care integration in the context of U.S. health care reform and describe a model for strategic oncology and palliative care integration	Complexity-based integration model favors early stratification of patient palliative complexity, matching those palliative complexities (e.g., emotional distress, financial difficulties, high symptom burden) with the oncology practice's resources (e.g., time and expertise), then deploying specialty palliative care services if warranted to complement, fill gaps, and add extra support
Tuca <i>et al.</i> [2018] (37)	Spain	Quantitative	Prospective observational study	Multicenter (primary care centers, hospitals, medium long-term stay, and home palliative care teams)	Advanced cancer patients with an estimated prognosis $\leq 6$ months (n=324)	To identify the factors influencing the level of complexity, determination of complexity, propose predictive models, and build a complexity scale of palliative care	Factors influencing the determination of the level of complexity including socio-demographic and clinical data, symptom burden, functional and cognitive status, psychosocial problems, and existential-ethical dilemmas were identified, and the model of complexity was constructed. Variables influencing determination of PC complexity were as follows: high symptom burden (OR =3.19, 95% CI: 1.72–6.17), difficult pain (OR =2.81, 95% CI: 1.64–4.9), functional status (OR =0.99, 95% CI: 0.98–0.9), and social-ethical existential risk factors (OR =3.11, 95% CI: 1.73–5.77)
Hodiamont <i>et al.</i> [2019] (3)	Germany	Qualitative	Interviews (thematic framework)	Clinical experts and researchers, including the German Association for Palliative Medicine	Clinical/economical/political expert (n=42)	To describe criteria contributing to the complexity of palliative care situations from the professionals' view and related elements of a palliative care situation by locating the complex problem "palliative care situation" in a complex adaptive system	The complex adaptive systems of a palliative care situation consist of three subsystems: patient, social system, and team. Agents in the "system patient" are allocated to further subsystems on patient level: physical, psycho-spiritual, and socio-cultural. The "social system" and the "system team" are composed of social agents, who affect the CAS as carriers of characteristics, roles, and relationships. Environmental factors interact with the care situation from outside the system. The systemic view can support an understanding and framework for the development of care structures and concepts
Battisti <i>et al.</i> [2020] (38)	USA	Quantitative	Retrospective review	Pediatric tertiary care hospital	Patients admitted to a pediatric tertiary care hospital from the emergency department (n=4,157)	To identify gaps in the documentation of complex chronic diseases within the electronic health record, focusing on patients with complex chronic diseases	There were 12,648 unique children of whom 4,157 (32.9%) had complex chronic diseases. Of 528 (4.2%) patients; 18 years of age, 428 (81.1%) had complex chronic diseases and only 65 (12.3%) had code status discussions. Palliative care consultation increased odds of code status discussions (OR =21.4, 95% CI: 13.8–33.2), whereas African American race decreased odds of code status discussions (OR =0.42, 95% CI: 0.27–0.64)
Carrasco-Zafra <i>et al.</i> [2020] (39)	Spain	Quantitative	Observational retrospective study	Hospice	Advanced-stage cancer patients (n=501)	To describe the levels of complexity that may be present, to determine their most prevalent elements, and to identify factors that may be related to palliative complexity in advanced-stage cancer patients	The level of complexity was determined by the Diagnostic Instrument of Complexity in Palliative Care (IDC-Pa <sup>®</sup> ) and classified as highly complex, complex, or non-complex. Of the 501 patients studied, 44.8% presented a situation classed as highly complex. The highly complex items most frequently observed were the absence or insufficiency of family support and/or caregivers (24.3%) and the presence of difficult-to-control symptoms (17.3%). The main factor related to the presence of high vs. non-complexity was that of performance status OR =10.68, 95% CI: 2.81–40.52, for PPS values <40%). However, age was inversely related to high complexity

Table 2 (continued)

Table 2 (continued)

Authors/publication date	Country	Design	Method	Type of institution	Population	Aim of study	Key findings
Busquet-Duran et al. (7) [2020]	Spain	Quantitative Cross-Sectional Study	Cross-Sectional Study	Primary care services and home care support teams (n=43)	End-of-life patients (n=832)	To describe differences in complexity across disease groups in specific home care for AD/EOL patients, both in general and as relates to each domain and subdomain	The HexCom includes 6 domains of needs (clinical, psychological/emotional, social/family, spiritual, ethical, and death-related), 4 domains of resources (intrapersonal, interpersonal, transpersonal, and practical), and 3 levels of complexity (H, M, and L). Moderate complexity was observed in 385 (47.0%) cases and high complexity in 347 (42.4%). The median complexity score was 51 for cancer patients and 23 for patients with dementia (P<0.001). The highest complexity was observed in the social/family domain. Patients/families used interpersonal resources most frequently (80.5%)
Kamal et al. (40) [2021]	UK	Quantitative	Registry data (retrospective cohort study)	Specialty palliative care consultations	Patients who have been consulted for specialized palliative care and have no deficiency in complexity score (n=3,121)	To examine whether patient and consultation characteristics, as captured in consultation requests, are associated with the number of unmet palliative care needs that emerge during the consultation, as an indicator of complexity	Complexity scores, including quality-of-life, symptoms, advance care planning, and prognosis, were created on a 13 point-of-care scale, ranging from 0 (least complex) to 13 (most complex). Patients had an average complexity score of 6.7. Female gender, nonwhite race, and neurological (e.g., dementia) and noncancer primary diagnosis were associated with increased complexity scores

n, the number of samples; OR, odds ratio; CI, confidence interval; PC, palliative care; CAS, complex adaptive systems; AD/EOL, advanced disease/end-of-life; HexCom, Hexagon of Complexity; H, high; M, moderate; L, low.

of intensity (23,35). Mental health included factors such as emotional distress, mood disorders, and grief (22,34,36).

In the social domain of complexity, the factors were social status (2,4,7,17,23,32,36,37,39) and financial problems (2,36). Social status included factors such as social roles and family roles (7,17,39). For example, financial problems included factors such as the underestimation of the financial burden of cancer patients and the financial difficulties of day-to-day living when patients are homeless or single mothers (2,36).

In the spiritual domain of complexity, the factors were existential problems (23,26,37) and spirituality (18,36). For example, ethical dilemmas were mainly adaptation of treatment, euthanasia, and requests for medically assisted suicide (23). Spirituality was mentioned in terms of the quality-of-life aspect, and tools were used to measure spiritual distress, but it was not clear as to the definition of this factor (18,36).

#### Factors influencing complexity in healthcare setting

Fourteen studies reported the factors influencing on complexity in healthcare setting (2,4,7,13,18,20,23–26,32,34,38,39). The factors influencing complexity were healthcare providers' role (4,13,20,24) and the needs assessments of patients and relatives (13,26,32). For example, the role of the healthcare provider is telling the truth when treatment was unlikely to be effective and the inability to advocate for the patient were factors influencing complexity (13). In addition, differences in the expertise and skills of healthcare providers were factors influencing complexity (24,26).

#### Factors influencing on complexity in socio-cultural setting

Three studies reported the factors influencing complexity in the socio-cultural settings (2–4). The socio-cultural factors of complexity were societal cultures (2–4) and social capital (2,4). The socio-cultural factors of complexity included social systems and social capital, as palliative care is comprised of interacting with each other, such as patients, families, team members, and other care providers (4). In addition, socio-cultural differences among regions and countries were factors influencing complexity (2).

#### Interaction of the factors influencing complexity in palliative care

Ten studies reported interactions of the factors (2–4, 14,16,34,36,37,39,40). In all studies, patient complexity arose from the interaction of physical, psychological, social, and

**Table 3** Study summary

Details of study design	Study
Country/region	
Europe	(2-4,7, 16, 18,20-24,26,27,32,34,35,37,39,40)
USA	(13,15,17,30,31,36,38)
Australia	(19,25,29)
South America	(14,33)
Canada	(28)
Published years	
1990–1999	(24,25)
2000–2009	(13,15,16)
2010–2020	(2-4,7,17-33), (35-40)
Study methods	
Quantitative	(7, 15,22,23,29-31,33,35,37-40)
Qualitative	(2-4,14,18-20,25-28,32)
Case study	(13,34,36)
Review	(16,17,21,24)
Type of institution	
Palliative care units or Hospices	(2,4,14,15,20,22,26,28,31,33,37-39)
Academic societies or Professional teams	(7,18,19,23,27,29,30,35,40)
Telephone or Health centers	(25,32)
Population	
Cancer patients	(13,14,16,22,23,27,29-31,37,39)
Non-cancer patients	(7,15,32,33,35,38,40)
Healthcare providers and/or relatives	(2-4,20,34)

spiritual factors. Similarly, interactions of patient factors as well as healthcare settings and socio-cultural setting factors influencing complexity were also reported (2,4). Pask *et al.* also reported that providing palliative care effectively requires consideration of pre-existing, cumulative, and invisible factors (2). Further, Hodiamont *et al.* reported that elements in palliative care interact at all levels to influence complexity (3). Thus, complexity changes based on dynamic interactions, including non-identifying variables (34). On the other hand, interactions among healthcare providers and between healthcare environments reduced complexity factors (2). Tuca *et al.* reported that defining criteria of complexity for patients receiving palliative care could assist professionals and nonprofessionals in discussing appropriate care in a multidimensional and multidisciplinary approach (37).

## Discussion

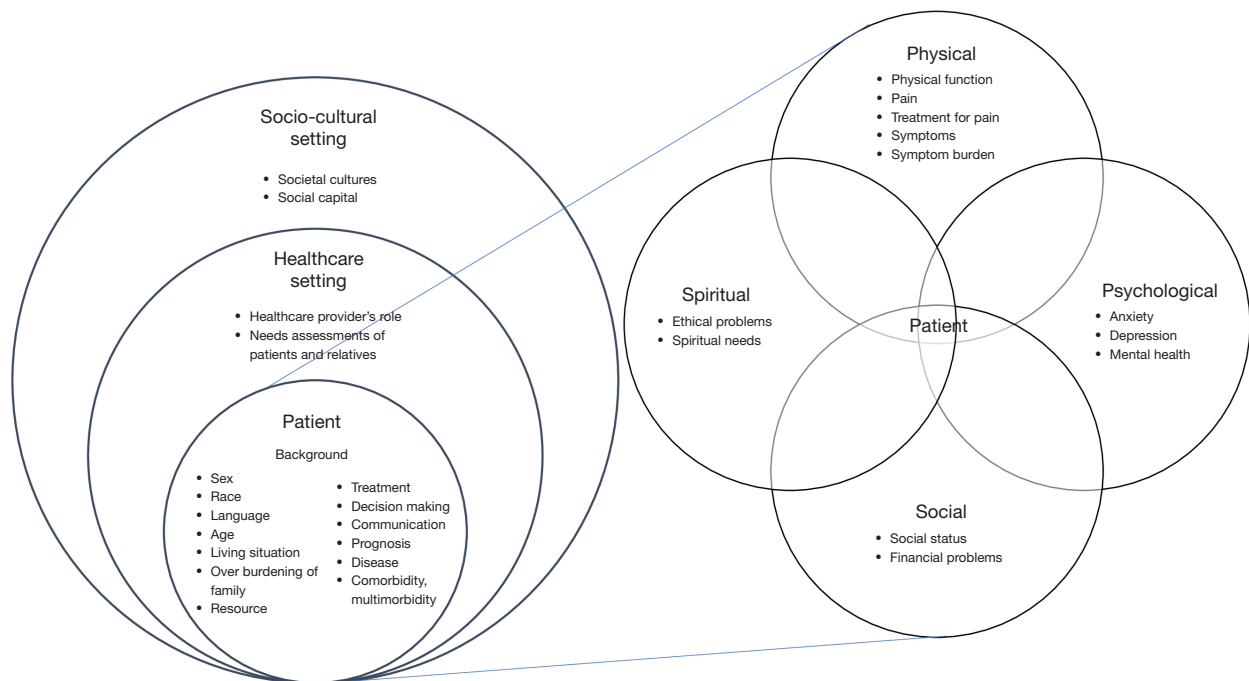
In this integrative review, we identified considered the integration of influences on complexity in the context of palliative care. The main findings of the review are as follows: (I) we enhanced our understanding of factors influences on complexity in palliative care; (II) we listed the factors influences on complexity in palliative care.

First, we identified a total of 29 detailed influences on complexity in palliative care, 25 perceptions of the patient, including background and physical, psychological, social, and spiritual; two perceptions in the healthcare setting; and two perceptions in the socio-cultural setting. Our results were similar to Schaink *et al.* five-part classification of factors that influences complexity for patients with

Table 4 Factor influences on complexity in the context of palliative care

Authors/publication date	Patient																						Healthcare setting		Socio-cultural setting				
	Background											Physical				Psychological			Social		Spiritual		Healthcare provider's role	Needs assessments of patients and relatives	Societal cultures	Social capital			
	Sex	Race	Language	Age	Living situation	Overburdening of family	Resource	Treatment	Decision making	Communication	Prognosis	Disease	Comorbidity, Multimorbidity	Physical function	Pain	Treatment for pain	Symptoms	Symptom burden	Anxiety	Depression	Mental health	Social status					Financial problems	Ethical problems	Spiritual needs
Morrissey (13) [1997]							x																		x	x			
Bottorff et al. (14) [1998]							x																						
Cowan et al. (15) [2002]									x																				
Hemming and Maher (16) [2005]									x							x													
Hinds et al. (17) [2005]										x																			
Pastrana et al. (18) [2010]									x																				
Johnson et al. (19) [2011]							x	x						x	x		x												
Quinn and Bailey (20) [2011]																										x			
Reid et al. (21) [2011]							x																						
Gaertner et al. (22) [2012]											x			x			x					x							
Tuca-Rodriguez et al. (23) [2012]					x						x	x	x		x				x	x		x					x		
Watts (24) [2012]											x															x			
McVey et al. (25) [2014]					x	x						x	x																
Axelsson et al. (26) [2015]									x		x		x	x			x									x		x	
Hackett et al. (27) [2016]																													
Oliveira et al. (28) [2016]					x						x		x																
Pidgeon et al. (29) [2016]																													
Phongtankuel et al. (30) [2017]		x			x																								
Thrane et al. (31) [2017]													x	x															
Carduff et al. (4) [2018]									x				x				x									x			x
de Veer et al. (32) [2018]																													
Santos et al. (33) [2018]																													
Martin-Rosello et al. (34) [2018]																													
Mateo-Ortega et al. (35) [2018]		x																											
Pask et al. (2) [2018]																													
Burt et al. (36) [2018]																													
Tuca et al. (37) [2018]																													
Hodiamont et al. (3) [2019]																													
Battisti et al. (38) [2020]																													
Carrasco-Zafra et al. (39) [2020]																													
Busquet-Duran et al. (7) [2020]																													
Kamal et al. (40) [2021]																													

x, marks the inclusion of factors of complexity in the context of palliative care.



**Figure 2** Model of complexity in palliative care [figure modified with permission from Carduff *et al.* (3)].

chronic diseases: medical/physical health, mental health, demographics, social capital, and health and social experiences (8). For example, our results were similar to those for the experience of two or more chronic diseases and the use of socioeconomic resources, not just factors related to the disease, as factors influence complexity (8). On the other hand, factors that influence complexity in palliative care in our study included younger age, prognosis, and spirituality. Palliative care covers not only end-of-life care, but also symptom management during the treatment phase, care for family members, and many other aspects, all of which influence complexity in palliative care (41,42). Our review included factors that influence complexity extracted from a variety of methods: quantitative studies, qualitative studies, case studies, and reviews. In addition, our review identified factors of complexity in palliative care, not only for cancer patients but also for non-cancer patients and their families. Factors influence complexity in palliative care change because of the different illness trajectories of cancer and non-cancer patients (43). Regardless of the disease, healthcare providers should need indicators to recognize those who need palliative care. Hence, these complexity influencing perceptions are necessary for patients to receive appropriate palliative care at the right time and for health care

providers to conduct a multi-disciplinary team approach.

Second, we listed the factors that influence complexity in palliative care. We additionally modeled perceptions that influence complexity in palliative care with reference to the palliative care complexity framework of Carduff *et al.* which expands on the patient complexity framework of Schaink *et al.* (4,8) (Figure 2). Using this model would help inexperienced healthcare providers perceive the factors influences on complexity in palliative care. On the other hand, it may be burdensome for healthcare providers to measure the 29 perceptions we identified in clinical practice. Grant *et al.* reported six tools in a systematic review of classification systems for determining the complexity of patient care in palliative care (5). For example, Instrument Diagnosing Complexity in Palliative Care (IDC-Pal) is assessed by healthcare providers from the perspective of the patient, family and environment, and health care organization (34). However, no tool covered the factors of complexity that we identified. The perspective of complexity in palliative care that we have identified is necessary because influences on complexity vary with the patient's situation and according to the experience and skills of the health care providers assessing this complexity (3,4).

In addition, the factors influence complexity vary from

dynamic and fluid interactions (2-4,34). Therefore, multiple tools collecting data on patients in palliative care would reveal factors that influence on complexity and lead to appropriate care. In the United Kingdom, the outcome assessment and complexity collaborative project (OACC) has combined tools in routine practice to identify patient symptoms and problems in palliative care (44). However, the OACC focuses on complexity at the individual level and lacks factors in the healthcare and socio-cultural setting. On the other hand, natural language processing of medical records might be useful in the context of differing perceptions among healthcare providers. Natural language processing of data linked to community health databases and medical records is beginning increasingly available to identify patients with complex needs for palliative care (45,46). Furthermore, longitudinal prospective data are needed to examine the changes and relationships among factors of complexity over time.

### *Strengths and limitations*

This integrative review followed established systematic methods and investigated factors influences on complexity in the context of palliative care. It reviewed included studies from different countries and socio-cultural regions. However, this review had certain limitations. First, the gray literature was not searched as one of the primary objectives was to map the complexity of the palliative care context with peer-reviewed academic research. Given that this was not a full systematic review, the review protocol was not registered. Second, we did not focus on the patterns of interaction of the various factors of complexity, but we acknowledge that these are important areas and will be the focus of future research. Therefore, our identified influences on complexity may not necessarily be reductive factors to complexity. Finally, we added the identified factors to the previous study model. Our model could help inexperienced health care providers recognize the factors that influence complexity in palliative care and provide appropriate care, in addition to helping them understand the common complexities of multidisciplinary team care. Thus, we do not limit the interpretation of complexity in palliative care. In the future, changes in treatment methods and social circumstances might exclude or add new factors to those we have identified.

### **Conclusions**

Our integrative review integrates and describes the

factors of complexity in the context of palliative care. We identified 29 factors influencing complexity and developed a model based on the complexity framework in palliative care. The perspective of the complexity in palliative care that we identified is necessary because what is complex differs from person to person who assesses it. Notably, it is necessary for inexperienced healthcare providers to perceive the factors of complexity for appropriate care planning. Furthermore, longitudinal prospective data are needed to examine the changes and relationships among factors of complexity over time.

### **Acknowledgments**

*Funding:* This work was supported by Ministry of Health, Labour and Welfare (MHLW) Cancer Research Program (grant No. 19EA101 to MM).

### **Footnote**

*Reporting Checklist:* The authors have completed the PRISMA reporting checklist. Available at <https://apm.amegroupp.com/article/view/10.21037/apm-22-623/rc>

*Conflicts of Interest:* All authors have completed the ICMJE uniform disclosure form (available at <https://apm.amegroupp.com/article/view/10.21037/apm-22-623/coif>). MM serves as an unpaid editorial board member of *Annals of Palliative Medicine* from February 2022 to January 2024. MM also reports that this work was supported by MHLW Cancer Research Program (grant No. 19EA1011). The other authors have no conflicts of interest to declare.

*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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**Cite this article as:** Ohinata H, Aoyama M, Miyashita M. Complexity in the context of palliative care: a systematic review. *Ann Palliat Med* 2022;11(10):3231-3246. doi: 10.21037/apm-22-623