

Palliative care for the oldest old: recommendations from the first Italian Consensus Conference

E.S. Zanetti¹⁻³, G.B. Guerrini^{3,4}, D. Chiesa⁵, D. Bellandi⁶, C. Bertelli⁷, C. Carabellese⁸, S. Di Meo⁹, P. Lora Aprile¹⁰, G.F. Massarelli¹¹, F. Nicoli^{12,13}, P. Ponton¹⁴, S. Sperotto⁹, G. Zaninetta^{13,15}, F. Lonati²

¹ University of Rome "Tor Vergata", Rome, Italy; ² APRIRE Network; ³ Italian Society of Gerontology and Geriatrics; ⁴ Brescia Solidale Foundation, Brescia, Italy; ⁵ Habilita Care & Research Hospital, Sarnico, Italy; ⁶ Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro Italy; ⁷ Associazione Nazionale Tumori, Italy; ⁸ Clinical Institute Città di Brescia, San Donato Group, Italy; ⁹ Fondazione Casa di Dio, Brescia, Italy, Extrahospital Geriatric Association, Italy; ¹⁰ Territorial Healthcare Agency Spedali Civili Brescia, Italy; ¹¹ Italian College of General Practitioners and Primary Care, Florence, Italy; ¹² Association "On the Other Side: Doctors, Nurses, Operators and Patients Together"; ¹³ Department of Biotechnology and Life Sciences, Center for Clinical Ethics, University of Insubria, Varese, Italy; ¹⁴ Domus Salutis Clinic, Teresa Camplani Foundation, Brescia, Italy; ¹⁵ Agency for health care N.3 "Alto Friuli - Collinare - Medio Friuli" - Gemona del Friuli, Italy; ¹⁶ Italian Palliative Care Society

In all care settings (hospital, health and social services facilities, and intermediate and home care), recognizing the need for palliative care for the oldest old – that is, when care and assistance for prevention, cure or rehabilitation purposes should aim at maximizing comfort and control of disturbing symptoms to safeguard the quality of life – is a challenging task.

The early identification, among the oldest old, of those who could benefit from palliative interventions has proved effective in improving their quality of life and that of their families, as well as in reducing costs and improving the appropriateness of interventions.

To answer this need, the non-profit APRIRE Association (Assistenza PRIMaria In RETe) – Health at km 0 – has promoted the Consensus Conference "Palliative care for the oldest old at home, in nursing homes and in hospices". A Consensus Conference is one of the tools that allow achievement of an inter-party agreement on especially controversial and complex issues through a formal process; it favors the choice of directions for clinical practice that are as uniform as possible, and determines the means to provide patients with the best quality of care in relation to the available resources.

This consensus document was discussed and approved on October 24, 2018 in Rome by a panel of designated members of a number of scientific societies (Extrahospital Geriatric Association, Italian Association of Family and Community Nurses, Italian Association of Psychogeriatrics, Italian Palliative Care Society, Italian Society of Gerontology and Geriatrics, Italian College of General Practitioners and Primary Care, Italian Society of Geriatrics Hospital and Territory), the Department of Biotechnology and Life Sciences, Center for Clinical Ethics, University of Insubria, Varese, the National Federation of Physicians, Surgeons and Dentists, the National Federation of Nursing Professions, the National Council of the Order of Psychologists and the Italian National Institute of Health.

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INTRODUCTION

The World Health Organization (WHO) has long stated that the principles of palliative care should be applied as early as possible in the course of a chronic disease ¹; particularly considering that in high-income countries 75% of deaths are caused by advanced progressive chronic conditions. The palliative approach is comprised of 2 phases: the first phase, often months or years before death, corresponds to the early identification of individuals with palliative care needs based on the recognition of specific indicators or variables; the second phase concerns the last days or weeks of life ². Identifying the need for palliative care allows progressive overcoming of a preventive, curative and rehabilitative approach in favor of care interventions aimed at maximizing comfort and controlling disturbing symptoms, to ensure quality of life. Recognizing the need for such change appears especially challenging in settings in which older adults are cared for (i.e. hospital, social care facilities, intermediate care and home care).

The oldest old refers to a person who has undertaken the last journey of their aging path, characterized by: very advanced age (> 85 years); a growing difficulty in establishing a new clinical-functional balance in response to aging-derived changes; accumulation over the years of the consequences of chronic (poly)pathology; a condition of growing “frailty” (i.e. beyond the somatic and cognitive phenotype, a state of increased vulnerability to stress, with increased risk of disability, functional decline, as well as more frequent hospital admissions and higher mortality) ³; coexistence of multiple, chronic diseases (and consequently chronic symptoms and polypharmacy) that are reciprocally interacting ⁴; high risk/ presence of functional “disability”, which in most cases is progressive ⁵; high prevalence of cognitive impairment; need for socio-medical support and, not infrequently, a weak support network (family and/or social network).

In this perspective, when caring for the oldest old, medicine is faced with 2 challenges:

1. The need to deal with the complexity and instability marking the clinical and existential condition of these patients. That is, maintaining the balance between therapeutic obstinacy and abandonment (ageism) and integrating evidence-based medicine with a multidimensional care, a functional approach and the enhancement of new clinical-functional balances.
2. The need to identify, along the continuum that often characterizes the path to disability, the threshold beyond which a clinical condition becomes irreversible and the symptomatic and palliative approach becomes essential.

TOPICS AND OBJECTIVES OF THE CONSENSUS CONFERENCE

The following topics to be discussed by the experts were identified by the Organizing Committee:

- identification of the oldest old needing palliative care;
- early planning of care and joint discussion on end of life by the physician, the cared-for person and the caregiver;
- nursing palliative care models in the oldest old;
- artificial nutrition and hydration;
- assessment and management of pain in the non-communicating person;
- appropriateness of pharmacological therapies and diagnostic tests for elderly patients with limited life expectancy;
- family support interventions;
- continuity of care.

The following objectives were set:

1. Define prognostic criteria for terminality that are specific for the oldest old.
2. Identify the appropriate palliative interventions for the care of the oldest old, at home as well as in nursing homes and hospices.
3. Identify the interventions needed to support family members as well as formal and informal caregivers.

The Organizing Committee, in agreement with the experts, formulated 12 questions related to the above objectives (Box 1). For each question, a systematic literature review was conducted according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) methodology ⁶ and by searching Medline, Cochrane Library and CINAHL databases.

IDENTIFICATION OF THE OLDEST OLD NEEDING PALLIATIVE CARE

The early identification of the oldest old who could benefit from palliative care has proved to be effective in improving the quality of life of elderly people and their families as well as in reducing costs and improving the appropriateness of interventions ²⁻⁴. A review of the literature ⁷ has shown that the palliative approach to elderly residents of nursing homes improves clinical outcomes, care processes and the perception of care quality by family members. In particular, the palliative approach improves the management of pain and other disturbing symptoms (e.g. dyspnea, fatigue) and the appropriateness of drug therapies. It also reduces the use of invasive interventions such as physical restraint and percutaneous endoscopic gastrostomy.

Question 1: Which indicators allow the establishment of a prognosis and the need for palliative care for the oldest old?

In older adults, the identification of those who can benefit

Box 1. Topics and questions addressed by the consensus conference.

Identification of the oldest old needing palliative care Question 1: Which indicators allow the establishment of a prognosis and the need for palliative care for the oldest old? Question 2: Does the use of prognostic mortality indices improve prognostic reliability in the oldest old? Question 3: Are tools for assessing palliative care needs reliable in the oldest old?
Early planning of care and joint discussion on end of life by the physician, the cared-for person and the caregiver Question 4: Does the discussion on end-of-life and advance care planning improve the concordance between preferred and received end-of-life care?
Nursing palliative care models in the oldest old Question 5: Which aspects of palliative nursing are associated with better outcomes?
Artificial nutrition and hydration Question 6: What are the criteria for initiating, not initiating or suspending artificial nutrition? Question 7: What are the criteria for initiating, not initiating or suspending artificial hydration?
Assessment and management of pain in the non-communicating person Question 8: Is the use of an objective pain assessment tool effective in the non-communicating person?
Appropriateness of pharmacological therapies and diagnostic tests for elderly patients with limited life expectancy Question 9: Which drugs and which diagnostic tests are potentially inappropriate in elderly patients with limited life expectancy? Question 10: Which drugs should be used to treat pain in the oldest old? Question 11: Is antimicrobial therapy appropriate in the elderly with limited life expectancy?
Family support interventions and continuity of care Question 12: What interventions are effective for caregivers' support?

from palliative care (including symptom management, psychosocial support, and the sharing of treatment goals and the patient's expectations and wishes) is made possible by multidimensional assessment (MDA), which allows prompt recognition of functional, cognitive and nutritional decline. MDA has proved the most effective tool in identifying the needs and potentials of older adults, in establishing the short- and long-term prognosis and setting an individualized treatment plan. The MDA is especially useful in the oldest old, since multimorbidity, clinical-functional instability, frailty and disability increase with age^{8,9}.

In people with advanced frailty, the following indicators are more discriminating than the severity of the clinical condition in establishing the prognosis and the need for palliative care¹⁰:

- functional indicators: non-iatrogenic loss of ≥ 2 activities of daily living (ADLs) or clinically assessed functional decline not related to concomitant conditions in the past 6 months;
- nutritional indicators: loss of $> 10\%$ of body weight or clinically assessed nutritional decline not related to concomitant conditions in the past 6 months;
- emotional indicators: presence of emotional stress with psychological symptoms not related to concomitant acute conditions;
- geriatric syndromes: events occurring in the past 6 months; such as no resolution of pressure ulcers (stages 3-4 according to the National Pressure Ulcer Advisory Panel, NPUAP), recurrent infections (≥ 2 events), delirium, persistent dysphagia or > 2 falls;

- Resource use: ≥ 2 unplanned admissions to hospital (or specialized care facilities) over the past year due to complications of chronic illness. Need for ongoing care at home or at a nursing home;
- In people with dementia: non-iatrogenic loss of ≥ 2 ADLs in the past 6 months, difficulty in swallowing or refusal of food.

In a longitudinal evaluation, functional and nutritional indicators were those demonstrating – through their deterioration – a better prognostic ability¹⁰.

To identify the clinical features most strongly associated with 1-year mortality, Thomas et al.¹¹ reviewed 33 prospective cohort studies published before August 2010. According to a multivariate analysis, the domains associated with 1-year mortality in the studies of older hospitalized adults were nutritional status (7/13 studies), physical function (9/13 studies), nutritional status and physical function (6/13 studies). The domains associated with in-hospital mortality were physical function, cognitive function and nutritional status. In studies of nursing home residents, physical function and nutritional status correlated with 1-year mortality in all and in 4 of 5 studies, respectively. In the institutionalized elderly adults with dementia, physical function, pressure lesions and nutritional status correlated with 1-year mortality better than the diagnosis of disease and cognitive function. In those patients, 1-year mortality also positively correlated with breathing difficulty (need for oxygen therapy in the previous 14 days) and the presence of pressure lesions of NP-UAP stage > 2 .

Question 2: Does the use of prognostic mortality indices improve prognostic reliability in the oldest old?

In a systematic review, Yourman et al.¹² analyzed the quality and limitations of prognostic mortality indices in older adults. All valid prognostic indices for mortality were included for patients aged ≥ 60 years. The prognostic indices for intensive care-specific, disease-specific and in-hospital mortality were excluded. For each prognostic index, data on the clinical setting, potential bias, generalizability and accuracy were considered.

The authors reviewed 21,593 titles: only 24 papers were included and identified 16 indices predicting the mortality risk from 6 months to 5 years for older adults in a variety of clinical settings: the community (6 indices), nursing homes (2 indices) and hospitals (8 indices). No study was free from potential biases. Although 13 indices had area under the curve (AUC) values > 0.70 , none had an AUC value > 0.90 . Only 2 prognostic indices were independently validated by investigators who had not been involved in their development. No index had been tested prospectively. The authors of the review concluded that the available evidence is insufficient to recommend the systematic use of prognostic indices in clinical practice.

Thomazeau et al.¹³ reviewed the effectiveness of 22 tools in identifying the risk of mortality (at 3, 6 and 12 months) in acute care inpatients aged ≥ 65 years (5 studies), ≥ 70 years (7 studies), ≥ 75 years (4 studies) or ≥ 80 years (1 study). The selected tools assessed functional autonomy, malnutrition, comorbidity, cognitive disorders and reason for hospitalization. Few of these tools had an AUC value ≥ 0.70 . However, the authors concluded that the availability of a tool for assessing the mortality risk in older adults in acute care settings might help in their management by better guiding the clinical approach and indicating the need for palliative care.

Brown et al.¹⁴ examined the prognostic indices for 6-month mortality rates in people with dementia. Their systematic review included 7 studies, 2 of which were set in hospice care settings, 2 in nursing homes and 3 in long-term care facilities. All studies agreed on the need to include the severity of dementia as a prognostic criterion for 6-month mortality, but consensus was lacking about the tool that should be used.

Rikkert et al.¹⁵ performed a systematic review to assess the reliability, validity and feasibility of clinically relevant staging scales for dementia as a syndrome and more specifically for Alzheimer's dementia. Out of 963 articles, 23 (2.4%) met all the inclusion criteria. The authors identified 12 different staging tools that had been developed since the 1980s. The evidence was best for the Clinical Dementia Rating (CDR) scale, which has been internationally studied and is available in 14 languages. The extended CDR scale¹⁶ includes 2 more severity

stages, CDR 4 (profound dementia) and CDR 5 (terminal dementia), with an average survival of 24 and 12 months, respectively. The Bedford Alzheimer's Nursing Severity Scale (BANS-S) can differentiate cognitive and functional conditions in individuals with advanced dementia¹⁵. Compared with the other assessment tests, which exhibited a floor effect in 40% of examined individuals, the BANS-S and extended CDR scale showed a more uniform score distribution over their ranges.

RECOMMENDATION 1. Periodically assess the nutritional indicators, functional state and cognitive function within the geriatric multidimensional assessment (MDA). A progressive worsening increases the risk of 12-month mortality. Additional studies are required to establish whether clinical management could improve with routine use of prognostic indices based on geriatric MDA.

RECOMMENDATION 2. In elderly people with dementia, use the Clinical Dementia Rating Scale (CDR) and/or the Bedford Alzheimer Nursing Severity Scale (BANS-S). Using these scales improves prognostic reliability.

Question 3: Are tools for assessing palliative care needs reliable in the oldest old?

The availability of tools that can identify the need for palliative care could help ensure better care. Two groups^{17,18} independently performed systematic reviews of the international literature to evaluate the tools used in primary care to identify patients with palliative care needs in Europe and Australia. None of the 7 tools identified had been validated or widely implemented. Subsequent studies of some of those tools did not provide sufficient evidence to recommend their routine use:

- the clinical utility of the Gold Standards Framework Proactive Identification Guidance was assessed in a single study¹⁹ of 501 hospitalized patients of all ages, with inconclusive results;
- the Supportive and Palliative Care Indicators Tool (SPICT) was validated in a study of a population of elderly patients (mean age 84 years): the study demonstrated a significant association with 1-year mortality (sensitivity 0.841; specificity 0.579) and with predictions by experienced geriatricians on patient survival. Because geriatricians were able to identify most patients with limited prognosis based on their clinical skills, the added value of SPICT in an acute geriatric ward could be questioned²⁰. Further studies are needed to evaluate the added value of SPICT in other hospital settings and in primary care;
- the NECesidades PALiativas CCOMS-ICO (NECPAL CCOMS-ICO) tool, which combines the

“surprise question” with additional indicators, has been validated in a large institutionalized population aged > 65 years. The prognostic accuracy of the surprise question and NECPAL is 52.9 and 55.2%, respectively; therefore, the tool’s prognostic utility should be considered with caution. Research is underway to improve the prognostic ability of the NECPAL tool, combined with other parameters, to increase its specificity and reduce false positive results ¹⁰.

Despite the above limitations, according to Maas et al. ¹⁷, general practitioners should be encouraged to combine their clinical expertise with the use of 1 assessment tool for early identification of patients who could benefit from a palliative approach. This would be the first step towards improving the quality of life of people currently living and dying with unrecognized – and therefore unmet – palliative care needs.

Walsh and colleagues ¹⁸ emphasized the need for early identification tools that are both easy to use and accessible to clinicians regardless of their individual expertise and palliative care skills.

Assuming that geriatric MDA can improve diagnostic accuracy, optimize treatment, improve prognosis, restore and maximize functionality, improve the quality of life and reduce costs, Hermans et al. ²¹ performed a systematic review of the literature on nursing homes to identify all validated MDA-based tools for assessing the need for palliative care. Among the 5 tools identified in their review, the McMaster Quality of Life Scale (MQLS) ²² is the most accurately validated from a psychometric perspective. However, the most complete content-wise is the interRAI Palliative Care instrument (interRAI PC) tool ²³, which is comprised of 74 items in 17 sections. The interRAI PC has been validated for nursing home residents with palliative care needs. Despite the number of items, it only takes 20 minutes to complete.

The systematic review by George et al. ²⁴ identified 7 studies proposing criteria or tools for assessing palliative care needs for emergency department (ED) patients. Four studies had been conducted in elderly people (> 64 years) with advanced clinical conditions or multiple chronic diseases, at risk for repeated access to ED services or with advanced dementia. The review confirmed that assessing the need for palliative care for ED patients is fundamental. The assessment should occur through a structured process, including: a first-level assessment that is performed by the triage nurse using the data collected during triage and ideally taking only 1-2 extra minutes; a second-level assessment – on patients with “positive” results – performed by qualified personnel using tools that assess functional and social aspects, the patient’s symptoms and the burden of caregivers.

RECOMMENDATION 3. Systematically use a tool for assessing the need for palliative care. Use of such a tool improves the identification of people needing a palliative approach.

EARLY PLANNING OF CARE AND JOINT DISCUSSION ON END OF LIFE BY THE PHYSICIAN, THE CARED-FOR PERSON AND THE CAREGIVER

Question 4: Does the discussion on end-of-life and advance care planning improve the concordance between preferred and received end-of-life care?

According to a recent International Consensus Conference ²⁵, advance care planning enables people with decision-making ability to identify their values, reflect on the meanings and consequences of serious illness scenarios, define goals and preferences for future treatments and medical care, and discuss them with family members and healthcare professionals.

Sharp et al. ²⁶ performed a review on conversations about end-of-life care with frail and older adults without a prevalent diagnosis but with multiple comorbidities and cognitive impairment, estimated to account for about 40% of deaths. Their review identified barriers to end-of-life discussions that were not found in studies of other populations, including a reluctance of family members to discuss end-of-life care, the passive expectation that others would make decisions for them and uncertainty about the prognosis. The authors concluded that although most older adults would like to discuss their end-of-life care, only a minority are given this opportunity.

The European Association for Palliative Care recommends that the decision-making process also be shared with patients with dementia and their families: this implies that the process should start as soon as the diagnosis is formulated, when the person can still be actively engaged and express their preferences, values and needs ²⁷.

The effectiveness of advance care planning has been investigated in several studies. In their review, Houben et al. ²⁸ concluded that advance care planning for different adult patient populations with chronic conditions improves concordance between preferred and received end-of-life care. Brinkman-Stoppelenburg et al. ²⁹ observed a reduction in the often inappropriate and traumatic hospitalizations of institutionalized frail adults, and Graverholt et al. ³⁰ observed a significant increase in the number of residents who died at nursing homes.

RECOMMENDATION 4. Discuss end-of-life care planning with the person and their family: this improves the concordance between the preferences stated and the care received.

NURSING PALLIATIVE CARE MODELS IN THE OLDEST OLD

Palliative care can be difficult to articulate. It is not a level of care (i.e. critical care, rehabilitation, hospice or other) or a disease management program but rather a philosophy of care and an organized, highly structured system for delivering care³¹. Palliative care is interdisciplinary in nature and the expertise of the healthcare professionals involved may overlap. Thus, hospice and palliative care nursing requires a firm theoretical foundation: nursing roles are complementary to those of other healthcare professionals³². The goal of palliative nursing is to improve the quality of life of the cared-for person.

Question 5: Which aspects of palliative nursing are associated with better outcomes?

The review by Luckett et al.³³ identified several palliative care models adopted in the different care settings and highlighted their features:

- **Case management.** This is a recurring feature of many successful models. Case management is a collaborative process requiring coordination between several services (health, social, religious) and entails planning of a care pathway based on the needs of the person and their family. Case management ensures continuity of care over time and during transition between care settings; it is also associated with better clinical outcomes and reduced institutionalizations and hospital admissions. Case management is more effective when it is high intensity and includes effective inter-service communication, and when specialists are available to assist people with complex needs³⁴;
- **Shared care.** This represents an opportunity for people to benefit from specialist care combined with the continuity of care provided by team nurses, who maintain responsibility for all aspects of care. The shared care model is based on coordination within a defined care pathway. The Cochrane review by Smith et al.³⁵ suggests that shared care is effective for managing depression. Shared care interventions for patients with other chronic conditions should be developed within research settings, so that further evidence can be considered before they are introduced routinely into health systems;
- **Specialist care.** Specialist care services have been widely adopted internationally to improve care outcomes for under-served populations. A Cochrane review examined the effectiveness of specialist care services in primary and hospital care: the authors concluded that specialist care services can improve outcomes, ensure delivery of more effective, evidence-based care and reduce the use of hospital services. However, none of the studies

included in the review made a comparison between specialist care services for palliative care³³.

For the cared-for person and their family, the need must be emphasized for an early identification of well-being (comfort care) goals that take into account the respect of dignity on the physical, emotional and spiritual levels, and for redirection of care interventions for the management of the different problems (e.g. pressure ulcers) to ensure the quality of life.

RECOMMENDATION 5a. Plan palliative nursing in all care settings, considering the needs and preferences of the cared-for person and their family, and favoring comfort-oriented interventions.

RECOMMENDATION 5b. Enhance the skills of palliative care teams to improve symptom identification and control and quality of life.

RECOMMENDATION 5c. Ensure care continuity during transitions between services, facilities and care settings.

RECOMMENDATION 5d. Ensure a prompt response after a sudden change in a person's clinical state.

ARTIFICIAL NUTRITION AND HYDRATION

Question 6: What are the criteria for initiating, not initiating or suspending artificial nutrition?

In 1998, the WHO stated that *"Intravenous feeding is contraindicated in terminally ill patients. It does not improve weight gain, nor does it prolong life. Enteral feeding (nasogastric tube, gastrostomy, or jejunostomy) has a very limited place in terminal illness. It should be used only in patients who would clearly benefit. Artificial feeding should not be used in moribund patients"*³⁶. More recently, a Cochrane review³⁷ stated that in the absence of good-quality studies to support any recommendation regarding the use of medically assisted nutrition in palliative care patients, physicians must make a decision based on the expected benefits and possible complications in each patient's circumstances.

Artificial nutrition should be prescribed and initiated when there is a reasonable clinical hypothesis that the survival expected according to the natural evolution of disease is reduced by concomitant malnutrition, secondary to the inability to take food orally. As with any therapy, the risk/benefit ratio must also be assessed for artificial nutrition³⁸. This ratio has been shown to be unfavorable in people with advanced dementia: feeding via percutaneous gastrostomy or jejunostomy does not improve survival³⁹ and is associated with a high risk of complications, including increased perioperative

mortality^{40 41}. Enteral nutrition in people with severe dementia is only indicated when the comorbidity limiting oral nutrition is potentially reversible⁴².

RECOMMENDATION 6a. Implement a decision-making procedure – involving the patient, their family and healthcare professionals – for initiating/not initiating/suspending artificial nutrition. For the non-communicating person, consider the advance directives, if available. The procedure should consider clinical condition, expected benefits, any possible damage and quality of life, as well as the person's psychological, relational, spiritual and social well-being. Suspend artificial nutrition when the expected benefits are not observed.

RECOMMENDATION 6b. Initiate artificial nutrition only when a reasonable clinical hypothesis exists that the survival expected according to the natural evolution of the disease is reduced by concomitant malnutrition, secondary to the inability to take food orally.

RECOMMENDATION 6c. Do not use percutaneous gastrostomy or jejunostomy nutrition for persons with advanced dementia. This procedure does not improve survival and – unless indicated for a potentially reversible condition limiting the ability to take food orally – is associated with a high risk of complications.

Question 7: What are the criteria for initiating, not initiating or suspending artificial hydration?

No clear indications exist for artificial hydration in the terminally ill: a Cochrane review⁴³ found no significant evidence supporting medically assisted hydration for patients receiving palliative care. Furthermore, most studies included patients with end-stage cancer and it is not known whether their results can be extrapolated to other clinical conditions and to the oldest old.

Therapeutic decision should not merely rely on the presence of clinical signs of dehydration. Specifically, in the presence of comorbidity, caution is required in assessment and its interpretation. The consequences of hydration and to what extent hydration could contribute to relieving symptoms and improving quality of life must be evaluated.

Caution is advised in fluid administration for individuals with heart failure, pulmonary stasis, edema, ascites or symptoms of increased intracranial pressure. In particular, intravenous fluid administration can quickly lead to volume overload. Subcutaneous administration, on the other hand, does not pose any danger in this regard, although evidence for the efficacy of subcutaneous fluid administration by hypodermoclysis comes from relatively small randomized controlled trials or from observational studies⁴³. The systematic review by Forbat

et al.⁴⁴ highlights the paucity of good-quality studies in elderly populations with chronic diseases and, particularly, the lack of evidence-based indications for infusing fluids via hypodermoclysis. Therefore, further studies are required to provide empirical evidence-based directions on mode, site, volume and speed of fluid infusion. The effectiveness of artificial hydration, its benefits and possible disadvantages, must be re-assessed daily. Parenteral hydration can alleviate the discomfort associated with mucosal dehydration and dryness of the oral cavity; however, it can worsen peripheral edema, ascites or pleural effusion and increase bronchial secretions^{45 46}. If fluid administration requires inserting a central venous catheter, the insertion-associated risk and the risk of infection should be evaluated. Hydration is of no benefit in people with a short prognosis and could even lead to complications in their clinical picture⁴⁶.

Fritzson et al.⁴⁷ performed a historical cohort study of 530 patients who died in hospital in the Västerbotten county (Sweden) between January 2011 and June 30, 2012. Through stratified randomization, they identified 140 patients who had received parenteral hydration and 140 age-, sex- and main disease-matched controls who had not. The median age was 80 years in each group. The groups were compared for documented presence of dyspnea, respiratory secretions, anxiety, nausea and confusion during the last 24 hours and the last week of life. The comparison showed a statistically significant prevalence of dyspnea among subjects who had received hydration: 51 *versus* 22% in the last 24 hours ($p < 0.0001$) and 70 *versus* 45% in the last week of life ($p = 0.0005$). In patients receiving parenteral hydration, a statistically significant prevalence of delirium and respiratory secretions was observed; no difference was found in the prevalence of anxiety or nausea.

In a longitudinal study of dying patients, no sign of suffering was attributable to a decline in oral nutrient and fluid intake: a gradual decrease in nutrient and liquid intake combined with the provision of good oral hygiene prevented the negative effects of terminal dehydration⁴⁸. Among the interventions reported in the literature, oral hygiene has been the focus of several studies⁴⁹⁻⁵¹. Although the complications of unattended oral care (discomfort, pain, mucositis, halitosis, changes in eating habits, reduction of social relationships, risk of pneumonia in the elderly with dysphagia) are known, studies do not agree on interventions and procedures to ensure effective oral care and no efficacy studies are available on methods and products used for oral care⁴⁹.

The Canadian Dental Association suggests some palliative interventions to reduce discomfort from xerostomia in older adults, like moistening the oral cavity with swabs soaked in saline or alcohol-free mouthwash.

Lemon and glycerin-soaked swabs are not recommended, since they worsen xerostomia. The use of a lanolin lip balm several times a day is recommended. Crushed ice can be used in non-dysphagic people ⁵².

RECOMMENDATION 7a. Implement a decision-making procedure that involves the patient, their family and healthcare professionals for initiating/not initiating/suspending artificial hydration. For the non-communicating person, consider the advance directives, if available. The procedure should consider clinical condition, expected benefits, any possible damage and quality of life, as well as the person's psychological and spiritual well-being. Suspend artificial hydration when the expected benefits are not observed.

RECOMMENDATION 7b. When the person and their family are notified of the decision not to initiate or to suspend artificial hydration, they should also be notified of the interventions that will be implemented to reduce the discomfort associated with distressing symptoms such as thirst and dry mouth.

ASSESSMENT AND MANAGEMENT OF PAIN IN THE NON-COMMUNICATING PERSON

Pain assessment is complex when referred to people with dementia or, more generally, with communication difficulties ⁵³. Cognitive decline makes the person unable to identify pain, remember it, quantify it, spontaneously state its presence, which is often revealed by other signs such as behavioral changes, neurovegetative alterations, sleep and appetite disorders, motor disturbances, or vocalizations ⁵⁴.

Self-assessment of pain is the most accurate and reliable measure of pain intensity for patients of all ages. The numeric rating scale, the visual analogue scale, the face pain scale and the verbal descriptor scale can be used in subjects with mild to moderate cognitive impairment ⁵⁵⁻⁵⁸.

Question 8: Is the use of an objective pain assessment tool effective in the non-communicating person?

Most pain assessment tools found in the literature are based on the assumption and the recommendations by the American Geriatric Society (AGS) ⁵³. The AGS identified 6 areas that should be checked to indirectly assess the presence of pain:

1. Facial expression
2. Negative vocalization
3. Body movements
4. Changes in interpersonal relationships
5. Changes in basic activities
6. Changes in mental state

However, in people with advanced dementia

– accounting for a considerable proportion of non-communicating people – ascribing any behavioral response to a wide range of stimuli to the presence of pain may be difficult mainly for sleep disturbances and their relationship with pain and dementia. On this topic a systematic review is inconclusive ⁵⁹. Furthermore, most assessment tools are validated to ascertain the presence of pain but not to measure its intensity. According to Husebo et al. ⁶⁰, it is not known whether a greater number of pain behaviors means more pain. In addition, all assessable behaviors have the same weight: since no study has tried to differentiate the intensity of pain, it is not possible to recognize certain behaviors (e.g. screaming or agitation) as indicators of greater pain. Behavior observation may identify pain in an individual but provides no information on the cause of pain. Therefore, pain assessment should not depend solely on behavior observation by means of standardized tools; rather, it should be one component of a multidimensional approach to pain assessment. The use of an observational assessment tool is not contraindicated, although no review or meta-analysis supports one in particular. The review by Lichtner et al. ⁶¹ summarized systematic reviews on the psychometric features and clinical utility of 28 pain assessment tools for patients with dementia. The authors concluded that there is limited evidence of their reliability, validity and clinical utility. In general, it appears that no tool is best and, given the abundance of tools, it is not advisable to develop new ones on the same conceptual basis. Furthermore, research on the clinical utility of such tools should include an evaluation of their impact on treatment choice and outcome. Husebo et al. ⁶⁰ also concluded that there is no agreement on which assessment tool should be used, and emphasized the need for tools for both identifying the presence of pain and evaluating the effectiveness of therapy. However, they provided some indications:

1. Behavior assessment must be performed by somebody who knows the patient. This indication is based on the evidence that self-assessment of pain is the gold standard. When self-assessment is not possible, a so-called “silver standard” is suggested, i.e. referring to the caregiver who is in charge of assistance and surveillance on a daily basis. In fact, there is a general consensus that pain assessment in non-communicating people should be based on the observation of their behavior during ADLs: the caregiver or the healthcare professional who knows the patient best is most suited to noticing changes in behavior.
2. In choosing an observational assessment tool, one should consider its applicability in daily practice as well as the clinical utility of the assessment in

making a decision about what intervention is most appropriate.

RECOMMENDATION 8a. Assess the presence of pain in the non-communicating person through a multidimensional approach, observing their behavior in daily life activities: changes in usual behavior (relationships and activities) suggest the presence of pain. The caregiver or healthcare professional who knows the person best will be most suited to noticing behavioral changes.

RECOMMENDATION 8b. Use an observational tool to assess the presence of pain. Consider clinical utility to choose the most appropriate tool for each setting.

APPROPRIATENESS OF PHARMACOLOGICAL THERAPIES AND DIAGNOSTIC TESTS FOR ELDERLY PATIENTS WITH LIMITED LIFE EXPECTANCY

Question 9: Which drugs and which diagnostic tests are potentially inappropriate for older adults with limited life expectancy?

In recent years, several criteria for pharmacological appropriateness in older adult patients have been published: the Beers Criteria⁶², START and STOPP⁶³, and more recently, the Holmes' Criteria^{64 65}, focusing on inappropriateness of prescriptions for patients with terminal dementia, and STOPPFrail⁶⁶ for "frail" patients with limited life expectancy. In particular, the STOPPFrail criteria are proposed as a tool for evaluating therapy in terminally ill older adults (≥ 65 years) with severe cognitive and/or functional decline and limited life expectancy (≤ 1 year), where the primary goal is symptom control rather than the prevention of disease progression. A panel of geriatricians, specialists from different disciplines, general practitioners and clinical pharmacists examined a list of 27 criteria: 2 general criteria (the opportunity to suspend drugs in cases of lack of indication or poor adherence) and 25 criteria related to 25 classes of drugs whose use is considered to be inappropriate for patients with the above characteristics. The expert panel reached a full consensus on 25 criteria; a sufficient level of consensus was not reached for 2 drug classes (anticoagulants and antidepressants).

Just as drug therapy requires continuous adjustments based on the patient's clinical evolution, the need for diagnostic investigations should also be carefully evaluated. Several authors^{67 68} have reported that nursing home residents with advanced dementia very frequently undergo unnecessary clinical procedures, often causing hospitalization, cardiopulmonary resuscitation or enteral feeding.

There are no published guidelines indicating what diagnostic tests are recommended and in which clinical

situations. Therefore, the indications should be assessed on a case-by-case basis. For patients in emergency situations, diagnostic investigations are deemed acceptable if they can clarify the clinical picture and allow diagnosis of a condition (e.g. an intestinal obstruction) whose possible resolution (e.g. via surgical intervention) could improve the symptoms and quality of life. The decision to undertake a diagnostic path with the sole objective of identifying a pathology that may have occurred but has no chance of being treated (e.g. the search for a possible neoplastic pathology that could not be appropriately treated) is entirely different.

RECOMMENDATION 9a. Along with the clinical evolution, systematically verify the aims of the therapies: pathogenetic therapy, or substitution therapy, or palliative therapy.

RECOMMENDATION 9b. Periodically reconcile current therapies to identify any possible inappropriate drug and the risk of non-adherence in relation to the clinical evolution.

RECOMMENDATION 9c. For the older patient with limited life expectancy, only undertake diagnostic investigations that are useful for identifying a clinical condition that could be resolved through an appropriate intervention to improve the symptomatology and quality of life.

Question 10: Which drugs should be used to treat pain in the oldest old?

For older patients with persistent pain, the systematic reviews by Makris et al.⁶⁹ and Husebo et al.⁶⁰ recommend a stepped approach with acetaminophen as the first choice, followed by opioids. The use of 2 drugs with complementary effects should be preferred to that of a single drug at a high dose. Non-steroidal anti-inflammatory drugs are not recommended for long-term use. It is advisable to consider the use of a selective serotonin reuptake inhibitor or a serotonin-norepinephrine reuptake inhibitors for patients with depressive syndromes and pain. The importance of using both a pharmacological and a non-pharmacological approach such as physical therapy, occupational therapy and cognitive training must be emphasized.

RECOMMENDATION 10a. When treating pain and any distressing symptoms, always assist the patient in the therapeutic choice and respect their will, if possible.

RECOMMENDATION 10b. Treat chronic pain in older patients with acetaminophen or, if this is not effective, with opioids. Treat neuropathic pain with antidepressants and anticonvulsants. Do not use non-steroidal

anti-inflammatory drugs for the treatment of chronic pain in older patients.

Question 11: Is antimicrobial therapy appropriate in the older patient with limited life expectancy?

Infections are among the main clinical adverse events in older adults, especially in the oldest old. In older people, and particularly in the most frail or cognitively impaired, correctly diagnosing infections at both the clinical and instrumental level poses greater difficulty, thus entailing an increased risk of an inappropriate antimicrobial use. Besides contributing to the selection of multiresistant bacterial strains, the inappropriate use of antimicrobial therapy may expose patients, especially the most clinically and functionally unstable, to unnecessary discomfort⁷⁰. Therefore, the literature highlights the need for a broader use of criteria for diagnosing infections, e.g. the McGeer criteria⁷¹, in clinical practice and the establishment of specific criteria for people with dementia⁷².

The decision to treat with antimicrobials can be aimed at prolonging life and/or improving its quality. Data on the impact of antimicrobial therapy on survival, especially in patients in the terminal stages of life, are contradictory. In a prospective study of 323 nursing home residents⁷³, older patients with suspected pneumonia treated with antibiotics lived longer than their untreated counterparts. Conversely, according to a study conducted on 110 nursing home residents, which represent a subgroup of the SPREAD study, antimicrobial therapy was not associated with life prolongation in patients who had at least one suspected urinary tract infection during 1 year⁷⁴.

An aggressive treatment of infections without a concomitant palliative approach worsens the quality of life⁷⁵. According to the study by Givens et al.⁷³, antimicrobial therapy of suspected pneumonia prolongs survival, but does not improve comfort. In 193 Dutch nursing home residents with dementia and pneumonia, the – very high – level of discomfort (pain and dyspnea) did not differ significantly between those treated with or without antimicrobials⁷⁶. In contrast, in another study of 559 patients with dementia and pneumonia, also conducted in the Netherlands, antimicrobial therapy was independently associated with a reduced discomfort⁷⁷. The above question currently lacks a conclusive answer, which could be provided by carefully designed trials comparing symptom control and survival in patients receiving antimicrobials or high-quality palliative care⁷⁸.

RECOMMENDATION 11a. In clinical practice, systematically use diagnostic criteria that are appropriate for different infections.

RECOMMENDATION 11b. Order antimicrobial

treatment when clinically suspecting infection as the cause of pain, dyspnea or other symptoms. In any case, order palliative interventions to reduce the patient's discomfort.

FAMILY SUPPORT INTERVENTIONS AND CONTINUITY OF CARE

Family support is a fundamental aspect of palliative care: family members play a central role in providing care, despite the contribution of healthcare professionals and regardless of whether the person is being assisted at home, in a hospital or in a nursing home⁷⁹.

Question 12: What interventions are effective for caregivers' support?

An adequate support to the family system entails a preliminary assessment of the system itself and analysis of the needs, expectations and abilities of each family member; in particular, the caregivers' burden should be measured⁸⁰.

Health literacy assessment in informal caregivers: the assessment of knowledge and cognitive skills, particularly of health literacy (HL), allows tuning both communication interventions, especially for consistency with progressive communication and shared care planning, and educational interventions.

The concept of HL refers primarily to the "*cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health*"⁸¹. HL has been included in various health policy documents such as the European health policy framework "Health 2020", because measuring these skills is viewed as a component in the processes of identification of the topics or populations requiring greater attention in the health field⁸². Issues associated with inadequate HL can lead to negative outcomes, both individually and socially⁸³. At-risk populations are socio-economically disadvantaged groups, migrants and ethnic minorities, the elderly, people with chronic diseases and the disabled⁸⁴.

HL is a measurable construct. Since the 1990s, several tools have been developed to measure HL⁸⁵. However, a periodic screening to assess HL through one of the tools described in the literature has not improved results and it is not recommended^{86 87}.

Caregiver burden assessment: the caregiver burden (CB) is defined by Zarit et al.⁸⁸ as "*The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning*", thus outlining the multidimensionality and the subjectivity of the burden experience⁸⁹. CB is one of the most significant problems affecting caregivers of older adults with chronic illness⁹⁰. Female sex, low educational level, residence with the care

recipient, higher number of caregiving hours, depression, social isolation, financial stress, lack of choice in being a caregiver and the use of fewer coping strategies⁹¹ are the main risk factors for the development of CB.

Support to the caregiver(s): a Cochrane review⁹² selected 11 randomized controlled trials that assessed the effectiveness of support interventions on psychological health (coping with the caregiver role, psychological distress, quality of life) and physical health (quality of sleep) of informal caregivers of people in the terminal phase of a disease. Direct interventions addressing the caregivers' needs were distinguished from those providing patients with care or services, and consisted in counseling and support, facilitation in problem solving, emotional support, financial advice and directions for patient care. They were provided by nurses, social workers and family therapists, and entailed 2-9 contact sessions. They were also provided after the cared-for person's death.

Indirect, nurse-provided interventions supported caregivers throughout patient care. Nurses assessed their needs and planned supportive interventions by promptly activating the appropriate professionals or services. Candy et al.⁹² concluded that, although it is not clear which mode of support can provide the highest benefit, emotional support and information on management of the loved one's care were common features of the interventions that were useful to "buffer" psychological distress. The authors encourage healthcare professionals to inquire about caregivers' concerns and consider that they can benefit from additional support to cope with their care task.

Lopez-Hartmann et al.⁷⁹ reviewed the effectiveness of supportive interventions for caregivers of frail older people living at home. They concluded that the effect of supportive interventions to the caregiver is overall modest and inconsistent between studies.

Caregivers can be supported through Information and Communication Technology: a clear advantage of technology-based interventions is the possibility for the caregivers to access support and information 24 hours a day from their homes. Cassie and Sanders⁹³ examined the use of phone and IT services to provide assistance and directions to family caregivers, and observed that technology-based interventions could reduce depression, burden and anxiety.

Yu⁹⁴ reported preliminary results of a randomized controlled trial on the effects of a health and social case management model to support caregivers of frail older adults. The model was based on the results of the review by Lopez-Hartmann et al.⁷⁹. Family caregivers who were supported according to this model achieved a significantly greater improvement on the Caregiver

Burden Index ($p = 0.03$) and subscales of the Medical Outcomes Study 36-item Short-Form Survey, including vitality ($p = 0.049$), social role functioning ($p = 0.047$) and general well-being ($p = 0.049$). The study by Yu provides preliminary evidence that collaboration between health and social workers, together with a case management approach, is crucial to effective caregiver support⁹⁴.

RECOMMENDATION 12a. Consider the resources of the family system; relational, emotional and affective needs; possible resilience of individual family members; and concerns and expectations of caregivers to plan support interventions.

RECOMMENDATION 12b. Consider the health literacy and educational level of caregivers to provide them with information they can understand and use. However, note that no health literacy assessment tool among those described in the literature was able to improve the results.

RECOMMENDATION 12c. Assess the adaptation potential and risk factors related to the characteristics of the caregiver and the family system (burden, well-being and health, as well as individual, social, relational and financial resources).

RECOMMENDATION 12d. Plan interventions to support the caregiver task.

RECOMMENDATION 12e. Adopt a case management model. Assign case management to a professional with the necessary skills to address the needs expressed by the patient and their caregiver.

RECOMMENDATION 12f. Promote collaboration between healthcare and social professionals for planning integrated interventions for caregiver support.

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CONFLICT OF INTEREST

The Authors declare no conflict of interest.

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