The Aging Population and Dementia: The Need for Comprehensive Palliative Care

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ABSTRACT

Dementia is a progressive condition that gradually impairs cognitive function, memory, and daily living skills. This disease not only impacts the individual but also has significant consequences for their families and caregivers. The global prevalence of dementia is on the rise, including in Indonesia. It's estimated that approximately 1.2 million people in Indonesia are currently living with dementia, a number projected to quadruple by 2050. Patients with dementia often experience a range of symptoms and complications, including pain, difficulty eating, shortness of breath, and susceptibility to infections. For those in advanced stages of the disease, family and caregivers play a crucial role in their well-being. However, this role can be emotionally taxing, making support essential. Palliative care offers a promising approach to enhancing the quality of life for both dementia patients and their families. By prioritizing symptom management, psychological support, and respecting patient autonomy, palliative care can help alleviate suffering and promote well-being throughout the disease's progression.

Keywords: *palliative care, dementia, intervention.*

INTRODUCTION

The global population, especially the elderly, is rapidly growing. In Indonesia, the number of elderly individuals has increased to approximately 13% of the total population and is projected to reach 19% by 2045.[1] Concomitantly, the prevalence of dementia is also on the rise, with an estimated 1.2 million Indonesians currently living with this condition. This number is expected to quadruple by 2050. While the prevalence of dementia in Asia is lower compared to Europe or America, the increasing elderly population poses a significant challenge.

Dementia is a neurodegenerative syndrome characterized by a progressive decline in cognitive function, affecting memory, orientation, language, calculation, learning ability, reasoning, and visuospatial skills.[2] The symptoms of dementia are not limited to cognitive impairment but also encompass physical and emotional aspects. For instance, individuals with dementia often experience pain, insomnia, eating disorders, and mobility issues.

Palliative care is defined as an approach aimed at improving the quality of life of patients and their families facing life-threatening illnesses, through the prevention and relief of suffering.[3] It involves the early identification and assessment of physical, psychological, and spiritual problems, intending to provide appropriate interventions. Research has demonstrated that a well-implemented palliative care approach can significantly alleviate the symptoms of dementia, such as pain, shortness of breath, and psychological distress, thereby enhancing the quality of life for patients.[4] Individuals with dementia and their caregivers often experience significant emotional stress. Emotional and psychosocial support are essential components of palliative care, helping patients and their families cope with the disease. Furthermore, palliative care focuses on supporting caregivers, reducing their stress, and enhancing their ability to provide care. Ultimately, palliative care ensures that patients can live their remaining days with comfort and dignity.[5,6]

Therefore, palliative interventions for individuals with dementia are crucial to equip healthcare professionals, caregivers, and families with a comprehensive understanding of the disease progression, associated symptoms, and challenges faced by patients. Moreover, these interventions aid in managing the physical, psychological, and social symptoms commonly experienced by patients and provide optimal care for their families. The ultimate goal of palliative care is to improve the quality of life of patients. Two commonly used questionnaires for assessing the quality of life in dementia patients are the Quality of Life in Dementia scale (QUALIDEM) for those who can still make decisions and the Quality of Life in Late-stage Dementia scale (QUALID) for those who have lost decision-making capacity.[7]

DEMENTIA

Dementia is a clinical syndrome characterized by a progressive decline in cognitive function, primarily affecting memory. Several types of dementia have been identified, including Alzheimer's disease (AD), vascular dementia (VD), dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). According to the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), dementia is classified as a major neurocognitive disorder. Cognitive impairment can progress through various stages, such as mild cognitive impairment (MCI), early-stage dementia, mild-to-moderate dementia, and severe dementia or behavioral and psychological symptoms of dementia (BPSD).[8] Individuals with MCI exhibit subtle cognitive impairments, such as difficulty remembering recent events. While their daily activities are generally unaffected, they may experience mild challenges in tasks requiring concentration or problem-solving. As dementia progresses, cognitive decline becomes more noticeable (early-stage dementia). Individuals may struggle with tasks that require complex thinking, such as planning or organizing. Memory loss becomes more pronounced, particularly for recent events. In this mild-to-moderate dementia, cognitive impairments become more severe. Individuals may have difficulty with tasks requiring multiple steps, such as getting dressed or preparing meals. They may also experience changes in personality or behavior. In the advanced stage of dementia, individuals require significant assistance with daily living activities. They may experience severe memory loss, confusion, and difficulty communicating. Behavioral and psychological symptoms of dementia (BPSD), such as agitation, aggression, or wandering, may also become prominent.

The symptoms of dementia are highly variable and depend on the specific type of dementia. Memory loss is the most common symptom, but difficulties with language, thinking, and social behavior are also frequently observed. In some types of dementia, such as Alzheimer's disease, symptoms tend to progress gradually. However, in other types, symptoms may appear suddenly or fluctuate. Additionally, movement disorders such as gait disturbances can be a symptom of dementia, particularly in vascular dementia or dementia with Lewy bodies.

A retrospective survey of caregivers in the UK reported several common signs and symptoms experienced by individuals with dementia in the last year of life: confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%), and loss of appetite (57%).[9] While these symptoms can also occur in patients with cancer, individuals with dementia may experience them for a longer duration. Poorly controlled dementia symptoms can significantly reduce the quality of life for both patients and their caregivers. Other studies have shown that inadequate end-of-life care, both in hospitals and at home, highlights an unmet need for palliative care, especially in the last year of life.

THE ROLE OF PALLIATIVE CARE IN DEMENTIA MANAGEMENT

For patients with dementia, palliative care is expected to provide pain relief, avoid unnecessary examinations, treatments, and transfers, enhance comfort, and offer quality end-of-life care. Additionally, palliative care plays a crucial role in providing emotional and spiritual support, ensuring the fulfillment of basic patient needs, and preventing common complications in advanced dementia, such as infections and malnutrition. For caregivers and families, palliative care can enhance their understanding of what to expect during the dying process, facilitate effective communication with healthcare professionals, assist families in coping with the disease and grief, and reduce the caregiving burden. For the healthcare system, palliative care is essential in centering care around the patient with advanced dementia, raising awareness of the needs of this population, and improving communication skills among healthcare professionals. Several studies have demonstrated positive outcomes associated with palliative care interventions; however, further research is needed to identify the most effective interventions for specific patient populations.[10,11]

A palliative care team typically consists of physicians, advanced practice providers (nurse practitioners and physician assistants), nurses, social workers, and spiritual care providers as needed. For example, physicians may prescribe medications to manage pain, shortness of breath, or other symptoms, while social workers support patients' psychosocial needs and spiritual care providers address spiritual concerns.

PALLIATIVE CARE INTERVENTIONS IN DEMENTIA MANAGEMENT

Advanced Care Planning

Advanced care planning should commence at the early stages of the disease when patients are still capable of participating in decision-making. Early involvement of the palliative care team throughout the disease trajectory has been shown to have positive effects on various clinical outcomes. These include preventing overly aggressive care, enhancing comfort and quality of life for individuals with dementia, and providing support to caregivers and families. The first step in advanced care planning is to establish life goals and desired care preferences. This should be documented in writing to ensure clear communication and decision-making. Next, it is crucial to designate a medical surrogate, someone who will make healthcare decisions on the patient's behalf if they become incapacitated.[12] Engaging in open conversations about the disease's progression and expectations is essential. Discuss with healthcare providers the anticipated challenges and potential outcomes of dementia, including the decline of basic bodily functions like swallowing and fighting infections. Before complications arise, it is advisable to discuss treatment preferences for specific clinical issues. This includes decisions about cardiopulmonary resuscitation, artificial nutrition via nasogastric tube or other methods, and mechanical ventilation. Collaborate with healthcare providers to understand the benefits and drawbacks of each option based on medical evidence and align these choices with the patient's established care goals. [12] It is important to review and update the advanced care plan regularly, especially when the patient's health status changes. This ensures that the plan remains aligned with the patient's evolving needs and preferences.

Decision-Making Capacity in Dementia

When making decisions for individuals with dementia, it is essential to consider their decision-making capacity. Not all individuals with dementia, even those who appear fully conscious, can make decisions for themselves. A person with dementia must possess the following mental capacities to make a decision. A person with dementia has the right to make their own decisions whenever possible. It is crucial to provide them with all the necessary support and resources to enable them to make and express their choices effectively. Treating individuals with dementia as incapable of decision-making should be avoided unless all reasonable efforts have been made to assist them.[13] It is important to recognize that a person's decision-making capacity is not based solely on the perceived quality of their decisions. Even if others disagree with their choices, it does not automatically mean they lack the ability to make informed decisions. For individuals who are deemed to lack decision-making capacity, any decisions made on their behalf must prioritize their best interests. Caregivers and healthcare providers must ensure that these decisions align with the individual's values and preferences.

When making decisions for a person who lacks capacity, it is essential to consider options that minimize any restrictions on their rights and freedoms. The goal should be to preserve their autonomy and dignity as much as possible. By following these principles, healthcare providers and caregivers can support individuals with dementia in maintaining their decision-making autonomy and ensuring that their needs and preferences are respected.[13]

In practical terms, caregivers and family members who know the patient well can help clinicians assess whether or not the patient can make their own decisions. The following questions can be used as a guide:

1. Is there a concern about the individual's decision-making capacity? If so, proceed to the next question. If not, the person can likely make the decision independently.
2. Can the individual decide on additional support? This might involve providing more information, allowing extra time for deliberation, or using alternative communication methods. If the person can decide with support, they have the capacity. If not, they may need assistance.
3. Does the individual meet all of the following criteria?
    a. Understanding: Do they comprehend the information necessary for decision-making?
    b. Memory: Can they retain the information long enough to make a decision?
    c. Reasoning: Are they able to evaluate and weigh the available information?
    d. Communication: Can they express their decision, even if through nonverbal means?

If the answer to all of these questions is yes, then the person can decide for themselves. If the answer to any of these questions is no, then the person cannot currently make that decision for themselves. For everyday decisions such as what to eat or what clothes to wear, family or caregivers can make these decisions. For more complex decisions, such as long-term care, healthcare professionals may need to be involved.

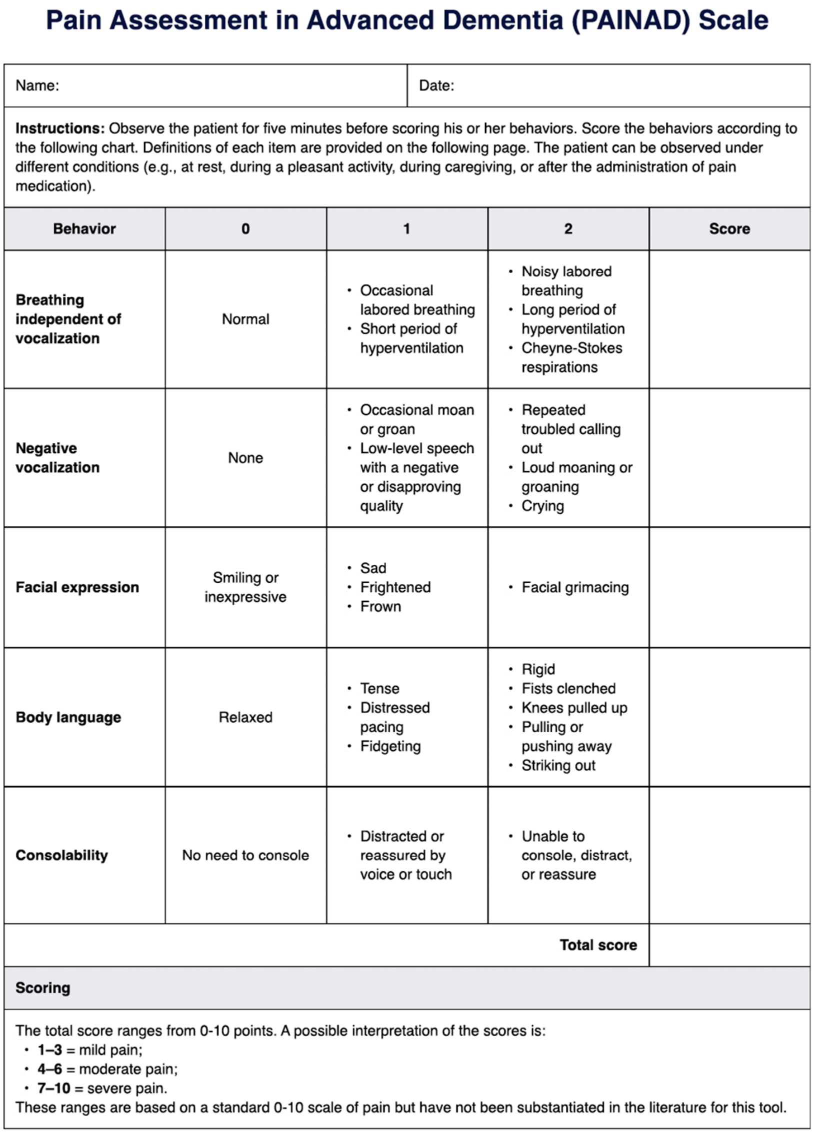
Management of Behavioural and Psychological Symptoms of Dementia (BPSD)

Nearly all patients with advanced dementia (90%) will experience behavioral and psychological symptoms of dementia (BPSD). These symptoms can be distressing for both patients and their caregivers and are a strong predictor of institutionalization in hospitals or nursing homes. The most common symptoms observed in patients with dementia and BPSD are wandering and agitation.[10] Challenging behaviors such as aggression and resistance to care may indicate unmet needs, such as undetected or poorly treated pain, delirium, or infection. Basic aspects of personal care, such as providing glasses or hearing aids due to common age-related sensory impairments, should be considered first.[12] Environmental modifications, such as reducing noise or providing outdoor spaces or gardens where individuals can walk, may help reduce agitation. Psychological interventions, such as analyzing the events preceding the occurrence of BPSD, the specific behaviors observed, and their consequences, can be used as a non-pharmacological approach.

However, if the behavioral and psychological symptoms of dementia (BPSD) become a threat to the individual or others, pharmacological interventions may be considered. Richmond Agitation Sedation Scale (RASS) can be used to evaluate behavioral and psychological symptoms.[14] If the RASS score is +3 or more, pharmacological management can be administered. Pharmacological management such as antipsychotic drugs whether typical or atypical may have several side effects, including Parkinsonism, prolonged QT interval, increased risk of stroke and death.[10,12]

Pain Management in Dementia Patients

Patients with dementia often experience a decline in mobility, leading to stiffness, joint pain/arthritis, pressure ulcers, and infections such as pneumonia and urinary tract infections.[12] One of the most common symptoms observed in these patients is pain. Untreated pain can manifest as depression, agitation, and challenging behaviors due to the individual's inability to communicate the source of their discomfort. To assess pain in dementia patients, the Pain Assessment in Advanced Dementia (PAINAD) scale can be used.[15] This scale evaluates behavioral categories such as breathing, vocalization, facial expression, body language, and consolability as indicators of pain. The interpretation of these behaviors is more accurate when caregivers or family members are familiar with the person with dementia over an extended period. The PAINAD scale is illustrated in **Figure 1**.[15]



Pain Assessment in Advanced Dementia (PAINAD) Scale

Name:	Date:

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, or after the administration of pain medication).

Behavior	0	1	2	Score
Breathing independent of vocalization	Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
			Total score	
Consolability	No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	

Scoring

The total score ranges from 0-10 points. A possible interpretation of the scores is:
- **1–3** = mild pain;
- **4–6** = moderate pain;
- **7–10** = severe pain.

These ranges are based on a standard 0-10 scale of pain but have not been substantiated in the literature for this tool.

Figure 1. PAINAD Scale[15]

Non-pharmacological interventions that can be applied include massage, passive movements to prevent joint stiffness, and hot or cold compresses. Relaxation techniques, reduced stimulation, music, naps, or the presence of a trusted person can significantly help alleviate pain symptoms. If non-pharmacological interventions are insufficient, medical management can be provided based on the symptoms experienced. The World Health Organization (WHO) pain management guidelines can be used as a reference for analgesic administration. [16] This involves a stepwise approach, starting with non-opioid medications (e.g., paracetamol or non-steroidal anti-inflammatory drugs), progressing to weak and then strong opioids, with additional analgesics (e.g., neuropathic agents or psychotropic drugs) as needed. Acupuncture can also be used as an adjunctive treatment.[17]

Nutrition Management in Dementia Patients

Patients with dementia are at risk of experiencing difficulties with eating and swallowing. Loss of taste and appetite are common progressions of the disease. The goal of nutrition management in dementia is to ensure adequate caloric intake and macro and micronutrients to maintain metabolism, avoiding the harmful effects of malnutrition and sarcopenia such as increased frailty, loss of physical function, worse cognitive decline, and increased rates of infection and mortality. Enteral feeding is still preferred over parenteral nutrition. If a dementia patient experiences severe eating difficulties, two enteral feeding methods can be considered: nasogastric tube (a tube passed through the nose and into the stomach) or percutaneous endoscopic gastrostomy (PEG).[9] However, studies have shown that neither nasogastric tube placement nor PEG reduces the risk of infection (such as aspiration pneumonia from nasogastric tubes or diarrhea from PEG), improves comfort, or prevents malnutrition. As the disease progresses and patients reach the end of life, the goal should shift from nutritional adequacy to comfort and symptom relief, even if it means allowing the patient to fast. On the other hand, allowing a dementia patient to fast can cause guilt and discomfort for family and caregivers, as it may conflict with their values and cultural beliefs. Patient autonomy, comfort, and safety should be prioritized, with the least invasive methods of providing nutrition and hydration. Respecting food preferences, routines, and timing, including more snacks and finger foods, can aid in this strategy, as in advanced dementia, the idea of healthy eating is less important than individual preferences for quantity and pleasure.[9,18]

Infection Management in Dementia Patients

Patients with dementia, particularly advanced dementia, are at risk of developing infections such as pneumonia and urinary tract infections. A study reported that over an 18-month observation period, 53% of nursing home residents with advanced dementia experienced febrile episodes, and 41% developed pneumonia, contributing to 71% of dementia-related mortality cases.[19] The use of antibiotics to treat fever and recurrent infections is one of the most controversial issues in this field. The appropriate administration of antibiotics can increase life expectancy compared to those who do not receive antibiotics. However, in patients with advanced dementia, the administration of antibiotics can delay death, thereby exposing the patient to a higher risk of prolonged pain and suffering and prolonging the dying process.[10]

Management of Dyspnea in Dementia

Shortness of breath can occur in approximately 12-52% of patients with dementia and is often associated with lung infections, such as pneumonia.[7] Dementia patients, especially those with advanced dementia, have limited communication abilities, resulting in underreporting of shortness of breath. Non-pharmacological management can be provided, such as sitting upright with arms supported at the sides or in a forward-leaning position. Additionally, the sensation of fresh air to cool the facial area of the nose, cheeks, and mouth by opening windows, using fans, or applying cool and damp cloths can reduce the perception of shortness of breath.[7]

Emotional and Spiritual Management in Dementia

In the palliative care of patients with dementia, emotional and spiritual needs also play a significant role and should be considered. It is important to affirm their expressions of faith and values, maintain their connections and dignity, their identity as human beings, and their sense of purpose, be part of their community, and communicate with God according to their respective religions. Some things that can be provided to patients with dementia include facilitating prayer and using familiar photos and songs. Furthermore, maintaining physical contact, such as holding hands, hugging, and making eye contact, are all part of a spiritual approach that can also be given to dementia patients.[20]

End-of-Life Care

The goals of care change in the terminal phase of dementia, focusing on maintaining comfort and dignity for the individual, while also providing support to family, caregivers, and friends. Early advanced care planning can help families and caregivers prepare for end-of-life care, including early discussions about death.

Most people with early-stage dementia live at home with family members who care for them, while almost all patients with advanced dementia are cared for in nursing homes, and there is a high burden on family and caregivers. Although nursing homes are a common place for end-of-life care and many people with dementia die in nursing homes or hospitals, the place they want to die is their own home. According to surveys in several countries, nursing homes are the most common place of death in developed countries, about 93% in the Netherlands and 49% in Wales, for example. Meanwhile, hospitals are the most common place of death in South Korea and France. In Mexico and Italy, home is the most common place of death.[7]

Several tools can be used as a reference to estimate if a person is in the final stages of life, such as the Mini-Suffering State Examination Scale (MSSE) and the Advanced Dementia Prognostic Tool (ADEPT). A higher MSSE score indicates a higher risk of death within a 6-month observation period.[7] The Mini Suffering State Examination (MSSE) is a tool used to assess the level of suffering in patients with advanced dementia. It consists of ten items related to various aspects of suffering, including pain, discomfort, and distress. Each item is scored as "yes" (1) or "no" (0). The total score ranges from 0 to 10, with higher scores indicating a higher level of suffering. A score of 0-3 suggests a low level of suffering, 4-6 indicates an intermediate level and 7-10 signifies a high level of suffering. The MSSE can be a valuable tool for healthcare providers in identifying and addressing the suffering experienced by patients with advanced dementia.

Support for Family and Caregivers

Approximately 20% of family caregivers of dementia patients experience symptoms of depression due to the difficulty in assessing the patient's needs.[21] Often, in patients with advanced dementia, there is an inability to make decisions, which places a significant burden on family caregivers, especially when there has been no advanced care planning established while the patient is still capable of making decisions. When caring for dementia patients, there is a high risk of caregiver burnout, particularly for those caring for patients with advanced dementia who exhibit behavioral and psychological symptoms. Some important issues related to dementia care include:[9,22]

Social, Psychological, and Emotional Support

Caregivers and family members of individuals with dementia require significant social, psychological, and emotional support. With advancements in technology, communication has become more accessible. For instance, phone calls to family and friends and video calls can bridge geographical distances. Having a platform to share experiences and express concerns serves as a coping mechanism that can alleviate the burden of caregiving. Studies have shown that assistance with daily living activities can reduce stress as caregivers often juggle multiple roles and responsibilities. Additionally, caregivers themselves may experience physical or mental health issues due to the demanding nature of caregiving, highlighting the importance of access to professional healthcare.

Receiving Individualized Information

A study has shown that support for families and caregivers is crucial, as they often feel they do not receive adequate information about caring for patients with dementia. Each dementia patient requires a unique care plan, as there are many factors to consider, including family dynamics, culture, language, socioeconomic status, and lifestyle. Therefore, providing individualized information that takes into account these factors is essential. The Satisfaction With Care at the End of Life in Dementia Scale (SWC-EOLD) can be used to assess the needs of families and caregivers and evaluate areas for improvement. Some factors assessed by the SWC-EOLD include decision-making, communication with healthcare professionals, understanding of dementia, and medical and non-medical care for dementia patients. Education regarding the progression of dementia and preparation for end-of-life care is crucial for patients, families, and caregivers.[23]

Training for Caring for Patients with Dementia

Family members and caregivers should receive training and education on how to care for patients with dementia, as these patients often require assistance with daily activities. Additionally, some patients may use medical devices such as feeding tubes and urinary catheters, which require trained family members or caregivers to help with cleaning and preventing infections. Family members and caregivers should also be educated on how to recognize pain, shortness of breath, or signs of an emergency so they can provide first aid at home.

Finding Balance

Once physical, mental, and educational support is in place for dementia care, families and caregivers can find their unique balance in caring for their loved ones. After all, each family faces its unique challenges.

Bereavement *Support*

Families and caregivers are also at risk of experiencing grief after the loss of a patient with dementia. Several risk factors have been identified for persistent grief among families and caregivers, including the loss of a spouse, the relatively young age of the patient, low educational status, living with the patient with dementia, having a primary caregiver, experiencing depression and caregiver burden, inadequate coping mechanisms, and lack of social support. Palliative care teams also play a role in bereavement support in several ways, such as providing support groups facilitated by trained nurses and doctors, addressing spiritual needs, and offering medical management when necessary.[24]

CHALLENGES IN PALLIATIVE CARE FOR DEMENTIA PATIENTS

1. **Delayed Diagnosis**
   A study has shown that most dementia patients are diagnosed at an advanced stage, and 84% of patients with dementia are only referred for palliative care when they are in the final stages of the disease.[25] Dementia is often not recognized as a terminal and life-limiting illness, resulting in inadequate consideration or management of end-of-life care. Patients with advanced dementia often cannot express their wishes regarding current and future care due to limitations in verbal and written expression. This adds complexity to meeting current care needs and developing future care plans.[7]

2. **Access to Care**
   A lack of understanding that dementia is a terminal illness that can limit life as the disease progresses often results in inadequate care for dementia patients, whether at home, in hospitals, or nursing homes. There is also a limited acceptance of the role of palliative care outside of cancer and end-of-life care, with reluctance from patients, caregivers, and medical specialists to involve palliative care early on. This reluctance is often rooted in the misconception that involving palliative care equates to giving up on the patient when in reality, it is quite the opposite.

3. **Shortage of Specialized Personnel**
   Palliative care should ideally be involved from the early stages of dementia, yet there is often a shortage of specialized palliative care professionals. The scarcity of palliative care resources—including funding, beds, specialized nurses, outreach services, and palliative care trainees and doctors—hinders the management of patients with dementia. Furthermore, a lack of training, expertise,

and confidence among palliative care physicians in managing neurodegenerative disorders like dementia may compromise the quality of care provided and access to specialized palliative care services.[7]

CONCLUSION

Dementia is a chronic neurodegenerative disease that necessitates early palliative care. Key elements of palliative care in dementia management include: early integration of palliative care into multidisciplinary dementia care, provision of continuous palliative care across various settings (hospitals, homes, nursing homes), anticipation and response to the holistic needs of the person and their family, and education of caregivers and staff to support the delivery of palliative care.

CONFLICT OF INTEREST

There are no potential conflicts of interest.

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REFERENCES

1. Badan Pusat Statistik. Proyeksi penduduk Indonesia 2015-2045. Jakarta; 2018.
2. Emmady PD, Tadi P. Dementia [Internet]. 2021 [cited 2021 Sep 9]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK557444/
3. World Health Organization. Palliative care. 2020.
4. Brooker DJ, Argyle E, Scally AJ, Clancy D. The enriched opportunities programme for people with dementia: A cluster-randomised controlled trial in 10 extra care housing schemes. Aging Ment Health. 2011;15:1008–17.
5. Givens JL, Selby K, Goldfeld KS, Mitchell SL. Hospital transfers of nursing home residents with advanced dementia. J Am Geriatr Soc. 2012;60:905–9.
6. Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. Age Ageing. 2006;35:187–9.
7. Eisenmann Y, Golla H, Schmidt H, Voltz R, Perrar KM. Palliative care in advanced dementia. Front Psychiatry. 2020;11.
8. Shaji K, Sivakumar P, Rao Gp, Paul N. Clinical practice guidelines for the management of dementia. Indian J Psychiatry. 2018;60:312.
9. Hughes JC, Jolley D, Jordan A, Sampson EL. Palliative care in dementia: issues and evidence. Advances in Psychiatric Treatment. 2007;13:251–60.
10. Sampson EL. Palliative care for people with dementia. Br Med Bull. 2010;96:159–74.
11. Walsh SC, Murphy E, Devane D, et al. Palliative care interventions in advanced dementia. Cochrane Database of Systematic Reviews. 2021;2021.
12. Malhi R, McElveen J, O'Donnell L. Palliative care of the patient with dementia. Dela J Public Health. 2021;7:92–8.
13. Alzheimer Society. Assessing the mental capacity of a person with dementia. Available online on: https://www.alzheimers.org.uk/get-support/legal-financial/assessing-mental-capacity-dementia
14. Sessler CN, Grap MJ, Brophy GM. Multidisciplinary management of sedation and analgesia in critical care. Semin Respir Crit Care Med. 2001;22:211–26.
15. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. J Am Med Dir Assoc. 2003;4:9–15.
16. Anekar A, Hendrix J, Cascella M. WHO analgesic ladder. 2024.
17. Lloyd-Williams M, Payne S. Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? Int J Palliat Nurs. 2002;8:370–5.
18. Ciccarelli PA, Mattos EBT. Nutrição enteral em idosos com demência em cuidados paliativos. Revista Bioética. 2021;29:427–36.
19. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. New England Journal of Medicine. 2009;361:1529–38.
20. Camacho-Montaño LR, Pérez-Corrales J, Pérez-de-Heredia-Torres M, et al. Spiritual care in advanced dementia from the perspective of health providers: A qualitative systematic review. Occup Ther Int. 2021;2021:1–11.
21. Triandafilidis Z, Carr S, Davis D, et al. Improving end-of-life care for people with dementia: a mixed-methods study. BMC Palliat Care. 2024;23:30.
22. Bressan V, Visintini C, Palese A. What do family caregivers of people with dementia need? A mixed-method systematic review. Health Soc Care Community. 2020;28:1942–60.
23. Yeh JC, Newman J, Main R, Hunt LJ. Improving end-of-life care for persons living with dementia: bereaved caregivers' observations and recommendations. J Pain

Symptom Manage. 2021;62:579–86.
24. Crawley S, Sampson EL, Moore KJ, Kupeli N, West E. Grief in family carers of people living with dementia: A systematic review. Int Psychogeriatr. 2023;35:477–508.
25. Mo L, Geng Y, Chang YK, Philip J, Collins A, Hui D. Referral criteria to specialist palliative care for patients with dementia: A systematic review. J Am Geriatr Soc. 2021;69:1659–69.