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Sustainable Improvements in Dementia Care for an Expectably Increasing Number of Dementia People: Challenges and Opportunities

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ABSTRACT

Background: Aging, low literacy, and vascular risk factors are agents to boost or maintain the numbers, with more and more elevated costs for informal caregivers and society. Widely public health priority recognition implies changes and challenges in some European countries involving political engagement, needs that in dementia care are unmet. A preliminary diagnosis of the gaps and a prioritization of strategies to be implemented in Portugal should be addressed. The World Health Organization framework for meaningful engagement could work, as it has already done for other chronic diseases to reach some of the goals to improve healthcare.

Methods: A review of the current situation and some of the initiatives delivered through healthcare professionals with recognized experience in dementia areas and patients' associations, in a South Europe country over the last few years. In view of the remaining gaps, proposals from the literature will be provided to improve care experiences.

Conclusion: We defend that is essential that Portugal deepen patient-centered care, integrated care pathways, and equal access for rural or marginalized populations to specialist assessment for an early diagnosis. Improving the quality of dementia care in care homes or managing a dementia care program to link resources for patients and caregivers, are key themes that need proactive preparation for the coming years. We present 8 recommendations for dementia care in Portugal.

Keywords: Dementia, Alzheimer, Health Policies, Clinical Pathway, Person-centered Care.

Introduction

Dementia and cognitive impairment are health situations with high prevalence, costs, and burden of disease worldwide¹⁻⁵. In Portugal, the prevalence studies followed different methods^{6,7}, but the estimated numbers of people with dementia are over 200.000³.

Costs in antidementia drugs were evaluated in a 2015 Portuguese study, with almost 80.000 patients with a dementia diagnosis, in 37M€/year⁸. On the other hand, World Alzheimer Report from 2016 appraised that only 40-50% of dementia cases are identified in highly developed countries, suggesting numbers higher than reported⁹.

To worsen these numbers, evidence shows unmet needs for patients and caregivers, that find social and healthcare systems fragmented, confusing, with difficult access and insufficient responses¹⁰.

Globally, there are theoretically positive aspects for Portuguese dementia patients as they get free access to a National Health System, with some specialized centers¹¹, and there is a growing interest in psychogeriatrics and geriatrics training¹². Nonetheless, there are some barriers that should be overcome. Primary care practitioners have scarce confidence to diagnose dementia and to manage its behavioral disturbances, without enough time to know the person with dementia¹³. Ineffective care pathways without access to specialist services, transfer people with dementia to inappropriate care settings, such as emergency departments, with unnecessary medical interventions, extended lengths of stay in acute care settings, and poor experiences of care¹⁴. Other factors affecting the timely diagnosis of dementia include stigma, poor health literacy cultural understanding of dementia, fear, and financial costs. Informal caregivers report difficulties in how to seek non-medical support or inability to access appropriate services and being actively turned away by service providers. Few studies focused on counselling services for people with dementia or educational services for the population^{13,15}. Critical to person-centered dementia care is “knowing the person”, and developing mechanisms to share and make accessible information with all health sectors, private, public, or tertiary care¹¹.

In Portugal, a national questionnaire addressed to health services involved in dementia care was driven some years ago. Preliminary analysis revealed insufficient human resources in primary care for impairment cognitive assessment, with regular specialized assessment required for the most accurate diagnosis. A rational use, with the

design of integrated referral networks, would improve local healthcare support for dementia patients and caregivers¹⁶.

A strategy for a dementia area with prioritized issues and a proposal for a dementia pathway care was designed by a multidisciplinary team of experts in the area in 2018¹⁶.

As a result, in April 2023, a national guideline about diagnostic and therapeutic approaches for patients with cognitive impairment and dementia was updated and announced¹⁷, but few more amendments have been effective so far.

Our goal is to describe the issues that were projected, what is working, and to suggest based on the World Health Organization (WHO) framework for a meaningful engagement, what is still missing⁴.

Methods

Original scientific articles published in Medline-Pubmed mostly in the last three years, international guidelines, and review of the Portuguese national strategy presented in 2018, with a description of the key concepts, namely the dementia care pathway proposal and the priorities, relevant to our objectives, were included. Our goals are: first, the characterization of the actual initiatives and the gaps, comparing with dementia care in Europe. Second, the development of a summary with proposals to improve dementia care standards based on the last World Alzheimer Report 2022¹⁸, the WHO framework for mental health and neurological conditions⁴, and the CASCADE (Community Areas of Sustainable Care and Dementia Excellence in Europe) approach.

NATIONAL HEALTH STRATEGY FOR DEMENTIA IN PORTUGAL

The document published in 2018, tried, according to international programs, to address the main issues for a health strategy for dementia in Portugal, and to put forward a prioritization. The aim was the creation of public health policies (PHP), with consecutive plans and actions through a Health Plan for Dementia. It was developed by a multidisciplinary team with plural knowledge and origins, to meet the adequate response to a complex phenomenon. It highlighted the need for investment in an improvement of the care network, with the concept of the continuum of care¹⁶.

The main goal was to improve the quality of life of people with dementia regardless of the disease stage, their families, and caregivers, with the definition of a care pathway to enhance access to

specialized care without distance or minority restrictions, within the limits of sustainability. Optimizing the use of available resources implied integrated health and social care, with fluent communication and information storage systems across organizational boundaries. Person-centered care would be enabled with adequate primary care assistance and effective integrated care systems.

Alzheimer Portugal, a private institution of social solidarity, is the only organization nationwide devoted to promoting the quality of life of people with dementia and their families and caregivers. In 2009 published the “National intervention plan in Alzheimer’s” about Alzheimer’s policies and collaborated in the elaboration and dissemination of other strategic international recommendations¹⁹. At the technical-scientific level, the National Health Board, published in 2011 the standard for therapeutic approach of cognitive impairment, recently updated^{16,17}. An attempt was fulfilled for dementia figures to be comprised within national health statistics²⁰. Some Portuguese teams engaged in European multicentric studies such as Access to Timely Formal Care (Actifcare)²¹ or RHAPSODY (Research and Strategy for Dementia in Young)²² with national and international recommendations for formal and informal care, and educational materials about young-onset dementia.

Alzheimer Portugal goes on with training programs for health professionals and caregivers, about different features such as dementia prevention, rights of dementia people, and public health initiatives dissemination.

Private institutions devoted to the diagnosis and care of neurodegenerative diseases have subscribed to these efforts to increase the population literacy, in the last years, but the population access is mostly locally restricted.

GAPS AND UNMET NEEDS

Facilitated access and early identification

A national Portuguese survey addressed to health services involved in care assistance to people with dementia showed scarce human resources in primary health for an accurate dementia assessment, with usual referrals to specialized assistance¹⁶. The management of the medical care of people with dementia and the support of caregivers must rely on primary medical services. In Portuguese interior regions, these are sometimes the only services available. Where secondary services exist, their use should be reserved for complex problems¹⁸.

In other countries, dementia assessment, diagnosis, and care are largely provided by specialists, who in many locations are in insufficient numbers, with rising waiting lists¹⁸.

Socioeconomic barriers and the territorial dispersion of patients advocate for the management of dementia patients in primary care⁵. In Portugal, this is not just an issue for dementia care, but a problem widely prevalent for any differentiated health resource.

An accurate diagnosis in an early stage may identify reversible causes that can potentially be treated. It offers more opportunities to plan while the person living with dementia is competent enough to make decisions about financial and care planning¹⁸. The estimated rate of undetected dementia is 62% globally, and the many barriers to dementia care in primary care have been well documented²³, with long lists of patients, and consequently, insufficient time for better communication and assessment of each patient.

Integrated care

There is a multitude of support regional services: nursing homes, assisted living, residential care, hospice, and home health environments, but the information and support services are fragmented. There is not enough evidence of continuity or team collaboration. Some initiatives have been developed in one of the USA's largest African-American regions to ensure access to community resources for self-care and caregiving²⁴ such as digital community resource referral systems that integrate with electronic medical records and generate a personalized community resource guide at the point of care, indicating clinical guidelines, expert opinion, and best available evidence (transportation services, group exercise classes). A similar framework should be developed, with regular monitoring in Portugal.

Health dementia illiteracy and stigma about dementia

Clinical and civic practice around dementia in Portugal has shown us that, similarly to other countries, there is a reduced awareness about dementia and its consequences.

The stigma surrounding dementia is also a recurrent phenomenon both in consultations and in contact with populations. Many people living with dementia as well as their caregivers deny their diagnosis. This phenomenon, caused by either psychosocial or neurocognitive factors (such as anosognosia), is described in the literature, where strategies to understand and manage these realities are also offered²⁵. Attributing difficulties and cognitive

impairment to normal aging is a social phenomenon both in the country and in the literature²⁵.

Impaired self-awareness in dementia has been linked to negative consequences, having major psychosocial implications: it negatively influences the course of the illness, being more likely to present a poorer quality of life, to engage in high-risk situations, and to refuse treatment. It leads to an increased need for family support, with a higher caregiver burden, and it amplifies the cost of dementia for society, through earlier institutionalization and increased need for care for patients and their caregivers²⁶.

Standard of dementia care pathway: integrated diagnosis and care

While many countries have developed national dementia strategies, practical guidance of post-diagnostic support fulfillment is very restricted. Its delivery varies across countries: primary versus specialized-based dementia care, public versus private healthcare system, and primary care practice alone versus multidisciplinary team based including specialist support. A significant number of studies published about dementia care models²⁷, propose as the most effective one that recommends primary care case management with collaborative efforts of family physicians and nurses and focuses on all aspects of dementia care including neuropsychiatric symptoms associated with the disease as well as caregiver's burden and distress²⁸. In Portugal, there are small regional samples, without the spread of knowledge to extrapolate these initiatives to other areas. In large urban areas, the primary care physicians' insufficiency became worse after the COVID-19 pandemic hampered any initiative.

The barriers to post-diagnostic support of dementia people are like those that impede the diagnosis of dementia itself. These include lack of available information, insufficiency of primary care practitioners to get actively involved in the post-diagnostic management of dementia, deficiency of knowledge and skills about post-diagnostic support, minimal or untimely support by specialists, and unsustainable services with inadequate access. This concern is relevant in Portugal.

Healthcare workforce development

Having a sufficient and skilled workforce to provide evidence-informed care is central to dementia strategies. These care providers should have the knowledge and experience to provide quality care. Lifelong learning is critical for new competencies acquisition, and refreshing of previous acquirements, reflecting on quality care¹⁸.

The support provided to caregivers, something that is central to the well-being of people living with dementia, is frequently inadequate in numerous nations. Training for care workers is often insufficient. In many countries, the primary source of care is the family, who can struggle to access information and ends up triggering burnout in the caregiver¹⁸.

Alzheimer Portugal and private centers have promoted initiatives like workshops and talks for caregivers' elucidation and support over the last few years.

New treatments' reliability

After two decades of symptomatic treatments for Alzheimer's patients, a new era seemed to begin with the accelerated and controversial approval of Aducanumab in 2021. Next, new ongoing approaches, with invasive requirements, may be initiated²⁹.

Soon, these new monoclonal antibodies (mAbs) that are being approved, will require an advanced medical infrastructure to be safely conducted³⁰. Positron Emission Tomography (PET) or Cerebrospinal fluid (CSF) lumbar puncture to show abnormal amyloid- β levels, baseline Magnetic Resonance Images (MRIs) that show no vascular changes, and follow-up MRIs for routine monitoring for Amyloid-related imaging abnormalities (ARIA) early in the treatment period.

Patients must be proximate to infusion centers or other infusion resources for mAbs to be provided. For those that can be administered subcutaneously, caregivers must have access to proper training, or the availability of home nursing services to provide regular subcutaneous treatments. Testing for the Apolipoprotein E (APOE) genotype is recommended for the safe use of other mAbs, given the side effects described in this group so far³¹.

There are few skilled physicians knowledgeable to diagnose the early phase of Alzheimer's disease and differentiate it from other forms of dementia or cognitive decline, who use validated screening tests and understand how to interpret the findings of adjuvant investigations. Interest in dementia among neurologists is not encouraging. It takes time to perform a cognitive workup, with little to offer in terms of treatment. Other specialists have taken over most of the care for people living with dementia around the world (geriatricians, geriatric psychiatrists, general practitioners, and even internal medicine specialists). As neurologists will be probably the ones to initiate and monitor mAbs

therapy, education, and training must be ensured to gain specialization in dementia diagnosis and care¹⁸.

Given all these challenges, the availability of the mAbs or other new treatments will be strongly dependent on the local organization of healthcare, reimbursement of care, and availability of ligands and drugs. For some countries such as Portugal, it will take many years to prepare the healthcare system to be ready to diagnose and treat the increasing number of patients who will be eligible. There is not only a matter of a few specialists with skills in dementia care and experience in clinical trials with mAbs. The scarcity of tertiary referral hospitals' responsiveness to growing demand, and sometimes long from the residence area, results in consultation avoidance, disease progression, and finally a moderate stage of disease and behavioral disturbances that compel caregivers to seek help in a burnout phase, when the response to treatment is almost partial.

On July 22nd, World Brain Day, the slogan was "Leave no one behind". The WHO's 13th General Programme of Work is based on achieving universal health coverage (UHC), addressing health emergencies, and promoting healthier populations³². A framework for meaningful engagement of people living with neurological conditions was developed to empower people with lived experience to fully participate in health processes, addressing the systemic inequities around the world. In this way, they could provide an understanding of barriers and gaps, with innovative, inclusive, and contextually appropriate solutions⁴. Evidence shows that meaningful engagement with person-centered care as a core strategy improves health outcomes like hospital readmissions, adherence to treatment, and quality of life by increasing access to specialized healthcare professionals^{33,34}.

Disorders of the nervous system as dementia are the leading cause of Disability-adjusted-life-years (DALYs), and the second leading cause of death globally³⁵. Profound health inequities are associated with neurological disorders that affect old people, living in poverty, rural or remote areas⁵. Understanding and awareness of the barriers to seeking health care is the first step to addressing the needs of people with dementia. Health systems as the Portuguese, have not yet got an adequate response to the burden of dementia or other neurological disorders. The number of health professionals is insufficient for the treatment gaps³⁶. Integrated health and social care are at the front line of best quality dementia care³⁷. In acute

care settings, the feasibility of person-centered care is questionably³⁸.

The intersectoral global action for neurological disorders 2022-2031 proposed by WHO, is based on an integrated, person-centered framework⁵. It relies on six guiding principles. First, universal health coverage (UHC) and people-centered assistance. Dementia patients should have access along with their caregivers to personalized plans, that allow them informed choices and shared decisions about the care they receive. Second, integrated care across the life course, with evidence-based protocol and guidelines, organized by stages of care. Digital health solutions can optimize continuity of care through information-sharing and remote consultation through telehealth. Third, healthy behavior promotion across the life course. Fourth, health workers capacity-building, training, support, and empowerment of people with dementia and their caregivers, with accessible and evidence-based information on available resources in the community such as training programs. Fifth, engagement of the research community, health professionals, policymakers, and the private sector in promoting innovation, and ensuring equitable and affordable access in low- and middle-income countries. Sixth, implementation of research in low- and middle-income countries to know the barriers for most vulnerable groups, and how to overcome them.

National awareness campaigns must address the lack of information and education about dementia among the population and healthcare professionals, as this is still a barrier to an early diagnosis. Life-long learning should start early in schools and be extended through universities and medical schools, and health professionals' careers³⁹.

The arrival of new therapeutic agents for AD has the potential to reduce the patient and family burden of disease, but the high out-of-pocket for patients and the resources that will be needed (visits to a clinic to provide infusion, and advanced imaging to monitor adverse effects) will place barriers to access, especially for rural patients without a transportation capacity or those with lower incomes⁴⁰.

Nonpharmacological interventions should be further researched and implemented as possible cost-effective interventions globally⁴¹. The interventions should be tailored to individual needs, and patients and caregivers' interests.

Primary care clinicians will need to incorporate validated tools to aid in the early detection of AD. Specialized dementia centers with a

multidisciplinary team (neurologists, psychiatrists, geriatricians, neuropsychologists) will need to develop the expertise for different types of dementia diagnosis with biomarkers support. Guidance and workflows will need to be developed to right patient referral for the various novel treatments available. Collaboration beyond the clinics and after hours, with emergency departments and radiologists will be required. Healthcare systems should make time available for an accurate diagnosis, with compassionate disclosure of results and for listening to patients and caregivers to share decision-making before any treatment initiation. Electronic medical record tools can be used to follow patients, integrate with the pharmacy, and reduce documentation time. They may help, definitively, in clinical landscape change⁴².

There are still challenges in the expansion of tele-interventions for dementia care. These include issues relating to a lack of logistics and infrastructure to support virtual connectivity especially in lower- and middle-income countries. At the same time, the target population may have low levels of digital literacy and awareness or may not accept tele-interventions as valid interventions¹⁸.

National dementia plans need to become a policy priority, with building models of post-diagnosis support, linked to key action areas of WHO's Global action plan on dementia to be quickly implemented. Regional plans for dementia care were drafted in 2018. In 2021 they should have been implemented, but no action was evident so far despite the efforts of the Experts Executive Group⁴³. Most of the gaps mentioned are present in Portugal. Proposed solutions evidence-based do exist, as we show below. A Consensus National Expert Meeting would help to force the start-up of the necessary actions to improve dementia care in the meantime in Portugal.

Based on international and national experience found in the literature, recommendations for the listed issues will be put forward in this section:

1. Promptly access and early identification.

Most people living with dementia are diagnosed and followed in primary care practice. To provide appropriate post-diagnostic support, primary care professionals should be efficiently supported. The multidisciplinary approach that synchronizes all healthcare professionals within different specialties to communicate and work together is the most effective way to deliver the best post-diagnostic support that people living with dementia and their caregivers need. Successful management models are associated with few emergency department visits and hospital admissions²⁸. Training initiatives⁴⁴ through

workshops organized by Alzheimer Portugal, private and public health institutions, and industry are performed regularly to promote education and update on dementia care knowledge. A regular meeting from the National Scientific Group for Dementia and Elderly (Grupo de Estudo de Envelhecimento Cerebral e Demência - GEECED) joins the main national basic and clinical research, with foreign guests to discuss the last news or discoveries. On the other hand, new more accurate and easier blood tests were tested recently for AD identification^{45,46}. Finger-prick blood tests could improve the diagnosis in a primary care setting or areas with relatively few resources. Pilot studies ongoing need to be replicated, and continuing education from the pregraduate stage to primary care physicians update is imperative.

2. **Integrated care. Person-centered care.** The medical follow-up of a person living with dementia, at all stages of the disease is part of a global person-centered management approach to prevent and treat complications. Identifying these complications requires a systematic assessment conducted at each follow-up medical visit, with a multidisciplinary approach, covering nutrition, autonomy, and physical capacities, gait and balance disorders, neuropsychiatric symptoms, sensory impairment, iatrogenesis, cardiovascular risk factors, pain, social environment, and cognitive worsening. This assessment must be adapted for the people living with dementia's lifestyle and stage of disease. Multidisciplinary teams integrated by neurologists, geriatrics, nurses, psychologists, and nutritionists should work in devoted and specialized centers. The last survey carried out about care delivery in Portuguese health services involved in dementia people care, showed that just in 50% of cases, a global assessment of the needs (somatic, psychological, and social) was performed¹⁶.

Many studies have shown how the meaningful engagement approach can improve outcomes and quality of life in a person-centered care perspective⁴. This proposal involves patients and caregivers with lived experience in co-creating relevant policies, programs, and services based on what matters to them⁴. An integrated approach is critical for maximizing resources in view of current funding restrictions for global health⁴⁷. Regional plans defined by an experts' panel were addressed in Portugal to rip out with this multidisciplinary, patient-centered clinical pathway, but these initiatives were paused, without guidelines or driving

initiatives from health policies and the government.

- 3. Continuum post-diagnostic care.** Despite the shock of the diagnosis, even if expected, certainty of diagnosis was considered by patients and family members as helpful. Discussion by the diagnosing physician, a nurse, or a psychologist about legal and financial management, driving, work, and social benefits as well as managing stigma and other people's reactions to the diagnosis, is considered extremely useful¹⁸. Post-diagnostic management of people living with dementia is defined as "holistic, integrated continuing care in the context of declining function and increasing needs of family"¹⁹. From the onset, it encompasses the ongoing assessment of the dementia patient as well as any comorbidities, and the support provided to caregivers. Continuity of care can be optimized using digital-health solutions that encourage information-sharing between professionals, patients, and caregivers, allowing remote consultation through tele-health⁵. The COVID-19 pandemic in Portugal, as in other countries, facilitated the boost of tele-health. Tele-health persists as a quick and easy contact tool in case of sudden deterioration. However, the generalized use of wearables or devices as a monitoring source or as rehabilitation assistants is not extended. COGWEB[®] training online has been largely widespread over the last years as a cognitive training personalized plan, guided by professionals, and suitable for different levels of difficulty⁴⁸. The outcomes after the first year of implementation were promising, but like other private initiatives such as "Community Senior Brain Gym" in Sintra, near Lisbon, is not affordable for everyone. Technologies used to collect real-time data, with encryption and blockchain to preserve patients' privacy, can be integrated into care and research programs⁴⁹. There is no place for Nihilism and inactivity after a diagnosis of dementia. People diagnosed with dementia should be offered the same rehabilitation and continued support opportunities as those who had a stroke. This requires planning in partnership with the patient and the caregivers' access to multidisciplinary support, and where multidisciplinary services are not available, they should be directed to information and online supports, such as local Alzheimer associations¹⁸. In Canada, innovative new models of dementia care have been developed to better address the needs of people living with dementia and caregivers. Aligned with the Chronic Care Model, the delivery of support and services is

individualized and based on the needs of the person with dementia and the caregiver⁵⁰. Core to this model is a collaborative approach between primary care, specialist care, and community agencies including their local Alzheimer's Society. For complex cases, digital technologies are used to extend the reach of specialist expertise into rural and remote regions that would otherwise not have this access. Various evaluative studies have demonstrated lower budgets and high levels of satisfaction for people living with dementia, their caregivers, and healthcare providers with models of quick access to full-service dementia care from one location close to home, within their own communities. Innovative models in Canada highlight the importance of multidisciplinary dementia management within primary care and the need for cross-sectoral collaboration in supporting people with dementia and their caregivers⁵¹.

- 4. Care pathways.** Interdisciplinary care for people with dementia needs evidence-based guidelines¹⁷, with an organization of care by stages. Multiple contributions over the last years tried to position dementias as a public health priority with policies or action plans⁵². In Portugal, a strategic summary was formulated based on international good practices evidence. The draft was focused on care pathways, from population sensibilization to late-stage palliative care. Specific recommendations were launched for a standard of care in each phase of the disease. The clinical care pathway must be coordinated and person-centered, with identification of the health and community resources (public, private, and social institutions), definition of referral criteria to secondary care from primary care, and a tailored integrated care plan for each patient. Proximity, access, equity, and continuity are basic principles to be considered¹⁶. Care plan management requires an integration of care, focused on the preferences and needs of dementia people and their caregivers, with an active intervenient role. Person-centered healthcare is considered the gold standard for complex conditions such as dementia as it emphasizes timely access to appropriate services and support and meeting individual needs⁵³. By focusing assessment and management on the preferences and values of individuals and caregivers, people can be supported to live well with dementia. Much has been learned about the importance of a multi-disciplinary approach, care navigation, and collaboration across the continuum of healthcare providers and community services to

ensure changing care needs are met and enable people living with dementia to stay at home for as long as possible⁵⁴. The age-friendly health system is an initiative from the John A. Hartford Foundation and Institute for Healthcare Improvement, in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States, implemented in 2023 in a public hospital in Cantanhede (a small village in the center of Portugal)⁵⁵. It introduces a screening program for geriatric syndromes with successful results introducing exercise and cognitive stimulation therapy programs. This action could be replicated in other public or private institutions, with outcomes monitoring.

5. **Healthcare workforce development.** Health and social care workers should have enough knowledge about attitudes and skills to deal with dementia patients. Training standards vary globally, and there is uncertainty about the best training to be delivered. Some training standards provide specific and comprehensive guidance focusing on knowledge and skills (i.e. English Dementia Training Standards Framework⁵⁶); some are outcomes-based, meaning the knowledge and skills are linked to the outcome they should lead to for dementia patients (i.e. Scottish Promoting Excellence Framework⁵⁷); and some countries do not have specific standards for dementia training, but instead include more generic requirements for staff to be appropriately skilled and knowledgeable within wider care quality standards (i.e. Australian Aged Care Quality Standards⁵⁸). From published research, surveys, and experiences with training programs, some conclusions can be drawn: it must be tailored to the experience and the role of the learner, it should include specific tools for certain issues like pain or behavioral disturbances, and learners must be engaged through videos or simulation⁵⁹. Most nursing homes or day centers for the elderly in Portugal are not tracked or have any seal of quality. This point should be a matter of concern for health and social policy authorities.
6. **Public awareness: prevention significance.** Improving consciousness and education about dementia, with a possible early diagnosis and treatment is one of the main priorities of any dementia national plan⁶⁰. Pedagogic efforts through social media, or multimedia platforms with adequate information adapted to different levels of literacy and population heterogeneity should be addressed regularly. Prevention is profusely highlighted in the literature as the key element in managing the

global high incidence and prevalence of dementia. Updated estimates indicate that up to 40% of dementias are related to modifiable lifestyle, vascular, and environmental risk factors, providing a clear prevention potential⁶¹. WHO, in 2019, published *Guidelines for Risk Reduction of Cognitive Decline and Dementia*, supporting the multidomain paradigm of prevention, with evidence-based guidance globally preventive strategies to develop and implement. The FINGER clinical trial (Finnish Geriatric Intervention Trial to Prevent Cognitive Impairment and Disability)⁶² was the first large, long-term randomized controlled trial demonstrating that it is possible to prevent cognitive and functional decline among elderly persons at risk of dementia, through a multidomain lifestyle-based intervention. It is important simultaneously translating the results into applications. EURO-FINGERS is one of the initiatives that try to communicate about dementia risk reduction and motivate people to adhere to healthy lifestyles⁶³. Portuguese efforts once again are not enough broadcasted. Brain Aging and Dementia National Group regular meetings have some talks about prevention initiatives, but these relevant issues don't become common knowledge even to other neurologists.

7. **New treatments' reliability.** Many monoclonal antibodies have been tested over the past two decades. Many lessons have been learned over their ability to reduce the amyloid brain levels when they are administered in high enough doses and for a long enough time, but with the risk of brain swelling (ARIA-E) or hemorrhage (ARIA-H) as the amyloid is cleared off the blood vessels. MAbs are currently being assessed in patients with mild cognitive impairment or mild dementia due to Alzheimer's disease and there are few health professionals with skills to assess and diagnose early Alzheimer's. The technology required for mAbs administrations currently limits their access globally. Emerging technologies like blood biomarkers and subcutaneous administration may facilitate global use. The biggest issue now is how much clinical benefit is demonstrable considering costs and risks⁶⁴.
8. **Portuguese Consensus Meeting.** Efforts were initiated and must be refreshed. Experts on dementia care, healthcare and social care workers, and patients' association members should be joined in different assemblies to address the issues that were identified. The purpose will be a final report with a

prioritization of the actions and an agenda to get the necessary government commitment.

Conclusions

The fight against dementia must begin with efficient prevention and global awareness about red flags to avoid the misattribution of first symptoms to normal aging. A holistic approach is mandatory for dementia care. New treatments are being developed, but health systems' infrastructure changes are required for their implementation. On the other hand, no-AD dementias are far from having a disease-modifying treatment.

Patients' and caregivers' engagement is critical for driving the clinical care pathways. Value-based healthcare with a patient-centered philosophy, has already proven its value for other chronic conditions to improve clinical outcomes and quality of life. Integrated and continuous care from diagnosis to

the end of life relies on enough number of primary care physicians and specialists, with knowledge and skills, to work into team-based interdisciplinary models. Digital health can help in patient information global access with the protection of privacy and in the availability of resources where caregivers could seek advice. Changing the growing numbers and the ongoing clinical pathway depends on politicians' commitment, health workers, and patients' and caregivers' engagement.

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References

1. Nichols E, Steinmetz JD, Vollset SE, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*. 2022;7(2):e105-e125. doi:10.1016/S2468-2667(21)00249-8
2. Wimo A, Seeher K, Cataldi R, et al. The worldwide costs of dementia in 2019. *Alzheimer's & Dementia*. Published online January 8, 2023. doi:10.1002/alz.12901
3. Gonçalves-Pereira M, Verdelho A, Prina M, Marques MJ, Xavier M. How Many People Live with Dementia in Portugal? A Discussion Paper of National Estimates. *Portuguese Journal of Public Health*. 2021;39(1):58-68. doi:10.1159/000516503
4. World Health Organization. *WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions*.; 2023.
5. World Health Organization. *Intersectoral global action plan on epilepsy and other neurological disorders 2022-2031*. Published online 2023.
6. Gonçalves-Pereira M, Cardoso A, Verdelho A, et al. The prevalence of dementia in a Portuguese community sample: a 10/66 Dementia Research Group study. *BMC Geriatr*. 2017;17(1):261. doi:10.1186/s12877-017-0647-5
7. Ruano L, Araújo N, Branco M, et al. Prevalence and Causes of Cognitive Impairment and Dementia in a Population-Based Cohort From Northern Portugal. *American Journal of Alzheimer's Disease & Other Dementias*. 2019;34(1):49-56. doi:10.1177/1533317518813550
8. Santana I, Farinha F, Freitas S, Rodrigues V, Carvalho Á. Epidemiologia da Demência e da Doença de Alzheimer em Portugal: Estimativas da Prevalência e dos Encargos Financeiros com a Medicação. *Acta Med Port*. 2015;28(2):182-188. doi:10.20344/amp.6025
9. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. *World Alzheimer Report 2016: Improving Healthcare for People Living with Dementia: Coverage, Quality and Costs Now and in the Future Report Improving Healthcare for People Living with Dementia Coverage, Quality and Costs Now and In the Future*.; 2016.
10. Alzheimer Europe. *Comparing and Benchmarking National Dementia Strategies and Policies*.; 2017. www.un.org
11. Burns A, Robert P. *Dementia Care: International Perspectives*. Oxford; 2019.
12. Ribeiro O, Fernandes L, Firmino H, Simões MR, Paúl C. Geropsychology and psychogeriatrics in Portugal: research, education and clinical training. *Int Psychogeriatr*. 2010;22(6):854-863. doi:10.1017/S1041610210000347
13. Fernandes L, Mateos R, Engedal K, et al. The state of psychogeriatrics in Europe: challenges and opportunities in six European countries. *Int Psychogeriatr*. 2015;27(8):1243-1246. doi:10.1017/S1041610214002191
14. Houghton C, Murphy K, Brooker D, Casey D. Healthcare staffs' experiences and perceptions of caring for people with dementia in the acute setting: Qualitative evidence synthesis. *Int J Nurs Stud*. 2016;61:104-116. doi:10.1016/j.ijnurstu.2016.06.001
15. Caldas de Almeida M, et al. *Projeto VIDAS — Valorização e Inovação Em Demências (POPH/QREN 2013-15)*.; 2015.
16. Saúde - Gabinete do Secretário de Estado Adjunto e da Saúde. *Diário da República n.º 116/2018, Série II de 2018-06-19*. Published online 2018.
17. Direção-Geral da Saúde Portugal. *NORMA CLÍNICA: 053/2011. Atualização. Abordagem Diagnóstica e Terapêutica Do Doente Com Declínio Cognitivo Ou Demência*.; 2023. www.dgs.pt
18. Gauthier S, Webster C, Servaes S, Morais JA, Rosa-Neto P. *World Alzheimer Report 2022: Life after Diagnosis: Navigating Treatment, Care and Support*.; 2022.
19. Nicaise S, Palermi F, Monegasque Association for research on Alzheimer's disease (AMPA). *ALZHEIMER AND THE MEDITERRANEAN REPORT 2016. OVERVIEW-CHALLENGES-PERSPECTIVES*.; 2016.
20. Direção-Geral da Saúde Portugal. *PORTUGAL: Saúde Mental Em Números - 2015. Programa Nacional Para a Saúde Mental*.; 2015.
21. Kerpershoek L, de Vugt M, Wolfs C, et al. Access to timely formal dementia care in Europe: protocol of the Actifcare (ACcess to Timely Formal Care) study. *BMC Health Serv*

- Res. 2016;16(1):423.
doi:10.1186/s12913-016-1672-3
22. Kurz A, Bakker C, Böhm M, et al. RHAPSODY – Internet-based support for caregivers of people with young onset dementia: program design and methods of a pilot study. *Int Psychogeriatr.* 2016;28(12):2091-2099. doi:10.1017/S1041610216001186
23. Lang L, Clifford A, Wei L, et al. Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. *BMJ Open.* 2017;7(2):e011146. doi:10.1136/bmjopen-2016-011146
24. Abramsohn EM, Jerome J, Paradise K, Kostas T, Spacht WA, Lindau ST. Community resource referral needs among African American dementia caregivers in an urban community: a qualitative study. *BMC Geriatr.* 2019;19(1):311. doi:10.1186/s12877-019-1341-6
25. Clare L, Gamble LD, Martyr A, et al. Psychological processes in adapting to dementia: Illness representations among the IDEAL cohort. *Psychol Aging.* 2022;37(4):524-541. doi:10.1037/pag0000650
26. Bertrand E, Landeira-Fernandez J, Mograbi D. L'impact psychosocial de l'anosognosie dans la démence de type Alzheimer. *Rev Ibero Am Gerontol.* 2013;2:52-69.
27. Khanassov V, Rojas-Rozo L, Sourial R, Yang XQ, Vedel I. Needs of patients with dementia and their caregivers in primary care: lessons learned from the Alzheimer plan of Quebec. *BMC Fam Pract.* 2021;22(1):186. doi:10.1186/s12875-021-01528-3
28. Khanassov V, Vedel I, Pluye P. Barriers to Implementation of Case Management for Patients With Dementia: A Systematic Mixed Studies Review. *The Annals of Family Medicine.* 2014;12(5):456-465. doi:10.1370/afm.1677
29. Scheltens P, De Strooper B, Kivipelto M, et al. Alzheimer's disease. *The Lancet.* 2021;397(10284):1577-1590. doi:10.1016/S0140-6736(20)32205-4
30. Cummings J, Rabinovici GD, Atri A, et al. Aducanumab: Appropriate Use Recommendations Update. *J Prev Alzheimers Dis.* Published online 2022. doi:10.14283/jpad.2022.34
31. Lin P, Cohen JT, Neumann PJ. Preparing the health-care system to pay for new Alzheimer's drugs. *Alzheimer's & Dementia.* 2020;16(11):1568-1570. doi:10.1002/alz.12155
32. World Health Organization. *Thirteenth General Programme of Work, 2019–2023: Promote Health, Keep the World Safe, Serve the Vulnerable.*; 2019.
33. World Health Organization. *Mental Health Crisis Services: Promoting Person-Centred and Rights-Based Approaches.*; 2021.
34. Vojtila L, Ashfaq I, Ampofo A, Dawson D, Selby P. Engaging a person with lived experience of mental illness in a collaborative care model feasibility study. *Res Involv Engagem.* 2021;7(1):5. doi:10.1186/s40900-020-00247-w
35. Feigin VL, Nichols E, Alam T, et al. Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;18(5):459-480. doi:10.1016/S1474-4422(18)30499-X
36. World Health Organization. *Atlas: Country Resources for Neurological Disorders, 2nd Ed.*; 2017.
37. World Dementia Council. *World Dementia Council Global Care Statement: Statement on Importance of Care and Support.*; 2017.
38. Dewing J, Dijk S. What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia.* 2016;15(1):106-124. doi:10.1177/1471301213520172
39. Daley S, Williams M. *Innovative Dementia Education Programs for Undergraduate Healthcare Students.*; 2022.
40. Rosenthal MB. Novel Alzheimer Disease Treatments and Reconsideration of US Pharmaceutical Reimbursement Policy. *JAMA.* Published online July 17, 2023. doi:10.1001/jama.2023.11702
41. Brodaty H, Jeon Y-H, Gresham M, et al. *Non-Pharmacological Interventions for People Living with Dementia as Part of Post-Diagnostic Care.*; 2022.
42. Widera EW, Brangman SA, Chin NA. Ushering in a New Era of Alzheimer Disease Therapy. *JAMA.* Published online July 17, 2023. doi:10.1001/jama.2023.11701
43. Portuguese Government. *Diário da República n.º 251/2021, 1º Suplemento, Série I de 2021-12-29.* Published online 2021.
44. Dresden SM, Taylor Z, Serina P, et al. Optimal Emergency Department Care Practices for Persons Living With Dementia: A Scoping Review. *J Am Med Dir Assoc.* 2022;23(8):1314.e1-1314.e29. doi:10.1016/j.jamda.2022.05.024

45. Abstract 80275 (Finger-prick blood test). *Alzheimer's Association International Conference (AAIC) 2023*. Published online July 19, 2023.
46. Abstract 78819 (Primary care). *Alzheimer's Association International Conference (AAIC) 2023*. Published online July 19, 2023.
47. World Health Organization. *Global Expenditure on Health: Public Spending on the Rise?*; 2021.
48. Tedim Cruz V, Pais J, Ruano L, et al. Implementation and Outcomes of a Collaborative Multi-Center Network Aimed at Web-Based Cognitive Training – COGWEB Network. *JMIR Ment Health*. 2014;1(1):e2. doi:10.2196/mental.3840
49. World Health Organization. *A Blueprint for Dementia Research*. Accessed May 31, 2023. <https://www.who.int/publications/i/item/9789240058248>
50. Lee L, Hillier LM, Heckman G, et al. Primary Care–Based Memory Clinics: Expanding Capacity for Dementia Care. *Can J Aging*. 2014;33(3):307-319. doi:10.1017/S0714980814000233
51. Wong WWL, Lee L, Walker S, et al. Cost-utility analysis of a multispecialty interprofessional team dementia care model in Ontario, Canada. *BMJ Open*. 2023;13(4):e064882. doi:10.1136/bmjopen-2022-064882
52. World Health Organization. *Global Action Plan on the Public Health Response to Dementia 2017 - 2025*.; 2017.
53. American Geriatrics Society Expert Panel on Person-Centered Care. Person-Centered Care: A Definition and Essential Elements. *J Am Geriatr Soc*. 2016;64(1):15-18. doi:10.1111/jgs.13866
54. Lee L, Molnar F, Hillier LM, Patel T, Slonim K. Multispecialty Interprofessional Team Memory Clinics: Enhancing Collaborative Practice and Health Care Providers' Experience of Dementia Care. *Can J Aging*. 2022;41(1):96-109. doi:10.1017/S0714980821000052
55. Lundy J, Hayden D, Pyland S, Berg-Weger M, Malmstrom TK, Morley JE. An Age-Friendly Health System. *J Am Geriatr Soc*. 2021;69(3):806-812. doi:10.1111/jgs.16959
56. Skills for Health, Health Education England, Skills for Care. *Dementia Training Standards Framework*.; 2018.
57. Scottish Government. *Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers*. Published online 2010.
58. Commonwealth of Australia. *The Aged Care Quality Standards*.; 2019.
59. Surr CA, Parveen S, Smith SJ, et al. The barriers and facilitators to implementing dementia education and training in health and social care services: a mixed-methods study. *BMC Health Serv Res*. 2020;20(1):512. doi:10.1186/s12913-020-05382-4
60. Pot AM, Petrea I. *Improving Dementia Care Worldwide. Ideas and Advice on Developing and Implementing a National Dementia Plan*.; 2013.
61. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*. 2020;396(10248):413-446. doi:10.1016/S0140-6736(20)30367-6
62. Ngandu T, Lehtisalo J, Solomon A, et al. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. *The Lancet*. 2015;385(9984):2255-2263. doi:10.1016/S0140-6736(15)60461-5
63. World Health Organization. *Global Status Report on the Public Health Response to Dementia*.; 2021.
64. Cummings J. *Anti-Amyloid Monoclonal Antibodies for the Treatment of Alzheimer's Disease*.; 2022.