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Healthcare Models in Alzheimer's Disease

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Abstract

Alzheimer's disease is currently a health care problem and in the future, when we have effective treatments, it will become a public health priority. Health systems should adapt to this situation. New technologies are tools that can improve healthcare and lower costs. The mobile phone with call or video call conference is going to suppose a radical change in the control of these patients. The telephone assistance to patient or relatives is very satisfactory for both due to the rapidity in the response to their problem and the comfort with which they are attended to. Also the health system reduces the costs of face-to-face consultation. In addition, this telemedicine could be applied for cognitive stimulation, with specific programs for each patient and for the follow-up of patients in their homes, delaying their entry into residences. The objective is to turn the patients and their caregiver into cotherapists together with the nurse and the physician, in the follow-up of Alzheimer's disease.

Keywords: healthcare, Alzheimer's disease

1. Alzheimer's disease: public health priority

Alzheimer's disease (AD) is a degenerative disease produced by the accumulation of beta-amyloid and tau protein in the brain. From the clinical point of view, it is characterized by a prodromal phase with mild cognitive impairment, which is followed by the dementia phase [1].

Early dementia screening by a primary care physician should be completed once a patient or a knowledgeable informant has noticed decline in memory or difficulty [2]. Screening is not indicated at the general population level [3, 4], because currently there are no specific treatments to block the progression of cognitive decline in AD and other neurocognitive dementias. Is very important reasons from a patient's social and personal perspective that an early diagnosis is important as Alzheimer's disease is a terminal illness; you can minimize some of the effects if you understand the disease and know what to do [5]. Numerous screening tests are available for confirmed cognitive impairment, and laboratory tests and imaging studies should be obtained to rule out reversible etiologies. If patients meet diagnostic criteria for AD, clinicians should educate patients and caregivers on the expected course and help them complete advance directives. Troublesome behaviors should be managed with nonpharmacotherapeutic measures first. Drugs for improving cognition can be prescribed but do not prevent

disease progression [6]. Patients with advanced illness need end of life care (EoLC) with adequate pain control and palliative care interventions to shorten their hospital stay. Bamford et al. [7] take seven factors influencing good EoLC for people with dementia (**Table 1**). By incorporating stakeholders’ perspectives and preferences when planning and developing coordinating interventions, we may increase the likelihood of successful implementation and patient benefits [8].

In 1984, the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association (NINCDS-ADRA) developed the first diagnostic criteria for Alzheimer’s dementia [9]. In 2011, the National Institute of Aging/Alzheimer’s Association (NIA-AA) revised these criteria including two new phases of the disease and introduced the utilization of biomarkers in research. Firstly, the introduction of the use of biomarkers would aim to detect pathological changes of AD before the onset of cognitive symptoms—“the preclinical phase” [10]. Secondly, the introduction of a mildly symptomatic but not dementia phase, which defines the onset of mild cognitive symptoms, was introduced. Clinical biomarkers such as deposition of A β seen on PET imaging were introduced to increase the clinical likelihood of diagnosis of AD on the presentation of mild cognitive impairment (MCI) however, these are yet to be utilized for routine clinical use [11]. In 2014, the International Working Group updated their clinical entity of prodromal AD by introducing improved biomarkers for AD and defining a criteria for atypical and non-AD dementia [12]. And finally, the diagnostic standard for dementia is the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*. DSM-5 recognizes two cognitive syndromes: major neurocognitive impairment and mild neurocognitive impairment. The diagnosis of major neurocognitive impairment requires objective cognitive

Summary of the seven factors influencing good EoLC for people with dementia

Undertaking timely planning discussions to ensure plans are discussed when the person with dementia has capacity and that they are documented and disseminated as appropriate.
Recognising end of life and providing supportive care to ensure effective management of key symptoms (e.g. pain, anxiety and nausea), and minimise distress by providing comfort in a familiar environment.
Co-ordination and continuity of care includes liaison between day and night staff in services and having established links with local services (e.g. hospices), particularly for support out of hours.
Working effectively with primary care can be facilitated by having a named liaison person in the practice. For care homes, liaison can be improved by regular routine visits and limiting the number of general practices with which residents are registered.
Managing hospitalisation includes avoiding unnecessary admissions by appropriate out-of-hours support and documentation of wishes and preferences. It also involves managing admission and discharge effectively where hospitalisation is necessary.
Continuing care after death to enable family members to be supported by known members of staff who cared for the person with dementia at the end of life. This continuity of care is valued by family members.
Valuing staff and ongoing learning facilitates staff retention and results in a more skilled and knowledgeable workforce. Stable staff teams are more able to detect emotional vulnerability in their colleagues and ensure timely and appropriate support.

Table 1.
Summary of the seven factors influencing good EoLC for people with dementia.

decline that is severe enough to interfere with activities of daily living and is not caused by delirium or another neurologic, medical, or psychiatric disorder [13].

The socio-health needs of dementias are similar, regardless of their etiology, although there are some peculiarities that characterize each of them like hallucinations in dementia by Lewy bodies, behavioral problems in frontotemporal dementia, and social and emotional level of loneliness, which is higher in Korsakoff syndrome [14]. This social and emotional loneliness is more frequent and earlier in a residence of the patients with Korsakoff syndrome [15].

In 2010, annual healthcare costs attributable to dementia were between \$41,000 and \$56,000 per person [16]. About three quarters of these costs are from institutional and home-based long-term care. Although these estimates place a monetary value on informal care provided by family members and friends, they do not account for the substantial non-monetary costs to caregivers in terms of negative consequences to social, physical, and psychological well-being [17]. If we can delay dependency and institutionalization, by even a couple of years, it has the potential to save hundreds of billions in direct healthcare costs and even more in terms of improved well-being for caregivers.

The AD from the clinical point of view is today a public health problem recognized by the WHO [18], because it is a very frequent disease. It is estimated that 46.8 million people live with dementia in the world in 2015. This number is expected to double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050. This translates to approximately two new cases per 1000 people age 65–74, 13 new cases per 1000 people age 75–84, and 39 new cases per 1000 people age 85 and older, and the greatest risk factor by far is aging [19–21]. It is also a disease with great impact on the health of the patient, who becomes totally dependent, and the family environment, for their involvement in the care from the physical and psychological point of view. On average, a person with Alzheimer's disease will spend more years (40% of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stages. However, currently, and from an epidemiological point of view, it is not a priority in health, given that although we have a screening test for the population, we do not have a drug with the potential to significantly modify the natural course of the disease. The quality of care received by a person with dementia positively is critical to the physical and mental health of the person with dementia [22]. It is a challenge for socio-health systems to determine what needs should be provided and financed.

2. Needs and demands socio-health of the patients

Dementia is a chronic and progressive disease, with an average survival of more than 10 years. Patient and the family environment with this disease go through different phases that have different needs and demands. The needs are determined by the interventions that have shown efficacy through scientific studies, while the demands are determined mainly by sociocultural factors. A clear example of this is that new generations accept new technologies much better than previous generations [23]. Any socio-health system should try to provide its patients and caregivers with those needs and demands as efficiently as possible (actions with studies that demonstrate their effectiveness and that are viable from the economic point of view). In general, caregivers claim and request less formal attention than in other pathologies [24]. Each patient with dementia and its family have different characteristics and needs that require individual attention [25]. The NICE guide recommends periodic evaluation and caregiver programs, including telephone or Internet support. Such supportive interventions could be effective both preventive

and therapeutic of the consequences of the burden [26]. The unmet needs may be higher in caregivers with lower education and individuals with early-stage dementia and low-income. The identifying and treating symptoms of depression in patients with dementia and caregivers are necessary for them to know their other unmet needs [27].

Socio-sanitary assistance to dementia has the highest degree of complexity, comparable to multi-pathological patients, according to the categorization of chronic patients adopted by the Department of Health of the United Kingdom, the approach of the Kaiser Permanente. These patients require a comprehensive and continuous treatment, which must be based on the coordination of healthcare and social assistance, as well as between the different levels of care (primary care and specialized care). And more specifically in health care, the link between the specialist physician and the case management nurse of the unit with primary care is key, so that this assistance has a versatility that allows ensuring adequate care more appropriate [28].

The personalized care plan focuses on the patient with the disease but involves the entire family environment of the patient, understanding this environment widely, including friends and volunteers, among others.

The aim of the personalized care plan are: (1) promotion of the autonomy of the patient with activation and self-management of care and improvement of their quality of life; (2) pharmacotherapeutic optimization at all times during the disease; (3) prevent complications, cognitive and functional impairment, and ultimately dependence; (4) integral assessment of the patient from a biomedical or clinical, psychological, functional and socio-family point of view; (5) establishment of a prognosis in each phase of the disease; (6) establish advance planning of decisions.

The needs or demands of patients and caregivers with dementia are typified and all socio-health systems establish different socio-sanitary responses to similar pathologies [26, 29, 30]. However, this assistance must be individualized in each specific user always, considering it as a biopsychosocial organism, with its particular desires and preferences. Therefore, assistance to users with AD must be protocolized in a multidisciplinary way and provided individually to each patient and caregiver.

In spite of the increase of the income in residences in the last years, the family environment is the therapeutic reference that is more effective, efficient, and very difficult to substitute for the emotional implications that it has. And above all, it is preferred by most patients with dementia [31–33]. The competence of caregivers is essential for the life quality of patient with dementia, and multicomponent interventions may be appropriate for nurses to practice [34].

3. Social sanitary assistance management tools

We must overcome health care in the terms of first-visit patients and regulated reviews (at 3, 6, 9, or 12 months) and use management tools that use information and communication technologies to satisfy the needs and demands, avoiding referrals, appointments, and bureaucratic reviews.

Among the emerging management tools in recent years that are most useful are:

1. Caregivers: we have to pay much more attention to the caregiver or caregivers and use them as cotherapists, throughout the process, especially in the final phase [35].
2. Case management nurse [36, 37]: together with the medical specialist or general practitioner who is, usually, the axis around which health care is provided. The case management nurse coordinates all the actions of the patient and their

family. The liaison nurse of the dementia unit, within a neurology service, was the axis around which social-health assistance was established. In our study [37], the case management nurse of the dementia unit, was the axis around which social-health assistance was established.

3. Coordination with de Alzheimer's association using their ability to bring together the patient and the family environment, using their infrastructures and volunteering to monitor users [38, 39].
4. Digital clinical history: access to the digital clinical history instantly, from any terminal of the health system (both primary care and specialized care), allows to efficiently solve healthcare problems in relation to the patient without the inconvenience of having to travel or the delay of having to wait for an appointment.
5. Prescription on line: also accessible from any terminal of the health system. It allows to see the medication prescribed by any doctor to the patient. It has the potential to establish alerts, system of interactions and allergies, and maximum duration of treatments, among others.
6. Telecare: At the beginning it arose to solve the problems of accessibility in remote areas and sanitary underfunded, allowed accessibility by spacing distances. Subsequently, it was considered that telemedicine contributed essential quality by facilitating the continuity of care, and recently it is considered an efficient and essential tool in the organization of health care. The application of technology in health has become a strategic objective to address the demographic challenge and allow "aging at home."

The modalities of telecare can be very diverse, and the telemedicine projects of attention to users with dementia performed include [1] support for patients so that they can continue to live independently; [2] support services for informal caregivers through "online" training, video conferencing with professionals, telealarm with videoconference, and cognitive stimulation; [3] networks for patient and caregivers; [4] monitoring of the state of the patient, personalized intervention, and adaptive care; [5] platform that integrates smart home technologies, with sensors and interoperability with professionals and institutions; and [6] computer programs to caregivers to improve their overload, mainly emotional.

The main problems of this technology are the risks of privacy in relation to data protection and health care. Other issues technological aspects that are solved with the progress of technology: complexity of use, cost of acquisition and technical failures.

The main resistance for its establishment is given by the three protagonists of the assistance: patients and caregivers, professionals, and mainly the managers of the health administration [40].

These tools used by each socio-health system according to their possibilities allow a better assistance to patients and caregivers.

4. Health model units of cognitive disorder and conduct

Dementia is the paradigm of disease that practically in its entirety is diagnosed and/or followed by the national health systems (public and free). It is a disease that does not start abruptly and for which medicines are expensive. Patient assistance involves the neurologists and other specialists who directly assist patients with neurological problems. The growing complexity of neurology in general, as a specialty, with

the improvement of diagnostic methods as well as therapeutic interventions, means that the assistance provided by a neurologist or psychiatrist or geriatrist is greater.

The guiding principles of the assistance in the unit of memory are [1] universality and equality; [2] integrality and transversality, with coordination of all the members; and [3] efficiency and sustainability. This unit must be endowed with the human and material resources to meet its objectives [41, 42].

- Comprehensive care for affected people and support for caregivers in all phases of dementia.
- Information, training, and advice to affected people, caregivers, associations, and professionals involved in dementia assistance.
- Sensitization of public opinion, institutions, entities, and media.
- Adequacy of health and social resources, as well as the establishment of protocols and joint procedures.
- Promotion of volunteering and promotion of associations.
- Promote lines of research and intervention.

To fulfill these objectives, within the unit there should be another specialist doctor (neurologist, psychiatrist, and geriatrist), nurse manager of hospital cases, clinical psychologist or neuropsychologist, and social worker.

In primary care, it should consist of a family doctor and nurse who manages primary care cases and social work. The coordination and communication between these professionals is key in dementia care process.

To carry out all its objectives, you should use the tools, mainly new technologies, of which the health system has: digital clinical history, prescription “online,” and telecare.

Key aspects in the operation of the unit that should be considered:

1. Management of communication at all levels: horizontal internal, between the members of the unit among themselves and with the other professionals of the organization; internal vertical, with the address of the hospital and primary care center; external with patients and relatives, with associations of relatives of patients and with society in general [43].
2. Control of the satisfaction of all those who participate in the unit: patients and relatives, professionals, and the administration in relation to the activities developed in relation to the healthcare process.
3. Establish indicators of care process, health outcomes, and specific situations: all this must be reflected in an annual report of the unit, which includes all the activity of the unit carried out, mainly in the care, research, and teaching areas.

The personalized attention in the chronic disease improves the indicators of physical and psychological health, as well as the ability to manage the disease with respect to usual care. The differences increase when they are more complete and more intense and integrated into the routine. Care with a more personalized and graduated approach allows to maintain the autonomy and integration of the patient in his environment [44, 45]. The coordination at the health level between primary and specialized care, with a social worker and in association with Alzheimer’s patients’

relatives, all tools being available (telephone, email, digital medical record, prescription “online”), is key for the success in monitoring patients and caregivers [37].

5. Future perspectives

The optimism generated by recent and anticipated developments in the understanding and treatment of Alzheimer's disease presents a great opportunity to innovate and adapt our services to incorporate the next exciting development in the field of dementia [46]. Almost 100 treatments are currently being investigated, often targeting individuals earlier in the disease process, and a very promising phase II work has been published about the antibody aducanumab [47]. Today, health services in Europe would not be prepared to treat patients with Alzheimer's disease that are subsidized by an effective treatment [48]. It seems likely that interventions will be available in the near future for people diagnosed with prodromal dementia. This would fundamentally transform how the Alzheimer's disease is perceived, diagnosed, and managed.

There are two key points: [1] equity in access of patients and caregivers and [2] specific preparation of professionals. There will be a need for substantial education and training for primary and secondary care professionals about new disease-modifying treatment for Alzheimer's disease. In primary care this would need to focus on early symptoms and risk factors. In secondary care it would cover the safe and effective use of biomarkers. A reconfigured service would require seamless collaboration between disciplines, patient groups, and specialties in order to expand the dementia-focused clinical services to include an Alzheimer's disease service. While many people currently present with moderate or severe dementia, in the future, hopefully the majority of people will be diagnosed much earlier, even in the prodromal/preclinical stages. A distinct approach for the preclinical, prodromal, and dementia stages of Alzheimer's disease would be necessary.

- Healthcare systems will need to identify and engage with prodromal populations who might benefit from such interventions. These people may not be in contact with health services or, if they are, this will not be because of Alzheimer's disease.
- Realistic planning is needed now to direct the evolution of services to optimize appropriate patient access and prepare protocols for phase IV testing of these treatments to inform real-world practice and commissioning decisions.

Although in the near future we will have treatment for Alzheimer's disease, the social-health system will have to continue providing assistance in stages of dementia, in an integral and personalized way, adapting to the specific needs of each case that is determined by the type of dementia (frontotemporal, dementia by bodies of Lewy, and Korsakoff syndrome), characteristics of the patient, or caregiver environment.

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