The Italian fund for Alzheimer's and other dementias: strategies and objectives to face the dementia challenge

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Abstract

The Italian Fund for Alzheimer's and other dementias was approved and signed in December 2021. The Fund is financed with 15 million euros in three years. The main goal is to provide new strategies in the field of dementia with a Public Health perspective. The Fund includes eight main activities that will be monitored and supervised by the Italian National Institute of Health: 1) development of a guideline for the assessment, management and support for people with dementia and their families/carers; 2) updating of the Dementia National Plan (DNP); 3) implementation of the documents of the DNP; 4) conducting surveys dedicated to the Italian Dementia Services; 5) promotion of dementia prevention strategies; 6) training strategies for healthcare professionals, families and caregivers; 7) creation of a National Electronic Record for Dementia; 8) evaluation and monitoring of activities promoted by Regions and Autonomous Provinces in the field of dementia, together with the dementia National Permanent Table. These activities are outlined in detail in the present paper.

INTRODUCTION

Dementia represents a global challenge for public health [1]. Age is the main risk factor for dementia and it was estimated that nearly 14 million elderly individuals (age >65) live in Italy [2]. Around 3 million people are directly or indirectly involved in dementia care, and 1.2 million are the individuals with dementia [3]. In Italy, the social and healthcare costs for dementia care are estimated at around 10-12 billion euros per year [4].

Several international public health initiatives world-wide urged countries to develop and/or implement their national dementia plans to place structural, financial, and human resources for giving adequate support and care management for people with dementia [5].

While several research and public health initiatives are noteworthy in the field of dementia, relevant issues still negatively affect the management of dementia care in Italy. Indeed, strengthening interventions are needed to improve every aspect of dementia care management. In contrast, the different aspects of dementia management are still addressed separately, thus significantly

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limiting the possibility of actually implementing an integrated approach to dementia.

The Ministry of Health (MoH) in close cooperation with the Italian National Institute of Health (Istituto Superiore di Sanità, ISS), the Regions, and the three major National families and patients associations (www.alzheimer.it, www.alzheimer-aima.it, www.alzheimerunitiitalia.it) approved the Italian Dementia National Plan (DNP) in 2014, also to address some of the mentioned issues, which were already under observation [6].

More recently, the law 30 December 2020 n. 178, article 1, paragraph 330, established the Alzheimer's and other dementias Fund, with funding of 5,000,000 euro annually for a three-year plan (2021-2023). The Fund's Decree, concerning specific regulations, was approved by the State-Regions Conference on December 2, 2021, and signed by the MoH and Ministry of Economy (MoE) on December 23, 2021 [7].

To guarantee the monitoring and implementation of the DNP and related documents produced by the Permanent National Table (NPT) for dementias coordinated by the MoH, the decree establishes the criteria and methods for the use of the Fund.

In application of the DNP and according to the law no. 178 of 2020, Regions and Autonomous Provinces (APs) will develop three-year action plans, to address specific critical areas in the diagnosis and care of patients with dementia through experimental and innovative solutions. Five main research areas of interest have been identified (*Table 1*). The ISS, as a component of the Permanent National Table for dementias, will not only support the definition of the three-year action plans of the Regions and APs but will also contribute to their monitoring and implementation. The eight main activities, indicated by the Plan, will be briefly described below and in the *Table 1S* available online as Supplementary Material.

ACTIVITY 1 - TO DEVELOP A GUIDELINE FOR THE ASSESSMENT, MANAGEMENT AND SUPPORT FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES/CARERS

The MoH, with the support of the ISS, provides the development of a guideline on the diagnosis and treatment of patients with dementia within the National Guidelines System (SNLG), based on the best scientific evidence of the physiopathology and treatment options and good clinical practices on dementia. All relevant National institutions will be involved as part-

ners or stakeholders together with patients and families associations and a number of scientific societies.

The guideline will offer a quality assessment of the most relevant and high-quality scientific literature and an evaluation of the benefits/risks assessment of pharmacological and non-pharmacological treatments for dementia. Based on the methodology proposed by the *NGD Methodological Manual* [8], an adaptation and update of the document NG97 published by the National Institute for Health and Care Excellence (NICE) from the UK in 2018 will be proposed.

ACTIVITY 2 - UPDATE OF THE ITALIAN DNP

The MoH, with the support of the ISS and the dementia NPT, will update the Italian DNP. The Italian DNP currently in use consists of four actions and 17 related objectives. It will be updated following recent scientific advances in dementia prevention, early diagnosis and the organization and provision of care services. It will be also updated taking into account the global action plan on the public health response to dementia 2017-2025 adopted by the 70th World Health Assembly, which represents the most recent and important international commitment to improve the lives of people with dementia, their caregivers, and their families.

In addition, various questions on dementia will be addressed, from a public health perspective. Some emerging aspects of dementia such as early onset dementia, dementia in migrants and cognitive deficits following COVID-19 will be part of the DNP update.

ACTIVITY 3 - IMPLEMENTATION OF THE DOCUMENTS OF THE DNP

The MoH, through the NPT, and with the technical support of the ISS, has produced the four following documents between 2017 and 2020 [9]:

a. *National Guidance on diagnostic and therapeutic care pathways for dementias*
b. *National Guidance on the use of information systems to characterize dementia*
c. *National Guidance for Building Dementia Friendly Communities*
d. *Recommendations for the governance and clinical care in the treatment of dementia*

Objective of this activity is to ensure that Regions and APs included in their local planning the recommendations coming from these documents, at the same time evaluating their actual implementations.

Table 1

Five areas of interest in the diagnosis and care of patients with dementia to implement research in public health with experimental or observational study designs in order to increase scientific knowledge

Improving the early diagnosis of Minor Neurocognitive Disorder/Mild Cognitive Impairment and developing a prediction model of conversion to dementia that would be useful for clinical practice
Timely diagnosis of the Major Neurocognitive Disorder
Experimenting, evaluating and disseminating telemedicine interventions to ensure continuity of care in different dementia care settings
Experimenting, evaluating and disseminating of tele-rehabilitation to provide rehabilitation models that guarantee a better participation, inclusion, and quality of life of patients with dementia and their families/caregivers
Experimenting, evaluating and disseminating of psycho-educational, psycho-social, and cognitive interventions in patients with dementia

ACTIVITY 4 - SURVEYS DEDICATED TO THE DEMENTIA SERVICES

Three surveys will be carried out in the main health facilities for the treatment and management of dementia located in Italy: Centres for Cognitive Disorders and Dementias (CCDDs), nursing homes (NHs), and dementia day centres (DDCs). Previously, between 2014 and 2018, three surveys were conducted to characterize dementia services in Italy, obtaining an online map of dementia facilities available on the "Dementia Observatory" website [10]. An update of the online map appears urgent, also considering new scenarios in the organization of health services due to the future impact of the possible approval of new drugs, at European and Italian level.

Representatives from all Regions and APs will be called to participate in updating all dementia service listings. A questionnaire will be addressed to all dementia services with the aim of developing structure, process, and outcome indicators to supervise the levels of assistance and care management in all Italian territories. The results from the new surveys will allow to have an update of all structural and human resources highlighting the disparities between different Regions and territories in the field of prevention, diagnosis, management and pharmacological, cognitive, and psychosocial treatments.

ACTIVITY 5 - PROMOTE PRIMARY AND SECONDARY PREVENTION STRATEGIES

Although age is the main and unmodifiable risk factor for dementia, a growing evidence on dementia prevention is now available. Seven potentially modifiable risk factors (low education attainment, diabetes, mid-life hypertension, mid-life obesity, smoking, depression and physical inactivity) were identified in 2014 by the *Lancet Commission* [11]. The number of Alzheimer's disease (cases attributable to potentially modifiable risk factors) has been estimated to be around a third of AD cases worldwide. The collaboration between the Dementia Observatory and the PASSI (Progressi delle Aziende Sanitarie per la Salute in Italia) surveillance system has yield to an overview of the Italian regional distribution on the seven modifiable risk factors, highlighting a huge variability; according to this data, 6.4% and 6.5% case of dementia and vascular dementia, respectively, would be avoidable by reducing of 20% the prevalence of all those factors [12]. Recently, the *Lancet Commission* updated to twelve the modifiable risk factors for dementia, by further including: air pollution, alcohol consumption, hearing impairment, traumatic brain injury, and low social contact [13].

The main goal of this activity is to provide policy makers with the strongest scientific evidence on primary and secondary prevention strategies for dementia. Furthermore, information campaigns must be designed and implemented to facilitate the inclusion of marginalized people and those with specific risk factors. Estimates of cases with dementia and MCI will be defined for each Region and APs. Finally, with the support of the PASSI surveillance system and the statistics of the National Institute of Statistics (ISTAT), the prevalence of the risk factors attributable to dementia in each territory will be assessed. Moreover, a review of the regional prevention plans will be performed for identifying which risk factors related to dementia are targeted. Together, all these activities will promote primary and secondary prevention strategies for dementia, integrating this information within regional plans, the National Plan for Prevention, and the National Plan for Chronic Diseases.

ACTIVITY 6 - EDUCATION AND TRAINING OF HEALTHCARE PROFESSIONALS AND FAMILY MEMBERS OF PATIENTS WITH DEMENTIA

The management of patients with dementia requires the integrated expertise and skills of several specialists in dementia care. In addition, other specialists such as nutritionists, physiotherapists, and social workers are crucial professionals equally involved. However, caregivers and family members still play a key role in managing their loved ones with dementia. In our country, partners and sons still represent the main caregivers of dementia patients. However, recent data show that caregivers are less represented by family members in favour of paid staff [14].

A new National survey on 10.000 caregivers will be conducted to investigate caregivers' conditions in caring for people with dementia and to establish a training path for family members of these patients. Subsequently, focus groups will be conducted to better understand economic and social needs of the families of patients with dementia after the COVID-19 pandemic.

The focus groups and the survey will involve all Italian Regions and will be aimed at allowing the development of appropriate training courses for healthcare professionals involved in the management of dementia and for the families of patients affected by dementia. In particular, three training courses will be carried out: for caregivers, for family members and for healthcare professionals involved in rehabilitation (occupational therapists, psychologists, physiotherapists).

ACTIVITY 7 - CREATION OF A NATIONAL ELECTRONIC RECORD FOR DEMENTIA

The design and implementation of an electronic medical record for data collection of patients with dementia as a part of a National Dementia Information System is the major objective of this activity.

In this project, the electronic medical record will be defined for all Regions and APs and its implementation will be promoted in current clinical practice. The source of these clinical data will be integrated with the current healthcare administrative databases working at regional level and connected with the New Health Information System (NHIS) of the MoH.

In Italy, there are few and different regional experiences in the use of electronic medical records. In Veneto the implementation of the electronic medical record in CCDDs (CaCeDem) has already been promoted while a pilot project on four CCDDs is underway in Lazio.

The National Electronic Record for Dementia and the use of data from NHIS are propaedeutic for a Na-

tional Dementia Information system. In this regard, an algorithm for the identification of cases of dementia by using four sources of data of the NHIS has been validated in four Italian regions [15]. Although a standardized and validated methodology is now easily accessible, this experience showed the opportunity to consider more sources of data of the NHIS, and to replicate the study on a population covering all the spectrum of dementia, form mild to severe forms. Therefore, a validation study is planned with this aims in two Italian Regions, in a primary healthcare setting.

ACTIVITY 8 - EVALUATION AND MONITORING OF THE REGIONAL PLANS/PROJECTS

The ISS Dementia Observatory, as a member of the National Permanent Table, will contribute to the evaluation and monitoring of the interventions provided in the three-year plan as required by article 3 of the Decree of the Ministry signed by the MoH and the MoE on December 23, 2021, and also reported in the technical annex. The evaluation and monitoring of the regional activities will be carried out through the acquisition of half-yearly reports. Each Regional Plan will be assessed and monitored according to the five areas of interest. In addition, the ISS will encourage the collaboration between regions and APs that will submit projects with similar and/or overlapping topics (*Table 1*).

FUTURE PERSPECTIVES

There is a need to implement public health initiatives regarding financial and structural support to services, as well as to plan additional human resources dedicated to dementia. With the aim of implementing and monitoring the Italian DNP, the Fund we have been presenting represents the first Public Health initiative, in Italy, that allocates funding of this magnitude (15 million euro) for dementia. The WHO Global plan on dementia has urged governments to develop national policies on dementia by 2025 [1] and with this specific approach, Italy aligns itself with the standard of other advanced countries. Obviously, since in Italy the costs of dementia have a huge economic impact on the health system, the funding currently allocated is not sufficient to carry out all the actions necessary to implement diagnostic tools and infrastructures, treatment options, and care pathways for patients with dementia. However, this initiative represents the first step towards the achievement of adequate resources capable of addressing the upcoming challenges on dementia. The management of patients with dementia requires a multidisciplinary and multi-professional approach, with continuous collaboration between several healthcare professionals as well as those working in many sectors other than health. This cooperative and integrated approach aims to improve the synergistic effect of the quality of care and, consequently, to improve the quality of life of patients with dementia and their families.

Conflict of interest statement

The Authors have no conflicts of interest to declare.

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