# COMMENTARY

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## The Italian Dementia National Plan

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#### Abstract

The Italian Dementia National Plan was formulated in October 2014 by the Italian Ministry of Health in close cooperation with the regions, the National Institute of Health and the three major national associations of patients and carers. The main purpose of this strategy was to provide directive indications for promoting and improving interventions in the dementia field, not limiting to specialist and therapeutic actions, but particularly focusing on the support of patients and families throughout the pathways of care. Four main objectives are indicated: 1) promote health- and social-care interventions and policies; 2) create/strengthen the integrated network of services for dementia based on an integrated approach; 3) implement strategies for promoting appropriateness and quality of care; and 4) improve the quality of life of persons with dementia and their families by supporting empowerment and stigma reduction. These objectives and the pertaining actions are described in the present paper.

#### Key words

- dementia
- Alzheimer's disease
- national plan
- Italy
- public health
- national strategies

Italy is currently the second European country (after Germany) with the highest proportion of older people (aged 65 years or more). It has been estimated that more than 12 millions of elderly persons lived in Italy in 2013, accounting for the 21.2% of the total national population. Accordingly, Italy ranks second in Europe as regards to the aging index (calculated as the number of people aged 65 and over per 100 youths under age 15), with 144 elders per 100 young people. This ratio has been projected to almost double by 2051 [1].

Population aging is leading to a dramatic increase in the prevalence of most of age-related, chronic diseases, including dementia [2, 3]. To date, more than 1 million of individuals affected by dementia – including 600 000 subjects diagnosed with Alzheimer's disease (AD) – live in Italy [4]. In parallel, more than 3 millions of Italian persons are directly of indirectly involved in the assistance of people living with dementia, with estimated social and health-care costs of 10-12 billion euro per year [5]. As in other developed countries, these numbers are expected to significantly increase in the upcoming decades [2, 3, 6].

It is noteworthy that Italy has been the first country to introduce "memory clinics" in the health-care scenario, thus activating centers specifically dedicated to the diagnosis and management of AD and other dementias. In 2000, approximately 500 Alzheimer's Evaluation Units (UVA) were constituted by the Ministry of Health in all the Italian regions aiming at coordinating, with the support of general practitioners, the complex process of care of individuals affected by dementing illnesses. To date, nearly 2000 health professionals (neurologists, geriatricians, psychiatrists, psychologists, rehabilitation professionals, social workers, nurses, and administrative staff) work in UVA. These units still play a central role in the network of health-care and social-care services devoted to dementia.

Beside these meritorious initiatives, several relevant issues still negatively affect the management of the "dementia" problem in Italy. In particular, there are profound disparities in terms of available resources and services across the individual Italian regions, resulting in a substantial lack of national standards. As a result, centers of clinical excellence coexist with services that need urgent adaptive and strengthening interventions. The different aspects of dementia management (*i.e.*, diagnosis, assistance, rehabilitation) are still approached in separate moments and processes, thus strongly limiting the possibility of actually implementing an integrated approach to dementia. This model, based on

converging health- and social-care pathways, has already been shown to be effective and efficient in the management of other chronic-degenerative medical conditions. Along the same lines, there is still a scarce integration and collaboration between hospitals, primary care, community services and home care, potentially negatively affecting the continuity of care required by demented patients [7, 8].

Aiming at improving the complex process of dementia care by targeting these major issues, the first "dementia national plan" was formulated in October 2014 by the Italian Ministry of Health in close cooperation with the regions (health and social sectors), the Istituto Superiore di Sanità (National Institute of Health) and the three major national associations of patients and carers (www.alzheimer.it; www.alzheimer-aima.it; www. alzheimeruniti.it) [9]. In Italy there are 19 regions and 2 autonomous provinces (Trento and Bolzano) with a range of inhabitants included between about 130 000 in the region Val d'Aosta and 10 000 000 in Lombardy. The main purpose of this strategy was to provide directive indications for promoting and improving interventions in the dementia field, not limiting to specialist and therapeutic actions, but particularly focusing on the support of patients and families throughout the pathways of care. In the plan, four main objectives are indicated, as described below in the article. For each objective, a series of pertaining actions is then reported, as resumed in Table 1.

The objective are also reported below:

• Objective 1. Promote health- and social-care interventions and policies

This objective includes three main purposes:

- a) increase knowledge of the general population, patients, families, and health professionals concerning prevention, timely diagnosis, treatment and care of dementias:
- b) foster research to improve the care and quality of life of people with dementia and their carers; and
- c) organize and implement epidemiological and surveillance activities in order to better plan and support dementia care.
- Objective 2. Create/strengthen the integrated network of services for dementia based on an integrated approach

Two priorities are specifically addressed:

- a) promoting prevention, timely diagnosis and taking charge of persons with dementia by encouraging intersectoral policies; and
- b) homogenize dementia care, reduce care fragmentation, devoting special attention to social disparities and conditions of social and health fragility/vulnerability.
- Objective 3. Implement strategies for promoting appropriateness and quality of care

Three main points are indicated:

- a) identifying and implementing strategies pursuing the rationalization and appropriateness of available resources in order to improve the delivery and monitoring of the services provided;
  - b) improve the quality of care delivered at home and

within residential facilities; and

- c) promote the appropriate use of pharmacological treatments, technologies and psychosocial interventions
- Objective 4. Improve the quality of life of persons with dementia and their families by supporting empowerment and stigma reduction

Three crucial aspects are pointed out:

- a) deliver correct information to patients and families concerning dementias and available services to allow timely diagnosis;
- b) improve the quality of life of people with dementia and their social integration, also by promoting strategies of personal and familial engagement; and
- c) empowering persons and communities involving families and associations in services planning.

The dementia national plan has been approved in October 2014 by the State-Region Conference [9]. During the first year of emanation, the formal implementation of the plan will be monitored at the regional and national level. The adoption of the plan will be then evaluated by considering measures and indicators identified in the context of activities of permanent confrontation and monitoring, as contemplated by Objective 1.

Beside the above-mentioned objectives, several other priorities are indicated and will represent matter of future discussion and tailored actions:

- identification of quality standards and measures for monitoring activities;
- elaboration of guidelines concerning crucial aspects such as diagnosis communication, informed consent, and use of legal options;
- discussion on ethical issues such as advance directives and accessibility to palliative care;
- formulation of guidelines dedicated to patients developing dementia in working age; and
- focus on early onset dementias.

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**Table 1**Objectives, main purposes and actions indicated by the Italian Dementia National Plan

#### Objective 1. Promote healthand social-care interventions and policies

#### Objective 2. Create/ strengthen the integrated network of services for dementia based on an integrated approach

## Objective 3. Implement strategies for promoting appropriateness and quality of care

# Objective 4. Improve the quality of life of persons with dementia and their families by supporting empowerment and stigma reduction

#### Main purposes

- a) Increase knowledge of the general population, patients, families, and health professionals concerning prevention, timely diagnosis, treatment and care of dementias
- b) Foster research to improve the care and quality of life of people with dementia and their carers
- c) Organize and implement epidemiological and surveillance activities in order to better plan and support dementia care

#### Main purposes

- a) Promoting prevention, timely diagnosis and taking charge of persons with dementia by encouraging intersectoral policies
- b) Homogenize dementia care, reduce care fragmentation, devoting special attention to social disparities and conditions of social and health fragility/vulnerability

#### Main purposes

- a) Identifying and implementing strategies pursuing the rationalization and appropriateness of available resources in order to improve the delivery and monitoring of the services provided
- b) Improve the quality of care delivered at home and within residential facilities
- c) Promote the appropriate use of pharmacological treatments, technologies and psychosocial interventions

#### Main purposes

- a) Deliver correct information to patients and families concerning dementias and available services to allow timely diagnosis
- b) Improve the quality of life of people with dementia and their social integration, also by promoting strategies of personal and familial engagement
- c) Empowering persons and communities involving families and associations in services planning

#### Actions

- 1.1. Promoting strategies of primary and secondary prevention
- 1.2. Mapping available services and resources at national and regional level with the participation of local communities
- 1.3. Promoting interventions aimed at constituting an integrated regional care network based on agreed quality standards
- 1.4. Including the achievement of dementia-related objectives when evaluating general directors and managers of identified services
- 1.5. Supporting and coordinating national research in public health
- 1.6. Establishing a national table for permanent confrontation and for monitoring the implementation of the plan
- 1.7. Creating a national dementia information system

#### Actions

- 2.1. Creating, reorganizing, and strengthening of a network of services and resources in order to configure an integrated system ensuring diagnosis, timely take in charge, continuity of care, and a correct approach to demented patients and their families
- 2.2. Organizing an integrated network of services meeting specific quality criteria with particular attention to: dimensioning resources according to local needs; networking the different professionals consenting a multidimensional and multidisciplinary approach to dementia; accessibility of services; sharing and implementing integrated pathways of care
- 2.3. Formulating a specific service charter providing information on available services in order to ensure the transparency of the offer

#### Actions

- 3.1. Developing and updating guidelines and consensus documents concerning the main preventive and care priorities, in the framework of the National System of Guidelines and involving scientific associations; monitoring the diffusion and implementation of guidelines by adopting agreed indicators
- 3.2. Promoting the training of professionals working in health- and social-care services, also developing shared activities involving general practitioners and carers; promoting systematic audit activities to enhance self-assessment of professionals and improve clinical practice

#### Actions

- 4.1. Promoting national and regional campaigns to raise awareness of the general population, decrease social stigma, and support respect and dignity of people with dementia
- 4.2. Supporting active involvement and awareness of families/caregivers
- 4.3. Monitoring health conditions and quality of life of carers
- 4.4. Sustaining association and volunteer networks
- 4.5. Supporting opportunities facilitating the contact with persons with dementia and their relatives, promoting informal support



- Istituto Nazionale di Statistica. Rapporto annuale 2014. La situazione del Paese. ISTAT; 2014. Available from: www.istat.it/it/archivio/120991.
- Alzheimer's Disease International. World Alzheimer Report 2009. The Global Prevalence of Dementia. ADI; 2009. Available from: www.alz.co.uk/research/world-report-2009.
- World Health Organization Alzheimer's Disease International. Dementia: a public health priority. WHO-ADI;
  2012. Available from: www.who.int/mental\_health/publications/dementia\_report\_2012.
- ALCOVE Project. Alzheimer cooperative valuation in Europe. Available from: www.alcove-project.eu.
- Wimo A, Jönsson L, Gustavsson A, McDaid D, Ersek K, Georges J, Gulácsi L, Karpati K, Kenigsberg P, Valtonen H. The economic impact of dementia in Europe in 2008cost estimates from the Eurocode project. *Int J Geriatr Psychiatry* 2011;26(8):825-32.
- Alzheimer's Disease International. World Alzheimer Report 2010. The Global Economic Impact of Dementia. ADI; 2010.

- Available from: www.alz.co.uk/research/world-report-2010.
- 7. Callahan CM, Boustani M, Sachs GA, Hendrie HC. Integrating care for older adults with cognitive impairment. *Curr Alzheimer Res* 2009;6(4):368-74.
- Pimouguet C, Bassi V, Somme D, Lavallart B, Helmer C, Dartigues JF. The 2008-2012 French Alzheimer plan: a unique opportunity for improving integrated care for dementia. J Alzheimers Dis 2013;34(1):307-14.
- D. Italia. Presidenza del Consiglio dei Ministri Conferenza Unificata. Provvedimento 30 ottobre 2014. Accordo, ai sensi dell'articolo 9, comma 2, lett. c) del decreto legislativo 28 agosto 1997, n. 281, tra il Governo, le regioni e le province autonome di Trento e di Bolzano, le province, i comuni e le comunità montane sul documento recante: «Piano nazionale demenze. Strategie per la promozione ed il miglioramento della qualità e dell'appropriatezza degli interventi assistenziali nel settore delle demenze». (Rep. atti n. 135/CU). Gazzetta Ufficiale n. 9, 13 gennaio 2015.