

Community support programmes for people affected by dementia in Athens, Greece

Overview

Faced with a rising incidence of dementia among Greece's ageing population and relatively few targeted health and social services, the Athens Association of Alzheimer's Disease and Related Disorders (AAADR) was founded to support those affected by dementia. Created by health professionals and informal caregivers in Athens, the organization developed as a platform to begin providing services lacking from the National

Insurance Plan. This has included the introduction of a range of free services such as neuropsychological assessments, cognitive training, physical activity interventions and nonpharmacological therapies delivered out of four AAADR-run day care centres located across Athens. Alongside these efforts, patients, caregivers and providers involved with AAADR have advocated for greater government action to fill gaps in services and address health system bottlenecks.

In 2013, after extensive public campaigns run over several years, the government established a multistakeholder working group to develop a national dementia action plan; the resulting document was accepted in late 2014. With a formal government commitment now in place, AAADR is hopeful that funding for their services, currently primarily financed through donor funds, will become more sustainable and those affected by dementia will have improved access to care.

Problem definition

Changing demographics in Greece have contributed to a trend of population ageing, with 19% of the population over the age of 65 in 2011.¹ This has contributed to increasing morbidity trends and prevalence of chronic diseases, including dementia and more specifically Alzheimer's disease.² This growing burden of illness is evident from the rising disability-adjusted life years (DALYs) for Alzheimer's which increased from 733 per 100 000 population in 2000 to 1006 per 100 000 in 2010.² Without a national dementia plan in place, this growing trend placed significant pressure on health services. Unfortunately, these trends have paralleled reductions in both health and social care budgets due to austerity measures following the 2008 financial crisis. In 2008, health

services accounted for 10.2% of the gross domestic product (GDP). However, over the next two years this fell by 1.2%, representing a loss of US\$ 2.6 billion at purchasing power parity.³ In effect, health services delivery for dementia and Alzheimer's was not comprehensive, with social health insurance covering only a few medical services and providing limited support for informal caregivers who were left to provide the majority of care (Box 1).

Health service delivery transformations

Timeline of transformations
With a shifting demographic and lack of comprehensive services available for dementia patients, the Athens Association of Alzheimer's Disease and Related Disorders (AAADR) was founded in 2002 as

Box 1

What problems did the initiative seek to address?

- Shifting demographics towards an ageing population.
- Increasing prevalence of dementia and Alzheimer's disease.
- Limited scope of services available for the treatment of dementia.
- Lack of support for caregivers of patients with dementia.
- Inadequate resources available for dementia care due to austerity measures.

a nonprofit organization dedicated to addressing health and social challenges related to dementia (Table 1). In 2007, wanting to fill observed gaps in services delivery for people

with dementia and their caregivers, AAADRDR opened their first day care centre to provide a variety of social and support services not currently available within the existing health system. Most recently, in 2014, lobbying efforts have led the government to adopt the National Action Plan for Dementia. Actions are currently being taken to realize the goals laid out in the Plan and AAADRDR continues to play a pivotal role in delivering dementia related services.

Description of transformations

Selecting services. AAADRDR has worked to expand the scope of services that are available to people with dementia in order to more fully address the entire spectrum of the condition. AAADRDR's day care centres for people with dementia offer free services including neuropsychological assessment,

cognitive training, physical activity interventions and a range of nonpharmacological therapies such as speech, occupational or art therapy. Home care services are available to people unable to access centres. In addition, AAADRDR organizes educational programmes and support services for caregivers such as support groups, individual counselling and information on caring for people with dementia.

Designing care. AAADRDR takes advantage of the latest available evidence on dementia to offer services aligned with best known practices. AAADRDR day care centres offer a range of programmes that can be adapted to individual needs and circumstances; people with dementia and their caregivers help to design the direction of care by choosing services applicable to their needs from a general pool of offered services.

Organizing providers. AAADRDR day care centres house a multidisciplinary staff including physicians, psychologists, speech therapists, social workers, nurses and physiotherapists. Centres also rely heavily on trained volunteers and medical students. Staff members work as a team to offer a holistic package of services within centres. Co-location of services allows people with dementia and their caregivers to more easily access a wide variety of health professionals. Further, a home care programme ensures access to psychologists and nurses for those unable to reach the centres.

Referrals to services provided by AAADRDR can be made by general practitioners, neurologists or other specialists. AAADRDR belongs to a network linking 29 independent organizations addressing dementia. As part of this network, AAADRDR is able to refer patients to other relevant community programmes and organizations.

Table 1

What were the chronological milestones for the initiative?

2002	AAADRDR founded by providers and caregivers as a nonprofit organization to advocate for the needs of people affected by dementia and fill observed gaps in available dementia-related care.
2004	AAADRDR begins running dementia awareness campaigns in Athens and across Greece.
2007	First dementia day care centre operated by AAADRDR opened in municipality of Pangrati; three additional centres later opened.
2009	Greek Alzheimer's Initiative signature collection campaign launched to push the government to develop a national dementia strategy.
2013	Working group to draft a national dementia strategy formed by the Ministry of Health.
2014	National Action Plan for Dementia accepted by the government.
Present	Actions to realize the goals laid out in the Plan underway; AAADRDR continues to support care improvements for people affected by dementia.

Managing services. A seven-member multistakeholder board elected every three years oversees and manages AAADRDR activities with input from a scientific advisory team. AAADRDR is in charge of running its four day care centres and coordinating services for people with dementia and their caregivers in partnership with municipal governments. Centres and other services are funded through the combined support of the European Commission's European Social Fund, national and local governments, as well as AAADRDR membership fees and donations.

Improving performance. Ongoing monitoring of day care centre activities and their impact on health outcomes is conducted by the centres in order to assess benefits for service users. Satisfaction surveys are also carried out to ensure high-quality service provision that meets people's needs

Table 2

How was the delivery of health services transformed through the initiative?

Before	After
Selecting services	
Limited services available for people with dementia; some drug treatments offered but no alternative treatments, prevention services or social care available.	Holistic package of services to target full spectrum of dementia offered through day care centres; social support services available to people with dementia and their caregivers; some home care services available.
Designing care	
No involvement of people with dementia or their caregivers in the treatment or management of their condition.	Services delivered are chosen through assessing latest available evidence; people with dementia and their caregivers choose and define personalized care packages from a wide range of services offered by AAADRDRD.
Organizing providers	
Primary care providers are the main point of contact for people with dementia.	Multidisciplinary team of professionals and volunteers co-located in day care centres; psychologists and nurses conduct home care visits; primary care providers and other specialists continue to provide medical services externally and provide referrals to AAADRDRD centres. ⁴
Managing services	
Management of services delivery for people with dementia largely non-existent.	AAADRDRD board oversees and manages the organization; AAADRDRD day care centres run in partnership with local municipalities; necessary funding sourced from the European Commission, national government and private donations.
Improving performance	
No specialized training on caring for people with dementia available.	Ongoing monitoring of services conducted by day care centres; user satisfaction surveys provide feedback on quality of services; centre volunteers complete two-month training courses; online training programme run for private caregivers; wide variety of educational materials, seminars and workshops offered to informal caregivers.

and expectations. A number of resources and learning services are in place to expand the skills of health professionals, patients and caregivers. This includes a two-month training programme for centre volunteers, a self-study e-learning programme for professional caregivers and several programmes to improve the health literacy and capabilities of informal caregivers.

Engaging and empowering people, families and communities
Cofounded by people with dementia and their caregivers, AAADRDRD is well connected to its target population. Relatives and caregivers of people with dementia continue to direct the organization through representation on AAADRDRD's governing board. This, along with AAADRDRD's extensive work with grassroots level volunteers, has ensured services are highly

relevant and community orientated. For example, the Alzheimer Café is a support group run by the day care centres. The Café brings people together for exchanging information about dementia, provides a source of emotional support for participants and promotes socialization among peers. Other group programmes run by the centres also encourage people to interact through group therapy sessions. Many other

centre activities, including memory training, are light-hearted and fun for participants. Expanding its community network further, AAADRDR also works in partnership with KAPI centres (popular government run senior centres) to raise awareness about dementia and to promote early diagnosis and treatment among senior citizens.

Raising public awareness on dementia has been a principle focus of AAADRDR's work and public campaigns have helped bring the issue of dementia into the public spotlight and onto the government's agenda. Awareness-raising activities have included, for example, an annual Memory Walk through central Athens held on World Alzheimer's Day and signature collection campaigns petitioning for government action. AAADRDR also publishes a number of educational resources online, as well as a tri-annual newsletter on the organization's activities. While dementia had previously been a stigmatized condition in Greece, education on the issue through awareness-raising efforts led by AAADRDR is helping to change public perception.

Health system enabling factors

Municipal governments support the running of established day care centres in their districts and the Ministry of Health provides some additional support. Recent changes at the government level, including the adoption of the National Action Plan for Dementia, signal a shift in the policy environment in support of AAADRDR's activities. In addition to political support, a number of other system factors must be given adequate attention for sustainability to be realized, such as the provision of a sufficient number of human resources, a dependable source of long-term funding and development of needed infrastructure.

Outcomes

Outcomes recorded from research conducted in the Pangrati day care centre (Box 2) provide an example of the impact of AAADRDR services.

Box 2

What were the main outcomes achieved by the Pangrati day care centre between 2007 and 2010?

- Around 2000 people attended the memory clinic between 2007 and 2010, allowing them to benefit from neurological examination and neuropsychological assessment.
- Nonpharmacological support programmes offered by the centre were attended by 105 people with dementia and 64 caregivers per month.
- Home care services were offered to 80 people with dementia and 70 family caregivers per month.
- Feedback questionnaires conducted with caregivers indicated largely positive experiences and feelings regarding centre services.
- Approximately 150 volunteers completed the two-month training programme offered by the centre.

Change management

Key actors

Strong grassroots action has led the way in developing and delivering dementia care services in Greece and achieved widespread support for the initiative. Key actors to first mobilize included a small group of caregivers of people with dementia who began advocating for increased attention on the lack of dementia services. This group grew to include the support of a number of concerned health professionals and like-minded nongovernmental organizations (NGOs) across Greece (Box 3). More recently, the initiative has established the support

of both national and municipal governments and, in 2013, the national government established a multistakeholder working group, including representatives from AAADRDR, to develop a national dementia action plan. While gaining political support required extensive advocacy efforts over many years by AAADRDR members, these efforts finally paid off and the initiative now benefits from political support.

Box 3

Who were the key actors and what were their defining roles?

- **AAADRDR.** NGO with 4500 members working on raising awareness of dementia in Greece; led by a seven-member board elected every three years; runs four day care centres in the Athens region; relies heavily on volunteers for successfully implementing activities.
- **Dementia network.** United network of 30 or so NGOs across Greece working on issues related to dementia; partnerships between individual network organizations (including AAADRDR) allow members to support each other's work.
- **National government.** Currently funds 30% of AAADRDR day care centre costs; recently approved a national dementia plan and appointed a steering committee to guide its implementation.
- **Municipal governments.** Assist AAADRDR in the running of day care centres within their local areas.

Initiating change

As a disease-specific organization, AAADRDR was quickly able to establish links with similar groups both within Greece and

internationally. Extensive networking and partnership opportunities helped to raise AAADR's profile and gather support behind the urgent need to address increasing dementia in Greece. AAADR currently has almost 4500 active members supporting its work.

To drive national action on dementia, extensive public awareness campaigns and government lobbying efforts eventually succeeded in pushing the government to develop the National Action Plan for Dementia.

Implementation

Running of day care centres in Athens is coordinated and managed by AAADR, overseen by their multistakeholder board. AAADR privately secured operating funds from a variety of sources (primarily the European Commission) to enable the set-up and running of their day care centres. These centres rely on volunteers to help keep their programmes and services running. Strong links and good

working relationships exist between professionals, volunteers and users of services which helps to ensure smooth running of the centres.

Implementation of the National Action Plan for Dementia has not yet begun as this document was only recently approved by the government. A national dementia committee has, however, been established by the government to help guide implementation of the Plan.

Moving forward

It is hoped the newly accepted National Action Plan for Dementia will provide more structure in the development of dementia-related services delivery moving forward. Having a national plan in place should strengthen government commitment to dementia and help to secure stable sources of financing, thus contributing to improvements in services delivery.

Highlights

- Highly motivated actors directly affected by dementia or working in related fields played an important role in identifying and understanding gaps in services delivery.
- AAADR, as a specialized, recognizable agency, quickly built a large network of supporters and established meaningful connections within the existing national and international arena to raise recognition of the needs of dementia patients.
- Sustainability of the initiative relies on growing the government's commitment, securing funding and resources, and continuing investment in education for both providers and caregivers.

1 World Health Organization. (2015). *European Health for All Database*. Retrieved from <http://data.euro.who.int/hfad/>

2 Institute for Health Metrics and Evaluation. (2014). *Global burden of disease cause patterns*. Retrieved from <http://vizhub.healthdata.org/gbd-compare/arro>

3 Simou, E., & Koutsogeorgou, E. (2014). Effects of the economic crisis on health and healthcare in Greece in the literature from 2009 to 2013: A systematic review. *Health Policy* 115(2-3): 111-9.

4 Sakka, Paraskevi. (2010). Towards a Dementia Action Plan in Greece. [PowerPoint slides]. In 20th Alzheimer Europe Conference *Facing Dementia Together*.