Forget Me Not
Improving dementia care in Andean countries

Project summary

HelpAge International
age helps

Contents

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Introduction

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In 2010, 35 million people worldwide had some kind of dementia and it was estimated that this number would double every 20 years.[1] The number of cases is increasing very fast: in 2010 it was estimated that an additional 7.7 million people were being affected every year. This figure is three times higher than the number of new cases of AIDS. To illustrate the size of the problem, at the summit on non-communicable diseases held in New York in 2011 the increase in the number of cases was described as a new "epidemic", even though the disease is not contagious.

Latin America is one of the most rapidly ageing regions in the world, and an increase in cases of dementia is therefore inevitable. It is estimated that 7.8 million people are affected in the Americas: 4.3 million in North America and 3.4 million in Latin America.

Figures are not available for every country. Even so, it is reasonable to assume that the prevalence found in countries that do have information – between 5 and 8% of older people with dementia – will be similar across the region. In the countries where the project was carried out, the total numbers of people with dementia are: 40,000 in Bolivia; 256,000 in Colombia; 147,000 in Peru; and 1.33 million in Brazil (see estimates in the ADI World Report 2012).

Dementia is not like other diseases because of:

- The seriousness of the loss of functionality and autonomy. The people affected need care as well as medical treatment.
- The complexity of the need for support, which is high and often has to be borne by families. According to the figures presented in the ADI World Report 2010, the estimated cost worldwide amounts to 604 billion dollars per year. This includes health service costs, the cost of social care and the carer's loss of job opportunities.

The complexity of the needs arising from dementias means that they cannot be addressed by the health services alone. A high level of cross-sectoral coordination is required between the family, the community, authorities and social services.

Studies and testimonies show that there are still no clear responses to the issue of dementias on the part of the different agencies. Are dementias a specialisation? A mental health issue? Non-communicable diseases? This situation reflects the lack of knowledge and awareness

What is the situation regarding dementias and responses to these diseases in the region and the Andean countries? What is the situation that the project sought to respond to?

Even though mental health accounts for 22% of the burden of disease, it is only allocated 2% of public spending on health, and funding usually goes to psychiatric hospitals.

A review of mental health plans (or plans on non-communicable diseases) reveals that policies and programmes do not include dementias other than by mentioning them in passing. Furthermore, when actions are taken to introduce dementia screening and

1 Alzheimer's Disease International world report, 2010. http://www.alz.co.uk/research/world-report

care, their small budgets and limited implementation confirms that mental health is not seen as a priority in the region's countries.

Consequently, it is estimated that less than 1% of the population is able to access mental health services, and less than 10% (or more likely less than 5%) of existing cases of dementia are diagnosed and given treatment.

Problems found in health systems include the following:

- Because health services give priority to mothers and children, the system is not equipped to provide care for non-communicable diseases or mental health.
- Service providers, particularly primary health care staff responsible for screening, do not have sufficient knowledge of dementias, how to diagnose cognitive impairment, and what to do if a case is identified.
- There are no models or guides for dementia care, no referral and counter-referral procedures and no continuity in the services provided by the different levels of care.
- There are not enough specialists, and people in rural areas and/or indigenous communities are often unable to access them.
- There are still a lot of doubts about which tests to use in the first-line services. The test needs to be able to detect dementia early enough and also be sufficiently specific. The Mini Mental State Examination is still being used while other alternatives are explored.

There are other difficulties that go beyond the health services:

- Policy-making authorities, health care providers and communities have little knowledge of mental illness.
- The community has little understanding of mental illness. People are unable to recognise mental health disorders in older people, and think that their symptoms are "normal".
- Families struggle financially and logistically to provide or obtain care. This leads to older people being excluded and/or abandoned.
- Older people with dementia are discriminated against and stigmatised; sometimes they are abandoned because people think they are "possessed" or "bewitched".
- Care systems are only just starting to be developed: 98% of older people with dementia live at home and only 2% are in institutions.
- 5% of carers are formal, although this does not mean that they are trained to provide specialised care. 95% of carers are informal and have no training; the majority are family members and women, and many are domestic workers.
- Various studies show that 80% of carers suffer from caregiver stress syndrome; 50% suffer from depression and are at risk of becoming ill.
- In rural areas, many older people with dementia live alone.

The proposal

Why this focus on describing the difficulties and challenges involved here? Because there is an emerging problem and much to be done. Nevertheless, no single institution or project will ever be able to offer a comprehensive, miraculous solution to the situation. HelpAge proposed to bring several initiatives together in the same project. These initiatives often came from the community (support groups and associations) or small organisations with a commitment to learn and disseminate knowledge and good practices.

The **Forget Me Not** project, supported by European donors, was carried out in Bolivia, Colombia and Peru between April 2013 and 2015. Its overall aim was to improve dementia care in these Andean countries, while working towards the following long-term agenda:

- Promote and analyse existing initiatives for replication and scale-up.
- Show how interventions can complement each other.
- Propose simple solutions to the problems – or part of the problems – described above.

Specific objectives

1. Improve access to suitable mental health services for 18,000 older people (9,900 women), 1,500 of whom have dementia or another mental illness.
2. Raise the awareness of 3,000 family members and carers and 50,000 members of the community (including 25,000 older people) about the causes, care and impact of mental illnesses.
3. Establish models of care by sharing and publicising experiences.

Results achieved

- **19.850**
  older people were reached by the project; 5,820 were directly involved in the activities.
- **1.441**
  carers – family, non-family and institutional – were trained, achieving an increase of more than 95% in their knowledge.
- **76**
  campaigns were carried out with the participation of about 42,400 people of all ages.
- **984**
  older people were screened for dementia and 990 people with cognitive impairment were given the relevant follow-up.
- **136**
  health facilities took part in the project and 917 members of staff received information and training.
- **3.497**
  family members were given guidance and support.
- **10**
  Support groups were set up and 9 community initiatives promoted.

The project also proposed the intervention models described in the other publications in this toolkit.

Going beyond the numbers, the project showed that it is possible to change the situation!

Gender issues

Dementia, particularly dementia caused by Alzheimer's, affects women more than men, so it is important to ensure that they have equal access to screening and care.

The person responsible for caring for someone with dementia is usually a woman (daughter, wife, etc.); even in formal care homes the carers are usually women. Women today play a multiplicity of roles, meaning that they take on a range of tasks including their paid jobs, domestic chores and caring, which in many cases poses a major dilemma.
Relationships and roles tend to change in families where one member suffers from dementia. For example, 70-year old Leonor is the carer of her husband Joaquín, who has Alzheimer's. They look well together and seem very affectionate to each other. However, Leonor says that this situation is new and that Joaquín treats her better since he was diagnosed with Alzheimer's 13 years ago.

There's almost nothing I miss from the past. With Joaquín I had to live a very passive life. It was a male-chauvinist time, women's role was confined to the home, studying was an impossible illusion and work even more so. Romance was non-existent and thanks weren't expressed very often either. But I keep all those memories in the past and it's now that I'm living my idyll of love. I feel as though our roles have been reversed. Joaquín looked after me all our lives and now it's my turn. You should live through the illness with love, it might be an opportunity to experience a different life.

Care and carers

As the issue of care arose in all the communities the project worked in, the organisations running it were equally concerned and worked to explore and reinforce it.

In Peru, Grupo Vigencia developed courses for carers of older people in a dependent situation and carers of older people with dementia (3 courses for carers and 1 course for family carers), in coordination with the municipal governments of San Juan de Miraflores, Metropolitan Lima, Comas, Independencia and Villa María del Triunfo.

The project promoted links between carers (setting up formal networks) and municipal governments, with the aim of enabling a proper care delivery system to be developed at the local level.

Fundación Acción Familiar contra el Alzheimer Colombia has a lengthy track record of supporting carers and families of people affected by dementia. Through the project, the Foundation managed to strengthen their capacities and ran courses and workshops to support family carers and give them a breathing space. Because of the level of demand, it also organised talks to inform and train carers working in institutions and groups of volunteers.

There was a significant demand for training for carers, particularly family carers, and the organisations implementing the project had a lot of applicants for the planned courses and activities. There was a demand for full or institutional training, but they also organised numerous one-off training events, together with the accompaniment, support and breathing space activities.

Within the project there was a debate about how to monitor the performance of carers. Internationally, the Zarit scale is the method most commonly used to measure carers' levels of stress. However, the existing scales are unable to provide a complete evaluation of carers' needs or problems, or the changes in their performance. The project therefore developed its own scale, which will need to be studied further.

Awareness-raising

One of the main underlying problems found as the project was being designed was people's lack of knowledge and awareness. Work was therefore done to organise information talks, campaigns, radio programmes and other activities aimed at institutions and the general public. Older people's organisations were key players in this process and they participated actively in the different events.

1. Forum with older people's organisations, Colombia.

Another result of the activities carried out was to strengthen the relationship with health services to identify cases, and with different authorities.

Following the various campaigns, the opinions and knowledge of people in the rural community of Quilmaná in Peru changed positively in just a few months. Before the campaign, less than 30% of people there were clearly informed about Alzheimer's; after the work done, the percentage with knowledge of the disease rose to 48%.

In Cochabamba, Bolivia, the groups of young volunteers who participated in fairs also contributed to the process of spreading information and knowledge.

Although families need to use the internet to find out about the resources available, young people and the general public do not go online to obtain information. In many cases, their levels of knowledge on dementias and Alzheimer's are even lower than those of older people.


2.


3.

2. Young volunteers attend fairs, Cochabamba, Bolivia.
3. Campaigns in schools, Peru.

Health services

As they should be, health services are the first point of contact for people with dementia and their families, because they play a key role in prevention and early detection of the disease.

The Horizons Foundation in Bolivia, the Memory Institute (IMEDER) in Lima, Peru and the Montes de María Development and Peace Foundation (FDPMDM) in Colombia coordinated their work with the primary health services run by local authorities to increase their knowledge of dementia as well as improving the care they provide.

- Fundación Horizontes provided training to rural health service networks in La Paz and the Northern Health Services Network in Santa Cruz.
- IMEDER worked with the health centre in Quilmaná.
- FDPMDM provided training to more than 80 health centres in the departments of Sucre and Bolivar and to Departmental Health Secretariats.

Screening days in La Paz, Bolivia.

The purpose of the workshops was to strengthen the system's capacities for early detection and organise a care pathway. Another aim was to encourage staff to change their attitudes.

One of the initial and key activities in the work with health centres was the screening campaigns, using the Mini Mental State Examination. Other tests were tried out but without much success. It is important to explore new early detection tests that can be used with specific groups such as people who are illiterate and those who speak indigenous languages.

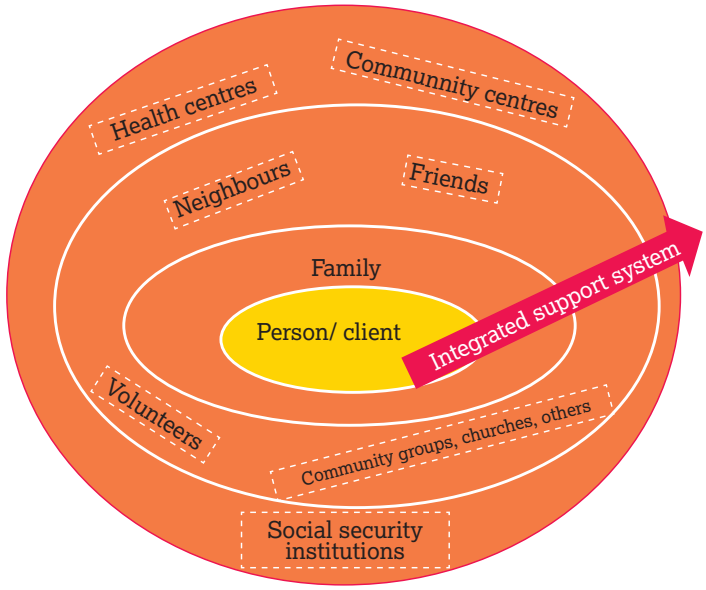
FDPMDM managed to coordinate with the large-scale programme in Colombia that provides reparations to the victims of the internal armed conflict, which has mental health screening and rehabilitation brigades. At the start of the project these brigades did not address the mental health problems affecting older people specifically, particularly those with dementia. By the end, however, the Foundation had managed to mainstream specific training tools and ways to coordinate with the brigades.

Screening days in Colombia.

Conclusions

- The project's activities and results led to the design of intervention models that can be replicated. They can also be used to bring about changes in policies and promote local initiatives such as the carers' networks in Lima, the Integrated Support Centre for Older People (Spanish acronym CIAM) that was set up in Quilmaná, Peru, or the Older People's Centre in El Salado, Colombia.
- The project's results were shared with national authorities in the three countries.
- One important initiative worth highlighting is the Neurocognition Laboratory in Santa Cruz, Bolivia, which has started working to confirm the presence of cognitive impairment in people referred from 2nd level services and design rehabilitation for patients with dementia. The NeuroLab will also operate through an online platform, providing access to telemedicine services from anywhere in Bolivia.

Although the entry point for people with dementia will often be the primary health care service, multi-stakeholder coordination should be the cornerstone of any action to address their needs.



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