Let’s talk about Dementia in Latin America and the Caribbean

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Paola Barbarino
CEO
Alzheimer’s Disease International

Moderator: María Laura Oliveri
Before we start...

40 minutes + 15 minutes

Questions via chat

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Presenter: Paola Barbarino
CEO
Alzheimer’s Disease International
Around the world, there will be one new case of dementia every 3 seconds.

The total estimated annual worldwide cost of dementia in 2020 is over US$1 trillion. This figure will rise to US$2 trillion by 2030.

Estimated growth in number of people with dementia 2020–2050:
- 2020: 50 million
- 2030: 82 million
- 2050: 152 million

Dementia in Latin America and the Caribbean

The Americas
11.4 million people with dementia

Latin America
6 million

North America
5 million

The Caribbean
480,000

Dementia

An umbrella term for a collection of symptoms that are caused by disorders affecting the brain. There are over 100 types of dementia.

- **Alzheimer’s disease** Most common, accounting for approximately 50-75% of all dementias

- **Vascular dementia** Second most common dementia, accounting for approximately 15-25% cases

- **Mixed dementia** At least 1 in every 10 people is diagnosed with a mixed dementia – most common is a combination of Alzheimer’s disease and vascular dementia

- **Frontotemporal dementia** Second most commonly diagnosed dementia in people under the age of 65.

- **Lewy body dementia** A complex condition affecting 10-15% of those with dementia.

- **HIV-associated dementia** A consequence of HIV infection, typically seen in advanced stages of the disease.

Source: Kate Swaffer, 2020
Dementia and mental health

• Positioning of dementia within mental health
  – WHO Brain Health Unit

• Leave no one behind
  – MH and neurological conditions should be treated as any ‘visible’ health condition would

THE LINKS:

• Mental health of people with dementia and carers

• Similarities in symptoms and experiences
  – Lack access to services and support, face stigma and are denied their human rights
  – Need to focus on risk factors and psychosocial determinants

But dementia presents unique problems
Dementia and NCDs

- Dementia risk profile very similar to other major NCDs, with common occurrence of comorbidities, but often grouped separately
- Expanding evidence base:
  - WHO Guidelines;
  - 2020 Lancet paper: Dementia prevention, intervention, and care

"Including dementia"
About Alzheimer’s Disease International (ADI)

- Established in 1984
- The umbrella organisation of Alzheimer associations around the world
- 102 member associations & federations
- 18 associations on the Membership Development Programme (MDP)
- Official Relations with WHO

Our vision is prevention, care and inclusion today, and cure tomorrow
WHO’s Global action plan on dementia

Towards a dementia plan: a WHO guide

Action areas

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation
ADI’s Objectives

• **Raise global awareness** about dementia
• **Build and strengthen Alzheimer associations** throughout the world
• **Support associations** so they are better able to meet the needs of people with dementia and their carers
• **Advocate for people** with dementia and their carers on a global level
• **Stimulate research**, especially in lower and middle-income countries
Real concern that the progress made under the Global plan will be reversed by COVID-19 on the national and international level, especially as there has not been an adequate focus on non-communicable diseases.
Countries with plans on dementia or in development in 2020

Source: ADI (2020)
From plan to impact III
World Alzheimer’s Month

- World Alzheimer’s Month held around the world since 2012
- World Alzheimer’s Day, 21 September
- Global importance of World Alzheimer’s Month following adoption of Global Plan on Dementia in May 2017
- 2019: Activities held in over 90 countries this year and growing
- 2020: Primarily virtual campaign given COVID-19 restrictions

www.worldalzmonth.org
World Alzheimer’s Month 2020: Let’s talk about dementia

#Parlonsdeladémence
#WorldAlzMonth
www.worldalzmonth.org

#Hablemosdedemencia
#WorldAlzMonth
www.worldalzmonth.org
World Alzheimer Reports

www.alz.co.uk/publications
World Alzheimer Report 2020

Dementia related design and the built environment

- In partnership with Wollongong University, Australia
- Cross cultural approach
- Focus: progress to date, best practice and innovation across multiple environments including in home/domestic settings, day and residential care, hospitals and public buildings and spaces

www.alz.co.uk/worldreport
1. Encouraging improved awareness and attitudes towards people with dementia – with a focus on healthcare practitioners
2. Stimulating people to start talking about dementia – that first difficult conversation
3. Encouraging people to seek out more information, advice, support and even a diagnosis

ADI-PAHO regional awareness raising campaign
AD​I-PAHO regional awareness raising campaign

- Dementia affects everyone differently but there are some common warning signs
- This interactive quiz provides information and encourages people to seek out further information, advice and support if they have concerns
- The importance of timely diagnosis
ADI-PAHO regional awareness raising campaign

• Risk factors for dementia
• Be physically active, enjoy social activity, challenge your brain, follow a healthy diet, look after your heart
• Shared with many other non-communicable diseases
Additional outcome of campaign

Alzheimer association / federation

Ministry of Health

July 2020: Dominican Republic launched a plan

PAHO country office
COVID-19 and dementia

- Mental health issues - Isolation, anxiety, stress, depression
- Older people disproportionately affected, including discrimination
- Complications of other NCDs and exacerbated/new NCDs
- Scarcity of resources and triage decision making
- Delayed diagnosis, transition
- Post diagnostic support challenges – face to face
- Interruption of clinical trials and research
Our rapid response to COVID-19 was enabled through

• Working with our Asian members when lockdown started in Europe

• Coordinating with our contact in China, Prof. Wang, to write about caring during COVID-19

• Reading about COVID-19 and realising that our natural constituency and the ‘at risk’ age range overlapped

• Understanding very quickly that there was a problem with triage and I wrote about it on LinkedIn to raise awareness

• Gathering resources from all over the world very quickly

• Organising member webinars to support each other in early March - learnt a lot

• Realising that there was huge interest in what we were doing, we started working with the press and opened our webinars to the public
As our resources began to gain traction

• We launched an emergency appeal in April and started raising much needed funds

• We side-lined our business plan and much of the work we already had in progress in favour of focusing on COVID-19

• We made some strategic decisions about alliances and partnerships

• We exploited our agility and nimbleness to its maximum extent

• As we had some staffing changes we ensured that health and mental wellbeing of the whole team was prioritised above all
Our motivation: future focus

We were concerned that:

1. Our constituency’s rights were trampled
2. That there was not enough information on practical issues
3. That governments would deprioritise dementia after all returned to normality
## ADI’s response to COVID-19

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<td>Additional support for Alzheimer's &amp; dementia organisations</td>
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<td><strong>Resources in English, Spanish, Portuguese, Arabic, Greek</strong></td>
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ADI’s response to COVID-19

- ADC presentation (English): Almost 10k views

- Publication of a Lancet article 'Dementia care during COVID-19' by Huali Wang, Paola Barbarino, Serge Gauthier et al.
ADI’s response to COVID-19:
Realising the overlap and raising awareness

"We are living through unprecedented times, but one thing is clear: ADI’s natural constituency, people affected by dementia and their families, are amongst the hardest hit. We have a global network and it has been natural for our members to collaborate through this crisis, show solidarity and work together. But we have also learnt that there are hard truths that we all need to face. This is the spirit in which we have reengineered ADI to be at the forefront in providing, guidance, evidence-based information and cohesion through these difficult times. Our aim is to help you understand the impact on our community as events unfold and take better and more informed decisions. Stay safe.‖ - Paola Barbarino, Chief Executive of Alzheimer’s Disease International (ADI)

COVID-19 and dementia: Difficult decisions about hospital admission and triage

COVID-19 is a new viral infection that presents an unprecedented problem for everyone, including people with dementia and their families and carers worldwide. Although the scale and impact of COVID-19 varies from country to country, at an individual level, people affected by dementia and their families and carers are having to cope with rapidly changing information and guidance at a time when they have been asked to isolate from their regular support systems in the wider community.

Age, dementia and the allocation of health resources during and beyond COVID-19

Dr Linda Barclay, Department of Philosophy, Monash University and Glenn Rees, Chair of Alzheimer’s Disease International

The extraordinary circumstances of the COVID-19 pandemic bring into sharp focus a fact of life that most of us ignore: that health care resources are always limited. This is very true for people with dementia and more generally for people with disabilities. They are limited by political and economic decisions concerning expenditure on medical research, drug subsidies, health care funding and so on. These long-term issues will not be resolved in mid-crisis, but they are relevant to the way the crisis is handled. It is an opportunity to draw attention to longstanding issues and not give up in despair.

This article explores issues in health resources allocation, measurement of quality of life, the options open to decision makers and the importance of transparency in decision-making. There is no simple answer to complex decision making but the clear requirement is for transparent decision making in judgments that impact on people’s lives. The need goes beyond guidelines that are understood and acceptable to doctors and consumers and relevant in times of crisis at the bedside to broader issues of health policy, structural and legal issues.
COVID-19 and dementia webinars
Major concerns for people living with dementia & carers

1. Excess dementia mortality in long-term care facilities, in hospitals, and at home, but data is sorely lacking

2. Diagnosis rates for dementia have decreased during the outbreak – impact on cognitive decline

3. Palliative and end of life care must be supported, including at home

4. Triage guidelines must not be used in discriminatory way

5. Psychosocial support for both people with dementia and carers
COVID-19 and dementia: future gazing

- Unavailability of support and social services?
- Political de-prioritisation of dementia?
- Impact of COVID-19 on diagnosis of dementia
- Disruption of clinical trials?
- Development of vaccinations?
ADI and IADB collaboration

• Over the two decades the number of people with dementia will increase by 52% in North America and 52% in the southern Latin American cone.

• The number of people aged 65 and over in the Americas has nearly doubled since 1995, from 62 million to 116 million in 2019

• We don't have members yet in Antigua and Barbuda, Bahamas, Belize, Colombia, Dominica, Grenada, Haiti, Panama, Paraguay, Saint Lucia, Saint Vincent and the Grenadines
ADI and IADB collaboration

• Supporting people who are part of the silver economy to live at home and in the community for longer:

• What kind of public-private sector collaborations could we encourage?

• What sort of policy responses could facilitate this?
THANK YOU.

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Visit our website: www.alz.co.uk

Follow my global advocacy work on Linked In, Twitter and Instagram @paola.barbarino
Questions and Answers
Panorama of Aging and Long-term Care

Thank You

https://www.iadb.org/panorama-of-aging

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