Global Experiences of Dementia Stigma

Perspectives of people with dementia and caregivers

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Scope

• Global survey
• Over 2500 responses from 54 countries
• 4 languages: English, Spanish, Chinese, Greek
• People with dementia and caregivers

• 157 people with dementia
  – Self-reported: dementia, mild cognitive impairment, Alzheimer’s disease, vascular dementia, and frontotemporal degeneration
  – With access to a computer and the ability to use it
  – A highly educated respondent group
Key Priorities

• Reducing stigma through information, awareness raising and education.

• But first, need to know how people are experiencing stigma in order to help overcome it.
Experiences

- Not Respected
- Treated Like a Child
- Mocked

Treated as Human

- Being Marginalized
- Social Exclusion
- Focus on My Abilities
“People overprotect you…[and]…avoid conversation. People talk to the person you are with and not you.”

Person with dementia, Canada

“They call me ‘Monchito’ [‘little Moncho’] instead of Moncho as they used to call me before. They are all really good people but I feel that they treat me like a child.”

Person with dementia, Spanish survey
“I am afraid to tell others I have dementia. People are always impatient toward me, and sometimes make fun of me.”

Person with dementia, Chinese survey

“Friends, family are uncomfortable and say they don’t know how to behave ‘normally’ around me anymore – they didn’t really give our relationship a chance to move forward.”

Person with dementia, USA
“Some of my friends have moved on as I can no longer be a part of what I used to do.”

Person with dementia, UK

“Came out straight after diagnosis, writing or contacting over 150 friends, and received less than 5 responses.”

Person with dementia, Australia
Changes are needed

• Awareness campaigns at the societal level typically focus on:
  – Increasing research dollars towards cure
  – Risk reduction (physical and brain health)
  – Mortality statistics (x leading cause of death)

• While important, these strategies have little to no impact on people who currently experience dementia and the marginalization they face

• And, may increase the fear of dementia
Proposal for Societal Stigma Reduction

Aim
For people to acknowledge their dementia symptoms and obtain the help they need

Fear-inducing
• Mortality statistics may not help people acknowledge symptoms or ask for help
• Media coverage using language such as ‘tsunami’, showing people with dementia in late stages or describing severe behavior challenges as ‘worse than death’
  (Studies conducted in NZ, Belgium, UK)

Possible solution
More positive images of people with dementia
(i.e. one can live well with dementia with the right support)
Proposal for Individual Stigma Reduction

**Aim**
Develop meaningful relationships, treating people with respect

**Fear-inducing**
Getting dementia might be ‘my fault’ if I haven’t done enough physical or brain exercises

Fear of engaging with other people if they might treat a person with dementia differently

**Possible Solutions**
Increasing programs and supportive services for people to support remaining abilities in contrast to a focus on disabilities
Example Programs

• Peer groups and dementia cafes for people with dementia
  – People with dementia report not feeling so alone

• Singing for the Brain/Choirs
  – People with dementia participating with people without dementia – inclusion programs

• Buddy Programs/Side by Side
  – One on one support to establish a meaningful relationship or maintain hobbies

• Dementia Adventure
  – People with dementia enjoying leisure and vacations
• Dementia Friendly Communities
  – Developing local stakeholder groups to improve access to improving daily life for people with dementia in the community
  (dementia-friendly transportation, dementia-friendly banks and dementia-friendly supermarkets, etc.)

• Globally in 48 countries, US and Canada
  • Africa: 4 countries
  • Central and South America: 3 countries
  • Asia Pacific: 12 countries
  • Europe: 24 countries
  • Middle East: 3 countries
Take home messages from survey

- Other people (friends, neighbors, etc.) must initiate maintaining the relationship

- Include people with dementia in conversations; ask the person what is helpful for him/her to be successful

- Accommodate to the new level of abilities of the person (at home and in the community)

- Social exclusion happens to caregivers too

- Caregivers also feel marginalized
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International perspectives on supporting people with dementia and caregivers

Scotland’s 10 Year Journey
January 2018

Michelle Miller
Portfolio Lead: Focus on Dementia
Session Overview

Attendees will:

1. Learn more about Scotland’s dementia strategy and progress.
2. Learn how Scotland is supporting the implementation of the dementia strategy into practice.

- Context
- Workforce
- Implementation of Policy into Practice
- Questions
CONTEXT
Dementia in Scotland

5.4 million population

90,000 People living with Dementia
16,000 People newly diagnosed each year (incidence data, 2017)

Scottish Government priority since 2007
Third Dementia strategy May 2017
Scotland’s Dementia Strategies 2010-2020

Scotland’s National Dementia Strategy: 2013-16

Scotland’s National Dementia Strategy: 2017-20

Charter of Rights for People with Dementia and their Carers in Scotland

Stepping out of the shadows
Scotland’s Vision

Our shared vision is of a Scotland where people with dementia and those who care for them have access to timely, skilled and well-coordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them.

Scottish Government, Dementia Strategy 2017
“Suffering from dementia... this is a term we really do not like. We are living with it and getting on with it with laughter and love and that makes a difference. We are being heard and our opinions valued.”

Agnes Houston, Chair, Scottish Dementia Working Group
Dementia Local Delivery Plan Standard

To deliver expected rates of dementia diagnosis, all people newly diagnosed with dementia will have a minimum of a year’s worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan.

*(Scottish Government Target, introduced 2013)*

Alzheimer Scotland 5 Pillars Model
Dementia Post Diagnostic Support
Alzheimer Scotland 5 Pillars Model
Alzheimer Scotland 8 Pillars Model

Dementia Practice Coordinator – a named, skilled practitioner who will lead the care, treatment and support for the person and their carer on an ongoing basis, coordinating access to all the pillars of support and ensuring effective intervention across health and social care.

Support for carers – a proactive approach to supporting people in the caring role and maintain the carer’s own health and wellbeing.

Personalised support – flexible and person-centred services to promote participation and independence.

Community connections – support to maintain and develop social networks and to benefit from peer support for both the person with dementia and the carer.

Environment – adaptations, aids, design changes and assistive technology to maintain the independence of the person and assist the carer.

Mental health care and treatment – access to psychiatric and psychological services to maintain mental health and wellbeing.

General health care and treatment – regular and thorough review to maintain general wellbeing and physical health.

Therapeutic interventions to tackle symptoms of the illness – dementia-specific therapies to delay deterioration, enhance coping, maximise independence and improve quality of life.

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WORKFORCE
WORKFORCE

14 Alzheimer Scotland Nurse Consultants (one in each region in Scotland)

130 Dementia post diagnostic support practitioners

700 trained Dementia champions as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals and at the interface between hospital and community settings.

Dementia Ambassadors: dementia champions working in Social Care
Dementia Advisors employed by Alzheimer Scotland
Education: Promoting Excellence Resources
Supporting Implementation of Policy into Practice
Focus on Dementia

Aim: To Improve the quality and experience of care and support for people with dementia, staff and carers (supporting commitments 1-7 of Scotland’s dementia strategy) by March 2020

Outcomes

- Improved Access to Care and Support
- Improved Quality of Care
- Improved Experience
- Improved Engagement
- Improved nationally co-ordinated support

Improved Knowledge and Understanding of dementia good practice and QI in dementia context
Diagnosis and Post Diagnostic Support

Integrated Care Coordination

Advanced Care

Primary Care, Community, Acute Hospitals, Specialist Dementia Units
Our approach to supporting improvement

- Design
- Understand
- Evaluate
- Embed/Sustain
- Spread learning
- Implement

Keeping the person at the centre
Improving Access to Care and Support

Focus on Dementia

Improving diagnosis and post-diagnostic support
Improving Quality of Care and Support
Quality Improvement Framework - Shaped by personal outcomes

- I am confident in the people who support me following my diagnosis
- I experience high quality post-diagnostic support at the right time and at the right level for me
- I know more about my dementia and have adjusted to my diagnosis
- I feel listened to and what matters to me is at the heart of decisions about me
- I feel better about the future knowing I have made plans.
Improving Knowledge and Understanding
Value Based Outcomes: Global Benchmarking

International Consortium for Health Outcome Measurement (ICHOM)
Our successes in Scotland

Meaningful participation: people with dementia and carers
Partnership working
National Focus: Sharing practice and supporting implementation
http://ihub.scot/focus-on-dementia/

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