Equity and Access through Collaboration in Dementia Care

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Equity and Access through Collaboration in Dementia Care

• Overview
• System of dementia care
• Singapore experience
• Collaborations in dementia care
• Challenges
Estimated that in 2015 - 46.8 million people worldwide are living with dementia. In 2050 131.5 million.

One new case of dementia every 3 seconds.
Equity and Access

- Equity - justice according to natural law or right; *specifically*: freedom from bias or favoritism
- Access - freedom or ability to obtain or make use of something
Kyoto Declaration 2004

Minimum actions required for the care of people with dementia

• Provide treatment in primary care
• Make appropriate treatments available
• Give care in the community
• Educate the Public
• Involve communities, families and consumers
• Establish national policies, programs and Legislation
• Develop human resources
• Link with other sectors
• Monitor community health
• Support more research

https://www.alz.co.uk/adi/pdf/kyotodeclaration.pdf
Global Alzheimer’s Disease Charter

6 principles to make Alzheimer’s disease and other dementias a global priority:

• Promote **awareness and understanding** of the disease
• Respect the human **rights** of people with the disease
• Recognize the key **role** of families and carers
• Provide **access** to health and social care
• Stress the importance of optimal **treatment** after diagnosis
• Take action to **prevent** the disease, through improvements in public health
The ideal system of care

- Prevention
- Awareness
- Recognition
- Assessment
- Diagnosis
- Management and treatment
- Crisis management
- End of life
Improving healthcare for people living with dementia
Coverage, quality and costs now and in the future
The huge majority of people with dementia have not received a diagnosis, and so are unable to access care and treatment. Even when dementia is diagnosed, the care provided is too often fragmented, uncoordinated, and unresponsive to the needs of people living with dementia, their carers and families.
Singapore
719 sq Km
Population: 3.9 million residents
12% aged 65 and above
Multi-ethnic
Development of Dementia Care in Singapore

1980s

Need

Ageing population
Lack of awareness
Smaller families
Dementia on the rise
No services for dementia
Need

New Horizon Centre (Dementia Day Care Centre)
Awareness
- Public
- Healthcare professionals
- Memory walks
- Newsletter

Services
- Caregiver support
- Dementia Day Care

Training
- Family
- Foreign Domestic Helpers
- Health professionals
- Dementia Care Mapping

Fund raising
Need
Dementia Day Care
Day Care Services

New Horizon Centres

- Physiotherapy and Occupational Therapy
- Social & Recreation Activities
- Reminiscence Therapy
- Arts Therapy
- Extension of day care hours (Saturday)

*Person-Centred Care Approach*
Family of Wisdom (FOW)

- Piloted in 2013 & modelled after the FOW programme in Taiwan
  - Caregiver and client attend 3 hour activity session

- Aims to:
  - Provide respite and emotional support
  - Increase social interaction and meaningful activities for PWD & their caregivers.
  - Empower caregivers with required skills and knowledge to cope better in daily caregiving.
Family of Wisdom
Clients and caregivers actively engaged
Alzheimer’s Disease Association

• Project on “Arts and Dementia“2013 funded by the National Arts Council
• Photography and Tours of the Peranakan Museum
Developing Partnerships
Partnerships

• Mutually beneficial relationship between organizations
• Opportunity for hospitals and community organizations to identify shared goals, uncover gaps, and join forces to achieve improved health care and quality of life for individuals in their communities
Partnership

• Model of partnership
  – Clear objectives
  – Who are the partners

• Collaborative planning
  – Shared goals
  – Coordinated work plan
  – Assign lead person
  – Flexibility

• Operational issues
Partnerships

• Trust
  – differences in scope of expertise, work ethic, and communication
  – building a foundation of respect
  – transparent about goals
  – “we have come to learn”

• Philosophy
  – Person centred care
Young Onset Dementia Services

- Support Group
- Counseling session – genetics counseling
- ‘The Tangle Brain’ book for children
- SYNC clinic – specialized clinic for young onset only
- ESTEEM – Cognitive Stimulation program, collaboration with the Family of Wisdom run by Alzheimer’s Disease Association (Tiong Bahru)
In the midst for 2\textsuperscript{nd} edition

- Targeted for children age 7 to 14 years old
Activities for people with young onset dementia @ ESTEEM at ADA Tiong Bahru
St. Andrew’s Community Hospital

- Rehabilitation for people with dementia after a stroke or fracture was limited
- Started a ward for people with dementia
  - Design for dementia
  - Trained staff
  - Activity programmes
- Collaboration with Changi General Hospital in training, clinical support, case discussions and peer support
St. Andrew’s Community Hospital
Wards – Entrance
Wards – Cosy Corners
Dementia ward - Toilet
National Priority

• Dementia Blueprint 2004
  – To establish a comprehensive and integrated blueprint on dementia care in Singapore
• National Dementia Strategy 2009
Current Dementia Care

- Fragmented and inadequate to meet the increasing need
- Psychosocial management of dementia is essential
- Yet dementia care mainly provided by hospitals
  - Hospitals, rather than primary care clinics, are managing majority of patients with dementia, including stable dementia cases
  - Resulted in long waiting time for a new case evaluation of 2-5 months at the hospitals’ memory clinics
- Lack of community based dementia services
  - Home based, day care, respite and institutional services
- Lack of trained manpower
National Dementia Strategy 2009

• Stigmatisation and awareness of dementia
• Develop collaborative models of shared care
• Build up manpower
• Build capacity for dementia care in the community including dementia daycare, caregiver support and respite care services
National Dementia Network

• Resource panel consisting of the key professionals who are actively involved in dementia work to advise the Ministry of Health on:
  – The national needs for dementia services and manpower
  – Co-ordination and training in dementia care
  – Strategies to improve standards and continuity of care for people with dementia

• In 2010
  – developing initiatives to facilitate care that is coordinated, integrated and promotes ageing-in-place to ensure that patients’ medical and social needs are met holistically
National Dementia Network

• Network of committed people
• Relationships – sharing, collaboration
• Dynamic
• New models of care
• Support of governmental agencies
  – Ministry of Health
  – Ministry of Social and Family Development
  – Ageing Planning Office
  – Agency for Integrated Care
Dementia Networks

- Improve the system of care required by people with dementia, their families and caregivers
- A vehicle to facilitate people and resources coming together locally, regionally and provincially to improve the system of care (including service delivery, education and research) for persons with dementia, their families and caregivers.
- Dementia networks formalize, improve and build on existing relationships/linkages and provide a means to achieve what autonomous organizations cannot do on their own.

http://brainxchange.ca/Public/Files/Dementia-Networks/Dementia-Network-Guide.aspx
Networks rely on:

• A willingness and the ability of members to work together towards common goals in order to improve the system of care for persons with dementia, their families and caregivers

• Some level of organization and in kind contribution from members

• The use of influence, persuasion, consensus building and information sharing to improve and build on existing linkages between organizations
Challenges

- Leadership
  - Not ownership
- Membership
  - Stakeholders
  - Catchment
- Partnerships
  - Community has strengths and resources to build on
  - Equal stake
- Goals
- Communication
- Health and Social Systems
Integration

• Integrate – “to make whole”
• Comprehensive care
• Integration
  – Disciplines
  – Acute and long term care
  – Hospital and community services
  – Health and Social services
An Integrated Team for Dementia Care across the Disease Continuum

- Case management
- Care coordination
- Public awareness, education & outreach
- Dementia friendly community

- Thye Hua Kwan (THK) CREST ClubHeal

- Eldersitter/iPAL
  THK & NTUC
  - Client: Engagement & companionship
  - Caregiver: Skills, support & respite

- ClubHeal
  O’Joy COMIT
  Clarity
  - Counselling, psychoeducation
  - Caregiver support

- Snr Care Centres
  Shared Care Partners
  - Sree Narayana
  - SWAMI Home
  - AWWA, St Luke
  - Structured Day activity programmes
  - Respite

- Primary Care
  - Yishun Polyclinic

- YCH
  KTPH
  - Specialist care
  - Home Medical Care
  - Leadership, training and support (community partners)

Courtesy of Dr Philip Yap, Geriatrician, Khoo Teck Puat Hospital
What makes collaboration work?

• Commitment from leadership, management and staff on the ground
• Training and willingness to share
• Regular review meetings and open communication
• Willingness to pool resources for the common good.
• Partners rather than a specialist & novice relationship
Obstacles

- Professional arrogance
- Territory
- Rivalry
- Dysfunctional teams
- Empire building
- Management systems
- Funding
Equity and Access through Collaboration in Dementia Care

- Need for collaborations in dementia care
- Importance of partnerships and dementia networks
- Challenges
- Integration of care
Patience
Persistence
Courage
Determination