Dementia & Dementia Care

IPL SYMPOSIUM
2018 - 2019

Mohammad Saib

m.saib@mdx.ac.uk
Online Evaluation

Scan this QR Code
AIM: To enable practitioners to discuss and reflect on their practice in a continually changing socio-political context and to address the issues raised within numerous highly pertinent reports that have culminated in the Implementation Plan of the Prime Ministers Challenge 2020 (DH, 2016) of the need to develop a skilled health and social care workforce in dementia care

Learning Outcomes

• Interpret the demographic profile of the UK and appraise its significance for health and social care practice (including diversity and equality) in relation to people with dementia and their families.

• Critically review and evaluate the evidence-base of different approaches to the management of people with dementia from diagnosis to end of life dementia care and relieving stress on family carers and promoting safety and positive risk taking.

• Critically reflect on decision-making in complex situations and justify the application of communication and therapeutic skills which maintain personhood for the people with dementia and their carers.
ONS Projections (e.g. 146% increase in over 90s and 85% increase in over 80s in next 20 years)
Demographics of Dementia in the UK

There are approximately 850,000 people known to be living with dementia in the UK, and this number is expected to almost double within 30 years.

In the UK, dementia affects:

- 1 in 6 people aged over 80
- 1 in 25 people aged 70–79
- 1 in 100 people aged 65–69
- 1 in 1400 people aged 40–64
There are approximately 850,000 people known to be living with dementia in the UK, and this number is expected to almost double within 30 years.

In the UK, dementia affects:

- 1 in 6 people aged over 80
- 1 in 25 people aged 70–79
- 1 in 100 people aged 65–69
- 1 in 1400 people aged 40–64

INFOGRAPHICS.
Dementia is a term used to describe a collection of symptoms including memory loss, problems with reasoning and communication, and a reduction in a person's ability to carry out daily activities such as washing, dressing and cooking.

The most common types of dementia are: Alzheimer's disease, vascular dementia, mixed dementia and dementia with Lewy bodies.

Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary (Dementia Gateway, Social Care Institute for Excellence, 2018).
Spectrum of Needs (NDS, 2009)
The Dementia Journey

1. Awareness of Difficulties
2. Assessment Diagnosis
3. Living with Dementia, Support for Person with Dementia, Support for Carers
4. End of Life Care
Incidence

![Bar chart showing incidence of new dementia cases per year in the UK from 1995 to 2015. The chart indicates a trend of increasing cases due to ageing population, with a reduction marked in 2015.](www.england.nhs.uk)
The Well Pathway for Dementia

Preventing well
Diagnosing well
Supporting well
Living well
Dying well

© Middlesex University
What is dementia

Dementia is caused by diseases of the brain, the most common of which is Alzheimer's.

- Alzheimer’s disease: 62%
- Vascular dementia: 17%
- Mixed dementia: 10%
- Rarer causes of dementia: 5%
- Dementia with Lewy bodies: 4%
- Frontotemporal dementia: 2%

A Person with Dementia
Models for Understanding Dementia

Include:

• Bio-medical
• Normal Ageing
• Psychological – Personhood
• Social/Disability

Models of understanding dementia influence responses to people with dementia and those who care for them
Bio-Medical Model

• Dominant explanatory model in Western society

• Dementia as a neuro-psychiatric condition

• Causes include genetic and environmental factors which negatively influence organic functioning
Bio Medical Model

- People with dementia are seen as passive victims of a progressive and irreversible disease process.
- A person’s presentation is directly attributable to physical processes.
- Focus is on assessing for deficits and dysfunction.
- Key responses are medical/nursing interventions.
- Limited focus on social networks e.g. family/carers etc.
Medical Model Approaches to Care and Treatment

• Anti–dementia drugs

• Management of “Neuro-psychiatric symptoms”

• Management of other physical conditions
Dementia as Normal Ageing

- In some non-Western societies dementia is seen as part of the normal range of effects due to the ageing process.
- Person does not become “medicalised”, and may continue to be integrated within the family system, with adjustments made according to the situation and the capacity and resources of the family.
Person-Centred Model

• Originated with the pioneering work of Tom Kitwood and the Bradford Dementia Research Group, in the 1980s and 1990s

• At that time it was seen as the “New Culture”, in contrast to the existing dominant approaches, which were seen as undermining and disrespecting to people with dementia
Personhood

“A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”

(Kitwood, 1987)
The Enriched Model of Dementia

- Dementia = NI + H + B + P + SP

NI = Neurological impairment
H = Health and physical fitness
B = Biography
P = Personality
SP = Social Psychology
Person-Centred Care

- Physical and mental health
- Neurological impairment
- Physical environment
- Sensory ability
- Social environment
- Biography and personality
- Well-being and quality of life

from Kitwood, 1997
Carer of a Person with Dementia
Person Centred Care

• DAWN BROOKER - VIPS

  • https://www.youtube.com/watch?v=a9zHr1SbdRY

  • https://www.youtube.com/watch?v=sClfIPfhTmg
Social/Disability Model

The Social Model Definition of Disability

The loss or limitation of opportunities to take part in the community on an equal level with others because of physical and social barriers

and refers to being disabled as having an impairment that is defined as

The loss or limitation of physical, mental or sensory function on a long-term or permanent basis.
Social/Disability Model

- Person with dementia is seen as experiencing increasing disability due to a progressive neurological condition
- Active coping required – and assistance with this
- Emphasis on practical and environmental support to promote maximal well being (work with strengths, compensate for lost abilities)
- Key professionals: OT’s, Social Care Professionals, Other members of the MDT (e.g., SALT)
- Advice and support to families and communities
# Social/Disability Model

## The Medical Model
- YOU are the problem. It is about what you can’t do. The most important thing is about a cure for dementia.
- People with dementia can’t 'make decisions
- People with dementia are victims and sufferers and need our sympathy
- People with dementia are passive dependents
- Dementia policies and services do things to and for people with dementia

## The Social Model
- A cure would be great of course, meanwhile there are lots of barriers for people with dementia. These include the attitudes of others and the physical environment. Let’s look at what people with dementia can do
- People with dementia should be at the centre of the process of making decisions, wherever possible, and should be supported to participate fully.
- People with dementia have rights, deserve respect, and are much more than their dementia
- People with dementia can be active citizens
- Policy and services do things with people with dementia
Model of Community Support for Dementia

**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.

- **Therapeutic interventions to tackle symptoms of the illness** – dementia-specific therapies to delay deterioration, enhance coping, maximise independence and improve quality of life.
- **Support for carers** – a proactive approach to supporting people in the caring role and maintain the carer’s own health and wellbeing.
- **General health care and treatment** – regular and thorough review to maintain general wellbeing and physical health.
- **Personalised support** – flexible and person-centred services to promote participation and independence.
- **Mental health care and treatment** – access to psychiatric and psychological services to maintain mental health and wellbeing.
- **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.
The Dementia Journey

- Awareness Of Difficulties
- Assessment Diagnosis
- Living with Dementia
  Support for Person with Dementia
  Support for Carers
- End of life care
Changes over time

Behavioural problems

Physical problems

Frailty
Symptoms in advanced dementia

- Continence
- Oral intake
- Mobility and movement
- Severe memory loss
- Inability to recognise faces, objects, environment
- Severe communication problems
- Severe problems with thinking, reasoning, planning
- Gradual loss mobility
- Physical agitation, repetitive movements, periods physical inactivity
- Problems with eating and drinking (incl. chewing, swallowing)
“Dementia is on one hand a long term condition, but it is on the other hand, an issue in relation to end of life”

David Nicholson chief executive NHS England

“During the dementia project, professionals have often said that they find it hard to define when end of life care begins”

Out of the Shadows Report by NCPC 2009

• Waiting until we are certain may mean we are too late.

• Care should be based on need not diagnosis
What do people with dementia die of?

- Mainly infections
  - bronchopneumonia
  - aspiration pneumonia

- Cardiovascular
  - myocardial infarction
  - stroke - especially if on antipsychotics

- Other
  - pulmonary emboli - 8% in one series
  - occult malignancy 4-8%
So how do we recognise advanced dementia?

![Graph showing trajectory of function over time with stages of death and cancer, organ failure, physical and cognitive frailty, and other categories. Source: Murray, S.A. et al.]

- **Cancer (n=5)**
- **Organ failure (n=6)**
- **Physical and cognitive frailty (n=7)**
- **Other (n=2)**
But what do the family understand?

• “following a diagnosis of dementia the person and family should be provided with written information about the course and prognosis of the condition”

• NICE Guidance 1.4.6.2

• If never formally assessed at a memory clinic the family may never have understood natural progression of dementia

• Not just a memory illness

• Reduced oral intake is the natural history of advanced dementia

• Infections are the most likely mode of death
What conversations need to happen once we recognise advanced dementia?

• Listen to their concerns and explore their understanding

• Do they understand the prognosis?

• Given this information discuss what is in this person's best interests? What are the priorities?

• Discuss the need to consider every intervention and medical decision in terms of balance of benefit and burden

• Reassure them we are not giving up but shifting focus from fixing things to ensuring comfort
“At any stage, time is the greatest gift you can give to people with dementia. Make time just to be with them as a comforting presence, especially when their lives are drawing to a close”

Barbara Pointon MBE (2008)
Typical Example of the EOL Care of a Person with Dementia

1. **PWD at home**
   - Supported by:
     - Family carers
     - Social carers
     - Falls team
     - District nurses
     - GPs
     - Admiral nurses
     - Mental Health Services for Older People

2. **PWD in a care home**
   - Supported by:
     - Family carers
     - Social carers
     - Community matron
     - District nurses
     - Falls team
     - GPs
     - Mental Health Services for Older People

3. **Medical or social crisis occurs**
   - Example:
     - Carer respite
     - Carer breakdown
     - Illness of carer
     - Urinary tract infection
     - Fall
     - Dehydration
     - Confusion

4. **Emergency services called**
   - Supported by:
     - Camidoc
     - NHS Direct
     - Ambulance service
     - GPs

5. **PWD admitted to hospital**
   - Supported by:
     - Rapid response team
     - A&E staff
     - Medical Admissions staff
     - Care of the elderly multi disciplinary team

6. **Does the PWD die in hospital?**
   - No -> **PWD discharged from hospital**

   - Supported by:
     - Care of the elderly multi disciplinary team
     - Hospital matron
     - Discharge team
     - Social care assessors
     - Community matron
Dementia & Dementia Care

• “We have come to know that every individual lives, from one generation to the next, in some society, that he lives out a biography, and he lives it out within some historical sequence”

• (Mills, 1959: 10)
A Proposed Model of a DFC

- The place
- The people
- The networks
- The person with dementia
- The resources
Dementia Friendly Communities

• https://www.youtube.com/watch?v=KmwJXCl0l2A

• https://www.youtube.com/watch?v=9B7soEBgfHI
DEMENTIA

THE NICE-SCIE GUIDELINE ON SUPPORTING PEOPLE WITH DEMENTIA AND THEIR CARERS IN HEALTH AND SOCIAL CARE
Another Health & Social Care Guideline

Dementia Core Skills Education and Training Framework

This Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care.
Post Session Reading / Useful websites


• Cantley C. Ed (2001) *A Handbook of Dementia Care*. Buckingham. OUP.

Post Session Reading / Useful websites


Post Session Reading / Useful websites

• All-Party Parliamentary Group on Dementia (2009). *Prepared to Care.*
  London: APPGD

  London: Alzheimer’s Society.

Post Session Reading / Useful websites


Post Session Reading / Useful websites


• Department of Health (2010) Quality outcomes for people with dementia: Building on the work of the national dementia strategy. TSO.

• Helen Sanderson Associates (2012). *Progress for Providers: Checking your progress in delivering personalised support for people living with dementia*
  http://www.in-control.org.uk/media/114740/progressforprovidersdementia.pdf
Post Session Reading / Useful websites

• NCF Older People and Dementia Care Committee (2007). *Key Principles of Person-centred Dementia Care.*
  http://www.nationalcareforum.org.uk/content/Key%20principles%20of%20person-centred%20dementia%20care.pdf

  http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/English
Post Session Reading / Useful websites


Post Session Reading / Useful websites


  [www.scie.org.uk/publications/briefings/briefing03](http://www.scie.org.uk/publications/briefings/briefing03)

- [www.alzheimers.org.uk](http://www.alzheimers.org.uk)


Post Session Reading / Useful websites

- Royal College of Nursing (2013) *Making a difference in dementia: nursing vision and strategy.*

Post-Session Activities or Material

• Some videos that may serve to raise awareness of dementia and dementia care

Barbara’s Story
• https://youtu.be/DtA2sMAjU_Y?list=UUbJBh2MFKrX6Lf8bJ7_ZGWQ

Finding Patience
• https://www.youtube.com/watch?v=Q7zJL8nPqFg&feature=youtu.be

Finding Patience (The Later Years)
• https://youtu.be/VgVKw-Wfxy4
Cognitive Stimulation Training
https://www.youtube.com/watch?v=kJ813fPeWzA

Validation Therapy
https://www.youtube.com/watch?v=CrZXz10FcVM