JCECC: End-of-Life Care in RCHE
Professional Seminar on
End-of-Life Care in Advanced Dementia

Healthcare Needs and Challenges in Advanced Dementia

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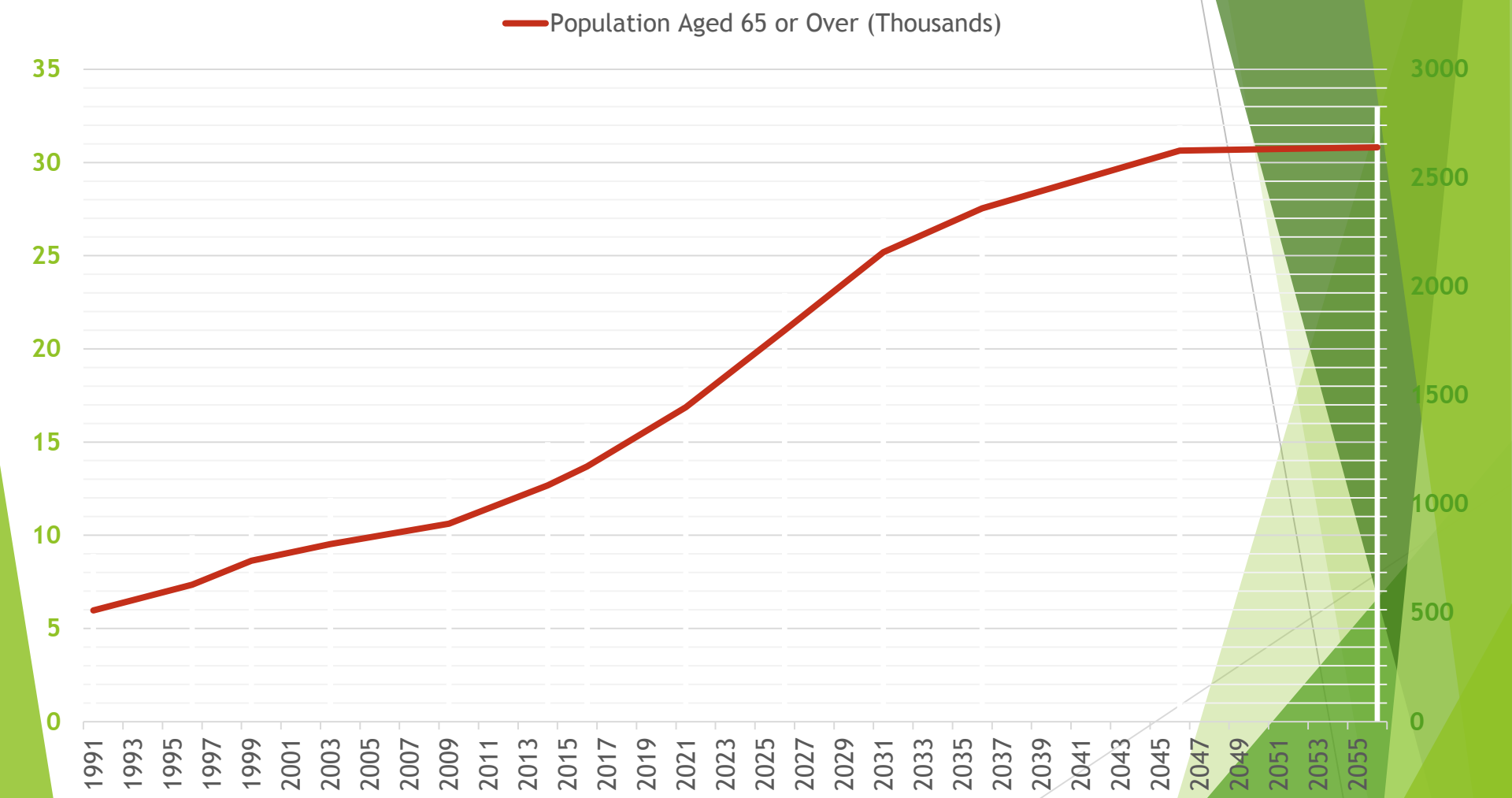
HK Population Trend (Aged 65 or Over)
(and Projection after 2016)



(Census and Statistics Department, Hong Kong SAR)

Clinical Presentation of Dementia

Decline in intellectual function affecting memory and other cognitive functions

(ICD-10, 1992)

Cognitive decline from a previous level of performance in at least one cognitive domain (i.e. complex attention, executive function, learning and memory, language, perceptual motor or social cognition) (DSM-5, 2013)

Impaired functioning of daily activities

Clear consciousness and not due to other conditions

± Behavioural and Psychological Symptoms of Dementia (BPSD)

Conceptualizing Advanced Dementia

Late stage :

The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious.

(World Health Organisation, Dementia: a public health priority 2012, p.7)

Conceptualizing Advanced Dementia

- Usually unaware of time and place
- Have difficulty understanding what is happening around them
- Unable to recognize relatives, friends and familiar objects
- Unable to eat without assistance, may have difficulty in swallowing

(World Health Organisation, Dementia: a public health priority 2012, p.7)

Conceptualizing Advanced Dementia

- May have bladder and bowel incontinence
- Change in mobility, may be unable to walk or be confined to a wheelchair or bed
- Behaviour changes, may escalate and include aggressive towards carer, nonverbal agitation (kicking, hitting, screaming or moaning)
- Unable to find his or her way around in the home

(World Health Organisation, Dementia: a public health priority 2012, p.7)

Clinical course of advanced dementia

- Prospectively followed 323 nursing home residents for 18 months.
- Advanced dementia defined as at stage 7 on the Global Deterioration Scale:
  - Profound cognitive deficits (inability to recognize family members)
  - Minimal verbal communication
  - Total functional dependence
  - Incontinence of urine and stool and
  - Inability to ambulate independently

(Mitchell et al, N Engl J Med 2009;361:1529-38)

Clinical course of advanced dementia

- Most common complications were eating problems (86%), febrile episodes (53%) and pneumonia (41%)
- High mortality rate: 6-month mortality rate of 25% and a median survival of 1.3 years
- Within 3 months before death, many underwent burdensome interventions of questionable benefit

(Mitchell et al, N Engl J Med 2009;361:1529-38)

What is a good death?

Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve:

1. Being treated as an individual, with dignity and respect;
2. Being without pain and other symptoms;
3. Being in familiar surroundings; and
4. Being in the company of close family and/or friends.

(Department of Health, UK, End of Life Care Strategy 2008, p 9)

Specific difficulties in Advanced Dementia

- Presentation varies, depending on various factors, such as health, BPSD, personality, environment
- Co-morbidities are common
- Unable to express and complain
- Many decisions need to be made
- Patients have lost mental capacity to make decisions
- Many are cared in institutions

What are the needs of a patient with advanced dementia?

- Holistic needs assessment and approach
- Communication with patient and family
- Making decisions about end-of-life care
- Meet physical needs
- Pain Management
- Management of behavioral and psychological symptoms
- Support for carers and family

Working out “Best Interests” in UK? (1)

- Working out what is in someone’s best interests cannot be based simply on someone’s age, appearance, condition or behaviour.
- All relevant circumstances should be considered when working out someone’s best interests (paragraphs 5.18–5.20).
- Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision (paragraphs 5.21–5.24).
- If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent (paragraphs 5.25–5.28).

(Mental Capacity Act 2005’s Code of Practice, 2007)

Working out “Best Interests” in UK? (2)

- Special considerations apply to decisions about life-sustaining treatment (paragraphs 5.29–5.36).
- The person’s past and present wishes and feelings, beliefs and values should be taken into account (paragraphs 5.37–5.48).
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy (paragraphs 5.49–5.55).

(Mental Capacity Act 2005’s Code of Practice, 2007)

“Best interests” is more than “medical best interests”

Many patients with mild dementia can make treatment decisions

- **Subjects:**
  33 patients with dementia
  33 cognitively intact controls
- **Mental capacity measured:**
  Clinician ratings based on
  Mental Capacity Act 2005, UK
- **Intervention:**
  MacCAT-T interview
- **Outcome:** 54.5% of patients in this study are mentally competent to make treatment decisions during interview

(Lui et al, Am J Geriatr Psychiatry 2009; 17: 428-436)

To certify one's mental capacity requires appropriate assessment

(Lui et al, Hong Kong Med J 2014; 20: 59-62)

Barriers to end-of-life care have long been recognized

- Dementia not seen as a terminal illness appropriate for palliative care approach
- Nature of advanced dementia and treatment decisions
- Psychological and emotional challenges of withholding treatments such as antibiotics and tube feeding
- Assessment and management of pain in cognitively impaired individuals
- Management of behavioural problems and psychiatric symptoms
- Challenging caregiver stress and bereavement issues
- Economic and systemic disincentives for providing excellent end-of-life care to patients with dementia

(Sachs et al, J Gen Intern Med 2004;19:1057–1063)

Perceived barriers by health care professional for those with advanced dementia in UK care homes

Three main barriers to care integration were identified:

- Societal attitudes and governmental policy
- Care home organisation
- Fragmented approach to care

(Kupeli et al, Dementia 2018;17(2): 164–179)

Perceived barriers by health care professional for those with advanced dementia in UK care homes

Care home staff experience:

- High role burden
- Demanding working condition
- Very low pay
- Limited professional development opportunity

(Kupeli et al, Dementia 2018;17(2): 164–179)

Facing Challenges

- More collaboration and communication
- Advance care planning
- More support to carers
- Dignity and respect for patients are of paramount importance

Thank you

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