The Chinese University of Hong Kong
The Nethersole School of Nursing
CADENZA Training Programme

CTP 004 – Dementia: Preventive and Supportive Care

Web-based Course for Professional Social and Health Care Workers

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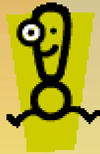
CHAPTER TWO

Manifestations of dementia: physical, behavioral and psychosocial perspectives

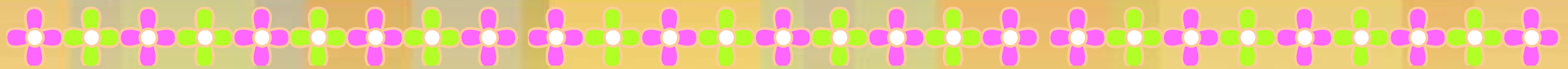


Outline

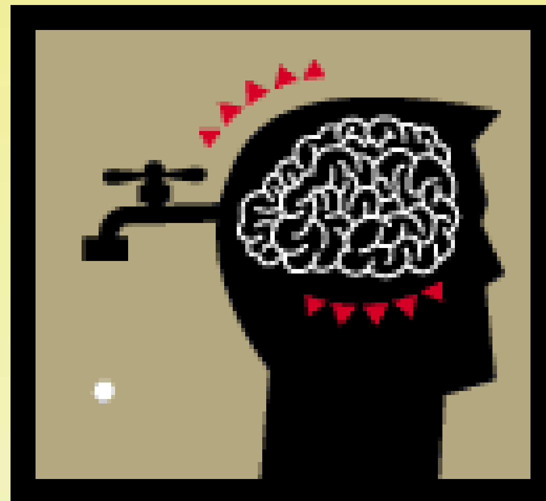
- Cognitive impairment in dementia
- Behavioral and psychological symptoms of Dementia (BPSD)
- Physical impairment in dementia
- Impact of dementia on quality of life of older people
- Needs assessments for older people with dementia

Introduction

- Dementia is a syndrome characterized by cognitive and non-cognitive symptoms
- As the disease progresses, physical symptoms also reveal
- All symptoms cause significant impacts on the quality of life
- Importance of recognition and in-depth knowledge on how to assess the above symptoms so as to facilitate care planning



Cognitive impairment



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1. Memory function
2. Attention and concentration
3. Orientation
4. Executive function
5. Perception
6. Language
7. Motor execution

Cognitive impairment – 1. Memory function

- **Memory function**
  - Ability to register, store and recall memories involves different aspects of cognition
  - Dementia affects nearly all aspects of memory function
    - Episodic memory
      - Short/long term memory
    - Remote memory
    - Working memory
    - Prospective memory
    - Semantic memory

Cognitive impairment – Episodic memory

- Short-term memory

  - Recall of material or event after a period of up to 30 seconds

  - Dementia-related impairment
    - Usually occur in patient with Alzheimer's disease (AD)
    - Connected with difficulty in attention
    - e.g. patient may not able to keep a telephone number in mind while dialing it
    - Severe impairment in memorizing recently acquired information

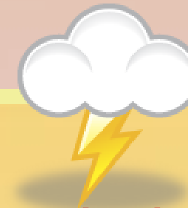
Cognitive impairment – Episodic memory

- Long-term memory

  – Recall of material/event occurs at 30 seconds or longer time (e.g. days, weeks) ago

  – Dementia-related impairment
    - Impairment in encoding (entering information into memory) or retrieval processes
    - e.g. Recalling lists of words, sentences and stories, recognizing words, faces or pictures

Cognitive impairment – Remote memory

- Remote memory
  - Memory of remote events in one's life
  - E.g. where we have lived, names of schools attended
  - Dementia-related impairment 
    - Remote memory for early time periods in one's life may preserve in early stage
    - e.g. still remember some important old telephone numbers
    - Function declines as the disease progresses and become forgotten in latter stage

Cognitive impairment – Working memory

- Working memory

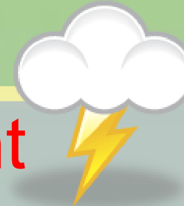
  - Ability to hold information in a short-term store while carrying out other processing operations
  - e.g. having a conversation while driving or preparing a meal

- Dementia-related impairment

  - Exacerbated impairment in dual task performance (Grober & Sliwinski, 1991)

Cognitive impairment – Prospective memory

- Prospective memory

  - Remembering to carry out an action at the appropriate time
  - e.g. remember to post the letter when walking through the mail box

  - Dementia-related impairment
    - Prospective memory tasks might be very sensitive to the early stages of dementia
    - Since prospective memory tasks also involve a retrospective component (remembering what needs to be done) (Huppert et al., 2000)

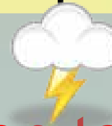
Cognitive impairment – Semantic memory

- **Semantic memory**

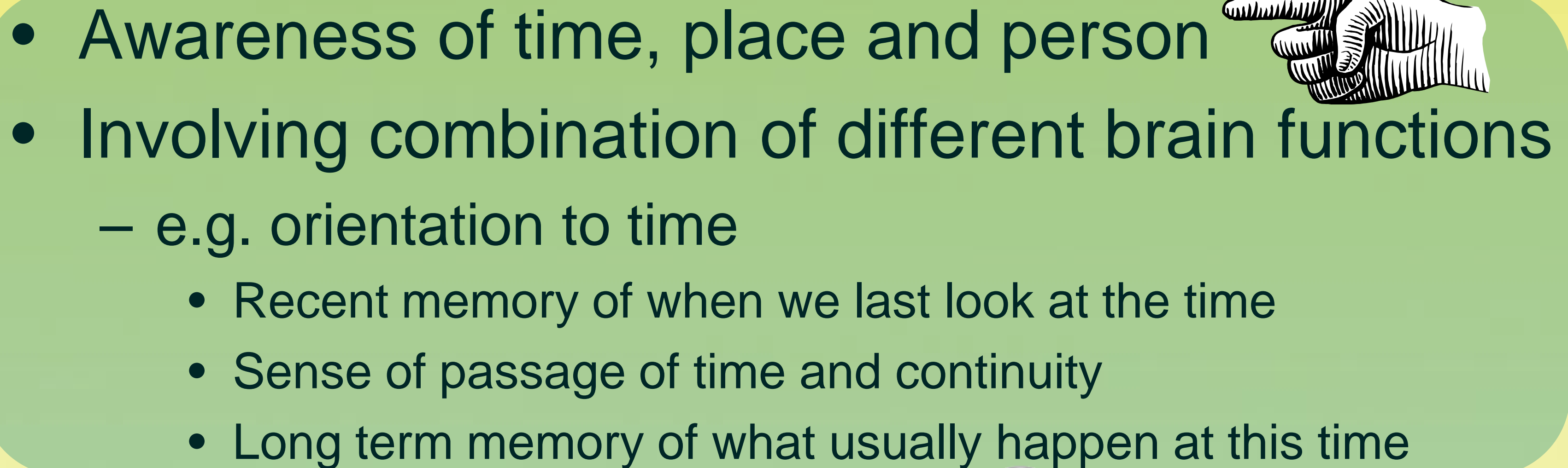
  - Memory of meanings, understandings and other concept-based knowledge unrelated to specific experiences
  - E.g. Is a cat an animal?
    - You can probably answer without refer to a learning experience of cat

  - Dementia-related impairment
    - Difficulties in word finding and picture naming
    - e.g. patient can distinguish between major categories (animal and tool) but can't distinguish between members of the same category (cat and dog)

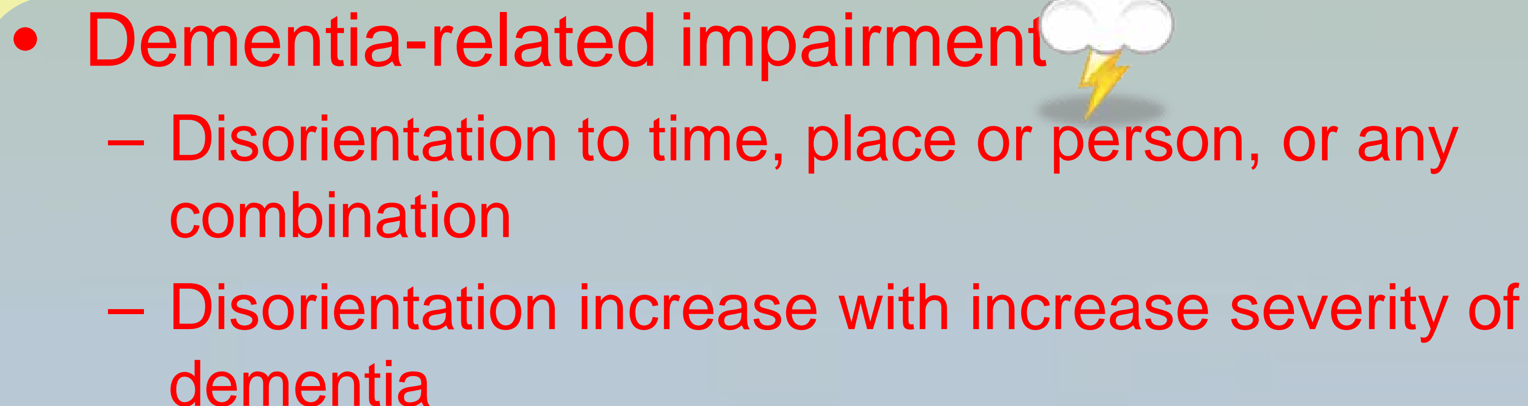
Cognitive impairment – 2. Attention and concentration

- Attention
  - "Ability to focus one's mind and consciousness on a particular object, task or thought " (Jacques & Jackson, 2000)
- Concentration
  - Ability to sustain attention over a period of time
- Dementia-related impairment 
  - Impaired ability to direct attention to stimulus being interested in
  - Easily distracted by irrelevant things
  - May 'get stuck' on irrelevant object once attention is gained
  - e.g. patient starts to cook a meal but stop in the middle to watch TV

Cognitive impairment – 3.Orientation



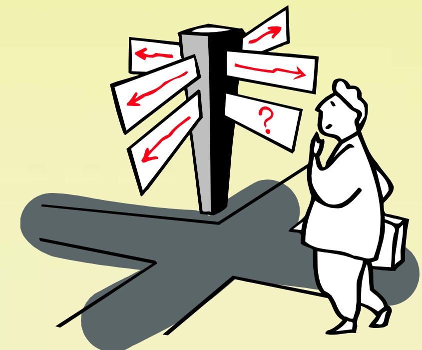
- Awareness of time, place and person
- Involving combination of different brain functions
  - e.g. orientation to time
    - Recent memory of when we last look at the time
    - Sense of passage of time and continuity
    - Long term memory of what usually happen at this time



- Dementia-related impairment
  - Disorientation to time, place or person, or any combination
  - Disorientation increase with increase severity of dementia

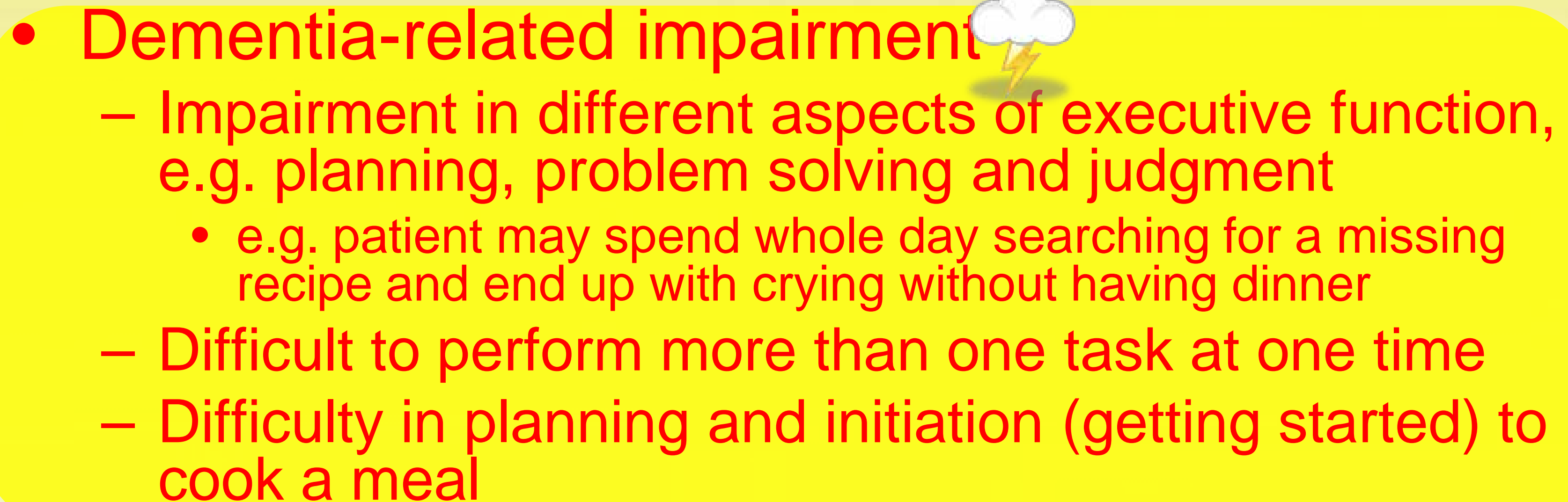
Cognitive impairment – Orientation

- Spatial disorientation
  - Misperceiving immediate surroundings, not being aware of one's setting, or not knowing where one is in relation to the environment
  - Lead to fear, anxiety, delusion
  - Safety problem
    - Patient may prone to serious accident



Cognitive impairment –
4. Executive function

- Cognitive capacity to plan and perform goal-directed behaviour
  - Think abstractly
  - Make connections among relevant facts
  - Generate logical alternatives in problem situations

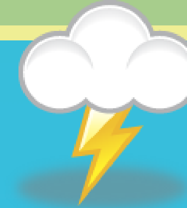


- Dementia-related impairment
  - Impairment in different aspects of executive function, e.g. planning, problem solving and judgment
    - e.g. patient may spend whole day searching for a missing recipe and end up with crying without having dinner
  - Difficult to perform more than one task at one time
  - Difficulty in planning and initiation (getting started) to cook a meal

Cognitive impairment – 5. Perception

- **Perception** is the process of attaining awareness or understanding of sensory information

- Dementia-related impairment



  - Agnosia
    - Impairment of ability to recognize or identify familiar objects, entities, people or stimulus while the specific sense is not impaired (Colman, 2006; Mahoney et al., 2000)
      - e.g. patient may recognize a pencil as comb, putting iron into fridge, etc.
    - Safety hazard if a person puts inedible things in his/her mouth

Cognitive impairment – 6. Language skills

- Dementia-related impairment
  - Aphasia: loss of ability to use language to communicate
  - Trouble in word finding
  - Impaired ability to name an object (anomia)
  - Speech may be fluent but lacks content, stereotyped

Am I pretty?

…………

Cognitive impairment – 7.Motor execution

- Dementia-related impairment

Apraxia

- Loss of the ability to execute or carry out learned purposeful movements
- E.g. problems remembering how to perform the steps of routine motor tasks such as dressing, walking and eating

Behavioral and psychological symptoms of Dementia (BPSD)

Behavioral and Psychological Symptoms of Dementia (BPSD)

- Dementia associated with high prevalence of BPSD
- BPSD is defined as "symptoms of disturbed perception, thought content, mood or behaviour that frequently occurs in patients with dementia" (Finkel & Burns, 1999)
- Simple methods of grouping BPSD
  - ***Behavioural symptoms***
    - Observations of the patient
  - ***Psychological symptoms***
    - Assessed by interviews with patients and relatives

Importance of BPSD in dementia patient?

Physical impact
- Poorer prognosis
- Rapid rate of cognitive decline
- Illness progression
- é impairment in ADL

Social impact
- Caregiver burden
- Patient institutionalization

(Finkel 1996)

BPSD

Behavioural symptoms

- Agitation
- Aggressive behaviour
- Wandering
- Abnormal vocalization
- Disinhibition
- Eating disorder
- Insomnia

Psychological symptoms

Psychosis
- Hallucination
- Delusion
- Delusional misidentification

Depression

Anxiety

Apathy

BPSD: Behavioural symptoms

- Agitation
  - Aggressive behaviour
  - Wandering
  - Abnormal vocalization
- Disinhibition
- Eating disorder
- Insomnia

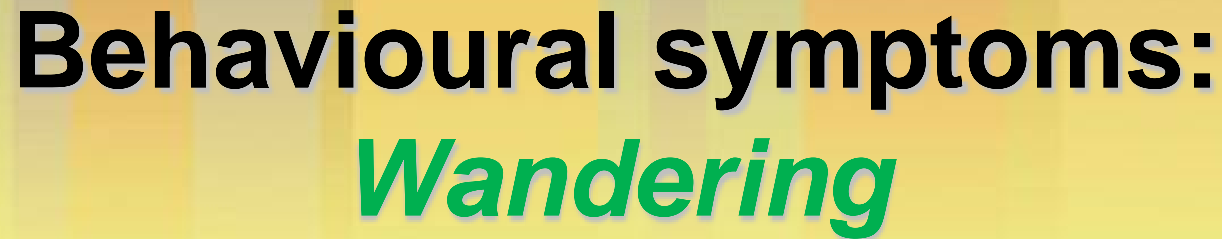
Behavioural symptoms: Agitation

- "Inappropriate verbal, vocal, or motor activity which is not explained by needs or confusion *per se*" (Cohen-Mansfield & Billig, 1986)
- Increased agitation in the afternoon and evening has been documented in patient with dementia
- Manifested by physical or vocal behaviors or both:
  - Aggressive behaviour
  - Physical non-aggressive behaviour
    - e.g. Wandering, restless, pacing
  - Verbally non-aggressive behaviour
    - e.g. abnormal vocalization, constant request for attention

Behavioural symptoms: *Aggressive behaviour*

- An overt act involves delivery of noxious stimuli to another organism, object or self
- Physical aggression
  - Assault the others, kicking, biting, grabbing people

- Verbal aggression
  - Screaming, cursing, temper outbursts, making strange noises



- Tendency to move about in aimless or disorientated fashion, or in pursuit of an indefinable or unobtainable goal (Snyder et al., 1978, Stokes, 1986)

Nine key features of Wandering

Attempts to Leave home

Checking/ Trailing

Pottering

Aimless walking

Unable to get home without help

Walking with inappropriate purpose

Night-time walking

Excessive activity

Walking with proper purpose but improper frequency

Behavioural symptoms: *Abnormal vocalization*

- Making noise for
  - No purpose
  - Responding to the environmental stimuli
  - Trying to elicit an environmental response
  - Compensating deafness
  - Seeking attention
- Usually seen in people with dementia in residential setting
- Being referred by care staff as 'shouting', 'screaming' or constant demands for 'attention'

Behavioural symptoms: Disinhibition (1)

- Inhibition is the act or process of restraining or preventing something, (Colman, 2006)
- Disinhibition in dementia is the loss of inhibition
  - Speech disinhibition
  - Emotional disinhibition
  - Behavioural disinhibition
  - Sexual disinhibition

Behavioural symptoms: Disinhibition (2)

- Speech disinhibition
  - Difficulty in shifting from one topic to another (phenomenon named "Perseveration") or stuck speech
  - e.g. repeat over and over on a word, a phrase or a story (Jacques & Jackson, 2000)

Behavioural symptoms: Disinhibition (3)

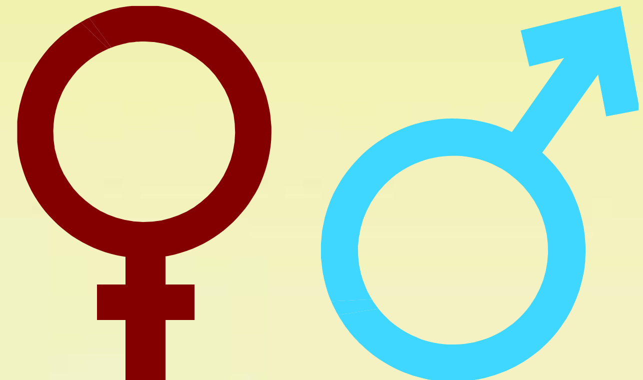
- Emotional disinhibition
  - Loss of emotional control
  - Emotional lability
    - changeability of one or more than one emotion
    - e.g. patient loses control with flooding tears on face when someone talk about his/her long-dead relative, but then suddenly change to outburst of anger after a tiny argument
  - Emotional incontinence
    - Emotional outburst comes completely without warning/causes
    - e.g. sudden laugh during a conversation, occur for few seconds and suddenly recover
  - Stuck emotion
    - Loss of ability to move away from a particular emotion
    - e.g. spend most of the day in tears, even she may feel happy at part of the day

Behavioural symptoms: Disinhibition (4)

- Behavioural disinhibition
  - Perseveration of action
    - Difficult to change from one action to another
  - Old habits
    - Reappearance of old habitual action
  - Rituals
    - Establish of new repetitive habitual action
  - Dressing and undressing
    - Wearing of eccentric clothes or undress in public
  - Restlessness
    - Increase in energy and activity, cannot stay steady
  - Theft
    - Take others belongings and believe it's belonged to them

Behavioural symptoms: Disinhibition (5)

- Sexual disinhibition
  - Uncontrolled sexual activities or desires
  - Patient may look for sexual contact in a disinhibited way, or even masturbate in a public area.
  - Very embarrassing



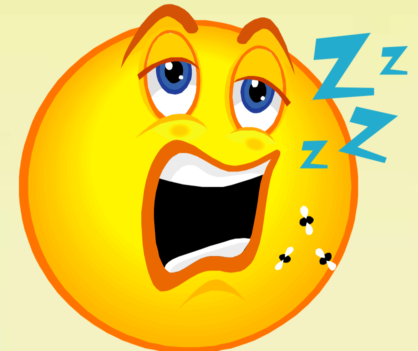
Behavioural symptoms:
Eating disorder

- Change in preference for sweet foods
- Increase or decrease consumption
- Eating non-food substance
- Often require close caregiver supervision during meals

Behavioural symptoms: Insomina

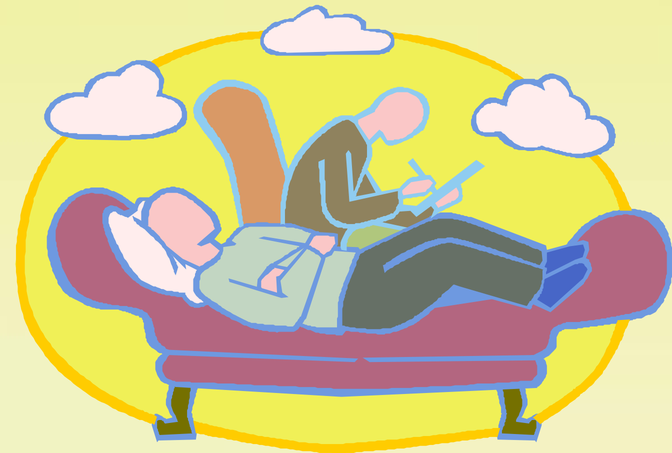
Sleep disturbances due to:

- Loss or damage of the pathways in the suprachiasmatic nucleus
  - Area that initiates and maintains sleep
- Changes in the circadian rhythm
- Increased sleepiness and number of naps in daytime
- Night-time wandering



BPSD: Psychological symptoms

- Psychosis
  - Hallucination
  - Delusion
  - Delusional misidentification
- Depression
- Anxiety
- Apathy



Psychological symptoms: Psychosis

Hallucination

- Defined as perceptions in the absence of a stimulus
- Visual hallucination
  - Most common is dementia with Lewy bodies
  - In form of animals/insects, strangers, relatives in the house, children
- Auditory hallucination
  - Talking voices of other persons
- Olfactory hallucination
  - Sensation of smell

Psychological symptoms: Psychosis

Delusion

- False, unshakable ideas or beliefs that are held with strange conviction and subjective certainty

Delusion of theft: One's possessions are being hidden or stolen

Delusion of reference: belief that somebody is being talked about

Delusion of persecution: Belief that somebody else do harm to somebody

Delusion of abandonment: Belief that someone is going to be abandonment

Psychological symptoms: Psychosis

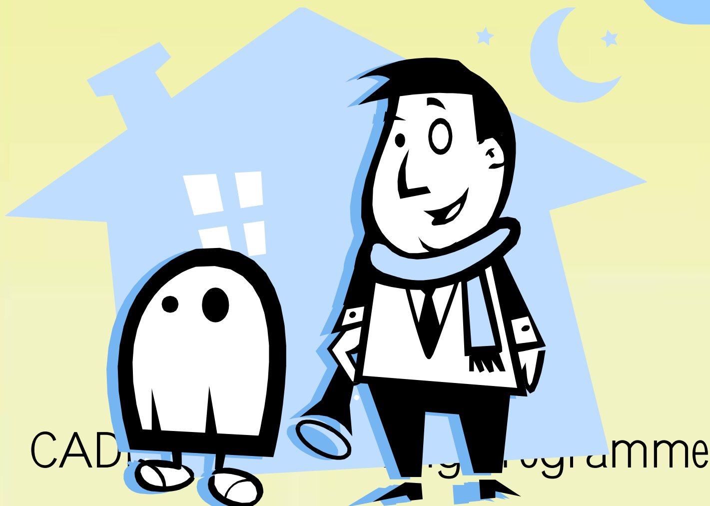
Delusional misidentification

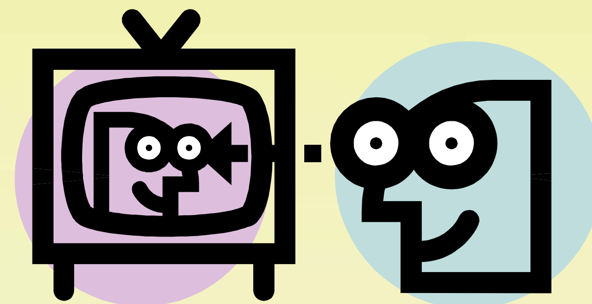
– Belief that the identity of a person, object or place has somehow changed or has been altered

Capgras delusion
close relative or spouse has been replaced by an identical-looking impostor

Delusional Misidentification of mirror image
Belief that self-mirror Image is somebody else

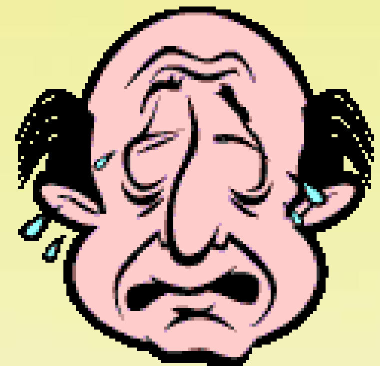
Delusional Misidentification of TV image
Belief that people on the TV are exists in real space





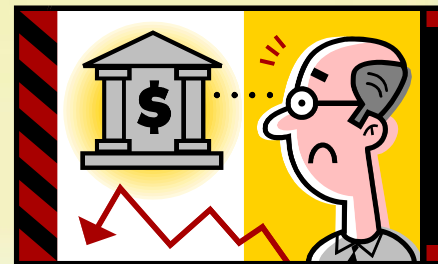
Psychological symptoms: Depression

- Psychiatric disorder
  - Pervasive low mood, diminished interest and ability to experience pleasure
  - *Sign and symptoms*
    - Depressed mood, or loss of interest or pleasure in nearly all activities
    - Significant weight loss or gain
    - Sleep disturbance: Insomnia or hypersomnia
    - Fatigue or loss of energy
    - Feelings of worthlessness or guilt
    - Recurrent thoughts of death or suicidal ideation
    - Diminished ability to think or concentrate



Psychological symptoms: Anxiety

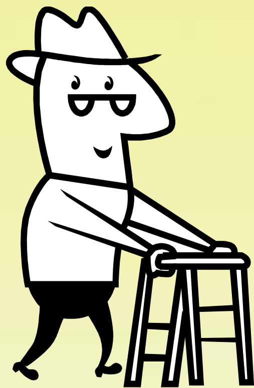
- State of uneasiness, accompanied by dysphoria and somatic signs and symptoms of tension
- Patient with dementia may have one or several specific fears or worries
  - fear of losing things
  - fear of getting lost when going outside
  - worry that he/she may cause embarrassment in the public or act without control



Psychological symptoms: Apathy

- State of indifference: Lack of interest or concern
- Appear passive, demonstrate inattention to external environment
- e.g. patient not participate in meaningful activity often sits motionless, stares into space

Dementia manifestation: Physical impairment



Physical impairment

- Factors affecting physical function in dementia patient
  - Physical factors
    - Dementing process è brain pathology
    - Immobility
    - Medications
  - Cognitive factors
  - Social factors
  - Environment factors

Physical impairment

- Brain pathology
  - Progressive cortical, extrapyramidal systems dysfunction led to neuromotor changes
  - Infarct in vascular dementia causing weakness of extremities, gait abnormalities, etc.
  - Parkinsonism symptoms of patient with dementia with Lewy bodies
  - Progressive cerebral pathology led to inability to walk and even stand

Physical impairment

- Immobility
  - Improper use of physical restraints: result in the loss of muscle mass, strength and flexibility
  - Deconditioning and loss of endurance due to disuse → decrease in exercise tolerance
  - Prolonged sitting or bed rest → limb contractures

Physical impairment

- Medication
  - Side effects of medications
  - E.g. Neuroleptic drugs for controlling psychosis may induce extrapyramidal side effects
  - *(details will be covered in chapter 3)*

Physical impairment

- Cognitive factors
  - Recognizing places, things or people (disorientation, agnosia)
  - Difficult to follow instructions
  - Executing a sequence of actions (apraxia)
- May contribute to impairment in ADL functions

Physical impairment

- Psychosocial factors
  - Mood disturbance:
    - Depressed mood, anxiety, etc.
  - Effect on self-esteem
    - May be difficult for older people who are used to be independent without accepting any personal assistance
  - Dependency
    - The patient may no longer want to perform some activities if they cannot do things in the way that they used to do
- Patient will have low motivation in family and social participation

Briller et al., 2000

Environment factors

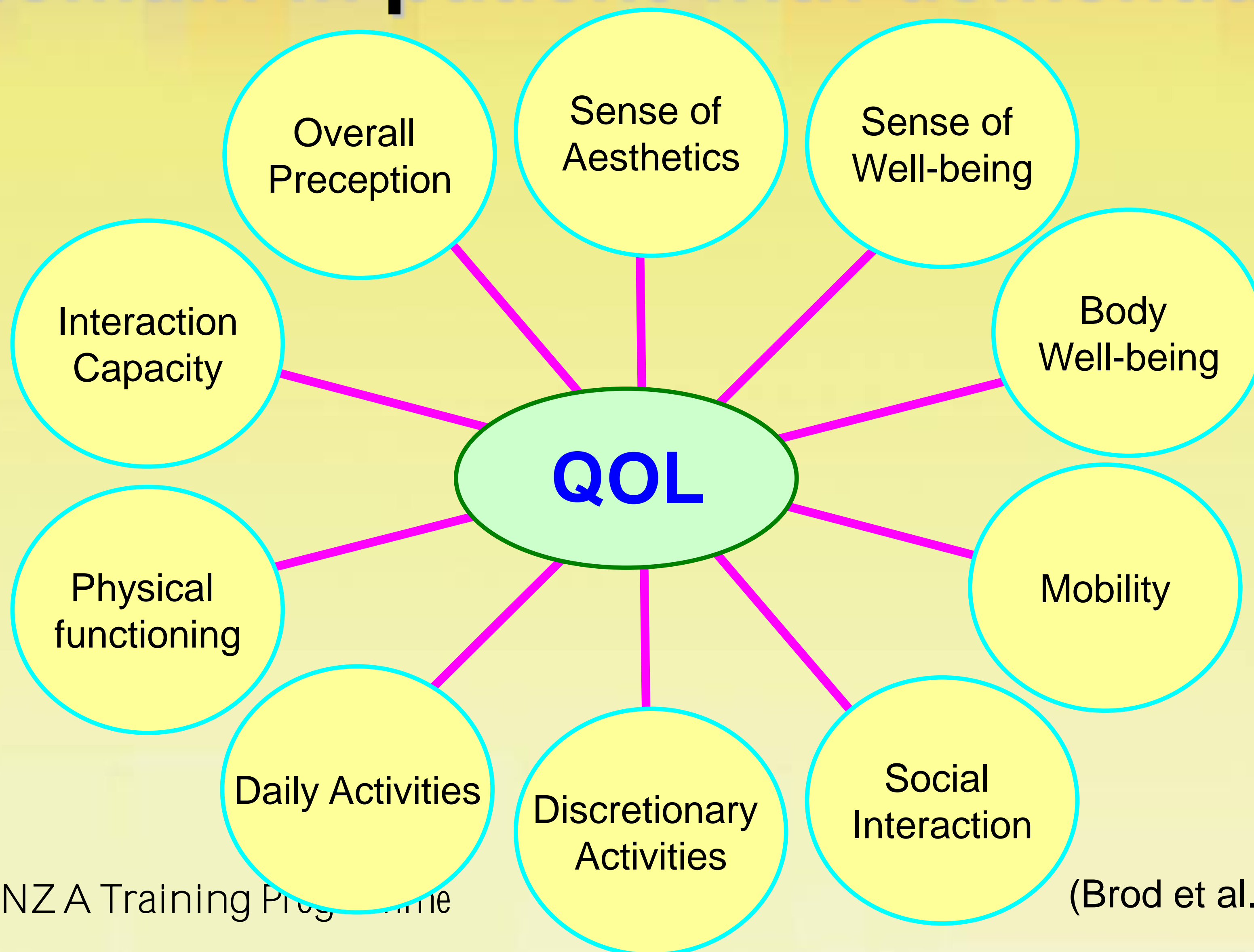
- Environment can either support or limit the functional abilities
- Patient with dementia may find tiring and frustrating if the environment is not supportive
  - Even some assistive devices seem helpful, they may need time to read or figure out cues in the environment

<<Refer to Chapter 4: Environmental modification>>

Impact of dementia on quality of life of older people

- “Multidimensional concept encompassing physical, social and psychological domains” (Birren et al., 1991; Carla et al., 2007)
- Has been used to refer to people's overall evaluation of their lives in general or of various components of life (Brod et al., 1999; Cambell et al., 1976)

Conceptual framework of QoL domain in patient with dementia



(Brod et al., 1999)

What is being affected in patient with dementia?

- Daily activities
  - Personal self-care
  - ADL
- Physical health
- Psychological well-being
- Cognitive function
- Behaviour
- Social functioning and satisfaction
- Caregiver's perspective

Measuring QoL in patient with dementia

- QoL is a subjective, individual experience
  - Individual assesses and evaluates his/her own QoL based on the degree of importance that he/she gives to each component (Whitehouse and Rabins, 1992)
  - Patients with dementia are no different in performing the measurement
  - Additional time, patience and vigilance required to measure self-reported QoL accurately in patient with dementia
  - Points to consider:
    - Subject's ability to comprehend the questions being asked
    - Subject's awareness of his/her internal subjective feeling

(Brod et al., 1999)

Measuring QoL in patient with dementia

- Rating of QoL in patient with dementia
  - Self rating [patient-reported outcomes (PROs)]
    - Mild-moderately severe dementia can be considered good informants of their own subjective states
    - Gold standard in validating new QoL measures
  - Proxy rating and proxy observation scales
    - More severe stages
    - Biased with rater's expectations, mood, burden of care, and the specific relationship with the person being rated

Examples of QoL scale in dementia

- Dementia Quality of Life Scale (DQoL)
  - 29-item scale which assesses several domains
  - Brod et al. (1999) reported that the scale has good reliability and construct validity

Domains:

Physical functioning	Daily activities
Discretionary activities	Mobility
Social interaction	Interaction capacity
Bodily wellbeing	Sense of wellbeing
Sense of aesthetics	Overall perceptions

Examples of QoL scale in dementia

- Quality of Life—Alzheimer's Disease Scale (QoLAD)
  - 13-item, brief, self-report assessment scale
  - Logsdon et al. (1999) and Thorgrimsen et al. (2003) have shown that the scale has very good reliability and validity

Domains:

Physical Health	Energy	Living situation
Mood	Memory	Family
Marriage	Friends	Fun
Money	Chores	Self and life as a whole

Quality of life in dementia (Selwood et al., 2004)

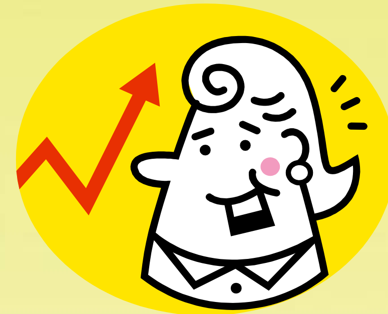
- Aim of study:
  - To study longitudinal change in QoL over a period of one year in people with dementia aged ≥65 years
- Methods:
  - 60 people with dementia were selected from different settings
  - Outcome measures included following domains:
    - QoL (QoLAD, DQoL), depression, anxiety, cognitive functions

Quality of life in dementia (Selwood et al., 2004)

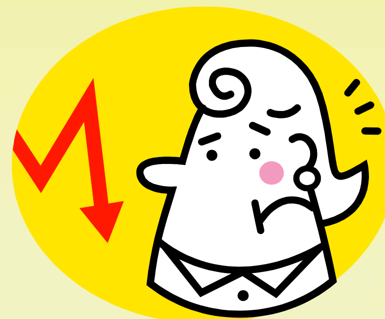
- Result:
  - There were no significant differences between baseline and follow-up in any of the QoL scores
  - Significant correlation between QoL and both anxiety and depression score

Quality of life – other research findings

- Predictors of higher quality of life (Hoe et al., 2006; Burgener & Twigg, 2002; Logsdon et al, 1999)
  - Lower level of depression and anxiety
  - Higher level of functional ability
  - Educational level
  - Social contact and activity
  - Less cognitive impairment
  - *Fewer unmet needs*



- Predictors of lower quality of life (Ready et al, 2002; Thorgrimsen et al, 2003)
  - Poor physical health
  - Memory
  - Loss of role
  - Increased boredom
  - Loneliness



Quality of life of people with dementia in residential care homes (Hoe et al., 2006)

- Aim of study (Hoe et al., 2006)
  - To compare the views of residents with dementia with the views of staff as to their QoL
  - To look at factors associated with these ratings
- Methods:
  - Outcome measures include:
    - ADL, cognitive function, behaviour, anxiety, depression, QoL (QoLAD)

Quality of life of people with dementia in residential care homes (Hoe et al., 2006)

- Results
  - There were 119 residents and staff completed the study
  - Residents' high QoL score was strongly correlated with less depressed mood and less anxiety, fewer unmet needs
  - In contrast, better QoL as rated by staff correlated most strongly with increased dependency and behaviour problems

Implication of Hoe et al. study

- Ratings of quality of life by dementia residents
  - Influenced most strongly by their mood
- Ratings by staff who cares dementia residents of the latter's quality of life
  - Influenced most strongly by levels of dependency and presented challenging behaviours
- Poor consensus! !
- This may indicate a proper need assessment to know patient needs

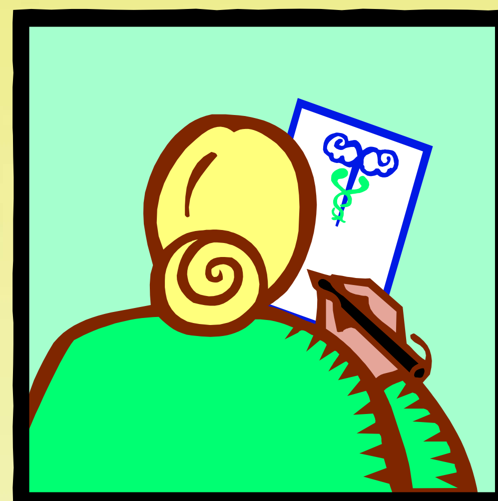
Needs assessment for patients with dementia

CADENZA Training Programme

- Address patient-centered care
- Is a staged process:
- Begins by
  - *Specific difficulty identification*
  - *Assess for any presence and efficacy of current help*
  - *Recognize patient's perceived needs*
  - *Identify intervention to meet the needs*
- Take into account patients, carers and professionals perspectives

Assessment tools

- Some assessment tools commonly adopted in patient with dementia
  - Physical mobility and balance
    - Elderly Mobility Scale (EMS)
    - Berg Balance Scale (BBS)
  - ADL and IADL
    - Barthel Index (BI)
    - Lawton Index for IADL
  - Cognitive domains
    - Mini-mental State Examination (MMSE)
    - The Clock-drawing test
  - BPSD
    - Geriatric Depression Scale (GDS)
    - Cohen-Mansfield Agitation Inventory (CMAI)
    - Neuropsychiatric Inventory (NPI)
    - Cornell Scale for Depression in Dementia



Formal needs assessment for dementia

- Care Needs Assessment Pack for Dementia (CareNap-D)
- Developed by McWalter et al (1996)
  - Identify the care needs of older individuals with dementia
  - Specify the type of care to meet individual's needs
- 57 activity/behavioural items encompassing within 7 domains

CareNap-D

1. Health & mobility

2. Self-care and toileting

7. Community living

CareNap-D

3. Social interaction

6. Housecare

5. Behaviour & mental state

4. Thinking & memory

Needs of patient with dementia in Hong Kong

- **Local study on 197 community-dwelling older Hong Kong people (Chung, 2006)**
- **Unmet needs fell into 3 domains**
  - Social interaction
  - Thinking and memory
  - Behaviour and mental state
- **Needs related to staging of dementia**
  - Early stage: memory and thinking
  - Middle stage: social interaction and management of behavioural manifestations
  - Advance stage: Self-care, thinking and memory, household management & community living

Summary

- Patient with dementia suffers from a variety of symptoms
  - Physical
  - Cognitive
  - Behavioural and Psychological
- Affect their QoL
  - Discrepancy between patient's and carer's view of QoL
- Needs assessment is required to know what patients/caregivers really want

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