

Inside Dementia

- Brief introduction to definitions and types of dementias
- Impact of dementia on environment
- Impact of dementia on relationships
- Strategies for coping

Definition

- Disease of the brain that impairs a broad range of functions:
 - Memory (more than expected for age),
Concentration, Attention, Language, Spatial,
Judgement, Insight & Organisational skills
(executive difficulties)
- Deficits significantly impair social and occupational functioning

Definition (contød)

- Broad range of disorders, depending on cause
- Deteriorating condition
- Needs to be clearly distinguished from other illnesses which may mimic the symptoms
 - Amnestic syndromes
 - Delirium
 - Depression

Signs and Symptoms

- Memory impairment often prominent as early symptom, but not always
 - Difficulties learning new material or remembering recent conversations or events, misplacing valuables, lapses in attention to important details, e.g., switching off cooker
- Impaired reasoning, judgement & insight,
 - e.g., underestimating risks in activities; poor awareness of memory and other deficits;

Types of Dementia

- Alzheimer's Disease
- Vascular dementia
- Lewy Body dementia
- Fronto-temporal dementia
- Less common forms e.g., Pick's disease, CJD, HIV, Huntington's

Alzheimer's Disease

- Gradually progressive intellectual decline across a range of functions
- Begins slowly
- Initial impairment of memory for recent events
- Rapid loss of new information; excellent recall of past
- Other intellectual functions become impaired in time
- Build-up of protein and tangles in brain cells, loss of brain cells = loss of functions

Vascular Dementia

- Caused by cerebrovascular disease (blood supply)
- Associated with abrupt onset, e.g., stroke
- Fluctuating, stepwise course
- Includes more focal or patchy difficulties
- Early treatment of blood pressure and vascular disease can help prevent further progression

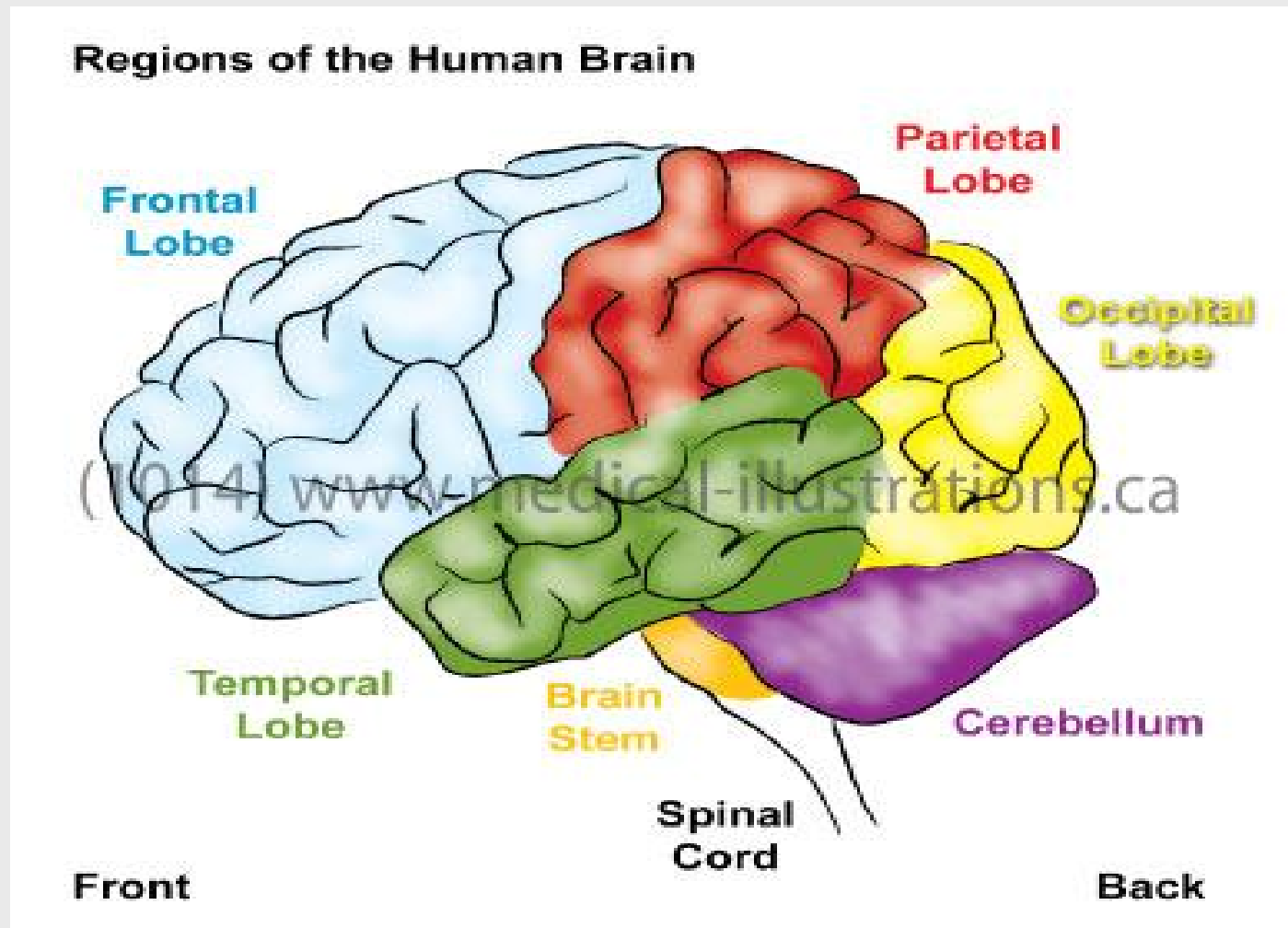
Dementia with Lewy Bodies

- Similar to Parkinson's Disease
- Early hallucinations and delusions
- Day-to-day variation in intellectual function
- History of falls
- Tremor
- Sensitivity to neuroleptic medication
- Prominent attention, executive, and visuo-spatial impairment *versus* memory difficulties early on

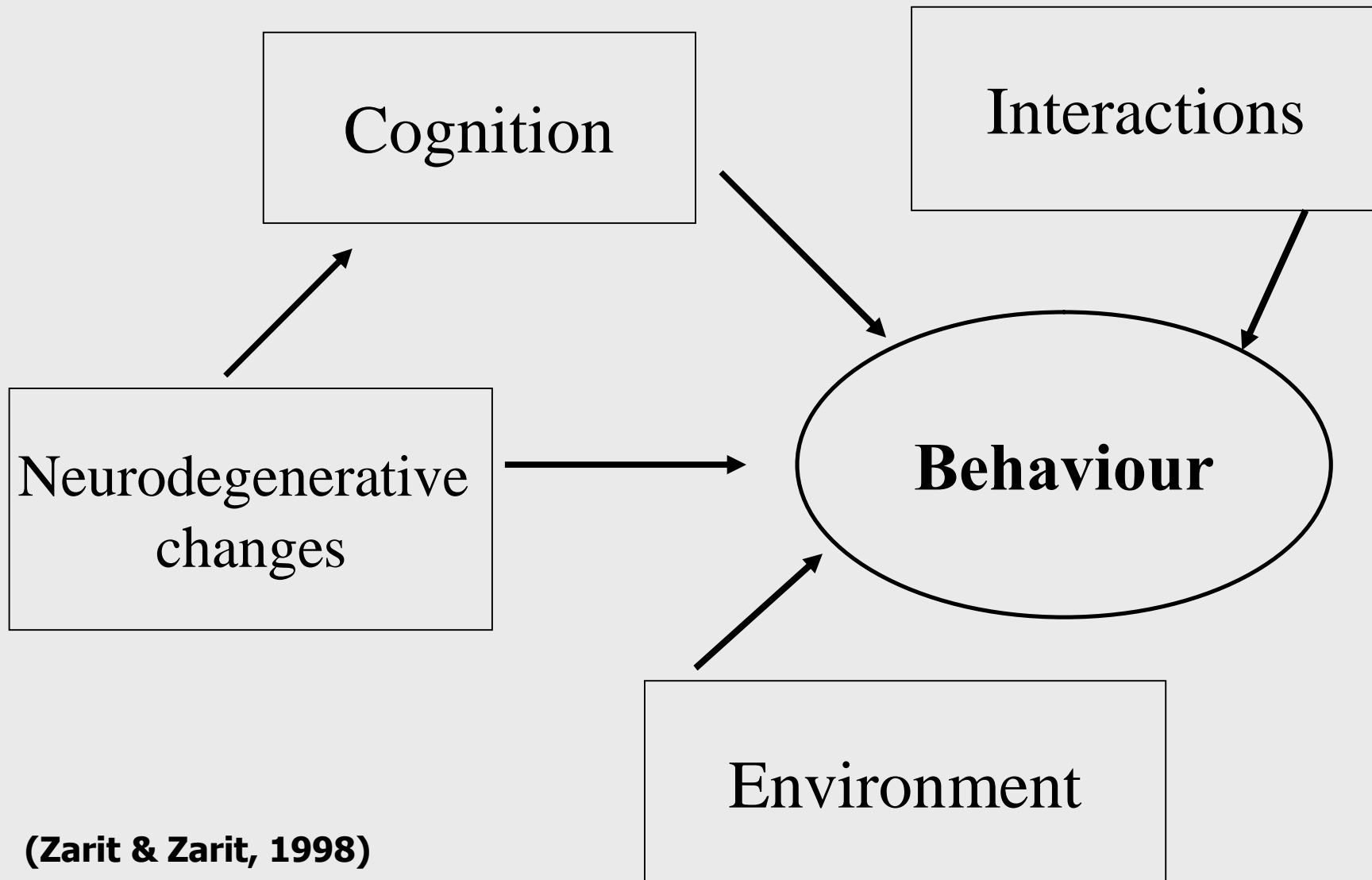
Frontal lobe dementias

- Less common
- Early changes in personality, executive skills, social skills, emotional blunting, behavioural disinhibition, and language abnormalities
- May be mistaken for psychiatric disorder early on
- Slowing of intellectual and motor functions

Brain regions



Interaction between Dementia & Environment



(Zarit & Zarit, 1998)

Challenges of dementia

- Memory impairment ó initially short term memory (memory for new events)
- Memory ability can fluctuate
 - Good recall of old memories but poor retention of new information (can frustrate and confuse)
- Memories are EMOTIONAL
- Relationship between memory and attention difficulties

Challenges of dementia

- Processing and following long instructions or doing tasks that require sustained attention
 - e.g., reading a book requires you to remember characters etc., cooking you need to remember what you just did and when you did it, following tv programme;
- Difficulty learning new tasks
- Fear and intense anxiety due to forgetting where s/he is and why

Challenges of dementia

- Body clock disturbances and disorientation
- Complex Motor Tasks
 - Consciously co-ordinating action e.g. dressing, feeding, cooking, making phonecalls

Challenges of dementia

- Language ó
 - Word findings difficulties
 - Naming difficulties
 - Difficulties with the production and/or understanding of speech, reading or writing
 - Use of inappropriate language

Challenges of dementia

- Inappropriate behaviour that is out of character e.g. verbal abuse, eating voraciously/ carelessly ó can be due to inability to monitor and inhibit behaviour
- Perseveration (õbroken recordö) ó repetition of patterns, ideas or requests ó person cannot shift from one idea or action to another
- Lack of empathy or caring ó due to difficulty taking another person's perspective
- Mood swings ó due to difficulty monitoring and inhibiting emotional response

Challenges of dementia

- Delusional beliefs/ paranoia ó sometimes function to help the person deal with memory loss e.g., öWho stole my money?ö
- Depression/apathy
 - May make the person difficult to engage. Challenging because it feels hopeless and difficult to change
 - May affect the will to communicate/ speech is often sparse, quiet, monotone

Other Difficulties

- Difficulties identifying objects by sight, hearing or speech alone (agnosia)
 - Spatial agnosia – difficulty finding way around
 - Prosopagnosia – inability to recognise familiar faces
 - Anosognosia - body neglect

Challenges to Relationships

Person with dementia

Failure to maintain relationships as a result of:

- Memory difficulties
- Executive difficulties (apathy, disinhibition, lack of initiation)
- Communication difficulties
- Difficulties with empathy and relating
- Social withdrawal resulting in a reduction in social network and activities
- Feelings of infantilisation

Challenges to Relationships

Person with dementia

- Loss of role and role reversal
- Decreased independence/ increased dependency may cast light on the nature of dynamic between carer and person being cared for, and may have throw back to earlier dependent relationships

Emotional experience (Person with dementia)

- Frustration
- Fear
- Anger
- Isolation;
Loneliness
- Embarrassment
- Abused
- Sadness
- Disappointment
- Insecurity
- Resentment
- Loss
- Patronised
- Depersonalised
- Helpless
- Hopeless
- Powerless
- Suspicious

Behaviour as Unmet Need

- Interactions /communications are attempts to attain goals which are about needs (physical, social, emotional, spiritual)
- When a goal or need is denied, the result is continuous corrective action to attain the goal/need
- Challenging behaviour can be viewed as corrective action in an attempt to communicate (verbally & non verbally) about an unmet need or emotional state
- Corrective action is less sophisticated, more primitive because of cognitive decline in dementia

Challenges to Relationships

Carer

- Increased practical burden of care
- Demands of balancing commitments
- Increased perceived burden of care
- Different tolerances and stress responses
- Decrease in reciprocity within relationship
- Direct impact of new behaviours on relationship
- History of refusal and saying "No!" (rules around that)

Challenges to Relationships

Carer

- Role reversal
- Exaggeration of old patterns of behaviour
- Decrease in social activities/ network
- Experience of loss and grieving
- Insecurity about future, including prognosis, financial burden, coping ability

Emotional experience (Carer)

- Drained
- Overwhelmed
- Sad
- Angry
- Frustrated
- Lonely
- Irritated
- Afraid
- Disappointed
- Abused
- Abandoned
- Insecure
- Resentful
- Guilty

Identifying Emotional Distress



If someone is frightened they will typically see themselves as vulnerable and unable to cope in that situation

If someone is depressed they will see themselves as being inadequate, worthless and see their situation as hopeless



Identifying Emotional Distress

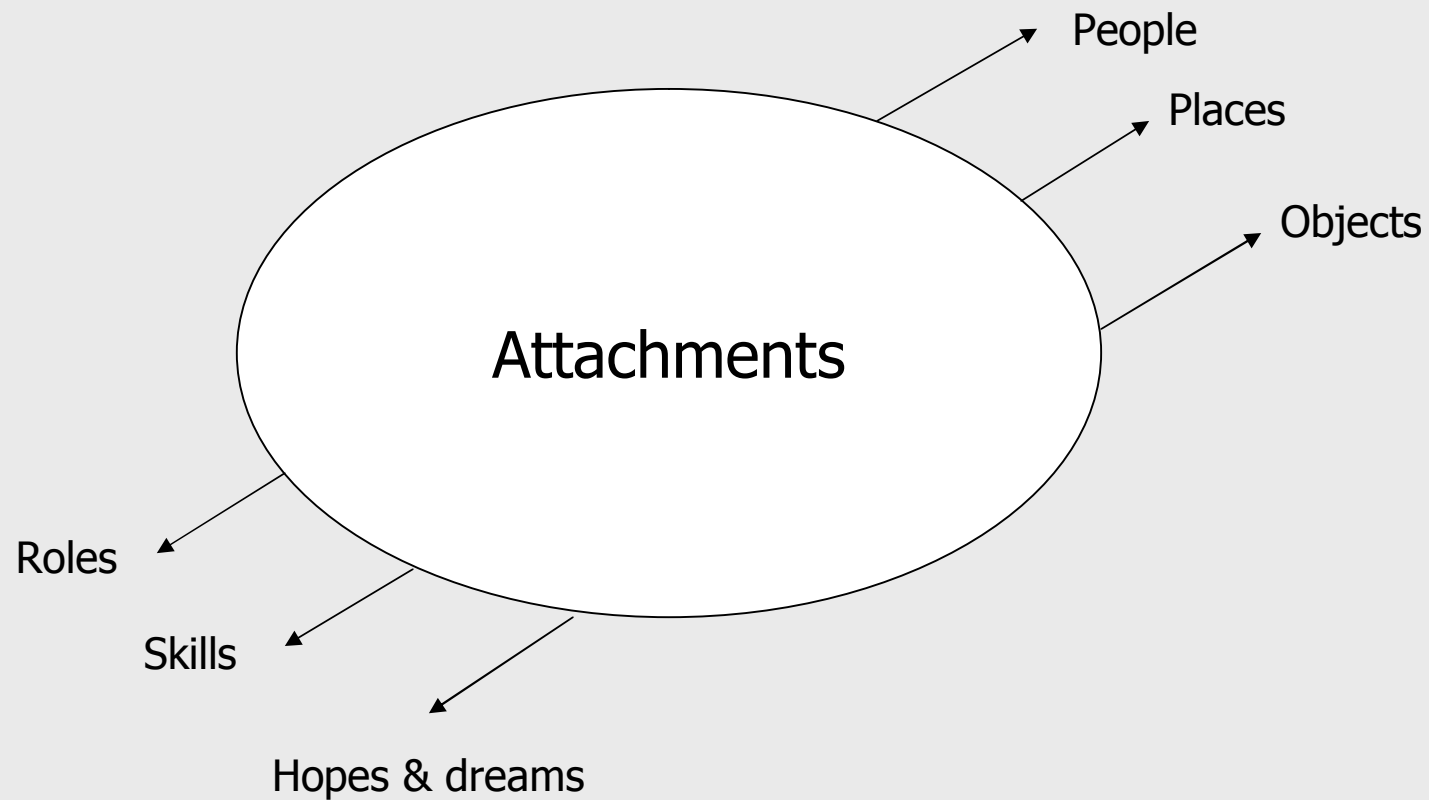


When someone is feeling aggressive they will perceive themselves as being intentionally abused or misused in some way

Issues to be aware of í

- Guilt...wide range of past actions may evoke guiltí irrational beliefs central
- Ambivalence in relationships
- Resentments
- Difficulty in balancing conflicting needs
- Feeling demanded of & history of this
- Stress in witnessing distress in the person
- Past conflicts and history of managing these
- Difficulties adapting to change
- Overidentification & Projection

Attachment and Loss



Carer Adaptation to Role

- Adjustment to role of carer
- History of caring (can work for & against)
- No. of stressors on carer
- Perception of stress
- Degree of ambivalence towards caring / patient
- Anger / disappointment at how things have turned out
- Own history of adaptation & adjustment

Carer Adaptation to Role

- Attributions for behaviour
- Formulation of own stress response as abnormal
- Fear of blame / failure
- Perfectionism & standards of care
- Response to protest, refusal, $\neg\emptyset$
- Ability to observe, reflect, establish objectivity
- Relationship factors (quality, rules, etc.)
- Envy /Resentment Dynamic

Model of Stress (Lazarus & Folkman, 1972)

<i>Stressors</i>		<i>Outcomes</i>
<ul style="list-style-type: none">■ Neurobiological■ Cognitive &■ Affective (emotional) function■ Behavioural■ Specific challenges/ stresses of the condition		<ul style="list-style-type: none">■ Disability■ Distress■ Pain

Model of Stress (Lazarus & Folkman, 1972)

<i>Stressors</i>	<i>Mediators</i>	<i>Outcomes</i>
<ul style="list-style-type: none">■ Neurobiological■ Cognitive &■ Affective (emotional) function■ Behavioural■ Specific challenges/stresses of the condition	<ul style="list-style-type: none">■ Individual/family capacity to meet challenges■ Beliefs re: illness & disability■ Emotional response■ Attributions■ Experience living with individual■ Perception of coping■ Flexibility/rigidity & change■ Characteristic patterns of stress response■ Appraisal of success■ Presence of psychopathology■ Quality of relationships■ Past experiences of loss	<ul style="list-style-type: none">■ Disability■ Distress■ Pain

Some Common Solutions

- Identifying the particular unmet need at a particular point in time
- Activity
- Stimulation (multi-sensorial)
- Reassurance
- Comfort (physical, psychological)
- Physical care (practical)
- Treat pain or illness
- Change medications

Helping the person with dementia

- Maintenance of pre-morbid interests, habits, likes & dislikes
- Time to process clear & simple communication
- Ascertaining consent to handle, assist with Activities of Daily Living
- Appropriate levels of assistance

Helping the person with dementia

- Providing structure where the individual cannot (balance of respect for autonomy & supporting deficits)
- Orientating the individual to person, place & time as necessary
- Use of memory aids where instructions are forgotten / repetitive questioning

Helping the Carer

- Time off to increase resilience (day-care, respite care)
- Use of distraction
- Avoiding correction & unnecessary presentation of deficits
- Avoiding excessive reasoning in the light of cognitive impairment
- Non-confrontational interventions

Helping the Carer

- Respect for own and person's space, emotions & needs (including the need to choose, self-determine and have some control)
- Challenging unobtainable standards
- Flexible routines
- Accessing support
- Therapy for complex issues

Self-Care

As a priority this can be difficult to accept but its practice has long-term effects on the ability of the carer to continue caring

Multiple Pathways to Experience of Dementia

