Dementia:

Non-Pharmacological intervention and caregivers' management

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Outline

A. The profile of dementia

B. The pain of personal losses

C. Non-pharmacological intervention

D. Caregivers' management

A. The profile of dementia

DEMENTIA:
A DISEASE OF **COGNITION**

For best care we need to keep in focus this essential feature.

COGNITION is **the ability to manipulate information** to cope with:

- the environment
- self
- others

Cognition is a function of the Brain

Cognition involves:

1. recognition: or identifying information
2. memory: or recalling information
3. using language: or expressing information
4. carrying out learned motor behaviour: or using information to act
5. executive functions: or organizing information for living

Memory problems ?

Not always dementia...

Disorders of Mild Memory Function

- **NORMAL AGEING**
- **MILD COGNITIVE IMPAIRMENT**
- **DEMENTIA**

(These can merge into each other)

Examples of ***Cognitive*** difficulties

- Recognition (Agnosia,)

  Am I losing *recognition* of objects and people's faces?

- Memory

  Is my forgetting such as *names, telephone numbers and where I put things* affecting my function?

- Language (Aphasia)

  Am I forgetting *common words* or losing my *trend of thought* while conversing?

Examples of ***Cognitive*** difficulties

- Learned motor behavior (doing) (Apraxia),

  Do I have difficulty *getting dressed* or *using objects* like the TV remote, telephone or stove?

- Executive Functions sequencing, planning, organizing

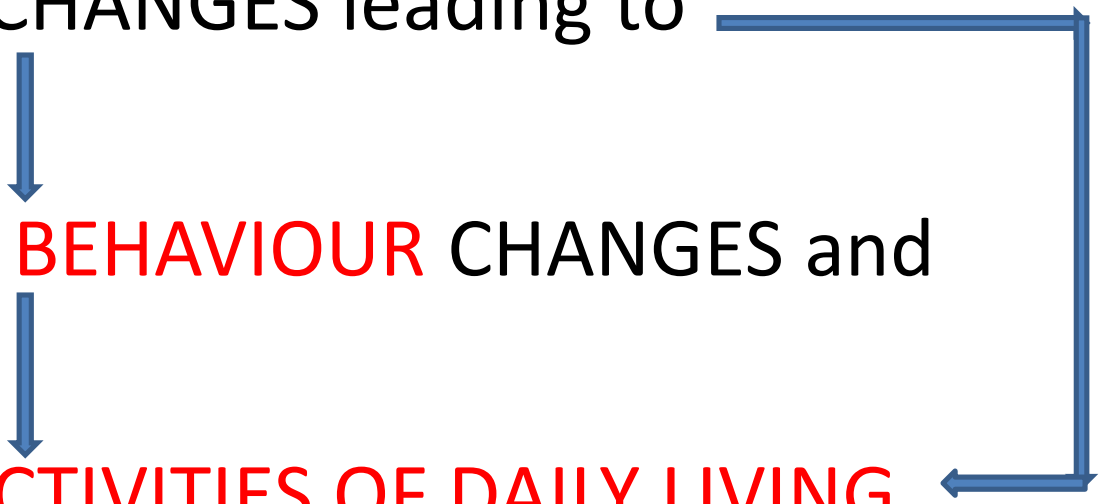
  Am I having difficulty *doing complex tasks* like balancing my cheque book or following the plot in TV movies and books?

Other features of **DEMENTIA**

- *Problem Moods and Behaviours*
  - depression, irritability, aggression, inappropriateness, agitation, apathy
- *Psychiatric symptoms* (e.g. psychosis, vulnerability to delirium)
- Changes in *Activities of Daily Living*
  - dressing, hygiene, handling money, household appliances, hobbies, social events

Thus in **DEMENTIA** the Clinical Profile includes:

- COGNITIVE CHANGES leading to
- MOOD AND BEHAVIOUR CHANGES and
- IMPAIRED ACTIVITIES OF DAILY LIVING



How to prevent under-diagnosis of dementia

- All caregivers should be taught how to carefully observe persons at risk who tend to compensate and conceal in early stages

- Have a high index of suspicion with minor reported changes

- As well as the patient interview, ask caregivers and surrounding family and friends for any giveaway symptoms or behaviours.

The Progression of Dementia

Stages of DEMENTIA

- **Mild** – 2 to 4 years
- **Moderate** – 2 to 10 years
- **Severe** – 1 to 3 years

Let us look from the patient's perspective

The Transition Process

Aspects and stages

1. **Cognition-** being less connected

Mild Stage	Moderate Stage	Severe Stage
• Some regular *loss of recent memory* (e.g. re conversations & events). Repeated questions. • Problems *expressing self* and *understanding others (language)* • *Writing* and *using household and other objects* become difficult.	• *Persistent & pervasive memory loss* *Less awareness of current events* • *Rambling speech*, unusual reasoning. • *Inability to learn new things.* • Problems *recognising family and friends*. • Confusion *about*, *time, and place.* Lost in familiar settings	• *Severe to total loss of verbal skills.* • *Loss of recognition* of familiar people and places • Confused about *past and present* • Generally *incapacitated*

Aspects and stages

2. **Mood and Behaviour-** being increasingly "cranky"

Mild Stage	Moderate Stage	Severe Stage
• Some *initial depression* and *apathy* • *Mild personality changes*. (e.g. irritability, disinhibition, regression).	• *Mood* or *behavioral* symptoms accelerate. • *Impulsive* behavior. (e.g. irritability & aggression – aggravated by stress and change.) • *Delusions and paranoia*. • *Sleep problems* (sometimes reversal of sleep cycle and night wandering) • Slowness, rigidity, tremors, and gait problems impact *mobility* and coordination.	•*Extreme problems with mood and, behavioral problems,* • *Hallucinations,* and *delirium*.

Aspects and stages

3. Activities of daily living – coping less and less

Mild Stage	Moderate Stage	Severe Stage
•*Connects and is active but needs some reminders* for tasks • Difficulties with sequencing impact *driving*.	• Need for *significant structure, reminders, and assistance in affairs*. • Problems coping with *new situations*. • Carrying out less *tasks that involve multiple steps* (such as getting dressed) • Loss of sense of smell affects *desire for food*	• Largely *incoherent or mute* *Mostly inactive*. patients need total support and care • *Falls* possible and *immobility* likely. • *Incontinence* • *Difficulty swallowing,*, weight loss, illness., seizures, or skin infections. • Often *die from infections or pneumonia*

Aspects and stages

4. General – needing increasing outer control

Mild Stage	Moderate Stage	Severe Stage
• Independent living with *monitoring.* • Adequate hygiene and judgment.	• One can still *connect* and *do* things. Yet has deficits one *can no longer "cover up".* • *Some degree of supervision* needed	• Mostly *disconnected*. • Needs *constant supervision*

B.The Pain of Personal Losses

Loss of AUTONOMY
"I have no say"

- From **CONTROL** of one's life to
  - *dependency on others (role reversal with children)*

- From **INDEPENDENCE** to
  - *being supervised*

- From **STRUCTURING** the life one wants to
  - *taking anything one gets*

- From **ACTIVE PARTICIPATION IN COMMUNITY** to
  - *isolation*

Loss of SELF-ESTEEM

" I will become nobody"

- From having **ALL OF ONE'S ABILITIES** to
  being considered less than whole

- From **SELF PROTECTION** to
  being totally vulnerable

- From being **USEFUL AND SIGNIFICANT** to
  making no difference

- From being a **UNIQUE PERSON WITH INHERENT DIGNITY** to
  being considered an "inmate"

Loss of Life Fulfillment

"Life holds nothing for me"

- Aesthetic pleasures
- Attachment (The giving and receiving of love)
- Creativity
- Transcendence: living above one's struggles

The Grief from Personal Losses

STAGES :

- Denial …
- Anger …
- Bargaining …
- Depression …
- Acceptance…

Be aware of cycling through stages

Personal Losses and related grief comprise the essential end targets in non-pharmacological intervention

C. Non-pharmacological Interventions

What is the best care for dementia?

- **Goals**:
  - Delay disease *progression*
  - Improve *quality of life*
  - Support *dignity, self-respect*
- **Targets**:
  - Cognition
  - Behaviour and mood,
  - Activities of daily living (function)
  - Personal losses
- **Types of care**:
  - Pharmacological
  - Non-pharmacological

Pharmacological Treatment -A "passing glance"

1. Management of Cognitive decline

– **Cholinesterase Inhibitors** for Mild to Moderate Dementia

- Donepezil **(Aricept)**
- Galantamine (**Reminyl**)
- Rivastigmine (**Exelon**)

– Add **Memantine** for greater severity

Pharmacological Treatment -A "passing glance"

Cholinesterase Inhibitors and Memantine

- *Slows cognitive decline*
- Affects *behavioral* measures
- *Slows ADL decline*
- Reduces *caregiver burden*
- *Delayed nursing home placement* by 1.2 years

Pharmacological Treatment
-A "passing glance"

2. Behavioural Management

For: irritability, aggression, agitation, apathy

1. *Antipsychotics*: increased risk of death in elderly patients with dementia. Atypicals better tolerated.

2. *Benzodiazepines*: sedation, risk of falls, worsening cognition, respiratory supressant.
   - Cautious use for prominent anxiety, infrequently otherwise.
   - **Lorazepam, Oxazepam** have no active metabolites
   - Consider **Buspirone instead of Benzodiazepines** for anxiety.

3. Possible benefit (open verdict): **Valproate, Carbemazapine, Citalopram.**

Periodically reduce or stop medication to assess ongoing need.

Pharmacological Treatment
-A “passing glance”

For depression use:

SSRI’s

Importance of Non- Pharmacological intervention

- This is as important as using medications.

  Without it the help of medications would be almost pointless and much less effective.

- Management can be for the "long distance"
  People usually live with AD anywhere from 2-10 years
  Some can have it as long as 20 years.
  Thus care to enable the best quality of life can be for the "long run"

Best Non -Pharmacological Care is

A **WHOLE TEAM** MATTER AND

A **WHOLE PERSON** MATTER

- The Whole Professional Team,
- The Whole Family and
- The Whole Community

together

for

The Whole Person

Participating teams

- Professional Whole Person Team
  Primary care and specialist physical care, Physicians, Psychiatrists/psychologists, Nurses, Social Workers, Pastors (Body, Mind, Social, Spirit)
- The family Team (nuclear and extended)
- Community Team
  - Family
  - Other Caregivers
  - Friends
  - Neighbours
  - Congregation
  - Workplace
  - Government Agencies
  - Support and Advocacy Groups

The Patient is at the centre as an active participant!

What can be done by

the Whole Team for

the Whole Person

apart from using medication?

Types of Non-Pharmacological Interventions

1. General care

2. Managing behavioural problems

1. Non-Pharmacological General Care:
Outline of Steps

I. Facilitate team meetings for planning practical measures for future living

I. Enable provision of whole person direct care

II. Encourage whole person healthy lifestyles

III. Encourage environmental modifications

I. Facilitate team meetings for plannning practical measures for future living

- Involve the patient, the family and other caregivers
  (vary composition of meetings according to need)
- Use psycho-education and anticipatory guidance
- Facilitate explicit planning
- Involve the patient with maximum respect and validation

Can we always involve the patients?

I. Facilitate team meetings for planning practical measures for future living

AREAS FOR PLANNING INCLUDE:

- *Planning for family teamwork:*
  - Budgeting, listing tasks and dividing responsibilities etc.
- *Financial*
  - Advance Directives
- *Medico-legal* planning
  - Include power of attorney?
- *Clinical Care* planning :
  - medical management strategy
  - personnel, day care, assisted living, nursing home?

I. Facilitate team meetings for planning practical measures for future living

ENABLE FACTORS FOR TEAM SUCCESS:

- Any plan of must be discussed by all, *including the patient,* at all stages
- Seeking consensus building through conflict management
- Using effective communication and conflict management skills
- Developing compassion & clarity with each other vs
  - conceptualization
  - settling old scores
- Appropriate self-education on Dementia for all
- Seeking guidance about what to anticipate

Facilitate Best Team Member

Approach to caring for the Patient

ALL WE NEED TO DO:

a) Listen

- open ended questions,
- indirect leading,
- eliciting feelings,
- reflecting,
- stay calm and be understanding.
- help the patient express his or her *reflections* and *feelings* about one's story of dementia

b) Preserve the patient's *autonomy, self esteem*, and *life fulfillment* as much as possible

c) Help him or her grieve what cannot be preserved.

Preserve the patient's autonomy, self esteem, and life fulfillment as much as possible.

Do the "BALANCING ACT" in each area

Seek strategies for optimum possible negotiated balance

Loss of AUTONOMY

"I have no say"

<u>Balance</u> between:

- **CONTROL** of one's life and
  dependency on others (role reversal)
- **INDEPENDENCE** and
  being supervised
- **STRUCTURING** the life one wants and
  taking anything one gets
- **ACTIVE PARTICIPATION IN COMMUNITY and**
  isolation

Loss of SELF-ESTEEM

" I will become nobody"

Reverse:

- having **ALL OF ONE'S ABILITIES** to
  being considered less than whole
- **SELF PROTECTION** to
  being totally vulnerable
- being **USEFUL AND SIGNIFICANT** to
  making no difference
- From being a **UNIQUE PERSON WITH INHERENT DIGNITY** to
  being considered an "inmate"

Loss of Life Fulfillment

"Life holds nothing for me"

Help optimize:

- Aesthetic pleasures
- Attachment (The giving and receiving of love)
- Creativity
- Transcendence: living above one's struggles

b) Address the Grief from Personal Losses

Remember the stages, with cycling:

- Denial …
- Anger …
- Bargaining …
- Depression …
- Acceptance…

II. Enable the Provision of Whole Person Direct Care:

- BODY
  - ***Monitoring*** *physical illnesses and care*
    - *Watch chronic diseases!*
  - ***Alternative Care:*** *Protecting the Brain*
    - ✓Antioxidants: Vitamin E, Blueberries, Turmeric, Selenium
    - ✓Brain enhancers: Vitamin B Co, Omega 3 Fatty Acids (e.g. Fish Oil, Flaxseed)
    - ✓Lowering of Homocysteine : Fruit and vegetables (7-9 servings)
    - ✓Brain Neurotrophic Factor: Exercise
  - ***Massage***
  - ***Other home care***

1. Non-Pharmacological General Care:

II. Enable the Provision of Whole Person Direct Care:

- MIND
  - *Counselling for **grief of personal losses***
  - *Counselling for **resilience**: **Building** trust, hope, gratitude, humour, altruism*
  - ***Problem oriented counselling** and psychotherapy*

- SOCIAL
  - *.**Support from family, church and community**: calls, visits, entertaining, support groups, day centres etc.*

- SPIRITUAL
  - ***Pastoral care***

III. Encourage

Whole Person Healthy Lifestyles

For example:

- BODY
  - Exercise, Nutrition (healthy and tasty food)
- MIND
  - Creative hobbies, Recreation, Outings, Closeness to nature, Maximum practical activities
- SOCIAL
  - Social reaching out (e.g. family, friends, colleagues), Pets, Voluntarism
- SPIRIT
  - Faith, Forgiveness, Devotions and Music, Church involvement

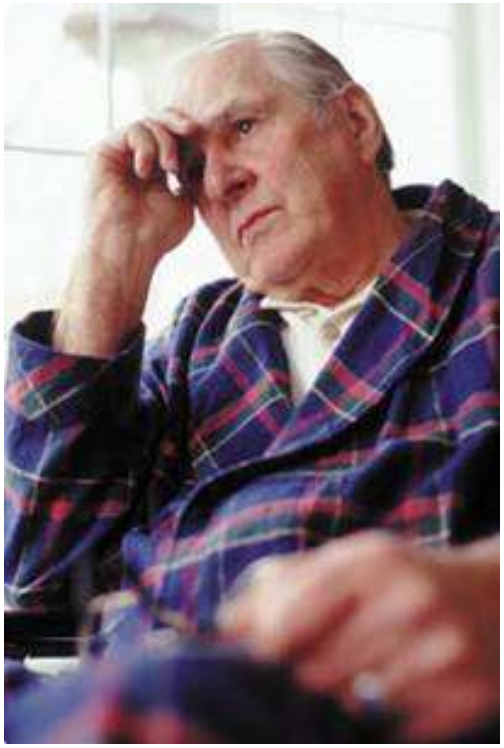
Promote maximum independence , usefulness and mobility of the patient

IV. Encourage Environmental Modifications

- Moderate *stimulation* though brain exercises, music, family pictures, conversations, reminiscences
- *Memory* measures:
  - clocks, calendars, to-do lists, name tags, alert bracelets,
- *Supports* for disabilities:
  - Night lights, rails, walkers. etc. Support adequate vision and hearing
- Protection in behaviour problems
  - For example: secure exits

2. Non-Pharmacological Interventions: **Behavioural problems**

(Irritability, aggression, inappropriateness, agitation, apathy)



Between 70 to 90% of people with AD eventually develop behavioral symptoms, including *sleeplessness, wandering and pacing, aggression, agitation, anger, depression*, and *hallucinations and delusions*.

2. Non-Pharmacological Interventions: **Behavioural problems**

Steps:

I. Assess the overall situation

II. Attend to needs

III. Educate caregivers in best approaches to the patient

2. Non-Pharmacological Interventions: **Behavioural problems**

I. Assess the overall situation

- Physical *discomfort*
- Physical *pain* or illness
- Psychiatric or depressive symptoms
- A *change* in living situation or routines
- *Hunger*
- *Loneliness*
- *Boredom*
- *Frustration*
- *Interpersonal issues*
- *Other emotional difficulties*

2. Non-Pharmacological Interventions: **Behavioural problems**

II. Attend to needs

- Provide reassurance
- Use distraction as necessary
- Monitor and manage changes in living situations or routines
- Institute behavioral interventions. e.g.
  - counselling,
  - problem solving
- Make appropriate referrals

III. Educate caregivers in best approaches to the patient

Interaction skills for intervention with the upset patient

Educate team members to:

- Be patient and flexible. Don't argue or try to convince.
- Clarify the patient's *wishes*
- Acknowledge requests and respond to them
- Empathize and help with the *trauma of change*
- Exercise compassion and clarity in requesting what is necessary
- Break down tasks
- Try not to take behaviors personally. Remember: it's the disease talking, not your loved one

D. Caregivers' Management

Where are people with AD cared for?

- family homes
- assisted living facilities (those in the early stages)
- nursing homes (special care units

Who are the AD Caregivers?

- **Spouses** – the largest group. Most are older with their *own health problems*.
- **Daughters** – the second largest group. Called the "*sandwich generation*," many are married and raising children of their own. These children may need extra support if a parent's attention is focused on caregiving.
- **Grandchildren** – may become major helpers.

- **Daughters-in-law** – the third largest group.
- **Sons** – often focus on the *financial, legal, and business aspects* of caregiving.
- **Brothers and Sisters** – many are older with their *own health problems*.
- ***Helpers, practical and registered nurses –*** *Often bear the brunt of behavioural problems*
- **Others** – friends, neighbors, members of the faith community.

The Demands of Care-giving

AD takes *a huge physical and emotional toll*.

Caregivers must deal with *changes in a loved one's personality a*nd provide *constant attention for years.*

Thus, caregivers are especially vulnerable to physical and emotional stress.

Caregiver crisis risks for monitoring and intervention

- Grief (Denial, anger, bargaining, depression, acceptance)
- Suspended life plans
- The conflicts of "role reversal"
- Exaggeration of pre-existing family conflicts and abuse
- Elder abuse
- Guilt
- Stress → Distress → Burnout

Caring for Caregiver Stress

1. The best approach:

- Facilitate adequate competence in care (appropriate to role and level)
- Have a supportive attitude, empathy, patience and promote mutual respect
- Promote Involvement in a supportive teamwork by all
- Ensure conflict resolution at all times with all others involved.
    - Manage *hierarchy* and *role* issues
    - Be a *mediator* and *interpreter*
- promote a whole person approach to SELF-CARE

CARING FOR CAREGIVERS STRESS

2. Action

- Provide special skills training for wholistic dementia team care along with “literacy” in teamwork, stress and wholeness
- Provide adequate supervision and resources
- Provide respite services (time off, outings etc)
- Encourage healthy lifestyles and health screening annually and when necessary
- Enable practical problem solving
- Facilitate intervention for risk based crisis
- Carry out referral to services and resources for caregiver needs and crises as necessary
- Establish support groups

PEER SUPPORT PROGRAMS

- *Peer support programs* can help link caregivers with trained volunteers.
- *Other support programs* can offer services geared to caregivers dealing with different stages of AD.
- *Jamaica Alzheimer's Outreach Association*

  52 Duke St. 927 8967

Use Technology for Care giving

Computers can provide information and support to family caregivers through:

- *websites eg. Alzheimers Association USA*
- *blogs*
- *chat rooms*
- *Q & A modules*
- *medical advice forums*

These features have become very popular among users because they reach many people at once, are private and convenient, and are available around the clock.

Points discussed

A. The profile of dementia

B. The pain of personal losses

C. Non-pharmacological intervention

D. Caregivers' management

- DEMENTIA IS THE **#1** HEALTH PROBLEM WORLDWIDE FOR THE 21ST CENTURY

- Advances in dementia are far behind those made for Cancer and HIV

- It must become a priority special interest

Let us have BEST PRACTICES to support caregivers for dementia care and by advocacy for institutional change.

We need a **NATIONAL DEMENTIA POLICY AND PROGRAMME** by the GOVERNMENT and CHURCHES and NGOs including:

1. **Screening** skills and tools for **every primary care physician**
2. Specialist Dementia **Clinics** with **Community Services** for all four health regions,
3. Dementia **Education**, **Day Centres** and Caregiver **Support Groups** in every region
4. A designated **medical officer** coordinating public Dementia services in the Ministry of Health.
5. The **integration** of Dementia with Programmes for Non-Communicable Disease (NCD) prevention.

Dementia requires

the **whole team**

and

the **whole nation**

caring for

the **whole Patient**

and

the **whole Caregiver**

When Team Factors and Members' Approach to the patient are done with *care and compassion* and to *enhance the dignity of the patient*, they will significantly contribute to minimizing the pain of personal losses


CAN WE DO IT?
YES WE CAN !

Thank You!

References

1. Ahmed ,H. U. *Dementia: An Overview. Retrieved on 25/03/11.*
from <http://www.slideworld.org/slideshow.aspx/Dementia-An-Overview-ppt-2843227>

2. Anderson, H. S. Alzheimer's Disease. Retrieved on 25/03/11,
from< http://emedicine.medscape.com/article/1134817-overview>

3. Caring for Alzheimer's Disease Patient. A publication of the Geriatric
Mental Health Foundation

4. Dementia should be a national priority. (2009, September 17). The Gleaner,p.1.

5. Elizabeth, M. *Alzheimer's Disease: An Understanding of Alzheimer's Disease. Retrieved on 25/03/11, from*
*www.curtis1.com/curtis/powerpoints/**alzheimers**.ppt*

6. Johns Hopkins University Bloomberg School of Public Health (2007, June 11).
Alzheimer's Disease To Quadruple Worldwide By 2050. *Science Daily*. Retrieved March 29, 2011,
from < http://www.sciencedaily.com /releases/2007/06/070610104441.htm>

7. Julian, K. *Update in the Diagnosis, Treatment and Prevention of Dementia. Retrieved on 25/03/11, from**www.ucsfcme.com/2009/slides/.../24_**Dementia**_Julian.pdf*

References

8. Misah, K. *Alzheimer's Disease and it's Treatments*. Retrieved on 25/03/10. from < http://faculty.smu.edu/jbuynak/alzheimers%20presentation.docx.ppt >

9. Practice Guidelines for the treatment of Psychiatric Disorders. American Psychiatric Association, Virginia

10. Publication on Alzheimer's Disease. Alzheimer's Disease: Unraveling the Mystery Retrieved on 25/03/11, from <http://www.aapina.org/oldsite/GERO/resources/documents/Slides%20UnravelingtheMystery.ppt>

11. Redden, W. M. *The Clinical Pharmacology of Approved AD Therapies.* Proceedings of panel discussion on *Effective Treatment of Alzheimer's Disease: Translating Guidelines into Practice* at the Annual Meeting of the American Psychiatric Association 2009.

12. Tariq, S. H, Tumosa, N, Chibnall, J. T, Perry, H.M.,& Morley, J.E. November, 2006. The Saint Louise University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia . J am Geriatri Psych .

13. The World Alzheimer's Report (2010). *The Global Economic Impact of Dementia.* Alzheimer's Disease International: London. Retrieved 29/03/11, from < http://www.alz.co.uk/research/files/WorldAlzheimerReport2010ExecutiveSummary.pdf>