Top Ten Most Challenging Problems in Caring for People with Dementia

Yustiani DIKOT¹,², Kusuma D. SUHARYA², Tara P. SANI²,³

¹University of Padjadjaran, Bandung, Indonesia.
²Alzheimer’s Indonesia, Jakarta, Indonesia.
³Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia
Indonesian population in 2017: 263,150,146
Population > 60 yrs: 8.7%

**Indonesia: Life Expectancy**
- Male: 67.3 years
- Female: 71.4 years
- Average: 69.3 years

Estimated PWD: 1.2 millions

*Increasing number of elderly population in Indonesia has big potential to mental health problems / degenerative diseases, one of them is Dementia*
World Alzheimer report 2015

2015. The global impact of dementia:
50 million people worldwide are living with dementia, in Indonesia estimated 1.2 million PWD in Healthcare should be continuous, holistic and person-centred, treating the whole person according to their values and preferences, not as a set of separate health conditions or problems. Care should be integrated across all levels of care provision, and health and social care providers.
Priority in National Health Program

• **Improve quality of mother and child:**
  – Quality of health care
  – Improve nutrition
  – Improve access to health provider

• **Preventive and curative of disease:**
  – Vaccination and basic immunisation
  – Early detection of noncomunicable disease
  – Providing unit for prevention and overcome infectious disease

• **Healthy life style:**
  – Supervising healthy market
  – Program fish consumption
  – Wisdom to use medicine
  – Campaign healthy live in media
POLICY

(Dementia National Plan – 1st in ASEAN)

Seven Action Steps
1. Campaign on Public Awareness and Promotion of Healthy Lifestyles
2. Advocacy on human rights for people with dementia and their caregivers
3. To ensure access and information of quality services
4. Implementation of early detection, diagnosis and holistic management of cognitive disorders and dementia
5. Establishment of System to Reinforce professional and sustainable human resources
6. Establishment of System to Reinforce Cognitive Health Programs as main factor to increase literacy of nation based on life course approach
7. Implementation and Application of Research on cognition and dementia

Conclusion

National Strategy Towards Healthy and Productive Brain in Old Age
National Dementia Plan

• Collaboration of Department of Health with
  – Department of social welfare
  – Local Government
  – Organisation of aging program:
    • Indonesia Alzheimer Fondation (ALZI)
    • Indonesian Ageing Institution (LLI)
    • Central for Ageing studies (CAS)
    • Etc
Knowledge of People about Dementia

• Questionnaire delivered among participants of public awareness of Dementia in Bandung.
• 83 participants complete the questionnaire contains of:
  – Age
  – Education
  – Knowledge of dementia
  – Source of knowledge about dementia
  – Is demensia a normal ageing process
  – Is dementia a genetic disease
  – Is it preventable
  – Is it treatable
Knowledge of people attending dementia seminar

- On September 2018 in World Alzheimer month seminar we distribute quessioner of knowing about dementia.
- Questioner completed by 83 participants, 18 (21.69%) man and 65 (78.31%) women.

The level of education of the participant is higher >12 yrs -75%; national average education 6.7 yrs.
IS DEMENTIA SAME WITH “PIKUN”?

- Pikun is a local term for forgetfullness in elderly (Age associated memory impairment)

![Pie chart showing percentages]

- **YES**: 55%
- **NO**: 27%
- **NOT ANSWERED**: 18%
SOURCE OF DEMENTIA KNOWLEDGE AND INFORMATION

Do you know what DEMENTIA is? (N=83)

- Know: 74%
- Do not know: 12%
- Not answered: 14%

Source of information for dementia:

- TV: 27
- Newspaper/Magazine: 31
- Seminar: 31
- Others: 13

Information media:

- TV
- Newspaper/Magazine
- Seminar
- Others
IS DEMENTIA A NORMAL AGING PROCESS?

- 64% yes
- No need medical check

(N=83)
IS DEMENTIA A HEREDITARY DISEASE?

- 6% Yes it’s a hereditary disease
- 71% not a hereditary disease, it’s a normal ageing
KNOWLEDGE OF DEMENTIA SIGNS

- Know 1 sign are 19, most is forgetfulness.
- There are mitoses in "normal ageing" there will be get symptoms of:
  - Forgetfulness
  - Stubborn
  - Disoriented
  - Incontinence
  - Repeat old stories
  - Withdraw from social affair
IS DEMENTIA PREVENTABLE?

- Yes: 77%
- No: 15%
- Not Answered: 8%

IS DEMENTIA CURABLE?

- Yes: 46%
- No: 30%
- Not Answered: 24%
A private clinic (internal medicine and neurological diseases)

2017: 3 patients diagnosed as MCI and 109 with dementia

Data collected Most Challenging Problems in Caring for People with Dementia
Relation of caregiver and PWD

• 62 % caregiver are spouse of PWD
• 20% caregiver are PWD’s children
• 7 % caregiver are daughter in law
• 11% paid caregiver
Number of Patients in various Type of Demensia

NUMBER OF PATIENT

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCI</td>
<td>0</td>
</tr>
<tr>
<td>AD</td>
<td>45</td>
</tr>
<tr>
<td>VAD</td>
<td>25</td>
</tr>
<tr>
<td>AD+VAD</td>
<td>40</td>
</tr>
<tr>
<td>PD</td>
<td>5</td>
</tr>
<tr>
<td>LD</td>
<td>0</td>
</tr>
<tr>
<td>FTD</td>
<td>0</td>
</tr>
</tbody>
</table>
Patients Level of Education

- Elementary
- Junior High School
- High School
- University
- Post Graduate

Education Levels:
- < 60 yo
- 60 - 69 yo
- 70 - 80 yo
- > 80
Top Ten Most Challenging Problems in Caring for People with Dementia

- Personality and behaviour change
- Bathing and toileting
- Eating
- Poor judgement
- Communication problem
- Wondering
- Time/place disorientation
- Financial problem
- Memory impairment
- Lost of motivation

Number of Caregiver

1  2  3  4  5  6  7  8  9  10
Alzheimer’s Indonesia’s caregiver data from other cities

• The top three problems in caring PWD from other cities:
  – verbal aggression
  – communication problems
  – grooming/bathing problems

• When compared to, similar problems were observed - although the order seems to differ: (Suharya KD, 2018).
Action of ALZI to help Caregiver and PWD

• Support for caregiver:
  • Caregiver meeting (Jakarta: monthly; other areas: sporadic)
  • Respite care: rare
• Support for PWD: minimal
• Care facilities:
  • Day care: in planning
  • Long term: needed
Conclusions

• Personality/behaviour changes appeared to be the most challenging problem for dementia caregivers in Bandung.
• Understanding caregiver problems will help us formulate the best approach to help improve the quality of life of caregivers and care-recipients.
• Caregiver meeting were establish since 2013 by ALZI but only in big cities (18 ALZI chapters ), help them to comunicate their problems and sharing experience amongs them.
• Implementation of National Dementia plan must be adopted in National Health Care through all level of health care system,public awareness and early diagnosis is the key to improve the quality of life of PWD,family and caregiver.
• Nursing home and respite care is still our dreams
Thank You