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Out of the shadows campaigning and educating in Germany

Global Action against Dementia Legacy Event Japan – New Care & Prevention Models

Tokyo, 5th/6th November 2014

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Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz



Different materials and methods

- Empowerment to people with dementia through meetings and support groups
- Education programs for caregivers (also E-Learning course)
- Attractive advanced training to find volunteers
- Brochures, leaflets, DVDs,....
- TV-spots, Posters in the public





- People with dementia
- Caregivers
- Volunteers
- Health care professionals
- Children and young people "Alzheimer and you"
- Other groups like policemen, fireworkers, bank officers, salespersons,....
- General public





"Alzheimer and you"

- Competition für young people
- Education materials for teachers
- Interactive Website









People with dementia – part of the community









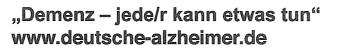
"Greetings from the sea"

Campaigning through desorientation:

"It can happen to be confused about the place where you are but to loose orientation completly is bad. There are 1,5 Mio. people with dementia in Germany. Do not forget them!







Welt-Alzheimertag 2014





























The case for increased awareness and concern Global Dementia Legacy Event Minato-ku, Tokyo, Japan November 5, 2014 Splaine Consulting

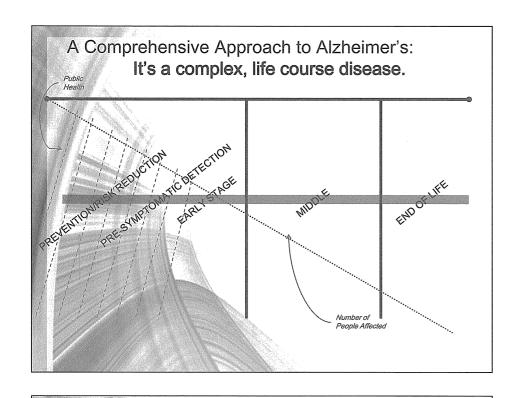
Consulting Agreements as of 10/1/2014 Alzheimer's Disease International Consumer Voice (aka NCCNHR) Eli Lilly Bayer A.G. (non-U.S.) Alzheimer's Association (US) Healthy Brain Initiative Elder Justice ACTion, Elder Justice ACTion SC Alzheimer's Association GA/GA Dept Aging National Center on Elder Abuse (US) Also: Splaine is CEO and principal member, Cognitive Solutions LLC

Conflict of Interest

• None of the views represented here are those of my clients nor have they had any control or input into this presentation.

Overview

- The state of Alzheimer's and dementia
- What makes dementia different?
- Domains of dementia friendly communities



Goals for national plans

- NOT Ageing, but health and public health
- Increase awareness, reduce stigma
- Implement to the limit of the evidence available
- Inclusion of persons with the disease
- Not necessarily new spending, better spending

What makes ADRD Different?

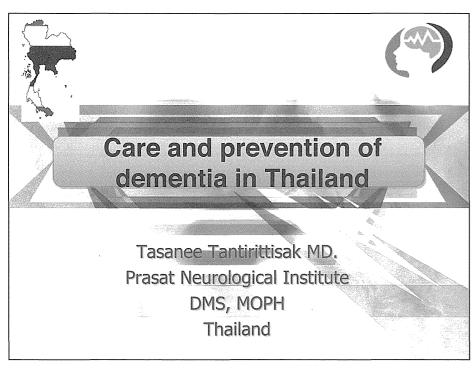
- Families are the caregivers.
- Gap between prevalence and diagnosis
- Diagnosis late in disease process
- · Co-morbid chronic diseases
- Lack of attention to population health/risk
 Siloed budgets and systems
- Stigma, nihilism, ageism plus capacity
- Duration of disease process, care
- Special pops: complicated lives

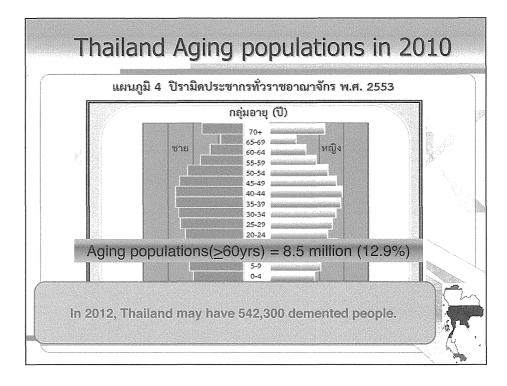
Domains of Dementia Friendliness

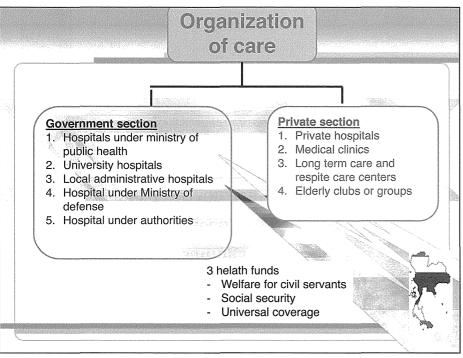
- Public awareness and access to information
- Inclusive planning processes
- Access and consideration for dementia in local businesses or public services
- Creation of activities such as memory café led by persons with dementia
- Community based innovation in services
- Access to transportation

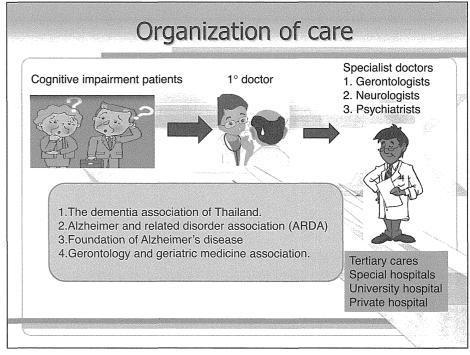
Contact information

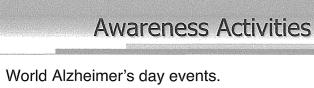
- www.splaineconsulting.com
- www.cognitivesol.com
- mikesplaine@verizon.net



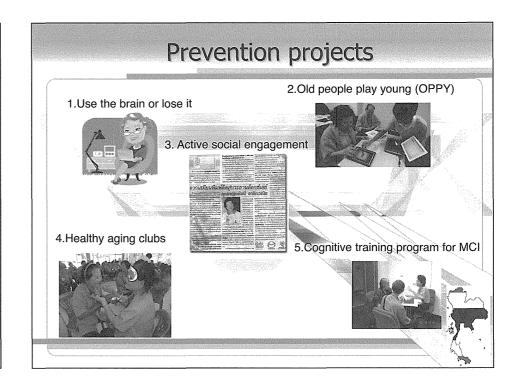




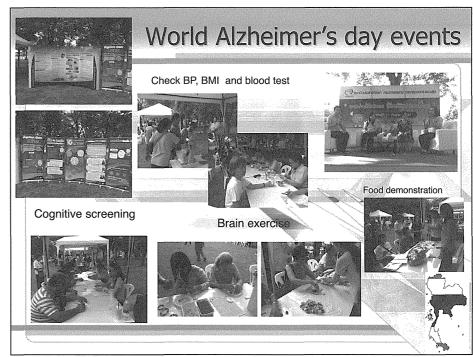


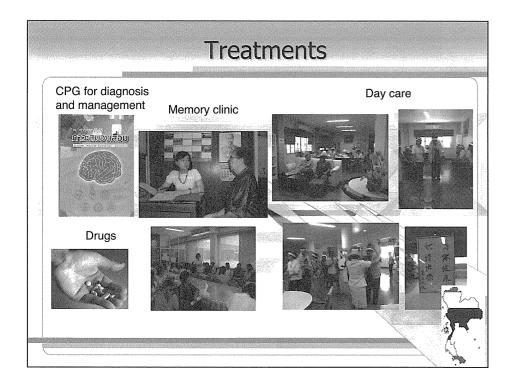


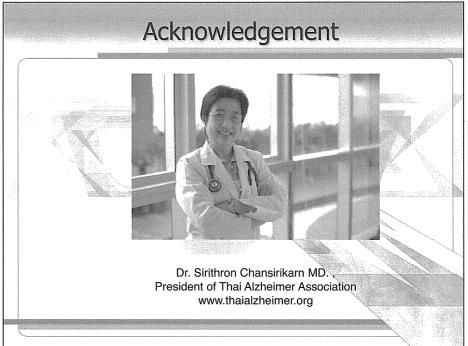
- Short movies
- **Educations:**
 - talk
 - News letter
 - events (world AD month)
 - website (azthai.org), (Thai memory test.com)
- Capacity building for medical personals (nurse, doctors), caregivers (informal=family)
- Healthy elderly clubs.

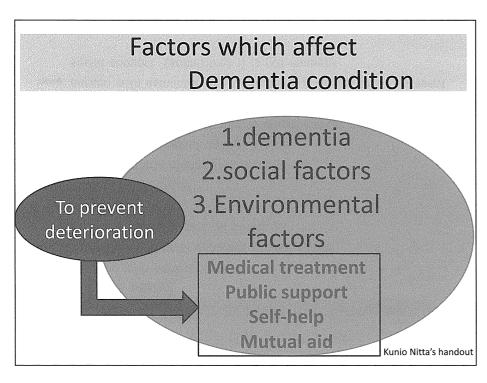












The structure of the dementia condition

$D=P\times B\times H\times NI\times SP$

D; Dementia

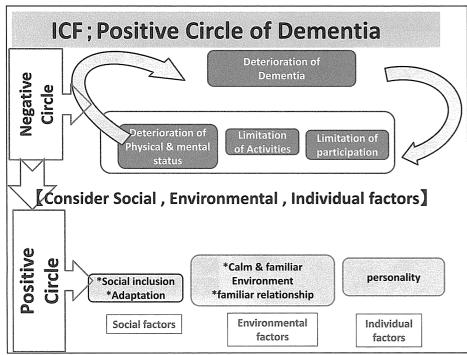
P; Personality

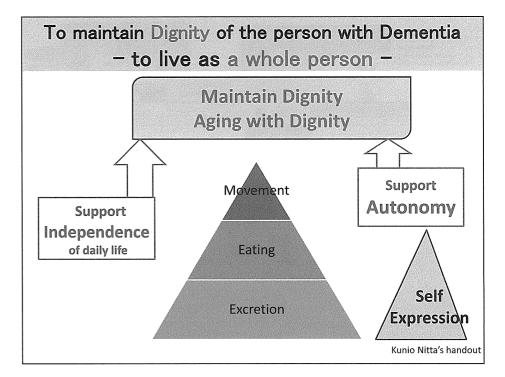
B; Biography

H; Physical-health

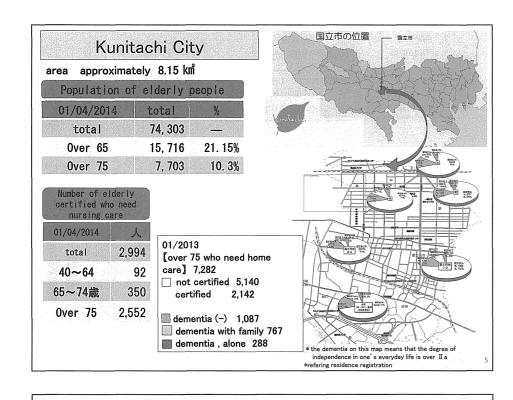
NI; Neurological Impairment

SP; Social Psychology





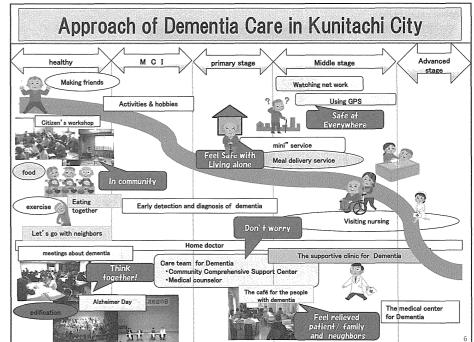


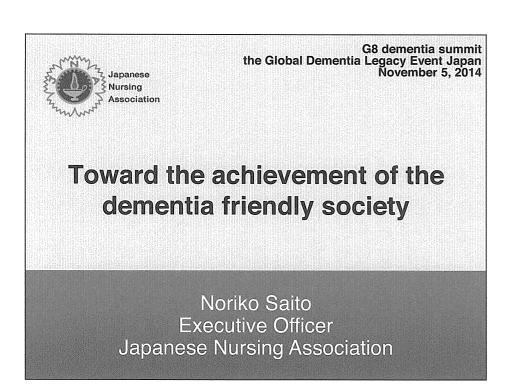


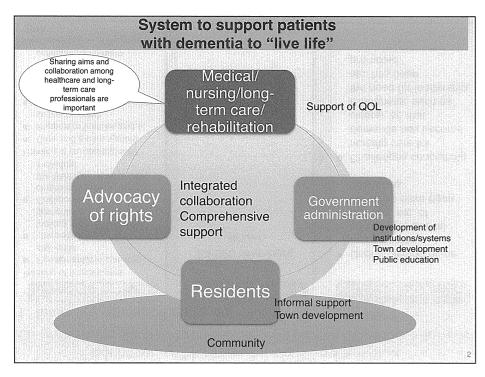
The 56 visiting care cases of dementia patients who are living alone

[findings in this study]

- 1 Cooperation with medical care
- inform the doctors of accurate patient status the need of medical care on dementia
- 2 Family support
- mitigate care burden resolve conflicts among family members
- 3 Recognize the changes of patient status
 - who should notice them, and to whom convey the information
- 4 Need of community support
 - person with dementia can't live alone with the help of present social support (sometimes it is not enough)

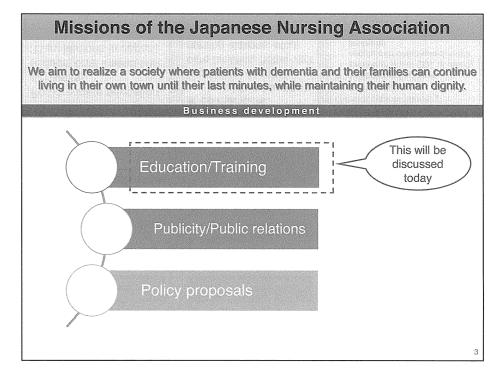






Society to aim at

- Patients can receive continuous medical/nursing/long-term care services of high quality from the early to the terminal phases of illness, and there are least burdens on the patients and their families.
- Patients and their families can continue living in their own town and home as members of their community.
- There is no prejudice against dementia, and patients' wishes and rights are respected, and their dignity is maintained.
- Residents, healthcare and long-term care professionals, and government administrations collaborate for realizing dementia friendly society.



Education and training currently implemented by the Japanese Nursing Association

1. Intensive education on dementia among nursing staff

Contents of education and training

Training of practitioners

- Fundamental knowledge of dementia
- Understanding of and looking after patients with dementia
- Collaboration at a community level to protect the lifestyle that suits each individual

Training of managerial staff

- Care and a care system
- Support of families and a support system
- Staff education/staff support
- Task management
- Development and implementation of a collaboration system

*Implemented as of fiscal year 2014

Number of participants

24,920 members (total)

Outcome

- Understanding of the fundamental knowledge, clinical practice, etc. of dementia have been enhanced.
- Challenges concerning nursing care for dementia has become clearer, so that awareness, such as the need for leadership, etc. has been promoted.

Education and training currently implemented by the Japanese Nursing Association

2. Preparation of specialists in dementia care among nursing staff

Contents of cultivation of professionals

Certified Nurse in
Dementia Nursing
Education for more than
6 months/615 hours
(Educational
institutions: 8 institutions
in Japan)

Certified Nurse
Specialist in
Gerontological Nursing
Postgraduate education
(26 units)
(Educational institutions:
33 institutions in Japan)

Number of certified members

Certified Nurse in Dementia Nursing

480 members

 (as of October 2014)

 (working at hospitals, clinics, care facilities, home-visit nursing stations, etc.)

Certified Nurse Specialist in Gerontological Nursing

66 members

 (as of October 2014)

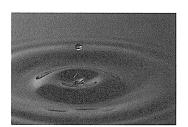
 (working at hospitals, care facilities, home-visit nursing stations, etc.)

Contents of activities and outcomes

Certified Nurse in Dementia
Nursing

- Expansion of the life functions of people with dementia, prevention and alleviation of BPSD
- Enhancement of understanding, and quality of care for, dementia by providing education and training opportunities to local medical practitioners and other relevant workers
- Awareness campaign aimed at local residents
 Certified Nurse Specialist in Gerontological Nursing
- Same as above
 - Ethical coordination⇒
 Enhancement of QOL of elderly people with complicated health problems
 - Education, research

The Multilayered Human Resource Development System to Support People Living with Dementia



Tokyo Dementia Care Research and Training Center, Japan

Kumiko Nagata

Shifts of Targets in Dementia Care and **Human Resource Development in Japan** 2000 2010 2014 Individual Individual Care n Local Community Integrated Care Community Dementia Care Various in municipalities human **Dementia Support Doctors** resources and Primary Care Doctors Supporters Senior Leaders, Leaders & Care Staffs in all Japan **Care Staffs**

Attained Targets of Dementia Care

Increase of varieties in dementia care professionals

- Doctors, nurses, pharmacists
- · Care workers, Care managers
- Welfare workers

Increase of varieties in dementia supporters

- Local residents, families
- Stores, Banks, Transportations
- Police, Fire authorities etc.

Increase of promoters at municipalities

- Dementia Support Doctors
- Promoters of Community Dementia Care
- •Leaders of Dementia Care

Challenges of Human Resource Development in Dementia Care

[in Quantity] The amount of human

- resources developed are unable to keep up with the rapid increase of people with dementia.
- Many care staffs leave their workplace after development training.
- *Local government cannot identify the number of people trained as the trainings are done by various different organizations.

[in Quality] Not- enough works have been

- done together on shared value "for people with dementia to continue living with hope and respect in their communities."
- •There are,
 •Gaps between what has been learned and what to practice
- Lacks of continues learning opportunities to acquire the most updated, various knowledge

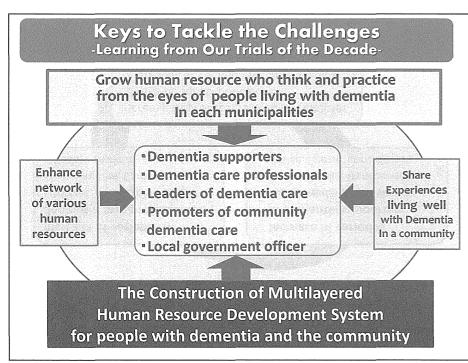
Disparities among local governments widen In human resource development & reservation

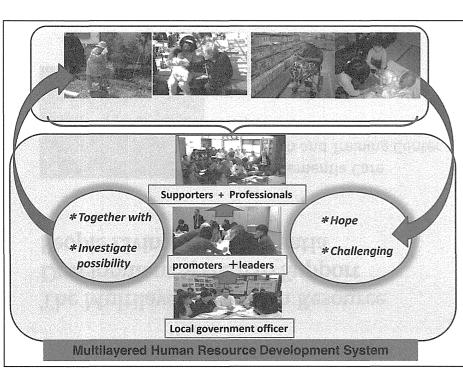


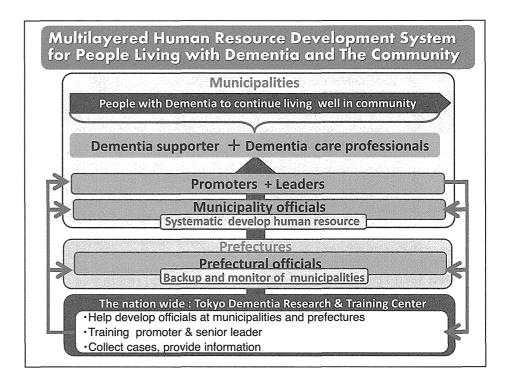












What Will be Important in Human Resource Development - Based on Our Trails -

- Share the values and objectives thoroughly at each layer of dementia care.
 - "People with dementia will live in their communities with hope, dignity."
- 2. Examine every case of practice after training for evaluation.

 Also, establish the ways to share what are found.
- 3. Build a human resource development system that evolves with people living with dementia.









Person with dementia as a lecturer on "Medicine, Care & Support That We Need"

Evaluation taken place with people with dementia

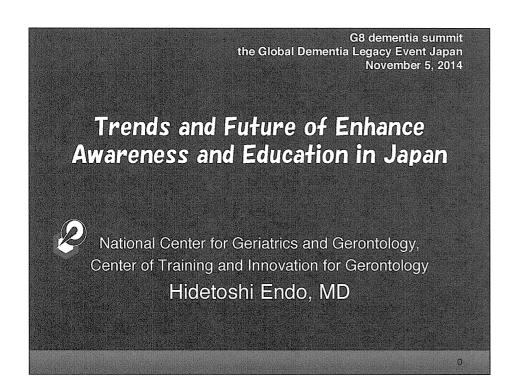


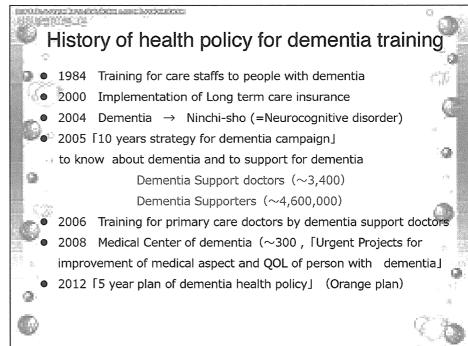




Pursue possibility of living well together

Thank you for your kind attention





Aim of education and training for dementia

- To stop the stigma for dementia
- To enhance awareness to public for dementia
- To educate families to understand dementia and BPSD for reducing care burden
- To educate medical and care staffs for improvement of care
- To make an early diagnosis for AD bucause of future treatment



Target of education and training dementia ~Leadership by government and local government~

- People with dementia(at hospital or clinics)
- Families(schools for families in clinics or hospital)
- Health care professionals(lecture, group-work and e-learning and others)

(Doctors, Nurses, Care staffs)

- Shop keepers, policeman and others(Dementia supporters)
- Students (Dementia supporters)
- Volunteers



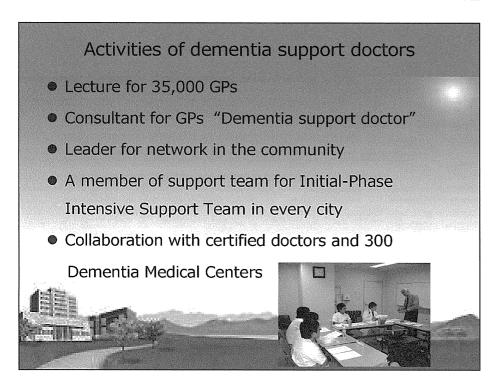
Tools of education to dementia ~For enhance awareness~

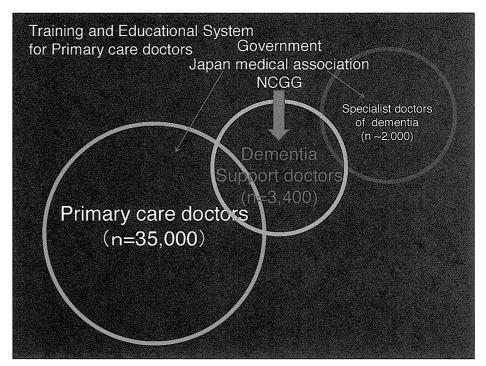
- Lecture(using textbooks, DVD) for Doctors, and professionals by government
- Group work(conference)
- TV programs(NHK and others)
- Books(many books related dementia)
- Movies(Everyday is Alzheimer's et al.)
- Internet(ninchisyo-forum.com et al.)
- NCGG Information services http://monowasure.org/ninchi/



Evervdav is Alzheimer







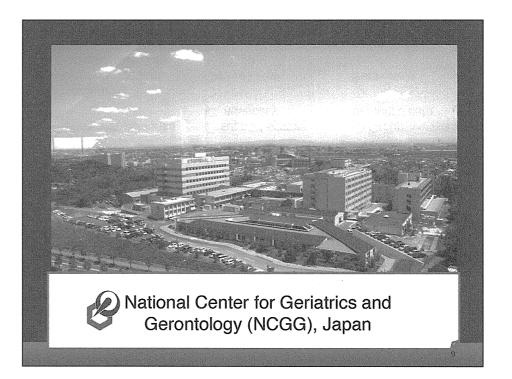
Target	Leaders of Education and training	Mass- communication
Doctor	© 3400 support doctors (35000 primary care doctors)	0
Professionals (Care manager, OT, nurse)	460 Certified nurses	0
Families	⊚ School in clinic	Association
Person with dementia	O support system IC, advocacy	O Group, dementia café
Community residence, student shop staff, policeman&+	O Caravan Mate 4600000	© Supporters

Future aspects of education related dementia

- More and continuous education and training for care staffs and families, the innovative care principle "Person centered care" is very important, one of example is DCM to reduce care burden from BPSD and to improve BPSD
- Mutual Understanding the importance of good practice and framework of education and training in Integrated Community care system

 Necessity of Worldwide Support system for education and training system in developing countries, by WHO or others.





資料3