National & local dementia strategy in Japan: Living with Dementia in the Community

Satoko HOTTA, Ph.D
Professor, International University of Health and Welfare Graduate School

Outline
- International Comparison on National Dementia Strategy
  - Focusing on Palliative Care Contents
- Transition in Long-term care in Japan
  - Population aging in Japan
  - Long-Term Care Insurance System (2000-)
  - toward Community-based Integrated Care system
- Orange Plan, National dementia strategy in Japan
  - Background
  - Orange plan, New Orange plan
- Engaging Communities
  - Fujinomiya-city
  - And more

Palliative care

Definition by WHO
- An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor to postpone death
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated
Palliative care for elderly

Palliative Care for Older People: Better Practices

- Published by WHO Europe in 2011
- In the past, palliative care was mostly offered to people with cancer in hospice settings
- Palliative care must now be offered more widely and integrated more broadly across health care services
- Example of good practices for older adults with dementia
  - Multidisciplinary guidelines
  - Education for care home staff and general practitioners
  - A guide for caregivers

Palliative care in dementia

EAPC white paper in 2013 (van der Steen et al., 2014)

1. Applicability of palliative care
2. Person-centred care, communication and shared decision making
3. Setting care goals and advance planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive, burdensome or futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. Family care and involvement
10. Education of the health care team
11. Societal and ethical issues

Model of changing care goals

Dementia progression and suggested prioritizing care goals (van der Steen et al., 2014)

Palliative care in national dementia strategy

Methods

- Qualitative evaluation of national dementia plans from 14 countries
- Focus on palliative care content using EAPC white paper

Results

- Not explicitly referred in the eight of the 14 countries
- All countries lacked “prognostication and timely recognition of dying” and spiritual caregiving (Nakanishi et al., in press)

Reference
Independent section

England

Objective 12: Improved end of life care for people with dementia.

Northern Ireland

Action 29. Develop palliative and end of life care services for people with dementia within the framework of the palliative and end of life care strategy.

Sweden

Palliative care in the final stages of life (71-72 in the list of conditions and treatments)

Some sentences

Scotland

Right-based care: We will take more action specifically in relation to dignity and respect, including attention to human rights and the principles and requirements of mental health and incapacity legislation, including: earlier identification of people with palliative care needs, to promote advance care planning, to facilitate the sharing of key information across settings through the development and roll out of the Electronic Palliative Care Summary.

Finland

Proper treatment and care is a worthwhile investment: the provision of timely support, care and services is based on (…) c) good palliative and end-of-life care when prolonging life is no longer meaningful.

Australia

Key Priority Area 1: Care and Support Outcomes: Palliative Care.

Call for palliative care

Palliative care and dementia statement

First WHO ministerial Conference on Global Action against Dementia, March 16-17th, 2015

Worldwide Hospice Palliative Care Alliance (WHPCA) published the statement:

The WHPCA requests ministers to ensure that:

1. National dementia strategies are developed which include explicit reference to palliative care. Palliative care is a person-centred approach and should be available from the point of diagnosis. However, we particularly call on ministers to ensure the inclusion in national dementia strategies of prognostication, timely recognition of dying and preparations for the last phases of life. These are areas, which have been shown to be neglected.

Some sentences, not palliative

Japan

The national government will continue additional benefit schedules for “coordination system with healthcare provider” and “provision of end of life care” under the public long-term care insurance program to enhance service provision for increasing impairment and end-of-life care of residents in “group homes”.

Wales

UHBs and LAs to publish plans for developing specialist dedicated young onset and rare dementia services. Plans to be based on the following principles: (…) end of life care.

South Korea

Medical practices that are unlikely to have effects on people with dementia at last stage should be avoided. The guideline should be established and disseminated for management of people with dementia at end-of-life stage to provide high-quality care services.
Transition in Long-term Care in Japan

Life Expectancy at Birth

<table>
<thead>
<tr>
<th>Country</th>
<th>Life expectancy (years)</th>
<th>Country</th>
<th>Life expectancy (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Rank</td>
<td>Females</td>
</tr>
<tr>
<td>Brazil</td>
<td>67</td>
<td>21</td>
<td>74</td>
</tr>
<tr>
<td>Canada</td>
<td>78</td>
<td>2</td>
<td>83</td>
</tr>
<tr>
<td>USA</td>
<td>75</td>
<td>15</td>
<td>80</td>
</tr>
<tr>
<td>China</td>
<td>70</td>
<td>19</td>
<td>74</td>
</tr>
<tr>
<td>India</td>
<td>61</td>
<td>23</td>
<td>63</td>
</tr>
<tr>
<td>Israel</td>
<td>78</td>
<td>2</td>
<td>82</td>
</tr>
<tr>
<td>Japan</td>
<td>79</td>
<td>1</td>
<td>86</td>
</tr>
<tr>
<td>South Korea</td>
<td>73</td>
<td>18</td>
<td>80</td>
</tr>
<tr>
<td>Spain</td>
<td>69</td>
<td>20</td>
<td>74</td>
</tr>
<tr>
<td>Malaysia</td>
<td>78</td>
<td>8</td>
<td>82</td>
</tr>
<tr>
<td>Singapore</td>
<td>77</td>
<td>8</td>
<td>82</td>
</tr>
<tr>
<td>Pakistan</td>
<td>62</td>
<td>22</td>
<td>63</td>
</tr>
<tr>
<td>Finland</td>
<td>75</td>
<td>15</td>
<td>82</td>
</tr>
</tbody>
</table>

"Rank" is the order of the 24 countries listed, from longest to shortest life expectancy.

Speed of Population Aging (year)

Structure of Long-term Care Insurance System
Long-term care services

- Community-based services
  - Regular visiting/direct-response long-term care
  - Daily visit long-term care
  - Outpatient long-term care for a dementia patient
  - Multifunctional long-term care in a small group home
  - Community-based long-term care for a dementia patient (group home)
  - Daily life long-term care for a person admitted to a community-based facility
  - Admission to a community-based facility for preventive daily long-term care of the elderly covered by public aid
  - Continuous service

- In-home services
  - Home visit long-term care (home help service)
  - Home visit nursing
  - Home visit rehabilitation
  - Guidance for management of in-home medical long-term care
  - Daily life long-term care admission to a specified facility
  - Use of specified equipment provided by public aid

- Chronic care services
  - Outpatient daily long-term care (day service)
  - Outpatient rehabilitation

- Short-stay services
  - Same as long-term care for daily life long-term care (short-stay)

- Facility services
  - Creation of outpatient medical and support facilities
  - Creation of specialized facility for the elderly receiving long-term care

- Covered by fee

- Services designated/supervised by municipalities

Small scale multifunctional in-home care

- User home
  - "Visitation" based on condition and wishes
  - "Overnight stays" based on condition and wishes

  - Staffing is not fixed, so work can be performed flexibly. Regardless of the needs of the users, they are received from a familiar caregiver.

  - Use centered on "commuting"
  - "Overnight stays" based on condition and wishes

  - Users pay a fixed monthly fee depending on the degree of long-term care required

24 hour round-the-clock care

- Conduct short-hour regular home visits with integration and close collaboration between home visit long-term care and home visit nursing care services.
  - Responses to telephone calls from users and home visits on an as-needed basis (Use of ICT devices)
  - Short-hour regular home visits

Transition needed!

- Demographic change (Ageing, declining birth rate)
- Disease structure change (Multi-morbidity, Continuous → Chronic care, long term "care-cycle")
- Change in definition of “Health”
- Change in concept of “Support” : Medical model to Ecological model, ICF

  - Quality of Life (context, narrative × individual, family, community, sustainability)

- Fragmentation of care and support, lack of continuity
- Emerging (total and useless) cost
- …and shortage of Care workforce
Community-based integrated care: 2 concepts bringing together

Community-based care

Community-based care features a health system that is based upon and driven by community health needs. Moreover, it is tailored to the health beliefs, preferences, and societal values of that community and assures a certain level of ‘community participation’ (Plochg and Klazinga, 2002).

Integrated care

a discrete set of techniques and organizational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels (Kodner and Kyriacou, 2000).

Toward community-based integrated care

Orange Plan: Five-Year Plan for Promotion of Measures against Dementia
History of dementia care policy

- 1987 Reports by “MHW Headquarters for the Promotion of Dementia Elderly Measures”
  - Promotion of “Wards for dementia elderly”
  - Establishment of “Day-Service Center for Dementia”
- 1994 Reports by “The Committee for Dementia Elderly Measures”
  - Establishment of “Group Home for Dementia”
  - Enactment of “Long-Term Care Insurance Act”
- 2004 Change of the Japanese terminology for “Dementia”
- 2005 Launch of “ten-year conception of raising awareness and community development for dementia”
  - Launch of “Training of Dementia Support Doctors”
  - Launch of “Dementia Supporters Training Program”
- 2008 Reports by “Emergency Project for Improvement of Medical Care and Quality of Life for Persons with Dementia”
  - Prevalence survey of dementia
  - Promotion of Medical Center for Dementia
- 2012 Reports of “Direction of Future Dementia Measures”
  - Development of Dementia Care Pathway
  - “Five-Year Plan for promotion of Dementia Measures (Orange Plan)”
  - Development of “Initial Phase Intensive Support Team”
- 2015 “Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)”

Current issues on dementia care

- The symptom of dementia aggravate due to delayed consultation and intervention
- Prolonged hospitalization in psychiatric hospitals
- Difficulty in admitting general hospitals which persons with dementia occasionally experience
- Qualitative/quantitative shortage of LTC care services for supporting persons with dementia to keep living in familiar communities
- Insufficient community support for persons with dementia and their families
- Coordination between healthcare and LTC care professionals being not always seamless

Reactive, post-crisis care

Proactive care
Orange Plan

1. Development of Standard Dementia Care Pathway
2. Earlier Diagnosis & Intervention
3. Improve Health care services
4. Improve LTC services
5. Promote daily living and family support in the community
6. Reinforcement of Measures for Younger Onset Dementia
7. Acceleration of Human Resources Development

Training Programmes

- For anyone (2005-)
  - Caravan Mates (6h)
  - Dementia Supporters (90 min) 4.7 million (2013)

- For LTC Professionals
  - Dementia Care Leader Training
  - Practice Leader Training
  - Practitioner Training

- For Doctors in the community
  - Dementia Support Doctors
  - Seminar for doctors in clinics

- For Doctors and Nurses in General Hospital

Dementia Life Support Model: Normative Integration

- Principles of dementia care
  - Person-centered care
  - Care in the community promoting participation to the society
  - Activating self care, decision making
  - Continuous support from early-stage to end of life
  - Supporting family carers
  - Integrated support: community/social care/health care

- Dementia Life Support Model: Integrated life support including health and social care

- Dementia Life Support training (4h)

New Orange Plan

- Early Support (Initial Phase Intensive Support Team, etc.)
- Improving Ability of Care Providers (Training Programs)
- Coordination of Medical Care and Long-term Care (Dementia Coordinator)
- Risk Reduction (Nationwide Prospective Dementia Cohort)
- Cure (Project for Psychiatric and Neurological Disorders)
- Age and Dementia-Friendly Community
- “Dementia Supporters” already 5.8 million ⇒ 8 million
- Safety (Cross-ministerial support: watching system in the community, etc.)
Innovations in Fujinomiya-city as a case of Engaging Communities

Quick Scan

- Population: 135,492
  - 65+: 31,980 (23.6%)
- People with dementia: 3,000
- Caravan Mate: 250
- Dementia Supporter: 9,000 (6.6%)

Principle of dementia care policy

- Starting from People with dementia and carers need
- Creating tailor-made network around EACH of them
- Harmonizing individual support network and community care network in Fujinomiya-city
  - NOT making Dementia SPECIFIC network
  - Enrich community care network, community involvement through focusing on dementia care
1 Creating dialogue: Mr. & Mrs. Sano's story

- 2008 Mr. & Mrs. Sano came to community general support center (Mr. Sano with YOD)
- 2013 Mr. and Mrs. Sano became Caravan Mate!!!

2 Sharing social issues in the community

- With local carers association (2008, 2013)
  - Workshop to share burdens, problems and solutions
- With local citizens (2008-)
  - Promote dementia supporters programme starting from happenings in the community
- With LTC service providers (2008-)
  - All careworker survey to sort out issues and training need
- With doctors (2008-)
  - Establish dementia support medical care providers network committee
- With various stakeholders (2008-)
  - Connecting findings, ideas and suggestions between people working in the community
- With schools (2009-)

3 Team building in the community

- With local citizens (2008-)
  - Educate caravan mate, support voluntary activities
- With LTC service providers (2009-)
  - Support trainings organized by LTC service providers association
- With doctors (2009-)
  - Doctor → caravan mate → dementia support doctor
- Seminar for networking
4 Continuous dialogue and practice around each cases

- Care conference
  - Community care conference (2009-): each case
  - Case conference in community general support center (2010-): sort out community issue
  - Multidisciplinary care conference: involve family, local citizens, caravan mate, professionals, community general support center, local government…

- Doctors study group on memory loss (2010)

- Chief care managers activate local resources and networking (2011-)

- Seminar for care managers (2011-)

Future Issues in Fujinomiya-city

- Multidisciplinary care conference
- Promote professional integration in 14 areas
- Promote network between PWD and develop "Dementia Friendly" evaluation framework
  - Collaboration with DFJI
  - Definition of DFC from PWD perspective
  - Dementia strategy evaluation framework involving PWD’s participation

- Promote social involvement for better QOL
  - Action meeting (2013-)
  - Dementia Support Tourism (2013-)
  - Employment support (2012-)
  - Run-tomorrow 2013

Conceptual framework for integrated care based on the integrative functions of primary care
Appendix 1) Ecological map in Higashi-Ohmi city

製作・資料提供: 魅知普請の創寄り（東近江市内のキーパーソンが集う会）

出所: 『京都式オレンジプラン（京都認知症総合推進計画）』
http://www.kyoto-houkatucare.org/

Appendix 2) 10 I-message in Kyoto-pref. Orange Plan

Network to promote social innovation for DFC(2013-)
through collaboration between various sectors

Origin goes back to Dementia Project
“How private sector can get more direct involvement in the social issues surrounding dementia?”

Continuous future sessions on shared principles and service guidelines

June 2014 Dementia Friendly Japan Summit

Appendix 3) Dementia Friendly Japan Initiative

Words for a Journey: The Art of Being with Dementia
http://journey.sfc.keio.ac.jp/
Transition needed!

- Demographic change (Ageing, declining birth rate)
- Disease structure change (Multi-morbidity, Continuous → Chronic care, long term “care-cycle”)
- Change in definition of “Health”
- Change in concept of “Support”: Medical model to Ecological model, ICF

Quality of Life (context, narrative × individual, family, community), sustainability

- Fragmentation of care and support, lack of continuity
- Emerging (total and useless) cost
- …and shortage of Care workforce

Core competencies for caring for patients with chronic conditions

1. Patient-centred care
   - Interviewing and communicating effectively
   - Assisting changes in health-related behaviours
   - Supporting self-management
   - Using a proactive approach

2. Partnering
   - Partnering with patients
   - Partnering with other providers
   - Partnering with communities

3. Quality improvement
   - Measuring care delivery and outcomes
   - Learning and adapting to change
   - Translating evidence into practice

4. Information and communication technology
   - Designing and using patient registries
   - Using computer technologies
   - Communicating with partners

5. Public health perspective
   - Providing population-based care
   - Systems thinking
   - Working across the care continuum
   - Working in primary health care-led systems

Continuous dialogues
- Start from PWD
- Promote sense of ownership
- Across the sector
- Across the community
- Individual – Community issue
- Promote HAPPINESS in the community as a whole
- Promote shared community management

Global innovation platform on DFC
- Exchange best practices
- Share definition, principle
- Share process, framework
- Promote knowledge translation

Run 伴: Organized by Dementia Friendship Club