Families Dealing with Dementia: Insights from Mainland China and Hong Kong

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Overview

- China’s aging population
- Prevalence of dementia in China
- Challenges in provision of care
- Actions and plans for the future

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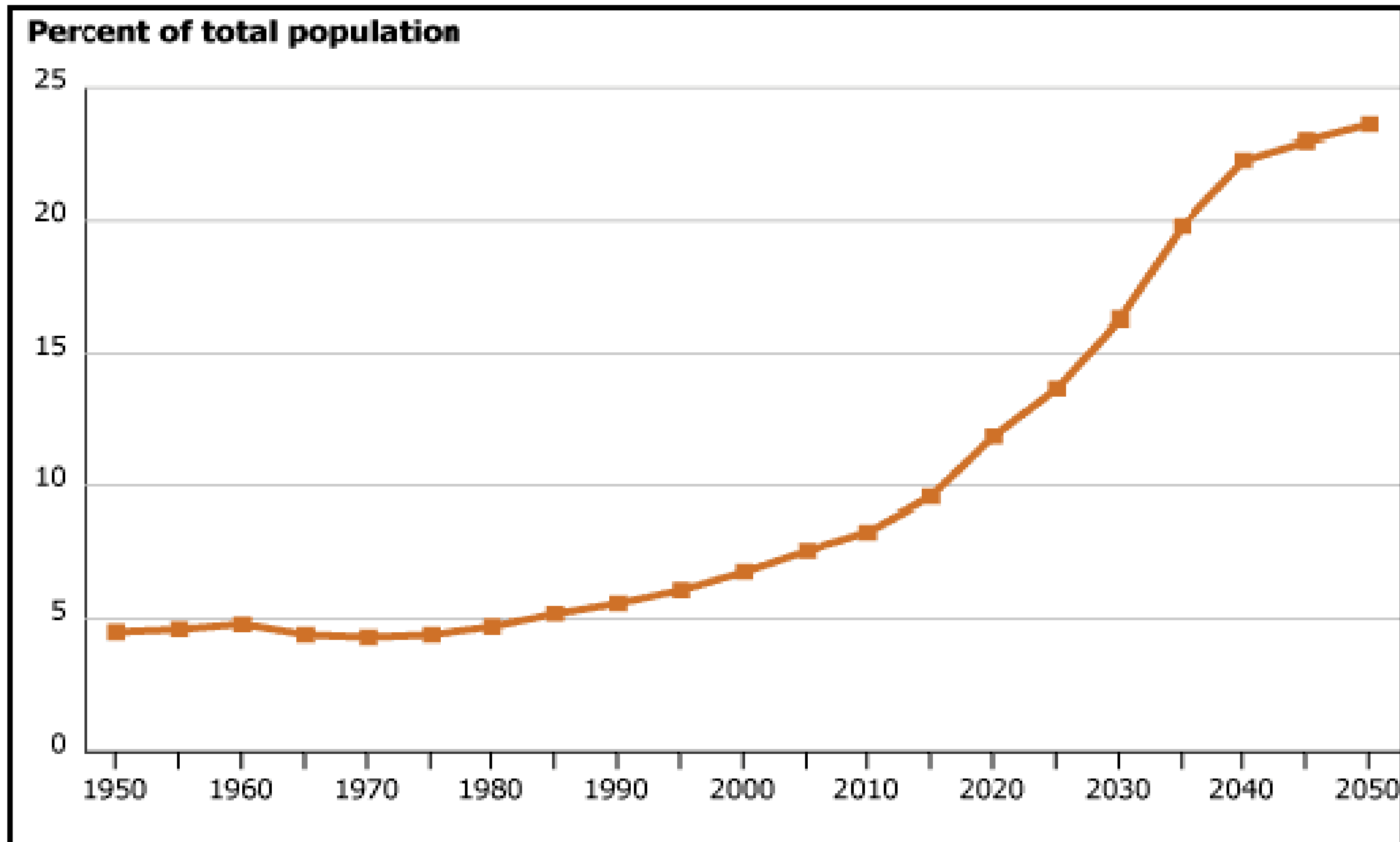
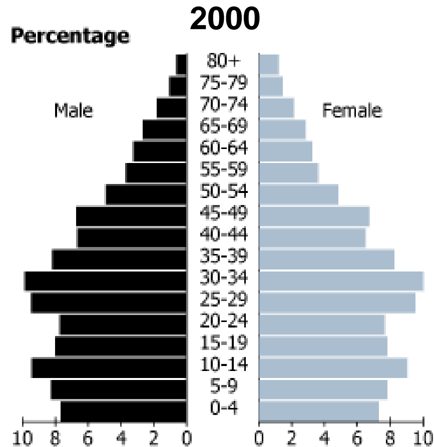
Source: www.lonelyplanet.com/worldguide/china

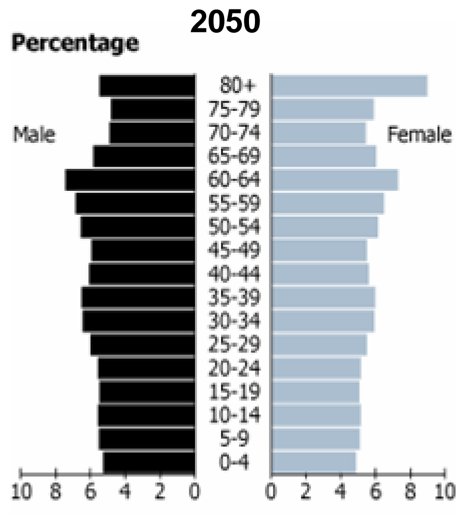
The Aging Population - 1



World Population Prospects: The 2004 Revision (United Nations Population Division, 2005).

The Aging Population - 2





- Older women outnumber men, among them, about 60% are over 80 years old
- Estimated 83 million with disability, 53% are older adults
- 65% of older adults live in rural areas
- Ratio of working-age adults available to support each elder declining rapidly
- Aging ahead of modernization

World Population Prospects: The 2004 Revision (United Nations Population Division, 2005).

"By 2040, the total number of China's older population will reach 397 million, which equals to the total population of the five countries: Germany, France, UK, Italy and Japan."

- *Center for Strategic & International Studies*

Dementia and Aging in China

- Increase of elders with dementia is expected to be 300% in China between now & 2040
- Dementia prevalence at least 4% at age 60 - 1.21 million new dementia cases per year
- 6 to 26.1 millions of people with dementia from 2001-2040

Ferrie, et al. (2005).

Projected change in demographics

(Table 1) Characteristic	Value
Total Population	>1.3 billion
Population aged > 60 (2006)	130 million
Population aged > 60 requiring NH-level care (estimated 5% of 130 million)	6.5 million
Population aged > 60 requiring NH-level care without a caregiver (estimated 5% of 6.5 million)	325,000
2030 projected population aged> 60	336 million
2030 projected population aged >60 requiring NH-level care (estimated 5% of 336 million)	16.8 million
2030 projected population aged > 60 requiring NH-level care *without* a caregiver (estimated conservatively with 10% do not have caregiver; change rate in 25 years)	1.68 million 517%

Flaherty, J. H., Liu, M. L., Dong, B., Ding, Q., & Li, X., et al. (2007)

Current Challenges - 1

- The 4-2-1 problem
- Change in traditional roles
- Disproportionate male to female ratio
- Out-migration of workers
- Gap between urban and rural
- Huge pressure on social security, medical care and social services
- Infrastructure not in place – existing eldercare institutions can serve less than 1.2% of the aging population, compared with 8% in developed countries

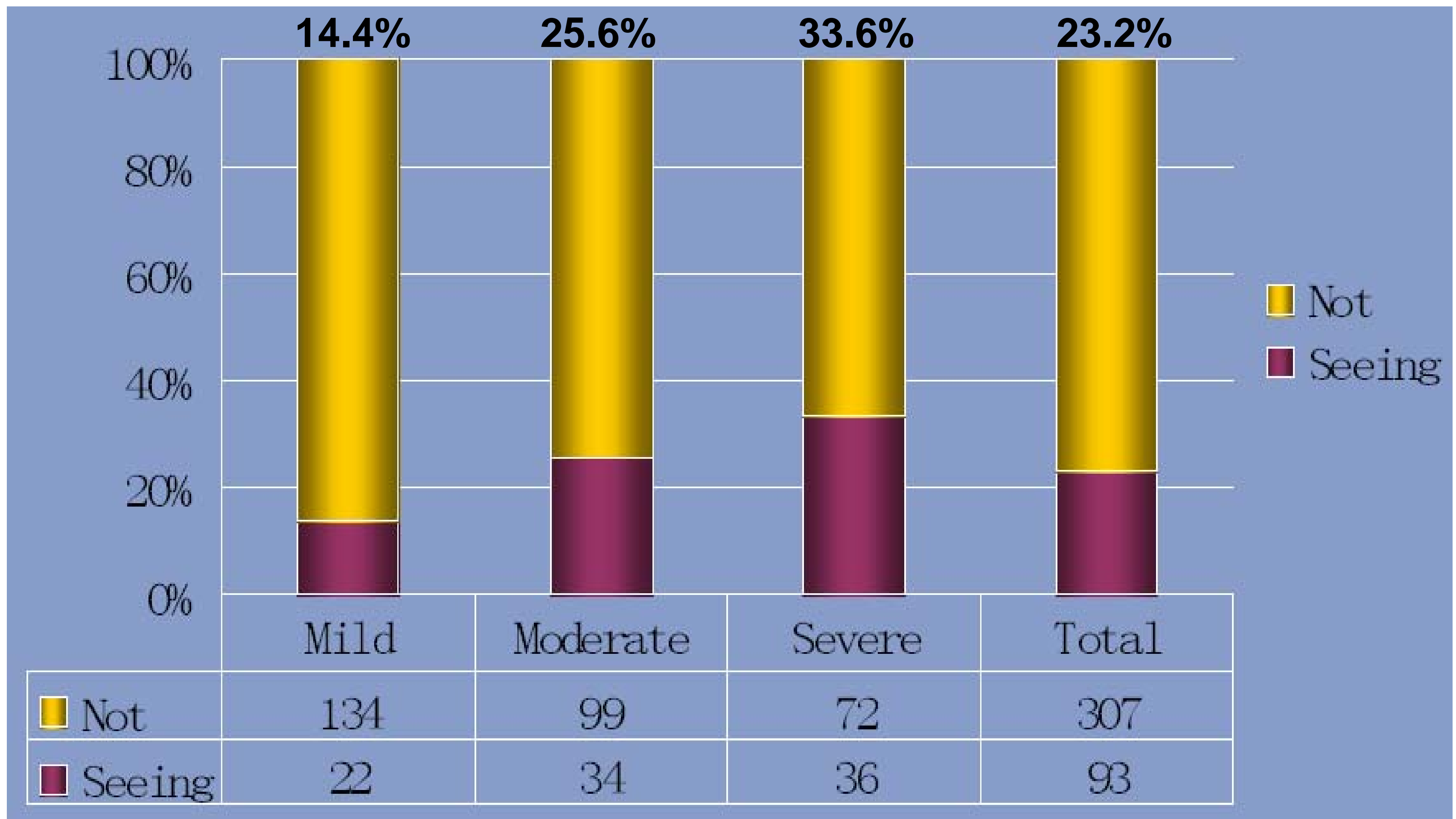
Current Challenges - 2

- Supply can't meet demand -- there is a lack of trained workforce

(Table 2) Characteristic	Value
Physicians / 1,000 population (2001)	1.06
Nurses / 1,000 population (2001)	1.05
Community health workers / 1,000 population (2001)	0.08
17,000 Certified psychologists (2007)	10% of that of other developed countries per capita
13,000 Mental health professionals, of whom around 2,000 are trained psychiatrists (2002)	1 per 100,000

Flaherty, J. H., Liu, M. L., Dong, B., Ding, Q., & Li, X., et al. (2007); *The Economist*, (2007); Chang, D. E., & Kleinman, A. (2002).

Proportion Seeing Doctor
by Severity of Dementia, 1998-1999



Zhang ZX, et al. (2004). Acta Acad Med Sin, 26, 116-121. Article in Chinese.

Dementia in Beijing, Xian, Shanghai, and Chengdu

- **Objective: Estimate prevalence of dementia in rural and urban Beijing (northeast), Xian (northwest), Shanghai (southeast) and Chengdu (southwest)**
- **Sample: 34,807 community residents age 55+; 405 families with dementia patients interviewed: Largest study to date.**
- Results:
  - Prevalence for Alzheimer's disease was 4.8%, and 1.1% for vascular dementia
  - Most patients (96%) were cared for at home by family caregivers – HOWEVER this is changing!
  - 48.8% of caregivers considered the impairment of cognition, behavior and daily living activity in demented persons as a result of normal aging
  - Half of the caregivers spend 8+ hours each day on caregiving

Zhang ZX, et al. (2005) Archives of Neurology, 62, 447-450;
Zhang ZX, et al. (2004). Acta Acad Med Sin, 26, 116-121. Article in Chinese.

Who Provides Care to the Demented Elder?

- Typically, the family has provided the care necessary. Use of institutions has been historically low (partly due to their lack of availability & cost) and elders in China have been maintained at home.
- This causes stress and burden to the primary caregiver, just as it does for US and European samples studied. However this has not been widely acknowledged (due to cultural norm of "saving face") and so development of services to assist caregivers in their role has been slow – due in large part to the strongly held cultural norm of "filial piety" which assumes that care of the elder with dementia will be provided primarily (perhaps exclusively) by the family – not the government.

Family Roles with Regard to Dementia Care

- “Among hundreds of virtues, **filial piety** is the most important one” (bai shan xiao wei xian, a traditional Chinese proverb).
- It is a central concept in Confucianism & addresses how children should treat their parents. It encompasses many things (e.g. support, deference, respect & love).
- Sung (1995) defines filial piety as a 2-dimensional construct: **behavioral** (making sacrifices, taking responsibility) and **emotional** (harmony, love, respect).
- Given the thousands of years that this construct has been an important part of Chinese culture, there is still pressure to perform acts of filial piety today. However, this varies greatly by region (urban vs. rural) and by other factors influencing modern Chinese society.

Filial Piety (continued)

Filial piety is heavily influenced by societal trends – modernization, urbanization, and globalization occurring rapidly in China today.

- It is generally agreed upon by scholars from Hong Kong & mainland China that the practical meaning of this construct is evolving at this time & is having much less influence than in past.
- In Hong Kong, data indicates that many adult children no longer put their parents as first priority (Ng et al, 2002) – related to greater opportunities for education & career advancement, higher incomes, and changing social values (desire for more independence)
- In Taiwan & mainland China, studies have consistently found that the older generation retains their expectations for filial piety. Thus, inter-generational conflict is common regarding dementia care: who will do it?

Public Policy Impact

- Modern care systems need to take account of modifications of this traditional value (Choi 2002). Development of public services may be reduced & under-developed if an unrealistic & idealized form of filial piety is assumed, where younger generations are expected to be the PRIMARY providers of care to their aging parents & parents-in-law.

Public Policy Impact

- In current & future Chinese societies, although children & family are still thought to be the most reliable source of cargiving for demented elderly, more and more **public resources** will need to be provided, as the traditional belief of filial piety is increasingly eroded. This is an urgent need, since at present, few publicly sponsored programs exist for the care of the demented elderly – particularly in mainland China.
- In Hong Kong there is a more well-established network of services and providers at this time.

Actions in Mainland China, 2001~2007 Clinician-centered

To increase knowledge of clinicians:

- Nationwide training course, workshop, seminar, case-report with pathological discussion…
- International communication *(Harvard University, UCLA, UCSF, Stanford, etc.)*

Focusing On:

- Early detection methods
- Chinese medical journals and textbook publishing more on this field
- Neuropsychological tests in diagnosis of dementia
- Scientific cutoff point for MMSE

Actions in China, 2001~2007 Health Care and Education

- **Improved access to health care professionals**
  8 **Centers/Dementia Clinics in China**
  40 Memory-disorder-specific Outpatient Clinics
  Medical and health-care organizations web sites
- **Health education to raise public awareness**
- **'World AD Day' annual activity since 2001**
  National mobilization (Policy makers, Experts) to face challenge
  To set up open clinics in parks and communities to offer advice about dementia
  To generate informational flyers/brochures regarding dementia
- **Mass media: TV, Radio, News paper**
- **Publish guidelines and periodical pamphlets and handbook for patient and care-giver**

Actions in China: Government

Listed dementia as a priority of disease prevention and treatment in mental health in 10-year government plan announced in 2002

Research supported by government to inform policy and the allocation of resources for improved health & welfare - specifically, terms of medical insurance coverage are being revised to cover more pharmacological treatments for dementia.

Actions in Hong Kong

- Residential care facilities are increasing: they are built by the government & some are subsidized.
- Home based and day care services are increasing.
- Respite services have been developed for caregivers – other services (e.g., loans of equipment for rehabilitation & support groups are also increasing rapidly, funded by the government.

Dementia Care Management program (Chien & Lee, 2008), conducted in Hong Kong

Objectives:

- **This study tested the effectiveness of a dementia care management program for Chinese families of relatives with dementia on caregivers' and patients' health outcomes over a 12-month follow-up period. It was conducted in Hong Kong; investigators were affiliated with the Chinese University of Hong Kong School of Nursing and Tuen Mun Hospital, N.T., Hong Kong.**

Conceptual Model

This program was developed from the evidence-based REACH program (REACH investigators, 2006) & prior work by Fung and Chien (2002)

Methods (I)

- The Dementia Care Management program is a six month educational and support program for family caregivers
- A controlled trial was conducted with 88 primary caregivers of persons with dementia in two dementia care centers in Hong Kong.
- Family members were assigned randomly to either the dementia care program or standard care, which included pharmacotherapy and written educational materials, for example.
- The two conditions were compared for patients' symptoms and institutionalization rates and caregivers' quality of life, burden, and social support upon recruitment and six and 12 months after group assignment.

Methods (II)

- The program consisted of 12 sessions that were held every other week and lasted two hours each. They apparently were a mixture of home visits & small group discussions.
- Case managers prioritized problem areas so interventions were “tailored” to some extent within the structured protocol
- There were five phases—orientation to dementia care (1 session), educational workshop about dementia care (3), family role and strength rebuilding (6), community support resources (1), and review of program and evaluation (final session).

Sample Characteristics (n=88)

- 64% were women
- 32% were spouses
- 68% had a high school education
- Mean CG age = 43.6 years
  range: 34-65
- Mean CR age = 67.8 years
  range: 64-79
- Average # hours/day spent caregiving = 5.2 hours
  range: 3.1-8.3 hours
- Severity of dementia:
  Mild to Moderate: 80%
  Severe: 20%

Results (I)

- **Over the 12-month follow-up period, patients with family members in the dementia care program showed significantly greater improvements in symptoms and institutionalization rates, and their caregivers reported significantly greater improvements in quality of life and burden, compared to those in the standard care group.**

Multivariate Outcomes MANOVA $F = 4.8$, $df = 5, 82$; $p = .005$

	Dementia care management Program (N=44)						Standard Care (N=44)						
	Baseline		6 month		12 month		Baseline		6 month		12 month		
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	F[a]
Family Caregiving Burden Inventory[b]	68.1	14.9	56.7	15.7	48.3	13.9	67.8	15.7	63.0	15.1	65.9	16.3	7.1
World Health Organization Quality of Life Scale[c]	64.9	15.0	75.1	16.8	81.4	16.0	67.1	15.5	69.8	16.7	65.2	17.5	6.7
12-item Neuro-psychiatric Inventory[f]	81.2	9.1	68.1	10.2	64.2	11.8	83.8	9.5	84.5	9.8	85.1	12.1	3.6
Institutionalization over the past 6 month:													
Number of times[g]	5.1	0.9	3.2	1.0	2.9	1.1	5.5	1.2	5.4	1.3	6.4	2.1	4.1
Duration(days per month)[h]	13.2	4.0	11.1	5.1	9.4	2.3	14.2	3.8	16.9	5.1	17.1	5.2	5.2

Notes for Superscript

- b : Scores range from 0 to 96: higher scores = greater caregiving burden.
- c : Scores range from 28 to 144: higher = better perceived quality of life.
- f : Scores range from 12 to 144: higher scores = higher levels of symptom severity.
- g : Average number of residential placements or hospitalizations
- h : Length of institutionalization in a residential home or hospital unit

Conclusions

- **The findings provide evidence that the dementia care management program did improve the psychosocial functioning of Chinese persons with dementia and their caregivers.**

Selected References

- A Disease Management Program for Families of Persons in Hong Kong With Dementia by Wai Tong Chien, Ph.D., R.M.N., Yuet Ming Lee, M.Phil., R.G.N., PSYCHIATRIC SERVICES, ps.psychiatryonline.org, April 2008 Vol. 59 No. 4, 433-436.

- REACH II Investigators (alphabetical order: Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S., **Gallagher-Thompson, D**., Gitlin, L., Klinger, J., Koepke, K. M., Lee, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L. & Zhang, S.) (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. Annals of Internal Medicine, 145, 727-738.

- Fung, W.Y. & Chien, W.T. (2002). The effectiveness of a mutual support group for family caregivers of a relative with dementia. Archives of Psychiatric Nursing, 14, 134-144.