



Hong Kong Psychogeriatric Association Newsletter

香港老年精神科學會會訊

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MESSAGE FROM THE NEWSLETTER COMMITTEE

This issue of the HKPGA newsletters focuses on dementia from the global and local perspectives. In a recent WHO report, the burden of dementia has been recognized as a public health priority. Our immediate past President, Dr. SW Li shares his expert experience on renaming dementia in Hong Kong. We would also like to make an erratum on page 8 (third paragraph) of the April issue:- "The Montessori principles were first adapted by Dr. Cameron Camp, an American gerontologist in the 1980s." To save a tree, please send us your latest contact email address at info@hkpga.org and visit www.hkpga.org for upcoming events.

THE WHO REPORT 2012 - DEMENTIA: A PUBLIC HEALTH PRIORITY



The world's population is ageing. Improvements in health care in the past century have contributed to people living longer and healthier lives. However, this has also resulted in an increase in the number of people with non-communicable diseases, including dementia. Although dementia mainly affects older people, it is not a normal part of ageing. Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities.

Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. It is one of the major causes of disability and dependency among older people worldwide. There is lack of awareness and understanding of dementia, at some level, in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families and societies physically, psychologically and economically. Dementia can no longer be neglected but should be considered a part of the public health agenda in all countries.

The objective of this report is to raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of inclusion, integration, equity and evidence.

BURDEN OF DEMENTIA

We have a growing body of evidence on the global prevalence and incidence of dementia, the associated mortality and the global economic cost. Most of the information is from high-income countries with some data becoming increasingly available from low- and middle-income countries (LMIC).

Prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth. The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds.

The total estimated worldwide costs of dementia were US\$ 604 billion in 2010. In high-income countries, informal care (45%) and formal social care (40%) account for the majority of costs, while the proportionate contribution of direct medical costs (15%) is much lower. In low-income and lower-middle-income countries direct social care costs are small and informal care costs (i.e. unpaid care provided by the family) predominate. Changing population demographics in many LMIC may lead to a decline in the ready availability of extended family members in the coming decades.

Research identifying modifiable risk factors of dementia is in its infancy. In the meantime, primary prevention should focus on targets suggested by current evidence. These include countering risk factors for vascular disease, including diabetes, midlife hypertension, midlife obesity, smoking, and physical inactivity.

COUNTRY PREPAREDNESS FOR DEMENTIA

The challenges to governments to respond to the growing numbers of people with dementia are substantial. A broad public health approach is needed to improve the care and quality of life of people with dementia and family caregivers. The aims and objectives of the approach should either be articulated in a stand-alone dementia policy or plan or be integrated into existing health, mental health or old-age policies and plans. Some high-income countries have launched policies, plans, strategies or frameworks to respond to the impact of dementia.

There are several key issues that are common to many national dementia policies and plans, and these may be necessary to ensure that needs are addressed in an effective and sustainable manner. These include: scoping the problem; involving all the relevant stakeholders, including civil society groups; identifying priority areas for action; implementing the policy and plan; committing resources; having inter-sectoral collaboration; developing a time frame; and monitoring and evaluation.

The priority areas of action that need to be addressed within the policy and plan include raising awareness, timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, prevention and research.

People with dementia and their families face significant financial impact from the cost of providing health and social care and from reduction or loss of income. Universal social support through pensions and insurance schemes could provide protection to this vulnerable group.

Formal recognition of the rights of people with



dementia and their caregivers through legislation and regulatory processes will help reduce discriminatory practices. Fundamental to upholding a person's rights is the recognition of capacity in persons with dementia. Where capacity is impaired due to dementia, legal provisions should recognize and protect the right to appropriate autonomy and self-determination including substitute or supported decision-making and procedures for implementing advance directives. Education and support relating to ethical decision-making and human rights should be an essential part of capacity-building for all involved in providing dementia care, including policy-makers, professionals and families.

HEALTH AND SOCIAL SYSTEMS DEVELOPMENT

The health and social care needs of the large and rapidly growing numbers of frail dependent older persons should be a matter of great concern for policy-makers in all countries. This is particularly so for LMIC which will experience the greatest increase in ageing in the coming decades.

This challenges governments to develop and improve services for people with dementia, focusing on earlier diagnosis, provision of support in the community, and a responsive health and social care sector. Integrated and coordinated health and social pathways and services will be needed to cater for the changing needs of people with dementia and their caregivers. Such pathways should ensure that the needs of specific or minority population groups are taken into account.

Improved community support will assist families to provide care for longer and to delay or reduce reliance on high-cost residential care. Where resources are finite, especially in LMIC, a focus

on community outreach could be an efficient use of scarce resources to improve the quality of life of people with dementia and their caregivers. The effectiveness of task shifting (with appropriate guidelines and training) in LMIC should be further evaluated as a solution to the under-supply of a professional workforce.

Capacity-building of the workforce is essential to improve knowledge and awareness of the benefits of a coordinated response to care. Dementia care, long-term care and chronic disease management incorporating a multidisciplinary team should form part of professional education and should be supported by the development of appropriate practice guidelines. In a world with an increasingly mobile population, the migrant workforce brings its own set of challenges that need to be understood and addressed.

SUPPORT FOR INFORMAL CARE AND CAREGIVERS

Dementia has an immense impact on the lives of the family, and particularly the person who takes the primary role in providing care. Most care is provided by family and other informal support systems in the community and most caregivers are women. However, changing population demographics may reduce the availability of informal caregivers in the future.

The provision of care to a person with dementia can result in significant strain for those who provide most of that care. The stressors are physical, emotional and economic. A range of programmes and services have been developed in high-income countries to assist family caregivers and to reduce strain. The beneficial effects of caregiver interventions in decreasing the institutionalization of the care recipient have been clearly demonstrated.



Evidence from LMIC also suggests that home-based support for caregivers of persons with dementia, emphasizing the use of locally-available low-cost human resources, is feasible, acceptable and leads to significant improvements in caregiver mental health and in the burden of caring. Despite evidence of effectiveness, there have been no successful examples of scale-up in any of the health systems in which the evaluative research has been conducted. Further research should focus on implementation in order to inform the process of scale-up.

Despite the availability of services in some countries or parts of countries, there are barriers to uptake. Lack of awareness of services, lack of understanding or stigma attached to the syndrome, previous poor experience with services, and cultural, language and financial barriers creates obstacles to service utilization. Information and education campaigns for the public – including people with dementia, their caregivers and families – can improve service utilization by raising awareness, improving understanding and decreasing stigmatizing attitudes.

Support is needed to enable informal caregivers to be able to continue in their role for as long as possible. Support includes information to aid understanding, skills to assist in caring, respite to enable engagement in other activities, and financial support.

AWARENESS-RAISING AND ADVOCACY

Despite the growing impact globally, a lack of understanding of dementia contributes to fears and to stigmatization. For those who are living with dementia (both the person and their family), the stigma contributes to social isolation and to delays in seeking diagnosis and help.

There is an urgent need to improve the awareness and understanding of dementia across all levels of society as a step towards improving the quality of life of people with dementia and their caregivers. Governments have a role to play in resourcing public awareness campaigns and in ensuring that key stakeholders are involved in such campaigns.

Awareness-raising campaigns should be relevant to the context and audience. They should be accurate, effective and informative and should be developed in consultation with people with dementia, their families and other stakeholders, including civil society.

THE WAY FORWARD

The findings of this report demonstrate that dementia is a global public health challenge. A range of actions is required to improve care and services for people with dementia and their caregivers. These actions include advocacy and awareness-raising, developing and implementing dementia policies and plans, health system strengthening, capacity-building, supporting caregivers and research. The actions need to be context-specific and culturally relevant.

*This executive summary is reprinted with permission from *Dementia: a public health priority* (ISBN 978 92 4 156445 8), published by the World Health Organization and Alzheimer's Disease International in 2012. The Foreword of this report is written by Dr. Margaret Chan, Director General of the World Health Organization. The full report is available at http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html*



RENAMING DEMENTIA IN HONG KONG

專訪-李兆華顧問醫生



李醫生是香港老年精神科學會 (HKPGA) 的前任會長，亦是十個關注「癡呆症」(dementia) 的醫學及長者團體組成聯席會議的主要成員，讀者可透過本專訪了解將癡呆症改名為「認知障礙症」的前因後果及內幕。

記: 首先多謝李醫生百忙中接受訪問，能否介紹一下有關城中熱話: **Renaming dementia**的背景?

李: 我們很早已知道國際組織DSM-V classification task force 會將dementia改名。其後在2010年中與中國大陸及台灣的老人精神科專業團體聯合舉辦第一屆兩岸三地的專業研討會，已構思將未來dementia的中文譯名統一。及後得知香港市民十分關注 高錕教授患病，亦於同年十月舉辦 癡呆症改名比賽，提議dementia改名為「腦退化症」。當時我作為HKPGA的會長，覺得這個名字有不當之處。於同年十一月我得到本會委員的支持下發出公開信，作出首個專業團體的回應¹。

記: 為什麼HKPGA對改名「腦退化症」有所保留?

李: 因為「腦退化」這個名稱並不準確。因為「癡呆症」有百分之三十五至四十是血管性與其他原因引起的，並不是所有的癡呆症也是退化性的。另一方面，患有退化性腦科疾病(如帕金森病)的病人也不一定有「癡呆症」。作為一個專業團體，我們雖然鼓勵公眾消除對癡呆症的誤解及歧視，令患者及早接受治療，但另一方面，我們也要與有關的醫學知識及與世界接軌。需知道精確傳釋醫學知識十分重要。正所謂「名不正 則言不順」。

記: 那HKPGA在過程中參與了甚麼呢?

李: 公開信發出後，各專業團體都認同本會的立場。同時，亦引起一些立法會議員的關注。2011年二月有議員在立法會提問²: 為何政府不專重專業團體? 政府在答辯中回應了「腦退化」並不是官方的名稱。其後有共十個專業團體支持HKPGA的立場並組成了一個專業聯盟。其組織成員有: Hong Kong Psychogeriatric Association, Hong Kong Neurological Society, Hong Kong Society of Psychiatrists, Hong Kong Alzheimer's Disease Association, Hong Kong Brain Foundation, Hong Kong Association of Gerontology, Hong Kong Geriatric Society, Hong Kong Stroke Society, Chinese Dementia Research Association and Mental Health Association of Hong Kong. 聯盟舉行了七次聯席會議，進行一系列的問卷調查、記者招待會、公眾教育及撰寫學術報告³。

記: 那為何選擇「認知障礙症」作新中文譯名?

李: 聯盟在十多個初步提名的名字中經過詳細的考慮，終於選取「認知障礙症」。這是因為它主要能表達英文Major Cognitive Disorders的原意及在中文語法上厘清其階段性，「症」字包含了Major 的意思。我們希望兩岸三地政府能採用「認知障礙症」，各地的市民及團體有更好的交流，令患者及早得到治療。

記: 李醫生你可否分享個人在這次經歷中的感受?

李: 我的感受是行動的重要。一個人亦可引起社會的關注，但成事則要眾志成城。

參考資料

1. Li, S.W. (2010, Feb 19). Renaming campaign on Chinese name of dementia as 「腦退化症」. Hong Kong Psychogeriatric Association official website. Retrieved October 3, 2012, from <http://www.hkpga.org/main.php?id=80>

2. 立法會2011年2月11日內務委員會會議文件, 立法會 CB(3)451/10-11號文件.

3. Lau, K.K. (2011, Aug). A new Chinese terminology for dementia and cognitive impairment. Hong Kong Medical Journal, 17(4), 342.



KEY MESSAGE OF THE WHO REPORT 2012

- Dementia is not a normal part of ageing.
- 35.6 million people were estimated to be living with dementia in 2010. There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds. The accelerating rates of dementia are cause for immediate action, especially in LMIC where resources are few.
- The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence. The costs are estimated at US\$ 604 billion per year at present and are set to increase even more quickly than the prevalence.
- People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.

Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems.

- Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders – at international, national, regional and local levels.
- People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.
- The time to act is now by:
 - promoting a dementia friendly society globally;
 - making dementia a national public health and social care priority worldwide;
 - improving public and professional attitudes to, and understanding of, dementia;
 - investing in health and social systems to improve care and services for people with dementia and their caregivers;
 - increasing the priority given to dementia in the public health research agenda.



COUNCIL NEWS

After the unprecedented success for local training of problem-solving therapy (PST) in December 2011, the HKPGA Council has invited 2 renowned trainers, Dr. Shu-lin Chen from the Zhejiang University (China) and Ms. Grace Niu from the Palo Alto University (USA) to conduct basic and advanced workshops for PST for local professionals at the Boy's and Girl's Clubs Association of Hong Kong in November 2012. The basic course will be held on 9 Nov 2012 (Friday) and the advanced course will be held from 11 to 13 Nov 2012 (Sunday to Tuesday). Please contact Ms. Iris Poon via 2881 4236 for registration and the details.

The HKPGA's Annual General Meeting cum Annual Scientific Symposium will be held at the Ballroom of the Hyatt Regency Hotel, Tsim Sha Tsui, Hong Kong on 10 Nov 2012. We are honoured to have Dr. Shu-lin Chen, representative of China; Dr. Jess Leung, representative of Hong Kong, and Dr. Keiko Nomura, representative of Japan to share their expert knowledge on management of elderly depression, screening for cognitive disorders in acute hospital and evaluation of cognitive and walking performances during a cerebrospinal fluid tapping in patients with idiopathic normal pressure hydrocephalus respectively on that day.



EVENTS CALENDAR

| <i>Date</i> | <i>Activity</i> | <i>Venue and contact</i> |
|--------------------|-----------------------|---------------------------------------|
| Nov 9, 2012 | Basic PST workshop | BGCA of Hong Kong, Wanchai |
| Nov 10, 2012 | HKPGA's AGM cum ASM | Hyatt Regency Hotel, Tsim Sha Tsui |
| Nov 11-13, 2012 | Advanced PST workshop | BGCA of Hong Kong, Wanchai |



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