SYLLABUS

TC18: Dementia in the Developing World

Monday, November 14, 2011 14:45 - 18:15 Hall J

Marrakesh, Morocco, November 12-17, 2011

XXth WORLD CONGRESS OF NEUROLOGY

XXth WCN 2011 MARRAKESH World Congress of Neurology

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SMN SOCIETE MAROCAINE DE NEUROLOGIE

DEMENTIA IN THE DEVELOPING WORLD

Chairperson: **Mostafa El Alaoui Faris**, *Morocco*

14:45 **DEMENTIA IN DEVELOPING COUNTRIES: AN OVERVIEW**
Mostafa El Alaoui Faris, *Morocco*

15:00 **EARLY-ONSET DEMENTIA IN THE DEVELOPING WORLD**
Maria Benabdeljlil, *Morocco*

15:30 **DEMENTAI IN AFRICA**
Adesola Ogunniyi, *Nigeria*

16:00 **DISCUSSION**

16:15 *Coffee Break*

16:45 **DEMENTIA IN LATIN AMERICA**
Raul Arizaga, *Argentina*

17:15 **DEMENTIA IN ASIA**
Ennapadam S. Krishnamoorthy, *India*

17:45 **DISCUSSION**

Early-onset dementia

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Outline

- Introduction
- Epidemiology of early-onset dementia (EOD)
- EOD in developing countries
- Diagnostic approach : the "dementia plus" concept
- The major causes of dementia
- Other degenerative dementias
- Other causes of EOD
- Management of EOD
- Conclusion

Introduction

- Early-onset dementia (EOD) : onset before age of 65 years
- EOD can present a substantial diagnostic challenge but can also provide important biological insights
- Underrecognized and represents a difficult clinical situation, especially early in the dementia course
- Careful investigation to identify treatable processes
- In developping countries:
  - low educationnal level → difficulties in cognitive testing
  - more infectious cases

Epidemiology of EOD (1)

- Few population-based studies on the epidemiology of EOD
- Very few data on EOD in developing countries
- Harvey et al. (2003) in UK : prevalence at 54 cases / 100 000
- Ikejima and col. (2009) in Japan : prevalence of 42 / 100 000 between the ages of 18 to 65 years

Epidemiology of EOD (2)

- Various proportion of EOD among dementia patients : 28.6% (Harvey et al., 1998) to 46.6% (Fujihara et al., 2004)
- In our experience in the Memory Center of Rabat (MCR) : EOD represents 44.5% of dementias (155 EOD / 349 dementia)
  - High proportion : young patients probably more referred than elderly because diagnosis of dementia and its causes are more difficult than in elderly

EOD in developing countries

- Apparently low prevalence of dementia and AD:
  - Mental illness remains a stigmatised condition
  - Lack of information about AD and dementias
  - Families tolerate a wide range of deviant behaviour
  - Families are relucant to take their parent to the hospital
  - Lack of confidence for modern physicians
  - Dementia sufferers may not survive for long

→ Patients seen late in the disease course

Diagnostic approach

- Clinical concept of « dementia plus » syndromes : cognitive impairment + additional neurological or systemic features
- Useful to guide a structured approach to diagnosis
- Clinical assessment : careful neurologic and general examination
- Cognitive assessment : low educationnal level, lack of valid neuropsychological instruments make the diagnosis difficult
- Behavioural and psychiatric assessment
- Investigations : cerebral imaging, blood tests, neurogenetics, CSF examination, neurophysiology, biopsies…

The major causes of dementia

- Alzheimer's disease, vascular disease, fronto-temporal lobar degeneration, and dementia with Lewy bodies : most common diseases that cause dementia, in the elderly *and* in younger patients, although not in patients < 35 years (Kelley et al., 2008)
- However, etiologies distribution depends on the methodology of the study : inpatients and / or outpatients
- Clinical features of these diseases in younger patients can differ from those seen at a later age

In the Memory Center of Rabat

- Study of 155 consecutive inpatients and outpatients with EOD
- Etiopathogenic mechanisms are various :
  - Most frequent : degenerative (44.5%),
  - Followed by vascular, than infectious mechanisms (respectively 16.8 and 16.1%)
- Not the same distribution of etiologies according to age bracket:
  - Before 45 years : essentially infectious and inflammatory diseases; degenerative etiologies uncommon
  - After 45 years : degenerative and vascular etiologies

Comparison of etiologies among EOD Cohorts

	Harvey, 2003 - UK	Panegyres, 2000 - Australia	Shinagawa, 2007 - Japan	Fujihara 2004 - Brazil	Mc Murtray, 2006 - US	Our series 2009
No. participants	185	112	185	141	278	155
AD (%)	33.5	25.9	38.5	21.3	17.3	34.8
VaD (%)	18.4	6.3	12.6	5	28.8	16.8
FTLD (%)	12.4	38.4	21.4	36.9	2.5	3.9
LBD (%)	6.5	0.9	0.5	NR	NR	1.3
Infectious (%)	1.1	5.4	Not Reported (NR)	NR	0.7	16.1

Alzheimer's disease (AD)

- Presenile AD may manifest at the fourth decade, frequently familial (2 to 5% of AD cases)
- Autosomal dominant AD more common in individuals with younger onset
- Sporadic AD in individuals < 50 years is rare
- Features could be similar to individuals with late onset sporadic AD
- Genetically heterogeneous :
  - presenilin (PS) 1 gene mutations on chromosome 14
  - rarely, mutations in the b-amyloid precursor protein (APP) gene on chromosome 21
  - PS-2 gene on chromosome 1

AD (2)

- Familial AD generally have myoclonus, relative preservation of naming
- Sporadic EO-AD : prominent speech production deficits, parietal signs may be the presenting feature, then memory impairment
- Rarely, features that are not seen in LO sporadic disease
  - *PS1 deletions and some point mutations :* spastic paraparesis, with white matter changes (Assini et col., 2003)
  - Cerebellar ataxia rarely (Anheim, 2007)
- Investigations :
  - morphologic and metabolic imaging
  - decreased amyloid β1–42 and increased tau concentrations in CSF

Vascular dementia (VD)

- Generally second cause of EOD, like in our study
- Multi-infarcts dementia
- Small vessel disease : subcortical dementia, gait "apraxia", pseudobulbar palsy and urinary incontinence
- Impairment of episodic memory less prominent than in AD
- Brain imaging findings : white matter changes, lacunar or large infarcts
- Intensive investigation might identify rarer causes :
  - mitochondrial disease, CADASIL, Sneddon's syndrome, cerebral vasculitis (primary or systemic), amyloid angiopathy,...

Frontotemporal lobar degeneration (FTLD)

- 3 clinical syndromes :
  - behavioural variant (bv) FTLD
  - semantic dementia
  - progressive non-fluent aphasia
- Age at onset : 45–60; males more frequently affected
- Family history in 20 to 40% of patients
- In Autosomal Dominant FTLD :
  - Progranulin (GRN) gene mutations
  - Microtubule-associated protein tau (MAPT) gene mutations → younger age onset

1 - bv-FTLD

- Clinical presentation : behavioural disturbances and rigidity, personality change, loss of social skills, emotional lability and impulsivity, hyperorality
- Executive dysfunction, decreased verbal fluency, impaired abstraction, motor and verbal perseveration and stereotypies
- Families may attribute behavioural changes to marital difficulties or "mid-life crisis"
- Misdiagnosis frequent as resistant depression or AD
- Disproportionate frontal atrophy may be evident on MRI

2 - Semantic dementia

- Resembles a progressive fluent aphasia, with increasingly empty and circumlocutory (but grammatically correct) speech due to *loss of semantic knowledge* about the meanings of words and objects
- Anatomically :
  - focal, predominantly left anterior temporal atrophy
  - asymmetry, existence of an anteroposterior gradient of atrophy : distinguish semantic dementia from AD on MRI

3 - Primary progressive non-fluent aphasia

- Insidious deterioration in speech production
- Phonemic and syntactic errors and word-finding difficulties, frequently accompanied by orofacial apraxia
- Circumscribed left perisylvian atrophy on MRI

Lewy Body Disease (LBD)

- Synucleopathy, second most common cause of dementia in the *elderly*
- Relatively uncommon in younger populations
- Cognitive syndrome with frontal/parietal involvement, well formed visual hallucinations, and fluctuations, followed by the development of parkinsonism
- Clinical presentation similar to that in older patients
- Investigations : REM sleep behavioural disorders, early slowing and transient temporal slow wave activity on EEG, decrease in cardiac MIBG uptake (myocardiac scintigraphy)

Other degenerative dementias
Parkinson's disease dementia

- Dementia : common feature of advanced PD, but develops less frequently and with a longer latency in patients with EO
- Patients with EO-parkinsonism : genetic cause more frequent
  - mutations in the parkin (*PARK2)* gene
  - α-synuclein triplications and glucocerebrosidase gene mutations : can be associated with prominent cognitive impairment

Other degenerative dementias
Huntington's disease

- CAG trinucleotide expansion, IT15 gene on chromosome 4
- Onset generally in middle life, with progression of subcortical dementia and behavioural decline
- Common neuropsychiatric symptoms of depression, apathy, aggression, disinhibition, and social disintegration, may precede chorea and other extrapyramidal signs
- Brain imaging : bilateral atrophy of the caudate nucleus head
- Diagnostic and predictive genetic testing widely available

Other causes of dementia

- Some are « curable dementias » : relatively short course or fluctuating
- Frequently infectious or inflammatory mechanisms
- Two clinical situations :
  - Patient known suffering from another disease who presents with cognitive disorders (for example : HIV, lupus, Behcet'disease ...)
  - Inaugural cognitive symptoms → careful examination, and numerous investigations, depending on clinical and paraclinical findings

Some other causes of EOD

- Inflammatory and immunological diseases : multiple sclerosis, Behcet disease, systemic vasculitis (lupus…), "steroid-responsive" and autoimmune encephalopathies, paraneoplastic limbic encephalitis…
- Infectious diseases : HIV, Syphilis, Prion diseases, Herpes, tuberculosis…
- Metabolic disorders : inherited or not
- Other : Wilson's disease, alcohol related dementia, traumatic brain injury, hydrocephalus, Sleep apnoea,…
- Sometimes, unknown origin

HIV dementia (HIV-D)

- Peculiar cause of EOD in some developing countries
- Won et al (2004) : 30% of HIV-D among patients seen in an infectious disease clinic in Uganda
- Decreased incidence of HIV-D with introduction of active antiretroviral therapy, but stable prevalence
- Greater frequency of patients with milder forms of cognitive impairment
- Subcortical dementia syndrome : early changes of mental slowing, memory impairment and behavioural changes
- Motor features : early falls and difficulty in fine dexterity
- With disease progression : global dementia + signs of a vacuolar myelopathy

Treponemic dementia

- Incidence of syphilis has increased with HIV co-infection in developpe coutries
- Syphilitic dementia : 12,2% of our EOD cases
- Apathy, decline in personal care, irritability and loss of judgement
- With disease progression, cognitive symptoms more marked, loss of concentration and memory impairment, progressing to a generalized dementia
- Frequent florid psychiatric symptoms : paranoid ideation and both visual and auditory hallucinations
- Diagnosis : positive serology in serum anf CSF

Management of EOD

- Depends on the etiology
- EOD has a dramatic impact on quality of life and important family burden : employable age, parent of young children
- Economic familial consequences : patient mean earner of the family
- Lack of long-stay medical institutions for young demented patients
- In developing countries : lack of specialized structures for diagnosis and management of dementia

Conclusion

- EOD : diagnostic difficulties in developing countries
- Large diversity of etiologies → need structured approach based on all clinical features and careful investigation
- Often delayed diagnosis in developing countries
- Alzheimer's Disease is the first cause of EOD, followed by Vascular dementia
- Other etiologies less common : inflammatory, infectious, genetic and metabolic disorders
- Management presents challenges that differ from LOD

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Dementia in Africa

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World Congress of Neurology
Marrakesh, Morocco, November 2011

Lecture Outline

- Introduction
- Pioneering studies of dementia in Africa
- Neurocognitive impairment
- Dementia diagnosis and differential diagnosis
- Descriptive epidemiology
- Analytic epidemiology
- Prediction of dementia
- Neurocognitive impairment in HIV infection
- Management of Dementia
- Conclusion

Introduction

- Health care priorities in Africa: how high up on the list is dementia?
- Reasons for scanty data on dementia in Africa

Pioneering studies of dementia in Africa

Indianapolis-Ibadan
10/66
Newcastle/Indianapolis/Kenya
Bordeaux/Francophone countries
Others

Neurocognitive Impairment

- Cognitive domains
- Validated assessment methods in Africa
- Confounders
- Assessment of functionality
  ADL vs. IADL
- Classification of cognitive impairment in the elderly (MCI vs. Dementia)

Dementia diagnosis

- Diagnostic criteria
- Neuropathologic findings in dementia
- Differentiating types of dementia in Africa
- Staging dementia
- Relevant laboratory tests

Descriptive epidemiology

- Prevalence of dementia in Africa
- Reasons for variation in rates
- Dementia and mortality
- Incidence of dementia

Prevalence of Dementia in African countries:

Country	Place	Prevalence rate %	Authors
South Africa	Cape Town	8.6	Ben-Arie 1983
Nigeria	Ibadan	2.29	Hendrie et al 1995
Egypt	Assiut	4.5	Farrag et al 1998
Nigeria	North central	6.4	Ochayi & Thacher 2006
Nigeria	Southwest	10.1	Gureje et al 2006
Benin	Djidja	2.6	Guerchet et al 2009
Republic of Central Africa	Bangui	8.1	Guerchet et al 2010
Congo	Brazzaville	6.7	Guerchet et al 2010
Nigeria	Zaria	2.79	Yusuf et al 2011

Analytic epidemiology of dementia

- Sociodemographic risk factors
- Genetic risk factors
  - Role of apolipoprotein E
  - Unique mutations in Africa
- Vascular risk factors
- Diet and dementia
- Are there protective factors against dementia in Africa?

Neurocognitive impairment in HIV/AIDS

- Classification of neurocognitive decline
- Prevalence of HIV associated dementia
- Risk factors for HIV associated dementia
- Role of HAART

Predicting dementia in Africa

- Weight loss
- Elevated blood pressure in the elderly

Differential diagnosis

Management of dementia

- Culturally-appropriate modes of care
  - Home-based care vs. Institutional care
  - Care giver characteristics in Ibadan
- Symptomatic care
- Acute care
  - Hospital management
  - Respite care (palliative)
- Cost of care

Conclusion

- State of knowledge on dementia in Africa
- The way forward
  - need for collaboration within and outside Africa
  - Advocacy

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Cognitive impairment and dementia in Latin America

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Mainly situated in the southern hemisphere, South America has near 380 million inhabitants distributed in 18 million square kilometres.

Thinking in demographic terms, it is a generally considered that South America is a young region. The region has to deal with health problems such as perinatal and infantile mortality and transmissible diseases. But a silent greying process, faster or slower according to regions and countries, is affecting the whole continent and adding to the afore mentioned problems, those related to an ageing population.

Each month, worldwide, there are 800,000 more persons over the age of 65 years, and 70% of them live in the developing world. As part of this developing world, South America is faced with the problems of an accelerated ageing process combined with the complex conditions of the emerging economies. (Arizaga, 1999).

The World Health Organization (WHO), through the Global Burden of Disease, developed estimates of the percentage of people dying of each major cause worldwide. Deaths are classified in three broad causal groups: Group I (communicable, maternal, perinatal and nutritional conditions), Group II (non-communicable diseases) and Group III (injuries).

Table I shows the proportionate burden from each cause for developing and developed regions. Surprising, perhaps, is that for several developing regions more people die of Group II causes than Group I cause. Only in India and Sub-Saharan Africa do Group I causes still dominate.

	Developing regions	Developed regions
Group I	41,9 %	6.1 %
Group II	47.4 %	86.3 %
Group III	10.7 %	7.6 %

In South America and the Caribbean, there are almost twice as many deaths from non communicable diseases as from Group I causes. (Murray and López, 1996).

The crude death rate in Latin America is lower than the world average and similar to the rates of developed countries (World Bank, 1998 a). The birth rate has also decreased, as a

result of increased access to higher educational levels. The Latin American average annual population growth rate was 1.9 % between 1980 and 1996 and projected to decrease to 1.4 % between 1996 and 2010 (World Bank, 1998 b).

Some indicators help to understand the socio-economic and demographic South American scenery. If we compare the present to twenty years ago, there is a marked slowing of both birth and death rates. This is a clear result of the increase in literacy and average in school years in the region and the displacement from rural to urban areas. The decline in the death rate during this period corresponds with the improvement of the life expectancy at birth, as a result of increased access to vaccines, antibiotics and the adoption of healthier living habits. The percentage of GNP directed to health shows a clear improvement. And the same occurs with the number of physicians and nurses.

The population ageing is particularly remarkable in Argentina, Chile and Uruguay. In Argentina the growth of population over 65 was threefold compared with the growth of general population in the period 1950-2000. More striking is the data that population over 80 had grown six times more than general population growth in the same period .

The DALY (Disability Adjusted Life Year) expresses years of life lost to premature death and years lived with a disability of specified severity and duration. One DALY is thus one lost year of healthy life. A “premature” death is defined as one that occurs before the age to which the dying person could have been expected to survive if they were a member of a standardised model population with a life expectancy at birth equal to that of the world’s longest-surviving population, Japan.

Dementia is the fourth cause of DALYs in the developing world. Table 2 shows the burden of different pathologies in developing countries (Bergen, 1996).

Most common causes of disease burden in adults 60 years and older in developing countries (by disability adjusted life years). (Bergen, 1996).

	Female	Male
1	Cerebrovascular disease	Cerebrovascular disease
2	Ischaemic heart disease	Ischaemic heart disease
3	Chronic pulmonary obstructive disease	Chronic pulmonary obstructive disease
4	**Dementia**	**Dementia**
5	Respiratory infections	Tuberculosis
6	Carditis	Respiratory infections
7	Diabetes mellitus	Carditis
8	Tuberculosis	Stomach cancer
9	Falls	Lung or tracheal cancer
10	Cataracts	Cirrhosis

The concept and management of dementia, for research groups and specialised centres in South America, probably is similar as that of their equivalents in the developed countries. But the situation is different regarding general practitioners. Many of them in the region believe that memory loss or other cognitive deficits are normal components of the ageing process. (Mangone and Arizaga, 1999; Mangone et al, 2000). As a consequence the referral of the cognitive impaired individuals to the specialist occurs generally when the impairment is severe or at least moderate.

The costs of dementia to society is the value of all goods and services that are given up to prevent, diagnose, treat and otherwise cope with dementia. Economic costs of AD are significant for health systems. Individuals, families and carers are affected both in the economic aspect and in the quality of life..

In a study performed in Argentina, the annual direct costs of dementia increase in direct relation with cognitive deterioration level (from US$3420.40 in mild to US$9657.60 in severe AD) (Allegri et al, 2008)

Translated versions of neuropsychological tests and scales are available in different countries. Although the language of South American countries, with the exception of Brazil, is Spanish, the regional language variations require that the version of a neuropsychological test must be adapted by local neuropsychologists and linguists. Word frequency and meaning and denomination of objects show an impressive variation between the different countries. It is highly probable that a test translated in one country may not be applicable in another.

Tests are tools that need to be adapted to the population before being administered to the individuals. It implies more than a simple translation.

At the beginning of the study of the cognitive profile, brief screening tests are generally used, like the Mini Mental State Examination, the Short Portable Mental Status Questionnaire, or the Blessed information-Memory-Concentration test. The MMSE has provided extensive clinical utility around the world, but in Latin American countries scores must be interpreted in the light of cultural effects.

Different psychological batteries are used in South America for the evaluation of cognitive impairment: the Mattis Dementia Scale, the Alzheimer's Disease Assessment Scale - ADAS , the SKT, the Trail making A & B ,the Wechsler Adult Intelligence Scale, the Wechsler Memory Scale, the Boston Naming Test, the Token Test , the Wisconsin Card Sorting Test, the Benton Visual Test and others.

The Functional Status Scale is used to study the Instrumental and Basic Activities of Daily Living. The Hamilton Depression Scale is also helpful in diagnosing and determining the severity of depression.

Future work by South American research groups must include the validation and harmonisation of instruments to make possible the performance of multicentric epidemiological and clinical studies and drug trials with fully comparative results.

In all South American countries there exist auxiliary diagnostic tools including blood and cerebrospinal fluid laboratory tests, computed tomography, single photon emission computed tomography, magnetic resonance imaging and positron emission tomography. In some countries determination of some genetic markers is available. Medical information, distances, type of healthcare system, costs and reimbursements generate a wide spectrum of accessibility to these diagnostic instruments.

Epidemiological data about dementia, cognitive impairment and risk factors are lacking in South America. Epidemiological studies are scarce and those performed are not found in publications, especially in indexed ones.

In Uruguay, Ketzoian et al (1997) in a study of the general population, found a dementia prevalence ratio of 4.03 per thousand. The distribution was: 60 % Alzheimer's disease, 15 % vascular dementia, 8 % mixed (degenerative plus vascular) and 17 % other and unknown aetiologies.

An epidemiological survey in the urban area of Catanduva, Brazil was performed to study the prevalence and incidence of dementia in a Brazilian elderly population. 1681 randomly selected individuals aged 65 or more were initially evaluated with MMSE and the Pfeiffer Functional Activities Questionnaire (PFAQ). According to the educational-adjusted cut-off scores individuals were selected for clinical, neurological and cognitive evaluations. Demented patients were submitted to laboratory tests and brain CT. Re-screening was performed 39 months after the prevalence study. Dementia was diagnosed in 7.1 % of individuals, with Alzheimer's disease being the main clinical diagnosis (55.1 %). Multivariate analysis disclosed significant association between dementia and age, low education and female sex. A dementia incidence of 13.5/1000 individuals was found. Incidence rates were higher among illiterates and individuals aged 85 and older. Mortality rate during the 39 months was higher among patients with dementia (Nitrini et al, 2000).

A cross sectional population based epidemiological study was performed in 1994 to determine dementia and cognitive impairment in Chilean urban-rural population aged 65 and

more. The normal screened individuals were re-screened later for the incidence study. (Quiroga et al, 2000 a). The study revealed an annual incidence of 1.78 % for dementia and of 1.82 % for cognitive impairment. Considering subtypes 83 % presented Alzheimer's disease, 14.2 % VaD and 2.8 % dementia asssociated with Parkinson. An annual incidence of Alzheimer's disease of 1.5 % in individuals aged 65 and more was reported in Chile (Quiroga et al, 2000 b). In this study E4 isoform of apolipoprotein E appeared as an important risk factor for the development of the disease (OR= 3.8).

A cross-over study in a 65 and older people population to determine the prevalence of cognitive impairment was performed in elderly people assessed in a university geriatric centre in Rio de Janeiro (Lourenco, 2000). Using the MMSE, a prevalence of 22.4 % of cognitive impairment was found.

In Sao Paulo, Brazil, a study for evaluating the influence of medical conditions on the performance of MMSE was conducted in 384 individuals (Ventura, 2000). Reported memory problems showed statistically significant influence on MMSE. Previous diseases and arterial hypertension, diabetes, hypercholesterolemia and smoking didn't show effects on MMSE.

The Research Group on Dementia of the Argentine Neurological Society evaluated cognitive deterioration in 500 people without memory complaint (they were occasionally at the hospital accompanying a patient). In the group over 60, 10.5 % had severe and 14.1 % mild to moderate cognitive deterioration according to the Short Portable Mental Status Questionnaire of Pfeiffer (Research Group on Dementia ANS, unpublished).

In Cañuelas (Argentina) the MMSE was used in a sample of individuals 65 years old and more. Mean age was 70.9 (± 7.5). 560 male, 893 female. Education (in years): 5.53 (±3.54). Mean MMSE score: 24.5 (± 4.7). Using a MMSE average cut-off of 22 (considering age and school years) cognitive impairment was found in 23.2% of the sample. The prevalence considering age was:

60 -69 years old	16.9%
70 -79 years old	23.3%
80 years old and over	42.5%
Whole sample	23.2 %

The 10/66 Dementia Project is an epidemiological dementia study that was conducted in Latin America, India and China. The prevalence of 10/66 dementia varied between 5·6% and 11·7% by site, whereas that of DSM-IV dementia varied between 0·4% and 6·4%. The

prevalence of 10/66 dementia was higher in every site, and was generally around double that of DSM-IV dementia (Llibre Rodriguez et al, 2008)

When the prevalence of DSM-IV dementia in 10/66 sites was compared with the consistent, pooled estimate from the 12 European sites in the EURODEM meta-analysis (indirectly standardising for age and sex), the prevalence in urban Latin American sites was about four-fifths of that in Europe (Llibre Rodriguez et al, 2008).

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Transcultural Perspectives in Dementia

- Diagnosis, Impact, Caregiving & Research

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India

- 7th largest country in terms of area
- Over 1 Billion population- second most populous
- Nearly 30 states- a union of states
- Significant diversity- 24 official languages- 542 dialects
- A paucity of doctors: 3500 psychiatrists and a 1500 neurologists for this population
- Concentrated in urban areas
- A diverse range of healthcare services- but with urban concentration

Importance of dementia in a developing nation like India

- In the process of significant development- demographic shift
- Increasing longevity with greater affluence, improved health care, impact of primary prevention programs
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- Much lower prevalence figures in India
  - between 1.9 and 3.6 % in various studies
  - 10/66 study dementia prevalence in India around 2% (Chennai and Vellore)
- This data compares well with that from several developing nations (US-Nigeria Project; 10/66 worldwide data etc.)

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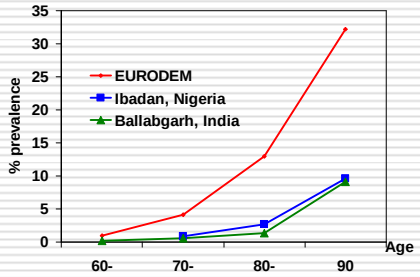

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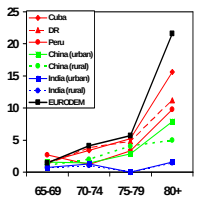

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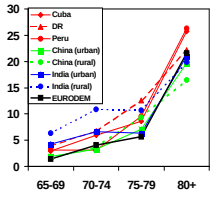

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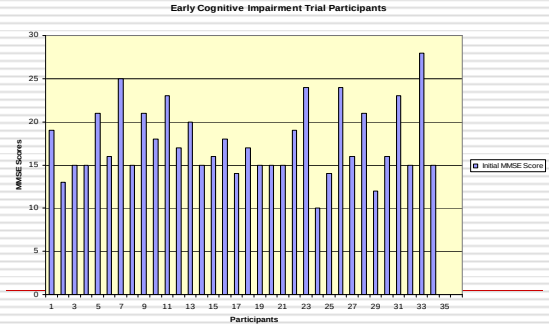

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Caregiver Experiences (Shaji et al, 2003)

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- Receiving help from others- for example extended family living close by
- Better financial status
- Premorbid relationship with the Dementia sufferer?

Caregiver support

- Few had received medical help- none were in continuing contact with health facility
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Correlation Matrix [N=40 (Patients=20, caregivers=20)]

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In the 10/66 studies

- Caregivers have a considerable burden of stress across cultures and are likely to suffer from depression
- There are however rural-urban differences: Caregivers in rural areas have lower levels of stress/ depression except when person with dementia suffers from BPSD
- Are there other (social) factors that protect caregivers in rural settings?

Need for culturally relevant research and care paradigms

- Perhaps we should do away with the "one size fits all" approach in dementia care and research
- Perhaps people with dementia in developing nations need unique clinical and research solutions – culture free, culture fair and unassuming
- The 10/66 protocol of assessment and the 10/66 caregiver intervention are good examples – the need, however, is to go much further

Caregiver Intervention: The Cartoon Book Approach

Cartoon Book

- Pictures and Text
- Easily understood- easily transferred
- Used to illustrate key concepts

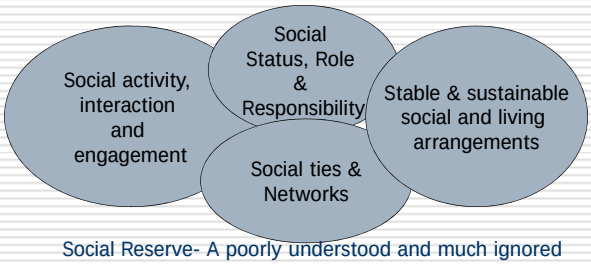
Need for caution in interpreting data across cultures

- In the developing nation context mild and moderate forms of dementia (without BPSD) do not appear to constitute a burden
  - No perception of cognitive impairment
  - No perception of disability
  - Lower levels of caregiver stress in rural areas
- The burden of dementia may be genuinely lower in developing nations especially in rural areas
  - Not just the artefact of a reporting bias
  - Not wilful concealment due to stigma
- *Is burden also not just a "perception"?*

Need to develop a bi-directional transcultural understanding

- Perhaps we should examine the native wisdom in these "less-developed" cultures?
  - Does the social isolation of development convert those with borderline cognitive impairment into cases with dementia?
  - Do "independent" living arrangements in developed nations or urban areas increase the disability of the person with dementia?
  - Indeed, do these arrangements result in greater disability for the dementia sufferer and caregiver? I.e. the disability is consequent to "development" rather than despite it!

The need to focus on the role social reserve in diminishing disability due to dementia



Social Reserve- A poorly understood and much ignored concept worthy of further exploration

The impact of sociological change in developing nations

- Steady erosion of the traditional family and social fabric due to socio-cultural and economic change
  - Rural-urban migration
  - Urbanization & changing lifestyles
  - Changing family structure/ dynamics
  - Changing social priorities- Westernization of thought in traditional cultures
  - The impact of Globalization: PICA Syndrome
- As these changes take firm root, will they lead to a higher prevalence of dementia or greater disability thereof?

Socialization is strongly associated with patient QoL in a qualitative study in Northern India (Subbulakshmi & Alphonse, 2009*)

	B	Std. Error	Beta	t	Sig
LIVING	**3.445**	**2.320**	**.202**	**1.485**	**.158**
SOCIAL	**8.764**	**3.559**	**.534**	**2.463**	***.026***
SPIRITUAL	**4.718**	**3.553**	**.208**	**1.328**	**.204**
ATTITUDE	**2.158**	**4.367**	**.099**	**.494**	**.628**

Presented at the TS Srinivasan Conclave on the Ageing Brain and Mind: February 2009, New Delhi

Group I	Group II	Group III
Joint family	Nuclear family	Living alone
Good social support	Average/partial	Poor/no
Highly optimistic	Moderate	Pessimistic
High spiritual strength	Moderate	Low
Nominal health issues	Less	More
= Good QoL	= Average QoL	= Poor QoL

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Preserving traditional living arrangements may improve QoL and diminish disability and burden for elderly people with and without dementia across cultures

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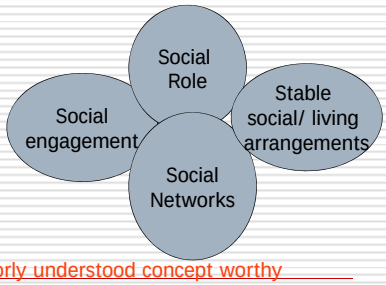

Social Reserve- A poorly understood concept worthy of further exploration

Take home messages

- While dementia exists across cultures, it probably has a differential impact on the caregiver
- The impact on caregiver probably influences perceived disability due to dementia across cultures
- Social reserve may have a profound influence on disability due to dementia
- The solution to the emerging dementia epidemic may well lie in traditional arrangements for support and caregiving
- Health policy for dementia in developing nations like India should be shaped around this understanding

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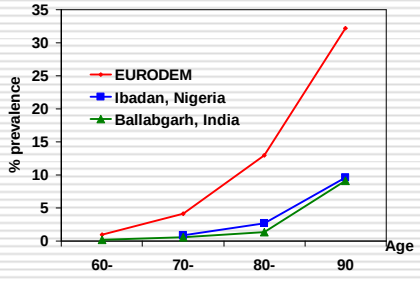

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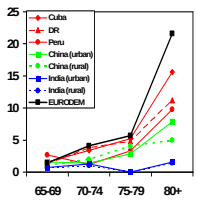

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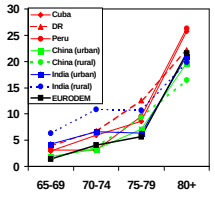

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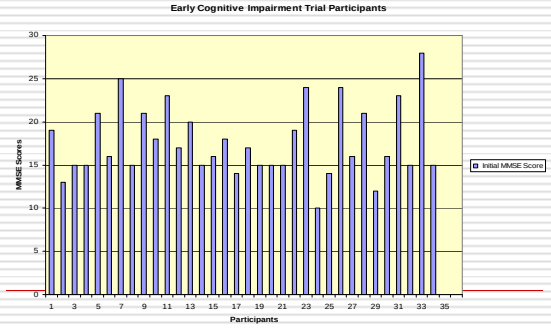

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- Perhaps we should do away with the "one size fits all" approach in dementia care and research
- Perhaps people with dementia in developing nations need unique clinical and research solutions – culture free, culture fair and unassuming
- The 10/66 protocol of assessment and the 10/66 caregiver intervention are good examples – the need, however, is to go much further

Caregiver Intervention: The Cartoon Book Approach

Cartoon Book

- Pictures and Text
- Easily understood- easily transferred
- Used to illustrate key concepts

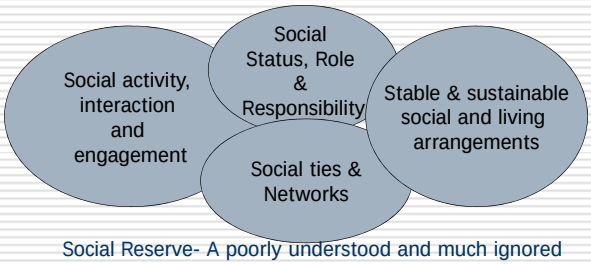
Need for caution in interpreting data across cultures

- In the developing nation context mild and moderate forms of dementia (without BPSD) do not appear to constitute a burden
  - No perception of cognitive impairment
  - No perception of disability
  - Lower levels of caregiver stress in rural areas
- The burden of dementia may be genuinely lower in developing nations especially in rural areas
  - Not just the artefact of a reporting bias
  - Not wilful concealment due to stigma
- *Is burden also not just a "perception"?*

Need to develop a bi-directional transcultural understanding

- Perhaps we should examine the native wisdom in these "less-developed" cultures?
  - Does the social isolation of development convert those with borderline cognitive impairment into cases with dementia?
  - Do "independent" living arrangements in developed nations or urban areas increase the disability of the person with dementia?
  - Indeed, do these arrangements result in greater disability for the dementia sufferer and caregiver? I.e. the disability is consequent to "development" rather than despite it!

The need to focus on the role social reserve in diminishing disability due to dementia



Social Reserve- A poorly understood and much ignored concept worthy of further exploration

The impact of sociological change in developing nations

- Steady erosion of the traditional family and social fabric due to socio-cultural and economic change
  - Rural-urban migration
  - Urbanization & changing lifestyles
  - Changing family structure/ dynamics
  - Changing social priorities- Westernization of thought in traditional cultures
  - The impact of Globalization: PICA Syndrome
- As these changes take firm root, will they lead to a higher prevalence of dementia or greater disability thereof?

Socialization is strongly associated with patient QoL in a qualitative study in Northern India (Subbulakshmi & Alphonse, 2009*)

	B	Std. Error	Beta	t	Sig
LIVING	**3.445**	**2.320**	**.202**	**1.485**	**.158**
SOCIAL	**8.764**	**3.559**	**.534**	**2.463**	***.026***
SPIRITUAL	**4.718**	**3.553**	**.208**	**1.328**	**.204**
ATTITUDE	**2.158**	**4.367**	**.099**	**.494**	**.628**

Presented at the TS Srinivasan Conclave on the Ageing Brain and Mind: February 2009, New Delhi

Group I	Group II	Group III
Joint family	Nuclear family	Living alone
Good social support	Average/partial	Poor/no
Highly optimistic	Moderate	Pessimistic
High spiritual strength	Moderate	Low
Nominal health issues	Less	More
= Good QoL	= Average QoL	= Poor QoL

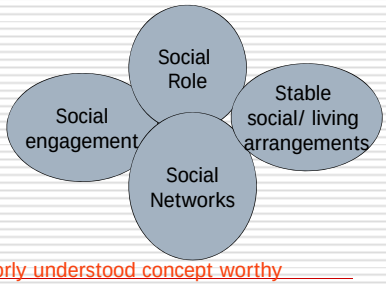
Socialization is strongly associated with patient QoL in a qualitative study in Northern India

(Subbulakshmi & Alphonse, 2009*)

Presented at the TS Srinivasan Knowledge Conclave on the Ageing Brain and Mind: February 2009, New Delhi

Preserving traditional living arrangements may improve QoL and diminish disability and burden for elderly people with and without dementia across cultures

SOCIAL RESERVE



Social Reserve- A poorly understood concept worthy of further exploration

Take home messages

- While dementia exists across cultures, it probably has a differential impact on the caregiver
- The impact on caregiver probably influences perceived disability due to dementia across cultures
- Social reserve may have a profound influence on disability due to dementia
- The solution to the emerging dementia epidemic may well lie in traditional arrangements for support and caregiving
- Health policy for dementia in developing nations like India should be shaped around this understanding