Multiculturalismo e Demenza

Growing old is inevitable, growing up is optional.

GRG, 11-12-2009
Stefano Boffelli
Anne-Mei The; In Death’s Waiting Room: Living and Dying with Dementia in a Multicultural Society (Amsterdam University Press, 2008)

The story behind In Death’s Waiting Room is a penetrating human drama that concerns us all—as our “greatest generation” continues to age, more and more families are contending with the onset of dementia in their elderly parents and grandparents, a trend that will only continue as the global population of senior citizens continues to grow with certain speed.

Anne The carried out two years of hands-on ethnographic research in an Amsterdam nursing home for patients with various forms of dementia. In Death’s Waiting Room reveals what usually remains hidden in these modern-day centers of care: the decision to stop treatment, 

the poverty and voodoo rituals of the black Caribbean nursing staff looking after predominantly white patients, the difficulties faced—and caused—by relatives, and the tensions and aggressions between residents.

This immensely readable and moving volume also shares the touching moments of humor and compassion, while at the same time forcing us to consider our own potential confrontation with dementia, in our own or our parents’ lives. From conversations with underpaid nurses to confrontations with family visitors who insist on prolonging treatment against all odds, this searing book is a truly necessary guide to some of the most wrenching aspects of old age.
Multiculturalismo: una definizione difficile

Diagnosi di demenza nelle diverse aree geografiche e nelle diverse culture

La demenza nelle aree dove convivono le minoranze etniche nei paesi ricchi: vantaggio o svantaggio?

La visione della demenza nelle diverse culture (paziente e familiare)

La visione del demente da parte del medico: barriere diagnostiche

Futuro: integrazione (dei servizi?)
Il multiculturalismo - secondo la definizione di Stuart Hall – «describe le caratteristiche sociali ed i problemi di governance di qualsiasi società in cui convivono comunità culturali differenti che tentano di costruire una vita comune conservando, allo stesso tempo, qualcosa della loro identità “originaria”».

Lo studio del multiculturalismo si associa al fenomeno dell’immigrazione, al conseguente radicarsi di una cultura non monolitica e di stili di vita diversi.

Si tratta di fenomeni e situazioni che includono una ridefinizione dell’idea di democrazia.
Potremmo dire che la multiculturalità indica una condizione caratterizzata dalla convivenza di più culture che può trovare gli esiti più diversi a seconda delle strategie e delle pratiche seguite per definire i loro rapporti.

Quali obiettivi, quali metodi e strumenti per perseguirli? La multiculturalità è rappresentabile come un mosaico, le cui tessere possono variamente disporsi.

È una possibile condizione di stratificazioni di etnie diverse quanto a lingua, cultura, usi, costumi, credo religiosi.

Essa richiede una politica per la definizione dei rapporti tra i diversi gruppi e tra essi e la cornice istituzionale.
Il multiculturalismo è quella concezione secondo la quale, in una società in cui sono presenti più culture e comunità, è desiderabile che esse convivano nel reciproco rispetto senza che vi sia un’assimilazione, diretta o indiretta, alla cultura e al gruppo dominante.

E’ una concezione cui si richiamano i gruppi minoritari che vogliono ottenere il riconoscimento della loro identità culturale, ritenendo che la garanzia dei diritti individuali offerta dalla democrazia liberale non protegga la propria cultura o i propri modi di essere e sia quindi necessario introdurre speciali diritti di gruppo.

Ha iniziato a diffondersi nella cultura nordamericana a partire dagli anni Sessanta in seguito alla crisi dell’ideologia del melting pot, del “crogiuolo” in cui la molteplicità etnica si fondeva in un’unità plurale (e pluribus unum); ideologia che nascondeva un’assimilazione alla classe dominante con il mantenimento della discriminazione nei confronti delle minoranze.

Il multiculturalismo punta al riconoscimento di “diritti collettivi” riferiti a comunità, prima che a individui, e ritiene che anche i rapporti tra culture diverse, oltre a quelli tra individui, debbano richiamarsi ai valori della libertà e dell’uguaglianza.
In his essay "Mistaken identity", Kenan Malik argues that multiculturalism perpetuates a racist definition of culture. Radostin Kaloianov dismisses this critique as being based on false conclusions, turning instead to what he considers to be the genuine limitation of institutionalized multiculturalism: its concentration on only a narrow spectrum of differences.

Eurozine, 2-2009
a. le culture sono pensate come qualcosa di definito che si concretizza in individui che ne diventano così rappresentanti o portatori. Nulla di più falso: l’individuo non è sovradeterminato sino a questo punto dalla cultura. Provare per credere: immaginate di trovarvi in Giappone e di dover rispondere a chi, giapponese, applicasse nei vostri confronti proprio questa modalità di pensiero considerandovi ambasciatore e portatore della cultura italiana. Un brivido vi percorrerà la schiena: quale cultura italiana? Pizza, spaghetti, gondola e mandolino oppure strudel e parlata ladina?

b. Le culture sono sostanze o essenze già predeterminate e identificate. Idem per "identità". Scrivero Zoletto: siamo di fronte ad un errore epistemologico di fondo. "L’utilizzo di categorie astratte come quelle di cultura o identità che, attraverso una generalizzazione e una sostanzializzazione di supposte caratteristiche etniche, sorvola quelle che sarebbe meglio invece descrivere come singolarità e pluralità di appartenenze e modi di essere".

c. L’equivoco dell’omogeneità linguistica: spessissimo noi vediamo nella omogeneità linguistica il principale indicatore dell’identità etnica o culturale secondo la seguente equazione: "lingua = cultura = etnia " (a cui si potrebbe aggiungere anche = religione). Nulla di più falso come testimoniano gli studi di antropologia, ed in particolare di antropologia dei flussi e dei confini.
Globalism

- Aims at developing students’ knowledge and understanding of peoples and cultures of other lands, including their values, customs, institutional systems, resources, environmental adaptations, and societal challenges.
-Develops awareness of human diversity and the commonalities in human experience.
-Implementing units on other countries with the goal of teaching about other cultures and other lands.
-Emerged out of growing interconnectedness and interdependence among nations created by technology. For example, pollution, depletion of ozone, political concerns, corruption, human rights abuses, terrorism, nuclear war, economic development, poverty, overpopulation...
Multiculturalism & Globalism

- Both needed to prepare students for national & global citizenship
- Both seek to develop a broader understanding of human commonalities and human diversity
- Both help students develop skills of informed decision making on issues of equity within the national and global community
- Both are complementary and can be implemented simultaneously
DON'T SAY A WORD! WE MUST RESPECT HIS CULTURE!

SO WOULD THAT BE A FUNERAL OR VIRAL CULTURE?

MY CULTURE RIGHT OR WRONG
Un esempio

- la differente visione dei concetti in tema sanitario: la salute
What is health?

Health is shaped by:

- Attitudes, beliefs and values
- Sex, age, religion and socio-cultural groupings
- History, knowledge and dominant understandings about health and illness
- Professional versus consumer experiences
Definitions of Health

- World Health Organization (WHO): “a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity.”

- Bircher: “a dynamic state of well-being characterized by a physical and mental potential, which satisfies the demands of life commensurate with age, culture, and personal responsibility.”

- Saracchi: “a condition of well being, free of disease or infirmity, and a basic and universal human right.”

- Australian Aboriginal people: “…Health does not just mean the physical well-being of the individual but refers to the social, emotional, spiritual and cultural well-being of the whole community. This is a whole of life view and includes the cyclical concept of life-death-life.

http://www.who.int/bulletin/bulletin_board/83/ustun11051/en/
WHO definition of ‘Health’ – critical appraisal

- WHO definition of health is utopian, inflexible, and unrealistic, and that including the word “complete” in the definition makes it highly unlikely that anyone would be healthy for a reasonable period of time.

- ‘a state of complete physical mental and social well-being’ corresponds more to happiness than to health.

- Words ‘health’ and ‘happiness’ designate distinct life experiences, whose relationship is neither fixed nor constant.

- Failure to distinguish happiness from health implies that any disturbance in happiness, however minimal, may come to be perceived as a health problem.

http://www.who.int/bulletin/bulletin_board/83/ustun11051/en/
Sociology of health

Sociological lens –

- social patterns – age, sex, race, class, culture, geography, community profiles

- processes – interest groups, beliefs and history

- social relationships – power
Epidemiologia:

Lancet 2005: diverse realtà determinano atteggiamenti culturali differenti fra i Paesi
Global prevalence of dementia: a Delphi consensus study

Cleusa P Ferri, Martin Prince, Carol Brayne, Henry Brodaty, Laura Fratiglioni, Mary Ganguli, Kathleen Hall, Kazuo Hasegawa, Hugh Hendrie, Yueqin Huang, Anthony Jorm, Colin Mathers, Paulo R Menezes, Elizabeth Rimmer, Marcia Szczazafca, for Alzheimer’s Disease International

Summary

Background 100 years after the first description, Alzheimer’s disease is one of the most disabling and burdensome health conditions worldwide. We used the Delphi consensus method to determine dementia prevalence for each world region.

Methods 12 international experts were provided with a systematic review of published studies on dementia and were asked to provide prevalence estimates for every WHO world region, for men and women combined, in 5-year age bands from 60 to 84 years, and for those aged 85 years and older. UN population estimates and projections were used to estimate numbers of people with dementia in 2001, 2020, and 2040. We estimated incidence rates from prevalence, remission, and mortality.

Findings Evidence from well-planned, representative epidemiological surveys is scarce in many regions. We estimate that 24·3 million people have dementia today, with 4·6 million new cases of dementia every year (one new case every 7 seconds). The number of people affected will double every 20 years to 81·1 million by 2040. Most people with dementia live in developing countries (60% in 2001, rising to 71% by 2040). Rates of increase are not uniform; numbers in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in India, China, and their south Asian and western Pacific neighbours.

Interpretation We believe that the detailed estimates in this paper constitute the best currently available basis for policymaking, planning, and allocation of health and welfare resources.
Figure 1: Prevalence studies worldwide

- Red: Regions well covered with several studies of good methodological quality
- Light red: Some studies but insufficient to derive regional estimates with confidence
- Light orange: Single epidemiological studies
- Light blue: No epidemiological studies

Figure 2: Number of people with dementia in developed and developing countries

- Red: Developing countries
- Blue: Developed countries

Year
- 2001
- 2020
- 2040

Number of people with dementia (in millions)
<table>
<thead>
<tr>
<th>Region</th>
<th>Population (millions), aged &gt;60 years (2001)</th>
<th>Consensus dementia prevalence (%) at age &gt;60 years</th>
<th>Estimated annual incidence per 1000</th>
<th>New dementia cases (millions) per year, 2001</th>
<th>Number of people (millions) with dementia, aged &gt;60 years</th>
<th>Proportionate increase (%) in number of people with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Europe (EURO A)</td>
<td>89.6</td>
<td>5.4</td>
<td>8.8</td>
<td>0.79</td>
<td>49, 69, 99</td>
<td>43, 102</td>
</tr>
<tr>
<td>Eastern Europe low adult mortality (EURO B)</td>
<td>27.4</td>
<td>3.8</td>
<td>7.7</td>
<td>0.21</td>
<td>10, 16, 28</td>
<td>51, 169</td>
</tr>
<tr>
<td>Eastern Europe high adult mortality (EURO C)</td>
<td>44.6</td>
<td>3.9</td>
<td>8.1</td>
<td>0.36</td>
<td>18, 23, 32</td>
<td>31, 84</td>
</tr>
<tr>
<td>North America (AMRO A)</td>
<td>53.1</td>
<td>6.4</td>
<td>10.5</td>
<td>0.56</td>
<td>34, 51, 92</td>
<td>49, 172</td>
</tr>
<tr>
<td>Latin America (AMRO B/D)</td>
<td>40.1</td>
<td>4.6</td>
<td>9.2</td>
<td>0.37</td>
<td>18, 41, 91</td>
<td>120, 393</td>
</tr>
<tr>
<td>North Africa and Middle Eastern Crescent (EMRO B/D)</td>
<td>27.5</td>
<td>3.6</td>
<td>7.6</td>
<td>0.21</td>
<td>10, 19, 47</td>
<td>95, 385</td>
</tr>
<tr>
<td>Developed western Pacific (WPRO A)</td>
<td>34.5</td>
<td>4.3</td>
<td>7.0</td>
<td>0.24</td>
<td>15, 29, 43</td>
<td>99, 189</td>
</tr>
<tr>
<td>China and developing western Pacific (WPRO B)</td>
<td>151.1</td>
<td>4.0</td>
<td>8.0</td>
<td>1.21</td>
<td>60, 117, 261</td>
<td>96, 336</td>
</tr>
<tr>
<td>Indonesia, Thailand, and Sri Lanka (SEARO B)</td>
<td>23.7</td>
<td>2.7</td>
<td>5.9</td>
<td>0.14</td>
<td>6, 13, 27</td>
<td>100, 325</td>
</tr>
<tr>
<td>India and south Asia (SEARO D)</td>
<td>93.1</td>
<td>1.9</td>
<td>4.3</td>
<td>0.40</td>
<td>18, 36, 75</td>
<td>98, 314</td>
</tr>
<tr>
<td>Africa (AFRO D/E)</td>
<td>31.5</td>
<td>1.6</td>
<td>3.5</td>
<td>0.11</td>
<td>5, 9, 16</td>
<td>82, 235</td>
</tr>
<tr>
<td>TOTAL</td>
<td>616.2</td>
<td>3.9</td>
<td>7.5</td>
<td>4.6</td>
<td>243, 423, 81.1</td>
<td>74, 234</td>
</tr>
</tbody>
</table>

Table 2: Number of people with dementia in 2001, projections for 2020 and 2040, and percentage increases, by WHO region
The suggestion of a lower prevalence of dementia in developing regions than in developed regions is reinforced by the consensus judgment of our panel.

More research is needed to establish the generalisability of existing data and to explore differences between urban and rural areas.
Methodological factors might also be relevant; mild dementia could have been underdetected in the least developed regions because of difficulties in establishing social impairment.

The lower prevalence in Africa and south Asia, if genuine, might be partly explained by lower survival with dementia rather than lower incidence.

However, incidence estimates in Nigeria and India are also much lower than in developed countries. Differences in level of exposure to environmental risk factors might have contributed, with low levels of cardiovascular risk and hypolipidaemia in some developing countries both having been advanced as explanations.
High levels of mortality in early life could also be implicated; constitutional and genetic factors that confer survival advantage in early years might go on to protect against neurodegeneration or delay its clinical manifestations.
Achieving progress with dementia care in developing countries has much to do with creating the climate for change. Poor awareness is a key public-health problem with important consequences: affected people do not seek help, and if they do health-care services tend not to meet their needs; dementia is stigmatised, and sufferers can be excluded from residential care and denied admission to hospital;

no constituency is available to lobby government; and families tend to have less support or understanding from others and experience substantial strain.
Epidemiologia:

- Diversi atteggiamenti culturali portano a diversi risultati
19th Alzheimer Europe Conference
Brussels, 28-30th May 2009

Epidemiology and Disease Burden of Dementia in Hungary

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Content

- Epidemiology of dementia in Hungary
- International context
- Cross-sectional study in 2008
  Aim: to investigate epidemiology, health status, health care utilisation and costs of dementia in Hungary
- Results
Dementia in Hungary

Based on the estimation of the demented in Hungary there is a noticeable difference between the domestic and the internationally published data.

- According to international data of Hungary the number of demented is about 100 thousand – UNDERESTIMATION? (Wimo, Winblad, Jönsson 2007)

- According to previous Hungarian studies, the number of the demented vary between 530 and 917 thousand – OVERESTIMATION? (Ersek et al 2009)
Alzheimer’s patients Caregivers Survey in Greece

Dr Paraskevi Sakka

Neuropsychiatrist

Chairwoman, Athens Association of Alzheimer’s Disease and Related Disorders
Head, Neurodegenerative Brain Diseases Department, HYGEIA Hospital, Athens, Greece
Caregivers Survey

In July 2008, Alzheimer’s Associations in Athens and Thessaloniki conducted a survey among caregivers of Alzheimer’s patients which was supported by a pharmaceutical company.

**Aims:** To record caregivers stance towards caring and their opinion on current status of Dementia treatment in Greece.
Results
Caregivers sources of information on AD

- Patient’s Doctor: 60
- Other doctor/ specialist/ psychologist: 44
- Magazines/ Newspapers articles: 52
- TV/ Radio programs: 51
- Books: 35
- Friends & Relatives: 34
- Internet: 19
- Alzheimer Association: 6
- Seminars/ Conferences: 2
Results

Caregivers experience of living with patients

Total mean scores for each statement (N=200)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Likert rating scale 1 to 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't want the patient to be institutionalized</td>
<td>4.55</td>
</tr>
<tr>
<td>I am anxious about the disease course</td>
<td>4.49</td>
</tr>
<tr>
<td>It is my duty to make the patient feel as comfortable as can be</td>
<td>4.48</td>
</tr>
<tr>
<td>I miss the person the patient was before AD</td>
<td>4.03</td>
</tr>
<tr>
<td>Nursing the patient demands a lot of time</td>
<td>3.79</td>
</tr>
<tr>
<td>I feel bad that I can't do more for the patient</td>
<td>3.64</td>
</tr>
<tr>
<td>Nursing the patient defines my daily schedule</td>
<td>3.61</td>
</tr>
</tbody>
</table>

% of caregivers who scored 4 or 5 on the Likert scale

Likert rating scale 1 to 5
5= Totally applicable
1= Not at all applicable
Caregivers Survey - Conclusions

- Caregivers of AD patients are mainly women, 45+ years old, of middle to upper education.
- Most of them are first degree relatives, living with the patient and not paid for caregiving.
- The key source of information regarding AD are health professionals.
- On average, patients receive 4 prescribed medicines in total. Most have tried 1-2 AD medicines since diagnosis.
- Caregivers seem to be rather skeptical about AD treatment effectiveness.
La demenza:

Visione differente (paziente/famiglia/servizi) quando le culture coesistono/convivono
Epidemiologia delle minoranze etniche negli USA

- Afro-Americani: 12.3%
- Asiatici: 3.6%
- Americani Indiani/Nativi Alaska: 0.9%
- Ispanici/Latini: 12.5%
- Altri: 5.5%
- Totale: 34.8%

L’impatto della demenza sulle minoranze, e la risposta dei professionisti sanitari ai loro bisogni, è significativa in ragione della importanza della popolazione di minoranza.
In che modo la demenza colpisce le minoranze etniche?

- L’ipotesi del doppio rischio → L’handicap sociale dovuto a: Age + Race

- Il “Triple jeopardy” = Age + Race + Dementia
Identifying the Poorest Older Americans

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⁴La Follette School of Public Affairs, Institute for Research on Poverty, University of Wisconsin, Madison.
⁵U.S. Population Reference Bureau, Washington, DC.

Objectives. Public policies target a subset of the population defined as poor or needy, but rarely are people poor or needy in the same way. This is particularly true among older adults. This study investigates poverty among older adults in order to identify who among them is financially worst off.

Methods. We use 20 years of data from the Consumer Expenditure Survey to examine the income and consumption of older Americans.

Results. The poverty rate is cut in fourth if both income and consumption are used to define poverty. Those most likely to be poor defined by only income but not poor defined by income and consumption together are married, White, and homeowners and have a high school diploma or higher. The income poor alone display sufficient assets to raise consumption above poverty thresholds, whereas the consumption poor are shown to have income just above the poverty threshold and few assets.

Discussion. The poorest among the older population are those who are income and consumption poor. Understanding the nature of this double poverty population is important in measuring the success of future public policies to reduce poverty among this group.
Table 4. Income and Consumption Poverty Status by Demographic Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Ages 55–64 Years</th>
<th></th>
<th>Ages 65–74 Years</th>
<th></th>
<th>Age 75+ Years</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Y Poor</td>
<td>C Poor</td>
<td>Y and C Poor</td>
<td>Y and C Above 100% of Threshold</td>
<td>Y Poor</td>
<td>C Poor</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (%)</td>
<td>56.7</td>
<td>54.3</td>
<td>58.7</td>
<td>51.1</td>
<td>57.4</td>
<td>59.3</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>64.4</td>
<td>53.2</td>
<td>51.0</td>
<td>85.1</td>
<td>52.9</td>
<td>38.7</td>
</tr>
<tr>
<td>Widowed</td>
<td>16.0</td>
<td>19.2</td>
<td>22.3</td>
<td>6.7</td>
<td>32.7</td>
<td>37.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>15.0</td>
<td>20.8</td>
<td>22.7</td>
<td>5.6</td>
<td>10.2</td>
<td>14.8</td>
</tr>
<tr>
<td>Single</td>
<td>4.5</td>
<td>6.8</td>
<td>4.1</td>
<td>2.5</td>
<td>4.2</td>
<td>8.8</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>High school dropout</td>
<td>60.3</td>
<td>81.2</td>
<td>83.9</td>
<td>26.0</td>
<td>65.2</td>
<td>81.5</td>
</tr>
<tr>
<td>High school graduate</td>
<td>26.1</td>
<td>14.6</td>
<td>11.4</td>
<td>40.1</td>
<td>22.6</td>
<td>14.4</td>
</tr>
<tr>
<td>Some college</td>
<td>7.6</td>
<td>3.0</td>
<td>3.2</td>
<td>15.5</td>
<td>6.5</td>
<td>2.5</td>
</tr>
<tr>
<td>College graduate</td>
<td>6.0</td>
<td>1.2</td>
<td>1.5</td>
<td>18.4</td>
<td>5.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>69.8</td>
<td>50.0</td>
<td>49.4</td>
<td>90.0</td>
<td>67.9</td>
<td>52.6</td>
</tr>
<tr>
<td>Black</td>
<td>28.8</td>
<td>47.5</td>
<td>48.6</td>
<td>6.9</td>
<td>28.9</td>
<td>40.3</td>
</tr>
<tr>
<td>Other race</td>
<td>1.4</td>
<td>2.5</td>
<td>2.0</td>
<td>3.1</td>
<td>3.2</td>
<td>7.1</td>
</tr>
<tr>
<td>Housing status</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Homeowner</td>
<td>83.9</td>
<td>62.5</td>
<td>65.6</td>
<td>94.0</td>
<td>78.6</td>
<td>48.9</td>
</tr>
</tbody>
</table>


Notes: Sample size equals 21,667. We weight all data to be representative of the U.S. older adult population. Our unit of observation is the individual. The official U.S. Census poverty threshold for a 2-adult, 2-child household from 2003 is used and then adjusted using the square root of family size as an equivalence scale.

Y = Income; C = Consumption.
Childhood Living Conditions, Socioeconomic Position in Adulthood, and Cognition in Later Life: Exploring the Associations

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²Department of Social Work, Stockholm University, Sweden.
³Center for Health Equity Studies, Stockholm University & Karolinska Institutet, Sweden.

Objectives. This study examined the association between childhood living conditions, socioeconomic position in adulthood, and cognition in later life. Two questions were addressed: Is there an association between childhood living conditions and late-life cognition, and if so, is the association modified or mediated by adult socioeconomic position?

Methods. Nationally representative data of the Swedish population aged 77 years and older were obtained from the 1992 and 2002 Swedish Panel Study of Living Conditions of the Oldest Old (SWEOLD). Cognition was assessed with an abbreviated version of the Mini-Mental State Examination scale. Childhood living conditions were assessed by self-reports of childhood living conditions.

Results. The results showed independent associations between conflicts in the household during childhood, father’s social class, education, own social class in adulthood, and cognition in later life. Exposure to conflicts during childhood, having a father classified as a manual worker, low education, and/or being classified as a manual worker in adulthood was associated with lower levels of cognition in old age. There seemed to be no modifying effect of adult socioeconomic position on the association between childhood conditions and cognition in later life.

Discussion. This suggests the importance of childhood living conditions in maintaining cognitive function even in late life.

In che modo la demenza colpisce le minoranze etniche?

- Il Salsa study:

- Chi sono i meno diagnosticati?
  - Poveri
  - Bassa scolarità
  - Basso livello culturale e contatti sociali
  - Cioè: le minoranze etniche
Why study dementia in diverse populations?
Results from the Sacramento Area Latino Study on Aging

MN Haan, Professor, Epidemiology
University of Michigan

Funding: NIA AG 12975, DK 60753, AG10129, AG10220; USDA 00-35200-9073
Robert Wood Johnson Scholars (045823), Claude Pepper Center (F014308)
What is meant by diversity?
Elements of understanding ethnic and ancestral differences

International or Regional differences
  - Culture, economics and ancestry in different locations

Cross-cultural differences
  - Culture, economics and ancestry of different groups living within the same/proximal geography

Changing places or changing culture
  - Immigration (change in geography)
  - Cultural change in place (cultural orientation)
Measuring ancestry and ethnicity

- History
- Economics
- Culture
- Migration
- Geography
- Ancestry
- Genes
Cognitive anthropology: defining culture in relation to cognition

- Tomasello (1999)
  - Culture is a fundamental feature of human existence based on an innate predisposition in humans
  - Cultural evolution (change) is a more potent force than genetic evolution in changing human lives

- Nisbett (2002)
  - Cultural practices engender and sustain specific cognitive processes which in turn perpetuate specific cultural practices
Is there assessment of culture as an explanatory factor in representative cohort studies of dementia risk?

- Only two representative population-based cohort studies of dementia risk have included explicit measures of culture
  - Sacramento Area Latino Study on Aging
  - KAME (Japanese in Seattle)

- Measures: migration, language, time in country, diet, social patterns of friendship, generations since immigration, bicultural flexibility, socioeconomic consequences of migration...

- Issues: appropriateness of cognitive assessment is not only an issue of language, best techniques for translation?
Existing evidence for differences in dementia risk by ancestry, culture or ethnicity: North American cohort studies

- **Mexicans:**
  - Sacramento Area Latino Study on Aging
  - CUPA project (Mexico City)
- **African Americans**
  - Indianapolis
  - Chicago
- **Various ancestries:**
  - European Americans, Caribbean Hispanics and African Americans in North Manhattan
- **Asian**
  - Hawaiian Japanese:
  - KAME study
- **Studies of European ancestry populations**
  - Cardiovascular Health Study
  - Pennsylvania
  - Chicago
  - Seattle
  - Utah
Differences in dementia incidence rates within North America by ancestry or ethnicity

<table>
<thead>
<tr>
<th>White/Study location</th>
<th>Incidence rates per 1,000 py</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pennsylvania</td>
<td>19.3</td>
</tr>
<tr>
<td>Utah</td>
<td>25.5</td>
</tr>
<tr>
<td>Seattle</td>
<td>20.3</td>
</tr>
<tr>
<td>NYC</td>
<td>30.8</td>
</tr>
<tr>
<td>Chicago</td>
<td>24.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ancestry</th>
<th>Incidence rate per 1,000 py</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Am.</td>
<td>29.5 - 32.2</td>
</tr>
<tr>
<td>Mexican Am.</td>
<td>12.0</td>
</tr>
<tr>
<td>Mexican*</td>
<td>20.9</td>
</tr>
<tr>
<td>Caribbean</td>
<td>19.0</td>
</tr>
<tr>
<td>Asian Am.</td>
<td>18.4</td>
</tr>
</tbody>
</table>

* Severe cognitive impairment
North American variability in dementia risk

- Within European ancestry populations there is important variability in dementia risk related to place and methodological differences.
- The more limited studies of other ancestry/ethnic groups suggest variability within and between ethnic groups.
- What’s missing?
  - Population based research on Native Americans, South/east Asians, other groups
  - Effects of immigration on risk...
Ancestry and dementia risk
Some issues in measuring ancestry

- Population stratification within an ‘ancestral/ethnic group’
- Admixture as a measure of ethnicity?
  - Health effects may reflect consequences of societal reaction to phenotype rather than as marker of underlying genetic factors
  - Genetic predisposition to disease ≠ admixture
- Interactions between genetic factors and cultural factors
- Changes in culture related to migration & adaptation that modify disease risk within a group thought to be homogeneous genetically
Example of population stratification: Admixture among US ‘Hispanics’ by Region (based on 6 loci) (Bertoni 2003)
Differences in ApoE distribution by Mexican or European ancestry and country of residence

**Anye4:**
- Mexican: 14.2%
- Mexican American: 13.4%

**Anye4:**
- White American: 25.9%
- White European: 28.4%

E4: explains <10% of dementia cases in SALSA
Does ApoE4 influence dementia risk equally in all population groups?

What may modify effects of APOE4 on dementia risk across diverse populations?

- Socioeconomic and cultural factors
- Early life factors such as immigration, poverty, nutrition
- Vascular processes (atherosclerosis, lipids, metabolic, inflammatory and immune response)
- Other genetics factors such as PPARα
Sacramento Area Latino Study on Aging (SALSA)

Cohort study:
Representative population based sample from Sacramento, California area
Who:
1,789 Latinos aged 60+, 85% Mexican American, 15% Central American +
60% < 9th grade education
50% were born in Mexico
Birth cohort: 1900-1935

Baseline: 1998-99
Followup: 1999-2008
Primary Goals:
Study of cognitive decline and dementia incidence
Metabolic and vascular factors
Socioeconomic status, Nativity, immigration, cultural factors
Genetic factors (ApoE, PPARs, HT genes, Psych etc)
Infections, stress markers, inflammation
Imaging (MR, PET) substudies
Socioeconomic status and cultural factors in Sacramento Area Latino Study on Aging participants by country of birth

<table>
<thead>
<tr>
<th>Nativity</th>
<th>Mexico</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Attended School (%)</td>
<td>20%</td>
<td>6% **</td>
</tr>
<tr>
<td>Mean years of education</td>
<td>5.0</td>
<td>10.0 ***</td>
</tr>
<tr>
<td>Income (%&lt;$1k per month)</td>
<td>60%</td>
<td>30% **</td>
</tr>
<tr>
<td>Own home (% yes)</td>
<td>56%</td>
<td>78% **</td>
</tr>
<tr>
<td>Spanish speaking only (% yes)</td>
<td>88.6%</td>
<td>26% ***</td>
</tr>
<tr>
<td>Cultural orientation score (mean)</td>
<td>13.6</td>
<td>31.0 ***</td>
</tr>
</tbody>
</table>
SALSA 21-point cultural orientation scale

Do you speak Spanish?
Do you speak English?
Do you prefer to speak Spanish/English?
Do you associate with Anglos?
Do you associate with other Mexicans and/or Latinos?
Language preferences for media
Reading and writing preferences by language
Do think in English/Spanish?
Do you travel to Mexico or to another Latin American country?
Childhood friends Latino/Anglo?
Present friends Latino/Anglo?
Does your family cook Mexican/Latino foods?
Do you identify yourself as Latino/Anglo?
How often do you talk on the phone to friends or relatives in Mexico or other Latin American countries?

Scale properties by nativity

<table>
<thead>
<tr>
<th></th>
<th>Mexico</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>13.6</td>
<td>30.9</td>
</tr>
<tr>
<td>SD</td>
<td>9.4</td>
<td>9.9</td>
</tr>
<tr>
<td>Median</td>
<td>10.0</td>
<td>32.0</td>
</tr>
<tr>
<td>Range</td>
<td>0-54</td>
<td>3-56</td>
</tr>
<tr>
<td>Alpha</td>
<td>0.88</td>
<td>0.87</td>
</tr>
</tbody>
</table>

adapted from Cuellar
Cultural orientation is associated with dementia/CIND rates overall which is modified by E4 status in the SALSA (proportional hazards models)

- **Anglo**: P=0.04, RR=1.61
- **Middle (ref)**: RR=1
- **Mexican**: P=0.002, RR=2.03

- **Anglo**: RR of E4 vs. no E4 = 2.35
- **Middle**: RR=1.14
- **Mexican**: RR=2.32

P=0.01
Later age at migration from Mexico is associated with lower risk of dementia/CIND in SALSA participants who were born in Mexico. Low education is associated with higher risk.

Hazard Ratio

- Education <6 years: 1.93
- Born in Mexico: 1.17

P-value: 0.0007

p-value: <0.05

RR vs. Earliest age

Age at Migration

- Age >= 50
- Age 20<50
- Age <20

- REF
Fattori culturali proteggono dalla demenza nei migranti (dieta, stile di vita), ma solo se restano a lungo nella regione di origine.

La migrazione comporta l’assunzione di fattori di rischio che intervengono modificando sia lo status genetico sia lo status culturale (integrazione non vantaggiosa).

In questo studio le diagnosi sono precoci perchè si tratta di una popolazione selezionata.
E in Europa?
EuroCoDe
WP4: survey of social support in Europe

Dianne Gove, Alzheimer Europe
Brussels, 30 May 2009
1. Objectives of WP4

- To carry out a survey of existing social support in the EU members states and also in Iceland, Norway, Switzerland and Turkey

- To write a comparative report of the kinds of services available in each country

- To draft recommendations for policy makers on how to improve the provision of social support to people with dementia and carers in Europe
Information obtained

1. Availability of 41 different services/forms of support in each country

2. Degree of state/self funding for each type of service/support

3. Factors limiting access

4. Whether NGOs, volunteers or church groups also provide such services
Availability of suitable services

Some services are:

- available but inappropriate
- not widely available
- simply lacking
Barriers to support

- Barriers which prevent people with dementia from accessing existing support.
  - Legal obligation to care for close relatives
  - Priority given to people on a very low income
  - Access limited to severe cases
  - Access dependent on specific diagnoses
  - Geographical location
  - Long waiting lists
  - Linguistic and cultural differences
Examples of good practice

- Respecting dignity and autonomy
- Social inclusion and psychosocial support
- Supporting independent living
- Support for minority groups and for people living in rural areas
- Respite for carers
Top 10 Things to NOT Say to Someone with a Chronic Illness

10. You can't be in that much pain.
9. Stop being lazy and get a job.
8. You just want attention.
7. Your illness is caused by stress.
6. No pain... no gain!
5. It's all in your head.
4. If you just got out of the house...
3. You're so lucky to get to stay in bed all day!
2. Just pray harder.
1. But you LOOK so GOOD!

Care Enough to be Informed

www.mychronicillness.com
Pregiugizi e preconcetti

- Da ambo le parti......
Fattori a supporto dell’ipotesi

- Una sorta di Institutional Racism-discrimination che esiste nelle Strutture Sociali e nella pratica istituzionale, inserendo il razzismo in un contesto storico, culturale, socio-economico, politico

- Color-blindness- (I “ciechi del colore”) trattano le minoranze nello stesso modo della maggioranza bianca (o nativa), negando differenze culturali e le varie esperienze delle minoranze
  - Una sorta di non intentional racism, ma che ignora le diseguaglianze strutturali insite nel sistema
Fattori a supporto dell’ipotesi

- Una mancanza di conoscenza (Cultural Awareness): è difficile giungere alla diagnosi di demenza quando la persona malata possiede differente cultura e linguaggio rispetto al medico che deve prendersene cura.

- È importante che medici e specialisti siano a conoscenza (aware of) della propria ED ALTRUI cultura, e del clima sociale imperante.

- I valori culturali dovrebbero essere rispettati, ma non dovrebbero essere usati per giustificare una assenza/carenza di servizi.
Fattori a supporto dell’ipotesi

- La maggior parte dei servizi disponibili per le demenze sono focalizzati alla popolazione nativa (USA: white, English-speaking clients) determinando una minore accessibilità dei servizi per le minoranze etniche.

- Perché le organizzazioni delle minoranze etniche specifiche non possono essere consapevoli delle implicazioni della demenza, le famiglie appartenenti a minoranze etniche possono essere isolate a causa di una mancanza di sostegno, piuttosto che di una scelta consapevole.
Fattori a supporto dell’ipotesi

- Linguicism (linguismo)- una forma di pregiudizio che comporta un giudizio sul tipo di ricchezza, istruzione, stato sociale, ed altri tratti in base al loro uso del linguaggio.

- Miscommunication-se vi è una barriera linguistica che esiste tra persone di madrelingua e non di madrelingua inglese (operatori sanitari e pazienti, per esempio), possono verificarsi errori di comunicazione, che ostacolano la cura efficace; sono il risultato di una limitata padronanza della lingua inglese (limited English proficiency LEP).
Fattori a supporto dell’ipotesi

- Stereotipi
- Il mito che tutte le famiglie minoritarie tendono ad occuparsi della loro famiglia estesa, compresa l'assistenza sanitaria e la demenza
- I gruppi minoritari tendono ad essere visti come un gruppo omogeneo con caratteristiche facilmente identificabili
- Anche se le famiglie minoritarie da diversi gruppi etnici possono tradizionalmente avere una famiglia estesa e convivente, ciò non dovrebbe essere visto come la norma
Una visione tradizionale delle Minoranze Etniche (Immigrants in the U.S.)

- Nonostante questo modo di vedere sia ancora in divenire e/o talora già sistematizzato, non deve essere inteso come una norma culturale nè causare stereotipi culturali.
Traditional Latino Views of Family and Alzheimer’s

- L'unità della famiglia è estremamente importante nella Comunità Hispanic/Latina, essendo il centro delle attività e del supporto sociale.

- La cura per gli anziani può essere fornita dai membri dalla famiglia allargata, che può risiedere nella stessa casa.

- Figli e nipoti possono portare a conoscenza i membri più anziani della famiglia sulla esistenza di servizi diagnostici e verso l’accesso all’assistenza sanitaria.

- I medici sono rispettati e considerati come figure di autorità.

- I Latinos possono ricevere informazioni sulla salute e l’assistenza sanitaria dai media in lingua spagnola, compresi i giornali, radio e televisione.

- Le barriere linguistiche possono impedire l'accesso alle informazioni per l'assistenza sanitaria e altri servizi.

- In particolare nella fase iniziale, la malattia di Alzheimer è considerata normale invecchiamento.

- Le famiglie possono rifiutarsi di cercare i servizi perché non vogliano portare la vergogna sulla propria famiglia.
La famiglia è il fondamento della vita quotidiana

I familiari hanno un forte senso del dovere nel prendersi cura fra loro.

Gli anziani sono molto rispettati e obbediti.

Esistono legami familiari transgenerazionali: spesso le famiglie vivono insieme.

Le famiglie possono opporsi a cure a lungo termine, ritenendo che sia vergognoso ricoverare i propri familiari nelle case di cura.

Forti meccanismi culturali interni contribuiscono a plasmare il loro sistema di sostegno, che include i valori che riguardano la cura e il sostegno dei familiari anziani.

Le barriere linguistiche possono impedire l'accesso alle informazioni per l'assistenza sanitaria e altri servizi.

Il Morbo di Alzheimer e le altre forme di demenza possono essere percepiti come forme di malattia mentale, con conseguente vergogna, e questo senso può estendersi oltre la diagnosi individuale per tutta la famiglia.

I sintomi comportamentali della demenza possono essere visti come una conseguenza naturale dell'invecchiamento.
Does Household Composition Explain Welfare Regime Poverty Risks for Older Adults and Other Household Members?

Tsui-o Tai and Judith Treas

The Department of Sociology, University of California, Irvine (UCI), Irvine, California.

Objectives. This cross-national study examines the poverty of older adults and their household members and relates the risk of poverty to macrolevel state approaches to welfare as well as to microlevel composition of households.

Methods. Data on individuals in households with older adults for 22 countries come from the Luxembourg Income Survey. Robust cluster analysis relates the risk of poverty to the type of state welfare regime; the characteristics of the household head (age, gender, marital status, and education); as well as the household’s numbers of earners, older adults, and children.

Results. Persons in households with older adults are significantly less likely to be poor in countries with social democratic and conservative welfare regimes than in Taiwan, an exemplar of limited social welfare programs. Controlling for country differences in household composition increases the differences in poverty risks. Living with fewer children, more older adults, and more earners lowers the risk of poverty, as does having a married and better educated household head.

Discussion. Countries with more generous social welfare provisions have lower risks of poverty despite having household characteristics that are comparatively unfavorable. As Taiwan demonstrates, household composition, particularly a reliance on multigenerational households, compensates for limited state welfare programs.
Social Network Types and Subjective Well-being in Chinese Older Adults

Sheung-Tak Cheng, Coty K. L. Lee, Alfred C. M. Chan, Edward M. F. Leung, and Jik-Joen Lee

1Department of Applied Social Studies, City University of Hong Kong, China.
2Asia-Pacific Institute of Ageing Studies, Lingnan University, Hong Kong, China.
3United Christian Hospital, Hong Kong, China.
4Department of Social Work, Chinese University of Hong Kong, China.

The study examined social network types in a sample of 1,005 older Chinese adults in Hong Kong and the networks’ relations to subjective well-being. Given the nature of kinship in Chinese society, we broke down social support provision by closeness of blood ties (immediate kin, distant kin, and non-kin). Using K-means cluster analysis, we identified 5 network types: diverse, friend focused, restricted, family focused, and distant family. The latter was characterized by few immediate kin but mostly distant kin. Diverse and family-focused networks were most beneficial to well-being, whereas restricted networks were least. Distant family networks were associated with only marginally lower well-being than family-focused networks and were comparable to friend-focused networks. Results suggested the importance of the extended family in support provision for Chinese older adults, especially in the absence of immediate kin and friends. Implications of the present findings for other cultural groups are discussed.

Key Words: Social network—Kinship—Subjective well-being—Elderly—Hong Kong Chinese.
Fattori a supporto dell’ipotesi

- Quali differenze con l’Italia?
  - Minore % minoranze
  - Integrazione linguistica
  - Minori diseguglianze sociali (poorer are served)
  - Nessuna discriminazione (legislativa) sul piano sanitario
  - Geriatricamente: pochi casi ancora (vecchi familiari ricongiunti, pochi immigrati invecchiati)
Il numero dei migranti anziani in Europa è in rapido aumento. Stanno raggiungendo l'età della pensione i lavoratori emigrati durante il grande flusso migratorio degli anni '50-'60. Per la prima volta nella loro storia molti Paesi europei verranno confrontati con una consistente presenza di anziani non originari del Paese. Attualmente è la Francia, seguita dall'Inghilterra e dalla Germania ad avere il maggior numero di migranti anziani. Nei prossimi anni in Germania i migranti ultra sessantacinquenni passeranno da quasi trecentomila a più di mezzo milione. Questa rapida crescita cambierà consistentemente la struttura sociale della popolazione anziana di molti Paesi europei.
Come cambia la etnia in futuro?

Dalle ricerche europee emerge poi che i migranti utilizzano poco le strutture socio-sanitarie per anziani del Paese ospite.

Spesso perché non ne conoscono l'esistenza, altre volte a causa delle grandi differenze culturali che esistono all'interno di queste strutture. Il cibo, il modo di organizzare la vita e il tipo di rapporti sociali sono talmente estranei e diversi da quelli conosciuti dai migranti che per loro è difficile potersi adattare in questo ambiente.

L'isolamento dalla società del Paese ospite caratterizza gli anziani migrati in Europa. I contatti sociali sono limitati quasi esclusivamente alla propria famiglia e a una ristretta cerchia di connazionali.

Le condizioni economiche del migrante anziano sono spesso molto disagiate, non solo appartiene alle categorie sociali più povere, ma spesso percepisce una ridotta pensione di vecchiaia.

Come cambiare le cose?

- Aumentare la soglia di sensibilità per:
  - Diagnosi precoce
  - Terapia continuativa
  - Cura socio-assistenziale
Recommendations for Improving the Healthcare of Elderly Minorities

- Diffusione delle informazioni (tv, radio, carta, internet)

- Disponibilità di traduttori esperti, ed interpreti per malati e loro familiari, per la comunicazione efficace con il personale sanitario

- Maggiore disponibilità di informazioni sulla demenza tradotte nelle diverse lingue, disponibili e diffuse sia nelle aree sanitarie che alla popolazione
May 21

World Day for Cultural Diversity for Dialogue and Development

United Nations Educational, Scientific and Cultural Organisation promotes this day to create greater awareness of the crucial relationship between culture and development and the important role of information and communication technologies in this relationship.

South Australia

**NORTHERN LIGHTS MULTICULTURAL FESTIVAL**

The festival, organised by Ambulatory and Primary Health Care and Salisbury Community Health Services, created opportunities for many local community members to access information and make direct enquiries with the various service providers. It was a great opportunity to meet and talk to many people in the community in an informal environment. The South Australian Premier, Mike Rann, also made a guest appearance and had time to chat to providers. African, Asian, Bosnian and Indigenous groups provided cultural displays and music to entertain those who attended. Another highlight was the food with a selection available from a number of countries, alongside the traditional sausage sizzle.

**HELPING FAMILIES IN NEED**

The work of a Multicultural Service Officer (MSO) often extends outside the boundaries of normal Centrelink business, and well into the community that Centrelink serves. Amalia Vosnakis, MSO, works very closely with customers from African communities, most of who have only lived in Australia for a short time and have few material possessions.
Recommendations for Improving the Healthcare of Elderly Minorities

- 2- Istruzione del personale
- “Cultural training” per i medici ed il personale: so support minorities with dementia and their families in culturally sensitive ways

- Intervenire per determinare una eguaglianza razziale, attraverso training e awareness:
  - management,
  - recruitment procedures
  - and qualification requirements that affect the ways in which minorities are served
Multicultural Training Products

Multicultural Customer Service Training—CD ROM

This CD ROM features audio, video and interactive exercises covering four modules:

- Multicultural Service Issues
- Interpreters and Translations
- Intercultural Communication
- Ethnic Naming Practices.

It may be helpful for professionals and customer service staff who have a culturally diverse clientele, including the community and government sectors.

There are two versions available. One version is designed for individual use and can be loaded onto a PC. The second version is designed to be run from a server and is licenced for multiple users.

Cost: $50.00 for individual loading
Cost: $500 for the server version

A 50 per cent discount applies if your organisation has previously purchased the Guide to Ethnic Naming Practices.


Ever wanted to know how different ethnic naming practices work? Does the family name come first or last? Why are parents’ last names different to their children’s? This product can help.

The guide features naming conventions of 66 languages.

Cost: $24.95

Working with Interpreters —DVD

This video/DVD covers common problems faced when working with interpreters, and step-by-step strategies for running streamlined 3-way interviews.

It includes nine scenarios in a variety of settings including Centrelink, banks, councils and doctors’ surgeries. Debriefs are also included.

The DVD features two extra segments with tips on how to work with telephone interpreters and interpreters for the deaf and hearing impaired.

You can use the self-study guide to work through the video/DVD independently, or run group presentations using the trainers’ guide.
Training outcomes for participants

- Increased knowledge, skills, awareness about culture, cultural diversity and culturally competent service delivery
- Broadening the definition of culture to include a multi-dimensional layered understanding of various social identities including race, ethnicity, language, gender, age, ability, sexuality, religion, spirituality, education, class etc
- Greater understanding of issues affecting CALD and Indigenous communities and how to respond more effectively for improved service delivery
LEBANESE DRUZE FORUM IN SOUTH AUSTRALIA
Lebanese people have been in South Australia for many years. Every year the older members of the Lebanese Druze community get together in Adelaide to celebrate their contribution to Australia and also to their own community. Tanya Kaplan, Centrelink Multicultural Service Officer, (MSO) was invited to attend a forum at Ingle Farm in Adelaide’s north-eastern suburbs last year. Tanya provided information about Age Pension, Carer Payment, Carer Allowance, entitlements, and other pension related information to 60 members of the Lebanese Seniors Group.

New South Wales
FILIPINO SENIORS INFORMATION DAY
A successful Filipino Seniors Information Day event was held at Fairfield Community Hall late last year. The Fairfield Social Worker, Multicultural Service Officers and Financial Information Service Officers from Liverpool and St Marys Customer Service Centres all worked together with community and government agencies to link seniors and their carers to local services and to increase their understanding of Centrelink services. The event attracted more than 80 people with 20 community workers, who were provided with information about Age Pension and carer payments, a police safety and security session, and a session about staying independent at home. Seniors and their carers learnt how to access different services such as carer support and there were stalls providing information from a range of organisations including Transcultural Mental Health, Legal Aid, Dementia Advisory Service, Carelink and Carer Respite Centre, PACSI and Aged and Disability Services.
Recommendations for Improving the Healthcare of Elderly Minorities

3- Educazione e ricerca sanitaria (Outreach work)

L’interazione con le organizzazioni delle comunità etniche può determinare una educazione sanitaria crescente ed una maggiore conoscenza del problema soprattutto nelle zone frequentate dalle mioranze etniche anziane; crea inoltre un legame di partnerships con queste organizzazioni.

La ricerca migliorerà i servizi per i gruppi minoritari con demenza ("ethnogeriatric" research).
Weten over vergeten: Dementia education for Turkish, Moroccan and Surinamese people
Nienke van Wezel, Alzheimer Nederland, Netherlands, n.wezel@alzheimer-nederland.nl
The number of elderly migrants with dementia has been heavily increasing over the years. Nevertheless, in non-western cultures the concept dementia is mainly unknown and undiscussed. On top of that, migrant people are often unfamiliar with Dutch care facilities. This causes a lack of knowledge to make the right choices at the right times during the disease. Early recognition of dementia is essential for good coping and to provide better and longer informal care. To stimulate the use of Dutch care facilities by elderly migrants, it is crucial to understand how personal care experiences and the perception of dementia by non-western informal caregivers, are influenced by culture.
In 2007/2008, Alzheimer Nederland developed ‘Weten over vergeten’, an educational project which includes a specially created method. With this project, regional departments of Alzheimer Nederland and migrant organisations organise information meetings for migrant people. The goal of this project is to enhance and strengthen the connection between regional care networks and elderly migrants. In addition, this project aims to increase knowledge about dementia and available support facilities among this target group. For this purpose, regional departments and migrant organisations go through an intensive introduction and exchange programme.
In 2009, 36 meetings are planned reaching 650 migrant participants. A unique part of this project is the use of personal experiences of the target group. Next to information about dementia, the personal experiences help to illustrate culturally influenced problems and to find proper solutions.
In 2009/2010, the project will be implemented in other Dutch regions. In 2009, Alzheimer Nederland will start a promotional research in order to gain insight into the perception and care burden experienced by Turkish and Moroccan informal dementia caregivers.
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Conclusioni
National Alzheimer’s associations help to raise awareness and create a framework for positive engagement between policymakers, clinicians, researchers, caregivers, and people with dementia.

Most of Alzheimer Disease International’s 75 members are associations in developing countries. Their advocacy, empowered by evidence of prevalence, effect, and need will foster the development of more responsive services.

For many low-income countries the most cost-effective approach will be community primary care to support and advise family caregivers. Day care and residential respite care are expensive but important elements of a community service. Residential care is unlikely to be a government priority, but private nursing and residential care homes are already opening to meet the new demand.

If government policies are well formulated and planned with the projections described in this paper in mind, the inevitable shift of resource expenditure towards older people can be predicted and its consequences mitigated.

The health and social care needs of the large and rapidly growing numbers of frail, dependent older people should be a matter of great concern for policymakers in developing regions.

"Se voi avete il diritto di dividere il mondo in italiani e stranieri allora io reclamo il diritto di dividere il mondo in diseredati e oppressi da un lato, privilegiati e oppressori dall’altro. Gli uni sono la mia patria, gli altri i miei stranieri"

Don Lorenzo Milani