The new player: media portrayal, public perception

Marc Budge
The “big picture”

Media portrayal

Public Perception

Health professionals & social agencies

Provide knowledge, care & support
Evolution in knowledge, attitudes & perceptions......

Keeping pace ????
Knowledge and attitudes: where are they now???

- Public
- Health professionals & Service providers
- Media
Outline

1. Context of an evolving health system

2. Media portrayal

3. Public perception, knowledge and attitudes
   - Australian
   - International

4. Bringing the above three together
Health Care System c2008-2013

Funding Lags?

Investment & Support

“Tertiary”

Community Support

Web Info.

“Primary”

Communitie Centres

Doctor’s Office

Telemedicine

Smart Medical Home / RCF

Technology & Skill

Center for Future Health
University of Rochester
Convergence of sensing, communications, information systems & medical assessment

Your Home Is Your Personal Health System
The Spectrum of Care

100% % Self Care 0%

0% % Professional Care 100%

Self Care

Professional Care

most care is shared care

Less Complex Case More Complex Cases

HOME

Hospitals

COMMUNITY
The New Health Care Relationships: Me, My Doctor, the Internet, and My Chat Group
2. Media portrayal
in the movies....
History of dementia in the movies


- CBS initially refused to finance 1985 film “Do You Remember Love?” as no-one would want to watch a film about something as depressing as Alzheimer’s.

- The film, about a couple whose love triumphs over Alzheimer’s disease, went on to which win three out of six Emmy nominations.

Dementia in the movies

- **Segers**: search of fiction films, TV films & shorts released before 2005- main character suffering from degenerative dementia.

- 60% of characters with dementia are women

- 80% live at home. Rest institutionalised
- Role of latter limited to lying in bed (“Agnes of God” & “Noel”)

- Wandering popular theme in movies
- Screenwriters choice for highly educated people is for dramatic impact rather than educational purposes

In the movies today

• British actress Julie Christie was nominated for a Bafta award for her portrayal of a woman with Alzheimer's disease. In Away From Her, Ms Christie plays Fiona, who has been married to husband Grant, played by Gordon Pinsent, for over 40 years.

• As they get older Fiona becomes more forgetful, until the couple realise she is suffering the onset of Alzheimer's disease and the pair eventually agree she must go into a care home.

• But while in the care home, as she is separated from Grant, Fiona seems to have forgotten her husband and fallen for another man.

• Ms Christie has been nominated in the Best Actress category of the Bafta awards for her moving portrayal.
Dementia on the TV

- E.R.
- All Saints
- Gray’s Anatomy
- House
- RPA

- Mother and Son
- Coronation Street

During one episode, character (Mike Baldwin) with AD.

Episode broadcast with number of British Alzheimer Society helpline.

Calls peaked at absolute record on that evening.
Dementia in the news: a survey of NZ newspapers

- Print media often focus on negative aspects of disease-e.g. negative aspects of residential care

- More positive light result of celebrities living with dementia prepared to speak about it- Ronald Reagan, Iris Murdoch, Hazel Hawke

- Paper analysed print media for words “Alzheimer’s” and “dementia” (1996-2002)

- What was missing- advertisements- dementia care was rarely mentioned. Often attempt to stress “normality” and good health. Only community newspapers dementia care appeared

Dementia in news ....continued..

What was missing?

- Advertisements- dementia care was rarely mentioned
- Often attempt to stress “normality” and good health.
- Dementia care advertisements only appeared in community newspapers

• Survey found Alzheimer’s disease was represented as
  - ‘disease of the century’
  - ‘mind-robber’
  - ‘never-ending funeral’
  - ‘a slow death of the mind’

Obituaries

• “Brilliance dimmed by disease”

• When British writer Iris Murdoch died- photo and accompanying caption: “Philosopher and novelist who fell from flights of genius to watching The Teletubbies”

• Often viewed as a cruel event in someone who was gifted

Others

• Personal stories
  – Voice of the sufferer is usually heard through others
  – Usually via wives and daughters, e.g. Nancy Regan, Susan Pieters-Hawke

• Negligence tales
  – Elder abuse in residential homes

• Missing people reports
  – Can imply failure to keep people safe
  – While titles can be blunt they are preferable to humorous ones such as... “elderly man suffering dementia spends 13 hours walking dog”

Conclusions

- Media (newspapers) remain a powerful transmitter of stereotypes regarding dementia i.e. “victims of disease” but also “victims of the health services”

- Advocacy organisations are especially significant as they are called upon to respond to both negative and positive media reports

- Stereotypes of ageing are often linked with stereotypes of dementia
FIGURE 1. Sources of stigmatizing language in newspaper stories.
CONCLUSIONS:

- A total of 21% of all stories (excluding wire stories) contained language judged stigmatizing.
- Reporters were the most common source of the stigmatizing language.
- A total of 20% of analyzed stories had medical errors or exaggerations,
- The latter most often overstating treatment effectiveness.
To move forward........

We need to better understand the correlates of public attitudes toward:

• specific risk factors or
• stigmatized persons with dementia

to build a foundation for effective public campaigns
3. Public perception
Australia
Market Research Report

Australians’ understanding and experience of Alzheimer’s disease and dementia

November 2007

Prepared for:

Pfizer Australia
38-42 Wharf Road
West Ryde NSW 2114
• almost 75% of all Australians would take a test (if available) to reveal if they are going to develop Alzheimer’s disease

• 47% of Australians know a family member or friend who has Alzheimer’s or another form of dementia
When would you like to know?

- There is mixed opinion as to when Australians would like to be informed that they are going to develop Alzheimer’s disease or dementia at 65 years or later.

- Most people would like to be informed before they start developing signs or symptoms, with just over 40% wanting to know at a younger age (before 40 years).

- A small percentage indicated they do not wish to know beforehand; 4% selected ‘over 65 years’.

- 37% indicate in either their 40s or 50s

- A further 14% selected ‘60 to 65 years’
4.1.4 Concern about developing Alzheimer’s disease or dementia for self

Q67: Level of concern about developing Alzheimer’s disease or dementia myself - by total - Chart 4

Base: 1,380 panel members
('no answers’ not included)

**DEMENTIA and yourself....**

<table>
<thead>
<tr>
<th>Concern Level</th>
<th>2007</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very concerned</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>Somewhat concerned</td>
<td>23%</td>
<td>19%</td>
</tr>
<tr>
<td>A little concerned</td>
<td>30%</td>
<td>33%</td>
</tr>
<tr>
<td>Not concerned at all</td>
<td>27%</td>
<td>31%</td>
</tr>
<tr>
<td>Don't know</td>
<td>7%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Very concerned  Not concerned
Q66: Actions might help to reduce the risk of developing Alzheimer's disease or dementia - by total - Chart 14
Base: 1,380 panel members

Actions might help to reduce the risk of developing A.D.

- 2004
- 2007 much higher overall

<table>
<thead>
<tr>
<th>Action</th>
<th>2004</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping mentally active</td>
<td>66%</td>
<td>84%</td>
</tr>
<tr>
<td>Eating a healthy diet</td>
<td>40%</td>
<td>69%</td>
</tr>
<tr>
<td>Keeping socially active and connected</td>
<td>0%</td>
<td>68%</td>
</tr>
<tr>
<td>Exercising regularly</td>
<td>34%</td>
<td>67%</td>
</tr>
<tr>
<td>Having low or moderate alcohol consumption</td>
<td>45%</td>
<td>56%</td>
</tr>
<tr>
<td>Reducing or quitting smoking</td>
<td>27%</td>
<td>52%</td>
</tr>
<tr>
<td>Reducing high blood pressure</td>
<td>20%</td>
<td>41%</td>
</tr>
<tr>
<td>Reducing high cholesterol</td>
<td>17%</td>
<td>35%</td>
</tr>
<tr>
<td>Avoiding head injury</td>
<td>35%</td>
<td>35%</td>
</tr>
<tr>
<td>Nothing can be done</td>
<td>29%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Market Research Report  Australians’ understanding and experience of Alzheimer’s disease and dementia
More positive outlook in 2007 that actions can be taken to help reduce the risk of developing Alzheimer’s disease or dementia.

• Only 10% of Australians feel ‘nothing can be done’.

• This is significantly lower than in the 2004 wave (29%).

• > 50% feel most of these actions might help reduce the risk of developing these conditions.
Pfizer report ...continued..

• Compared to the results from a 2004 survey
  – 18% more Australians believe staying mentally active might help reduce their risk of developing dementia (84% up from 66%)
  
  – 25% more believe reducing or quitting smoking may help to reduce their risk (52% up from 27%).
Risk reduction cont’d

Just over two thirds of Australians believe that adopting a healthy lifestyle may help prevent dementia including:

– eating a healthy diet,
– staying socially active & connected,
&
– exercising regularly
Stigma

Just over 50% of Australians feel that people with dementia are unfairly treated or discriminated against because of their condition.

........2006 Colmar Brunton Report ->
Report on Exploratory Research to Support a National Communications Strategy on Dementia

Report
8 November 2006

Sample: N=1004
Importance of dementia relative to other health issues

- Overall, based on the mean of all responses, cancer was rated the most important health issue.
- Dementia and Diabetes were rated as the least important health issue, out of the six health issues mentioned.

Q3. I am now going to read out to you 6 health issues. If you had 100 points to split between all of these issues, how would you do so based on how important you think the issue is? Give more points to the issues you think are most important and less points to the issues you think are less important. Base size: n=1004
Early signs of dementia

- The most common early sign of dementia cited by the general public was general memory loss or forgetfulness (71%), followed by short-term memory loss (23%).
- Confusion (15%) and disorientation (11%) were also mentioned.
- 10% of the general public did not know what the early signs of dementia were.

Q4. Now we have some questions about dementia...it does not matter how much you know about dementia...we are just interested in your thoughts and opinions... what are the early signs of dementia (including Alzheimer’s Disease)?
Base size: n=1004
Quality of life for people with dementia

• 73% of the general public perceive that people with dementia have a lower quality of life than the average Australian.

Q6. How do you think the quality of life for someone with dementia (including Alzheimer’s disease) compares to the quality of life for an average Australian? Please use a scale from 1-10 where 1= Much lower quality of life and 10= Much higher quality of life.

Base size: n=1004
Reducing the risk of dementia

- 46% of the general public believe that there is something that can be done to reduce the risk of developing dementia.
- 54% of the general public either think that nothing can be done to reduce the risk, or don’t know.

Q10. Do you think there is anything that can be done to reduce the risk of developing dementia (including Alzheimer’s Disease)?
Base size: n=1004
Reducing the risk of dementia

- Of the people who think something can be done to reduce the risk of dementia, 49% believe that keeping mentally fit can help a person reduce the risk of developing dementia.
- 27% mention a healthy diet, followed by physical exercise (21%).

Q11. What do you think a person can do to reduce the risk of developing dementia (including Alzheimer’s Disease)?
Base size: n=466 (those who answered “yes” to Q10)
The most common sources of information the general public are aware of about dementia are the internet (38%) and GP’s (31%).

Q26. What sources of information are you aware of about dementia?
Base size: n=1004
The most reliable sources of information reported by the general public include GP/doctor, internet browsing/searching, another medical professional, and the library.

Few respondents cited TV/media (4%), psychologist (4%) clinic (4%), and local government/council (2%).
International
“Britons 'ignoring' dementia signs

British stoicism is holding back older people from seeking treatment for Alzheimer's disease....... research suggests.”

N = 2550 in survey of the UK, France, Germany, Spain, Italy and Poland
Average time between first symptoms and diagnosis:

<table>
<thead>
<tr>
<th></th>
<th>Country</th>
<th>Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Germany</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td>Italy</td>
<td>14</td>
</tr>
<tr>
<td>3</td>
<td>Spain</td>
<td>17</td>
</tr>
<tr>
<td>4</td>
<td>Poland</td>
<td>23</td>
</tr>
<tr>
<td>5</td>
<td>France</td>
<td>24</td>
</tr>
<tr>
<td>6</td>
<td>UK</td>
<td>32</td>
</tr>
</tbody>
</table>
Losing Mental Capacity is Greatest Fear

When you think about aging, what do you fear more: diminished physical ability or losing mental capacity?

- Losing mental capacity: 62%
- Diminished physical ability: 29%
- Don't know: 9%

Taking Our Pulse: The PARADE/Research!America Health Poll
Charlton Research Company, 2005
Physical and Mental Health Are Equally Important to Americans

Considering your own health, do you think that mental health or physical health is more important or are they equally important?

- Physical health more important: 89%
- Mental health more important: 5%
- Equally important: 6%

Taking Our Pulse: The PARADE/Research!America Health Poll
Charlton Research Company, 2006
Americans Think Habits and Personal Choices Trump Genes

Which do you think is more important in determining how healthy you are?

- 70% Personal habits and choices
- 23% Genetics and inherited family traits
- 7% Don't know

Taking Our Pulse: The PARADE/Research!America Health Poll
Charlton Research Company, 2006
Great Expectations for Medical Breakthroughs

Please tell me whether you think the following medical breakthroughs will occur within the next 20 years.

- A cure for diabetes: 65%
- A cure for Parkinson's disease: 59%
- A cure for Alzheimer's disease: 54%
- A cure for heart disease: 52%
- A cure for cancer: 48%
- A cure for AIDS: 47%

Taking Our Pulse: The PARADE/Research!America Health Poll Charlton Research Company, 2005
'Brain Health' Public Opinion Poll

- Oct 2006, Leger Marketing conducted public opinion poll on behalf of the Alzheimer Society of Canada

- To determine the general public's level of knowledge regarding brain health & Alzheimer's disease.

- N= 1859 adults
Physical Health vs. Brain Health

• 78% of Canadians- brain health is as important as physical health, with an additional 19% saying it is actually more important

• However, when asked to name the first thing that comes to mind when describing a 'healthy person', 63% of people said physical fitness, and 32% said healthy eating habits

• Only 5% of people answered being socially or intellectually active as attributes of a healthy person.
4. Bringing it together

generation

knowledge

communication

management
..... an example......

- generation
- knowledge
- communication
- management
The 3 Dementia CRCs

– Assessment and Better Care Outcomes

– Prevention, Early Intervention and Risk Reduction

– Consumers, Carers and Social Research

Translating dementia research into practice
Dementia CRC2- Research Programmes

Programme A: Understanding Risks for Dementia

Programme B: Development of Diagnostic Tools/Algorithms for Early Dementia

Programme C: Development of Risk Reduction Interventions

Programme D: Modelling Impacts of risk reduction on cognitive decline and Dementia
Current literature: review early pathophysiology and “established” risk factors

Gaps identified: use DCRC to help leverage studies OR bring together ‘minds’

“clearing house”

2006-7-8
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“clearing house”....website

Biomarkers
Genetics
Oxidative stress

Cognitive testing
Brain Imaging

Risk factor identification
Intervention Modelling

2006-7-8
2007-8
Current literature: review early pathophysiology and “established” risk factors

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2006-7-8

2007-8

Biomarkers

Genetics

Oxidative stress

Risk factor identification

Cognitive testing

Brain Imaging

Intervention Modelling

“Message” Development

Who ?
What ?
How ?

Public Health messages

Professional messages

Early diagnostic and risk prediction paths / models

2008-9
The new player: media portrayal, public perception
National Geographic,
November 2007

REMEMBER THIS IN THE ARCHIVES OF THE BRAIN
OUR LIVES LINGER OR DISAPPEAR.
Mind Your Mind
Acknowledgement

• Karen Gravenmaker, DCRC2

• Staff of Alzheimer’s Australia