How to develop a ‘counterframe’ giving a new perspective on dementia? Presentation of results of research on framing and re-framing dementia

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Re-framing dementia-workshop
Dundalk, Ireland 21 June 2012
How to develop a ‘counterframe’ giving a new perspective on dementia?

1. Public perception of dementia as an aggressive and merciless illness, ‘a never ending funeral’
2. Media reinforce this extremely negative perception
3. Ignorance and society’s negative reactions

Introduction

Those with the illness feel insecure and anxious
Further lack of understanding
Awkward reactions
The burden of dementia becomes heavier to bear than it is in reality

Ambition: re-defining dementia towards a more balanced image
What’s a frame?

How to develop a ‘counterframe’ giving a new perspective on dementia?
What’s a frame?

• **FRAME ≈ PERSPECTIVE, A SOCIALLY SHARED ORGANIZING PRINCIPLE**
  - Each frame leads to another interpretation of reality
  - E.g., gambling: an expression of an individual weakness, or a recreational activity?
How does framing work?

- **Basic mechanisms**
  - Simplification
  - Figurative analogy
  - Causal reasoning
  - Selection and construction
Research Design

• **Objective 1**: gain insight into the prevalent frames on dementia in the media
  – RQ 1: What are the dominant frames used to represent dementia and what alternative counterframes could be proffered?

• **Objective 2**: can we *use* these counterframes?
  – RQ 2: Could a message regarding dementia that was inspired by an alternative frame have an impact and appear as credible and comprehensible to the public?
Content analysis

• **Study 1**
  – Analysis of the already existing common imagery on dementia
  – Data material:
    • *Audiovisual material*: films, documentaries, online video exerts (YouTube), docusoaps etc.
    • *Print*: novels, graphic novels, (auto-) biographies, brochures, websites, magazines, (inter-)national newspapers etc.
Methodology

• 3 phases
  – (1) Inventorisation of framing devices and reasoning devices (*open coding*)
  – (2) Detecting patterns and dimensions in more than 3000 citations (*axial coding*)
  – (3) Composing a ‘framing matrix’ with 6 dominant and 6 alternative counter-frames

• Evaluation
<table>
<thead>
<tr>
<th>Year</th>
<th>Issue</th>
<th>Date</th>
<th>Article Title</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>1983</td>
<td>Dedication</td>
<td>aug 94 i</td>
<td>Ronald and Nancy Reagan Research Institute in 1995, dedicated specifically to funding basic science research on mechanisms and molecules associated or potentially linked with AD</td>
<td></td>
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<tr>
<td>1984</td>
<td>Dedication</td>
<td>aug 94 ii</td>
<td>In favor of US government support of stem cell research</td>
<td></td>
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<tr>
<td>1985</td>
<td>Dedication</td>
<td>aug 94 iii</td>
<td>Ronald Reagan was diagnosed in his eight decade of life and managed to survive nearly a decade with the condition</td>
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<tr>
<td>1986</td>
<td>Dedication</td>
<td>aug 94 iii</td>
<td>In essence, a caregiver must deal with watching a loved one die twice</td>
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<tr>
<td>1987</td>
<td>Dedication</td>
<td>aug 94 iii</td>
<td>There are so many memories I can no longer share, which makes it very difficult. When it comes right down to it, you’re in it alone</td>
<td></td>
</tr>
<tr>
<td>1988</td>
<td>Dedication</td>
<td>aug 94 iii</td>
<td>It is this basic shortcoming of our current methods that saddens us most regarding the decline and death of Ronald Reagan, that it was inevitable despite our best efforts. This is not to say there is no hope. Tremendous research is currently underway in basic science and clinical settings to understand the pathology, genetics, and patient care issues of AD in order to find novel strategies for treatment of Alzheimer's disease. To this end, a new journal, Current Alzheimer Research, has been started. This peer-reviewed research journal is meant to disseminate up-to-date knowledge in different aspects of current AD research.</td>
<td></td>
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<tr>
<td>1989</td>
<td>Yves Dumas</td>
<td>2005 9</td>
<td>Monsieur T. a poignardé sa femme de cinq coups de couteau. [...]. Il est incapable de répondre. Il ne semblait pas comprendre les faits qui lui étaient reprochés et ne souvénait pas d'avoir tenté d'assassiner sa femme</td>
<td></td>
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<tr>
<td>1990</td>
<td>Yves Dumas</td>
<td>2005 10</td>
<td>Mais Monsieur T. restait apathique et ne paraissait pas concerné de son propre cas. L'expertise psychiatrique ainsi que le dossier médical ont prouvé que Monsieur T. n'était pas en pleine possession de ses moyens au moment des faits et venait de succomber à une crise aiguë de démence</td>
<td></td>
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<tr>
<td>1991</td>
<td>Yves Dumas</td>
<td>2005 11</td>
<td>La maladie de A. est une affection dégénérative du cerveau. Cette déshance, dont l'étiologie n'est pas encore connue, est associée à des lésions histologiques spécifiques, la présence de plaques séniles, la dégénérescence neurofibrillaire et l'atrophié corticale.</td>
<td></td>
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<tr>
<td>1992</td>
<td>Yves Dumas</td>
<td>2005 13</td>
<td>Le 6 juillet 2004, Monsieur T. a agressé sa femme. Il a manifestement agi dans le but de la tuer comme les blessures de la victime, toute situées autour du poumon gauche, à quelques centimètres du cœur, le prouvent</td>
<td></td>
</tr>
<tr>
<td>1993</td>
<td>Yves Dumas</td>
<td>2005 17</td>
<td>Ce livre a pour but de m'accompagner à l'idée que je pourrais être un jour ou l'autre atteinte par la maladie d'A.</td>
<td></td>
</tr>
<tr>
<td>1994</td>
<td>Yves Dumas</td>
<td>2005 17</td>
<td>Ou que, plus terrible encore, la personne avec que je vis pourrait en être atteinte</td>
<td></td>
</tr>
<tr>
<td>1995</td>
<td>Yves Dumas</td>
<td>2005 17</td>
<td>Imaginer le pire</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Yves Dumas</td>
<td>2005 17</td>
<td>Des projections et statistiques savantes indiquent que d'ici à quelques années des millions de personnes seront atteintes de cette maladie.</td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Yves Dumas</td>
<td>2005 18</td>
<td></td>
<td></td>
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How to develop a ‘counterframe’ giving a new perspective on dementia?

Framing dementia

– Results

• 6 dominant frames
• 6 counterframes

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<th>Frames</th>
<th>Counterframes</th>
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<td>1B Unity of body and mind</td>
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<td>2 The invader</td>
<td>3 The strange travelling companion</td>
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<td>4A Faith in Science</td>
<td>4B Natural ageing</td>
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<td>5 The fear of death and physical degradation</td>
<td>6 Carpe Diem</td>
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<td>7A Reversed roles</td>
<td>7B Each in turn</td>
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<td>8A No reciprocation</td>
<td>8B The Good Mother</td>
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Framing dementia

• DOMINANT FRAMES
1A Dualism of body and mind

- **Cultural theme**: cartesian dualism: a human being consists of a material body and an immaterial soul
- **Definition**: people with dementia lose their identity and personality
- **Cause**: dementia takes the soul away
- **Consequences**: people with dementia only exist in a material way, they are no longer among us
- **Moral judgement**: loss of personality denies the ideal of individuality, independancy and self-fulfilment
- **Solution**: euthanasia as the last triumph of reason
1A Dualism of body and mind

How to develop a ‘counterframe’ giving a new perspective on dementia?
2 The invader

• Cultural theme: an enemy, a thief or an assassin who suddenly strikes, a lurking monster
• Definition: dementia steals one’s (successful) life
• Cause: dementia can strike at any time
• Consequences: a monster that eats the brain, it takes all your abilities and skills away
• Moral judgement: always be prepared
• Solution: one has to fight the enemy
2 The invader

- ‘Discovering what the enemy was, did not make the toll the disease would take any easier to bear’
- ‘The disease just keeps up its relentless march’
- ‘a killer’, ‘a monster’, ‘struggle’
4A Faith in science

- **Cultural theme**: belief in scientific (and medical) progress
- **Definition**: dementia is a disease with a well-defined pathology
- **Cause**: has yet to be discovered
- **Consequences**: people with dementia become cases/numbers and become invisible behind the diagnosis
- **Moral judgement**: hope; one day science will find a cure for dementia
- **Solution**: the need for more funding and research, medication can already slow down the process
4A Faith in science

From *The Times*
January 28, 2010

Neuron breakthrough offers hope on Alzheimer’s and Parkinson’s

How to develop a ‘counterframe’ giving a new perspective on dementia?
5 The fear of death and physical degradation

- **Cultural theme**: everyman’s fate: death
- **Definition**: to have dementia is a complete catastrophe
- **Cause**: dementia is a death sentence
- **Consequences**: mourning before the actual death, one becomes a widow(er) of a living husband/wife
- **Moral judgement**: fear for degradation and death
- **Solution**: prostration, resignation and submission
5 The fear of death and physical degradation

• ‘The slow decline’, ‘descent’
• ‘Loss and mourning’, ‘widowship’, ‘the long goodbye’
• ‘The never ending funeral’, ‘an excruciating curse’
7A Reversed roles

- **Cultural theme**: the expectations of a child to his parents and vice versa
- **Definition**: people with dementia become a child once again
- **Cause**: dementia makes you lose ‘adult’ characteristics such as independence and autonomy
- **Consequences**: the reversal of the role between parent and child
- **Moral judgement**: violation of the norm of autonomy and self-control
- **Solution**: hiding them, putting them away in an institution
7A Reversed roles

- ‘Grandma is becoming a little child’
- ‘a very old little child’
- ‘The horror of the inversion between child & parent’
8A No reciprocation

- **Cultural theme**: the reciprocity of social relations
- **Definition**: dementia hits the entire environment
- **Cause**: persons with dementia lose their autonomy
- **Consequences**: the actual victims of dementia are the ones who surround the person with dementia
- **Moral judgement**: guilt of the heavy burden imposed on the caregiver
- **Solution**: more support, dilemma of institutionalisation
8A No reciprocation

How to develop a ‘counterframe’ giving a new perspective on dementia?
How to develop a ‘counterframe’ giving a new perspective on dementia?
1B Unity of body and mind

- **Cultural theme**: no dominance of the reason
- **Definition**: people with dementia may lose their cognitive capacities, they never lose their identity and humanity
- **Cause**: dementia can’t touch the humanity of a person
- **Consequences**: people with dementia have a rich emotional life, they can still enjoy physical contact and proximity
- **Moral judgement**: people with dementia are still individuals, human beings (personhood)
- **Solution**: empathy, seek emotional contact, meet them in their own language
How to develop a ‘counterframe’ giving a new perspective on dementia?

- ‘Thankful eyes’
- ‘Carressing’, ‘touching’, ‘humor and laughing’
- ‘The disease is never bigger than the person’
- ‘Learning/decoding their own language’
3 The strange travelling companion

- **Cultural theme**: an unexpected travel companion that one meets along the road
- **Definition**: dementia as coping with destiny
- **Cause**: dementia will cross many paths
- **Consequences**: people should cope with it, trying to maintain as much autonomy as possible
- **Moral judgement**: social norm which states that one always has to be strong
- **Solution**: keeping matters in own hands, acceptance, coping
3 The strange travelling companion

• ‘an unknown lodger in my head, leaving mess behind’
• ‘There are always two of us now’
• ‘My little friend, Alzheimer’
• ‘a journey that will lead me to the sunset of my life’
4B Natural ageing

• **Cultural theme**: aging is part of life
• **Definition**: dementia is not a disease, it is not different from ‘normal’ aging symptoms
• **Cause**: a ‘failed form’ of aging
• **Consequences**: dementia will remain incurable, there is no such thing as hope for a cure
• **Moral judgement**: keep people with dementia in society
• **Solution**: care and prevention, not cure

How to develop a ‘counterframe’ giving a new perspective on dementia?
6 Carpe Diem

- **Cultural theme**: seize the day
- **Definition**: people with dementia can still enjoy life for a long time
- **Cause**: Life is short anyhow
- **Consequences**: try to live it to the fullest on a day to day basis
- **Moral judgement**: social norm to enjoy life
- **Solution**: learn to find happiness and comfort in the small things of life
How to develop a ‘counterframe’ giving a new perspective on dementia?
7B Each in turn

- **Cultural theme**: the expectations of a child to his parents and vice versa
- **Definition**: persons with dementia return to the carelessness and happiness of childhood
- **Cause**: learned behavior and social inhibitions fall away
- **Consequences**: the children take over, for it is their turn
- **Moral judgement**: the reciprocity of the relation between parents and their children
- **Solution**: to learn their parents in a different way, proximity
How to develop a ‘counterframe’ giving a new perspective on dementia?
8B The Good Mother

- **Cultural theme**: charity as a universal value
- **Definition**: people with dementia deserve to be helped
- **Cause**: people should help everybody, even when they have dementia
- **Consequences**: caregivers fulfill their moral duty
- **Moral judgement**: the moral duty to help others
- **Solution**: caring for each other, growing with the patient, keeping the patient at home for as long as possible
How to develop a ‘counterframe’ giving a new perspective on dementia?
Experiment

- **Study 2**
  - Experiment to test the counter-frames and to develop a strategy to communicate them effectively to the public
  - Representative sample of 1,000 Belgians
  - Development of campaign advertisement with experimental manipulation
Experimental conditions

- **Base line**
  - “Behind every patient with Alzheimer’s, is a living person”
Experimental conditions

• **Body copy**
  
  “People with Alzheimer’s disease or other forms of dementia suffer from a gradual loss of brain function. Despite the deterioration in their memory, people with Alzheimer’s remain sensitive to emotions and the quality of relationships. Help them to find happiness in the little things of life”

**Call-to-action:** Carpe diem-frame
Experimental conditions

- Two executions of strategy in **headline**

1. **Unity of body and mind-frame**: “Willy is losing his memory little by little, but he still cheats at whist”

2. **Death and degradation-frame**: “Willy, already buried by his friends and family, and yet he’s still alive”
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Experimental design

**stimuli**

- Evaluation (scale 0-10)
- Very easy / very difficult to understand; not at all credible / very credible (5 point scale)
- Interpretation (certainly not / certainly agree with statements)
- Control: experience of dementia, feelings about person on picture, usefulness of conducting campaign (costs and benefits)
- Demographic: region, sex, age, level of education
Results /1

• Evaluation of ad
  – Favourable average rating of the campaign ad (7.6 / 10)
  – ‘Death and physical degradation’-frame was rated as the most appealing, understandable, and credible version
  – Most important predictor of appreciation: assessment of overall effectiveness of campaigning activities towards dementia ($\eta^2 = .21$)
Results /2

– Women more favourable than men
– Younger people (<= 29) more favourable than older people
– No main effects of educational level and of experiences with dementia
Results /3

- Men with direct experiences with dementia more favourable than men with indirect experiences
- Women with direct experiences less favourable than women with indirect experiences, but still more favourable than men
• Self-efficacy
  – No role of heading
  – 90% of those taking part was in complete or partial agreement with idea: those with dementia can be helped to continue to enjoy life to the full
  – 88% disagreed completely or partially with: there’s not much point in looking after those with dementia
  – 74% agreed with: someone with dementia could still experience a relationship with other people
– Self-efficacy of people with direct experiences higher than of people with indirect experiences
– Self-efficacy of women till the age of 29 is the most favourable, of men of 50 years and older the least favourable
– Self-efficacy of higher educated people with direct experiences is the most favourable, of lower educated people with indirect experiences the least favourable
Conclusions

• All versions of ad well-received (7.6/10)
• Demographic variables (e.g., gender and age) have some influence, but it seems that the developed campaign could be successfully targeted at a broad audience
• Communication advice to make greater and more resolute use of counterframes, without minimizing seriousness and concealing the last phase
Discussion

• Reactions depend strongly on the conviction that a campaign can be of real use ⇒ use of plain text; a newspaper article,…

• Testimonial by someone with dementia ⇒ “My name is Louis and I have Alzheimer’s …”

• Difficult to change people’s attitudes, or behaviour, after seeing one ad ⇒ advertisement must be part of a wider campaign ⇒ alternative frames gradually become dominant