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Author contact	baldwin.vangorp@soc.kuleuven.be + 32 (0)16 323179
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Frames And Counter-Frames Giving Meaning To Dementia: A Framing Analysis Of Media Content

Baldwin Van Gorp^a, Tom Vercauysse^{a,b}

^a K.U. Leuven, Institute for Media Studies, Parkstraat 45, 3000 Leuven, Belgium

^b Research Foundation - Flanders (FWO), Belgium

Abstract

Media tend to reinforce the stigmatization of dementia as one of the most dreaded diseases in western society, which may have repercussions on the quality of life of those with the illness. The persons with dementia, but also those around them end up being imbued with the idea that life comes to an end as soon as the diagnosis is pronounced. The aim of this paper is to understand the dominant images related to dementia by means of an inductive framing analysis. The sample is composed of newspaper articles from six Belgian newspapers (2008-2010) and a convenience sample of popular images of the disease in movies, documentaries, literature and health care communications. The results demonstrate that the most dominant frame postulates that a human being is composed of two distinct parts: a material body and an immaterial mind. If this frame is used, the person with dementia ends up with no identity, which is in opposition to the Western ideals of personal self-fulfilment and individualism. For each dominant frame an alternative counter-frame is defined. It is concluded that the relative absence of counter-frames confirms the negative image of dementia. The inventory might be a help for caregivers and other professionals who want to evaluate their communication strategy. It is discussed that a more resolute use of counter-frames in communicating about dementia might mitigate the stigma that surrounds dementia.

Introduction

Dementia is a term that groups a range of neurodegenerative illnesses of which Alzheimer's disease is the most well-known and prevalent variant. Dementia is characterized by a degradation in cognitive faculties, which results in a progressive loss of functions and autonomy (WHO, 2004). Apart from the pressure resulting from forecasts about an increase in the number of people living with dementia (e.g., Castellani, Rolston & Smith, 2010; Luengo-Fernandes, Leal & Gray, 2010; Mura, Dartigues & Berr, 2010), it is one of the conditions people fear most, along with cancer and heart diseases (Pin, Bodard & Richard, 2011). People perceive dementia as an aggressive and merciless illness (e.g., Blay & Peluso, 2010; Werner, 2005).

On a social level, people with dementia easily lose their social networks and run the risk of isolation and solitude or 'social death' (Sweeting & Gilhooly, 1997), they have greater difficulty in accessing support services, suffer from a poor self-image and may experience discrimination (Naue & Kroll, 2008). One is reasonably led to think that dementia is seen with much greater fear in the West, where death and old age represent an important taboo and family ties are weaker than in other parts of the world (cf. Ferreira & Makoni, 2009; Leibing, 2002). Furthermore, even disclosing the diagnosis of dementia to the patient is often experienced as very difficult or stressful for general practitioners (Cantegreil-Kallen, et al., 2005; Tarek, Segers & Van Nechel, 2009; Werner & Heinik, 2008).

Further, the media tend to reinforce this negative perception (Clarke, 2006; Kirkman, 2006). Studies on the image of dementia highlight three important aspects. First, the media clearly focus on the terminal stage of the illness, which then seems to become representative of the entire degenerative process. It is as if as soon as a diagnosis of dementia is made, the person in question automatically becomes incapable of taking any autonomous decisions (Carbonnelle, Casini & Klein, 2009). Second, the person who has the condition is rarely given the opportunity in the media of speaking for him/herself: as a general rule, someone speaks on his or her behalf (Clarke, 2006; Kirkwood, 2006). Finally, the media often emphasise the heavy weight that the illness exerts on the family (Pin le Corre, et al., 2009; Werner, Goldstein & Buchbinder, 2010).

Studies show that the theme of dementia has been discovered in recent years by the most diverse media (Segers, 2007), which is an indicator of the illness's social impact (Adelman & Verbrugge, 2000). However, while dementia has received more attention, the condition continues to be one that is affected by a stigmatizing image. In some respects, this image is not in line with reality as, for instance, when it is suggested that all of those with dementia are incapable of taking their own decisions. Moreover, many of the consequences, such as the stigma, isolation or the frustration that comes from a feeling of incomprehension, are not only physical symptoms of dementia, but are often reinforced by the perception that society has of the condition. This may partly be a self-fulfilling prophecy: ignorance and society's negative reactions have the effect of making those with the illness feel insecure and anxious, which may lead to awkward reactions, which in turn lead to even further lack of understanding. If this is true, taking care of a person with dementia becomes heavier to bear than it is in reality.

In this paper an inductive framing analysis is used to systematically set out the various ways in which the media define dementia. This is not a question of the subjective experience of those with the illness themselves and those close to them or of those in the world of medicine, but rather an analysis of how dementia is represented in the news and popular culture in its widest sense. In fact, it is presupposed that the image that many people currently have of dementia does come via some indirect experience gleaned from TV, novels or the Internet.

The objective of this research is to gain insight in the prevailing images in a broad range of media and look for alternatives, which presupposed being able to understand the existing images. This is why the research question is the following: What are the dominant frames used to represent dementia and what alternative frames could be proffered?

Framing and the construction of social reality

Framing as a concept originated in the field of social psychology (Bartlett, 1932), but it is now applied in many disciplines. In communication science, framing in its broadest sense refers to the manner in which the media and the public represent a particular topic or issue (Reese, 2001). Frames are tools that are used in communication to decide which elements of reality should be selected, and which elements need a central position to present an issue as comprehensible as possible to a diversity of audiences (Entman, 1993).

Framing appears to be somewhat manipulative. However, from a constructionist perspective, framing is a process that is only partially conscious on the part of the person who creates a message (Van Gorp, 2007). This is because each culture possesses a repertoire of symbols and world-views that its members can use as a tool-kit to attribute meaning to the various events and issues with which they are confronted (Gamson & Modigliani, 1989; Swidler, 1986). When authors frame a message, they connect a topic to notions that are part of this 'common ground' within a given culture, such as values, archetypes and shared narratives (cf. Clark, 1996). It is thus possible that communicators who transmit the dominant message regarding dementia are not really conscious of the long-term effect that they create by constantly returning to the same mental images. Each association between the issue and a broader, cultural phenomenon offers a new perspective from which reality can be perceived. In order to emphasize the dynamics unfolding between frames and individual cognitive constructs, frames are considered to exist beyond people's minds, precisely as culture is not just in an individual's head (Polletta, 2004).

Methodology

Inductive framing analysis

Conducting an inductive framing analysis is not straightforward. Frame analysts must take into account that their own mental constructs may interfere with the identification of a frame (Van Gorp, 2010). One way of monitoring such interference is by taking a systematic approach that encompasses a number of parallel phases in which the researcher constantly scans and compares the research material (Corbin & Strauss, 2008).

The main product of an inductive framing analysis is an overview of interpretative frame packages (Gamson & Modigliani, 1989; Van Gorp, 2007). Each frame package is an integrated structure of a core frame, framing devices, and reasoning devices. The core frame is the implicit cultural phenomenon that defines the package as a whole, for instance, a value or an archetype. The framing devices are manifest elements in a message that function as demonstrable indicators of the frame, such as vocabulary, catchphrases, and depictions; all of which contribute to the rhetorical structure of a message (Gamson & Modigliani, 1989; Kitzinger, 2007; Tankard, 2001). Reasoning devices form a route of causal reasoning that may be evoked when dementia is associated with a particular culturally embedded frame.

Sample

The sample consisted of news and media content concerning dementia, which comprised books (n = 20), audiovisual material (n = 13), and public health care brochures (n = 15) (see Appendix). The main criterion for selection was the easy accessibility of the source for the general public in Belgium (e.g., publications on sale in regular book shops) without the material necessarily being locally produced. The most (audio-)visual material was based on the main search results for 'dementia' on www.imdb.com or www.youtube.com. However, to enhance the diversity of the material, a theoretical sampling followed to include less accessible material but with possible divergent content, like small-scale documentaries and niche books. The corpus was constructed in order to saturate the defined frames rather than being representative of a very dispersed 'population'.

In addition, a representative sample of Belgian newspaper coverage between March 1st 2008 and July 1st 2010 was selected by using the online databases www.pressbanking.be (for the French-language papers) and www.mediargus.be (for the Dutch-language papers). The first date was chosen because it was during that month that Hugo Claus, a famous Belgian writer who was living with dementia, died by euthanasia. This resulted in a feasible time span of approximately two years and it guaranteed extended media attention on dementia during some time. The sample comprised 552 articles, 58% in Dutch and 42% in French.

Analysis procedures

Three phases of analysis were conducted in parallel. The first phase consisted of applying an open coding system. A datasheet was created with 2,980 citations and illustrations from the sample. Each of these was given a code: key terms that came from the material itself, notably the metaphors used, the images, and recurring arguments. Each element represented a potential framing device, capable of invoking, at the recipient's cognitive level, a framework of thought that corresponded to the frame as it appeared in the text. The manifest reasoning devices, the elements that formed part of a certain thought process were also included in the inventory.

During the second phase, called the axial codification (Corbin & Strauss, 2008), the codes were listed and then reduced to a smaller number of significant codes. This restricted list was used to review the analysed material once more and to re-order the codes.

In the third phase, the frame packages were created, each with a logical chain of specific reasoning devices and framing devices. The overall idea, which created a logical and coherent whole based on all of the devices, was the frame itself. This stems from various cultural elements such as values, norms and archetypes. The frame packages were then regrouped in a frame matrix (see Table 1).

The authors did all the coding during the first three phases of the inductive analysis independently. There were regular moments of feedback during which possible divergences were discussed. Especially pictures turned out to be more ambiguous than written texts and were sometimes susceptible to different interpretations depending on the context in which they were used. This phase lasted until the authors reached a saturation point when no new frames were being detected. Next, the design shifted to a deductive phase during which, as a way to verify the predefined frames, every new citation had to be fitted with at least one frame package. During this process no new frames were detected. It is not possible, however, based on the qualitative data, to determine the exact frequency of use of a frame, nor to make other calculations of this type. In fact, initially, the texts were coded in function of words and parts of a sentence were isolated, but as soon as the frames began to emerge more clearly, the analysis moved to

paragraph level. Finally, it was in function of the whole text that codes, which at that stage referred to the completed frame packages, were attributed.

Finally, a workshop was organized in which the preliminary results of the analysis were presented to a group of experts. The 25 participants, who had very different profiles, were selected on the basis of their expertise in the field of dementia. A first group of 3 doctors, 3 neurologists and 6 researchers worked in the field of dementia. A second group consisted of 5 campaign developers, 3 filmmakers, 3 authors, 1 science journalist and 1 illustrator who had experience with the representation of dementia in the media. This extra expert checking and further reflections about the researchers' own positions offered more analytic rigor to the results of the applied qualitative approach.

Results

Six frames and six counter-frames

The analysis brought about six dominant frames and six related counter-frames. For the counter-frames there were two possibilities. Either it was a question of alternative frames that used the same framing devices, but which used this particular jargon to invalidate the dominant idea, invert the reasoning and call into question its relevance (as indicated in Table 1 by the letters A and B). Or it was a question of autonomous frames that were used as such, without reference to the formulations and reasoning of the dominant frame in order not to prime the related dominant frame. In that regard, Lakoff (2004) noted that if you instruct the audience not to think of an elephant, the first thing people think of is an elephant.

Table 1 shows the twelve frame packages, each composed of a central cultural theme (the frame), a specific definition of dementia, its causes and consequences, the moral values that are involved and the possible actions that can be taken. The last column of the table shows some manifest framing devices that may trigger the latent causal reasoning in the people's minds. In the following frame descriptions, every word or sentence that is placed between 'quotations marks' is a direct example from the sample. Full references can be found in the Appendix. It must be noted that the given examples, though they are certainly indicative, do not cover the full range of the frame package. The complete datasheet from the inductive coding can be obtained from the first author on request.

1A. Dualism of body and mind. This frame, which is also by far the most dominant one, postulates that a human being is composed of two distinct parts: a material body and an immaterial spirit or mind (cf. Lagerlund, 2007; Ostenfeld, 1987; Rozemond, 1998). If this dualistic image of man is used to define dementia, it is likened to a pathology that, little by little, deprives a human being of his mind. Since, in this conception, it is the mind that defines personality and human identity, the person with dementia ends up with no identity. When all mental capacities have finally disappeared, people with dementia become 'empty shells' (e.g., *De Standaard*, 29 Mar. 2008, pp. 18-20). Dementia is therefore often characterized as a 'progressive death that leaves the body intact' (*Téléoustique*, 17 Sep. 2008, p. 5) and uses metaphors of darkness in contrast with the light of reason. When the famous Belgian writer Hugo Claus died after voluntary euthanasia, the Prime Minister said in his eulogy that Claus died 'just in time before he would have imploded into a dark black hole' (*De Morgen*, 19 Mar. 2008, p. 3).

1B. Unity of body and mind. The counter-frame opposed to the conception of the separation of body and mind has as its essential characteristic that of renouncing the normative aspect of dualism. Persons with dementia still retain their physical dimension and, notably, their emotional life related to it. As Annie Ernaux (1999, p. 88) wrote in her book about her mother's life with Alzheimer's, 'Existing is being caressed

and touched'. The focus is placed not on what has been lost, but rather on what remains: a rich emotional life thanks to which the illness never becomes greater than the person (cf. Fazio, 2009). Although persons with dementia are often no longer able to speak they can still express emotions, for example through their 'grateful eyes' (Van Wouwe & Molenberghs, 1994).

2. *The invader*. The second dominant frame exploits the idea that dementia is an external character with whom one is suddenly confronted. This intruder then takes the form of a 'demon' (Jelloun, 2008, p. 78) or devil that takes possession of the person. Variations on this personification include the 'parasite' (Piel, 2009, p. 197), or some kind of thief or monster, always on the lookout and for whom anyone can be the victim, irrespective of age or status.

Previous research has already shown the military metaphors that are often used in the context of dementia (Annas, 1995; cf. AIDS and cancer, see Sontag, 1989; for SARS, see Wallis & Nerlich, 2005), and this is particularly true for this frame. As part of this logic, the solution lies in adopting a 'combative' attitude (*Knack*, 27 Jan. 2010, pp. 62-66) and 'arming oneself for a long campaign' (*Kerk en Leven*, 6 Dec. 2006, pp. 13-14).

3. *The strange travelling companion*. The counterpart to the menacing personification, perceived to be an enemy that must be fought at all costs, consists of considering the illness as someone that is 'met along the road' (Rosseels, 2009, p. 69) and with whom one must learn to cope. This personified illness is sometimes called 'my friend Alzheimer' (Van Rossum, 2009, p. 12). One therefore gets to know this astonishing and unexpected travelling companion who will accompany the persons with dementia for the rest of their days. It is therefore essential to get used to him, not to feel his presence as a burden and, above all, to retain control over one's existence. The person with the illness may tolerate him, but if he becomes too intrusive, he should be put firmly back in his place.

4A. *Faith in science*. According to the third dominant frame, dementia is seen as a biological affection, with a pathology that can be described in scientific terms. Compared with other dominant frames, this one has the particularity of being the only one that tries to sketch out a future full of hope. This often makes the headlines in newspapers: 'Neuron breakthrough offers hope on Alzheimer's and Parkinson's' (*Timesonline*, 27 Oct. 2010). Faith in science thus enables people to hope that one day a cure for this disease will be found (Mangialasche et al., 2010; Urakami, 2010). However, this frame also often implies a loss of identity and personal history for persons with dementia who are considered as patients and are reduced to the status of 'cases'. In other words, the person disappears behind the diagnosis. As Carla Rosseels (2009, p. 104) wrote, people with dementia are not to be 'reduced to their illness'.

4B. *Natural ageing*. The fundamental difference between the science-based frame and its alternative corresponding counter-frame, is that the latter refutes the status of 'illness' attributed to dementia. Here, it is not an illness, but rather a variant of the natural process of ageing of the human brain, even if here it takes an extreme form. Whitehouse and George (Whitehouse & George, 2008) are advocates of this frame. From their point of view, scientists are seen as alchemists looking for the illusory philosopher's stone or the elixir of life. However, the 'Fountain of Youth' (Whitehouse & George, 2008, p. 5) cannot be found. The logical consequence of this reasoning is that cure must be replaced by care.

5. *The fear of death and degeneration*. The fourth dominant frame concentrates entirely on the end of life, which awaits every human being, whether ill or not. According to this reasoning the diagnosis of dementia means that the life of the person with dementia is over. Unlike the frame of body-mind dualism, it is not the idea of a loss of personality which is frightening, but rather death itself, whose unavoidable nature leaves us with no perspective other than simple resignation. At the individual level, the diagnosis of dementia means nothing more than a fatal prognosis. At the collective level, this frame is linked to the demographic mutations, creating an apocalyptic picture. People speak of 'a ticking time bomb' (Braam,

2008, p. 67), a 'collective terror' (*Téléoustique*, 17 Sep. 2008, p. 5) and a 'tsunami of dementia' (Van Broekhoven, 2008, p. 267).

6. *Carpe diem*. In the counter-frame, the accent is no longer placed on the 'catastrophe' that follows the diagnosis, but rather on the time still left to live. The idea here is that people with dementia have many more moments to enjoy and so they hang on to the beauty of life and refuse to see its sad side. The message transmitted is to look for happiness and comfort in the smaller things of life. This frame stood for example at the centre of the 2009 RTVKempen docusoap on dementia under the telling title 'Pluk de dag' (*Seize the day*). This frame has its own vocabulary, which refers to happiness, love and the simple pleasures of life. It often takes the form of testimonies from those with dementia and their families.

7A. *Reversed roles*. The first frame concerning the relationships between those with dementia and those around them (the family, close carers and other carers) is inspired by the classic distribution of roles between parents and their children. In this case, dementia is seen as something that takes persons back to their earliest years and makes them live 'once again as a little child' (Jaouen, 2002, p. 167). Descriptions of typically infantile behaviour adopted by those with dementia are often found in this frame as they become 'very old little children' (Laborde, 2002, p. 142). It is often both painful and embarrassing for children to have to look after their parents, doing even the most intimate and banal things for them. A daughter whose mother was living with dementia exclaimed: 'the horror of the reversal between mother and child' (Ernaux, 1997, p. 87). The alternative is to request the help of others to assume such care, or even foresee them living institutionalized.

7B. *Each in turn*. Childhood is also the starting point for the next counter-frame, but this is associated with another logic: not a return to dependency, but a return to one's origins, which enables those with dementia, free from the constraints imposed on adults by society, when they appear to be 'as happy as a child can be' (Bernlef, 1984, p. 102). Children of people with dementia accept that in life, each has his or her own turn and the moment has come for them to be their parents' parents. This vision can also be considered as a specific variant of the frame 'Unity of body and mind'. Here, people with dementia are not treated as children, but as the vulnerable adults that they really are (cf. Lyman, 1988).

8A. *No quid pro quo*. The frame of 'no quid pro quo' also involves those around the person with dementia and this at two levels: on the one hand because of the load that the carers have to bear without there being any reciprocity, and on the other hand because of the loss of a spouse or a parent, the loss of the past that they shared. Nancy Reagan described her 'ordeal' with dementia as 'very cruel' because for the caregiver, 'it's a long goodbye' (*Newsweek*, 21 June 2004, p. 32). In this frame, not the persons with dementia are affected, but rather those close to them. The efforts needed to look after someone with dementia are emphasized, such as feeding and keeping constant watch. This sometimes leads to horrible headlines in the newspaper: 'Man could no longer cope with his demented wife—murder and suicide draw focus on the problems in informal care' (*De Morgen*, 7 Jun. 2009, p. 2). In exchange for all the effort, the carer receives hardly any gratitude or recognition.

8B. *The Good Mother*. The counter-frame attached to the archetype of the 'Good Mother' is essentially a transposition of the 'Body-mind unity', but within the perspective of family caretakers. Here, it is essential that persons with dementia continue to be considered as persons in their own right, 'to be respected as they are' (Laborde, 2005, p. 92). Despite the burden that caring represents, going to the aid of someone who needs help is seen as a natural obligation, in the image of the Good Mother who proves her unconditional love for her children. Respect for the persons with dementia and their individual preferences occupy a central place in this frame. The objective is to enable emotional contacts to take place and, by being part of the person with dementia's own universe, enable them to experience all of the love that is felt for them.

Frame	Cultural theme	Definition of the problem	Cause (why is it a problem?)	Consequences	Moral values involved	Possible solutions/actions	Metaphors, choice of vocabulary	
...	Dualism of body and mind	Cartesian dualism: a person is made up of a body (passive) and a spirit/soul (active or even supernatural/divine)	People with dementia lose their identity and humanity	Dementia confiscates a person's spirit/soul but leaves the body provisionally intact	People with dementia exist only at material level; lacking autonomy and self-control; no further communication is possible	The loss of identity is in opposition to the ideals of personal self-fulfilment and individualism	Revolt, obstinacy, keeping control; euthanasia permits reason to be the last triumph over a degenerating body	Plant, empty shell, a slowly invading emptiness, a sieve, a flickering light bulb, light/dark/ darkness, fog, desert
1B	Unity of body and mind	No pre-eminence of reason; the body and mind form an in dissociable whole	People with dementia lose their mental capacities but not their identity and above all not their humanity	Dementia leaves those with the illness with their sensory and emotional capacities for a long time	People with dementia retain a rich emotional life and at physical level they become more sensitive to touch and proximity	People with dementia remain 'whole' people	Try to establish emotional contact, meet them in their own language; personhood, humanity	Fragility, vulnerability; the patina of age
2	The invader	Thief/assassin/ intruder who is lying in wait and can knock unexpectedly; the demon that takes possession of someone	Dementia is a thief who steals a person's (happy) life and whose arrival everyone fears	Dementia has an eye on all of us: it often strikes the elderly, but sometimes affects younger people too	If dementia takes hold of someone, little by little, it destroys everything that the person has built up throughout his/her life	Dementia is an evil creature, an enemy to be fought; you have to react, not let yourself go	Arm yourself to fight this external enemy, even if you know that you will lose in the end	Thief, invader, demon, monster, ghost; warlike vocabulary: siege, defence against the terrible illness
	The strange travelling companion	A travelling companion whom you meet out of the blue and who accompanies you to the end of your journey	Dementia is a meeting at an inopportune moment, a meeting that you have to learn to deal with	Dementia can cross the path of many people, it's the ransom of an ageing population	You have to learn to live with it, try to retain as much of one's autonomy and 'governance' over one's	The moral norm demands that you show yourself to be strong in the face of adversity	Acceptation / appeasement; continue to live as well as possible up to the end	Travelling companion, flatmate, strange lodger in our head, with whom we have to come to terms

life as possible

4A	Faith in science	Medical science that has an increasingly better understanding and seems to be capable of performing miracles	People with a brain condition should be treated as patients	The disease itself remains largely an enigma for science; a cure thanks to medicine still seems out of reach	Cerebral lesions, memory deficit; people with the disease tend to disappear behind the diagnosis	One has to have confidence in science, which is the only possible solution	We need more research, clinical trials and financial resources; faith in science; the myth of eternal youth	Illness, diagnosis and treatment (cure), medical jargon
4B	Natural process of ageing	Ageing is a natural process that is part of life; one can try to 'deal with it successfully' but wishing to prevent it is unrealistic	Dementia is not an illness because there is no significant difference from the normal process of ageing of the brain	Dementia is an extreme form of the brain's process of ageing; it merely enables the 'negative' aspects of ageing to appear	Dementia will always be incurable; looking for a medicine to cure it would be like searching for a pill to ensure eternal youth	People with dementia are an integral part of our society	Encourage preventative behaviour; an active and healthy life; staying involved in a social network; empowerment	Active seniors but not 'wanting to stay young at any price'
5	The fear of death and degeneration	Death, the terrible destiny that awaits us all	Dementia is a total catastrophe, an annihilation; people are affected with an irreversible and incurable process of degeneration	Dementia is synonymous with being condemned to death; it's an ageing illness that people already close to death get	Lost before it starts; for those close, it's the loss of a dear one before he/she has actually died	Progressive deterioration; anxiety about dying, indignity	Prostration: only death can bring deliverance	Living dead, images of the apocalypse and decrepitude; language of death, mourning and separation
6	Carpe diem (carpe diem)	Making the most of the present	Those with dementia still have some good years left	Life is short for everyone, so we must take advantage of every single moment	We must live from day to day, find happiness in the little things in life	Make the most of life and the little things that make up happiness	Have confidence in people who do everything to ensure that life is worth living	Make the most of the day; take life as a gift, the

right up to the end present

7A Reversed roles	Parents and children have pre-defined and reciprocal roles to assume	People with dementia behave like children again; parent/children roles are reversed	The person with dementia strays from typical adult behaviour: autonomy, responsibility, adherence to social norms of behaviour	Since the children now have to look after their parents, the usual roles are reversed; people with dementia are seen as a burden	The norm that demands an adult person to be able to control his/her urges is no longer respected	Hide away those with dementia, get rid of them; put them in an institution so that they are out of sight	The dependent child
7B Each in his/her turn	Idem: parents and children have pre-defined and reciprocal roles to assume	People with dementia experience a return to their beginnings, to the happiness and care freeness of their childhood	Idem, but those with the illness are not necessarily aware of this because their inhibitions and social proprieties disappear	Parents and children (their entourage) are companions of misfortune, sticking together in acceptance of what is happening	Each in turn: after the parents have looked after their children, it is then their turn to look after their parents	Discovering a parent from another perspective, understanding him/her better; warmth, closeness	Parent and child go hand in hand; youth rediscovered (freedom, play, happy go lucky); freedom from inhibitions social constraints
8A No 'quid pro quo'	Each and everyone has the right to get the most out of life; everything has a price, one gets nothing for nothing	The real victims of dementia are those around the person with the illness; it's an illness that affects the whole family	The person with dementia loses his/her autonomy: so someone has to do everything without getting anything in return	When recognition is lacking, there is a risk of loss of contact and isolation	When the need for help becomes too great for the carer, the person with dementia has to be institutionalised urgently	Offer/accept support for family carers in the advanced stages of the illness; institutionalisation is the best solution	A heavy burden to bear; accent on the need for care and compassion; collateral damage of dementia

The loving and devoted mother who sacrifices herself unconditionally for her children

Nature has made us so that we take care of each other and this is true for those with dementia too

People with dementia should be able to count on their close carers and understanding professional carers

Surrounding the patients with love and accepting his/her lot with patience and resignation

Love of one's nearest and dearest as a universal value; our moral duty to act this way

Keep the person with dementia at home for as long as possible; respect one's promise up to the end

Extend a helping hand, offer support and listen attentively

Combinations of frames

What has been described so far does not mean that every source uses only one frame. According to the analysis, several of the frames are combined. One of the most common combinations within a single text associates, for example, 'Dualism of body and mind' and 'The invader'. In this case, dementia is a thief that takes over someone's mind. These frames also combine with that of 'Faith in science', when the hope is expressed of being able to unmask this mysterious thief named Alzheimer. In some instances, even three frames may be combined, such as 'The invader', 'Fear of death and degeneration' and 'Faith in science'. Since the latter implies that the illness will be able to be cured one day, an apocalyptic image of the condition is often the first thing to be mentioned. Once the urgency of tackling the illness has been established, it becomes easier to plead for providing researchers with the necessary funds, in conformity with the 'Faith in science' frame.

The use of frames

None of the defined frames is the privilege of a single source; most sources use a combination of multiple dominant frames. Nor is there a notable difference between written media and (audio-)visual media. However, there seem to be some patterns. Changes in personality and the gradual loss of identity, themes that are characteristic of the 'Dualism of body and mind' frame, are ever present in the (auto)biographies of people with dementia and the accounts of those close to them. This is less the case in healthcare professionals' communications, where the 'Strange travelling companion' frame is more evident. For carers, it is therefore less a question of loss than of maintaining as much contact as possible.

The frame 'Faith in science' is especially present in documents relating to younger people with dementia. The abnormal nature of this situation sustains the hope of seeing science make new progress. Scientists are numerous in their use of negative frames, especially that of 'The invader' (and victory over him) and 'Faith in science'. These frames contribute to making the problem an issue for society. This serves the interests of science by making pleas for the necessary budgets more logical. One also notes a dramatization of the illness among other actors who depend on these financial resources, such as fundraisers. Overall, the accounts of those with dementia and their families are those that contain the most alternative frames, principally 'The strange travelling companion' and 'Carpe diem', but also the 'Unity of body and mind' and 'The Good Mother' frames. One of the participants in Renée Beard's study (et al., 2009, p. 233) on the experience of those with dementia said: 'I am more than my illness!'

Discussion

The starting point of this research was the acknowledgement that the problem of dementia is seemingly made worse by the negative regard in which the illness is held by society and which favours long-term stigmatization. An inventory of dominant frames was developed that might be helpful for professionals and caregivers who wish to evaluate their communication strategy. In fact, framing implies the existence of alternative counter-frames that may offer a 'new' perspective to the disease. Therefore, this study paid particular attention to identifying alternative frames that might act as counterweights. This was a normative premise, but one that seemed to be justified, mainly on the basis of the idea that the stigmatization of dementia weighs on the shoulders of those with the illness as well as those close to them and indeed more broadly on the whole of society.

An inductive framing analysis of the content of the material assembled enabled six dominant frames to emerge, five of which revealed a negative vision. The only exception was the 'Faith in science' frame, which offers hope for finding a cure for dementia. Among the negative frames, the one that postulated a separation of body and mind was by far the most dominant. Sick people no longer have their place in a society that celebrates the values of the mind, as Downs (2000) noted. Only two real counter-frames were found: frames that function autonomously and ignore the terminology of the dominant frames. These were, on the one hand the frame 'Carpe diem', which is the counterpart of the frame 'Fear of death and degeneration'. To the frame of 'The intruder', the frame 'The strange travelling companion' may function as a counterpart.

The framing approach in this research contributes and builds on the existing findings by providing more understanding of how people integrate images of dementia presented by all kind of media, and that form their lens for viewing dementia. The general public as well as researchers, academia, general practitioners and caretakers share a set of cultural ideas, values, and expectations about social roles that are used to give meaning to dementia. The analysis confirms previous studies like the acknowledgement made by Clarke (2006) relating to American and Canadian magazines: what is missing is the voice of those with dementia themselves. The relative absence of counter-frames confirms the negative image of dementia. The accent is above all placed on the person of dementia's loss of capacities, decline, vegetative state—even hell—of the lives of those with dementia, the refusal of dependence and degeneration, the desire to wish, oneself, to pull the plug, the disappearances and the wandering, and finally the mental illness. The frequent recurrence of the 'Faith in science' frame also corroborates Kirkman's findings (2006) that that the medical frame dominates news coverage on dementia. Trends and structural problems can only make the headlines if something special happens, and that seems to be true also for dementia. This may explain why the news media in Belgium provide coverage of dementia mainly when they can report on medical discoveries.

The inventory implicitly suggests making greater and more resolute use of counter-frames in communicating about dementia in order to render it more socially acceptable. Nevertheless, the analysis shows that this risks coming up against an obstacle: in fact it is as important for those with dementia as it is for all other actors concerned that the theme of dementia remains a priority, notably for decision makers, scientists and the media. It is therefore also tempting to call upon the dominant frames so that the issue does not lose its urgency. The dominant frames appear the best suited to ensure the financing of scientific research and certain specialist associations. However, this coin also has its reverse side, notably a fatalistic perception of dementia at the individual level. While the strategy might have positive effects in the short term (more funds raised), it would nevertheless perpetuate the negative connotation and stigma associated with the illness over the long term. A practical application of the results of this study can be viewed on the

website www.onthoumens.be. The framing analysis has served as the basis of this Internet platform that was developed by the Flemish government to make the society more dementia friendly. For instance, the website includes a database with free images on dementia that fit within the defined counter-frames.

The research provided learning about our underlying cultural frames in relation to dementia and what the illness represents for society and how it is perceived as a problem. However, despite the numerous sources analysed and the systematic way in which they were analysed, the approach does not provide unquestionable figures. Neither is it possible to exclude all subjective interpretation on the part of the researchers, independently of knowing whether this would be useful or desirable. A suggestion for future research is to do a quantitative content analysis, in order to measure to what extent the inductively reconstructed frame packages are actually applied in a representative sample of texts. Other suggestions for further research are to repeat this study cross-culturally to detect possible differences in frames, also between Western and non-Western countries. Based on this study, it is not possible to state whether the same frames, or counter-frames, dominate the interpersonal communication in the health care sector or in the communication between doctors and their patients. Further, the credibility and thus the eventual deployability of counter-frames, such as *Carpe diem*, should be tested in audience research. Perhaps, the alternative conceptions are seen as incompatible with the negative prevailing images.

REFERENCES

- Adelman, R.C., & Verbrugge, L.M. (2000). Death makes news: The social impact of disease in newspaper coverage. *Journal of Health and Social Behavior*, 41(3), 347-367.
- Annas, G. (1995). Reframing the debate on health care reform by replacing our metaphors. *New England Journal of Medicine*, 332(11), 744-747.
- Bartlett, F.C. (1932). *Remembering: A study in experimental and social psychology*. Cambridge: Cambridge University Press.
- Beard, R.L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23, 227-235.
- Blay, S.L., & Peluso, E.T.P.P. (2010). Public stigma: The community's tolerance of Alzheimer disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-171.
- Cantegreil-Kallen, I., Turbelin, C., Olaya, E., Blanchon, T., Moulin, F., Rigaud A-S., & Flahault, A. (2005). Disclosure of diagnosis of Alzheimer's disease in French general practice. *Am J Alzheimers Dis Other Demen*, 20(4), 228-232.
- Carbannelle, S., Casini, A., & Klein, O. (2009). *Les représentations sociales de la démence: de l'alarmisme vers une image plus nuancée. Une perspective socio-anthropologique et psychosociale*. Bruxelles: Fondation Roi Baudouin.
- Castellani, R.J., Rolston, R.K., & Smith, M.A. (2010). Alzheimer disease. *Dis Mon*, 56, 484-546.
- Clarke, J.N. (2006). The case of the missing person: Alzheimer's disease in mass print magazines 1991-2001. *Health Communication*, 19(3), 269-276.
- Clément, S., & Rolland, C. (2008). Dédratiser l'image de la maladie. *Cerveau & Psycho*, 26. Retrieved from <http://www.cerveauetpsycho.fr>.
- Corbin, J., & Strauss, A.L. (2008). *Basics of qualitative research*. Thousand Oaks, CA: Sage.
- Downs, M. (2000). Dementia in a socio-cultural context: An idea whose time has come. *Ageing and Society*, 20, 369-375.
- Entman, R.M. (1993). Framing: Toward clarification of a fractured paradigm. *Journal of Communication*, 43(4), 51-58.
- Fazio, S. (2009). Persistence of Self in individuals with Alzheimer's disease: Evidence from language and visual recognition. *Dementia*, 8, 39-59.
- Ferreira, M., & Makoni, S. (2009). Narratives and the construction of elderliness: Towards a cultural and linguistic construction of late-life dementia in an urban African population. *International Psychogeriatrics*, 21, 793-795.
- Gamson, W.A., & Modigliani, A. (1989). Media discourse and public opinion on nuclear power: A constructionist approach. *American Journal of Sociology*, 95, 1-37.
- Kirkman, A.M. (2006) Dementia in the news: The media coverage of Alzheimer's disease. *Australasian Journal on Ageing*, 25(2), 74-79.
- Kitzinger, J. (2007). Framing and frame analysis. In E. Devereux (Ed.), *Media studies: Key issues and debates* (pp. 134-61). Los Angeles: Sage.
- Lakoff, G. (2004). *Don't think of an elephant! Know your values and frame the debate*. White River Junction, VT: Chelsea Green Publishing.
- Leibing, A. (2002). Flexible hips? On Alzheimer's disease and aging in Brazil. *Journal of Cross-Cultural Gerontology*, 17(1), 213-232.
- Luengo-Fernandez, R., Leal, J., & Gray, A. (2010). *Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom*. Retrieved from www.dementia2010.org.
- Mangialasche, F., Solomon, A., Winblad, B., Mecocci, P., & Kivipelto, M. (2010). Alzheimer's disease: Clinical trials and drug development. *The Lancet Neurology*, 9, 702-716.
- Mura, T., Dartigues, J.-F., & Berr, C. (2010). How many dementia cases in France and Europe? Alternative projections and scenarios 2010-2050. *European Journal of Neurology*, 17, 252-259.
- Naue, U., & Kroll, T. (2008) "The demented other", identity and difference in dementia. *Nursing Philosophy*, 10, 26-33.
- Pin, S., Bodard, J., & Richard, J.-P. (2011, May). Different perspectives on Alzheimer's disease: Perceptions, opinions and attitudes among the general public, immediate assistants and professional assistants. *Evolutions*, no. 25.
- Pin le Corre, S., Benchiker, S., David, M., Deroche, C., Louassarn, S., & Scodellaro, C. (2009). Perception sociale de la maladie d'Alzheimer: Les multiples facettes de l'oubli. *Gérontologie et société*, 128-129, 75-88.
- Polletta, F. (2004). Culture is not just in your head. In J. Goodwin, & J. M. Jasper (Eds.), *Rethinking social movements: Structure, meaning, and emotion* (pp. 97-110). New York: Rowman and Littlefield.
- Reese, S.D. (2001). Introduction. In: S.D. Reese, O.H. Gandy & A.E. Grant (Eds.), *Framing public life: Perspectives on media and our understanding of the social world* (pp. 1-31). Mahwah, NJ: Erlbaum.
- Segers, K. (2007). Degenerative dementias and their medical care in the movies, *Alzheimer Dis Assoc Disord*, 21(1), 55-59.
- Sontag, S. (1989). *AIDS and its metaphors*. New York: Farrar, Straus and Giroux
- Sweeting, H., & Gilhooly, M. (1997) Dementia and the phenomenon of social death, *Sociology of Health & Illness*, 19(1), 91-117.

- Swidler, A. (1986). Culture in action: Symbols and strategies. *American Sociological Review*, 51(2), 273–286.
- Tankard, J.W. (2001). The empirical approach to the study of media framing. In S.D. Reese, O.H. Gandy, & A.E. Grant (Eds.), *Framing public life: Perspectives on media and our understanding of the social world* (pp. 95-106). Mahwah, NJ: Lawrence Erlbaum.
- Tarek, M.E., Segers, K. & Van Nechel, C. (2009). What Belgian neurologists and neuropsychiatrists tell their patients with Alzheimer disease and why. *Alzheimer Dis Assoc Disord*, 23(1), 33-37.
- Urakami, K. (2010). Diagnostic biomarker for early stage of Alzheimer's disease: Current state and view in the future. *Psychogeriatrics*, 10, 49-52.
- Van Gorp, B. (2007). The constructionist approach to framing: Bringing culture back in. *Journal of Communications*, 57, 60-78.
- Van Gorp, B. (2010). Strategies to take subjectivity out of framing analysis. In P. D'Angelo & J. Kuypers (Eds.), *Doing news framing analysis: Empirical and theoretical perspectives* (pp. 84-109). New York: Routledge.
- Wallis, P., & Nerlich, B. (2005). Disease metaphors in new epidemics: The UK media framing of the 2003 SARS epidemic. *Social Science & Medicine*, 60(11), 2629-2639.
- Werner, P. (2005). Social distance towards a person with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 20, 182-188.
- Werner, P., Goldstein, D., & Buchbinder, E. (2010) Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qual Health Res*, 20(2), 159-169.
- Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Ageing & Mental Health*, 12(1), 92-99.
- Whitehouse, P. J., & George, D. (2008). *The myth of Alzheimer's*. New York: St. Martin's Press.
- World Health Organization (2004). *Atlas Country Resources for Neurological Disorders*. Geneva: WHO.

APPENDIX

Description of the sample

Newspapers included in the sample: De Morgen, De Standaard, Gazet van Antwerpen, Het Laatste Nieuws (Flanders), Le Soir, La Libre Belgique, La Dernière Heure and La Meuse (Walloon and Brussels capital region).

Audiovisual material: Away From Her (Film, S. Polley, Canada & USA, 2006); De Zaak Alzheimer (Film, E. Van Looy, Belgium & the Netherlands, 2003); De zondvloed (Film, P. Ghesquière, Belgium, 2006); Deep Blue Sea (Film, R. Harlin, USA & Australia, 1999); Helaasheid der dingen (Film, F. Van Groeningen, Belgium, 2009); Iris (Film, R. Eyre, UK & USA, 2001); Les Mots de Madame Jaquot (Documentary, M. Desmarres, Belgium, 2007); Malcolm and Barbara: Love's Farewell (Documentary, P. Watson, UK, 2007); Mum and Me (Documentary, S. Bourne, UK, 2008); My Name is Lisa (Film, B. Shelton, USA, 2007); Pandora's Box (Film, Y. Ustaoglu, Turkey, France, Germany & Belgium, 2008); Pluk de Dag (Docusoap, RTVKempen – Mechelen, Belgium, 2009); Verdwaald in het geheugenpaleis (Documentary, K. Van Es, Belgium, 2010); The Notebook (Film, N. Cassavetes, USA, 2004)

Literature: P. Allegaert (red.) (2009). Uit het Geheugen [Exhibition catalogue]. Tielt: Lannoo; J. Bayley (1998). Iris: A memoir of Iris Murdoch. London: Abacus; T. B. Jelloun (2008). Sur ma mère. S.I.: Gallimard; J. Bernlef (1984). Hersenschimmen. Amsterdam: Querido; S. Braam (2008). Ik heb Alzheimer: Het verhaal van mijn vader. Amsterdam: Nijgh en Van Ditmar; A. Ernaux (1997). Je ne suis pas sortie de ma nuit. Paris: Gallimard; H. Jaouen (2002). Mamie mémoire. S.I.: Gallimard; M. Jürgs (2001). Alzheimer. Baarn: Tirion; F. Laborde (2002). Pourquoi ma mère me rend folle. Paris: Flammarion; F. Laborde (2005). Ma mère n'est pas un philodendron. Paris: Flammarion; F. Piel (2009). J'ai peur d'oublier [autobiography]. Neuilly-sur-Seine: Michel Lafont; R. Pulkkinen (2006). De Grens. Amsterdam: De Arbeiderspers; P. Roca (2007) Rimpels [comic book]. 's-Hertogenbosch: Silvester; O. Rosenthal (2007). On n'est pas là pour disparaître. S.I.: Gallimard; C. Rosseels (2009). Dement en toch dichtbij. Antwerp: Houtkiet; C. Van Broeckhoven (2006). Brein & Branie: Een pionier in Alzheimer. Antwerp: Houtkiet; G. Van Broeckhoven (2008). De Voltooid vergeten tijd: Alzheimer. Antwerp: Standaard Uitgeverij; J. Van Oers (2006). Vlinderpark Alzheimer. Tielt: Lannoo; E. Van Rossum, (2009). Een vreemde kostganger in mijn hoofd [autobiography]. Amsterdam: Van Gennepe; P. Van Wouwe, P. & C. Molenberghs (1994). Mathilde pakt de zon. Leuven: Uitgeverij P.

Dienst Onderzoekcoördinatie
Huis Bethlehem
Schapenstraat 34
B-3000 Leuven
België
Tel.: +32 16 32 40 65
Fax: +32 16 32 41 98
onderzoek@kuleuven.be
www.kuleuven.be

