Aagje Swinnen, Mark Schweda (eds.)
Popularizing Dementia

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Popularizing Dementia

Public Expressions and Representations of Forgetfulness

[transcript]

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Representation of Alzheimer's disease among non-specialists

A cross-cultural study between Paris and Boston

MARIE-CHRISTINE NIZZI

> You see a bird, I see an antelope; the physicist sees an X-ray tube, the child a complicated lamp bulb; the microscopist sees coelenterate mesoglea, his new student sees only a gooey, formless stuff. Tycho and Simplicius see a mobile sun, Kepler and Galileo see a static sun.
> (Hanson 1965: 17)

With characteristic elegance, Norwood Hanson reminds us of how much our theories influence the way we perceive any given phenomenon. We experience the world and we make sense of it based on our repertoire of ideas and concepts. The same object – say an X-ray tube or a topographic map – is perceived very differently after one acquires the knowledge necessary to decrypt its meaning and use it appropriately. As much as we tend to forget it, our knowledge is deeply context-dependent.

This paper examines the context-dependence of the ways in which Alzheimer's disease (AD) is represented. It compares the ways in which non-specialists represent AD in two different cultural settings, Paris and Boston. We start from the assumption that people who represent the same object differently possess different understandings of what the object is. Hence, we expect that the study of social representations among non-specialists can shed light on how a disease studied internationally as a single theoretical construct can take on very different meanings in different cultural contexts.

In the past 15 years, there has been a growing awareness that late-onset dementia poses an increasing number of social and medical challenges both in the scientific community and in society at large. Initiatives have been launched around the world to promote research, improve diagnosis, come up with efficient medication, and develop appropriate care facilities. However, there is a significant gap between the relative agreement among scientists discussing AD and the diversity in socio-economic policies in countries with drastically different health care systems.

In this paper, we focus on two contexts: Paris (France) and Boston (United States). Both cities are major cultural, medical and university centers, with populations of about 5 million for the city and its closest suburbs and average annual incomes of about $50.000 in 2011. The prevalence of AD in both areas is similar, averaging around 15 percent of the senior population. At the national level, it is estimated that roughly 1.5 percent of the total population in France suffer from AD and about 1.7 percent of the population in the United States. AD is the fourth highest cause of death in France and the sixth highest in the United States. Thus, for all intents and purposes, the prevalence of the disease is comparable in Paris and Boston. The two, however, differ markedly in cultural and socio-medico-politic contexts, and, more specifically, in the way their local governments handle communicating information about AD to the general public.

THE IMPORTANCE OF THE SOCIO-CULTURAL CONTEXT

Paris

France has a long history of nation-wide Alzheimer plans funded by the government and advertised in the media via massive information campaigns. In the past 15 years, three such plans have been launched, one in 2001, one in 2004 and one in 2008. From this situation, we can expect Parisians to have had very considerable exposures to systematic information campaigns about AD. At the time of data collection, France had

- 427 local AD clinics taking care of 350.000 patients annually;
- 27 regional memory centers supporting diagnosis of atypical cases and research via the creation of a national database (BNA);
- 350.000 patients receiving full health care cost coverage for Long Term Condition (ALD).

The first national plan, promulgated in 2001, was supported by the then French Minister for Health, Bernard Kouchner, with the primary goals of informing the public and improving diagnosis. At the time, there were 400.000 cases of AD with an estimated increase of more than 100.000 cases per year. In October 2001, the government announced a series of measures to meet the socio-medico-economic challenge of AD ("Programme pour les personnes souffrant" 2001). In response to one of these measures, "Goal 4," which insists on the need to "inform and support" patients and their families, the government allocated 150 million francs annually for five years to create a network of 1.000 local Centers for Information and Coordination (CLIC) to help families and inform the general public. A fund with an annual budget of 16.5 billion francs was established to support patients with AD beyond the universal health care system (medical and technical help at home, support for caregivers, etc.). Starting in January 2002, this Personal Allocation for Autonomy (APA) was given to every senior citizen over 60 in proportion to their degree of dependence (AGGIR scale). The plan also allocated a) 79 billion francs to the creation of 7.000 openings in daycare over four years, adding to the 3.600 existing ones, to be jointly funded by the universal health care and the APA; and b) 5 million francs to fund a network of 232 local clinics for diagnosing and treating patients with dementia through the joint action of specialized neuropsychologists and inter-regional coordination centers (Circulaire 2002).

In 2003, a team called Prospective Instance for AD was created with the mission of identifying the general public's main needs and concerns using a two-year national survey. This work resulted in the promulgation of a brochure nationwide in 2005 geared towards educating the general public about the disease and the new structures created by the 2001 plan. The campaign of 2004, supported by the then French Minister for Health, Philippe Douste-Blazy, allotted 15 million euros to extend the initial measures by 100 new memory clinics and 13.000 new daycare and assisted living openings by 2007. At the time, 827.000 patients were receiving the APA and there are 427 CLICs. Of special interest was the decision to designate AD as a long-term condition, which gave patients the right to full health care coverage by the government (Décret 2004). In 2007, the government declared AD a "great national cause" and a massive information campaign was launched using an array of media (internet, TV, radio, newspapers, billboards, and flyers in health care facilities). The campaign main-

ly revolved around familiarizing the public with AD's early symptoms and with the impact of the disease on patient autonomy in everyday life.

Between 2008 and 2012, informing the public again became the center of the government's plan. It announced the launch of a nation-wide qualitative survey to "identify the representation of AD in the general public," which would be repeated annually and reported in the media to give the public some feedback. Of specific interest in the 2008 plan was the focus of Measure 37 "Investigate the social representation and attitude of the public about Alzheimer's disease." After a preliminary assessment of the current representation across the world based on previous literature (Scodellaro and Deroche 2008) and three follow-up studies in France in 2009 ("Plan Alzheimer" 2012), the main line of communication was set as "providing the public with a richer knowledge of the symptoms to fight the current prevalence of fear in the social representation of Alzheimer's disease." Under the French presidency of the European Union the same year, France declared AD a European priority and allocated funding for joint research programs and the launching of a heavily advertised international conference with feedback to the general public in the media.

Boston

In contrast, in Boston, information about AD is conveyed by a decentralized cohort of actors. The city has just begun to implement state information campaigns for the general public. At the time of data collection, their state campaign had not yet been launched. From this situation, we can expect Bostonians to have been much less exposed to systematic information campaigns about AD.

At the federal level, the United States adopted the "National Alzheimer's Project Act" in 2011. It announced a large public education campaign with the goal of "informing to fight fear" (cf. "Building Awareness" 2013). Other sources of information regarding symptoms, clinical trial, and current research include the National Institute of Aging (NIA), which has established the Alzheimer's Disease Education and Referral Center, and the Administration on Aging (AOA), one out of four units of the Administration for Community Living (ACL) charged by the US-Department of Health and Human Services to provide general policy coordination. Interestingly, one of the missions of the AOA is to "advance state initiatives toward coordinated systems of home and community-based care – linking

public, private, and non-profit entities that develop and deliver supportive services for individuals with AD and their family caregivers"[1] through their Alzheimer's Disease Supportive Services Program (ADSSP). One state-level conduit for such programs is the Executive Office of Elder Affairs. Additionally, the NIA created 29 Alzheimer Disease Centers (ADCs) to conduct research, treatment, and education; two of which are located in Massachusetts.

At the other end of the spectrum from the federal level is the Massachusetts/New Hampshire Chapter of the Alzheimer Association. Every year, it organizes a number of actions to raise awareness through a helpline, several care guides, walks and fund raising events throughout the state, as well as specific actions with local partners such as Tufts Health Plan which offered a free dementia-consultation to their members in 2013. However, most of these actions reach people with a preexisting interest in AD rather than the general public in the way a systematic state plan could. Moreover, they rely mostly on individual partnerships rather than impacting the entire network of actors. Some other, more generalized initiatives, such as the distribution of 100.000 flyers on World's Alzheimer's Day in 2012 in partnership with Dunkin' Donuts, are a step towards educating the general public (Annual report of the Alzheimer Association 2013).

In 2010, Governor Patrick Deval convened the Alzheimer's disease and Related Disorders (ADRD) State Plan Task Force, born from a partnership between the Massachusetts Executive Office of Elder Affairs and the Alzheimer's Association, Massachusetts/New Hampshire Chapter. To identify the concerns and needs of Massachusetts citizens, "four listening sessions were held throughout the state, involving more than four hundred people." In 2012, the report declared its first recommendation as "informing the population" and stressed the following points:

- AD patients and families often do not know where to get information;
- even when structures exist, a majority of primary care physicians indicated that they were not knowledgeable about these resources;[2]
- respite services are not affordable for the majority of families in the Commonwealth.

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1 http://www.aoa.gov/AoARoot/AoA_Programs/HPW/ALz_Grants/index.aspx.
2 Results from a survey conducted by the Massachusetts Medical Society in collaboration with the Alzheimer's Association in 2010.

These conclusions were extremely important as they outlined the specific context set by the health care system in Massachusetts. As the report explained, "the therapeutic benefits of respite services for the person with Alzheimer's or a related disorder are not defined as 'medically necessary' by federal, state or private insurers, and thus most often do not qualify for reimbursement through these programs." However, the recent adoption of the Affordable Care Act, which includes an Annual Wellness Visit, could become a means for launching an information campaign targeted at both health care providers and Medicare recipients. The Task Force's recommendations were intended to be implemented "over the next 5 years by the Executive Office of Health & Human Services (EOHHS), Elder Affairs and the Alzheimer's Association of Massachusetts and New Hampshire in conjunction with other stakeholders through the establishment of an Alzheimer's Team" (State Plan Workgroup 2012).

In 2013, the same year Boston was hosting the Alzheimer's Association International Conference (AAIC), Massachusetts was the first American state to register with the Alzheimer's Early Detection Alliance (AEDA), with the goal of helping to "provide all state employees with information about early warning signs of Alzheimer's and resources to support those affected and their families." Interestingly, the official announcement on www.mass.gov included a link to the Massachusetts and New Hampshire Chapter Home page on the Alzheimer Association's website – which lists ten signs of AD, stages, risk factors, etc. The state's partnering with the Alzheimer's Association was a result of efforts by the Massachusetts administration under Patrick Deval to implement recommendations to increase awareness within the ADRD State Plan. This partnership was another step towards approaching the public's accessibility to information about AD more systematically, while advertising the state's initiative in the media.

In 2014, the Department of Public Health, announced a "Request for Promulgation of Proposed Amendments to 105 CMR 150,000: Licensing of Long-Term Care Facilities, Regarding Minimum Standards for Dementia Special Care Units." The text underlined that

currently, 105 CMR 150.000 does not have specific requirements for facilities or nursing home units that advertise themselves as providing specialized care for dementia. The proposed regulatory amendments would establish minimum standards for these nursing units, and require training on dementia care for direct care workers,

therapeutic activity directors and supervisors of direct care workers in both traditional nursing units and DSCUs.

This text and the ADRD State Plan are a strong sign that Boston is implementing a systematic course of action with regard to AD that includes an information campaign targeted at the general public as well as health care providers. We anticipate that a survey posterior to the implementation of this plan would find a modification in the social representation of AD currently described in the literature (Ayalon 2004; Connell 2007; Cutler 2002; Metlife Foundation 2006; Roberts 2003; Steckenrider 1993).

POPULATION AND METHODS

In this survey, we investigate the social representation of Alzheimer's disease in two matched samples: a French sample collected in Paris and an American sample collected in Boston (see table 1; total n=100, 50 females, mean age = 44, from 23 to 87 years old), following the method established in the field (Abric 1994; Chauchat 1995; Doise 1986; Doise et al. 1992; Flament 1994; Moscovici 1961; Verges 2001). We are interested in how the core elements of representation of AD vary across these two samples as a function of nationality, gender, age, and personal contact with persons suffering from AD.

We hypothesize that the social representation of AD is context-dependent, so we expect to find different representations across countries that are related to the different exposure of the general public to large information campaigns in Paris and Boston. AD affects primarily women and persons over 50 years old. Therefore, demographic variables are interesting for assessing the degree to which the representation within a homogenous population might vary with respect to age and gender. The last variable hypothesizes that being in direct contact with a person suffering from AD (here called a patient) will provide the respondents with a firsthand knowledge, likely richer and less stereotypical than respondents without such knowledge. To test our hypotheses, we analyze our data first for the total sample and then group by group.

Table 1. Population statistics

N=	Subjects	Females	Age <44	No contact	At home
French	50	25	24	30	11
American	50	25	26	23	11

Respondents were asked to provide the first five ideas that popped into their mind when they thought about Alzheimer's disease. Then, they were asked to give each of these items a *grade* on a scale measuring how representative the item is of AD, from one (not representative) to ten (very representative). Later, we also coded items by *order in which they were stated* on a scale from one to five, as an objective measure of what comes to mind first.

Following the social representation literature (cf. Moscovici 1984, 1988; Jodelet 1991), we defined the following categories for the total population and for each sub-group:

- the *heart* of the representation – items mentioned by at least 50 percent of the respondents at a rank of mention inferior or equal to three;
- the *body* of the representation – items mentioned by at least 25 percent of the respondents at a rank inferior or equal to three;
- the *contrast area* – items mentioned by at least 10 percent of the respondents at a rank inferior or equal to three;
- *two peripheries* – items mentioned respectively by over 25 percent and 10 percent of the respondents at a rank superior to three but with a representativity grade superior to 9.

To simplify the cross-cultural comparison over many sub-groups, we reduced the data reported here to the *heart* of the representation, the *body* of the representation, and the *margins* of the representation (items mentioned by at least 10 percent of the population at a rank <3 or with a grade >9). The data was analyzed in R through multidimensional scaling, considering frequency tables, co-occurence patterns, configuration analysis, and cluster analysis. Frequencies across groups were compared using Chi square. For purposes of clarity, the names of the items were shortened in the figures below. For instance, the respondents' term *memory loss* was shortened to *memory* in the figures. In the same way, *loss of self*, *loss of independence*, *loss of communication*, and *mood disorder* were shortened. The item *pa-*

tient stands for the name of a loved one who is ill, for instance when a respondent said "my grandmother."

RESULTS

Two nations = Two representations?

We were first interested in finding out whether the two groups of respondents living in comparable cities with a comparable prevalence of AD but with very different levels of exposure to public campaigns of information about the disease would show any differences in their representations of AD. Our first hypothesis anticipated that the social representation of AD would vary depending on cultural context. To test this hypothesis, we ran a cluster analysis on the raw data from our total sample, that is, we asked our model to pair items that often come up together without specifying which respondents were French and which were Americans.

The dendrogram below (figure 1) shows the output of this analysis. After the analysis, we counted the respective occurrences of each item in the two samples and colored them with respect to the nationality that mentioned the item most often. Throughout this section, French items are colored in blue and American items in red. For an item mentioned by both groups, a cut-off was chosen at 75 percent: If the item is mentioned by each group between 50 and 74 percent of its occurrences, then it was considered a shared item.

Indeed, the model ends up with two clusters, mapping remarkably well onto nationality. Cluster 1 is composed of 87 percent French items and cluster 2 of 97 percent American items. Without indicating any difference pertaining to nationality, our multidimensional scaling analysis finds the two samples within the structure of the data itself.

Fig. 1: Cluster analysis for total sample
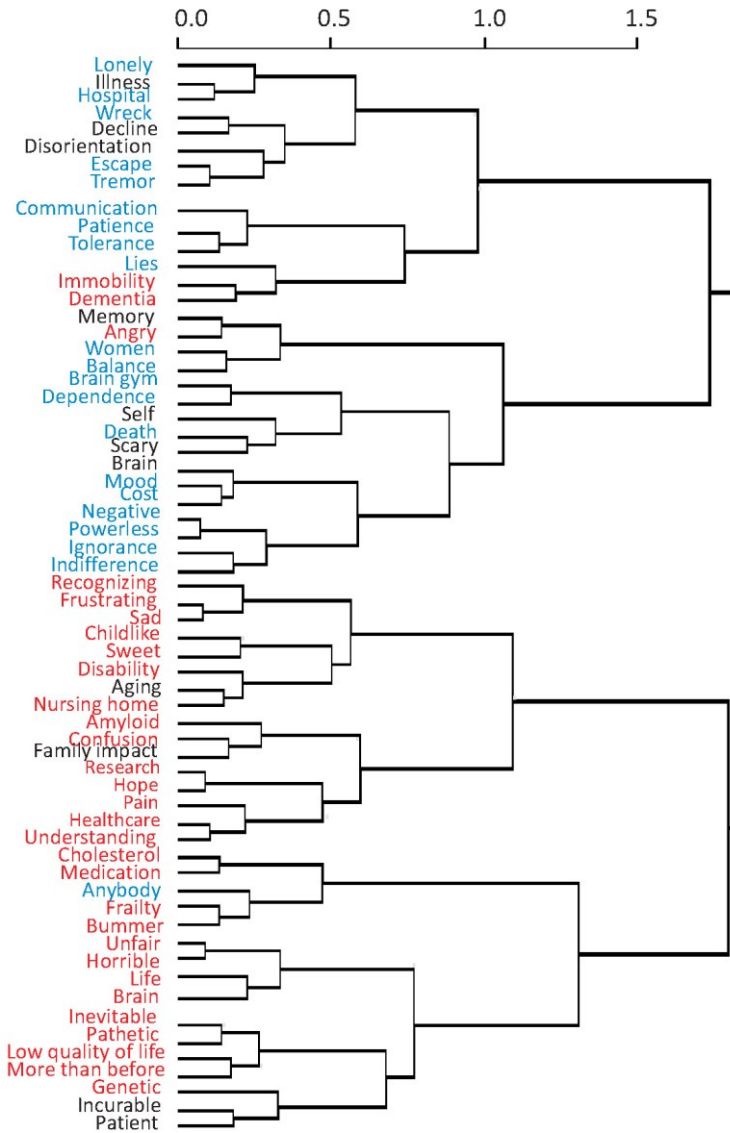
We then performed a configuration analysis to visualize the distance be-tween the two representations in a two-dimensional space. Again, we mapped the raw data with no information about nationality and let the model organize items in space: Items that are represented close to each other tend to be mentioned together. The configuration plot below (figure 2) shows the result of this analysis. To make the plot more intuitive, we again colored each item according to the nationality that mentioned it most often. As we can see, the spatial mapping of the data also shows a clear separation between the French and the American representations, with the shared items appearing in grey in the middle.

Fig. 2. Configuration plot for total sample
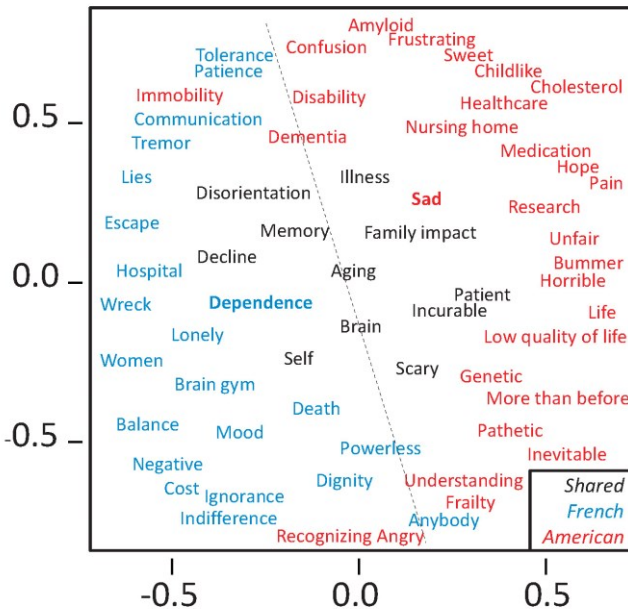
Based on these two analyses, we conclude that the representation of AD is not homogeneous among our respondents and that indeed there are two distinct representations that map onto the respondents' nationality. This confirms our first hypothesis that French and American respondents have different representations of AD.

To further understand the nature of this difference, we performed a frequency analysis on the response items. The stars in the tables below indicate that the difference across the two groups is statistically significant, as measured by a Chi square test with Bonferonni correction for multiple comparisons. The colored or bold items are the items mentioned by only one of the two groups. Items are presented in decreasing order based on the number of occurrences (i.e., for the next table, *aging* was mentioned by more American respondents than *sad*, etc.).

Table 2. Representation French/American

Total sample (n=100)	American	French
Heart > 50%	Memory	Memory Dependence ***
Body > 25%	Aging Sad *** Dementia ** Family impact Patient	Self Aging
Margins >10%	Brain Decline Scary Health care	Illness Lonely Disorientation Family impact Scary Brain Decline Patient Incurable Communication

We can draw several observations from this table. First, the two samples have two main items in common: *Memory loss*, not surprisingly, is mentioned by 56 percent of American respondents and 68 percent of French respondents, and *aging* is mentioned by 40 percent and 28 percent, respectively. Respondents place these items at the center of their representation of AD no matter which country they are from. However, the next thing worth noticing is that differences between French and American respondents seem to be driven by two other items: *sad* for the American respondents and *loss of independence* for the French respondents (figure 3). These two high-frequency items (mentioned by 40 percent and 52 percent of the re-

spondents, respectively) are also the ones for which the discrepancy between the two groups is the highest (p<0.0000). Therefore, s*ad* and *dependence* seem to polarize the American and French representations.

Fig. 3. National gradient for shared items
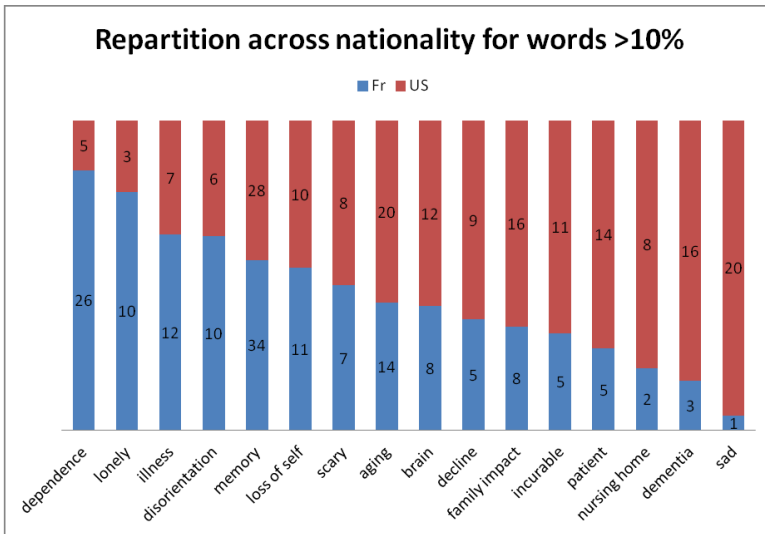
A third observation comes from the items mentioned by just one group, such as *dementia* and *health care* for the American respondents and *loss of self*, *illness*, *lonely*, *disorientation*, *incurable*, and *loss of communication* for the French respondents. The mere quantity is interesting in that it reveals that the French respondents have a much richer, more diversified representation of AD than the American sample, which is consistent with their exposure to many more information campaigns. Moreover, the items mentioned by the French only focus on specific symptoms of AD (such as *disorientation*, *loss of self*, or *loss of communication*) whereas the items mentioned by both samples are non-specific to AD and could also apply to Parkinson's disease for instance (*family impact, brain, decline, scary*). The American respondents share with the French respondents this general unspecific representation but add *dementia* as a specific characterization. From this data, it looks as if the American representation is poorer in terms of specific symptoms of the disease. Since massive campaigns of information had already occurred in France at the time of data collection, it is

possible that part of this expertise effect was influenced by the campaign's message, resulting in a higher representation of symptoms in the French sample.

Having established the items on which the representations shift between the two groups, we were interested in looking at the structure of the representation in each group based on the thought process that leads respondents from one item to the next in their responses. In other words, we wanted to identify which mental pathways the French and American respondents followed when they thought of AD. To do this, we mapped the items each respondent gave with respect to the directionality of their answer. For instance, 10 respondents went from *memory loss* to *dependence* in the French sample, but none went from *dependence* to *memory loss*. In figure 4, only direct connections are mapped, with the minimum set at two.

Fig. 4. Mental pathways (French followed by American)
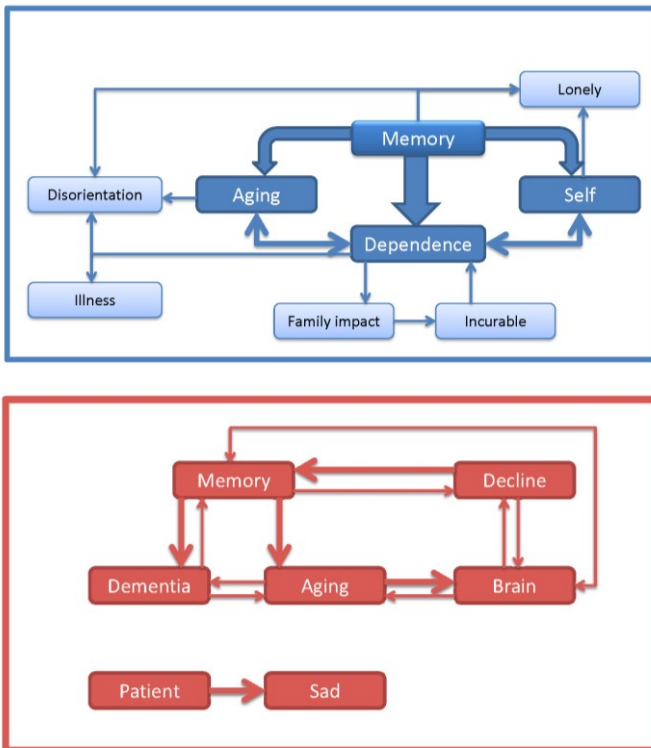
always starts at *memory* and then loops through *aging* or *self* towards *dependence*. From there, three secondary circuits loop from *dependence* to *family impact*, *incurable*, and *illness*, from *memory*, *aging*, and *dependence* to *disorientation*; and from *memory* or *self* to *lonely*.

For the American sample (in red), what first jumps to attention is the presence of two separated circuits: the main circuit and another circuit linking *patient* to *sad*. Since *sad* is highly characteristic of the American representation, it is important to check whether this effect was driven solely by the American respondents who had been in direct contact with a patient. In other words, if the high frequency of *sad* among the American respondents is only a result of the frequent use of the term by respondents who were in contact with a patient, then it may be less representative of the other American respondents. The other thing noticeable in the American mental pathway is that it is much more diffuse. No connection occurs more than four times across the entire sample. Moreover, it is completely bidirectional and much more distributed than the French pathway, with no obvious secondary circuit. This is very informative because it shows that the American pathway is barely structured in a way that is not available to raw frequencies or multidimensional scaling. This corresponds to a scattered representation, where individual representations do not add up cumulatively to form a coherent collective pattern. From this analysis, we can conclude that American respondents share individual items but not a common structured representation of AD. The French sample, on the other hand, shows an expertise effect in its collective hierarchical and mostly unidirectional mental pathway.

The impact of gender and age

Since our first hypothesis was confirmed, showing that French and Americans have two distinct representations of AD, we will analyze the effect of our three other variables within the two groups (i.e., the effect of age among the French respondents, etc.). Results are reported in the same tables to allow visual comparison across nationality. However, comparisons for statistical significance are made within nationalities.

AD affects women more than men, both in terms of patients (1/6 women vs. 1/11 men) and in terms of caregivers (60 percent are women), and those ratios are stable across countries. This asymmetry suggests that there might be an effect of gender on the representation of AD. The results re-

ported in table 3 indicate that both samples showed a gender effect in their representation, although of a different nature.

The main difference in the French sample appears immediately: Both genders have similar mentions of memory loss (64 percent vs. 68 percent), yet women mention loss of autonomy far more frequently than men (72 percent compared to 40 percent). From this, we can conclude that women contribute at least partially to biasing the French representation towards *loss of independence*. French women also tend to associate AD with its impact on social life (*loss of independence, lonely, family impact, mood disorders*) whereas French men associate AD more with personal decay (*loss of self, patient, decline, incurable*).

In the American sample, the difference between women and men is less pronounced. Yet, we notice that only women mention *scary*, and they focus on the need for *research* in comparison to American men who focus on *decline* and *incurable* (as with French men). Perhaps it is not surprising that the fear reported by American women is associated with *confusion* in their representation, whereas French women detail a series of symptoms, thus giving a concrete characterization to the disease (cf. Cutler and Hodgson 1994).

Both female representations are consistent with women performing most of the care-giving activity and reflect the asymmetry in favor of the French sample in being more informed than the American sample. However, within nationalities, it is worth noting that the distribution of specific symptoms is even across gender in the French sample (respectively *disorientation*, *mood disorder* and *loss of communication*) and evenly absent in the American sample. This result appears to reinforce the hypothesis that the overall difference between our samples is driven by exposure to information campaigns rather than by gender effect.

Table 3. Effect of gender

Gender	Fr Women	Fr Men	US Women	US Men
> 50 %	Dependence* (72) Memory (64)	Memory (68)	Memory	Memory
> 25 %	Lonely Illness	Dependence (40) **Self** Aging	Sad Aging Family impact Dementia **Scary***	Aging Patient Dementia Sad Family impact
Margins	Disorientation **Family impact** Aging **Mood Disability Brain** Scary	Illness **Research** Disorientation scary **Patient Decline Incurable** Lonely **Communication**	Brain Patient **Confusion Research**	Brain **Decline Incurable Illness Disorientation**

Our hypothesis with respect to the effect of age was that the representation of AD would evolve along the lifespan. Indeed, three observations from the results reported in table 4 appear to support this hypothesis. First, the heart of the representation is different across age groups: Young respondents mention *aging* significantly more often than older respondents (p=0.0003), and for the American sample, only older respondents mention *sad*. Second, the representation of young respondents is very homogeneous. For instance, memory is mentioned by 84 percent of young versus 50 percent of older French respondents, and by 69 percent of young versus 42 percent of old American respondents. Third, if we look at the margins, there is an asymmetry between younger and older French respondents that is similar to the one we observed between French and American respondents, in that the young French respondents identified more general items (*incurable, family impact, lonely*, and *dementia*) compared to the symptom-oriented responses of older French respondents (*loss of communication, tremor, mood disorder*).

Table 4. Effect of age

Age	Fr < 44 yo	Fr > 44 yo	US < 44 yo	US > 44 yo
> 50 %	Memory*(84 %) Dependence (63) **Aging*** (50)	Memory (50) Dependence (50)	Memory (69) Aging (54)	Sad (50)
> 25 %	Self Disorientation Illness	Self	Brain Dementia Sad Family im-Pact Patient	Memory Family im-pact Dementia Patient Aging
Margins	**Incurable* Family impact Lonely Dementia**	Illness **Scary Brain Communi-cation Tremor Mood Decline** Disorienta-tion	Decline **Scary Dependence**	**Illness** Brain **Health care** Decline **Frustrating**

We suggest that the difference across age groups reflects the source of their information: In probably being more receptive to information in the media, younger respondents may have acquired a more stereotypical, homogeneous knowledge about AD, whereas older respondents most likely relied on a variety of personal experiences with aging through their own experiences, and/or that of their parents or friends. This raises another possible factor, which could be embedded in our observation of the age effect: Older respondents are more likely to be in direct contact with a person suffering from AD. To check the possible contribution to this factor, we ran one more analysis.

Is having first-hand experience determinant?
We predicted an effect based on direct contact with a patient. Specifically, we expected the respondents in direct contact with a patient to have a rich-

er, more accurate representation of AD. Not surprisingly, contact did significantly affect the frequency of mentions of a loved one who is ill in both samples (US p=0.0002; Fr p=0.01).

More surprising is the very clear interaction effect of direct contact on the heart of the representation in the French sample. Whereas *memory* is prioritized by respondents with no personal contact, *loss of independence* is inversely prioritized by the respondents in direct contact with a patient. The fact that *dependence* is mentioned more often by women and respondents in direct contact with a patient is consistent with most of the caregivers and patients being female. However, this effect is not replicated in the American sample, suggesting that there is also a cultural component to this predominance of *dependence* in the French sample. A similar interaction of smaller magnitude occurs in the American sample between *memory*, again prioritized by the respondents with no contact, and *sad*, prioritized by the respondents in direct contact. The fact that this interaction caused by direct contact on the heart of the representation replicates in both samples for the items that were driving the representations apart is a major finding: It means that the divergence across nationalities is at least partially driven by the difference across respondents in direct contact with a patient.

We can also comment on the items mentioned only by one group: In the French sample, only the respondents without contact mention the need for *research*. We suggest that this is a direct byproduct of the information campaigns as they are closely related to research funding. Respondents who rely on their personal experience are less likely to think at the institutional level but rather at the level of everyday life challenges. In the American sample, only the respondents older than 44 years and in direct contact with a patient mention *health care*. We suggest that this illustrates the relative lack of systematic campaign of information towards the general public in Boston: Only people who struggle personally with AD think about the implications in terms of care, insurance and treatment. Moreover, by merging the information in table 5, we can say that *scary* is mentioned only by respondents older than 44 years with no direct contact to a patient in the French sample, but is mentioned only by respondents younger than 44 years and without any direct contact in the American sample.

Table 5. Effect of direct contact

Contact	Fr No contact	Fr contact	US No contact	US Contact
> 50 %	Memory (77)	Dependence (70)	Memory (70)	**Patient*****
> 25 %	Dependence (47) Self Aging **Disorienta- tion**	Memory (45) Illness **Communi- cation Patient***	Aging Brain Family im- pact Sad (30) Decline Dementia **Illness**	Sad (48) Memory (44) Dementia Aging Family im- pact **Incurable**
Margins	Lonely Illness **Research** Family im- pact **Dementia** Brain **Scary Tremor**	**Incurable** Family im- pact Aging Self **Decline** Lonely Brain **Mood**	**Scary Dependence**	Brain **Self Health care** Decline

CONCLUSIONS: UNIQUE REALITIES BEYOND A SHARED FEAR OF THE UNKNOWN

In this paper, we have investigated the social representation of Alzheimer's disease in two comparable samples from Paris and Boston. We hypothesized that the representation of AD would vary as a function of the cultural context. Specifically, we were interested in the effect of systematic information campaigns towards the general public on their representation of AD. The French sample has been exposed to several systematic information campaigns, which is not yet the case with the American one. Indeed, in 2009, a national review about the public's perceptions of AD among the US-population concluded that "[t]he majority of studies indicated that the US public lacks specific information about Alzheimer's disease and current treatments" (Anderson et al. 2009: 8). Following our hypothesis, the French sample should show an expertise effect, with a richer, more homogeneous and more structured representation than the American sample.

Indeed, the analysis of the mental pathways of each group – an innovative methods measuring the directionality of self-generated responses – showed how much more structured and homogeneous the representation of the French sample was compared to that of the American sample. In terms of content of the representation, beyond the expected agreement on *memory* and *aging*, we found a strong difference across nationalities, both in the structure and in the content of the representations, suggesting not only an expertise effect but also a cultural effect. Based on raw frequencies, American and French respondents prioritize the *sadness* and the *loss of independence* very differently in their representation. We interpret this inverse polarity as representative of a cultural bias, apparent even in the lower-frequency items that do not reach the central representation. One third of the items mentioned solely by American respondents point at emotions of the respondent *(frustrating, unfair, anger, bummer, hope, pathetic, horrible)* and only one item is a symptom of the disease (*not recognizing*). In contrast, the same proportion of items solely mentioned by French respondents focuses on symptoms of pathological aging (*loss of dignity, loss of balance, running away/getting lost, lying*) and only one points at the respondents' emotions (*powerless*). In terms of nature of the representation, we can thus conclude that the French respondents focus on the idea of *loss* (mentioned three times more often than *memory*, the item with overall highest frequency in the French sample) and describe primarily the experience of the patient: one of illness, solitude and dependence, characterized by a progressive loss of self, communication, and sense of orientation (cf. Nizzi 2013). The American respondents, on the other hand, seem to describe the impact of the disease outside of the patient, with two main poles: their own feelings (*sad*) and the societal impact (*family impact, health care*). This is consistent with the findings summarized by Anderson and colleagues: "[R]eports documented that survey respondents expressed a great deal of concern about the disease, both from a personal perspective and the potential of caring for someone else" (2009: 9). We assumed that this difference was caused at least in part by the different exposure to broad information campaigns towards the general public.

It is important to note, however, that this study has several limitations which require that we are cautious with our interpretation. The sample size and the recruitment areas are limited and we relied on collective data for socio-economic status. Additionally, as is the case for all cross-cultural

studies, many other factors can contribute to the differences we observed across countries. For instance, different health care systems seem crucial in how a disease is experienced and thus represented, as are differences in the stigma associated with the disease in each culture. But other unidentified factors might also contribute to our findings. One way to determine whether the differences in representation between Parisians and Bostonians is caused by the difference in the level of information would be to re-test the Bostonian sample in five years, after the effects of the recent political measures have had time to reach the general public. If the same differences in representation were still found after the Bostonian population has reached a similar level of information as the Parisian one, we would be able to exclude that the difference in representation is mainly driven by a difference in information.

Our results also underline the effect of having a personal contact with a patient, which constitutes a first-hand source of information (Blendonet al. 2012). Across nationalities, respondents in direct contact with a patient show more divergent patterns of responses than those without such contact. The two interactions we observed between *memory* and *dependence* in the French sample and *memory* and *sad* in the American one imply that the divergence we observed over the total sample was in part driven by the difference across respondents in direct contact with a patient. In other words, the main difference between the French and the American representation does not seem to be driven by gender or age but rather by the difference in the items given by these subsets of respondents that have a first-hand personal experience of AD. This result suggests that the difference in cultural contexts mainly affects respondents who personally have to deal with the concrete modalities of the local health care system. This effect is further reinforced by the fact that information campaigns focus on the symptoms of the disease, thus providing a unified representation to people who lack a direct experience of the disease, whereas respondents relying on first-hand experience are most likely to mention items specific to their individual experience, thus reflecting a more diverse representation.

Finally, the specific pattern of response for the item *scary* is interesting in relation to the hypothesis of both the French and the Massachusetts government that more information about AD would decrease the fear in the general public. This hypothesis seems to be supported by the fact that only respondents with no contact mention *scary*, independent of their nationali-

ty. We can argue that people in direct contact with a patient know in fact more about the disease than other people and the fact that they do not mention *scary* seems to justify the hypothesis linking more information to less fear. In our survey, we also learn something more: Only older French and younger American respondents (all with no direct contact) mention *scary*. If we are correct to assume that younger populations are more likely to have been reached by information campaigns in the media (on the internet for instance), then the fact that young French respondents do not mention *scary* when older French respondents do might be a result of the information campaigns and a proof of their efficiency in reducing fear of the disease. The American sample confirms this interpretation as it is the younger Americans who mention *scary* but not the older Americans who might have more opportunities to get indirect personal information. Therefore, the younger Americans would be especially vulnerable to fear in a context where no massive information campaign has happened yet. Once the new measures have been in effect for some time, a study among young Massachusetts residents could measure the reduction of fear following information campaigns, thus providing a measure of efficiency in a different medico-cultural context than Paris.

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