

# **THE IMAGE OF PATIENTS AND CAREGIVERS IN THE SOCIAL PERCEPTION OF ALZHEIMER'DISEASE – RESULTS FROM A LITERATURE REVIEW AND A QUALITATIVE STUDY**

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## **BACKGROUND**

Alzheimer's disease (AD) is among the diseases that are most **feared** by the population. One explanation lies in the double or triple **stigmatization of the sufferer** (Wilkinson, 2002). Alzheimer's victims are indeed :

- Suffering from cognitive disorders;
- Mostly elderly;
- Mostly women.

An analysis of the social perception of the disease seems necessary to approach this stigmatisation and its consequences. These further analyses, based on data from two French studies, are centred on the social image of the AD in lay public.

## **LEARNING OBJECTIVES**

- 1/ To understand better the social image of Alzheimer's disease
- 2/ To identify how patients and caregivers are perceived; and be aware reflect on our own representations ;
- 3 / Highlight possible improvements in the social image of the patient.

## METHODS

### The “DEOMA” – device of opinion surveys on AD

Farmed out to the National Institute of prevention and health education (Inpes), the measure # 37 of the National Alzheimer Plan 2008-2012 is divided into several opinions surveys on AD (Table 1).

Results presented below are based on surveys # 1 and 2.

1/ <b>Literatur review on social representations of AD</b>	<b>August 2008</b>
2/ <b>Qualitative study with general population, caregivers and health professionnals</b>	<b>August 2008</b>
3/ Quantitative survey with 2 013 people aged 18 and over (general population)	December 2008
4/ Qualiative study with sufferers and caregivers	February 2009
5/ Part of the « GP Health Barometer »	Early 2010
6/ Quantitative survey with sufferers and caregivers	October 2009
7/ Quantitative survey with formal caregivers	October 2009
8/ Repetition of quantitative surveys	From 2011

### The review of literature

- Systematic research of English and French literature edited from 1995 to July 2008.
- Database : Pubmed, PsychINFO, the BDSP and the Cochrane Database of Systematic Reviews (CSDR).
- Are excluded :
  - studies in languages other than English or French;
  - thesis, books' chapters or books;
  - Studies solely concerning subjective perceptions by Alzheimer's subjects or concerning social representations of health, perceptions of care or beliefs among genetic screening.

A total of **37 abstracts** (on 78 eligible references) met all inclusion criteria and remained as potential material for this review (Table 2).

- Extraction of data in a standardized assessment form (study design, participant characteristics, theoretical basis, main themes, main results) and critical analysis.

<b>Place of study</b>	- Europe (16) : <ul style="list-style-type: none"> <li>○ UK (7)</li> <li>○ Facing Dementia Survey (3)</li> </ul>
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	<ul style="list-style-type: none"> <li>- Israël (9)</li> <li>- USA and Canada (4)</li> <li>- Other countries (5)</li> </ul>
<b>Fields of study</b>	<ul style="list-style-type: none"> <li>- Social psychology (24)</li> <li>- Sociology or anthropology (9)</li> <li>- Nursing sciences (2)</li> <li>- Other fields (2)</li> </ul>
<b>Methods of study</b>	<ul style="list-style-type: none"> <li>- Quantitative survey (21)</li> <li>- Qualitative study (14)</li> <li>- Literature review (2)</li> </ul>
<b>Population of study</b>	<ul style="list-style-type: none"> <li>- Parents or friends (18)</li> <li>- Lay public (13)</li> <li>- Health professionals (8)</li> <li>- Medias (2)</li> </ul>

### The qualitative study

- 26 semi-directive interviews with health professionals (general practitioners – GP-, nurses, pharmacists) and 12 focus groups of lay public (5 to 10 persons), with a total of **130 persons interviewed.**
- For the general population, selection criteria are :
  - Age : 35-50 or 55-70
  - Proximity to disease : not concerned directly by AD / concerned by not caregiver / regular caregiver
- Two locations : Paris – and suburbs - and Toulouse (a city in Sud West of France)
- All interviews and focus groups (Table 3) are audio and video-recorded, retranscribed and analysed (?) by thema-analysis.

<b>TABLE 3 – Guide for the interviews and focus groups</b>
General perceptions of AD
Knowledges on AD : causes, treatments, differents forms of AD...
Care of AD and professionnals involved
Attitudes et role playing (announcement of the diagnosis)
Level of information on AD
Needs and expectations about AD'care

## RESULTS

### Part I – How researchers are studying social representation of AD ?

**Knowledges of AD** are the main theme studied in the international literature. Within the field of mental health literacy, the studies tend to highlight the reasons for the under-diagnosis; this fact could be due to lack of knowledge on the etiology of the disease.

**Few researcher analyse directly social representations** of the disease or attitudes resulting from these perceptions.

This review highlights the pervasiveness of **medical or psycho-medical Alzheimer's research** in social science.

## **Part II – Alzheimer's disease, a disease of the relatives**

### **AD is a disease of the relatives.**

Historically, AD has emerged on the political agenda to address the pressures on relatives (burden of the caregiver). We should not forget that:

- in France, 40% of people with Alzheimer's disease or related disorders live at home;
- relatives are the first source of help for the sufferer; caregivers are mostly children or spouses; and this assistance continues beyond institutionalization;
- the media focuses on daily difficulties of caregivers through tragic stories (murder-suicide, euthanasia, fugues).

In both the literature review and the qualitative study, the **crucial role of caregivers** is ubiquitous; they are :

- **Custodians of the diagnosis, guarantee the care and welfare (to?) the patient** (Corner et Bond, 2004; Downs, 2000).

In the qualitative study, **feelings of powerlessness** ("do not know what to do") and **guilt** ("do not do or not do enough") are frequently expressed by the caregivers themselves and by those less concerned (health professionals or lay public) .

*"It's an accompaniment more for the family than for the patient. We try to be attentive to the comfort because they are people who feel a little alone. "Pharmacist  
"We wondered if there was enough" Relative of sufferer, but not regular caregiver  
"It even happens to the guilt, because sometimes it is assumed that this did not need"  
(je ne comprends pas la dernière citation) Relative of sufferer, but not regular caregiver*

- **However, they are not spared from the social exclusion that affects the patient.** Caregivers unanimously express their loneliness in the care of their relatives ones suffering from Alzheimer's: they must ensure a permanent presence and **do not know where to turn for support.**

*"With this disease, the family does not know what to do, we are alone." Caregiver*

Another manifestation of the exclusion is reported in the literature: it is the **consequence of a strategy for the family to manage « deviant » behaviors** or the stigma of the disease (McRae, 1999). (Je ne ferais pas deux paragraphes mais un seul car la citation explique ce qu'est cette stratégie).

As McRae concluded, *" it is possible to avoid the courtesy stigma on Alzheimer's disease if symptoms of the disease are concealed from others. Collusion and cover up are, however, stressful and may involve avoidance of face-to-face contact with others which entails a further cost of decreasing social contact for the person who has the*

*disease and possibly increased isolation for an already increasingly housebound familial caregiver.” (p.68)*

**Part III – The absence of sufferer**

Globally, the patient is absent from social representations of AD (Table 4).

Review of literature	Qualitative study
<p>The <b>social image of patients</b> corresponds to people (Clarke, 2006; Ngatcha-Ribert, 2004) :</p> <ul style="list-style-type: none"> <li>- in advanced stages of the disease;</li> <li>- described as losing their personality;</li> <li>- dehumanized or already dead.</li> </ul> <p>In the care, patients are perceived as « <b>incompetent</b> » (Rolland, 2007 ; Downs, 2000) :</p> <ul style="list-style-type: none"> <li>- For hearing and accepting the diagnosis ;</li> <li>- For taking part to treatments and critical decisions.</li> </ul> <p>On the other side, a minority of studies claim the participation and expression of sufferers.</p> <p>The <b>stigma</b> against people suffering from Alzheimer’s disease (Rimmer et al, 2005; Werner, Heinick, 2008) :</p> <ul style="list-style-type: none"> <li>- They have “deviant behavior”;</li> <li>- They tend to isolate themselves.</li> </ul>	<p>In the qualitative study, the patient is <b>virtually absent of evocations</b> in both the general public than among caregivers and health professionals.</p> <ul style="list-style-type: none"> <li>- He/she is “in his/her bubble”, he/she is protected by his/her cognitive disorders, he/she doesn’t suffer;</li> <li>- He/she has no identity;</li> <li>- He/she cannot be a partner in the care..</li> </ul> <p><i><b>Excerpts from interviews or focus group</b></i>  <i>"We have less contact, he withdrew in his shell (...) It is no longer my brother. After a while, people get tired of all these difficulties and he is exhausted to make as much effort, he renounces. "Sister of a sufferer</i>  <i>"We see a body but we know this is not the person. "GP</i></p>

**DISCUSSIONS**

These studies underscore the very negative social image of the patient with AD and the ambivalence characterizing the status of caregiver.

Avenues for research:

- ▶ **To implement studies and surveys of people who are ill themselves.** This means going against the usual stereotypes (shared by caregivers, professionals and researchers themselves) on the ability of patients to express their views. This means also removing obstacles to the identification of sick people, obtaining their consent and facilitating their expression. Inpes is realizing a survey of sufferer and caregivers. Results will be available in autumn 2009.

- ▶ **To analyze deeper the stigma against Alzheimer' victims** and its consequences in terms of potential discrimination.

Avenues for action:

- ▶ **To work on social representations of ageing and ageism;**
- ▶ **To fight against the stigmatization of AD** through training, health education, promoting action which guarantee the place and the speaking of sufferer.

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