Knowledge, opinions and behaviour of the French public with regard to Alzheimer’s disease

Background

By including measure 37 and solution S1 in the third strategic component of the 2008-2012 ‘Plan Alzheimer’, this project aims to improve ‘awareness of perceptions of the disease’. This measure was entrusted to the Institut national de prévention et d’éducation pour la santé (Inpes – The French National Institute for Prevention and Health Education), which started an Alzheimer’s disease opinion survey programme (French acronym: DEOMA) among different populations in the summer of 2008. This system of information offers a precise description of perceptions, opinions and attitudes of patients, formal and informal carers, healthcare professionals and the general public about Alzheimer’s disease. It enables us to pinpoint similarities and disparities in points of view between groups that are more or less involved with this pathology and identify their specific needs and expectations. The findings tell us what initiatives to reinforce or launch to better support patients, their family friends and professionals.

The questions posed as part of the ‘Baromètre santé 2010’ to a representative sample of people aged between 15 and 85, who are resident in France and French speakers, form part of this tool and are aimed at determining the frequency of the care provided to patients, while
measuring the general perceptions, attitudes and opinions concerning the pathology. This survey also gives an evolving measure of certain indicators based on a preliminary survey conducted on the general public in 2008 (summary available in French on the dedicated DEOMA website: http://alzheimer.inpes.fr/pdf/fr/resultat-grd-public.pdf).

**Methods**

In order to plan its prevention actions, Inpes needs to know and understand the attitudes and behaviours of the population: for this reason, it has conducted regular surveys on the general population, known as the ‘Baromètres Santé’, since 1992. These offer copious data for actors and decision-makers in public healthcare on the practices and knowledge of the population in terms of health.

The ‘Baromètre santé 2010’ is based on a probabilistic twofold sample (random sample of one household, followed by an individual within it). The survey, entrusted to the Institut Gfk-ISL, was conducted by Computer-Assisted Telephone Interview (CATI) between 22 October 2009 and 3 July 2010.

In order to use as exhaustive a survey basis as possible, the ‘Baromètre santé 2010’ included, in addition to households with a landline (red and orange lists included), households contactable only by mobile telephone and those totally ungrouped. The phone numbers were randomly generated. The reverse telephone directory was used to send a prior notification letter to households on the white list (it was offered to those on the red list *a posteriori*), which emphasises the importance of the study in order to reduce the number of refusals to respond.

In order to be eligible, a household had to consist of at least one French speaking person in the age range considered (15 to 85 years old in the context of the ‘Baromètre santé 2010’) who speaks French. Within the household, a single individual was randomly selected from among the eligible members in the household, following a description of all household members. Anonymity and respect for confidentiality were guaranteed by a process of deleting the telephone number approved by the authorisation of the French data protection authority (CNIL).

To ensure that this would be a representative survey, the data was weighted by the number of eligible individuals and telephone lines in the household (particularly to compensate for the fact that an individual in a large household is less likely to be randomly selected), and set
As with all phone surveys conducted in France, obtaining the participation of the people sought proved quite difficult: the refusal rate was almost 40%. In the end, 27,653 individuals aged between 15 and 85 were surveyed as part of the ‘Baromètre santé 2010’. Answering the questionnaire took an average of thirty-six minutes.
To not overrun the average optimal time for the survey, it was decided that certain topics would not be addressed to the entire sample, but only to one of the randomly selected subsamples. Therefore, questions about Alzheimer’s disease were only put to 4,518 people.

**Results**

1. **Contact with Alzheimer’s disease**

More than a quarter of French people know someone with the illness among their family and acquaintances

More than a quarter of people surveyed (26.9%) said that they either have or have had someone in their circle of family friends, and neighbours who has Alzheimer’s disease (21.2% a single person, and 5.7% several). Of these, 32.9% say that they either are or have been carers in daily tasks and actions; people aged 65-85 were those most concerned here.

Almost 3/4 of carers provide care on a regular basis

Among those who say they either provide or have provided care for a patient in his or her daily tasks and actions, the frequency of the care breaks down as follows: 29.5% say they either provide care or have provided care every day; 20.0% several times a week; 22.2% once a week; 10.4% 2-4 times per month and 17.9% once per month or less often. As a result, almost 3/4 of people providing or who have provided care either do so or have done so regularly, that is, at least once a week. Regular caring is split along age lines, with older people being faced with this situation more often than younger people.

2. **Fears and sense of being informed about the disease**
Alzheimer’s: the 4th most feared disease for those questioned
Cancer (54.7%), traffic accidents (52.0%) and consumption of processed foodstuffs (45.8%) are the three risks or diseases most feared by the French population from a list of 10 items proposed as part of the 2010 Health Barometer. Alzheimer’s disease occupies 4th position: 39.1% of people questioned said they were afraid of this disease.
This fear is expressed more among women (44.3%) than men (33.5%). People aged between 55 and 85 (52.6%), those who have a middling to poor perception of their own health (54.5%) as well as those who either are or have been directly confronted by the illness, through at least one person affected among their families and friends (46.3%), are the most affected.

People who are reasonably well informed
Among the 13 health topics proposed as part of the 2010 Health Barometer, Alzheimer’s disease came 10th in terms of how well informed people felt: 55.6% of people asked consider themselves ‘very well’ or ‘quite well’ informed. Smoking, contraception, alcohol and AIDS were the health topics on which a large majority of French people considered themselves well informed (>80%).
Almost 60% of women (vs. 52% of men) and 60.5% of people aged between 35 and 85 said they consider themselves ‘very well’ or ‘quite well’ informed on the subject of Alzheimer’s disease. This is also the case for people who have a tertiary-level qualification (59.6%) as well as those directly affected by the illness by a patient whom they are close to (60.0%). It seemed that the feeling of being informed was not related to fear of the disease.

3. Attitudes and opinions towards Alzheimer’s disease

Opinions on Alzheimer’s disease
The majority of people surveyed believe that the illness is affecting more and more people (79.4%). They all agreed on the devastating effects the illness can have on the person’s family (91.4%, of whom 65.4% strongly agreed). A shade more than half are conscious that nothing can be done to avoid the disease (51.2%) and, lastly, 56.9% think it is normal to ‘lose one’s faculties’ while getting older.

Almost 1/3 of French people feel uncomfortable about Alzheimer’s disease
Even if a large majority of the people questioned say that they do not or would not feel any uneasiness in the presence of an Alzheimer’s patient, 31.7% did however express such an uneasiness. This is particularly the case with men (33.1%), people aged between 65 and 85 (43.7%), people directly affected by the disease through having one person affected within their family (36%), as well as those who fear the disease (37.7%).

**The vast majority of people surveyed would prefer to know the diagnosis of the illness**

The vast majority of people questioned (90.1%) would prefer to know the diagnosis of the disease if they had any symptoms of it. This is the case for 92.2% of women and 87.8% of men. Fear of the illness is also associated with the desire to know the diagnosis (92.4%).

**4. Awareness of the Plan Alzheimer**

A little more than half of the people interviewed (56.1%) have already heard of the Plan Alzheimer, although this knowledge was still fairly hazy (19.8% said they genuinely knew what it was about). According to age, 62.7% of people aged 35 and over said they had heard of the Plan Alzheimer, while 22.8% said they genuinely knew what it was about. Awareness of the plan was strongly linked with the interviewee’s social standing: 65.8% of those on higher income knew of the plan.

**Discussion elements**

This survey, conducted on a sample of 4,518 people aged between 15 and 85, which is representative of the population of France, makes it possible to confirm and refine certain results of the previous survey carried out in 2008 by Inpes on a sample by quotas of 2,013 people aged 18 and over.

More than a quarter of people asked said they either have or have had at least one person affected by Alzheimer’s disease in their circle of family friends. A shade more than 6% of all the people questioned regularly either provide or have provided care (at least once a week) to a person with Alzheimer’s disease; the older subjects are most often confronted with this situation. The survey conducted in 2008 made the same observation.
These results reflect the social importance of Alzheimer’s disease giving affects a significant part of the French population to a greater or lesser extent. Other surveys have managed to confirm the importance of social support in the care of elderly people who have lost their independence (Soulier and Weber, 2011; Fontaine et al, 2007). However, care produces not insignificant repercussions on the professional and social life and health of family and friends that are well documented (Zarit, 1980; Andrieu et al, 2003).

Our results also show that Alzheimer’s disease stands among the diseases or risks that the public fears most, after cancer, traffic accidents and consumption processed foodstuffs. Almost 80% of the people questioned believe that the disease is affecting an ever increasing number of people, and more than 90% think that the disease can have devastating effects on the patient’s family. This perception of the consequences and the scope of the disease particularly reflects that held by women, persons over 55, those who have or have had someone close to them affected by the disease, as well as people with a poor perception of their health.

The survey conducted in 2008 by Inpes clearly demonstrated that a great majority of people associated the disease, even in the initial stage, with difficulties in completing daily tasks and actions, and the incurable nature of the illness was acknowledged by most, even though the hope of finding a treatment in the next few years was common among the general public.

These results echo those of European surveys on the perception of Alzheimer’s disease. According to the Facing Dementia Survey (Bond et al., 2005; Rimmer et al., 2005), 93% of people surveyed in the six countries and 91% of family and friends believe that Alzheimer’s disease has devastating effects on the family circle.

In our survey, few enough people felt themselves to be well informed about Alzheimer’s disease, by comparison with cancer or AIDS. Persons over 35, those who have achieved a higher level of education and those who currently know or have previously known someone affected by Alzheimer’s disease have the feeling of being better informed than others.

As with the survey carried out in 2008, a feeling of being well informed does not appear to be correlated with expressions of fear regarding this pathology. Nonetheless, surveys conducted abroad via quizzes or restricted scaling on etiology, risk factors or the development of the illness, referred to an association between the level of awareness of Alzheimer’s disease (Cutler and Hodgson, 2001; Proctor et al., 2002; Werner, 2003) and the fear that it produced.
Our survey, however, based on statements and using different indicators, finds no association in the cross-section representing the French population.

Besides confirming this negative representation of Alzheimer’s disease, the 2010 Health Barometer has also provided an indication of awareness of the Plan Alzheimer. Even if this indicator has not changed since 2008, a little more than half of people surveyed know about this plan, but only 1/4 genuinely know what it is about. In 2008, the survey demonstrated that the population surveyed recognised the importance that the public authorities had granted to the fight against Alzheimer’s disease: almost half among them knew about the Alzheimer Plan and almost 40% thought that the disease was a priority for the public authorities. Their expectations largely focused on research, giving families respite relief and establishing care homes.