Alzheimer’s disease Health Literacy: A challenge for Communication Professionals

TATIANA NUNES1, MAFALDA EIRÓ-GOMES2,

ABSTRACT

Alzheimer disease seems to be one of the greatest issues in occidental societies. In this paper we will discuss the level of knowledge among undergraduate communication students in Portugal and how the results helped developing the actual Portuguese Alzheimer Association’s communication program.

KEY-WORDS

Alzheimer’s Disease, Dementia, Health Communication, Health Literacy, Knowledge

INTRODUCTION:

The authors believe that while being a public health issue “health literacy” is also a main problem and responsibility for the communication professionals and researchers. It’s true that on one hand contemporary occidental societies seem to have less problems with contagious diseases, on the other hand this new century has challenged humanity with environmental degradation and natural and man-made disasters. The last but not the least we are confronted with a huge increase in chronic diseases. Among these the degenerative ones seem to have a greater impact both in the realm of families as well as in society understood as a whole.

The main purpose of this paper is to discuss and enlighten the level of Alzheimer literacy among Portuguese undergraduate students. Health Literacy and especially mental health literacy is one of the most difficult aspects to deal within the Portuguese society. For the first time there's been a quantitative approach to what Portuguese

1 MA Alzheimer Portugal - Associação Portuguesa de Familiares e Amigos de Doentes de Alzheimer.
School of Communication and Media Studies, Polytechnic Institute of Lisbon. tnunes@escs.ipl.pt
2 PhD Escola Superior de Comunicação Social e-mail.agomes@escs.ipl.pt
undergraduate communication students know about Alzheimer Disease. We should note that there are no data at all concerning this issue in Portugal till the moment.

As Crisp (2001) has pointed out, in mental and degenerative neuronal diseases with a high level of mental implications may be because its symptoms are expressed in cognitive, affective and behavioral levels it is as if the disease takes the place of the individual.

The objectives of the research were two folded. First to get an idea about how was the theme seen by young people, and second, to help getting evidence to improve the Alzheimer Association communication program. As due to the lack of resources it was not possible to have a representative sample of the Portuguese population, we chose as our universe the students doing their graduation in communication (communication sciences, journalism, public relations, publicity) studies.

The choice was not an innocent one. We wanted to target future professionals that will be in charge of mediating the great amount of public information concerning these kind of diseases on one hand, and on the other they – thanks to the kind of studies they’ve been pursuing, humanities – are in a non-technical sense representatives of all those that don’t have any contact with health related professions.

We’ll present the main methodological options as well as a discussion of the most important results as well as how these affected the way the Portuguese Association has since then been dealing with its public campaigns intending to increase literacy among those that in a near future will be faced, in on or other way, with this immense problem.

**Methodology**

The present study consists of a quantitative research, with analysis of surveys, conducted to Portuguese public university students, attending undergraduate degrees in the area of communication.

**Departing Question**

What is the knowledge level of students about Alzheimer's disease?
**Research Objectives**

This research aims to assess the state of knowledge of students of communication on Alzheimer's disease. Therefore, it is important to analyze the existing knowledge concerning different aspects of the disease.

The specific objectives that are intended to research are:

- Assess the knowledge of the main symptoms of Alzheimer's disease;
- Assess the knowledge about the impact of Alzheimer's disease to the patient's daily life;
- Assess the knowledge about the diagnosis of Alzheimer's disease;
- Assess the knowledge about the risk factors of Alzheimer's disease;
- Assess the knowledge about ways of treating Alzheimer's disease;
- Assess the knowledge about caring for a person with Alzheimer's disease;
- Assess the knowledge on the development and progression of Alzheimer's disease.

**Definition of the universal set**

The universal set under study is composed by undergraduate students who attend courses in the field of communication, in particular relating to Social Communication, Journalism, Public Relations, Corporate or Organizational Communication. There were not considered students who are attending degrees in the areas of Communication Design, Advertising or Multimedia. All degrees examined have in common professional outputs related to public relations, corporate communications, journalism and communication.

For the study are therefore considered all students who are attending undergraduate degrees, either University or Polytechnic, during the academic year 2009/2010.

Accordingly, and based on the data of DSIEES - Statistical Information Services Directorate of higher education, the universal set of this research is characterized by being a finite universe, composed of 4878 individuals. Due to the fact that is not available, till the date of March 12, 2011, data on the number of students enrolled in
university courses in the academic year 2010/2011, the information considered relates to
the number of students in the academic year 2009/2010.

These 4878 students are spread across 42 degrees in 22 different institutions:

- Instituto Politécnico da Guarda - Escola Superior de Educação, Comunicação e Desporto;
- Instituto Politécnico de Bragança - Escola Superior de Comunicação, Administração e Turismo de Mirandela;
- Instituto Politécnico de Coimbra - Escola Superior de Educação de Coimbra;
- Instituto Politécnico de Leiria - Escola Superior de Educação e Ciências Sociais;
- Instituto Politécnico de Lisboa - Escola Superior de Comunicação Social;
- Instituto Politécnico de Portalegre - Escola Superior de Educação;
- Instituto Politécnico de Setúbal - Escola Superior de Educação;
- Instituto Politécnico de Tomar - Escola Superior de Tecnologia de Abrantes;
- Instituto Politécnico de Viana do Castelo - Escola Superior de Ciências Empresariais;
- Instituto Politécnico de Viseu - Escola Superior de Educação de Viseu;
- Instituto Politécnico do Porto - Instituto Superior de Contabilidade e Administração do Porto;
- Universidade da Beira Interior;
- Universidade da Madeira;
- Universidade de Coimbra - Faculdade de Letras;
- Universidade de Trás-os-Montes e Alto Douro;
- Universidade do Algarve - Escola Superior de Educação e Comunicação de Faro;
- Universidade do Minho;
- Universidade do Porto - Faculdade de Letras;
- Universidade dos Açores - Ponta Delgada;
- Universidade Nova de Lisboa - Faculdade de Ciências Sociais e Humanas;
- Universidade Técnica de Lisboa - Instituto Superior de Ciências Sociais e Políticas.
Observation Unit

The observation unit to be used in research consists of a representative sample of the universal set under study, which intends to reflect what is the national reality concerning knowledge about Alzheimer's disease.

Selection Procedure Sample / Sampling Method

Taking into account the size of the sample, was used for selection of the same, the method of random sampling, because all elements of the population have the same probability of belonging to the sample. In line with is, it is intended to infer the characteristics of the universal set from the characteristics of the sample.

Calculation of Sample Size

Being in the presence of an investigation with a finite universe, we proceeded to calculate the sample size through a statistical formula to determine its size (n) on the basis of the estimate of the proportion of population (Cf: D’Ancona, 2001).

\[
 n = \frac{N \cdot \hat{p} \cdot \hat{q} \cdot (Z_{\alpha/2})^2}{\hat{p} \cdot \hat{q} \cdot (Z_{\alpha/2})^2 + (N - 1) \cdot E^2}
\]

Where:

- \( n \) = Number of individuals in the sample;
- \( N \) = Universe;
  \( N = 4878; \)
- Confidence level = 95%;
- \( Z_{\alpha/2} \) = critical value that corresponds to the desired degree of confidence;
  \( Z_{\alpha/2} = 1.96; \)
- \( E \) = Margin of error or maximum error of estimated
  \( E = 0.05; \)
• $p = \text{Proportion of population that belongs to individuals who we are interested in studying;}$
  \[ p = 0.05; \]

• $q = \text{Proportion of population of individuals who do not belong to the category we're interested in studying (} q = 1 - p);$
  \[ q = 0.05; \]

**Calculation:**

\[
n = \frac{N \cdot p \cdot q \cdot (Z_\alpha/2)^2}{p \cdot q \cdot (Z_\alpha/2)^2 + (N - 1) \cdot E^2}
\]

\[
n = \frac{4878 \cdot 0.05 \cdot 0.05 \cdot 1.96^2}{0.05 \cdot 0.05 \cdot 1.96^2 + (4878 - 1) \cdot 0.05^2}
\]

\[
n = 356,18
\]

Thus, the sample of this research consists of 357 undergraduate communication students.

**Segmentation of Sample by Institution and Degree**

In order to obtain a representative sample of the universe, we needed to calculate what percentage of students is surveyed in each of the 42 courses in the field of communication. So, for each of the courses, was calculated the representative percentage in the total universe and the corresponding representative value of the sample.
Table 1 - Segmentation of Sample by Institution and Degree

<table>
<thead>
<tr>
<th>School</th>
<th>Degree</th>
<th>Total of Students</th>
<th>Students to enquire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instituto Politécnico da Guarda - Escola Superior de Educação, Comunicação e Desporto</td>
<td>Communication and Economic Relations</td>
<td>47</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Communication and Public Relations</td>
<td>165</td>
<td>12</td>
</tr>
<tr>
<td>Instituto Politécnico de Bragança - Escola Superior de Comunicação, Administração e Turismo de Mirandela</td>
<td>Communication Technologies</td>
<td>88</td>
<td>6</td>
</tr>
<tr>
<td>Instituto Politécnico de Coimbra - Escola Superior de Educação de Coimbra</td>
<td>Organizational Communication (post-employment scheme)</td>
<td>49</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Social Communication</td>
<td>68</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Social Communication Course: Journalism and information</td>
<td>48</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Social Communication Teams: Creating Content for New Media</td>
<td>61</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Organizational Communication</td>
<td>68</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Organizational Communication Teams: Corporate Communication and Public Relations</td>
<td>56</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Organizational Communication Course: Marketing Communications</td>
<td>59</td>
<td>4</td>
</tr>
<tr>
<td>Instituto Politécnico de Leiria - Escola Superior de Educação e Ciências Sociais</td>
<td>Social Communication and Multimedia Education</td>
<td>104</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Social Communication and Multimedia Education Course: Social Communication</td>
<td>41</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Human Relations and Organizational Communication</td>
<td>160</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Social Communication and Multimedia Education (post-employment scheme)</td>
<td>84</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Social Communication and Multimedia Education (post-employment scheme) Course: Social Communication</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>Instituto Politécnico de Lisboa - Escola Superior de Comunicação Social</td>
<td>Journalism</td>
<td>224</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Public Relations and Corporate Communication</td>
<td>222</td>
<td>16</td>
</tr>
<tr>
<td>Instituto Politécnico de Portalegre - Escola Superior de Educação</td>
<td>Journalism and Communication</td>
<td>46</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Journalism and Communication Profile: Journalism</td>
<td>36</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Journalism and Communication Profile: Corporate Communications: Advertising and Public Relations</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>Instituto Politécnico de Setúbal - Escola Superior de Educação</td>
<td>Social Communication</td>
<td>52</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Social Communication Branch: Cultural Communication</td>
<td>35</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Social Communication Branch: Journalism</td>
<td>49</td>
<td>4</td>
</tr>
<tr>
<td>Instituto Politécnico de Tomar - Escola Superior</td>
<td>Social Communication</td>
<td>122</td>
<td>9</td>
</tr>
</tbody>
</table>


4 Calculated using the calculation of the percentage represented by the number of students in the total population and the corresponding value representative sample using the formula: Number of students surveyed = (number of students x 100) / 4878.
In order to achieve the objectives of the research, questionnaire surveys were applied to the entire representative sample of the population, namely, 357 communication students, distributed in proportion to the size and composition of the universe, by 22 institutions and 42 degrees.

To achieve the objectives of this research, we applied the *The Alzheimer’s Disease Knowledge Scale.*

---

The Alzheimer's Disease Knowledge Scale (ADKS)

“The ADKS is designed for use in both applied and research contexts, capable of assessing knowledge about Alzheimer’s disease among laypeople, patients, caregivers, and professionals.” (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009, p. 236).

The Alzheimer’s Disease Knowledge Scale is a questionnaire composed of 30 True or False questions, that takes approximately 5 to 10 minutes to be answered, covering various aspects of Alzheimer's disease: “risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management.” (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009, p. 236).

According to the authors, the scale can be used in different research contexts, always with the aim of evaluating knowledge about Alzheimer's disease.

“This new scale, the Alzheimer’s Disease Knowledge Scale (ADKS), could be used in a number of circumstances to examine what people know about AD. For example, the effectiveness of public information campaigns could be evaluated by administering the ADKS to broad samples of community residents. Similarly, giving the ADKS to health care or social service staff might pinpoint education needs or indicate the success of education efforts. The ADKS also could be given to patients and caregivers seeking a dementia evaluation to determine what they know, and to dementia support groups to guide psychoeducational efforts. Finally, researchers might use the ADKS to examine familiarity with AD as both a predictor variable and an outcome variable, depending on their research questions.” (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009, p. 236).

Thus, one can see that it makes sense to apply the ADKS following this work, once intended to precisely assess the knowledge about the disease, to identify in what areas of aware there is a need for a greater stake, to be drawn a public information campaign, namely a health literacy campaign.
The ADKS was applied by the authors to the various target audiences, in particular, college students, adults, workers of senior centers, caregivers of people with dementia and professionals in the field of dementia. Despite its limitations in what regards the low level of confidence of the internal consistency of the scale, and that the scale of important affairs to analyze multiple about Alzheimer's disease, it is considered that this is an important tool which fulfils the objectives of this study, that is, it is a range that “contains representative items that, as a set, likely reflect a person’s general knowledge about AD (Alzheimer Disease).” (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009, p. 246).

**Characterization of the survey**

The survey applied to assess knowledge about Alzheimer's disease, is divided into three large areas, like the questionnaire applied by Carpenter, Balsis, Otilingam, Hanson and Gatz, in the *Alzheimer's Disease Knowledge Scale*.

Firstly, there are four questions, with which we intend to trace the socio-demographic profile of the respondent, in particular in what concerns the educational institution, and course that attends, what is the age, gender and nationality.

Thus, the first four questions are:

1. **Institution and course**
   With this issue we intend to find out in which institution and course the student is admitted, in order to be characterized as a representative sample of the population. The answer is intended to identify only one of the establishments and courses presented.

2. **Gender**
   With this issue we intend to characterize respondents in terms of gender, male or female. The answer is one of the two options: "male" or "female".

3. **Age**
The third question seeks to typify the respondents with regard to its age. The response options presented are numbers in the range scale of two years, starting on 18 and finishing in 30 or more years.

4. Nationality
The fourth question is to know the nationality of the students included in the sample under study. The desired response is to choose one of the options: "Portuguese" or "Other", and, in this case, the respondent should indicate their nationality.

By its turn, the second set of issues seeks to assess what is the relationship of the respondent with the problems of Alzheimer's disease, that is, if the student know, lived, cared for or worked with someone with Alzheimer's disease, or if they have attended any training or information on the subject. In this follow-up, we also asked respondents to rate their knowledge about Alzheimer's disease, on a scale of 1 to 10.

In this way, issues 5 to 10 are:

5. Have you ever cared for someone with Alzheimer's?
With the fifth question we intended to know if the respondents have been formal or informal caregivers of someone with Alzheimer's disease. The response options are "Yes" or "No".

6. Have you ever worked or made any voluntary action among people with Alzheimer's disease or other dementia?
With the sixth issue, the aim is to assess whether the respondents have already had some contact with some Alzheimer's patients, either as formal caregivers or as a volunteer. The response options are "Yes" or "No".

7. Have you ever attended any support group, course, training, or information related to Alzheimer's disease?
The seventh question intends to check if the students in the study already had some contact with the subject of Alzheimer's disease, in some support group, training, course or information session. The response options are "No" or "Yes"
and, in this case, the respondents should select one or more of the following options: "Support Group"; "Course"; "Training"; "Information session".

8. Do you know or have known someone with Alzheimer's?
With the eighth issue, the aim is to assess whether the respondents know, whether or not someone with Alzheimer's disease. The response options are "Yes" or "No".

Before the completion of the pilot questionnaire this question was worded as follows: "Do you know someone with Alzheimer's disease?".

9. Have you ever searched for information about Alzheimer's disease?
The ninth question aims to assess whether the respondents have sought information about Alzheimer's disease and, if they already have sought, in what context this search occurred. The response options are "No" or "Yes, as part of a school project/scholar"; "Yes, because it was diagnosed Alzheimer's disease to a family member/friend/acquaintance"; "Yes, for personal interest in the topic"; "Yes, following a news story or report".

10. On a scale of 1 to 10, rate your knowledge about Alzheimer's disease.
The last question presented to respondents prior to the application of The Alzheimer's disease Knowledge Scale, aims to evaluate how respondents rank their own knowledge about the disease. The answer is the selection of a number, on a scale of 1 to 10, where 1 means "I don't know anything about Alzheimer's disease" and 10 "I know everything about Alzheimer's disease".

Finally, the third phase of the questionnaire consists of 30 questions to answer True or False, defined for The Alzheimer’s Disease Knowledge Scale (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). These questions are divided by 7 main themes, such as can be seen in table 2.
Table 2 - Questions of The Alzheimer’s Disease Knowledge Scale

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Question</th>
<th>Correct Answer</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>People with AD are particularly prone to depression.</td>
<td>True</td>
<td>Life impact</td>
</tr>
<tr>
<td>11</td>
<td>Most people with AD live in nursing homes.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>It is safe for people with Alzheimer’s disease (AD) to drive, as long as they have a companion in the car at all times.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>It has been scientifically proven that mental exercise can prevent a person from getting AD.</td>
<td>False</td>
<td>Risk factors</td>
</tr>
<tr>
<td>13</td>
<td>People in their 30s can have AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Having high cholesterol may increase a person’s risk of developing AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Prescription drugs that prevent AD are available.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Having high blood pressure may increase a person’s risk of developing AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Genes can only partially account for the development of AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Tremor or shaking of the hands or arms is a common symptom in people with AD.</td>
<td>False</td>
<td>Symptoms</td>
</tr>
<tr>
<td>22</td>
<td>Trouble handling money or paying bills is a common early symptom of AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>One symptom that can occur with AD is believing that other people are stealing one’s things.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Most people with AD remember recent events better than things that happened in the past.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>People whose AD is not yet severe can benefit from psychotherapy for depression and anxiety.</td>
<td>True</td>
<td>Treatment and management</td>
</tr>
<tr>
<td>12</td>
<td>Poor nutrition can make the symptoms of AD worse.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>When a person has AD, using reminder notes is a crutch that can contribute to decline.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>AD cannot be cured.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>People with AD do best with simple instructions giving one step at a time.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>When people with AD begin to have difficulty taking care of themselves, caregivers should take over right away.</td>
<td>False</td>
<td>Caregiving</td>
</tr>
<tr>
<td>7</td>
<td>If a person with AD becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>When people with AD repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Once people have AD, they are no longer capable of making informed decisions about their own care.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>When a person with AD becomes agitated, a medical examination might reveal other health problems that caused the agitation.</td>
<td>True</td>
<td>Assessment and Diagnosis</td>
</tr>
<tr>
<td>10</td>
<td>If trouble with memory and confused thinking appears suddenly, it is likely due to AD.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Symptoms of severe depression can be mistaken for symptoms of AD.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>AD is one type of dementia.</td>
<td>True</td>
<td>Course</td>
</tr>
<tr>
<td>3</td>
<td>After symptoms of AD appear, the average life expectancy is 6 – 12 years.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>In rare cases, people have recovered from Alzheimer’s disease.</td>
<td>False</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>A person with AD becomes increasingly likely to fall down as the disease gets worse.</td>
<td>True</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Eventually, a person with AD will need 24-hr supervision.</td>
<td>True</td>
<td></td>
</tr>
</tbody>
</table>

Adapted from Carpenter, Balsis, Otilingam, Hanson, & Gatz, (2009)
Pilot Survey

We conducted a pilot survey, from 9 to 11 April, 2011, in order to check how long the recipients take to perform the questionnaire and, on the other hand, with the aim of detecting non-relevant issues or questions that are worded in an ambiguous or unclear.

The group that participated in the realization of the pilot survey consisted of 10 students of the master degree in Public relations at Escola Superior de Comunicação Social. In this sense, it was possible to test the survey on a group similar to the population of the study, having in common the fact that they are students in the area of communication but, this time, being postgraduate students.

We asked, therefore, the 10 elements of the group to respond to the questionnaire and, in the end, to respond to the following questions (Cf: Bell, 1993):

1 - How long it took to complete the questionnaire?

2 - The instructions were clear?

3 – Did you found some unclear or ambiguous question?

4 - In your opinion, it was omitted any important topic?

5 – Do you considered the course questionnaire format/attractive?

6- Any comments?

The results of the pilot questionnaire led us to realize that the questionnaire response time ranged between 4 and 10 minutes and that, for all respondents, the instructions were clear, and was not omitted any important topic. For all respondents, the format of the questionnaire was clear/attractive.

In what concerns the existence of any unclear or ambiguous question, two of the respondents considered our first Portuguese translation of the statement "When a person with AD becomes agitated, a medical examination might reveal other health problems that caused the agitation." as unclear ("Quando uma pessoa com Doença de Alzheimer se torna mais agitada, uma avaliação médica pode revelar outros problemas de saúde que sejam a causa dessa agitação").
We therefore proceeded to the reformulation of the question to be posed as "Quando uma pessoa com Doença de Alzheimer se torna mais agitada, é importante que seja avaliada por um médico, pois podem haver outras causas para essa agitação que não estejam relacionadas com a Doença de Alzheimer".

Furthermore, also one of the respondents revealed that considered the question "Do you know someone with Alzheimer's disease?" ambiguous, because it was not clear whether it was referring only to the present or the past, too. So the question was rephrased to "Do you know or have known someone with Alzheimer's disease?"

After reformulated the sentences, these were presented to respondents who had initially considered the confusing phrases, and all agreed that the sentences were now quite noticeable clearer.

**Application of surveys**

The surveys used in this research were applied in electronic format through the application Google Forms. For this purpose, were contacted by email all responsible/coordinators/directors of the courses that make up the study sample, asking them to cooperate in order to pass the link to their students, so that they respond to the survey.

The e-mail contacts were held on April 11, 2011, being collected responses from that day until May 11, 2011.

During this period, 410 students answered the questionnaire in electronic format. However, it has not been possible to collect all of the desired sample, due to lack of responses from students at some universities. Thus, it has not been possible to collect any response from students from 4 degrees from the Escola Superior de Educação e Ciências Sociais do Instituto Politécnico de Leiria: Social Communication and Multimedia Education; Social Communication and Multimedia Education - Branch: Social Communication; Social Communication and Multimedia Education (post-laboral); Social Communication and Multimedia Education (post laboral) - Branch: Social Communication. In this institution, the only course that got responses was the
degree in Human Relations and Organizational Communication but, however, only 6 of the 12 responses were required.

In this follow-up, it is also noteworthy that we only got 1 of the 3 responses sought by students of the degree in Journalism and Communication at the Escola Superior de Educação do Instituto Politécnico de Portalegre.

Faced with these constraints on research, we obtained a total of 326 valid responses to the survey.

**Results**

After the analysis of the surveys applied to a representative sample of university students attending courses in the area of communication, it turns out that on average, students give the right answer to 18.98 of the 30 questions about Alzheimer's disease. When comparing these results with those of the study of Carpenter, Balsis, Otilingam, Hanson, & Gatz, (2009) it turns out that the Portuguese students have less knowledge about the disease than students surveyed in the study, with an average rating on The Alzheimer's Disease Knowledge Scale of 20.19 correct answers.

Concerning the areas of knowledge in which respondents have more wrong answers it is, first of all, the "risk factors" of Alzheimer's disease, with a percentage of 50.88% of wrong answers. In second place comes the theme "Caregiving", with 44.78% of wrong answers and, thirdly, the category "Symptoms" with 37.95% wrong answers.

**Table 3 - Wrong answers to questions of The Alzheimer's Disease Knowledge Scale**

<table>
<thead>
<tr>
<th>Question</th>
<th>Wrong answers (%)</th>
<th>Content</th>
<th>Average Wrong Answers (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with AD are particularly prone to depression.</td>
<td>31.6</td>
<td>Life impact</td>
<td>27.3</td>
</tr>
<tr>
<td>Most people with AD live in nursing homes.</td>
<td>30.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is safe for people with Alzheimer’s disease (AD) to drive, as long as they have a companion in the car at all times.</td>
<td>20.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It has been scientifically proven that mental exercise can prevent a person from getting AD.</td>
<td>79.8</td>
<td>Risk factors</td>
<td>50.88</td>
</tr>
<tr>
<td>People in their 30s can have AD.</td>
<td>27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having high cholesterol may increase a person’s risk of developing AD.</td>
<td>77.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription drugs that prevent AD are available.</td>
<td>35.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having high blood pressure may increase a person’s risk of</td>
<td>68.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In table 3 we can see the answers and thematic areas in which there have been more wrong answers. The answer that has a lower percentage of wrong answers is "When a person has AD, using reminder notes is a crutch that can contribute to decline." with only 6.4% of wrong answers and, at the other end, we found the question "When people with AD begin to have difficulty taking care of themselves, caregivers should take over right away." with 81.3% of wrong answers.

Faced with these results it was concluded that the main areas in which we need to bet on a health literacy campaign are, precisely, in the risk factors and in symptoms of Alzheimer's disease, as well as on information specifically targeted to caregivers about how to care for someone with Alzheimer's disease in the daily life.
There are three areas that need to be improved and invested, being the ones where the major failures on Alzheimer's disease exist: how to care for someone with Alzheimer's disease; What are the main symptoms of the disease; and, finally, how we can reduce the risk of developing the disease.

FINAL REMARKS

Based on the results obtained in the quantitative research on the Alzheimer’s Disease Knowledge Scale in Portugal, we concluded that it was imperative a reformulation of Alzheimer Portugal Association’s communication strategy, seeking to meet the needs of the main target groups of the Association: people with Dementia and their carers and families. On the other hand, it seemed important to provide more and better information in the themes with more failures, i.e. at the level of symptoms and risk factors of the disease.

Therefore, it was created a specific area on the website for caregivers of people with Dementia, where you can find various information about the disease, about how to deal with a person with Alzheimer's disease on a daily basis, either at the moment of diagnosis or in everyday situations, such as feeding, hygiene, sleep, the doctor visits, changes in behavior, among others. It was also provided targeted information to family members and to their quality of life, as well as specific information about residential care or about changes in the home environment that are important to perform.

Regarding the symptoms of Alzheimer's disease and the leading risk factors, was also created a specific section for each area, explaining not only their importance, but also providing examples.

However, there is still a long way to go in what is health literacy, specifically in the field of Alzheimer's disease. It is urgent, therefore, that we can unite efforts in order to be able to change these values and increase knowledge about the main symptoms and risk factors of Alzheimer's disease, because only in this way we will boost early diagnosis and, consequently, improve the quality of life of patients and caregivers.
We know that we're doing the first steps in health communication in what Alzheimer’s disease is concerned in Portugal, but we hope that in a near future we'll be able to understand in a better way how to improve health literacy in this area.

REFERENCES


