Public education about normal forgetfulness and dementia: importance and effects

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Abstract

In the Netherlands considerable attention has been given to dementia, but hardly any is paid to normal forgetfulness. Two information meetings about the differences between normal forgetfulness and dementia were organized in order to meet current information needs. Evaluation of those meetings gave more insight into the characteristics of people who are worried about their diminishing memory and provided the opportunity of measuring changes in knowledge and anxiety. Almost 50% of the 450 participants indicated that they were worried about their memory; 66% of these people reported being more or less reassured afterwards. Although the level of knowledge increased, no correlation was found between increased knowledge and decreased anxiety. Because of people's anxiety about possible dementia, it is important to provide the general public with more information about this subject. More research, with a control group, is necessary to draw conclusions about the effectiveness of health education in this area.

Keywords: Forgetfulness; Dementia; Health education; Effectiveness

1. Introduction

People are deluged with information about health and diseases. In the last decade, considerable information has become available about aging, dementia, and Alzheimer's disease and this development can mainly be explained by a sharp increase in the total number, as well as in the proportion, of aged individuals in the population as a whole [1]. With advancing age, not only do physical functions diminish, but the cognitive functions also change [2-4]. A large number of elderly people regard this cognitive decline as the final proof of their deterioration. Elderly people start to ascribe normal forgetfulness to something abnormal; this could lead to a further increase in anxiety, thereby creating a vicious circle.

However, earlier research shows that most people's worries about dementia are unsubstantiated [5]. Individual (negative) beliefs and expectations with regard to memory capacity and abilities, appear to influence memory complaints and test per-
formances of elderly people [6,7]. Bandura has described this as perceived Memory Self-Efficacy (MSE), meaning the extent to which an individual is inclined to make an effort in memory related tasks, regardless of his or her potential memory skills [8]. Worries and uncertainty about memory are reflected by the increasing popularity of memory training programs [9,10].

Education in this area is important because the literature reveals many misunderstandings about memory problems and dementia [11-13]. For example, many people think that forgetfulness in elderly people always results in dementia. Among health-care professionals, these misunderstandings and prejudices might cause a less than adequate way of coping with elderly people with memory complaints [14]. There are few articles on education about memory problems and dementia in the literature, and none on information programs for people who worry about their forgetfulness [15]. This does not necessarily imply that there is no education or information available for this target group, but might reflect a lack of a systematic evaluation of these education activities.

Over the past 5 years, Dutch daily and weekly news magazines have produced a flow of information about dementia [15]; the emphasis of these articles is on research into dementia and into the increasing shortage of beds for demented patients in nursing homes. Hardly any attention is paid to information about the disease, the course of the disease, the problems that might occur, and health-care possibilities. Furthermore, there are very few articles about memory and forgetfulness compared with the number of publications about dementia. This current flow of information about dementia and the lack of information about normal forgetfulness, might cause an ‘epidemic of anxiety about dementia’. From experience in the Maastricht Memory Clinic, it appears that many elderly people who are forgetful are worried and are living with the idea that ‘I am becoming demented’ [16]. They are unaware that memory complaints are often part of the normal aging process [17] and can also occur when a person is suffering from depression [18].

It can be concluded that until now, hardly any attention has been paid to public education about normal forgetfulness and dementia. As far as we know, no systematic research has been carried out into the effects of this type of education. In order to fill the current gaps and to meet the current needs, two information meetings were organized, in order to provide people with more information about forgetfulness. In order to assess the effects of these meetings, all participants filled in a pretest and a post-test questionnaire. The information meetings were a joint project by the Regional Green Cross Organization, the Maastricht Memory Clinic, and the University of Limburg.

The goal of the project was twofold: (a) to acquire relevant information about the people who are worried about their diminishing memory, e.g. some demographic characteristics (age and gender), needs, interests, and reasons for attending the information meeting; (b) to assess the effects of the information on the participants by measuring changes in knowledge and anxiety. In this way it can be assessed whether changes in the content or organization of the information meetings are necessary.

2. Methods

2.1. Target group and recruitment

The information meetings, ‘Forgetfulness: often a normal phenomenon’, were organized for people who were interested in the subject for whatever reason. The recruitment was carried out by the Regional Green Cross Organization who made use of the regional newspapers, free local papers and the local radio, and erected posters in community centers, libraries, physicians’ offices and pharmacies. Both meetings had the same content and they took place in Maastricht (large city) and Gulpen (small town).

2.2. Content of the information meetings

Both meetings consisted of two parts of 30 min each, separated by a 20-min pause. In the first part, two lectures were presented with slides. The first lecture, by a neuropsychologist, described the functioning of normal memory and the changes in how it works during normal aging. The second lecture, by a neuropsychiatrist, provided information about the differences between normal forgetfulness and dementia. The content of both presentations was mainly based on scientific knowledge.
regarding age-associated cognitive functioning and on questions asked by patients of the Maastricht Memory Clinic [12]. During the interval, people could hand in written questions. After the interval there was plenty of time for questions and discussion.

2.3. Questionnaires

The pretest and post-test questionnaires consisted of structured questions. People had to be able to answer all questions within a few minutes. Therefore the questionnaire had to be short and it did not provide for information on interesting variables such as social class, education level or occupation. In the first questionnaire, completed 10 min before the meeting started, questions were asked about the motives for attendance. The answers were given beforehand and people could indicate 'yes' or 'no'. Questions were also asked regarding subjects about which people would like more information. People were asked whether they were worried about forgetfulness and/or afraid of dementia ('yes' or 'no'). Five questions were asked to assess knowledge about the subject. In the second questionnaire, completed at home 3 weeks after the meeting, questions were asked to determine whether people had acquired more knowledge and insight into the functioning of memory and about the differences between normal forgetfulness and dementia. To assess knowledge, people answered the same 5 questions as in the pretest questionnaire. Furthermore, the respondents were asked whether their possible worries and anxiety had decreased, whether they intended to undertake any action as a result of the information received, and, if so, what they were planning to do, and also, the way they would like to receive further information in the future. Finally, seven additional questions were asked about issues that were discussed during the information meeting. Two weeks after the post-test questionnaire, all respondents received a booklet containing information provided by the two lectures.

3. Results

3.1. Response

The interest in the information meetings was overwhelming; approximately 450 people attended. Because of this unexpectedly high attendance, there were not enough questionnaires available. Of the 390 questionnaires that were handed out, 356 (91%) were filled in and returned. Code numbers were used to guarantee anonymity. All 347 people whose name and address were known, received a post-test questionnaire at home, 3 weeks after the meeting. The response to the post-test questionnaire was 71% (n = 246). For 207 respondents, data from both the pretest and the post-test questionnaires were available, i.e. 57% of the total number of questionnaires that were handed out. For 140 respondents, only data from one questionnaire were available.

3.2. Demographic characteristics

Seventy-three percent of all respondents were women. The average age of the respondents was 58 years, in the range 21–88 years. More than 27% of the respondents were younger than 50 years, 51% were between 50 and 70 years, and 22% were older than 70 years.

3.3. Motives for attendance

By using structured questions we gained an insight into the motives for attending the information meeting. People could give more than one reason. From Table 1, it appears that 50% of the respondents attended the meeting because of worries about their memory. Among the people who gave more reasons, 46% were worried about their memory and were also afraid of incipient dementia; 48% were worried about their memory without being afraid of dementia, and 4% were afraid of developing a dementia syndrome but were not

Table 1 Motives for attending the information meeting

<table>
<thead>
<tr>
<th>Motive</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am worried about my memory</td>
<td>50</td>
</tr>
<tr>
<td>I am afraid of incipient dementia</td>
<td>28</td>
</tr>
<tr>
<td>I am worried about the memory of someone I know</td>
<td>27</td>
</tr>
<tr>
<td>I am afraid someone I know is developing a dementia syndrome</td>
<td>15</td>
</tr>
<tr>
<td>I am professionally interested in the subject</td>
<td>12</td>
</tr>
<tr>
<td>Dementia occurs in my family</td>
<td>3</td>
</tr>
</tbody>
</table>

Number of respondents, 356.
worried about their memory. Ninety-three people (27%) were worried about the memory of someone in their social environment, namely, one of their parents (37%), their spouse (35%), a friend or acquaintance, both parents (9%), and a brother or a sister (9%). Thirty-nine people (11%) were worried about their own memory and were also worried about the memory of someone they knew.

People who were worried about their memory, were significantly older than the group of people without these worries \( (T = 5.2, P < 0.001) \) and people who were afraid of incipient dementia were also older than people who were not \( (T = 7.2, P < 0.001) \). No differences were found between men and women.

People who attended only because they were professionally interested in the subject were, on average, 18 years younger (43 vs. 61 years) than people who attended because of different personal motives \( (T = 7.7, P < 0.001) \).

### 3.4. Changes in worries after the meetings

We investigated whether the information meeting soothed or aggravated the concerns of people who were worried about their own memory or about the memory of someone else. The results are presented in Table 2.

<table>
<thead>
<tr>
<th>Worries after the information meeting among people who were worried beforehand</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Worries about my own memory have</strong>&lt;sup&gt;a&lt;/sup&gt;:</td>
<td></td>
</tr>
<tr>
<td>Decreased considerably</td>
<td>27</td>
</tr>
<tr>
<td>Decreased a little</td>
<td>39</td>
</tr>
<tr>
<td>Not changed at all</td>
<td>34</td>
</tr>
<tr>
<td>Increased</td>
<td>0</td>
</tr>
<tr>
<td><strong>Worries about the memory of someone in my social environment have</strong>&lt;sup&gt;b&lt;/sup&gt;:</td>
<td></td>
</tr>
<tr>
<td>Decreased considerably</td>
<td>21</td>
</tr>
<tr>
<td>Decreased a little</td>
<td>31</td>
</tr>
<tr>
<td>Not changed at all</td>
<td>47</td>
</tr>
<tr>
<td>Increased</td>
<td>1</td>
</tr>
</tbody>
</table>

<sup>a</sup> Number of respondents, 111.  
<sup>b</sup> Number of respondents, 62.

Sixty-six percent of all people who were worried before the meeting, were more or less reassured after having attended the information meeting. No respondent indicated that he or she had become more worried. The worries of 34% of all people remained the same as before, which could mean both high as low. Fifty-two percent of all people who were worried before the meeting about the memory of someone in their social environment \( (n = 62) \), were more or less reassured after the information meeting. The worries of 47% of this group of people remained the same as before. Only one respondent became more worried after the meeting. All other respondents who did not worry before the meeting, did not worry after it.

Of the 39 people who were worried about their own memory and also about the memory of someone they knew, only 21 people filled in the post-test questionnaire. Two people in this group indicated that they were less worried about their own memory, but that they were still worried about someone else. Two other people were less worried about someone else's memory, but they were still worried about their own memory. In two other cases people's own worries increased and also their worries about someone else increased. In all other cases, all people's worries had decreased considerably.

### 3.5. Knowledge

Before the meeting started, people indicated whether or not they agreed with five statements on common misunderstandings about dementia and forgetfulness. These statements concerned the central message of both lectures and assessed the people's level of knowledge \( (\text{Cronbach's } \alpha = 0.53) \). People who really could not give an answer were allowed to fill in 'I don't know'. Table 3 presents the results of the pretest and post-test questionnaires.

All questions in the post-test questionnaire were answered better than those in the pretest questionnaire. The percentage of correct answers for the first question increased by 10%. The percentage of correct answers for the second to the fifth questions increased by 6, 31, 12, and 10%, respectively. The third question was still answered incorrectly, very often. After the meeting, 41% of all par-
Table 3
Answers to questions assessing knowledge

<table>
<thead>
<tr>
<th>Question</th>
<th>I agree (%)</th>
<th></th>
<th>I don’t agree (%)</th>
<th></th>
<th>I don’t know (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before</td>
<td>After</td>
<td>Before</td>
<td>After</td>
<td>Before</td>
<td>After</td>
</tr>
<tr>
<td>1. Elderly people have poor memory</td>
<td>21</td>
<td>12</td>
<td>73</td>
<td>83</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>2. Elderly people cannot learn new things</td>
<td>10</td>
<td>6</td>
<td>85</td>
<td>91</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>3. Your memory will improve if you learn</td>
<td>60</td>
<td>34</td>
<td>28</td>
<td>59</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>shopping lists and other things by heart</td>
<td>55</td>
<td>67</td>
<td>32</td>
<td>30</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>4. Worrying can cause memory complaints</td>
<td>10</td>
<td>3</td>
<td>85</td>
<td>95</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>5. The forgetfulness of people aged 65 years or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>older is usually a prodrome of dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Number of respondents, 200.
Correct answers are shown in bold.

Participants were unaware that memory is not improved by learning shopping lists and other things by heart. The fourth question, about whether worrying could actually lead to memory problems, was also answered incorrectly, relatively often. The percentage of ‘I don’t know’ was somewhat lower in the post-test questionnaire.

Seven additional questions assessing the attendants’ knowledge were asked in the post-test questionnaire. More than half of the respondents (52%) incorrectly thought that the human memory can be compared with a muscle which can be made stronger by a lot of exercise, 34% of all people incorrectly said that concentration has nothing to do with the functioning of memory, and 17% incorrectly indicated that medication, such as sleeping pills, has no influence on the working of the brain. A comparison between the pretest and post-test answers for these questions was not possible. An indication for reassurance after the meeting appeared from the fact that 96% of participants agreed with the statement that forgetfulness is a normal phenomenon, and 96% also indicated that dementia is accompanied by more problems than just problems with memory.

From the post-test questionnaire, it appeared that the level of assessed knowledge significantly correlated with the age of the respondents \( r = 0.48, P < 0.01 \); the older the individual, the lower the level of knowledge. We then investigated whether there was a correlation between decreased worries and increased level of knowledge; a correction was made for age differences by using partial correlations. It appeared that there was no correlation between increased knowledge and decreased anxiety about someone’s memory.

All participants were asked whether they intended to undertake any action as a result of the information received. Nineteen people (9%) indicated that they would consult their physician and discuss their complaints and worries; 14 people (6%) were still worried, but were not going to do anything about it; seven people (3%) wanted to participate in a memory training program; five people (2%) were going to ask to be referred to a specialist. The other 81% were not worried (anymore) and did not intend to undertake any action.

3.6. Demand for further information

Several questions were asked in order to be able to take into account the needs and the wishes of the target group in future health education and information activities. Twenty-three percent of all respondents indicated that they had not received enough information at the meeting. The desired amount of information strongly correlated with the age of the respondents \( r = 0.41, P < 0.05 \); the younger the respondent, the more information was wanted. Seventy-eight percent of respondents considered that the information met their needs very well. Both lectures were considered to be under-
standable; 5% of the attendants found the information too difficult.

At the end, we asked the respondents how they would like to receive information in future education programs. Respondents could only give one preference. An information meeting in combination with a brochure, so that information can be read at home, had the highest preference (57%). An information meeting only was mentioned by 14% of the respondents; 13% preferred a talk group in combination with a brochure; 6% wanted a brochure only; 6% wanted the information to be given in a television program; 3% would like to participate in a talk group for people with memory problems; 1% chose the radio as their favorite source of information. Seventy-six percent of the participants were interested in a brochure on the subject and most of them wanted a brochure in combination with an information meeting or a talk group.

4. Discussion

Most information and education activities pay a lot of attention to dementia, but hardly any attention to normal forgetfulness, memory problems, and the working of the memory. In order to gain more insight and a better understanding of the information need about this subject, two information meetings about normal forgetfulness were organized and evaluated.

The major goal of this project was to acquire relevant information about the target group and to investigate whether information leads to a higher level of knowledge and to a reduction in anxiety and worries about forgetfulness and/or dementia. In health education activities it is of essential importance that the information is planned systematically and that the information is also geared to the level of knowledge and the needs of the target group [19]. With a view to future education programs, it is important to have sufficient information about the target group beforehand and it is also necessary to investigate whether the information is understood and whether the objectives of the program are actually achieved. It is also of great importance that the education is provided by, or organized in cooperation with, persons or organizations who are experts in both the field of health education and in the field of memory problems and dementia.

In this study, 66% of all people who worried about their memory before the meeting were more or less reassured after having attended the information meeting. Although their level of knowledge increased, no correlation was found between increased knowledge and reduced anxiety. However, the central message of the meetings, 'Forgetfulness: often a normal phenomenon', was well understood. Decreased anxiety can partly be explained by the large number of people who were present, as participants could see that they are not the only people who are worried, or who forget from time to time. A limitation of this project is that it was not possible to determine whether the people who were worrying unnecessarily were reassured by the information. No objective information was available about their cognitive functioning; we only had information about their own subjective experience. As we did not use a control group who did not get the information, we cannot draw conclusions about possibilities of information bias or social desirability. Furthermore, it should be noted that the people who attend an information meeting are not representative of the total group of people who worry about their memory and who desire information about this subject. Our participants are representative of a so-called convenience sample. No information is available about the level of education of the attendants, but it can be expected that the number of people who are highly educated is relatively high in this sample.

In the implementation and distribution of future educational programs, special attention should be paid to the accessibility of the total target group, including the older elderly and people from lower socio-economic groups.

In contrast with other health problems that health education is aimed at, we are not dealing with a motivational or skills problem (e.g. smoking or unsafe sex), but much more with an information problem [20]. Although no research has been conducted into the consequences of unnecessary anxiety about dementia, it is plausible that this could eventually lead to more complaints of a
A decrease in the quality of life and therefore an increase in health-care costs. By providing the general public with systematically planned education programs about the differences between normal forgetfulness and dementia, many might be prevented from unnecessarily becoming anxious and uncertain about dementia. Further research should be conducted in order to draw conclusions about the effects of these types of interventions. A control group must be used, in order to account for the possible influence of other media.

An information meeting is one way to provide the general public with information about health issues. Another source of information is a brochure. A brochure can serve as an independent medium or as a supportive medium used in combination with a meeting, a talk group, or a consultation with a physician. An advantage of a brochure is that a large group of people can be reached in a relatively cheap and simple way. In order to fill the gaps and meet current information needs, a brochure was developed in 1992 at the request of the Dutch Alzheimer’s Association [21]. This brochure, ‘Forgetfulness or Dementia?’, was partly based on the results of this project. The effects of this brochure have been assessed by Commissaris et al. [22].

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