

REPORT ON THE PILOT TRAINING FOR FAMILY CARERS OF PERSONS WITH ALZHEIMER DEMENTIA ON E-LEARNING PLATFORM WITHIN ELMI PROJECT

GENERAL INFORMATION

The report from the pilot training for family carers of persons with Alzheimer dementia on e-learning platform was made as part of the project *Enhancing labour market integration of elderly family carers through skills improving* (ELMI), funded with support from the European Union funds within LLP Leonardo da Vinci Transfer of Innovation program. The project was implemented by the consortium including the following institutions: Asociația Habilitas Centru de Resurse și Formare Profesională, Romania (project coordinator), Anziani e Non Solo Società Cooperativa, Italy; Romanian Alzheimer Society, Romania; E.N.T.E.R.- European Network for Transfer and Exploitation of EU Project Results, Austria; Caritas Confederation, Romania; Center for Family and Social Care – Czech Republic. The Polish partner – University of Łódź is represented by the Institute of Adult Education and Social Gerontology.

As part of the implementation of ELMI project a number of activities have been planned, aiming at the transfer of e-learning training for people who take care or took care, as non-professionals, of people suffering from Alzheimer dementia. All the suggested solutions were fully developed in Italy. The trainings in a form of e-learning courses were implemented, after a necessary adjustment, in Romania, Czech Republic and Poland.

THE PILOT OBJECTIVE

The aim of carrying out the pilot stage was the evaluation of training materials published on the e-learning platform. Particular attention was drawn to the issue of how helpful the training will be in the process of becoming a professional Alzheimer dementia patients' carer.

PILOT STAGES

The pilot consisted of five succeeding stages:

- 1) Recruitment of pilot participants.
- 2) Information meeting for pilot participants.
- 3) E-learning platform training.
- 4) Carrying out evaluation – interviews with participants.

- 5) Introducing changes to the teaching modules according to instructions of pilot stage participants.

Duration of all pilot stages in total was 5 months (30.04.2015-30.09.2015).

RECRUITMENT OF PILOT STAGE PARTICIPANTS

10 people took part in the pilot stage – 8 women and 2 men, aged from 22 to 67. The following criteria were taken into consideration when choosing them: a person recruited to the project should be actively taking care of a person with Alzheimer dementia at the moment, be interested in working in the care sector, be at a risk of professional burnout syndrome and have access to the Internet. The training on the platform was completed by 10 people (the data acquired on the basis of participants' declarations).

INFORMATION MEETING FOR PILOT PARTICIPANTS

The information meeting for the pilot stage participants was organised on 1st July in the Faculty of Educational Sciences building at Pomorska 46/48 in Łódź. During the meeting the employees of the Institute of Adult Education and Social Gerontology presented the objective of running the pilot stage within ELMI project. During the meeting participants learnt about the assumptions of the project and became familiar with the functioning of e-learning platform, where training materials were placed. During the meeting, the participants were given the Caregiver Burden Scale according to Zarit and were asked to fill it in.

E-LEARNING PLATFORM TRAINING

Within the project, the partner from Poland was to choose two training modules which, after the right compilation and adaptation, were placed on the e-learning platform. The participants of pilot from Poland went through two modules, including eight didactic units. The first module was related to communication and caregiving relations, and included the following didactic units – the nature of communication and relation in caregiving, efficiency rules, types and channels of communication, the course of communication process based on relations in caregiving, and coping with difficulties in communication with a person suffering from Alzheimer disease. The title of the second module was – Care: risk of stress and professional burnout. As part of this topic, the following didactic units have been prepared for implementation – difficulties in providing care (relational, financial, organisational, etc.), coping with intense stress by caregivers of people suffering from Alzheimer dementia –

causes, symptoms and diagnosis, professional burnout syndrome of Alzheimer disease patients' carers – causes and symptoms, diagnosis, coping with stressful situations.

During the training, no problems related to functioning and use of e-learning platform were noticed.

An integral part of the course were tests assessing the participants' knowledge. The tests' results made it possible to come to the conclusion that the project participants acquired high levels of knowledge provided during the training, both in the module on communication and care relations, and on stress and burnout. A strong majority of questions was answered correctly (80%).

CARRYING OUT EVALUATION – INTERVIEWS WITH THE PARTICIPANTS

The report was prepared on the basis of information from video interviews and during individual talks with pilot participants. The most important opinions are presented below:

1. What did you learn during the training that will help work as a caregiver?

To some extent, the training was helpful to all the people being tested. The participants considered the information gained from the module about **stress** more useful because they learnt how to "help themselves" and "solve stress problems". Almost all of them emphasised that **exercises** were an advantage as they gave them the possibility to check their knowledge in practice, except for one participant who considered exercises to be useless.

Moreover, it was stressed that it was a chance to **think about a strategy of acting and communicating so as to prepare to cope with difficulties**. One of the participants said that the module about communication did not bring anything new to her way of conduct because **she had her communication strategy for a long time** (it is based on rising her voice when a sick person does not do what they are told), and because it is efficient, she was not going to modify it.

In general, the training participants considered the module about coping with stress to be more useful.

2. What, in your opinion, could be changed or improved in the training?

The project participants, especially younger ones, emphasised the fact that many issues were familiar to them to some extent, so the material seemed to be "**too obvious**", and thus sometimes **boring**. The oldest participant said that the content was **too difficult**, and the exercises did not do much good and were unnecessary.

Everybody stressed that **there were too few modules**, and the content was limited only to relation with a patient and not, for example, **with their close and more distant relatives**.

What is more, some participants considered the material to be "**too academic**", i.e. there were names of scientists, classifications that seemed useless and sometimes made less clear what they already knew. There was too much "content-related material".

The test checking the knowledge was similarly assessed as "like a test just for obtaining a grade" that checked only "**what was remembered**", and not **what was taught in practice**. The oldest participant of the training said that the tests were difficult.

In the module about communication the information sometimes "mixed, overlapped, and had similar subjects". What is more, **there was too much material**, which sometimes was annoying.

From a technical point of view, some participants reported inconveniences connected with perception of the course materials – **slides moved either too fast or too slow**. One of the interviewees found the voice (in a foreign language) disturbing as it overlapped with the Polish voice-over. It was also reported that the slides were **too rhythmical and monotonous**, and thus sometimes "drowsy-making".

That is why **the exercises that forced participants to focus their attention and forget about "cold facts" only** were so valuable.

One of the participants would add **short films demonstrating the contents "in real life"** that „would break the monotony of the text read and rhythmically changing slides”.

It was also suggested that if **the speaker was „present” on the screen**, the emotions expressed by him as well as his facial expression would be visible, and “which would facilitate memorising" the message. One could also feel like they were talking to the person reading the given module.

3. What is your experience, as an Internet training participant of ELMI project? How can you describe your experience as a learner?

All the participants experienced gaining knowledge and learning on the Internet platform for the first time. All of them agreed that the possibility to gain knowledge via the Internet was an advantage. According to the respondents, it **allows for using the material whenever time permits**, which is a great advantage. What is more, such a form of studying gives participants the possibility to **come back to the material** and revise it according to one's needs.

Making exercises "woke (the participants) up and forced (them) to think". One of the participants said that this is **"a training for people who can think, who search and want to develop and improve their life quality and their contact with a sick person"**.

The advantage for almost all the respondents (except for one participant) were the exercises which made it possible to check knowledge in practice. It was stressed **that they lacked the possibility to exchange information with other training participants** and they also lacked a **"teacher"**, meaning a person who could answer the questions that came up and deal with doubts and problems. One of the participants said she felt like "the recipient of information", not a student as there was no teacher. According to some participants this is not a good way to learn for everybody, it is only good for some people.

4. Is the ELMI training, in which you participated, helpful in the process of becoming a professional caregiver? If so, in what way?

The majority of participants said that the training **may be helpful in becoming a professional carer, but it cannot be the only source of knowledge.**

They considered **practical exercises and contact with experts and professionals** necessary.

Moreover, the respondents said that in reality they face more difficult situations than the ones mentioned in particular modules. One of the respondents thinks **the training shows "over-sentimental reality", "too optimistic" and not quite real.**

The participants stressed that **a broader perspective was missing** – there was no advice for the whole family, no other, alternative forms of care.

What is more, some training participants had their doubts concerning **the problem of care transfer from a relative to an unknown person.** It was stressed that "different emotions appear when one takes care of a close person and different when one takes care of an unrelated, unknown person".

Most respondents said that even though the training can be helpful in becoming a professional carer, they **wouldn't like to follow this path after the death of their dependants. They would rather direct it to families of people who have just been diagnosed with Alzheimer, as a source of basic information and support.**

Burden Scale according to Zarit

The subject of the pilot research within ELMI project was also assessment of the burden imposed on carers of Alzheimer disease patients. To measure such burden Zarit's

Burden Scale was applied (1980)¹. The survey objective was to show a change in the scope of burden of Alzheimer disease patients' carers having completed the e-learning training. Below are subsequent items measured on a five-grade scale.

1. How often do you feel that you haven't got enough time for yourself?
2. How often do you feel overtaxed with responsibilities ?
3. How often do you feel like you've lost control over your life?
4. In regard to the relative for whom you are caring, how often do you feel uncertain about what to do for your relative?
5. In regard to the relative for whom you are caring, how often do you feel like you should do more for your relative?
6. In regard to the relative for whom you are caring, how often do you feel Like you could do a better job of caring?
7. When you are with the relative for whom you are caring, how often do you feel a sense of strain?
8. When you are with the relative for whom you are caring, how often do you feel anger
9. When you are with the relative for whom you are caring, how often do you feel embarrassment?
10. When you are with the relative for whom you are caring, how often do you feel uncomfortable about having friends over?
11. How often do you feel that your relationship with the relative for whom you're caring negatively impacts your social life?
12. How often do you feel that your relationship with the relative for whom you're caring negatively impacts other relationships with family and friends?
13. How often do you feel that your relationship with the relative for whom you're caring negatively impacts your health?
14. How often do you feel that your relationship with the relative for whom you're caring negatively impacts your privacy?
15. How often do you feel you receive excessive help requests?
16. How often do you feel all the responsibility falls on one caregiver?
17. How often do you fear the future regarding your relative?
18. How often do you fear not having enough money to care for your relative?
19. How often do you fear not being able to continue caring for your relative?

¹ Gerontologist, 20(6), 649-55

20. How often do you wish to leave the care of your relative to someone else?

21. How much does your spouse/loved one depend on you as the caregiver?

The respondents

10 people taking care of people with Alzheimer disease, at risk of professional burnout syndrome, participated in the survey, including 8 women and 2 men aged 22-67. There was no control group so it is not clear whether the differences in measurement are caused by completing the e-platform training or by other factors not researched by us.

Variables

An independent variable controlled in the whole research was:

- E-learning platform training

Dependant variable (tested) was:

- Caregiver's burden measured in Zarit's Burden Scale.

Research hypotheses

During the ELMI project, the participants had a chance to get to know educational materials on the e-learning platform so it was expected that:

H1. After the training, there will be a significant decrease in the burden level of carers who take care of people suffering from Alzheimer disease.

Data analysis method

To compare the results from a pre-test and a post-test obtained by the participants of the e-learning training, the *t*-test was applied for dependent samples. The analysis was made with the use of PASW Statistics 18.

Table no. 1. Basic statistics on *t*-test for dependent samples

Variables	Average (M)	Standard deviation (SD)	t	df	p
Pre-test	23.19	5,555	2.232	20	.037
Post-test	21.29	4,660			

The analysis shows substantial differences ($t(20)=2.232$; $p<0.05$). It means that there are important differences between a caregiver's burden before and after the training completion on the e-learning platform. Pre-test (M=23.19; SD5.555) and post-test (M=21.29; SD 4.660).

Discussion on the results

Hypothesis 1., which says that after the participation in the e-learning training, there will be a significant burden decrease in case of Alzheimer disease patients' carers, was positively verified. However, the results should be treated with caution. Detailed analyses show that 8 out of 21 results were contradictory to the hypothesis (question 1, 5, 10, 12, 13, 14, 17, 20) and in case 2, no changes appeared (question 3, 4). The whole research should be repeated on a much bigger sample and in a much shorter time interval, to eliminate the influence of intervening variables.

CHANGES IN EDUCATION MODULES ACCORDING TO THE INSTRUCTIONS OF THE PILOT PARTICIPANTS

The changes will be introduced after receiving all fragmentary data (reports from the Czech Republic, Romania and Poland).