

Supporting distant PSYCHO-eEducational activities with a bio - feedback device

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Abstract

Caregivers of patients with dementia mainly face the problems such as psychological pressure in a daily basis, lack of knowledge and/or training about caring the patients and lack of knowledge about the consequences of dementia in patients' behavior. These issues reveal the demand both for the support and the training for caregivers. Following this direction, we developed a web based platform to provide distant support for caregivers who are not able to participate in face to face sessions. This platform integrates services (i.e. teleconferencing, content management, learning management) and tools, such as a bio-feedback device for stress awareness to support distance learning and psychological support of the caregivers. This paper presents this platform, along with preliminary encouraging results concerning its usability and its usefulness not only for the caregivers but also for the psychologists who are training and supporting them.

Keywords: affective computing, bio-feedback, emotional regulation, e-learning, caregiver support

Introduction

This paper deals with distance education and psychological support of caregivers of patients with dementia. Alzheimer's Disease (AD) is a progressive and degenerative disease of the brain and the most common type of all dementias. The number of patients with AD is estimated to triple by 2050 (Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos, 2014). Therefore, the number of the dementia caregivers will also increase. Apart from the cognitive impairment of their patient, caregivers must deal with the behavioral and psychological problems of the patients. Nowadays, there is a general consideration about the caregivers of patients with AD, because it seems that their life and health is affected and it is getting worse. Dementia usually causes severe mental disabilities, which interfere with daily life. Long-term care of patients suffering from dementia is a very difficult and demanding every day procedure. Therefore, there is an intense need for caregivers' supporting. This support tries to (a) upgrade the care provided to the patient and (b) provide focused emotional scaffolding to the caregiver, who is experiencing daily intensive feelings of anxiety, sadness and loneliness. Caregivers often encounter tough conditions and weariness, isolating themselves from their social life. In particular, the caregivers of people with AD are frequently suffered from psychological distress, financial problems, depression (up to 20%-50%), anxiety and social isolation (Ask, Langballe, E. Holmen, Selbæk, Saltvedt, & Tambs, 2014).

In Greece, in most cases, the caregiver of a patient with dementia is a member of his/her family (patient's sibling or one of his/her children). As a result, the disease does not only affect the patient's life but also daily routine of the whole family. Usually, the caregivers are

not healthcare professionals, thus they are not familiar with the basic caregivers responsibilities as well as with the symptoms of the disease. Moreover, they usually have no knowledge and skill about how to manipulate extreme and problematic situations. Because of patient's progressive inability the caregiver is obliged to spend more and more time in care giving. This fact is dramatically reducing caregiver's personal time and as a result, his/her life is changing a lot. Consequently, they belong to a high risk group to suffer from stress and depression. These symptoms may cause caregivers mental and physical exhaustion. Thus, it is vital for the caregivers to take care their health (Signe & Elmståhl, 2008), in order to be able to effectively deal with the new situations caused by the caring of the patient.

Training programs for caregivers of patients with AD are expected to support the caregivers to this direction. Many researchers (Cooke, McNally, Mulligan, Harrison, & Newman, 2001) have shown that the knowledge on the issues of dementia supports caregivers to reduce their stress and to create a more realistic picture of what they should expect from the patient. Therefore, the trained caregivers set more realistic and thus feasible goals. As a result, the patients' satisfaction is increasing as well as the caregivers are not disappointed. Both the knowledge about dementia and the psychological support help the caregivers and health professionals to learn how to relax, to be more flexible in decision making and to have feasible expectations about their situation.

However, most of the training programs for caregivers are delivered face-to-face. Nevertheless, there are caregivers who lack of time because of the caring the patient. Therefore, web based interventions for family caregivers seem to be a good alternative solution. The majority of the caregivers cannot participate in face to face training sessions about dementia and the caring a patient with dementia due to the fact that they should care the patient the whole day. The same goes for the face to face psychological support. Thus, e-services for supporting distant communication, training and psychological support could be a solution for caregivers' support. According to the literature, the internet-based interventions have positive results on reducing the depression symptoms and anxiety of the caregivers (Davis, Tremont, Bishop & Fortinsky, 2011).

There are many different ways of providing distant support to caregivers of patients with dementia. This support could take place at the same time (namely synchronous) or during different time (asynchronous). Synchronous services may offer a common virtual/electronic space, where participants are able to communicate with in real time. A typical service to support such a scenario is videoconference, where each participant is able to see and hear the others. Participants in a teleconferencing session could be a doctor or a psychologist and the caregivers. Furthermore, the caregivers could use asynchronous services, such as a forum in a learning management system for discussing issues about learning content for dementia or for exchanging their experiences about the caring of their patients.

To this direction, ASPAD (Augmentation of the Support of Patients suffering from Alzheimer's Disease and their caregivers, <http://aspad.csd.auth.gr>) project which is a national project which provides a holistic support of patients suffering from Alzheimer's Disease (AD) by augmenting the care of the patients, services for the people affected and their families. One of the main ASPAD objectives is the caregivers' support from distance. As stated before, several mistakes done and difficulties faced by the caregivers are obliged to the lack of knowledge on dementia issues and how to manage them. For this reason, ASPAD project educates the dementia caregivers. One of the main objectives of ASPAD project is to investigate novel distance learning educational programs to reduce the caregiver burden. Thus, to facilitate distance learning activities, this research is trying to

reduce the “didactical distance” between the trainer and the trainees as well as to support the awareness about the emotional status of the trainees. Concerning the distant psychological support of caregivers this work is trying to inform the psychologist about the emotional status of the caregivers.

This paper is presenting (a) the ASPAD platform developed to support the distant training and psychological support program augmented with the awareness of the caregivers’ stress level; (a) the description of ASPAD training program and system usage in order to offer synchronous and asynchronous distant support for caregivers of people with dementia; (c) preliminary results of the distant education and psychological support program concerning the attitude of the users towards the training and psychological support program, and the usability of ASPAD platform.

ASPAD platform design

This section is presenting the ASPAD platform developed to support the distant training and psychological support program augmented with the awareness of the caregivers’ stress level. ASPAD platform (Figure 1) is installed in two servers: (a) the web Server that serves the asynchronous learning platform and (b) Teleconference Server.

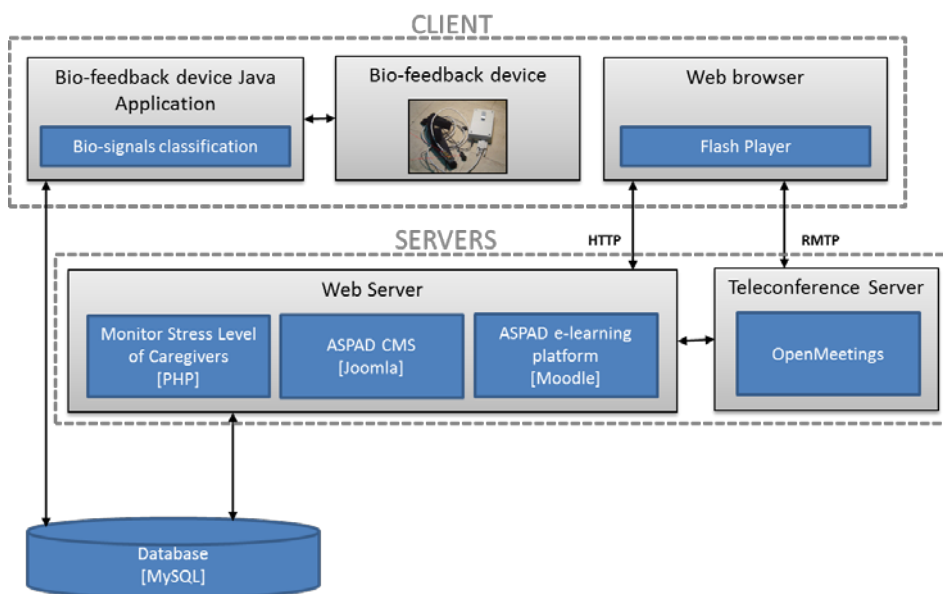


Figure 1. ASPAD platform

Web Server hosts (i) Joomla (<http://www.joomla.org/>) content management system that is used for supporting the management of the learning content; (ii) the Moodle (<https://moodle.org/>) learning management system that is used for supporting the organization of the courses and the groups of caregivers; (iii) a PHP application that is used for monitoring the anxiety measurements. Teleconference server is hosts the OpenMeetings web-conferencing (<http://openmeetings.apache.org/>) platform for supporting the real time distant psychological support session as well as e-learning sessions.

From the client side the participants should have an adobe flash compatible web browser as well as a client java application installed in every participant's personal computer to classify online physiological measurements. This special client is used in order to collect stress level information from bio-feedback devices, attached to each caregiver. This device has been developed in Multimedia Lab of the Department of Informatics of Aristotle University of Thessaloniki [17]. This prototype bio-feedback device applies three physiological techniques, in order to collect bio-signals from human body using as less obtrusive sensors as possible. These techniques are Galvanic Skin Response (GSR), the skin temperature and Heart Rate (HR) measurement. Physiological reactions to stressful situations are usually resulting in increased GSR, decreased skin temperature and increased HR.

ASPAD intervention using the biofeedback device

This section describes training program, pilot intervention and ASPAD usage in order to offer synchronous and asynchronous distant support for caregivers of people with dementia.

The caregivers have been organized in groups of five (5) members each in order to have a better contact with them. The caregivers were volunteers to use the ASPAD platform using the biofeedback device. In every session the psychologist presents two lessons. For each group the sessions take place once a week for about two hours. The first 6 lessons refer to the definition of dementia, its types, its main characteristics, the definition of Mild Cognitive Impairment (MCI), the epidemiology in dementia, the inheritance in dementia and the comorbidities. The next 12 lessons refer to the behavioral and psychological problems in dementia. The last 2 sessions refer to the personal sessions from distance that the psychologist met with the caregivers one by one. The first personal session takes place at the middle of the whole sessions (lesson 10) and the second personal session took place at the end of the lessons (lesson 23). The last lesson (lesson 24) is a session were all the caregivers can talk to each other, asking questions and expressing their experiences of the program. However, it is essential to mention that the psychologist in every session gives 30' time, in order for the caregivers to ask questions, share their thoughts, experiences and talk about things that they have in mind.

The scenario of the distant psycho-educational activity is depicted in Figure 2. Before the first psycho-educational session, every caregiver experienced a psychometric test by a specialist psychologist while he/she was measured by the bio-feedback device. During this test, the psychologist asked every caregiver to remember and re-live a recent stressful situation and then to apply the diaphragmatic breath in order to relax. Besides during this test the psychologist was watching every participant's bio-signal values and he/she was estimating the caregiver's anxiety level in percentage format. The bio-signal values labeled by psychologist's anxiety level estimation were stored to the database under each participant's user code. Every set of these labeled data formed a specific training set for every participant. During the evaluation activities (learning sessions) every caregiver was connected to a measuring bio-feedback device at the same time while participating in an online supportive session. The real-time measurements were classified using machine learning technique called "Gaussian regression algorithm" (Rasmussen & Williams, 2006). A bio-feedback application received the result of the classification procedure and displayed in real-time a visualized response on the computer screen where the subject could recognize his/her anxiety states through a chromatic code (red for anxiety, green for relaxation, orange for normal anxiety) besides to a percentage indication of his/her anxiety levels. Every time the subject reached high anxiety levels, the application encouraged him/her to

use the diaphragmatic breathing. Besides the bio-feedback application was communicating over TCP/IP with a monitor application displaying a screen with participant names and small boxes next to them. Each box was colored according to the online measurement evaluation considering the three emotional areas (relaxation, normal anxiety and high anxiety) and the percentage anxiety levels of the participant. The psychologist, during the session could watch this monitor application and decide for the appropriate adaptive interventions.

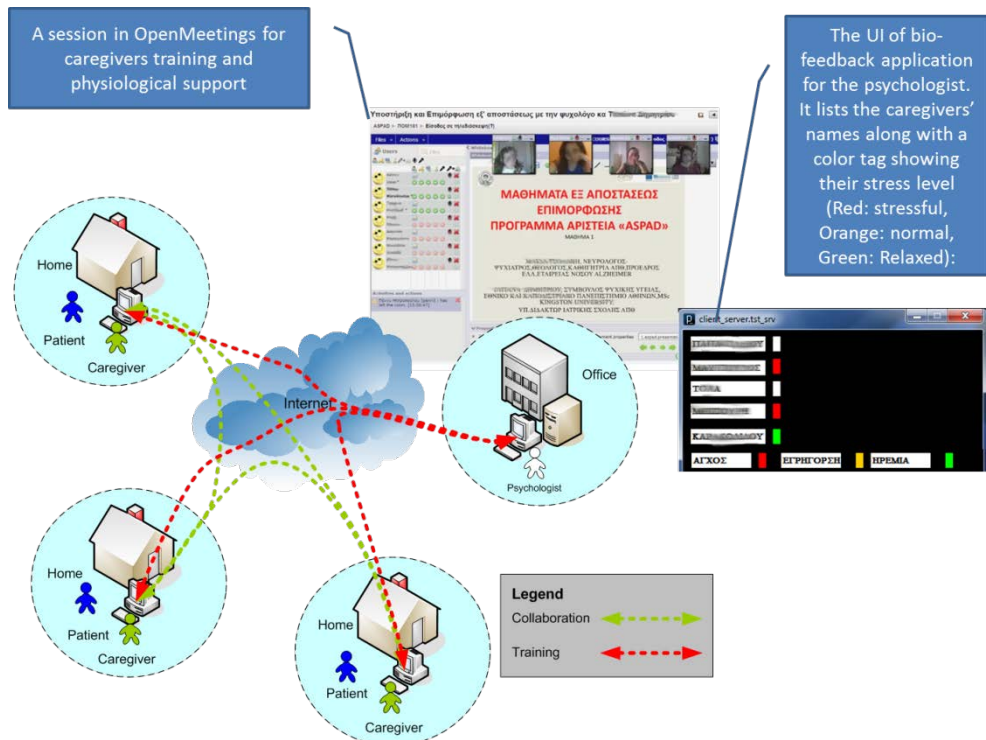


Figure 2. ASPAD platform

Evaluation

This section is presenting the evaluation procedure and participants as well as the evaluation results concerning both psychologist's and caregivers' point of view

Procedure and participants

ASPAD program has completed 2 cycles of e-learning and psychological support programs (each of them included 12 sessions where presented 24 lessons). One experienced psychologist was the trainer in both cycles. One computer engineer supported both cycles as technical staff. During the first cycle one (1) group of five caregivers has participated and there were two (2) drop-outs. Similarly, during the second cycle we had 1 group with 5 participants in total and there was 1 drop-out. Seven (7) of our participants completed all sessions. However, only four (4) of them have answered to the usability questionnaires. .

More specifically they were four females and their mean age was 57.75 (SD = 3.15). The three participants were primary caregivers of patients suffering from dementia on moderate and severe stage. The patients were caregivers' relatives. In all cases the care giving was taking place at home. Caregivers were recruited from Family Units in two day centers of the Greek Association of Alzheimer Disease and Relative Disorders (GAARDR), Thessaloniki, Greece. In order to assess the usability of ASPAD platform supported by the bio-feedback system we used the USE questionnaire. Furthermore in order to evaluate the participant's attitude towards ASPAD platform supported by the bio-feedback system we used the following instruments:

- The Use questionnaire (Lund, A. M., 2001) consists of 30 items measuring the usefulness (8 items), ease of use (11 items), ease of learning (4 items) of the examined system and user satisfaction (7 items). Furthermore in the context of this survey the user can list three positive features of the examined system and three negatives. Each item is scored on a 7-point Likert scale (Likert, 1932) (from 1= strongly disagree to 7 = strongly agree).
- The User Attitude towards an examined system is an instrument adapted from Douka (2010). This questionnaire has been used in order to rate the ASPAD system supported by the bio-feedback system regarding the following characteristics: Comprehensive, Sensible, Educational, Easy, Enjoyable, Interesting, Satisfactory, Well done, Scientific, Serious, Well prepared, Important, Innovative, Pedagogic, Modern, and Different. This questionnaire consists of nineteen items. Each item is scored on a 5-point Likert scale (Likert, 1932) (from 1=strongly agree to 5=strongly disagree). This is a reverse - scoring questionnaire.
- A semi structured interview, for assessing the willingness of the users to use the system in future and to investigate its positive and negative aspects.

The results of the ASPAD program were really important. The next paragraphs present the opinions of the psychologist and the patients.

Psychologist's point of view

As mentioned before one experienced psychologist was the trainer in both cycles. According to her observation, caregivers seemed to be very interested in asking questions and sharing their experiences. In addition, it is worth to mention that the caregivers expressed many questions during the sessions. The questions were related to the topic that discussed in each session like "the types of dementia", "the stages of dementia", "ways of dealing with behavioral and psychological problems that their patients", etc. Moreover, most of the caregivers during the private sessions asked from the psychologist for advices on how to manage their patients and how to talk to them. Furthermore, in many cases the psychologist enforced them to talk to each other, when the lesson was over and the caregivers found that very helpful. They expressed their questions, thoughts and experiences and they were very polite and cheering to one another. Overall, most of them seemed to enjoy the process.

The ASPAD platform gave the opportunity to the caregivers, who could not attend a traditional face to face group due to geographic and time constraints, to participate in an online psycho-educational group. All the caregivers were using the teleconference tool (Open-Meetings) for attending the online lessons. Some of them were also connected to the bio-feedback device and were watching their real time measurements of anxiety level through the bio-feedback application. This application seemed to be very helpful to the trainees in order to have awareness of their emotional state, to share this awareness with the group and try to change it by taking a deep breath and making positive or functional

thoughts. As well, the bio-feedback application was an important tool for the psychologist. Having the awareness about the emotional state of caregivers, the psychologist can focus on their feelings, discuss with them their thoughts and make the appropriate interventions in order to help them reduce their anxiety level.

This procedure facilitated distant learning activities and reduced the “distance” between the trainer and the trainees. The bio-feedback application helped the online psycho-educational group to resemble more with the face to face group.

Caregivers' point of view

Concerning the ASPAD system application, most of the participants didn't have major problems to use it. Technical staff sent to the participants' brief user instructions. All participants found these instructions very useful to follow. Therefore, after the first two lessons, the participants felt very comfortable to use the system. Nevertheless, if any problem occurred the psychologist asked from the technical staff to help the participant immediately and therefore they were not any technological issues during the sessions.

The results concerning the usability of the system are very encouraging. Three of the four users (user2, user3 and user4) agree or strongly agree that the ASPAD platform is useful, ease of use, easy of learning and there are satisfied or very satisfied from it. However, user1 had a different opinion from the others and his/her score result was close to mostly disagree to user satisfaction gained by the examined system. User1 has encountered many problems with her Internet connection during online sessions. Therefore, her attitude towards the usability of the systems was rather negative. Two of the caregivers (User 2 and User4) mentioned that at first they felt stressed when they used ASPAD platform while they were connected to the bio-feedback device, but after the first two sessions, they got used and became more familiar to the whole system and they surpassed any inconvenience. ser3 was more familiar with computerized environments and she had minor problems with the examined system.

The results concerning the attitude of the caregivers towards the ASPAD platform was also very encouraging. Again three of the four users (user2, user3 and user4) have positive/strongly positive attitude towards the ASPAD platform. On the other hand, the score of user1 in most items is strongly negative.

During the interview three users (user2, user3 and user4) mentioned that they would recommend this kind of distant psychoeducational-activities supported by bio-feedback to others. User1 complained about technical problems caused mainly by the teleconference tool (OpenMeetings). Moreover, all the participants mentioned that these activities are time-consuming and it is positive that they can attend them in a distant learning model from their own place. All the users claimed that such activities promote caregivers' socialization and communication which is a very important feature.

Conclusion

As it is mentioned already ASPAD program using biofeedback devices has completed 2 cycles. The attitude of the majority of caregivers and the psychologist towards the ASPAD training and psychological support program in general is quite positive. Similarly the usability of the system has been characterized good or very good from the majority of the users. One of the participants complained about technical problems concerning the teleconference tool. This was our main concern after this evaluation and we decided to

replace OpenMeetings with Big Blue Button as the teleconference tool of our educational platform.

As a next step is a large scale evaluation of the ASPAD system concerning its usability, user satisfaction as well as effectiveness and impact of psychological and educational support.

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