

Received: 2016.07.06  
Accepted: 2016.08.01  
Published: 2016.10.10

# The Opinion of Professional Caregivers About The Platform UnderstAID for Patients with Dementia

Authors' Contribution:

Study Design A  
Data Collection B  
Statistical Analysis C  
Data Interpretation D  
Manuscript Preparation E  
Literature Search F  
Funds Collection G

**BDEF 1 Roksana Malak**  
**BCEG 1 Agnieszka Krawczyk-Wasielewska**  
**ABG 1 Ewa Mojs**  
**B 2 Bartosz Grobelny**  
**B 3 Katarzyna B. Głodowska**  
**AB 4 José Carlos Millán-Calenti**  
**AC 5 Laura Núñez-Naveira**  
**AG 1 Włodzimierz Samborski**

1 Department of Rheumatology and Rehabilitation, Poznań University of Medical Sciences, Poznań, Poland  
2 Department of Clinical Psychology, Poznań University of Medical Sciences, Poznań, Poland  
3 Department of Social Sciences, Poznań University of Medical Sciences, Poznań, Poland  
4 Gerontology Research Group, Department of Medicine, Faculty of Health Sciences, Universidade da Coruña, A Coruña, Spain  
5 Research, Development and Innovation Department, Gerontological Complex La Milagrosa, Provincial Association of Pensioners and Retired People (UDP) from A Coruña, A Coruña, Spain

**Corresponding Author:** Roksana Malak, e-mail: [rmalak@ump.edu.pl](mailto:rmalak@ump.edu.pl)

**Source of support:** This article was written as part of work done under the research grants AAL5/1/2013 and AAL5/2/2013 (UnderstAID – a platform that helps informal caregivers to understand and aid their demented relatives)

**Background:** The person with dementia should be treated as an unique person regarding symptoms directly associated with dementia, such as problems with memory, hallucinations, and delusions, as well as other physical, mental, or neurological deficits. The symptoms not directly typical of dementia, such as musculoskeletal disorders or depression, should be also be considered in order to improve the quality of life of a person with dementia. That is why professional caregivers have to broaden their current knowledge not only of medical symptoms but also of the patient's psychosocial condition and increase their inquisitiveness about the individual condition of the patient. The aim of the study was to get to know the opinion of professional caregivers about the UnderstAID platform and its usefulness for informal caregivers.

**Material/Methods:** Participants in the study group consisted of professional caregivers: nurses, sociologists, psychologists, physiotherapists, and occupational therapists, all of whom specialized in geriatrics and had experience in working with people with dementia. All professional caregivers answered 24 questions that refer to positive and negative aspects of the UnderstAID platform.

**Results:** The study group of professional caregivers highly appreciated that the application could give support to caregivers (mean score of 4.78; 5 points means that they totally agreed, and 1 point means that they totally disagreed) and that a wide range of multimedia materials helped the informal caregivers to gain a better understanding of the contents (mean score of 4.78). There was a statistically significant correlation between the age of the professional caregivers and the frequency of positive opinions that the UnderstAID application gave support to caregivers of relatives with dementia ( $p=0.028$ ) and the opinion that videos, photos, and pictures may help the informal caregivers to gain a better understanding of the contents ( $p=0.028$ ).

**Conclusions:** A group of professional caregivers positively assessed the UnderstAID platform. Caregivers, especially older caregivers, highly appreciated the usefulness of videos, photos, and pictures for gaining a better understanding of the contents.

**MeSH Keywords:** **Ageing • Caregivers • Dementia • Depression • Life Support Care • Physical Therapists**

**Full-text PDF:** <http://www.medscimonit.com/abstract/index/idArt/900444>

 2001  2  —  19



## Background

Various symptoms of dementia may affect the quality of life of the elderly with dementia. Neuropsychiatric symptoms, depression, and poor sleep quality in elderly people with dementia lead to loss of autonomy and independence [1]. That is why dementia has a psychosocial impact not only on persons who suffer from dementia but also on informal and formal caregivers who take care of them. That is why the state and problems of people who take care of a person with dementia should be considered [2].

These are a lot of various symptoms associated with dementia. Some of them refer to the medical state, for instance, hallucinations, delusions, aberrant motor behaviors, balance problems such as falls and fall-related injuries, sometimes rigid muscles and hunched posture, or even symptoms related to the urogenital diaphragm or diaphragm of the pelvis such as urinary or fecal incontinence. Other symptoms may be related to psychosocial and cognitive difficulties such as lower self-esteem and feelings of low worth, less attention, social isolation, memory loss, and problems in learning, attention, concentration, orientation, problem solving, calculation, language, and geographic orientation. What is more, it is a progressive and largely irreversible syndrome [3]. Various aspects of a person with dementia that are affected make the caregivers' role challenging [2,4].

It seems that people with dementia often suffer from other symptoms that are not directly connected with dementia. That is why professional caregivers have to broaden their current knowledge not only of medical symptoms but also of their psychosocial condition. The caregivers often may need support, especially because the largest group of caregivers in Poland are spouses who are close to the age of patients ( $\geq 65$  years) [5]. The aim of the professional care should be to consider and identify interventions that may be effective in supporting the well-being of the caregivers of seniors with dementia [3]. Otherwise, professional or informal caregivers whose work is really demanding may be burdened. The caregiver burden may lead to less effective work, stress, or even to psychosocial difficulties with caring. However, presented research has suggested that depression and overload of the caregivers are not always related to time spent on the care and the Global Deterioration Scale (GDS) score of the patient with dementia [6].

To reduce the risk of burden, the caregivers should be provided with information and educational materials, including how to improve their well-being and emotional health and how they can cope with everyday difficulties or even the feeling of frustration. Smart technologies are being developed to support health care professionals in a variety of ways, including

provision of information and support resources online [7]. The application should be widespread and easy to use because dementia is still very common in society. Currently, 11% of older adults are living with Alzheimer's disease and other types of dementia [8]. What is more, the application should address the real problems of caregivers and their patients. The everyday tasks that professional caregivers have and the typical human feelings and emotions that may appear while working with a person with a difficult illness such as dementia should be listed. The real advancing technologies that support care of elderly with dementia should include examples of how the caregiver may resist the emotional reaction that cannot appear at work and how others specialists with greater experience deal with everyday tasks and feelings. Such an application should enable contact with a huge number of specialists. It should enable the discussion about how to cope with the everyday situation.

The aim of the study was to get to know the opinion of professional caregivers about the UnderstAID platform and its usefulness for informal caregivers.

## Material and Methods

The project UnderstAID project was accepted by the Bioethical Committee at Poznan University of Medical Sciences on 8 November 2012 (number 990/12). The study was performed in a group of professional caregivers: nurses, sociologists, psychologists, physiotherapists, and occupational therapists. Most of the research group were women (78%); men comprised just 22% of all the study participants. Participants were between 23 and 54 years old; their average age was  $38.5 \pm 10.4$  years. Inclusion criteria were specialization in geriatrics, experience in working with people with dementia, and possession of a smartphone or tablet with an internet connection. All professionals answered 24 questions that referred to positive and negative aspects of the UnderstAID platform. UnderstAID is the name of a platform for informal caregivers of people with dementia. It was created as a part of a project co-funded by the European Union under the Ambient Assisted Living Joint Programme. It was founded in order to help people with dementia and their informal caregivers cope with everyday situations. The project takes place in Denmark, Spain, and Poland. This study refers to the usefulness of the platform in Poland. As a part of the examination of the program, the specialists logged into the UnderstAID application, completed the questionnaire on the website, chose the level of dementia, browsed the contents of the platform, and chose the type of information, such as quick fixes, simple insight, explanations, or details. The example question from the questionnaire for professionals was whether the UnderstAID application will improve the skills of the caregivers when taking care of their relatives with

**Table 1.** Usefulness of the UnderstAID platform in the care of patients with dementia.

	Mean
UnderstAID application can give support to caregivers of relatives with dementia	4.78
UnderstAID application will improve the skills of the caregivers when taking care of their relatives with dementia	4.56
The chance to get information immediately is an added value to the UnderstAID application	4.34
Caregivers of relatives with dementia will decrease their stress burden caused by the caregiving tasks	4.12
The contents of the application can make the caregivers feel more confident and competent when performing their caregiving tasks	4.56
The learning contents and the terms used are suitable for the informal caregivers	4.0
Videos, photos, and pictures may help the informal caregivers to gain a better understanding of the contents	4.78
If you were an informal caregiver and the application were put in the market, would you be interested in buying it?	4.2

dementia or if videos, photos, and pictures may help the informal caregivers to gain a better understanding of the contents.

Data were analyzed using STATISTICA 8.1 (StatSoft).

## Results

A group of professional caregivers dealing with dementia patients were asked a series of questions concerning the potential usefulness of the UnderstAID platform. The questions could be answered in terms of a five-point scale: 1 for totally disagree; 2 for disagree; 3 for neither disagree nor agree; 4 for agree; and 5 for totally agree. All the answers varied in the range from 3 to 5. None of the respondents marked answers 1 and 2. Average study group results are presented in Table 1.

Professional caregivers had to indicate what the exact benefits will be for informal caregivers resulting from using the UnderstAID platform. All of them found more than one answer to be true; on average they indicated about 5 benefits of using the platform. The results are presented in Table 2.

There was a statistically significant correlation between the age of the professional caregivers and the frequency of positive opinions that UnderstAID application gives support to caregivers of relatives with dementia ( $p=0.028$ ) and the opinion that videos, photos, and pictures may help the informal caregivers to gain a better understanding of the contents ( $p=0.028$ ). Older professional caregivers gave a higher evaluation to the UnderstAID platform, and they thought that videos and photos were really helpful.

## Discussion

The population is aging as life expectancies increase. That is why the diagnosis of dementia will appear with increasing frequency. Currently, 11% of older adults are living with Alzheimer's disease and other types of dementia. It is still generally acknowledged that most people with dementia stay in their home and their relatives take care of them. Patients have difficulties with engaging in and benefiting from professional care [8]. The fact is that informal caregivers provide approximately 75% of the care at home, including help with activities of daily living (ADLs) [5,9]. It is important to develop a dementia support system for informal caregivers. The professionals specialized in dementia care should provide support to informal caregivers [10].

It has been reported that support might have an impact on decreasing depressive symptoms, increasing quality of life, and improving caregiver satisfaction and reaction to care recipient behavior problems [10]. Nowadays, when the internet is widespread almost in all countries, it can be used to give such support. That is why the UnderstAID platform, as an application available on the internet, contains videos, photos, and pictures on how to cope in everyday situations. Estimation of the reliability of the platform was the subject of the previous study in order not only to show opinions but also to make changes if they were necessary. Our earlier studies have shown that the platform is a useful tool for dementia caregivers [11]. Specialists consider the platform as a tool that may give a better understanding of the contents. Understanding the biopsychosocial (BPS) model of dementia is one of the most important aspects of improvement of the ability to develop interventions for people with dementia [12,13]. BPS is a practical tool designed to encourage staff to develop personalized interventions and treatment plans for people with dementia.

**Table 2.** Ranking of benefits from using the platform UnderstAID.

What would the benefits be for the users?	% of caregivers
Improvement of their knowledge about dementia	78
Increased self-confidence	78
Better relationship with the cared-for relative	67
Better organization of the free time	44
Better quality of life	44
Reduced caregiving burden	44
Increased satisfaction in the caregiving	44
Reduced social isolation	33
Better social and family support	22
Inclusion in the technological age	22

The comprehensibility of the challenging behavior of people with dementia leads to improvement in the ability of professionals to provide care. However, it seems that this relationship may be also valid for informal caregivers [12].

The professionals who were older estimated the platform to be a proper support for caregivers. It should be mentioned that the study was conducted among specialists who took care of people with dementia. That is why it can be concluded that the older the professional, the more experienced they were. The majority of caregivers are middle-aged (35–64 years old). Many caregivers of older people are themselves elderly. The average age of caregivers caring for someone aged 65+ is 63 years [5,14]. Some studies showed that advanced experience in caregiving led to a positive perception of caregiving because it increased caregivers' feelings of pride in their ability to meet challenges of their work [15].

The UnderstAID platform seemed not to be the tool that gives a caregiver special skills, but it is the application that helps caregivers to understand the process of caregiving. Especially the materials presented in videos, photos, and pictures help caregivers to understand current practice and treatment [3]. A huge majority of informal caregivers (80–95%) request mobile systems and find that interactive features assist in caregiving. Smart technologies were developed to support informal caregivers by providing information and support resources online. The professionals in the present study found that the UnderstAID application would not improve the skills of the caregivers, but it would help them to better understand the content. That opinion seems similar to the opinion regarding the Internet-Based Savvy Caregiver, based on the validated Savvy Caregiver program, which improves knowledge about caregiving. Those applications support care for older adults and family caregivers. However they aren't intended for learning the special skills needed for caregiving. There are special programs

that are intended to provide a caregiver with the special skills. For instance, the European Skills Training and Reskilling (STAR) project was created and evaluated as a multilingual e-learning tool. That is why it was reported by professionals to help caregivers acquire new skills [16].

The professionals found that it is hard to say that the UnderstAID reduced caregiving burden. However, it seems that those applications, which are widespread in the internet, are effective in decreasing caregiver burden [17]. The fact that the specialists estimated the utility of the platform before it was used may have made them skeptical.

The UnderstAID platform will not reduce social isolation or inclusion in the technological age because the quality of the disease may "force" a person to need almost constant devotion from a caregiver who stays at home with them and considers their individual features. Successful interventions should be individually tailored and take into consideration a person's needs, abilities, customs, preferences, and favorite activities [18]. To summarize, we noticed that planning a therapy for a person with dementia (as for a person with mild cognitive impairment) should be considered [19]. However taking care of caregivers should be also take into account in planning therapy.

## Conclusions

A group of professional caregivers positively assessed the UnderstAID platform, particularly in the improvement of caregiver knowledge about dementia and increased self-confidence of caregivers. Caregivers highly appreciated the usefulness of videos, photos, and pictures to enable a better understanding of the contents. Presentation of platform contents in the form of multimedia was particularly well rated by older caregivers.

## Statement

This article was written as part of work done under the research grants AAL5/1/2013 and AAL5/2/2013 (UnderstAID – a platform that helps informal caregivers to understand and aid their demented relatives).



## References:

1. Pereira LSM, Soares SM: Factors influencing the quality of life of family caregivers of the elderly with dementia. *Cien Saude Colet*, 2015; 20(12): 3839–51
2. Kimura NRS, Maffioletti VLR, Santos RL et al: Psychosocial impact of early onset dementia among caregivers. *Trends Psychiatry. Psychother*, 2015; 37(4): 213–19
3. Health Quality Ontario: Caregiver- and patient-directed interventions for dementia: an evidence-based analysis. *Ont Health Technol Assess Ser*, 2008; 8(4): 1–98
4. Greenwood N, Pelone F, Hassenkamp AM: General practice based psychosocial interventions for supporting carers of people with dementia or stroke: A systematic review. *BMC Fam Pract*, 2016; 17(1): 3
5. Krawczyk-Wasielewska A, Malak R, Mojs E et al: Recommendations of the Alzheimer's disease international concerning the care of patients with dementia and the situation in Poland. *Eur Sci J*, 2014, Spec. Ed. Vol. 3: 184–89
6. Bednarek A, Mojs E, Krawczyk-Wasielewska A et al: Correlation between depression and burden observed in informal caregivers of people suffering from dementia with time spent on caregiving and dementia severity. *Eur Rev Med Pharmacol Sci*, 2016; 20(1): 59–63
7. Bossen AL, Kim H, Williams KN et al: Emerging roles for telemedicine and smart technologies in dementia care. *Smart Homecare Technol Telehealth*, 2015; 3: 49–57
8. Isbel ST, Jamieson M: Views from health professionals on accessing rehabilitation for people with dementia following a hip fracture. *Dementia (London)*, 2016 [Epub ahead of print]
9. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA*, 2004; 292(8): 961–67
10. Lethin C, Leino-Kilpi H, Roe B et al: Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study. *BMC Geriatr*, 2016; 16: 32
11. Jajor J, Rosolek M, Skorupska E et al: "UnderstAID – a platform that helps informal caregivers to understand and aid their demented relatives" – assessment of informal caregivers – a pilot study. *J Med Sci*, 2015; 84(4): 229–34
12. Revolta C, Orrell M, Spector A: The biopsychosocial (BPS) model of dementia as a tool for clinical practice. A pilot study. *Int Psychogeriatr*, 2016; 22: 1–11
13. Spector A, Orrell M: Using a biopsychosocial model of dementia as a tool to guide clinical practice. *Int Psychogeriatr*, 2010; 22(6): 957–65
14. Family Caregiving Alliance. Fact Sheet: Selected Caregiver Statistics. California Department of Mental Health. San Francisco, 2005
15. Yu H, Wang X, He R et al: Measuring the caregiver burden of caring for community-residing people with Alzheimer's Disease. Ginsberg SD (ed.), *PLoS One*, 2015; 10(7): 0132168
16. Hattink B, Meiland F, van der Roest H et al: Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom. *J Med Internet Res*, 2015; 17(10): 241
17. Bossen AL, Kim H, Williams KN et al: Emerging roles for telemedicine and smart technologies in dementia care. *Smart Homecare Technol Telehealth*, 2015; 3: 49–57
18. Smith M, Buckwalter K: Behaviors associated with dementia. *Am J Nurs*, 2005; 105(7): 40–52
19. Bidzan L, Bidzan M, Pączalska M: The effects of intellectual, physical, and social activity on further prognosis in mild cognitive impairment. *Med Sci Monit*, 2016; 22: 2551–60