

Aleksandar Bulajić, Tamara Nikolić, Cristina C. Vieira (Eds.)

Navigating through Contemporary World with Adult Education Research and Practice



**Institute for Pedagogy and Andragogy, Faculty of Philosophy, University of Belgrade, Serbia
ESREA - European Society for Research on the Education of Adults
Adult Education Society, Serbia**

NAVIGATING THROUGH CONTEMPORARY WORLD WITH
ADULT EDUCATION RESEARCH AND PRACTICE

Editors

Aleksandar Bulajić, Tamara Nikolić, Cristina C. Vieira



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ФИЛОЗОФСКИ ФАКУЛТЕТ

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Belgrade, 2020

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Natalija Gojak

University of Belgrade, Belgrade, Serbia

Zorica Milošević

University of Belgrade, Belgrade, Serbia

EDUCATIONAL SUPPORT TO FAMILIES WITH A MEMBER SUFFERING FROM ALZHEIMER'S DISEASE¹

Abstract

Alzheimer's disease is one of the most common causes of dementia syndrome, gradually making a person dependent on someone else's care and help. Alzheimer's disease affects the functioning of the entire family of a member living with diagnosis, it puts family in a state of social need and can generate a non-developmental family crisis. Due to the multiple negative effects caused by this crisis, various services and support programs for families with a member with Alzheimer's disease are developing. One type of these support programs is adult education. Considering the global trend of increasing number of people with diagnosis of Alzheimer's disease, we recognize the need to make adult education more accessible to their families. It is necessary that such programs are available to families of people living with Alzheimer's disease, and we decided to investigate what should be the content of such educational programs. Our research question is: what are the educational contents that are useful for families' members of people with Alzheimer's disease? In the search for an answer, we conducted 7 in-depth semi-structured interviews. Given that we are starting from the assumption that the process of creating educational content should be participatory, that all actors involved in the life of a member's living with Alzheimer's disease family should be included in it, research participants were families' members of people living with Alzheimer's disease, social care experts and caregivers. We searched for the similarities and differences in their opinions, in order to reach what is common. Our goal was to reach a compromise in the participants' thinking, to reach the *cross-sectional content* of educational programs for the families of a person with Alzheimer's disease. The research results show that the opinions of the research participants are very similar, they have more in common in their opinions than differ-

1 This paper is part of a research project being undertaken at the Institute of Pedagogy and Andragogy, Faculty of Philosophy in Belgrade, titled "Models of assessment and strategies for improvement of quality of education" (179060), supported by the Ministry of Education, Science and Technological Development of the Republic of Serbia.

ences. Everyone agrees that members of families of people with Alzheimer's disease need both the educational content about the Alzheimer's disease itself, as well as the educational content related to family functioning and community services. This suggests that relatives of a person living with Alzheimer's disease need a comprehensive education that will support them in various aspects of their lives.

Keywords: family life education, Alzheimer's disease, education for families of people living with Alzheimer's disease, educational needs

Introduction

With the development of neoliberal capitalism, all services have been put on the market and became commodified, and the main systemic ideal became the ideal of the greatest possible profit. Such changes influenced adult education, which became market-oriented. The privatization and commodification of services affects social categories that require socially organized help to meet their basic needs. Social services have become less and less accessible to them (Abendroth, 2014; Lynch, 2006; Stark, 2018; Wallace & Pease, 2011). In the neoliberal system, the old are marginalized, and dysfunctional old people are faced with additional restraints. This is the case with old people who suffer from Alzheimer's disease, which is one of the most common causes of dementia syndrome, gradually making the person dependent on someone else's care and help.

Alzheimer's disease affects the functioning of the entire family of a member living with Alzheimer's disease, it puts family in a state of social need and can generate a family crisis. Therefore, families' members, as *hidden victims* (Zarit, Orr & Zarit, 1985) of Alzheimer's disease, need help and support with coping and managing the given situation. Education can be recognized as one type of such support, and as a research problem in the broadest sense we can ask the question: what role can adult education play in this situation? Can it play the role of social support that the members of a person's living with Alzheimer's disease family need? From the perspective of andragogical assumptions, we accept a positive answer to the question posed, and furthermore, we can ask a number of specific questions relating to different aspects of that education. One of those questions is what should be the content of such education? Are these contents focused solely on the caregiver aspect of a member living with Alzheimer's disease, or they also cover other aspects of family members' lives? We can also ask who should create those educational contents for families' members, ie. who should be involved in the content creation process? In this paper, following a theoretical reflection on the answers to these questions, we will present our research

on the assessment of the usefulness of specific educational contents for families' members of people living with Alzheimer's disease. The paper is organized into four sections: theoretical considerations, followed by the presentation of research methodological framework, presentation and interpretation of research results, and concluding considerations.

Theoretical considerations: educational programs for families' members of people living with Alzheimer's disease

Alzheimer's disease is one of the most common cause of dementia syndrome, due to brain changes. This disease is progressive and interferes with the functioning of higher cognitive functions: memory, thinking, orientation, calculation and insight, learning and language. Deteriorations in these cognitive functions are also accompanied by exacerbations in the sphere of emotional control, social behavior and motivation (WHO, 1994; WHO, 2012). These changes alter a person's overall functioning and gradually, but surely, deprive him/her of his/hers autonomy and make him/her dependent on someone else's care and help, even to satisfy the most basic needs.

Everywhere in the world, family represents the main source of support and care for a people living with Alzheimer's disease and a cornerstone of the social protection system (Amity, 2014; WHO, 2012). The family is a natural, least restrictive environment for the person with diagnosis. However, a person living with Alzheimer's disease is not isolated in the state of social need, but also brings family members with whom they interact and who care for them into this condition. The disease puts the whole families in a state of social need and can generates a crisis. Life with a family member with Alzheimer's disease represents an non-developmental, involuntary family crisis (Goldner-Vukov, 1988), a crisis that does not arise from developmental tasks during the family life cycle. The crisis disrupts the psychosocial balance of families of people living with Alzheimer's disease and paints theirs overall functioning, requiring major changes and adaptation to an unplanned situation. Since Alzheimer's disease is progressive, the intensity of care for a member living with Alzheimer's disease changes over time, as do the roles that families' members need to assume. With the progression of the disease, when the person with diagnosis of dementia becomes completely dependent on someone else's care, more intensive involvement of the family is necessary for every activity of a person living with Alzheimer's disease, in order to meet the most basic needs. The care for a family member becomes more demanding over time and turns into twenty-four hour activity. The family

crisis deepens, and families are facing increased demands to change family functioning and adapt to the given circumstances.

Still, in their studies of hysteria, Freud and Breuer wrote about the negative effects of nurturing on the caregiver's personality and behavior – describing and analyzing the Elisabeth's case, they concluded that nurturing leads to sleep disorders, self-neglect, and constant worry (Sorensen, Duberstein, Gill & Pinquart, 2006). Many contemporary studies, which are not solely conducted within the framework of psychoanalysis, came to the same results. There are numerous allegations in the literature to the negative effects of nurturing on members of families of people living with Alzheimer's disease (Amity, 2014; Burgeois, Schulz & Burgio, 1996; Sorensen, Duberstein, Gill & Pinquart, 2006; WHO, 2012). Sorensen, Duberstein, Gill and Pinquart classify these effects into psychosocial and physiological consequences, consequences for health behavior and the general health of families' members (Sorensen, Duberstein, Gill & Pinquart, 2006). The most commonly cited and analyzed psychosocial effects are stress, depression, anxiety, and burnout (Burgeois, Schulz & Burgio, 1996; Sorensen, Duberstein, Gill & Pinquart, 2006; WHO, 2012). Also, perceived quality of life and life satisfaction, as well as self-esteem are also lowered within population of families' members of people living with dementia. With the progression of the disease, social isolation of these families also arises, because of the obligations to take care of the family member living with Alzheimer's disease. They don't have time to maintain social contacts and friendships, the amount of free time available to them is reduced, and the way they spend their time is also changed (Amity, 2014; WHO, 2012). Those caring for a family member living with dementia report poor health, reduced physical activity, sleep deprivation and frequent use of medication, leading to an increased mortality rate for them (Sorensen, Duberstein, Gill & Pinquart, 2006).

By identifying the negative effects of caregiving on families' members described above, the creation of various support programs begins. During the 1980s, various services and support programs for families with a member with Alzheimer's disease began to develop in the West, and education can be recognized as one type of those support programs. Education aimed at families' members of people with Alzheimer's disease has many aspects, and when analyzing the educational programs available, we came to the conclusion that content is an aspect that has not received much attention. Namely, the authors in their papers mostly do not explain how they *come* to the contents of educational programs, how they created it, which contents families' members consider necessary, how was theory the basis for the content creation, who created the content, etc. Most research efforts are focused on examining the effects of different types of interventions, including educational ones. As Bourgeois, Schulz, and Burgio note: "The content of interventions is one of the least

understood aspects of the intervention literature. With a few notable exceptions, the specific content and procedural details of interventions are reported in abbreviated fashion making it difficult to fully understand what was done” (Bourgeois, Schulz & Burgio, 1996, p. 82).

The absence of papers addressing the educational needs of families' members themselves is also noticeable. Instead of first detailing the needs for different contents, authors seem to create educational programs based on a deductive analysis of the literature, based on their assumptions and the implications provided by the theories behind it. Of course, this is also a legitimate and correct way to *get* potential content, but we also believe that family members' education should be based on their own educational needs, so that it can serve and help them. If not, education may lose some of its power to attract and support families in this type of crisis. Thus, research by Zarit and Leitsch shows that the lack of service that is based on the needs of families' members is one of the reasons for the poor use of available services among this population (Zarit & Leitsch, 2001). If we accept the dominant deductive approach to creating content of educational interventions for families of people with Alzheimer's disease, then as participants of the created intervention should be chosen the people who need this type of intervention. However, we come across critiques that this is not happening, which is later reflected in the demonstrated effects of the given interventions. As Acton and Kang said: “Perhaps recruitment of participants with problems that might be affected by intervention would result in better outcomes. An examination of the caregiver intervention literature reveals that very few researchers screen participants for characteristics and problems related to the specific intervention being tested or the measured outcomes” (Acton & Kang, 2001, p. 357). This claim is supported by Ducharme and his associates, stating that one of the main reasons for the modest effects of educational interventions is the mismatch of their content with the needs of families' members (Ducharme et al., 2009). Therefore, we agree with Acton & Kang that “tailoring interventions to meet the needs as perceived by caregivers may produce more meaningful outcomes” (Acton & Kang, 2001, p. 358). All of the above leads us to the conclusion that more attention should be paid to the issue of families' needs for different educational contents. This would make education more *attractive* to families' members of people living with Alzheimer's disease, having them more prepared and motivated to engage in it, and the produced effects would be more meaningful.

In order to change the noted deficiencies, Ducharme and associates developed an educational content creation model based on the participation of family members of people with Alzheimer's disease and based on their educational needs (Ducharme et al., 2009). This model has 4 stages:

1. Exploring family members' educational needs;
2. Developing and validating a program proposal based on expressed needs;
3. Formalizing program through intervention mapping and;
4. Testing and qualitatively evaluating the program.

Family members are involved in each stage of the model. However, we are of the opinion that this model needs to be expanded and that, in addition to families' members of people with Alzheimer's disease, it is necessary to include other actors who participate in family life. The situation of families with a member with Alzheimer's disease involves many *parties*, informal and formal caregivers and family support. Three *sides* are important to our paper: experts working in the field of social protection; caregivers who help families in meeting the basic needs of people with Alzheimer's disease; and families' members themselves. We are of the opinion that all these *parties* should be involved in creating the content of the educational program, since everyone knows the partial needs of families that arose from a given crisis situation. Specifically, we may ask the question: do social care experts adequately and sufficiently know the prospect of everyday life with a person with Alzheimer's disease diagnosis, what it looks like to care for and nurture them, what are the difficulties and challenges that family members face? Basing the program solely on the opinion of experts, which is the dominant practice, will not provide adequate help to families. But we can also ask the question: would family members be able to fully recognize, perceive and express their needs without the expert's advice? Furthermore, starting with the systematic approach to the family, we can also view the caregivers as part of the family system. They participate in the daily life of families and help them meet the basic needs of people living with Alzheimer's disease. Therefore, formal caregivers are likely to have a good understanding of what aspects of care and functioning families need help with, what their difficulties are, what knowledge and skills may be of use to them. Their insights and opinions can be particularly significant if they work in multiple families, so they can give us a more general picture of what typical difficulties and challenges such families face. Therefore, we start from the assumption that the creation of the educational program's content should be a participatory process for all actors, that this content should be the result of common perceptions of the above mentioned *parties* about what educational contents are needed and useful to families' members of people with Alzheimer's disease. This assumption lies at the basis of a participatory approach to the creation of educational content, which we opted for.

In addition to the question of who (should) create the content of educational programs for families of people living with dementia, we can also ask: what the

contents of these programs are? Are these contents focused solely on the caregiving aspect of a member living with Alzheimer's disease, or do they cover other aspects of family members' lives? Reading and analysis of educational programs for families of people living with Alzheimer's disease has led us to conclude that educational programs are diverse in content and of varying degrees of generality. Some programs are narrow and specific in nature, focusing only on one aspect of the family members' lives, mainly on the caregiving aspect. These programs are largely based on the behavioral paradigm and aim at developing skills and gaining knowledge about specific situations. The most frequent contents of these educational programs are the stress reduction skills development and behavioral changes. Other programs, however, are of a more general nature and focus on various aspects of the family members' lives. Such programs provide a comprehensive *package* of knowledge and skills that are presumed to be able to support families in a given crisis.

By analyzing the educational programs available, we also recognized that we can identify the 3 levels to which all contents are directed: a person with Alzheimer's disease/personal, family and community levels. The *personal* level refers to a person with Alzheimer's disease. The goal of the contents we recognize at this level is to make the person's with Alzheimer's disease quality of life as good as possible, to support family members to provide the highest quality care and to be well prepared for the caregiving role. Therefore, all the contents that are targeted at the domain of care of a person living with Alzheimer's disease are classified in this level. The *family* level includes all contents that are focused on the aspect of family functioning. The purpose of these contents is to understand the new role of family members in the context of new functions, tasks, responsibilities. These programs support existing family strengths and develop new ones to make the family as functional as possible in a given crisis. The *community* level includes all those programs whose contents seek to meet family members with the various forms of socially organized support to the family, with the available services and their rights.

All topics that appeared as contents of educational programs can be sorted by the specified levels. In our research, we will look at these levels as areas of a potential educational program, and topics – as contents of those areas. For the sake of systematicity and better transparency, for the purposes of our research we have created the so-called *Information sheet*, which lists all potential topics/contents of the educational programs, and then these potential contents are sorted by area: *personal*, *family* and *community* (Table 1). We foresee the possibility that this list is incomplete and that some other contents may support families of people living with Alzheimer's disease as well.

Table 1.
Content of the Information sheet – potential content of the educational program

<u>Area:</u> <u>PERSON WITH ALZHEIMER'S</u> <u>DISEASE/PERSONAL</u>	<u>Area:</u> <u>FAMILY</u>	<u>Area:</u> <u>COMMUNITY/</u> <u>ENVIRONMENT</u>
<p>Contents:</p> <ul style="list-style-type: none"> - About Alzheimer's disease - Early symptoms of Alzheimer's disease - Alzheimer's disease stages and their symptoms - Different treatments for Alzheimer's disease and their significance - Preparation for expected tasks and responsibilities - Biological and physiological (basic) needs of a person with Alzheimer's disease and ways of satisfying them (responsibilities and tasks of family members in that process) - Psychological and socio-cultural (developmentally higher) needs of a person with Alzheimer's disease and ways of satisfying them (responsibilities and tasks of family members in that process) - Emotionality, sensitivity and sensibility of a person with Alzheimer's disease - Sexuality of a person with Alzheimer's disease - The most severe problems and difficulties in the individual stages of Alzheimer's disease - Ways to cope with and overcome problems and difficulties - How to make the environment safer for a person with Alzheimer's disease - Use of assistive technology in the care for a person with Alzheimer's disease 	<p>Contents:</p> <ul style="list-style-type: none"> - Understanding the new role in the family – caring for a family member - Redistribution of responsibilities and tasks in the family - Flexibility of the family to the changes required by the member living with Alzheimer's disease - Development of non-violent communication in the family - The importance of developing emotional connection in the family - The importance of open affective response in the family - Stress management skills development and burnout prevention in the care for a person with Alzheimer's disease - Problem solving skills - Spirituality development as a way of overcoming a difficult situation - Home budget management skills 	<p>Contents:</p> <ul style="list-style-type: none"> - Rights of people with Alzheimer's disease and their families - Socially organized help for families with a member with Alzheimer's disease – social protection services - The role and services of NGOs in supporting the families - Safe and secure use of the Internet in finding the needed support - Neighborhood as a source of family support - Self-help groups – creation and utilization of a network of people with a similar family situation - Different ways to prepare for a caregiving role in the family

Methodological framework of the research

The described lack of research that explores the opinions and educational needs of families' members motivates our research, so therefore we decide to define the following *research question*: what educational contents would be useful to families' members of people living with Alzheimer's disease? In the previous part of the paper, we have already argued that we believe that creating content for these families' educational programs should be a participatory process. Everyone involved in the life of the family is partially aware of its needs, which have emerged from the crisis the family is in. Of all the formal and informal caregivers of the family member living with Alzheimer's disease, three groups are significant to our research: social care professionals; caregivers who help families meet the basic needs of people with Alzheimer's disease; and families' members themselves. We are of the opinion that the content of educational programs for families with a member with Alzheimer's disease should be a compromise between these actors' opinions. Therefore, in order to achieve the *cross-sectional content*, we have separated the research question into 4 more specific sub-questions. Those are:

1. Which educational contents do families' members think might be useful to them?
2. Which educational contents do caregivers (geronto-caregivers, home caregivers) think might be useful to families' members of people living with Alzheimer's disease?
3. Which educational contents do experts think might be useful to families' members of people living with Alzheimer's disease?
4. What are the similarities and differences in opinions among families' members, caregivers, and experts regarding educational contents that might be useful to families' members of people living with Alzheimer's disease?

The answers to these research sub-questions will lead us to differences, and therefore – similarities in opinions of these three categories of research participants, which will allow us to discover *cross-sectional content* of educational support for families of people living with Alzheimer's disease.

Data collection procedure

The qualitative paradigm was the basis for the methodological foundation of our research, and for data collection we used an in-depth, semi-structured interviews. Specifically, there was a set of questions that was used as the basis for interviewing each research participant. But, in accordance with the characteristics of the semi-structured interview, space was given to the research participants that helped new meanings and topics of education, which may have been

unpredictable to us at the time, to emerge. During the interview, we had the freedom to ask additional questions if we considered the answers to be significant, but the participants themselves had the opportunity to add something beyond that set of previously prepared questions as well. That is why we have opted for a qualitative research approach, which, due to its epistemological nature, enables openness. Openness is one of the main features of qualitative methods and techniques, which allows participants to express their meanings and question the researcher's assumptions (Viligi, 2016). All interviews were recorded with audio aids and then transcribed, in order for us to be able to analyze and interpret as authentic data as possible. Before the start of each interview, we asked research participants for consent to record the conversation.

The *Information Sheet* (Table 1) was distributed to the research participants prior to the interviews. The list of areas with individual contents is not conclusive, but was open to suggestions and proposals from all research participants. Our aim was to find out the opinion of the research participants on the usefulness of the offered contents.

The data collection and transcription was followed by a phase of their analysis. We used qualitative content analysis (Morgan, 1993) to analyze the given answers and thematic analysis of Braun and Clarke (Braun & Clarke, 2006; Clarke & Braun, 2013) to identify new patterns, topics that may represent the contents of educational programs.

Research participants

Interviews were conducted with three categories of research participants: families' members of people living with Alzheimer's disease, caregivers and social care professionals. With regard to the first category of participants, any family member (any kinship) involved in the care for a member living with Alzheimer's disease could participate in the study. The focus was solely on families where the member with Alzheimer's disease was not institutionalized. We led interviews with a total of 7 research participants: 2 families' members of people living with Alzheimer's disease, 2 participants from the caregiver category, and 3 participants from the expert category.

Presentation, analysis and interpretation of research results

Family members' opinions on the usefulness of educational contents

Families' members perceived all contents related to knowledge about Alzheimer's disease as being extremely useful to them in a crisis situation. This kind of knowledge would be especially useful to them at the very beginning of Alzhei-

mer's disease, when diagnosed, because they felt *the most lost then*. At that time, they generally had neither the knowledge, nor the practical skills they needed to successfully nurture a family member with Alzheimer's disease. Thus, the time/development of the disease variable influenced the usefulness assessment of these contents, with the progression of the disease the usefulness of these contents decreased. As families' members said, they were informed over time and knew *what to expect* from the disease. Also, families' members had an opinion that all contents related to the disease are intertwined and conditioned, and that the usefulness of each of these contents should not be evaluated individually. They suggested to unite all educational contents related to Alzheimer's disease, and to talk about a complete block of contents, that would cover different aspects of the disease (symptoms, stages of development, problems and difficulties...). In the person with Alzheimer's disease/personal area, these research participants evaluated the *Sexuality of a person with Alzheimer's disease* and *Use of assistive technology in the care for a person with Alzheimer's disease* as useless content. Families' members were very uncomfortable discussing the sexuality of their relatives, while pointing out that assistive technology is inaccessible to people with Alzheimer's disease, and because of that inaccessibility they felt that these educational contents would not be useful to them. Topics from family area were also found to be helpful to relatives. Particular emphasis is placed on the topics of *Stress management skills development and burnout prevention in the care for a person with Alzheimer's disease*, as well as the *Redistribution of responsibilities and tasks in the family*, since it is often the case that the entire care for a member living with Alzheimer's disease falls onto one person. Within this area, the *Spirituality development as a way of overcoming a difficult situation* and the *Importance of open affective response in the family* were highlighted as useless contents. Families' members had an opinion that spirituality should not be imposed as a desirable mechanism for dealing with a crisis, and they saw emotional connection as an aspect that the family needs to deal with before the crisis. Community/environment area contents were also assessed by families' members as helpful, notably content on rights, as well as available social protection services. *Neighborhood as a source of family support* and *Different ways to prepare for a caregiving role in the family* were evaluated as useless.

Caregivers' opinions on the usefulness of educational contents

Caregivers evaluated all educational contents related to Alzheimer's disease in the person with Alzheimer's disease/personal area as being useful to families' members. Their caregiving experience showed them that relatives of a person with Alzheimer's disease do not have adequate knowledge about Alzheimer's disease, especially at the very beginning of the disease development. Families, as caregivers said, are mostly lost and confused, not having a clear idea of what to do with members living with Alzheimer's disease, how to care for them, or how to handle certain situations. It is at these moments that caregivers, as they

pointed out, play the role of transmitters of the necessary knowledge and skills, so that the family can provide a member living with Alzheimer's disease with the necessary and adequate care. Caregivers stated that families mostly don't know how to care for the basic needs of a person with Alzheimer's disease, which is why they are hired. Therefore, they found all contents from the Alzheimer's disease domain to be very useful to families' members. The educational contents from this area that were assessed as useless are the *Sexuality of a person with Alzheimer's disease* and the *Use of assistive technology in the care for a person with Alzheimer's disease*, for the same reasons why families' members considered them useless. Caregivers also believed that educational contents from the family area are very important and useful for families to cope more effectively with the crisis. The most useful contents in this area are the *Stress management skills development and burnout prevention in the care for a person with Alzheimer's disease* and the *Redistribution of responsibilities and tasks in the family*. Three contents in this area were described as useless; these are: *The importance of open affective response in the family*, *Spirituality development as a way of overcoming a difficult situation*, and the *Home budget management skills*. Although caregivers had varying experiences with the level of family members' familiarity with their rights and the social services available to them, they found the educational content to be very useful in this regard. They found contents about the self-help groups extremely useful, and considered that it would be encouraging for families' members to connect with people who are in a similar family situation. In the community/environment area, the *Neighborhood as a source of family support* and the *Different ways to prepare for a caregiving role in the family* were described as useless.

Experts' opinions on the usefulness of educational contents

Social protection experts also believed that contents related to Alzheimer's disease and care should be combined into one unit, one block of content. They pointed out that such a block of content is necessary and useful to families' members at the beginning of the disease development, but that this usefulness diminishes over time as the competencies of families' members evolve with the development of the disease. As they said, it's not the same whether the disease is at the onset of the development or in the late stage, so the educational needs of families' members are not the same in these cases. *Sexuality of a person with Alzheimer's disease* was assessed as a taboo topic, as a useless content that should not be imposed on families' members. Experts also found the educational contents from the family area helpful. The analysis showed that the *Development of non-violent communication in the family* was especially highlighted, as experience showed them that in such crisis situations communication in families often takes on the characteristics of aggression, especially in the late stages of Alzheimer's disease, when the care for the member becomes most demanding. As useless

contents from the family area experts evaluated: *The importance of developing emotional connection in the family*, *Spirituality development as a way of overcoming a difficult situation* and *Home budget management skills*. Contents from the community/environment area were also considered useful, with a particular emphasis on the contents that seek to inform families' members on their rights and available social services. *The role and services of NGOs in supporting the families*, *Neighborhood as a source of family support*, and *Different ways to prepare for a caregiving role in the family* were considered useless contents.

The 'cross-sectional content' of the educational program

Based on the conducted analysis we can, also, respond to the last research sub-question and create a new list of potential educational contents. This list represents *cross-sectional contents*, which we sought through guided interviews. By examining the usefulness of all individual educational contents, through interviews with families' members, caregivers and experts, we have enabled the participation of a wide range of actors in determining the content of a potential educational program for families of people living with Alzheimer's disease. Therefore, this approach to creating the educational programs content can be described as participatory, and contents as cross-sectional, because they represent an expression of similarities and differences in opinions of the mentioned categories of research participants about their usefulness.

As we searched for cross-sectional contents that represented a compromise in opinions of all research participants categories, we decided to include only those contents that at least two categories of research participants agreed to be useful to families' members in the following list (Table 2). We removed from the list all those contents that did not meet the stated criterion, as well as those that research participants suggested they are useless and should be eliminated. Also, thematic analysis allowed us to identify new meanings, new topics/contents of educational programs that were not in the *Information sheet*. These topics are *Caregiving skills development* and *Placing a family member with Alzheimer's disease in the nursing home: a psycho-moral dilemma and guilty conscience*. The topic of *Caregiving skills development* refers to training in practical nursing skills, which would be led by a nurse, as research participants recommended. The aim of this training would be to develop practical skills of family members, such as wound dressing, help with nutrition of a member living with Alzheimer's disease, care for the hygiene, etc. Given that it relates to care, we classify this topic in the person with Alzheimer's disease/personal area. In the family area, we classify the content of *Placing a family member with Alzheimer's disease in the nursing home: a psycho-moral dilemma and guilty conscience*. The research participants often referred to the psychological difficulties and moral barriers that family members face when considering placing a person living with Alzheimer's disease in the

nursing home as one of the possible options. Placing an old person in a nursing home is often a taboo subject, so education would provide an opportunity for families' members to discuss their dilemmas with others.

Table 2.

Cross-sectional content of the educational program

<u>Area:</u> <u>PERSON WITH ALZHEIMER'S DISEASE/PERSONAL</u>	<u>Area:</u> <u>FAMILY</u>	<u>Area:</u> <u>COMMUNITY/ ENVIRONMENT</u>
<p>Contents: <i>Alzheimer's disease content block:</i></p> <ul style="list-style-type: none"> - About Alzheimer's disease - Early symptoms of Alzheimer's disease - Alzheimer's disease stages and their symptoms - Preparation for expected tasks and responsibilities - The most severe problems and difficulties in the individual stages of Alzheimer's disease - Ways to cope with and overcome problems and difficulties - Different treatments for Alzheimer's disease and their significance - Biological and physiological (basic) needs of a person with Alzheimer's disease and ways of satisfying them (responsibilities and tasks of family members in that process) - Psychological and socio-cultural (developmentally higher) needs of a person with Alzheimer's disease and ways of satisfying them (responsibilities and tasks of family members in that process) - Emotionality, sensitivity and sensibility of a person with Alzheimer's disease - How to make the environment safer for a person with Alzheimer's disease - <i>Caregiving skills development</i> 	<p>Contents:</p> <ul style="list-style-type: none"> - Understanding the new role in the family <ul style="list-style-type: none"> - caring for a family member - Redistribution of responsibilities and tasks in the family - Flexibility of the family to the changes required by the member living with Alzheimer's disease - Development of non-violent communication in the family - Stress management skills development and burnout prevention in the care for a person with Alzheimer's disease - Problem solving skills - <i>Placing a family member with Alzheimer's disease in the nursing home: a psycho-moral dilemma and guilty conscience</i> 	<p>Contents:</p> <ul style="list-style-type: none"> - Rights of people with Alzheimer's disease and their families - Socially organized help for families with a member with Alzheimer's disease - social protection services - Safe and secure use of the Internet in finding the needed support - Self-help groups – creation and utilization of a network of people with a similar family situation

Concluding considerations

Based on the analysis and interpretation of the research results, the first conclusion we can draw is about the extent of similarities in the opinions of families' members, caregivers and experts. Namely, there are no major discrepancies, contrary, opposing opinions and attitudes in their views. Most of them share the same opinion, both individual research participants within one category of participants, as well as different categories of participants among themselves. The differences between the different categories of participants can be seen mostly in the intensity of the perceived usefulness of educational contents. Another conclusion is that all participants in the study find most of the offered educational contents useful to families' members of a person with Alzheimer's disease. Interestingly, we obtained such data in a research with three categories of research participants. We believe that these results reflect unpreparedness of families for the caregiving role: due to the unpreparedness, which also reflects the lack of systematic support for these families, it is considered that most of the educational contents on the offered list would be useful and important.

By analyzing the statements of research participants, we have noticed that families' members lack many knowledge and skills that would help them go through a given family crisis, in different domains. Families' members not would only benefit from educational contents from the personal area, but they would also benefit from educational contents regarding other aspects of their lives, from the family and community/environment area. This tells us about the need for comprehensive education for family members of a person with Alzheimer's disease, that will not focus on just one aspect of their lives, but that will provide them with comprehensive support. Therefore, we view all those educational programs that are narrow in their orientation, focused only on one aspect of the family members' lives, as insufficient and inadequate. It is necessary to provide families of people living with Alzheimer's disease with a comprehensive education that will allow them to be more functional in a given crisis. Such education, as a form of socially organized support to families of people living with Alzheimer's disease, would bring many benefits: for people living with Alzheimer's disease, families, the social protection system and the whole society. However, in order to enable these benefits to be realized, we need to think more carefully about all elements of educational support and to explore them more. Primarily we are referring to the content aspect of the educational programs and all the questions that we have raised in the paper regarding this aspect.

We also believe that, alongside careful reflection and development of comprehensive educational programs, other forms of support for families of people with Alzheimer's disease should be available. These other forms of support make education possible to families, complement it, support it and enhance its effects, and should therefore be available to families along with education. We

are primarily referring to day care, transportation and home care services, which would relieve families' members of people living with Alzheimer's disease for a certain period and allow them time they can spend educating themselves. Education alone is not sufficient to truly support families of people with Alzheimer's disease, it is just one piece of intervention and it should be accompanied with others kinds of support that family members need. In one study we come to the following statement: "A problem experienced by this sample of caregivers was finding the time and freedom to come to the caregiver training program. They were uncertain about whether they could find anyone to stay with their loved one while they attended the training program" (Robinson, 1988, p. 70). Therefore, we believe that in addition to education, families should have access to a range of support services, which form the structural preconditions for the realization of education. Families' members of people living with Alzheimer's disease need systemic support that will help them in the diverse areas of their lives.

Although a representative sample was not our goal, we believe that in order to make generalizations, it is necessary to conduct the research with a larger number of participants. A small number of research participants limit our research, so we recommend increasing the number of research participants in future. Also, based on our research results, we recommend examination of whether and in what way the usefulness of the educational contents listed in the *Information Paper* varies over time. Does the time variable, i.e. progression of the disease make some educational contents lose their usefulness? Or increase? In the data obtained we can see that the usefulness of educational contents varies with the development of the disease. But we do not precisely know whether this applies to all offered educational contents, nor in what way their usefulness varies. Also, it would be interesting to identify the positive consequences that caregiving can have on the personalities of families' members of people living with Alzheimer's disease in some future research. Although this topic does not seem andragogical, understanding the positive consequences caregiving can have on the personalities of families' members would have andragogical implications. Such an understanding would give us an insight into some other potential educational contents that would aim at developing that positive consequences. Thus, entire focus of educational programs would not be exclusively on repairing the negative consequences caregiving has on families' members of people living with Alzheimer's disease. At the end, we believe it would be significant to have people with Alzheimer's disease as research participants in future researches. We are aware that the realization of such participation would be possible only in the early stages of Alzheimer's disease, when the persons' cognitive abilities are still preserved to the necessary extent. But, it would be interesting to see if their opinions would agree with the opinions of their relatives, caregivers and experts, as well as whether they would provide us with some new insights and potential educational contents.

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