State of Art Research

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Project partners

Stichting Amsterdam European Mobility ***Project Coordinator***	
Stepp Strategie Servizi Sviluppo SRLS	
Alzheimer Athens Association	
Foundation Compassion	
ECSA Kosova	
Dementia Care	

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Reader expectations

The State of Art document is the starting point for the design of our Curriculum. The aim of this document is to offer a complete overview about the methodologies used until now to train the Dementia family caregivers in each partner country, and to identify, validate, and assess migrants' skills and core competences, previous work experience, and other relevant attributes.

It includes:

1. **Research** of methodologies and tools for training dementia family caregivers in each partner country.
2. **Analysis and evaluation** of methodologies used in each Dementia partner organisation.
3. **Assessment** acquired by focus groups and surveys in each partner country.

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About the Digital Tools for Dementia Caregivers project

According to statistics from Eurocarers (European network of organizations representing family Caregivers) 80% of the assistance and care provided to non self-sufficient people, within European countries, is provided by family and friends. This means, in numbers, there are approximately 100 million family caregivers in Europe.

These data clearly show how, on average, European welfare relies heavily on the welfare contribution of families. However, families often do not have sufficient resources to take care of their loved ones on their own. Focusing on Dementia Disease, The Dutch Government has published the "Dementia Delta-Plan", a new National Dementia Strategy 2021-2030, with the specific aim of ensuring people with dementia and their loved ones to receive appropriate support. To reach the success of the strategy this big goal includes:

- Innovation – focusing on the use of both technological and non-technological deve-lopment
- International – focusing on collaborations in relation to dementia research
- Communication – focusing on sharing the knowledge and experiences acquired

"Digital Tools for Dementia Caregivers" responds both to the National Dementia Strategy to the European Call of support this category and proposes a highly innovative educational model that leads to the development of a professional curriculum based on the use of Digital Competences applied to the caregiving process. It combines innovation with the need of supporting family members in providing assistance to patients with dementia disease. At the same time involve international partners with the aim of sharing knowledge and good practices so that the results from national become of European impact. Moreover, since, digital tools in healthcare training are evolving, we consider it is destined to bring positive and longlasting impact on the organisations and the target, also after the project lifetime, as it can always be updated and adapted.

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The Partnership

Stichting Amsterdam European Mobility: Stichting Amsterdam European Mobility (A'DamMob), is a professional organization founded in 2012 and located in Amsterdam specialized in training, research in the field of Digital Competence applied in various disciplinary sectors. Its goal is to offer learning opportunities to students of all ages to help them to acquire skills and create professional profiles that reflect the demands of the current world of work. It represents the meeting point of the most qualified academic and professional resources in the various areas of expertise. A'DamMob courses allow participants to develop knowledge and train excellent skills , through an approach characterized by dynamism , independence , creativity and attention to people The values at the basis of the activities , such as multidisciplinarity, passion, dynamism, energy, interaction, the ability to listen and to do together, allow us to create interdisciplinary courses of higher education and contribute to the future of the territory in a international perspective

Website: www.adammob.com

STEPP: STEPP is an innovative business project developer founded in Florence in 2015. Its job is focused on sectors that have to do with social innovation, such as education and training, socio-economic development, technological innovation, and research.
By social innovation, we mean a type of innovation made up of ideas, creativity, and methodologies to transform theoretical principles and research into the prosperity of a community that is increasingly attentive to sustainability and the development of “intelligent” territories. We want the success of brilliant ideas, investing time, resources, and experience with a final goal: connecting research and innovation to create a virtuous ecosystem that allows innovative ideas to become successful projects.

Website: www.stepp-up.com

Foundation Compassion Bulgaria: Foundation Compassion Alzheimer Bulgaria is a non-governmental organization, established in 2004. Our mission is to improve the quality of life for people living with Alzheimer’s disease and Dementia in Bulgaria, by changing the current attitude and practices towards them and providing access to treatment and social support. The organization was established in Varna and has a team and an office also in Sofia (since 2007). The organization is member of Alzheimer's Disease International, EFID network and National Patient organisation. Current activities: provision of innovative social services for families with patients with Alzheimer/dementia (legal, psychological consultations, including e-mail and telephone consultations), music-therapy, art-therapy and other non-pharmacological methods, Alzheimer café, information campaigns for prevention, lobbying in Bulgaria for improved services and accessible treatment.

Website: http://alzheimerbulgaria.org

Alzheimer Athens: Alzheimer Athens Association is a non-profit organisation founded in 2002 by people with dementia, their relatives and health care professionals interested in Alzheimer’s disease. It aims to raise awareness of all forms of dementia and improve the quality of life of people with dementia and their families. Currently the Association numbers 5500 official members, has a staff of 70 health professionals and 55 active volunteers and is run by a 7-member elected board. Alzheimer Athens Association runs six

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Day Care Centers in Athens and one in Arta, offering daily care to people affected with Alzheimer's disease or other forms of dementia. The Centers' staff consists of a number of physicians, psychologists, speech therapists, social workers, nurses and physiotherapists, as well as administrative personnel. Alzheimer Athens Day Care Centers' activities include:

- Memory clinic: The Association Memory Clinics offer neurological and neuropsychological evaluation to people over 60 and provide timely and accurate diagnosis of Alzheimer's disease and other forms of dementia.
- Non-Pharmacological interventions for people with dementia include cognitive training sessions, physical training programmes and other specific therapies (art therapy, speech therapy, occupational therapy, reminiscence therapy), individually or in groups.

Website: https://alzheimerathens.gr/

Dementia Care: Dementia Care is a Social Promotion Association with registered office in the Municipality of Nicotera, Prov. of Vibo Valentia, which operates throughout the entire territory of the Calabria Region and also nationally and internationally. The Association is registered with RUNTS.
The association aims to work in favor of people with different abilities by promoting and implementing any action that leads to the improvement of the quality of life, in particular, of people suffering from neurodegenerative syndromes and other forms of cognitive decline and deterioration of various types and degrees (e.g. Alzheimer's disease and other forms of dementia) extending these actions also to their family members and caregivers who are dedicated to caring for these patients.

ECSA Kosova: ECSA Kosova was founded in 2016, and will support and enhance the EU studies in Kosovo, region but also contribute to EU challenges by cooperating with the EU institutes, centers, and Universities. ECSA Kosova aims to address the EU accession challenges such as research, digitalization, training, and employment, considering its importance for the Western Balkans including Kosovo.

- Promotion of research activities relating to European integration;
- Promotion of EU and international and EU programs;
- Promotion of the digitalization process;
- Dissemination of information on current university research activities relating to European integration through publications and interactive networks,
- Support students, youth, and academics with regard to European Union research, training, and other activities.

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THE IMPORTANCE OF TRAINING FAMILY CAREGIVERS

According to the Report of the World Health Organization and Alzheimer Disease International, dementia is a worldwide public health priority: in 2010, 35.6 million people were suffering from dementia with an estimated double increase in 2030, a triple increase in 2050, with 7.7 million new cases per year (1 every 4 seconds) and with an average survival, after diagnosis, of 4-8 years. For example, in Italy, the total number of patients with dementia is estimated at over one million (of which about 600,000 with Alzheimer's dementia). In Greece it is estimated the number of people with dementia is equal to 201.766. In the Netherlands, there are an estimated 245,560 people with dementia.

The rapid aging of European society makes the scenario dramatic from the social point of view and the costs of the disease, so much that the European Parliament asked that dementia become a health priority for the Member States, invited to develop specific national programs and to make research funds accessible.

According to statistics from Eurocarers (European network of organizations representing family Caregivers) 80% of the assistance and care provided to non self-sufficient people, within European countries, is provided by family and friends. This means, in numbers, there are approximately 100 million family caregivers in Europe.
These data clearly show how, on average, European welfare relies heavily on the welfare contribution of families. However,families often do not have sufficient resources to take care of their loved ones on their own. So, while waiting for scientific research to make available new possibilities for intervention, training and updating are one of the main resources. Dementia care is such a delicate process that requires cautious behaviour of family caregivers in every step, for this reason this project aims to combine innovation with the need of supporting family members in providing assistance to patients with dementia disease. There is an increasing need to integrate existing skills, with new approaches and digital competences, able to properly meet these new challenges. The project, aims to develop an Consortium for developing a new and up to date training curriculum to respond to the needs of are service beneficiaries and properly take advantage of new opportunities offered by technologies.

The size and complexity of dementia problems determine basic needs such as:

- Developing new innovative skills for the family caregivers involved;
- A strong commitment to updating active carers;
- A serene caregiving experience from both the patient's and the family caregiver's point of view.

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HOW DIGITAL TOOLS CAN IMPROVE FAMILY CAREGIVERS' SKILLS

As the population across the globe continues to dramatically increase, the prevalence of cognitive impairment and dementia will inevitably increase as well, placing increasing burden on families and health care systems. Technological advancements over the past decade provide potential benefit in not only relieving caregiver burden of caring for a loved one with dementia, but also enables individuals with dementia to age in place. Technological devices have served to improve functioning, tracking and mobility. Similarly, smartphones, tablets and the ubiquitous world wide web have facilitated the dissemination of health information to previously hard to reach populations largely through use of various social media platforms.

Dementia education has been also noted to enhance care management and social support seeking behaviour by informal caregivers (e.g., seeking counselling, joining discussion forums, and informal support groups. Disparities in levels of formal education among higher- and lower-educated caregivers can also impact the quality of care, but provision of dementia education can reduce knowledge disparities among higher- and lower-educated caregiver groups. Other barriers to caregiving include insufficient information about behavioural symptoms of dementia and accurate understanding of the benefits of timely diagnosis. Studies have shown benefits to care partners' caregiving abilities when interventions include psychoeducation, and are targeted at increasing communication between the informal caregiver and caree. Overall, dementia education for informal caregivers seems to have a positive influence on both the care and the health outcomes of persons with dementia.

Benefits of dementia education are well supported, and informal caregivers indicate receptiveness to a variety of educational modes, including community-based and internet-based resources and online portals. Internet-based interventions have been shown to improve caregiver confidence, reduce perceived burden, increase self-efficacy, decrease anxiety, decrease feelings of depression, and increase dementia knowledge. A recent systematic review of psychoeducational interventions for caregivers of people with dementia who live at home included studies that delivered technology-based interventions and found that the technology-based interventions reduced caregiver burden. Some examples of technology-based interventions for caregivers include websites, tailored web-based interventions with expert recommendations, hybrid interventions that include an online component and an interactive telephone component (e.g., dementia care consultation, and interventions with a telephone-only component. Studies comparing dementia education versus participation in a network of caregivers found that interventions containing both an educational component and an interactive component had the greatest benefit and impact on skills, stress, attitudes, knowledge, self-efficacy, and perceived caregiver burden. Interactive components of interventions, featuring discussion boards, email, and multiple forms of informational presentation (e.g., video, case-based vignettes), were the most highly rated.

Digital modes of education, such as knowledge conveyed via electronic devices, media, internet, closed-circuit computer networks, or web-based platforms, have an equivalent impact on learning as face-to-face modes. Additionally, such learning offers an advantage of remote or asynchronous delivery, where each participant progresses through educational material in a self-paced manner. Asynchronous digitally based learning holds additional benefits for individuals living in remote or rural areas, where long wait times for specialized services and a lack of information/local educational programs are common. Recent changes within health services and efforts to move services to virtual methods due to the COVID-19 pandemic,

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have seen online-based learning gain a new importance. Searching and summarizing existing research on current modes of digital education for informal care providers can serve as an important step toward implementing digital dementia education programs for caregivers and enhancing access to educational and support resources.

Past systematic reviews have examined internet-based interventions for caregivers of persons with dementia, focusing on evaluation methods, including qualitative interviews, satisfaction-based interviews, organizational feedback, as well as interventions delivered via telephone, and computer. The present review examined the effect of digital dementia education delivered via technology with remote delivery capabilities, including smart phone applications, telephone, video, computer (online and network), and focused on studies with pre and post measures in order to more accurately determine the impact of digital education. Increased availability and ownership of smart devices with access to the internet have changed digital delivery of information within the past decade, as well as motivation to engage in education in part due to increased focus on remote and asychronous approaches for education necesited by the pandemic. Consequently, the current state of art explores the evidence base for different technologies used for dementia education.

RESEARCH ON METHODOLOGIES AND TOOLS USED UNTIL NOW IN TRAINING ACTIVITIES FOR FAMILY CAREGIVERS IN EACH PARTNER COUNTRY

The Netherlands. The number of persons with dementia in developed countries is estimated to nearly double to 14.3 million by 2050. Dementia is one of the most expensive conditions in the world, particularly toward the end-of-life. The Netherlands is the highest spender on long-term care of all Organisation for Economic Cooperation and Development (OECD) countries. The overall costs of dementia correspond to 10.3% of the total Dutch health care budget. The Netherlands instituted various policies to reduce the costs of long-term care, including dementia care, by shifting residential care to home and community care. The literature is scant on whether these policies decreased nursing home stays and reduced costs, or if extended in-home stays triggered crises situations, leading to unplanned hospitalizations, institutionalization, and increased costs. To prevent crisis situations of community-dwelling persons with dementia, care services should be tailored to the needs of persons with dementia and their informal caregivers, because unmet needs are associated with lower quality of life and nursing home placement.

The Netherlands has many care services available for community-dwelling persons with dementia and their informal caregivers such as day care, home care, and case management. Peeters et al. found that 92.6% of Dutch dementia informal caregivers received a form of professional support. However, 67.4% indicated that they needed more additional support. Van Der Roest et al. found that the most frequent unmet care needs of persons with dementia and caregivers were information on dementia, psychological distress, and daytime activities. Utilization of dementia care services can depend on factors such as awareness of services, accessibility, affordability, and appropriateness to the user. There is an evidence gap on how persons with dementia and informal caregivers value available care services. Providing care packages that include care services that are valued by persons with dementia and their informal caregivers may help prolong community living and avoid crisis situations.

People with dementia prefer to live at home for as long as possible. In the Netherlands, it is estimated that 70% of people with dementia currently live in the community. Many of these require 24-h support and

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care from a next of kin, typically a spouse, child, or other relative. Given that the number of people with dementia is expected to double over the next 20 years, growing numbers of relatives will be expected to provide care for a relative with dementia. However, caregivers themselves can experience high levels of burden and stress as a result of this role, ultimately leading to mental illness or early institutionalization of the dementia sufferer.

A prospective cohort study reported that half of all caregivers experienced excessive burden that increased over time and led to aggression, depression, anxiety, and poorer physical health. Evidence also suggests that caregivers are at increased risk of serious illnesses and death. Research on the effect of long-term caregiving has shown that it has long-term consequences. Indeed, in one study, psychological well-being among caregivers did not improve to levels comparable with those in non-caregivers after the person they cared for died or was admitted to a nursing home.The high levels of burden to which a caregiver is exposed, typically through the poorer cognition and neuropsychiatric symptoms of the person with dementia, can also increase the risk of the care recipient being placed in a nursing home. Psychological morbidity in caregivers is also a predictor of mortality for people with dementia.

Developing effective interventions that target caregivers can benefit both the caregiver themselves and the person for whom they care. There is extensive literature on this issue, but heterogeneity of interventions and outcomes make it difficult to identify the most effective and relevant interventions. Most reviews have only indicated mild to moderate effect sizes with common interventions, while some subgroup analyses have shown stronger positive effects. Interventions in these subgroups have tended to incorporate the following: group training, social support, cognitive interventions, intensive programs, multi-model programs with multiple components, programs that focus on the caregiver/patient dyad, caregiver training, caregiver family involvement, adapting to caregivers' needs, and providing psychological education.

The Dutch Government has published a new National Dementia Strategy 2021-2030, outlining its future priorities in relation to dementia policy in the country. This work builds on the Dementia DeltaPlan, which ran between 2013 and 2020, focused on three key strands of work:

1. Facilitating research to prevent or cure dementia
2. Care enhancement
3. Creating a dementia friendly society.

Continuing along the themes outlined in the previous strategy, the Dutch National Dementia Strategy (2021-20130) sets out its mission as: *Persons with dementia and their loved ones can continue to function as valuable members of society and receive appropriate support and care. Sufficient scientific research is carried out into the possibilities for preventing, treating, and curing dementia.*

Similar to the DeltaPlan, three key areas of focus are identified:

- A world without dementia – focusing on dementia research.
- Persons with dementia matter – focusing on reducing stigma and prejudice.
- Tailor-made support when living with dementia – focusing on improving supports and services.

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Each of the themes provides an analysis of the challenged faced, what the strategy aims to do and how it intends to meet the aim.

In addition to these overarching themes, the strategy also identifies four underlying areas which are key to ensuring the success of the strategy. These include:

- Innovation – focusing on the use of both technological and non-technological developments
- Young person with dementia – focusing on the specific needs of this population
- International – focusing on collaborations in relation to dementia research
- Communication – focusing on sharing the knowledge and experiences acquired from the work of the strategy.

Other Projects

The Meeting Centers Support Program (MCSP) for people with dementia and their informal caregivers tries to tackle these problems by offering combined support for both by a small professional staff and volunteers at an easy accessible, socially integrated location in the neighborhood. People with dementia are offered meaningful recreational, creative, and therapeutic activities in the Meeting Center (their "club"), the caregivers can attend informative meetings and discussion groups, and both can participate in social activities and utilize individual consultation. This combined form of support is highly appreciated by people with dementia and informal caregivers, and both benefit from it. This is evident not only from the great increase in the number of Meeting Centers over the past 25 years (there are now 163 centers across the Netherlands and about 25 in other countries in and outside Europe) but also from repeated scientific research. Several studies have shown that the users of the Meeting Centers are almost unanimously (very) satisfied with the offer and that compared to regular day care, the participants with dementia using MCSP have fewer behavioral and mood problems and higher self-esteem, their informal caregivers feel more competent, nursing home admission is postponed, and lonely informal caregivers have fewer health complaints. However, recent figures show that nationwide only around 10–20% of the people with dementia (and informal caregivers) in the Netherlands use different forms of organized daytime activities (7% of those use indicated day care). To ensure that more people can receive appropriate psychosocial support it is therefore important that, in addition to day care, alternative forms of activities and support become available that better meet the varied individual needs of people living with dementia and their caregivers in different stages of the disease.

In order to meet the variety of individual needs and preferences of people with dementia and their informal caregivers, innovative interventions have been developed and offered in the last decade. Three of these interventions, which have also been assessed very positively by people with dementia and caregivers themselves, are DemenTalent, Dementelcoach, and STAR e-Learning.

The DemenTalent volunteer project meets the needs of people with dementia for autonomy, being useful by contributing to society as a volunteer and to maintain dignity. Practice shows that people feel they have value again and that this promotes social participation and more independent functioning. The project also contributes to a more positive image of dementia and counters stigmatization.

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Dementelcoach offers informal caregivers tailored telephone support for the problems they experience as caregivers, in which a great deal of attention is paid to the burden experienced by caregivers and methods for reducing stress and transgressive behavior toward the person with dementia. A controlled trial showed that the coaching increased caregivers' feelings of competence, decreased psychosomatic complaints when applied in combination with day care for the person with dementia, and was highly appreciated by caregivers. Another recent study showed that telecoaching diminished depression in caregivers and improved self-efficacy.

STAR e-Learning is a course recently developed in a European project and accessible via the Internet (www.startraining.eu). The course consists of 8 modules for informal caregivers and volunteers (in addition to 6 advanced modules for professional caregivers) and is aimed at increasing their knowledge and skills in order to provide the person with dementia with person-oriented care, to deal with behavioral changes, to prevent or decrease neuropsychiatric problems, and to take good care of themselves as caregiver. STAR education was positively evaluated in a randomized controlled trial (RCT) in the Netherlands and the UK, both on user-friendliness and usefulness. Informal caregivers who had completed the STAR course proved to offer more person-oriented care and to have more empathy for the person with dementia.

In the individualized Meeting Centers Support Program (iMCSP) project (2016–2019), we investigated the implementation of these three interventions (DemenTalent, Dementelcoach, and STAR e-Learning) in existing Meeting Centers for people with dementia and their caregivers. The expectation was that, by adding these individualized, person-oriented interventions parallel to the regular group-oriented support program offered by the Meeting Centers to date, the variation in people's needs and preferences could be better addressed, so that more people with dementia and informal caregivers would make use of the activities and support. The implementation study, on which we reported elsewhere, showed that different stakeholders (such as Meeting Centers' personnel, Alzheimer Association, local government) indeed experienced the new iMCSP interventions as added value to the regular MCSP. In addition, we evaluated the characteristics of participants of iMCSP compared to regular MCSP and No day care users, and the impact of the individualized interventions on people with dementia and caregivers compared to regular group-oriented MCSP and compared to not receiving day care.

Italy. Thanks to the survey, promoted by the Dementia Observatory of the Higher Institute of Health, it is known that in Italy the total number of patients with dementia is estimated at over 1 million, of which around 600 thousand suffer from Alzheimer's disease. Caregivers amount to about 3 million and these are also affected by economic and organizational consequences. The trend is growing so much that, according to the projections of the Ministry of Health, in 2051 there will be 281 elderly people for every 100 young people, with a consequent increase in all age-related chronic diseases, including dementia.

Training caregivers is a necessary action: to help a person in a functional way it is therefore essential to know every nuance of the problem; in these cases, caregivers contribute to outlining the course of care, through periodic meetings with the team which are also useful for clarifying the needs, requests and difficulties of family members. The purpose of training is therefore to promote theoretical and practical aspects, aimed at overcoming obstacles and barriers, through the conscious use of tools and learning. A number of researches show that informal caregivers want to receive more training in order to be able to provide better care (COFACE, 2017). The availability of training for informal carers is fragmented across

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OECD countries and, in most cases, it is provided through local initiatives and relies heavily on the voluntary sector. In most OECD countries, free training (at least online) is available.

Among the projects in progress of the ISS Dementia Observatory, various training initiatives have been implemented for rehabilitation health professionals and for family members and caregivers of patients, which provide for the creation of FAD courses, both face-to-face and face-to-face distance. These two courses complete the existing training offer of the Dementia Observatory, which has been organising, for years: a course in the clinical epidemiology of dementia, a course on drafting a PDTA in dementia and a course for general practitioners , and, this year, a specific course on dementia and migrants.

Dementia is also a priority in WHO's mental health action programme, which has also developed iSupport, an e-health solution that provides information and skills training for carers of people living with dementia. While the effectiveness of face-to-face support interventions has been demonstrated, the growing gap between care services and demand raises a demand for alternative methods of providing support and education to informal caregivers (Boots , De Vugt, Withagen, Kempen, & Verhey, 2016). This gap can be bridged through the implementation of integrated intervention programs, which benefit from the use of internet devices and eHealth support paths.

The use of technology in caregiver support pathways has shown promising results in terms of outcome. E-learning interventions have proved to be useful tools for the informal caregiver, as the recipients of the program have appreciated the transmission of multimedia contents, promoting learning and making the material more interesting. In general, a significant satisfaction emerges with respect to rapid and effective communication with health professionals, or other caregivers through the use of virtual platforms. Furthermore, the opportunity to personalize the use of electronic devices favors monitoring and communication in different settings involving various care figures (Nai-Ching,C. & Demiris, G., 2015).

To date, several studies have demonstrated the effectiveness of personalized eHealth programs in increasing the sense of self-efficacy and reducing the perception of stress and depression (Boots De Vugt, Smeets, Kempen, & Verhey, 2017). In fact, the use of eHealth makes it possible to facilitate shared decision-making processes, facilitating the assumption of an active and participatory role in the care process.

Access to online treatment modalities can be an advantage for caregivers who have difficulties in accessing the network of traditional services. Adherence to remote programs also leads to significant savings in terms of money and time. Online interventions therefore present greater usability, especially for caregivers who need greater flexibility in carrying out their care tasks, bringing the intervention directly into their homes and reducing the perception of social isolation (Hopwood et al., 2018).

The combination of online and offline treatments has shown positive results (Wentzel., J., Van der Vaart, R., Bohlmeijer, E.T. & Van Gemert-Pijnen, J.E.W.C., 2016). In particular, caregivers of people with early-onset dementia have shown greater participation in web-based interventions, as younger generations have a greater propensity for online content (Boots et al., 2018). However, studies on the effectiveness of interventions delivered via the web have allowed us to point out some limitations in their application. One of the most sensitive aspects is related to adherence to treatment and the high risk of dropping out of caregivers who only benefit from online treatment (Cox, Schepers, Ketelaar, Van Heugten, & Visser-Meily, 2018). It can therefore be deduced that the integration of web-based programs must be developed on the

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basis of a personalization of the intervention with respect to the characteristics of the user and the needs expressed.

Blended-care: the advantages of the integrated online-offline model

Although these programs move in the direction of self-managed interventions, the results show the importance attributed to the presence of a support figure, such as psychologists or other trained operators. Direct contact with care professionals allows for the sharing of doubts or questions and the personalization of practical suggestions. In the same way, it is possible to provide psychological support, in order to reduce the sense of isolation and favor the understanding of individual experiences inherent in the caregiving experience.

From this point of view, providing participants with contact with a therapist as support during the treatment period allows to increase adherence to the treatment itself (Johansson, Michel, Andersson, & Paxling, 2015). Clear communication appropriate to the participant's abilities is in fact essential to promote understanding of the aims and to convey the instructions necessary to start the project.

The intervention program via the web is therefore not proposed as a replacement for an emotional, practical and psychoeducational support path, but as an integrated method alongside the face-to-face intervention. The online component takes the form of a flexible aspect, the proportions of which are adequate and adapted to the treatment, on the basis of the contents and the stage of the disease the caregiver has to deal with. The adjective "blended" in fact describes an interconnected and not separate model with respect to the entire treatment process, contributing equally to the intervention together with face-to-face meetings.

Recent studies have subjected intervention programs with these characteristics to an evaluation of their effectiveness, even within pathways dedicated to caregivers of patients with dementia.

In particular, the blended care program "Partner in Balance" for caregivers of patients in the early stages of dementia has promoted an activity of integration between learning paths and online support and face-to-face assessment sessions with a health professional (Boots et al., 2016; Boots et al., 2017). The intervention is mainly based on self-management principles to help caregivers find a balance between the care activity and their daily life. In fact, the participants in these interventions express a good usability of the goal-setting approach, which allows them to translate the contents of the program into daily life. However, difficulties often arise in formulating goals. The help of a professional is therefore important in the phase of identifying specific and measurable goals. The "Partner in Balance" program in fact provides for an initial meeting with a personal coach in order to familiarize the participants with the program, establishing the objectives and the modules to be conducted.

In this way we proceed to the construction of tailored-made online modules, which include psychoeducational aspects, behavioral modeling, change plans, feedback via email from the tutor over a period of 8 weeks. Furthermore, participants can interact with each other via a discussion forum.

Starting from these intervention models, it is possible to create new contents, based on the emergence of specific needs of partners or other family members in the role of caregiver (Bruinsma et al., 2021). From

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the outcome evaluation emerges the importance attributed to face-to-face sessions, as a fundamental element for building a relationship with the individual participant.

The presence of a family coach, with whom direct contact was established, facilitated the commitment to completing the modules and allowed greater freedom of expression and sharing in online contexts. Furthermore, this element in the presence offers the possibility of recognition for the participants, increasing awareness of their own behaviors and emotions.

The analysis of caregiver needs: a model for personalized.

The construction of a personalized intervention based on the caregiver's needs promotes the acquisition of a greater sense of competence in managing the person with dementia. As a result, it is possible to foster a positive perception of one's role of care, focusing on learning skills and exploring individual and community resources. Some studies have focused on identifying the most significant elements for caregivers of patients with dementia who have participated in online support programs (Hopwood et al., 2018). The results showed that peer support provided by online participants was one of the most shared themes. Some programs, for example, offer the opportunity to develop an informal online support network through which to share contacts and practical information about individual care in a mutual-aid setting.

A similar approach, using videoconferencing methods, has facilitated online group meetings once a week. The virtual meeting groups were directed by a professional psychologist, allowing the communication exchange between the participants and the conveyance of information on dementia.

These studies (ibidem) suggest that programs that include group interaction and the possibility of eye contact between participants are more effective than the use of chats, forums or simple messaging in increasing the state of well-being and perception of effectiveness of the 'intervention. The qualitative analysis of the data has in fact highlighted several benefits, including a sense of understanding through shared experience, gratification in helping others, reduction of social isolation.

Another significant aspect of online interventions includes the transmission of information, which appears to be more effective if calibrated on the basis of individual information needs. Within support programmes, it is important to include modules for developing skills intrinsic to the caring role. Among these, decision making skills seem to have particular importance and are often lacking or ineffective in the complex management of the patient with dementia. Some interventions have proposed tools to support this function, favoring ways of identifying priorities in the decision-making process (Hopwood et al., 2018).

However, the chronic and progressive nature of dementia determines the emergence of different needs and skills based on the various stages of the disease. For this reason, effective integrated intervention programs must be individualized and coherent with the problems related to a given phase of the care process. Interventions in the early stages of illness can prepare caregivers for their future tasks, in a phase where stress and care burden are relatively low (Boots et al., 2017). These programs have been shown to be effective in reducing stress, increasing a sense of self-efficacy, and delaying patient institutionalization. Identifying caregiver needs based on individual situations and facilitating the adaptation process therefore favor a positive management of the care process (Boots et al, 2016; Boots et al., 2017; Cox et al, 2017).

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The digital revolution makes it possible to promote proactive action by family members, facilitating the sharing of decision-making processes and access to personalized sources of information (Nai-Ching & Demiris, 2015).

Therefore, it can be concluded that the integrated use of eHealth is prefigured as an opportunity to offer continuity of care and to develop an interconnected intervention network to support the role of the caregiver

Greece. In Greece, apart from the NGOs for people with dementia (like Alzheimer Athens Association), unfortunately there is no other organised effort or training for caregivers. Nevertheless, NGOs for people with dementia can be found all over Greece now. In order to find information concerning the NGO near to the area of a person, the Panhellenic Federation of Alzheimer's Disease and Related Disorders, another NGO, was founded in 2007 in order to work as a link (http://www.alzheimer-federation.gr).

The Panhellenic Federation consists of 39 linked Associations of Alzheimer's disease all over Greece. Its' main objective is the coordination and cooperation of companies - members in the context of social contribution and awareness of the patient's with dementia and their caregivers' needs. Its' aims are the creation of structures, services and conditions that improve the quality of life of patients and their carers, the promotion of research, the education and training for all the stakeholders, the provision of useful information and advice on dementia problems and the prevention of the marginalisation of people with dementia. In all these associations, there is at least one programme for caregivers' support.

Of course, there are also private (after payment) individual professional psychologists who can support caregivers in Greece. As most of these NGOs could be far from the caregiver's home, digital tools were created in order for the Alzheimer Athens association to provide its services wherever there is an internet connection.

Bulgaria. In Bulgaria Foundation Compassion Alzheimer Bulgaria provides trainings for the staff of the Nursing homes for people with dementia, as well as to other operators such as companies providing care at home. The approach is based on person-centered care.

For the family caregivers the organisation provides support and consultations, groups for self-help and Alzheimer café. Those activities are led by a clinical psychologist and the accent is again on person-centered care and effective approaches for communication.

Summary of the current situation, according to the Strategic Guidelines[1] for diagnosis, prevention, treatment and care for people with dementia in Bulgaria[2]:

- insufficient training of the staff in the specialized homes, institutions, health facilities that care for people with dementia;

[1] Strategic Guidelines for diagnosis, prevention, treatment and care for people with dementia in Bulgaria**,** **http://www.dementia-bulgaria.com/downloads/strategy_231219.pdf**

[2] The study is part of the project "Together we promote, respect and act – inclusive society for all ages and stages of dementia" is implemented in the period January 2018 – January 2019 by Foundation Compassion Alzheimer Bulgaria and is awarded by European Foundations Initiative on dementia with the award "Valuing the expertise of people living with dementia"

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- lack of professionally trained assistants for the daily care of people with dementia at home;
- insufficient awareness and sensitivity of society about Alzheimer's disease and other dementias and about the possibilities of diagnosis, therapy and care for patients and their families, policies to overcome stigma, ethical aspects.

There are a few NGOs working on those issues in the country. They provide training to family caregivers, often on a project basis.

In the last few years thanks to several Erasmus plus projects there are opportunities for the caregivers to get trained. For example the project Lily, implemented by Civic association Alzheimer-Bulgaria. This project aims to provide a blended training programme (class sessions and elearning course) for carers of frail older people and people with dementia based on Lily theory model developed by Norman and Skinner (2006), integrating additionally dimensions presented by Chan & Kaufman (2011), Gilstad (2014) and adapted to fit the web 2.0 technology requirements. The e-learning programme will facilitate the class goals and will include selected modules that will assist carers training[3].

Foundation Compassion Alzheimer Bulgaria implemented in Bulgaria the project “Move your hands for dementia”. “Be connected" M.O.O.C. (Massive Open Online Course) was elaborated and it provides instruments to adult and senior educators to improve their competences on dementia health literacy. Formal and non-formal adult educational settings are involved. Another result was the Community of Practice (CoP) addressed to adult educators to share ongoing training on living with dementia, and to people living with dementia, family members and caregivers to share tools to support their daily needs: personal care, leisure management, cognitive stimulation, assistive technology devices, and personal support services[4].

Key results of a pilot sociological survey on the needs of people with dementia and their relatives[1] The study was conducted from December 3 to 28, 2018, and included an online survey, in-depth interviews and focus-group discussions (held in Varna and Sofia) with relatives of people living with dementia. 142 people participated in the survey. The study is not representative, it has a pilot character and aims at marking key problems of people with dementia and their relatives in our country. Two thirds of the study participants are young people in the most active age - between 18 and 45 years. The remaining one third are individuals between 46 and 65 years. People over the age of 66 are under 5% of all survey participants.

Of all the participants in the survey, the share of people from Sofia is almost 80%. 17% of respondents live in the country, and just under 5% are currently abroad. As expected, among the respondents who filled in the online survey, the largest group is of children who have a parent living with dementia - nearly 40% of the study participants are daughters and sons of dementia sufferers. At second place are ranked the grandchildren of people living with dementia - just under one third of all respondents who completed the survey. A little bit more than 10% is the proportion of other relatives of people with dementia.

[3] https://elily.eu/about-the-project

[4] https://myh4d.pixel-online.org/index.

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57% of respondents know people who are currently suffering from dementia, and nearly half of them or 31% of those who have filled in the questionnaire are currently taking care of their relatives who are affected by the disease. One third of respondents do not have dementia. A total of 43% of all study participants have relatives with dementia who passed away. The overlap between the two shares shows that one in five respondents has several cases of dementia in the family - relatives who have already passed away and relatives for whom they are caring in the current moment.

Participants in the study were best informed on two topics:

1) The impact of dementia on their social life (fewer than one fifth think that they are fully informed) and
2) External manifestations of the disease (again about 20% say they are fully informed).

Altogether, about three-quarters of the respondents believe that they are informed ("fully informed" and "rather informed") about the topics related to the visible aspects of dementia - social life, mental health, external manifestations of the disease. People who have relatives who are affected by dementia are slightly better informed on these topics than people who do not have relatives and friends affected, but the differences are not significant.

More significant are the topics on which survey participants are not informed. The issue of 1) the different forms of support for those, living with dementia and their relatives - over 82% of respondents say they are not familiar with this topic. There is a lack of information on social institutions that provide support to people affected by dementia (77% are not informed on this subject, as the share of those who are not informed at all significantly exceeds the share of respondents who say that are "rather not informed" - 33 against 44% of all respondents) and 2) the issue related to medical institutions for patients affected by dementia (two-thirds of the survey participants have no information on the topic, with over one third not being informed at all). There are also problems related to early diagnostics, which is not yet at a sufficient level in our country and with problems related to lack of sufficient follow-up of the patient after the diagnosis. People with dementia have a huge need for information at these stages. More generally, the main problem in the study was the lack of information - "What the relatives should do at any stage of the disease after the diagnosis" – this exactly should be provided by the medical team.

Education and training. But, although they feel informed and have a personal experience with dementia, participants in the study, including those who are currently caring for dementia relatives or having relatives who have died as a result of dementia, are still experiencing need for training. From what kind of training exactly? The most people needed training on the topic: "How to communicate with a person with dementia", 42% have significant need of such training and 47% are more likely to need training. The second need is: "How to care for a person with dementia," with 44% of respondents feeling the need for training. Relatives who care for people with dementia, as a rule, have no training on how to do this and learn from practical experience. They often face the impossible choice whether to work to have a financial opportunity to support their sick relative, or to devote themselves to care 24 hours a day, but not to have enough means to survive.

Participants' willingness to learn is a sign of empathy and reveals the potential for initiating volunteer campaigns, organizing self-help groups, engaging neighborhood communities around the issues of

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dementia, and building neighborhoods, buildings and institutions that are friendly to those affected by the problem and which can provide a good life in the community.

Kosovo. Health care in Kosovo is affected by numerous shortcomings, as Kosovo has among the lowest ratios of physicians and nurses in Europe, with 1.44 physicians per 1000 inhabitants compared to the European Union (EU) average of 3.4 doctors per 1,000 population (Hoxha. et al.). The additional challenge is the low level of salaries in the public sector, and the limited capacity of absorption of additional staff in the health care system, followed by the difficult working conditions, especially for the nurses, and other health professionals. (Kosovo 2.0) in 2018, produced a report *Aging with Alzheimer's* based on an interview with the Head of a Neurological Clinic within the University Clinical Center of Kosovo Dr. Nexhmedin Shala, who pointed out that there is no information about how many persons with Alzheimer's there are in Kosovo. In addition, he declared that there is no study, in terms of age, or groups based on their place of living and there is also a lack of Association in Kosovo. This fact confirms that there are no specific investments for Dementia care, respectively there is not a single Dementia Center in Kosovo, public or private. In addition, there are no organizations providing training for the caregivers.

Until the year 2017, there was not any organization in Kosovo licensed to offer specific care for elder people. According to different reports, there are only 4 houses for elderly people, which don't support the needs and demands of older people. According to the different analysis, around 44.4% of older people in Kosovo declared that they don't perform any activity, therefore this fact will have a negative impact on their physical and mental health.

Furthermore, International Community support for Dementia challenges in Kosovo is marginal. Dementia Care International, in 2021 has supported two professionals from the Kosova Center for Rehabilitation of the Torture Victims, (KCRT) Dr. Feride Rushiti and Clinical Psychologist Selvi Izeti. These professionals participated in an intensive three-week Spark of Life Master Leadership Program supported by the Dementia Foundation Spark of Life, with the idea to create specialized practitioners of this model of care and introduce this into Kosovo for the first time. In our interview with them, apart from their willingness to introduce this model, they still couldn't realize it, due to the specific activities of their Institution.

Compared to other countries, Kosovo faced additional challenges, which increased the problems regarding health and social care, including dementia care, such as:

i) The migration process has a negative impact on the health and social care of older people, as young people due to different challenges are working abroad and, therefore cannot have a direct presence in Kosovo and take care of their parents.

ii) Migration of medical professionals to the EU countries mostly, to Germany due to better conditions of life and work, which is becoming a complex issue not only for Kosovo but also for Albania and other Western Balkan countries.

iii) Low level of pension and social schemes for retired people, which doesn't allow them to fulfill their basic requirements and ensure better health care.

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iv) Lack of public and private institutions that specifically could enable them to socialize, and perform physical activities which consequently reduces dementia challenges, but also facilitates the role of the family caregivers.

v) Additionally, in Kosovo society, there is a stigma associated with dementia and other mental disorders, therefore, how to adapt, and ensure that people with the condition can live within them for as long as possible, still is a challenging process.

Finally, based on the many interviews performed with the Dementia family caregivers, the current situation in Kosovo reflects that there was no support, specific program, or training from the institutions until now. On the contrary many Family caregivers have continuously used their individual approach, respectively contact with their relatives who are usually Psychologists or Psychiatrists to obtain as much as more information on how to behave with the patients and facilitate the process of caregiving.

ANALYSIS AND EVALUATION OF THE PREVIOUS METHODOLOGIES USED IN TRAINING ACTIVITIES FOR FAMILY CAREGIVERS IN EACH PARTNER ORGANIZATION.

DEMENTIA CARE (ITALY)

The term Caregiver is used to indicate "the one who "provides care", that is, looks after someone who has suffered a decrease or loss of autonomy for various reasons, and specifically due to dementia.
From a research by CENSIS, we learn that:

- Family members dedicate an average of seven hours a day to direct assistance and almost eleven hours to supervising the sick relative;
- Caregivers are mainly women with families and children: especially daughters are the most active subjects in assistance;
- The care overload adds up to the commitment linked to the performance of the other roles;
- 66% of caregivers had to leave their jobs, 10% asked for part-time work, 10% had to change jobs;

There is a lack of information on the disease and on the services offered by public, private and voluntary social services. It therefore emerges that that of the caregiver is a heavy task, often undertaken in response to situations of necessity or emergency, such as the onset of the disease and in many cases the person called to carry out care tasks finds himself unprepared.
The commitment required of the caregiver in terms of assistance is directly proportional to the degree and speed of the loss of autonomy of the person he takes care of; as the needs of the patient grow, the personal time that the caregiver dedicates to carrying out increasingly complex care tasks increases, ranging from simple basic care activities (nutrition, hygiene, etc.) to health interventions (administration of drugs, , cleaning of medical devices, etc.) and specific relational skills (as a result, for example, of cognitive impairment or psychiatric discomfort).

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The caregiver becomes an irreplaceable resource for the patient, but due to the emotional and care burden he is burdened with, he can also become the second victim of the disease. The "burden of assistance" perceived by the caregiver has been defined as "caregiver burden" which expresses the overall impact of the physical, psychological and social needs in providing assistance. It is essential to determine the level, type and cause of the burden in order to optimize all interventions (psychological, social, welfare and pharmacological) aimed at reducing it.

The association aims to work in favor of people with different abilities by promoting and implementing any action that involves improving the quality of life, in particular, of people suffering from neurodegenerative syndromes and other forms of cognitive decline and deterioration of various types and degrees (e.g. Alzheimer's disease and other forms of dementia) extending these actions also to their family members and caregivers who are dedicated to caring for these patients. The association also intends to work to promote the usability and accessibility of public and private services by insufficiently informed people and families.

As part of the aforementioned activities of general interest and consistently with its mission, the association aims to carry out the specific activities mentioned below, by way of example and not exhaustively, in favor of people suffering from illnesses, disabilities and particularly pathologies neurodegenerative and other forms of cognitive decline and deterioration of various types and degrees: 1. Promotion of initiatives aimed at the psychophysical well-being of the person through the creation of specific spaces and activities aimed at particularly encouraging the implementation and dissemination of innovative therapeutic and rehabilitative approaches in order to promote integration in the family context as much as possible, social, work; 2. Offer of support services within work teams in order to promote psychophysical well-being and a harmonious, rewarding and collaborative work environment. 3. Promotion of initiatives aimed at increasing and improving the professionalism of the operators responsible for the care and assistance of these patients, also through appropriate professional development activities. 4. Support actions and psychological and social assistance for the families in which people with the aforementioned problems live, as well as for the caregivers responsible for providing assistance; 5. Training activities aimed at caregivers and family members of patients, in order to improve their skills in carrying out care functions; 6. Promotion of listening centers and mutual self-help initiatives to encourage solidarity between families and social relations in local communities; 7. Collaboration with the local health and social care teams responsible for community services and home services or at residential and semi-residential facilities, also through the organization of appropriate training activities for the aforementioned operators; 8. Information and awareness among public opinion and figures professionally involved in Alzheimer's disease and other dementias; 9. Collaboration with research bodies for the study of the causes, prevention, assistance and therapy regarding people suffering from dementia and other similar pathologies; 10. Protection of the rights of the patient and his family for the purpose of improving legislation and the practice of public structures towards such patients, as well as promotion of socio-cultural initiatives and events, conferences, conferences in order to disseminate information on

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these problems ; 11. Promotion of pilot centers for diagnosis and assistance and for the training of specialized socio-health personnel. 12. Development of innovative forms in the field of co-programming and co-design with public and private bodies and third sector organisations; 13. Organization of conferences and events regarding psychological, pedagogical and socio-health issues relating to problems related to neurodegenerative diseases and other similar pathologies.

ALZHEIMER ATHENS (GREECE)

Individual and Group programs for Caregivers

Caring for a person with dementia significantly affects the emotional health of carers and every aspect of their daily life. The Alzheimer Athens Association practically supports the caregivers by organising many programs both on an individual and group level.

Individual programs

Individual sessions: Counselling caregivers on issues related to dementia. Sessions can be held both in person and online.

Carers Psychiatric Support Clinic: The psychological burden of caregivers often leads to physical symptoms and increased use of health services. The Alzheimer Athens Association, in its effort to alleviate the psychological burden of caregivers, operates a psychiatric support clinic for caregivers in Day Care Centers.

Group Programs

Group programs are designed to meet the needs of caregivers at every stage of the disease, offering guidance, support and relief.

Alzheimer Caregiver Online - You have questions, we have answers: It is an online meeting and discussion of caregivers of people with Dementia, which is coordinated by a Psychiatrist, Psychologist and Social Worker, with the aim of informing caregivers about issues related to care.

School of Caregivers: The Alzheimer Athens Association organises seminars, which aim to train caregivers on issues related to dementia, such as the symptoms and progression of the disease, practical issues for the daily care of people with dementia, legal and social issues, etc., but also to inform about the programs and services of the Day Centers and more generally about the actions of the Company. The speakers of the School of Caregivers are distinguished and experienced health professionals in the field of dementia, of multiple specialties (neurologist, psychiatrist, psychologist, social worker, lawyer). At each meeting, there is always an opportunity for open dialogue so that carers can express their concerns and experiences, both with the specialists and with other carers.

Caregiver Training and Counseling Group: The group aims to educate and support caregivers through information and the acquisition of new skills to manage the problems they face. The group has few members and is completed in 8 2-hour meetings.

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Difficult emotions management group “Caring for carers”: What's it like to "lose" my man while he's still by my side? Anger, frustration, sadness, loneliness, guilt are some of the most common emotions we experience when we are called to care for people with dementia. But when we are mentally and physically exhausted, do we provide adequate care? The group aims, through experiential techniques, on the one hand to bring us in touch with the difficult emotions we experience when we take care of our people with dementia, and on the other hand to learn to take care of ourselves. The group is coordinated by psychologists trained in psychotherapy, has few members and is completed in 10-12 meetings, lasting 2 hours.

Nursing care seminars for carers of people with dementia: Understanding the pathology of the Third Age and the complications that people with dementia can present greatly helps the work of caregivers. The goal of these seminars is for the caregiver to acquire knowledge about the diseases of the Third Age and basic nursing management skills, improving the daily life and quality of life of both him and the person he cares for. The seminars cover 4 thematic sections and are held in hourly weekly meetings of 4-5 people.

FOUNDATION COMPASSION ALZHEIMER (BULGARIA)

In Bulgaria Foundation Compassion Alzheimer Bulgaria provides trainings for the staff of the Nursing homes for people with dementia, as well as to other operators such as companies providing care at home. The approach is based on person-centered care.

For the family caregivers the organisation provides support and consultations, groups for self-help and Alzheimer café. Those activities are led by a clinical psychologist and the accent is again on person-centered care and effective approaches for communication.

The trainings for the family caregivers usually comprises the following content: 1) what is dementia, risk factors, stages, the role of the caregiver; 2) Medical guidelines for coping with psychotic symptoms (hallucinations, aggressive behavior, sleep disorders, etc.) - basic approaches when seeking help and support from the caregiver (neurologist); 3) Effective communication with a person with dementia. Practical advice for solving basic everyday caregiving problems (clinical psychologist); 4) Personalized care. Principles of the method. Benefits for the person with dementia and the carer. Examples from practice (social worker/psychologist); The supportive and responsible role of the caregiver in carrying out daily care, tailored to the capabilities and needs of the person with dementia. Examples of caregiving strategies that work. Advice for dementia carers and their loved ones.

ECSA KOSOVA (KOSOVO)

Kosovo society assigned larger roles to extended families and greater social connections, therefore considering values of respect and dignity for the elderly as a duty and source of pride. This fact caused many families to avoid reaching out to healthcare professionals, and consequently, this is one of the reasons leading to the lack of careers or professional social services and professional organizations dealing with dementia challenges in Kosovo. Considering the lack of institutional support for the Dementia Caregiving Process in Kosovo, therefore, the support is based only on an individual approach and the individual needs of caregivers and Psychiatric advice. Based on this fact this an extreme need for awareness of society and

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decision-makers about it. Regarding the impact of digital tools on the caregiving process, in Kosovo, it is assumed that digital tools could help the process of caregiving although most of them didn't apply it. Some respondents declared that the caregiving process also depends on the patient's situation, as some of them have very heavy health situations, therefore the support to the caregivers was impossible to apply. Therefore, according to them, the use of digital tools depends very much on the health level of the patient. Furthermore, according to the respondents, there was not any technological or financial support from the institutions during their activities. The respondents who used digital tools think that the use of digital tools could increase the communication process between family members and patients, better orientation, and better coordination.

In addition, according to the analysis, the main comments from the family caregivers interviewed are as follows:

(i) Implementation of Digital Tools is crucial in Kosovo to address, and respond appropriately to the challenges and support the process of caregiving; such as:

- Support from specialist services based on individual needs
- a 24/7 mobile service that responds onsite within 48 hours.

(ii) Kosovo needs a sufficient number of educated and trained professionals for dementia care, which professionals could support directly the dementia patients but also partially family caregivers;

(iii) A combination Program of Family and professional Caregivers could be the best support for Dementia patients. Based on the individual experience of our respondents is shown that the best support could arise from the family members, but considering that some patients experience severe dementia complicated by physical aggression or other behaviors, there is a need for additional Professional Dementia Caregivers to facilitate the process of caregiving. In order to realize this program the local institutions should offer institutional, professional, and financial support to family members acting as caregivers.

(iv) In the medium term, there is a critical need for establishing a specialized Centre for Dementia in which older people can meet and socialize, but also in this centre should recruit and train Dementia Caregivers;

(v) Individual Programs for the caregivers currently, could be the most adequate instrument in the case of Kosovo, due to the lack of a specialized Dementia Centre, which could be applied to the Group Programs.

(vi) Developing Mobility Individual Services for Caregivers is essential, but initially, there is a need to identify and have the appropriate number of Dementia patients and, consequently caregivers, which in Kosovo's case is missing.

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Focus Groups Results

ITALY by Dementia Care

The sample survey, in Italy, was carried out by the professionals belonging to the "Dementia Care" association, in the persons of the Psychologist-Psychotherapist Dr. Vittoria Vardé expert in

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neuropsychology and the Social Worker Specialist Dr. Agata Bongiorno at the Center for Cognitive Disorders and Dementias located in Cinquefrondi (RC).

The investigation took place in two phases. At first the focus group was held and then a questionnaire was administered.

The focus group saw the involvement of 10 cargivers aged between 50 and 60 who, on average, have been caring for a family member suffering from Alzheimer's disease or other forms of dementia for more than 2 years.

First, the objectives of the survey and the role of each participant within the study were shared. After establishing a climate of trust and involvement, each participant was invited to freely and openly share their experience as caregivers and their level of training and knowledge with respect to Alzheimer's disease and other forms of dementia.

Following the focus group, a questionnaire was administered consisting of twenty questions, more specifically four open-ended questions and sixteen closed-ended questions, mostly in funnel-like succession, with the choice of answer alternative.

The tool used for the sample survey was the administration of a questionnaire consisting of twenty questions, more specifically four open-ended questions and sixteen closed-ended questions, mostly with funnel sequence, with the choice of alternative answer.

It was preferred to administer the questionnaire through the paper self-administration mode, since only a part of the ten participants chosen for this survey possess skills and mastery with the technological instrumentation, necessary for a correct electronic compilation.

That investigation revealed the following:

1. Demographic characteristics of caregivers

- The majority of the caregivers interviewed are female (as can be seen from the graph 7/10 they are female) which confirms that this is a cultural issue. Even if this trend is changing and the number of men who share with their partners or family members the management of everyday life is growing.

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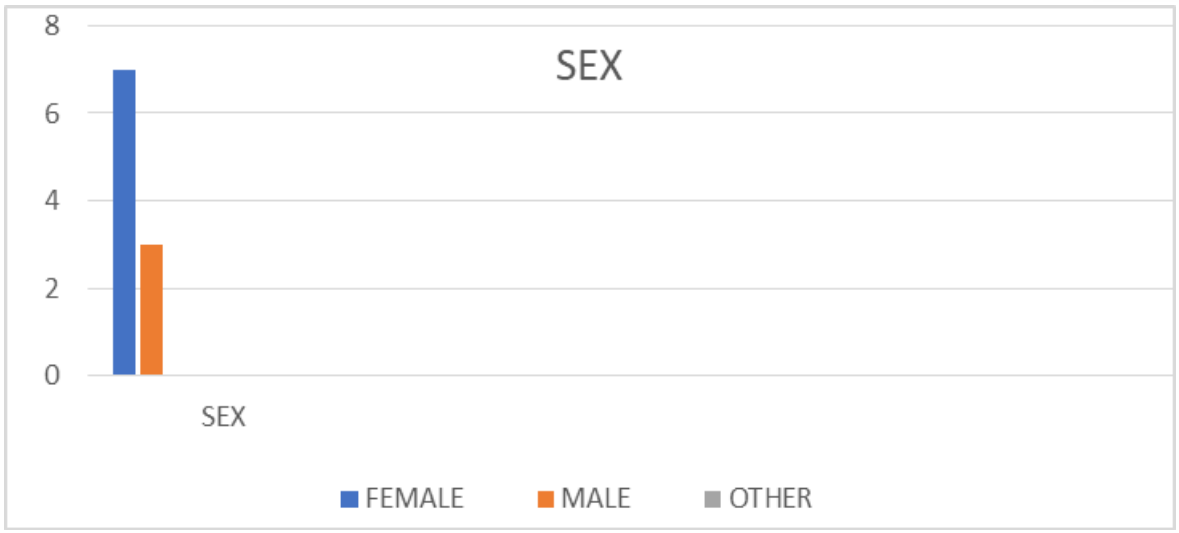

Figure 1: Graph reflecting the gender results of the caregivers who participated in the survey.

- The majority of caregivers are between 50-60 years old. The majority of support is provided by a member of the close family circle. In fact, the interviewees declare that they have undertaken the activity of caregiver for family needs, in order to mainly assist a parent and in a limited number of cases the partner/spouse. In Italy we are witnessing a significant demographic change; The aging of the population has led to an inevitable increase in chronic degenerative diseases, especially Alzheimer's disease, which represents 54% of all dementias. According to the report by the World Health Organization and Alzheimer Disease International, dementia is a global public health priority.

In these subjects, care services take place mainly within families.

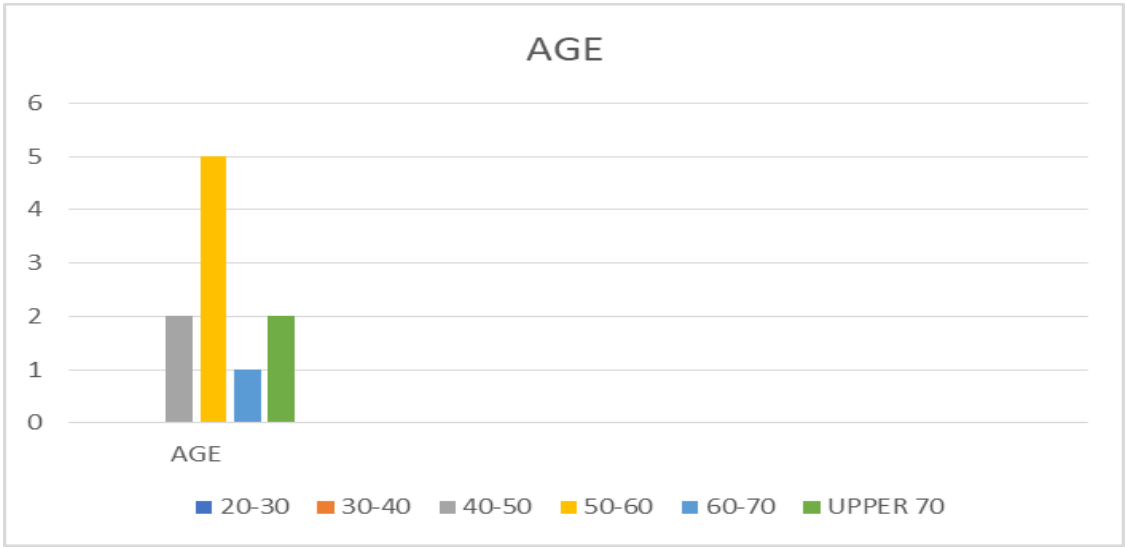

Figure 2: data obtained with respect to the average age of the caregivers who participated in this survey

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- The majority of the sample of caregivers (specifically 6/10) have experience of caregiving assistance for more than three years.

Figure 3: Data obtained with respect to years of experience in the caregiving sector.

- All participants did not follow any training to become a family caregiver.

Figure 4: data obtained with respect to any training followed by caregivers.

- Caregivers spend more than 4 hours a day taking care of the patient.

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Figure 5: care time spent by the caregivers involved in this survey.

Figure 6: results obtained with respect to the training of the caregivers chosen for this survey.

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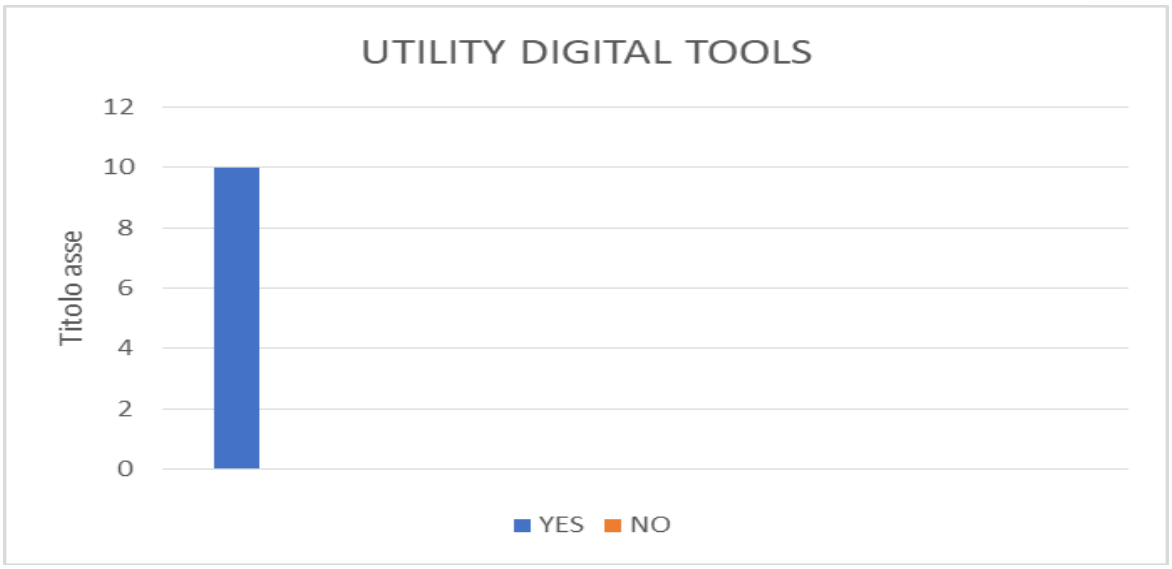

Figure 7: Awareness of selected caregivers regarding the usefulness of digital tools.

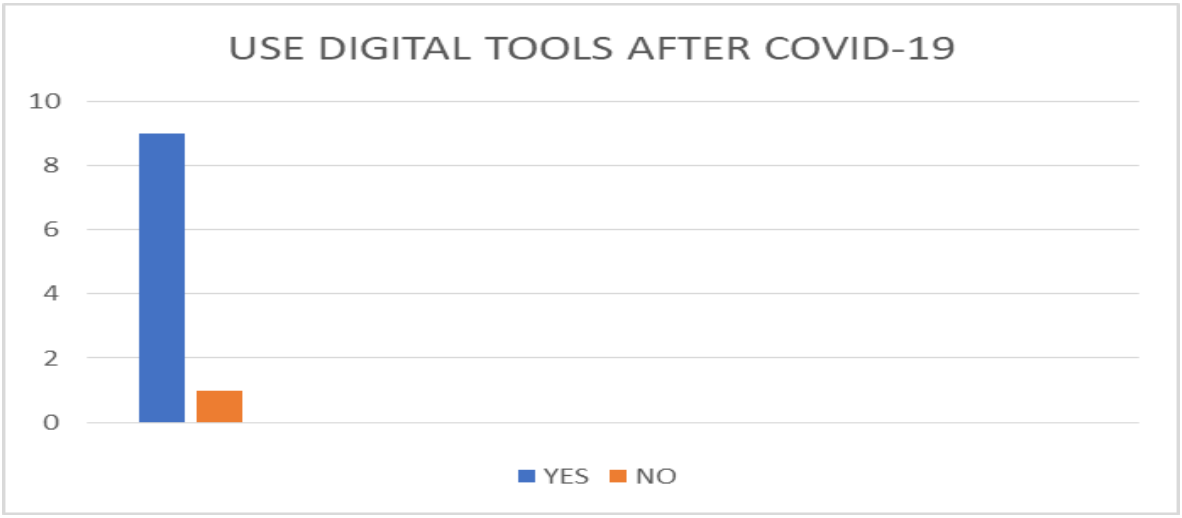

Figure 8: Recognition of digital tools as a training resource for caregivers.

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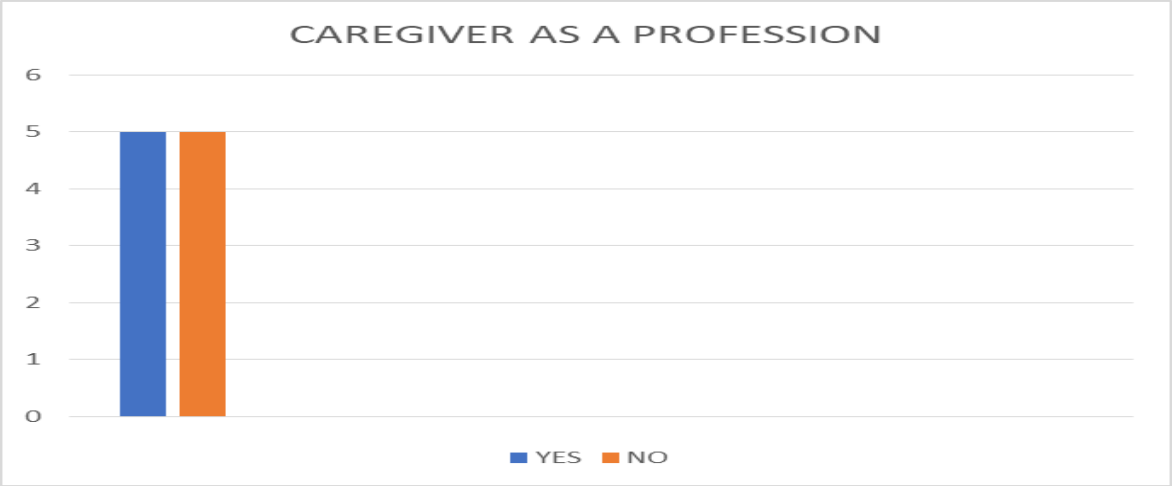

Figure 9: results obtained regarding the possibility of turning the caregiving experience into a profession.

Training caregivers is a necessary action: to help a person in a functional way it is therefore essential to know every nuance of the pathology.

In conclusion, from the survey carried out, aimed above all at probing possible training through digital tools, it emerged that the sample concerned has never undergone training either digitally or traditionally.

GREECE by Alzheimer Athens Association

The present report is the result of 2 focus groups of caregivers, one held online and the second held face-to-face. These focus groups were organised as a part of the Erasmus+ program KA220-ADU - Cooperation partnerships in adult education "Digital Tools for Dementia Family Caregivers". The intention of the focus groups was to identify facilitators and barriers from the precedent support they had as caregivers in order to allow the identification of the various interventions already used, analysing their effectiveness. More precisely, the objectives were:

- Analysis and evaluation of the previous methodologies used in training activities for family caregivers;
- Research and in-depth reading of the training needs analysis;
- Definition of the adopted methodologies;
- Development of the theoretical structure to implement the model, which will be provided to the staff involved in the training as instructor.

A questionnaire was prepared in advance in order to guide and help the analysis of the results of the focus groups. The questionnaire was prepared in English and then translated in Greek for the Greek caregivers to answer.

Both focus groups were held on the 6th of July 2023, guided by the psychologists specialised in caregivers' support of the Alzheimer Athens Association. Data have been analysed by using SPSS v.24.

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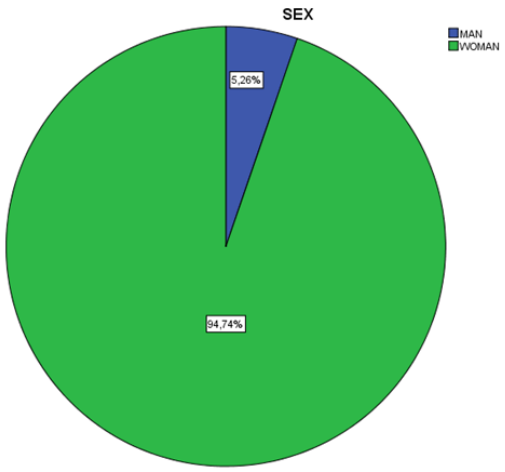
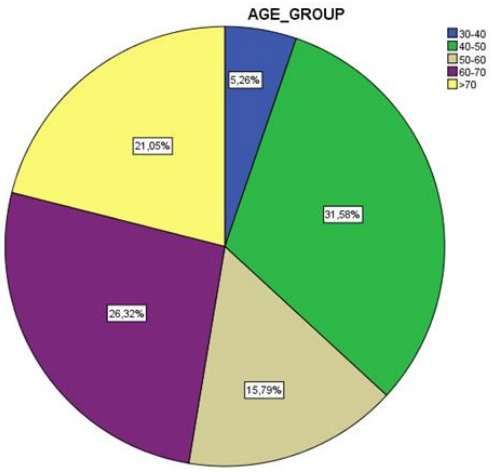
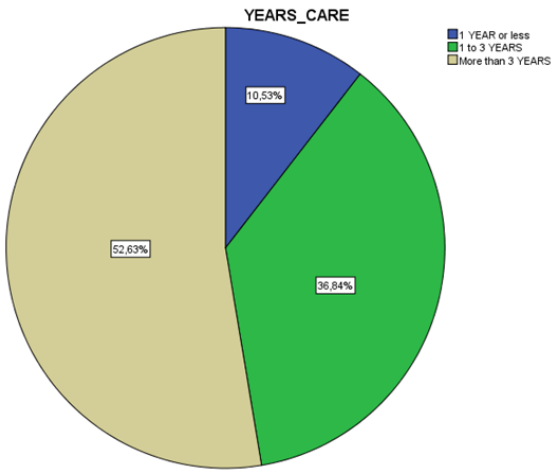
All participants (19) were caregivers in programmes of Alzheimer Athens Association.

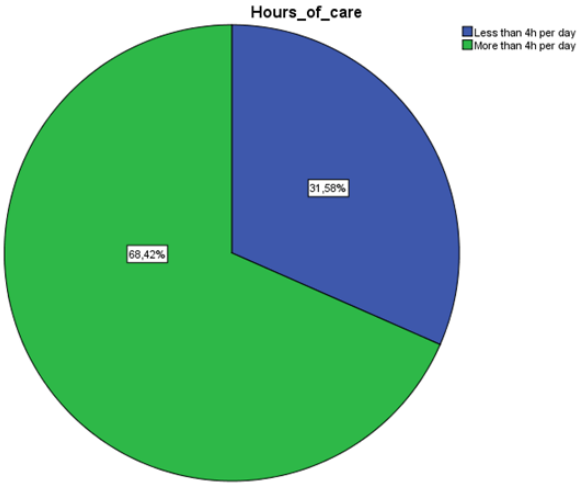
Concerning sex and age, 94.7% were women and most of them from 40-50 years old (31.6%) and from 60-70 (26.3%). Most of the caregivers provide care to a close family member (mother, father, spouse, aunt) and only 1 provides care to a family friend.





Concerning the years of caregiving most of them are caregivers for more than 3 years (52.6%) and provide care for their patients more than 4 hours per day (68.4%).





Concerning caregivers' education most of them declare that they did not have an education in order to be family carers (52.6%). From those who had searched for an educational programme, most of them had chosen an online training (55.6%).

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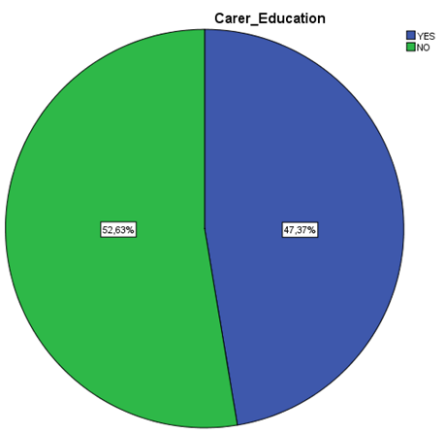
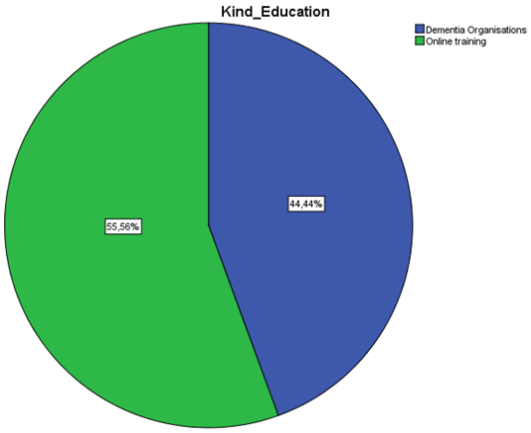
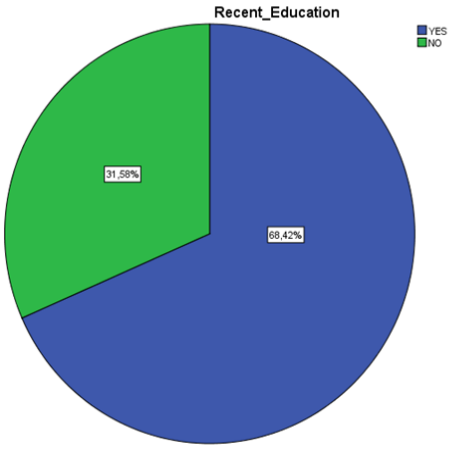
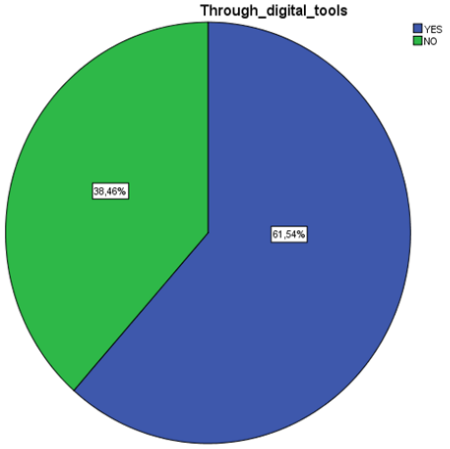


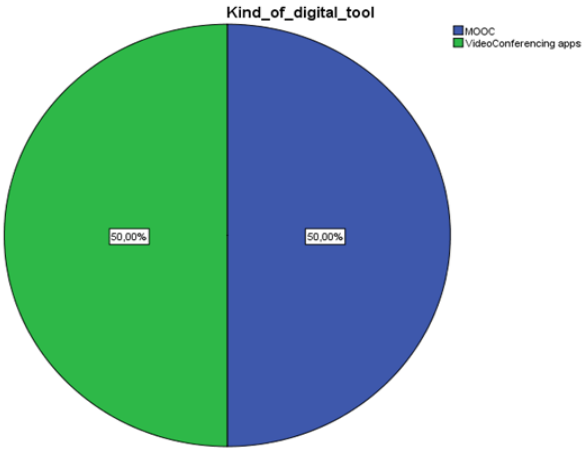


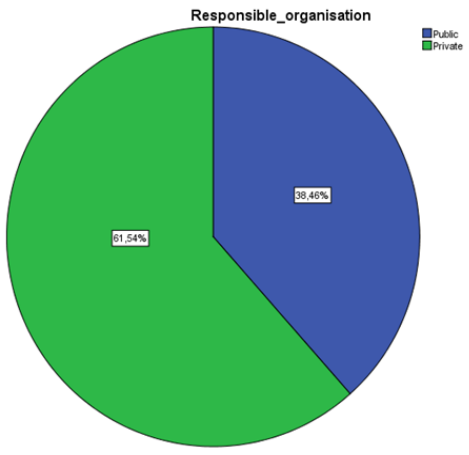
Moreover, most of the caregivers (68.4%) declare that they had a recent education concerning caregiving and that most of them had this training by using digital tools (61.5%).





Concerning the specific tool used for digital training, caregivers reported to use equally (50%) MOOC and videoconference applications (50%) and to have completed these educational programs mostly in private organisations (61.5%).





Most of the caregivers have found the educational training much useful (50%) and have seen a big impact of the training on their patient.

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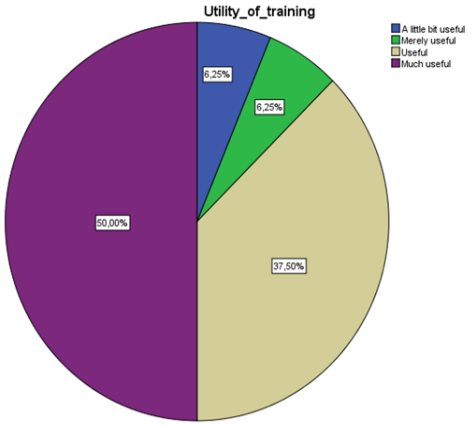


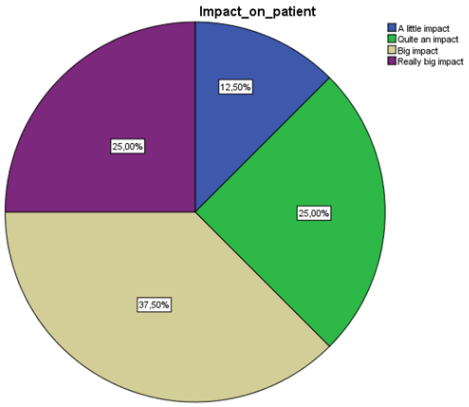
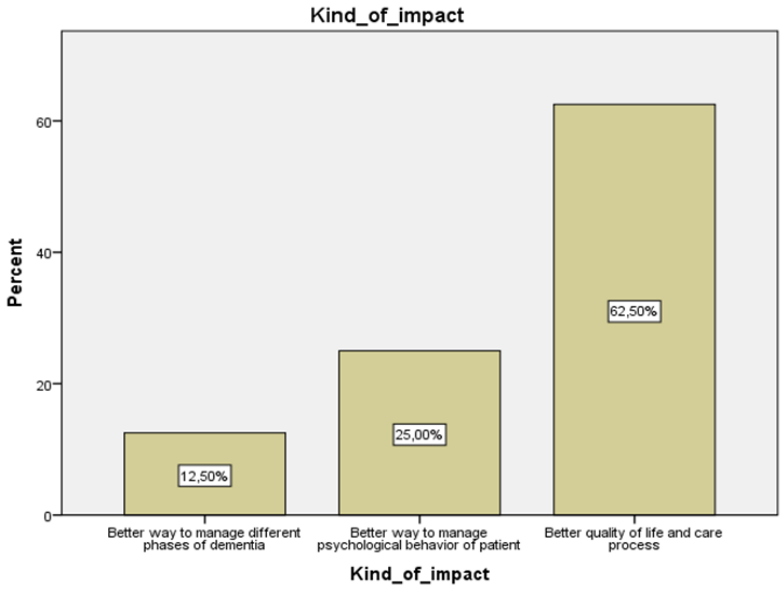


Table 1 shows the kind of impact that training had on the patients.

	Frequency	Percent	Valid Percent	Cumulative Percent
Better way to manage different phases of dementia	2	10,5	12,5	12,5
Better way to manage psychological behavior of patient	4	21,1	25,0	37,5
Better quality of life and care process	10	52,6	62,5	100,0
Total	16	84,2	100,0	



Most caregivers (68.4%) have found the digital tools useful for their training and they do not report problems (66.7%) during the use of digital training. Concerning the problems endured during the use of digital tools, most caregivers mentioned lack of digital skills and one mentioned internet connection problems.

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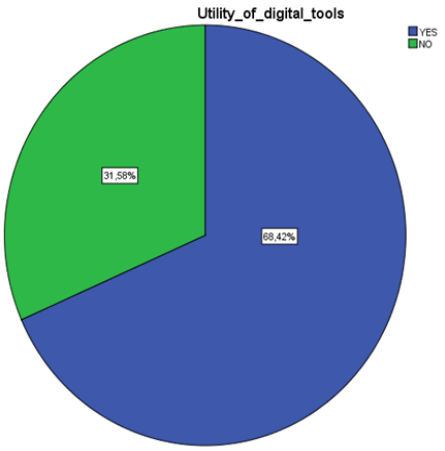
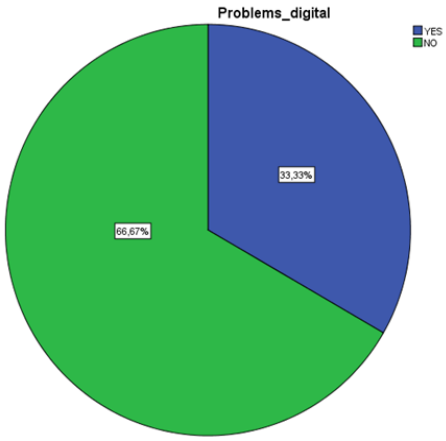
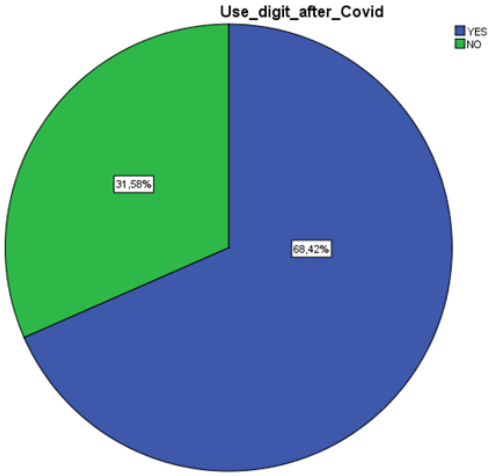
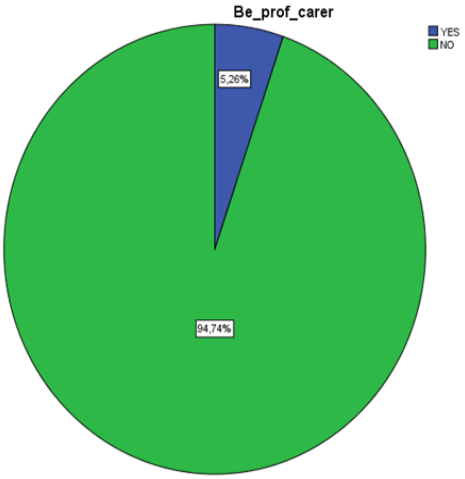




Finally, most of the caregivers (68.4%) have found the digit tools so useful that they claim that they will use them even after the pandemic period of Covid-19. This means that even if they have been obliged to use digital solutions because of Covid-19 restrictions, they have been convinced that these tools are very useful concerning at least educational programmes. Concerning tools that caregivers would like for the future, it would be good if there were some open platforms with video instructions.



Concerning the use of caregivers' personal experience at a professional level, it seems that the vast majority of caregivers do not wish to follow caregiving as a profession.



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BULGARIA by Foundation Compassion

All participants (11) were caregivers from the network of Foundation Compassion Alzheimer Bulgaria.
Demographic characteristics of caregivers
They are 6 women and 5 men. 2 men are at the age group 20-30 years; one man between 50-60 years and one man above 70 years. Most of women - three- are at 50-60 years; two are between 40-50 years and one is between 30-40 years.
8 persons are caregivers from more than 3 years, one man is caregiver from 1-3 years and two other men are from less than a year.
To the question how and why did you become a caregiver the respondents give various answers:
- "Because I worked abroad as a caregiver"
- "This is the work that I love"
- "I want to help people" (man, became a caregiver 3 months ago)
- Less than a year ago (man). "I am satisfied to see results from the work done."
- "I am not a family caregiver, but a caregiver in a social service"
- "I first helped my father care for my mother (both on-site in Bulgaria and remotely from the US) after a stroke advanced the development of her dementia. After Dad passed away unexpectedly, I took care of Mom until the end" (man)
- A caregiver since 2009: "Because I wanted to support the family having person with Alzheimer's disease. And to be in support for my family"

The replies of the other respondents are: that one person became a caregiver from 2017 when her mother became ill; another person started when she started taking care after her grandfather in 2010; another says that 6 years ago because of the circumstances. Two men are caregivers: one to his mother and another to his wife.
Only one person takes care for less than 4 hours a day, and one person for 4 hours. All other carers provide care for more than 4 hours.

EDUCATION AND TRAINING

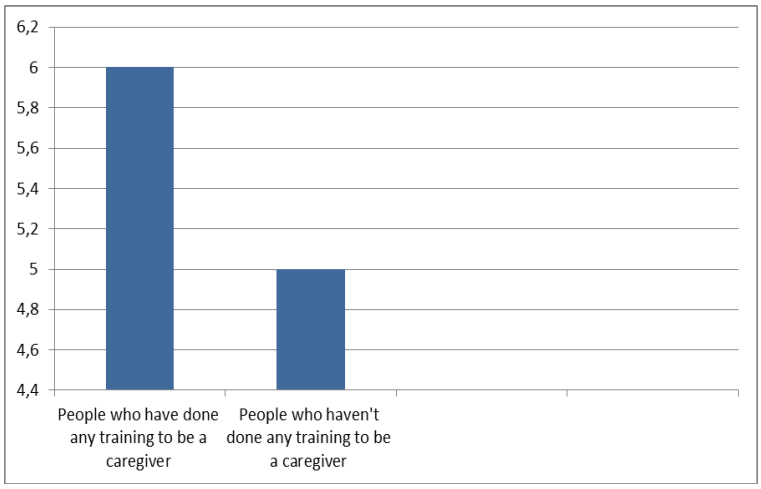

Fig. 1 Number of people who have gone any training to become a caregiver

The replies to the question Have you done any training to be a caregiver are:

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Yes – 6 people (3 women and 3 men)
No – 5 people (3 women and 2 men)
6 people have recently attended a training or courses/activities related to caregiving (more than 50% of the respondents) and with the use of digital instruments/platforms.

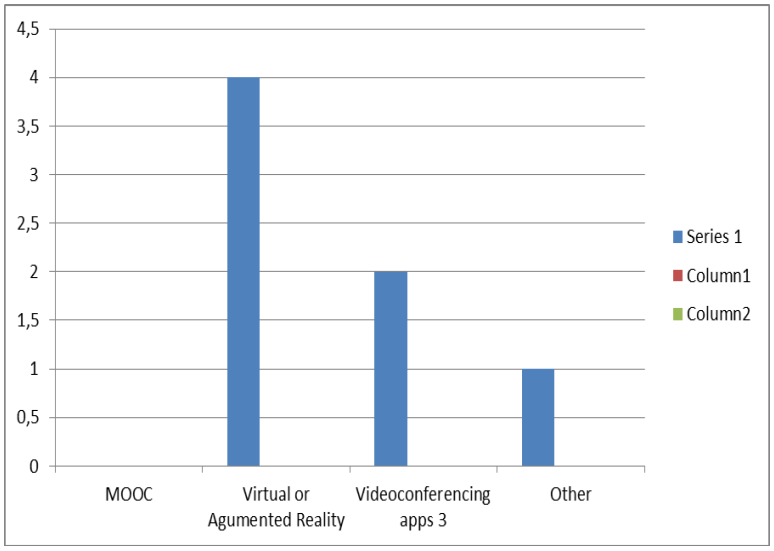

Fig. 2 Number of persons who have used in a recent training/activity digital tools

Type of education passed
9 people declare having passed training on caregiving, of whom: university education (1 person), education in a center for treatment of dementia – 4 persons; 2 people having online courses and 2 people state that they had more than one training.
Usefulness of the training passed for caregiving within the home/family
Six people/more than 50 % ot the respondents admit that the training was extremely useful and almost the same share is for those who you evaluate that the impact on their patient was excellent. (two more people assess is as very good).

Impact of the training (with digital tools) on the patient

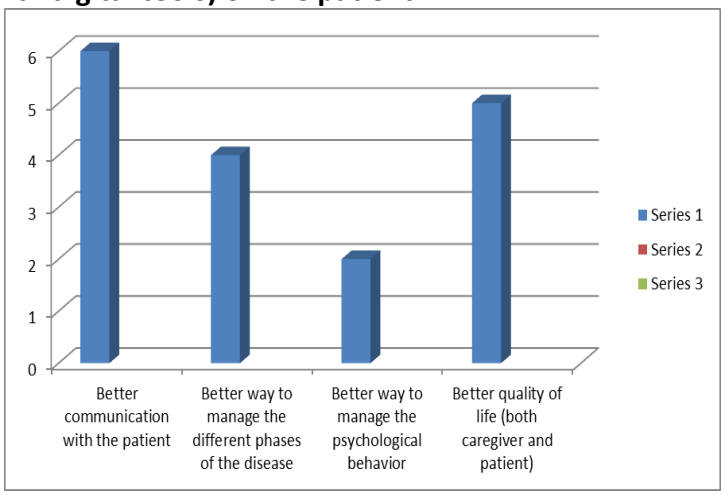

Fig. 3 Number of people sharing that the training had an impact on the patient

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8 people didn't experience barriers in the use of digital instruments/platforms. Only one person state that the internet was a barrier for him. More than 90% of all respondents think that the use of digital instruments in the caregiving process would be helpful. They (90%) are keen to use these technologies after the end of the pandemics

Needed digital instruments in the future

- Computers (stated by 2 people), more equipment, computer, patience, meetings for exchange of experience that may be online and in live format between caregivers, group meetings of people with dementia and their relatives for visits on different places, going out in the nature, conversations, music, dances, cooking, I would love to take my mother to such kind of events, so that she is not alone and that she can have conversations with other people, to do some things, to relax, and to feel better.
- Seminars and courses
- Online access to specialists/experts in the care of people with dementia who can offer specific recommendations for the specific person I care for given their condition and specific problems/needs/peculiarities; the form of access may be different, but there must be an active audiovisual connection
- Online meetings for sharing of experience by different specialists and colleagues.
- Zoom.

When asked whether they would like to turn caregiving into professional activity, the results show that less than 50% or five people would do so (all women). Those who are not willing to become a professional caregivers are six persons (all men who took part in the survey and one woman).

KOSOVO by ECSA Kosovo

For compiling this document - the report, we used a qualitative research design involving Dementia Family Caregivers involved in the caregiving process. To ensure appropriate inclusiveness the data were collected through interviews (n = 10) included at the main city of Kosovo, namely Prishtina.

Regarding the Questionnaire, the design was prepared after many discussions, and in close cooperation with partners of the project. The design was prepared in English and later translated into the local language to be accepted and understood by the respondents. The interviews are organized face-to-face in order to have more opportunities for depth information about the caregiving process. The analysis is supported by Prof. Dr. Dashamir Berxulli, a Psychologist, and additionally by Dr. Feride Rushiti and psychologist Selvi Izeti. The process is organized initially by addressing the Age and Gender of the respondents followed by other dimensions: (i) Background of the Caregiver, (ii) Professional Commitment of the caregiver (iii) The impact of digital tools on the caregiving process.

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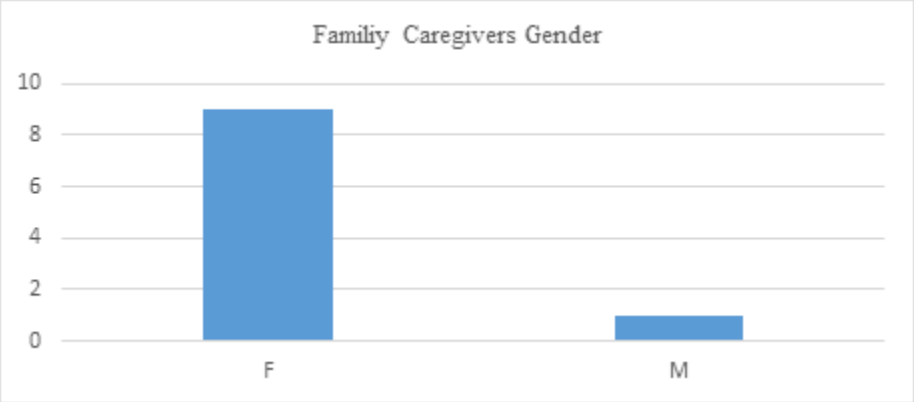

Figure 1: Gender of Family Caregivers

According to the analysis the majority, from 9 of 10 respondents are female, which could be also a reflection of the commitment of females to their families, namely parents.

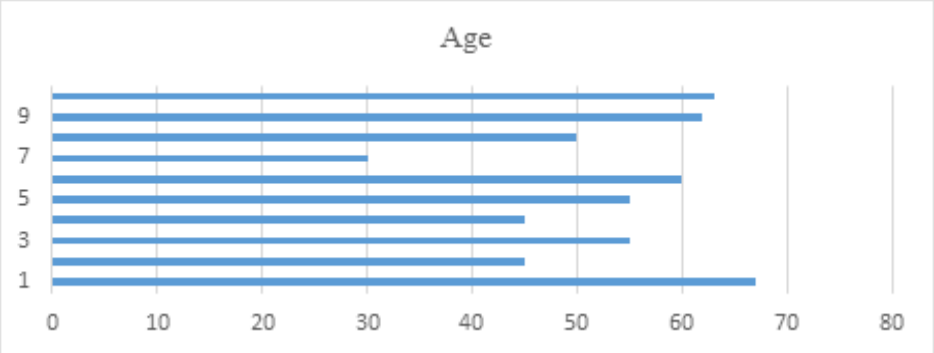

Figure 2: Age of Family Caregivers

Regarding the age of the family caregivers, most of them are mature, respectively from 50 to 60 years old. It seems that they are committed to helping their family members based on the fact that the best support for a patient is from their child. In addition, according to the WHO (World Health Organization) among the most important targets of the plan is Support for the Dementia Careers.

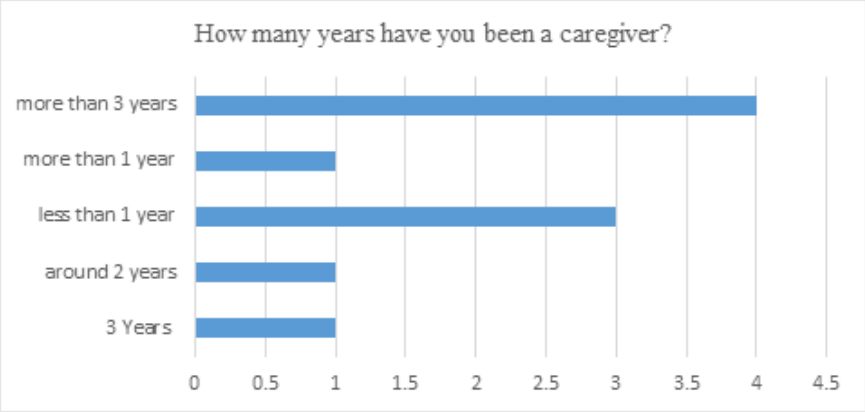

Figure 3: Experience as a Caregiver

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Analyzing the report, only 4 respondents out of 10 have more than 3 years' experience in the caregiving process. Most of the caregivers declared that they have usually other professions, but due to the need, they are involved in the caregiving process.

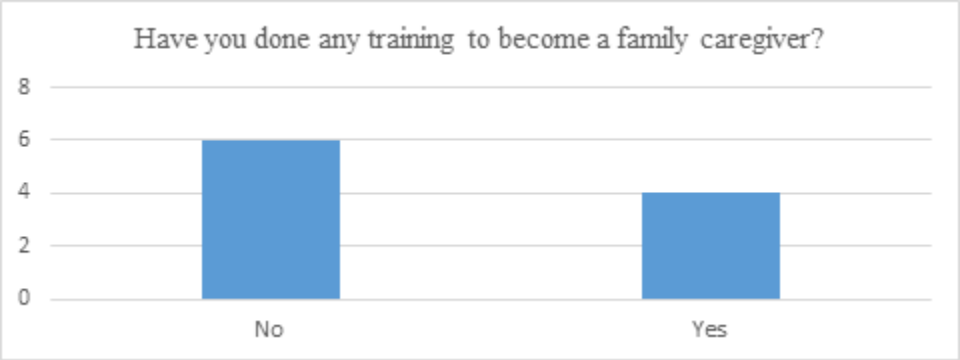

Figure 4: Training

Around 60% of the respondents didn't participate in any professional training, while most of them are in continuous consultation with their relatives which are doctors, psychologists, etc.

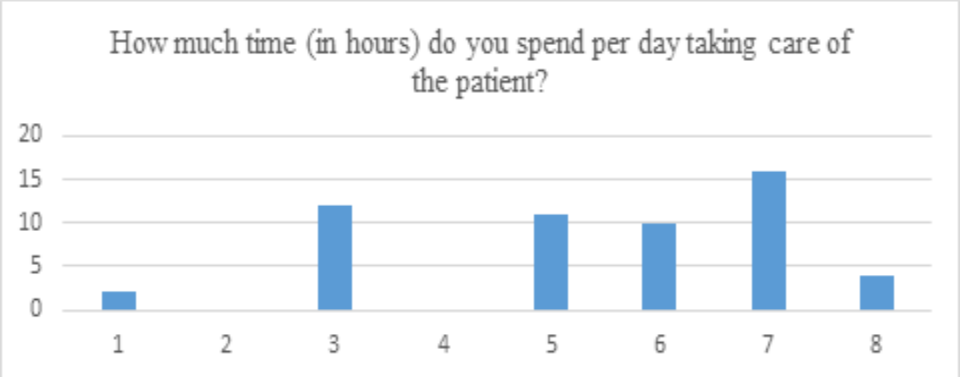

Figure 5. The time that you spent taking care of the patient

Based on the report most of the family caregivers are dedicated to their parents as they stay more than 3 hours. Based on the discussion with some of them we learned that they live in a similar accommodation, therefore they care for a long period.

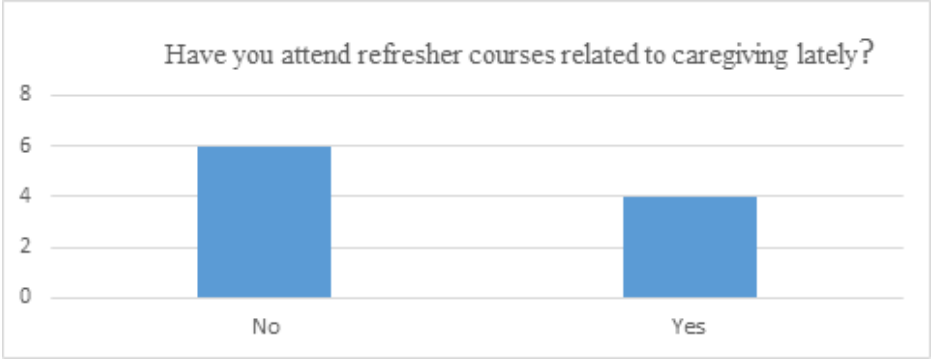

Figure 6: Courses and training

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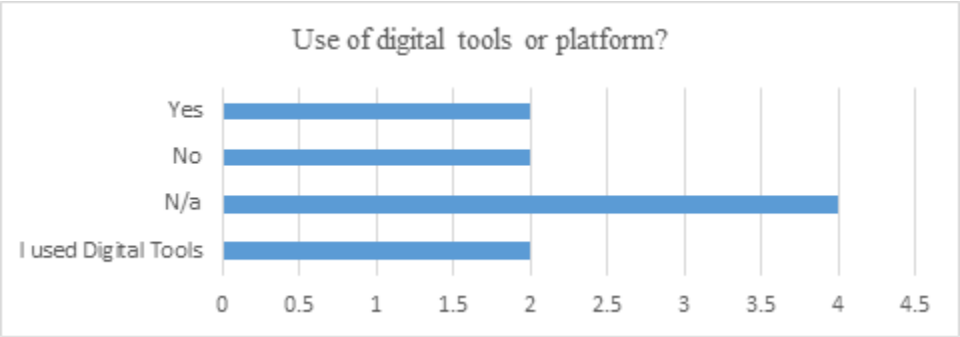

Figure 7: Use of Digital tools

According to the report, only 2 family caregivers used digital tools.

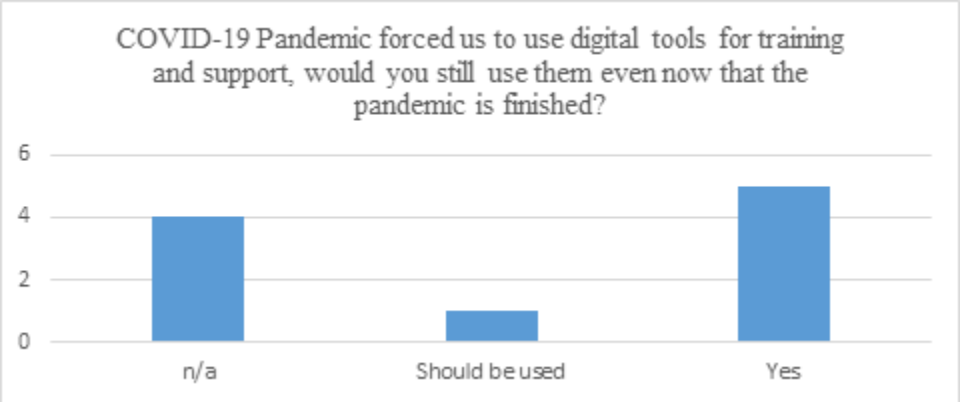

Figure 8: Covid 19 and use of digital tools

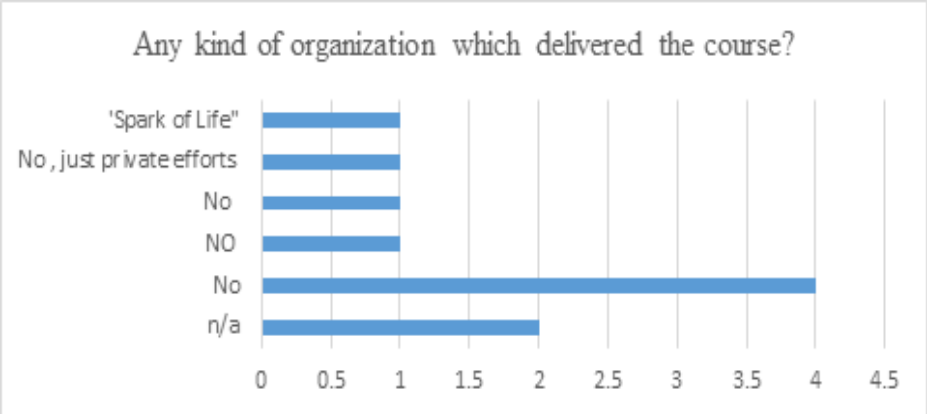

Figure 9: Organisations which supported Dementia Caregivers

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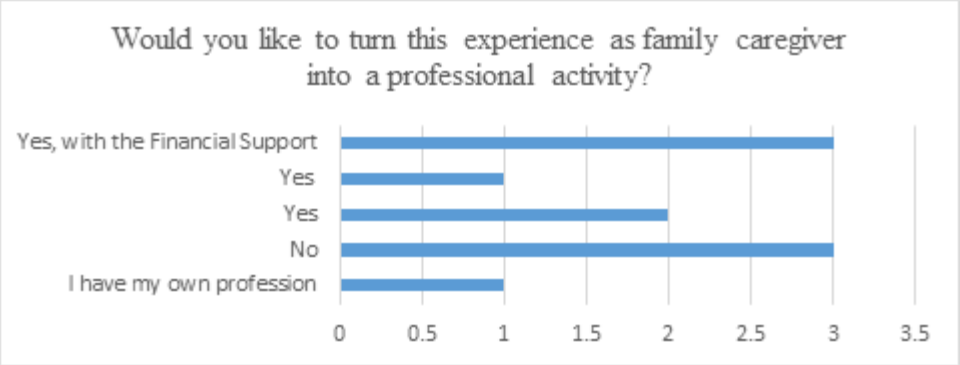

Figure 10: Caregiving as a Profession

Although Dementia Care is seen as a difficult profession, around 60 percent of the respondents declared that in case of financial support from the institutions, they could turn this experience into the profession.

Conclusions

An important step for the realisation of the "Digital Tools for Dementia Family Caregivers" project was the selection of focus groups in order to identify facilitators and barriers from the past experiences of caregivers and analyse methodologies and training activities adapted to the needs of families.

This report will be the basis for the Curriculum building.

The acquisition of data was realised through a specific survey, created and delivered to the partner associations of Italy (Dementia Care), Greece (Alzheimer Athens Association), Bulgaria (Foundation Compassion), and Kosovo (ECSA Kosovo). Several notable conclusions can be drawn from its results.

First of all, it can be appreciated that the majority of caregivers across the countries involved are predominantly female. This information reflects a cultural aspect in which women generally take on care-giving responsibilities within families. It is important to fight against this ideology and try to include more men in this field and ensure equitable support for all caregivers, regardless of gender.
The second matter has to do with the age range of caregivers: people from 30 to 70 filled the questionnaire but a significant portion of them fell within the 50-60 age bracket. This highlights the impact of demographic shift: due to longer average life expectancy, more people tend to suffer from dementia diseases and necessitate targeted interventions. It is crucial to carry out promotion actions of intergenerational solidarity in care-giving, in order to support older caregivers and to bring in younger people and the new generation.

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Regarding the duration of care-giving experience, it varies among participants, with a notable percentage providing care for more than three years. This emphasises the long-term commitment and dedication required of dementia caregivers (most of them are familiar ones) but at the same time it underlines the need for sustained help and adequate resources to prevent burnout and stress, ensuring this way the wellness of both caregiver and patient.

From the educational point of view, the survey results reveal a concerning lack of formal training among caregivers, particularly in Italy where none of respondents received any training to become caregivers. This means that more training programs must be implemented, made accessible to everyone and tailored to the specific needs of dementia caregivers. It would be better to include both traditional and digital modalities, in order to satisfy the diverse learning preferences of individuals and adapt to their technological proficiency levels.

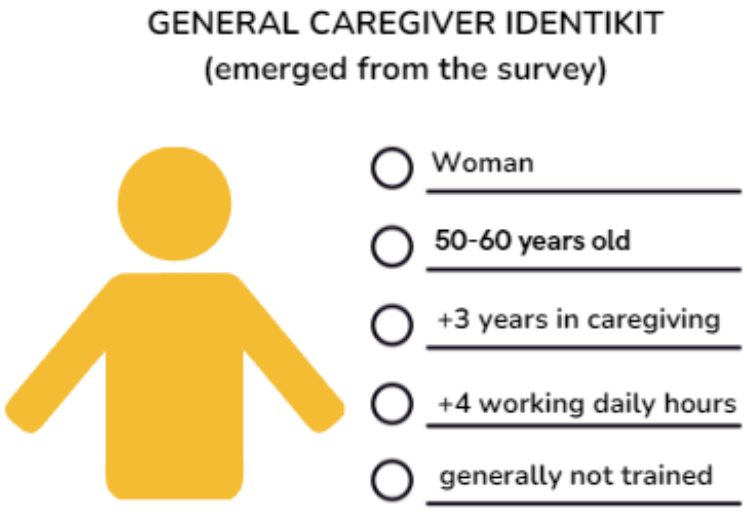

Figure 11: Caregiver's identikit

Talking about technology, Greece and Kosovo reported higher adoption rates of digital tools for caregiver training compared to Italy and Bulgaria. It is essential to recognise the potential of digital technologies in closing gaps between people and the access to training and education, giving them the possibility to develop their skills and abilities and improve and facilitate communication. This leads to a positive perception and feedback of digital tools among caregivers who have utilised them. Many have seen how useful and effective they can be in enhancing care-giving knowledge and upgrading their competences.

In conclusion, the survey results underscore the critical importance of supporting dementia caregivers through targeted training, education, and access to digital tools, in order to provide them with valuable resources, alleviate some of the burdens, increase their confidence and mental well-being.

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