IO1A4. COMPARATIVE REPORT – TRAINING CURRICULUM

EDUCATIONAL APP FOR CAREGIVERS
OF PEOPLE WITH DEMENTIA
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1. CURRENT SITUATION OF CAREGIVERS OF PEOPLE WITH DEMENTIA IN PARTICIPANT COUNTRIES

1.1. Current situation of caregivers in participant countries

In Denmark, working with people with dementia is considered a special task that requires trained staff, usually social and health care workers or social and health care assistants (the educations for these two professions are described below). It is very rare for relatives of persons with dementia to do the care task at home without help. Nursing staff are working with people with dementia in three different places (with different conditions): a) home care, b) 'ordinary' care centers and c) special dementia sections/dementia care centers.

In Spain Informal care is the most frequent way of care in the country: It is estimated that el 89,4% of dependent people receive family care. A combination of both formal and informal care is used by 11.9% of dependent population. Formal caregivers develop their performance according to the catalogue of LTC services in the country are developed in the System for Personal Autonomy and Care of Dependent Adults' (SAAD), mostly in home help services and residential care services. The formal caregivers are expert in auxiliary nursery care, social and health assistant in LTC facilities, social and health assistant in domiciliary care.

In Romania, Long-term care is focused almost exclusively on informal care. Changing social norms in recent years in the Romanian society, together with the phenomenon of massive emigration have led to an increase in the number of elderly people living alone, but would need care at home or in the residential system. Informal care, especially towards elderly people, is one of the most traditional form of care and welfare in Romania.

In Italy the actors directly involved in the organization of LTC services are municipalities through social services providers and local health authorities (Aziende Sanitarie Locali - ASL), with a further participation of the National Institute of Social Security (Istituto Nazionale di Previdenza Sociale - INPS) as a provider of the main cash benefits. While other players are involved in planning and funding these services – i.e. the central State, Regions and provinces. Additionally, in Italy a significant share of LTC expenditure is funded directly by households. Moreover, a large part of caregiving is still provided by informal carers, especially in regions where public services are less advanced and in families that cannot afford the cost of private services. Privately purchased home care, as mentioned above, is often provided by foreign persons. In Italy there are 2 main profiles in elderly care: •Domestic care workers: these workers are employed directly by families or through work agencies to take care of older persons at home, often in co-habitation or full time and Assistant nurses (Operatore SocioSanitario - OSS): that of OSS is a formal VET qualification recognized by Region.

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Current situation of caregivers in participant countries

DK	ES	IT	RO
In Denmark, working with people with dementia is considered a special task that requires trained staff. It is very rare for relatives of persons with dementia to do the care task at home without help.	The long-term care (LTC) for the elderly have traditionally been organized within the family. Formal caregivers developed their activities in home help services and in residential care services- The System for Personal Autonomy and Care of Dependent Adults' (SAAD) is a reference for the formal care.	The actors directly involved in the organization of LTC services are municipalities. Besides, a significant share of LTC expenditure is funded directly by households. Moreover, a large part of caregiving is still provided by informal carers.	Informal care, especially towards elderly people, is one of the most traditional form of care and welfare in Romania.

1.2. Caregivers' tasks

Denmark. Care Staff perform the following job functions of particular importance for people with dementia: Observation and early detection of disease, Reporting and planning, Basic care, Activity and socializing and Interaction with relatives. In Denmark, when staff try to create" sparkling moments", they draw on the competences they have gained through education and experience. However, there is a broad consensus that they need to acquire more competencies as they face major challenges in providing a person-centered care. A study shows that dementia skills, general skills and personal skills are needed.

In Spain, the most frequent tasks that formal and informal caregivers of people with dementia usually perform are the following: basic activities of daily living. Instrumental activities of daily living Emotional support activities. Supporting the dependent on health activities. Activities of daily living represent more than 56% of their work time, especially tasks focused on personal hygiene, dressing and undressing, etc. Regarding the qualification of formal caregivers, a minimum qualification (certificate of professionalism, Ministry of Labour) is required by LTC organizations in the following job post: caregivers, home caregivers, personal assistants and directors of care institutions.

- Basic activities of daily living. The goal is to maintain the autonomy and independence of dependent people: eating, dressing, grooming, moving around the house, toilet and incontinence problems, getting up / lying down.
- Instrumental activities of daily living. They are aimed at maintaining the autonomy of the person at home: shopping, preparing meals, other household chores, taking measures, controlling medications, etc.

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• Emotional support activities, as offering advice, counselling, companionship and trying to keep the dependent's network of social relationships. Keeping in mind that the disease makes it difficult or impossible to collaborate with the caregiver due to loss of speech, inability to resolve thoughts and emotions. Taking into account that the disease makes it difficult or impossible to collaborate with the caregiver because of the loss of speech, inability to resolve thoughts and emotions.
• Supporting the dependent on health activities that can be observed in the accompaniment of consultations and physical rehabilitation services and therapeutic activities. As well as in activities of control, monitoring and supervision of the prescribed medical treatments for the person with dementia.

In Italy, The domestic care worker supports a frail elderly person in daily life activities, temporary or permanently lacking of autonomy. OSSs have competences both a social and health care sector and work in close collaboration with other health professionals according to a "multi-professional approach". The training CV for OSS qualification is an example of programs proposed by the individual VET providers and approved by Regions. We want to underline that, even if there are specific guidelines defined at national level according to the State-Regions Agreement , there may be variations between the programs offered at regional level which includes didactic modules referring to specific issues, for a more suitable inclusion in the services. As you can see in the example below, there are no specific modules dedicated to dementia, but the topic is covered transversally across some modules.

Caregivers' tasks

DK	ES	IT	RO
Competency challenges A study shows that dementia skills, general and personal skills are needed.	The most frequent tasks are the following: Basic activities of daily living. Instrumental activities of daily living Emotional support activities. Supporting the dependent on health activities.	The domestic care worker supports a frail elderly person in daily life activities. OSSs have competences both a social and health care sector.	

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1.3 Caring for the person with dementia

Nursing staff in Denmark are working with people with dementia in three different places (with different conditions): a) home care, b) 'ordinary' care centers and c) special dementia sections/dementia care centers. Required skills are the following:

- Professional dementia skills (social-pedagogic educational approach): Being able to handle the following aspects: Focus on the whole person - the important life story, The person's day has 24 hours, Specific relational, competencies, The person's lack of self-understanding, Persons with challenging behavior, The unhappy person, Younger persons with dementia, Collaboration with relatives and Persons of non-Western background.
- General skills: Being able to deal with dilemmas (based on dementia knowledge), Being able to reflect and argue and Being able to formulate and convey significant observations.
- Personal skills: Being able to handle different needs all the time and having the courage of his/her profession and professionalism - regardless of the relatives' social status.

Spain. The figure of the caregiver is very important to ensure the quality of life of the patient with dementia. Caregivers must being prepared for facing with other complications that may arise associated with the disease, because as this disease evolves, symptoms such as difficulties in language, problems with movements and with decision-making appear, incapacitating and making the patient increasingly dependent. Caring for patients with dementia can create significant psychological, physical and financial pressure that can lead to caregiver syndrome. In most cases, the qualification required by LTC organisations to the caregiver are focused on support care activities indicated by the interdisciplinary team, physical care activities at dependent persons, socio-health care activities and psychosocial care activities. In general, we can see a lack of specific skills on caring for people with dementia, especially knowledge of the symptoms of the disease and attitude in the face of behavioral changes. With this in mind, stakeholders consider that a higher level of qualification on dementia could improve the quality of care and the wellbeing of the people with dementia.

Italy. Public LTC in elderly care includes three main kinds of formal assistance: community care, residential care and cash benefits. Italy does not have any national legislation concerning cash benefits to households in order to support the care of relatives, even if several Regions have developed these schemes so far. Italy does not have any national legislation concerning cash benefits to households in order to support the care of relatives, even if several Regions have developed these schemes so far. These cash benefits were originally thought of as a measure to support relatives – typically the partners or daughters/sons of the elderly person – while now they are mainly targeted at co-funding private home-helpers and formal caregivers. The majority of domestic care workers still do not have any formal qualification, even though the number of workers who have attended training as Family Assistants (or similar) is extending.

Romania. The provision of the care services is carried out according to the individualized plan of assistance and care, elaborated by specialized personnel, based on the recommendations made by the evaluation team. Informal and formal carers benefit from facilities and support services, allowances, counseling services, respite care services, according to the law, only for the people who are officially recognized as having a disability.

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Caring for the person with dementia: required skills

DK	ES	IT	RO
Three skills areas: • Professional dementia skills (social-pedagogic educational approach). • General skills: Being able to deal with dilemmas (based on dementia knowledge. • Personal skills: Being able to handle different needs all the time	Required skills are: • Support care activities indicated by the interdisciplinary team, • Physical care activities at dependent persons, • Socio-health care activities and • Psychosocial care activities. Not specific training in caring for people with dementia.	The majority of domestic care workers still do not have any formal qualification, even though the number of workers who have attended training as Family Assistants (or similar) is extending. Related to Oss Training CV, there are no specific modules dedicated to dementia, but the topic is covered transversally across some modules.	The provision of the care services is carried out according to the individualized plan of assistance and care, elaborated by specialized personnel, based on the recommendations made by the evaluation team

1.4. Rights of the person with dementia

The Convention on the Rights of Persons with Disabilities (UN, 2006) proposes to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free, and informed consent as well as being active members of society .

In Denmark, the approach to people with dementia is the person-centered. Person-centered care is based on a foundation of values and a philosophy of care that emphasize people's basic psychological needs. It is about meeting the individual where he or she is - and it is about understanding the symptoms and behaviours from the person's own perspective. Person-centered care requires an individual approach based on the person's life history and dignity.

In Spain, professional competency in the health care sector means the capacity to make responsible and balanced decisions. Competency is linked to the ethical principle of autonomy and to a horizontal doctor–patient interaction, far from ancient paternalistic relationships. It is contemplated in the Spanish law as the patient's right to be informed and to make free choices, particularly in cases of dementia.

In Italy, the Convention on the Rights of Persons with Disabilities (UN, 2006) has been ratified in Italy, among the first countries, in 2009. Therefore, its principles are embedded in the Italian legislation. The most significant law in Italy when it comes to legal rights of persons with

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disabilities (including those with dementia) is that introducing in 2004 the Support administration.

DK	ES	IT	RO
The approach to people with dementia is the person-centered, which requires an individual approach based on the person's life history and dignity.	Professional competency in the health care sector means the capacity to make responsible and balanced decisions	The Convention on the Rights of Persons with Disabilities (UN, 2006) has been ratified in Italy, among the first countries	

2. 2. TRAINING SYSTEMS AND PROGRAMS IN THE PARTICIPANT COUNTRIES.

2.1. Qualification of the caregiver of people with dementia

Denmark. The Danish Ministry of Education and Research describes the social and health care helper education as follows: "Through the education, you will learn to help and support the elder in such a way that the elder can live as good an everyday life as possible on his/her own. …. You will gain knowledge about the body, the most common diseases and about how you can prevent them. As a social and health care helper, you will also become able to communicate better and work together with the elderly and their next of kin." The education includes a basic training course, which takes place at a vocational school (SOSU Colleges) and lasts 20 or 40 weeks as well as a main course, which is structured as a mix between periods of internships and theoretical teaching.

In Spain, there is not a specific training CV for caregivers of people with dementia linked to the National Catalogue of Qualifications. In the field of non-formal education, we find a specific training CV for caregivers of people with dementia called *"Specialized Care for Alzheimer's Patients (250 hours)*[1]*"*. Regarding the qualification of formal caregivers, a minimum qualification (certificate of professionalism, Ministry of Labour) is required by LTC organizations in the following job post.
The Ministry of Education proposes an educational itinerary at secondary education level through the title of *Technician in Care for People in Dependency* (2,000 hours): Expert in auxiliary nursery care. This qualification are available at level 3 of the National Catalogue of Qualifications. On the other hand, the Ministry of Labour (SEPE[2]) –non-formal education system- proposes two professionals certificates: *Social health care for dependents in social institutions*

[1] Public Service of Employment, Spanish Ministry of Labour. SEPE: *–SANCO1- National file of specialties.*
[2] Europass supplement – SEPE SSCS0108 Social and health care for people at home.

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(450 hours[3]) – (facilities and *Social health care for people at home* (600 hours). These qualifications are available at level 2 of the National Catalogue of Qualifications.

In Italy, the domestic care workers still do not have any formal qualification at national level but just in some Regions and there are no legal requirements. The OSS qualification for formal home or residential care services has requirements defined at Regional level and varies a lot in relation to the specific Region. The training CV for assistant nurses is usually recognized as EQF Level 3 (although Emilia-Romagna Region recognizes it as EQF Level 4). To access the OSS training courses you must have completed compulsory school and be at least 17 years old. The training course is divided into 2 parts: a basic course which confers the OSS qualification and a specific and vocational course to achieve the higher qualification of OSSS (Specialized assistant nurses-Operatore SocioSanitario Specializzato). The training courses are annual for more than 1000 hours for the OSS qualification and an additional 400 hours if you wish to achieve the OSSS qualification. However, the number of OSS achieving the specialization qualification is very small and not all Regions offer the professional specialization course due to the low demand for OSSS profile. There are also professional retraining courses as OSS generally lasting 300 hours for people without this official qualification but with experience gained and documented in the socio-health /social assistance sector.

In Romania, no official curriculum has been implemented so far in Romania in the national educational system. Most of the vocational trainings for home care services for elderly are provided by private entities (NGOs and for profit companies), especially through European funds, but not exclusively, and are accredited by the National Qualifications Authority. It is important to mention that no face to face home care training focuses exclusively on patients with Alzheimer disease, and this situation generates vulnerabities for both .caregiver and care recipient.

[3] Europass supplement – SEPE SSCS0208 atención sociosanitaria a personas dependientes en instituciones sociales

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3 OPEN EDUCATIONAL RESOURCES FOR CAREGIVERS

In Denmark, Danish Dementia Research Centre (DDRC) is the one organization that publishes open educational resources in Denmark. The two examples presented below, the e-learning program and the app are well-known and recognized as reliable and valid information. At SOSU Østjylland, we use both in our teaching at the social and health care educations: A**BC Dementia e-learning and t**he App: knowledge about dementia.

Spain. In relation to the use of open educational resources in Spain, it is remarkable the e-learning platform of the National Institute for the Elderly (IMSERSO) which is freely available on the internet as well as some others e-learnings platforms (SEGG, Know Alzheimer, etc.), which provide caregiver with useful knowledge and skills for caring people with dementia.

Italy. For the purpose of this desk research we defined OER as "freely accessible digital learning resources on the topic of dementia" available in Italian language. Note that none of them is explicitly labelled as "openly licensed". Some of these resources are: A journey into the brain, Online training about Alzheimer and Dementia training for care professionals.

Romania. For patients with Alzheimer disease, even if there are currently no available face to face trainings for caregivers at national level, online educational resources have been developed by organizations like Habilitas, Romanian Alzheimer Society, EASI Romania and Ana Aslan Foundation. It is remarkable some European projects addressed to caregivers. CARERSUPPORT Project - innovative platform for informal carers' training, orientation and collaboration. CARE4DEM Erasmus+ project (2017-2020) aiming at developing a new and innovative model of mutual aid groups.

4. QUALITATIVE REPORT

Participants in the quality report:

Denmark:

- A Nurse and Health Anthropologist employed at a specialialized institution for people with dementia
- A Nurse and Teacher at Health Care Education. Former leader in home care service
- An Occupational Therapist at a dementia specialized nursing homes, Supervisor for health care students. Employed at a special institution for people with dementia with another ethnic background than Danish
- A Volunteer in elder care activities, DanAge
- An Occupational Therapist and Teacher at Health Care Education

Spain:

- A Sociologist, expert in Social Services. Spanish Confederation of Older People's Organisations. CEOMA
- A doctor, specialist in dementia. Spanish Confederation of Older People's Organisations. CEOMA
- An Expert on aging policies. Spanish National Committee of People with Disabilities

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Representatives, CERMI

- A Social worker, responsible of the program of docmiciliary care. Social Services Municipality of Toledo.
- A Psychologist, Representative of the association. Ciceron Association. Toledo.
- A Psychologist, director of a nursing home. Ciceron Association. Toledo.

Italy

- A Psychologist at a residential facility for the elderly
- An Expert and manager of the care area at a cooperative that deals with assistance to the elderly
- An Expert in training courses for OSS at a professional training centre
- A Psychologist responsible for the scientific coordination of the non-self-sufficient area at a cooperative that carries out socio-health and educational services
- A Nurse freelancer in the home care sector

Romania

- Romanian Society for Alzheimer Cluj Napoca (Nord-West Region),
- Romanian Society for Alzheimer Constanta (South-East),
- Community Support Foundation Bacau (Nord-East),
- General Directorate of Social Assistance and Child Protection District 6 Bucharest (capital region)
- General Directorate of Social Assistance and Child Protection District 1 (capital region).

Block 1. Current situation of caregivers of people with dementia

Denmark. The experts agreed that even though care staff in nursing home and home care are educated, they need more competences in the area of dementia. The informal caregivers in Denmark are mostly spouses because the generation live separately. Informal care is mostly in the early stages of dementia. When people with dementia get more affected, they usually move to a care facility. There are many support opportunities in Denmark to relieve the relatives, like Day care Centers. Anyway, the relatives to persons with dementia in general are more ill than other relatives.

Spain. There is a precarious situation related to the qualification of caregivers for caring people with dementia. In general, there is a shortage of knowledge about the science of caring dementia patients. Some areas for improvement are: Understanding the meaning of BPSD. Functional analysis of BPSD. To teach caregivers about the use of the ABC Model (Antecedent-Behavior-Consequence). Battle in the bathroom.-Prevention and management of behavioural disturbances. Stages of dementia and their correlation with the needs of the patient. Premorbid personality and its value to understanding BPSD.

Italy. It's recognized that Italy lacks a common line of training and practice, which may involve to different sort of care provided, based to the different experience acquired by each operator and / or by the training that, compulsorily and annually, the care services have to offer to staff. Some aspects for improvement; •it is lacking in relational aspect and approach to the user

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suffering from dementia. There is lack of knowledge with respect to the behavioral and psychiatric disorders associated with dementia and communication with the user and his family. The focus must be on relational care, and not only practical assistance and hygiene. It's underlined how important is to take advantage of an approach to global assistance, which considers not only the assistant as the central point but also the structure, the family and above all the care recipient.

Romania. Currently, caregivers of people with dementia do not have sufficient knowledge and skills to care for them. Training courses should develop both activities aimed at the physiological needs of the patient, management of acute situations that may occur, how to communicate with the patient, as well as specific activities for patients with dementia (social activities, games, practical activities, etc.). But first of all, caregivers must understand what this diagnosis represents and that most of the patient's attitudes is determined by the disease." The knowledge and the skills of the caregivers reach a satisfactory level. In the early stages of the disease, they do not know or deny the existence of the disease, afterwards most are not prepared for such a challenge and their reactions/ attitudes towards the sick person are inadequate. Caring for and respecting the dignity of those close to them requires specific knowledge and information, accessible at times of heavy pain and suffering.

DK	ES	IT	RO
Even though care staff in nursing home and home care are educated, they need more competences in the area of dementia.	There is a precarious situation related to the qualification of caregivers for caring people with dementia.	It's recognized that Italy lacks a common line of training and practice, which may involve to different sort of care..	Currently, caregivers of people with dementia do not have sufficient knowledge and skills to care for them.

Block 2. Content for a training CV proposal.

Despite considering all the content as relevant, we can see which content has been considered more important in relation to the current situation of the qualification of caregivers in the participant countries:

Denmark. Most experts agreed the above topics are already in the curriculum of the Danish care giving education. However, some of them are optional. More should be mandatory. They considered with a low level of priority the following: M7. Supporting the family of people with dementia In Denmark the family is not the primary caregiver of the person with dementia.M8. Institutional resources. The care system in DK is tax financed and institutions are public

Spain. Experts agreed on the following content. M5. How to approach someone with dementia? Empathy, affection and knowing how to respect the individual's wishes, needs and preferences of people with dementia are very important contents for a training CV.M7. Supporting the family of people with dementia. The family stays in contact with the caregiver, this connection is important if the emotional bond exists and is positive. The attitude of the family will determine

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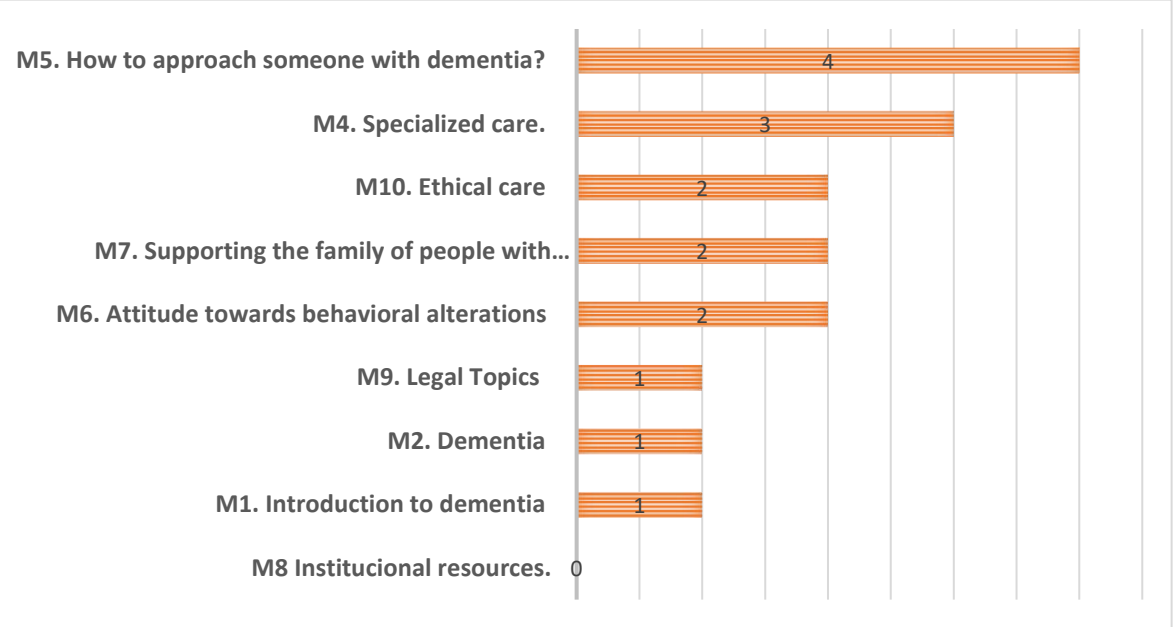
the evolution of the patient and the type of care for the patient in the future. I suggest explaining which respite measures for caregivers we can have. M10. Ethical behavior at workplace. All actors in long-term care must always take into account the ethical principles of care and the human rights of people with dementia.

Italy. Experts agreed on the following content: M4. Specialized care. It's a module related to the role and tasks of the caregiver to which add the relationship with the user during assistance.M4: how to alleviate the effects of restraint, implementing this type of activity by simulating situations… M5. How to approach someone with dementia? All experts agree that this is the module that should be further studied in the whole program, highlighting that with regard to the practical aspects of care and assistance, the OSSs are skilled while they have limitations in relationship skills. A connection has been detected between the M5 and M9 which underlines how in approaching a person, even more if in a state of serious difficulty in expressing one's will, there must be ethical behavior.

Romania. Experts agreed on the following content: M3. Be aware of aggravating factors. "Here we enter the area of prevention which is important and should be given a wider space." M4. Specialized care. "We are approaching practical issues of particular interest. They need to be treated extensively."M5. How to approach someone with dementia? "The person centered approach is the key to the intervention."M6. Attitude towards behavioral alterations. "Changes in behavior, respectively the opposite of what was the person with dementia, is one of the biggest challenges. The focus should be on the efficient management of crisis situations."

Bar graph .Rough approximation to the priorities of learning content in participant countries



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Comments about training content

Training modules	Spain	Romania	Denmark	Italy
M1. Introduction to dementia	Dementia is a syndrome that must be understood by caregivers.	Opinions from specialists: "Usually the problem of dementia is known. It is more experienced at stress levels and exhaustion for those who do not experience such experiences. In short, this introduction should be concise."	Basic knowledge about dementia is very important for anyone dealing with a person with dementia.	2 It's important to know the basic notions of dementia and it's necessary to start by explaining the functioning of memory, the aspects that concern it and all the various pathologies that can be related to diseases of cognitive degeneration, as well as to previous pathologies that add up to the cognitive problem (P2). However, they highlight that one should not focus too much on the medical aspects since it's beyond their competence (P1), while a participant advises not to go too deep into the part of the nervous system as it is not necessary (P4).
M2. Dementia	It is the same content that M1.	2Opinions: "It should be focused more on practical aspects, and less on theory"	It is important to know about the different forms of dementia in order to make an individual care plan	2Provide notions on the various types of dementia by emphasizing on the fact that they may have different beginnings, manifestations and courses with an approach not related to diagnosis, but to results related to the single type of dementia that must be recognized and managed. It is therefore more important to know the behavioural aspects than the health aspects of dementia (P2), explaining them in a simple and clear way so that they are easily understandable and that this knowledge can be used in practice (P5). Insert notions on non-healthcare and non-pharmacological treatment, based on the relational aspect which is what the operator can make the difference (P1, P2, P4).

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Training modules	Spain	Romania	Denmark	Italy
M3. Be aware of aggravating factors	--	1 Opinions: "Here we enter the area of prevention which is important and should be given a wider space."	Necessary in order to reduce the level of conflict with the persons with dementia	It is important to know the aggravating factors that influence the assistance, which aspects to pay more attention to and which capacities are lacking (P5). The OSS, rather than dealing with the prevention of complications, must be able to grasp the symptoms and avoid aggravating factors, both physical and behavioural (P2). He must therefore be able to identify and decode the signals, comparing them to those that are usual to understand if there may be something unusual that conveys symptoms or pain. The recognition of suffering is very important because people with severe dementia do not manifest it clearly, especially if the caregiver is not known (P2, P4). Many aspects related to dementia are missing, such as those related to the perception of hunger and the sense of satiety (P4).
M4. Specialized care.	It could be appropriate for other professionals. It seems to be an interesting module. Some content on the adapted housing and its equipment is lacking. Houses need to be accessible and safe.	1 Opinions: "We are approaching practical issues of particular interest. They need to be treated extensively."	Necessary in order to be able to support the identity of the persons with dementia in accordance with their life history	It's a module related to the role and tasks of the caregiver to which add the relationship with the user during assistance. When talking about tools, address the issue of restraint tools, focusing a lot on the importance of alleviating the effects of restraint and above all by thinking about why the decision is made to use them (P2). Specific assistance must be provided on the basis of the indications and information provided and continuously updated by the doctor (P5). During assistance, it is important that the operator communicates with the person, even just through looking, trying to make him understand what he is doing or what he is going to do (P4). It should be put after the M5 because specific assistance should be studied and organized on the basis of communication possibilities and information, such as a person's personality and history, which must be clear before tackling this module (P2).

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Training modules	Spain	Romania	Denmark	Italy
M5. How to approach someone with dementia?	Empathy, affection and knowing how to respect the individual's wishes, needs and preferences of people with dementia are very important contents for a training CV.	Opinions: "The person centered approach is the key to the intervention."	Necessary in order to ensure the life quality of the person with dementia, to make him/her feel included, accepted and loved.	All experts agree that this is the module that should be further studied in the whole program, highlighting that with regard to the practical aspects of care and assistance, the OSSs are skilled while they have limitations in relationship skills. The collaboration, updating and participation of the family and the user (wherever possible), as well as of the whole team that deals with the case is essential because it allows to have a lot of information about the person in order to build a relationship and an operational and communicative strategy. To encourage an increase in the relational skills with the user, it is suggested to make many practical examples, by experimenting with situations that have been very effective for the purpose of reflection and understanding. For better communication it is essential to develop and use all communication channels (gaze, tone, ability to understand if contact is welcome or not) and one's empathy (P2). It's necessary to consider the communicative difficulty, so accepting even not to actually communication in favour of a simple exchange of sentences (P4) and not to expect consistent answers. Must be prepared for the frustration that can derive from it, continuing to communicate without changing the tone of voice or facial expression, maintaining eye contact and if desired seek contact (P3). It's essential to encourage awareness of personal limits through a self-assessment of emotions and above all understand when to ask for help and support (P4). Communication and training in this regard should be practical, through role playing activities, videos and practical examples (P1).

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Training modules	Spain	Romania	Denmark	Italy
M6. Attitude towards behavioral alterations	To know how to approach someone with dementia is essential for his/her quality of life and prevention of Behavioral and Psychological Symptoms of Dementia (BPSD). The topic of memory loss is lacking.	Opinions: "Changes in behavior, respectively the opposite of what was the person with dementia, is one of the biggest challenges. The focus should be on the efficient management of crisis situations."	Necessary in order to be able to identify the underlying causes of the behavior of the person with the dementia	--
M7. Supporting the family of people with dementia.	The family stays in contact with the caregiver, this connection is important if the emotional bond exists and is positive. Families usually have the information needed for good care of their relatives. The attitude of the family will determine the evolution of the patient and the type of care for the patient in the future. I suggest explaining which respite measures for caregivers we can have.	1/3 Opinions: Here we are talking about the second, third if not more patients as a side effect. I would emphasize the stigmatization of people with dementia and their members.	In Denmark the family is not the primary caregiver of the person with dementia	The relationship with families is sometimes a challenge for OSSs, so that giving them tools to manage this relationship could respond to their need and these proposals are valid tools to help them to read and understand the discomfort, difficulties and suffering that the relatives may have to face (P1). However, this structured module places the family as an overburdened actor that must be supported, thus giving it connotations of passivity, but not by highlighting and not offering the perspective that the family could also be a resource and an ally (P2). It's essential that the family member becomes involved in everyday life and in the remaining skills to do nice things together, also to alleviate anxiety or guilt due to the fact that the person cares for a third party (P4).

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Training modules	Spain	Romania	Denmark	Italy
M8 Institutional resources.	Proper caring for a person with dementia means requesting and using the necessary resources for each person.	1/3 Opinions: "The existing ones should be mentioned and the development of services encouraged."	The care system in DK is tax financed and institutions are public	Useful module to have information to provide for support to the family and family caregiver if they need a mutual aid group, associations of relatives and specific residences, more than knowledge to be provided to patients. However, it's highlighted that there are other professional figures or the service itself indicated to provide this information.
M9. Legal topics.	This module is especially important. The family of the patient as well as long-term care services should always anticipate the necessary protection: self-care, life annuity, disability, legal representation, etc.	½. Opinions: "Very important aspects related to guardianship signing legal documents (See sale-purchase contracts, wills, etc.)"	The knowledge about legal topics is necessary to ensure the rights of the person suffering from dementia	According to experts, this module should not be deepened too much because these are other professional tasks rather than related to OSS performance (P5). However, attention should be paid to make them aware of which are the support figures for the person with dementia (support administrator, tutor) and what their duties are (P2). Instead, it's important to know the legal aspects of reference to OSSs' duties and responsibilities, which would also help them not to worry about the occurrence of unpleasant facts or accidents and in this sense, it would take a higher priority (P4).
M10. Ethical behavior at workplace.	All actors in long-term care must always take into account the ethical principles of care and the human rights of people with dementia. Ethical aspects are always necessary.	1-2 Opinions: "Ethical issues must prevail if we are to respect the dignity of people with dementia."	Necessary in order to ensure the integrity of the person with dementia. Necessary to ensure a good working environment for the professionals.	According to experts, this module should not be deepened too much because these are other professional tasks rather than related to OSS performance (P5). However, attention should be paid to make them aware of which are the support figures for the person with dementia (support administrator, tutor) and what their duties are (P2). Instead, it's important to know the legal aspects of reference to OSSs' duties and responsibilities, which would also help them not to worry about the occurrence of unpleasant facts or accidents and in this sense, it would take a higher priority (P4).

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Training CV. Specialized care for people with dementia

Keeping in mind the comments and suggestion of the experts, the training CV will include the following content.

TRAINING MODULES	LEARNING UNITS	TRAINING CONTENT
M1. Introduction to dementia	U1. The study of the human nervous system.	• The nervous system • Most frequent pathologies of the human nervous system.
	U2. What is dementia?	• Basic notions of dementia. • Symptoms of dementia. • Functioning of memory.
	U3. Other explanations of cognitive impairment	• Previous pathologies that add up to the cognitive problem.
M2. Dementia	U1. Common types of dementia:	Beginnings, manifestations and courses. • Alzheimer's disease • Vascular dementia • Lewy Body dementia • Frontal- temporal lobe disease
	U2. Diagnosing dementia.	• A correct diagnosis is important • Informing the person with dementia • The stages of dementia: Clinical dementia rating (CDR) • Living well. A dementia strategy: Better knowledge, early diagnosis, Services.
	U3. Medical treatment:	• Notions on non-healthcare and non-pharmacological treatment. • Relational aspect which is what the operator can make the difference
M3. Be aware of aggravating factors	U1. Physical condition: prevention of complications and conflicts.	General complications of dementia To recognize physical symptoms and avoid aggravating factors: • Respiratory. • Dental status • Dysphagia • Urinals and obstipation • Dermatological • Pain • Malnourishment
	U2. Senses and perception: prevention of complications and conflicts.	To recognize senses and perception needs and avoid aggravating factors: • Hearing, Seeing, Tactile, Smell and Taste • Perception of hunger and the sense of satiety
M4. Specialized care.	U1. Identity of the person with dementia and relational aspects related to basic activities of daily living.	• Meal • Personal hygiene • Dressing • Other activities of daily living
	U2. Technology, aids, housing and equipment.	• Technology and aids • Adapted housing and its equipment

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M5. How to approach someone with dementia?	U1. Person-centred care	• The person-centred model: P + B + H + N + S (Tom Kitwood) • Status of the neuropathological impairment • Status of health • Biography and life story • Personality • Environment, social psychology • Planning the supporting
	U2. Psychological needs	• Psychological needs • Comfort, Identity, Occupation, Inclusion, Attachment, Love • Practical aspects of care and assistance
	U3. Tips, how to communicate and interact with people with dementia	• Relationships skills. (Keeping in mind the communicative difficulty) • Empathy, affection and knowing how to respect the individual's wishes. • Practical examples.
M6. Attitude towards behavioral alterations	U1. Prevention and management of Behavioral and Psychological Symptoms of Dementia (BPSD)	• Behavioral and Psychological Symptoms of Dementia (BPSD) • Causes, prevention and management of BPSD: • Behavioral symptoms: Aggression, agitation / agitation, uninhibited behavior, irritability, repetitive routines. • Psychotic symptoms: Hallucinations and delusions • Affective symptoms: Depression / dysphoria, anxiety, apathy, euphoria • Vegetative symptoms: changes in appetite or/and sleep disorders
	U2. Tips, how to communicate and interact with people with challenging behavior	• Tips, how to communicate and interact with people with challenging behavior
M7. Supporting the family of people with dementia.	U1. De-stigmatizing Dementia	• Family problems caused by dementia • Family restructuring. • Family as a resource and an ally. • It is possible to live well with dementia.
	U2. How to cope with caregiver's syndrome.	• Caregiver needs • Family member becomes involved in everyday life
M8 Institutional resources.	U1. Institutional resources.	• Assistance, health and economic benefits of Public and Private Institutions. • Associations of relatives of dementia. • Foundations. • Support groups. • Residences
M9. Legal topics.	U1. Protection of people living with dementia	• Incapacitation • Tutelage. Knowledge of the corresponding current legislation.
M10. Ethics of care	U1. Human Rights of people living with dementia.	• Prevention abuse and mistreatment • Rights of the people with dementia
	U2. Ethics of care	• Freedom as a principle of action. • Ethical principles in psychosocial interventions for people with special needs • Ethical considerations around the family

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Block 3. Training CV and national vocational training systems. SWOT analysis

In the AppForDem project, we will propose an international curriculum together with some learning resources for caregivers of people with dementia. In your opinion, it is necessary a training CV for caregivers of people with dementia in national vocational training systems?

Spain. All the experts opinions consider positive and necessary a training CV for caregivers of people with dementia in the national vocational training systems. It would generate higher opportunities of employment to the formal caregivers. We must keep in mind that Dementia is one of the main causes of dependence and disability at older ages. Therefore, knowledge on dementia is very important for informal and formal caregivers. Improving the qualification level of caregivers will ensure the quality of life of people living with dementia.

Italy. All the experts who offered their contribution agree that a specific training program on the topic of dementia must be included in the vocational training systems, considering that the main problems related to aging are those related to cognitive impairment, after cardiological and neurological, and that many OSSs, once qualified, find work in the field of care to people with dementia.

Romania. All of the specialists interviewed consider that the training CV proposal could be implemented in national VET programs and perceive it as a valuable resource for caregivers working with dementia caretakers.

When asked about the utility of a training CV for caregivers of people with dementia in national vocational training system, in terms of strengths, weaknesses, threats and opportunities, the answers were the following:

Strengths:

- A new approach for this type of training, it fills a gap at the national level
- Covers many important aspects of Dementia,
- E-learning and distance training methods to reduce costs related to training times and places
- Facilitates social inclusion.
- Flexibility – you can take the cause whenever you have the time
- It is positive and necessary a training CV for caregivers of people with dementia in the national vocational training systems. It would generate higher opportunities of employment to the formal caregivers.
- To provide various knowledge that allow to analyse and collect information on various aspects, helpful to provide better assistance
- Focus on the ethical and legal aspects
- Gives a good understanding of challenging behaviors and the reasons behind it
- Help caregivers cope with the challenges of long-term care;
- Illuminates the situation of the caregivers and their challenges
- Improves the level of competences of the dementia care givers
- Increases self-esteem;
- Not abstract notions, but with concrete references to working realities
- Provides useful information;
- Reduces stress and physical, mental and emotional exhaustion;
- Strong technical information;
- The social workers can become vector for transmitting the information

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- To give the notion, if it is missing, and offer the operator the possibility of a space to stop and think and consolidate the already known practices
- We can create a resources library in the universities, research institutions, etc.
- We can ease the challenges that this disease raises;

Weaknesses:

- Does not allow exchange of experiences (because it is not Face-to-face)
- No social interaction (because it is not face-to-face)
- Requires IT competences (which could be a challenge for the target group in question)
- Official learning courses do not consider sufficiently the main practical aspects of caring for people with dementia.
- Caregivers have a lack of specific content related to BPSD: content should be explained in simple everyday vocabulary.
- A comprehensive approach will improve the caregiver's performance in the workplace.
- To insist and be redundant on already known and consolidated topics or practices
- The online course does not allow interaction, direct communication or socialization with trainers and other caregivers.
- The caregivers do not know how to access the information; they are not used to work online.

Opportunities:

- Being able to see what can be presented daily in the work area
- Care staff is under time pressure
- Change the perspective and attitude of the caregivers on the patient.
- Dependence of the web provider
- Developing inclusive support groups in areas that have not developed such services.
- E-learning as an opportunity to develop digital skills, especially for situations where it is the only way to communicate or work
- Employers do not give priority to re-training /in-service training
- For the piloting – widening the sphere for other professional categories as well.
- Have the basis for developing a reasoned operating system
- Improving the relationship with the family
- Innovation in care services allowing development and enrichment of the professional role
- Flexibility;
- -It gives the carers the opportunity to develop their knowledge and skill.
- It is possible to see a change in the attitude of the community towards people with dementia and their caregiver.
- No interest and motivation among care givers for re-training
- Offer practical group activities as an opportunity to develop a reflective community approach, especially useful for dealing with difficult situations and avoiding a sense of loneliness
- Practical and experiential training
- The material does not fit the target group – too high or too low level
- The national contexts are different so the training program does not fit to all countries •A training CV would facilitate a homogenization and rationalization in the use of the technical and material resources available in each country. It would motivate the updating and permanent renewal of content, based on a training CV developed in the international context´
- There is a lacking training programs for the social services providers.

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- Training of facilitators.

Threats:

- A training CV in each country would imply specific requirements for labour mobility of professionals caregiver among EU countries.
- Can be used not only in VET but in courses for NGOs
- Changes the approach to dementia
- Don't find consistency between the contents offered in the training proposal and the role and tasks that the professional is called to fill, understanding what the primary tasks are (i.e. practical assistance) and the tasks that complete the professional profile (i.e. the relational aspects)
- Due to the pressure and daily burdens as well as the physical, mental, emotional exhaustion, caregivers may not have the time or willingness to take and complete such a course;
- Ensures a better care for the person with dementia
- High level of the course
- Not to retain so much technical information.
- Raises the awareness of the importance of the involvement of relatives in professional care
- Raises the awareness of the need of assistance from volunteers
- Raises the status of dementia care (certificate)
- Sense of frustration due to seeing detachment between theory and reality.
- The physical and mental overload of informal care has implications for the caregivers' health.

Other considerations from experts.

It was highlighted by the participants that the program is generally very focused on the health aspect rather than on the social and relational one, to which instead it would be appropriate to devote more attention because it is what has been found to be most lacking in the preparation of the OSSs.

In the philosophy of the training CV, it is important to highlight an approach de-stigmatizing dementia. It is necessary to transmit that it is possible to live well with dementia. The objectives of care should focus on achieving that a person with dementia can live well, with a good quality of life.

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5. SUMMARY

Informal care (or family care) constitutes a significant share of the total long-term care (LTC) provision in Italy, Spain and Romania. In Demark, working with people with dementia is considered a special task that requires trained staff. It is very rare for relatives of persons with dementia to do the care task at home without help.

In all the cases, the tasks developed by caregivers are focused on Basic and instrumental activities of daily living, emotional support and activities, as well as supporting the dependent on health activities.

Concerning the qualification required in LTC activities, In Denmark, dementia skills, together with general and personal skills are needed to ensure the quality of care and dignity of the person. In Spain, the competencies required to formal caregivers are support care activities indicated by the interdisciplinary team, physical care activities at dependent persons, socio-health care activities and psychosocial care activities. In Italy, related to vocational training programs, there are no specific modules dedicated to dementia, but the topic is covered transversally across some modules. In Romania, the provision of the care services is carried out according to the individualized plan of assistance and care, elaborated by specialized personnel.

Related to the human rights of people with dementia, In Denmark it is considered that the approach to people with dementia is the person-centered, which requires an individual approach based on the person's life history and dignity. In participant countries, professionals recognized the Convention on the Rights of Persons with Disabilities (UN, 2006)

The Ministry of Education in Denmark considers that “through the education, the students will learn to help and support the elder in such a way that the elder can live as good an everyday life as possible on his/her own”. In Spain, a certificate of professionalism, from the Ministry of Labour, is required to work in long-term care activities. In Italy, the domestic care workers still do not have any formal qualification at national level and the training CV for assistant nurses is usually recognized as EQF Level 3. In Romania, no official curriculum has been implemented so far in the national educational system. Most of the vocational trainings for home care services for elderly are provided by private entities.

In the qualitative report, all experts considered very important the vocational education and training for caregivers of people with dementia. In Denmark, it is recognized that “even though care staff in nursing home and home care are educated, they need more competences in the area of dementia”. In other participant countries experts agreed on the lack of a specific qualification for caring people with dementia.

Regarding a proposal for a training CV “Specialized care for people with dementia”, experts agreed on the importance of all the contents, they highlighted the importance of the modules. How to approach someone with dementia, specialized care, Attitude towards behavioral alterations, ethical care and supporting the relatives of the patient.

Concerning a transnational training CV, experts considered the following strengths: the Training CV is a new approach for this type of training. It fills a gap at the national level; it covers many important aspects of Dementia and Help caregivers cope with the challenges of long-term care. E-learning and distance training methods to reduce costs related to training times and places.

Experts also considered the following weak points: the online course does not allow interaction, direct communication or socialization with trainers and other caregivers and highlighted that caregivers do not know how to access the information; they are not used to work online. As an opportunity they considered that it would motivate the updating and permanent renewal of content, based on a training CV.

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As a conclusion, an expert considered that in the philosophy of the training CV, it is important to highlight an approach de-stigmatizing dementia. It is necessary to transmit that it is possible to live well with dementia.

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7. GLOSARY OF TERMS

TRAINING PATH. Sum of learning sequences followed by an individual to acquire knowledge, skills or competences. Or Set of related education or training programmes provided by schools, training centres, higher education institutions or VET providers, which eases the progression of individuals within or between activity sectors.

UNIT OF LEARNING OUTCOMES (ECVET). Component of a qualification, consisting of a coherent set of knowledge, skills and competences, that can be assessed and validated; OR Set of knowledge, skills, and/or competences which constitute a coherent part of a qualification. A unit can be the smallest part of a qualification that can be assessed, transferred and, possibly, certified. It can be specific to a single qualification or common to several qualifications.

LEARNING OUTCOMES / LEARNING ATTAINMENTS. Set of knowledge, skills and/or competences an individual has acquired and/or is able to demonstrate after completion of a learning process, either formal, non-formal or informal. Statements of what a learner knows, understands and is able to do on completion of a learning process, which are defined in terms of knowledge, skills and competence.

ECVET. European credit system for vocational education and training (ECVET). Technical framework for transfer, validation and, where appropriate, accumulation of learning outcomes by individuals, to achieve a qualification. ECVET tools and methodology comprise a description of qualifications in units of learning outcomes with associated points, a transfer and accumulation process and complementary documents such as learning agreements, transcripts of records and ECVET users' guides.

EQF. EUROPEAN QUALIFICATIONS FRAMEWORK FOR LIFELONG LEARNING (EQF). Reference tool for describing and comparing qualification levels in qualifications systems developed at national, international or sectoral levels.
Comments:

- the EQF's main components are a set of eight reference levels described in terms of learning outcomes (a combination of knowledge, skills and/or competences) and mechanisms and principles for voluntary cooperation;
- the eight levels cover the entire span of qualifications from those recognising basic knowledge, skills and competences to those awarded at the highest level of academic, professional and vocational education and training;
- EQF is a translation device for qualification systems.

MUTUAL RECOGNITION OF QUALIFICATIONS. Recognition by one or more countries or organisations of qualifications (certificates, diplomas or titles) awarded in (or by) one or more other countries or organisations.

CERTIFICATE / DIPLOMA / TITLE. An official document, issued by an awarding body, which records the achievements of an individual following an assessment and validation against a predefined standard.

COMPETENCE. Ability to apply learning outcomes adequately in a defined context (education, work, personal or professional development) or Ability to use knowledge, skills and personal, social and/or methodological abilities, in work or study situations and in professional and personal development.

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Comment: competence is not limited to cognitive elements (involving the use of theory, concepts or tacit knowledge); it also encompasses functional aspects (including technical skills) as well as interpersonal attributes (e.g. social or organisational skills) and ethical values (Cedefop[4]).

CURRICULUM. Inventory of activities related to the design, organisation and planning of an education or training action, including definition of learning objectives, content, methods (including assessment) and material, as well as arrangements for training teachers and trainers. Comments: the term curriculum refers to the design, organisation and planning of learning activities while the term programme refers to the implementation of these activities.

TRAINING COURSE PLANNING AND DESIGN. Set of consistent methodological activities employed in designing and planning training initiatives and schemes against objectives set. Comments: training course planning and design includes analysis of training demand and needs, project design, coordination and implementation monitoring as well as assessment of training impact.

VALIDATION OF LEARNING OUTCOMES. Confirmation by a competent body that learning outcomes (knowledge, skills and/or competences) acquired by an individual in a formal, non-formal or informal setting have been assessed against predefined criteria and are compliant with the requirements of a validation standard. Validation typically leads to certification.

[4] Cedefop. Glossary of key terms. https://www.cedefop.europa.eu/en/events-and-projects/projects/validation-non-formal-and-informal-learning/european-inventory/european-inventory-glossary#C

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8. PARTICIPANT ORGANIZATIONS IN THE QUALITATIVE REPORT (CHAPTER 4)

DENMARK

- A Nurse and Health Anthropologist employed at a specialialized institution for people with dementia
- A Nurse and Teacher at Health Care Education. Former leader in home care service
- An Occupational Therapist at a dementia specialized nursing homes, Supervisor for health care students. Employed at a special institution for people with dementia with another ethnic background than Danish
- A Volunteer in elder care activities, DanAge
- An Occupational Therapist and Teacher at Health Care Education

ITALY

- Psychologist at a residential facility for the elderly
- Expert and manager of the care area at a cooperative that deals with assistance to the elderly
- Expert in training courses for OSS at a professional training centre
- Psychologist responsible for the scientific coordination of the non-self-sufficient area at a cooperative that carries out socio-health and educational services
- Nurse freelancer in the home care sector

ROMANIA

- Romanian Society for Alzheimer Cluj Napoca (Nord-West Region),
- Romanian Society for Alzheimer Constanta (South-East),
- Community Support Foundation Bacau (Nord-East),
- General Directorate of Social Assistance and Child Protection District 6 Bucharest (capital region)
- General Directorate of Social Assistance and Child Protection District 1 (capital region).

SPAIN

- Spanish Confederation of Older People's Organisations. CEOMA
- Spanish National Committee of People with Disabilities Representatives, CERMI
- Social Services Municipality of Toledo
- Cicerón Association – Nursing homes network. Toledo

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9. QUALITY QUESTIONNAIRE

Partners quality questionnaire: validation of the document: io1a4. Comparative report – Training CV

Name:

Organization:

Date.

Do you agree or disagree with the items described in this document?

Please fill in the questionnaire below and send it to the coordinator and the rest of the partners before 22 May, 2020:

Items	Your opinion	Comments and suggestions
1.Current situation of caregivers in participant countries	☐ Agree ☐ Disagree	
2.Training systems and programs in the participant countries.	☐ Agree ☐ Disagree	
3 open educational resources for caregivers	☐ agree ☐ Disagree	
4. Qualitative report	☐ agree ☐ Disagree	
5. Summary	☐ Agree ☐ Disagree	

Signature

Thanks for your cooperation

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