NATIONAL REPORT

ITALY

IO1a3. National proposals for training CV and OERS.

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1. CURRENT SITUATION OF CAREGIVERS OF PEOPLE WITH DEMENTIA

Dementia is one of the major causes of disability and dependence among older people around the world, with a decline in cognitive functions that lead to a loss of autonomy and to need constant support from specific figures.

1.1. Current situation of formal caregivers in Italy

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. This is an unregulated work activity, so it means that it doesn't require a specific training to be exercised, although many regions are offering non-compulsory courses to improve the quality of services provided. It's a job performed often by very low-skilled workers, predominantly from migrant backgrounds and at high risk of exploitation and abuse for both parties (worker and care-recipient), especially in cohabitation cases. It's very widespread in Italy: over 860.000 persons are regularly employed as domestic care worker, but an overall of 2 MLNs are esteemed when including people without a regular working contract.
- Assistant nurses (Operatore SocioSanitario - OSS): that of OSS is a formal VET qualification recognized by Regions. It's described in terms of professional standards (knowledge and skills)[1] and is released after a formal training of 1000 hours (1 year of training after compulsory education). It's a compulsory qualification to work in most public and private formal services offering care to older and disabled people.

  There are approximately 330.000 professionals with this qualification in Italy. OSSs are allowed to work inside hospitals as well as outside (primary assistance) both for residential and no-residential activities in the following areas: social sector, health services, social-welfare and socio-health, semi-residential in hospital and at home. OSSs have full competences in assuring hospital services/facilities but they are subordinated to personnel coming from others higher sanitary professional profiles (such as nurses) as well from others higher social professional profiles (such as social workers). Main activities are related to social and health care and addressed to the person and his living environment:

  a) direct assistance and residential help
  b) intervention sanitation and social
  c) management support, organizational and training

According to available data[2], the incidence of non-Italian workers in the social and health care field is relevant in the lower qualified professions, less in those requiring higher qualifications:

- 0,5% of medical doctors

[1] Emilia-Romagna Region - Regional Qualification System The qualification of "OSS" - Reading guide https://formazionelavoro.regione.emilia-romagna.it/qualifiche/approfondimenti/oss/allegati/GuidaallaLetturaProfiloOSS.pdf

[2] Piperno F, *Welfare e immigrazione. Impatto e sostenibilità dei flussi migratori diretti al settore socio-sanitario e della cura,* CESPI, Working Papers 55/2009, March 2009 and *Mercato occupazionale sanitario e migrazioni qualificate. Infermieri, medici e altri operatori sanitari in Italia,* EMN, Rome, 2006

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- 10,2% of registered nurses– mainly from Romania (37%) and Poland (16,3%)
- 15% of Assistant nurses
- 70% of Domestic care workers/privately hired caregivers

1.2. Main formal caregiver's tasks

The domestic care worker supports a frail elderly person in daily life activities, temporary or permanently lacking of autonomy. This professions support or replace the user in:

- personal hygiene
- housekeeping
- grocery shopping
- preparation of meals and feeding
- bureaucratic procedures
- company

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". It is important to underline that OSS and Nurses are "complementary" profiles even if, in practice, there are a lot of overlapping areas. They have to meet the basic needs of the person, within their areas of competence, in a social and health care, and promote the welfare and autonomy of the patients.

The main tasks that they have to manage are:

- Assists the person, especially if dependent or bed-bound, in everyday activities and personal hygiene
- Cooperates to activities aimed to maintain remaining psyco-physical capacities, re-education, re-activation and functional recovery
- Realizes recreational activities and socialization activities for individuals and groups
- Supports social and health care professionals in assisting ill persons, even if terminally ill and dying persons.
- Takes care of cleaning and hygiene of the patient 's living environment
- Supports the care recipient in managing his/her living environment
- Monitors and assists to the gathering of data about the needs and risky conditions of the care recipient.

1.3. Caring for the person with dementia

On the basis of the above, it's evident that there is not homogeneity throughout the Italian territory for the achievement of qualifications to cover specific assistance role for people with dementia. In addition, the long-term care (LCT) system in Italy[3] is characterized by a high level of institutional fragmentation, as the sources of funding, governance and management responsibilities are spread between local (municipalities) and regional authorities, with different modalities in relation to the institutional models of each region.

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

[3] Tediosi F., Gabriele S., *The long-term care system for the elderly in Italy*, ENEPRI research report no. 80, June 2010

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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, public LTC in elderly care includes three main kinds of formal assistance: community care, residential care and cash benefits. The Italian National Health Service (Servizio Sanitario Nazionale - SSN) plans and offers social and health care at home through the ASLs that manage ADI services (Integrated Home Care - Assistenza Domiciliare Integrata) coordinated and managed by a multiprofessional team that offers an integrated set of health and socio-health treatments on basis of the Individualized Care Plan – Piano Assistenziale Individualizzato (PAI) and other health services provided in residential settings. While personal social service, including both home management and personal care tasks, are provided by the SAD (Homecare Services – Servizi di Assistenza Domiciliare), coordinated by the municipal social services. It offers simple and complex social-assistance interventions based on the PAI, the Individualized care plan) whose management is the responsibility of the municipalities. LTC is provided by both public and private socio-health services to individuals, which offer their services through accreditation by local authorities according to specific requirements that guarantee the quality and unitary management of services.

The health care services provided by the SSN are free of charge, whereas social care is means-tested, therefore it is expected that, depending on the income, there will be a sharing or full coverage of the cost of the service by the user and possibly by family members.

For people in conditions of total disability and who, because of this, need constant support to carry out their daily activities, the National Institute of Social Security (INPS) provides a cash benefit (indennità di accompagnamento) after a specific request and verification of the condition of disability in cash recognized independent of their financial situation. This cash benefits are not directly linked to an obligation to purchase goods or services and aims to improve one's personal condition but they are generally being paid to cover part of the LTC expenses. Other cash benefits are provided by some municipalities depending on local regulations and are usually means-tested and recognized following a requirement check.

Italy doesn't 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[4]. The majority of domestic care workers still don't have any formal qualification, even though the number of workers who have attended training as Family Assistants (or similar) is extending.

1.4. Rights of the person with dementia

The protection of rights of persons with disabilities is one of the most important aspects for caring for people with dementia.

[4] Beltrametti L., *The financing strategies,* in Gori C. (edited by), *Regional reforms for the housebound*, Carocci, Rome, 2008

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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 disabilities (including those with dementia) is that introducing in 2004 the Support administration. It was introduced for the purpose of allowing a lesser intrusiveness of the limits imposed by the law in cases of interdiction and incapacitation, establishing a flexible and articulated system that protects persons suffering from disorders which are not so severe as to cause interdiction, and that allows them to determine the personal and pecuniary relationships which may be independently managed by them. Indeed, in the decree appointing the support administrator, the Guardianship Judge will write down the acts for which the support administrator will have the exclusive representation, and those for which he will have to assist the beneficiary. With the exclusion of the above, the beneficiary will retain the ability to act (see Article 409 of the Italian Civil Code).

Most Scholars, as well as the case-law, agree in stating that, compared to the institutions of interdiction or incapacitation, "the scope of the support administration should be identified with regard not to the different and less intense degree of infirmity or inability to attend to the very interests of the person lacking autonomy, but rather to the greater capacity of such instrument to adapt to the needs of that person, in relation to its flexibility and to the greater agility of its applicative procedure" (Court of Rome in judgment of 24 May 2011).

The institution of the Support Administration in Italy makes part of a wider international movement of judicial innovation aimed at countering the marginalising effects related to the XIX century concept of insanity, and at maximally appraising residual abilities of vulnerable subjects as well as sustaining their autonomy.

2. Training systems and programs in the country

As above-mentioned, 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, even though the number of workers who have attended training as domestic care workers or Familiar assistants is extending. Some municipalities have started to link the provision of economic support to buy these services to the employment of persons with the qualification of Domestic care workers (or similar) and to promote the qualification of those working in this sector.

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.

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2.1 Example of OSS training CV

The following training CV for OSS qualification is an example of programs proposed by the individual VET providers and approved by Regions, which are responsible for this type of training offer according to nationally established training and professional standards[5]. We want to underline that, even if there are specific guidelines defined at national level according to the State-Regions Agreement[6], 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.

SUBJECT	CONTENTS	HOURS	METHODOLOGY / EXERCISES
English language	- Basic grammar rules - Pronunciation rules - Written skills - Glossary of the care field	30	Workshop
Use of ICT	- The hardware of the PC - Basic software - How to search on the Internet work-related information	30	Workshop
Organization of social services	- Organizational models - Protocols and procedures - Standard indicators - Care plans - Concept of quality	30	Theory
Social services regulation	- The regulation of social services - The national and regional social and health care plans - The national working contract - Legal liability of the care workers - The professional profile of the health and social care worker - Professional ethic	30	Theory
Methodology of social work	- The role of the health and social care worker in the different social services - Main organizational models - Team working - Professional ethic - Individual care planning	30	Theory and workshop
Environmental hygiene	- Epidemiology of infective diseases - Epidemiology of hospital infections - Cleaning and sanification of environments - Waste disposal - Incoming, transfer and dismissal - Making the bed	30	Theory
Personal hygiene of the patient	- Introduction to anatomy and physiology - Care and cleaning of the body - Personal hygiene - The bath - Hygiene and composition of the corpse	50	Theory and workshop
Psychology and communication	- The helping relationship	50	Theory and workshop

[5] Unitary framework about the new provisions for the training of the Assistant nurses (OSS) concerning the Emilia-Romagna Region *Disposizioni per la formazione dell'Operatore Socio Sanitario in attuazione della L.R. 12/2003 e successivi dispositivi attuativi* http://servizissiir.regione.emilia-romagna.it/deliberegiunta/servlet/AdapterHTTP?action_name=ACTIONRICERCADELIBERE&operation=dettaglioByDatiAdozione&ENTE=1&TIPO_ATTO=DL&ANNO_ADOZIONE=2009&NUM_ADOZIONE=191

[6] https://fp.cisl.it/wp-content/uploads/2018/10/accordo-stato-regioni-22-02-2001.pdf

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	- Introduction to sympathy, empathy and antipathy in communication - Human and social relationships - Recreational activities - Relational dynamics with the different type of users - How to communicate with the suffering person		
First aid	- Definition of urgency and emergency - The emergency services - BLSD - Basic vital support - Poisoning - Introduction to wounds, traumas, burns…	50	Theory
Geriatrics and gerontology	- The ageing of population - Physical and psychological changes in older persons - Care needs according to the different pathologies - Types of care facilities	30	Workshop
Mobility and transportation	- Introduction to anatomy and physiology of osteoarticular apparatus - Technique to support in walking - Mobilization of the bedbound person - Transportation of materials within the care facility / hospital - Prevention of the bed-bounding related syndrome	50	Theory
Nutrition and elimination	- Main nutritional elements - Metabolism and KCLs needs - Introduction to physiology of the gastrointestinal apparatus - Assessment of the nutritional status - Hygiene of food - Feeding procedures - Types of diets used in the social care - Alteration and problems of elimination - Enema	50	Workshop
Care work techniques	- Observation of the patient - Protocols to assist patients with respiratory problems - The cardio-circulatory functions – how to measure blood pressure - Techniques to assist in feeding and elimination - Artificial nutrition – the management of the nasal-gastric tube - Use of bedpans and bed-bottles - Protocols to execute enema	50	Workshop
Work safety	- Safety on the workplace - The laws on safety on the workplace - The protective tools - Prevention of bio and chemical hazards - Prevention of fire hazards	20	Theory and workshop
Internship		450	Practice

3. Open educational resources available in the country (good practices).

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”.

A journey into the brain

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Developed by the Alzheimer's association and available in Italian from https://www.alz.org/it/cervello_italiano.asp it's an interactive training course explaining basic concepts about the brain and how it might be affected by Alzheimer disease.

All rights reserved by the Alzheimer's association.

Online training about Alzheimer

This is a static learning material providing basic information about Alzheimer Disease. The course is hosted on the website of a private home care service provider: http://www.alzheimerblog.it/corso-line-sessione-1/

Nothing is mentioned about the licence of use of this material.

Cognitive stimulation for dementia

This is a video-lesson of 45 minutes hold by a neuropsychologist. Accessible from : https://www.igeacps.it/corso/corso-gratuito-online-la-stimolazione-cognitiva-nella-demenza/

Nothing is mentioned about the licence of use of this material.

Dementia training for care professionals

This is a MOOC developed within the Erasmus project IDO - INNOVATIVE DIGITAL TRAINING OPPORTUNITIES ON DEMENTIA FOR DIRECT CARE WORKERS. It's made of 9 modules for an overall duration of 3 h 14 min and it is available in different languages from the Udemy platform: https://www.udemy.com/course/formazione-sulla-demenza-per-i-operatori-assistenziali/

Nothing is mentioned about the licence of use of this material.

4. QUALITATIVE ANALYSIS (BASED ON 5 INTERVIEWS IN-DEPTH) ABOUT A PROPOSAL OF TRAINING CV ON DEMENTIA

From February to March 2020, 5 in-depth interviews were conducted with experts in the field of care for the elderly, both in the field of assistance and vocational training, in order to gather their opinion on the current situation and preparation of the OSSs on the subject of dementia and the proposed training CV aimed at those who care for people with dementia.

The 5 experts who have been involved are:

- P1 - Psychologist at a residential facility for the elderly
- P2 - Expert and manager of the care area at a cooperative that deals with assistance to the elderly
- P3 - Expert in training courses for OSS at a professional training centre
- P4 - Psychologist responsible for the scientific coordination of the non-self-sufficient area at a cooperative that carries out socio-health and educational services
- P5 - Nurse freelancer in the home care sector

The topics of this research are divided into 3 blocks:

1. Current situation of caregivers of people with dementia

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2. Contents of a proposal for a training curriculum
3. Training cv and vocational training systems

4.1 Block 1. Current situation of caregivers of people with dementia

Q1. Could you please describe the current situation of formal[7] and informal caregivers of people with dementia in your country?

Do you consider that caregivers have adequate knowledge and skills about the required activities at the workplace?

Could you identify the caregiver's performance tasks that could be improved through training courses?

The experts consulted unanimously recognize two professional figures/formal caregivers who are different in terms of knowledge and training received. They are:

- OSS: the experts recognize that professional figures have useful knowledge learned during a training course. Despite this, it's described as generic, basic or standardized knowledge, therefore not specialized for clinical pictures such as dementia. All the experts agree in observing how often sensitivity related to the issue is connected with a greater experience, that allow to being better skilled. Move theoretical knowledge into practice is often a challenge for the less experienced OSS; nevertheless, in general, the OSS, by teaming up with other specialists in the sector, learns techniques and practices from other professions, opening up to experiential learning.
- Domestic care worker: for this worker the experts recognize a total lack of training, therefore any knowledge learned is attributable only to the goodwill of the worker to investigate issues and also inquire through collaboration with other professionals.

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.

The preparation generally offered to both OSSs and domestic care workers is recognized by experts as insufficient, also due to the complexity of treating the disease. In fact, although the performance may be sufficient in reference to practical aspects, it's lacking in relational aspect and approach to the user suffering from dementia. This is because, as previously mentioned, the training approach for OSSs is often notional and conceptual, not by focusing on how put the concepts into operational practices and techniques. Training courses, although more detailed and updated in recent years, should be modulated in relation to this issue, because for the moment the quality of the general care depends from the operator's sensitivity and experience. As for home care, it was reported that is a type of completely performance assistance, it's inadequate to deal with problems related to dementia, where the focus must be on relational care, and not only practical assistance and hygiene (P2). Finally, it has been added that both figures have training lacks with respect to the behavioral and psychiatric disorders associated with dementia and communication with the user and his family (P4). 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.

[7] Basic care staff and professionals in the care sector.

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As to improve caregiver's performance tasks, experts agree suggesting that the communication and empathic skills must be improved, through an experiential training method that allows to experience situations as working and globally approaching to the user with dementia. This goal could be reached for example with practical samples, cases and situations, inviting participants to reflect on how they might behave in front of these circumstances and proposing a role-playing activity in which the people in training interpret alternately the person with dementia and the care worker (P1). An effective and empathic communication and socialization is very important in care of people with dementia in order to enter into a relationship with the user and build the relationship on which to base the care intervention (P2). Enhancing it makes possible to provide a quality assistance with respect for the person, especially to recognize the sensations, such as suffering, because people with dementia are unlikely to clearly spell out their sensations (P2, P5). Regarding this latter, it has been emphasized that it's essential to know how to recognize and discern physical and/or psychic pain, and to know how to manage each of them (P5). Using an experiential training methodology is functional for understanding the reasons behind certain reactions and perceptions of the facts by patients affected by these pathologies (P2). Simulations and exercises for OSSs should be focused on how to deal with any resistance and refuses of the user with dementia in front of proposals and daily activities. Indeed, it's important to offer indications to create a strategy that allows to provide assistance with respect for the person, therefore without any kind of imposition or violence is inflicted on them (P3). Trials would be necessary on common practices such as movement and mobilizations, on spoon-feeding and nutrition of users with dysphagia, in general on the maneuvers to be implemented on these users. Experimenting with each other physically the maneuvers leads to learning through practice and to try on one's own skin what it means to be the object of assistance, helping to empathize towards a user who may have problems communicating sensations such as bother or pain (P4). Last suggestion is to offer moments of shared reflection, it's important that workers have opportunity and time to stop and think on the relational components, which are sometimes put in the background due to the large amount of work (P1).

Q2. Do you consider that the content of the official courses offered are useful for the day performance of caregiver of people with dementia?

The experts agree that the preparation that is provided is certainly useful, even if it is not exhaustive for all assistance tasks and should be updated and integrated, so that it is possible to have the tools that up to now OSSs have only with the experience. The experts reported the difficulty in understanding how much the daily OSS performance is due to the preparation related with OSS training and how much is due to professional experience. It is therefore pointed out that it's important that there is homogeneity in training and in providing a specific preparation on dementia topic, with fewer attention towards acquiring notions and higher on the building of empathic relationship and on knowledge of the personal life history, that could make the difference in providing assistance.

Q2.1. Could you suggest any good practice of vocational training (face-to-face learning, e-learning) which could be useful for caregivers of people with dementia?

The experts suggest that it would be useful to offer both frontal and digital training, with a very practical and experiential methodology through the use of videos, real cases, role playing and simulation resources, as well as centered on the psychological aspect to allow understanding and empathizing with a person with dementia. The e-learning and distance training part should be focused on theory, proposing many videos and exercises that are effective in learning. The frontal part should be an occasion for group work, roleplaying, case analysis, which allow the trained to be put in a condition to experiment and reflect.

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4.2 Block 2. Content for a training cv proposal

Q3. Considering the development of an app addressed to caregivers of people with dementia and available free on the internet: Could you please indicate the degree of priority of each item from 1 -Highest priority to 3–lowest priority and give your opinion about it? Which learning content would you add, change or delete?

Training modules	P1	P2	P3	P4	P5	T.	Opinions of the experts
• M1. Introduction to dementia and Alzheimer's disease.	2	1	1	2	1	1	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, Alzheimer's disease, Treatments.	1	1	1	2	1	1	Provide 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).
• M3. Physical and psychological complications in Alzheimer's patients.	2	1	1	1	1	1	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.	1	1	1	1	1	1	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

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							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).
• M5. How to approach someone with dementia?	1	1	1	1	1	1	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).
• M6. Supporting the family of people with dementia.	1	1	2	1	1	1	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

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							together, also to alleviate anxiety or guilt due to the fact that the person cares for a third party (P4).
• M7. Institutional resources.	2	3	2	3	1	2	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.
• M8. Legal topics.	2	3	2	3	2	2	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).
• M9. Ethical behavior at workplace.	1	1	1	2	2	1	Ethical principles should be considered with a holistic approach, especially towards the person rather than the workplace. It's in fact suggested to eliminate the wording "... at workplace" (P2) and to deal them in a simple and clear way (P4), in order to allow a full understanding and assimilation of the ethical principles that give value to their professionalism (P1) and which guide the operator's actions, without judgment and through an overview of the general situation of the person. It is suggested to add a specific part on the operator's rights and to deepen it (P3).

It has been suggested to change the order of some modules by placing M5 before M4 as it is considered important to first have awareness of social and relational factors and then formulate assistance and care on the information collected about the person. Therefore, anticipating the attention on all aspects concerning the knowledge of the problems and behavioural change of the person suffering from dementia and then the deepening of the practices (P2). In view of the fact that the general order of the program also depends on the role that the person in training goes to play, it would be useful to administer questionnaires to detect the training needs before organizing the training program in detail (P3).

With regard to the proposed training CV, it was suggested to add the following points:

- **M1**: Add the theme of early on-set of dementia (P2)
- **M2**: Add a part considered very important on non-pharmacological treatments and on the role of the OSS in the possibility of making a difference through the realization of activities and treatments of this type (P1, P2, P4)
- **M3**: Add many aspects related to neurodegenerative diseases, such as those related to the perception of hunger and the sense of satiety (P4)

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- **M4**: Add and deepen the theme of restraint tools with particular attention to how to alleviate the effects of restraint, implementing this type of activity by simulating situations to reason about the validity of the reasons that lead to making the decision to use them (P2)
- **M5**: 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 behaviour and the M9 can therefore be integrated and treated in the M5 (P2, P3). It could also add some content and some attention to the operator in the M5, so to pay attention not only to the user but also to oneself, as well as to the repercussions that there may be in the emotional sphere, such as frustration or detachment (P3)
- **M6**: Add a part that highlights how the family is a resource and an ally and how important it is to collaborate synergistically with them (P2)
- **M8**: Add a specific part on the duties and responsibilities of the operator towards the user, the family and the service (P4)
- **M9**: To be dealt in close relation to M5 and should be added a link between behavior with the person affected by dementia and ethical behavior (P2, P3)

Q3.1 Do you think that the training CV proposal could be implemented in national VET programs?

All the experts who have given their contribution agree that the program is useful and valid and could be included in official programs. It is also suggested that it should be included as training offered within a specific service and related to work within the service (P2). It has been reported to offer training as an opportunity to enter the working and operational reality, through the proposal of practical situations and collective confrontation, as well as providing the opportunity to visit the dedicated structures in order to show and reflect on how spaces are organized.

4.3 Block 3. Training cv and national vocational training systems

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?

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.

SWOT analysis

Strength:

- To provide various knowledge that allow to analyze and collect information on various aspects, helpful to provide better assistance
- E-learning and distance training methods to reduce costs related to training times and places
- 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
- Not abstract notions, but with concrete references to working realities

Weakness:

- To insist and be redundant on already known and consolidated topics or practices

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Opportunity:

- 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
- Have the basis for developing a reasoned operating system
- Being able to see what can be presented daily in the work area
- E-learning as an opportunity to develop digital skills, especially for situations where it is the only way to communicate or work
- Innovation in care services allowing development and enrichment of the professional role

Threat:

- 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)
- Sense of frustration due to seeing detachment between theory and reality

Would you like to add some other considerations in relation to these issues?

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's what has been found to be most lacking in the preparation of the OSSs. In addition, all experts agree that the training program would also be useful to informal caregivers, making the necessary changes and precautions, simplifying the language and selecting which modules to deepen and focus attention on. It also emerged that it was important to provide training designed with respect to the role and tasks that caregivers must face, providing many practical notions on the course of the disease and on the assistance to be provided, to avoid improvisation or damage to the person with dementia or the caregiver. As for the duration of the training course, it was reported by experts that it should be 40 to 50 hours maximum.

5. SUMMARY AND CONCLUSIONS

The study conducted in Italy showed that the two main professional figures involved in assisting people with dementia are the domestic care worker and the OSS and that only the latter is a qualified profession through an official training course. However, it has been found that the theme of dementia is generally treated in a transversal and non-specific way during the training programs aimed at the OSSs, although this is a professional figure who often finds work in contexts of assistance to elderly people, a user who it has a high incidence of cognitive degeneration and dementing pathologies. As regards the figure of Domestic care worker in Italy, in order to practice the profession, it is not required to have achieved a formal qualification and meet specific professional requirements, resulting in the lack of specific preparation on the topic of dementia. The data, as presented above, show that a high percentage of domestic care worker has a migrant background and that linguistic competence is of significant importance. Non-regulation of the profession can in fact have considerable repercussions on the quality of care and represent a double difficulty for domestic care workers, both in not being able to investigate effectively and exhaustively the theme of dementia and in the relationship and communication with the user and family, where present.

The proposed program has therefore proved to be very important to increase awareness of dementia and the various related problems that must be managed during the care of people affected by this pathology. It was in fact validated by all the interviewed experts who offered their opinion and also proposed a series of

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suggestions and modifications based on their professional experiences, advising to extend the offer to informal caregivers after making the necessary changes and precautions. The possibility of training through technological tools has highlighted how innovation of services is therefore an opportunity to develop and enrich the skills of professionals even from a digitalization point of view. It was emphasized by the participants that a training aimed at the OSSs on the theme of dementia should be focused more on the socio-relational aspects than on the health aspects, on which there has already been a preparation and effective practicality. To this end, according to what emerged from the interviews with the experts, is reported to be effective a training of a duration of not more than 40-50 hours and full of practical examples, putting the professional in a position to identify himself in the user. Nonetheless, it was considered appropriate to work on the awareness of identity and life story of the user as well as that the family, in addition to requiring support to deal with the situation of one's relative, is an important resource to be involved and collaborated with in providing formal assistance. This holistic and non-passive approach could in fact create a virtuous circle that would bring benefits to all who are involved in care process.

It has been highlighted that care of people with dementia, both for formal and informal caregivers, is not a simple task and that can have a strong impact on personal life also from an emotional point of view. Therefore, was confirmed and reinforced the awareness that specific preparation and skills on the topic is fundamental to improving the quality of assistance and to support for this burden. The care activity, formal or informal, of a person with dementia needs particular attention on an emotional level and it is essential to give space to the caregiver's experience and to what he feels, providing practical tools to listen and give voice to his own emotions in order to prevent discomfort that these can bring.

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