

NATIONAL REPORT

Denmark

Io1a3. National proposals for training CV and OERS.



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1. CURRENT SITUATION OF CAREGIVERS OF PEOPLE WITH DEMENTIA

In January 2018, the total number of inhabitants in Denmark was 5.7 millions. The average duration of life is 82.9 years for women and 79 years for male. Nevertheless, more than 1079 living Danes have celebrated their 100 years anniversary. This number is an increase of 30% the last 10 years. As in the rest of Europe an increased number of people with dementia in Denmark is expected in the coming years as a result of the growing elderly population. The incidence of dementia increases with age.

1.1. Current situation of caregivers in Denmark

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.

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.

Person-centered care is an attitude, approach, or frame of understanding that gives access to the person with dementia. Person-centered care therefore also requires training. One cannot expect the approach or attitude to be on the backbone right away. Conversely, it does not take any extra time. The moment it is incorporated, you may find that the approach creates better collaboration between staff and people with dementia, and that a wide range of conflicts can be avoided.

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.

They 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
- Interaction with relatives

Relationship work can be considered successful, when the staff help the persons with dementia to experience "sparkling moments" where they feel comfortable, relaxed and free from the grief and frustration, which they so often experience.

Competency challenges

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 study¹ shows that dementia skills, general skills and personal skills are needed.

Skills in the dementia area:

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
- Persons of non-Western background

General skills

- Being able to deal with dilemmas (based on dementia knowledge)
- Being able to reflect and argue
- Being able to formulate and convey significant observations

Personal skills

- Being able to handle different needs all the time
- Having the courage of his/her profession and professionalism - regardless of the relatives' social status

The study shows unequivocally that the biggest challenge in working with people with dementia is behavioral changes, even in the special sections for people with dementia where you have the staff with the strongest competencies.

1.2. Informal caregivers

Dementia is often called the disease of the relatives. There are several reasons for this. Dementia not only affects the dementia patient himself/herself, but also affects the whole family's life and health - literally. Relatives spend time and effort to make everyday life interconnected. They get sick, have to work less outside home or completely leave the labor market before they had planned. Being an informal caregiver as opposed to a professional caregiver is a very special situation where the informal caregiver usually does not have a professional background and often has the emotions in a tight spot. In addition, spouses may have promised each other that none of them will ever have to move to a nursing home. If it happens anyway because one of them simply gets too ill, it leaves the healthy spouse with a bad conscience. Even if he/she

¹ Dilemmaer som hverdagskost- Jobfunktioner og opgaveudvikling i arbejdet med borgere med demens, Bruno Clematide og Lone Grøn Kubix, KORA november 2017

did not know the full meaning of what was actually being promised! Relatives may also feel that their spouse with dementia is behaving inappropriately and doing what they can to cover up for them so that they avoid embarrassing situations (especially in fronto-temporal dementia). However, relatives can do something that the professionals cannot: they appreciate unconditionally the person with dementia and care for him/her; they have a unique knowledge of the weakened person's life, habits preferences and needs.

The majority (73%) of the relatives, who give care to people with dementia in Denmark are over 65 years old and must provide more care than relatives of persons with other chronic diseases must. An analysis, from 2011, of 469 members of the Alzheimer's association showed, that relatives of people with dementia in Denmark spend about six hours a day on average on care and supervision of their spouse or cohabiting partner. They are not a homogeneous group and the care burden is relative and depends largely on different factors. The care burden and the increased physical and mental burden can weaken the health of the individual relative.

Being a relative of a person with dementia may be associated with a significant and prolonged psychosocial strain, which can result in deterioration of health, social isolation, anxiety, depression, sadness, etc. Relatives of people with dementia feel more stressed and take more medication than other relatives do. They experience more family conflicts and social isolation, as their relatives downgrade their own network and give up on holidays or maintaining their hobbies and interests. The relatives may experience "losing" a person they care for and often feel an increased responsibility towards the person with dementia.

Both parts are exposed to a great emotional burden, as well as great practical, legal and social problems following dementia, also in the early stages.

In addition, it seems that children of parents with dementia do not appear to experience negative effects due to the care situation. It is the spouse to the person with dementia, who experiences this burden. This is probably due to the long and close relationship with the person with dementia - the closer the relationship, the heavier the care burden. Another reason may be that children have the opportunity to *choose* the role of primary care provider, as they do not live together with their parents. Spouses do not have any choice. In addition, children are more often active on the labor market, which creates a better opportunity to break free and enjoy freedom from the care role. The handling of and the burden due to the care situation depends on the quality of the child-parent relationship before the illness occurred.

As a relative, you have to deal with your own losses in relation to the person with dementia, but also in terms of seeing the person "disappearing" more and more, often over years. The persons with dementia and their spouses lose their shared history, they must constantly adapt and get used to the role of being the closest relative. It is in some ways comparable to other progressive disorders, however not completely. The prerequisite of the person with dementia for being present and being present for a longer period, fades in the progresses of dementia. It places special demands on relatives and professional caregivers.

2. TRAINING SYSTEMS AND PROGRAMS IN THE COUNTRY. DESK RESEARCH

In Denmark, we employ social and health care helpers, social and health care assistants and nurses to take care of the weak citizens.

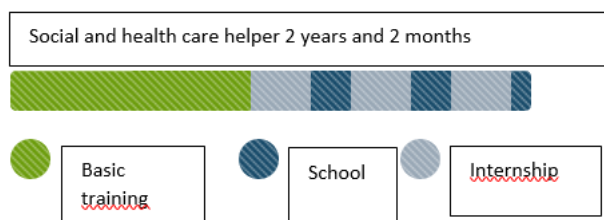
Hence, we will go through the two educations offered by the SOSU colleges in Denmark: Social and health care helper and social and health care assistant.

2.1. The social and health care helper education

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 support the elder in creating a good structure of everyday life. Among other things, you will help with personal hygiene, with domestic tasks such as cleaning and laundry and with activities, which increases the elder’s well-being. At the college, you will learn about health and well-being and about nutrition and exercise, so you can guide the elder. 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 for social and health care helpers

To give an insight into what is being taught during the education in order to gain the competences needed, the education will be explained here. The education is a mix between school and practical work (internship) at workplaces. It begins with a basic training course.



At the SOSU College, the following courses are compulsory:

- The role of the social and health care helper
- Meeting the person in need of care
- Personal help, nursing and care
- Health promotion, prevention and rehabilitation

Besides, there are optional courses:

- The cooperation between the person suffering from dementia and his/her next of kin
- Diet and exercise for vulnerable groups
- Quality of life and prevention of loneliness
- Meeting persons with mental illnesses
- The social and health caregiver’s tasks through the palliative course
- Well-fare technology and tasks involving tele-medicine

Through the internship at the working place, the students learn the work tasks that come with the education. After the basic training course, the local authority employs the students. Through the practical internship, the students have an internship supervisor, who will help them reach the described learning objectives for the internship.

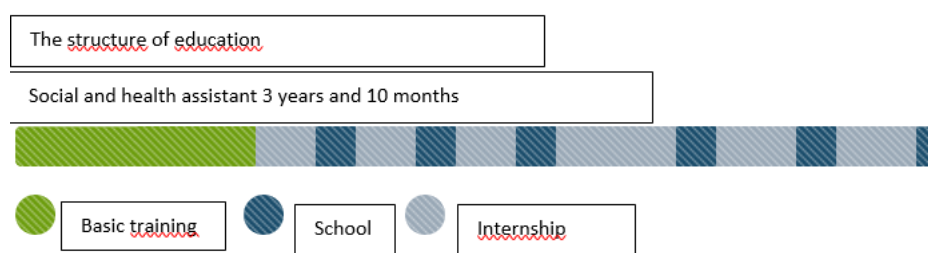
The learning objectives for the full education of the practical internships are as follows:

1. The student is able to professionally and independently take care of personal nursing and care as well as take care of personal and practical help in order for the person in need of care to maintain his/her possibility of self-expression and quality of life.

2. The student is able to, concerning the right of self-determination, motivate the persons in need of care to actively take part in their rehabilitations course, in order for their self-care, well-being and practical functional capacity to be kept as much as possible through everyday life.
3. The student is able to work with a focus on health-promotion and prevention, and act appropriately at changes in the physical, mental and social health care condition of the person in need of care.
4. The student is able to, concerning lifestyle and conditions of life, independently motivate and support the person in need of care in terms of health-promotion and prevention as well as to inform him/her about relevant private and local offers – among these contact to networks and volunteers.
5. From a professional view and the recommendations from the Danish Health and Medicines Authority for early detection, local procedures and rules, the student is able to initiate actions independently. Amongst this, screenings relevant for the everyday life of the person in need of care.
6. On basis of the state of nutrition of the person in need of care, the student is able to initiate relevant actions that focus on his/her diet and nutrition as well as the importance of a meal.
7. The student is able to independently support, guide, initiate and evaluate physical, cultural, creative and social activities together with the person in need of care in order to support him/her in managing his/her own life.
8. The student is able to independently inform and support the use of digital aids with a focus on training and practical help.
9. The student is able to document professionally the planned and accomplished effort of the care and training agendas in agreement with the workplace's guidelines, including using electronic documentation systems.
10. The student is able to establish a goal-oriented communication, accomplish and conclude the professional meeting with the person in need of care and the relatives as well as include relevant external partners.
11. The student is able to meet other people in an ethical, empathic and respectful manner as well as reflect over and give reasons for his/her own professional role in the process of human-to-human relations.
12. The student is able to handle conflicts and work to prevent violence in line with the guidelines for the work environment.
13. The student is able to independently relocate the person in need of care in agreement with the ergonomic principles and can independently apply and maintain aid facilities and relevant welfare technology.
14. The student is able to independently apply personal hygienic principles as well as contribute to the prevention of diseases spreading in line with national and local guidelines and to guide persons in need of care and their relatives about this.
15. The student is able to plan and carry out different tasks, which are understood and regulated by the Social Service Act and the Danish Health Act as well as the internships' practice for delegating assignments.
16. The student is able to work independently within his/her area of competencies and in line with local quality standards for unintended incidents etc., and be part of co-operation with relevant colleagues and interdisciplinary collaborators.

2.2. The social and health care assistant education

The Ministry of Education describes the education as follows: “Through the education, you gain basic knowledge of providing practical and personal help. Furthermore, you learn about nursing and care tasks and about how to plan activities that strengthen health and prevent illnesses. At the college, among other things you will learn about the body, the most common diseases and the connection between lifestyle and disease. You gain knowledge about hygiene, prevention of infection and about chemistry in, for example, care products and medicine. In addition, you will learn how to administer medicine for the citizen and to document the nursing you are performing. You must be able to communicate well and work with people in need of care, patients and relatives. You will also learn how to work with other health professionals and how to organize a coherent care program. As a social and health care assistant, you perform nursing tasks, plan activities and guide social and health care helpers in home care, nursing homes etc.”



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.

At the college, the following courses are compulsory:

- The meeting with the person in need of care and the patient
- The coherent person and patient care
- Quality and development
- Illnesses and nurse care (both physical and mental diseases)
- Health promotion, prevention and rehabilitation
- Pharmacology and medicine management

Besides, there are optional courses:

- The social- and healthcare assistant as team leader
- Network and co-creation with vulnerable groups
- A person's need for acute social-psychiatric treatment
- Pain relief in relation to physical and/or mental diseases
- The social- and healthcare assistant's role at hospital admission for persons with dementia
- A person in need of care, suffering from physical and/or a mental disability
- In depth nurse knowledge and professional development
- The social- and health care assistant's tasks in terms of the end of life

The internship is meant to give the students the opportunity to obtain vocational competencies in a professional community through execution and reflection of the daily work tasks within the professional

field. The learning objectives for the internship follow below. They are end-goals and by the end of the education, the work place must ensure that the students have reached them.

Internship learning objectives:

1. The student is able to implement and reflect on clinical nursing actions, including independently using the nursing process to collect data, identify, analyse, plan, perform and evaluate nursing/patients with basic needs.
2. The student is able to plan and initiate health care actions based on professional and clinical assessments, including the Health Board's early detection tools, and local procedures and guidelines.
3. The student is able to identify and respond independently to change in the health of the person in need of care/the patient. In case of unforeseen and complex issues, the student is able to perform nursing actions within his/her own field of competence and delegated nursing activities, including performing palliative care.
4. The student is able to assume a holistic approach that supports that the person/patient is coping of his or her own life independently, and in cooperation with the person/patient and relatives work with rehabilitation.
5. The student is able to work independently and interdisciplinary with health promotion and, from a holistic viewpoint, prevent the development of lifestyle diseases by guiding and motivating the person/patient to master his/her own life.
6. From a rehabilitative approach, the student is able to independently plan, perform and evaluate care, practical help and personal care for persons with physical, mental and social needs.
7. The student is able to independently organize and carry out physical, social, cultural and creative activities, and inform and advise on activities, including network and volunteers based on the individual person's interests and needs, and support him/her in making his/her own choices.
8. The student is able to independently prevent infection by national and local guidelines and hygiene standards, including special regimes and techniques, as well as advice persons in need of care, patients, relatives, colleagues and volunteers about this.
9. The student is able to independently take care of medication management in line with the internship's guidelines. He/she is able to observe the effects/side effects, document and cooperate with the person in need of care/the patient in the medical treatment.
10. The student is able to establish relationships that create cooperation with persons in need of care/patients, relatives and volunteers, including goal-oriented communication and using relevant communication methods.
11. The student is able to independently conduct pedagogical activities and guide colleagues.

12. The student is able to communicate in a way that supports the integrity and self-determination of persons in need of care and patients in conflict management and violence prevention. Doing this, he/she should be able to take into account his/her own and others' security

13. The student is able to independently communicate and document professional actions in relevant documentation systems to support patient-safe transitions and continuity in the overall person/patient course and increase its quality.

14. The student is able to independently coordinate and organize their own and others' work as well as support and participate in teamwork around task solving with the need of the person/patient as goal.

15. The student is able to coordinate and participate in the collaboration on the needs of a person in need of care/patient for inter-professional and cross-sectorial activities, including self-initiation, completion and documentation of social and health care services in connection with reception, admission, discharging from hospital and homecoming of the person.

16. The student is able independently to carry out person care using technology and guidelines based on experience-based knowledge and evidence.

17. The student is able to support the development of good practice for quality assurance and patient safety in inter-professional cooperation.

18. The student is able to relate critically to and support the development of a good physical and mental working environment, including performing relocations as well as assessing space conditions in compliance with the occupational health and safety rules and the application of welfare technology.

19. The student is able to reflect on and make qualified choices in relation to ethical and professional dilemmas that follow working as a professional social and health care assistant, such as confidentiality, use of power, patient rights, duty of care and consideration for the quality of life of the person in need of care/patient.

20. The student is able to plan and explain his or her own work and competence as an authorized healthcare professional in accordance with relevant legislation and others' areas of competence.

In general, to give care requires knowledge in the area of nursing, in caring, and in the social and psychological area, - and focus should always be on the personal life history. In the home care facilities, the professionals work with goal-oriented nursing plans and they have focus on work with the closest relatives, on making space for the people with dementia to express their feelings and they are aware how the buildings and surroundings affect the residents.

The individual professional must be good at making solid relation with the person with dementia, to be able to interpret the person's needs and he/she has to be good at reflecting and creative in solutions.

At the same time, the job is mentally very demanding because people with dementia do not get better.

2.3. Re-training Courses. Retraining of employed and unemployed staff: Institutionalized Education or Labour Market Education

The SOSU Colleges offer a number of courses for employed caregivers dealing with dementia. The VET Colleges in Denmark are known for a very practical approach to teaching. Teaching is usually planned in dialogue with the municipalities, who are the employers. It can be a single course or a series of continuous courses depending on the needs of the municipalities.

The courses are nationwide and have the same learning objectives. The titles are:

1. Early detection of dementia in care work. 3 days' course
2. Persons with dementia - disease awareness. 5 days' course
3. The meaningful life - people with dementia. 5 days' course
4. Persons with dementia - activities and quality of life. 5 days' course.
5. Inappropriate behaviour and outward reaction by persons with dementia. 5 days' course
6. Palliative care for people with dementia. 4 days' course

Early detection of dementia in care work.

Here, the focus is on the early detection and diagnosing of dementia. The course includes teaching on observations and dissemination to relevant parts. It must be done in collaboration with the person with dementia and the relatives with respect for the integrity of the persons.

Persons with dementia - disease awareness

Based on experience, the participant must be able to respond appropriately to the needs and wishes expressed by the persons with dementia. They should be able to recognize the symptoms of brain damage and observe purposefully in relation to the behavioural pattern of the persons. In addition, the participant must be able to express his/her own values, desires and needs in order to maintain commitment and joy in the work.

The meaningful life – people with dementia

Participants must be able to attend to the individual needs that arise in everyday life for a person with dementia. They need to know the social pedagogic approach and the symptoms and stresses people with dementia experience. Participants must be able to organize the work with the person with dementia and their relatives based on life history, and they must know the legislation on the use of coercion.

Persons with dementia - activities and quality of life.

The participant learns, based on previously acquired knowledge and own practice experiences, independently to create conditions for new activities and social relationships with and for people with dementia - in both individual and group activities based on the person's life history and personality. Focus is also on communication with the person with dementia and their relatives. Besides, to keep your knowledge in the field up-to-date.

Inappropriate behavior and outward reaction by persons with dementia

Here, participants must work preventively in relation to outreach behavior by people with dementia. They must understand the importance of the environment and the context that the person is living in. They must be able to use concrete tools in working with the person with dementia and have an understanding of what can trigger the behavior. The participants learn to identify dilemmas in the work and take care of themselves

Palliative care for persons with dementia

Based on experience and knowledge of dementia, the participant is learn to identify symptoms and events that indicate that a person with dementia is dying. The participant learns independently and in collaboration

with others to provide a holistic care to people with dementia and together with their relatives contribute to a dignified end to life. The focus is also on the ethical dimensions of care.

3. OPEN EDUCATIONAL RESOURCES AVAILABLE IN DENMARK

Danish Dementia Research Centre (DDRC) is the one organization that publishes open educational resources in Denmark. The DDRC research programs cover a wide spectrum of clinical and translational research, including studies on epidemiology, biofluid markers, brain imaging, neurogenetics, genotype phenotype correlations, patient-specific stem cells, disease course, neuropsychology, drug trials, non-pharmacological interventions and health service research. The research is funded by external grants and donations from public and private foundations. The center is located at Rigshospitalet (the biggest hospital in Denmark) and based in the Department of Neurology. The Danish Dementia Research Centre comprises three sections: Copenhagen Memory Clinic, Dementia and Neurogenetics Research Unit and National Info & Education Centre for Dementia. 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.

3.1. ABC Dementia e-learning

ABC Dementia is a free e-learning program for employees, who work with people with dementia. The course can be taken at one's own pace. ABC Dementia automatically remembers how far you have come from time to time. You learn about dementia through writing, cases, movie clips, exercises and tests. The texts can be read aloud and when all modules have been reviewed you can print a course certificate. The e-learning program consists of four different target groups

ABC Dementia care

Ten modules and a test have been developed. The duration of the modules is from 20 minutes to 1 hour. The target group is people, who work with support and care for people with dementia, for instance social and health care helpers and -assistants, occupational therapists, physiotherapists and nurses.

The modules contain cases, exercises, movie clips, short texts and virtual environments. You can visit the virtual care center "Møllebo" and meet 6 residents with various dementia diseases. You can test your own knowledge in specific care situations. ABC Dementia does not require that you have a specific education or profession.

Contents:

- Dementia
- The brain
- Prevention of behavioral disorders
- Person-centered care
- Collaboration with relatives
- A meaningful everyday life
- Dementia-friendly environment
- Legislation and dilemmas

ABC Dementia for Doctors

The target group is doctors in education in geriatrics, psychiatry, neurology and general medicine. The module deals with assessment, treatment and follow-up in dementia.

ABC Dementia for Doctors is based on specific patient cases and affects both investigation, treatment and follow-up. The individual cases are presented through films, exercises, photos, text and professional illustrations. It takes approx. 2 hours to review. In the course of the development, a number of doctors in education have served as a test panel, and the completed e-learning course has received a positive reception.

ABC Dementia in hospital

The target group is nurses and social and health care assistants in hospitals. ABC Dementia in hospital teaches you about dementia through cases, exercises and movie clips. The entire e-learning takes approx. 2-2½ hours.

Contents:

- Dementia and cognitive impairment
- Person-centered care
- Communication and collaboration with patients with dementia
- Delir - symptoms, treatment and prevention
- Pain and pain assessment
- Collaboration with relatives

ABC Dementia friendly hospital

Target group: Everyone who is working in a hospital. At ABC Dementia Friendly Hospital, you get an introduction to what it is like to be a patient when you have dementia at the same time, or are otherwise cognitively impaired. People with dementia are a vulnerable patient group that you can meet in all hospital wards. Knowledge of dementia can provide better understanding and communication with the patient and thus help increase safety and security. ABC Dementia friendly hospital consists of one module and takes approx. 20 minutes to complete.

Contents:

- Introduction to dementia
- Knowledge of the challenges faced by patients with dementia in hospitals
- Tools to spot patients with cognitive impairment
- Good advice on communicating with patients with dementia
- Ideas for how to create peace and security
- Good cooperation with relatives

3.2. The App: knowledge about dementia

The following is what the app itself tells.

This app is for those, who meet elderly people or work with people with a dementia in home care, nursing homes or at the hospital

1. Why focus on dementia
2. What is the app?
3. Who is behind
4. App language usage, etc.
5. Disclaimer

1. Why focus on dementia?

As age increases, the risk of developing a dementia disease is also increasing.

People with dementia change, become gradually unable to take care of themselves, and are therefore at risk of developing other diseases that can threaten health.

Dementia disease also makes it difficult to express physical symptoms, as dementia greatly affects the person's behavior and thus affect the interaction with others in the daily care.

In your daily contact with the person with dementia, you can observe to ensure proper care and treatment. It is important to be aware whether the person is developing dementia as well as being aware of other symptoms of disease or behavioral changes.

2. The app provides the following tools:

Tools to see changes in the person's physical, mental and social condition.

A quiz where you can test your knowledge of observation of physical symptoms when persons have dementia.

A reference book where you can find knowledge about dementia and symptoms and different subjects in the field of dementia.

A number of good advice that you can apply in your collaboration with the person with dementia, their relatives and your colleagues.

You can also search the app's content via a search function

3. Who is behind

The Danish Dementia Research Centre (DDRC) has developed the academic content of the app. If you have comments about the app or just want to know more about dementia, visit them at

www.videnscenterfordemens.dk

4. App language usage, etc.

The academic content of the app is based on content from www.videnscenterfordemens.dk.

The texts are written with a healthcare perspective on dementia, knowing that other professional areas may highlight other aspects of dementia.

It is also a selection of themes and areas of attention in the field of dementia.

In municipalities, hospitals and in general practice there are not always the same attitudes towards the use of the terms patient, user or person. The words used are associated with different roles and positions.

In the app, the concept of the person with dementia is used, since the care of the persons always should be based on the fact that there is a human being behind the disease.

5. Disclaimer

The information contained in the app "Knowledge about Dementia" may not and cannot be used to diagnose or determine treatment. The information is of a general nature and cannot be used as a substitute for the advice, examination or treatment of a physician. It is therefore essential that you consult a doctor if you have questions or concerns concerning your own or others health.

All content in the app is written by professionals in the dementia area associated with The Danish Dementia Research Centre. The content is descriptive and does not constitute recommendations and guidelines for how to diagnose, treat and care berries.

The Dementia efforts in Denmark are structured differently from region to region and from municipality to municipality. The content is academically approved by a wide range of professionals and will be continuously revised in relation to the research produced in the field.

4. QUALITATIVE REPORT

From 27 of April to the 30. of April 2020, individual interviews were held with experts in the care sector on the situation of the qualification and the proposal for a training CV addressed to caregivers of people with dementia. Due to the Corona crises, the interview were made over the phone.

Participants that were participating in the quatitative report were:

- A Nurse and Health Anthropologist employed at a specialized 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 bacground than Danish
- A Volunteer in elder care activities, DanAge
- An Occupational Therapist and Teacher at Health Care Education

The topics of this research are divided into 3 blocks: current situation of caregivers, contents of a proposal for a training curriculum and proposals for the future.

BLOCK 1. CURRENT SITUATION OF CAREGIVERS OF PEOPLE WITH DEMENTIA

Q1. Could you please describe the current situation of formal² 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 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.

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

There was general agreement among the experts that during the recent years, there has become more and more focus on the importance of teaching subjects and issues related to dementia care in the caregiver educations in Denmark, but still it is not sufficient.

The topics included in the curriculum proposal in this project are all relevant and useful for the day performance of caregivers of people with dementia.

However, it was mentioned that it is important that the material that will be developed, will not only be texts for reading: It should contain also dilemma-games and simulation exercises

² Basic care staff and professionals in the care sector.

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?

Good practice no 1 Re-training in Dementia - Face-to face

The training was organized for social- and health care assistants working in the elder care sector with persons suffering from dementia. The training course was planned as an “action learning” course. It was a 5 days’ course spread over 2 X 2 days and a summing up day at the end. Between the two days, the participants met twice with their trainer and had sparring about the tasks they have solved in the interim periods.

The participants were obliged to prepare for the course: It was assumed that they had completed “ABC – Dementia” (An online course on dementia of about 6 hours) before attending the training course.

The current course level: the European Qualification Framework (EQF) 4

The functional sequences

2 days of training	6 weeks at work 1 meeting	2 days of training	6 weeks at work 1 meeting	1 day Summing up
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The course participants worked with learning loop periods at the workplace between the training days at the SOSU college, for the purpose of transfer. They were divided into staff groups from 4 care homes and they met in learning loop groups at work with the participation of trainers from SOSUØstjylland as facilitators. Each participant had to “identify/select” a person with dementia at their work place, a particular person that they found challenging. On day two of the course, they formulated a problem (dilemmas and action) and based on the dilemmas and action, a task/assignment was developed.

The case was taken home in own work practice. Here the participants applied the theory they have learned to deal with the problem, focusing on the quality of life and well-being of the person with dementia. Actions had to be implemented in collaboration with the leader and learning partners/groups - involving the person with dementia, relatives and colleagues. For the first learning loop meeting, the participant brought a video recording of a situation, where new actions were being tested. (This way of working with new actions in practice, required the consent of the participants.) For the second learning loop meeting, the main topic was how the employee can continue to develop and maintain a person-centered care culture. What are the barriers and how can the organization maintain its implementation; what are your leaders’ tasks and what are your tasks?

Course contents:

Day 1 and 2:

Analysis of function, behaviour and everyday life (Application of ICF, the brain with focus on sensing and perception)

- ICF's thinking applied to people with dementia
- What conditions do people with dementia have?
- Perception disturbances
- Neuro Education
- Appropriate response to the reactions of the person with dementia

- Thinking and theory of everyday life. Social Educational Approach (Tom Kitwood)
- The *person* first of all
- The malignant social psychology
- Strengthening personal identity
- Evidence in the field

Introduction of reflection diary and presentation of the task for 1st learning loop / learning in practice.

Day 3 and 4:

- National Action Plan for the dementia area and the municipality
- Neglect of care and use of power
- Dilemmas
- Life history and activity choices to promote quality of life / Gary Kielhofner)
- Meaningful activities

Work with relatives and volunteers, expecting the parties to agree.

The needs of the relatives:

- to receive information on the course and prognosis of the disease
- to be able to be involved in care and daily activities
- observation of the relative's mental state. Awareness of depression and burnout
- relief
- support and acceptance for the relatives to have their own freedom
- preparation for changed / new identity

Collaboration with the volunteers

- Who are they?
- How do we collaborate?

The good working life and taking care of yourself / Creating a learning culture

- Common reflection among colleagues
- Scheduled dialogues with colleagues or immediate superiors

Preparation for learning loop / learning in practice. Introduction of reflection diary and presentation of task for 1st learning loop / learning in practice. Last day: Collection of tasks, sparring for solutions and suggestions for future implementation and facilitation of questions.

Good Practice no 2 “DEAL” E-learning

“DEAL: Dementia, Education, approach, Life” is an ERASMUS+ KA2 project. The project periode is from 1st November 2018 to 31st December 2020. The rationale of the project is the need for strengthening competences and skills in dementia care. This need is evident for all European countries - even though at

different levels and in different shades. However, in order to increase skills and competences that are RELEVANT, there must be a link – a partnership – between education and work place. The two parts must know each other's' challenges and strong sides, they must work together to improve the training/teaching as well as the quality of the work in the sector. This does not always happen – and causes frustration for both parts.

Strengthening competences can be interpreted in many ways – in the DEAL project is included the aspect of *the approach* to the person with dementia - and that is why the partnership is composed in the way it is: from each of the four participating countries. Denmark, Holland, Italy and Greece there is a partner representing working life (employers of care staff / nursing homes) and one partner representing educational institutions.

The activities of the DEAL project are the following:

- **Workshop on practice in the field of dementia in Denmark, Holland, Italy and Greece:** 2 days workshops at national local level in each country, where representatives from education (teachers/trainers) and care organizations (caregivers) meet, discuss challenges and possible solutions and develop SWOT analysis. The workshops give recommendation for the contents of training material.
- **Development of a training program/training course/training material** in two steps with the piloting in between.
- **Piloting where the applied method is PDSA:** Plan, Do, Study and Act, which is a part of theoretical and methodological framework called System of Profound Knowledge, developed by Edward Deming.
- **Production of a video aiming at elevating the status of the care for people with dementia.** In general, care for people with dementia has a low status. It is considered challenging, difficult and painstaking. People suffering from dementia have a wide range of difficulties such as personality changes, loss of memory, loss of physical functions and agitated behaviour. The care is characterized by ethic and other dilemmas for the caregiver, meaning that it is not always possible for him or her to find an optimal solution, and this can be very frustrating.

The partnership will produce a video promoting the care work for people with dementia. The video will show that it is meaningful and rewarding to work with them in spite of all the difficulties. It will show examples of best practice, sparkling moments and situations where the approach is successful.

Policy report. The partnership will develop a policy report addressing decision makers in the field of education at national level. The report will contain recommendations and suggestions for improvement of the training/education of caregivers giving care to persons with dementia.

BLOCK 2. CONTENT FOR A TRAINING CV PROPOSALQ3.

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 CV proposal

TRAINING MODULES	LEARNING UNITS
M1. Introduction to dementia	<ul style="list-style-type: none"> • The study of the human nervous system. • Most frequent pathologies of the human nervous system. • What is dementia? • Types of dementia. • Other explanations of cognitive impairment
M2. Dementia	Common types of dementia

	<ul style="list-style-type: none"> • Alzheimer's disease • Vascular dementia • Lewy Body dementia • Frontal- temporal lobe disease • Diagnosing dementia • Medical treatment 	
M3. Be aware of aggravating factors	Physical condition/ prevention of complications: <ul style="list-style-type: none"> • Respiratory. • Dental status • Dysphagia • Urinals and obstipation • Dermatological • Pain • Malnourishment 	<ul style="list-style-type: none"> • Hydration Senses and perception: <ul style="list-style-type: none"> • Hearing • Seeing • Tactile • Smell • Taste
M4. Specialized care.	<ul style="list-style-type: none"> • Meal • Personal hygiene • Dressing • Other activities of daily living • Technology and aids 	
M5. How to approach someone with dementia?	Person-centered care (Tom Kitwood) <ul style="list-style-type: none"> • Status of the neuropathological impairment • Status of health • Biography • Personality • Environment, social psychology 	Psychological needs <ul style="list-style-type: none"> • Comfort • Identity • Occupation • Inclusion • Attachment • Love Tips, how to communicate and interact with people with dementia
M6. Attitude towards behavioral alterations	<ul style="list-style-type: none"> • 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 Tips, how to communicate and interact with people with challenging behavior	
M7. Supporting the family of people with dementia.	<ul style="list-style-type: none"> • Family problems caused by dementia • Family restructuring. • Caregiver syndrome. • Caregiver needs 	
M8 Institutional resources.	<ul style="list-style-type: none"> • Assistance, health and economic benefits of Public and Private Institutions. • Associations of relatives of dementia. • Foundations. • Support groups. • Residences 	
M9. Legal topics.	<ul style="list-style-type: none"> • Incapacitation • Tutelage. • Knowledge of the corresponding current legislation. 	
M10. Ethical behavior at workplace.	<ul style="list-style-type: none"> • Freedom as a principle of action. • Ethical principles in psychosocial interventions for people with special needs • Ethical considerations around the family 	

OPINION OF THE EXPERTS ABOUT PRIORITIES FOR CAREGIVERS

Training modules	Priority level: 1 (highest) 3 (lowest)	Opinions of the experts
M1. Introduction to dementia	1	Basic knowledge about dementia is very important for anyone dealing with a person with dementia.
M2. Dementia	1	It is important to know about the different forms of dementia in order to make an individual care plan
M3. Be aware of aggravating factors	1	Necessary in order to reduce the level of conflict with the persons with dementia
M4. Specialized care.	1	Necessary in order to be able to support the identity of the persons with dementia in accordance with their life history
M5. How to approach someone with dementia?	1	Necessary in order to ensure the life quality of the person with dementia, to make him/her feel included, accepted and loved.
M6. Attitude towards behavioral alterations	1	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.	2	In Denmark the family is not the primary caregiver of the person with dementia
M8. Institutional resources.	3	The care system in DK is tax financed and institutions are public
M9. Legal topics.	1	The knowledge about legal topics is necessary to ensure the rights of the person suffering from dementia
M10. Ethical behavior at workplace.	1	Necessary in order to ensure the integrity of the person with dementia. Necessary to ensure a good working environment for the professionals.

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

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. (This is also agreed by Aarhus Municipality)

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?

Strength:

- Covers many important aspects of Dementia,
- Gives a good understanding of challenging behaviors and the reasons behind it
- Illuminates the situation of the caregivers and their challenges
- Focus on the ethical and legal aspects
- Improves the level of competences of the dementia care givers
- Flexibility – you can take the course whenever you have the time

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)

Threats:

- Dependence of the web provider
- Care staff is under time pressure
- Employers do not give priority to re-training /in-service training
- The material does not fit the target group – too high or too low level
- No interest and motivation among care givers for re-training
- The national contexts are different so the training program does not fit to all countries

Opportunities:

- Raises the status of dementia care (certificate)
- Changes the approach to dementia
- Ensures a better care for the person with dementia
- Raises the awareness of the need of assistance from volunteers
- Raises the awareness of the importance of the involvement of relatives in professional care
- Can be used not only in VET but in courses for NGOs

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