Collaboration with relatives op persons with dementia and another ethnic background

Short description of the module

This module consists of three parts, dealing with the education of relatives in regards to manifestation and symptoms of dementia, possibilities of support for the person's relatives and / or support persons in cases when relatives experience excessive emotions, fatigue and psycho-emotional exhaustion. The module provides insight into creating a safe and supportive environment for clients with dementia at home. Last, we describe the collaboration in nursing homes

Subsections

1. Education of relatives in regards to manifestation of dementia and communication with persons with dementia, support systems for relatives and organization of service of persons with dementia
2. Care challenges of persons with dementia
3. Creation of safe and supportive environment for clients with dementia at home
4. Nursing home for persons with dementia and persons with dementia and another ethnic background

Education of relatives in regards to manifestation of dementia and communication with persons with dementia, support systems for relatives and organization of service of persons with dementia

As society ages, adult children increasingly face parental disability, illness and inability to take care of themselves. In Latvia, relatives with dementia are still often cared for at home. This is due to various reasons – lack of vacancies in care institutions and lack of money. However often this choice is dictated by feelings of guilt and fear of condemnation by public. One does not want to be labelled a "bad child"! This is often even more pronounced in families with another background.

The key element in developing cooperation with the relatives of a person with dementia is the education of the relatives, so they understand, what dementia is, how it manifests itself and what prognoses are, so one must provide information about:

- The course and prognoses of the illness, since relatives often believe that the person will get better and the person with dementia will improve his condition. Relatives from another ethnic background may not even share our view on what causes the illness and what it means for the person who suffers from dementia.
- Possibilities of social aid (where one can receive it and what are the main types of social support available, and encouragement to use them)
- Legal issues, clarification of matters as regards capacity to act and emergency help and / or care against the patient's will (inheritance, will, aggressiveness, inability to take care of oneself, life- threatening situations and possible solutions)

The best way to deal with the problem encountered is to help the person with dementia to deal with dementia symptoms him / herself as far as possible, and be flexible and non-judgemental when providing them with help and support. Denial of the diagnosis is a common impediment for receiving support and help in providing care. Denial is most common in the early stage of dementia. It is emotionally very hard to admit to oneself that something is wrong with you and anything is better than the dementia diagnosis. The close relatives feels the same way and may explain away the changes they se. In immigrant families, they may not know the disease or think that it is a sign of getting old.

In a situation such as this, the disease progresses and the person does not receive timely help. Over time, people with dementia know that something is wrong. People react differently, some can be reasoned with and some cannot. Arguing, persuading and trying to prove something to a person with dementia can prove to be harmful because it affects the relation and the person might become restless and confused. Throughout the cause of the disease, one should acknowledge the patient's current perception of reality

Dementia affects all family members and the family as a whole significantly. The biggest physical, emotional and financial load falls on people, who have taken on the everyday care of a dementia patient. The additional emotional burden of not knowing, how long one will have to work in such difficult circumstances – poses risks to the physical and mental health of carers, who often experience symptoms of depression and anxiety, various illnesses.

An accessible and helpful form of support is – support groups for relatives of dementia patients. Participants of support groups have mentioned the following from being part of the group:

- Support and possibility to meet people, who are in similar circumstances;
- Possibility to leave the house, meet people;
- Practical ideas in dealing with difficult situations;
- Information gained as regards social services for people with dementia and their carers;
- Learning to live with the sense of loss, mourning, guilt, anger and other emotions, which arise in the process of caregiving;
- Mastering new stress management methods, such as relaxation, etc.

However, it is known that people with another ethnicity are less likely to accept help, due to different circumstances. They keep to themselves, they might have language barriers, and they could think that it is inappropriate to get help because they themselves should take care of their own parents and so on.

Various support methods (for example, sufficient informative and material support, training, support in providing everyday care, dealing with difficult situations) can diminish health risks and improve life quality of the relatives of the client and / or support persons. It is important that the citizens of other ethnicities can get the information in their own language and that we consider how to get hold of people who are illiterate.

According to the data provided by America National Association of Relief for Relatives of Dementia Patients, work with dementia patients is three times more labour intensive, than is usual. Caring for a person with dementia is much more difficult psychologically, than caring for a patient with somatic illness. To lessen the emotional load, caregivers / support persons / relatives must understand that they are unable to change anything. All they can do is provide care and love.

Positive answers to all emotions of the person in care will help maintain calm and reassured, which will benefit both: the person with dementia absorbs and "mirrors" the emotional state of the caregiver. Moreover, this is working even by persons with severe dementia, who has decline in mostly all cognitive function.

Gerontologist Laura Veimena in her book "Parunāsim par demenci"/ "Let's talk about dementia" suggests that, "Caregiver, who is familiar with specifics of dementia, thinks about his / her future and takes care of his / her health. He / she will not change this principle, even if the patient will have to move to an establishment for people with impaired memory or another appropriate establishment. As you will begin to expand your knowledge about dementia, a deep and meaningful relationship can develop between you and the person you care for. This will give you strength and confidence to take care of your loved one."

Creating a support plan for a person with dementia

It is imperative that a person with dementia maintains physical, cognitive and social activities, that help improve functioning, interpersonal relationships and well-being of a dementia patient, the goal being to maintain as high a quality of life in at all stages of dementia as possible.

Various social support services are needed, to meet individual needs of a person with dementia:

- information, training and support for life with memory problems for people with dementia and their caregivers;
- intensive support and rehabilitation;
- support groups for people with dementia and their caregivers;
- counselling (of a psychologist) and emotional support;
- independent advocacy (to avoid someone taking advantage of people with dementia);
- support for employment and daytime activities;
- information about benefits and care possibilities provided by the state;
- support in planning future, for example, matters regarding inheritance and guardianship;
- choice and accommodation of living space;

- help at home and outside of it, possibly, an assistant;
- helpful technologies;
- planning and support for crisis situations.

Being conscious of an existing support plan, various activities help reduce stress and promote socialization. A person with dementia can make optimal use of his / her remaining abilities, retain self-esteem and a feeling his / her life has a meaning.

Poor well-being and behavioural problems may also be caused by secondary factors and symptoms, not directly related to cognitive disorders. When planning daily activities one must take into account various factors, for example, physical health, pain and other physical discomfort. One must establish whether the person has symptoms of depression and anxiety, what medication the person is using and whether or not it has side effects. It is important to mind the person's previous life experience (culture, faith), physical environment and psychosocial factors.

Social support services for a person with dementia

To determine the set of support services for a person with dementia, levels of care are distinguished:

1) First level of care — the person's physical or mental abilities are moderately limited. He / she is able to and does perform self-care in accordance with his / her needs and state of health; requires minimal support of the staff for a certain number of hours a week. Provider of the social care service ensures supervision of the client as specified by the medical practitioner; usually we do not see people with immigration background in the system at this stage.

2) Second level of care — the person's physical or mental abilities are moderately or severely limited. He / she is able to and does perform self-care in accordance with his / her needs and state of health, but there is a possibility of a decrease in abilities or skills; a little support of staff needed daily. Provider of the social care service ensures supervision of the client as specified by the medical practitioner and observes the changes in functional disorders; At this stage persons with immigrant background is absent in the system

3) Third level of care — the person's physical or mental abilities are severely limited. His / her abilities to perform certain self-care actions is impaired; needs regular support of staff on a daily basis. Provider of the social care service ensures supervision of the client as specified by the medical practitioner and observes the changes in functional disorders; still people with immigrant background is absent or very rarely in the system

4) Fourth level of care — the person's physical or mental abilities are severely limited, pronounced inability of self-care, the person is needs complete care and supervision all day-and-night. Provider of the social care service ensures supervision of the client as specified by the medical practitioner and observes the changes in functional disorders. At this stage, we begin to encounter more and more persons with another background. The relatives are now worn out and cannot take care of their relatives any longer. This often means that they are too late to get the

help they needed, they might have become ill and the person with dementia will have problems settling in.

Based on the results of the assessment of an individual’s needs and established level of care, following social care services are provided:

A person with level 1 or 2 of care could be in need of – boarding house, day care centre, nursing home, with “safety button” service included, group home (apartment) or another social care service at the place of client’s residence.

A person with level 3 or 4 of care – services in an institution of long-term social care and social rehabilitation, if services in the place of residence are insufficient to provide necessary social care there is sometimes possibilities to move to a nursing home

Social support services (care level 1 or 2):

Service "Safety button"

Service "Safety button" possibility for continuous communication, informative support and assistance twenty-four hours a day for persons, who are at risk of finding themselves in a helpless position due to age or functional disorders.

"Safety button" operates with a special intercom, equipped in accordance to individual special needs of a person. One push of a button alerts the alarm transmitter, which connects to Home Emergency Service Central. Specially trained specialists then get in contact with the customer of the “safety button”, assess his / her situation and provide appropriate assistance. If necessary, a spare key service, emergency medical team, relatives, neighbours, family doctor, caregiver, and other specialists or services are involved. Emergency assistance and care is available 24 hours a day, including weekends and public holidays.

Service of companion - assistant

Service of companion-assistant provides physical and informative support to persons, who lack skills needed for communication and need the presence of a companion / assistant, or whose physical or mental disorders encumber their movements outside their place of residence, when visiting state or municipal institutions and organizations to tackle household matters, as well as health care service providers.

Service "Warm meals-on-wheels"

Delivery of warm meals to the place of residence is provided to persons, who, due to physical or mental disability, are unable to prepare warm meals, and to persons, who cannot cook due to their conditions.

Service of video-visit

Service of video-visit provides remote monitoring and daily communication possibilities in the place of residence for persons, who receive home-care services from a care provider with the goal to provide the persons with the possibility to maintain as independent a lifestyle as possible and to prevent deterioration of a person's emotional state.

Home care service

Home care service is a social and – health care services delivered by a social service provider, including adjustment of accommodation and technical aids and staff for persons who require care services and wish to continue living in their place of residence.

Day care centre services for persons with dementia

Day care centre for persons with dementia (all day):

- provides social care and social rehabilitation,
- succession of rehabilitation process,
- maintaining of social skills,
- educational and leisure occupation,
- participation of clients and their relatives in solving specific social problems,
- ensures psychosocial assistance to relatives of the clients,
- support and self-help group activities,
- organizes the conjunction of social resource system to solving the problems of specific individuals, social groups and society.

Social care services (level 3 or 4 care):

The service of a long-term social care and social rehabilitation establishment for persons with dementia includes planning and providing the content and scope of social services according to the client's needs, explaining the goals, scope and regularity of the social services provided, and the necessary changes in accordance with the client's changing functional condition or other circumstances. It is important to involve the client's family or household members in the process of providing social services, if deemed necessary. Supporting persons provide the maintenance or development of the client's cognitive abilities, introduce activities that promote development of skills and movements, as well as leisure activities and relaxing activities, such as walking in fresh air – that is, social services and social assistance needed by each client individually.

Particular challenges in diagnosing dementia in people from ethnic minority groups

There may be particular challenges associated with diagnosing dementia in people from minority ethnic groups, and it often takes several years from the first symptoms appear until the diagnosis is made. This may be because they do not recognize the early symptoms of dementia, but perceive them as common signs of aging such as forgetfulness. Linguistic, cultural and educational factors can also challenge the diagnostic assessment. In particular, the use of formal cognitive tests usually requires knowledge of the language and culture as well as skills acquired in school. It often takes a long time before the diagnosis is established and this only happens when there are severe cognitive impairments or behavioural changes.

In some cases, linguistic and cultural factors may affect the symptom picture. For example, cultural expectations of older people can lead to memory and everyday level of functioning being perceived as relatively well- preserved for some time in the course of the disease, and an early symptom of dementia in multilinguals is often language difficulties in the most recently acquired language.

When people from ethnic minority groups come to the doctor with cognitive complaints, it is therefore important to overcome any language barriers, e.g. by using an interpreter, and be aware that linguistic, cultural and educational factors can affect the performance of a cognitive test. In addition, psychological and behavioural changes in dementia (BPSD) can be expressed and experienced differently in different cultures. It can be an additional burden for both the person with dementia and the relatives who experience such atypical symptom pictures. Not only is there often limited knowledge about dementia in ethnic minority groups, but if the person with dementia has atypical symptoms that the outside world does not associate with dementia, it can be experienced as particularly stressful.

In some cultures, there is a strong stigma associated with dementia and mental illness. The families isolate themselves or become isolated in the local environment. In some cultures, the disease may be perceived as spiritual obsession, or one may think one is affected because the family has not been strong enough in their faith. It is not something you want to show to the outside world, and asking for help can be perceived as shameful.

Many families with ethnic minority backgrounds see it as a natural duty to care for and care for their elderly family members until they die. Receiving help is almost the same as saying that it is too hard or too difficult to care for an elderly family member. In practice, this means that in many families you have your old parents living in, or that you move in with them yourself. The dementia disease can have great significance for the family, who often have to take over the home, both in relation to practical and financial / administrative conditions. It can have major consequences for the family if you also have work and small children. It can also cause conflicts in the sibling group, for who is to take care of mom or dad? Often the daughter or daughter-in-law is given the responsibility of caring for the elderly. She does, but may think it's unfair, and then conflicts can arise. Family life, both in terms of the division of roles and dynamics, often changes markedly. In many cases, there will be an expectation that adult children and possibly grandchildren will take over if elderly family members become ill and need help and support.

It can be particularly important for people with dementia from ethnic minority groups to meet like-minded people and caregivers who speak the same language, for example in day care and nursing homes. It is also important that they have activities that match their wishes and needs, and that fill everyday life with linguistically and culturally meaningful activities, if they are to be able to actually participate in activities outside the home.

Several international population studies have confirmed that there is a tendency for an earlier onset age and greater incidence of dementia in some minority ethnic groups. It is believed that this is related to a greater incidence of risk factors that can lead to dementia in these groups, such as high blood pressure, diabetes, blood clots and low level of education / socioeconomic status.

Care challenges for clients with dementia and another ethnic background

Interacting and communicating with clients with dementia, families face both challenges and gains simultaneously. Among other challenges, there are the excessive emotions, associated with deterioration of a loved one's abilities. At the same time, family members experience fatigue and exhaustion due to intensive involvement in all processes. Many experience isolation and loneliness, as well as financial and employment difficulties – a client with dementia demands full attention, which reduces one's opportunities for socialization and active involvement in everyday activities.

Benefits for the family involved in the care process are a deeper emotional connection with their loved one. At the same time, family's skills of problem solving and building relationships may improve and develop, to be able to better and more systematically support their family member with dementia. If family members attend support groups, new relationships, new experiences are formed.

Whilst looking after a person with dementia, carers can develop a sense of guilt, which is a distracting factor for the support person / relative / carer. Even though the support person feels emotionally stable in the existing situation and accepts full responsibility for the process of looking after a person with dementia, many relatives / support persons are experiencing a sense of guilt and feel psycho-emotionally drained. Support providers and carers may feel emotional stress, since they are not always able to do everything necessary, which might spark a sense of shame and inability to enjoy one's personal life and achievements.

These unfounded emotions are extremely destructive and can lead to depression and tension – physical, psychological and emotional – and, as a result, to serious depression and nervous breakdown. It is of paramount importance to know and remember: if the "caregiver / healthcare provider" will not take care of him / herself, the care provided to person with dementia will be of poor quality, because the persons with dementia "read", absorb and "reflect" the psycho – emotional state of their caregivers / relatives.

Relatives / support persons / caregivers may feel loss in relation to the person with dementia, when losing emotional and cognitive connection with one another.

A person with dementia gradually stops playing his / her social role in daily life. The existing situation changes all aspects of life – both domestic and social. Over time, a person with dementia will eventually lose his / her physical and mental abilities, and at some point will no longer understand many everyday things and will not recognize his / her relatives. This will result in a significant change in family relationships, making it impossible to return to the previous situation.

Relatives with another ethnic background have the same challenges as everyone else who cares for a person with dementia but they use the service system less. It is not yet sufficiently investigated why elderly people from ethnic minorities with dementia do not make so much use of health care and municipal services. However, this may be due to a lack of knowledge about dementia and existing services, cultural differences in the view of who is responsible for supporting and caring for older family members and cultural and linguistic barriers to using the existing services. However, the right action can increase the quality of life for the person with dementia and reduce the level of stress for the relatives. This is even more crucial in relation to ethnic minorities, where the relatives often have cared for the person with dementia for a long time without any specific knowledge of dementia or any kind of dementia support, assistance or counseling. There is compelling evidence that caregivers of persons with dementia themselves are at risk of becoming ill.

Creation of a safe and supporting environment at home for persons with dementia

When taking care of a person with dementia it is important to establish the client’s self-care skills (whether the relative is able to feed him / herself, go to the toilet and clean up after that, wash, maintain his / her personal hygiene, dress, among others, in accordance with the season and weather conditions, etc.).One must establish, whether he / she is able to independently find his / her way around his / her immediate surroundings, move around independently and communicate with other people, and recognize his / her relatives, etc.

Cooking, housekeeping, doing laundry, taking of medication, use of telephone, planning and managing of one’s budget, visiting a store and shopping, use of transportation are all and important part of everyday life for a person with dementia. Therefore, it is imperative to understand, if the person with dementia is currently able to independently cook, clean the house, use the telephone and simple household appliances (electric or gas stove, washing machine, etc.). Can the person use the medication prescribed to him / her in accordance with the doctor’s instructions, independently plan and manage his / her finances, do his / her own shopping, use public transportation, etc.

Visual support can be of great help to provide the person with dementia support in everyday situations and grant him / her as much independence in self-care as possible. For example, portable whiteboards or billboards with photographs, that show the sequence of things to be accomplished during the day, or the sequence of cooking a meal, the sequence of getting dressed, etc.

Check home safety:

- Remove carpets,
- Ensure good lighting
- Write „names” of rooms or give them other mode of identification (for orientation).
- Assess the safety of surroundings.
- Mark your loved one’s clothes with his / her name, address and telephone number.
- Use clothing with easy to do up fasteners (not buttons and zippers).
- Provide the patient with food he can eat whilst moving.
- Stay close during meals and when taking medicine.
- Warn your neighbours about your loved one possible could stray from home.
- Inform the police and provide them with a photograph of your loved one.
- Provide your loved one with a safety bracelet.
- Install safety switches on the doors.

To a relative of a person with dementia, who is someone with memory disturbances, confusion and difficulty learning new things, it might mean, and that their loved one may forget where the things he / she needs are placed and how to use them. Adaptation of space and environment can help a person with dementia orient him / herself and be independent; therefore, they must be equipped as best suits the needs of a person with dementia:

Lighting

Good lighting reduces the risk of possible confusion and falls, it ought to be as even and natural as possible, it is advisable to limit reflections and shadows. Leaving curtains, open can provide better lighting, giving up blinds, and not obscuring windows with plants. Light switches must be easy to find and comfortable to use, automatic lighting with motion sensors (which turn on when the person enters) can also be used. Vision should be checked regularly.

Restriction of noises

People with dementia often complain of background noises. One must take into account, that carpets or curtains absorb background noises, whereas tiles and laminate do just the opposite – they amplify noise. If a person with dementia uses a hearing aid, this amplification of sound may cause discomfort. A television set or a radio left in the background can also create redundant noises. In any case, a person with dementia needs regular hearing check-ups. Noise also reduces the ability to concentrate.

Safe flooring

Rugs or smaller sized carpets should be avoided – people with dementia may perceive them as objects that need stepping over, and fall. Glossy flooring may give an impression that the floor is wet and it may seem to your loved one too dangerous to move around on. The most suitable flooring is a carpet with colours that are in contrast with the walls, one should avoid colours of natural objects, for example, green (grass) or blue (water). Many persons with dementia have disturbed perception of senses.

Contrasting colours

It is advisable to choose objects of contrasting colours. For example, bright furniture, that stands out against the tones of walls or flooring, a toilet rim of a different colour, e. t. c. To avoid confusion, do not chose variegated or striped patterns. This is also important in connection with eating; the food and the plate should be different colours

Reflections

Mirrors, reflection in windows, may cause confusion and anxiety; the person may not recognize him / herself. This also apply with pictures, they may be perceived as if someone is looking

Reminders

Inscriptions or pictograms on doors of various spaces, for example, toilet may facilitate orientation. Pictograms on cabinet doors, drawers are also helpful. Reminders ought to be clear, contrasting, with both the denoting word and pictogram on them, and situated slightly lower than usual, because older people tend to look downward.

Household objects

It is possible to purchase household items especially suited for people with dementia, such as clocks / watches with a large display, showing the day, the date and time, telephones with large keys, appliances that provide automatic reminders (for intake of medicine, locking the door, etc.). The abovementioned appliances are sometimes called assistive technologies. The tables should be of appropriate height, stable, with rounded corners.

Fall risk prevention for persons with dementia living in their own home

If the client's relatives are made aware / educated about the risks of falling, everyday life of a person with dementia is safer. Preventive measures to reduce the risks of falling in one's home:

- 15 minute long, regular exercises to improve muscle tone strength, endurance and equilibrium of a person with dementia
- If possible, walks and attending of a swimming pool
- Performing of everyday activities in a safe way, avoiding over excessive bending or stretchind. If a person with dementia is bending down or getting up from a chair, he / she needs to lean against something, to restore equilibrium
- Use footwear of an appropriate size, with low heel and non slippery sole
- Mind that the glasses of spectacles are clean, if the eyesight of a person with dementia deteriorates
- Mind the side effects of medicines used by the person with dementia
- Provide for sufficient lighting
- Avoid carpets indoors
- Place furniture so as not to obstruct one's way
- Use contrasting colours in decorating the rooms
- Avoid chairs on wheels
- Place rubber mats at the sinks
- Avoid slippery flooring surfaces

To promote a supportive environment, the planning of daily activities of a person with dementia includes:

Everyday activities

1. Household chores: cleaning up, work in the garden.

2. Meal: preparing of and enjoying a meal.

3. Self-care: washing up, shaving, getting dressed.

Planning of the day

4. Getting to know daily activities of a person with dementia and agreeing upon daily plans.

5. Revise daily schedule and identify fields in which the support is needed.

6. Optimize daily schedule.

Pleasant activities

8. Identify and plan pleasant activities.

9. Realize the planned pleasant activities.

Other activities

10. Creative: drawing, playing of a musical instrument.

During daily activity, persons with dementia may experience negative emotional reactions (anger, denial, refusal to collaborate, anxiety, etc.). Anxiety or aggression may be a way for a person with dementia to signal their emotions and needs – for example, aggression may be a reaction to helplessness, frustration and confusion. The person who feels unheard or misunderstood, endangered or scared may well react with aggression. Sometimes a loved one feels embarrassed or irritated, because he / she needs help with chores he / she used to perform on their own. Because of this, the person refuses to do the things he / she does not wish to do.

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