

Communication with persons from another ethnic background with dementia

Short description of the module

Methodological recommendations provide a brief overview of basic principles of communication in work with a person with dementia, about the formation and maintenance of positive communication, as well as the impact of the communication on the client / patient's quality of life. The module provides an insight in how to build positive communication with a person with dementia and another ethnicity. This module includes suggestions on how to develop a more successful mode of communication with clients with dementia, their relatives and caregivers.

Communication with a person with dementia

Problems connected to language can manifest themselves in various ways, depending on the individual and the stage of the disease, but they occur in all types of dementia, because of language control centre of the brain being affected. Language disorders include the inability to find the correct words, or the person is speaking fluently, but without meaning, etc. Thought processes of a person with dementia are seriously affected, this in turn affects their ability to communicate.

In later stages aphasia occurs. This is marked by loss of speech articulation and the ability to perceive the speech/meaning of what is said by others. People, who have known the person suffering from dementia and have been in contact with him/her for longer periods will have an easier time establishing communication. In later stages of the disease the person with dementia has difficulty speaking and perceiving words, so body - language ought to be used – calm and safe movements, as well as gestures the person with dementia might recognize and perceive, thus creating a common system of signs. With the disease progressing, it is possible touch becomes the only means of communication.

Communication consists of three components:

- body language – facial expression, posture, gestures;
- tone of voice and pitch;
- verbal language – words.

Patient care often is mentioned in connection with innovative approaches. However, the key to a good daily life for persons with dementia is stability and routine. Simple sentences and constancy of habits are a basic condition for the care of a client with dementia. Before choosing the type of communication, it is imperative to identify, which type of communication is most easily perceived by the client. A person with dementia has difficulty following a conversation, especially with several people talking at the same time.

When the condition develops and the disease progresses, the person might no longer be able to express him / herself verbally, which may cause anxiety both in the patient, as well as his / her caregivers. This might mean that the person is unable to convey feelings of pain, discomfort or

sickness. In order to start communicating with a person with dementia, it is very important to prepare for the conversation and tune into it.

Verbal communication

Dementia is defined as a memory disorder with disturbances to at least one other cognitive function, such as speech (aphasia) or executive function (for example, planning attention or abstract comprehension). Speech is the ability to express thoughts and ideas through words, in order to communicate with others. We need to separate language from speech. Speech is the motor performance of conversation. One of the symptoms of dementia, amongst all others, is the inability to find words, form sentences and understand what is being said.

Difficulty in communication is one of the earliest symptoms of dementia especially in Alzheimer's dementia. Language disorder is the main problem for most patients with dementia, especially when the illness progresses and crosses over from a moderate to a severe stage. The first sign of impaired communication of a person with dementia is the inability to find words, especially when naming persons or objects. The person might substitute the word with an incorrect one, or similar one or not find a substitute at all. Progressing dementia causes a person to forget names of one's family members, friends, causes confusion in regards of family relations; not recognizing one's family is a common trait for persons with dementia.

- When starting a conversation with a person with dementia, give them enough time for processing of information and coming up with an answer. One should attempt to allow a person with dementia to express their thoughts fully and to choose their own words at all times.
- Guessing what a person with dementia is saying should be avoided.
- Speech disorders can be perceived as a weak speech system, which involves difficulty in finding words, recalling words or anomie. People with dementia use fewer words, less common words, less foreword phrases, less compound sentences and more incomplete fragmentary sentences.

Lexical deficit tends to be more severe than syntax deficit, which confirms the hypothesis, that lexicon of a person with dementia is more sensitive than syntax. A person with dementia speaks slowly, articulation is distorted, and one replaces sounds, uses unnecessary pauses, tends to start sentences anew, segments syllables and has difficulty forming long sentences. The ability to communicate decreases over time to a point, where a person with dementia is only able to express him/herself in one syllable.

Before entering a conversation with a person with dementia, one should assess environmental risks, which might impede communication.

- Environment – good lighting, minimal distractions in the background
- Attention – all attention prior to communication must be paid to the person one is communicating with

- Position – one ought to position oneself in a place, where one is seen by the communication partner clearest; one ought to be able to look each other in the eyes
- Proximity – one ought to be close, but not invade the other’s personal space. This point is culturally very different
- Body language – be open and relaxed. This is also a matter of culture what you perceive as relaxed
- Time – it is enough just to spend time together with a person; if you feel rushed or tense, relax a little, because the other person will feel your emotions
- Prepare – think and plan topics for your discussions, use the environment to improve communication
- Time – use the time of day when one feels most “awake”
- Fluctuations – days can be different, so use the best days and find means to adjust to the “bad” ones
- Other needs – such as thirst, hunger, should be met before the start of the conversation

How to speak:

- Clearly and calmly – language should be simple, sentences and questions – clearly formulated.
- Tempo – a little slow, allowing for time to process sentences and find the answers.
- Tone – avoid sharp, elevated tone.
- Short and concise - short, simple sentences.
- Flow – talk conversationally, avoid posing several questions simultaneously.
- Speak with them, not about them – be patient and respectful, do not speak as if they were not present, or as you would with a child.
- Humour – try to laugh about mistakes or misunderstandings with the patient. It might improve therapeutic interaction and lessen tension BUT be sensitive and do not laugh about the person.
- Inclusion – include the person in conversations with others, that might call for slight adjustment in terms used. This might help a dementia patient keep a sense of identity and self-worth and lessen the sense of isolation and exclusion at the same time.

What to say?

Avoid asking questions that require that you know facts

Questions – avoid a too broad or complicated format, as it might evoke dissatisfaction or agitation, if the person cannot find an answer.

Closed questions – might be most appropriate, because open or optional questions might cause confusion.

Concentrate – stick to one idea at a time. Giving the ability to choose is important, but too many abilities might be confusing.

Understandable information – if a person has trouble understanding, divide information into sections for it to be easier manageable.

Rephrase, not repeat – use non - verbal communication as an aid.

Short and frequent interaction – if the person is easily tiresome.



Promote or correct? When we reprimand or correct a person with dementia because he or she cannot remember things correctly or repeatedly makes the same mistake, it is often an attempt to hold on to what the person once was. However, the reprimands often create conflicts and great frustrations for both parties. If we continue to reprimand, it can help to create anger or break down the dementia sufferer's self-image and ultimately his or her self-esteem.

Listen

Listening is one of the most important elements of communication, and it is more than just a physical hearing process. Active listening is the highest form of listening, and therefore it is a special communications skill. It requires listening not only to what is being said, but also to capture the intentions and feelings of the speaker. This should be done slowly, using appropriate body language, showing interest in the speaker's words.

It is a vitally important tool in communicating with a person with dementia

- Listen – carefully, offering encouragement
- If you do not understand fully – rephrase what was being said and check, whether you have understood correctly. The speaker's reaction and body language are good indicators.
- Alternative formulation of phrases – if a person has trouble choosing the words or finishing a sentence, ask him/her to explain it differently. Observe their body language, facial expressions and behaviour, because these can give you clear indications about how they are feeling and help you understand, what is being said.
- Do not rush – devote plenty of time to respond, because processing information and answering can take even more time?
- Do not interrupt – as it can break the thought model, therefore wait.
- Expressing feelings – whether they be sad or happy, let them express what they are feeling. Sometimes it is best to just listen and show that you are there.

In verbal communication, one ought:

- To speak slowly, in short sentences, using easy words,
- To remind who one is once in a while, when meeting every time state one's name,
- Do not to show anger, if the person repeatedly asks: who are you?
- To pay attention to one segment of information, discuss what has been said,
- To ensure your interlocutor is using hearing-aid or glasses, if he / she has hearing or visual impairment. Glasses will help him / her read your lip movements,
- To see that the room is well lit,
- To show a calendar, watch, photos and other items of personal significance,
- To not ask questions, which demand good memory,
- To find out how a dementia patient is feeling and what has changed his / her mood, if the patient has become verbally aggressive,
- If the patient has become verbally aggressive, to change the theme of the conversation to a calmer, more secure one, as it might provoke aggression in the patient,
- If the person with dementia is hallucinating, do not contradict his / her misleading conceptions, acknowledge his / her feelings, try to reorient him / her to reality,
- Music is an important background to a conversation; a client's relative knows the patient best, he / she knows, what music he / she has listened to; maybe it is possible to have background music that calls forth memories

Non-verbal communication

The more the disease progresses, the stronger the non-verbal connection. Intonation is stronger than words. In later stages a touch and a calm smile is more effective than affirmations and words of support, which are undoubtedly important at the time illness is just starting to develop. Non-verbal communication is communication without words – with the help of gestures, facial expressions, postures, eye expressions and different sounds. Non-verbal signs and signals are used to replace and supplement verbal information. Non-verbal communication is older than the verbal one. Non-verbal communication is controlled by subconscious. Non-verbal communication provides information about a person's inner experiences, his/her emotional state. Sometimes these means are more eloquent than words. Australian "body-language" specialist A. Pease claims, that words convey 7% of information, sound (such as voice, intonation, etc.) - 38%, facial expressions, gestures, postures (non-verbal communication) - 55 %. In other words, we can say, that what matters is not what you say, but how you say it.

During non-verbal communication, it is important to note:

- Whether the person with dementia recognizes you,
- How he / she reacts when seeing you,
- Watch his / her body-language is expressing.

Non-verbal communication can be the main instrument, especially with progressing dementia. In later stages of the illness it can become one of the main means of communication. It is therefore important to learn to control and use one's body language to gain information from people with dementia. It is also important to be able to correctly interpret a person's body language and

recognize what is being said, to offer safe support in their communication. Use of pictograms might also be useful.

Means of non-verbal communication are necessary to:

- Regulate the process of communication, create psychological contact between interlocutors;
- Enrich meanings behind said words, promote interpretation of the verbal text;
- Express emotions and depict interpretation of the situation.

There are 3 main systems of symbols in Non-verbal communication:

Optokinetic symbols:

- Facial expressions – eyes, a look conveys information best. The mouth shows both positive emotions – such as joy, excitement – and negative ones – anger, fear. Brows can express surprise, anger.
- Gestures – complement verbal information, express emotions constantly.
- Postures – show attention toward the interlocutor and the theme of the conversation.

Paralinguistic symbols:

- Tone of voice (timid, aggressive, business-like)
- Timbre of voice (high-pitched, gruff)
- Pitch of voice (low, high)

Extra linguistic symbols:

- Various noises (hm, ē, nū)
- Laughter, cry. They include: intervals, sighs, cough and regulate the flow of speech. They complement and maintain speech connections, substitute and express verbal utterances and demonstrate emotional states.



Gestures and posing. People evaluate one another even before they speak. So, just by assuming a certain posture or walking you can make an impression as a very self-assured or – quite the opposite – very nervous person. Gestures allow one to emphasize the meaning of what has been said, add meaning to and express emotions, however one must remember not to exaggerate with

this in, for example, business communication. The nonverbal communication is highly dependent on cultural upbringing and norms.

Facial expressions, outer appearance and facial expression. One's face is the main transmitter of one's mood, emotions and feelings. Eyes are deemed to be the mirror of one's soul. Many lessons on helping children recognize emotions start with identifying basic feelings as portrayed in pictures (anger, fear, joy, surprise, sadness, etc.). However, in some cultures it is impolite to look people in the eyes.

Distance between interlocutors and touch. The person him/herself determines the distance, which makes it comfortable to communicate with others and the ability to touch other people depending on the closeness of individual interlocutor.

Intonation and vocal qualities. This element of communication combines both verbal and non-verbal means of communication. With the help of various intonations, volume, voice signals and rhythm one phrase can be expressed in such different manners as to change its meaning to a opposite one. Intonation with which words are uttered transmit feelings, for example, joy, excitement, fear, anxiety, anger and sadness. A person spends one's whole lifetime learning to recognize feelings, that are transmitted by intonation of others.

Create a positive mood for communication. Attitude and body language convey feelings and thoughts more clearly than words. A positive, respectful attitude, facial expression, tone of voice and physical touch will help convey your message and demonstrate your wish to help and collaborate.

Engage the person's attention. It would be best to diminish interferences and noise – one should turn off the radio or television, close the door or move to a quieter environment. Before you speak, make sure your interlocutor is ready for a conversation. It would be preferable to address the person suffering from dementia by name, to identify oneself by name and connection, as well as use non-verbal cues and touch, to help concentrate on the conversation. It is important to maintain eye-contact and be on the same level as your interlocutor.

To formulate the message and/or information clearly and thoughtfully. Use simple words and sentences. Speak slowly, clearly, and surely. Refrain from speaking more loudly. If the person does not understand the message or question the first time, repeat it, using the same wording. If the person still does not understand, wait several minutes, and formulate your question one more time. In stead of pronouns (he, she, they) or abbreviations use names of people and places.

Ask simple questions. Ask just one question at a time; "yes" or "no" questions are best. Refrain from asking open questions or giving too many choices. For example, ask: "Which shirt would you like to wear? The white one or the blue one?" Or better yet, show them their choices – visual prompts and indications help clarify the question and might help with finding the answer.

Listen with your ears, your eyes and heart. Be patient, wait for an answer. If you see the person struggling to find words, you may suggest the possible variants. Follow non-verbal clues and body-

language, react accordingly. One ought to always listen for the meaning and feelings behind the words.

Divide activities into several sections. This will greatly facilitate completion of many activities. You can encourage your loved one to do everything possible, gently remind him / her of the steps he / she tends to forget and help with the steps he / she can no longer complete on his / her own. Use of visual cues, for example, gesturing to where dinner plates are, can also be very helpful.

When communication becomes difficult, try to distract attention and make a pause. If your communication partner is distressed, try changing the theme or environment. This can be achieved by, for example, asking for his / her help or going for a walk. Before distraction it is important to communicate with the person on an emotional level. You may say: "I can see that you are feeling sad – I'm sorry you are distressed. Why don't we go and grab a bite to eat?"

Answer with confidence. People with dementia often feel confused, worried, and unsure of themselves. They also get mixed up and can confuse reality by "remembering" things that have never taken place. Try to avoid attempts to prove them wrong. Concentrate on the feelings they express (which are real) and answer with expressions of verbal and physical comfort, support and assurance. Sometimes just holding hands, touching, embracing, and praising a person will work and they will react when all else fails.

Remember the good old days. Remembering the past often times is a soothing, reassuring activity. Many people with dementia might not remember what happened just 45 minutes ago, but at the same time clearly recall their lives 45 years ago. One should therefore avoid questions based on short-term memory. For example, do not ask a person what they had for dinner. Try asking general questions about a person's past instead – it is very likely this information has remained intact.

Do not lose your sense of humour. Use humour whenever possible. However never at the expense of the person with dementia. People with dementia tend to keep their social skills and usually love having fun and laughing together.

One of the conditions for successful communication with the client is creation of a well-thought-out environment. The client should be around his favourite and beloved personal belongings, things connected with memories and evoking positive emotions (such as a favourite pieces of clothing, picture albums, favourite press releases, books, cards, various nick-necks, sorting through which is amongst favourite soothing pastimes, etc.)

Retaining of communication abilities is the key to promote the client's connection between the institution and the real world outside it. Encourage the client's wish to write letters, read newspapers, take a bus, attend events, etc. All of this will promote maintaining a close relationship with client's relations, friends.

The above basic rules for communicating with people with dementia also apply to people with a different ethnic background. For immigrants who have learned another language in adulthood, this can be an additional challenge, as the later learned language is usually weakened first. The

mother tongue is often preserved longer, but in many cases, it may be a language not spoken by the nursing and care staff. Language barriers can therefore be a major challenge in multicultural care for the elderly. Such barriers can also lead to isolation and loneliness and in some cases to the person with dementia being considered to have more advanced dementia than is actually the case. When you have dementia, it is important to be able to speak the language you master best. Experience shows that it is advantageous to connect nursing and care staff and people with dementia who have a common language and common cultural background, but this should be discussed with all parties in advance. Such interconnection can contribute to a greater quality of life in the form of security and increased well-being. A common language can make it easier to understand cultural values and traditions, and ensure good and adapted services throughout the course of the disease. Nevertheless, you should be aware that some immigrants with dementia do not want treatment and care from people with the same background. There may be hierarchies and caste systems that make contact difficult or vulnerable.

Learn some common, everyday words, expressions and song stanzas in the person's native language. By using words and phrases from the other person's language, you show that you value the person and that you are curious and interested. It can create security, act as a distraction in difficult situations, and can help alleviate restlessness and anxiety. A creative use of the other's language can strengthen the social relationship and make it easier to collaborate on treatment and activities.

A common misconception is that people with dementia have lost interest in communicating with others. Then there is an easy risk to overlook or misunderstand non-linguistic initiatives. By being aware of non-linguistic initiatives and being curious about what the person is trying to communicate, you can create successful interactions despite the lack of common language.

Communication through an interpreter



When staff and patients do not share the same language, staff are robbed of one of their most important tools. It easily creates frustration and makes everyday life difficult, but can also mean that the legislation's requirement for informed consent is not met. However, the interpretation is a service that differs from other services, in that sense that we as users ourselves only with difficulty can control content and quality.

One interpreter orally reproduces - and in another language - a person's speech, others listen the moment the words are said. That sounds very simple so far. However, interpreting requires that both the interpreter and the healthcare professional master a range of skills and are trained to collaborate with each other. In addition to skills in the mother tongue and in the foreign language, the interpreter must be able to master the time pressure under which the interpreter's memory must work. Great demands are placed on the interpreter's accuracy. The interpreter's ability to concentrate, stress tolerance and perseverance are other factors that determine what we can succeed in relation to the citizen.

An easy and often used alternative to the professional interpreter is the use of relatives. In studies, however, several organizations express concern about this, and in particular the use of children. The use of relatives as interpreters can have significant consequences for patient safety compared to the use of a professional interpreter. This is about insufficient dissemination, e.g. due to lack of skills and understanding of health professional terms as well as withholding of vulnerable but important information, which may mean that the citizen is not adequately informed about the disease or treatment.

The use of relatives also makes it difficult to maintain confidentiality between doctor and patient and one can put the relative in a difficult situation, as they are involved in issues they may not feel like. It is also considered that children should not take on the role of interpreter, as this can create an imbalance in the relationship between child and parent and that the child receives information that can be difficult to handle emotionally. The child is given a responsibility that breaks down the safe framework. A child should not hear about poor housing conditions, ailing finances and life-threatening illnesses and not mention these problems at all.

There are significant risks to patient safety when using unauthorized translators. In summary, American and Swiss studies point to the following consequences of lack of or little understanding between doctor and citizen due to language barriers:

- Longer consultation time and more consultations
- More referrals and examinations and more treatments
- Increased risk of misdiagnosis and incorrect treatment
- Increased risk of patients not following the doctor's instructions and failing to take necessary medication

Increased risk of patients not being referred, not attending consultations or not being properly examined

The primary difference between a trained and a non-trained interpreter is that the trained interpreter has the necessary competencies in language and culture and interpretation. The trained interpreter can translate correctly and act neutrally, knows and understands the interpreter situation and can act in relation to the interpreter situation, has respect for both the interpreter situation and the parties, and manages to create trust in his own person and function.

An interpreter is a professional who masters at least two languages and the culture behind the languages, and who is able to apply that knowledge to translate messages correctly and ethically soundly between two people without a common language. The interpreter's most important competencies are:

- Linguistic competencies - mastery of the terminology relevant to the interpretation situation and the linguistic nuances in Danish and foreign languages
- Interpreting and ethical competencies - awareness of how to technically mediate the conversation as well as obligations regarding confidentiality, neutrality and impartiality
- Cultural competencies - insight into the culture behind the languages that are interpreted on / off
- Personal competencies - responsibility, situational awareness and tolerance
- Subject-specific competencies - knowledge within the area that is interpreted in, for example social law or the health area

Collaboration between the professional and the interpreter should always be with the citizen in focus. The interpreter is a link between the professional who cares the foreign-speaking citizen. You must work together to ensure that the patient receives good treatment. The interpreter's most important task is to help the professional and the citizen understand each other, without getting involved in the conversation. The interpreter therefore remains neutral and only clarifies comprehension problems without interpreting what is said - that is, translates verbatim without actively participating in the conversation and does not try to influence the outcome of the conversation.

As a professional, you must be aware of whether the interpreter and the citizen know each other. If this is the case, the interpreter is incompetent and must not be used for the consultation.

The conversation takes place between the professional and the citizen, and the interpreter must only contribute to a common understanding between you. Speak clearly and distinctly, and directly to the citizen, and give the interpreter time to translate correctly. The interpreter receives a lot of information during a conversation, and may need a little thinking time to gather the information before it is translated between the professional and the citizen. Pay attention to how the citizen feels along the way - and stop the conversation if there is a need to talk to the interpreter about developments in the process.

In a course of dementia, the language will gradually disappear, but an interpreter may still be needed, as it is possible that the person from an ethnic minority still understand some of his mother tongue and in any case, an interpreter can "translate" the cultural meaning to a possible behavior.

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