Advancing practice in the care of people with dementia

4th Edition

Module 8:

Therapeutic communication and relationships

Dementia Training Australia

Contents

Module 8: Therapeutic communication and relationships

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Introduction

This module explores communication patterns in relation to quality assessment and interaction with people living with dementia. Communication is a dynamic, ongoing process that has varying levels of complexity. Effective communication skills are essential in order to elicit accurate and complete data from clients. The module is designed to assist you to reflect on the development of rapport and relationship building with people with dementia and their carers.

The health care professional works with both the family/carer and the person living with dementia, and acts as a mediator and facilitator to achieve optimum care outcomes. The family/carer and the person with dementia can both become clients and are active partners in communication. Knowing the person's story is essential if meaningful assistance is to be offered. Experiencing dementia can be terrifying, funny, sad, hopeful and/or spiritual. To each person it is a different journey and one that the health care professional must try to understand.

Objectives

On successful completion of this module you will be able to:

- Discuss therapeutic techniques in communication with the person
- with dementia
- Reflect on your own communication style and its impact on the person with dementia
- Assess the patterns of information flow between the health professional and client
- Begin to understand the journey of dementia for the clients
- Apply your knowledge of dementia to an education plan for your clients
- Analyse your own reactions to the observed behaviour of your clients
- Assess the need for referral for support networks and facilitate client contact with these networks
- Plan for ongoing assessments and client support for decision-making

Module topics

Topics?

Suggested activities and readings for this module

Bryden, C. (2005). *Dancing with dementia. My story of living with dementia*. London, Jessica Kingsley Publishers.

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Dementia Australia. (2018). Dementia Language Guidelines. https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf

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Swaffer, K. (2019). My dementia story. https://www.youtube.com/watch?v=u-pdkClmr6M

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Effective communication and dementia

Good communication

An essential ingredient of quality care is good communication. Good communication within a consultation is about two-way interaction such that each person is fully engaged in what is being communicated. Memory impairment is commonly associated with dementia; however, communication abilities can also decline. Effective and therapeutic communication with the person with dementia can become more difficult. Difficulties in communication will depend on the stage of dementia. People with mild cognitive impairments or early stage of dementia may simply have some difficulties with word finding while a person who is living with a more advanced stage of dementia may have more serious communication impairments (Conway & Chenery, 2015).

Communication is defined as:

> *"an interaction between two (or more) parties, who are reversibly either the sender or receiver of information. It consists of verbal aspects such as tone and speech, but also of non-verbal aspects like body language and touch"*
>
> *(Machiels, Metzelthin, Hamers & Zwakhalen, 2017, p 38).*

Effective communication supports quality dementia care in the following ways:

- Promoting the continuity of self and enabling health professionals to 'know the person'
- Allowing health professionals to be 'present' to the person and make the person more important than the task
- Providing a meaningful activity during the provision of care

(Conway & Chenery, 2016).

Common issues encountered in communication with people living with dementia include difficulty in:

- Thinking of words
- Understanding requests
- Making needs understood
- Participating in conversations

These changes can lead to further social isolation and negatively impact the person's quality of life. Communication impairments can also impact on the carer, contributing to carer stress and reducing their quality of life (Conway & Chenery, 2016).

There are normal sensory changes related to ageing. These need to be considered and accommodated when communicating with older people.

Visual acuity diminishes after the age of 50. Almost 10% of Australians over 55 years of age are visually impaired. Over 1% are blind (Jarvis, Forbes & Watt, 2012).

Hearing loss is also more common in older people. Over 50% of people aged between 60- and 70-years report hearing loss. This incidence increases as people age more. Impaired hearing is more common in older men. Another change is reduced auditory reaction time after the age of 70-years. This means there is a delay in receiving and sending nerve impulses (Jarvis et al, 2012). Ensure you have assessed the person for these changes and that they have the use of any assistive devices that may be required e.g. reading glasses, hearing aids etc.

Communication strategies useful for people living with dementia

There are strategies to improve communication with older people generally. These are reviewed below before looking at additional strategies to utilise when communicating with people living with dementia.

Avoid stereotyping older adults – assess as an individual

- Be careful not to give inappropriate or demeaning responses
- Adapt your style of communication to the actual abilities of the person

Avoid the use of 'elderspeak' – this can be patronising. It can make people feel disrespected and powerless

- Avoid simplified vocabulary, older people generally retain their vocabulary. Use correct medical terminology and follow up with a nontechnical explanation

- Do not use endearing or diminutive terms e.g. ‘love’, ‘sweetheart’
- Avoid exaggerated intonation

Monitor and manage your own non-verbal behaviour

- This includes eye contact, facial expressions, voice tone, rate of speech, speech volume, body positioning, and use of space
- Maintain eye contact appropriately.
- If the person is hearing impaired – increase your volume slightly and speak a little more slowly. Do not shout.
- Avoid behaviours such as looking at your watch, appearing impatient, talking as you leave the room – these behaviours may communicate to the person that either they or the information is not important
- Remember – your nonverbal communication is more likely to be believed, especially if it contradicts your verbal communication

Minimise background noise and distractions

- Consider age-related hearing impairment
- Background noise has an adverse effect on receiving information

Face the other person – have your face at the same level as theirs

- Remember that older people with hearing impairments may compensate by trying to lip read

Carefully construct your sentences when delivering critical information

- Long complex sentences challenge memory as several different pieces of information must be held in order to understand the entire sentence
- Split individual pieces of information into separate sentences

Use visual aids to assist with clarification and reinforcement

- These need to be well designed and avoid irrelevant information
- Use these aids in an interactive manner to ensure you and the listener are both paying attention to the same information

Ask open-ended questions and genuinely listen

- Encourage the person to respond to questions from their point of view and in their own words
- Ask questions and paraphrase in order to clarify information and let the older person know you have been listening

Express understanding and compassion to assist with fear and uncertainty regarding ageing and chronic illness

- Convey genuine interest
- Be sensitive to the person’s willingness to discuss feelings

Try to discover the person’s living situation and social contacts

- Older people are more likely to be living in circumstances that put them at risk for abuse or exploitation

Include the person in the conversation even if the carer or family member is in the room

- Take care not to disenfranchise the older person
- Create a 'triadic' conversation – maintain direct communication with the older person
- Maintain eye contact with the older person
- Do not refer to the older person as if they are not there – e.g. 'does she complain about...'
- Direct conversation back to the older person if the carer or family member starts to talk over the older person
- Ask the older person to verify information provided by the carer or family member

Customise care planning by including the person's cultural and spiritual beliefs

- Ensure your approach is holistic and inclusive
- Do not stereotype

Avoid ageist assumptions when discussing recommendations for preventative care or treatment options

- Discuss all aspects of health behaviour. Older people are just as capable of changing health behaviours as younger people
- Do not confuse normal age-related changes with treatable problems. E.g. 'it's because of your age'.

Check the person comprehends the conversation

- Compensate for age-related impairments with vision and/or hearing
- Use an interpreter if English proficiency is limited
- Provide a brief summary of discussion and recommendations

Incorporate technical knowledge with emotional appeal when discussing treatment options

- There is a direct correlation between the amount of time spent explaining a treatment regime and consequent adherence by the person
- People respond better to messages associated with connectedness to family and community
- Encourage older people to envision time with family and loved ones as part of the goals of treatment

Be cautious with humour – it may be misunderstood or cause offence

- Humour can ease tension in health settings but may be misunderstood
- Use discretion.
- Do not comment on appearance, age, culture, body shape, or sex. Especially during a physical examination
- Assume the person prefers a formal manner of address until they indicate otherwise

Recognise when the person is competent with information technology (IT)

- Provide reputable online sources for the person to utilise
- Utilise IT devices that facilitate collaborative use
    - Touch screens are easier to use than a traditional screen with a mouse. (GSA, 2012).

Additionally, a few simple strategies will promote communication with a person with dementia.

Body language, communication and dementia

Facial expression, gestures, stance and voice tone all become more important when talking and communication with someone who has cognitive impairment.

If a person with dementia feels threatened, undermined or confused by communication with them they may react in a negative way to interventions; for example, conversation or information can increase agitation, undermine their confidence, and increase their feelings of isolation.

People with dementia will be aware of stress in the health professional. It is important to be calm, patient, happy and kind (Strandroos & Antelius, 2017).

It is also important to use a soft voice tone and ensure you are at eye level with the person, as a perception of being 'stood over' can make the person with dementia feel threatened (GSA, 2012).

Equally, standing or sitting 'side-on' can be perceived as less threatening than a face-to-face, 'head on' stance. Take care with standing too close or touching as this can be perceived as threatening by the person living with dementia. Rapport needs to be established (Veselinova, 2014).

Health professionals must also be receptive to the body language and non-verbal cues of the person with dementia.

Environmental awareness aids communication

Is the lighting enough to aid communication? In conversation we usually look at the face and body of the person talking to us. It helps us to understand content and intent. Make sure you have some light on your face. Try to maximise independence and social inclusion (Veselinova, 2014).

Furniture placement is also a form of communication. Does the furniture placement indicate this is a suitable place to sit for a conversation? (Standroos & Antelius, 2017).

Identify yourself and address the person by name

This helps to orientate the person with dementia (Veselinova, 2014).

Does the person with dementia have hearing or vision difficulties?

Make allowances for visual and hearing deficits and, wherever possible, ensure glasses and hearing aids are worn. Often people with dementia do not tolerate hearing aids for long periods as the aid amplifies background noise. Check that glasses are clean and that hearing aids are clean and working and fit properly (Veselinova, 2014).

Minimise distractions and make sure you have the person's attention

Noise is a major distraction and can affect communication, although the noise of a busy healthcare environment may not be obvious to the health professional who is accustomed to communicating in such an environment. As well as external environmental noise there is also the insidious 'internal noise' which may affect the client, such as fear, anxiety, pain or hunger. The presence of other people can be a significant distraction; there may be some issues on which the client will not be forthcoming, for example, if family members are present, or if there are other people who can overhear the conversation (Veselinova, 2014).

Speak calmly and distinctly

For effective communication, speak simply; without treating the person with dementia as a child, without shouting or becoming angry with them if they do not understand. Shouting also affects the tone of your voice and makes understanding more difficult. Do not get angry even if you are becoming frustrated. We will all have seen people talking too loudly at people with dementia. A loud voice does not make information clearer whereas speaking more carefully and/or rephrasing what is said may.

Use simple, direct statements and information

- Use words the person can understand
- Keep sentences simple. Allow the person to deal with one thing at a time
- Do not press for an answer if that worries or confuses them
- Ask questions that require a "yes" or "no" response if that aids conversation and understanding
- Do not ask the person to clarify negative sentences.

If you do not understand the content of their conversation:

If you do not understand what they have said you can ask them to repeat it. Sometimes conversing with someone with dementia is not necessarily about understanding; it is about showing care, concern, inclusion and love towards them

Avoid speaking slowly

Speaking slowly places an additional burden on working memory. People must retain the individual words in a sentence for a longer time before they can comprehend the completed sentence. Speaking slowly increases the likelihood of misunderstandings. Your aim is to enunciate clearly with the appropriate intonation (GSA, 2012).

Adjust question style to conversational goals

Do not allow questions to become a type of test for the person living with dementia. If you need a specific answer utilise closed-ended questions e.g. 'Would you like an apple? Are you tired?

Open-ended questions encourage conversation. Try to utilise semantic memory (knowledge of meaning, concepts, customs) rather than episodic memory (knowledge of specific events at specific times). 'What music do you like to listen to?' is better than 'What music did you listen to yesterday?' (GSA, 2012).

Consider sentence structure

Sentences can be either right-branching or left-branching. A left branching sentence has an embedded clause that interrupts the main clause. E.g. ‘If you don’t want to miss the show, you should take a seat’. Right-branching sentences require less temporary storage of information e.g. ‘Take your seat and you won’t miss the show’.

Avoid sentences beginning with subordinate conjunctions:

- If
- Although
- Even though
- While
- Since
- Given
- After
- Before
- As long as
- Once
- Because
- Unless

Try to connect two ideas in one sentence by using ‘and’ (GSA, 2012).

Utilise strategies of repetition and paraphrasing

Repetition can assist the person living with dementia recall what was forgotten from the previous sentence. Paraphrasing changes the content or structure of the original statement – this can facilitate comprehension (GSA, 2012).

Consider strategies when English is not the primary language

A shared language is essential for communication. There are both practical and social consequences when people rely on different languages. A lack of proficiency in English places the person living with dementia at a higher risk of social isolation when in an aged care facility. In this situation, non-verbal communication becomes even more important (Strandroos & Antelius, 2017).

Correcting wrong information

It is not necessary to constantly correct the validity of the person's statements if it includes wrong information. In fact, this can increase frustration. Focus on the emotion behind the words. Does the person want their mother? Or are they seeking comfort? Even if the conversation is incorrect it still has meaning to that individual. This makes it valid for them (Veselinova, 2014).

Give visual cues and write things down

A picture can tell a thousand words. This strategy is useful for triggering recall. It utilises strengths of the person and reduces cognitive demands (Lanzi, Burshnic & Bourgeois, 2017).

Give physical cues

This can be a successful strategy in some situations. Mealtimes can sometimes be problematic for people living with advanced dementia. An instruction that ’it’s time to eat’ or placing a tray in front of the person may not be enough. Placing the fork or spoon in the hands of the person living with dementia may assist with initiating independent eating. Utilising previous experience with known objects may be successful. Consider this strategy with other familiar items such as a hair comb, drinking glass, or toothbrush (Strandroos & Antelius, 2017).

Consider other barriers

Pain is often under-recognised and under-treated in people living with dementia. There are many adverse effects of untreated pain. One is a negative impact on communication and social interactions. Depression and anxiety will also negatively impact communication (Veselinova, 2014).

Avoid jargon

Avoid use of health 'jargon' that may not be understood by a non health professional and may add to anxiety. Do use correct medical terminology but ensure you follow up with a non-technical explanation (GSA, 2012).

Use generation-appropriate language to make things more meaningful. If the person does not seem to understand try using different words and phrases (GSA, 2012).

Communication support strategies for health professionals

Health professionals have been shown to benefit from communication training, particularly in relation to working with people living with dementia. One validated training method utilizes the MESSAGE approach (Conway & Chenery, 2016).

The MESSAGE strategies can be summarised as follows:

M

Maximise attention
1. Attract attention
2. Avoid distraction
3. One at a time

E

Watch your **E**xpression and body language
1. Relaxed and calm
2. Show interest

S

Keep it **S**imple
1. Short, simple and familiar
2. Clear choices

S

Support the conversation
1. Give time
2. Find the word
3. Repeat then rephrase
4. Reminders of the topic

A

Assist with visual **A**ids
1. Gestures and actions
2. Objects and pictures

G

Get their message
1. Listen, watch and work out
2. Behaviour and non-verbal messages

E

Encourage and **E**ngage in communication
1. Interesting and familiar topics
2. Opportunities to talk

Language surrounding dementia

The importance and impact of the language surrounding dementia and people living with dementia cannot be underestimated.

In this video Kate Swaffer talks about the power of language: https://www.youtube.com/watch?v=TaHDKCWzMog

Adapted from Bryden (2015, p 229).

A more detailed version is available from Dementia Australia (2018): https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf

ACTIVITY

"Sticks and stones will break my bones" Reflect on what Kate meant when she talked about this.

How does the media portray people living with dementia?

Can you think of examples of stigmatising language used by healthcare professionals?

How would you respond to a colleague using stigmatising language?

Bryden (2015) summarises the the preferred language surrounding dementia:

Talking about dementia: **Dementia, Alzheimer's disease, a form or type of dementia**	**NOT:** **dementing illness, demented, affliction, senile dementia, senility**
Talking about us: **Person/ people with/living with/ with a diagnosis of dementia**	**NOT:** **sufferer, victim, dement/ demented, afflicted, offender, absconder, attention-seeker**
Talking about carers and supporters: Living alongside/ with/ caring for/supporting a person with dementia, family member, carer	**NOT:** **person living with dementia, carer burden, burden of care**

Communicating the diagnosis

People living with dementia are sometimes given negative messages when receiving a diagnosis. Christine Bryden (2015) describes the diagnosis as 'pointing the bone'. She describes a 'defeat of spirit and hope' and feelings of fear and dread. Every mistake is interpreted as an example of irreversible decline (Bryden, 2015).

Kate Swaffer (2016) discusses the concept of 'prescribed disengagement'. She states that health professionals and service providers encourage people with a new diagnosis to disengage from paid work or study, plan for their inevitable decline, and enjoy what 'limited' time they have left (Swaffer, 2016).

Health professionals need to consider the way diagnoses and treatment plans are communicated. A strengths-based approach is needed. Swaffer (2016) talks about living, surviving, and thriving beyond dementia.

Loved ones and family members usually respond as either 'carers' or 'deniers'. The extreme carer reaction disables the person with dementia and creates feelings of dependence and helplessness. The denier reaction may be a way to mask feelings of anger and/or grief (Bryden, 2015).

ACTIVITY

Watch this video with Christine Bryden: https://www.youtube.com/watch?v=7E49cK17qs0

Reflect on Christine's perspective and advice.
Do you use her advised strategies to promote communication?
Are there strategies you could try and incorporate into your 'toolbox' of communication techniques?
Have you ever said, 'that happens to me – I lose my keys" when talking to a person living with dementia? What are your thoughts of Christine's response to this?

ACTIVITY

Watch this video with Kate Swaffer via this link: https://www.youtube.com/watch?v=u-pdkClmr6M

Kate describes being diagnosed with younger onset dementia and how she has risen to the challenge of living with dementia.
Did you have to think about getting dressed today?
How would you react to this diagnosis?
How do you like people to communicate with you?

The Clinical Practice Guidelines and Principles of Care for People with Dementia (Guidelines Adaptation Committee, 2016) provide recommendations for communicating the diagnosis of dementia.

These may be summarised as:

- The diagnosis needs to be communicated by a medical practitioner
- The medical practitioner needs to demonstrate honesty and respect, and utilise an individualised approach when communicating to the person and their carer/family
- There needs to be recognition of the person's right to know; or conversely, their right to not know. Support to manage this situation is essential. Conflict will need to be resolved by further discussion over time.
- Information about dementia needs to be provided in a clear manner, including: the generally slow progression, availability of symptomatic treatments, and ongoing research seeking improvement
- Take care with people who have a history of depression and/or self-harm. They may be at higher risk, especially in the first few months post-diagnosis. Counselling services need to be offered as additional support

Adapted from the Guidelines Adaptation Committee (2016).

Information and Support

- Provide information about:
  - Signs and symptoms of dementia
  - Course and progress of the condition
  - Treatment options
  - Sources for financial and legal advice
  - Medico-legal issues, including driving

- Provide contacts for social support groups
- Provide both verbal and written information about appropriate community services. E.g. Dementia Australia, My Aged Care, NDIS

(Guideline Adaptation Committee, 2016).

Assessment of information flow between clients

Communication between health professionals, clients and families tends to be hierarchical, one-directional and driven by clinical needs (Omori et al, 2019). Consultations with medical practitioners to discuss a diagnosis of dementia often include a close caregiver or family member. This represents a complex triadic conversation with the potential for a relative imbalance of power. Care needs to be taken to avoid either the health professional or carer becoming paternalistic and neglecting the input of the person living with dementia (Sakai & Carpenter, 2011).

There may be an interdependency between people with dementia and their carer or family member. There is some evidence that paternalistic practices lead to the older person with or without dementia being overlooked and the carer assuming the role of the key decision maker. Older people with dementia risk being doubly stigmatised due to ageing and the diagnosis of dementia (Donnelly, Begley, & O'Brien, 2019).

There are many variables as to how this triadic relationship between the health professional, the person living with dementia, and the carer or family member may be manifested. The health professional needs to assess the situation and the nature of the relationship.

It is not enough to have the person with dementia physically present during the discussion. Care must be taken to actively involve the person living with dementia; ensure they are being 'talked to' rather than 'talked at'. Ensure you as the health professional, are aware of organisational pressures such as discharge deadlines, limited resources and time pressures and avoid hurried decision-making practices (Donnelly et al, 2019, p 2988).

If one partner has been the dominant provider and decision-maker in the relationship their reaction to the diagnosis and future information will colour how that information is received and internalised. How the carer reacts to having to decide on care, or other matters, has an impact of the long-term care outcomes.

Where there has been a loving relationship with a spouse the carer will want to provide the best care for as long as possible. Other less loving relationships may mean the carer will find alternative care providers more quickly. If the carer is a daughter or son, the ramifications on other family relationships must be considered. Just how much information can be absorbed by the person with dementia and how important this is must be determined with the carer. Some carers will not let any adverse information be discussed in front of the person; others will insist all discussion is open and any distressed responses from the person dealt with. Often spouses protect their loved one by refusing to discuss what is happening with others, or even hiding some of the problems they face. This may be a form of denial or pride, or control and face-saving. Health professionals need to listen and elicit how the carer and family interact with any information they receive. Family dynamics will impact on the outcomes for care.

A priority for the health professional is to discuss with the family the need for independence as long as possible. Carers may take away independence by either meaning to be helpful, or in frustration at the reduced functional status of the person.

Remember, the sense of self is enhanced by independence and a feeling of control over one's environment. To take that away only exacerbates confusion and loss of self. Frustration at not being able to do what in the past was an easy task may lead to altered behaviour and outbursts that were not part of the person's personality prior to the dementia.

This information is important for the health professional; a relationship of trust must be established with clients so these issues can be raised, and interventions discussed.

ACTIVITY

Reflect on how you assess the relationships within family members and the dynamics of communication.

Are you making assumptions when you talk to people about dementia?

Consider how you can improve your assessment skills when talking to clients and how you document your findings.

Assessment of needs and support

When assessing the situation of a person living with dementia, the health professional needs to approach interventions from a perspective of living well.

- Ensure the person with dementia and their immediate family/carers have information and referrals.
- Encourage application to either My Aged Care or NDIS so that supports may be put in place as soon as possible. It is important to do this early as there can be extensive waiting lists for some services.
- Encourage an active and healthy lifestyle to minimise co-morbidities and functional decline (Guideline Adaptation Committee, 2016).

Development of an education plan for clients

Following assessment consider how clients should get information about dementia. Do you have information resources at hand; for example, the series of help sheets from Dementia Australia? Should you gather information into a packet ready for such planning?

In conjunction with the person living with dementia and family/carer, write a care plan for your clients and copy it for them to take with them after the consultation. Include issues they have raised and instructions on how to use the information.

Suggested items for information may be:

- What is dementia?
- How does it affect people?
- Financial and legal advice referrals
- Medication issues
- Helping the carer – time for yourself
- Nutrition and hydration needs

- Strategies for coping with altered behaviour
- Environmental changes

The plan should be revisited and amended as time goes by and other issues are raised. Encourage the clients to bring the plan with them on visits and make it the basis for discussion. Keep the information at the level of client understanding and do not use medical or professional jargon. Sometimes a clear description of diagnostic tests is helpful (e.g., CT Scans, blood tests).

This process gives people something to take with them and make notes of what other information they require. Care plans give a sense of personal involvement for the carer and the health care professional. The person with dementia will also appreciate being involved with sorting out problems and getting strategies to deal with them.

Summary

This session has provided a background to the role and importance of effective communication in the care of people with dementia. The session has explored communication patterns in relation to quality assessment and interaction with people with dementia. It has also shown that communication is a dynamic, ongoing process with varying levels of complexity.

Issues about relationship building and facilitating information exchange have been raised. Listening to the experiences of people with dementia and those who care for them is the only way to create meaningful exchanges.

Ongoing support for both the person living with dementia and their family/carer includes giving time to the family/carer alone to enable them the opportunity to raise personal issues family/carer

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