

Advancing practice in the care of people with dementia

3rd edition

Module 7: Therapeutic communication and relationships



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Module 7: Therapeutic communication and relationships

Introduction

This session explores communication patterns in relation to quality assessment and interaction with people with dementia. It will be seen that communication is a dynamic, ongoing process that has varying levels of complexity. Effective communication skills are essential if you are to elicit accurate and complete data from clients. The process of communication will be examined, as will some of the many factors that contribute to the success or otherwise of our interaction with the clients identified. The session 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 is the interface between the carer and the person with dementia and acts as a mediator and facilitator to achieve optimum care outcomes. The carer and the person with dementia both become clients and are active partners in communication.

Understanding the life of the clients and their reactions to dementia are 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 (Crisp, 2000).

Objectives

On successful completion of this session 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

Effective communication and dementia

- Communication traps
- Therapeutic communication
- Environmental issues
- General communication strategies

Communication through the trajectory:

- Diagnosis and responses
- Assessment of information flow between clients and health professionals
- Assessment of needs and support
- Development of an education plan for the clients
- Medication and treatment options
- Guardianship and legal issues
- Community referral and support options

End-of-life decision-making

Current controversies and issues

Summary

Resources

References

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

Braudy Harris, P. (2002). *The person with Alzheimer's Disease. Pathways to understanding the experience*. Johns Hopkins University Press. Maryland.

Caracciolo, F. (2006). *Alzheimer's: a journey together*. Jessica Kingsley Publishers. London.

Crisp, J. (2000). *Keeping in touch with someone who has Alzheimer's*. Victoria: Ausmed.

Davis, R. (1989). *My journey into Alzheimer's Disease*. Tyndale House. Illinois.

Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Bristol: Open University Press.

Pieters-Hawke, S., & Flynn, H. (2004). *Hazel's Journey: A personal experience of dementia*. Sydney: Pan Macmillan Australia.

Steckbeck, L. (2011). *Prevention and care of Alzheimer's disease - A practical*

guide to reducing your risk, slowing the progression and living with dementia.

PWS Publishing, Pompano Beach, FL, USA.

Suggested readings for this session

Good communication

Effective communication and dementia

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. Effective and therapeutic communication with the person with dementia can become more difficult.

Issues that arise include:

- Word-finding difficulties
- Altered fluency of speech
- Reduction in conversation skills – interrupting, not responding, ignoring other speakers, becoming self-centred
- Difficulty in expressing emotions
- Reduced ability to understand and interpret what is being said
- Altered writing and reading skills
- Agnosia – inability to name familiar objects
- All compounded by
- Co-existing hearing and vision problems

For the person with dementia, understanding what you are saying and their ability to make you understand their world can be highly variable; each person will react to different stimuli in different ways. This means we have to be more conscious of the way we present ourselves and how we give and receive information when we talk to someone with dementia.

A few simple strategies will promote communication with a person with dementia.

Body language, communication and dementia

Your facial expression, gestures, stance and voice tone all become more important when talking and communication to someone who is cognitively impaired.

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

It is therefore 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.

Equally, standing or sitting 'side-on' can be perceived as less threatening than a face-to-face, 'head on' stance. 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 sufficient 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.

Identify yourself and address the person by name

This helps to orientate the person with dementia

Does the person with dementia have hearing or sight 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.

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.

Speak slowly, 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 slowly 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

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.

Give visual cues and write things down

A picture can tell a thousand words.

Minimise distracting noise

Avoid Jargon

Avoid use of health 'jargon' that may not be understood by an outsider and may add to anxiety.

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

Activity

Good communication summary

Think of words and phrases that may be misunderstood when interacting with people. During the next week listen to verbal interactions around you and note the effect of tone of voice, and use of language on the person with dementia.

Take some time now to consider what mechanisms you can recognise in yourself that may affect your communication with clients. Think about clients with whom you have been involved who you have described as 'difficult' and explore why they were described in this way

In summary, useful guidelines for therapeutic and effective communication with the person with dementia are:

- Address the client by the family name unless you receive permission to use a given name
- Explain the purpose of the task you are undertaking and the expected timeframe, in an unhurried calm manner
- Allow the client time to answer at her/his own pace
- Communicate at the client's level of understanding, considering age, gender, level of education and culture
- Avoid using jargon, slang or clichés
- Use body language that conveys your interest and concern
- Make brief notes while assessing
- Seek information from close family members or friends if the client is unable to communicate, or enlist the aid of an interpreter, if appropriate
- Ensure that the setting for the assessment is optimum - quiet, private, comfortable and free from distractions
- Be flexible - everyone is different
- Rely on non-verbal cues - voice, touch, movement, body language
- Recognise non-verbal cues from patient to determine emotions
- Maintain self-esteem - feelings and emotions preserved
- Rephrasing things may help
- Ask them to describe information about a word they cannot find

- Give clues to a word they cannot find
- Use orientating names/words wherever possible; for example, “your daughter Mary”
- Ensure glasses/hearing aids are worn wherever possible
- Give clear, simple instructions
- Use closed questions
- Use of pointing at or touching physical objects to prompt recognition.

(The above information is based on expert opinion)

The table below summarises poor techniques to promote therapeutic communication with people with dementia		
Table 7.1: Summary of non-therapeutic communication techniques		
Technique	Definition	Therapeutic threat
Failure to listen	Not receiving client's intended message	Places needs of practitioner above those of client
Failure to probe	Inadequate data collection represented by eliciting vague descriptions, getting inadequate answers, following standard forms too closely; not exploring client's interpretation	Inadequate data base on which to make decisions; client care not individualised.
Being judgemental	Approving or disapproving statements	Implies that the practitioner has the right to pass judgement; promotes a dependency relationship
Excessive reassuring	Attempting to do magic with words	Negates fears, feelings and other communications of client
Rejecting	Refusing to discuss topics with client	Client may feel that not only communication but also the self was rejected.
Defending	Attempting to protect someone or something from negative feedback	Negates client's right to express an opinion
Giving advice	Telling client what practitioner thinks should be done	Negates the worth of client as a mutual partner in decision making
Stereotyped responses	Use of trite meaningless verbal expressions	Negates the significance of client's communication
Changing topics	Practitioner directing the interaction into areas of self-interest rather than following lead of client	Non-verbally communicates that the practitioner is in charge of deciding what will be discussed; possible to miss important topics for individual client <i>From Sundeen et al. (1939, p.124)</i>

Diagnosis and responses

Communication through the trajectory

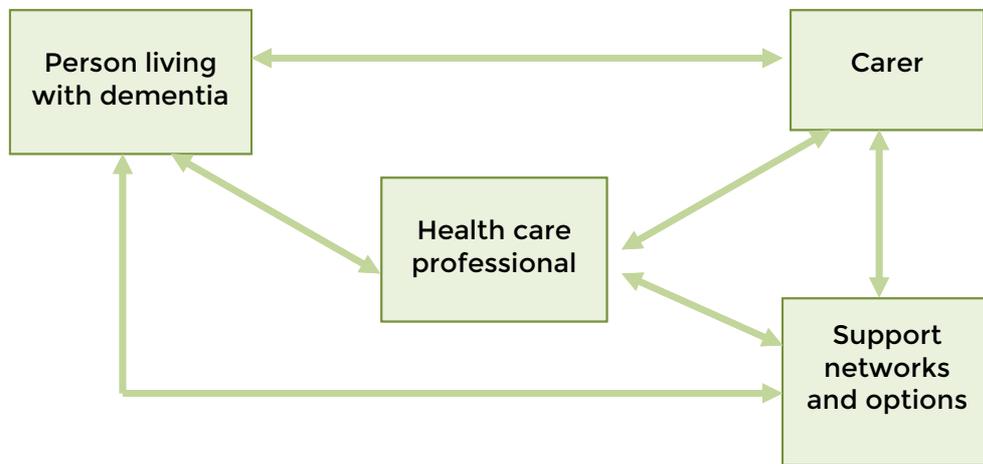
This topic is based on the premise that there is constant flow of information between the carer, the health care professional and the person with dementia.

This interaction allows the healthcare professional to unravel the experience of the clients and to go on the journey with them.

The model allows for interaction with other experts and support groups.

Too often healthcare professionals impart knowledge they think clients should know and give advice they think is helpful, when what the client wants is support and listening. Sharing the experience is a multi-way process, not just a knowledge imparting session.

Figure 7.1: Model of information flow



Activity

Please read the first chapter of Hazel's Journey. Make a list of the words used to describe the impact of her diagnosis on both her and her family.

You will find that metaphors and words used to describe the feelings of being told the diagnosis are polarised; and in essence form a dialectic. On the one hand there is relief at finally getting a diagnosis for something that has probably been worrying for some time. On the other hand the enormity of the diagnosis and what will happen in the future is devastating.

Words and phrases commonly expressed

Like a body blow	-----	Could be worse - cancer
Almost overpowering	-----	We can manage
Carries heavy baggage	-----	Take it a step at a time
Spectre of inevitability	-----	Cure may be found
Helpless degeneration	-----	Strength and character
nothing can destroy		
Loss of self	-----	Maintain spirituality
Offers little sense of hope or escape		Keeping a sense of humour
Sense of fear and dread	-----	Keeping a sense of humour
Horrible	-----	He/she can't remember the
worst		
Nightmarish	-----	Maybe it won't get worse

The overall feeling of the 'power of the label' is beautifully discussed in this book. The determination to remain a person and not be defined by the disease is the essence of constructive interpretation and engagement by the health professional. So often the person with dementia is not part of the discussion and the collective 'we' is used; it is meant to be inclusive but in reality it is exclusive.

Early diagnosis can be so overpowering that the family may lose sight of the person who has dementia. In their need to find information, and to do something constructive and positive, family members react in different ways.



Activity

Assessment of information flow between clients

Telling people they have Alzheimer's disease or another form of dementia can add to the challenges of day-to-day coping as the future becomes bleak and the progressive nature of the disease overwhelming. On the other hand early diagnosis can lead to therapies and medication that may be helpful and delay the progress of deterioration. It is no wonder clients are on an emotional see-saw. Consider how the clients you have had contact with coped with the diagnosis and the aftermath. What did you learn from this?

As the model of information flow shows, how information is received and dealt with by both the person with dementia and their carer is essential for the health professional to determine before further help can be offered.

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.

Paramount for the health professional is to discuss with the family the need for independence as long as possible. Carers often take away independence by either meaning to be helpful or in frustration at behaviour. 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 so a relationship of trust must be established with clients so these issues can be raised and interventions discussed.

The experience of dementia is personal and unique. We cannot live the life of the other but we can try to understand what is happening to them and believe that what they tell us is real for them.

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.

Reading

Chapter 8 of Kitwood, *Requirements of a caregiver*. Kitwood gives a daunting overview of the caring process from a professional carer perspective. Family caregiving is also complex and demanding and requires much support.

As the health professional establishes a relationship with the client the matter of how they are coping and what support can be offered must be discussed.

Assessment of needs and support

A response of “I’m all right” is not helpful. As the disease progresses the behaviour of the person with dementia will alter. Carers often will not raise their feelings of not being able to manage but they will show signs of stress and tiredness that astute observation will detect. Denial of loss of skill is one way to reject the issue of something being wrong. Many people with dementia are extremely good at covering up and may go on for a long time confabulating and protecting self. The healthcare professional must consider who is best placed to give accurate descriptions of behaviour and not dismiss the carer as overly protective or fancifying.

Carers need time to express their worries and discuss issues about care. This requires personal time, without the person with dementia in the room. Appointments for the carer are as important as those for the person with dementia.

Christine Bryden offers clear ideas about helping in her book.

Reading



Activity

Read Chapter 4 of Dancing with dementia.

Summarise the major points made and consider whether these points are discussed with your clients.

From the perspective of a person living with dementia, Christine makes very clear the need for getting the right diagnosis, getting immediate treatment, self-esteem, needing lots of clues for daily living, lack of stress, understanding how hard it is, personal values and dignity, finding help and support, accessing information, emotional support, empowerment and hope, use it or lose it, one thing at a time, touching our emotion and spirit, connecting with us, enter our reality, carer not martyr, spirituality and connectedness.

Using your assessment notes make a list of what you have discussed with your clients and see whether you have covered the points raised in the chapter.

Development of an education plan for the clients

Following your assessment consider how your clients should get information about dementia. Do you have information resources at hand; for example, the series of help sheets from Alzheimer's Australia? Should you gather information into a packet ready for such planning? In conjunction with the client and family 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?
- Strategies for coping with altered behaviour
- Medication issues
- Helping the carer - time for yourself
- Nutrition and hydration needs
- 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 clients 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

Medication and treatment options

Options for medication should be discussed following a comprehensive diagnostic assessment. The local doctor or specialist geriatrician may decide to offer some of the new memory-enhancing drugs, but this must be in light of assistance, not cure. Prolonging plateaus or slowing the progress of the dementia is worth attempting. See Module 4 for more information regarding the pharmaceutical effects of drugs.

Medication for other health-related problems should be continued and monitored as some can exacerbate other problems such as falls, depression or eating patterns. Depression is common in the early stages of the dementing process and should be recognised and treated. The differences between loss and grief and depression are often difficult to untangle but prolonged depressive symptoms are not normal and should be treated.

Other treatments may include stopping smoking, lowering blood pressure, reducing weight, exercise regimes, nutrition advice and lifestyle choices. See Modules 1 and 4 for more information regarding minimising risk factors and treatment.

The current lifestyle patterns of the clients should be encouraged to continue if altering them is understood to be too major a change. However, a slight modification to healthier lifestyle patterns as well as some mental exercise is seen as important. Taking part in group activities may be helpful for some people; others do not function well in groups. Discussion with the person with dementia and the carer will elicit what the client usually enjoys; these activities may be set as goals in the care plan.

Guardianship and legal options

As facilitator, the healthcare professional is often the one who raises issues of personal, financial and healthcare options with the clients. The matter of who decides, and when, to manage family finances is essential for peace of mind for all. Often the person with dementia cannot let go the role they had in the family and refuse to hand over any legal or financial matters. It may be easier to get an accountant or lawyer to establish the plan for the future and get them to discuss signing documents with the person.

Family dynamics are also involved in personal and legal matters, especially where second marriages or blended families are concerned. Advice can be offered but understanding the parameters around such advice is important as it may convey a feeling of giving in or loss of control for the client who has dementia. See Module 5: Social and lifestyle considerations for more information on legal considerations.

Community referral and support options

The trajectory of dementia is very personal and unique. Support services may be needed for some clients earlier than others. The carer will often deny support when they would benefit from respite or other services. Day-to-day household matters can be difficult to continue when you are constantly monitoring behaviour or worried about leaving the person with dementia to others for periods of time. Gentle reminders that the carer needs a break and help if they are to continue to provide care and avenues for them to 'let off steam' to others in the same circumstances, need to be found.

Healthcare professionals should have knowledge of local respite services; home help and carer support providers are in a position to make arrangements for the clients.

End-of-life decision-making

Decisions for healthcare are equally important. End-of-life decision-making needs to be discussed at some point in the relationship, before the person with dementia loses capacity, and a plan set out as a Medical Power of Attorney document or Advance Care Plan according to state laws.

The matter of wills and family involvement should be clarified to give some peace of mind when the health of the person deteriorates. Nutrition, hydration and comfort are the major concerns of carers at the end of life and pain management may be an issue. Discussion must be held with the carer and family to explain the palliative care process and the comfort that can be provided. Hospitalisation is usually not a good option unless there is an attached hospice that can deliver appropriate palliation.

Cultural backgrounds will impact on care issues and must be respected. See Module 5: Social and lifestyle considerations for more information regarding end-of-life decision-making and advanced care planning. Make a list of all the services in your area. How many times have you referred clients to them in the past? What were the outcomes? Did you discuss this with the providers? Feedback is essential to improve services. Waiting times and ease of access are factors to consider.



Activity

Current controversies and issues

- Carers of clients who have dementia don't usually consider they need counselling; rather, someone to talk to and ask information of. Sharing the experience is more important than medical procedures.
- Early diagnosis can be either helpful or increase anxiety.
- End-of-life care is best discussed when the clients are ready to talk about it.
- Legal issues regarding Power of Attorney should be dealt with as soon as possible.
- Treatment is important, either medication or other therapy, may be helpful and should not be disregarded.

Case study

Finding support that is appropriate for the needs of clients is important. Mr and Mrs Brown came to your office because Mr Brown (aged 52) was constantly forgetting things and his personality seemed to be changing. He was normally a quiet, pleasant man who was slow to anger and never had arguments. Mrs Brown said they were having constant arguments over silly things such as what to have for dinner. This was not like him at all and she was worried he was developing something in his brain.

After tests and referral to the psychogeriatrician Mr Brown was diagnosed with Frontal Lobe Dementia. The diagnosis was devastating to all the family and ultimately led to friction between the son and his mother. One other sibling, his sister, was more concerned about her mother than her father, how she would cope and what could they do for them both.

As the disease progressed the problems at home became worse as Mr Brown was getting up during the night and creating havoc in the house. Respite was a solution suggested so Mrs Brown took him to a nursing home that offered respite for two weeks.

On returning home Mr Brown was sullen, moody and generally more difficult to live with. Mrs Brown blamed herself for this deterioration and vowed she would never do this again.



Activity

The evidence base

Unfortunately Mr Brown developed pneumonia and was admitted to the public hospital for two weeks. His deterioration was now very noticeable.

Mrs Brown came to you for some help. It was clear she thought he was dying and that in some way she had contributed to an early demise by letting him go to respite.

She was grieving and depressed. She also had not discussed end-of-life wishes with any of the family and was now afraid to raise this with her son, who constantly denied his father was “mentally ill”. Mrs Brown was not prepared for ‘the end’, as she phrased it, and it was clear she had not considered how this could be dealt with.

How could you resolve some of the issues Mrs Brown raised? As her health care provider what will you do? Consider what you have done differently to reduce the level of distress experienced by Mrs Brown.

Evidence for improving practice in the form of listening to the experience of the clients is qualitative in nature and is found in the reference material provided. No clinical trials or summations of experience were found.

Effective relationship-building between clients and the healthcare provider can only be judged by the outcomes of care from both the client’s and the professional’s perspectives. Experience is unique and can only be shared where there is trust. In accounts of personal experiences it would be possible to deduce where positive events had made a difference for the person with dementia, but this may not happen for all.

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 those with dementia and those who care for them is the only way to create meaningful exchanges. At the same time the health care professional does not abandon the option of treatments and support networks that can assist the carer to continue to provide care. Ongoing support for both carer and the person with dementia includes giving time to the carer alone so that personal issues can be raised.

Resources

General information regarding communicating with the person with dementia.

Alzheimer's Australia: <http://www.fightdementia.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx>

Family and Caregiver Counselling in Dementia: Medical Necessity. Position paper American Association for Geriatric Psychiatry. 2001.

http://www.aagponline.org/index.php?src=news&submenu=forthepress_submenu&srctype=detail&category=Position%20Statement&refno=39

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