Communicating with older people with dementia

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Abstract

Being able to communicate with older people with dementia requires a high level of competence in assessment of specific and individual communication challenges and needs of the person. One of the most effective means of assessment and skills development is the use of reminiscence interventions, memory books or life-story work. There is considerable evidence that communication skills can be developed and enhanced through education and skills training. This article aims to invite and encourage readers to reflect on their present knowledge and skills in communicating with older people with dementia.

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Aims and intended learning outcomes

The aims of this article are to challenge healthcare professionals to examine their communication behaviours and to gain some insights and develop skills in enabling better communication when working with older people with dementia.

After reading this article, you should be able to:

- Discuss the challenges faced by people with dementia and their caregivers when communicating.
- Critically evaluate your own knowledge and skills in assessing the communication needs of people with dementia.
- Examine some of the strategies that can be used to enhance communication with people with dementia.
- Reflect on your communication skills when working with people with dementia and their caregivers.

Introduction

Communication refers to exchanges between people when engaging in social and formal interactions. Social communication is supported by conversation, which is an informal interchange of thoughts and information by spoken words, but which may also include non-verbal interactions. Non-verbal communication includes gestures and facial expressions that may include non-verbal aspects of speech, such as accent, tone of voice and speed of speaking (Collins English Dictionary 2009). People with dementia may struggle with myriad changes that impinge on their communication abilities. It is important that caregivers understand the effect these changes can have on the lives of people with dementia and develop communication skills that will support and enable them to manage sensitively all aspects of care.

Box 1 Communication deficits experienced by people with dementia

- Problems finding the right words.
- Lack of coherence or logic in speech.
- Repetition of ideas.
- Decreased attention span.
- Regularly forgetting recent events, names and faces.

(Alzheimer's Association 2013)

Skilful and sensitive communication is important in providing high quality care and good quality of life and wellbeing for older people with dementia. Caring for and communicating with older people with dementia is complex and Junaid and Hegde (2007) remark that 'it is perhaps not an exaggeration to liken it to a sophisticated art'.

Communication skills are essential to establish relationships in care environments, enable people with dementia to engage in positive social activities, optimise residual memory and communication ability (Broughton *et al* 2011, Smith *et al* 2011), and reduce the impact on disturbed behaviour (Potkins *et al* 2003). A decline in communication ability for older people with dementia is usually progressive and gradual, with the condition affecting expressive and receptive (comprehension) language abilities (Box 1).

Box 2 Mood changes that are influenced by communication deficits

- Loss of confidence.
- Becoming emotionally labile, for example, tearful for no apparent reason.
- Appearing easily irritable.
- Showing little or no emotion/apathetic.
- Having delusions of persecution, for example, believing that property has been stolen.
- Becoming disinhibited, for example, impulsive or euphoric.

(Alzheimer's Association 2013)

Emotional distress with erratic changes in mood may be present too (Box 2). The older person may also experience sensory deprivation as well as altered sensory states (Boxes 3 and 4).

When older people demonstrate these changes, it can even lead to them being perceived as having dementia when they do not (Heine and Browning 2004). Sensory deficits in older people may have a profound effect on health outcomes such as falls and fractures, depression and mortality, and they have been implicated in risk of increasing cognitive changes (Potkins *et al* 2003, Lin *et al* 2004, Tay *et al* 2006, Whitson *et al* 2007).

Consequently, interactions with older people, with or without dementia, may become challenging and frustrating for family members, friends and caregivers. There may be difficulties and conflict between them and the person with dementia, increasing stress and adversely affecting the quality of their relationships and ability to meet their mutual communication needs (Small *et al* 2003, Egan *et al* 2010, Wilson *et al* 2012).

Capacity for self-care and social interaction skills may also be compromised when communication skills are affected. It is well known that people with dementia may exhibit and express their frustration and anger by agitation or 'resistiveness to care' (Talerico *et al* 2002, Williams *et al* 2009, Williams and Herman 2011), and by other 'acting out' behaviours as a response to unmet needs (Kong 2005, Kovach *et al* 2005, Cohen-Mansfield *et al* 2007).

Now do time out 1.

1 Different forms of dementia

Time out

Go online or use a standard textbook to identify the main types of dementia syndromes. Find out what specific communication issues arise for the different types of dementia.

Box 3 Altered sensory states

- Hearing and vision loss.
- Dysphasia: either expressive, that is, impairment of the power of expression by speech or writing; or receptive, that is, impairment of the power of comprehension of spoken or written language.
- Aphasia: total loss of the ability to communicate verbally or in writing.
- Visuospatial deficits, for example, difficulty in appreciating the position of objects in space.
- Visual hallucinations that can be frightening and lead the person to believe that they are at risk in some way.
- Vivid dreams.
- Disorientation, for example, regarding night and day or time and place.

(Alzheimer's Association 2013)

Assessment

There is much variation in communication disability and language impairment among people with dementia and the importance of differentiating between the needs of individuals with different forms of the disease has been emphasised (Maxim and Bryan 2006, Haberstroh *et al* 2011). An awareness of the range of possible difficulties that an older person may experience as a result of dementia is important when considering strategies to enhance communication between caregivers, and the person with dementia. This requires a careful assessment of specific language deficits and communication patterns based on observation and history obtained from the person with dementia and family members (Frazier-Rios and Zembrzuski 2004).

One effective method of collecting details on the communication needs of a patient is to use a memory book (Bourgeois *et al* 2001, Burgio *et al* 2001) or a life-story approach (Keady and Jones 2010). The terms memory book and life-story work are often used interchangeably in the literature. The purpose of creating such documents is to work with

Box 4 Impact of hearing loss for older people

- Social isolation and withdrawal.
- Confusion.
- Disorientation.
- Miscommunication.
- Decreased self-esteem.
- Sense of vulnerability.
- Insecurity.
- Loss of confidence.
- Feelings of exhaustion.
- Depression.
- Reduction in functional activities.

(Heine and Browning 2004)

people with dementia and their significant others to remember, share and record information about them. This can include gathering information about the individual from resident records, staff, family and the person with dementia to build a composite and comprehensive profile. This may include details on specific language problems, coping mechanisms, preferences about care and living arrangements, medication history, and physical and mental health (Keady and Jones 2010).

Now do time out 2.

2 Assessment

Time out

Think about your assessment practices and procedures when assessing the communication abilities of the people for whom you care. How do you carry out and document your assessment? Would you describe the assessments as methodical? How often do you update these assessments?

Listening skills

In communication listening is an essential skill and involves close attention being paid, not only to words, but to emotions of excitement, enthusiasm, interest, anger or fear, expressed by the speaker. Listening is a 'multidimensional construct that consists of complex: a) cognitive processes, such as attending to, understanding, receiving and interpreting messages; b) affective processes, such as being motivated and stimulated to attend to another person's messages; and c) behavioural processes, such as responding with verbal and nonverbal feedback' (Bodie and Jones 2012). There are several recognised 'types' of listening. These include:

- Active listening, where the listener listens with all of his or her senses (Barker 1971, Haight *et al* 2003).
- Active-empathic listening, which requires active, conscious and emotional involvement of a listener in attempting to understand what the other is feeling during an interaction (Drollinger *et al* 2006, Bodie 2011, Gearhart and Bodie 2011).
- Compassionate listening, during which the primary objective is to recognise the connectedness between those who are communicating (Rehling 2008).
- Supportive listening, which involves emotional support, is person-centred and non-verbally immediate (Jones 2011, Bodie and Jones 2012).

The two components of supportive listening are (Bodie and Jones 2012):

1. Being person-centred, where the listener uses 'comforting messages', that is, expressions of sympathy and condolence, to legitimise the other's feelings.

2. Using behaviours such as head nods, eye contact and leaning forward to communicate and signal approach, involvement, attentiveness and awareness.

Terms such as 'comforting communication', where the goal is to alleviate or lessen emotional distress experienced by the other person, are also referred to in listening literature (Burleson 2003). This type of listening also has particular relevance to communicating with people with cognitive impairment in stressful circumstances. Here, the aim of the listener is to help the other person cope with emotional distress and address 'matters residing at the core of our being: our sense of self, the things we aspire to, our hopes, our fears, and our deepest feelings' (Burleson 2003).

There are positive outcomes that stem from listening and listening-related competencies that lead to more productive interactions, greater relational satisfaction and better healthcare provision. Furthermore, listeners with high people-orientation are non-judgemental and usually try to find common ground in the communication interaction (Villaume and Bodie 2007).

Now do time out 3.

3 Listening skills

Time out

Consider how you have listened to older people with dementia. Reflect on the effectiveness of your listening skills. Can you identify different 'types' of listening skills that you use?

Verbal communication

It becomes more difficult for a person with dementia to understand what is being said to them or to respond so that others can understand them, therefore the language used, tone and volume of words spoken and also non-verbal communication become increasingly important (Williams and Herman 2011).

Williams and Herman (2011) found that the emotional tone used by staff when communicating with residents in care homes during care interactions was associated with variations in resident behaviours; for example, tones that conveyed higher levels of control correlated with increased resistiveness to care.

Older people with dementia can also exhibit resistiveness to care when staff speak to them using infantilising communication, referred to as 'elderspeak' in some literature. Herman and Williams (2009) found that residents most often reacted to infantilising communication by screaming, yelling and crying.

There are a number of strategies that can enhance communication interactions with people with dementia. These include (Wilson *et al* 2012):

- Slowed speech rate.

- Verbatim repetition.
- Use of closed questions, for example, questions requiring a yes or no response.
- Simple sentences, that is, reduced complexity of the sentence.
- Asking one question.
- Providing the person with one direction or one idea at a time.
- Minimal use of pronouns.

Communication is more successful when questions emphasise interpretation of a word, sentence or other language form, rather than episodic memory of the person with dementia; that is, people can successfully respond to open-ended questions when the response does not require them to recall past information (Small and Perry 2005).

Box 5 lists the ten most commonly recommended communication strategies reported in the literature (Small *et al* 2003).

Small *et al* (2003) developed a questionnaire that was administered to caregivers asking them to indicate how often they use each strategy and if they thought it improved communication with their spouses.

The researchers found a positive relationship between caregiver reported use and perceived effectiveness of the strategies. The strongest relationship was the use of short, simple sentences; closed questions; verbatim repetition, and paraphrased repetition.

However, Small *et al* (2003) suggest that some of these strategies may be unhelpful. For example, slowing of speech did not improve comprehension of sentences for people with dementia because of deficits in working memory and, in some instances, it was counterproductive (Small *et al* 2003). Slower speech requires someone to retain information over a longer period, therefore the person with dementia might forget the earlier part of the conversation by the time they hear the end (Small *et al* 2003).

Box 5 Ten communication strategies often mentioned in the dementia caregiving literature

1. Eliminate distractions, for example, television and radio.
2. Approach the person slowly and from the front; establish and maintain eye contact.
3. Use short, simple sentences.
4. Speak slowly.
5. Ask one question or give one instruction at a time.
6. Use 'yes' or 'no' rather than 'open-ended' questions.
7. Repeat messages using the same wording.
8. Paraphrase repeated messages.
9. Avoid interrupting the person; allow plenty of time to respond.
10. Encourage the person to 'talk around' or describe the word he or she is searching for.

(Small *et al* 2003)

When carrying out activities of daily living, closed questions have been found to enable completion of activities, whereas open-ended questions were more likely to lead to conversations that dealt with emotions and relationships (Small *et al* 2003, Wilson *et al* 2012). However, in some circumstances, people with dementia have been shown to make positive and meaningful responses to open-ended questions, particularly when these questions have demonstrated respect and the topics of conversation were person focused (Small *et al* 2003).

Wilson *et al* (2012) also found that caregivers used two task-focused verbal communication strategies that are not commonly found in the literature. These were verbal praise and use of the person with dementia's name while pointing to an object, handing the object to the resident and demonstrating an action. However, the authors point out that it remains unclear as to which communication strategies are the most effective or are potentially hindering when undertaking activities of daily living with people with dementia.

Now do time out 4.

4 Reflect on your communication with residents and families

Time out

Ask a colleague to observe your practice over one day and make notes on how you communicate with residents and their family members. Ask your colleague to share these observations with you in a supportive and positive manner. What strategies did you use most often? How effective were these in enhancing your engagement with the person with dementia?

Non-verbal communication

When people cannot understand language, non-verbal communication with caregivers whom they trust is of primary importance, and facial expression and touch should convey sincerity and kindness throughout the interaction. Communication approaches should follow the core principles of an ethic of care, that is, attentiveness, responsibility, competence, responsiveness and trust (Barnes and Brannelly 2008).

Furthermore, it is important not to underestimate the awareness that a person with dementia may have of the environment and others around them. People with dementia still retain other capacities that may be used to enhance communication experiences such as: long-term memories; the ability to respond to senses such as smell, touch and taste; a sense of humour; and other social skills, such as singing and dancing.

There are many reports of carers relating episodes of someone with dementia unexpectedly speaking or acting in a way that surprises them and indicates that the person may be more aware of the environment and situation than had been assumed. Such episodes have been referred to as 'episodes of lucidity' (Normann *et al* 1998, 2002, 2006).

Normann *et al* (2006) found that lucidity could be promoted by close contact between caregivers and people with dementia and supporting the person using concepts of confirmation, approval, recognition, acceptance and communion. For example, people with dementia who exhibited 'episodes of lucidity' took more outdoor walks with the caregiver than those who did not exhibit these episodes (Normann *et al* 2006).

A high frequency of 'episodes of lucidity' occurred during supportive conversation, particularly through sharing the person's view, repeating and reformulating the person's utterance and not emphasising errors. When demands were made on the person with dementia, the response was to go from lucidity to non-lucidity. Using this approach, communication can be understood as more than just transmission of information, but as a certain way of relating to the other (Normann *et al* 2002).

Singing and the use of music to accompany communication have been highlighted in many texts as strategies that can enhance the experiences of the person with dementia (Hammar *et al* 2010, 2011). Singing may fit equally in the contexts of verbal (use of voice), and non-verbal communication, where musical instruments may be used and where the voice is also a musical instrument.

When caregivers sing for, or together with, people with dementia during caregiving activities, communication is enhanced, often evoking more vitality and positive emotions (Götell *et al* 2002, 2009, Kverno *et al* 2009). Three types of caring sessions were compared in a study by Götell *et al* (2009). They compared 'usual' care with no music, with care and background music playing, and with caregiver singing to and/or with the person with dementia. Compared with no music, background music and caregiver singing improved communication between caregiver and patient, creating a joint sense of vitality.

Götell *et al* (2009) also found that positive emotions were enhanced and that aggressiveness was reduced. Background music was found to increase the sense of playfulness, and caregiver singing enhanced the sense of sincerity and intimacy in the interaction.

Other non-verbal communication includes (Small *et al* 2003, Maxim and Bryan 2006):

- Sitting face to face.
- Establishing eye contact.
- Using gestures to help explain commands.
- Using a calm tone of voice.
- Using instrumental touch to support or guide the person through tasks.
- Using overemphasis and exaggerated facial expression.
- Keeping distractions to a minimum.
- Giving the patient time to respond.
- Moving slowly.

There is a great deal of literature about the impact of interventions that aim to provide sensory stimulation for people with dementia that include non-verbal communication, such as touch and smell. However, the general consensus from reviews of studies is that the evidence is modest and insufficient in justifying the interventions as being practical and sustainable and that more research, particularly in the form of clinical trials, is needed (Holt *et al* 2003, Vink *et al* 2003, Verkaik *et al* 2005, Seitz *et al* 2012, Woods *et al* 2012).

Now do time out 5.

5 Non-verbal communication

Time out

Make a list of the non-verbal emotional expressions of some of your residents with cognitive impairment. Confirm with a colleague what you believe the resident was trying to convey or express. How attentive are you and colleagues to such non-verbal signals?

Education and training

There is a strong consensus that systematic, individualised communication strategies may encourage people with dementia to express their needs, preferences and ideas (Acton *et al* 2007).

A number of systematic reviews on communication skills training programmes for care home staff concluded that such programmes have a positive effect on verbal and non-verbal communication outcomes for staff and residents with dementia (McGilton *et al* 2009, Egan *et al* 2010, Vasse *et al* 2010). Vasse *et al* (2010) identified two overall types of interventions: structured and communicative sessions at set times and communication strategies in activities of daily living, particularly training programmes for staff.

Factors that increased the effectiveness of the training programmes were: longer training periods, interactive participation during the training and individual attention to trainees. Individual attention with supervision and inclusion of refresher programmes also increased the effectiveness of training programmes (Vasse *et al* 2010).

Using a variety of conversational measures, Bourgeois *et al* (2001) and Burgio *et al* (2001) demonstrated improvements in the quality and quantity

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Reminiscence interventions and life review work have been shown to improve communication between caregivers and people with dementia

of conversational interactions between caregivers and people with dementia through memory book use. Reduced verbalisations by caregivers appeared to encourage increased contributions by people with dementia, such as duration of speaking time. Conducting a life review or constructing a memory book emphasises active listening (Haight *et al* 2003), further supporting the importance of caregivers developing listening skills as a means of improving communication with older people with dementia.

The use of aides such as these is upheld in the systematic review by Vasse *et al* (2010), where life review and reminiscence interventions showed positive results in communication outcomes. Training that emphasised obtaining the life stories of people with dementia, observing social interactions and the impact of the social world on the person, and promoting the skills of interpersonal engagement, especially in relation to feeling expression, were found to be highly effective (Egan *et al* 2010, Vasse *et al* 2010).

Studies reviewed by McGilton *et al* (2009) were focused on formal caregivers in institutional settings and demonstrated positive changes in communication behaviour, skills and knowledge by healthcare professionals. They were found to use more positive statements, use more open-ended questions and were rated as being more involved, warmer, less patronising and less likely to show disapproval.

Outcome measures for residents showed a decrease in verbal expressions of anger, less agitation and an increase in responsiveness and eye contact with healthcare professionals. McGilton *et al* (2009) concluded that due to considerable variation in intervention content and duration and mode of delivery it was difficult to identify which interventions were more effective than others.

A number of models of communication training have been evaluated. For example, TANDEM, a psychoeducative training programme for informal caregivers of people with dementia in Germany, used components of reminiscence and demonstrated improvement in quality of life (Franzmann *et al* 2010, Haberstroh *et al* 2011).

The programme involved (Haberstroh *et al* 2011):

- Presenting past experiences.
- Expressing relationship aspects, for example, reading physical expressions such as a caress of the caregiver's hand or lifting of the corner of the mouth, to understand the underlying emotion.
- Focused attention.
- Comprehending relationships rather than content.
- Remembering old experiences, for example, connecting new information to old information.

The Caring for Aged Dementia Care Resident Study (CADRES) in Australia used a person-centred education intervention that constantly reinforced the universality of human emotions and shared humanity, and that people with dementia retain their emotional life throughout the illness (Stein-Parbury *et al* 2012). The education programme focused on communication strategies that used activities such as reminiscence and discussion of feelings.

The interactive participation during the training, which involved role-play activities and interaction with other participants, was evaluated as the most

valuable aspect of the training (Stein-Parbury *et al* 2012), a factor upheld in the systematic review by Vasse *et al* (2010).

A person-centred communication skills intervention, based on work by Kitwood (1997) and the 'VIPS' model developed by Brooker (2007), was used to improve the quality of dementia care provided by paraprofessional (trained workers who are not members of a given profession but assist professionals) caregivers in long-term care facilities in the US (Passalacqua and Harwood 2012). This education programme used similar approaches to those outlined previously, emphasising 'Valuing people' (V), 'Individualised care' (I), 'Personal perspectives' (P), and 'Social Environment' (S). Participants gave positive evaluations. There was a reduction in caregiver depersonalisation of residents, an increase in yes/no questions and an increase in giving choices between two options (Passalacqua and Harwood 2012).

There are many developments in education and training programmes aimed at increasing skills in communicating with older people with dementia that have been evaluated over recent years. These studies consistently conclude that increasing caregivers' communication skills significantly improves the quality of care and quality of life of older people with dementia.

Now do time out 6.

6 Improving communication for others

Time out

In collaboration with colleagues, design a short teaching session about communicating with people with cognitive impairment. What would you include in the session? What techniques might you use to teach communication skills?

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7 Review your own communication

Time out

Start a diary or journal titled 'Communication and dementia' and reflect on your interactions with residents and their families and on the type of communication skills and strategies that you have used. Record situations where you thought you had performed well. Record situations when you thought you could have managed the interaction better using strategies that you have learned. Do this for one month and review changes in your practice.

Conclusion

Skilful and sensitive communication is important to the provision of quality care and in maintaining and extending quality of life for older people with dementia. Emotional support and stimulation needed by a person with dementia particularly focuses on communication, reassurance and security using verbal and non-verbal approaches.

There is good evidence that the communication skills of healthcare professionals and family caregivers can be increased through education and training.

Now do time out 7.

8 Practice profile

Time out

Now that you have completed reading the article you might like to write a practice profile. Guidelines to help you are on page 38.

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Practice profile

What do I do now?

- Using the information in section 1 to guide you, write a practice profile of between 750 and 1,000 words – ensuring that you have related it to the article that you have studied. See the examples in section 2.
- Write 'Practice Profile' at the top of your entry followed by your name, the title of the article, which is: '**Communicating with older people with dementia**', and the article number, which is **NOP429**.
- Complete all of the requirements of the cut-out form provided and attach it securely to your practice profile. Failure to do so will mean that your practice profile cannot be considered for a certificate.
- You are entitled to unlimited free entries.
- Using an A4 envelope, send for your free assessment to: Practice Profile, RCN Publishing Company, Freepost PAM 10155, Harrow, Middlesex HA1 3BR by **May 2014**. Please do not staple your practice profile and cut-out slip – paper-clips are recommended instead. You can also email practice profiles to practiceprofile@rcnpublishing.co.uk. You must also provide the information that is requested on the cut-out form. Type 'Practice Profile' in the email subject field to ensure you are sent a response confirming receipt.
- You will be informed in writing of your result. A certificate is awarded for successful completion of the practice profile.
- Feedback is not provided: a certificate indicates that you have been successful.
- Keep a copy of your practice profile and add this to your professional profile. Copies are not returned to you.

1. Framework for reflection

- Study the checklist (section 3).
- What have I learnt from this article?
- To what extent were the intended learning outcomes met?
- What do I know, or can I do, now, that I did not/could not before reading the article?
- What can I apply immediately to my practice or client/patient care?
- Is there anything that I did not understand, need to explore or read about further, to clarify my understanding?
- What else do I need to do or know to extend my professional development in this area?
- What other needs have I identified in relation to my professional development?
- How might I achieve the above needs? (It might be helpful to convert these to short/ medium/long-term goals and draw up an action plan.)

2. Examples of practice profile entries

- **Example 1** After reading a CPD article on 'Communication skills', Jenny, a practice nurse, reflects on her own communication skills and re-arranges her clinic room so that she will sit next to her patients when talking to them. She makes a conscious decision to pay attention to her own body language, posture and eye contact, and notices that communication with patients improves. This forms the basis of her practice profile.
- **Example 2** After reading a CPD article on 'Wound care', Amajit, a senior staff nurse on a surgical ward, approached the nurse manager about her concerns about wound infections on the ward. Following an audit which Amajit undertook, a protocol for dressing wounds was established which led to a reduction in wound infections in her ward and across the directorate. Amajit used this experience for her practice profile and is now taking part in a region-wide research project.

3. Portfolio submission

Checklist for submitting your practice profile. Have you:

- Related your practice profile to the article?
- Entitled your entry 'Practice Profile' and included your name, the title of the article and the article number?
- Written between 750 and 1,000 words?
- Kept a copy of the practice profile for your own portfolio?
- Completed the cut-out form and attached it to your entry?

Continuing professional development: practice profile

Please complete this form using a ballpoint pen and CAPITAL letters only, then cut out and send it in an envelope no smaller than 23 x 15cm to:

Practice Profile
RCN Publishing Company
Freepost PAM 10155
Harrow, Middlesex HA1 3BR

Full title and date of article:

Article number:

First name:

Surname:

Job title:

Place of work:

Address:

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Daytime tel: