Dementia communication using empathic curiosity

In this article...

- Empathetic curiosity and how it can be used in dementia care
- How this approach can be used to aid communication
- A case study to demonstrate its use

Authors
Phil McEvoy is managing director at Six Degrees Social Enterprise and honorary research associate at the University of Manchester; John Eden is psychological wellbeing practitioner at Six Degrees Social Enterprise; Rachel Plant is PhD student at the University of Manchester.

Abstract

Communication skills training materials in dementia care usually focus on reminiscence. This is important because talking about past events can help people with dementia to retain their sense of self. This article examines the use of an alternative set of communication skills known as empathic curiosity, which may help to promote meaningful communication in the here and now with people who are living with dementia.

Social relationships are extremely important for people living with dementia. Like all of us, they want to feel connected to their friends, families, the communities they come from and the places in which they live. These connections play an important role in helping them to retain their sense of identity and personal wellbeing (Department of Health, 2009; Aked et al, 2008).

This point is illustrated by the relationships that can develop among people with dementia living in long-term residential care, such as that between Lucy and Carl (Box 1). Lucy and Carl both experience difficulty in recalling information and maintaining their train of thought, but they socialise with each other and maintain their bond of friendship.

The social relationships that people with dementia have with their caregivers are particularly important. Research has shown that some negative effects of dementia can be reduced in supportive social environments in which caregivers use person-centred approaches (Eggenberger et al, 2013). The quality of life of people with dementia improves when caregivers are trained to develop their communication skills; this may also reduce levels of care-related stress and burnout (Eggenberger et al, 2013).

Many communication skills training materials focus on reminiscence interventions, memory books or life-story work (de Vries, 2013). These types of interventions focus upon early memories. Talking about past events can help people with dementia to retain their sense of self; they find it enjoyable and it can help to improve their mood and general wellbeing (Woods et al, 2005).

This article examines how an alternative set of communication skills, called empathic curiosity, can be used. This may help to promote meaningful communication about the here and now. The article gives a brief introduction to the concept of empathic curiosity and an outline of the skill sets that support the approach. It also provides a case study that illustrates what empathic curiosity may look like in practice.

Empathic curiosity

The value of empathic curiosity is that it may help to open up spaces in which people with dementia can talk about the experiences they are currently having and how they are trying to control them.

When we respond to a person with...
BOX 1. LUCY AND CARL INTERACTION

Lucy: I think I was dozing when you came up.
Carl: I think you were.
Lucy: I really can sleep anywhere, I guess.
Carl: That’s good. As long as you don’t skip any meals.
Lucy: Yeah. I don’t want to miss any meals.
Carl: Get up and go to bed, go to bed.
Lucy: What?
Carl: Get up everyday and stay up for about half hour and go to bed, take a nap, and sleep all day again.
Lucy: My, I couldn’t do that.
Carl: You might if you’re a good sleeper.
Lucy: No I couldn’t sleep that much. I don’t go to bed early. I, I don’t go to bed ‘til, until midnight a lot of times.
Carl: Midnight? You never told me that before.

Source: de Medeiros et al (2012)

People with all levels of impairment are sensitive to non-verbal signals we give, such as establishing eye contact, leaning forward and adopting a calm tone of voice. These signals indicate we are looking to engage with them and that there is an open space in which they may be listened to.

For people with mild impairment, this may involve looking out for non-verbal disruptions in body posture and conversational flow. For example, when someone pauses, falters, looks away, shakes their head or laughs to themself, these disruptions may indicate that they are distracted by their background thoughts. Asking people with dementia about their thoughts at these times can prompt them to start talking aloud about concerns or issues that are on their mind (Carey, 2008).

Being sensitive to pacing issues
It is essential to give people with dementia the time and space to find their words or to communicate what they are trying to say through their actions.

Nurses tend to spend less time interacting with patients who have moderate to severe impairment than those with mild to moderate impairment (Cahill and Diaz-Ponce, 2011). One reason for this is that nurses may not always give themselves enough time and space to absorb what these patients are trying to communicate or achieve through their actions. They may use a related word when they cannot locate the exact word they wish to use, or use a gesture to signify something they cannot name – this could be pouring to signal the function of an object such as a cup. If we talk over people with dementia or fail to read their communications because we see them as meaningless, they may react by acting out their frustrations or withdrawing into silence (Acton et al, 2007).

Searching for the meaning of simple metaphors
Searching for the meaning of simple metaphors used by people with dementia may be an effective repair strategy that helps to deal with breakdowns in the thread of a conversation.

These breakdowns often occur when people with dementia experience difficulties in finding words. For example, they may pause for a while as they are trying to remember a word or phrase, use an alternative word that has a similar but different meaning, or use a word that has a similar sound to the word that they are intending to use (Savundranayagam and Orange, 2014).

Understanding these metaphors can help to open up spaces in which people with mild to moderate impairment may be able to talk about the experiences they are having now and how they are trying to control them (Cameron and Deignan, 2006).

For example, in the conversation below, the interviewer (I) asks Ms Edgar (not her real name), who has mild impairment “How do you mean, ‘standing on the side?’” (Hedman et al, 2013). This helped...
Discussion

Nursing Practice

her to identify the feelings she was experiencing as she was trying to come to terms with her condition and the impact it was having on her sense of self (McEvoy and Plant, 2014):

Ms Edgar: And then when you kind of discover that, when you realise, then it’s really tough. [...] You become incredibly sad, you do then, because then there is....
I: Mm.

Ms Edgar: But still, I did think I was kind of... I don’t know, I wasn’t... I was still standing on the side.
I: Mm.

Ms Edgar: So I think it has been going slowly but steadily....
I: Mm. How do you mean "standing on the side"?

Ms Edgar: Yes, that certain moments you’re sad, and then there is... eh... as if it, well, it’s not true and it... Well, I don’t know.
I: Mm.

Ms Edgar: As if you didn’t take it in, after all, in some way, more than during certain moments.
I: Mm.

Ms Edgar: Certain... but I started searching on the internet a lot and read and so on.

Pay close attention to our own responses

When people with dementia were asked the question, “How have things been going for you lately?” (Ostwald et al, 2002), a theme that repeatedly came up was their worry about the impact of the decline in their cognitive ability and increasing dependency on their carer and/or family.

Working with people who have dementia in a person-centred way is challenging. It can be far easier (though less rewarding) to emotionally distance ourselves by focusing on the task-related aspects of caring than to maintain an approach that requires higher levels of personal engagement.

Adopting an empathic and curious approach requires us to give more of ourselves as we have to pay close attention to “minute particulars” that occur during our interactions and how we are responding to them (Hobson, 1985). In the process, we may have to deal with negative feelings such as frustration, sadness or guilt, which are generated within ourselves, and the heightened sense of personal vulnerability that these feelings can arouse. The feelings may not go away entirely but we can learn to understand and tolerate them.

Case study

This case study is taken from a paper that examined how empathic curiosity can be used to resolve emotional distress (McEvoy et al, 2013). It illustrates how the skill sets in Box 2 above can be used to build rapport and understanding.

Joyce Smith (not her real name) is an older woman who was admitted to an intermediate care unit after a stay in hospital following a fall. Her short-term memory had deteriorated and she was finding it difficult to recall information. Her conversation was fragmented and she had started to grimace in a disorientated way that was difficult to follow.

During the previous night, Mrs Smith had been confused and disorientated. Thinking that she was at home, she had wandered around searching for the toilet and she had been assisted by nursing staff (including a male staff member).

The interaction below occurred the following morning when a psychological wellbeing practitioner noticed that Mrs Smith’s hands had begun to tremble and that she had started to grimace in a distressed way. (PWPs are graduates who are trained to provide basic interventions that can be used with people who have common mental health problems such as depression and those related to anxiety.)

Spotting that Mrs Smith might be upset, the PWP turned down the volume on the television set to reduce the background noise and calmly approached her. She then used an empathic and curious style of questioning to help her to identify the source of Mrs Smith’s distress.

PWP: Your hands are trembling there...
Mrs Smith: Yes, they are, they are. I... er... I....
PWP: You look a little worried?

Mrs Smith: Yes, well I am. It’s all so strange all of this here... [pause] And then there’s all the men [trembling increases].
PWP: The men?
Mrs Smith: Yes! The men! They’re so... I’m scared... and, it’s... but all the people are so friendly here, so friendly, really they’re so friendly... but... [said in faltering voice].
PWP: Everyone’s been friendly?
Mrs Smith: Yes, but... [body tenses up].
PWP: But you’re frightened of the men here?
Mrs Smith: Yes [body relaxes, trembling much reduced].
PWP: Would it help if only the women here come into your room? If no men come into your room?
Mrs Smith: Oh, thank god for that because everyone’s so friendly.

The PWP gently shared her observation with Mrs Smith, “Your hands are trembling there.” Mrs Smith affirmed that this was the case but was hesitant in her reply. The PWP was sensitive to Mrs Smith’s needs and gave her time to respond. After a pause, the PWP put the open question to her: “You look a little worried?” This gave Mrs Smith the freedom to respond without jumping to any premature conclusions which she was concerned. The PWP did not jump to any premature conclusions about what her concern about the men were and simply reflected back her statement in an enquiring way, asking: “The men?”

Mrs Smith then responded in a more emotive way. She clearly stated that she

Box 3. Severity of impairment in ability to communicate

<table>
<thead>
<tr>
<th>No impairment</th>
<th>Very mild</th>
<th>Moderately severe</th>
<th>Severe</th>
<th>Very severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>• No obvious signs of dementia</td>
<td>• Signs are barely noticeable</td>
<td>• Increase in memory loss, including inability to remember personal details</td>
<td>• Inability to recall the names of family members or carers, but still able to recognise familiar faces</td>
<td>• Loss of language skills</td>
</tr>
<tr>
<td>• Some forgetfulness and memory loss</td>
<td>• Repetition</td>
<td>• Confusion about location or chain of events</td>
<td>• Increased paranoia or even hallucinations</td>
<td></td>
</tr>
<tr>
<td>• Increase in memory loss and forgetfulness</td>
<td>• Loss of concentration</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

was scared, but played down her fears “Really they’re so friendly.” It would have been easy for the PWP to close off the conversation at this point by agreeing with Mrs Smith. However, instead of doing this, she continued the conversation by exploring the meaning of “being friendly”.

Being friendly could be considered in its literal form as a phrase to describe the demeanour of staff and the style of their interactions. It could also be used as a way for Mrs Smith to communicate the parallels she recognised between the nursing care staff and other people with whom she has had supportive relationships.

It became clear that she was using the word metaphorically to convey that she understood that the demeanour of the staff was more than a “friendly” facade. She wished to express that she understood that they were acting in a caring and compassionate way and explain how important it was to her to reciprocate this and/or to acknowledge it to the staff (as we often do with those with whom we have relationships). She was aware that the fear and anxiety she displayed had the potential to be interpreted as rejection or ingratitude which she clearly did not feel.

Allowing Mrs Smith to continue the flow of her thoughts as they occurred – irrespective of how disjointed they may have seemed – helped her to express, articulate and manage her conflicting emotions. By encouraging her to think aloud and accepting what she said at face value, the PWP demonstrated a deep respect for Mrs Smith’s personhood and gave her space to think.

Mrs Smith’s ability to understand the situation she was in was far greater than was immediately apparent. She aptly demonstrated this by the way in which she described the ambivalent feelings she had, feeling both anxious about the presence of strange men whom she did not know and grateful for the friendliness of the reception she had received.

Conclusion

The PWP in the case study helped Mrs Smith to maintain her focus on the here and now by paying close attention to her responses and trying to avoid making unfounded assumptions. In doing so, she was able to help Mrs Smith clarify her concerns. This was important because, all too often, people with dementia are regarded as living entirely in the past and as having no capacity for meaningful engagement. When we underestimate the potential of people with dementia in this way, we tend to marginalise them. We also reinforce a culture of dependency by undermining the capacity they have to make choices and decisions for themselves (Sabat, 2001; Kitwood, 1997).

Adopting an empathic and curious stance may help us to foster more balanced, person-centred relationships with people who are living with dementia and form relationships that are based upon equality and common understanding, rather than power and dependency.

References


Cahill S, Diaz-Ponce AM (2011) “I hate having nobody here. I’d like to know where they all are”: Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? Aging and Mental Health; 15: 5, 562-572.


