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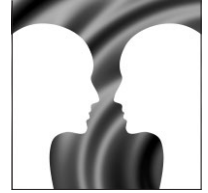


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# Dementia care: using empathic curiosity to establish the common ground that is necessary for meaningful communication

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## Accessible summary

- Empathic curiosity is a standpoint that we adopt when we focus our attention on the perceptual experiences of people with dementia, as they are experiencing them in the here and now.
- Adopting an empathic and curious stance may help to establish the common ground for meaningful communication and help to cultivate relationships that are based upon equality and common understanding, rather than power and dependency.
- Four key sets of communication skills can support this approach: (1) asking short open questions in the present tense; (2) picking up on emotional cues; (3) giving time and space for the person with dementia to find their words and share responsibility for steering the course of a conversation; and (4) exploring the use of metaphors.
- Providing access to training and supervision that supports these communication skills may be an essential element of building an informed and effective dementia care workforce.

## Abstract

Over the past two decades the advocates of person-centred approaches to dementia care have consistently argued that some of the negative impacts of dementia can be ameliorated in supportive social environments and they have given lie to the common but unfounded, nihilistic belief that meaningful engagement with people with dementia is impossible. This discussion paper contributes to this welcome trend by exploring how carers can use empathic curiosity to establish the common ground that is necessary to sustain meaningful engagement with people who have mild to moderate dementia. The first section of the paper gives a brief theoretical introduction to the concept of empathic curiosity, which is informed by perceptual control theory and applied linguistics. Three case examples taken from the literature on dementia care are then used to illustrate what empathic curiosity may look like in practice and to explore the potential impact that adopting an empathic and curious approach may have.

## Introduction

Over the past two decades advocates of the person-centred tradition within dementia care have consistently argued that some of the negative impacts of dementia can be

ameliorated in supportive social environments (Kitwood & Bredin 1992, Sabat & Harré 1994, Kitwood 1997, Sabat 2001, Harris 2002, O'Connor *et al.* 2007, Chenoweth *et al.* 2009). Evidence-based approaches such as dementia care mapping (Brooker 2005), listening to life stories (Usita

& Hyman 1998) and centre stage diagrams (Keady *et al.* 2007) have also given lie to the common but unfounded, nihilistic belief that meaningful engagement with people with dementia is impossible. These interventions are potentially beneficial for many reasons. They can act as mediating interventions that enable people with dementia to connect with others, maintain a high quality of life and contribute to the social networks in which they live (Department of Health 2009).

This discussion paper contributes to this welcome trend by exploring how carers can use empathic curiosity to establish the common ground that is necessary to sustain meaningful engagement with people who have mild to moderate dementia. The first section of the paper gives a brief theoretical introduction to the concept of empathic curiosity. Three case examples taken from the literature on dementia care are then used to illustrate what empathic curiosity may look like in practice and explore the potential impact that adopting this relational stance may have.

## Empathic curiosity

The meaning of the word empathy is to understand the mindset and behaviour of another person by putting oneself in their place (Stueber 2012). Key aspects of empathy include tuning into the emotional experiences of others (experience sharing), drawing inferences about their mental states (mentalising) and responding with prosocial concern (Decety & Jackson 2004, Zaki & Ochsner 2012). Empathic responses communicate an appreciation of what other people are experiencing and they can help to build feelings of connection, mutuality and trust (Hobson 1985, Bruneau 1989). Empathic listening involves not only attending to the words that are spoken, but also to how the words are expressed (Rogers 1975), being sensitive, moment by moment, to changes in felt meanings and the emotions a person may be experiencing. Empathic curiosity is a meta-communicative (Bateson 1973) standpoint that we adopt when we try to focus our attention on the perceptual experiences of another person, as they are experiencing them in the here and now.

The term meta-communication describes the underlying tone that we communicate, rather than what we directly say or do, and because of this it can be difficult to pin down. However, very often this underlying tone may resonate more powerfully at an emotional level that reflects the state of feelings than the words we use (Cashdan 1988). The approach to empathic curiosity outlined in this paper is informed by perceptual control theory (PCT), a theoretical approach which maintains that the way in which we cope with the demands of living in this world is mediated

by our sensory perceptions and the internal processes through which we try to control them. According to PCT, we respond to the world as we see it and this is always in relation to our perceptual reference points (Powers 1973, Mansell 2005), which are influenced by our social histories and store of autobiographical memories (Conway & Pleydell-Pearce 2000).

We tend to think of the difference between dementia sufferers and non-dementia in absolute rather than relative terms. However, all of us as living people act in purposeful ways (Dennett 1991) to exert control over our bodies and our environment. Either consciously or subconsciously we act to avoid the loss of control over those aspects of our lives, over which we want to exert some degree of influence (Mansell & Carey 2009). The literature on dementia care is replete with examples that underscore this point. It is recognised that people with mild dementia often skilfully protect themselves from threats to their self-identity by controlling the way in which they present themselves to others, using strategies such as concealing memory lapses and making light of their difficulties (Clare 2003). Even in severe dementia, behaviours that may appear to be incomprehensible may be more appropriately understood as meaningful attempts by dementia sufferers to control their perceptual experiences (Sabat 2001). For example, a recently published case study described how a man with severe dementia was observed to protect himself from an abusive carer. When the carer attempted to wipe his face with a tissue without any prior warning, he reacted angrily saying, 'No, no', and tried to hit out at her (Kelly 2010, p. 115). Incidents like this highlight the dangers of impersonal care provided by institutional carers who lack empathic understanding of the dementia sufferers whom they are responsible for caring for (Tappen *et al.* 1997).

From a control theory perspective, the value of empathic curiosity is that it can help to foster greater engagement and insight by opening up conversation spaces in which people can share their phenomenological experiences. Empathic listening is facilitated by paying close attention to the 'minute particulars' that occur during conversation (Hobson 1985). This involves picking up on cues such as non-verbal disruptions in conversational flow or metaphorical clues that may signal emotional concerns or needs (Gibbs & Cameron 2008) and asking short non-intrusive questions that open up space for people to talk about their present experience, if they want to (Carey 2009, McEvoy *et al.* 2013). Adopting a curious attitude helps to direct attention towards the purpose behind a person's behaviour, their salient concerns and the personal values that are meaningful to them. This is a form of conversation that the linguist Lynne Cameron (2007) describes as both dynamic

and dialogic. It is dynamic in the sense that what happens in the moments of talk (Cameron 2007) enables individual people to locate their personal experience and compare it with the experience that they want to have (Carey 2008). It is dialogic in the sense that it occurs in the presence of another, who gives them the freedom and space to talk aloud about the thoughts that are at the forefront of their minds. The thoughts may be of memories from the past, their situated experience or the expectations they have about their future. Three case studies below identify what empathic curiosity may look like in practice and illustrate the potential impact that adopting this meta-communicative stance may have.

### Case study one

This short piece of text comes from a report of a qualitative study that explored the preservation of self in people with dementia living in a residential care home (Surr 2006, p. 1725). It illustrates the principle of allowing the person with dementia to steer the flow and set the tone of the conversation. The interviewer (CS) used an unstructured interviewing technique that allowed the residents to set their own agenda and direct the flow of the interview themselves. In the text of the conversation below she encourages one of the participants Olga (O) to talk about her experience.

CS: Do you like living here?

Olga: Not here . . . I do not very much, you know, because it's not for me, you know, it's not mine, it's the others they're having plenty there. So . . .

CS: It's hard living with other people, isn't it.

Olga: Yes. (laughs)

CS was aware that Olga had experienced difficulty settling into the residential home and asked '*Do you like living here?*' This simple question was posed in ordinary language and phrased in the present tense. It was short, engaging and it was not couched with an implicit suggestion that Olga should frame her response in a particular way. Olga's immediate reaction was to say '*Not here*'. She then paused for a moment before she continued. Olga explained that '*it's not for me*' and she contrasted her experience with the experience of other residents, '*they're having plenty*'. Having plenty is a metaphor that is used to convey the perception of being in possession of a lot of something. There was a brief disruption in the conversational flow as Olga hesitated, '*So . . .*'. At this point CS recognised that Olga may be feeling like an outsider who did not belong in this new environment. However, she held back from expressing a judgement or making any suggestions about what Olga should do. Instead, she simply validated her experience in a neutral empathic

manner by saying, '*It's hard living with other people, isn't it.*' Olga's confirmation '*Yes*' and laughter signalled her appreciation that CS had listened and understood.

### Case study two

The two conversational passages below come from a case study that examined the speech of Tina (T), a woman with Alzheimer's disease, to two different audiences (Ramanathan-Abbott 1994). They illustrate how the type of prompts that we use may influence the course of a conversation. In the first passage, Tina speaks to her husband Nick (N) who adopts a directive stance.

N: What else do you remember about your childhood, Tina?

You grew up in Peoria

T: Ya [. . .]

N: and you mentioned your mother and ah [. . .] when you were a small girl there was some problem at the time

T: What was that Nick?

N: Well you tell me

T: Well my daddy died?

N: Well that was one,

But before that

[. . .]

N: you were ill/very ill

[. . .]

N: What did they do to you?

T: Oh they cut a hole in my back they couldn't give an anaesthetic

Nick repeatedly prompted Tina to pick up the aspect of the storyline that he perceived to be important and this appeared to stifle the flow of the conversation. Most significantly, when Tina located the death of her father as the significant event that had been searching for '*my daddy died?*' he overrode her by saying '*Well that was one, but before that.*' Tina intuitively grasped that Nick's intention was to help her to tell her story and she endeavoured to work with him to construct the storyline, but she was very hesitant and struggled to establish the narrative thread that he was looking for.

The second passage comes from a conversation that Tina had with an interviewer (I). The interviewer took a less directive stance and the dynamic of the conversation was qualitatively different.

I: When you look back over your past, Tina, what is it that stands out most?

T: Ah [. . .] well I guess the thing that stands out the most is Ah my memories of my illness.

I: Really

T: and ah the fact that I couldn't really walk.

I: How old were you?

T: Oh let's see,  
I was in kindergarten.  
I: Ya, you were really young  
T: [. . .] and ah I daddy used to have to carry me,  
And ah [. . .] you know.  
It was a bad situation,  
But it brought us all close together.  
And ah you see  
They cut this wound on my back without anaesthetic

The interviewer initiated this conversation with the open question about the events of the past, '*What is it that stands out most?*' She confirmed that she was listening and interested in hearing what Tina had to say by acknowledging her initial response with the word '*Really*'. This seemed to have been said in such a way that it gave Tina permission to carry on speaking. It also signalled that she would be given the time she needed to think and compose her thoughts. A signal of an impending interjection at this point of the conversation may have interrupted the flow of Tina's thoughts and diverted the conversation away from her concerns. The interviewer continued to maintain an open and receptive stance and posed some curious follow-up questions. For example, '*How old were you?*' Tina responded by speaking about the circumstances of her childhood and salient features of the experiences that she had when she was growing up. The conversation with the interviewer was suffused with more personal meaning than the conversation Tina had in the presence of Nick. Tina spoke more fluently about her autobiographical memories and explained how the childhood illness she had had impacted upon the relationship she had with her family.

### Case study three

The final example is taken from a recently published paper that examined how people with mild to moderate dementia express their sense of self. It illustrates the value of empathic listening and paying close attention to the metaphors and language of the person with dementia uses. In the segment of conversation below, the interviewer I and Ms E, a woman who had mild dementia, discussed the feelings she experienced as she tried to come to terms with her condition (Hedman *et al.* 2013, p. 720).

Ms E: And then when you kind of discover that, when you realize, then it's really tough. [. . .] You become incredibly sad, you do then, because then there is ?  
I: Mm.  
Ms E: 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 E: So I think it has been going slowly but steadily ?  
I: Mm. How do you mean standing on the side?

Ms E: 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 E: As if you didn't take it in, after all, in some way, more than during certain moments.

I: Mm.  
Ms E: Certain ? But I started searching on the Internet a lot and read and so on.

As Ms E talked, the interviewer repeatedly responded with non-lexical speech sound 'mm', which has no fixed meaning. 'Mm' can signal a particular standpoint such as 'I'm suspending judgement on what you're saying', or convey an invitation to continue talking as 'I'm with you, please carry on'. Here it seemed to communicate a sense of empathic understanding. Ms E was groping for words to describe her experience and the interviewer's response indicated that this was a safe relational space in which she would be given the time she needed to gather her thoughts. The tentatively phrased opening to the curious question '*How do you mean standing on the side?*' acted as a tuning device (Cameron & Deignan 2006) in the sense that it invited Ms E to reflect upon the meaning of the metaphor that she had used to describe her experience. Standing on the side is a phrase that is frequently associated with a particular position such as the side of a stage or road. In this instance Ms E used the metaphor in a reflexive way to describe how the insidious onset of dementia had affected her sense of self. '*Certain moments you're sad, and then there is . . . eh . . . as if it, well, it's not true.*' After the brief interjection the interviewer carried on listening, again using the non-lexical sound 'mm' to convey the sense that 'I am with you'.

### Discussion

The case studies highlight the role that adopting an empathic and curious approach may play in improving communication with people who have mild to moderate dementia. Four key sets of communication skills supported this approach.

1. Asking short, open questions in the present tense. The question that CS posed to Olga in Case Study One '*Do you like living here?*' was a good example of this skill. At first sight this question looks very ordinary. Yet, in the context of the conversation in which it was embedded, it helped to open up a non-threatening space in which Olga knew that she has permission to talk to CS, if she wanted to.
2. Picking up on emotional cues. For example, as CS did when she noticed Olga's hesitancy. At this point, CS gently opened up space for Olga to talk about her experience of living in the nursing home.

3. *Pacing and control.* This involves giving the person with dementia time to think, find their words and share the responsibility for sustaining a conversation in a collaborative way. In Case Study Two, Tina was given the time and freedom she needed to steer the course of the conversation with the interviewer, but not during the conversation with her husband Nick. This resulted in qualitatively different types of interaction. Having the opportunity to exercise this type of control is important for all people. It helps us to assimilate information and it promotes feelings of subjective well-being (Declerck *et al.* 2006). However, it is particularly important for people with dementia. If they are not given the time and space they need to think things through and identify the words they want to say, they may not be able to exploit their conversational capabilities (Nolan *et al.* 2004).
4. *Exploring the use of metaphors.* The interviewer's curious question 'How do you mean standing on the side?' in Case Study Three illustrates the value of exploring the use of metaphors via a process of guided discovery (Padesky 1993). It prompted Ms E to speak about her experiences and explain how she had come to terms with her diagnosis.

Using these communication skills may be far easier in theory than in practice, and health and social care workers may require training and supervision to support them in developing their competencies. However, the potential benefits of developing these communication skills is that they act at a meta-communicative level to help to facilitate meaningful engagement of a type that helps people with mild to moderate dementia to explore their feelings, relationship to others and place in the world.

## Concluding comments

Health and social care workers are frequently given specialist communication skills training and supervision to deal with challenging interpersonal situations such as a breaking bad news (Maguire 1999). However, in the field of dementia care, despite some isolated examples of good practice such as the Marte Meo Counselling initiative (Alnes *et al.* 2011), training in interpersonal communication skills for carers is poorly developed (Spalding & Khalsa 2010; Lawrence *et al.* 2012). Providing access to communication skills training and supervision is an essential element of building an informed and effective workforce (Department of Health 2009) and it should be given more emphasis as a strategic priority.

A recently published review of communication skills training in dementia care (Eggenberger *et al.* 2013) identified that communication skills training can help to sig-

nificantly improve the quality of life and well-being of people with dementia, by increasing positive interactions with caregivers. The authors of the review outlined a list of seven communication principles that underpin good functional communication which included verbal skills, non-verbal and emotional skills, attitudes, behavioural management, tools, self-experience and theoretical knowledge. Training in these skills is likely to improve caregivers' communication competencies, confidence and knowledge. However, whilst they may be necessary, they are not necessarily sufficient to ensure high-quality communication unless greater attention is paid to the qualitative character of the relationship that caregivers establish with dementia sufferers. In essence, we are relational beings and the empathic interchanges that we have with others have a significant effect on both our sense of self and how we feel about the world. The meta-communicative tone that is associated with the empathic and curious approach outlined in this paper is important to consider, as it may help to establish the relationships that are based upon equality and common understanding, rather than power and dependency.

In order to unravel the key components of this meta-communicative stance and determine whether the approaches that are explored in this paper can be effectively utilised in practice, detailed empirical research is needed, such as recently conducted analysis of the conversational strategies used by people with semantic dementia in everyday environments carried out by Kindell *et al.* (2013). This discussion paper is pitched at the initial pre-clinical phase of the Medical Research Council's Framework for Developing Complex Interventions (Campbell *et al.* 2000). It has explored theoretical leads rooted in control theory and applied linguistics that may help to generate developments in the field. The next stage along this continuum of development is to identify more precisely the mechanisms that may explain how the approach may work and the influence of confounding or contextual factors that may need to be taken into account when caregivers look to engage with people with dementia in an empathic and curious way. For example, a professional caregiver may sometimes get a very different response from a person with dementia than their spouse, even though their communicative stance is apparently the same. There may also be circumstances, when adopting these approaches may be perceived as intrusive or unwelcome. The cultivation of empathic curiosity may therefore be as much of an art, as it is a science. The psychotherapist Theodor Reik (1949) described the intuitive dimension of this meta-communicative stance as listening with the third ear for what bothers people, occupies their thoughts and arouses their emotions.



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