ARTICLE

Giving a voice to people with advanced dementia

Amanda Henwood and **Maggie Ellis** on 'Adaptive Interaction'

Research suggests that mirroring is an effective technique that can be used to aid communication in advanced dementia. However, the evidence supporting this technique needs substantiation and application guidelines need to be made clearer. This article explores a recently developed mirroring technique called 'Adaptive Interaction' that addresses these shortcomings with compelling evidence. The challenges of implementing wider social interventions within dementia care settings are discussed and some key suggestions for future research are made.

questions

What are the potential barriers preventing the widespread implementation of social interventions in dementia care?

What steps could researchers take to encourage the implementation of social interventions in dementia care and improve the evidence base supporting interventions?

resources

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www.connectedbaby.net

We enter the world with a yearning for social connection. This instinctual desire for social contact can be seen in a baby's early attempts at interaction, for example, smiling, making eye contact, and crying. As adults, we observe these communication attempts with awe. Quite naturally, we reflect the sounds and gestures that infants make in an attempt to encourage social exchange; if a baby pokes his tongue out, we respond by poking our tongue out too. By reciprocating their attempts at engagement we allow infants the opportunity to participate in meaningful social interactions, even before they are able to speak. We take this process for granted during the early months, but could it also be key in old age?

The restrictions on communicative ability demonstrated by new-born babies bear important similarities to those experienced by people with advanced dementia. Advanced dementia is the term given to the late stages of dementia in which cognitive abilities have deteriorated so much that speech-based communication is no longer possible. As cognitive skills deteriorate, those living with advanced dementia experience difficulty with the pronunciation and the cohesive interpretations that linguistic communication demands. This can often result in a loss of the ability to speak.

While more advanced communication skills such as speech are prone to deterioration in dementia, the fundamental communicative behaviours present at birth remain intact (Ellis & Astell, 2004). Abilities established during infanthood, such as, gestures, sounds and eye contact, are amongst the first to develop and also amongst the last to decline.

Memory difficulties also mean that interaction attempts by caregivers can be quickly forgotten, which can lead caregivers to believe that the person with dementia is no longer able or no longer wishes to communicate (Astell & Ellis, 2006). As a result, the person with advanced dementia becomes viewed primarily in terms of their disabilities, their attempts at communication become devalued, and successful attempts at social interaction appear out of reach. Neglect of this basic social need has the potential to exacerbate feelings of incapacitation, frustration and low self-esteem experienced by people with dementia (Kasl-Godley & Gatz, 2000). In addition, a lack of socialisation opportunities has been shown to dramatically increase behavioural disturbances and aggression in people with dementia (Astell & Ellis, 2012; Burgio & Fisher, 1999). In fact, social neglect even has the potential to exacerbate the physical and cognitive deterioration associated with the disorder (Astell & Ellis, 2012; Kitwood, 1997).

But what is being done to target the issue of social neglect in severe dementia? Alarmingly, the importance of social interaction has long been overlooked in the history of dementia treatment and care, which has tended to prioritise the physical over the social aspects of the disorder. However, following the pioneering accounts of figures such as Kitwood (1997), Lyman (1989) and Katzman (personal communication 1975 cited in Chaufan et al., 2012) in recent years, the implications of social isolation in dementia have been highlighted as a fundamental concern. This recognition has initiated the development of a number of communication techniques that are aimed at reducing social isolation in severe dementia.

Many of these social interventions use

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mirroring (a technique in which communication attempts are reflected back to the person initiating them) as a means of bridging the communication gap among this population (Feil, 1993; Killick & Allan, 2001).

Social interventions – mirroring

Two important advocates of mirroring in care settings are John Killick and Kate Allan, who have used it to reflect the actions and sounds of individuals with dementia (Killick & Allan, 2001). This involves taking note of the speed, intensity and position of movements so that caregivers are completely attuned to the actions of the individual with whom they are engaging.

For example, they describe an encounter with a lady with late-stage dementia who, despite showing an initial reluctance to engage in communication, appeared to show a positive response to mirroring. She initiated actions such as pointing, stroking and shaking the other person's hand, all of which were directly replicated by the caregiver, allowing an ongoing interaction to take place. The lady signified a preference for this unspoken mode of communication by placing her finger to her lips to indicate that words were not necessary. Despite her limited capacity for language, she concluded the interaction with the words 'wonderful'. This highly positive response suggests that simplified methods of communication that utilise mirroring certainly appeal to those with severe communicative impairments.

Another example in which mirroring has been used successfully to promote social interaction is highlighted by Feil (1993), who used mirroring as part of an approach she calls Validation Therapy: a philosophy of care developed for people in the later stages of dementia, which promotes unconditional acceptance of the person with dementia and their situation. Feil (1993) describes an interaction with a lady called Mildred who has extreme communicative impairments and has lost the ability to speak. She explains that Mildred's previous job as a legal secretary was something that brought immense value to her life. During the reported engagement, Mildred was moving her hands quickly as if she were typing at high speed on a typewriter. The caregiver, recognising the significance of this action for Mildred, joined in by replicating the typing movement. The caregiver commented on Mildred's ability as a strong typist and asked her how many words she was able to type in a minute. Mildred, despite not having spoken a word in six months, responded by saying the number aloud with pride. In this example it appears that Mildred's lack of verbal communication may have been a result of her unfulfilled psychological needs, such as the need for recognition and appreciation of her hard work. Therefore, mirroring appears to have been able to provide a communicative outlet for Mildred based on its ability to access a source of great value in her life and validate her contribution.

Those living with advanced dementia experience difficulty with the pronunciation and the cohesive interpretations that linguistic communication demands

Mirroring as communication can also be facilitated by music, which has been shown to elicit a fundamental, emotion-based human connection (Pace et al., 2011). Aldridge (1996) explains that receptivity to music is an ability that remains in the late stages of dementia despite deterioration of cognitive abilities. One noteworthy example of a music-based mirroring social intervention is creative music therapy, developed by Nordoff and Robbins (1971). In this, music is selected to match a person's emotional state. For example, if somebody is feeling sad, a slow, melancholy musical sound might be played as a means of connecting with that person. While the specific guidelines for the application of this technique are notably vague – 'there is no typical session' – a number of individuals with advanced dementia have benefited from this musical intervention in terms of increased social participation and general wellbeing (i.e. smiling and greater social engagement: Nordoff & Robbins, 2011). Thus, mirroring through music can also be considered a useful tool that enables carers and loved ones to connect with people with dementia on a more primitive and engaging level.

Importantly, however, despite the noted potential of the mirroring techniques discussed, many are lacking reference to any specific theoretical framework. Instead, the strategies implemented appear to be a manifestation of strong values, intuition or more general, non-intervention-specific, research (i.e. the effects of music on psychological wellbeing). In addition,

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these existing techniques are not supported by any intervention-specific empirical data; they are reliant on personal observation, which is unquantifiable and highly subjective. Thus the demand for a more compelling evidence base supporting the use of mirroring interventions is clear.

Adaptive Interaction

Adaptive Interaction appears to respond to this demand, taking a progressive step towards communicating more effectively the potential of mirroring for individuals with advanced dementia. Adaptive Interaction is built on the principles of Intensive Interaction (Jefferies, 2009): a mirroring technique developed for people with severe learning difficulties and with a strong evidence base (Astell & Ellis, 2006; Nind & Hewett, 2005). Intensive Interaction relies on reflecting the deeply learned communicative abilities of the socially impaired individual, such as eye gaze, facial expressions, gestures and sounds. Conceptually, one can think of it as similar to the early communications between a mother and child; since it is recognised that newborns often reach out to their mothers using these fundamental communicative behaviours to initiate a reaction, mothers automatically view their child's efforts as intentionally communicative. Thus, attempts at communication by young children are valued highly by mothers, who often respond by reflecting any communicative activity in a playful, caring and engaging manner. This natural assumption of ability and purpose is crucial to the successful social development of that child (Zeedyk, 2008). Similarly in a caregiving situation, paying attention to sounds, movements and expressions, can help to develop the communication abilities of the socially disadvantaged individual, creating opportunities through which a successful interaction can be built upon session by session. In identifying these fundamental signals as critical for social development, social abilities can be enhanced (O'Neil & Zeedyk, 2006) and a basic framework is created from which opportunities for interaction can be established.

Unlike Intensive Interaction however, Adaptive Interaction focuses on the present moment. This is because we cannot assume that people with advanced dementia who have significant memory difficulties will necessarily be able to recall previous encounters. To communicate effectively with these individuals, it is important that caregivers adapt their reactions to whatever social action the person with dementia is engaged in at the time. For example, if they place their hand on one side of their chair, caregivers might respond by placing their hand on the other side of the chair, initiating a game-like scenario in which the person with dementia can engage. In this sense, unlike the rigidity of many other mirroring approaches, which focus only on direct reflection, the nature of Adaptive Interaction takes on a certain level of spontaneity. This is believed to enrich what can often be quite repetitive engagements. In this way, interactions remain highly personalised to the abilities of the person with dementia and their present state of mind.

Adaptive Interaction takes a progressive step towards communicating more effectively the potential of mirroring for individuals with severe dementia

Perhaps the most important development brought about by this technique is the establishment of a control condition. Baseline interaction sessions were used by Ellis and Astell (2011) as a way of comparing the response elicited by Adaptive Interaction to one elicited by a 'typical' interaction. Baseline sessions were initiated by speech consisting of routine-based questions such as 'Have you seen the weather today?' and 'Have you had breakfast?'. Closed questions such as these are typical of the interactions normally initiated by caregivers when caring for people with advanced dementia (Ellis & Astell 2011). Comparing the behaviour elicited by Adaptive Interaction to that elicited by a 'typical' interaction is particularly important here, as often just someone's presence alone can enhance mood and improve the behaviour of people with advanced dementia (Neal & Wright, 2003). The inclusion of a baseline session rules out some important alternative explanations for positive affect, and also allows the researchers to take into account the individual nature of each encounter in order to present an accurate and non-biased account of the observed effect.

Ellis and Astell (2011) recorded six interactions per participant over the course of two weeks, during which the communicative behaviour of five individuals with advanced dementia was analysed, including physical contact, facial expression, eye gaze, imitation, gestures and vocalisation. The results revealed a statistically significant increase in communicative behaviour (as measured using microanalytic behavioural coding of video taped sessions) for the Adaptive Interaction compared with the baseline session – a marked improvement in communicative abilities in response to the intervention.

So, by incorporating control measures and supporting results with empirical evidence, Adaptive Interaction has significantly progressed the standard of research in this area of study. However, in order to effectively communicate and develop the potential of social interventions in dementia care, it is also necessary to confront some more general concerns.

The wider struggle

Despite recognition of the importance of a more humanistic approach to dementia care, it appears that prioritisation of research funding for dementia remains centred on a biomedical approach. This is

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a reality that restricts researchers' ability to communicate potential and encourage the implementation of social interventions. Chaufan et al. (2012) explain that this is largely due to the common classification of dementia as a pathological 'disease' that requires physical treatment and prevention. The difficulty of communicating the importance of social interventions in dementia is also exacerbated by common stigmatisation of the illness itself. Brooker (2003) explains that prejudiced attitudes, which arise from a tendency to associate cognitive deterioration with a lack of humanity, often lead to a devaluing of people's right to effective care. The result is a dehumanising provision of service that fails to meet the needs of a highly vulnerable population.

That being said, there is evidence that the increasing body of literature highlighting the importance of social interventions is helping to shift these considerably outdated views. In addition, the rapid expansion of our ageing population is creating a growing demand for quality care in dementia. Indeed, international leaders in the field have proposed a shift from focus on a biomedical approach, to focus on a multidisciplinary approach to dementia care that takes into consideration the biological, social and psychological factors affecting the illness (Portacolone et al., 2013). It is believed that looking at these issues side by side will help to reduce the frequently unfulfilled social and psychological needs of people with dementia. This recognition highlights an exciting direction for future research in the field of dementia care and a growing shift towards holistic concerns.

In summary, it appears that mirroring presents striking potential as a means to help alleviate the detrimental effects of social isolation in cases of advanced dementia. Adaptive Interaction in particular offers a clear and highly personalised approach supported by empirical evidence. However, before techniques such as this can be considered for widespread implementation within dementia care settings, it is crucial that current techniques are further developed to bring their status in line with the biomedical approach. To remain relevant, it may be important for future developments of social intervention techniques to consider a multidisciplinary approach whereby behavioural and biological results are combined. Not only will this make scientific findings more compelling but also it presents exciting opportunities through which to better communicate the potential of existing techniques. Consideration of these aspects must become the central emphasis of future research. Without the progression and development of social intervention techniques, adequate standards of care, in particular for those with advanced dementia, will remain largely unattainable. Critically, the potential to optimise care for those living with advanced dementia will be missed.

Amanda Henwood *is a psychology MSc graduate from the University of St Andrews*
amandahenwood@ymail.com

Dr Maggie Ellis *is Fellow in Dementia Care at the University of St Andrews*