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**IMPROVING NONVERBAL COMMUNICATION BETWEEN
CAREGIVERS AND PEOPLE WITH ADVANCED DEMENTIA:
THE EFFECT OF STAFF TRAINING IN INTENSIVE
INTERACTION ON QUALITY OF LIFE.**

Section A: Nonverbal communication with people with advanced dementia: a review of caregivers' perspectives and current interventions.

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Section B: Training care staff in the use of Intensive Interaction techniques: the effect on the Quality of Life of nonverbal residents with dementia.

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Summary of MRP

Section A provides a critical analysis of the extant literature into staff and family caregivers' perceptions of the use of nonverbal communication to make a connection with people in the advanced stages of dementia; alongside that on interventions aimed at enhancing social interaction through nonverbal communication and their effect on Quality of Life (QoL). The clinical implications of the results are discussed and directions for future research considered.

Section B is a study that aims to assess the feasibility of a full scale randomised control trial, to ascertain whether or not training care staff to use Intensive Interaction techniques could improve QoL for residents with advanced dementia. The impact of training on communication behaviours and a QoL outcome measure were assessed, alongside consideration of feedback on the training and the efficacy of the study design.

Section C is an account of the reflections of the author on the research process and the learning that has been achieved through this.

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Section A:

Nonverbal communication with people in the advanced stages of dementia: a review of caregivers' perspectives and current interventions.

Gail Dampney-Jay

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Abstract

In advanced dementia language-based communication is typically severely impaired. This prevents verbal participation in interactions, leading to progressive social isolation and reduced Quality of Life (QoL). In contrast, nonverbal communication remains relatively intact, offering a potential means of maintaining social contact. However, there is insufficient research into caregivers' perceptions of using this form of communication and into the efficacy of nonverbal communication interventions in improving QoL

Databases were searched using the terms: dementia AND nonverbal communication. Boolean operators were used to include multiple variants of these terms, for example: (dementia OR Alzheimer) AND (nonverbal communication OR eye contact). A secondary search used the terms: (advanced dementia OR severe dementia OR end stage dementia) AND communication. After exclusions, 18 relevant studies were identified.

The literature indicated that caregivers perceived those with advanced dementia as having a retained ability to make social connections through nonverbal means and that empathy, time, knowledge of the person and reference to mothering experiences, facilitated this. Intervention studies suggested that use of nonverbal techniques and staff training in nonverbal communication may improve QoL for residents; however the literature is limited and further research is required. The use of mirroring is one avenue for further research.

Introduction

Dementia has been defined as a clinical presentation characterised by a progressive deterioration in memory and other cognitive abilities, which impair functioning and cannot be explained by delirium or another psychiatric disorder (McKhann et al., 2011). In 2012 the World Health Organisation (WHO) estimated that there were 35.6 million people worldwide living with dementia (WHO, 2012a), described it as a global health priority and outlined the need to improve QoL for those living with the disease (WHO, 2012b).

QoL has been defined as the “perception of individuals of their position in life” (WHOQOL Group, 1995, p.1405); it is a multidimensional construct with social interaction being one key element. Dementia typically has a significant impact on communication skills to the extent that, by the latter stages, language often becomes functionally redundant (Kempler, 1995). This removes the ability to participate in social interactions through verbal means and research has demonstrated that this typically leads to progressive social isolation (Abad, 2002) and by inference has a detrimental effect on QoL.

Whilst language decays over the course of dementia, nonverbal communication may remain comparatively intact (Acton, Mayhew, Hopkins, & Yauk, 1999; Bucks & Radford, 2004). Even in the advanced stages of Alzheimer’s, people have been observed to make facial expressions of sadness at the departure of a loved one (Magai, Cohen, Gomberg, Malatesta, & Culver, 1996) and react appropriately according to the facial expression of a caregiver (Asplund, Jansson, & Norberg,

1995). Therefore, nonverbal communication offers a potential means for maintaining a social connection and in this manner enhancing QoL.

The repertoire of nonverbal communications exhibited by people in the advanced stages of dementia and the available tools for interpreting these, including for pain assessments, has been subject to a significant body of research (Schiaratura, 2008). However, caregivers' perceptions of the utility of engaging in this way and what they believe facilitates such interactions are less well established. Explorations of such perceptions through qualitative research can help to develop hypotheses in research areas, such as this, that are in their infancy (Veltri, Lim, & Miller, 2014). Moreover, there is increasing recognition in health and social care that an appreciation of users' views is essential in developing successful interventions (Department of Health, 2002), by identifying themes that they perceive to be salient and illuminating potential barriers to uptake.

With regards to interventions, a number of approaches that utilise elements of nonverbal communication, including "Validation", "Snoezelen" and "Namaste care", as well as more general communication training packages, have been well reviewed (Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). However, these are within multi-modal interventions that make it impossible to tease apart the impact of the nonverbal elements. Touch and massage are areas that have been separately reviewed (Hansen, Jørgensen, & Ørtenblad, 2006); however, this is typically utilised predominantly for relaxation or healing through energy fields rather than communication. To date there have been no reviews that solely focus on the efficacy of nonverbal communication interventions as a means of establishing a social connection and the resultant impact on QoL.

This review aims to simultaneously cover the two gaps in knowledge that have been highlighted. By addressing these together it seeks to both help develop hypotheses for this emerging research area and to consider which hypotheses have already been tested, thus illuminating potential areas for future research. To do so it aims to answer the questions:

1. Do caregivers consider nonverbal communication a viable means for connecting with people in the advanced stages of dementia?
2. If so, what do they believe facilitates such interactions?
3. Do interventions aimed at enhancing social interaction through nonverbal communication improve QoL for people with dementia?
4. If so, what element/s of nonverbal communication are effective in doing so?

Method

Literature Search

The literature search covered: PsychINFO, MedLine, Web of Science, ASSIA, CINAHL and Cochrane Database of Systematic Reviews. Each database was reviewed from establishment to October 2014 using the appropriately truncated search terms: (dementia OR Alzheimer OR Lewy Body OR Picks Disease OR frontotemporal lobar degeneration) AND (nonverbal communication OR nonverbal interaction OR nonverbal behaviour OR facial expression OR eye contact OR gesture OR kinesics OR manual communication OR mirroring OR imitation OR body language OR prelinguistic OR pretherapy OR intensive interaction OR adaptive interaction OR embodied OR attuning). A secondary search of the same databases used the terms: (advanced dementia OR severe dementia OR end stage dementia)

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AND communication (see Appendix A for full search terms by database). The keywords and references of all relevant papers were also reviewed.

Papers were included if they: 1) researched caregivers' perspectives on using nonverbal communication; or considered the impact of a nonverbal communication intervention; and 2) participants included either people with dementia or their caregivers. Papers were excluded if they: 1) considered a multi-modal form of communication in which the nonverbal elements could not be separated out; 2) considered repertoire of retained nonverbal communication, the development of a nonverbal assessment tool, nonverbal communication for pain assessment or the exclusive use of massage or touch, as these have been separately reviewed; or 3) were a review article or commentary. Leaving a total of 18 relevant papers. Figure 1 details application of these criteria and number of papers identified.

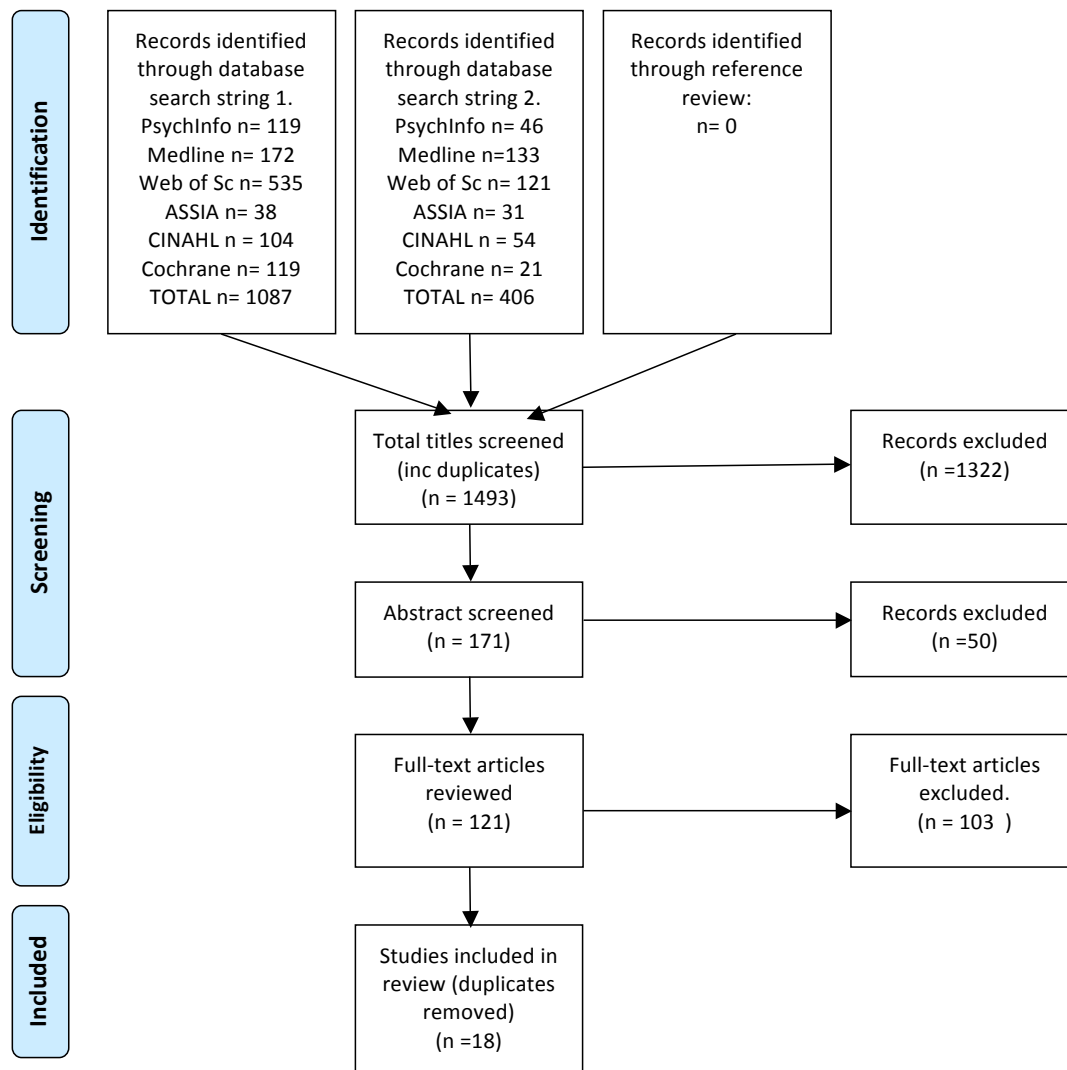


Figure 1. Application of exclusion criteria. Diagram adjusted from Moher, Liberati, Tetzlaff and Altman (2009).

Review of the Literature

The literature review will address each of the proposed research questions in turn, initially considering caregivers perspectives and then moving on to look at the efficacy of nonverbal communication interventions. The literature in this area is in its infancy and a variety of research methods and outcome measures have been utilised.

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As a result, they will be critiqued according to the pluralistic quality criteria developed by Barker and Pistrang (2005, see Appendix B for details). A summary of each paper's methodology and how it compares to the quality criteria is provided in Appendix C.

Caregivers' Perspectives of Nonverbal Communication

Eight qualitative papers were identified that were of relevance to the initial two hypotheses:

1. Do caregivers consider nonverbal communication a viable means for connecting with people in the advanced stages of dementia?
2. If so, what do they believe facilitates such interactions?

The papers used interviews, focus groups or video recordings of interactions, with the participants being a mixture of staff and family caregivers and, where details were provided, all were caring for people in the advanced stages of the dementia. A range of methodologies were employed to analyse the data including grounded theory, thematic analysis, content analysis and hermeneutic approaches.

De la Cuesta (2005) identified that family caregivers considered their relatives to be capable of transmitting and receiving messages, despite having no residual language use, and that overtime they developed a unique language that encompassed touch, gestures, gaze and tone of voice. It was further highlighted that sentiment, love and confirmation of another's experience could be transmitted bi-directionally. This was supported by Walmsey and McCormack (2014), who illustrated the depth of intimacy that could be conveyed, using the following transcribed example: "Richard leans over and kisses Deborah's forehead Deborah moves her eyes from left to right over Richard's face, and opens her mouth slightly" (p.632).

This belief in a retained ability and desire to communicate was given importance in the majority of other papers. In fact it was seen as a pre-requisite for other caring skills. Kitwood's (1990; 1998) theories of personhood and malignant social psychology posit that, due to deep rooted fears of becoming frail and dependent, care environments often position those with dementia as 'patients' who are inferior and have less ability, in doing so the person's primary social personae is lost. Kontos and Naglie (2007; 2009) drew on these theories in their analysis, which indicated that in order to empathise, staff first needed to acknowledge that selfhood, and as such the ability to experience emotions and have the desire to share these with others, persists irrespective of the level of cognitive impairment.

Whilst this perceived capability was key across the papers, inferences should be made with caution and appropriate recognition that this is not a direct assessment of the person with dementia's capacity. There may be secondary gains for a caregiver of holding the belief that the recipient of care is able to connect with them, for example giving greater meaning and pleasure to caring tasks and a sense that a loved one has not been lost (Duffy, Oyebode & Allen, 2009); thus it is possible that assessments of residual communication capability may be inflated. Furthermore, four of the five studies using staff participants explicitly sought those who were considered good at communicating, as such it must be recognised that this belief in a continued ability to communicate may not be reflective of that held by the caregiver population as a whole.

Some variations in beliefs about capacity to connect were acknowledged. A number of family members described times when their relative's eyes looked dead or blank (Quinn, Clare, Jelley, Bruce & Woods, 2014). Furthermore, in the interviews of

Eggers, Ekman and Norberg (2013), there was a sense that, in the latter stages of the disease, interpreting body language and facial expressions became difficult and caregivers used trial and error or acted in a way that they thought best for the patient. In these instances the opportunity to make a social connection with the person, and the belief that they had the ability to communicate, appeared to have been lost.

In five papers explicit reference was made to interacting in a motherly way, for example demonstrating compassion and mercy through “soft hands and soft voices” (Runqvist & Severinsson, 1999, p.802). One participant explicitly stated that it was like being a mother to her mother (de la Questa, 2005). Reference is made to developmental theories of mother infant interactions (Pawlby, 1977), in which there is reciprocal imitation between mothers and infants. By acting as though the infant’s cues are comprehensible the mother creates a feeling in the infant that what they are communicating has meaning. Haggstrom, Jansson and Norberg (1998) concluded that similarly by imputing meaning and reading the feeling behind the seemingly incomprehensible cues of people with severe dementia, caregivers can create a feeling of contact with those they are caring for.

The ability to put ones self in another’s shoes and to empathise were recurrent themes throughout the literature. Kontos and Naglie (2007) gave numerous examples of caregivers imputing meaning and devising appropriate reactions through reference to their own experiences: “I gave her a hug and she calmed down . . . I know how the warmth of a hug feels when I’m sad or down” (p.558). Furthermore, having historical knowledge of the individual was considered important across the studies as it enabled interpretation of behaviours, such as when a repetitive motion may have been associated with a previous career. The subtlety of responses offered by people in the

advanced stages of dementia was also a recurrent theme. Family caregivers described looking for “a twinkle in the eye” (Quinn et al., 2014, p.264) that told them a connection had been made. A need to take time to develop knowledge of and look out for these cues was considered salient.

A theme that emerged through this review but was not highlighted in the individual research was the extent of verbal communication that was still used by caregivers. Throughout the research there were examples in which nonverbal communications were responded to with speech: “Remember Penny?... (Helen moves her left hand to her chin, and taps her fingers several times against her chin, before placing one finger inside her mouth). Having a think are you? Or chewing your finger?” (Walmsey & McCormack, 2014, p.633). The efficacy of this response is not clear; however given that receptive language is also typically impaired in advanced dementia (Kempler, 1995) the level of understanding by the recipient is questionable. The use of speech may reflect caregivers’ reliance on their typical means of communication due to a lack of alternatives.

All but one paper reviewed demonstrated methodological rigor, with scores of between 7.5 and 8.5 out of nine when compared to the quality criteria (Barker & Pistrang, 2005; see Appendix C). However, the remaining paper gave little detail of the interpretation process or of any reliability or validity checks and scored 4.5 out of nine on the quality criteria (Häggström et al., 1999; Rundqvist & Severinsson, 1999). Further, only two of the papers (Quinn et al., 2014; Walmsey & McCormack, 2014) disclosed information regarding their personal perspective. Given that the researchers are likely to hold strong ideas regarding the residual capacity of people with severe dementia, this may have affected their interpretations and is a significant omission.

Efficacy of Nonverbal Communication Interventions

Ten papers were identified that had relevance to the second two hypotheses:

1. Do interventions aimed at enhancing social interaction through nonverbal communication improve QoL for people with dementia?
2. If so, what element/s of nonverbal communication are effective in doing so?

To aid the critique the studies have been loosely grouped according to the methodology of the research.

Case studies of interventions. Six papers have considered the impact of attending to and utilising different aspects of nonverbal communication, through single or series case studies. These case studies offer something that is often missed in larger trials, which is the opportunity to pay attention to fine detail and idiosyncratic changes.

Behavioural communications. Theories of embodied language indicate that both bodily and behavioural descriptors form an important part of a person's communicative repertoire, alongside their verbal skills (Liehr et al., 2002). Ito, Takahashi and Liehr (2007) hypothesised that by paying attention to behavioural communications of negative emotions, care staff would be able to react appropriately and reduce agitation. Through a single case study they provided examples of when ignoring these behavioural warning signs, such as restless eye gaze, led to a gradual progression of agitated behaviour. This was compared to instances where the behaviour was attended to and meaning, for example concern about belongings, was imputed into the behaviour and reacted on, which led to more positive interactions. This study begins to indicate that paying attention to behavioural indicators can improve interactions. However, whilst scoring 7.5 out of 9 on the quality criteria and

meeting the aims laid out by the study, there are clear limitations in terms of what can be inferred from the results. Being only a single case design with no validated outcome measures or any structured method of observation, it is difficult to extrapolate from. Moreover, the participant in this study was assessed as having moderate rather than severe dementia and retained much language ability, therefore whilst the authors attributed changes to the behavioural cues it is difficult to rule out the impact of verbal communications.

Clowning. The work of Ruud (2012) also considered embodied language. Drawing on Kitwood's (1990; 1997) theories of personhood, which aim to shift emphasis from cognitive deficit to the social relationships in which a person is embedded, Ruud considered the body as a fundamental source of selfhood and means of communication that is separate from cognition. As a result, the innovative intervention of MiMakkus clowns is explored. These clowns have been developed to make contact with people who are no longer able to respond through the usual cognitive means, the idea being that they consciously try "to join in with the way the other person experiences the situation" (Ruud, 2012, p.462). The study takes an ethnographic approach and does not claim to be an assessment of efficacy, further it scored only 5.5 out of 9 when compared to the quality criteria. However, the case study of a woman whose language was reduced to repetition of the same phrase and showed little awareness of others has relevance to this review's questions. The MiMakkus clown tried a variety of techniques aimed at connecting with the emotion underneath her presentation but it was not until the clown changed the personal space between them, by coming into very close proximity, that the situation changed:

I [the clown] was taken completely by surprise by her kiss on my cheek...Her voice quieted, the talking stopped...I answered her by getting even closer to her and stroking her arm. I was given lots more kisses, but what moved me more than anything was the complete tranquility that came over her (Ruud, 2012, p.472).

This case study provides insight into how paying attention to communication through personal space and bodily contact can have surprising results. It also calls into question the opportunities that many people in the advanced stages of dementia have for such close human contact, which has been shown to be a basic human need and to have significant impact on wellbeing (Field, 2010). Boundary issues also need to be recognised, however, and this is not an area that the paper explores. The paper also indicates the need to take time to tap into whatever individual element of nonverbal communication might capture a particular person's interest.

Mirroring. The developmental theories of mother-infant interactions, which were discussed in Section 4.1, have led to four papers considering how the use of mirroring could aid communication with people with advanced dementia. Over three papers, Ellis and Astell (2006; 2010; 2011), present a series of case studies investigating the use of methods from Intensive Interaction, a mode of nonverbal communication developed in the learning disability field (Caldwell, 2005). Intensive Interaction focuses on mirroring a person's behaviours in order to connect with them and communicate in a way that makes sense to that individual. An initial single case study (Astell & Ellis, 2006) utilised video recordings of the spontaneous communication behaviour of Jessie, a woman with severe dementia, when interacting with one of the researchers. The analysis compared Jessie's reactions to three different

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communication behaviours displayed by the researcher: spontaneous imitation, deliberate imitation and maintaining a still face. They found that a greater proportion of direct eye gaze was achieved when the researcher deliberately imitated the nonverbal behaviours of Jessie, compared to spontaneous imitation or maintaining a still face (Kogan & Carter, 1996). Further, there was a slightly higher rate of positive emotional expressions and a greater number of reciprocated turn-taking. However, no indication was given as to whether or not these differences were statistically significant.

This research was then extended through a series of five case studies (Ellis & Astell, 2010) in which a baseline was employed using ‘typical’ interactions based on the usual verbal questioning used by caregivers. The participants’ baseline reactions were compared to when the researcher used the principles of Intensive Interaction. The use of the latter revealed that each participant had a rich and unique nonverbal communication repertoire. However, again no statistical data comparing the two conditions was presented, nor were any details provided regarding whether standardised observation schedules were used or whether the raters were blind to condition. As such it is hard to reach any firm conclusions as to this techniques efficacy over and above standard verbal communication, or to generalise from the results.

A final study by Ellis and Astell (2011) considered the effect of training caregivers in a nursing home in the use of Intensive Interaction techniques. The results state that after training staff members were able to recognise the individual ways in which the residents communicated and felt better equipped to respond appropriately; however, the same design limitations apply as previously. These studies

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provide an initial indication that the deliberate imitation of nonverbal behaviours may enhance engagement in communication and increase positive emotional expressions; however the limitations of the designs, each meeting only half or less of the quality criteria, restricts the inferences that can be made from this research.

Rousseau and Métivier (2007) also developed an intervention based on developmental theories; however they considered how a person's automatic mirroring of another's nonverbal cues could be used to promote relaxation in people with advanced dementia. A researcher was taught to empathise through body language and then to aid relaxation through their communication style, for example by assuming a calming voice and slow steady breathing rhythm. It was proposed that the resident would mirror this communication and thus move in to a state of greater relaxation. Levels of anxiety were assessed before and after the intervention using a specially adapted measure, which indicated considerable changes between pre and post scores. This study suggests that purposeful imitation may have the potential to enhance positive interactions through a number of different mechanisms. However, the same design limitations apply as in the previous case studies, with the paper scoring only 5 out of 9 on the quality criteria and, as such, clearly further research is needed to more robustly examine this possibility.

Within participants design. Cevasco (2010) refers to the large body of research on the impact of health professionals' nonverbal behavior on patient satisfaction and long-term health outcomes (Griffith, Wilson, Langer, & Haist, 2003). Utilising a counterbalanced, within participants design, with 38 people in the early to middle stages of dementia, they compared a music therapist's use of: affect and proximity; affect only; proximity only; and no affect or proximity. A significant

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difference in positive affect according to treatment condition was found and they concluded that using positive body language and facial expressions combined with proximity to a client promotes the best connection. Interestingly the 'proximity only' condition led to lower participation rates than using neither proximity nor affect. Cevasco (2010) proposed that when the therapist drew closer to the participants but did not engage with their facial expressions that this went outside of normal social expectations, which may have surprised participants and led to their momentary withdrawal.

This research is helpful in considering how different elements of nonverbal behaviour may be naturally combined and how interfering with this natural order in an intervention may actually be deleterious to connection. The quality of research represented a slight improvement on the previously discussed studies, scoring 6.5 out of 9, and the increased sample size makes inferring from the data to a wider population easier; however, caution must be undertaken when inferring from these results to interactions with people in the advanced stages of dementia as their residual communication repertoire may be very different from the participants in this study.

Further research would be helpful to elucidate whether or not a similar impact was found on people in the advanced stages of dementia, this may be of particular interest due to the higher physical care needs of such individuals possibly leading to greater habituation to the physical proximity of carers. Furthermore, the impact of using affect and proximity in different combinations during a one to one interaction would be of interest, as would consideration of individual differences in reaction to these. With regards to the previously mentioned research on mirroring, further

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investigation in to how proximity and reflection of affect impacts on such interactions would help further knowledge of how to practically apply the technique.

Staff training. Three studies considered the impact of training staff in care homes to utilise nonverbal communication. Kontos, Mitchell, Mistry and Ballon (2010) reviewed the literature on person centred care (Kitwood, 1998) and concluded that embodied self expression is often overlooked. Accordingly they developed a staff training programme which aimed to sensitise staff caregivers to the importance of embodied self expression. Using a pre and post intervention qualitative design, outcomes were measured using a thematic analysis of focus group and interview data from 24 staff members who undertook the training.

The resultant theme ‘Meaning beyond dementia’ demonstrated that care staff had moved to seeing residents’ actions as meaningful self expression, as opposed to merely symptoms of dementia. Similar themes emerged as in the qualitative papers discussed in Section 4.1, including an increased recognition of a need to seek information from patients’ families and the need to put themselves in the other person’s shoes. The theme ‘Influence of the Approach to Care’ indicated that staff became more aware of how their own behaviours might be interpreted by residents, for example that rushing could be seen as not caring.

Whilst this research suggests that training in the this manner may improve caregivers sensitivity to nonverbal signs, it did not appear to provide staff with information on how they could use their own body language in a positive way to forge a connection. Furthermore, it gives very little information as to whether or not the residents QoL was actually improved. Whilst it scored well on the quality criteria, meeting 8 out of 9 indicators for the quality of qualitative research, it would be

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beneficial to follow up this work with a quantitative study using a randomised control trial and standardised, blind rated measures in order to give greater insights into effects on residents.

Magai, Cohen and Gomberg (2002) drew on developmental theories and the literature on expressed emotion (Kuipers, 1992) to hypothesise that people in the advanced stages of dementia might be particularly sensitive to emotional, nonverbal cues; yet conversely, caregivers may be more likely to express their negativity in front of clients due to an inaccurate perception that their cognitive decline also equates to a loss of emotional sensitivity (Bledin, MacCarthy, Kuipers & Woods, 1990). As a result, they developed an intervention package aimed at increasing awareness of the emotional sensitivity of dementia patients and of the patients' nonverbal emotional signs, alongside helping caregivers to monitor their own expressive behaviours.

A randomised control trial, with 20 staff participants and 91 resident participants, was used to test the efficacy by comparing the impact of staff receiving the intervention training package, a placebo training and a wait list control. A wide range of validated outcome measures were employed to assess behavioural and psychological symptoms, mood and agitation levels of the participants with dementia, alongside coding of their facial expressions during an interview. The only measure that was found to differ significantly across the treatment conditions was the facial interview data, with a greater increase in positive emotion being recorded by participants who were cared for by those who had received the nonverbal sensitivity training, with a moderate effect size ($d = 0.7$). However, caution must be employed when extrapolating from this result as multiple measures were utilised and statistical comparisons made, thus inflating the possibility of Type One errors. Conversely,

issues of power were not addressed in this paper, and thus the lack of significance on the other measures may simply reflect a need for a larger sample size. This could also reflect a difficulty in finding appropriate measurements for changes that may be very subtle, a difficulty that was not present in the smaller trials that were able to use idiosyncratic measures.

Clare et al. (2013) reviewed the literature on levels of awareness and highlighted that people with severe dementia continue to react to sensory stimuli; however the extent of expression is influenced by the environment. Moreover, they suggest that those who are considered unresponsive may be given less contact by caregivers and without this reinforcement may reduce attempts at communication. In accordance they developed a tool to help care staff recognise signs of awareness. Sixty six staff were randomly assigned to either the 'care as usual' control or the intervention group; those in the intervention group were trained in the use of the tool, encouraged to undertake regular structured observations looking for signs of awareness displayed by the residents, were given training in communicating with those with severe dementia and were given regular supervision throughout. Results indicated that family assessments of resident QoL improved significantly more for those in the intervention homes than in the control homes, with a medium effect size ($d=0.72$). However, there was no significant differences between the conditions regarding staff rating's of resident QoL, measures of positive responses, staff and resident wellbeing nor any behaviour measures. The same limitations regarding issues of power, inflation of the possibility of Type 1 errors, and difficulties finding appropriate measures, apply as those discussed with reference to Magai et al. (2002). Further, it is possible that family ratings were influenced simply by seeing that their

relative was receiving additional attention from staff rather than as a direct result of the training.

These two larger scale studies begin to give an indication that staff training in the use of nonverbal communication may have a positive impact on the QoL of residents in the advanced stage of dementia. The greater control in these studies, in particular Magai et al.'s (2002) use of a placebo training, helps to eliminate the influence of confounding variables, and the larger sample numbers make inference to the wider population easier, although appropriate recognition must be given to the discussed design limitations. These improvements are reflected in the increased scores on the quality criteria of 7 and 8 for Magai et al (2002) and Clare et al (2013) respectively.

Discussion

This review aimed to evaluate the literature on caregivers' perceptions of the use of nonverbal communication as a means to make a connection with people in the advanced stages of dementia and what they believed facilitated this. The evidence in this review suggests that caregivers do consider those with advanced dementia as still being capable of participating in social connections and that they use a large nonverbal repertoire to achieve this. However, it is possible that the natural selection process of who will put themselves forward for this type of research will have biased results to a degree. Quotes that were taken before some of the staff training interventions indicate alternative views that were not expressed in the qualitative papers. For example, one caregiver in Clare et al.'s (2013) study stated: "I've got to observe [X] but she doesn't do anything, that's going to be well boring" (p.134). The training changed these perceptions considerably but this gives an idea of alternative

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attitudes that are likely to be prevalent in the caregiver population and points to some barriers that may need to be overcome.

A number of factors were identified that caregivers perceived as being helpful in facilitating such interactions, including use of empathy, drawing on family knowledge of the resident's past and having time to consider subtle cues. The need to draw on the experience of being a mother or being mothered was a particularly recurrent theme in the qualitative research and the developmental literature was referred to as the theory behind a number of interventions. Thus it is suggestive that by utilising natural nonverbal communication styles it may be possible to forge a deep bond. This, however, raises the question of why such interactions are not always natural with people in this group. One possible explanation is concerns about infantilising patients. What may seem entirely natural with an infant may appear mocking or derogatory with an adult. However, such concerns are addressed in the Intensive Interaction literature (Nind, 1999), in which it is clearly stated that this method does not advocate treating individuals with learning disabilities as though they were babies, but rather seeks to utilise the rudimentary elements of communication and sociability that might be the only accessible option to a person.

A number of gaps in knowledge remain regarding caregivers perspectives. It would be beneficial for researchers to access alternate views that were less represented in the studies discussed, for example caregivers who do not perceive nonverbal communication to be important. In order to elucidate the possible secondary gains of different perspectives it would be helpful to undertake a qualitative study that directly asks what might be gained from either seeing the person as having continued ability and emotional experience or indeed from seeing them as begin

devoid of these. Finally, it would be helpful to understand further what might lead some caregivers to feel reluctant to employ nonverbal communication in order to look at potential barriers to the uptake of any interventions.

This review further sought to establish the efficacy of utilising nonverbal interventions for improving QoL for people with dementia and which elements of nonverbal communication were helpful in doing so. The literature is very much in its infancy but tentatively suggests that interventions that employ bodily mirroring and which pay attention and use body language and proximity may be beneficial. Further, paying close attention to certain behaviours that are used as a communication of discontent may help care staff to make a more positive connection with residents. However, the number of participants and uncontrolled nature of the majority of these studies makes it hard to draw any firm conclusions.

Where larger scale trials have been performed the evidence is somewhat inconclusive, with only one outcome measure in each of the trials picking up any change. This may be reflective of a difficulty in selecting appropriate outcome measures. The study by Clare et al. (2013) in itself indicates that at the severest stages of dementia the signs of awareness that need to be identified in order to form a connection are very subtle, this in turn also means that the signs of an improvement in QoL are likely to be very subtle as well. As such, whilst there is worth in completing standardised assessments, such as the QUALID, larger scale studies perhaps also need to utilise some of the methodologies from the smaller trials such as pre and post behaviour analysis. It should also be noted that by utilising multiple measures, possibly in an attempt to capture these idiosyncratic changes, the chance of Type 1 errors is inflated and therefore significant findings must be interpreted with caution.

One area that has become apparent throughout the majority of this research is a tendency for caregivers to reply to nonverbal communications with a verbal response. The neuropsychological evidence suggests that in the advanced stages of dementia it is not only expressive but also receptive language that is impaired (Kempler, 1995). As such there is a danger that caregivers are responding to people with dementia in a way that is incomprehensible to them. This adds to Kitwood's (1990; 1998) theories of malignant social psychology, by indicating that the person with dementia's means of communicating may inadvertently be being treated as inferior by caregivers, thus reinforcing the loss of sense of self.

The qualitative research on staff training indicated that by encouraging caregivers to attend to nonverbal communications they began to see the resident as a person, rather than a 'thing' to be cared for. This is consistent with Kitwood's (1997) theories of person centred care, which highlight the importance of recognising the individual outside of the dementia. Furthermore, a drive towards this person centred approach has been proposed as being key in improving the quality of dementia care (NICE, 2006). The research reviewed here may be one method of promoting a person centred approach and as such has potential importance for improving care quality.

However, whilst the staff training interventions that have been described may help staff to portray a more caring nonverbal attitude they do not seem to provide specific nonverbal means through which a connection can be made. In contrast, the four case studies that have looked at mirroring appear to offer a potential avenue for responding in a way that is concurrent with the person with dementia's way of understanding. However, whilst there is good evidence for the use of this technique

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with people with learning disabilities (Caldwell, 2005), the current evidence for use with people with dementia is very limited.

Future Research

This review has demonstrated the need for further research into explicit techniques for responding to nonverbal communications in a nonverbal way. Whilst the studies reviewed considered a number of elements of nonverbal communication and increasing sensitivity to this, only those on mirroring offered specific techniques for giving nonverbal responses. As a result, being the only method detailed, the use of mirroring and techniques based on Intensive Interaction is arguably the most promising line for future research. The current body of research needs to be extended in a number of ways. Firstly it needs to utilise baseline data and control groups in order to reduce the impact of confounding variables. It also needs to look at the effect on QoL for the people with dementia involved in the research. To do this consideration needs to be given as to the most appropriate outcome measures for capturing subtle changes, potentially including standardised behavioural observation procedures. Finally, larger participant numbers are required in order to be able to make inferences to the wider population.

Conclusion.

This review indicates that nonverbal communication may be a viable means for connecting with people with advanced dementia and could have a positive impact on QoL. However, the evidence is in its infancy and further research is required, in particular into specific techniques for responding nonverbally. The use of mirroring appears to be the most promising direction in which to take this forward.

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Section B:

Training care home staff in the use of Intensive Interaction techniques:
the effect on the QoL of nonverbal residents with dementia.

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Abstract

Impairment of language-based communication is a hallmark of advanced dementia, which often leads to social isolation. However, nonverbal communication remains relatively preserved. Intensive Interaction (II), a nonverbal communication technique, offers a potential means for maintaining connections. This study assessed the feasibility of a full scale randomised control trial (RCT), to ascertain whether or not training care staff to use II techniques could improve Quality of Life (QoL) for residents with advanced dementia.

Using a non-randomised control design, staff in a nursing home were paired with a resident and offered training in II, with video recordings of their interactions and QoL measures for the resident taken before and after training and at 3 month follow-up. These were compared to outcomes in a control home in which care continued as usual.

Results from the intervention home indicated improved QoL, increased communication behaviours that facilitated and showed pleasure in interactions, and decreased behaviours that hindered and expressed displeasure. These changes were significantly different to those observed in the control home. Large effect sizes were suggestive of clinical relevance; however small sample sizes and lack of randomisation limited the scope for extrapolation. Further research through a full-scale trial is recommended.

Introduction

Dementia is a clinical presentation that impairs a person's functioning in day-to-day life due to a progressive decline in memory and other cognitive abilities (McKhann et al., 2011). It is a worldwide health challenge that has been described as exceptional in terms of the number of people affected, the economic burden it produces and the impact on people with the disease and their caregivers (Wortmann, 2012). In 2009 it was estimated that there were 35.6 million people worldwide living with dementia and that, due to the ageing population, this would increase to 66 million by 2030 (Alzheimer's Disease International, 2009).

The annual global cost of dementia was estimated at US\$604 billion, with the vast majority of this being spent on care facilities (Alzheimer's Disease International, 2010). However, despite this significant cost, there has been increasing recognition that many of these facilities are poorly equipped to meet the challenging needs of this population and that improvements need to be made in the provision of relationship-based care and support (Department of Health, 2012). Furthermore, the Social Care Institute for Excellence (2013) has highlighted communication as being a fundamental aspect of supporting people with dementia and go on to highlight the need for staff to recognise that nonverbal communication may be the main mode for interaction for people in the advanced stages.

Communication Impairment in Dementia

Communicating with people with dementia is an area that has been highlighted by both staff and family caregivers as particularly challenging (Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). By the latter stages of the

disease communication abilities are often severely impaired with individuals commonly having little or no speech and only making repetitive sounds or movements (Frank, 1994). This is often associated with a reduction in attempts by caregivers to engage the individual in interactions (Kitwood, 1997), except in pursuance of basic activities of daily living (Bowie & Mountain, 1993). Dementia sufferers have even been described as experiencing a social death (Sweeting & Gilhooly, 1997).

However, research has demonstrated that an urge to communicate and interact with others remains even in the very advanced stages of the disease (Ellis & Astell, 2004) and that continued interaction is essential for maintaining a sense of personhood (Downs, 2005). Furthermore, theories of phatic communication (Burnard, 2003) consider how interactions are important for sharing feelings and establishing sociability, rather than purely for sharing information. As such it has been suggested that improving interpersonal communication with those with advanced dementia could improve their QoL (Woods, 1999). The challenge lies in achieving this in spite of the person's reduced communicative repertoire.

Intensive Interaction

A range of communication interventions have been developed for people with dementia (Vasse et al., 2010), however the majority of these are language orientated. Intensive Interaction is a nonverbal approach for interacting with people with learning disabilities who have severe communication impairments. It was developed through reference to the developmental literature, in particular research into mother-infant interactions (Nind, 1996) and psychological theories of 'augmented mothering' (Ephraim, 1979). These theories explicate how pre-speech fundamental

skills are developed through regular interactions with a primary caregiver, in which the infant's vocalisations, facial expressions and other nonverbal gestures will be treated as meaningful, mirrored back to the child and expanded upon.

In accordance with these theories, Intensive Interaction focuses on utilising whatever nonverbal or sub-vocal communications a person has within their repertoire and perceives these behaviours as being intentionally communicative (Nind & Hewett, 2001). It encourages 'communication partners' to learn the nonverbal repertoire of the person and to respond to communication attempts with a reply that is within this repertoire, in doing so making the response meaningful to the person without speech. Caldwell (2005) has described this as learning the language of nonverbal people.

The aim of Intensive Interaction is not to achieve purposeful communication nor to meet specific outcomes but to focus on the quality of the interaction and the emotional connections that can be made (Nind, 1999). As such it can be seen as providing a nonverbally based form of phatic communication and aims to build close relationships that are not language orientated. The efficacy of Intensive Interaction in increasing the occurrence of social behaviours, such as smiling and eye contact, has been demonstrated in numerous studies; this research has taken place in school settings for pupils with profound and complex learning disabilities (Stothard, 1998; Watson and Fisher, 1997) and in small staffed houses in the community also with people with profound learning disabilities (Samuel & Maggs, 1998). Improved QoL has been reported as another benefit (Ellis & Astell, 2008a).

Intensive Interaction's Potential Applicability to Dementia

As it is not language orientated, Intensive Interaction may have potential for promoting phatic communication with people with advanced dementia. Whilst language is typically significantly impaired by the latter stages of the disease, nonverbal communication has been shown to remain relatively intact and many identifiable communication skills are retained (Orange & Purves, 1996). For example studies have shown a preserved ability to recognise and react to facial expressions of emotion (Guaita et al., 2009). However, there are clear differences in the cognitive profile of those with learning disabilities and those with dementia, in particular the progressive nature of memory impairment in dementia restricts capacity for new learning (Bier, Provencher, Gagnon, Van der Linden, & Desrosiers, 2007). As such it cannot be presumed that this technique is of value, an evidence base for this specific population is required.

Accordingly, Ellis and Astell (2008b) undertook a single case study to investigate the potential of the technique for this population. They observed the typical daily interactions that occurred for Edie, an 81-year-old woman with advanced dementia who lived in a nursing home and was immobile and unable to speak. Edie was found to spend the majority of time alone in her room with caregivers coming in for brief periods to perform care tasks. Typical interactions consisted of staff asking questions, such as "have you eaten your breakfast", to which Edie was unable to respond. Through these observations a standard communication condition was devised, comprising a set of questions similar to those observed. Ten-minute periods of interaction using this standard communication were then compared to the same period using the principles of Intensive Interaction. For the vast majority of the

standard communication condition Edie was disengaged with her eyes closed, communication behaviours observed included a high-pitched noise and chewing on her thumb. In contrast, the Intensive Interaction condition revealed that Edie retained a rich communicative repertoire, including sound, movement, eye gaze and facial expression, she took turns to communicate with the researcher and mirrored the nonverbal communications that were made. Further, this condition included periods in which Edie laughed and smiled. It was concluded that Intensive Interaction techniques had potential for developing communication with people in the advanced stages of dementia.

To extend the research, a series of four further single case studies were undertaken, in which the same methodology was applied (Ellis & Astell, 2010). The results indicated that for each individual a greater range of communication behaviours were displayed in the Intensive Interaction conditions compared to the standard interaction condition. Moreover, a significantly higher duration of neutral face was found in the standard communication condition and a significant increase in smiling and vocalisations in the Intensive Interaction condition.

In a further study, Ellis and Astell (2011) provided a training package on Intensive Interaction techniques to three staff members in a nursing home. The research aimed to examine whether or not it was possible to teach care home staff to use the techniques and whether or not they could overcome potential barriers to their use. After a six-week training period the staff members were able to recognise the individual ways in which the residents communicated and felt able to respond appropriately. Staff reported having enjoyed the training and found it beneficial. Through this series of studies Ellis and Astell coined the term Adaptive Interaction,

for the use of Intensive Interaction techniques with people with dementia; however whether or not there are sufficient differences to warrant a new name is under current debate and therefore the term Intensive Interaction will be used throughout this study.

In summary, the research to date indicates that Intensive Interaction techniques may help to draw out the preserved communicative repertoire of people in the advanced stages of dementia. Furthermore, initial investigations suggest that care staff found training in the technique beneficial and were able to increase their amount of communication with residents. However, the research to date has been small scale and without a control population with which to make a comparison. Moreover, there have been no investigations that directly consider the impact of using this technique on the QoL of people in the advanced stages of dementia.

Research Aims and Hypotheses

Accordingly, the current study aimed to consider the feasibility of undertaking a full scale RCT designed to answer the question: does training caregivers in Intensive Interaction techniques aid communication and improve QoL for residents with advanced dementia? The Medical Research Council guidelines highlighted the importance of assessing feasibility and piloting methods in order to foresee problems that could undermine results in full-scale trials (Craig et al., 2008). In accordance with these guidelines this study aimed to consider the acceptability of procedures, consider issues with recruitment and retention of subjects and provide information regarding likely effect size. Moreover, it made the following hypotheses: (a) that the amount of communicative behaviours that facilitate and demonstrate pleasure in interactions would increase for residents in the intervention home but would remain stable in the control group; (b) that the amount of communicative behaviours that hinder and

express displeasure in interactions would decrease for residents in the intervention home but would remain stable in the control group; and (c) the QoL would improve for residents cared for by staff who were given training but would remain stable in the control group.

Method

Design

The research employed a non-randomised controlled design involving two care homes specialising in dementia care. In the intervention condition selected staff received training in the use of Intensive Interaction techniques and practiced using these techniques with their communication partner, a resident with advanced dementia and severe communication impairment. Staff in the control home received no training and residents received care as usual.

Ethics

Capacity assessment undertaken by the author at the beginning of the study indicated that none of the resident participants had capacity at that time to give informed consent to participation; therefore, in accordance with the Mental Capacity Act, approval for the study was granted by the appropriate Social Care Research Ethics Committee (National Research & Ethics Service, 2009; see Appendix D). A personal consultee was identified for each resident to whom an information sheet was provided (see Appendix E). Before each interaction and recording of videos resident's were asked if they were happy to engage and responses honoured if given, including if nonverbal responses appeared to indicate disagreement. Staff were given a separate information sheet (see Appendix F) and direct informed consent was sought. All data

was treated confidentiality and the anonymity of participants was protected during the research process and dissemination of findings.

Participants

Participants were residents with advanced dementia and staff from the nursing home that cared for them. Due to the small scale and pilot nature of this study, a non-random convenience sampling strategy was employed. In order to minimise variations in care home environments a company with a number of homes in the local area was contacted and agreed to take part. They identified two homes, which housed participants who at the time met the inclusion criteria. The intervention home was selected by the area manager as currently having better capacity to undertake the training and thus the other home became the control. The reason behind this was possibly recently improved staffing levels in the intervention home.

Inclusion criteria for residents were that they should have severe dementia according to the Dementia Severity Rating Scale (DSRS; Clark & Ewbank, 1996; see Appendix G) and have no or only very limited verbal communication, being unable to verbally communicate needs or wishes. Six residents in the treatment home were identified as meeting these criteria. Due to the characteristics of the residents of the control home by the time the study took place, it was not possible to match the participants in terms of severity of dementia, with mean severity ratings of 51 ($SD = 2.9$) and 38 ($SD = 7.5$) for the intervention and control home respectively, which was found to be a significant difference ($U = 0.5, p = <.01$). Residual verbal communication capacity clearly differed between the groups with the least impaired member of the intervention home scoring 5 on the speech and language component of the DSRS indicating ‘Speech often does not make sense. Can not answer questions or

follow instructions' compared to the least impaired member of the control home scoring 3 which indicated 'Usually answers questions using sentences but rarely starts a conversation'. However, the control home was still able to provide an indication of natural change in communication during the study period.

The management of the home and the researcher discussed the aims and methods of the study with the staff in the home. The management then selected from staff who had expressed willingness to participate, this decision was based on the staff who knew the participating residents well, the training needs of the staff and the practicalities of who could attend the training according to shift patterns. Staff were then paired with a participating resident, in order to form a communication partnership. Partnerships were allocated in order to place staff with the resident who they typically spent the most time with during their daily caring duties. Descriptive statistics for all resident and staff participants are shown in Table 1.

Table 1.

Descriptive information for all participants

			Intervention	Control
Residents	<i>n</i>		6	6
Gender	Female		4	2
	Male		2	4
Age (years)	<i>Mean (SD)</i>		84.3 (6)	83.7 (7.9)
	Min		78	76
	Max		92	98
DSRS score	<i>M (SD)</i>		51 (2.9)	38 (7.5)
Verbal Ability	No use of words or			
	occasional use of single			
	words usually out of context		6	0
	Able to respond to some			
questions with one word or				
short answers		0	3	
	Able to have a conversation		0	3
Staff	<i>n</i>		6	6
Gender	Female		4	6
	Male		2	0
Job Role	Care staff		4	4
	Activity Coordinator		2	1
	Staff Nurse		0	1

Measures

All measures were administered at baseline (Time 1) and after completion of the intervention four weeks later (Time 2). In the intervention home the same measures were also collected at 3 month follow up (Time 3).

Behavioural observation. Video recordings were made of staff interacting with their communication partner. Staff were asked to communicate with the resident in the manner which they would usually do. Five minutes from the middle of each video clip was selected for coding. Where a video clip was less than five minutes, a corresponding length of time was selected from the middle of the participant's other recording. Numerous video clips were taken throughout as part of the training programme; however specific clips for the purpose of analysis were taken at the three time points, totalling 28 video clips for analysis.

In accordance with recommendations for behavioural coding (Agnew, Carlston, Graziano, & Kelly, 2009), each video was initially watched through several times by the author, and the repertoire of behaviours was recorded. Microanalytic coding categories were then developed through reference to the noted behaviours and coding categories utilised in previous studies (Ellis & Astell, 2011). As detailed in Table 2, the final coding categories encompassed eye gaze, facial expression, vocalisations, touch and imitation. Each clip was analysed using the Adobe Premiere CC programme, which allowed viewing at reduced speed and areas of the footage to be magnified.

Table 2.

Microanalytic Coding categories

Major Category	Sub Category	Notes for Analysis
Direction of Eye Gaze	Closed	Resident's eyes are closed.
	Elsewhere	Resident is focused away from the caregiver.
	Caregiver's body	Resident is focused on any part of the caregiver's body, for example looking at their hands during an activity.
	Caregiver's face or eyes	Resident's focus is directed at the caregiver's eyes or face.
	Can't tell	Direction of gaze is not visible.
Facial Expression	Neutral	May vary between individuals but appears to represent their face at rest
	Smiling	Or other expression indicating joy.
	Frowning	Or other expression indicating displeasure.
	Other	Any other expression such as surprise.
	Can't tell	Facial expression is not visible.
Vocalisation	Silent	The resident is not making any audible sound.
	Uses word/s	Resident is using distinguishable words.
	Laughing	Or other noise that seems to indicate pleasure.

	Shouting/screaming	Or other noise that seems to indicate displeasure.
	Other noise	Including audible breathing, whistling and making noise with hands such as clapping
Physical contact	Touch initiated by resident	Duration of any physical contact that was initiated by the resident
Mirroring	Caregiver mirrors resident	In instances where the mirroring was a continuous process, the length of time that each individual was doing the same as the other was counted as mirroring that of each other.
	Resident mirrors caregiver	

The feasibility and coverage of the coding categories were reviewed with an independent researcher. All videos were then initially coded by the primary researcher, who was not blind to condition. After coding, four of the 27 videos were randomly selected and re-coded by a trainee psychologist from the researcher's course who was blind to condition. However, the nature of the interactions are visibly different when using Intensive Interaction and as such a true blinding to condition was not possible, as will be considered further in the discussion. Comparison of the duration of each behaviour recorded by the two raters gave the following Cohen's kappa ratings: session 1 (intervention / Time 1) $\kappa = .99$; session 2 (intervention / Time 1) $\kappa = .96$; session 3 (control / Time 1) $\kappa = .93$; session 4 (control / time 2) $\kappa = .84$.

This indicated near perfect agreement between the two coders on all of the selected videos (Landis & Koch, 1977).

QoL measure. The QoL in Late-Stage dementia scale (QUALID; Weiner et al., 2000; see Appendix H) was also administered at all time points. This was rated by a care staff member who knew the resident well but was outside of the communication partnership.

Training feedback. Feedback on the training was collected from all staff participants through a questionnaire designed by the author. This included Likert scale questions designed to assess: the staff's perceptions of the quality of the training; the level of confidence staff achieved in using the skills; the relevance to their work; and the impact they believed it would have on the residents' QoL. Space for free text was also included regarding what they had found most helpful from the training and what they felt could be changed. A copy of the feedback questionnaire can be found in Appendix I.

Power calculation

The literature indicated likely effect sizes of $d = .84$ for communicative behaviour analysis (Ellis, 2009) and $d = .4$ for QoL measures (McCallion et al, 1999). In order to achieve a power level of .8 with a .05 probability level this required 38 and 156 participants respectively. However, as the focus of the research was on feasibility, attempts were not made to achieve full power.

Intervention

A full days training was undertaken, followed by a four week break for staff to practice the skills and identify any difficulties in their use, the intervention was then

completed by a further full days training to consolidate skills and address any problems. The training included a mixture of theory, resident observations, demonstrations of techniques and had a particular emphasis on developing and practicing the Intensive Interaction techniques with each staff member's assigned communication partner. Staff were encouraged to practice the techniques during their routine work and plans were made about how the staff could support each other to continue implementing the technique after the training. The training package was based on that which had been developed in the previous research in the area (Ellis and Astell, 2011) and was delivered by the authors of this study. These authors had received input from one of the key developers of Intensive Interaction, Phoebe Cauldwell, while producing the training package.

Procedure

Baseline data were collected in both the intervention and control homes (Time 1). The training package was the provided to the intervention home and care continued as normal in the control home. Four weeks after the initial baseline data collection, and after completion of the training, follow up data were recorded in both homes (Time 2). A further follow up data set was collected 3 months later in the intervention home (Time 3). In order to minimise additional comparisons and increasing the chance of Type 1 errors, only the measures where a significant difference at Time 2 had been found were repeated at Time 3.

Data Analysis

For each coding category and the QUALID results, a change score was calculated by subtracting the scores from data collection at Time 1 from the respective

results from data collection at Time 2. The change scores for each outcome were then compared using the Mann Whitney U test. Non-parametric analysis was chosen due to the small sample size and the data not being normally distributed. Where significant results were found post hoc analysis was undertaken using either further Mann-Whitney U tests or related samples Wilcoxon signed rank tests. Whilst median and range are considered the most appropriate descriptive statistics for this form of data, a review of results indicated that this overlooked some important information in which large changes were found for a small percentage of individuals within the group but outcome measures remained static for the majority. As a result both the mean and standard deviation and median and range are presented.

In order to address the hypotheses, and due to different behaviours being exhibited by different residents, an overall composite score for behaviours that facilitated and indicated pleasure in interactions (from hereon referred to as positive communication behaviours) and those that hindered and indicated displeasure with interactions (from hereon referred to as negative communication behaviours) were calculated. The positive communication composite was the sum of change scores on the sub-categories: eye gaze directed at face or eyes, smiling, laughing, making other noises and physical contact initiated by resident. The use of words was excluded from the analysis due to the difference in verbal ability between the two different groups, which led to significantly more variation in the control group. The negative communication composite was the sum of change scores on the sub-categories: eyes closed, frowning, shouting/screaming. The categorisation of these behaviours as either positive or negative was in accordance with relevant literature in the area of

behavioural coding (Burgoon, 2005; Guerrero, 2005) and were agreed by the second rater.

Results

Composite Scores

Table 3 details the mean pre and post intervention scores and standard deviations for the positive communication behaviour and negative communication behaviour composites.

Table 3.

Mean pre and post training scores (duration in seconds) for composites

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1 <i>M (SD)</i>	Time 2 <i>M (SD)</i>	Time 1 <i>M (SD)</i>	Time 2 <i>M (SD)</i>	<i>U</i>	<i>p</i> (1 tailed)	<i>r</i> (95% <i>CI</i>)
Positive Composite	89 (103)	270 (219)	109 (87)	117 (95)	6	.03	.56 (-.4 to .9)
Negative Composite	93 (95)	55 (81)	46 (110)	1 (3)	25	.16	n/a
Negative Composite	93 (95)	55 (81)	1 (1)	1 (3)	5	.04	.56 (-.6 to 1) (- outlier)

As can be seen in Table 3 there appears to be a larger increase for those in the intervention home on the positive behaviour composite, with the mean increasing from 89 to 270 seconds (*Mdn* from 61 to 204), than in the control home in which the mean only increased from 109 to 117 seconds (*Mdn* from 130 to 87). Statistical comparison of the mean change scores indicated that this was a significant difference,

with a large absolute effect size (Cohen, 1988); however the confidence intervals for the effect size are wide and encompass the zero, which indicates that we cannot be certain that the effect exists without collecting further data (Yatani, 2014). Post hoc analysis indicated a significant difference in the scores at Time 1 and Time 2 in the intervention group ($T = 6, p = 0.01$), but not in the control group ($T = 13, p = .3$). This indicated that positive communication behaviours increased for the residents cared for by staff who received the training but remained stable for those who received care as usual.

Initial analysis of the negative communication behaviour composite scores did not indicate significant differences between the groups. However, an outlier was present in the control group, in which the resident fell asleep almost immediately on commencing the Time 1 recording but was awake for the duration of the Time 2 recording. When this result was removed there appears to be a larger decrease for those in the intervention home, with the mean decreasing from 93 to 55 seconds (*Mdn* from 0 to 3), than in the control home in which the mean remained static at 1 (*Mdn* static at 0). Comparison of the mean change scores indicated that this was a significant difference with a large effect size (Cohen, 1988). However again, the confidence intervals for the effect size encompass the zero, therefore it is not certain that the effect exists. Post hoc analysis of intervention home scores indicated a significant difference ($T = 1, p = .02$) in Time 1 and Time 2 scores, with the mean duration of behaviours reducing from 93 seconds ($SD = 95$) to 55 seconds ($SD = 80$). In contrast the control home scores remained relatively stable with means of 0.6 ($SD = 1$) and 1.4 ($SD = 3$) at Time 1 and Time 2 respectively and no significant difference found between them ($T = 1, p = .33$).

Individual Behaviours

In order to better understand the results on the composite scores, results for individual behaviours were also analysed.

Direction of eye gaze. Table 4 depicts mean pre and post intervention scores and standard deviations for the amount of time the residents spent with their eyes closed, looking elsewhere, looking at their partner's body and looking at their partner's face or eyes, in the two different conditions.

Table 4.

Mean pre and post training scores (duration in seconds) for direction of eye gaze.

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1 <i>M (SD)</i>	Time 2 <i>M (SD)</i>	Time 1 <i>M (SD)</i>	Time 2 <i>M (SD)</i>	<i>U</i>	<i>p</i> (1 tailed)	<i>r</i> (95% <i>CI</i>)
Eyes Closed	56 (108)	51 (81)	45 (110)	0 (0)	15	.35	n/a
Elsewhere	147 (95)	119 (85)	131 (104)	192 (47)	28	.07	n/a
Carer's body	12 (22)	6 (10)	16 (22)	8 (11)	14	.29	n/a
Carer's face or eyes	68 (74)	109 (78)	81 (88)	78 (33)	21	.35	n/a

As can be seen in Table 4, numerical differences were found in the direction of eye gaze, with the mean time spent looking at the caregiver's face or eyes in the

intervention home increasing from 68 to 109 (*Mdn* 53 to 109) but remaining relatively stable in the control home moving from 81 to 78 (*Mdn* 61 to 82). However, these changes were not found to be significant. The difference in change scores for the proportion of time residents were looking elsewhere was found to be approaching significance, with the mean duration reducing from 147 to 119 (*Mdn* 124 to 155) in the intervention home and increasing from 131 to 192 (*Mdn* 130 to 199) in the control home. Numerical differences were also observed in the duration of time spent with eyes closed, with the mean in the intervention home remaining relatively stable at 56 and 51 (*Mdn* 3 to 20) but reducing in the control home from 45 to 0 (*Mdn* 0 to 0). However, this difference was not found to be significant and was also attributed to the outlier described in the previous section.

Facial expression. The mean pre and post intervention scores and standard deviations for the amount of time spent smiling, frowning, with a neutral expression or with another expression, such as surprise, are depicted in Table 5.

Table 5.

Mean pre and post training scores (duration in seconds) for facial expression

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1	Time 2	Time 1	Time 2	<i>U</i>	<i>p</i>	<i>r</i>
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		(1 tailed)	(95% <i>CI</i>)
Neutral	268 (58)	271 (42)	251 (34)	253 (38)	20	.41	n/a
Smiling	5 (10)	13 (18)	11 (16)	13 (19)	16	.41	n/a
Frowning	9 (19)	1 (3)	1 (1)	1 (3)	21	.35	n/a
Other expression	0 (0)	0 (0)	.2 (.4)	1 (2)	18	.5	n/a

As shown in Table 5, no significant differences were found between the change scores of the intervention and control home for the duration of different facial expressions. Whilst, not found to be significant, there was a numerical difference between the homes in the amount of change observed for the duration of time spent frowning. A slight decrease was noted in the intervention home with the mean moving from 9 to 1 (*Mdn* 0 to 0) but remained static in the control home at 1 (*Mdn* static at 0).

Vocalisation. The mean pre and post intervention scores and standard deviations for the amount of time spent using words, shouting or screaming, laughing, making another noise or being silent, are shown in Table 6 for each condition.

Table 6.

Mean pre and post training scores (duration in seconds) for vocalisations

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1	Time 2	Time 1	Time 2	<i>U</i>	<i>p</i>	<i>r</i>
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		(1 tailed)	(95% <i>CI</i>)
Uses word	5 (9)	2 (2)	61 (69)	53 (45)	24	.2	n/a
Shout/ Scream	28 (44)	2 (6)	0 (0)	0 (0)	24	.2	n/a
Laugh	1 (2)	1 (3)	3 (7)	2 (5)	15	.35	n/a
Other noise	16 (32)	29 (60)	15 (22)	18 (43)	7	<.05	.53 (-.5 to .9)
Silent	236 (46)	252 (61)	213 (74)	210 (63)	15	.35	n/a

As demonstrated in Table 6, there the mean duration of shouting in the intervention home reduced from 28 to 2 (*Mdn* stable at 0) but remained stable at 0 (*Mdn* static at 0) in the control home, however this difference was not found to be significant. A numerically larger increase in the mean duration of “other noise” was observed in the intervention home with the mean increasing from 16 to 29 (*Mdn* static at 0) compared to the control home where the mean only increased marginally from 15 to 18 (*Mdn* 6 to 0). This difference was found to be significant; however, post hoc analysis did not indicate a significant difference between the scores at Time 1 and

Time 2 for the intervention group ($T = -6, p = .18$), nor for the control group ($T = 5, p = .25$). It must also be recognised that the analysis has undertaken several comparisons thus inflating the chance of Type 1 errors.

Physical contact. Table 7 depicts the mean pre and post intervention scores and standard deviations for the amount of physical contact that was initiated by the resident.

Table 7.

Mean pre and post training scores (duration in seconds) for physical contact

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1	Time 2	Time 1	Time 2	<i>U</i>	<i>p</i>	<i>r</i>
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		(1 tailed)	(95% <i>CI</i>)
Physical contact	0 (0)	118 (147)	0 (0)	6 (11)	15	.35	n/a

As shown in Table 7, there was a greater increase in the mean duration of physical contact initiated by the resident in the intervention home with the mean moving from 0 to 118 (*Mdn* 0 to 55) compared to the control home in which the mean moved from 0 to 6 (*Mdn* 0 to 11). However, this difference was not found to be significant.

Mirroring. The mean pre and post intervention scores and standard deviations for the amount of time the caregivers and the residents spent mirroring each other's movements and vocalisations are shown in Table 8.

Table 8.

Mean pre and post training scores (duration in seconds) for mirroring.

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1	Time 2	Time 1	Time 2	<i>U</i>	<i>p</i>	<i>r</i>
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		(1 tailed)	(95% <i>CI</i>)
Caregiver mirrors resident	2 (3)	54 (71)	2 (4)	16 (37)	8	.07	n/a
Resident mirrors caregiver	3 (3)	84 (54)	4 (5)	21 (35)	12	0.2	n/a

As demonstrated in Table 8, there was a greater increase numerically in both caregiver mirroring in the intervention home, with the mean duration increasing from 2 to 54 (*Mdn* 2 to 83) compared to from 2 to 16 (*Mdn* 3 to 7) in the control home. Similarly a greater increase in resident mirroring was observed in the intervention home with the mean increasing from 3 to 84 (*Mdn* 1 to 16) compared to from 4 to 21 (*Mdn* 1 to 0) in the control home. However, neither of these differences were found to be significant.

QUALID Scores.

Mean change scores on the QoL measure for the intervention and control group are presented in Table 9.

Table 9.

Mean pre and post training scores on the QUALID

	Intervention		Control		Comparison of Mean Change Scores		
	Time 1	Time 2	Time 1	Time 2	<i>U</i>	<i>p</i>	<i>r</i>
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		(1 tailed)	(95% <i>CI</i>)
QUALID	27	16	18	24	3	<.01	.7
score	(7)	(4)	(7)	(8)			(-.3 to 1)

As shown in Table 9, there was a reduction in scores on the QUALID, which indicates an improvement in QoL, for residents in the intervention home, with the mean decreasing from 27 to 16 (*Mdn* 29 to 16). This was compared to an increase in scores, indicating a reduction in QoL, for residents in the control home, with the mean increasing from 18 to 24 (*Mdn* 18 to 27). This difference was found to be significant with a very large effect size (Cohen, 1988). However once more, the confidence intervals for the effect size encompass the zero, therefore it is not certain that the effect exists. Post hoc analysis indicated that there was already a significant difference ($U = 5.5, p = .04$) between the groups at baseline, with the control home being rated as having a higher QoL ($M = 18, SD = 7$) than the intervention home ($M = 27, SD = 7$). This difference was no longer significant by Time 2 ($U = 28, p = 0.13$), with the mean QUALID score in the intervention home decreasing ($M = 16, SD = 4$), and the score in the control home increasing ($M = 25, SD = 7$).

Three Month Follow Up

In the intervention home outcome measures were also collected 3 months after the end of training. However, due to the death of two of the resident participants and one set of unusable data only three communication partnerships were included in the

behavioural data analysis and four in the QUALID results. The analysis concentrated on the composite and QUALID scores on which significant differences had previously been found. Table 10 details the mean score on each of these at baseline, post training and at follow up for the remaining residents.

Table 10.

Mean composite and QUALID scores for the intervention home at baseline, post training and 3 month follow up

	Baseline		Post Training		Follow Up	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
	(Mdn)	(range)	(Mdn)	(range)	(Mdn)	(range)
Positive composite	81	70	288	195	121	105
	(97)	(138)	(261)	(388)	(181)	(182)
Negative composite	62	16	10	17	102	150
	(60)	(31)	(0)	(30)	(32)	(275)
QUALID	26	8	18	3	21	4
	(28)	(18)	(19)	(7)	(22)	(8)

Comparison of the post training mean and the follow up mean indicated a reduction of over 50% in the duration of positive communication behaviours. Further, whilst comparison of the baseline and post training scores no longer demonstrated a significant difference, either due to the decreased sample size or the scores of these particular residents ($T = 6, p = .06$), it did approach significance. In comparison there was clearly no significant difference between the baseline and follow up scores ($T = 5, p = .14$). Thus, there is a lack of evidence for a difference between baseline and follow up, this may have resulted from positive communication behaviours returning

to a duration that was comparable to before the intervention; however it is possible that improvements were maintained to a degree but that the study did not have sufficient power to find a continued significant difference.

Comparison of the post training mean and the follow up mean indicate a ten fold increase in the duration of negative communication behaviours. Again, comparison of baseline and post training scores no longer demonstrated a significant difference, ($T = 0, p = .06$) but did approach significance. Whereas, a clear lack of significance was demonstrated when comparing the baseline and follow up scores ($T = 3, p = .5$). In this instance it appears that improvements made through reduction in negative communication behaviours had not been maintained, as the mean score at follow up ($M = 102, SD = 150$) actually exceeded that at baseline ($M = 62, SD = 16$).

In comparison, only a slight increase was found on QUALID scores, indicating a slight reduction in QoL, between post training ($M = 18, SD = 3$) and follow up ($M = 21, SD = 4$). As in the previous two comparisons, the difference between baseline and post training scores only approached significance ($T = 1, p = .07$). However, in this instance the difference between baseline and follow up scores also approached significance ($T = 0, p = .06$), suggesting that improvements in QoL scores may to have been maintained. Again, greater power would have been required in order to fully ascertain whether the difference remained significant.

Individual scores.

There was considerable variation between which subcategories saw change for each individual. In order to illuminate this further the individual scores for each participant are detailed in Appendix J. Reference to these individual scores indicates that whilst there was considerable variation across the subcategories, the trends on the

major categories that showed significant results: the positive composite, negative composite and QUALID are consistent with what was indicated by the analysis of the means.

Training Feedback.

All staff rated the training as being excellent. Further, they all stated that they definitely felt more confident in working with residents who could not communicate verbally, definitely believed that Intensive Interaction techniques could improve the QoL of the residents and felt confident to use the techniques in their day-to-day work. Three staff members commented that watching back videos of themselves interacting had been a particularly helpful element of the course and two commented that having opportunities to practice was beneficial. No recommendations were made regarding possible changes to the course.

Discussion

Research Aims and Hypotheses

The aim of this research was to explore the feasibility of conducting a full scale RCT, to assess whether or not training care staff in the use of Intensive Interaction techniques could improve QoL for residents with advanced dementia.

Positive communication behaviour hypothesis. The first hypothesis proposed that the amount of communicative behaviours that facilitate and demonstrate pleasure in interactions would increase for residents in the intervention home but would remain stable in the control group. This hypothesis was borne out with residents in the intervention home demonstrating a significantly greater increase in positive communication behaviours when compared to those in the control home.

Given the theories behind Intensive Interaction (Caldwell, 2005) this possibly results from caregivers starting to recognise the individual resident's communicative attempts and beginning to respond in a manner that was comprehensible to them and which they could reciprocate in turn. It further suggests that developmental theories of preverbal communication skills may have relevance to working with people in the advanced stages of dementia.

Negative communication behaviour hypothesis. The second hypothesis proposed that the amount of communicative behaviours that hinder and express displeasure in interactions would decrease for residents in the intervention home but would remain stable in the control group. Again this hypothesis was borne out with a significantly greater decrease in negative communication behaviours in the intervention home when compared to the control home. Similar theories to those described in the positive communication behaviour section could be proposed to explain this, with the staff's use of communication techniques that were accessible to the resident's possibly leading to a decrease in negative reactions to communication attempts.

QUALID hypothesis. The final hypothesis proposed that the QoL would improve for residents cared for by staff who were given training but would remain stable in the control group. As hypothesised, significant differences were found on the QUALID outcome measure, suggesting that changes to communication patterns are associated with an improvement in QoL. Given that social interaction is a key element in the assessment of QoL (WHOQOL Group, 1995), it is possible that the enhancement of communication via the training was the mediating factor in this

change. However, without adjustments to the design, as will be discussed later, this cannot be concluded with any certainty.

Analysis of Sub-Categories. Other results that approached significance were the duration of time spent looking 'elsewhere' and the amount of time caregivers spent mirroring residents' movements and vocalisations. With regards to the eye gaze, this was considered to result from an outlier in the control group and as such to not be reflective of any particular change related to training. With regards to the increase in mirroring, however, this is a key component taught by the course and as such was likely to have been reflective of caregivers utilising the skills that they had been trained in.

The lack of a significant difference on other subcategories does not necessarily indicate that the null hypothesis should be accepted. As a feasibility study, this never intended to reach full power and therefore a larger sample size may have found more significant differences. Relatedly, the nature of the coding categories was intended to pick up highly individualised changes in behaviour, for one person a positive change could mean a decrease in shouting whereas for another this could be shown through increased eye contact. Greater sample numbers would help to ameliorate the difficulties presented by these individual differences.

Limitations of Design

Whilst the above results provide promising indications as to the utility of Intensive Interaction for people with advanced dementia, caution must be employed when extrapolating from these findings due to a number of limitations in the study design. Firstly, it must be recognised that whilst the absolute values suggested large effect sizes, the confidence intervals were wide and encompassed the zero; thus,

without recruiting larger numbers of participants, it is not possible to say with any certainty that the effect exists or indeed that it has clinical relevance.

Lack of randomisation. The non-random assignment of care homes in this study also limits the causal inferences that can be drawn. The intervention home was chosen by the organisation's management as they considered it to have better capacity to undertake the training. The influence of this is unclear but one possible interpretation is that better, and possibly recently improved, staffing levels were the reason it was chosen. This in itself could have resulted in the observed improvements in communication and therefore, without randomisation to condition, causal links must be made with caution.

Ecological validity. The ecological validity of using short periods of video recording as an outcome measure is questionable (Gardner, 2000). Staff may have acted in accordance with the training principles when being videoed but this does not necessarily mean that it is reflective of their day-to-day practice. Direct observations over a longer period, such as those used in Dementia Care Mapping (Brooker, 2005), would be one potential option for addressing this; however the level of detail that the analysis can achieve without video recording would be compromised.

Control of confounding variables. A number of issues were also highlighted with regards to controlling for confounding variables. Firstly, staff were instructed to interact with individuals as they would normally, as a result this led to considerable variations in conditions between baseline and post-training data collection (for further details see Appendix J). For example one of the control residents was initially filmed watching and dancing to a musical film with their communication partner, then in the follow up video they were simply dancing together. This inevitably led to a

considerable increase in eye contact. This highlights the difficult balance between controlling for confounding variables whilst maintaining ecological validity and recognising that there is significant variation that occurs in communication even on a day-to-day basis.

The current study design also means that it was not possible to say with any certainty that the improvements in QoL resulted from the use of Intensive Interaction techniques. Firstly, having care as usual in the comparison home did not control for the confounding variable of residents benefitting from simply having greater attention from staff. As such any future studies should look to employ a more rigorous control in which staff are provided with a generic communication training programme and are required to spend comparable amounts of time in communication with the participating residents. Further, in a larger scale study in which parametric analysis was possible it would be helpful to utilise mediation analysis with communication change being the hypothesised mediator between the intervention and QoL.

Variation in verbal ability. With regards to individual behaviours, the only sub-category to achieve a significant difference was for making 'other noises'. This theme may have shown a larger difference due to the disparity in verbal ability between the groups. As a result the intervention group may have been more likely to use sub-vocal communication, as this was all that they had at their disposal (Acton, Mayhew, Hopkins, & Yauk, 1999); therefore, when the staff, following training, encouraged sub-vocal interaction there was a notable increase. In comparison, residents of the control home were unlikely to use a lot of sub-vocal communication and therefore fluctuations would be small, potentially leading to the significant difference.

The influence of this disparity on the other coding categories is unclear.

Classic studies, such as that of Mehrabian (1972), suggest that even without verbal impairment as much as 93% of what we communicate may be through nonverbal, or sub-vocal channels. As such, despite their higher verbal ability, the control population offers information with regards to natural fluctuations in nonverbal communication.

What is less clear is whether those with a greater verbal deficit may demonstrate greater natural variability in their nonverbal behaviour due to their greater reliance on it. As such, in order to offer a more valid control any future studies should either attempt to match the control and intervention home participants in terms of their verbal ability, or should consider whether a within participants design would offer a better level of control.

Use of Video Analysis.

Near perfect inter-rater reliability indicates that the coding categories provide a reliable means through which to measure nonverbal communication, and as such would be helpful for use in future studies. However, some quality control issues and potential adjustments will need to be considered prior to their use. Firstly, the analysis of the videos highlighted how subtle some important behaviour changes are. For one individual, who had very little movement and could only make a few sounds, it was actually mirroring her audible breathing pattern that created a connection with her communication partner. When witnessed in person a clear interaction developed in which each exchanged phases of loud rapid breathing and when the caregiver stopped, the resident would increase the volume and pace of her breathing until the interaction was recommenced. This interaction was shown in the video recording; however in a larger scale study it is possible that these subtle behaviour changes may be missed.

Careful consideration would need to be given as to the quality of the recordings and the training of raters to enable as detailed analysis as possible. Furthermore, investment in specialised behavioural coding software would be advantageous.

Further consideration also needs to be given as to how to blind raters to condition. Firstly, with regards to collection of the QoL outcome measures, whilst the raters were outside of the communication partnerships, it was clear to staff working within the home that training had been undertaken. This would be somewhat ameliorated by having the tighter control group, however, the type of interaction encouraged by this training is visibly different to usual and therefore raters are likely to be aware of which training was being received. A possible solution would be to utilise family members, who typically spend less time at the homes, to give a secondary comparison rating on the QUALID where possible. A further difficulty is in blinding the raters of the videos to condition. The difference in the caregivers interaction style should be relatively apparent on videos, therefore consideration needs to be given as to whether some initial video analysis should be undertaken in which only the resident is visible and sound is removed, thus allowing greater blinding of condition to ascertain that results have not been influenced in this way.

Statistical analysis. The subtlety and richness of the data derived from this study brings a number of other challenges. In particular the statistical analysis strategy entailed a large number of comparisons. Such strategies increase the likelihood of Type One errors, in which significant results are found spuriously. This may be further enhanced in a larger scale study in which the number of coding categories is likely to increase due to a greater behavioural repertoire from a larger sample size. As such analysis of individual behaviours may need to be excluded in future research.

Acceptability of Procedures and Follow Up Data

This study also aimed to consider the acceptability of procedures, consider issues with recruitment and retention of subjects and provide information regarding likely effect size. Whilst the results from this study at the post-training stage were promising, the follow-up data suggests that changes in communication behaviours may not have been maintained over time. There are a number of possible explanations for this. Firstly, the techniques employed in this form of interaction are unusual and often meet with some hesitancy when first tried (Ellis and Astell, 2011). It is possible that without this support of the trainers in the follow-up period the use of the technique diminished. Qualitative research into caregivers' perceptions of using the skills would be helpful to elucidate this further.

Research has also indicated that involvement of line managers can improve outcomes from training (Ogilvy & Ellam-Dyson, 2012). Therefore, future studies should request management attendance at the training to ensure that support for this form of interaction was encouraged afterwards. It is also possible that the reduction in improvements by the follow up period was actually related to a decline in the cognitive functioning of the residents, as such maintaining the control group at follow up would be beneficial.

It must also be recognised, however, that the lack of significant difference on the positive behaviour composite by follow up may simply have reflected a lack of power in the design. The death of two of the participants highlights a recruitment and retention issue of working with a population group at such an advanced stage of the disease. The likely loss of participants would need to be accounted for when calculating power and sample numbers for any future studies.

Interestingly improvements on the QoL rating scales were maintained at follow up despite the changes to communication behaviours. This could indicate that the mechanism through which the improvement of QoL was achieved was not through the use of the Intensive Interaction techniques. However, with such small sample numbers definitive answers cannot be drawn due to the influence of other confounding variables. In particular, for two of the residents in the follow up sample significant medical problems were addressed in the time period between the post training data collection and the follow up. These are likely to have significantly improved the residents' day-to-day comfort levels and as such the improved QoL ratings may have been maintained through other factors outside of the communication paradigm. Increasing sample size numbers should help to ameliorate the influence of such variables, as would maintaining the control group to the follow up period.

Results from the staff feedback indicate that the training package was well received by staff. Furthermore, the outcome measures used appear to have been acceptable to the participants. Whilst initially there was considerable hesitation by the staff at the idea of being filmed, the feedback forms indicate that by the end of the training this was considered by some to be one of the most useful elements.

Recommendations for Future RCTs

In summary the recommendations for future RCTs suggested by this study are:

1. Increase the sample size to achieve full power
2. Improve control of confounding variables through randomising the allocation of care homes, improving the validity of the control condition and achieve greater similarity between environmental conditions at pre and post data collection.

3. Consider how the ecological validity of the video outcome measure could be improved
4. Match the intervention and control home participants in terms of dementia severity and verbal ability or if this is not possible consider a within participants design
5. The coding categories for the video analysis demonstrated robust inter-rater reliability but video quality control checks, training of raters, use of specialised video analysis software and measures to blind raters to condition will need to be considered.

Intensive Interaction and Person Centred Dementia Care

Kitwood's theories (1997) of malignant social psychology suggest that those with dementia are often conceptualised as 'patients' who are inferior and as such the sense of the individual outside of the dementia is lost. The Francis Report (The Stationary Office, 2013) highlights the need to put the person at the forefront of care in order to prevent future abuse scandals such as that which occurred in Mid Staffordshire. Furthermore, the Social Care Institute for Excellence (2015) highlights how person centred care can help prevent such abuses. Through training staff to use Intensive Interaction it appears that they may have been able to honour each individual resident's residual communication capacity, rather than treating it as inferior, and in doing so were able to interact with that person as an individual. As such it is consistent with the philosophy of person centred dementia care and has a potential role to play in improving the care of those living with dementia.

Conclusion

The results from this study suggest that Intensive Interaction techniques are a potentially beneficial means of improving interactions between residents with advanced dementia and their staff caregivers. It also indicates that there may be an associative improvement in QoL. The large effect sizes found suggest that these changes are clinically relevant, although this must be interpreted with caution due to the wide confidence intervals. As such, this study supports the need for a full scale RCT in this area in order to strengthen the evidence base and, if appropriate, give weight to recommendations for care organisations to train their staff in these techniques. An additional area for further exploration is in training family members to utilise the technique. Research suggests that family members also struggle to communicate with people in the advanced stages of dementia, and this often leads to a reduction in the amount of visits (Touzinsky, 1998). Teaching this technique may help to ameliorate this effect and improve QoL not only for the resident but for the visiting relative.

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Section C

Critical appraisal of the research process

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This study stemmed from my own experiences of working as a carer for people with dementia. I found myself in numerous situations in which I felt stuck and unable to make connections with residents due to my reliance on verbal communication. When I first arrived at the intervention home I saw that many of these feelings were reflected in the sense of impotence and pointlessness that was at times felt by the staff. It was a pleasure to witness how these feelings changed as the training proceeded and how attitudes made notable shifts. The staff began to see that communication was still possible and that meaningful interactions could be achieved, as a result they showed greater pleasure in their work and there was a sense of relationships developing between two individuals rather than between a patient and a carer.

Research Skills

Prior to commencing training I had an existing interest in Intensive Interaction and in dementia, as such I was confident of the area in which I wanted to undertake research. However, the process has highlighted the numerous steps involved from deciding on an area of interest to honing a feasible and clinically relevant research question. It has demonstrated the importance of having a sound knowledge of the available literature to ensure that you are not replicating an existing evidence base. As research in this area is in its infancy, this required networking with other professionals to gain details of the most up to date research that had not yet been published. Furthermore, this led to a collaboration with two researchers who had completed initial investigations in the area. I believe that learning to build relationships in this

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way has been key to the success of the project and is something that I would take forward into future research.

Navigating the process of applying for ethical approval, in particular with regards to working with people who lack capacity to give informed consent, has been a further area of skill development. Presenting my work at the ethics panel was an illuminating experience, I was surprised by the medical focus of the board and the lack of representation from other professionals. This highlighted the need to ensure that all information regarding the research is described in lay terms, and that all psychological theories behind the research are clearly described in a manner that is readily understandable. The experience also demonstrated the need to be very thorough when reviewing what I found to be relatively confusing instructions. I got to the point in which I had, what I believed, to be full ethical approval and had arranged training dates, only to realise a few days beforehand that I also needed to apply for site specific approval; this led to unfortunate delays that I would be able to avoid in any further research.

The practical difficulties in working with organisations was another area of learning for me. Attempting to arrange schedules that fitted the nursing homes, the trainers who were coming down from Scotland and with the course deadlines was at times a logistical nightmare. I can only imagine that on a larger scale project these difficulties become even more challenging. I believe that witnessing the enthusiasm of the staff following completion of the training and the difference it made in interactions with the residents, would allow me to be more confident in asserting the importance of the research when recruiting and making arrangements with participating homes.

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I have also gained considerable skills in the use of video analysis for research and insight into the technical requirements for collecting such data, in particular it has highlighted the need for on-going checks to ensure that the quality of the resultant videos are sufficient to enable detailed analysis. The selection of appropriate outcome measures has been a further area of learning, including balancing the need to utilise measures that have well founded psychometric properties but at the same time are practically viable for the application; for example regarding the length of time taken to complete. Finally, my knowledge of the practical application of statistical procedures has been significantly enhanced. In particular I feel I have a greater understanding of appropriate non-parametric statistics for use with small sample sizes and data that is not normally distributed.

Areas in which I would look to further my knowledge are in the collection and analysis of qualitative data, as I believe that this research area would benefit from further investigation into staff participants views on using the skills. In order to take the research forward to a full-scale trial, I would also need to develop my skills in large-scale recruitment and cluster randomisation.

Improvements to Design

With hindsight there are a number of elements of the study design that I would adjust in any future research. Firstly, whilst initially the training made a significant difference, this was not maintained by follow up. Involvement of line managers in training has been found to improve outcomes (Oglivy & Ellam-Dyson, 2012). Therefore, I would ensure that the management of any participating homes also undertook the training course, in order to maintain enthusiasm for the approach once input from the trainers finished. Evidence also suggests that in order to change the

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culture of a home, the full staff team need to participate in any training (Bowers, Nolet, Roberts, & Esmond, 2007). Whilst not possible in this small-scale research, this is something that I would endeavour to change in any future larger scale studies. Further, due to personal reasons leading to a period of time away from work, I was unable to feedback the results of the research as soon as I would have liked. I believe that this, alongside checking in with the home regularly after the training finished, may also have helped to maintain improvements.

Unfortunately due to delays in commencing the research, by the time the study began there were not sufficient residents in the control home with a similar degree of dementia severity and verbal ability to those in the intervention home. Whilst the data from the control home was still useful, the larger behavioural repertoire of those residents caused some issues in analysis due to the greater variability that they inevitably displayed at different times. Therefore, in order to avoid this I would attempt to ensure that a number of potential homes were identified at the beginning of the research, so that back ups were available should the characteristics of the residents change.

Greater control of environmental confounding variables is a further change that I would implement. There was significant variety in where the videos were taken, the time of day that they were taken and the activities that the communication partners were engaged in. This inevitably had an effect on the type of communication that occurred and again caused greater variability in the behaviours exhibited. As such I would endeavour to ensure that recordings at baseline and post training were taken at the same time of day and in the same room. I would also request that props, such as

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looking at pictures together, were not used, as this influences important factors such as eye gaze.

Ideally, if I were to carry out this research again I would make provision for the control home to receive the training after completion of the research, so long as the findings indicated that it was beneficial. Staff and personal consultees were aware that they would not receive the intervention before consenting; however the participants of the control home gave their time to this study but were not able to benefit directly from the results, which I believe raises ethical issues (Temple & Ellenberg, 2000). As such I would attempt to address the financial and time limitations that prevented this provision from the outset.

Implications for Clinical Practice

I am currently on my older adults placement and will be completing some work with the care home in-reach team regarding potential outcome measures that they could use to evaluate their service. From doing this research I think I am well placed to offer better guidance as to appropriate measures to utilise for resident populations who are have advanced dementia. Furthermore, I believe that discussion of this technique with the care home in-reach team, may offer further avenues to consider should they find that communication is an area of particular difficulty within a home. The research has also highlighted to me more generally the need to ensure all interventions are robustly monitored with appropriate outcome measures, to ensure that the limited resources of NHS teams are wisely spent and that evidence of the efficacy of a team's work is readily available for reporting to commissioners. As such in any future roles I would be looking to review monitoring protocols with the team.

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Through the research the difference that psychology input can make on a systemic level in older adults services has become more apparent. If I were to undertake any future employment with older adults this is an area of work that I would be keen to develop, either through consultation with care home in-reach teams or through direct work with the homes. Further, during referral and assessment procedures I would be more likely to question whether or not one-to-one work was the most appropriate option, or whether work with the wider system could achieve better outcomes.

I believe that the techniques studied have relevance for not only staff but for family caregivers of those in the advanced stages of dementia. As such in any future work with family caregivers in which communication problems of this nature were presented I would certainly discuss the techniques as a possible means of continuing an emotional connection. More generally I would also be more aware of looking to enhance the residual capacity of a person with dementia.

An understanding of Kitwood's theories of personhood and malignant social psychology (1998) have been essential during the whole research process. I believe these theories are relevant to older adults services even outside of dementia care, with older adults often being positioned as less capable in some way and their age becoming the central factor rather than looking at the whole person. When formulating with an older client these are factors that, if relevant, I would be looking to consider.

Finally, spending months focused on the use of nonverbal communication has really made me consider the messages that my own nonverbal behaviour sends. In fact in recent clinical work it has resulted in my checking out with a client how a

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particular stance that I had assumed was being interpreted. This greater awareness of my body language is something I will look to maintain during clinical practice.

Future Directions

The entire purpose of this study was to assess the feasibility of undertaking a full-scale randomised control trial, as such this is the natural next step in the research. Firstly, this would entail a considerably larger-scale project and as such would require funding. I was able to secure a small grant for this study from the local mental health trust and as dementia research remains a priority for them I would be looking to liaise with them further regarding potential funding applications. Further initial steps would involve recruitment of homes and training a group of people to be able to deliver the intervention, possibly using a peer-training model. I would also look to include a qualitative element to the work in order to explore participants views of using the skills, in order to shed further light on why the improvements were not maintained at follow up.

Another important area for exploration would be the impact of teaching family caregivers to use the skills. The literature review for Section A indicated that family members also experience significant problems in communicating with relations with advanced dementia. This can be very difficult emotionally as they feel that their loved one is lost to them. This often leads to a decline in visits due to a sense of not knowing what to do. As such I would seek to answer the question: can training family caregivers in the use of Intensive Interaction improve communication with their relative with advanced dementia and improve quality of life for both individuals? As no research has been done in this area to date an initial small-scale exploratory study would be the first step, perhaps a series of single case studies. Many elements of the

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current research design could be re-employed including video analysis of the interactions and use of the QUALID to assess the quality of life of the person with dementia. However, another measure would be required to assess the quality of life of the caregiver, such as that which has recently been developed by the carers' trust (Elwick, Joseph, Becker, & Becker, 2010).

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Appendix A – Literature Search Strategy by Database

Medline Search A

General key word

Dementia

Auto-explode function used to include the sub-headings:

- aids dementia complex
- alzheimer disease
- aphasia, primary progressive
- cadasil
- creutzfeldt-jakob syndrome
- dementia
- dementia, multi-infarct
- dementia, vascular
- diffuse neurofibrillary tangles with calcification
- frontotemporal dementia
- frontotemporal lobar degeneration
- huntington disease
- kluber-bucy syndrome
- lewy body disease
- pick disease of the brain
- primary progressive nonfluent aphasia

AND

In abstract or title

Nonverbal communication

Auto explode function used to include the sub-headings:

- blushing
- crying
- facial expression
- gestures
- kinesics
- laughter
- manual communication
- nonverbal communication
- sign language
- smiling

OR Non?verbal behavior?r OR Non?verbal* interact* OR Mirroring OR Exp Imitative behavior/ OR imitat* OR Body language OR Exp Eye contact/ OR Pre?linguistic OR Pre?therapy OR Intensive interaction OR Adaptive Interaction OR Embod* OR Attun*

Both strings were limited to human populations.

Medline Search B

General key word

Advanced adj3 dementia OR severe adj3 dementia OR end?stage adj3 dementia

Appendix A – Literature Search Strategy by Database

AND

In abstract or title

Communicat* OR social interact*

PsychInfo Search A

General key word

Exp dementia/

Auto exploded to include:

- aids dementia complex
- dementia with lewy bodies
- presenile dementia
- semantic dementia
- frontotemporal dementia
- senile dementia
- vascular dementia

OR exp alzheimer's disease/ OR exp picks disease/ OR fronto?temporal lobar degeneration

AND

In abstract or title

Exp nonverbal communication/

Auto exploded to include:

- body language
- eye contact
- facial expressions
- gestures
- manual communication
- nonverbal communication

OR kinesics OR non?verbal behavior?r OR non?verbal interact* OR exp mirroring/ OR imitat* OR pre?linguistic OR pre?therapy OR intensive interaction OR embod* OR attun*

Both strings limited to peer reviewed journals and human studies

PsychInfo Search B

General key word

Advanced adj3 dementia OR severe adj3 dementia OR end?stage adj3 dementia

AND

In abstract or title

Communicat* OR social interact*

Both strings limited to peer reviewed journals and human studies

Appendix A – Literature Search Strategy by Database

Web of Science Search A

Searched core collections of:

- Science Citation Index Expanded (SCI-EXPANDED) --1970-present
- Social Sciences Citation Index (SSCI) --1970-present

TS = (*dementia* OR *alzheimer* OR lewy bod* OR pick? disease OR fronto?temporal lobar degeneration)

AND

TS = (non?verbal communication OR facial expression? OR eye contact OR gesture? OR kinesics OR manual communication OR non?verbal behavior?r OR non?verbal* interact* OR mirroring OR imitat* OR body language OR pre?linguistic OR pre?therapy OR intensive interaction OR adaptive interaction OR embod* OR attun*)

Limited to:

Articles or reviews

In research area: PSYCHOLOGY, PSYCHIATRY, GERIATRICS
GERONTOLOGY, BEHAVIORAL SCIENCES, REHABILITATION, NURSING,
AUDIOLOGY SPEECH LANGUAGE PATHOLOGY or SOCIAL SCIENCES
OTHER TOPICS

Web of Science Search B

TS = (Advanced dementia OR severe dementia OR end?stage dementia)

AND

TS = Communicat* OR social interact*

Limited to:

Articles or reviews

In research area: PSYCHOLOGY, PSYCHIATRY, GERIATRICS
GERONTOLOGY, BEHAVIORAL SCIENCES, REHABILITATION, NURSING,
AUDIOLOGY SPEECH LANGUAGE PATHOLOGY or SOCIAL SCIENCES
OTHER TOPICS

ASSIA Search A

General keyword

dementia OR *alzheimer* OR lewy bod* OR pick? Disease OR fronto?temporal lobar degeneration

AND

General keyword

non?verbal communication OR facial expression? OR eye contact OR gesture? OR kinesics OR manual communication OR non?verbal behavior?r OR non?verbal*

Appendix A – Literature Search Strategy by Database

interact* OR mirroring OR OR imitat* OR body language OR pre?linguistic OR pre?therapy OR intensive interaction OR embod* OR attun*

ASSIA Search B

In abstract

Advanced dementia OR severe dementia OR end?stage dementia

AND

In abstract

Communicat* OR social interact*

CINAHL Search A

Dementia (exp, major concept): multi infarct, alzheimers, lewy body, vascular dementia, picks disease

PLUS: frontotemporal lobar degeneration, frontotemporal dementia

AND

Nonverbal communication (exp, major concept): body language, facial expression.

PLUS: (non#verbal* interact* OR non#verbal behavior#r OR eye contact OR gestur* OR kinesics OR manual communication OR mirroring OR imitat* OR pre#linguistic OR pre#therapy OR intensive interaction OR adaptive interaction OR embod* OR attun*)

Limited to academic journals

CINAHL Search B

In abstract

Advanced dementia OR severe dementia OR end#stage dementia

AND

In abstract

Communicat* OR social interact*

Restricted to academic journals

Cochrane Library

The titles of all Cochrane reviews with dementia in either the Title, Abstract or as a Keyword were reviewed.

Appendix B – Summary of Pluralistic Quality Criteria (Barker & Pistrang, 2005)

This has been removed from the electronic copy

Appendix C: Summary of papers and comparison to quality criteria.

Reference	Aims and Method	Participants	Results	Comparison to Relevant Quality Criteria
De la Cuesta (2005)	<p>Aim: to identify strategies used by Colombian family caregivers to manage the demands of caring at home for relatives in the advanced stages of dementia.</p> <p>Method: open interview questions with resultant data analysed using grounded theory.</p>	<p>N = 18 family caregivers in Columbia</p> <p>Gender 5 female, 3 male</p> <p>Age range 10 = 51-75 yrs 5 = 25-50 yrs 3 = < 25 yrs</p> <p>Relationship to PWD 11 spouses 7 children, siblings or nieces</p> <p>Years spent caring 7 for 7 - 8 yrs 9 for 2 - 4 yrs 2 for < 1 yr</p> <p>Hrs a week spent caring 11 gave 60 + hrs 7 gave 20 - 60 hrs</p> <p>Diagnosis of PWD 9 had Alzheimer's disease 4 had vascular dementia 4 had mixed dementia 1 had not received a diagnosis</p> <p>Stage of dementia 16 were completely dependent on their caregivers as they were at a very advanced stage of dementia. No details were given for the remaining 2 participants.</p>	<p>Major theme: - The craft of care</p> <p>Sub-themes: - Ruses of care - A language to communicate - Creating spaces and building tools</p>	<p>RATING: 8/9</p> <p>CONTEXT & PURPOSE: Yes. Considered the importance of family caregivers and the difficulties they face, suggested the need to better understand the strategies used to resolve these issues.</p> <p>APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p> <p>TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures.</p> <p>ETHICAL: Yes. Details of ethics approval, data treated confidentially, participants anonymised, informed consent given, participants' were aware of right to withdraw. Only paper that considered how clinical issues arising during fieldwork would be addressed.</p> <p>IMPORTANCE: Yes. Considered how a better understanding of the work of family caregivers could lead to greater appreciation and support by health professionals, and that ideas could be shared between family caregivers.</p> <p>PERSPECTIVE: No. Only stated that the author is a nurse.</p> <p>GROUNDING: Yes. Direct quotes given throughout.</p> <p>FRAMEWORK: Yes. Organised into a descriptive overarching theme and helpful subthemes regarding specific strategies.</p> <p>CREDIBILITY: Yes. Used respondent validation and emergent themes discussed with three different groups of care providers.</p>

Appendix C: Summary of papers and comparison to quality criteria.

<p>Eggers, Ekman & Norberg (2013)</p>	<p>Aim: to describe clinically skilled nursing staff's ways of understanding the expressions of people with advanced Alzheimer's disease. Method: interviews taken initially and then 8 years later, then analysed using content analysis.</p>	<p><i>N</i> = 8 staff caregivers at a psychogeriatric clinic on a ward for PWD in Sweden. Gender 7 female, 1 male Age range 28 - 54 yrs at first interview Job role 5 enrolled mental health nurses 3 registered nurses Experience in dementia care Ranged from 7 - 24yrs at first interview. Eligibility criteria To have been selected by the head nurse as skilled at their job</p>	<p>Themes and sub-themes Being in communication: - opening up for communion by attuning to patients' feelings - interpreting the patients' will, needs, and intentions by seeing the patients' perspective and by relating to their own life experiences. Doing communication: - Interpreting the patients expressions, on the basis of the knowledge about the patients previous life by contacting their family for information - Offering opportunities to the patients to express themselves, by respecting their attempts to communicate, allowing them the time needed and avoiding interrupting them - Interpreting the patients' expressions by observing, listening, asking, reflecting, respecting their reactions, and being aware of their reactions in lucid moments.</p>	<p>RATING: 7.5/9 CONTEXT & PURPOSE: Yes. Considered difficulties with verbal communication and the need for nurses to adapt their communication styles appropriately. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures. ETHICAL: Yes Details of ethics approval, data treated confidentially, participants anonymised, informed consent given, participants' aware of right to withdraw. IMPORTANCE: Yes. Considered clinical implications for training care staff. PERSPECTIVE: No. Details of perspective were absent. GROUNDING: Yes. Direct quotes given throughout FRAMEWORK: Partial. Divided into themes and sub-themes but there appeared to be some overlap between categories and they were too complex for easy interpretation. CREDIBILITY: Yes. Used consensus between three researchers.</p>
<p>Haggstrom, Jansson &</p>	<p>Aim: to illuminate individual skilled professional carers'</p>	<p><i>N</i> = 5 staff caregivers from a dementia care home in Sweden</p>	<p>Themes: - affect attunement and</p>	<p>RATING: 4.5/9</p>

Appendix C: Summary of papers and comparison to quality criteria.

<p>Norberg (1998)</p>	<p>ways of achieving an understanding of people with moderate or severe Alzheimer's disease.</p> <p>Method: observations of interactions between staff and residents, alongside individual and group interviews with the staff. No specific analysis method provided.</p>	<p>known for its excellent reputation.</p> <p>Gender 5 female, 0 male</p> <p>Age range 29 - 55 yrs</p> <p>Job role 2 nursing aides 3 nurses</p> <p>Caring experience Ranged from 10 - 27 yrs.</p> <p>Staff selection Staff chosen due to being assessed as good at achieving understanding with the residents.</p>	<p>completing a puzzle through explanatory connections of observation, knowledge about the residents' life histories and behaviour at the group dwelling</p> <p>- affect attunement within the context of caring as an intrinsic end</p>	<p>CONTEXT & PURPOSE: Yes. Considered communication difficulties in dementia and suggested the need to understand how skilled carers overcome these problems.</p> <p>APPROPRIATE METHOD: Partial. Interviews and observations appeared appropriate but lack of detail of the analysis technique made the appropriateness of this unclear</p> <p>TRANSPARENCY: No. Insufficient details given to be able to replicate the study. For example no details of interview questions or the method of data analysis used.</p> <p>ETHICAL: Partial. Details of ethics approval, proxy informed consent and anonymity, given for residents but not for staff.</p> <p>IMPORTANCE: Yes. Highlighted the need for caregivers to be able to develop their own individualised methods of communication.</p> <p>PERSPECTIVE: No. Details of perspective were absent.</p> <p>GROUNDING: Yes. Direct quotes given throughout</p> <p>FRAMEWORK: Partial. Organised into themes but these appeared to overlap significantly and had limited use for aiding understanding of the data.</p> <p>CREDIBILITY: No. Details of credibility checks were absent.</p>
<p>Kontos & Naglie (2007; 2009)</p> <p>The papers report on the</p>	<p>Aim: to explore perceptions of the breadth and importance of nonverbal self-expression by persons with severe cognitive impairment and how the recognition and support of such</p>	<p>N = 43 paid caregivers of PWD, who provided direct care and practiced in accordance with a person-centred approach.</p> <p>Gender 43 female, 0 male</p>	<p>Themes:</p> <ul style="list-style-type: none"> - sympathetic connection - shared bodily experience - socially acquired habits of the body - time efficiency 	<p>RATING: 7.5/9</p> <p>CONTEXT: Yes. Considered the dehumanising effect of current policies in dementia care and advocated a new care ethic that underscored the importance of bodily communication.</p>

Appendix C: Summary of papers and comparison to quality criteria.

<p>same data.</p>	<p>self-expression could improve person-centred dementia care.</p> <p>Method: thematic analysis of focus group data. Participants were shown a dramatic production of five bodily expressions of selfhood as a springboard for discussion prior to the focus groups.</p>	<p>Job role 16 nurses 10 occupational therapists 8 physiotherapists 7 recreational therapists 2 health care aides</p> <p>Place of work 29 in long term care facilities 11 in behavioural management units 3 in geriatric rehabilitation units.</p>	<p>- non-pharmacologic behavioural management</p>	<p>APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures. ETHICAL: Partial. Details of ethics approval and informed consent provided but no information regarding confidentiality, anonymity or other ethical issues. IMPORTANCE: Yes. Suggested that giving theoretical support to the intuitive practices used by some caregivers was a step towards developing a systematic approach to care that recognized and supported bodily expressions of selfhood. PERSPECTIVE: Partial. Detailed the type of care that they advocate but no further information. GROUNDING: Yes. Direct quotes given throughout FRAMEWORK: Yes. Helpfully organised into themes relevant to care. CREDIBILITY: Partial. Used consensus between the two researchers, consensus with an additional researcher or additional credibility method would have been helpful.</p>
<p>Runqvist & Severinsson (1999)</p>	<p>Aim: to describe and analyse caregiver's relationships with patients suffering from dementia.</p> <p>Method: explorative and descriptive, used open-ended interviews followed by a</p>	<p><i>N</i> = 6 paid caregivers on a long term dementia care ward in a hospital in Sweden, that was selected for its stability of staff and reputation for being 'calm'.</p> <p>Gender: 6 female, 0 male</p> <p>Age range</p>	<p>Themes:</p> <ul style="list-style-type: none"> - touching - confirmation - the values in the caring culture 	<p>RATING: 7.5/9</p> <p>CONTEXT & PURPOSE: Yes. Considered the difficulties with nursing practices in dementia care and the lack of interventions to address these. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p>

Appendix C: Summary of papers and comparison to quality criteria.

	hermeneutic transformative process for analysis.	25 - 50 yrs Eligibility Criteria: - to have worked on the ward for at least 3 yrs		TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures ETHICAL: Partial. Stated that informed consent was given and ethical reasons for not choosing an alternative design explored; but no information regarding confidentiality, anonymity or ethics approval provided. IMPORTANCE: Yes. Detailed implications for how caregivers' communication could be improved and how this could be supported e.g. through supervision. PERSPECTIVE: Partial. Detailed the assumption that they make in seeing the patient from a holistic perspective but no further information provided. GROUNDING: Yes. Direct quotes given throughout FRAMEWORK: Yes. Helpfully organised into themes relevant to care. CREDIBILITY: Partial. Used consensus between the two researchers, consensus with an additional researcher or additional credibility method would have been helpful.
Quinn, Clare, Jelley, Bruce & Woods (2014)	Aim: to explore how family members and care staff understand awareness in people with severe dementia and what this awareness means to them Method: focus group data analysed using thematic analysis.	<i>N</i> = 21 care staff and family members of people with severe dementia living in care homes CARE STAFF <i>N</i> = 12 Gender 12 female, 0 male Age range 29 – 57 yrs	Themes: - sense of identity - in depends what is in the eyes - you have got to look at the environment - you learn to read them - sometimes you get a response	RATING: 8.5/9 CONTEXT & PURPOSE: Yes. Considered the evidence for maintained awareness in severe dementia but the lack of understanding of how this could be used by caregivers. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes.

Appendix C: Summary of papers and comparison to quality criteria.

		<p>Job role 1 manager 1 nurse 10 care assistants</p> <p>FAMILY N = 11 Gender 6 female, 5 male Age range 29 – 87 yrs Relationship 3 husbands 3 daughters 1 wife 1 sister 1 son-in-law 1 nephew 1 niece</p>		<p>Detailed account of both data collection and analysis procedures. ETHICAL: Yes. Details of ethics approval, data treated confidentially, participants anonymised, informed consent given. IMPORTANCE: Yes. Considered how a better understanding of awareness could improve engagement with both family and staff caregivers and in doing so improve quality of life for PWD. PERSPECTIVE: Partial. Recognised own assumptions as researchers in the dementia field that awareness is maintained but did not recognise any personal influences. GROUNDING: Yes. Direct quotes given throughout. FRAMEWORK: Yes. Organised into themes, which are then drawn into a model of the concept CREDIBILITY: Yes. Used consensus between the 5 researchers.</p>
Walmsey & McCormack (2014)	<p>Aim: to explore retained awareness in individuals living with limited or absent speech due to severe dementia</p> <p>Method: phenomenological exploration of video recordings of interactions between people with severe dementia and their family members.</p>	<p>N = 12, consisting of 4 family groups, inclusive of a family member living with dementia.</p> <p>PWD N = 4 Gender 3 female, 1 male Age range 66 – 96 yrs Dementia severity All assessed as being at a severe stage on the Clinical Dementia Rating Scale and had limited or absent speech.</p>	<p>Superordinate theme:</p> <ul style="list-style-type: none"> - the dance of communication <p>Subthemes:</p> <ul style="list-style-type: none"> - in step communication (harmony, spontaneity and reciprocity) - out of step communication (disharmony, syncopation, and vulnerability) 	<p>Rating: 8/9</p> <p>CONTEXT & PURPOSE: Yes. Considered the evidence for maintained awareness in severe dementia and the influence of psychosocial factors on levels of awareness. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures. ETHICAL: Partial. Details of ethics approval and proxy consent for participants with dementia provided but no information regarding</p>

Appendix C: Summary of papers and comparison to quality criteria.

		<p>FAMILY MEMBERS <i>N</i> = 8 Gender 6 female, 2 male 2 Relationship 1 wife 1 husband 1 son 1 daughter 1 daughter-in-law 2 great-grand-daughters.</p>		<p>confidentiality, anonymity or ethics procedures for participants with capacity to consent. IMPORTANCE: Yes. Suggested that the study demonstrated retained awareness and ability to participate in interactions that was previously unrecognised in people with severe dementia and that this should be used to inform care and develop communication interventions. PERSPECTIVE: Partial. Details given of personal influences for the first author but no consideration of professional perspectives. GROUNDING: Yes. Direct quotes given throughout. FRAMEWORK: Yes. Organised into helpful themes that illuminate elements that aid and hinder communication. CREDIBILITY: Yes. Used consensus between the 2 researchers and production of an audit trail.</p>
<p>Ito, Takahashi and Liehr (2007)</p>	<p>Aim: to address the questions: (a) what disagreement behaviour does a Japanese elder in day care convey prior to agitation/aggression?; and (b) what actions by the care staff promote agreement behaviour? Method: observations of interactions in a day care facility for the elderly with dementia in Japan, transcribed and then analysed using content analysis</p>	<p><i>N</i> = 9, including a day centre attendee with dementia and staff of the centre PWD <i>N</i> = 1 Gender: 1 male Age: 79yrs Diagnosis: vascular dementia; MMSE: 9 DSS: 2, indicating moderate dementia STAFF <i>N</i>= 8 No further details given.</p>	<p>Noted disagreement behaviour messages: - deference - apology - escape Noted staff actions promoting agreement behaviour: - shift of focus to the familiar - patiently waiting for the situation to change - assuming responsibility on the client's behalf</p>	<p>RATING: 7.5/9 CONTEXT & PURPOSE: Yes Considered theories of embodied language and care trends in Japan. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Partial. Details of data collection and analysis procedure given but insufficient details of staff participants to allow replication ETHICAL: Partial. Details of ethics approval, informed consent for staff and proxy consent for resident provided but no information regarding confidentiality, anonymity or other ethical issues. IMPORTANCE: Yes.</p>

Appendix C: Summary of papers and comparison to quality criteria.

				<p>Implications and recommendations for professional caregivers are explored.</p> <p>PERSPECTIVE: Partial.</p> <p>Details given of cultural backgrounds of the researchers but no further exploration of assumptions, although it is stated that the researchers were sensitive to their biases.</p> <p>GROUNDING: Yes.</p> <p>Direct quotes given throughout.</p> <p>FRAMEWORK: Yes.</p> <p>Organised into themes that can helpfully be applied to recommendations for caregivers</p> <p>CREDIBILITY: Yes.</p> <p>Consensus among three different researchers with varying degrees of involvement in the study. Followed clear guidelines for establishing trustworthiness, including an audit trail.</p>
Ruud (2012)	<p>Aim: (a) to arrive at a better understanding of the point of clowning in dementia care; (b) to understand what daring and skills a clown needs in order to get close to people with dementia? In particular focusing on the use of the body as an instrument of connection; (c) to understand what can be learned from the ‘unconventional’ means that the miMakker employs about the nature of the relationship the clown and a person with dementia may establish together?</p> <p>Method: Auto-ethnographic reflections of training as a</p>	<p>Specific details of participants not provided but include the author, the miMakker clowns that were followed during her training and residents in the homes in which they were working.</p>	<p>Concludes that: (a) miMakker’s bring pleasure and peace by making contact ‘from heart to heart’; (b) can expose patterns of stigmatisation and social exclusion; (c) make contact with PWD through using the body to become engaged in ‘sensory conversations’.</p>	<p>RATING: 5.5/9</p> <p>CONTEXT & PURPOSE: Yes.</p> <p>Explores the development of miMakkus clowning, theories of personhood and embodiment, and how these could be employed to improve dementia care.</p> <p>APPROPRIATE METHOD: Yes.</p> <p>Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p> <p>TRANSPARENCY: Partial.</p> <p>Some details given of procedures, such as use of field notes, but insufficient details of participants, the intervention or how data was selected or analysed.</p> <p>ETHICAL: No.</p> <p>No details of ethics procedures provided.</p> <p>IMPORTANCE: Yes.</p> <p>Explores, what a greater concentration on embodied communication could offer dementia care and how this could be encouraged through the use of miMakkers.</p> <p>PERSPECTIVE: Yes.</p>

Appendix C: Summary of papers and comparison to quality criteria.

	miMakkus clown			<p>Details of professional background and how interest in miMakker clowns developed.</p> <p>GROUNDING: Yes.</p> <p>Direct quotes given throughout.</p> <p>FRAMEWORK: No</p> <p>No framework for understanding provided.</p> <p>CREDIBILITY: No</p> <p>No details of credibility checks, although as an auto-ethnographic study the purpose is to provide an account of the authors experience and thus checks of trustworthiness are not appropriate.</p>
Astell & Ellis, 2006	<p>Aim: (a) to examine the spontaneous conversation behaviour and urge to communicate of a participant with advanced dementia; (b) to assess the importance of spontaneous and deliberate imitation during communication with a person with advanced dementia.</p> <p>Method: single case study. Micro-analytic coding of video recordings of interactions using both spontaneous and deliberate imitation and the still face paradigm.</p>	<p><i>N</i> = 2</p> <p>PWD</p> <p>Gender: Female</p> <p>Age: 79</p> <p>Diagnosis: severe dementia</p> <p>Time since diagnosis: 4 yrs</p> <p>RESEARCHER</p> <p>Gender: female</p> <p>Role: carried out the interactions with the residents</p> <p>No further details provided</p>	<p>Participant demonstrated a retained urge to communicate, showing signs of discomfort when the author was maintaining a still face. She also demonstrated a range of retained communication abilities, in particular using nonverbal skills. The use of imitation was found to maintained the conversation, further deliberate imitation was associated with an increase in positive emotional expression, eye contact and turn taking.</p>	<p>RATING: 4/9</p> <p>CONTEXT & PURPOSE: Yes.</p> <p>Explores the use of imitation in communication interventions with people with learning disabilities and their potential relevance to PWD.</p> <p>APPROPRIATE METHOD: Yes.</p> <p>Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p> <p>TRANSPARENCY: Partial.</p> <p>Details given of data collection procedures and analysis; but no participant details of the author who acted as the interaction partner in the study.</p> <p>ETHICAL: Partial.</p> <p>Details of consent procedures given but no information regarding confidentiality, anonymity or other ethical issues.</p> <p>IMPORTANCE: Partial.</p> <p>Discusses the importance of imitation as a social behaviour but does not go on to consider the clinical implications of this.</p> <p>MEASUREMENT RELIABILITY & VALIDITY: No.</p> <p>No information is given of any checks on the reliability or validity of the behaviour coding used.</p> <p>INTERNAL VALIDITY: No.</p> <p>It is not possible to infer causal relationships from the design.</p>

Appendix C: Summary of papers and comparison to quality criteria.

				<p>EXTERNAL VALIDITY: Partial. Took place within a nursing home environment but with a researcher as the interaction partner rather than a member of care staff.</p> <p>STATISTICAL CONCLUSION VALIDITY: No No statistical analysis reported.</p>
<p>Ellis & Astell, 2010</p>	<p>Aim: To investigate the usefulness of the Intensive Interaction approach to facilitating communication and consequently supporting personhood in people with advanced dementia.</p> <p>Method: A small n study, using micro-analytic coding of video recordings of communication behaviours during interaction as usual and interaction using Intensive Interaction techniques.</p>	<p><i>N</i> = 6</p> <p>PWD <i>N</i> = 5</p> <p>Age <i>M</i> = 82.6 yrs</p> <p>Diagnosis All had very advanced dementia and lived in a nursing home</p> <p>RESEARCHER Gender: female Role: carried out the interactions with the residents No further details provided</p>	<p>Reported that the use of Intensive Interaction revealed that each individual had a repertoire of nonverbal behaviours that could be used as the basis of communication and social interaction. These included sounds, movements, directed eye gaze and facial expressions. No statistical results were reported.</p>	<p>RATING: 4/9</p> <p>CONTEXT & PURPOSE: Yes. Explores the use of imitation in communication interventions with people with learning disabilities and their potential relevance to PWD.</p> <p>APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p> <p>TRANSPARENCY: Partial. Some details given of data collection procedures but not how the data was analysed and no participant details for the author who acted as the interaction partner in the study.</p> <p>ETHICAL: No. No details of ethics procedures provided.</p> <p>IMPORTANCE: Yes. Discusses the importance of imitation as a social behaviour, considers the clinical implications of this and the future direction of research.</p> <p>MEASUREMENT RELIABILITY & VALIDITY: No. No information is given of any checks on the reliability or validity of the data collected.</p> <p>INTERNAL VALIDITY: No. It is not possible to infer causal relationships from the design.</p> <p>EXTERNAL VALIDITY: Partial. Took place within a nursing home environment but with a researcher as the interaction partner rather than a member of care staff.</p>

Appendix C: Summary of papers and comparison to quality criteria.

				STATISTICAL CONCLUSION VALIDITY: No No statistical analysis reported.
Ellis & Astell, 2011	<p>Aim: To explore the challenges of introducing Intensive Interaction into dementia care settings.</p> <p>Method: Training in the use of Intensive Interaction techniques provided to 3 staff members with feedback gathered after the training.</p>	<p><i>N</i> = 6</p> <p>PWD <i>N</i> = 3 All with advanced dementia, although no details provided of how this was assessed. No further details provided.</p> <p>STAFF <i>N</i> = 3 Job Role 1 nurse 1 nursing assistant 1 activities co-ordinator No further details provided.</p>	<p>Feedback from staff:</p> <ul style="list-style-type: none"> - all reported enjoying the training - one reported that the training ‘actually meant something’ unlike others they had experienced. - They felt better equipped to identify communication behaviours in PWD and to respond appropriately 	<p>RATING: 4.5/9</p> <p>CONTEXT & PURPOSE: Yes. Explores the use of imitation in communication interventions with people with learning disabilities and the research with PWD to date.</p> <p>APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims.</p> <p>TRANSPARENCY: No. Few details given of data collection procedures or how feedback was collected or analysed and insufficient participant details for replication.</p> <p>ETHICAL: Partial. Details given of recruitment procedures but not regarding maintenance of anonymity or confidentiality.</p> <p>IMPORTANCE: Yes. Discusses the importance of imitation as a social behaviour, considers the clinical implications of this and the future direction of research.</p> <p>MEASUREMENT RELIABILITY & VALIDITY: No. No information is given of any checks on the reliability or validity of the data collected.</p> <p>INTERNAL VALIDITY: No. It is not possible to infer causal relationships from the design.</p> <p>EXTERNAL VALIDITY: Yes. Took place within a nursing home environment, using the staff and resident populations that the intervention is designed for.</p> <p>STATISTICAL CONCLUSION VALIDITY: No No statistical analysis reported.</p>
Rousseau and Métivier	<p>Aim: to establish the capacity of Alzheimer patients to imitate</p>	<p><i>N</i> = 3</p>	<p>Participant 1, <i>M</i> anxiety level score:</p>	<p>RATING: 5/9</p>

Appendix C: Summary of papers and comparison to quality criteria.

(2007)	<p>another person during relaxation sessions in order to combat anxiety.</p> <p>Method: two case studies, in which a researcher was trained to empathise through body language and then to aid relaxation through their communication style. A specially adapted measure of anxiety was taken before and after intervention.</p>	<p>PWD N = 2 Diagnosis Alzheimer = 2 Anxiety levels Reported as having near constant high anxiety levels but no measurement of this was provided.</p> <p>RESEARCHER N = 1 Led the relaxation sessions States that they were trained to use body language to communicate relaxation but no further information provided.</p>	<p>Before relaxation: 22.6/30 Immediately after: 1/30 15 mins after: 2/30 1 hr after = 6.5/30</p> <p>Participant 2, M anxiety level score: Before relaxation: 22.3/30 Immediately after: 7.3/30 15 mins after: 9.7/30 1 hr after = 14.2/30</p> <p>No statistical analysis provided</p>	<p>CONTEXT & PURPOSE: Yes. Explores the difficulties of anxiety in PWD, how relaxation can assist with this and the use of imitation in communicating with PWD. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Partial. Details provided of data collection and analysis but further participant details would be required to enable replication. ETHICAL: No. No details of ethics procedures provided. IMPORTANCE: Yes. Discusses the potential use of this relaxation technique in clinical settings. MEASUREMENT RELIABILITY & VALIDITY: Partial. Anxiety measure was created with reference to research in the area, and results from initial use of the tool were inter-rated by several researchers. However, the researchers were not blind to condition and details of inter-rater reliability are not provided. INTERNAL VALIDITY: No. It is not possible to infer causal relationships from the design. EXTERNAL VALIDITY: Yes. The intervention took place as and when instances of high anxiety occurred naturally for the two participants in the home. STATISTICAL CONCLUSION VALIDITY: No No statistical analysis reported.</p>
Cevasco (2010)	<p>Aim: to determine the effects of one music therapist's nonverbal behaviour, affect and proximity, on participation and affect of individuals with dementia during a music</p>	<p>N = 39</p> <p>PWD N = 38 Gender 30 female, 8 male</p>	<p>% of individuals showing positive affect during each condition: 62% during affect and proximity combined, 53% during affect only</p>	<p>RATING: 6.5/9</p> <p>CONTEXT & PURPOSE: Yes. Explores the amount of time spent not engaged in interactions or activities by PWD and how nonverbal communication can effect levels of participation and wellbeing.</p>

Appendix C: Summary of papers and comparison to quality criteria.

	<p>therapy session.</p> <p>Method: a within participants design, compared a music therapist's use of affect and proximity, affect only, proximity only and no affect or proximity on the positive affect exhibited and participation levels of PWD. Data was collected using two on-site researchers making direct observations and the use of video recordings.</p>	<p>Diagnosis Early to middle stages of Alzheimer's disease and other related dementia</p> <p>Recruited from 7 different music therapy groups from 5 different facilities, including day centres and 'retirement centres'.</p> <p>MUSIC THERAPIST No details provided.</p>	<p>30% during proximity only 28% during no affect or proximity A Friedman analysis indicated a significant difference in individuals' affect according to treatment conditions, $F(3, 4) = 34.05, p = .001$</p> <p>Levels of participation for each condition: 79% during both affect and proximity combined 75% during affect only 71% during no affect or proximity 70% for proximity only A significant difference occurred for participation by treatment conditions, $F(3, 111) = 4.05, p = .009$</p>	<p>APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Partial. Details given of data collection procedures and analysis strategy; however further participant details would have been beneficial including PWD's age and a measure of dementia severity, as well as information regarding the therapists qualifications and gender. ETHICAL: No. No details of ethics procedures provided. IMPORTANCE: Yes. Discusses the clinical implications for training music therapists. MEASUREMENT RELIABILITY & VALIDITY: Partial. Two students completed the live observations and an additional student also analysed the recordings in order to be able to check the reliability of the data; however now statistical assessment of this is provided. Further, the therapist's behaviour was not monitored to ensure adherence to protocol. INTERNAL VALIDITY: Partial. The data suggests a causal relationship between the therapist's nonverbal behaviour and displays of positive affect and participation of PWD. However, details of potential confounding variables are not discussed and the design was within participants rather than using random allocation. EXTERNAL VALIDITY: Yes. Data was collected during the music therapy groups as they are usually run. STATISTICAL CONCLUSION VALIDITY: Yes. Appropriate inferential statistics and post hoc analysis applied.</p>
<p>Kontos, Mitchell, Mistry and</p>	<p>Aim: to discuss the qualitative evaluation of the effectiveness of a drama-based educational</p>	<p>Non-random convenience sampling strategy.</p>	<p>Themes: Meaning beyond dementia. - This highlighted new</p>	<p>Rating: 8/9 CONTEXT & PURPOSE: Yes.</p>

Appendix C: Summary of papers and comparison to quality criteria.

Ballon (2010)	<p>intervention to introduce to dementia practitioners person-centred care that emphasizes the notion of embodied selfhood (defined as non-verbal self-expression).</p> <p>Method: following delivery of the intervention to staff in 2 nursing homes, focus groups and semi-structured interviews were completed and the data analysed using thematic analysis.</p>	<p><i>N</i> = 24 staff of two nursing homes in central Canada.</p> <p>Gender 22 female, 2 male</p> <p>Age (yrs) ≤ 39 = 4 40-49 = 9 ≥ 50 = 9 Unknown = 2</p> <p>Job role: Personal support worker = 16 Registered nurse = 2 Registered practical nurse = 2 Allied health practitioner = 4</p> <p>Duration of employment at the facility (yrs): ≤ 1 = 3 1.5-3 = 5 ≥ 4 = 16</p>	<p>awareness of how residents' actions could be meaningful self-expressions.</p> <p>The influence of the approach to care. - Highlighted recognition of how their own actions influenced the interactions that they had with residents.</p>	<p>Considered the need for person centred care and how this can be implemented in care homes, in particular focusing on the possible efficacy of using drama based interventions. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes. Detailed account of both data collection and analysis procedures. ETHICAL: Yes. Details of informed consent, and procedures for maintaining confidentiality and anonymity provided. IMPORTANCE: Yes. The clinical implications of improving person centred care in this manner were explored including possible reduction in drug prescription and decreased psychological distress for residents. PERSPECTIVE: No. There is no explicit discussion of the authors' assumptions. GROUNDING: Yes. Direct quotes given throughout. FRAMEWORK: Yes. Organised into helpful themes that illuminate elements of the impact of the training. CREDIBILITY: Yes. Used consensus between the primary researcher and two research assistants for 20% of the transcripts.</p>
Magai, Cohen and Gomberg (2002)	<p>Aim: to assess whether or not training caregivers in "nonverbal sensitivity" would improve quality of life for residents, effect residents' behavioural and affective patterns, and improve staff wellbeing.</p>	<p><i>N</i> = 119 staff and residents of three nursing homes.</p> <p>PWD</p> <p>Age (yrs) <i>M (SD)</i> = 85.9 (7.8)</p> <p>% Female 93.4</p>	<p>Facial Expressions of Positive Emotion (<i>M, SD</i>) <i>Baseline:</i> Intervention = 2.6 (3.7) Placebo = 1.4 (2) Control = 2.7 (3.2) <i>6 weeks post intervention:</i> Intervention = 3.6 (4.5)</p>	<p>RATING: 7/9</p> <p>CONTEXT & PURPOSE: Yes. Considers PWD's sensitivity to nonverbal cues and whether caregivers' expressions of negativity may have an effect on their wellbeing. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic</p>

Appendix C: Summary of papers and comparison to quality criteria.

	<p>Method: randomised control trial in which the staff and residents of participating homes were randomly assigned to receive either the nonverbal sensitivity training, a placebo training in the cognitive and behavioural aspects of dementia or waitlist control. Outcome measures included:</p> <ul style="list-style-type: none"> - Behavioural pathology in Alzheimer’s disease rating scale - Cohen-Mansfield Agitation Inventory - Cornell scale for depression in dementia - Facial expressions of emotion during a semi-structured interview - Brief symptom inventory 	<p>% White 87</p> <p>CAREGIVERS <i>N</i> = 20 Age (yrs) <i>M (SD)</i> = 41.6 (6.2) Gender 20 female, 0 male Ethnicity 18% white, 82% African American</p>	<p>Placebo = 1.1 (1.7) Control = 2.3 (3.0)</p> <p>Significant difference found across treatment conditions ($F=(2,88) 2.3, p<.05, d=0.7$).</p> <p>No other significant differences found.</p>	<p>procedure were consistent with aims. TRANSPARENCY: Yes Detailed account of both data collection and analysis procedures. ETHICAL: No. States that informed consent was sought from both the resident and the guardian; however if a guardian is required this is suggestive that the resident is not able to give informed consent or alternatively if they do have capacity that a guardian should not be required. Further no details of staff consent or anonymity or confidentiality procedures provided. IMPORTANCE: Yes. Considers how the training could impact on care and how the training may need to be adjusted in light of the study. Also refers to future research directions. MEASUREMENT RELIABILITY & VALIDITY: Yes. Used a range of standardised measures that have demonstrated good reliability and validity. Where coding of facial expressions was used, this followed a standardised protocol with inter-rater reliability measured between 3 coders. INTERNAL VALIDITY: Partial. The data suggests a causal relationship between training caregivers in sensitivity to nonverbal cues and increased positive emotional expression. However, the design could be improved by increasing participant numbers so that there are more than one home in each condition. EXTERNAL VALIDITY: Partial. Data was collected in nursing homes where the training would be targeted; however the positive emotion data was collected via a semi-structured interview rather than through naturally occurring emotions expressed on the ward. STATISTICAL CONCLUSION VALIDITY: Yes. Appropriate inferential statistics and post hoc analysis applied.</p>
<p>Clare et al. (2013)</p>	<p>Aim: to establish whether training care staff to observe</p>	<p><i>N</i> = 110</p>	<p>QUALID family rated (<i>M, SD</i>):</p>	<p>RATING: 8/9</p>

Appendix C: Summary of papers and comparison to quality criteria.

	<p>and identify signs of awareness in residents with severe dementia resulted in improved quality of life for residents.</p> <p>Method: Pilot cluster randomised trial. Staff in 4 care homes received training and supervision in the use of AwareCare, while staff in four control homes continued with work as usual. Outcome measures of resident quality of life, wellbeing, behaviour and cognition, as well as staff attitudes and wellbeing and care practices in the home were compared.</p>	<p>PWD <i>N</i> = 65 Gender 51 female, 14 male Age (yrs) <i>M (SD)</i> = 83.5 Diagnosis 22 = dementia in notes 9 = dementia reported by manager 18 = Alzheimer 9 = Vascular 5 = Mixed Alzheimer and vascular 2 = Pick's disease FAST stage 6a = 2 6b = 2 6c = 4 6d = 2 6e = 11 7a = 16 7b = 18 7c = 5 7d = 4 7e = 1</p> <p>STAFF <i>N</i> = 57 Gender 45 female, 12 male Age (yrs) <i>M (SD)</i> = 38.9 Qualifications None = 11 NVQ Level 1 = 2</p>	<p><i>Baseline:</i> Intervention = 21.94 (7.14) Control = 21.80 (8.29) <i>Post Intervention:</i> Intervention = 19.00 (4.59) Control = 22.11 (7.84)</p> <p>Significant difference found between treatment conditions with a medium effect size ($F(1,29)=5.88, p=0.02, d=0.72$).</p> <p>No other significant differences found.</p>	<p>CONTEXT & PURPOSE: Yes. Considers the environmental influences on levels of awareness that are expressed by PWD and how training care staff to be responsive to signs of awareness could improve wellbeing for residents. APPROPRIATE METHOD: Yes. Choice of participants, data collection strategy and analytic procedure were consistent with aims. TRANSPARENCY: Yes Detailed account of both data collection and analysis procedures. ETHICAL: Partial. Details provided regarding PWD consent procedures in accordance with Mental Capacity Act guidelines. However, no details of staff consent, or anonymity or confidentiality procedures. IMPORTANCE: Yes. Considers the implications for the use of the AwareCare system and how this could influence care practices, as well as indicating directions for future research. MEASUREMENT RELIABILITY & VALIDITY: Yes. Used a range of standardised measures that have demonstrated good reliability and validity. Those collecting post-intervention measures were blind to condition. INTERNAL VALIDITY: Partial. The data suggests a causal relationship between training and supervision in the use of AwareCare and improvements on family rated QUALID scores. However, the use of 'work as usual' in the control home does not control sufficiently for the confounding variable of staff simply having benefitted from greater input, with this having a subsequent effect on residents. EXTERNAL VALIDITY: Yes. Data was collected in nursing homes where the training would be targeted. STATISTICAL CONCLUSION VALIDITY: Yes.</p>
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Appendix C: Summary of papers and comparison to quality criteria.

		NVQ Level 2 = 18 NVQ Level 3 = 20 Nursing qualification = 6		Appropriate inferential statistics and post hoc analysis applied.
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PWD = People/person with dementia, Yrs = years, Hrs = Hours, Mins = minutes

Appendix D – Ethics Approval

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**Developing the use of Adaptive Interaction (AI) as a means of
communicating with people with advanced dementia.
Information for Consultee**

Introduction

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility.

The information on the following pages is the same as would have been provided to your relative/friend.

Information about the research

Developing the use of Adaptive Interaction (AI) as a means of communicating with people with advanced dementia.

Hello. My name is Gail Dampney-Jay and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite [name of resident] to take part in a research study. (*name of resident*) has been assessed as being unable to give informed consent for his/her participation and therefore you have been identified, by Partridge House, as a person who is able to be consulted on his/her presumed wishes and feelings regarding their possible participation. Before acting as a consultee it is important that you understand why the research is being done and what it would involve for [name of the resident]. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

PART 1

What is the purpose of the study?

The study aims to teach care staff at a nursing home to use a communication technique known as Adaptive Interaction, in order to aid their communication with residents at an advanced stage of dementia. Communicating using speech can become almost impossible at this stage of the illness and as such it is important that a non-verbal method of communicating is developed for these individuals and their caregivers. Intensive Interaction is a technique that was originally developed to aid communication with people with learning disabilities and extreme communication problems. The technique involves attending to the sounds and movements made by the person with learning disabilities, and then mirroring and developing on these as a response. Adaptive Interaction was developed from this technique due to its potential to benefit people with advanced dementia and improve their quality of life by providing them with a method of communication that does not rely on speech.

Initial case studies with individuals have suggested that Adaptive Interaction is effective in increasing communication behaviours in people with advanced dementia. This study aims to expand the existing research by analysing the effect on residents' quality of life and on their communication behaviours of training care staff to use the technique. This is a feasibility study, looking at issues with the design of the research, and is a pre-cursor to a possible larger multi-site trial.

Why have they been invited?

[name of resident] has been chosen as a possible participant in this research as he/she has been identified as being at an advanced stage of dementia and as such could benefit from the communication techniques that will be used in this research. Approximately five residents of the care home will be participating in the training; each resident will be paired with one of five participating staff members from the home.

Do they have to take part?

[name of resident] does not have to participate in the study. If it is decided that they will not do so this will have no bearing on their future care in the home. They can also be withdrawn at any time during the study should concerns be raised.

Appendix E – Consultee Information Sheet and Declaration Form

What will they have to do?

In order to participate in this study the person you represent will be assigned a member of staff to act as their communication partner throughout the study. Prior to training starting, staff of the nursing home will be asked to observe the behavior of (*name of resident*) in order to complete an assessment of their quality of life (an example assessment form is enclosed). At this stage we would also take a five-minute video recording of the communication partner interacting as they would normally with (*name of resident*), this will allow a detailed analysis of each persons behavior during the interaction to be undertaken.

Participating staff at the nursing home will then attend training in the use of Adaptive Interaction techniques, which will involve one hour per week over a six-week period. During this period (*name of resident*)'s communication partner will be asked to use the techniques during their daily caring duties and will also be asked to dedicate a minimum of 50 minutes each week (approximately 10 minutes per shift) purely to using the technique to communicate with (*name of resident*). It will be made clear to all staff that they are only to attempt to engage with the individual if they appear willing to do so and to cease attempts if any signs of distress are shown.

The quality of life measures and five-minute video recordings for analysis of communication behaviour will then be repeated both immediately after training and at a three month follow up, to ascertain if there have been any changes.

Overall the study will take 6 months to complete.

What are the possible disadvantages and risks of taking part

Any instance of discomfort, risks or side-effects will be extremely unlikely in this study as the main aim is to help the participants to communicate. However, we would like to speak to you prior to the start of this research in order to ascertain if there are any particular signs that the person you represent displays when distressed so that we can be sure that all participating staff are made aware of these.

What are the possible benefits of taking part?

We cannot promise the study will specifically help [name of resident] but the information we get from this study will help improve the treatment of people with advanced dementia. Furthermore, involvement may improve quality of life for [name of resident] by enhancing staff ability to communicate with them.

What if there is a problem?

Any complaint about the way [name of resident] have been dealt with during the study or any possible harm they might suffer will be addressed. The detailed information on this is given in Part 2.

Will their taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about [name of resident] will be handled in confidence. The details are included in Part 2.

This completes part 1. Please read the additional information in Part 2 before completing the attached consultee declaration form.

PART 2

What will happen if I don't want them to carry on with the study?

You can request that [name of resident] is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected. However, if you do decide that they should be withdrawn from the study, we would like to use the data collected up to their withdrawal.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions [contact number]. If you remain unhappy and wish to complain formally, you can do this either through the Canterbury Christ Church University Complaints Procedure or through the management of (care home details). Details can be obtained from [insert details]

Will my taking part in this study be kept confidential?

All information which is collected about [name of resident] during the course of the research will be kept strictly confidential, and any information about them that leaves the care home will have their name and address removed so that you cannot be recognised.

All data collected during this study will be coded (anonymised) and kept on a password protected CD in a locked cabinet at the Canterbury Christ Church University Campus. Video-tapes will also be stored on a password protected CD and will have no information that links the tape to their personal information. The anonymised outcome data will be kept for 10 years after the study is completed but the videotape material will be destroyed immediately after study completion.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study and will be available to answer any questions you have about the research before, during and after it has been completed. I will write about the study for my Clinical Psychology Doctorate Major Research Project and will submit a report of the findings to a psychology journal. Both of these publications will be available for you and others to read. Please be assured that [name of resident] would not be named in any write-up.

Who is organising and funding the research?

This research is being funded jointly by Canterbury Christ Church University and Sussex Partnership NHS Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camberwell St Giles Research Ethics Committee.

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at (tel no). Please say that the message is for me, Gail Dampney-Jay, and leave a contact number so that I can get back to you.

Appendix E – Consultee Information Sheet and Declaration Form

Centre Number: PH
Study Number: 1
Participant Identification Number for this study:

CONSULTEE DECLARATION FORM

Title of Project: Developing the use of Adaptive Interaction (AI) as a means of communicating with people with advanced dementia.

Name of Researcher: Gail Dampney-Jay

Please initial box

I _____ have been consulted about _____ participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

In my opinion he/she would have no objection to taking part in the above study.

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from Canterbury Christ Church University, University of St Andrews, Sussex Partnership Trust or from regulatory authorities, where it is relevant to their taking part in this research. I agree to their GP or other care professional being informed of their participation in the study.

Name of Consultee

Date

Signature

Relationship to participant:

Researcher

Date

Signature

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file

Information about the research

Developing the use of Adaptive Interaction (AI) as a means of communicating with people with advanced dementia.

Hello. My name is Gail Dampney-Jay and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

PART 1

What is the purpose of the study?

The study aims to teach care staff at a nursing home to use a communication technique known as Adaptive Interaction, in order to aid their communication with residents at an advanced stage of dementia. Communicating using speech can become almost impossible at this stage of the illness and as such it is important that a non-verbal method of communicating is developed for these individuals and their caregivers. Intensive Interaction is a technique that was originally developed to aid communication with people with learning disabilities and extreme communication problems. The technique involves attending to the sounds and movements made by the person with learning disabilities, and then mirroring and developing on these as a response. Adaptive Interaction was developed from this technique due to its potential to benefit people with advanced dementia and improve their quality of life by providing them with a method of communication that does not rely on speech.

Initial case studies with individuals have suggested that Adaptive Interaction is effective in increasing communication behaviours in people with advanced dementia. This study aims to expand the existing research by analysing the effect on residents' quality of life and on their communication behaviours of training care staff to use the technique. This is a feasibility study, looking at issues with the design of the research, and is a pre-cursor to a possible larger multi-site trial.

Why have I been invited?

You have been chosen as a possible participant in this research as the nursing home in which you are employed has expressed an interest in their staff participating. Approximately five staff members will be participating in the training, each staff member will be paired with one of five residents from the home.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would have no bearing on your future employment in the company.

Appendix F: Staff information sheet and consent form

What will I have to do?

In order to participate in this study you will be matched with a resident who will be your communication partner for the duration of the study. Another participating member of staff will be asked to observe the behaviour of your communication partner in order to complete an assessment of their quality of life and reciprocally you will be asked to complete this measure for a resident from another communication partnership. This measure should take no more than five minutes to complete and an example form is enclosed. At this stage a five-minute video recording will be taken of you interacting as you would normally with your communication partner, this will allow the researchers to complete a detailed analysis of each persons behaviour during the interaction.

You will then be asked to attend training in the use of Adaptive Interaction techniques, which will involve one hour per week over a six-week period. During this period you will be asked to use the techniques during your daily caring duties with your communication partner. You will also be asked to dedicate a minimum of 50 minutes each week (approximately 10 minutes per shift) purely to using the technique to communicate with your partner.

Staff will then be asked to re-assess each participating residents quality of life using the same scale as before, both immediately after training and at a three month follow up. You will then be asked to participate again in video recordings of five-minute communication sessions both immediately post-training and at three month follow up, in order to allow analysis of behaviour and to ascertain if there have been any changes. You will also be asked to complete a post-training feedback questionnaire that will take no more than ten-minutes to complete.

Overall the study will take 6 months to complete. Time for your participation in this study has been arranged with the home and will be completed within work hours.

What are the possible disadvantages and risks of taking part

Any instance of discomfort, risks or side-effects will be extremely unlikely in this study as the main aim is to aid communication between staff and residents. Except in the unlikely case of any risk issues being identified, all staff members' details will be kept anonymous and quality of life measures and video recordings will not be used as judgments of the care offered by the home or by individual staff members.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with advanced dementia and may have a positive effect on your levels of job satisfaction.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Appendix F: Staff information sheet and consent form

PART 2

What will happen if I don't want to carry on with the study?

You are free to leave this study at any time without any bearing on your future employment in the company. However, if you withdraw from the study, we would like to use the data collected up to your withdrawal.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions [contact number]. If you remain unhappy and wish to complain formally, you can do this either through the Canterbury Christ Church University Complaints Procedure or through the management of (care home details). Details can be obtained from [insert details]

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the care home will have your name and address removed so that you cannot be recognised.

All data collected during this study will be coded (anonymised) and kept on a password protected CD in a locked cabinet at the Canterbury Christ Church University Campus. Video-tapes will also be stored on a password protected CD and will have no information that links the tape to your personal information. The anonymised outcome data will be kept for 10 years after the study is completed but the videotape material will be destroyed immediately after study completion.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study and will be available to answer any questions you have about the research before, during and after it has been completed. I will write about the study for my Clinical Psychology Doctorate Major Research Project and will submit a report of the findings to a psychology journal. Both of these publications will be available for you and others to read. Please be assured that you would not be named in any write-up. Anonymised quotes from open-ended questions on the training feedback questionnaire may be used in published reports.

Who is organising and funding the research?

This research is being funded jointly by Canterbury Christ Church University and Sussex Partnership NHS Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camberwell St Giles Research Ethics Committee.

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at (tel no). Please say that the message is for me, Gail Dampney-Jay, and leave a contact number so that I can get back to you. If you choose to participate you will be given a copy of this information sheet and a copy of your signed consent form to keep.

Appendix F: Staff information sheet and consent form

Centre Number: PH

Study Number: 1

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Developing the use of Adaptive Interaction (AI) as a means of communicating with people with advanced dementia.

Name of Researcher: Gail Dampney-Jay

Please initial box

1. I confirm that I have read and understand the information sheet dated 18/05/12 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my job role or legal rights being affected.

3. I understand that the data collected during the study may be looked at by the lead supervisors: Fergal Jones, Naji Tabet, Arlene Astell and Maggie Ellis. I give permission for these individuals to have access to my data.

4. I agree to for video-tapes to be recorded of me interacting with a resident from the home as detailed in the information sheet.

5. I agree that anonymous quotes from my interview may be used in published reports of the study findings

6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file.

Appendix G – Dementia Severity Rating Scale

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Appendix H: Copy of the QUALID outcome measure (Weiner et al., 2000)

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Appendix I: Copy of training feedback questionnaire

Adaptive Interaction Training Evaluation Form

To help us improve the quality of our training, we would appreciate your feedback!

Please circle the response option that best reflects your evaluation of the training provided:

- | | | | |
|-------------------------------------------------------------------------------------------------------------------|-------------------|-----------------|-------------------|
| 1. The trainer's knowledge of Adaptive Interaction was: | <i>Excellent</i> | <i>Ok</i> | <i>Poor</i> |
| 2. The exercises to practice using Adaptive Interaction were: | <i>Excellent</i> | <i>Ok</i> | <i>Poor</i> |
| 3. The pacing of the trainer's delivery was: | <i>Excellent</i> | <i>Ok</i> | <i>Poor</i> |
| 4. Was your interest held? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 5. Was your time well spent in this training? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 6. Would you recommend this training to others? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 7. Do you feel more confident in working with residents who do not communicate verbally? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 8. Do you think using Adaptive Interaction could help improve the quality of life of the residents you work with? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 9. Has your knowledge about communicating with people with dementia improved? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 10. Was the training applicable to your day-to-day work? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 11. Do you feel confident that you will use the techniques in your day-to-day work? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 12. Do you think that using the techniques could improve your work satisfaction? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 13. Do you think that you would be able to pass on what you have learnt to other staff members on the team? | <i>Definitely</i> | <i>Probably</i> | <i>Not Really</i> |
| 14. What are the key points you have learnt from the training? | | | |
| 15. What was particularly helpful about the training? | | | |
| 16. What would you recommend changing about the training? | | | |
| 17. Other comments or feedback: | | | |

- | | | | | | | | | | | | |
|---------------------------------------|------|---|---|---|---|---|---|---|---|----|-----------|
| 18. Overall please rate the training: | Poor | | | | | | | | | | Excellent |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 1

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	4	147	n/a
	Negative	277	210	n/a
Eye Gaze	Eyes Closed	270	210	n/a
	Elsewhere	13	25	n/a
	Carer's body	0	14	n/a
	Carer's face or eyes	4	38	n/a
Facial Expression	Neutral	280	287	n/a
	Smiling	0	0	n/a
	Frowning	7	0	n/a
	Other expression	0	0	n/a
Vocalisation	Uses word	0	0	n/a
	Shout/Scream	0	0	n/a
	Laugh	0	0	n/a
	Other noise	0	0	n/a
	Silent	287	287	n/a
Physical Contact		0	109	n/a
Mirroring	Caregiver mirrors resident	0	150	n/a
	Resident mirrors caregiver	0	156	n/a
QUALID		24	13	n/a

The interaction at Time 1 took place in a quiet corner of the resident's lounge, with the participant seated in an armchair and the caregiver sat next to her. The interaction at Time 2 was recorded in the participants room, with an identical set up regarding seating.

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 2

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	266	572	n/a
	Negative	5	18	n/a
Eye Gaze	Eyes Closed	5	18	n/a
	Elsewhere	116	172	n/a
	Carer's body	0	0	n/a
	Carer's face or eyes	179	110	n/a
Facial Expression	Neutral	296	294	n/a
	Smiling	4	6	n/a
	Frowning	0	0	n/a
	Other expression	0	0	n/a
Vocalisation	Uses word	0	0	n/a
	Shout/Scream	0	0	n/a
	Laugh	4	6	n/a
	Other noise	79	150	n/a
	Silent	217	144	n/a
Physical Contact		0	300	n/a
Mirroring	Caregiver mirrors resident	0	76	n/a
	Resident mirrors caregiver	0	141	n/a
QUALID		31	11	n/a

The interaction at Time 1 took place in the residents' lounge with the participant seated in an armchair and the caregiver seated in front of them. The interaction at Time 2 was recorded in a seating area in a hallway of the home with the resident in a wheelchair looking out of a window at the garden and the caregiver seated next to them.

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 3

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	97	496	182
	Negative	79	0	32
Eye Gaze	Eyes Closed	0	0	0
	Elsewhere	131	139	n/a
	Carer's body	55	0	n/a
	Carer's face or eyes	96	161	182
Facial Expression	Neutral	282	265	n/a
	Smiling	0	35	0
	Frowning	0	0	0
	Other expression	0	0	n/a
Vocalisation	Uses word	6	1	n/a
	Shout/Scream	79	0	32
	Laugh	0	0	0
	Other noise	0	0	0
	Silent	215	299	n/a
Physical Contact		1	300	0
Mirroring	Caregiver mirrors resident	2	24	n/a
	Resident mirrors caregiver	3	53	n/a
QUALID		31	20	23

The interactions at Time 1 and Time 3 were recorded in the participant's room, with the participant seated in an armchair and the caregiver sat next to them. The interaction at Time 2 was recorded in a hallway in front of a fish tank, with the participant in a wheelchair and the caregiver kneeling next to them.

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 4

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	4	108	0
	Negative	60	30	275
Eye Gaze	Eyes Closed	60	22	267
	Elsewhere	236	170	n/a
	Carer's body	0	0	n/a
	Carer's face or eyes	4	108	0
Facial Expression	Neutral	300	292	n/a
	Smiling	0	0	0
	Frowning	0	8	8
	Other expression	0	0	n/a
Vocalisation	Uses word	0	0	n/a
	Shout/Scream	0	0	0
	Laugh	0	0	0
	Other noise	0	0	0
	Silent	300	300	n/a
Physical Contact		0	0	0
Mirroring	Caregiver mirrors resident	0	7	n/a
	Resident mirrors caregiver	0	90	n/a
QUALID		26	21	22

The interactions at Time 1 and Time 2 were recorded in the resident's lounge with the participant seated in an armchair and the caregiver crouched next to the chair. The interaction at Time 2 took place in the resident's room with a similar seating arrangement.

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 5

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	142	261	181
	Negative	48	0	0
Eye Gaze	Eyes Closed	0	0	0
	Elsewhere	108	0	n/a
	Carer's body	0	0	n/a
	Carer's face or eyes	117	225	91
Facial Expression	Neutral	152	189	n/a
	Smiling	25	36	87
	Frowning	48	0	0
	Other expression	0	0	n/a
Vocalisation	Uses word	22	3	n/a
	Shout/Scream	0	0	0
	Laugh	0	0	0
	Other noise	0	0	3
	Silent	203	222	n/a
Physical Contact		0	0	0
Mirroring	Caregiver mirrors resident	7	2	n/a
	Resident mirrors caregiver	7	3	n/a
QUALID		15	18	15

The interaction at Time 1 was recorded in the resident's lounge, with the resident in a wheelchair and the caregiver in front of her assisting her to drink a cup of tea. The interaction at Time 2 was recorded in a seating area in a hallway of the home, with a similar seating arrangement. The interaction at Time 3 was recorded in the resident's room, with a similar seating arrangement but the caregiver providing the resident with a hand massage.

Appendix J: Results for Individual Participants and Context of Interactions

Intervention: Participant 6

		Duration of Behaviour (seconds)		
		Time 1	Time 2	Time 3
Composites	Positive	24	33	n/a
	Negative	89	72	n/a
Eye Gaze	Eyes Closed	0	58	n/a
	Elsewhere	275	206	n/a
	Carer's body	15	24	n/a
	Carer's face or eyes	10	12	n/a
Facial Expression	Neutral	300	300	n/a
	Smiling	0	0	n/a
	Frowning	0	0	n/a
	Other expression	0	0	n/a
Vocalisation	Uses word	4	5	n/a
	Shout/Scream	89	14	n/a
	Laugh	0	0	n/a
	Other noise	14	21	n/a
	Silent	193	260	n/a
Physical Contact		0	0	n/a
Mirroring	Caregiver mirrors resident	3	0	n/a
	Resident mirrors caregiver	5	128	n/a
QUALID		33	14	22

The interactions at Time 1 and Time 2 both took place in a seating area in the hallway, in which the resident spent the majority of their time. The caregiver and the resident moved between seated and standing positions in both. During part of the Time 1 interaction the caregiver used a balloon to try to initiate a throwing and catching game with the resident, which they usually enjoyed. No props were used during the Time 2 interaction. The interaction at Time 3 was recorded in the resident's lounge with the caregiver and the resident sitting on sofas at right angles to one another.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 1

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	133	93
	Negative	0	0
Eye Gaze	Eyes Closed	0	0
	Elsewhere	55	132
	Carer's body	34	0
	Carer's face or eyes	131	88
Facial Expression	Neutral	218	211
	Smiling	2	4
	Frowning	0	0
	Other expression	0	5
Vocalisation	Uses word	99	100
	Shout/Scream	0	0
	Laugh	0	1
	Other noise	0	0
	Silent	121	119
Physical Contact		0	0
Mirroring	Caregiver mirrors resident	2	0
	Resident mirrors caregiver	0	6
QUALID		15	17

The interaction at Time 1 was recorded in the resident's bedroom with the resident in an armchair and the caregiver in a chair next to them. They discussed the lunch menu and a broken call bell. The interaction at Time 2 was recorded in the dining room at breakfast time, with both the caregiver and resident seated at a table and discussing the breakfast options.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 2

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	10	57
	Negative	271	0
Eye Gaze	Eyes Closed	270	0
	Elsewhere	0	205
	Carer's body	0	18
	Carer's face or eyes	0	53
Facial Expression	Neutral	269	276
	Smiling	0	0
	Frowning	1	0
	Other expression	0	0
Vocalisation	Uses word	0	9
	Shout/Scream	0	0
	Laugh	0	0
	Other noise	10	0
	Silent	266	267
Physical Contact		0	4
Mirroring	Caregiver mirrors resident	0	0
	Resident mirrors caregiver	0	1
QUALID		29	26

The interaction at Time 1 was recorded in the resident's lounge. The resident was sitting in an armchair with the caregiver seated next to them. The resident fell asleep almost immediately as the recording began and remained this way until the end. At Time 2 the resident was in the dining room seated at a table with the caregiver, they were awake throughout this interaction.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 3

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	151	290
	Negative	0	0
Eye Gaze	Eyes Closed	0	0
	Elsewhere	257	193
	Carer's body	0	0
	Carer's face or eyes	43	107
Facial Expression	Neutral	204	208
	Smiling	34	39
	Frowning	0	0
	Other expression	0	0
Vocalisation	Uses word	9	20
	Shout/Scream	0	0
	Laugh	16	12
	Other noise	58	105
	Silent	265	163
Physical Contact		0	27
Mirroring	Caregiver mirrors resident	0	90
	Resident mirrors caregiver	14	91
QUALID		12	12

The interaction at Time 1 was filmed while the resident was watching a musical on the television and was singing and dancing along to this. The caregiver was talking to him as he did so but was not joining in with the dance. During the interaction at Time 2 the caregiver and the resident were listening to music and dancing together to the songs, when this had finished they walked across the room to make a cup of coffee together.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 4

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	126	153
	Negative	3	7
Eye Gaze	Eyes Closed	0	0
	Elsewhere	213	148
	Carer's body	8	24
	Carer's face or eyes	79	117
Facial Expression	Neutral	266	247
	Smiling	30	35
	Frowning	3	7
	Other expression	1	0
Vocalisation	Uses word	49	10
	Shout/Scream	0	0
	Laugh	0	0
	Other noise	17	1
	Silent	234	289
Physical Contact		0	0
Mirroring	Caregiver mirrors resident	9	3
	Resident mirrors caregiver	4	12
QUALID		20	30

The interaction at Time 1 was filmed in the conservatory at a table while the caregiver was assisting the resident to eat breakfast. the interaction at time 2 was also filmed while the caregiver was assisting the resident with breakfast but this time it was recorded in the main dining room. In both the caregiver and the resident were seated at a table together.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 5

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	230	28
	Negative	0	0
Eye Gaze	Eyes Closed	0	0
	Elsewhere	63	265
	Carer's body	1	3
	Carer's face or eyes	229	28
Facial Expression	Neutral	293	296
	Smiling	0	0
	Frowning	0	0
	Other expression	0	0
Vocalisation	Uses word	181	83
	Shout/Scream	0	0
	Laugh	0	0
	Other noise	1	0
	Silent	118	217
Physical Contact		0	0
Mirroring	Caregiver mirrors resident	2	0
	Resident mirrors caregiver	6	6
QUALID		11	30

The interaction at Time 1 was recorded in the residents room with the resident and the caregiver seated in armchairs next to each other. They discussed the resident's family and the music that they enjoyed. The interaction at Time 2 was recorded in dining room with the caregiver and the resident seated at a table next to each other, they were looking through old pictures and discussing them.

Appendix J: Results for Individual Participants and Context of Interactions

Control: Participant 6

		Duration of Behaviour (seconds)	
		Time 1	Time 2
Composites	Positive	5	80
	Negative	0	0
Eye Gaze	Eyes Closed	0	0
	Elsewhere	197	206
	Carer's body	52	0
	Carer's face or eyes	4	76
Facial Expression	Neutral	253	282
	Smiling	0	0
	Frowning	0	0
	Other expression	0	0
Vocalisation	Uses word	26	97
	Shout/Scream	0	0
	Laugh	0	0
	Other noise	1	0
	Silent	273	203
Physical Contact		0	4
Mirroring	Caregiver mirrors resident	0	0
	Resident mirrors caregiver	1	7
QUALID		29	26

The interaction at Time 1 was recorded whilst the resident and the caregiver were walking through the hallways of the home, something which the resident spent much of their time doing. They were walking side by side. The interaction at Time 2 began with the resident and the caregiver seated at a table in the dining room next to each other, approximately half way through the resident stood up and the rest of the film was taken while walking in the hallways as in the Time 1 video.

Journal of Dementia Care

Guidance for authors (September 2014)

Project updates & viewpoints

These articles generally focus on a project or piece of work in a local area. The aim is for practitioners to be able to share the story of their work, covering aspects such as the motivation and context for the project, who was involved, what work was undertaken (including method, approach and time-scales), financial considerations, examples of the project at work, implications for practice, lessons learned and future plans arising from the work. Articles may also give an update on a project or campaign, be an extended news story, or express an opinion or viewpoint. Length is flexible, but would generally be between 700 and 1500 words. Shorter pieces are more likely to be published quickly, and Letters to the Editor are always welcome.

Features

These are longer articles, generally around 2000-2800 words in length. This length gives more scope for depth and analysis, although it should still cover all the aspects suggested for shorter contributions (as above). A feature may report on a case study, a survey, a service reorganisation, a new project, a service evaluation, a research project, a major publication or campaign, or share good practice on a particular topic (for example, pain management). If you are interested in submitting a feature article, in the first instance please email Catherine Ross on catherine@hawkerpublications.com

Evidence for Practice/Research News

This section aims to keep readers up to date with research in dementia care and the current best evidence to support practice. We aim to provide a channel of two-way communication between researchers and practitioners, so that research findings influence practice and practitioners' concerns are fed into the research agenda.

We welcome contributions such as:

- Information on recently-completed studies available to readers
- Notice of the publication (recent or imminent) of peer reviewed research papers with practical relevance to dementia
- Requests or offers for sharing research information and experience in particular fields of interest.
- Short comment on important research papers recently published, drawing practitioners' attention to new evidence and key points that should inform practice.

Please send contributions for this research section to Sue Benson (sue@hawkerpublications.com).

References

For all contributions, please supply references in Harvard style, and set out as follows:

Journal article

Morrison RS, Sui AL (2000) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain and Symptom Management* 19 240-48.

Book or report

Royal College of Physicians, British Geriatrics Society and British Pain Society (2007) *The assessment of pain in older people: national guidelines*. London: RCP.

Photos are always extremely welcome, and should be sent as separate images, as high resolution as possible (at least 300 dpi) and in JPG or TIF format. Full caption information please too.

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Summary of the Results of the Study 'Can adaptive interaction techniques improve quality of life in advanced dementia: A feasibility study

The study assessed the feasibility of a full scale randomized control trial, to ascertain whether or not training care staff to use Adaptive Interaction techniques could improve quality of life for residents with advanced dementia.

Using a non-randomised control design, 6 staff in a nursing home were offered training in Adaptive Interaction techniques. They were paired with a participating resident and video recordings of their interactions and quality of life measures for that resident were taken before and after training and at 3 month follow-up. These were compared to outcomes in a control home in which outcome measures were taken for 6 staff and resident pairings but in which care continued as usual and no training was provided.

Results indicated that there was a greater increase in communication behaviours that facilitated and showed pleasure in interactions in the intervention group compared to the control group. This was found to be a significant difference, with a large effect size. Post hoc analysis indicated a significant difference between the scores at baseline and post-training in the intervention group, but not in the control group. This indicates that positive communication behaviours increased for the residents cared for by staff who received the training but remained stable for those who received care as usual.

After removal of an outlier, results also showed that there was a decrease in behaviours that hindered and expressed displeasure in interactions in the intervention home compared to a very slight increase in the control home. This was also found to be a significant difference with a large effect size. Post hoc analysis indicated a significant difference in baseline and post-training scores, with the duration of these behaviours reducing in the intervention group. In contrast the control home scores remained relatively stable without a significant difference.

Finally, there was a reduction in scores on the quality of life measure, which indicates an improvement in quality of life, for residents in the intervention home and a slight increase in scores, indicating a decline in the quality of life of residents in the control home. This difference was again found to be significant with a very large effect size. Post hoc analysis indicated that there was already a significant difference between the groups at baseline, with the control home being rated as having a higher quality of life than the intervention home. This difference was no longer significant after the intervention indicating that after training the quality of life of residents in the intervention home had improved to become more in line with that in the control home.