NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

Walmsley, Bruce D.; McCormack, Lynne "The dance of communication: retaining family membership despite severe non-speech dementia". Published in Dementia Vol. 13, Issue 5, p. 626-641 (2014)

Available from: <http://dx.doi.org/10.1177/1471301213480359>

Accessed from: <http://hdl.handle.net/1959.13/1063290>

The dance of communication:

Retaining family membership despite severe non-speech dementia

Abstract

There is minimal research investigating non-speech communication as a result of living with severe dementia. This phenomenological study explores retained awareness expressed through non-speech patterns of communication in a family member living with severe dementia. Further, it describes reciprocal efforts used by all family members to engage in alternative patterns of communication. Family interactions were filmed to observe speech and non-speech relational communication. Participants were four family groups each with a family member living with non-speech communication as a result of severe dementia.

Overall there were 16 participants. Data was analysed using thematic analysis. One superordinate theme, *Dance of Communication*, describes the interactive patterns that were observed during family communication. Two subordinate themes emerged: a) *in-step*; characterised by communication that indicated harmony, spontaneity and reciprocity, and; b) *out-of-step* characterised by communication that indicated disharmony, syncopation, and vulnerability. This study highlights that retained awareness can exist at levels previously unrecognised in those living with limited or absent speech as a result of severe dementia. A recommendation for the development of a communication program for caregivers of individuals living with dementia is presented.

Keywords: *retained awareness; non-speech communication; severe dementia; aged care; family relations*

Introduction

One of the most evocative sights in life is the reciprocal interaction between a mother and her pre-linguistic infant (Magai & McFadden, 1995). Yet, such infants appear withdrawn when their attempts to interact are unrequited. Similarly, adults living with dementia, whose speech has become restricted or absent, appear withdrawn when their efforts to engage are not returned (Magai, Cohen, Gomberg, Malatesta, & Culver, 1996; Norberg, Melin & Asplund, 1986). Appearing uncommunicative, such individuals are often considered *globally* unaware. Awareness and ability for meaningful interaction may be dismissed or overlooked (Clare, Woods, Whitaker, Wilson, & Downs, 2010) diminishing opportunities for reciprocal interaction. Impoverished daily interactions with family or aged-care staff are likely to compromise their quality of life and quality of care. Despite these risks, few studies have investigated awareness retained by people living with limited or absent speech as a result of severe dementia (see review by Clare, 2010). In this study, the authors recognise the complex biopsychosocial interplay between speech and dementia but are particularly concerned with the social cues and stimuli that may exacerbate loss of communication pathways, or support ongoing communication and family membership, for better quality of life.

Awareness can be defined as a realistic response to a specific aspect of one's environment, situation, functioning, or performance (Clare, 2010). It can be expressed through speech, behaviour, or emotion (Clare, 2010; Götell, Brown, & Ekman, 2007; Planalp 1999). Proposed to exist in a hierarchy, awareness ranges from unconscious behavioural response to higher levels encompassing perception of sensory information, complex movement, goal-directed behaviour, and self-awareness (Stuss, Picton & Alexander, 2001).

Traditionally, impaired awareness in people living with dementia was considered to stem from cognitive decline and dysfunction alone. Examples include awareness compromised by changing neurobiology which disrupts sleep-wake cycles (Woods & Martin,

2007) or reduces alertness (Edman, Brunovsky, Sjogren, Wallin, & Matousek, 2003).

However, meta-analytic reviews have found no clear relationship between cognitive decline and levels of expressed awareness in those living with dementia (Clare, 2004). For instance, some individuals with advanced symptoms of dementia have shown few markers of neuropathology at post-mortem, while others without symptoms have displayed neuropathology consistent with Alzheimer's related disease (Sevush & Leve, 1993; Snowden, Greiner & Mortimer et al., 1997). For others, levels of awareness were found to decline, stabilise, or improve over the course of a year, despite increasing pathology (McDaniel et al., 1995; Weinstein, Friedland, & Wagner, 1994). This indicates that other factors besides biological change influence displays of awareness in people living with dementia.

It is now recognised that an individual's symptoms of dementia are influenced by a multidirectional interplay between biological factors, psychological elements, and social systems (Downs, Clare, & Anderson, 2008; World Health Organisation, 2002). Accordingly, studies have demonstrated fluctuating awareness in people living with dementia in relation to psychosocial factors. For example, when treated as equals during relational interaction, displays of awareness in those living with dementia have been found to increase (Normann et al., 2002). Similarly, caregiver singing during personal care has been shown to increase displays of awareness, generating a reciprocal sense of vitality for aged-care staff and residents (Götell et al., 2007). Conversely, withdrawal has been observed in such individuals when faced with limited social contact, or sensory overload from a noisy environment (Norberg, Melin, & Asplund, 1986).

From a biopsychosocial context, intact cognitive functioning is but one aspect of awareness in people living with dementia. Despite cognitive deficits and memory decline their capacities for emotional and relational life, even in advanced stages of the condition, remain relatively intact (Sabat & Collins, 1999). For example, individuals living with

Dance of communication in severe dementia

moderate to severe dementia have been observed to display sadness, almost exclusively in the last two minutes of a family visit (Magai et al., 1996). Their facial expressions were considered to represent underlying awareness, as they were deemed a realistic response to their relative's imminent departure. Similarly, meaning has been interpreted from the body gestures and facial expressions conveyed between aged-care residents living with moderate to severe levels of dementia (Kontos, 2004). Looking-to or looking-away was interpreted as expanding or discontinuing conversation. Frowns, smiles and hand gestures appeared to be used in communicative ways (Kontos, 2004). Where speech was inarticulate, Kontos observed that it was delivered in turn, as in conversation. Further, the importance of relationships to residents living with moderate to severe dementia in aged-care was highlighted by Clare, Rowlands, Bruce, Surr, and Downs (2008). These participants indicated that regular family contact and acceptance from other residents helped them cope. They also reported that relational interaction and reminiscing helped them maintain their sense of identity in the face of cognitive decline (Clare et al., 2008).

Despite existing research on awareness in people living with dementia, few studies have investigated levels of awareness retained by those in more advanced stages of the disease. Even fewer studies have attempted to investigate awareness where speech in such individuals has become restricted or absent (see review by Clare, 2010). As such, the present study aims to explore *retained* awareness in individuals living with *limited or absent speech* due to *severe* dementia. This phenomenological study aimed to describe: a) expressions of retained awareness in the speech, expressed noises, facial expressions, and body gestures of a family member with restricted or non-existent speech due to severe dementia, and; b) understanding and receptivity in the relatives reciprocating that individual's expressions of awareness.

Method

Participants

Four family groups, inclusive of a family member living with dementia, participated in the study. The participants living with dementia resided at the same aged-care facility, and were recruited through the facility's Director of Nursing. Criteria for their inclusion were a diagnosis of severe dementia encompassing limited or absent speech. The Director of Nursing assessed these individuals as having *severe dementia at a profound sublevel*, with a rating of 4 on a scale of 0 to 5 on the *Clinical Dementia Rating Scale* (CDR; Morris, 1993). The CDR assesses cognitive and functional capacity to provide a symptom level, ranging from *none* to *severe*, with two severe sublevels of *profound* and *terminal*. Articulate speech in the participants living with dementia was non-existent or restricted to single words and phrases. Each received a CDR (Morris, 1993) communication ability rate as "speech usually unintelligible or irrelevant" and "unable to follow simple instructions or comprehend commands."

The family groups comprised of: 1) Tom aged 66 years, visited by his wife Donna, 2) Helen aged 96 years, visited by her son Gary, daughter-in-law Susan and great-grand-daughter Emily, 3) Deborah aged 69 years, visited by her husband Richard and their friend Nancy, 4) Ruth aged 91 years, visited by her daughter Karen and great-grand-daughter Chloe. English was the first language of all participants, including those living with dementia. In line with ethical practice, participant names and place names were changed.

Procedure

Following university Human Research Ethics Committee approval, guardians provided written consent for the participation of their family member living with dementia. Demographics were collected, and severity of dementia was assessed with the CDR (Morris, 1993). Filmed observational methods were used to capture four family group interactions, on three separate occasions over one month. The equipment was preset to run so that filming

Dance of communication in severe dementia

was as unobtrusive on the family visit as possible. Filming of each participant living with dementia began in their private room, approximately fifteen minutes prior to the family visit. Filming continued during the 'visit-as-usual' and for 15 minutes afterwards. Verbatim transcription of dialogue and expressed noises, along with observed and noted facial expressions and body gestures provided the data set for interpretation.

Epistemology

Epistemologically this study leveraged the philosophies of critical realism and symbolic interactionism. From a critical realist position it sought to describe the way in which the world is socially constructed, interpreted and understood. As such it provided a platform for phenomenological exploration of this complex subject area through a process of understanding and interpretation. It sought to critically reflect a real world where unobservable realities exist (Blaikie, 1991). According to the critical realist perspective, access to the individual's world is always mediated, thus a critical realist position is also a comfortable fit with symbolic interactionism which is concerned with: 1) the way people act towards things based on the meaning those things have for them; 2) the meanings that are derived from social interaction; and 3) the fluidity and ambiguity of meaning and how it is modified by interpretation.

Drawing on these philosophies the authors sought the *essence* or the underlying *meaning making*. It went beyond the semantic content of the data to examine the underlying features that gave form to the interactions. The development of the themes was interpretative, offering theoretical underpinnings to what appeared in the data (Braun & Clarke, 2006). Analysing the phenomenological data was underscored by a method of reduction to specific interactions, statements and themes in search for all possible meanings. At the same time, the authors were challenged to reflect on their own subjectivity and knowledge of the phenomenon under investigation, and to consciously recognise their own

biases and presuppositions that may have interfered with interpretation of data (Heidegger 1927/1962; Gadamer, 1983).

Credibility

Credibility and trustworthiness were addressed in a number of ways (Braun & Clarke, 2006; Smith & Osborn, 2008, Yardley, 2008). The first author conducted the twelve individual observational sessions and transcribed both the visual and verbal data set. Both authors independently analysed the data. Critical reflection and robust discussion between authors ensured that rich thematic evidence supported interpretation of the data. As such, each author recognised possible multiple and legitimate themes but arrived at a credible, and logical step-by-step path of ‘rich’ evidence around the phenomenon under investigation producing a detailed audit trail (Smith, 1996; Smith, Flowers, & Larkin, 2009). The audit trail encompassed the complete set of filmed recordings, transcripts, preliminary notes, diagrams, early interpretations and a pathway to final choice of convergent and divergent themes. Unlike nomothetic research, the authors did not aim to produce evidence of cause and effect or produce a satisfactory inter-rater reliability score.

First Author’s Perspective

The first author’s mother lived with dementia for ten years. His interest in retained awareness in people living with dementia stems from his personal experience. However, every attempt has been made to externalise these biases and bring credibility to interpretation through robust discussion, collegial input, and completely independent audits.

Analysis

According to Braun & Clarke (2006) each session was transcribed and systematically analysed (see Table 1).

Insert Table 1 here

Speech and non-speech interactions within four family groups were observed and described to capture important aspects of interaction, both positive and negative. One superordinate theme was identified: *Dance of Communication*. This described the positive and negative patterns of communication observed across all family groups. It also reflects the strong will of people living with dementia to retain membership of their relational group, and the willingness of family members to engage in a dance of communication that is sometimes ‘*in-step*’ and sometimes ‘*out-of-step*’. When family interactions were ‘*in-step*’, they were characterised by subthemes representing greater *harmony*, *spontaneity* and *reciprocity*. When interactions were ‘*out-of-step*’ the subthemes reflected greater *disharmony*, *syncopation*, and *vulnerability*. It was observed that all family groups could be both ‘*in-step*’ and ‘*out-of-step*’, depending on: a) presumptions of awareness, b) timing of reciprocal response, c) perceived interpretation, and d) what appeared to be pre-existing relational patterns. We now describe each of these thematic aspects of *Dance of Communication* in turn, supporting our findings with vivid extracts (Notations: Appendix 1).

In-step

‘*In-step*’ describes those interactions that flowed *in time* with reciprocal ease, appeared to have shared interpretation, or reflected a positive pre-existing relational pattern despite a family member living with dementia. The subthemes that encapsulated the domains of ‘*in-step*’ included *harmony*, *spontaneity*, and *reciprocity*. When family interactions were ‘*in-step*’, family members appeared to interact harmoniously, spontaneously and reciprocally. Timing of interactions flowed easily, with or without speech, and there was a sense between the interactive members that ‘meaning’ was understood. In all exerts from ‘*in-step*’ interactions, presumptions of retained awareness surfaced. Efforts to communicate also appeared to be recognised and understood. Within ‘*in-step*’, those living with dementia were observed to engage and interact (see Table 2).

Insert Table 2 here

Harmony. This subtheme describes a harmonic dance of interaction between family members. A sense of attunement and equality emerged during the interactions between family members.

For example, a sense of symmetry emerged between Donna and husband Tom, as she reminisced over family photos and he responded:

“Here you are, Macmillan Road, where you were born...” (Donna). (Tom leans forward, lowers his head to the page, and opens his eyes wider as he looks at the photo. His eyes track Donna’s index finger as she points to photos in an album. Tom also looks from photo to photo without her guidance, and turns his head from left to right as he looks from page to page).

Richard and Deborah’s interaction highlights a depth of harmonious intimacy despite Deborah’s severity of dementia. In this extract Richard and Deborah’s interaction displays equality. It offers an appreciation of Richard’s belief that Deborah retains a level of awareness. Her response appears to confirm this:

(Richard leans over and kisses Deborah’s forehead. She closes her eyes briefly, and moves her head backwards into the pillow). “I love you. See you when I come back.” (Richard). (Deborah moves her eyes from left to right over Richard’s face, and opens her mouth slightly. She turns and watches Richard as he leaves the room).

Harmony within the family groups often appeared to be followed by spontaneous and reciprocal relational interaction.

Spontaneity. This subtheme describes spontaneous expression by the individuals living with dementia and their relatives. Interactions danced back and forth, more effortlessly than usual. There were often displays of humour. The family group appeared united within a

Dance of communication in severe dementia

common emotional state. The individuals living with dementia appeared connected to the group.

For example, Donna has been turning through the pages of a photo album with Tom, recounting her memories as she points to each photo. As she reminisces, the pitch of her voice rises and her rate of speech increases. At one moment, she is slow to turn the album page. Tom unexpectedly responds:

(Tom quickly ducks his head to look at the inside of the page before she has turned it completely).

Similarly, Emily asks whether Helen has problems with her memory. Her grandmother Susan acknowledges this. Helen's expressiveness indicated awareness and response. Family members' responses were interpreted as recognising speech and non-speech harmony between themselves and the family member living with dementia. For example, Gary's exclamation of: "Oh look, yes!" also provides evidence that he sees Helen's behaviour as noticeable in a positive way. Additionally, all family members appear to treat Helen's behaviour as in some way coherent and understandable to them. As such, they appear to treat Helen's thoughts and behaviour as aligned with their own:

"Wait ...sometimes does she forget things?" (Emily). "Yes, sometimes she does."

(Susan). (Helen turns and leans forward to Susan). "Oh yes." (Helen nods her head and smiles at Susan). "Oh look, yes!" (Gary). (Susan smiles and laughs). "That's right!"

(Susan). (Helen shimmies her shoulders against the back of her chair, and knocks her knees together several times. She smiles and closes her eyes). (Susan laughs and turns to Emily). "Yes! I think she said: 'Yes, sometimes I do forget'."

Spontaneously, Helen characteristically ceased her repetitive chewing, briefly, in relation to: a) the rustle of a paper chocolate bag, and b) when her family was heard approaching:

Dance of communication in severe dementia

(Helen's family was heard talking as they approach Helen's room. She stops her repetitive chewing). "...Ta ta ta." (Helen turns in her reclining chair towards the door and bounces her legs several times against the footrest). "Be be be be." (Helen turns further towards the door and smiles at her family. "Hello." (Susan). "There she is!" (Gary). "Here's Emily, Helen." (Susan). (Helen makes a gargle sound as she lowers and raises her eyebrows ... and her eyes track Susan and Emily approaching). "Oh look at that." (Gary noticing Helen's response).

Family members' responses indicated timely recognition of speech and non-speech harmony between their own and the family member living with dementia. For example, Gary's exclamation of "There she is!" appeared a positive and spontaneous connection with Helen's behaviour and in line with his own interpretations.

Spontaneous but non-speech responses by Helen to the family's arrival, appear to engage her family. Communication appears established in this way and a two way dance between speech and non-speech interaction occurs. Timing and reciprocity create an '*In-Step*' family interaction. On this occasion, Susan and Emily's exclamations suggest a positive behavioural interaction and response to Helen that indicates they see Helen's thoughts and behaviour as understandable in the context of their interaction:

"Are you enjoying your chocolate Helen?" (Susan). Helen raises her eyebrows, leans forward to look at Susan, and smacks her lips together. "I think that was a yes!" (Susan nods her head at Emily). "Be, be, be, be, be, be" (Helen). ... "She said yes!" (Emily). Helen makes a gargle sound as she smiles and turns her head from Susan to Emily. ... "She said yes!" (Emily). Everyone laughs including Helen.

Reciprocation. This subtheme describes what appear to be reciprocal interactions between the non-speaking and speaking members of the families. In these interactions, the

Dance of communication in severe dementia

non-speech member exhibited effortful responses such as briefly closing their eyes, frowning, or furrowing their brows before responding. For example:

“Would you like some chocolate?”(Susan). (Helen turns sharply to Susan and rests her head back against the pillow. She closes her eyes for 3 seconds and frowns. She gently wrinkles her nose and looks at Susan). “Yegs-yu-thu.”

And:

“See look at the pretty colors.” (Karen). (Ruth lifts her head towards Chloe’s book, and then pulls her head backward as if trying to focus on the pictures). “Look, it’s Princess Barbie Coloring Book.” (Karen). (With her eyebrows furrowed in the centre, Ruth nods her head at Chloe). “Oh, oh, oh.” (Ruth). “It’s good isn’t it?” (Karen). (Ruth nods her head at Chloe). “Yeah.”

Similarly, family members’ desire to reciprocate was observed in attempts to illicit answers to confirm their interpretation of non-speech communication:

“Remember Penny? Remember Penny? ...” (Susan). (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?”(Susan).

Further, attempts at reciprocal engagement were observed in smiles and touch by Helen and Ruth to Emily and Chloe and a willingness to interpret non-speech cues as positive signs of engagement. The non-speech family member, in return, appears to respond ‘*in-step*’ with the speech cues. Speech and non-speech harmony was observed when Emily and Susan positively affirmed Helen’s behaviour in response to their interpretation of events:

(Helen closes her eyes briefly, and then looks at Emily and smiles). “I think she’s smiling at you.” (Susan). (Helen continues smiling at Emily, while Susan watches Helen and laughs). “She always smiles at you, she loves you. Was that a smile for Emily, Helen? Was it?” (Susan). (Helen closes her eyes briefly and then looks at

Susan). “Mm” (Helen raises her eyebrows and nods her head). ...“I think that’s a yes.” (Emily and Susan in unison).

Reciprocation was observed through family members’ responses that appeared positive and understandable. Karen indicates that she views Ruth’s thoughts and behaviour as aligned with her own:

(Ruth looks to Chloe, and with her eyebrows furrowed in the centre she extends her arm towards the little girl). “Oh, oh, oh, oh, oh, oh, oh, oh, ah.” (Ruth). “There you are. She wants to hold your hand.” (Karen speaks to Chloe).... (Ruth looks at her hand in Chloe’s).

Out-of-step

In contrast, ‘*out-of-step*’ describes a sense of discordant syncopation between speech and non-speech family members. Relational interactions appeared syncopated by family members who appeared to approach each other from a different sense of ‘time and place’. The subthemes that encapsulated the domains of ‘*out-of-step*’ included *disharmony*, *syncopation*, and *vulnerability*. When family interactions were ‘*Out-of-Step*’, participants living with dementia appeared diminished within their family group. Efforts by the individuals living with dementia to respond appeared frustrated. Attempts by family to engage again appeared syncopated often leading to what appeared to be disharmonious interactions. Discordant relational patterns were observed when delays, distressing noises, or interaction appeared to be overshadowed by past negativity. When interactions were ‘*out-of-step*’, the individuals living with dementia appeared vulnerable.

At ‘*out-of-step*’ times, the non-speech individuals living with dementia appeared to have difficulty responding or coping with their environment which was observed through facial, voice, and body gestures that conveyed negativity. These ‘*out-of-step*’ interactions were observed and interpreted in several ways (see Table 3).

Insert Table 3 here

Disharmony. This subtheme describes discordant relational patterns that surfaced within family groups. *Disharmony* was characterised by a sense that the standing of the individual living with dementia was diminished within their family group, and was observed by patterns of interaction with family members that indicated pre-existing relational conflict. For example, though Helen appeared to reciprocate moments of ‘in-step’ with Emily, a focus on her impaired ability within the family group reminds both speech and non-speech members of the family of her dependency. The authors interpreted disharmony and negativity in Helen’s downward gaze when she is excluded from conversation concerning her:

“You’d like to take her [Helen] for a walk wouldn’t you [Emily]? - but you can’t.”
(Gary). (Susan, Emily and Helen cast their eyes downwards. Susan sighs. Helen abruptly turns to Gary and holds her gaze on his face for a few seconds. Her jaw is still. ... She turns her gaze back to the centre of the room and looks downward. Her jaw remains still).

Similarly, despite the spontaneous affection between Gary and Helen, *disharmony* encapsulated observed interchanges that suggested negative dynamics from former family life as much as present dynamics. For example, there was a sense that Helen, the mother and former disciplinarian was being challenged, within the context of pre-existing issues:

(Gary mimics Helen’s gargle sound. She wrinkles her nose upwards and looks at him. ...He mimics her again). “Hey?” (Gary). (He mimics the sound of Helen’s repetitive chewing). “Hey?” (Gary). (...Helen wrinkles her nose upwards again).
...“You going to have a chat to Gary?” (Susan). ...“Um, no — you haven’t got your iron chord with you, have you?”(Gary).

Again, disharmony and challenge were observed:

Dance of communication in severe dementia

(Gary quickly pulls his hand away from Helen's sweater as she sharply turns her head to look him in the face. Her head bounces on the pillow and her eyebrows rise and fall while she makes a vocal sound for four seconds. Helen's face leans to Gary's face. In turn he leans more into Helen's face. Gary nods several times).

"OK? What are you trying to tell me?" (Gary). (Helen's face relaxes and she looks away. Gary swallows, looks away, pauses, and then turns back to Helen). "Are you going to rouse on me for getting you chocolate? Are you?" (Gary). (Helen looks back at him and her eyebrows rise).

Syncopation. This subtheme describes 'out of time' family efforts to communicate.

Though Donna and Tom appeared '*in-step*' while turning through family albums, Tom's lack of speech appears at times to exacerbate his dependency and cause syncopation in communication. For example:

(Donna closes the magazine and places it on the chair). (...Tom watches her, and makes a medium volume, slow, brief wail. He frowns and leans forward looking at the magazine lying in the seat of the chair). "Do you want it back?" (Donna takes the magazine off the chair and holds it to Tom. He looks at the magazine but makes no movement to take it). "Do you want it? Would you like it darling? — No, ok."

(Donna). (Tom watches the magazine as Donna places it back on the chair).

Often Deborah's and Helen's responses were delayed and '*out-of-step*':

(Deborah's face is expressionless and rigid as Richard enters the room and says "Hi." Eight seconds later he kisses her forehead. Seven seconds later her face relaxes, and she moves her eyes to look at his face).

Syncopation was further observed when cues of verbal communication left Helen's goodbye out of time with Susan's exit at the door:

Dance of communication in severe dementia

“See you later. Bye darling.” (Susan kisses Helen on the cheek). “Bye bye. See you.”

(Susan). (Seven seconds later, Helen frowns and leans forward in her chair, before turning to watch Susan who is walking out the door).

‘Out-of-step’ communication was more frequent after ten minutes of the family visit.

Extended period of focus with Emily appeared to leave Helen tired and ultimately unable to syncopate her responses with others. She appeared frustrated which was observed from her facial expressions and inarticulate speech:

“Gurgling, gurgling, b, ah.” (Helen). “What are you saying?” (Susan). (Helen briefly scrunches her face shut).

Similarly, despite earlier harmony with Donna, reminiscing now appeared to distress Tom:

“Ah look. There’s you. There’s you with her and Angela... All excited about the birthday cake. You remember? These are ones that you took. ...” (Donna). (Tom has been looking at the photos. Now he contorts his face, and makes a loud and high pitch wail. His wail stops abruptly when Donna kisses him on the forehead).

Vulnerability. Often preceded by disharmony and syncopation, this subtheme describes episodes of vulnerability in the individuals living with dementia. In particular, they appeared easily startled by loud noise or unexpected touch. This was noticeable during moments of fluctuating relational connection.

Vulnerability was observed further in Helen’s responses to Gary. When unexpectedly touched by Gary, Helen retracted herself and showed a startled response:

(Gary reaches over to adjust Helen’s collar. She moves her shoulder away, and catching sight of his hand on her sweater, she appears startled. Her eyes open wide, her eyebrows rise, and she quickly leans away. He continues brushing his hand over her sweater, but quickly pulls his hand away when she turns sharply to look at his face).

Dance of communication in severe dementia

In a further example, Helen appeared to react with fright:

(There is a metallic squeal from the corridor. Helen simultaneously closes her eyes, rolls her shoulders forward, and raises her left palm perpendicular to the noise).

Following family visits, each of the participants living with dementia appeared vulnerable in their aloneness. They appeared anxious and uncertain without the reciprocal interactions of family members. This was observed through: 1) Helen holding herself rigidly for 30 seconds after her family left, 2) Deborah eye tracking Richard and Nancy as they walked away, 3) Helen and Deborah turning to the doorway, sometimes twice, after their family left:

(Helen holds herself still, and rigid; looking straight ahead for 30 seconds after her family leave. Her left hand rests across the nape of her neck, and her right hand rests on the arm of the chair. ... Then she turns to look at the doorway twice, while she makes a faint voice. Finally she turns back to the centre of the room...).

And:

(Deborah turns to watch Richard and Nancy leave the room. Ten seconds later she turns back to the centre of the room, before turning again to look at the doorway).

Discussion

This study highlights the levels of retained awareness that can be expressed through words, vocal noises, facial expressions, and body gestures of people living with restricted or absent speech due to severe dementia. Furthermore, it has shown that communication can be enhanced through 'in-step' understanding and receptivity in relatives who are reciprocating these expressions of awareness, and diminished through 'out-of-step' interactions. For example, a sense of *harmony*, *spontaneity*, and *reciprocity* highlighted relational interactions that were 'in-step'. Conversely, when those interactions were 'out-of-step', family communication was characterised by *disharmony*, *syncopation*, and *vulnerability*.

Dance of communication in severe dementia

It was observed that all family groups could be both '*in-step*' and '*out-of-step*', depending on: a) presumptions of awareness, b) timing of reciprocal response, c) perceived interpretation, and d) what appeared to be pre-existing relational patterns. Each of the participating groups was unique in accommodating the fluctuating awareness of a relative living with dementia. Stories of food connected Helen's family. Alternatively, Donna used reminiscing supported by family photos. Richard, Nancy and Deborah relied on touch. Karen connected with Ruth through Chloe's stories. In each group there appeared to be definite patterns of interaction pertinent to earlier roles and patterns of communication, as well as commonalities across the families.

Patterns of relational interacting highlighted a convergence of themes across the data set. Similar to Kontos (2004) the facial expressions of participants living with dementia, despite their lack of speech, were used by in communicative ways. These included the use of eyebrows, eye contact, and smiles. Tone, volume, and direction of voice appeared to supplement limited and non-existent speech. Touch was used by all relatives to deepen relational connectedness. In each group, '*in-step*' interactions appeared to stimulate moments of spontaneity whereas '*out-of-step*' interactions seemed to heighten frustration and anxiety. Intensity of focus and the struggle to communicate through speech and non-speech cues was not able to be maintained for long periods of time.

In addition, each of the individuals living with dementia displayed retained awareness at levels exceeding those expected for their assessed severity of dementia. Consistent with the model proposed by Stuss, Picton & Alexander (2001), awareness fluctuated from fundamental levels of sensory and perceptual awareness to higher levels of complex movement (e.g. Tom ducking to see inside the pages of the photo album), goal directed behaviour (e.g. Ruth reaching for Chloe's lunch box) and self-awareness (e.g. Helen acknowledging her memory loss). Such observations of the participants living with dementia

Dance of communication in severe dementia

were inconsistent with their assessed communicative ability according to the CDR (Morris, 1993). As such, psychometric assessments such as the CDR may inadvertently be contributing to the underestimation of ability and resultant marginalisation of such individuals.

Consistent with Clare et al. (2008), Kontos (2004), Magai et al. (1996), and Sabat & Collins (1999) each of the participants living with dementia in the current study displayed a retained ability for emotional and relational life. Consistent with Götell et al. (2007) and Normann et al. (2002) positive relational interactions were characterised by increasing vitality in participants living with dementia and their relatives. As each of the family groups interacted, the possibility for individuals to transcend the assumed limitations of living with dementia became apparent. First, the participants living with dementia appeared more confident in their expression when situated within the harmonious, spontaneous, and reciprocal interactions of their relational group (e.g. Helen's shoulder shimmy and smiles focused on Emily). Second, often surprised by these episodes of expressive awareness in their relatives living with dementia, family members (e.g. Gary, Susan, and Karen) appeared to discard their assumptions concerning unawareness. During these moments, the family groups appeared to enjoy a deep relational connectedness supported by the responses of several family members during their visits. For instance, we observed shared harmony and spontaneity between Helen, Gary, Susan, and Chloe, as they express delight at Helen's quick responsiveness. Moreover, the interplay of speech and non-speech interactions in each of the family groups appeared to enliven expressions of awareness in the individuals living with dementia despite their lack of speech. However, at the end of the visit, the participant living with dementia appeared to retreat within themselves.

In particular, self-awareness within a family membership appeared to transverse time and place. For example, the non-speech family members appeared at ease within their

Dance of communication in severe dementia

relational group, which included conflictual interactions that indicated a hierarchical role within the group. Similarly, family members engaged in a dance that was sometimes '*in-step*' and sometimes '*out-of-step*' but which often reflected a familiarity and respect for the position held within the group.

As opposed to defining awareness in people living with dementia through psychometric assessments, this study provides insight into the *lived* experience of awareness for such individuals. Observing participants living with dementia during relational interaction, extends our understanding of the ways that awareness is experienced. Alternate descriptions such as harmonious, spontaneous, or discordant interactions shift the focus from the pathology (i.e. dementia) to the lived experience of the person, by highlighting the person as someone who is situated within a time and place, and relational context.

Observational studies are well placed to observe signs of awareness in people living with dementia. In this study, filming multiple observations captured the fluctuating expressions of awareness. Moreover, filming enabled a second and complementary source of body responsiveness data to verbal transcripts, and allowed detailed analysis of discrete expressions of awareness to aid interpretation. Despite being filmed, the family groups appeared to quickly adjust to the presence of the camera. Thus, interactions during the family 'visit-as -usual' are likely to represent everyday relational interactions for each of the family groups.

Limitations

A challenging aspect of this study was interpreting the level of awareness in participants living with dementia related to their individual experience. This was especially difficult in light of their limited or absent speech. Furthermore, there is no way of confirming interpretative analysis with the non-speech participants. Focus groups with family members following analysis would help to validate interpretation in further studies. However, this

qualitative study offers a rich insight into awareness in people living with severe dementia with resultant loss of speech. It is one of few studies that attempts to investigate awareness where speech has become restricted or non-existent (see review by Clare, 2010).

Conclusions and Recommendations

This phenomenological study offers new insights on awareness in people living with limited or absent speech due to severe dementia. By exploring the 'lived' experience of such individuals, it highlights the efforts and willingness of all family members dealing with severe dementia to retain membership of their family group previously unrecognised in research. This study does not aim to offer generalisability or cause and effect, but shed light on the complex communication patterns that occur in family interactions where a member lives with restricted or absent speech due to severe dementia. It has highlighted that: a) retained awareness may exist at a level previously unrecognised in dementia; and c) the 'lived' experience of individuals living with restricted or absent speech through severe dementia includes continued striving to retain family membership.

By demonstrating that retained awareness may exist at a level previously unrecognised in people living with limited or absent speech in severe dementia, this study has the potential to inform care and increase quality of life through the development of communication programs for families and staff. Importantly, the momentary relational interactions depicted in this study suggest that harmonious, spontaneous and reciprocal quality of life may be possible for people living with dementia for longer than previously expected.

References

- Blaikie, N. (2000), *Designing Social Research*, (1st ed.). Cambridge, United Kingdom: Polity Press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101. doi: 10.1191/1478088706qp063oa
- Clare, L. (2010). Awareness in people with severe dementia: Review and integration. *Aging & Mental Health*, 14(1), 20-32. doi: 10.1080/13607860903421029
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: an interpretive phenomenological analysis. *The Gerontologist*, 48(6), 711-720. Retrieved from <http://gerontologist.oxfordjournals.org/Content/48/6/711.full.pdf+html>
- Clare, L., Woods, R. T., Whitaker, R., Wilson, B. A. & Downs, M. (2010). Development of an awareness-based intervention to enhance quality of life in severe dementia: trial platform. *Trials*, 11(73). doi: 10.1186/1745-6215-11-73
- Downs, M., Clare, L., & Anderson, E. (2008). *Dementia as a biopsychosocial condition: implications for practice and research*. In B. Woods, & L. Clare. (Eds.), *Handbook of the clinical psychology of ageing*, (2nd ed.). Chichester, England: Wiley.
- Edman, A., Brunovsky, M., Sjögren, M., Wallin, A., & Matousek, M. (2003). Objective measurement of the alertness level in dementia. *Dementia and Geriatric Cognitive Disorders*, 15, 212-217. doi:10.1093/geront/44.6.797
- Gadamer, H. (1983). Hermeneutics as practical philosophy. In F. G. Lawrence (Trans.), *Reason in the age of science*. (pp. 88-138). Cambridge: The MIT Press.
- Götell, E., Brown, S., & Ekman, S. (2007). The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: A

qualitative analysis. *International Journal of Nursing Studies*, 46, 411-430.

doi:10.1016/j.ijnurstu.2007.11.001

Kontos, P. C. (2004). Ethnographic reflections on self-hood and embodiment in Alzheimer's disease. *Ageing & Society*, 24, 829-849. doi:10.1017/S0144686X04002375

Magai, C., Cohen, C., Gomberg, D., Malatesta, C., & Culver, C. (1996). Emotional expression during mid-to late-stage dementia. *International Psychogeriatrics*, 8(3), 383-395. doi:10.1017/S104161029600275X

Magai, C., & McFadden, S. (1995). The role of emotion in social and personality development: History, theory, and research. New York: Plenum Press.

McDaniel, K. D., Edland, S. D., Heyman, A., & the CERAD clinical investigators. (1995). Relationship between level of insight and severity of dementia in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 9, 101-104. Retrieved from http://journals.lww.com/alzheimerjournal/Abstract/1995/09020/Relationship_Between_Level_of_Insight_and_Severity.7.aspx

Morris, J. C. (1993). The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology*, 43(11), 2412-2414. Retrieved from <http://psycnet.apa.org/psycinfo/1994-19989-001>

Norberg, A., Melin E., & Asplund, K. (1986). Reactions to music, touch and object presentation in the final stage of dementia. An exploratory study. *International Journal of Nursing Studies*, 23(4), 315-323. doi: 0020-7489/86

Normann, H. K., Asplund, K., & Norberg, A. (2002). Episodes of lucidity in people with severe dementia as narrated by formal carers. *Journal of Advanced Nursing*, 28, 1295-1300. Retrieved from <http://www.ingentaconnect.com/content/bsc/jan/2002/00000039/00000004/art02298>

Dance of communication in severe dementia

Planalp, S. (1999). *Communicating Emotion: Social, Moral and Cultural Processes*.

Cambridge: Cambridge University Press.

Sabat, S. R. & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *Ageing and Society*, 12, 443-461. doi: 10.1177/153331759901400108

Sevush, S., & Leve, N. (1993). Denial of memory deficit in Alzheimer's disease. *American Journal of Psychiatry*, 150, 748-751. Retrieved from <http://www.psychservices.psychiatryonline.org/data/Journals/AJP/3598/748>

Smith, J. (1996). Beyond the divide between cognitive and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271. doi: 10.1177/1359105302007002397

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretive Phenomenological Analysis. Theory, Method and Research*. London: Sage.

Smith, J. A., & Osborne, M. (2008). Interpretive Phenomenological Analysis. In Smith, J. A. (Ed.). *Qualitative Psychology: A practical guide to research methods*. (2nd ed.). (pp. 53-80). London: Sage Publications

Snowden, D. A., Greiner, L. H., & Mortimer, J. A., et al., (1997). Brain infarction and the clinical expression of Alzheimer's disease. The Nun Study. *Journal of the American Medical Association*, 277, 813-817. Retrieved from <http://jama.jamanetwork.com/article.aspx?articleid=414570>

Stuss, D. T., Picton, T. W., & Alexander, M. P. (2001). *Consciousness, self-awareness and the frontal lobes*. In S. Salloway, P. Malloy, & J. Duffy (Eds.), *The frontal lobes and neuropsychiatric illness* (pp. 101-109). Washington DC: American Psychiatric Press.

Weinstein, E. A., Friedland, R. P., & Wagner, E. E. (1994). Denial/unawareness of impairment and symbolic behaviour in Alzheimer's disease. *Neuropsychiatry*,

Neuropsychology and Behavioural Neurology, 7, 176-184. Retrieved from

<http://journals.lww.com/cogbehavneurol/Abstract/1994/07000/>

Denial_Unawareness_of_Impairment_and_Symbolic.5.aspx

Woods, D. L., & Martin, J. E. (2007). Cortisol and wake time in nursing home residents with behavioural symptoms of dementia. *Biological Research for Nursing*, 9, 21-29.

doi:10.1177/1099800407303982

World Health Organization. (2002). *Towards a common language for functioning, disability, and health. The international classification of functioning, disability and health*.

World Health Organization, Geneva.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In Smith, J. A. (Ed.).

Qualitative Psychology: A practical guide to research methods. (2nd ed.). (pp. 53-80).

London: Sage Publications

Appendix: Notations

In the narratives, “—“indicated a pause in speech, while ellipses indicate the removal of nonessential material.

Table 1

Stages of thematic analysis

Stage	Process
1	Viewing the films and reading the transcripts several times each, for note making and a sense of participant expression of awareness.
2	Fresh viewing of the films and reading of transcripts to develop initial psychological concepts.
3	Clustering the psychological concepts into themes and subthemes, while maintaining the participant's authentic language and expressions.
4	Generating a thematic map of themes and subthemes.
5	Refining the essence of each theme, noting convergence and divergence across the data set.
6	Supporting the themes with vivid data extracts, and interpreting these in context of the research phenomenon and literature.

Table 2

Common patterns of 'in-step' interactions by the participants living with dementia

Observation	<i>'In-step'</i> interaction
1	There was a tendency of Helen and Ruth to briefly close their eyes, frown, or furrow their brows before initiating contact or responding. This was interpreted as a sign of effort in preparing to communicate.
2	All of the individuals with dementia displayed eye-tracking of a family member, or at times looked towards a family member. This was interpreted as a sign of their willingness to engage.
3	Helen, Ruth, and Deborah were observed to raise and lower their eyebrows while looking at family members, which was interpreted as emphasis of their desire to retain familial connection.
4	Helen and Ruth were observed to use voice in communicative ways to promote engagement with their relatives. They delivered their voice in-turn, as in conversation. Tone, volume, and direction of voice appeared to supplement or replace the meaning usually conveyed through speech.
5	Helen's cessation of repetitive chewing was observed to precede the sound of her family approaching or the rustle of a chocolate bag. This was interpreted as positive anticipation.
6	Helen and Ruth were observed to display greater expressions of awareness in the presence of their great-granddaughters. Within the context of the family visit, both Emily and Chloe appeared to accept comfortably their great-grandmother's symptoms of dementia.

Table 3

Common patterns of 'out-of-step' interactions by the participants living with dementia

Observation	'Out-of-step' interaction
1	A 7 to 15 second delay in responding was sometimes observed in Helen and Deborah in particular. This occurred when the non-speech member was cut short in response time or responses were not facilitated.
2	Tom and Helen often appeared hypervigilant to unexpected touch and environmental noise. Helen's hypervigilance was observed in her tendency to quickly open her eyes wide and look towards any experiences of unexpected touch, and her tendency to close her eyes, draw herself inwards and raise her hand against loud noise.
3	Helen was observed to use eye contact in communicative ways during incidences of relational conflict. She tended to direct and hold her gaze on the person she was interacting with, raise and lower her eyebrows and deliver voice. Eye contact appeared to powerfully convey meaning.
4	Helen used her voice in communicative ways, which she delivered in-turn, as in conversation. Rapidity, tone, volume, and direction of her voice sometimes appeared to convey displeasure. Her voice appeared to supplement or replace meaning otherwise conveyed through speech.
5	All the individuals with dementia displayed lower levels of awareness after extended interaction with relatives. Further attempts by such individuals to communicate appeared to cause them frustration.
6	Helen and Deborah were observed to become physically rigid for 30 seconds after family left.