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Severe dementia: *Relational Social Engagement (RSE)* during family visits.

Abstract

Objective: Few studies have utilised observation to investigate retained awareness when individuals with severe dementia interact with family members. Seeking evidence of retained awareness in those with severe dementia, interactive family visits in care homes were observed and analysed.

Method: Five family groups (14 individuals) completed 10/15-minute video recorded family interactions. Speech and non-speech interactions were analysed using Thematic Analysis.

Results: One superordinate theme: *Distinctive family bonds*; overarched two subthemes, *In-Step* and *Out-of-Step* describing positive and negative familial interactions. *In-step* interactions revealed family groups reciprocating *social support*, *having fun together*, and willing to go *on the ride* together. *Out-of-step* interactions characterised *social frustration*, *non-reciprocity*, and *sidelining* of members with dementia. Although awareness fluctuated, complex awareness was observed in the speech/non-speech expressions of those with dementia. In response, visitors appeared to treat those expressions and behaviours as understandable. Observed outcomes were *out-of-step* when visitors sought to retain the familiar and *in-step* when visitors sought to optimise all communication possibilities.

Conclusion: Video recorded family interactions and analysis revealed: (a) awareness was retained in the participants with severe dementia beyond assessed levels; and (b) *Relational Social Engagement (RSE)* occurred within family groups despite positive or negative interactions. Implications are discussed.

Keywords: *awareness; communication; dementia; families; Thematic Analysis*

Introduction

Family visits are important social opportunities for those living with dementia in care homes, especially when there is a limited availability of staff (Walmsley & McCormack, 2015a, 2015b, 2014). Even for residents in the profound stage of dementia, family visitors can facilitate their retained awareness beyond assessed levels, through interactions that are *in-step* (harmony, spontaneity, reciprocity) or *out-of-step* (disharmony, syncopation, vulnerability; Walmsley & McCormack, 2014). Where family visitors have the time to engage through sensory exchange and stimulation, connection is retained (McCormack, Tillock & Walmsley, 2016). However, when residents in these advanced stages of dementia respond ambiguously, staff can assume them to be “out of it” (Magai, Cohen, Gomberg, & Malatesta et al., 1996, p. 386) and family visitors can consider them to be “totally gone” (Boss, 2010, p. 141). In extreme circumstances, staff interact less and family members stop visiting (Boss, 2010; Magai et al., 1996; Walmsley & McCormack, 2016). However, further perspectives on retained awareness and social engagement when individuals in the severe stage of dementia interact with family visitors, could inform care.

Awareness represents a purposeful response to a specific aspect of one’s situation, functioning, or performance conveyed through speech, behaviour, and/or emotion (Clare, Marková, Roth, & Morris et al., 2011; Planalp, 1999). It is hierarchical, spanning sensory perception, movement and immediate appraisal, to goal directed behaviour and complex self-awareness calling upon judgement, attribution, comparison and reflection (Clare et al., 2011; Stuss, Picton, & Alexander, 2001). In the context of living with dementia, awareness fluctuates due to neuropathology, the individual’s response to living with dementia and their reactions to how others view and treat them (Clare, 2010; Downs, Clare & Mackenzie, 2006; Sabat, Napolitano, & Fath, 2004).

Where awareness has been studied during the severe stage of dementia, awareness ranges from sensory registration (Asplund, Norberg, Adolfsson, & Waxman, 1991; Magai et al., 1996; Norberg, Melin, & Asplund, 1986) to complex social engagement, especially when there is a positive researcher-individual relationship (Sabat, 2001). Relational intimacy and sincerity generate reciprocal vitality, positivity and playfulness between staff and residents (Götell, Brown, & Ekman, 2007; Normann, Asplund, & Norberg, 2002). Conversely, noisy environments or a lack of socialisation contributes to social withdrawal in residents living with dementia (Norberg et al., 1986). If staff come to see withdrawn residents as “non-people”, and “their own caring for the patient as meaningless and their work as worthless”, relationships can breakdown (Norberg, Helin, Dahl & Hellzen et al., 2006, p. 265).

However, family relationships are unique in both intimacy and duration, and their impact on awareness and social engagement in those living with dementia, is a new area of research. Indeed, if family visits decline, it can leave the in-resident family member in loneliness and unable to enjoy subsequent visits (Chang, 2013; Shin, 2011). In extreme cases, loneliness in residents living with dementia can give way to agitation, aggression, apathy and disinhibition (Bird, Llewellyn-Jones, Korten, & Smithers, 2007; Cohen-Mansfield, Dakheel-Ali, Marx, Thein et al., 2015). When this occurs and staff availability is limited, psychotropic medications become the first-line of treatment, despite the health risk over time (O’Neil, Freeman, & Portland, 2011). For these reasons, family visits present an important socialisation opportunity for residents living in the advanced stages of dementia

As a result, further insights into retained awareness and engagement during family interactions in the severe stage of dementia could inform care. Hence, this study seeks to interpret: (a) expressions of retained awareness in the speech, voice, facial expressions and body gestures of a family member living with severe dementia; and (b) the understanding and receptivity in the relatives reciprocating that individual’s expressions of awareness.

Method

Participants

Following ethics clearance, family members with guardianship status were invited to participate by the directors of aged care services at four care homes. Criterion for inclusion was an in-resident family member with severe dementia, as assessed by the directors using the Clinical Dementia Rating Scale (CDR: Morris, 1993, see Table 1).

Insert Table 1 here

Five family groups participated in the study (14 individuals, inclusive of a member with severe dementia; see Table 2).

Insert Table 2 here

Procedure

Participants were provided with details of the study and consent forms. All family members provided written consent for their participation directly or through a relative with guardianship status. Demographics were collected. The first author video-recorded two/15-minute visits per family at a time convenient to each family. Following an earlier study, fifteen-minute video-recorded observations provided rich examples of family interaction. Thus, the same time span was employed. The camera-recorder was set to run for non-obtrusive recording in the resident's room (Latvala, Voukila-Oikkonen, & Janhonen, 2000). To understand awareness-related phenomena, a broad conceptual framework was selected to accommodate the multi-faceted dynamic nature of awareness (Levels of Awareness framework: Clare et al., 2011). As such, a broad data-set of observable awareness (speech, voice, facial expressions, and body gestures) was selected.

Conceptual/theoretical underpinnings

From a critical realist stance, this study seeks to describe how the world is socially constructed, interpreted, and understood by family members. Aligned with symbolic

interactionism, meaning is assumed to be fluid, interpretable and derived from social interaction (Mead, 1934; Ashworth, 2000). As a result, this study does not seek to explain participants' psychological reactions and responses through a positivist construct of dementia, but rather provide a phenomenological investigation of their 'lived' experiences.

Analysis

Video-recorded family interactions (speech, vocalisation, facial expressions, and body gestures) were transcribed verbatim. Thematic Analysis offered an evidenced-based approach emphasising the value of ideographic insights for building upon theory (see Table 3; Braun & Clarke, 2006; Joffe, 2012; Willig, 2013).

Insert Table 3 here

Credibility

The primary author conducted the video-recorded observations and completed an initial thematic audit of the data. The two authors independently analysed the data. They then met to discuss and debate their independent interpretations arriving at agreed thematic evidence supported by vivid extracts. Unlike nomothetic research we did not seek causal evidence or inter-rater reliability. Instead, independent auditing aimed to deliver one account of the data that systematically achieved internal coherence and presentation of evidence (Braun & Clarke, 2006; Smith, Michie, Stephenson, & Quarrell, 2002; Spencer & Ritchie, 2012; Yardley, 2008). A supporting audit trail encompassed the video-recorded observations, transcripts, theme development, notes, diagrams and thematic definitions.

Authors' perspective

The first author has supported a parent who lived with dementia, and now works in the field of dementia care as clinical psychologist and researcher. The second author's clinical and research experience, in complex health and personal trauma, spans over two decades.

Results and analysis

Five family groups (14 individuals) participated in 10/15-minute video-recorded family interactions. Speech, voice, facial expressions, and body gestures were analysed using Thematic Analysis. One superordinate theme: *Distinctive family bonds*; overarched two subthemes, *In-Step* and *Out-of-Step* describing positive and negative familial interactions. *In-step* interactions were noted within family groups reciprocating *social support, having fun together*, and willing to go *on the ride* with their family member with dementia. *Out-of-step* interactions were characterised by *social frustration, non-reciprocity*, and *sidelining* of those with dementia. Although awareness levels fluctuated, complex levels of awareness were observed in the speech and non-speech expressions of those with dementia. In response, visitors appeared to treat those thoughts and behaviours as aligned with their own. When visiting relatives sought to retain the familiar, *out-of-step* outcomes were observed. However, *in-step* outcomes were observed when visitors were willing to optimise all communication possibilities (see Table 4). (Notation: Appendix). The results are presented on an individual level and patterns in broader types of communication are described.

Insert Table 4 here

In-step

During *in-step* attempts at social engagement, family members living in-residence showed unique interpersonal levels of awareness and social interaction that were embedded in *positive* distinctive family bonds. Visitors showed both flexibility and encouragement when responding to the thoughtful responses and postures of the resident, but treated the thoughts and behaviour of that person as aligned with their own.

Although common patterns of in-step interactions were observed, how each family dealt with the fluctuating awareness and engagement was unique. *In-step* patterns in communication were observed in visiting family members as: (1) checking hearing-aids and glasses; (2) positive eye contact to gain focused attention; (3) introducing the family visit

(e.g. reason for visit, name, relationship) and politely repeating this if necessary; (4) inviting engagement rather than demanding it; (4) short simple sentences; (5) staying on topic; (6) encouraging engagement through the senses; (7) avoiding repeated questions, especially direct questions taxing upon short-term memory; (8) allowing time for response; (9) reciprocating positivity and spontaneity; and (10) validating thoughts and emotions as aligned with one's own. In response, positive speech and non-speech expressions and gestures were common patterns in family members with dementia. For example, *in-step* non-speech patterns of communication included: (1) frequent eye contact, including looking to the relative; (2) frequent head nods; (3) leaning-in towards visiting relatives or objects such as family photos; (4) touch and holding hands; (5) kisses; (6) eye-crinkling smiles, laughter, laughter with upper body shaking; (7) relaxed facial expressions and body gestures; and (8) playful facial expressions and body gestures.

On the ride

On the ride interactions were experienced by visiting relatives as acceptance of social losses, flexible adjustment to developments, and positive approaches to engagement. Visiting family members were observed as being committed to reciprocity, and willing to optimise all communication possibilities.

Committed to authentic social connection with their partner, visiting spouses sought to invite their partner to engage, in way that was both respectful and accepting of social losses. As such, Joy made her social presence felt in a positive way with partner Harry. Her desire to reciprocate was observed in attempts to gain answers to confirm her interpretation of his wishes:

Joy: I've brought you something. (... *kneeling in front of him she holds a lunchbox towards him, holding his gaze*). I've come to see you. And I've brought you something. Your favourite. Well I think it's your favourite? Look.

Harry (PSD): *(Harry looks down into the container).*

Willing to follow the social lead of their partner with dementia, visiting wives were rewarded with unexpected intimacy. The artistic expression of dance was observed as a distinctive familial bond embedded in shared and personally meaningful memories, in turn facilitating Harry's complex goal-directed movements:

Harry (PSD): *(Stands up).*

Joy: Oh, we getting up? *(Kneeling, she moves aside and stands to join him).* Where are we going? *(She holds his right hand).* Do you want to dance?

Harry (PSD): *(Places his left hand in her right hand).*

Joy: *(Starts to sing).*

Both: *(They start swaying from side to side. Harry prompts Joy to pirouette ... They both stop dancing, and in unison bend their knees once).*

When the loci of self-awareness shifted from the head to the heart, love was observed as a distinctive and positive marital bond. In response, non-speech expressions and gestures of visiting relatives indicated reciprocity:

Pam (PSD): I don't know why I was late. *(She turns to look at him).* All I care about is you.

Doug: Is it darling? Well you're the love of my life. ... *(Holding her gaze he strokes the top of her fingers with his thumb. He swallows back tears and squeezes her hand).*

Social support

Social support was observed as a reciprocal need for social support between family members, regardless of dementia. This was observed as emotional support (expressions of empathy, understanding, and caring), esteem support (positive regard, encouragement, and validating self-worth), and information support (providing information and advice). Calling

upon complex levels of awareness in those with dementia, such awareness was observed to be reciprocated through speech and non-speech communication of in-resident members that was interpreted as appropriate and in context. The positive responses by visiting family members validated and maintained interactions.

In recognising his wife as a custodian of family history, Doug sought information to benefit their family. Pam's efforts to 'cover-up' her social losses were validated by Doug in a positive and sensitive way. His desire to reciprocate was observed in attempts to confirm his interpretation of Pam's level of interest, and his ongoing support of her esteem through encouragement and validation:

Doug: I found some photos at home. I brought them down just for you to tell me what and where they are. *(He moves his right hand several times back and forth across the back of a photo).*

Pam (PSD): *(Nods several times at Doug).* Oh right. Good on you Doug. *(She looks slightly away).* Cause I was, I was going to, going to *(Pam stutters and looks towards Doug. He continues stroking her fingers with his thumb)* start to do that-

Doug: -Were you?

Pam (PSD): -but I didn't get around to it.

Doug: Yeah there's a couple there ... that you've written on the back. —
Happy about that?

For the remainder of this family visit, Doug and Pam worked through a set of photos. With his encouragement, patience, and occasional prompting, Pam provided information on most of the photographs, as Doug recorded the details onto the back of the photographs.

Recognition was experienced as both a sense of achievement and positive relational reconnection:

Pam (PSD): Ah-

Doug: *(His face breaks into an eye-crinkling smile).*

Pam (PSD): *-yeah. (Her face breaks into a broad smile).*

Doug: *(Chuckles with belly shaking, eye-crinkling smile, looking at Pam's face).*

Dementia was disregarded when family members, now running all aspects of the household, continued to seek family expertise from a loved one with dementia. The commitment of in-resident members to reciprocate was observed in attempts to offer information and advice:

Dawn: That new bull.

Ross (PSD): Yeah?

Dawn: He's getting a bit aggressive.

Ross (PSD): That's the way they go.

Dawn: I know, but the last one didn't ...

Ross (PSD): Some are placid and some aren't. ... The Black Pole comes out in them ... they get a bit toey.

Dawn/Lisa: He's pawing the ground.

Ross (PSD): You got the horns off him? ... You can't have him around.

In need of social support, Ross receives both emotional support (expressions of empathy, understanding, and caring), esteem support (unconditional positive regard, encouragement, and validating self-worth) from his visiting wife and adult-daughter. Unfazed by Ross' upsetting and retrospective self-evaluation, Dawn and Lisa's empathic validation supported his more positive perspective on current social losses, which was interpreted from his relaxing facial expressions:

Ross (PSD): The last 12 months, I've been hopeless. *(Ross's voice is emotional and faint. He starts to cry).*

Dawn: Oh but you couldn't help that. It was ... the illness. ... It's a hard slog isn't it? *(Dawn kisses Ross on his right temple. ... She squeezes*

him in her embrace and ... then drapes her left arm over his shoulder to hold and occasionally rub his shoulder with her hand, while she cups his right knee against her right hand).

Lisa: It's been really hard Dad, (she extends her right hand to touch his left hand), but gosh, you've handled it all so well. I'm really proud of the way you've handled this ... You've been a great example to us. ... I really admire you Dad.

Ross: *(His face starts to relax).*

Lisa: Really; you've had an amazing life. And it's still continuing. There's always change isn't there? You should be proud of yourself. Are you?

Dawn/Lisa: *(Dawn turns to look at his face. Lisa holds eye contact with him).*

Lisa: ... Just think about it.

Ross: *(His face relaxes further).*

Having fun together

Familial bonds for having fun together were observed during storytelling and physical play. Absorbed in shared memories or activity, the fun of the moment presented all family members with opportunities for reciprocal well-being. Meaningful memories were seen to encourage two-way and three-way chatty conversations:

Cathy: They had beautiful big pancakes.

Esther (PSD): Oh yes, yes.

Cathy: Yes, they had beautiful big pancakes there.

Megan: Chocolate for breakfast. *(Everyone laughs).*

Esther (PSD): Yes. Yes!

Cathy: Only on holidays. Look!

Esther (PSD): Oh, look at the whole family. *(Everyone laughs).*

Opportunities for reciprocal well-being were also observed in commitment to change familiar ways of interacting. By flexibly reciprocating Harry's energetic and playful expressions, Joy validated Harry's thoughts and behaviour as aligned with her own. Immersed in the moment, interactions between Joy and Harry became increasingly spontaneous and almost automatic:

Joy: Do you want to play ball?

Harry (PSD): *(Harry moves his left hand, palm perpendicular in a slow loping left-right-circular motion. He opens his eyes, looks at the ball and smiles.... As they play his facial expressions become more animated and he starts to mumble with voice ... He smiles and throws the ball high ...)*

Becoming increasingly animated, Harry initiates a non-speech joke. Joy's reaction's and response appear to confirm this:

Harry (PSD): *(He leans forward from his waist, smiling, holding Joy's gaze, raises his eyebrows briefly, and moves in a way that suggests he will throw the ball high. Instead he quickly throws the ball low and straight to Joy).*

Joy: Ooop! *(Catches the ball, chuckling she quickly crouches down and then jumps up while stomping her feet, twisting her body around and leaning towards Harry with her arms outstretched).*

Harry (PSD): *(He leans back, raises his eyebrows, and with an eye-crinkling broad smile and his upper body shaking he chuckles, still holding Joy's gaze).*

Joy: You think that's funny!

As their playfulness gathered momentum, Harry started to speak. This presented reciprocal opportunities for well-being and validation of Joy's desire to reciprocate:

Harry (PSD): That was a good one. *(Smiling, he holds Joy's gaze).*

Joy: (*Laughs*). That was a good one. Yes. ... It makes a funny noise
 doesn't it? Listen. (*Bounces the ball across to him*). Makes a funny
 noise; can you hear?

Harry (PSD): (*Tilts his head, and rotates his head left to right, smiling*).

Commitment to reciprocate was observed in creative self-reflection and responses that compensated for communication losses:

Harry (PSD): (*Looks at Joy's face, runs his palm across the top of the ball and
 raises his eyebrows*). It's a very nice colour. ... It's a very nice one.

Joy: (*Smiles at him*). It's a nice ball, yeah. ... Do you know what colour it
 is?

Harry (PSD): It's the colour I like.

Out-of-step

Conversely, during *out-of-step* interactions, unique interpersonal levels of awareness and social interaction in family members with severe dementia were embedded in negative yet distinctive family bonds. During *out-of-step* interactions, family interactions evoked a reciprocal sense of syncopated irritation, frustration, rejection, and escape.

Each family group was unique in how they dealt with the fluctuating awareness and engagement, although common *out-of-step* interactions were observed. *Out-of-step* patterns in communication were observed in visiting family members as: (1) few attempts to confirm interpretation of the person's wishes; (2) demanding engagement rather than inviting it; (3) long complex sentences; (4) fast and rapidly changing topics; (5) fast changing and difficult questions, especially direct questions taxing upon short-term memory or requiring complex comparisons; (6) outpacing; (7) ignoring; (8) overlooking social cues of negativity; and (9) invalidating responses and reactions, including physically blocking the person from moving.

In response, negative speech and non-speech expressions and gestures were common patterns in family members with dementia. *Out-of-step* non-speech patterns of

communication included: (1) infrequent eye contact, including looking away from a relative, and looking about the room; and (2) during discord: (a) eyeballing visitors; (b) frowning; (c) biting bottom lip; (d) scratching elbows, face, behind ears, back of head; and agitatedly rubbing hands together; (e) groans and sighs; (f) frequent leaning away from a relative; (g) withdrawing or retracting from touch; and (h) attempting to walk away, or eventual slumped posture while looking downwards.

Social frustration

Social frustration was observed as negative patterns of communication involving fast changing and difficult questions by visitors and subsequent frustration in those with dementia. When social frustration spilled over to visitors as well, carer demands escalated to reveal spousal power plays and issues of control.

Impatience in visiting relatives disregarded social cues of negativity. For example, Ron became increasingly anxious and agitated as his visiting wife continued to ask questions that he could not answer:

Betty: Listen, have you got a new mate in your bedroom have you?

Ron (PSD): (*Slightly turns towards Betty and groans*). Ohhh, I don't know.

Betty: Listen, did you have a good sleep? (*She looks at Ron*).

Ron (PSD): (*Ron looks at Betty*).

Betty: You don't know?

Ron (PSD): (*Looks downwards*). No I don't.

Betty: And have you been going for walks with Dianne? (*Places her left hand on his right hand and leans into him*).

Ron (PSD): (*Sighs, rubs his palms together, looking downwards*). I don't know!!

Feeling powerless to positively change the communication patterns of visiting relatives, agitation in residents gave way to sarcasm:

Betty: Who was your best friend?

Ron (PSD): I suppose not me!

Betty: Bill Hamilton?

Ron (PSD): Well you can find out from him!

Where sarcasm was reciprocal, power plays emerged. Feeling helpless to re-engage spouses in care, visitors' frustration with self as carer gave way to carer-demands. Correctly sensing a challenge to self, in-residence spouses reciprocated with demands of their own, leaving their visitors appearing defensive:

Dawn: (*Dawn raises her voice speaking to Ross*). Well I'm here!

Ross (PSD): (*Turns to stare at Dawn*). That's a rare occurrence. I can tell you.

Dawn: Oh does it seem rare does it? I was only here on Thursday. Today's Tuesday. ...

Ross (PSD): (*Still staring at Dawn, he twists his body to scratch his leg*). How many visits out of — four days though were you here?

Underpinned by what appeared to be negative marital dynamics, power plays revealed marital suspicion and mistrust:

Ross (PSD): So who's — who's living out there?

Dawn: Me. Just me. — And Blue.

Ross (PSD): Blue what?

Lisa/Dawn: Blue, the dog.

Non-reciprocity

When social cues were overlooked or disregarded by visitors for too long, residents sought to reject and escape their visitors through social excuses, walking away, or self-withdrawal. At those times, residents appeared vulnerable in their desperation or subjugation.

For example, Esther pushed her family away towards the end of the family visit, leaving her visitors appearing uncertain and on-edge. Esther appeared vulnerable in desperation:

Megan: Do you want to come and have a cup of tea now?

Esther (PSD): Oh I think I might have to go. ... I'll have to be in a hurry. I've got to go down to Geelong, um, a long time ago ... I've got to go to oh-oh dear-o-dear ... Oh my god I won't be able to do that!

Megan: How about we go and have a cup of tea first?

Esther (PSD): No! No! No!!

During such discord, touch was no conduit for repair. Physically blocked from being himself, Ron sought to both reject his wife and escape. Responding inflexibly to Ron's negative evaluation, Betty's enforcement disregarded opportunities for reparative interactions:

Betty: *(She reaches to touch his hand).*

Ron (PSD): *(He withdraws his right hand from her touch. Ron pushes back with both hands against the arm of the chair but is unable to stand up because of Betty's left hand against his chest).*

Betty: No sit down. Sit down. No. No. No. Sit down ...

Ron (PSD): *(Turns to look at Betty).* Oh what are you talking about?!

When physical escape was impossible, in-residence members chose to self-withdraw. They appeared vulnerable in their apparent subjugation:

(Sitting at 45 degrees to Ron [PSD], Betty holds her left hand on Ron's [PSD] right shoulder, looking at his face as she continues asking questions. Responding little, Ron [PSD] sits with his shoulders slumped, hands on his knees, eyes cast downwards).

Sidelining

When cues of verbal communication appeared to outpace family members with dementia, and restrictive care practices reinforced depersonalisation, the best intentions of visitors to retain the familiar paradoxically sidelined those with dementia.

Seeking to retain familiar standards of dress for mothers in care, pushy adult-daughters unintentionally sidelined their mothers:

- Pam (PSD): Oh careful Tracy!
- Tracy: Oh sorry. (*Tracy, bent at the waist, forcefully attempts to put a shoe on Pam's foot*).
- Pam (PSD): Don't go too- (*Frowns, looking at Tracy who is bent-over adjusting Pam's shoe*).
- Tracy: -Mum-
- Pam (PSD): -rough! (*She frowns, watching her daughter bent-over adjusting Pam's shoe*). ... Arrghh!! ... Oh careful!

When at-home rituals collided with in-care routines, the social rhythms of in-resident family members were sidelined by the system. Attempts by wives to personalise care were disregarded. Operational priorities increased the shadow of dementia over all aspects of life:

- Dawn: Have you been having some of your special port of a night?
- Ross (PSD): No. ... I'm asleep before then.
- Dawn: Because I bought some ... down for you.
- Ross (PSD): Waste of time. ... Take it home.

When efforts to personalise care for a mother failed, regression briefly emerged in an adult-daughter. Not only sidelined by the system, the mother was paradoxically sidelined by the best intentions of her discordant family members. Paradoxically, her well-being was not supported:

- Tracy: Why don't we- (*Looking from the wall to Doug, oscillates her hand with thumb extended from her chest to the wall*).
- Doug: (*Looking at Tracy, his mouth ajar*).
- Tracy: -pretty this place up a bit? (*Crosses her arms, sighs*)
- Doug: Well how? (*Looking at Tracey, Doug shifts in his chair, frowns and holds his right hand up palm facing up. Then he holds his left hand*

palm-forward touching each finger as he speaks each point). She doesn't like the TV; doesn't like the radio; doesn't want a fridge.

Pam (PSD): *(Leans back, looks away from her feet, settling into her chair. She adjusts her glasses, clasps her hands in front of her chest. Rubbing the top of her right hand against the palm of her left, she looks at Tracy).*

Tracy: Doesn't have to be a TV. Doesn't have to be any of those things, but what about a vase with flowers in it? ... nothing can go up on the wall can it?

Discussion

Differently, this phenomenological study sought the experiences of those living with severe dementia to identify unique interpersonal levels of awareness and social interaction during family visits. The results were presented on an individual level and patterns in broader types of communication were described. The study findings indicate that (a) awareness was retained beyond assessed levels in those with severe dementia during family interactions; and (b) *Relational Social Engagement (RSE)*, whereby individuals display optimal engagement within family groups, was evident despite whether interactions were positive or negative. Uniquely, no researcher was present during the video-recorded interactions in this study, and interactions took place in privacy between immediate family members during a family visit 'as usual'. It was observed that families could be both *in-step* when visitors were willing to optimise all communication possibilities, and *out-of-step* when visiting relatives sought to retain the familiar. Additional *in-step* interactions were noted within family groups experiencing reciprocal *social support, having fun together*, and relatives willing to go *on the ride* with their family member with dementia. Further *out-of-step* interactions were observed as experiences of *social frustration, non-reciprocity*, and *sidelining* of those with dementia.

Within this study, although awareness levels fluctuated in family members with severe dementia, complex levels of awareness were observed in their speech and non-speech expressions during family visits. In response, visiting family members appeared to treat those thoughts and behaviours as aligned with their own. Observed levels of awareness ranged from sensory perception (e.g. Harry listening to the sound of the bouncing ball) and appraisals in the moment (e.g. Ron withdrawing his hand from his wife's touch) to complex goal-directed movement (e.g. Harry initiating dance) and retrospective self-evaluation (e.g. Ross' negative self-assessment for the previous 12 months). However, awareness levels appeared to fluctuate when those with dementia were challenged in their sense of continuous self. For example, Pam seeks to restore the status quo when she excuses her failure to record family photographic history because she "didn't get around to it". On one hand, Pam may have lacked awareness of change in her continuous self. On the other, she may have chosen a self-serving cover to maintain her sense of self as a custodian of family history.

The familial interactions within this study indicate that awareness was retained beyond assessed levels in all participants with severe dementia. The unique interpersonal levels of awareness and social interaction identified during the family visits were inconsistent with expectations set by the CDR (see Table 1). Although the CDR is a widely used and evidence-based dementia staging tool, like most other staging tools, it was developed before biopsychosocial views of disease (O'Bryant, Waring, Cullum, Hall et al., 2008; Rikkert, Tona, Janssen, & Burns et al., 2011; World Health Organisation [WHO], 2002). Within a construct of disease, investigation of the individual's social world and response to living with dementia may be overlooked. When functioning becomes reduced to set of categories and social abilities are decontextualised, the individual can be lost. In some cases, this extends to dementia stage-specific activities programming in which everyone in a particular category is

assumed to have the same needs despite most staging tools overlooking more complex and integrative forms of engagement (Power, 2014).

Furthermore, the unique relational interactions depicted in this study indicate that family visits present opportunities to express aspects of self, both negative and positive. For example, opinions (e.g. Harry: “It’s the colour I like”), beliefs about past and present attributes (e.g. Ross: “The last 12 months, I’ve been hopeless”), and various familial roles that were manifest in visitors. At times, those with dementia in this study conveyed their wishes to visiting family members through symbolism (e.g. Esther: “I’ve got to go down to Geelong, um, a long time ago”), rather than literally asking her family to leave. Furthermore, when these residents were anchored less in a place of cognition and more in a place of emotion, more authentic and genuine interactions were supported. For example, rather than discussing what someone had for breakfast, the topic moved to life-long love and marital commitment. Connection was made on a simpler and deeper level. However, when visiting family members remain caught up in frustrations of loss and a focus on deficits it may block their ability for more powerful yet subtle connections. Additionally, the momentary relational interactions depicted in this study suggest that family visits offer opportunities to restore psychosocial needs, for both residents and visitors. As such, desires to be taken seriously and feel useful, and experiences of belonging, connection, excitement, love, and even control were interpreted within familial interactions. However, when visitors overlooked the psychosocial needs of a family member with dementia, a reciprocal and commensurate response was observed in the resident. Hence, neither visitor nor resident experienced psychosocial needs fulfilment.

However, family visits may have the potential to ameliorate social isolation and loneliness that otherwise become a nexus of behavioural and psychological symptoms of dementia (Bird et al., 2007; Cohen-Mansfield et al., 2015). Indeed, in the severe stage of dementia, the efforts of family members to support and restore interpersonal awareness levels

and social interaction may be more important than ever before. However, when dementia disrupts interpersonal levels of awareness and social abilities, it requires new knowledge and skills in family members to facilitate effective communication. When that literacy and ability is lacking, and the member with dementia is assumed non-communicative, connections become broken and low expectations create a downward spiral of self-fulfilling prophecy. Furthermore, behavioural and psychological symptoms of dementia are directly correlated with family carer stress (Bradshaw, Goldberg, Schneider, & Harwood, 2013; Finkel, Costa e Silva, Cohen, Miller, & Sartorius, 1996; Woods, 2001), making social phenomenology from the perspectives of those with dementia and their family carers, an increasing governmental and care provider concern (Wimo & Prince, 2010).

In addition, poor remuneration and inaccessible training contribute to high staff turnover (Sargent, Harley, & Allen, 2008, 2009, 2010), which cumulative upon rotating staff rosters is likely to confuse residents and reduce interpersonal familiarity and trust with those who provide daily hands-on support. Indeed, the quality of moment-by-moment interpersonal experiences is believed to shape both resident wellbeing and sense of integrity as individuals (Nuffield Council on Bioethics, 2009), especially when emotional memory that forms through frequent interactions with another person, wither negative or positive, becomes more durable as dementia advances than memory for names, dates, and places (Power, 2014). Given the limited availability of care practitioners and high turnover of staff related to poor remuneration, inadequate training, time pressure, and emotional labour (Bailey, Scales, Lloyd & Schneider et al., 2015; Beck, Törnquist, Broström, & Edberg et al., 2012; Erickson-Lidman, Norberg, Persson, & Strandberg, 2013; Walmsley & McCormack, 2015a), family visits are an important opportunity for residents with dementia to socialise in a personally meaningful way. As a result, the findings of this study have implications for relationships

beyond family. In particular, opportunities for an individualised family focus to recover opportunities for RRSE, and translation to the relationships between staff and residents.

Within family groups, what appeared to be *distinctive family bonds* were observed, ranging from love, play, storytelling, and social support through to suspicion, mistrust, and power plays. Despite whether interactions were positive or negative, this study identified *Relational Social Engagement (RSE)* (see Figure 1), whereby individuals display optimal engagement within family groups. Conceptually, RRSE integrates the ability to access retained awareness and relational social engagement not previously expected during assessment. Situations where this can occur can be *in-step* or *out-of-step* and therefore positive or negative. The authors define RRSE as a complex and accessible set of relational interactions between family members that is situated in distinctive family bonds.

Although it may be difficult for those with dementia to challenge pathologising social views and treatment (van Lagenhove & Harré, 1999), this study offers a unique and qualitatively different perspective. Observed during complex negative interplay, when either resident or visitor was ignored, challenged or criticised, the responses of the other member indicated appropriate hurt, retort, or annoyance. As a result, residents were found not only to retain family membership but retain integrity as individuals. It would seem that *distinctive family bonds* within family groups offered the security and comfort for those with dementia to both spontaneously enjoy common ground and express differences.

Insert Figure 1 here

Limitations and strengths

Challenging aspects of this study were interpreting participant responses and interpreting subsequent awareness, especially when speech was limited or absent. However, the responses of visiting relatives lent support. Despite involving researcher interpretation, independent auditing brought credibility (Braun & Clarke, 2006). Although these families

may have been more positively engaged than others, the family visits did not restrict negative interplay. Nor did we seek generalisability, but the ‘lived’ experiences of a purposive sample. With the camera-recorder set to run, video-recording remained as unobtrusive as possible, and staging was not observed.

Conclusions and Recommendations

This study addresses an important dimension of the ‘lived’ experiences of individuals with severe dementia and their family members. In particular, it offers a window into the creativity that families bring to the dementia experience to remain connected socially, emotionally, and physically. Within this study, awareness was retained beyond assessed levels in those with severe dementia during family interactions; and *Relational Social Engagement (RSE)*, whereby individuals display optimal engagement within family groups, was evident despite whether interactions were positive or negative. *RRSE* highlights that embodied experiences, emotions, and familial relational connection become increasingly central to the social experiences of individuals in the later stages of dementia. The findings of this study suggest that focusing on family members is important and beneficial within dementia care, particularly when social isolation and loneliness in residents may become a nexus of behavioural and psychological symptoms of dementia, increasing stress for family carers, and relational breakdowns for staff. Thus, the study findings have implications for relationships beyond family, in particular those with staff, which could benefit from new perspectives on retained awareness, *in-step/out-of-step* communication, and psychosocial needs for harmonious, spontaneous, and reciprocal quality of care for longer than previously anticipated on the dementia journey.

References

- Ashworth, P. D. (2000). *Psychology and 'human nature'*. Hove, UK: Psychology Press.
- Asplund, K., Norberg, A., Adolfsson, R., & Waxman, H.M. (1991). Facial expressions in severely demented patients - a stimulus-response study of four patients with dementia of the Alzheimer type. *International Journal of Geriatric Psychiatry*, 6, 599-606.
- Bailey, S., Scales, K., Lloyd, J., Schneider, J., & Jones, R. (2015). The emotional labour of health-care assistants in inpatient dementia care. *Ageing and Society*, 35(2), 246-269.
- Beck, I., Törnquist, A., Broström, L., & Edberg, A. (2012). Having to focus on doing rather than being: Nurse assistants' experience of palliative care in municipal residential care settings. *International Journal of Nursing Studies*, 49, 455-464.
- Bird, M., Llewellyn-Jones, R., Korten, A., & Smithers, H. (2007). A controlled trial of a predominantly psychosocial approach to BPSD: Treating causality. *International Psychogeriatrics*, 19(5), 874-891.
- Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, 59, 137-145.
- Bradshaw, L. E., Goldberg, S. E., Schneider, J. M., & Harwood, R. H. (2013). Carers for older people with co-morbid cognitive impairment in general hospital: Characteristics and psychological wellbeing. *International Journal of Geriatric Psychiatry*, 28, 681-690.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101.
- Chang, S. J. (2013). Lived experiences of nursing home residents in Korea. *Asian Nursing Research*, 7, 83-90.
- Clare, L. (2010). Awareness in people with severe dementia: Review and integration. *Aging & Mental Health*, 14(1), 20-32.

- Clare, L., Markova, I. S., Roth, I., & Morris, R. G. (2011). Awareness in Alzheimer's disease and associated dementias: theoretical framework and clinical implications. *Aging & Mental Health, 15*(8), 936-944.
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., Regier, N. G. (2015). Which unmet needs contribute to behaviour problems in persons with advanced dementia? *Psychiatry Research, 228*, 59-64.
- Downs, M., Clare, L., & Mackenzie, J. (2006). Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort. In J. C. Hughes, S. L. Louw, & S. R. Sabat (Eds.). *Dementia: Mind, meaning and the person*. (pp. 235–258). Oxford University Press, Oxford.
- Erickson-Lidman, E., Norberg, A., Persson, B., & Strandberg, G. (2013). Healthcare personnel's experiences of situations in municipal elderly care that generate troubled conscience. *Scandinavian Journal of Caring Sciences, 27*(2), 215-223.
- Finkel, S. I., Costa e Silva, J., Cohen, G., Miller, S., & Sartorius, N. (1996). Behavioral and psychological signs and symptoms of dementia: A consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics, 8*(Suppl. 3), 497-500.
- 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.
- Joffe, H. (2012). Thematic Analysis. In Harper, D., & Thompson, A. R. (Ed.). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. (pp. 209-223). Chichester, UK: Wiley–Blackwell.

- Latvala, E., Voutilainen-Oikarinen, P., & Järnäs, S., (2000). Videotaped recording as a method of participant observation in psychiatric nursing research. *Journal of Advanced Nursing*, 31, 1252-1257.
- McCormack, L., Tillock, K., & Walmsley, B. D. (2016). Holding on while letting go: Trauma and growth on the pathway of dementia care in families. *Aging & Mental Health*: <http://dx.doi.org/10.1080/13607863.2016.1146872>
- 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.
- Mead, G. H. (1934). *Mind, self and society*. Chicago: University of Chicago Press.
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology*, 43(11), 2412–2414.
- Norberg, A., Melin E., & Asplund, K. (1986). Reactions to music, touch and object vation in the final stage of dementia. An exploratory study. *International Journal of Nursing Studies*, 23(4), 315-323.
- 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.
- Norberg, K., Helin, Y., Dahl, A., Hellzen, O., & Asplund, K. (2006). Nurses' attitudes towards people with dementia: the semantic differential technique. *Nursing Ethics*, 3, 264-274.
- Nuffield Council on Bioethics. (2009). *Dementia: ethical issues*. Cambridge, UK: Cambridge Publishers.
- O'Bryant, S. E., Waring, S. C., Cullum, C. M., Hall, J., Lacritz, L., Massman, P. J., Lupo, P. J., Reisch, J. S., Doody, R., and Texas Alzheimer's Research Consortium. (2008).

- Staging dementia using clinical dementia rating scale sum of boxes scores. *Archives of Neurology*, **65**, 8, 1091-1096.
- O'Neil, M. E., Freeman, M., & Portland V. A. (2011). *A systematic evidence review of nonpharmacological interventions for behavioral symptoms of dementia*. Washington, DC: Department of Veterans Affairs.
- Planalp, S. (1999). *Communicating Emotion: Social, Moral and Cultural Processes*. Cambridge: Cambridge University Press
- Power, G. A. (2014). *Dementia beyond disease. Enhancing well-being* Baltimore, USA: Health Professions Press.
- Rikkert, M. G., Tona, K. T., Janssen, L., Burns, A., & Lobo, A., Robert, P., Sartorius, N., Gabriela Stoppe, G., & Waldemar, G. (2011). Validity, Reliability and Feasibility of Clinical Staging Scales in Dementia: A Systematic Review. *American Journal of Alzheimer's Disease & Other Dementias*, **26**(5), 357-365.
- Sabat, S. R. (2001). *The experience of Alzheimer's disease: life through a tangled veil*. Oxford: Blackwell Publishers Ltd.
- Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, **19**(3), 177-185.
- Sargent, L., Harley, B., & Allen, B. (2008). Working in Aged Care: Medication Practices, Workplace Aggression, and Employee and Resident Outcomes. *Commissioned by the Australian Nursing Federation (Victorian Branch)*. Melbourne, Australia: University of Melbourne.
- Sargent, L., Harley, B., & Allen, B. (2009). Working in Aged Care: The Second Report. *Commissioned by the Australian Nursing Federation (Victorian Branch)*. Melbourne, Australia: University of Melbourne.

Sargent, L., Harley, B., & Allen, B. (2010) Working in Aged Care: The Third Report.

Commissioned by the Australian Nursing Federation (Victorian Branch). Melbourne: Australia: University of Melbourne.

Shin, K. A. (2011). Defamilisation of elderly care and the experiences of the aged. *Korean Journal of Sociology*, 45(4), 64-96.

Smith, J. A., Michie, S., Stephenson, M., & Quarrell, O. (2002). Risk perception and decision making in candidates for genetic testing in Huntingdon's disease: An interpretative phenomenological analysis. *Journal of Health Psychology*, 7, 131-144.

Spencer, L., & Ritchie, J. (2012). In pursuit of quality. In D. Harper, & A. R. Thompson, (Ed.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 209-223). Chichester, UK: Wiley-Blackwell.

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.

van Lagenhove, L. & Harre, R. (1999). Positioning and personhood. In R. Harre & L. van Lagenhove (Eds.), *Positioning Theory: moral contexts of intentional action*. (pp. 32-52). Oxford: Wiley-Blackwell.

Walmsley, B. D., & McCormack, L. (2014). The dance of communication: Retaining family membership despite severe non-speech dementia. *Dementia*, 13(5), 626-641.

Walmsley, B. D., & McCormack, L. (2015a). Stigma, the medical model, and dementia care: Psychological growth in senior carers through moral and professional integrity. *Dementia*: <http://dx.doi.org/10.1177/1471301215574112>

Walmsley, B. D., & McCormack, L. (2015b). Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*: <http://dx.doi.org/10.1177/1471301215573676>

- Walmsley, B. D. & McCormack, L. (2016). Synthesis of meaning: Negative and positive change in family members following the adversity of dementia. *Journal of Humanistic Psychology*: <http://dx.doi.org/10.1177/0022167814557547>
- Willig, C. (2013). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. (3rd ed.), Berkshire, UK: McGraw–Hill Professional Publishing.
- Wimo, A., & Prince, M. (2010). *World Alzheimer report 2010: The global economic impact of dementia*. London, UK: Alzheimer's Disease International.
- Woods, R. T. (2001). Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects. *Aging & Mental Health*, 5(Suppl. 1), S7-S16.
- World Health Organisation [WHO]. (2002). *Towards a common language for functioning, disability and health. The international classification of functioning, disability and health*. Geneva, Switzerland: World Health Organisation.
- 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

—	A pause in speech.
...	Removal of nonessential material.
^	Demographic information not previously requested.
PSD	Person with severe dementia

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Table 1

Clinical rating of severe dementia (CDR; Morris, 1993)

Stage	Rating	Symptoms
Severe	3 (scale 0 to 5)	<ul style="list-style-type: none"> • Severe memory loss only fragments remain. • Totally or almost totally disoriented. • No pretence of independent function off the unit. Appears too ill to be taken to functions off the unit or needs one to one assistance in all activities off the unit. • Requires total assistance with personal care; frequently incontinent. • No significant function in room or on the unit. • Unable to make judgements or solve problems; unable to seek appropriate help, needs staff help in all matters.

Table 2

Family groups at the time of video-recording

In-resident member, age (years)	Visitor/s, age (years), relationship	Caregiving (years)
Ross, 72	Dawn, 71, Wife	4
	Lisa, 48, Daughter	
Harry, 84	Joy, 80, Wife	4
Esther, 80	Megan, 57, Daughter	5
	Cathy, 27, Grand-daughter	
	Claudia, 2, Great-grand-daughter	
Ron, 84	Betty, 76, Wife	5
Pam, 74	Doug, 77, Husband	6
	Tracey, 51, Daughter	

Table 3

Stages of Thematic Analysis (Braun & Clarke, 2006)

Stage	Process
1	Researcher sets aside their pre-existing assumptions about the research phenomenon and literature.
2	Viewing the videos and reading the transcripts several times each, for note making and a sense of the participants' expressed awareness.
3	Viewing of the videos and reading the transcripts again, to develop initial psychological concepts.
4	Clustering the psychological concepts into themes and subthemes, while retaining the participant's authentic speech and non-speech expressions.
5	Generating a thematic map of themes and subthemes.
6	Refining the essence of each theme, noting convergence and divergence across the data set.
7	Supporting the themes with rich data extracts. Interpreting extracts in the context of the research phenomenon and literature.
8	Reflection by the researcher on their pre-existing assumptions that could influence their interpretation of the data. This is supported by an independent audit of the data with consensus reached through robust debate.

Table 4

Superordinate theme: Distinctive Family Bonds; overarching sub-themes

<i>In-step family interactions</i>
<ul style="list-style-type: none"> ▪ <i>On the ride</i>: Visitors' spontaneous adjustment to developments, and willingness to optimise all harmonious communication possibilities. ▪ <i>Social support</i>: Reciprocity of: (a) emotional support (empathy, understanding, caring); (b) esteem support (positive regard, encouragement, validating self-worth); (c) information support (information, advice). ▪ <i>Having fun together</i>: When immersed in fun, family interactions became energetic and almost automatic.
<i>Out-of-Step family interactions</i>
<ul style="list-style-type: none"> ▪ <i>Social frustration</i>: Negative communication patterns involving fast changing and difficult questions by visitors, social frustration, carer demands, and power plays. ▪ <i>Non-reciprocity</i>: Unable to positively influence family interactions by the end of a family visit, those with dementia sought to reject and escape their visitors. ▪ <i>Sidelining</i>: Verbal outpacing by visitors, restrictive care practices, and efforts to retain the familiar that paradoxically sidelined those with dementia.

Figure 1

Relational Social Engagement (RSE) during In-Step and Out-of-Step communication