NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

Walmsley, Bruce, McCormack, Lynne "Shame, hope, intimacy and growth: dementia distress and growth in families from the perspective of senior aged care professionals"
Published in Dementia Vol. 15, Issue 6, p. 1666-1684 (2016)

Available from: <http://dx.doi.org/10.1177/1471301215573676>

Walmsley, Bruce, McCormack, Lynne, Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals, Dementia (Vol. 15, Issue 6) pp. 1666-1684. Copyright © 2016 The Author(s). Reprinted by permission of SAGE Publications

Accessed from: <http://hdl.handle.net/1959.13/1328630>

**Shame, hope, intimacy and growth:
Dementia distress and growth in families from the perspective of
senior aged care professionals**

Bruce Walmsley ¹,

Lynne McCormack PhD¹,

¹ *University of Newcastle, Australia*

Acknowledgements:

We would like to acknowledge the generous contribution of the participants.

Address for correspondence:

Lynne McCormack PhD

Senior Lecturer/Clinical Psychologist

School of Psychology

Faculty of Science and Information Technology

University of Newcastle

Callaghan NSW 2308 Australia

E-mail: Lynne.McCormack@newcastle.edu.au

Ph: +61 249854543

**Shame, hope, intimacy and growth:
Dementia distress and growth in families from the perspective of
senior aged care professionals**

Abstract

Minimal research explores the impact of dementia and a dementia diagnosis on families from the unique vantage of senior health professionals. The participants of this study, eight senior aged care professionals provided unique interpretative insights into family dynamics and sense making on the journey with dementia, and their own role in that journey. Both positive and negative perspectives were sought. Data from semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA). One superordinate theme, *Dementia naiveté; redefined intimacy*, overarched *Embarrassed shame; Maintaining hope; Redefining a model of intimacy*; and *Redefined relational intimacy and growth*. Within these themes, the participants shed light on hurtful embarrassment and shame experienced by families associated with the diagnostic label given to a loved one. This label was perceived to either trigger separation, hurt, and immobility through ignorance, or precipitate a frenzy of naive yet hopeful energy for seeking that elusive cure. The participants saw their role as one of enacting a new way of connecting what was with what could be. Thus they modelled advocacy, integral care, and relational intimacy. Validation came in witnessing a redefining of intimacy in many families who were able to embrace that holistic and empathic approach to the shifting presentation of dementia. Psychological wellbeing was observed to occur when families embraced growthful domains e.g. acceptance, hope, relational closeness and altruistic concern for other families. Implications for future care models are discussed.

Keywords: *aged care, shame, hope, dementia, relational intimacy, IPA, communication, psychological growth*

Introduction

Stigma around ageing and death and assumptions of unawareness, especially when speech is lacking, leave many people with dementia languishing in aged care facilities (Cheung & Chow, 2006; Clare, Woods, Whitaker, Wilson, & Downs, 2010; Magai, Cohen, Gomberg, Malatesta, & Culver, 1996; Sartorius, 2007; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). Without stimulus, they become withdrawn, agitated, or angry. Unmet needs for belonging paradoxically detach many with dementia from carers and visiting family (Bird, 2000; Bird & Blair, 2003; Kitwood, 1997; Wallace, 2010). However, awareness may exist at levels previously unrecognised when social cues support communication pathways (Walmsley & McCormack, 2014a). It may even be that for some families, psychological growth and wellbeing is possible despite their distress (Walmsley & McCormack, 2014b). As little is known about how families make sense of the journey with dementia, senior dementia carers are uniquely positioned to offer a window of insight into the impact of dementia on families. Therefore, this study sought to understand how families make meaning of dementia, both positively and negatively, through the eyes of eight senior dementia professionals. Additionally it sought their subjective interpretations of their own role in that journey

Up to one-half of all people with dementia in developed countries are professionally supported at any given time, and most will eventually move into dementia care (WHO, 2012). Although relieving perceived burden on family and friends (Oldham & Quilgers, 1999), when an individual enters aged care it is often considered their last refuge and represents community isolation, dependence, and depersonalisation (Askam, Briggs, Norman, & Redfern, 2007; Meuser & Marwit, 2001). On one hand, residents describe dreaming of stimulating conversation and detachment from family (Clare, Rowlands, Bruce, Surr & Downs, 2008; Moyle, Venturto, Griffiths, Grimbeek, McAllister et al., 2011). On the other,

they describe gratitude for what they can still do and a return of pride during reminiscing activities (Clare et al., 2008).

Compounding this situation, residents describe withdrawing from carers seen as controlling, unaccommodating, or disinterested in their efforts to interact (Magai et al., 1996; Moyle et al., 2011; Norberg, Melin, & Asplund, 1986). Indeed, superficial and functional interactions can leave people with dementia feeling belittled, ashamed, and inadequate (Clare, 2010; Cohen-Mansfield et al., 2006; Henderson, 1998; Katsuno, 2005; Nuffield Council on Bioethics, 2009; Sapp, 2010). Others report being the butt of jokes and unfairly judged (Katsuno, 2005). Like any other situation where people are forcibly brought together rather than choosing friendship, relationships can degenerate. As such, in residential homes relationships too can degenerate with carers coming to see residents as ‘non-people’ and “their own caring for the patient as meaningless and their work as worthless” (Norberg, Helin, Dahl & Hellzen, et al., 2006, p 265).

Additionally, many people arrive at older age with ageism internalised and awaiting activation by situations that threaten their competence (Fiske, Wetherill, & Gatz, 2009; Levy, Ashman, & Dror, 1999-2000; Levy & Langer, 1994; Lineweaver, Berger, & Herzog, 2009). For many, the self-doubt activated by these stereotypes of memory loss cause them to withdraw from life, which for people with dementia can accelerate their decline (Bridges-Webb & Wolk, 2003; Fiske et al., 2009; Hogan et al., 2008). This has renewed the challenge for senior carers to review protocols of care. They must lead not only in physical care but advanced communication skills that support changing awareness and speech (Bartholomeyczik et al., 2006; Edvardsson, Sandman, Nay, & Karlsson, 2009).

Communication patterns change considerably throughout dementia. Cognitive foundations of communication give way to increasing emotional richness, and non-speech interactions eventually replace speech (Peterson, 2004; Taylor, 2007). Considered in the

broadest possible terms, communication in people with dementia also includes creative expression (e.g. dance, painting, and puppetry; Allen & Killick, 2010). Central to such communication is awareness. Considered an understandable response to specific aspects of an individual's context, awareness is conveyed through speech, behaviour, and emotion (Clare, 2010; Planalp 1999). Theorised to range from unconscious behavioural response to perception of sensory information, complex movement, goal-directed behaviour, and self-awareness, it is influenced by environmental context and social cues (Clare, 2010; Stuss, Picton & Alexander, 2001; Walmsley & McCormack, 2014a). Facilitating positive interactions, communication in the context of dementia families, also requires family members to believe that positive interactions are possible (Nuffield Council on Bioethics, 2009).

However positive interactions may be hindered for those families who experience dementia as a series of traumatic events (Walmsley & McCormack, 2014b). Beginning with the earlier distress of diagnosis (Bauer & Nay, 2003; Scott, Lewis, Loughlin, & Chambers, 2005) it is possible that witnessing helplessly as a family member experiences cumulative distressing events as a result of dementia may cause a traumatic response in some individuals. Representing an unexpected threatening event both uncontrollable and unpredictable, trauma challenges, even shatters, an individual's world view (see Joseph, 2011). A distressing search for meaning and meaning making can then ensue, the intensity of which varies according to the gap between the individual's previous world view and the new traumatic event (Joseph, 2011; Joseph & Linley, 2005).

Fortunately, a growing body of literature indicates that both primary and vicarious traumatic adversity can enable psychological growth encompassing greater wellbeing over time despite distress, even psychopathology (Joseph, 2011; McCormack & Joseph, 2013, 2014; McCormack & Sly, 2013; McCormack, Hagger & Joseph, 2011; Park, Cohen, &

Murch, 1996; Tedeschi & Calhoun, 1996, 2004). Positive outcomes include (a) personal change (e.g. personal strengths, greater wisdom, and compassion); (b) philosophical change (e.g. new life priorities, and enhanced spiritual beliefs); and (c) relational change (e.g. new relational approaches, and greater appreciation of others; Joseph, 2011).

Indeed, converging studies suggest that people may be ‘hard-wired’ for growthful adaptation (Joseph, 2011; Joseph & Butler, 2010; Joseph & Linley, 2006). Thus distress featuring the intrusion and avoidance of trauma-related information is increasingly considered a normal search for personal significance and comprehensibility in their current life, not a mental illness (see Joseph & Linley, 2008). Thus, both positive and negative assessment of any adversity must be acknowledged in coping with adversity and indeed for growthful adaptation to occur (Janoff-Bulman, 1992; Joseph & Linley, 2005; Lepore & Revenson, 2006; O’Leary & Ickovics, 1995; Smith, Dalen, Wiggins, Tooley, Christopher, & Bernard, 2008). Paradoxically as distress increases so does the opportunity for growth, yet once positive meaning making takes hold, distress ultimately declines (Butler, Blasey, Garlan, McCaslin et al. 2005; Linley, Joseph & Goodfellow, 2008). For dementia families, it may be that professionals can facilitate growthful adaptation by promoting agency and relational opportunities (see Deci & Ryan, 2001; Joseph, 2011).

This qualitative study sought to understand the impact of dementia on families from the unique vantage of senior health professionals. The participants, eight senior aged care professionals, provided unique interpretative insights into family dynamics and sense making on the journey with dementia, and their own role in that journey. Both positive and negative perspectives were sought. By choosing a qualitative method this study aimed to compliment positivist studies as they impact on dementia care families.

Method

Participants

Following university human ethics clearance, eight managerial dementia professionals from community and hospital dementia-care settings were recruited for individual interviews. At the time of the interviews: (a) Carol (59 years), Cheryl (58 years), Sandra (59 years) and Gillian (60 years) were directors of aged care services. In these roles for three to four years each, their length of service in the field of dementia spanned from 35 to 40 years; (b) Peter, 51 years old, was a general practitioner leading palliative support for a number of regional aged care facilities. In this role for three years, he had worked for 28 years in the field of dementia; (c) Fifty-six years old Stephen managed chaplaincy at a dementia care setting. In this role for three years, he had worked in chaplaincy for 20 years and in the field of dementia for 10 years; (d) Linda, aged 48 years, had been a nurse unit manager for one year of a 12 year career in dementia care; and (e) Kelly, 48 years old, was a regional manager of a peak body for dementia. In this role for three years, she had worked in the human services sector for 30 years and in the field of dementia for six years.

Procedure

Participants were provided with details of the study and consent forms were collected. The first author conducted the interviews at the participants' place of work at a time convenient to each. Semi-structured interview questions were guided by a process of tunnelling down to the topic of interest (Smith, 1996). As such, negative and positive subjective interpretations from the personal-self and professional-self perspectives were sought in regards to their lived experiences as dementia carers. Participants engaged willingly with little prompting. Freedom and spontaneity were encouraged to reveal the phenomenon of interest, allowing the researcher and participant to engage in the double hermeneutics of the dialogue. Demographic information was collected, including age, and length of time in their current role and in the field of dementia. Digitally recorded, the interviews lasted between 45 minutes to 2 hours each. They provided the data set for the study.

Epistemology

This study adopted a critical realist stance in describing the way that the world is socially constructed, interpreted and understood. Within a critical realist paradigm access to the world is always mediated. This fits comfortably with symbolic interactionism that is concerned with: (a) the way people act towards things according to their meaning for them; (b) meaning stemming from social interaction; and (c) the variable and uncertain nature of meaning that is modifiable by interpretation. A critical realist view encompasses hermeneutic enquiry, whereby people continuously interpret to make sense of their world and determine how to act (Gadamer, 1983). Spanning objectivism (only one valid perspective) and relativism (perspectives are alien from each other) a hermeneutic stance promotes multiple ways of meaning making (Bernstein, 1983). From a phenomenological and interpretative hermeneutical approach it explored a complex topic via understanding, interpretation, and critical reflection of a real world where unobservable realities exist (Blaikie, 1991).

Credibility

Credibility and trustworthiness of findings were enhanced in multiple ways (Smith & Osborn, 2008, Spencer & Ritchie, 2012; Yardley, 2008). The primary author conducted the interviews and transcribed the data set. Through IPA the two authors independently completed an initial thematic audit of the data. They then met to discuss and robustly debate their independent interpretations, arriving at agreed thematic evidence supported by vivid extracts (Smith, 1996; Smith, Michie, Stephenson, & Quarrell et al., 2002). Unlike nomothetic research, we did not seek causal evidence or inter-rater reliability. Instead, an audit provided the reader with one account of the data, systematically achieving internal coherence and presentation of evidence. A detailed audit trail was kept, encompassing the audio recordings of the raw data, the transcripts, descriptions of theme development, and

interpretations of notes, diagrams, and thematic definitions (Smith, Flowers, & Larkin, 2009; Spencer & Ritchie, 2012).

Authors' Perspective

The double hermeneutic process of IPA is influenced by what researchers bring to interpretation (Smith, 1996). However, preconceptions facilitate interpretation and further interpretation refines preconceptions (Heidegger, 1927/1962). The first author has experience of supporting a parent who lived with dementia. He now works as a clinical psychologist supporting families on the dementia journey. In this study, every attempt was made to externalise such preconceptions and bring credibility to interpretation through independent audit. The second author has worked with trauma and dementia for over two decades and was mindful to bracket biases and presuppositions through discussion and debate with the first author.

Analysis

Data was transcribed verbatim. Interpretive Phenomenological Analysis (IPA; Smith 1996; Smith, Flowers & Osborn, 1997; Smith & Osborn, 1998), a well-established analytic approach, was adopted (Brocki & Weardon, 2006; Larkin, Watts, & Clifton, 2006). Turning away from objectivist and restrictive biomedical views of disease (World Health Organisation, 2002), IPA recognises the constructed and biopsychosocial nature of illness and the importance of subjective 'lived' experience (Brocki & Weardon, 2006). Encouraging analysis "beyond the text to a more interpretative and psychological level" (Smith, 2004; p. 44), IPA requires detailed interaction with the data. As such, the underlying meaning making of participant dialogue is accessed by a method of reduction to specific interactions, statements, and themes in search for all possible meanings. Researchers draw upon their "interpretive resources" (Smith et al., 1999; p23) and through a double hermeneutic process make sense of the participants' interpretative process. Biases and presuppositions are

bracketed by the researcher to avoid influencing interpretation of the data (Heidegger 1927/1962; Gadamer, 1983). Analysis followed a recommended seven-stage IPA process for interviews (Smith, Flowers & Larkin, 2009). Table 1 provides the step-by-step analytic process.

Insert Table 1 here

4.4 Results and Analysis

One superordinate theme, *Dementia naivete; redefined intimacy*, overarched *Embarrassed shame; Maintaining hope; Redefining a model of intimacy*; and *Redefined relational intimacy and growth*. Within these themes, the participants shed light on hurtful embarrassment and shame experienced by families associated with the diagnostic label given to a loved one. This label was perceived to either trigger separation, hurt, and immobility through ignorance, or precipitate a frenzy of naive yet hopeful energy for seeking that elusive cure. The participants saw their role as one of enacting a new way of connecting what was with what could be. Thus they modelled advocacy, integral care, and relational intimacy. Validation came in witnessing a redefining of intimacy in many families who were able to embrace that holistic and empathic approach to the shifting presentation of dementia. Psychological wellbeing was observed to occur when families embraced growthful domains e.g. acceptance, hope, relational closeness and altruistic concern for other families (Notations: Appendix 1).

Insert Table 2 here

Embarrassed shame

This theme describes the coming together of these participants with families trying to make sense of a dementia diagnosis and relinquishing home care. The secrecy of families “embarrassed to tell” because others “don’t understand what dementia is” was recognised by these senior carers as part of the overarching stigma

of aged care, perpetuated through “helplessness,” shame, “fear,” and naivety. On one hand, they empathised with family members for shielding a relative from hurtful judgement by delaying or denying diagnosis. On the other they suspected ‘over-protectiveness’ kept families closeted. Free expression by all family members inclusive of the individual with dementia, was viewed by these participants as increasingly constrained by threats of discovery, judgement, and rejection:

....people say “Oh, they don't have dementia”... ..“Well I think he’s just putting it on”... ..it stigmatises a person ...everybody's afraid of it ...there's no cure.

However, relatives were witnessed unaware seeking to constrain the ‘embarrassing’ loved one when their behaviour was perceived to fall short of dignified behaviour.

. ...they expect Mum and Dad to be who they are. ...when they're not, they don't understand why.

Often choosing silence, carers oscillated between wanting to advocate for their patient, and turning a blind eye acutely aware of the embarrassment and distress in family visitors:

We had a gentleman ...he took to a doll that we had... his adult sons weren't happy...

Similarly caught unaware, carers witnessed desperate struggles for agency between residents living and dying with dementia. Seen as masking embarrassed shame and loss of self-esteem in a “hierarchical” environment, human competitiveness and status were observed alive and well. Motivating advocacy and altruistic-self, carers intervened to stop further hurt and minimisation. Residents regarded unaware by peers for lack of speech were boldly shielded from indiscriminate and verbal cowardly punches:

“That lady's got my shoes on. I wanted to buy those shoes but she's got them!” —
“She's silly! She can't understand.”

Invalidation

The stigma of dementia care permeated beyond death for these participants. Their existence and support was often negated by families who in their own distress denied association with dementia and its carers. Invalidated, they noted concealment:

...in the death notices ...they don't actually say died at ... a specific nursing home...

They mused at being excluded from “eulogies” while acknowledging that “... dementia as being part of the journey of that person” meant avoidance behaviours were often part of giving meaning to their journey. Unrecognised for the intensity of their role in monitoring high risk situation, they struggled with the dual role of enemy and ally. On the one hand they recognised a need to remain vigilant for opportunism by families who “take advantage,” yet on the other hand, become the conduit for relational trust in family interactions.

Despite their years of practice, perceived invalidation left participants questioning their competent-self both as carer and manager. They felt conflicted by the boundaries of care often expected in a medical model framework. Despite a commitment to autonomous and individualised care, self-doubt was experienced as they sensed the tension between family members and the paraprofessional teams. Uncertain, they sought to liaise with individuals around expectations and roles:

“Why do you feel the need to do this? Are we lacking in some way?”

Neglectful carers

The need to remain vigilant meant that at other times these participants experienced feeling “overwhelmed,” particularly when families resisted a more collaborative and inclusive care package:

I'd like families to be aware and be involved and not shirk responsibility...

Wryly noted by carers, families neglectful of their care responsibilities lashed out in blame:

You haven't done your job properly!

Indeed, family members perceived to be unreliable were considered “not prepared to give anymore” and were felt to “take advantage” of outreach support:

“I'm busy today, but someone needs to call in and see my mum. She's upset. She lost her brother last weekend.”

Though challenged by “frustration” and “disappointment,” their years of service allowed them to reflect with “empathy” at the difficult role faced by dementia families. They recognised that helplessness and avoidance in some family members was akin to trauma distress around the unpredictable and often threatening events circling dementia care:

So that's a very nice philosophical thing I could say sitting on my red chair here... Similarly, “distress,” “emotional burden,” and “guilt” were recognised as compounding the instability and unreliability of family support. With lives often put on hold due to the complex demands of dementia care, many family members were perceived as rejecting these senior carers' efforts to model appropriate care. They interpreted such rejection as guilt driven:

...if they feel guilty ...it's like a madhouse.

Maintaining hope

What now?

A solutions-focused approach was recognised as one way to release families from “frustration” and “depression”. Hope was seen as marking a turnaround in agency for many families and releasing them to consider present and future possibilities with greater optimism:

“What now?” – It leads to motivation in what you can proceed into now

From a personal perspective, the participants appreciated families who assertively organised themselves through “education, support groups, and establishing who does what” for their loved one:

“Well look it’s a fait accompli. I’m going to learn and understand it.” ...they embrace it. Very adaptive people...

With a sense of pride as carers, families who freed themselves of the embarrassment of stigma were seen embracing relational opportunities despite the shifting presentation of dementia:

...they tend to have a fairly realistic understanding ...of the disease; its impacts, its progression and its place I suppose in the whole family structure... that then frees them up to make the best of what they have left...

Shifting identity

However, participants witnessed in family members an emerging internal struggle with two views of self, that of ‘relative’ and that of ‘carer.’

I think it’s a real struggle to try and be the person who is the carer... ...first of all you’re the wife... ... that’s your relationship; second, you’re taking on a role...

Unable to help family members resolve these aspects of self, in light of the “dramatic change in the status of their relationship,” some were noticed becoming fused with self as carer. Enmeshed with a loved one seen as increasingly reliant on their support, and intensely involved with “education” and “support groups:”

...sometimes those families look for the cure... ...forget about communication... ... forget about the day-to-day...

The drive to remain hopeful was seen as clouding opportunities for enjoyable day-to-day relational opportunities outpaced by their search for the “big picture”. Remaining optimistic and hopeful for that elusive cure ultimately gave way to redefining hope adaptively.

Hermeneutic struggle

These participants were voyeurs on a journey where not only the patients’ needs but partners’ and children’s needs were played out within a relational frame of reference often reflecting an earlier time and place. The medicalised framework of

care in which they worked, poorly equipped them to support family members

wanting to retain pre-dementia interactions:

You need to establish what ...gives him comfort, ...he can still understand , ...he still can enjoy ...It doesn't matter what your needs are. When you come into this tiny little world, this is what you focus on...you just focus on their little world.

Sadly noted, families “committed totally in the wrong direction” lashed out in blame. ‘Fix-it’

expectations left carers feeling hollow and inadequate:

Most people are still in sort of a mind fail. “You know this is 2014. There is medical science. ...you're the doctor, fix it!”

With poignancy, family members were witnessed missing opportunities to enjoy their remaining time, resolve past wounds, and prepare for their loved one's death:

They struggle right to the end. They never ever accept it.

Redefining a model of intimacy

Witnessing the disabling effects of low dementia literacy motivated these carers to enact a new way of connecting what was and what could be. Thus they sought to model advocacy, integral care, and relational intimacy for uncertain families.

Validation came in redefining retained awareness, self, and communication in people with dementia.

Relational inroads

Filled with awe as dementia carers, expressions of retained awareness and relational preference were witnessed in residents, even those dying. Noticing these responses they interpreted residents' recognising relationships between themselves and other members of staff. Regarding behaviour as meaningful and understandable to them, carers were motivated to dispel misassumptions of global unawareness when speech was lacking:

We had a man who didn't speak the entire time that he was with us... he was on his deathbed ...he was going downhill very quickly ... he just looked really frightened ...and then Kim came in ... and his face just lit up the room. It was just amazing.

Revealing distaste for presupposing needs, these carers made the time to understand residents' 'lived' experience. Such efforts were interpreted as meaningful engagement and therefore encouraged them to prioritise a consistent, safe, and familiar presence. In turn, a respectful and patient will to bridge horizons did not go unrecognised by those with dementia:

They recognise a friendly face ...someone who is prepared to put the time in to understand what it is that they want. ...what it is that they're trying to communicate.

They recognised that they had an important role to play in modelling. Despite experiencing odd family behaviour "I spoke to the husband ...and on my left side his wife is answering me..." modelling a person focused approach generated intimacy that surprised the closest family members, eliciting an unexpected response from the husband living with dementia "Oh I've been..." as his wife registered that inroads to communication were still possible "How did you do that?"

Seeing the person

Dissatisfied with functional and superficial interactions, these participants bravely sought to honour spirit. This was interpreted as recognition that people with dementia remain the same person throughout their illness:

...we've got a sailor in here, and he is rude and rough, and he's still rude and rough but now without any inhibition.

Like a detective, clues for reconstructing residents' pre-dementia spirit were sought from observing adult childrens' behaviour:

Stigma and communication in dementia

I see people with dementia who have had very creative kinds of minds...artistic, social ...great networks of friends...I see her lovely daughters...how bubbly and friendly and what warm personalities they have...

Similarly, it was important for these participants to encourage staff to make time to listen to life histories to demystify unusual moods. Allowing time for narratives to be heard brought understanding and empathy from staff:

...she certainly has a background of depression, given that her husband and her son died around Christmas time and we've just gone through Christmas.

Holding the person

Drawing upon their evolving ease with non-speech intimacy "I am more tactile," these participants increasingly saw their role as coaches of intimacy, to help families reach beyond shame and lost hope. Observing residents' behaviour as coherent they guided family members to still look for meaning:

...we're all on ...this journey in life together ...people who have got very limited cognition still respond very well to a smile and a warm touch ...a friendly and loving approach.

Moments of guidance for uncertain family members helped them to seek "a decent adult conversation" despite dementia and deserving of deep respect as an adult:

He's a 70 year old man, and I'm going to have a decent adult conversation ...that's what we have to model all the time.

Without romanticising the lived experience of dementia, carers remained ready to support with "cues" and "prompts" to help others flourish:

He knows that if there is a difficult situation, that I will support him through that.

Restoring agency

Revealing a deep belief in individual agency, these participants sought to empower residents within the facility viewing it "as their home" with "some control

over it.” Promoting activities calling on earlier life-skills such as “making a cake for afternoon tea” was viewed as reflected managerial vision and purpose. Indeed, a restorative focus was revealed in metaphors that indicated their belief that individuals can make a difference:

...what I like particularly is to take an old antique that's ruined, and bring it back to new.

Wonder and curiosity, was witnessed in “all” residents interacting with babies and children during family visits. Conventional views on personal safety were questioned. They reflected that the more carers sought to protect residents the more that they stripped joy from life. Such interactions left them pondering the restorative impact of non-judgemental acceptance, reciprocal admiration, and agency:

...it's just amazing the reaction ...these babies get. ...little children... ...we've *never* had an incident — *never* — I don't know what it is.

Validation

Filled with deep fulfilment as carers, validation came in many forms even from residents on their “deathbed”:

...years later I can still see his face ...that's the reward that you get... ...you know that the systems and processes that we have in place for supporting people ...in the last phases of their lives are so important to them ...we know that we're going down the right track when you get that kind of response.

They mused on the reciprocity of this career path:

I just feel that it's very comforting for someone ... you hold their hand ... I get comfort from it, and they do too ... I think it's good for all of us to be wanted.

Revealing solidarity with residents, they encouraged family members to look beyond global awareness:

Stigma and communication in dementia

...we're all on ...this journey in life together ...people who have got very limited cognition still respond very well to a smile and a warm touch ...a friendly and loving approach.

These participants conveyed an advanced insight into dementia care:

...if you're saying something in a nice tone of voice ... you're conveying empathy

They equally recognised that expressing negative emotions trapped residents in a bewildering search for the source of their anxiety:

When they see you upset and ...agitated ... it's quite disconcerting ...for them

They also felt honoured that end of life care provided them a vision of the spiritual bridge between life and death:

I see them talking to someone who's not—I can't see. I see that satisfaction on their face...a peace. So, I believe that ...at the end of life, there is something there. I don't know what it is.

Redefined relational intimacy and growth

Growthful redefinitions

Able to embrace their holistic and empathic approach to care, families were seen experiencing psychological growth:

...they've noticed things in themselves ...their own self-growth ...personal journeys...things they thought they could never do or achieve...

Similarly, many families came to positively redefine relational intimacy in response to their relative's shifting presentation of dementia. It was a joy for carers to observe that redefined relational intimacy was possible over time:

...communication gets better with that parent ... they report that there is a closer relationship.

Noted with surprise, in some families changes in a loved one throughout their illness erased old conflict:

“Look my Mum’s nicer since she’s had dementia.”

Similarly, carers witnessed “a stronger family bond amongst the siblings” in many families as siblings once considered in a “shambles” “had to bond together” to coordinate support.

At times recognised by families for their vital support as carers, participants mused at unexpected family testimony. Positive life-changing outcomes were reported by families once “totally opposed” to holistic intervention:

...it happened the other day I walked into town and this guy walked up “Look you treated my mum, and that day ...you wouldn’t even know what you said, but that changed my life.”

Witnessing such positive change in families once closeted by stigma or seeking elusive cure offered carers the “courage to struggle with twenty more difficult, aggressive, disappointed, disillusioned families.”

Bold opportunities

These participants described families reaching beyond embarrassed shame and unrequited hope to extend relational opportunities to other dementia families. In witnessing reciprocity, families appeared to view residents’ thoughts and behaviour as aligned with their own:

You know it’s just brilliant to see that huge turn-around. And they get so emotional because they know that they’re making a difference in that person’s life.

Revealing the power of individuals to make a difference, it left these senior carers boldly musing at future opportunities to individualise care:

I think families could offer that individualised care program ...they've already got a relationship ...a history.

Discussion

The participants of this study, eight senior aged care professionals provided unique interpretative insights into family dynamics and sense making on the journey with dementia,

and their own role in that journey. Patterns of meaning making illuminated convergent themes across the data set.

From the perspective of senior carers, foremost, this study revealed that a diagnostic label of dementia brings a legacy of stigma and embarrassment to families. It highlighted the extent that dementia-related stigma was internalised by the families they sought to support. Stigma was seen to be activated in non-dementia family members when they perceived threat of judgement and in those with dementia when they perceived further loss of agency. Maintaining embarrassed shame and ignorance, it would seem that family members—healthy and well—were closeted by fear of being found out, judged, and rejected. In particular family members were found denying diagnostic labels and distancing themselves from a loved one with dementia. Similarly, members with dementia were seen distinguishing themselves from others diagnosed. In particular, they sought to minimise others lacking speech, in a desperate bid for comparative agency and respect. Maintaining shame, fear, and ignorance of rehabilitative possibilities, stigma both disrupted and motivated these carers in their attempts to model advocacy, holistic care, and relational intimacy.

This study also revealed that the unwelcome journey brings adjustment challenges to families journeying with dementia and the possibility that both negative to positive meaning making can occur. Supporting existing literature (see Janoff-Bulman, 1992; Joseph & Linley, 2005; Lepore & Revenson, 2006; O’Leary & Ickovics, 1995; Smith et al., 2008; O’Leary & Ickovics, 1995; Walmsley & McCormack, 2014b) meaning seeking and meaning making appeared to play a role in helping these families cope with the adversity of supporting a member with dementia. As such, families were witnessed moving through three stages of change from *embarrassed shame* and *Maintaining hope* towards *redefined relational intimacy and growth*. Senior carers believed that they facilitated families’ movement from the first to second stage by encouraging a solutions-focused mind set (e.g. what now?). Importantly,

enacting ‘a new way of connecting what was and what could be’ helped families move onto a third stage of positive change. This process was described as complex, dynamic, and oscillating. Further, change was unique for every family and indeed for individual family members. Accordingly, it would seem that family members moved from an experience of dementia dominated by negative domains (e.g. embarrassed-shame, denial, secrecy, fear, blame, obstructiveness, aggressiveness, disappointment, disillusionment, guilt, remorse, and relational distraction) to one accommodating growthful domains (e.g. acceptance, personal strengths, new perspectives, altruism, improved communication, relational valuing, and relational intimacy).

Importantly, this study offered examples of senior carers identifying and creatively responding to the retained awareness and communicative abilities of people with severe dementia whether speech or non-speech (see Walmsley & McCormack, 2013). In particular, it offered examples of senior carers recognising retained aspects of self in people with dementia, and even their ability to communicate preferences at end of life. Of note, the efforts of these senior carers to model *redefined relational intimacy and growth* reflected many elements of Kitwood’s (1997) positive person work (e.g. validation of feelings, celebrating milestones, creation through useful activities, individual recognition, facilitating trust, comforting touch, and holding distress). Often criticised for its vague conception and difficult application in real life settings (see Davis, 2004), it may be that the time afforded by carers to understand the ‘lived’ experience and unique needs of clients brought positive and new ways of connecting to life.

Just as individuals with dementia adapt to their changing awareness and communication, so must their family members. This study revealed senior carers modelling adaptive ways of connecting what was and what can be. This encompassed: 1) TBC; 2) adopt a philosophy of respect, patient determination, open mindedness; and 3) being present in the

moment. If family members become preoccupied with thoughts related to traumatic distress it may be that they will miss moments of relational opportunity. This study revealed that by defining their own intentional stance these senior carers assisted families in overcoming the misassumption of global awareness, especially when speech is lacking. Listening as if there was a message to receive was modelled effectively. This promoted advocacy, integral care, and relational intimacy for uncertain families. These participants challenged their own thoughts around intimacy in end stages of life in dementia care. They recognised imposed morality in care facilities can minimise and restrict individuality. The curiosity and openness shown by these carers highlights that our assumptions surrounding relational intimacy may be considerably different from the lived experience of those diagnosed.

Limitations

This qualitative study sought to understand the subjective interpretation of the lived experience of these senior dementia carers. It did not aim to generalise findings or provide causality. Following Walmsley & McCormack (2014a, 2014b), this study sought to understand the impact of dementia on families from the unique vantage of senior health professionals and provide further insight for future research.

Conclusions and Recommendations

This phenomenological investigation offered new insights on how senior dementia professionals make sense of the impact of dementia on families that they care for. It described insights into family dynamics and sense making on the journey with dementia, and their own role in that journey. Of interest was the coexistence of distress and growth over time, as families struggled to make sense of the unwelcome dementia journey. In seeking to enhance quality of care through communication programs, future research points to investigation of reciprocal intimacy within dementia families as they navigate a family members' experience of changing awareness and communication by speech. In particular, seeking to support

families holistically challenges traditional medical model views of dementia and lends weight to new individualistic models of support as individuals move through moderate and severe levels of dementia. Importantly it sheds light on cumulative distress experienced by family members and how that can impact on the trajectory of their relationship with their loved one with dementia when embarrassment and shame persist. Highlights for future studies could include exploring moral constraints imposed by family and staff in aged care facilities, and preparing family members for changes in their loved one that provide opportunities for healing, previously unexplored intimacy, and personal growth.

References

- Aldwin, C. M. Levenson, M. R., & Spiro, A. (1994). Vulnerability and resilience to combat exposure: Can stress have lifelong effects. *Psychology & Aging, 1*, 34-44.
- Allen, K., & Killick, J. (2010). *Communicating with people with dementia*. In J. C. Hughes, M. Lloyd-Williams, & G. A. Sachs. (Eds.), *Supportive care support for the person with dementia*, Oxford: Oxford University Press.
- Alzheimer's Society (2012). *Dementia 2012: A national challenge*. Alzheimer's Society: London.
- Alzheimer's Society (2008). *Dementia: Out of the shadows*. Alzheimer's Society: London.
- Alzheimer's Association (2008). *Voices of Alzheimer's disease*. Chicago: Alzheimer's Association
- Askam, J., Briggs, K., Norman, I., & Redfern, S. (2007). Care at home for people with dementia: as in a total institution? *Ageing & Society, 27*, 3-24
- Australian Institute of Health and Welfare (2012). *Dementia in Australia*. Cat. No. AGE 70. AIHW: Canberra.
- Bartholomeyczik et al., (2006).
- Bernstein, R. J. (1983). *Beyond objectivism and relativism: Science hermeneutics and praxis*. Philadelphia, USA: University of Pennsylvania Press.
- Bird, M. (2000).
- Bird, M., & Blair, A. (2003).
- 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.
- Blaikie, N. (2000), *Designing Social Research*, (1st ed.), Cambridge, United Kingdom: Polity Press.

Bridges-Webb & Wolk, 2003

- Brocki, J. M. & Weardon, A. J. (2006). A critical evaluation of the use of interpretive phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87-88.
- Caddell, L. S., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30, 113-126.
- Clare, L. (2010). Awareness in people with severe dementia: Review and integration. *Aging & Mental Health*, 14(1), 20-32.
- 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.
- Corley, M. C. & Minick, P. (2002). Moral distress or moral comfort. *Bioethics Forum*, 18(1-2), 7-14
- Edvardsson, D., Sandman, P., Nay, R., & Karlsson, S. (2009). Predictors of strain in residential dementia care support nursing staff. *Journal of nursing management*, 17, 59-65
- Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7, 362-367.
- Fiske, A., Wetherill, J. L., & Gatz, M. (2009). Depression in older adults. *Annual Review of Clinical Psychology*, 5, 363-389.
- Fontana, A., & Rosenheck, R. (1998). Psychological benefits and liabilities of traumatic exposure in the war zone. *Journal of Traumatic Stress*, 3, 485-503.
- 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.
- Heidegger, M. (1927/1962). *Being and time*. New York: Harper. (Original work published 1927).
- Henderson, C. S. (1998). *Partial view – an Alzheimer’s journal*. Dallas: Southern Methodist University Press.
- Hogan et al., 2008
- Jameton, A. (1993). Dilemmas of moral distress. Moral responsibility and nursing practice. *Women’s Health, Obstetric and Neonatal Nursing*, 31(4), 681-688.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Free Press.
- Joseph, S. (2011). *What doesn’t kill us: The new psychology of posttraumatic growth*. New York: Basic Books.
- Joseph, S., & Butler, L. D. (2010). *Positive changes following trauma*, *National Centre for PTSD Research Quarterly* (Summer).
- Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*, 9, 262-280.
- Joseph, S., & Linley, P. A. (2006). Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, 26, 1041–1053.
- Joseph, S., & Linley, P. A. (Eds.). (2008). *Trauma, recovery, and growth. Positive psychological perspectives on posttraumatic stress*. New Jersey: John Wiley & Sons.
- Joseph, S., Maltby, J., Wood, A. M., Stockton, H., Hunt, N., & Regel, S. (2012). The Psychological Wellbeing Post-Traumatic Changes Questionnaire: Reliability and

- validity. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(4), 420-428.
- Katsuno, T. (2005). Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society*, 25, 197-214
- Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press.
- Klaffke, S., & Staedt, J. (2006). Sundowning and circadian rhythm disorders in dementia. *Acta Neurologica Belgica*, 106, 168–175.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretive phenomenological analysis. *Qualitative Research in Psychology*, 3, 102-120.
- Larmont, J. (2008). Remembering the dance. *Journal of Dementia Care*, 16(2), 11.
- Lepore, S., & Revenson, T. A. (2006). Resilience and posttraumatic growth: Recovery, resistance, and reconfiguration. In L. G. Calhoun, & R. G. Tedeschi. (Eds.), *Handbook of posttraumatic growth: Research and practice*, 24-46, Mahwah, New Jersey, USA: Lawrence Erlbaum.
- Levy, B. R. Ashman, O., Dror, I. (1999–2000). To be or not to be: the effects of aging self-stereotypes. *Omega: Journal of Death and Dying*, 40, 409–420.
- 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.
- McCarthy & Deady, (2008).
- McCormack, L., Hagger, M. S., & Joseph, L. (2011). Vicarious growth in wives of Vietnam veterans: A phenomenological investigation into decades of ‘lived’ experience. *Journal of Humanistic Psychology*, 51(3), 273-29.
- McCormack, L. & Joseph, S. (2013)
- McCormack, L. & Joseph, S (2014)

McCormack, L. & Sly, R. (2013)

Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., & Murfield,

J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Ageing & Mental Health*, 15(8), 970-977.

National Audit Office (2007). *Improving services and support for people with dementia*.

London: The Stationary Office.

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.

Oldman, C., & Quilgers, D. (1999). The last resort? Revisiting ideas about older people's

living arrangements. *Ageing & Society*, 19, 363-384

O'Leary, V. E., & Ickovics, J. R. (1995). Resilience and thriving in response to challenge: An

opportunity for a paradigm shift in women's health. *Women's Health: Research on Gender, Behavior and Policy*, 1, 121-142.

Park, C. L., Cohen, L. H., & Murch, R. (1996). Assessment and prediction of stress-related

growth. *Journal of Personality*, 64, 71-105.

Potter, J. & Hepburn, A. (2005). Qualitative interviews in psychology: problems and

possibilities. *Qualitative research in psychology*, (2), 38-55.

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.

Sabat, S. R. (2010). *Maintaining the self in dementia*. In J. C. Hughes, M. Lloyd-Williams, &

G. A. Sachs. (Eds.), *Supportive care support for the person with dementia*, Oxford:

Oxford University Press.

- Sapp, S. (2010). Spiritual care of people with dementia and their carers. In J. C. Hughes, M. Lloyd-Williams, & G. A. Sachs (Eds.), *Supportive care for the person with dementia*. Oxford: Oxford University Press.
- Sartorius, N. (2007). Stigma and mental health. *The Lancet*, 370, 810-811.
- Schok, M. L., Kelber, R. J., Elands, M., & Weerts, J. M. P. (2008). Meaning as mission: A review of empirical studies on appraisals of war and peacekeeping experiences. *Clinical Psychology Review*, 28, 357-365.
- Smith, J. A. (2004). Reflecting on the development of interpretive phenomenological analysis and its contribution to qualitative research in psychology, *Qualitative Research in Psychology*, 1, 39-54
- Smith, J. (1996). Beyond the divide between cognitive and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: Assessing the ability to bounce back. *International Journal of Behavioural Medicine*, 15, 194-200.
- Smith, J., Flowers, P., Larkin, M. (2009). *Interpretive Phenomenological Analysis. Theory, Method and Research*. London: Sage.
- Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material Discourses of Health and Illness* (pp. 68-91). London: Routledge.
- Smith, J. A., Jarmen, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods*. London: Sage.

- 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.
- Smith, J. A., & Osborne, M. (2008). Interpretive Phenomenological Analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A practical guide to research methods*. (2nd ed.), (pp. 53-80). London: Sage Publications.
- 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.
- Spiro, A, Schnurr, P. P., & Aldwin, C.M. (1999). A life-span perspective on the effects of military service. *Journal of Geriatric Psychiatry*, 30, 92-128.
- Spradley, J. (1979). *The ethnographic interview*. Belmont, California: Wadsworth Group/Thomson Learning.
- Tedeschi, R. G., & Calhoun, L. G. (1996). Posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455-471.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic Growth: Conceptual Foundations and Empirical Evidence. *Psychological Inquiry: An International Journal for the Advancement of Psychological Theory*, 15(1), 1-18.
- Vernooij-Dassen, M. J., Faber, M. J., & Rikkert, M. G. O. et al., (2009). Dementia care support and labour market: the role of job satisfaction. *Aging & Mental Health*, 13(3), 383-390
- Wallace, D. (2010). *The view of the person with dementia*. In J. C. Hughes, M. Lloyd-Williams, & G. A. Sachs. (Eds.), *Supportive care support for the person with dementia*, Oxford: Oxford University Press.

- Walmsley, B. D., & McCormack, L. (2014a). The dance of communication: Retaining family membership despite severe non-speech dementia. *Dementia*, 13(5), 626-641.
- Walmsley, B. D., & McCormack, L. (2014b). Synthesis of meaning: Negative and positive change in family members following the adversity of dementia. *Journal of Humanistic Psychology*.
- Ward, R., Vass, A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). What is dementia care? Dementia is communication. *Journal of Dementia Care*, 13(6), 16-17.
- Willig, C. (2013). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. (3rd ed.). Berkshire, UK: McGraw–Hill Professional Publishing.
- 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.
- World Health Organisation. (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.

Notations

- indicated a pause in speech,
- ... ellipses indicate the removal of nonessential material.

Table 1

A process for IPA for interviews (Smith, Flowers, & Larkin, 2009)

Stage	Process
1	Bracketing of the researcher's pre-existing assumptions.
2	Select experiential claims, concerns and individual understandings. This involves line-by-line coding of the data.
3	Identification of emergent themes, noting convergence and divergence, commonality and nuance.
4	Cross-referencing of coded-data, psychological knowledge, and theoretical knowledge to interpret what the individual concerns of participants might mean for them within this surrounding context.
5	Generating an illustrative structural-map of themes.
6	Organisation of the data to allow an audit-trail of the data. As such, coded data can be traced from initial codes on the transcript to initial clustering of themes to final structure of themes.
7	Development of a narrative, with vivid extracts grounded in the data, to take the reader through your interpretation theme-by-theme.
8	Reflection by the researcher on their own biases and presuppositions which may have influenced the interpretation of the data. This is supported by an independent audit of the data with consensus reached through robust debate.

Table 2 Superordinate theme: *Stigma of continuing to care*: overarching four subordinate themes:

-
- *Embarrassed shame*
 - *Maintaining hope*
 - *Redefining a model of intimacy*
 - *Redefined relational intimacy and growth*
-