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Stigma, the medical model and dementia care:

**Psychological growth in senior health professionals through moral and professional
integrity**

Bruce D. Walmsley,

Lynne McCormack PhD

University of Newcastle, Australia

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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

**Stigma, the medical model and dementia care:
Psychological growth in senior health professionals
through moral and professional integrity**

Abstract

Minimal research explores the impact of a career in dementia care on senior health professionals. This study sought positive and negative subjective interpretations from seven senior health professionals regarding their experiences in dementia care. Data from semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA). One superordinate theme, *Honouring stigmatised self*, overarched four sub-themes: *Systemic stigma*, *Invalidated*, *Self-respect* and *Moral integrity and Growth*. Stigma was interpreted as systemically entrenched minimisation of aged care and the aged-care workforce, including poor remuneration and training. Participants experienced peer invalidation particularly when attempting to resolve complex professional and moral challenges in dementia care. These often occurred in the context of efforts to individualise care, constrained within a medical model. Paradoxically, external invalidation motivated a search for redefining ‘self’ and moral integrity. By wisely acknowledging career experience, growthful domains of self-respect, optimism, humility and innovation defined professional practice and personal choices. Implications are discussed.

Keywords: *aged care, dementia, health professionals, IPA, nursing, psychological growth*

Introduction

Unique to the journey with dementia, cumulative traumatic events offer dementia families the intrinsic motivation to positively redefine life (Walmsley & McCormack, 2014a). However, the impact that a career in dementia care has on health professionals supporting these families is poorly understood. In particular, there is minimal research seeking to understand how such professionals reconcile moral challenges commonly experienced when working in end-of-life care within a medical model. Similarly, little is known about how individuals make sense of this distress. It may be that despite distress, individuals can experience psychological growth over time from this career experience. Therefore, this study sought subjective interpretations from seven health professionals regarding their dementia experience. In particular it was interested in positive as well as negative meaning making of their experience in dementia care.

A person's expressions and experience of dementia reflects a dynamic interplay between biopsychosocial factors and their environment (e.g. neuropathology, health, physical setting and psychosocial context such as reactions to living with dementia and response to how others view and treat them; Downs, Clare, & McKenzie, 2006; Sabat, Napolitano, & Fath, 2004). In the past, incurable illnesses commonly caused death prior to an age where individuals might begin to develop dementia. Although dementia is not a normal part of ageing, extremes of life expectancy are becoming the norm in developed countries meaning that dementia has hit the radar of possibility for an increasing number of people (Australian Institute of Health and Welfare [AIHW], 2012; Alzheimer's Society, 2012). Aged care for 'senility' had its roots in 'benevolent asylums' that were established alongside 'voluntary hospitals' by wealthy philanthropists and religious charities dating back several centuries (Allen, Chapman, O'Connor, & Francis et al., 2008; Hunter, 2005). Indeed, these humanitarian beginnings of care of the poor and 'senile' remained unchanged until

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biomedical advancements midway through the 20th Century (Hunter, 2005). Such advancements began to attract government funding and a focus on medical training, treatment, cure and turnover of patients emerged (Hunter, 2005). It also brought commercial possibilities. In stark contrast to this burgeoning model of individualised health care, aged care in many ways has remained embedded in the earlier philanthropic model where the stigma of 'senility' and 'benevolent asylum' has remained in the poor underbelly of aged care.

Consequently, dichotomous values would seem to confuse the over-riding mission of aged care services. On the one hand a homogenised medical model approach has been superimposed on aspects of aged care without due regard for the pace and quality of aging (Beck, Törnquist, Broström, & Edberg, 2012; Clark, 2002; Hunter, 2005; Kitwood, 1993, 1998). On the other, the health professionals who work within that model lack the authority to diversify that model for the autonomy and wellbeing of clients until death (Edberg, Bird, Richards, Woods, et al., 2008; Erickson-Lidman, Norberg, Persson, Strandberg et al., 2013; Glasberg, Eriksson, Dahlqvist, Lindahl et al., 2006; Juthberg, Eriksson, Norberg, & Sundin, 2008). As a consequence, aged care as a valued profession remains on the periphery of the medical model.

For example, the aged-care workforce commonly experience insecure employment, challenging work conditions, low staffing levels and excessive paperwork (Martin & King, 2008; University of Melbourne, 2008, 2009, 2010). In particular, paraprofessional carers in the UK and Australia are poorly remunerated (Martin & King, 2008; UK Department of Health, 2011; University of Melbourne, 2008, 2009, 2010). Many in Australia are paid little more than a supermarket checkout operator and less than an entry-level zookeeper (Fair Work Ombudsman, 2010). In the UK, some do not even receive the national minimum wage (Hussein, 2011). Despite these conditions, many in the aged care workforce report relational

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bonds and satisfying interaction with dementia families (Brodaty, Draper, & Low, 2003; Gannon & Dowling, 2011; Pilkington, 2005). Others report relational reciprocity that transcends to care and protection of non-family clients, as if they were family (Gannon & Dowling, 2011; Phillips, Davidson, Jackson, Kristjanson, & Daly et al., 2006; Touhy, Brown & Smith, 2005). Nonetheless, the challenging nature of dementia care compounded by inaccessible training and poor remuneration encourages staff-turnover of nearly 40% per year (UK Department of Health, 2011; University of Melbourne, 2008, 2009, 2010).

Strikingly, aged care is the only division of medical services where the majority of its paraprofessional carers have no formal training prior to employment (Ayalon, Arian, Bornfeld, & Beard, 2009; Ballard, Fossey, Chithramohan, & Howard et al., 2001; Gallagher, Bennett, & Halford, 2006). In fact, these paraprofessional carers have the greatest client contact yet the lowest dementia literacy (Ayalon et al., 2009). Regrettably these carers are the most in need of training and the least likely to receive it (Arendts, Reibel, Codde, & Frankel, 2010; Hyer & Ragan, 2002). Most alarming, their time with clients offers little opportunity for reflective practice, in turn compounding poor dementia knowledge and poor practice (Ayalon et al., 2009; Gallagher, Bennett, & Halford, 2006). Inaccessible training subsequently justifies their poor remuneration (Innes, 2002; Martin & King, 2008).

On the margins of the curative medical model for more than 60 years, aged care has been bypassed by generations of health professionals. Many sought general practice or burgeoning specialist opportunities over the ‘supervision’ of an ‘institutionalised population’ (Hunter, 2005). For those who have sought aged care practice, they frequently face conflicting institutional, client and family demands that challenge moral integrity and interfere with their delivery of the ‘right’ support (Corley & Minick, 2002; Erickson-Lidman et al., 2013; Glasberg et al., 2006; Jameton, 1993; McCarthy & Deady, 2008; Westin & Danielson, 2006). Such moral distress can contribute to negative wellbeing (Edberg et al.,

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2008), emotional exhaustion (Juthberg et al., 2008) and poor coping (Glasberg et al., 2006; Redfern, Hannan, & Norman, & Martin, 2002). Compounded by the stigma of ageing, death and aged-care, this serves to dampen the enthusiasm of health professionals seeking to offer quality care (Cheung & Chow, 2006; Nuffield Council on Bioethics, 2009; Sartorius, 2007; Small, Froggatt, & Downs, 2007).

In particular, such health professionals are vulnerable to loss of social status and structural discrimination, when treatment facilities for stigmatised diseases are devalued (Link & Phelan, 2001, 2006). Labelled with undesirable differences, these health professionals experience loss of power and separation into 'us' and 'them' by adversarial groups (Link & Phelan, 2001, 2006). Indeed, it is possible that these health professionals experience 'courtesy stigma' by their affiliation with another stigmatised individual (Goffman, 1963). This is also witnessed in dementia families (MacRae, 1999).

Cumulative upon such stigma and moral distress, a long term career in dementia care can expose professionals to confronting and traumatic events. Health professionals powerless to adequately care, or exposed to unexpected, uncontrollable, often personally threatening and unpredictable events, may experience trauma responses not dissimilar to those exposed to the suffering and death of a loved one, chronic illness, violent assault, accidents and disasters (Breslau & Kessler, 2001). Should an individual's experience stretch comprehensibility beyond their existing world view, a distressing search for meaning may commence (Joseph, 2011; Joseph & Linley, 2005).

However, research indicates that adversity can in fact facilitate and co-exist with psychological growth (Joseph, 2011; McCormack, Hagger, & Joseph, 2011; Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996, 2004). Notwithstanding the potential for managerial distress in dementia care, a curvilinear relationship is suggested between individual distress and growth, whereby as distress increases so does the opportunity for

growth (Joseph, 2011). Indeed, once positive meaning making becomes routine, distress ultimately declines (Butler, Blasey, Garlan, & McCaslin et al. 2005; Linley, Joseph & Goodfellow, 2008). Subsequent growthful outcomes include: (a) personal change (personal strengths, greater wisdom and compassion); (b) philosophical change (new life priorities and enhanced spiritual beliefs); and (c) relational change (new relational approaches and greater appreciation of others; Joseph, 2011).

Indeed, converging studies suggest that people may be ‘hard-wired’ for psychological growth (Joseph, 2011; Joseph & Butler, 2010; Joseph & Linley, 2006) and that successful integration of trauma-related information occurs when the individual embraces personal significance and comprehensibility in current life (see Joseph & Linley, 2008). As such, positive and negative assessment of any adversity is necessary for growthful adaptation to occur (Aldwin, Levenson, & Spiro, 1994; Fontana & Rosenheck, 1998; Schok, Kelber, Elands, & Weerts, 2008; Spiro, Schnurr, & Aldwin, 1999). Environments furthering autonomy, competence, relatedness and time for meaning making promote psychological growth by encouraging individuals to resource integral ways of coping, sense of control and self-determination (Deci & Ryan, 2001; Joseph, 2011). In fact, growthful adaptation can be supported by the current best-practice person centred approach to dementia care (see Kitwood, 1997). This approach rejects a pure medical framework, in favour of a biopsychosocial approach to individualising care and restoring personhood and relational connection for individuals with dementia (Allen & Killick, 2010; Downs, 2010; Kitwood, 1997; Sabat, 2009). Unfortunately, the immediacy and demands of dementia care within the dominant medical model may compete with reflective time and experiential learning (Ayalon et al., 2009; Castle & Engberg, 2005; Zimmerman, Williams, Reed, & Boustani, 2005) as *“many residential direct care workers feel that they do not have sufficient time or opportunity to engage in the caring tasks for which they were employed”* (Martin & King 2008, p. 28).

Therefore, this qualitative study sought subjective interpretations of the lived experience of health professionals. It aimed to understand both the positive and negative impact of their experiences on their work, their personal lives, their beliefs about past and future dementia care and their sense of wellbeing. By choosing a qualitative method this study aimed to compliment positivist investigations particularly as they impact on health professionals.

Method

Participants

A purposive sample of interdisciplinary health professionals supporting the biopsychosocial and spiritual needs of individuals with dementia and their family members (see Hughes, Lloyd-Williams, & Sachs, 2010) were recruited. As such, we sought health professionals for whom the research topic held direct relevance (Smith & Osborn, 2008). Following university human ethics clearance, seven health professionals from four dementia care settings across three regions of south-eastern Australia were recruited for individual interview. Each participant supported individuals with dementia and their family members on a daily basis.

At the time of the interviews: (a) Cheryl and Sandra (aged 59 years) were Directors of Aged Care Services at different aged care facilities. Respectively, Cheryl and Sandra had overall nursing careers of 42 years and 41 years, including aged care for 19 years and 10 years; (b) Gillian (aged 60 years) was also a Director of Aged Care Services at an aged care facility. Gillian had a nursing career of 40 years, including aged care for 9 years. At the same aged care facility, 57 year-old Stephen lead chaplaincy. His chaplaincy service of 10 years had focused entirely on individuals with dementia and their family members. Gillian and Stephen worked alongside Peter (aged 51 years), who was a General Practitioner leading palliative-care for individuals with dementia at a number of regional aged care facilities. Peter

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had a medical career of 28 years, including 12 years of aged care; (c) Linda (aged 48 years) was a Nurse Unit Manager at a government hospital mental health unit for older people.

Linda had an overall nursing career of 14 years, including 12 years of aged care; and (d) Kelly (aged 48 years) was a Regional Manager with a national peak-body for dementia, based at a regional dementia resource centre. Kelly had a 30 year career in the human services sector, including 10 years focused on individuals and families living with dementia.

Procedure

Participants were provided with details of the study. Consent forms were collected and interviews conducted by the first author at the participants' place of work at a time convenient to each. The semi-structured interview questions were guided by a process of tunnelling down to the topic of interest (Smith, 1996). As such, interpretations of their lived experiences of dementia, both positive and negative were sought from the personal-self perspective and the professional-self perspective. The interview remained flexible, allowing interviewer and participant to engage in the double hermeneutics of the dialogue. Freedom and spontaneity were encouraged to reveal the phenomenon of interest. Participants engaged willingly with little need of prompting. Demographic information was collected. The interviews were digitally recorded and lasted between 45 minutes to 2 hours each. They provided the data set for the study.

Epistemology

This study adopted a critical realist perspective in seeking to describe the way in which the world is socially constructed, interpreted and understood. From a phenomenological and interpretative hermeneutical approach it offered a platform for phenomenological exploration of a complex topic, via understanding, interpretation and critical reflection of a real world where unobservable realities exist (Blaikie, 1991). Within a critical realist paradigm access to the world is always mediated. This fits comfortably with

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symbolic interactionism that is focused on: (a) the way people act towards things based on the meaning those things have for them; (b) meanings that derive from social interaction and (c) the variable and uncertain nature of meaning and how it is modified by interpretation.

Similarly, a critical realist view encompasses hermeneutic enquiry in which people continuously interpret to make sense of their world (Gadamer, 1983). This hermeneutic stance spans objectivism (only one valid perspective for meaning making) and relativism (perspectives are alien from each other) to foster multiple ways of interpreting experience (Bernstein, 1983).

Credibility

We sought to enhance the credibility and trustworthiness of our findings in various ways (Smith & Osborn, 2008, Spencer & Ritchie, 2012; Yardley, 2008). The primary author conducted the interviews and transcribed the data set. Adopting IPA the two authors independently completed the initial thematic audit of the data. They then met to reflect on and debate their independent interpretations, arriving at agreed rich thematic evidence supported by extracts (Smith, 1996; Smith, Michie, Stephenson, & Quarrell et al., 2002). Unlike nomothetic research, causal evidence or a satisfactory inter-rater reliability score was not sought. Instead, the audit aimed to provide the reader with one account of the data, systematically achieving internal coherence and presentation of evidence. Indeed, a detailed audit trail was kept throughout the analytic process (Smith, Flowers, & Larkin, 2009; Spencer & Ritchie, 2012). This included the audio recording of the raw data, the description of theme development, interpretation of notes, diagrams and preliminary and final thematic descriptions.

Authors' Perspective

The double hermeneutic process of IPA is influenced by what researchers bring to interpretation (Smith, 1996). However, preconceptions enable interpretation and further

interpretation refines preconceptions (Heidegger, 1927/1962). The first author supported a parent who lived with dementia and has worked as a clinical psychologist in older people's mental health. 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 robust discussion with the first author.

Analysis

Data collection through interviews was transcribed verbatim. Interpretive Phenomenological Analysis (IPA; Smith 1996; Smith, Flowers, & Osborn, 1997; Smith & Osborn, 1998), a well-established analytic approach to psychology research, was adopted (Brocki & Weardon, 2006; Larkin, Watts, & Clifton, 2006). Moving away from objectivist and restrictive biomedical views of disease (World Health Organisation [WHO], 2002), IPA recognises the constructed 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 calls for close interaction with the data. The latent 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 own “interpretive resources” (Smith et al., 1999; p23) and through a double hermeneutic process attempt to make meaning 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 IPA process for interviews (Smith, Flowers, & Larkin, 2009). Table 1 provides the step-by-step analytic process.

Insert Table 1 here

Results and Analysis

One superordinate theme, *Honouring stigmatised self*, overarched four sub-themes: *Systemic stigma*, *Invalidated*, *Self-respect* and *Moral integrity and Growth*. Stigma was interpreted as systemically entrenched minimisation of aged care and the aged-care workforce, including poor remuneration and training. Participants experienced peer invalidation, particularly when attempting to resolve complex professional and moral challenges in dementia care. These often occurred in the context of efforts to individualise dementia care constrained within a medical model. Paradoxically, external invalidation motivated a search for redefining self and moral integrity. By acknowledging wisdom gained through career experiences, growthful domains of self-respect, optimism, humility and innovation defined professional practice and personal choices. Implications are discussed (Notations: Appendix 1).

Insert Table 2 here

Systemic stigma

A personal struggle to make sense of entrenched stigma associated with aged care infiltrated this data. Often exhausted emotional, physically and psychologically, the participants' remuneration was juxtaposed by the intense working situations under which they supported staff, families and those with varying stages of dementia and dying. This sense of systemic stigma in their working lives was consolidated by the pay structure they were forced to work within:

...the nurse who works in ED [Emergency Department] seems to be held in higher regard than the nurse who works in the older person's unit...and if you work in a nursing home your wage is less...

In making sense of current events, many reflected upon their own early experiences working in aged care. In particular, they mused on images of earlier models of aged care that remained on the fringes of a progressive medicalised model of care in other

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areas of health. In many ways the negativity associated with the demise and dying of the aged remained reminiscent of ‘benevolent asylum’:

I’m thinking back to 1976 ... I went onto my first ward ...it had an awful name ...

‘The Hospital for the Incurables.’ In that hospital was just a mish-mash of people.

...they only wore gowns ... there were no activities...

Elements of guilt infiltrated their responses as they mused on the stigma of ‘senility’.

These memories appeared to unearth inner-discontent and a preference for advocacy:

I think the name [The Hospital for the Incurables] must have bothered me ... I

remember working on that ward and thinking that we could do better than that, even as

a 21 year old ... They deserve better.

They noted “it’s the old traditional thing” that continues to linger with other disciplines of medicine whereby aged care remains perceived as a dumping ground:

...a place where people die. There’s no active medicine. There’s not really any involvement.

Thus, striving for an individualised, modern approach to dementia care created a sense of inadequacy for these participants as they tried to make sense of the medical model’s focus on routine and one-size-fits-all practice. They realised that efforts to modernise the aged care system had paradoxically confused the over-riding mission to individualise dementia care:

...we still try to do personalised care ...but in a system like this the care happens in waves ...the trolley goes around ...medicinesactivities ...anything that is outside of the wave is really difficult to persist with — so that’s the challenge.

Invalidated

Sensing invalidation from peers, obstruction by their supporting professional body and professional disregard by non-dementia professionals, self- advocacy and moral integrity was often challenged. They experienced minimisation, disregard for

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their palliative management and were confronted by professional belittlement.

Incredibly, authoritative directives by colleagues whose attitude to the dying was one of a godlike expert reinforced this invalidation:

“You need to conclude this because this man’s family is suffering. Whatever you need to give him, I give you authority to give him so that you can just stop his life” ... I said “No” ...the man was seriously offended.

For all participants, it was as if the wiser and more collaborative they became in understanding and accommodating the needs of individuals living with dementia, the more likely they were to be censored by a profession that prioritises the expert stance. These participants experienced criticism, loss and rejection at the hands of professional bodies. Their invalidation included loss of accreditation. Their willingness to engage at the forefront of daily aged care within care homes, left them reduced as practitioners unable to supervise equally compassionate new health professionals:

...because I don’t do mainstream practice ...I can’t get accredited ...so I can’t employ a registrar. ...thing needs to change because I mean Dementia ... It’s going to be double ... where’s this going to end up?

Such invalidation left a gnawing frustration and inner-disquiet:

...the RACGP don’t classify me as a GP [General Practitioner] because I don’t do mainstream practice...

A turning point of sad acceptance where a restrictive medical model was recognised as a blunt edge inhibiting the opportunity for change produced intense self-reflection. This motivated a search for personal significance and comprehensibility in their current role:

I thought I could at some stage in the role make a difference but directly I can’t.

Self-respect

Such sadness brought efforts to embrace a new and personally authentic outlook. This allowed them to bypass the trappings of convenience, status and income of a modern medicine and accept the honour underlying their work despite poor monetary compensation. In time, they consciously chose to pursue an integral path:

...now it's much more fulfilling, it's one-third of the strain ... it's very rewarding for the staff, the patients and for me. Financially I'm being looked after ... totally enough to live a sustainable life. It's only a mind-set change that made the difference.

Moral dilemmas were frequent challenges and placed them at odds with the system in which they worked. They came to reject dismissive views that dementia care was "...a matter of just showering someone or feeding someone". Instead they sought, despite criticism, to offer the 'right' care to individuals living with an extremely variable end-of-life journey. Forced into conscious and purposive rumination these health professionals positively redefined their moral and professional integrity in dementia care:

I am very unusual... I see the person first not their medical condition. Indeed, this self-respect extended to considering themselves "a little bit different" to "very unusual" from the medical fraternity. Some even described themselves as an "optimist" and "entrepreneur" within a medical model founded on detachment and homogeneity.

Innovative thinking

Although often daunted by ageist censorship, lack of family support and medical model constraints, rather than despairing, these health professionals sought innovative practice. Similarly, they viewed clients as people living with agency rather than the passive recipients of care. This was interpreted from their view of self as a "supporter" of clients' individual needs and retained abilities. For example:

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...it's more planning and more thinking outside the square for me as to how we're going to give an extra bit of support...

Alternatively, at times controversial issues “never ever talked about” left them feeling “old school”. Therefore, they sought to consider other possibilities in relational intimacy rather than sit with their own biases and presuppositions. These professionals sought to challenge ageism internalised in themselves, clients, relatives, staff and the medical hierarchy:

Everyone has [sexual] needs, no matter how old they are, but I just wonder how I'm going to address it? ...Everyone's entitled to love no matter what.

They sensed ground breaking change within themselves and accepted that innovation was risky within a medical model that afforded little compromise between residents' personal freedom and their exposure to danger. Panicked at “the thought of finding someone dead” if they managed to walk out, or “scrutinised” by a medical hierarchy that decided “business continuity,” participants mused over practice-based evidence. Underpinned by their own maturation as health professionals, seniority and integral drive to “find the answer”, these health professionals found themselves questioning expert authority within the medical fraternity:

I was told as a student nurse you never get involved ... now I think "I do get involved.

I am committed to them. I have relationships with them.”

Moral integrity and growth

For these participants, their struggle with self-integrity allowed the emergence of personal qualities they regarded as growthful in their lives. It was as if a mature confidence was born out of their struggle facilitated by growthful domains of optimism, humility, innovation and self-respect.

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Maturation

Redefining life through emerging professional wisdom, acceptance of self and others had partly matured “as a natural progression as I’ve gotten older anyway” and dementia care that was recognised as having exposed them to the “challenges of getting older.” Over time, they recognised that everyone was vulnerable to conditions of ageing, even themselves:

...in time will I be that same person?

Indeed, fearful of their own risk of developing dementia they chose to “focus on the balance of life.” This included making the most of limited time with loved ones:

I try and spend more time with them - and do valuable things...

In fact, coming to terms with the incurable nature of dementia had generated positive redefinitions of personal journeys with dementia. Self-forgiveness furthered optimism and the capacity to help other families:

Hindsight is 20/20. ... You can't change what's in the past, but there's always potential to change what's in the future.

Similarly, internal-locus-of-control was strengthened in their personal lives. Rather than sit in blame of circumstances now recognised as lying beyond their control, these professionals chose to redirect energy towards opportunities for personal growth:

If things aren't going exactly right for me ... I try and change myself.

Humility

Coming to terms with medical model constraints also generated humility and acceptance of the difficult role faced by people with dementia and their family members:

So that's a very nice philosophical thing I could say sitting on my red chair here...

Similarly, an internal struggle with two views of self, that of ‘humble supporter’ and that of ‘dementia expert’ allowed objection to a medical hierarchy approach to dementia care. As

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such, they focused on “empowering and growth” and “what can we do,” in turn bypassing the dispassion and expertise of a medical fraternity inclined to “over-package people.”

Optimism

For these health professionals, there was a sense of dedication to a greater cause. This extended to a spiritual calling for some:

My ministry is my work.

For others, a personal family journey with dementia had precipitated their unexpected and growthful career:

Ten years ago I would have never dreamed I would be doing what I'm doing. Never. For all participants, there was a striving to free clients from the limits of fluctuating awareness and communication, if only for a moment:

...he was able to recall and enjoy... That's why I do what I do.

Similarly, they held an inherent belief that a holistic model of dementia care can reveal “the real value of life” for all those bound on the journey with dementia. In turn, they mused on its capacity to “make a difference in people’s lives”.

Discussion

This qualitative study found that the personal and professional impact of a career in dementia care on health professionals encompassed: (a) moral challenges that arose in the course of their work and impacted on self-integrity and their role as professionals within the medical fraternity; (b) an overall sense of professional stigma and systemic invalidation within dementia care that caused them to question their practices and self-integrity. Each professional’s struggle to make sense of their lived experience was unique. Moreover, patterns of meaning making illuminated convergent themes across the data set.

Stigma was perceived and experienced by these health professionals as systemic within aged care. This perception reinforced other studies that have found low pay and inaccessible training for health professionals (see Inness, 2002; Martin

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& King, 2008; UK Department of Health, 2011; University of Melbourne, 2008, 2009, 2010) and other implications from stigma (Link & Phelan, 2001, 2006). In seeking to understand the lived experience of this stigma, this study is novel in exposing out-of-date perceptions of aged care that linger in the medical fraternity. Harking back to the philanthropic beginnings of ‘benevolent asylum’ for the ‘senile’ and ‘incurable,’ these participants considered that aged care continues to be burdened by care that “happens in ways ...medicines ...activities ...” that disregards the living and dying individual. Such stigmatisation based on health professionals’ work within the context of ageing and dementia reveals courtesy stigma, as first conceptualised by Goffman (1963) and found in dementia families (MacRae, 1999).

Although meaning making was constrained by a medical framework of dementia care, participants experienced intrinsic drives to redefine their life positively through past and present moral challenges cascading throughout their career. Specific to this study the findings reveal that as psychological growth took hold, authority to flex autonomy and competence, bond with clients and wisdom gained through career experiences, were prioritised. In particular, it identifies that systemic stigma, professional invalidation and ill-conceived and homogenous aged care, present a barrier to good practice in caring for people living with dementia. By acknowledging their wisdom gained through career experience, growthful domains of self-respect, optimism, humility and innovation assisted them to redefine professional practice and personal choices.

Although this study found negative consequences of moral challenges (see Edberg et al., 2008; Glasberg et al., 2006; Juthberg et al., 2008; Redfern et al., 2002), it is novel in exploring concurrent opportunity for transformative positive change in personal, philosophical and relational realms. Specifically, their struggle with situations that triggered moral disquiet paradoxically created opportunities for self-

reflection. By recognising their wealth of knowledge and experience negativity gave way to growthful domains of optimism, humility, innovation and self-respect. Indeed professional-self in these participants evolved over time from that of an ‘uninvolved carer’ to that of confident ‘relational supporters,’ whereby clients were positioned as people with agency not the passive recipients of care (see Allen & Killick, 2010). Demonstrating an important aspect of Kitwood’s (1997) ‘person-centred dementia care’ in action, this finding highlights how a person centred approach can restore personhood in those with dementia and facilitate relational connection (see Allen & Killick, 2010; Downs, 2010; Sabat, 2009; Walmsley & McCormack, 2014b). This study supports a need for greater diversity of individualised care within a medical framework.

However of concern, this study exposes a dichotomy whereby modernising many aspects of dementia care through has paradoxically confused the over-riding mission to individualise dementia support. It may be that it is a focus on pace and regimen in dementia care settings that makes person centred approaches difficult to implement, not their vague conception (see Davis, 2004). Of further concern, in finding that psychological growth emerged over many years for these participants, such growthful care may be out of reach for many who embark on a career in dementia care as workforce turnover rates are approximately 40% per year (see Ayalon et al., 2009; UK Department of Health, 2011; University of Melbourne, 2008, 2009, 2010). This does not bode well for the personal and professional wellbeing of health professionals already struggling to support ageing populations (AIHW, 2012; Alzheimer’s Society; 2012). As the majority of people in developed countries will be touched in some way by aged care and dementia, the profile of dementia care needs

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to be lifted into the 21st century with concerted efforts to address remuneration and training, in turn diminishing the stigma that is systemic within aged care.

Limitations

As a qualitative study, this study aimed to explore the subjective interpretation of the lived experience of these health professionals. As such, we sought detailed insights on the experiences of a purposive sample, rather than generalise findings to all people in a similar situation (Harper & Thompson, 2012). This study sought insight into the impact that a career in dementia care has on health professionals supporting people with dementia and their family members. Individual interviews encouraged reflexive dialogue and a double hermeneutic process of meaning making (Heidegger, 1927/1962). Avoiding pre-formulated questions, the interview agenda with guiding topic headings encouraged participants to generate new insights (Willig, 2013).

Conclusions and Recommendations

This phenomenological investigation offered new insights on how health professionals make sense of moral challenges that commonly emerge while working within a medical model of dementia care. In particular, this study demonstrated the positive views and actions of health professionals and their intrinsic drives to redefine life positively through moral dilemmas accumulated throughout their career. Of interest, co-existing with distress was the possibility of psychological growth that may result from a career in dementia care. In particular, this may contribute towards challenging systemic stigma, professional invalidation and imposition of homogeneity that prevent good quality and individualised care for people with dementia and their family members. In seeking to enhance quality of care through communication programs for families and health professionals, future research merits exploration of the unique window of insight that health professionals can provide on

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ways of caring within dementia care settings. This research adds a new dimension to our understanding of dementia care and challenges traditional medical model views of dementia in favour of holistic models of support. In particular, this research calls for the profile of dementia care to be lifted into the 21st century with concerted efforts to address remuneration and training, in turn diminishing aged care stigma.

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Appendix: Notations

— A pause in speech.

... 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 interpretation of the data.
3	Identification of emergent themes, noting convergence and divergence, commonality and nuance.
4	Cross-referencing of thematic 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, thematic data can be traced from initial codes on the transcript to initial clustering of themes and 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: Honouring stigmatised self: overarching four sub-themes

1	‘Systemic stigma’
2	‘Invalidated’
3	‘Self-respect’
(a)	Innovative thinking
4	‘Moral integrity and growth’
(a)	Maturation
(b)	Humility
(c)	Optimism