

The Impact of Caring for a Loved One who has Alzheimer's Disease: Implications for Counselling and Psychotherapy

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When a loved one has Alzheimer's disease, resilience of the caregiver is tested to the limits of emotional and systemic survival. Research findings that underpin the collective narrative profiled in the thesis *A holistic snapshot of the impact of caring for a loved one who has Alzheimer's disease: The collective reality from onset to end of life and beyond* go beyond the primary base level of description. They encapsulate the essence of lived reality and pre-empt a need for action within and across local, national, and global communities.

Implications for clinical counsellors, psychotherapists, and professional supervisors are posed in questions for contemplation:

- When a client seeks support, is what presents on the surface of initial presentation what is at the core of the issue?
- Is there a major lifestyle factor underpinning the client's presenting distress?
- Is what the clinician sees on presentation really what emerges in the fullness of therapeutic intervention?

Keywords: *Alzheimer's, axiology, dynamic transformations, epistemology, identity shifts, intrinsic variables, ontology, resilience, triangulation of methodologies*

Context

As human beings, we are all creatures of habit and as much as we might thrive on challenge, adventure, and risk

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taking, there is in each of us some sense of comfort in knowing who's who, what's what, and where we fit. Our knowing is our constant and tied up with that constancy, is a certain degree of comfort and security, keenly balanced with our developed levels of resilience in the face of turmoil and conflict.

I'm OK. You're OK. We're OK.¹ God is in her heaven and all is right with the world. However, what happens when that security is totally shattered has potential to be expressed in secondary trauma – a polyvagal response as the body keeps the score (Porges, 2014, 2015; van der Kolk, 2014; Wyder & Bland, 2014).

With reference to Professor Judith Murray's model of loss and grieving (2005; 2016), my *world* that is, is turned upside down and inside out. Ever so slowly yet ever so surely it becomes my *world that was* and my *new world that is* and my *pathway to the future* become shrouded in the cloud of my unknowing.² However, rather than being focussed through the mystic's vision of a spiritual relationship with his God, the cloud of the caregiver's unknowing presents as a foreboding darkness that overshadows the vision of a mortal relationship with a care receiving loved one: "But now thou askest me and sayest, 'How shall I think on Himself, and what is He?' And to this I cannot

answer thee but this: 'I wot not.' (Underhill [Ed.], 2003, p. 14)

The caregiver is in the throes of a deep and dynamic internal transformation where the *pathway to the future* is a confused, convoluted, dichotomous maze. Someone I love has Alzheimer's. Such is the scenario confronting caregivers whose care receiving loved one has a life-changing condition marked by cognitive degeneration and loss of physical, behavioural, and social function. Coping is inexorably linked with resilience: which is all about discovering and engaging methods of successfully managing the demands of caregiving.

Methodology

Under the overarching umbrella of a qualitative paradigm, defined by Gergen (1999/2009) as "imagination in action" (p. 71), design, data collection, and analysis strategies were implemented within a framework of social constructivism which, according to Lincoln and Guba (2000), embodies an epistemology whereby the truth of related knowledge lies in created findings that are both transactional and subjectivist. The action model chosen incorporated processes of intuitive and narrative inquiry intertwined with elements of transpersonal and heuristic approaches.

A hybrid methodology was believed to be the most effective tool to achieve the aim and to answer the research question. The triangulation of methodologies enabled the research question to be explored from multiple perspectives, increasing the credibility and validity of the results, while explaining more fully, the complexity of human behaviour, and honouring the richness, diversity and sensitivity of experience (Cohen, L., Manion, L., & Morrison, K., 2005; Holstein and Gubrium, 2005).

Findings

Preparation for data analysis began with manually transcribing recorded interviews. It was in this personalised revisiting and re-engagement that common themes began to crystallise, and the collective narrative began to evolve. At the completion of inquiry, 34 participants, aged between 10 years and 90 years, had shared their stories across a time frame spanning 10 months (October 2015 to August 2016). Numbers included 23 primary caregivers or caregiving partnerships, four significant support persons, and five persons touched by vicarious connection. At the time of dialogue, primary caregivers and primary co-caregiving teams had collectively given 201 years of care, underpinned by unconditional positive regard.

Findings drawn from the body corpus of data that underpin the research are encapsulated in a collective narrative that profiles *A holistic snapshot of the impact of caring for a loved one who has Alzheimer's disease: The collective reality from onset to end of life and beyond*. These findings push through and go beyond the primary base level of description and project implications relevant to participatory therapeutic approaches taken in counselling and psychotherapy where a focus is on building resilience.

Coping

As explained in the report of Daly, McCarron, Higgins,

and McCallion (2013), coping is about "sustaining our place": moving from experiencing and interpreting threats to place to developing and implementing actions that are aimed at not only sustaining place, but also overcoming loss of social contact and risk of marginalisation. It was suggested by Daly et al that this is done through developing a toolkit of enabling factors that comprise protective, defensive, and inter-relational strategies conceptualised as "nurturative protecting" and "inter-relational labouring" (p. 505). Strategies include confirmation and upholding respect for personhood; claiming place rather than being dependent on others to grant or bestow; prioritising needs of both care receiver and caregiver; working to preserve dignity; nurturing *Self* and nurturing *Other*; acknowledging limitations; and recognising that at times, there is the need to prioritise *I* over *You*. Participants in the Daly et al. study also addressed the benefits of holding hope, developing strategies to manage emotions, respite, contingency plans, constructing a support network inclusive of other caregivers who could identify with similar emotions and challenges, and learning as much as possible about Alzheimer's disease and dementia.

Another key aspect to coping was identified by Fortinsky, Kercher, and Burant (2002), Gallagher et al. (2011), and Semiatin and O'Connor (2011) as "self-efficacy": a notion that reflects the work of Bandura (1977) and is often referred to in every-day conversation as the "self-fulfilling prophecy". For participants in this study of caregivers in south-east Queensland, each shared story presented with a "eureka moment" of discovery and as each unfolded, it reinforced the individual's sense of journey: an internal journey marked with a stamp of constant flux, as the caregiver became more deeply immersed in the realities that define a world of caregiving. As explained by Rosalind:

I feel it is my duty to look after him. I'm his carer. That's all I am and that's my whole life. It's the isolation that is so awful. I sometimes feel that I don't know who the real me is, any more. Or where the rest of me is. I'm losing me. I look in the mirror and I say to myself, "[Rosalind], where have you gone?"

The *Self* that is revealed, is a reflection of the realities that are embodied in lived experience and as storytellers discovered and shared their own "aha" moments, the principal researcher was also led to discover images and meanings that were relevant not only to the investigation of the research question, but also to the realisation of an intrapersonal transformation related to inside experience as caregiver for a loved one who had Alzheimer's. For caregivers, the experience of caregiving is more than a task. It is also an intensely personal and relational experience. The journey is evolving, and begins with an intuitive knowing that, in Alice's words, "There's a process going on here". This significant person in my life is doing weird and strange things. Something is so very wrong. Something is not OK.

A process of dynamic transformation

As caregiving activities begin to replace the "normal" activities of daily life, values, principles, expectations, and obligations begin to be reconciled. Change is in the air and life is spiralling out of control – defined by caregiving and impacted by the emerging needs of a loved one who has Alzheimer's. *How-I-Be* in this new world (the ontology of caregiving), impacts and is impacted by *what I do* and *why I do what I do* (the axiology of caregiving) which, in turn, impacts and is impacted by what I learn and *my accrual of knowledge* (the epistemology of caregiving), which impacts *what I do* and *why I do what I do*.

Caregiving: A construct of dynamic transformation

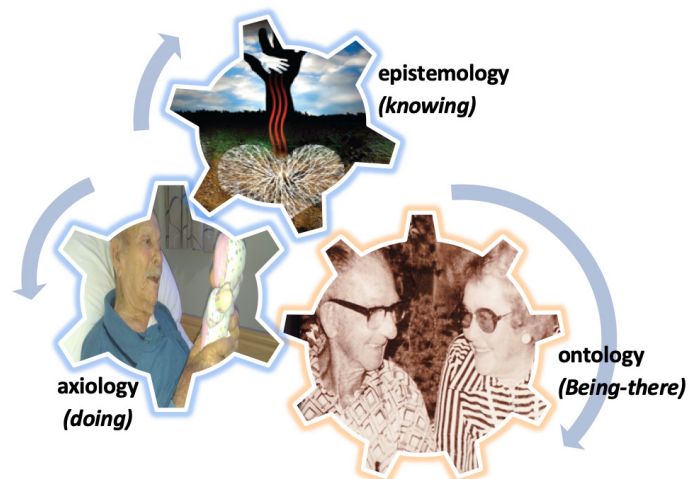


Figure 1: Caregiving: A construct of dynamic transformation:

The infinite loop of dynamic transformation is set in motion as *knowing* activates *doing* activates *Being-there* activates *doing* activates *knowing* activates *doing* (Boyland, 2018).

Image for *knowing* is supplied by and used with permission of Wendy Watego-Ittensohn. Photos for *doing* and *Being-there* are supplied by and used with the permission of families.

A cycle of dynamic transformation begins rotation. Movement is directional, interactive, and constant. The model of a three cogged rotating machine serves to illustrate that the doing of caregiving is influenced from alternating directions: from one direction by what is known and from the other direction by what is experienced. While doing is pivotal in the process of caregiving, it both influences and is influenced by movement in the caregiver's knowledge base and movement in the caregiver's emotional and somatic sense of *Self* while "Being-there", totally immersed in *the world that is*. The infinite loop is set in motion. There is no turning back and the cycling will continue until it begins to slow progressively³ or until there is *catastrophic failure*⁴. The cyclical model of the *infinite loop* is simple. The journey through the transitional rotations⁵ is complex. The individuality of each evolving story and each caregiving journey is expressed in words shared by Rosalind and Antony; each of whom had cared for a parent who had Alzheimer's, before now caring for a spouse who has Alzheimer's. As Rosalind explains, "No two patients are the same. [Owen] is so different from Mother. He is moody and anxious and cantankerous. With mother, it just crept up and she just became more eccentric as the years passed by". Antony simply states:

I thought I was beyond surprises. But my darling [Eva] was different again from both Father and Mother. I just kept learning and every day was a new day and every day I did what needed to be done. And that was my whole life. That was all I lived for.

Epistemology of caregiving

Epistemology is about a way of knowing and caregivers instinctively know that the knowledge they accrue through lived experience is their reality. Knowledge that they gather through testimony from a diverse array of sources also impacts their

reality and there are times when they can be undermined in a serious way by their own thoughts and actions or by the words and actions of others. The very experience of caregiving for a loved one who has Alzheimer's disease results in a turning upside down of all prior knowledge relating to caregiving. When the condition is slowly and progressively impacting the cognitive and functional capacity of the care receiver, all expectation about connections leaves the caregiver looking backwards and looking forwards while, at the same time, being lost in a maze of "now time" that is an ever-changing space: a space that is constantly shifting and clouded over by the unknown. The only constant, is the total absence of constancy.

The undermining of all that is known presents as a problem of epistemology. It is a learning process and there is no simple and universal following of direction that relates to what one "should do" in the situation where the presenting symptomatology and corresponding issues line up with a defined medical model of pathogenic reality. For such a very long time there is no variation to measured levels of intrinsic variables; no biomarkers against which subtle behavioural changes can be measured; no circulation problems; no breathing problems; and no bleeding. Nothing is broken and until the final stages of transition, there is no deformity. Every step of the caregiving journey takes the caregiver into uncharted territory: a place that is shadowed by a cloud of unknowing.

Some 73 years ago, Malinowski (1945) claimed that knowledge gives foresight and that with the gaining of foresight comes empowerment. 66 years later, Anderson (2011) spoke of the power of intuition and highlighted the concept of listening with the senses and with awareness that is open and attentive. While Malinowski and Anderson speak with reference to the researcher's gathering of knowledge as a source of data, the positions they present apply equally to the gathering of knowledge in any circumstance. The accrual of knowledge is, primarily, experiential and evidence-based. That is, the internalisation and evaluation of an experience is based on the sensory and emotional response to what is presenting within the confines of the world in which we live and function.

Reflecting on the principles positioned in these writings, it could be said that implication is closely aligned with perception. From the position of care receiver, what is presenting externally and what is observed on the outside is in opposition with the inside experience. From the position of caregiver, there is engagement with a loved one who outwardly appears to be the same person right up to the final stages of degeneration: which could be a transitioning that spans in excess of 20 years. In extreme circumstances of early onset, this journey could be 50 years of transitioning (Summers, 2014; 2015; Gupta, 2015). The process of transitioning is marked with fluctuations in empowerment and disempowerment accompanied by fluctuations in buoyancy that is encapsulated in resilience, and in a sinking sensation that issues from an absence of resilience.

From the professional position of a third party support person, the challenge is to link observation with intuition and foresight. For it is only through the transpersonal linking of the senses that the total experience can be identified and defined; and it is only when the presenting symptomatology is identified and defined as being related to something deeper and more sinister, that the professional clinician can tap into support strategies that empower and promote growth in resilience for the struggling caregiver who is trying to stay afloat.

While amazing progress is being made in diverse avenues of research,⁶ at this point in time and under general circumstances the condition can be neither fixed nor reversed. It does not go away and the loved one who has Alzheimer's does not get better. As Aaron shared with his son, Richard, in the early stages following diagnosis, "I'm the one with the brain problem and your poor Mum has to live with it". For Hal, the journey he shares with his mother knows no stability and it is his perception, that with the passing of each day, he is very quickly learning, "Both of us are on the slippery slope to nowhere".

The *Self* of this *Other*, who is known and loved, is not there in the same way. The persona of the presenting *Self* is becoming a stranger who has invaded the exterior shell of one who is known and loved and the caregiver's established sense of connection is gradually stripped away. As Lavinia reads from her journal, she shares:

Gradually, I moved from companion to minder and that was the sad bit. I was missing the person I loved as [Oswald] was getting frailer mentally and physically every week. What used to be so good isn't good any more. The time comes when I have lost my relationship with my husband. I am now his "mother". I am no longer his "wife". What I'm missing the most is being Someone Special to a Special Someone.

Yori tells of how expectations about caring for a loved one are "rolled inside-out"; Elizabeth speaks of relationships being "turned upside-down"; and Vince refers to the "topsy-turvy" state of thoughts and emotions. It is about change that moves from the inside to the outside at a functional level and from the outside to the inside at a relational level. The change is transitional, the impact is transformative, and both are evolving amidst the chaos of a world that is constantly changing. In the lived experience of negotiating one's way through the cycles of transition, it becomes about distancing, invisibility, truth, and reality. The impact of accruing knowledge, adjusting actions and reactions, and Being-there as the caregiver, is defined by Eleanor as she states:

I don't know who I am any more. I don't know who [Rod] is. He is not who he used to be and who he is, is changing all the time. He has a terminal disease but he's not sick. He is dying but he looks the same: so alive and well, but just not so sharp. Nothing has changed but everything has changed. There are times I just look at him and I say to both of us, "I don't know if I can do this." I am so scared of what lies ahead and for what could be such a long, long time.

Caregivers' Dissemination of Accrued Knowledge

Accrued knowledge is disseminated through behaviours associated with the doing of caregiving and through dialogic interchange with others. There is no element of luck underpinning the disseminated knowledge that relates to caregiving and the impact of caregiving: it is pure and true expression of lived experience. Actions and reactions reflect levels of gratification relating to the fulfilment (or lack thereof) of the caregiver's own intrinsic and basic needs⁷ as a human being whose life is immersed in a world of caregiving. Old knowledge is enhanced or replaced with new knowledge. Old beliefs and expectations are transcended by what is presenting in the shifting sands of time.

The cogs that denote *knowing*, *doing*, and *Being-there*

continue to revolve: keeping the *infinite loop* in motion. And, as the gap between *the world that was* and *the world that is* widens, the dynamic transformation of *Self* and *Other* continues to evolve.

Axiology of caregiving

As a way of doing, axiology is underpinned by a transitional knowing. Reflecting the position of Lincoln and Guba (2000) from a constructivist perspective, "doing caregiving" from a place of love moves towards a praxis of participation where the focus of concern is on liberation from degenerative oppression and freeing of the human spirit from the torments of the degenerative process. Actions are purposeful and the means is justified by the end.

Drawing on hypotheses posed by Lewis (1946/1962) and Wittgenstein (1922/2017) in relation to the generalisation and valuation of characteristic properties associated with a subject, it could be ascertained that when caring for a loved one in any circumstance of illness or injury, there is love, concern, consultation with professionals, and following direction. There are moral and social constructions and in general circumstances, the expectation is that if one follows the rules, all will be "OK".

However, for the caregiver whose journey is with a loved one who has Alzheimer's, there is an underlying mismatch between moral and social construction conventions and because the experience of caring for a loved one who has Alzheimer's disease is unlike any other experience of caregiving, expectations are also different. The sense of moral fabric is disoriented and the sense of *Otherness* in relationship is undermined, as voiced in the words of Angelica:

My motivation was my sense of duty and my sense of responsibility. I was always a little embarrassed and as time went on, my embarrassment became worse. I was frustrated and angry and tired and cranky and also a little bit frightened. And so to protect him, I closed in and I tried to hide his behaviour. I became isolated. But I could never bring myself to the point of being able to say, "I can't do this anymore". After all, I am a nurse.

Positions internally constructed by caregivers are played out in action according to perceptions and interpretations: exemplified in Isabella's and Iris' initial motivation to care for a parent in a self-sense of obedient compliance. This is in stark contrast to the motivating force that drove Alex, an 18 year old grandson, who is formally registered as the informal co-caregiver for his Nan, Helen: and he wouldn't have it any other way.

Caregiving actions not only define the construct of caregiving in aesthetic terms, they also reflect the values that underpin them – moral, ethical, spiritual. Tension is created between these axiological dimensions, as a strong sense of duty underpins the action pathway through the maze of emotional, relational, and functional transitions. As the action component of the data set is woven into construction of the collective narrative, the landscape that emerges is highly internal and personal – the care receiver needs to be cared for and the caregiver needs to care.

Ontology of caregiving

Turning now to the ontology of caregiving, which is about a way of "Being", it is helpful to reflect on Siegel's notion of the neurobiology of "we" (Siegel, 2008) where he explores the

transformative power of “Being-in-the-world” and references the concept of *I* as being more accurately expressed as a concept of *We*. In what Heidegger (1927/1962) defined in “ontologico-Temporal terms”, *Being* is about “presence” (“Anwesenheit”) (p.47) – “Being-present-at-hand” or “Being-present-in-the-world” (p. 245). In that presence, one is “concernfully absorbed” (p. 247) with what Murray (2005; 2016) refers to as *the world that is*. It is “Being-there” and it is about defining impact and confirming the internal relation between “human being” and “world”. The emerging hypothesis suggests that the way of Being-in-the-world of caregiving is incomprehensible in isolation from *knowing* about caregiving and *doing* caregiving. In essence, *Being* is about Being-there.

Thus, it is implied that understanding the way of Being-there or of Being-in-the-world impacted by caring for a loved one who has Alzheimer’s, is also incomprehensible in isolation from an insight into the world where one is totally consumed by the actions of caregiving. And herein lies its transformative power, as reflected in words shared by Yori:

I guess the hardest thing is adapting to the advancing baby mode – clean his bottom, shower him, catch his dribble, wipe his nose, shave him, and dress him. Some days are very difficult and in finding the compassionate in the Self, one also learns to be very, very patient. It’s OK if it doesn’t get done today. Most importantly, I’ve learned the value of tolerance and understanding and appreciation and how helpful that is for both of us.

I never imagined that I would be looking after a grown-up baby. I had to learn and I did learn new skills. I always had him around to do the ‘blokey’ stuff. Now I do everything. I mow the grass, I change the washers in the taps, and I do the house maintenance. I look at him as he stares and I wonder, “Who are you and where are you? Give me my husband back”. And as he changes with the coming and the going of each passing day, so do I.

Ontology of caregiving as a repositioning of identity

As the tapestry of the collective narrative grew, it became evident that as degenerative transitions merged and as the processes of everyday living shifted and changed, there was corresponding movement in conscious awareness. No longer was there a sense of security in knowing “who *I* am”, “who *You* are”, and “where *We* fit in the world”. Repositioning identity became inexorably linked with loss of freedom, redefining of roles and relationships, social isolation, social stigma, and preservation of dignity. Gratification of higher order needs became secondary to the need for survival on multiple levels – emotional, physiological, and spiritual.

Such dynamic transformations reflect the words of Jenkins (1996/2004/2008) who postulated the notion that identity is not fixed. Rather, suggests Jenkins, it evolves with life experience, self-awareness, self-reflection, and interactions with others. That is, identity has a relational value which involves knowing “who’s who” and hence “what’s what” (p. 5). One can only begin to imagine the internal tensions when an adult child is asked by a parent, “When did you become my mother?” (Alice). One might also ask how Being-there presents for a wife of 40+ years when she is referred to as, “That lady next door – oh, you know, what’s her name?” (experience of Angelica, as reported

by Rosaline), or the wife of 48 years who is referred to as, “That young hussy who tried to climb into bed with me” (experience of Alexas, as reported by Elan).

As the caregivers journey with their loved ones, their position of knowing who they are in relation to others continues to cycle through the *infinite loop*. Friends become as strangers, as those who were thought to be friends, withdraw. “What would be nice”, says Rousillon, “would be if some of my so-called friends could pick up the phone and just say, ‘How are you going?’ Just a minute or two slows the cycle and says that someone cares”.

In other circumstances, anonymity of being just another person in the crowd is replaced with moments of Being-there in the spotlight of embarrassment, as the social behaviours of the care-receiver transition to behaviours that are anti-social, attention seeking, sexually inappropriate, and embarrassing. Embarrassment was the experience for Audrey when Ratcliffe said to a young mother pushing a toddler in a stroller, “That kid should be pushing you”.

Given the changes in lived experience and the ways in which others treat both caregiver and care receiver – be that with empathy, sensitivity, and respect; or be that in ways that reinforce social stigma – perhaps the getting of wisdom could be said to come with building resilience and the development of a stronger sense of *Self*. Maybe the hypothesis is, that for the caregiving journey (or any life journey experience) to have a positive outcome, one needs to pass through a dying process or a shedding of one’s “old skin” in a process of dynamic transformation. One may also need to develop an added layer of resilience. Being able to acknowledge and accept that life is what it is, in any present moment in time, demonstrates that when love underpins all that is *good*, *bad* or *ugly*, one can compose a sense of *Self* that rises above the transformative energies of degenerative transitions. *Being-there* acquires a “meaning of reality” (Heidegger, 1927/1962, p. 245).

Summary of discussion

What is significant in the selected scenarios that have been profiled is simply a glimpse into the uniqueness of Alzheimer’s disease and the co-related uniqueness of the caregiving role. Alzheimer’s is different from other diseases in its presenting symptomology, the progressive nature of cognitive and functional degeneration, changes in the architectural structure of the brain, and the duration of time spanning the trajectory of transitional changes and the trajectory of care. Also of significance are aspects of incidence and prevalence that identify Alzheimer’s disease as a modern-day epidemic impacting social and economic resources on a scale of concern that is unprecedented at global, national, and state levels (Alzheimer’s Association, 2018; Alzheimer’s Australia, 2017; Queensland Department of Health, 2015).

With Alzheimer’s disease, observable change is subtle and caregiving need is unpredictable. Diagnosis is generally made with reference to behavioural changes that can take decades to become consciously and consistently observable: for example, Adam’s diagnosis followed eight years of his undergoing various processes leading to confirmation. For Brian and Heather Fischer whose story was profiled on *Four Corners*, July 10, 2017, Brian’s diagnosis was a process that spanned 11 years.

The epistemology emerging from this investigation is that the impact of caregiving for a loved one who has Alzheimer’s

is timeless, constant, intense, inconsistent in levels of intensity, isolating, lonely, oppressive, and internal. In their darkest moments, caregivers may be feeling as if set adrift in a fathomless sea or tumbling aimlessly amidst the shifting sands. They may be feeling lost in a maze of emotional turmoil or overwhelmed by an enveloping cloud of unknowing.

Just as change in the care receiver's brain is a long, slow process, so, too, is change within the *Self* of the caregiver. It is a "flight through the darkness" (Isabella) as one journeys through *Wayi*, (Ephesea). For Isabella, this image "summons up a world of contradictions" and she explains:

The dichotomy is that as I grow to understand more, I love him more. And because I love him more, I believe that I will be less distressed to know that he is out of the darkness that has enveloped his life.

When I loved him less, I missed him more and now that I love him more, I miss him less: and that is something that I really need to think about. I value that we both had to go through this darkness to get to the light. I've always had a father but we had to go through this for me to be able to get close to him and to have an understanding of him: where he came from and what he had to give up as such a little boy so that his family could survive. Maybe our journey has been into the darkness and out again.

Running parallel with these thoughts expressed by Isabella, there is also a point of consideration that all may not be as it appears to be. Reflecting on the observed reality of behaviours defining that which is cognitively, physically, and functionally degenerative, Ephesea speaks from a transpersonal and spiritual space. She defines Alzheimer's as *Wayi*, which in Jandai Aboriginal languages means "to let go". From a position of *Wayi*, Alzheimer's becomes "the sacred journey and the letting go of all bodily attachments, physical and emotional: beginning the journey of re-entering into the spiritual world from which we came" (Ephesea). For the caregiver, it is the letting go of relationship with a very special person, who is so loved.

Entwining the epiphanic and transcendent descriptors of a *flight through the darkness* and *Wayi*, maybe it could be said that moving through the Alzheimer's maze is the sacred journey through the darkness. In that space there is a letting go of all that holds one to that which is of the human experience while opening the door to transcendence into the spiritual realm where life began. It is going home. And when life has spun full circle, the journey for the care receiver is complete while the impact for the caregiver lingers on. For the caregiver, there is always a part of that journey through the trajectory of care that is never completed and even when the care receiver has transitioned through *Wayi*, there are fragments of impact that, for a lifetime, will lie embedded deep within.

Flying through the darkness

Figure 2: *Flying through the darkness*: Visual reframing of the Alzheimer's journey that impacts both care receiver and caregiver. Painted in acrylics on canvas by Isabella during initial dialogue, 23/10/2015 (Boyland, 2018).

As caregivers travel along the many pathways that define their journey, raw and confronting reality is exposed as it is lived. Finally, the point is reached when maintenance of well-being is at risk and what Powers (1998, 2005) defines as "intrinsic variables" begin to approach near lethal levels. It is



at this point when a caregiver might seek help and present for support in managing stress associated with the reality of lived experience: with little or no realisation that at the very core of the distress is an embodiment of secondary trauma.

Implications for counselling and psychotherapy

Considering implications that have emerged from analysis of the data set that profiles the collective narrative, one implication that calls for action is the need to challenge professional clinicians⁸ and those in mentoring positions⁹ to appreciate and to not minimise the potential scope of role related impact on well-being. With emphasis on "duty of care", professional responsibility demands validation of approaches and techniques used in therapeutic practice focused through a diagnostic framework for identifying and working with secondary trauma. An indirect implication that emerges from the research findings is the need for clinicians and professional supervisors to develop an acute sense of discernment in relation to the diversity of presenting scenarios that could be triggered by change related circumstances that impact identity and identity shifts. Associated impact could be a cycling of dynamic transformation set in motion by a shift in the client's values base, a disruption to lifestyle, or polyvagal disturbance to maintenance of emotional well-being and balance of intrinsic variables. When a client seeks support, the clinician has an ethical duty of care to not only "do no harm" but to also be conscious that in a contextual reframing of Alice's comment, "There's a process going on here"; and that all may not be as it appears to be on the surface level of initial presentation.

Being in *the world that is*, is what brings a client to the counselling room. And while the *world that was* can never

be reclaimed, it is the clinician's ethical responsibility and professional privilege to walk with clients as a *pathway to the future*¹⁰ is created. In the best-case scenario, the stepping stones to wellness are stamped with a footprint of resilience that denotes a balancing of needs gratification and confirms that the light at the end of the tunnel is not a big train. It is a lantern that diffuses the darkness, as a new day is born.

Footnotes

¹Notion of OKness developed by Eric Berne, 1966.

²With reference to the work of the unknown mystic of the fourteenth century. (Underhill [Ed.], 2003)

³Additional help and support is tapped – for example: “hands on” support, respite, emotional support such as counselling, or care receiving loved one is admitted to formal, residential care.

⁴Death of caregiver or death of loved one who is the care receiver.

⁵Each complete rotation equates with progression through one transitional stage in accord with Riesberg's global deterioration scale (Reisberg, Ferris, de Leon, & Crook, 2007).

⁶Refer to Bredesen, D. (2017) and Petrovsky, N. (2016).

⁷Refer to Glasser, W. (1984; 1999).

⁸For example, counsellors and psychotherapists.

⁹For example, professional supervisors, clinical supervisors, mentors, and educators.

¹⁰As stated above, world that is, world that was, and pathway to the future are concepts developed by professor Judith Murray (2005; 2016) in relation to developing a model of loss and grieving.

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