



**Someone I love has Alzheimer’s:
The impact of caring for a ‘Special Someone’ who has a diagnosis of
Alzheimer’s disease:
A review of the literature**

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Abstract

This paper discusses a review of literature related to caring for a loved one who has a diagnosis of Alzheimer's disease. The review is focused through a conceptual framework that encompasses 13 key constructs: Living with dementia: transitioning; Transitioning to the role of caregiver; Transitional change; Aspects of impact: stress response; Aspects of impact: loss and grieving; The ripple effect; Support; Barriers to support; Coping strategies; Coping with abusive behaviour; Maintaining dignity in the midst of chaos; When it is time; and End of life.

Beginning with a glimpse into how life unfolds for the care receiver, the discussion focuses on the impact of lived experience and culminates with the promise from the medical world to patients and families, that they will not be abandoned.

Introduction

Initially identified as 'an unusual disease of the cerebral cortex', it was in 1906 that Dr Alois Alzheimer presented a conference paper addressing both the symptoms experienced by a patient across the last five years of her life and the autopsy findings in relation to the condition of the patient's brain following her death (Alzheimer's Disease International, n.d.). George, Whitehouse and Ballenger (2011) advise that it is now over 100 years since the condition that was to become known by the name of its 'discoverer' was formally established as a distinct disease and described in an influential German psychiatry textbook – Kraepelin, Emil. (1910). *Psychiatrie* (eighth edition). George et al. also explain that since that time, the condition (as initially described) has undergone various permutations. They further state that ongoing evolution carries important implications for the clinical treatment and cultural placement of persons who are given the

diagnosis. For, while researchers in the field of neuroscience have made huge strides in understanding Alzheimer's disease, it is still both irreversible and progressive: culminating in severe dementia and death. Perhaps the most comprehensive definition of Alzheimer's disease is presented by Summers (2014) who, referring to the Alzheimer's Association (2009) states that...

Alzheimer's disease is a progressive disease, commencing with mild and relatively circumscribed deficits that gradually worsen to become a severe dementia with widespread and marked impairments to cognitive, social and behavioural functioning. The speed of progression of impairment is variable from individual to individual, with death occurring between two and 20 years post-onset, on average within 10 years. (p. 250).

Because of the nature of Alzheimer's disease and dementia, individuals living with these conditions can spend five times as long in hospital visits than all other causes of hospitalisation. While patients who have transitioned to an Alzheimer's related dementia are more likely to live in institutionalised health settings, the proportion of those in residential settings has increased from 26% in 2003 to 38% in 2009 (ABS 4102.0, 2012), indicating a significant rise in the focus of family and assisted caregiving. This review of literature sets the scene for a qualitative research project titled "Someone I love has Alzheimer's: The impact of caring for a loved one who has a diagnosis of Alzheimer's disease". The research investigation seeks to gain insight and understanding about the nature of the truths embodied in a world of the lived experience of informal caregivers. It is about the relationship between the caregiver and the experience of caregiving. However, while the focus of this project is on the caregiver, it needs to be acknowledged that the 'Special Someone' who is the care receiver is also transitioning from a life that was, through a life that is, to a life destined to be shrouded in a cloud of unknowing. Assuming a starting point of 'normal', (referenced as Stage One of 'Reisberg's Global Deterioration Scale' [Reisberg, Ferris, de Leon, and Crook, 2007/1982]), the intention of this review is to present a collective profile of the impact of the onset to post-death journey of caring for a loved one who has Alzheimer's. This review revisits and reframes Murray's (2016; 2005) notions of a 'world that was' and a 'world that is' to 'life that was' and 'life that is' in exploring the numerically-increasing rise of incidence of Alzheimer's disease

but relatively unknown impact of caregivers' experiences when caring for a loved one across the trajectory of caregiving

Literature Review

1. Living with dementia: transitioning

When reading reports that deal with aspects of living with Alzheimer's disease and Alzheimer's related dementias, similarities are noted across different cultural contexts. Significance of family observations of behavioural changes was noted by Williams, Klein, Little and Haban (1986) who stated that the observations made by family members of cognitive impairment and decline in a loved one, serve an important role in the description of dementia-related illnesses, such as Alzheimer's disease. Thirty years ago, Williams et al. explained that a common clinical practice was to interview family and to informally gather information about the severity and the history of intellectual impairment, such as memory disorder and loss of language and speech ability due to damage to the central nervous system. They reported the results of their study as revealing that family members made reliable judgments of everyday cognitive impairment and that observer ratings significantly enhanced diagnostic efforts: especially when used in conjunction with neuropsychological tests and also in cases in which the person with dementia could not participate in a full neuropsychological evaluation.

More recent reports also reflect the significance of family observations, with Bunn, Goodman, Sworn, Rait, Brayne, Robinson, McNeilly and Iliffe (2012) having observed that family members often recognise that something is wrong, even before the patient with dementia does. An example of the significance of family observation was presented in the work of Gierck (2015), who in discussion with her family doctor, made reference to her observations of her mother ...

I think Mum has lost a little edge too, in a good way. She's not so independent, so stoic that she has to battle on and do everything herself. She's allowing herself to depend on others. She's softening a little and it becomes her. (p. 16).

Aminzadeh, Molnar, Dalziel and Ayotte (2012) suggested that despite variations in systems of care, there seemed to be substantial consistency in core recommendations of most Western contemporary

clinical practice guidelines. These, they explained, indicated that primary care of persons with Alzheimer's should begin with "a recognition of the signs and symptoms of dementia, followed by a thorough multidimensional evaluation, sensitive diagnosis disclosure, collaborative care planning and ongoing monitoring and management of evolving needs of caregivers" (p. 86). Accurate and early diagnosis support a range of benefits, the most important being deemed by Summers (2015) to be the right of the individual to know what is happening to them, in keeping with overriding ethical codes that would not support withholding a diagnosis unless provision of that diagnosis would put the person at risk (for example, suicide) or if the person lacked capacity (M. Summers, personal communication, July 1, 2015).

Gil, Arroyo-Anllo, Ingrand, Gil, Neau, Ornon and Bonnaud (2001) directed research towards the correlation between onset of dementia and the impact on a reflexive sense of self-consciousness. Here, impact was presented as being the object of the person's own awareness and in this situation, focussed on the sensitivity of transition from what might be deemed to be 'normal', to the progressive onset of dementia.

In a study focused through the responses of participants in urban Iran, Mazaheri, Eriksson, Heikkilä, Nasrabadi, Ekman and Sunvisson (2013) consulted with six women and nine men who also made reference to the impact on family members. All participants were able to give concrete examples of their experiences of living with the progressive debilitation associated with Alzheimer's and reported the emergence of five common themes as they reflected on the transition from what Murray (2005) might describe as 'the life that was' to 'the life that is' . . .

- 1) struggling with a changing life which included participants' feelings about how they were perceived in the eyes of others
- 2) the irritation of forgetfulness and the increasing inability to undertake simple tasks
- 3) increasing dependence on others and being a burden on loved ones
- 4) feelings of embarrassment, incompetence, shame, confusion and loneliness
- 5) longing to be valued and finding strategies to deal with and mask progressive debilitation, even prior to diagnosis.

Cognitive and functional degeneration were said to be challenging to the participants' understanding of themselves as competent people and they spoke of feeling deeply unfulfilled, with

the reactions of others making them feel as if they were no longer themselves: but some other person.

Similar thoughts were expressed by participants in a study undertaken in the United Kingdom by Benbow and Kingston (2014), who suggested that producing a narrative that described the feelings of care receivers as they transitioned through Alzheimer's disease was both valuable and engaging and had the potential to contribute to future advancements in dementia care.

2. Transitioning to the role of caregiver

Recognizing and acknowledging that a 'Special Someone' who is deeply loved has Alzheimer's disease can be a distressing and emotional time. And while preparing for a diagnosis, support is needed by both caregiver and care receiver. However, all too often, this support is lacking. Emotions can run high and as reported by Varela, Varona, Anderson and Sansoni (2011), can range from shock to anger to grief and in many instances, there can also be associated stress, anxiety and depression. According to Varela et al., the first step in transitioning to the role of caregiver is to recognise the stage symptomatology being demonstrated in that 'Someone Special' and to seek formal diagnosis: as the decline in ability to function is co-related with the progression of debilitation. It is also reported by Varela et al. that significant aspects to be considered in taking on the role of caregiver is to determine who is to be in control of decision making, how needs are to be met and where that 'Special Someone' is to live after diagnosis.

In a study of spouse and adult child caregivers, Ott, Sanders and Kelber (2007) reported on the co-existence of grief and personal growth while transitioning to the role of caregiver. They explained that while grief was deemed to increase as the severity of the disease increased, the majority of caregivers who participated in their study also reported experiencing personal growth. Black, Gauthier, Dalziel, Keren, Correl, Hew and Binder (2010) focussed investigation on 'baby-boomers' and the burden of care. They reported that participants identified several areas of burden of care, including negative effects on emotional health: demonstrated through increased incidence of depression, more stress and greater fatigue. Financial costs were also deemed to be a significant factor in magnifying the burden of care.

Minority related aspects deemed to influence stories of caregiver transitions, included ethnic identity and associated cultural resources. In a multicultural study undertaken by Hinton and Levkoff (1999), the authors noted that African-American, Irish-American and Chinese-American caregivers focused their stories through a “what is at stake” lens (p. 468): seeing Alzheimer’s as a disease that erodes the core identity of a loved one, deteriorates their minds and results in a loss of identity. Hinton and Levkoff also noted that for Chinese caregivers, the focus on transition emphasised how families might manage confusion and disability: changes ultimately construed as an anticipated and expected aspect of growing old. Further outcomes of the Hinton and Levkoff study revealed that Puerto Rican and Dominican families perceived their elder’s illness in a context of tragic loss, separation, loneliness and family responsibility and their transition was deemed to have a loss and grief focus.

Calasanti and Bowen (2006) and Russell (2007) also referenced the role of the male as caregiver: spouse, partner, son. Focussing on the way gender might influence caregiving, it was suggested that while both female and male caregivers crossed traditional and stereotypical boundaries, different challenges were confronted by each gender. The experiences of the men who participated in the studies of Calasanti and Bowen and Russell refuted any contention that male caregivers merely mow the lawn, fix the car, wash the dog and pay the bills. Theirs are stories of adaptation, commitment, love and transition as illustrated in the words of ‘Ron’ who spoke of the “mixed blessing of having no sense of smell” (p. 13) and of ‘Roman’ who stated that six months of attending his wife’s personal hygiene needs, “cured me of biting my nails” (p. 14).

Finally, in considering the transitional impact from different cultural perceptions, the study of Navab, Negarandeh and Peyrovi (2012) reported on the lived experiences of Iranian families. Introducing a theme of “captivity in the whirlpool of time” (p. 1080), the focus of family stories revolved around reminiscence of the past and fear of the future. There was no speaking of the ‘now’ time: implying that there was no acknowledging the pervading circumstances of the currency of experience.

3. Transitional change

Change in a caregiver's life can be significant: as illustrated in research outcomes reported by Varela, Varona, Anderson and Sansoni (2011). Participants expressed that they had little time to themselves and felt that their own social life was being impacted. It was also noted that participants expressed feeling emotionally drained: with the general consequences of impact being associated with physical health and subjective psychosocial well-being. Caregivers also shared feeling that they were at risk of not receiving support from others, while exposing themselves to depression and physical vulnerability. This was highlighted by Varela et al. to be of particular significance as cognitive and physical deterioration of the care receiver progressed and as associated behaviour became increasingly stressful for both caregiver and care receiver. Transitional changes also included significant increase in depressive symptoms, along with decreased immune function, decreased wound healing capacity and autonomic and neuroendocrine dysregulation: all worsening with increased stress. Sleep quality was also reported to be inadequate or insufficient, as caregivers were often wakened through the night by their care receivers. This resulted in the caregivers' experiencing sleeping issues that continued well after the Alzheimer's patient had moved out of home or had died. Caregivers advised that they found themselves sleeping better when they were able to take breaks and it was reported that the weaker the social support for the caregiver, the worse the sleep quality: the corollary being that the stronger the social support for the caregiver, the better the sleep quality and the subsequent ability to cope with the presenting challenges of each day.

4. Aspects of Impact: Stress response

Stressors have the potential to be multi-dimensional and significant, particularly when that 'Special Someone' develops high levels of psychosis (including delusions and hallucinations), mood disturbances and cognitive fluctuations. According to Flaskerud (2000) and Lee, McKeith, Mosimann, Ghosh-Nodyal and Thomas (2013), caring incurs significant levels of stress that may affect emotional, mental and physical well-being. Aspects of impact were reported in terms of changes to lifestyle and role functioning abilities, through disruption of interpersonal relationships, social life and work life. It was also noted in both studies (Flaskerud and Lee et al.), that stress also presented as having a flow on impact associated with increasing financial strain.

Wang (2013) drew particular attention to the notion of chronic stress associated and when comparing the burden of stress differentiation between caregivers who care for a loved one with dementia and caregivers who care for a loved one with depression, Leinonen, Korpisammai, Pulkkinen and Pukuri (2001) reported significant connection between low functioning capacity of the care receiver and stress burden of the caregiver.

Flaskerud (2000) referred to loneliness as having a complex relationship in the process of caregiving and she suggested one aspect of loneliness as being associated with social isolation stemming from the constancy of care: especially when the duration and intensity of care became great. Yan and Kwok (2011) also reported intensity of care and constancy of contact associated with co-residing as being significant factors in stress burden: to the point where they were deemed to be predictors in initiating both verbal and physical abuse towards the care recipient.

Lee, McKeith, Mosimann, Ghosh-Nodyal, and Thomas (2013) proffered the notion that loneliness could also stem from the loss of mutuality and reciprocity in the relationship with the care receiver due to the onset of functional dependence, cognitive decline and general weakness and pain. Lee et al. also suggested that stress could be related to the number of hours per week engaged in providing care, severity of cognitive impairment, relationship with the patient, demonstrated behaviours of the patient and support that was received.

5. Aspects of impact: loss and grieving

In considering the notion of a 'grief response', Ott, Sanders and Kelber (2007) presented a definition in terms of "reaction to the perception of loss with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual" (p. 799). According to Ott et al., grief occurs when the safety and security that a person feels within a relationship becomes threatened. Ott et al. also posited the notion that despite the stress and strain that occurred between a caregiver and a care receiver, a bond existed that created an intense form of attachment and as the attachment changed as a result of disease progression, grief was the natural by-product.

Silverberg (2007) introduced a '3-A' grief intervention model for dementia caregivers and proposed that the model, 'Acknowledge, Assess, Assist', enfranchised the caregiver's grief experience through Acknowledging, Assessing and Assisting in grief management. Silverberg explained that from the time symptoms began to insidiously emerge, it could take well over ten years for Alzheimer's disease to run its course. This timeline was also supported by Summers (2014), who proposed a time frame of four to ten years from diagnosis to end of life. Silverberg also made reference to the impact on the primary caregiver in terms of emotional and physiological experience, expressing that in addition to the crippling effect for those inflicted with Alzheimer's disease and Alzheimer's related dementias, this lengthy time frame could have debilitating impact on family, who were grieving the loss of the loved one they knew, pre onset.

In profiling the general experience of caregiver grief, Large and Slinger (2013) identified six emergent themes: namely, challenges of caregiving; losses and changes in the relationship; the role of dementia in grief; striving despite dementia; utilising social support and death as a relief from caregiving.

Sanders, Morano and Corley (2002) referenced the constancy of expressions of loss in statements given by caregivers, particularly male caregivers. Findings of Sanders et al. concurred with outcomes cited by Loos and Bowd (1997), who reported implications of the experience of loss and grief as expressed by participants in themes of loss associated with social and recreational activities, loss of personal freedom and control over life events, loss of well-being and loss of occupation. Participants in the Loos and Bowd study also expressed feelings of deep guilt, accompanied by an increased sense of loss, when their loved one was transferred to institutionalised care: expressing feelings that the well-being of their loved one was at risk.

6. The ripple effect

When speaking of the impact of caring for a 'Special Someone' who has a diagnosis of Alzheimer's disease, it is important to consider just how far the impact is felt. Investigating the impact on extended family, Celdrán, Triadó and Villar (2011) reported that **adolescents** experienced a frequency of 15 varying emotions, as their relationship with a grandparent who had

dementia began to change. According to Celdrán et al., in general, the dementia process was seen as having a negative impact on relationships, eliciting fear and confusion. However, in some cases, there was seen to be potential for positive changes that were mainly related to the adolescent's ability to keep emotional contact, to express emotions and to be heard. In follow up studies to those of 2011, Celdrán, Villar and Triadó (2012) discovered that in situations where the grandparent moved into the grandchildren's home, the adolescents reported experiencing changes in their daily activities and identified mainly positive changes in the relationship they shared with their parents.

Similar impacts were reported by Hamill (2012) who advised that in her study, the trend seemed to be that the greater the affection adolescent grandchildren had towards their grandparent, the more they were inclined to offer help and the less concerned they seemed to be about the amount of time their parents gave in caring for their grandparents. Younger children also encounter Alzheimer's disease and Alzheimer's related dementia, particularly among grandparents and great-grandparents and in multi-generational households. Manthorpe (2005) warned that the needs of children may be easily overlooked. The advice was that younger children also needed information, needed to be encouraged to ask questions, needed to be reassured, needed to help to a level and scale with which they felt comfortable and above all, needed not to be overlooked and neglected.

7. Support

Support can be accessed in many places and according to Hogan and Schmidt (2002), social support is shown to facilitate healing as people transition, reconstruct their lives and find new meaning in life when major life events impact on the world that is, turning it upside down and inside out. In information provided by Alzheimer Europe (2014e), it was noted that as dementia progressively develops, so too do the needs of the person with the dementia and in turn, the needs of the caregiver. It was explained that while a particular solution may be helpful for a time, there is eventually a need to try different approaches. It was also explained that the caregiver can often feel alone and can tend to worry about coping. In support for the caregiver, it was suggested that it could be helpful to talk with others in a similar situation. The concept was posed that, often, personal accounts of others living with a care receiver who has dementia could be an invaluable support, normalising what is of the now and providing insight to what the future lived experience

might entail. It is advised that contact can be made through Alzheimer's Associations located throughout the world, with the mode of contact being by way of direct personal link with a local group or through social media crossing national and international boundaries.

Burns (2000) cited assistance available through primary health care providers in relation to dealing with patient behaviours and managing caregiver burden. Burns also suggested that caregivers need to be given written information on patient behaviour management, skills training and behaviour modification strategies to decrease stress burden. In addition, Burns referenced the lack of support provided by primary health care providers, attributing this deficit to lack of knowledge and associated time and resource constraints. In the study of Wackerbarth and Johnson (2002), caregivers identified the need for information concerning diagnosis and treatment and also information concerning legal and financial issues. Specific information about health plan coverage was also deemed to be important.

8. Barriers to support

Just as some caregivers experience personal growth in the midst of life changing events associated with the progressive debilitation of that 'Special Someone' who has a diagnosis of Alzheimer's disease, others can traverse an alternative pathway. These caregivers, become stuck in what Hogan and Schmidt (2002) referred to as "a crisis of meaning" (p. 616). In the quagmire of grief, there are those who experience a loss of self-confidence, become shrouded in a sense of unknowing and confused about who they are in the midst of what is perceived as being "both interpersonal and intrapersonal crises" (p. 629). Eppers, Goodall and Harrison (2008) reported that appropriately tailored interventions can improve the health and well-being of both caregiver and care receiver. They also suggested that individually developed multicomponent interventions, including a diversity of services, tended to decrease burden, improve quality of life and enable caregivers to provide at-home care for longer periods, prior to institutionalisation.

However, while 'multicomponent interventions' are recommended, services are not readily accessible to all caregivers. According to data published by Varela, Varona, Anderson, and Sansoni (2011), the Italian Health Care System provided little support for caregivers and barriers to using

support services that were provided were said to include the attitude of health care professionals or health care assistants as well as out of pocket expenses that the caregiver had to pay. Similar barriers were reported for caregivers in Canada with Strain and Blanford (2002) advising that while quite a range of services were available for Canadian residents (for example, day centres, cleaning services, personal care services, in-home nursing services, home delivered meals, respite in hospitals or nursing homes), caregivers chose to not use the services for reasons that included reluctance to leave their loved one with a stranger, personal and/or cultural attitudes about care giving, lack of knowledge of available services, perceptions that services were too expensive and perceptions that their 'Special Someone' presented with too many behavioural and emotional problems.

A significant factor as to whether a caregiver is able to access support services, is geographic location. With specific reference to older rural carers, Winterton and Warburton (2010) cited a range of social barriers deemed to inhibit participation and also deemed to be exacerbated by residing in a rural area. Additional factors reported by Winterton and Warburton to be of significance in rural communities, were the highly valued virtues of stoicism and resilience.

Coming from a more personal perspective, Daly, McCarron, Higgins and McCallion (2013) made reference to caregivers' experiencing feelings of abandonment where, in the midst of social marginalisation and the implications associated with progressing dementia, aspects of what might be deemed to be of the 'normal' life-world, were frequently thrown away.

9. Coping strategies

According to Ross, Hollimand and Dixon (2003), coping is about identifying the most difficult aspects of caregiving, dealing with them and celebrating the benefits and growth opportunities. Coping is also said to be about resilience: discovering and engaging methods of successfully managing the demands of caring for a loved one who has Alzheimer's disease or Alzheimer's related dementia.

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 sustaining place and overcoming risk of marginalisation and loss of social contact. 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 employed, included confirmation and upholding respect for personhood, claiming place rather than becoming dependent on others to grant or bestow, prioritising needs of both care receiver and caregiver, working to preserve dignity, nurturing self and nurturing that ‘Special Someone’, 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.

A key aspect to coping was identified by Fortinsky, Kercher and Burant (2002), Gallagher, Ni Mhaolain, Crosby, Ryan, Lacey, Coen, Walsh, Coakley, Walsh, Cunningham and Lawlor (2011) and Semiatin, and O’Connor (2011) as ‘self-efficacy’: a notion that reflects the work of Bandura (1986) and is often referred to in every-day conversation as the ‘self-fulfilling prophecy’. Fortinsky et al. proffered the notion that higher levels of self-efficacy are expected to lead to health-promoting behaviours and improved measures of physical and mental well-being for family caregivers of persons with Alzheimer’s disease. For Gallagher et al., ‘self-efficacy’ is about prediction of carer burden and carer depression in relation to symptom management, emotion-focussed coping, dysfunctional coping levels, patient function and/or neuroticism in relation to anxiety, OCD or perceived somatic complaints without any real evidence of disease or ailment. For Semiatin and O’Connor, ‘self-efficacy’ is about influencing “the development of affective filters that influence whether life events are cognitively construed, represented and retrieved in an affectively benign or distressing manner” (p. 686). Self-efficacy could also be a significant factor in the functioning of what Donovan and Corcoran (2010) defined as “uplifted caregivers” (p. 592) who were identified as being less likely to live alone with the care receiver, as experiencing fewer symptoms of depression and as having lower levels of both objective (related to self) and subjective (related to significant others) stress burden factors. Donovan and Corcoran also referred to the key coping strategies

deployed by the ‘uplifted’, which included engagement in positive behaviours and making adjustments to attitudes.

10. Coping with abusive behavior

Reporting the results of a survey conducted in 2010, Alzheimer Europe (2014f) noted that 220 family carers of people with dementia identified as follows ...

- Over one third of those surveyed reported experiencing significant abuse from the people they cared for.
- Those who reported abuse also reported a greater deterioration in the relationship.
- Dysfunctional coping strategies partially explained deterioration in relationship.

In a study conducted by Cooper, Selwood, Blanchard and Livingston (2010), over one-third of family caregiver participants reported significant abuse from the care recipient who had dementia and the abusive behaviours were reported as being a mix of verbal, psychological and physical orientations. It was noted that caregivers who reported more abuse also reported a greater deterioration in their relationship with the person with dementia and it was suggested by the authors that the extent to which caregivers used dysfunctional coping strategies could partially explain this incidence of abusive behaviour. Cooper et al. also suggested that some abusive behaviours may be indicators of neuropsychiatric symptoms, which are part of the dementia.

In keeping with this line of thought, VandeWeerd, Paveza, Walsh, and Corvin, (2013) observed that as Alzheimer’s disease progresses, the risk of abuse by both care receiver and caregiver increases. For VandeWeerd et al., considering risk factor from a perspective of caregiver burden, poor functional and psychological health and difficulties in coping with higher levels of functional impairment, avenues for abuse prevention may lie in increased physical, occupational and assistive device therapies for both caregiver and care receiver. The rationale underpinning such intervention was reported to have emerged from studies showing that many older adults were acting significantly below their functional capacity, with or without any contributing impairment.

Ahn and Horgas (2013) and Abbey (2015) referred to the notion that demonstration of abusive behaviours could be in direct correlation with pain frequency, pain intensity and the increasing inability for the person with Alzheimer's or Alzheimer's related dementia to verbally express that he/she is in pain. It is explained by both sources that with advancing dementia, the care receiver gradually loses the ability to process information, so is less likely to express pain in typical ways. The presence of pain may be expressed through agitated, aggressive, disruptive and abusive behaviours because of the inability to appropriately verbalize the pain experience.

11. Maintaining dignity in the midst of chaos

According to *The Pocket Macquarie Dictionary* (Bernard, 1989), dignity has to do with the notion of worthiness. In considering the wants expressed by participants in the studies reviewed above (Living with dementia: Transitioning) and reflecting on these through a lens of basic needs gratification as defined by Glasser (1984, 1989, 1999), it could be said that dignity has to do with a sense of 'worthness'. It's about being seen as important, being valued, contributing, having a sense of worth (basic psychological need for personal power). It is about being trusted to offer advice and opinion and to make decisions (basic psychological need for freedom). It is about being cognitively and physically able to engage in creative pursuits and pleasurable activities (basic psychological need for fun). It is about being respected rather than ridiculed, being loved rather than pitied, being treated with empathy rather than with sympathy (basic psychological need for connection, love and belonging).

This notion of 'worthness' could also be seen in correlation with the notion of 'personhood', as discussed by Smebye and Kirkevold (2013) when they spoke of personhood as being "the right of every human being regardless of capacity" (p. 1). Smebye and Kirkevold drew on ideas posited by Buber (1958) who, close to 60 years ago, postulated the notion that all real living, is meeting with mutual acknowledgement of the uniqueness of the other. Thus, the dignity of personhood can be seen as a product of relationships with others and as such, has the capacity to be nurtured and strengthened or diminished and weakened.

Looking at the notion of ‘worthness’ through the lens of a transpersonal caring relationship as discussed by Watson (2008/1979), it is about caregiving that conveys concern for the inner life world of the care-receiver. It is about being present, in the moment, in a spirit that invites full loving-kindness and equanimity. It is about being able to read the moment and it is about a Self that is open, responsive and sensitive to what is happening and to what is emerging for the Other. It is about understanding and appreciating that a significant caring moment can be a turning point that affects both caregiver and care-receiver and that ...

radiates out beyond the moment, connecting with the universal field of infinity to which we all belong and in which we all dwell. Thus the moment lives on.

Such an authentic spirit-to-spirit connection in a given moment transcends the personal ego level . . . and opens the (caregiver’s) intelligent heart and head to what is really emerging and presenting in the moment. (Watson p. 79)

12. When it is time

As much as family want to care for their ‘Special Someone’, the time will inevitably come when admission to institutionalised care is what is needed to best serve the needs of both the loved one whose debilitation has now progressed to advanced dementia and the caregiver who is unable to meet the needs of the care receiver. This may be due to social isolation, impact of caregiving on caregivers’ health, dementia related behaviours worsening with progression of cognitive impairment and loss of functionality, accelerated increase in daily care burden, need for more skilled care or a general need for more assistance linked with availability of support resources (Buhr, Kuchibhatla and Clipp, 2006; Sansoni, Anderson, Varolna and Varela, 2013; Sun, Durkin, Hilgeman, Harris, Gaugler, Wardian, Allen and Bergio, 2013 and Simard, 2014). It is noted that each of these factors, considered either singly or in combination, has the potential to escalate risk factored impact on caregivers’ well-being as well as risk potentiality for caregivers to demonstrate harmful behaviours towards care receivers. According to Anderson et al, Buhr et al., Sansoni et al., Simard, Sun et al. and Varolna and Varela, whatever the circumstance, admission to a care facility can have significant impact on the caregiver who, either temporally or permanently, relinquishes to

professionals, the provision of control and care that has been a major part of their being and their doing, for some considerable period of time.

Tornatore and Grant (2002) and Tornatore and Grant (2004) reported in relation to the subjective stressors associated with transition to institutionalise. Bloomer, Digby, Tan, Crawford and Williams (2014) addressed the need for good communication between clinicians and caregivers and the need for the caregiver to be deemed the expert in the care of their loved one. Bloomer et al. also referenced the need for the caregiver to be included in decision-making processes and to be given emotional support throughout the period of time their loved one is a patient in the professional care facility, whether that be for respite, medical attention, residential transition or palliative care.

Unfortunately, the hospital/institutional experience does not always conform to the ideal, as recorded by Gierck (2015) who stated that, “Some days caring and niceness seem mutually exclusive” (p. 217). As also reported in the studies of Jurgens, Clissett, Gladman and Harwood (2012) and Spencer, Foster, Whittamore, Goldner and Harwood (2013), the experience of care was often negative, with key themes in the cycle of discontent being focussed through events, expectations and relationships with staff.

Dissatisfaction is not the exclusive domain of Australian families. It is of global significance. Experiences discussed by Jurgens, Clissett, Gladman and Harwood (2012) were cited as tending to lead to caregivers’ becoming uncertain and suspicious which, in turn, led to periods of “hyper vigilant monitoring” (p. 1). Bloomer, Digby, Tan, Crawford, & Williams (2014) expressed similar thoughts to those expressed by Sansoni, Anderson, Varona and Varela, (2013); Sun, Durkin, Hilgeman, Garris, Gaugler, Wardain, Allen, and Burgio, (2013); Jurgens, Clissett, Gladman and Harwood (2012); Buhr, Kuchibhatla, and Clipp (2006); Tornatore and Grant (2004) and Tornatore and Grant (2002) all of whom suggested that patients with dementia and family caregivers needed support from professional staff, needed to be provided with information to reduce stress burden and to support caregiver health and well-being and needed to be considered as a unit. David Cooper (2014) referred to such considerations in terms of compassion, respect and dignity: “being with the

person and family . . . – one human being to another – seeing through the other person’s eyes and empathizing with that person’s pain, fear, joy, loss and sadness” (p. 11)

13. End of life

Relevant understanding of Alzheimer’s disease, together with an awareness and acceptance of the progressive onset of dementia related degeneration and debilitation is deemed to be integral to appreciating aspects of impact when caring for that ‘Special Someone’ who has a diagnosis of Alzheimer’s disease. Understanding, awareness and acceptance also demand that appropriate management of the stage of advanced dementia requires it to be recognized as a terminal condition that needs palliative care, the concept of which was born in the 1950s when, based on careful observation of dying patients, Dr Cicely Saunders first articulated her ideas about focusing on the care of the dying. Dr Saunders advocated that only an interdisciplinary team could relieve the total pain of a dying person, in the context of family (ASH Education, 2008). Simard (2014) noted that one of the biggest challenges facing professionals who counsel families whose loved one is living with advanced Alzheimer’s related dementia, is that the condition is irreversible, is terminal and that decisions and goals of care need to change as the disease progresses. Three possible goals of care are named by Simard as “prolongation of life”, “maintenance of function” and “comfort” (p. 169).

Kumar and Kuriakose (2013) claimed that interventions during the palliative stage need to be carefully chosen to ensure maintenance of the quality of life of the care receiver. They addressed the importance of advanced care planning whereby the individual’s wishes are made clear in relation to the care they would like to receive at a time when they may no longer be able to make such decisions or be able to make their wishes known. Kumar and Kuriakose suggested that caregivers and other family members need to be educated and encouraged to actively participate in discussions related to aspects such as artificial nutrition, cardiopulmonary resuscitation and other medical interventions. They also suggested that critical aspects to consider include how invasive interventions can be, when it is doubtful as to the amount of benefit compared with the amount of associated discomfort. The question to be considered is, “Would this be what the patient would want if able to make the decision, judged on decision making actions of the past?”

In discussing research that focuses specifically on the notion of ‘what the patient would want if able to make the decision, judged on decision making actions of the past’, Van Der Steen, Van Soest-Poortvliet, Achterberg, Ribbe and De Vet (2011) assessed family perceptions of the preferences of dementia patients regarding end-of-life wishes about death and dying. Two specific areas deemed to be most relevant were ‘treatment preferences’ and ‘preparation for end of life’: generally deemed to be the most significant conditions associated with a “good death” (p. 219). According to relatives, treatment preferences embodied maintaining dignity and freedom from pain, with particular reference being made to bladder and bowel control.

End of life preparation covers a diversity of aspects, including costs, means to end life, talking about feelings and spiritual counselling. In the study of Van Der Steen, Van Soest-Poortvliet, Achterberg, Ribbe, and De Vet (2011), it was deemed important to spend time with family and in situations where pets were deemed to hold a significant place in the family, it was also deemed to be important for the dying patient to be able to spend time with a much loved pet. Spiritual caregiving was reported as being relatively unimportant in the overall priorities presented in the study and in responses from approximately half the participants of the study of Van Der Steen et al., family were reported as being generally unfamiliar with their loved one’s feelings about fear of dying and preference for dying when conscious or unconscious: a condition of major relevance for palliative care sedation. This sense of unknowing was not part of Michele Gierck’s story as she shared her experience with her mother ...

For weeks I’ve been worried about how Mum can die when she’s so fearful of it. But today, she’s making that transition. My mother certainly has pain in her head, and there are moments of wanting to hang on, but there’s also a peacefulness. There is no longer fear of what beckons. She’s slowly slipping into the next stage of her journey which each of us must take alone. (Gierck, 2015, p. 231).

Reflecting on the expressions of Kumar and Kuriakose (2013) in the light of information emerging from the end-of-life survey conducted by Alzheimer’s Australia (2014b), it seems appropriate to conclude this literature review with words taken from the ASH Education Book (2008), which state ...

Palliative medicine is the continuation of the long struggle to accept life on its own terms, honestly and openly. Taking its place in academic medicine, this new subspecialty will enable future generations of physicians to gain generalist-level palliative medicine skills while advancing knowledge in the field and fulfilling our promise to patients and their families that we will not abandon them when our treatments fail and that, at all times, we will do all we can to relieve their suffering. (p. 465)

Conclusion

As the prevalence of Alzheimer's disease increases and as the residential-centering of caregiving continues, the spread of family experiences of a loved one's suffering will rise. We understand less of the complex social and personal experience than we do of the documented rise of Alzheimer's disease in Australia. Review of the literature traced the pre-diagnosis to death trajectory in relation to 'The impact of caring for a 'Special Someone' who has a diagnosis of Alzheimer's disease' and was focused through a conceptual framework that encompassed 13 key themes of the caregiver journey across the trajectory of caregiving. Transitional changes for both care receiver and caregiver introduced the review which discussed a diversity of complexities embodied in the social construct of caregiving. No element of lifestyle escapes impact as the trajectory of care is traversed and as degenerative dysfunction erodes life as it was, pre-Alzheimer's.

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