

All in a Day's Work: Spousal Caregiver Depression

The Prevalence of Mental Illness in Female Dementia Caregivers

Written by: Heather Moffatt

The face of Canada has changed dramatically in the last century; our population continues to age, slowly but steadily, as the global birth rate continually declines. Modern civilization has reshaped our demographic, it now allows for much longer lifespans, and multiple generations within families. Sadly with these changes comes a decline, in health and independence, the natural downward slope of human existence. Chronic disease, lack of mobility, and cognitive impairment, specifically Alzheimer's disease, are among the top reasons why older adults require care and assistance in later life (Papastavrou, 2011). Government, healthcare and social systems worldwide will be challenged to accommodate this inflation of demands, that will require an increase in all supportive care disciplines. Informing the general public of the concerns related to offering care to dementia sufferers is the first step in creating effective approaches to alleviating these negative outcomes.

Informal caregiving is broadly defined as the active caregiving and support of individuals who are unable to care for themselves. A role that is largely filled by family and friends, it is estimated that approximately 2.7 million Canadians are currently offering informal care to older adults (Alberts, 2011). The implications of caregiving have been well documented, and present a multilayered range of effects, known collectively as caregiver burden. Caregiver burden can have detrimental effects on the healthcare system as well, oftentimes leading to depression, anxiety, exacerbation of physical health issues, social isolation and financial strain for the people in charge of care (Papastravrou, 2011). There are specific challenges related to caring for someone suffering from dementia and studies have found that an increased level of burden, and comorbid psychological issues can affect caregivers in such situations (Alberts, 2011). Further, research (Alberts, 2011) suggests that nearly a quarter of the caregiving population in Canada is over 65 years of age, a statistic that increases the risk of negative consequences for the older caregiver.

Despite variations on the role definition of the caregiver, the international research on gerontological caregiving has found that depression is the primary mental health outcome associated with persons responsible for care (Khalaila, 2011). Depending on which coping mechanisms they employ, caregivers have been reported to experience different degrees of burden, regardless of compounding factors. Effective coping strategies can safeguard caregivers from psychological burnout, and maintain their overall well-being throughout the time spent giving care (Papastavrou, 2011). Coping is a means of controlling emotional, behavioral, and cognitive reactions to stressful stimuli, it can promote problem solving, relaxation, distancing, or emotional regulation (Papastavrou, 2011). Many primary caregivers of dementia patients experience depression in combination with other mental strain, a recent study found that over 50% of familial caregivers suffered from clinical depression as well as anxiety (Garcia, 2012). The same report elucidated further to include a demographic insight that showed women largely represent the informal care group affected by mental illness, specifically the wives of persons needing care (Garcia, 2012). Because of inherent female caregiving tendencies and marital commitment, it can be

suggested that wives experience greater rates of depression and mental health issues, than do husbands in the same position of managing spousal dementia.

Depression can affect many facets of one's life, and quickly consume the psyche of an otherwise healthy person; in a survey, 87% of caregivers were able to recognize their own depression (Watson, 2011). Health professionals have warned that previous bouts of mental illness make an individual prone to relapse, and sensitive to high levels of stress (Neundorfer, 2006). Despite the known fact that caring for a family member suffering from dementia can lead to the onset of depression, no history of psychiatric complaints could reliably predict a greater likelihood for depression in a selected group of caregivers (Neundorfer, 2006). Increasingly, research into Alzheimer's disease has shifted from evaluating the general quality of life of dementia patients, to looking more at the association between quality of life and resulting mental illness in the dementia caregivers (Rosness, 2011). Additionally, (Rosness, 2011) the study strove to understand the psychosocial state of spousal caregivers dealing with diminished marital rapport, feelings of isolation, and lack of communication, and determined that 75% of caregivers felt depressed in response to their deteriorating spousal relationship. Managing the care of a loved one with dementia is often unpredictable; problem behaviors including restlessness, agitation, and aggression are difficult for caregivers to anticipate and control (Ornstein, 2012). Oftentimes behavioral outbursts are met by a negative response and can increase psychological duress in caregivers who sense a decline in their spouse, which in many cases may develop into resentment or anger toward the care recipient (Ornstein, 2012).

As members of a democratic society, we personally uphold certain moral and social standards by which our decisions and actions are guided over the life course. Many caregivers feel a value based obligation to care for a spouse, or family member in need, which in turn can create feelings of guilt, burden, and depression (Losada, 2010). Guilt has been identified as a central factor by which distress and depression can affect caregivers, and although often self-recognized, it is caused mainly by concern for judgment by others (Losada, 2010). Studies have attempted to describe the psychological pressure put on caregivers of dementia patients, but have only recently found new evidence for dementia anxiety in the caregiver themselves (Alberts, 2011). The fear and worry of developing dementia can quietly affect the caregiver; dementia anxiety is thought to evolve from a lack of education, relationship to the care recipient, and in some cases, overall outlook toward Alzheimer's disease (Alberts, 2011).

Coping mechanisms have been targeted as an essential means of managing the health consequences of high stress levels (Garcia, 2012). Caring for an older adult is a taxing experience for any caregiver, but having the added stress of dementia can create unmanageable demands for the person in charge. Coping efforts highlight a mutual exchange between the individual and the environment, an active relationship constantly striving for equilibrium (Garcia, 2012). Most people dealing with stressful stimuli employ one of two primary coping methods, an engagement strategy, which tackles the stressor head on, by problem solving, and expressing emotions. Or a disengagement strategy, which is characterized by avoidance and evasion of issues, resulting in only short-term relief from the effects of the stressor (Garcia, 2012). The resolve of both coping tactics is to prevent psychological distress, either through problem-focused attempts, which seek to control the situation, or through emotion-focused coping, which regulates internal response (Garcia, 2012). To positively manage long-term exposure to high stress environments,

caregivers should take on the engagement approach to coping that encourages action, and confrontation of stressors, while venting negative emotions (Garcia, 2012). Adopting emotional-focused coping strategies is worthwhile for caregivers of dementia patients, who will inevitably encounter difficult situations throughout the care process that cannot be solved using problem-based approaches (Cooper, 2008). Distinct variations on coping methods have been observed between the genders of caregivers. It has been reported that women are more apt to seek out support services and find comfort in the company of friends (Papastavrou, 2011). Conversely women are also more prone to negative coping mechanisms that include clinging onto irrational hope and increasing levels of burden by frequently using wishful thinking devices (Papastavrou, 2011).

Spousal caregiving is the most common form of informal care offered to persons suffering from Alzheimer's disease and has unique aspects that can exacerbate or alleviate a variety of challenges (Tweedy, 2008). Most caregivers endure a similar list of objective stressors related to the care of a dementia patient, including cognitive decline, problem behaviors, ability to perform activities of daily living (ADLs), and instrumental activities of daily living (IADLs), which regulate dependency on the caregiver. Subjective stressors are individualized and can vary depending on the relationship of the caregiver and recipient. These include, but are not limited to, lack of social interaction, isolation, psychological burnout, responsibility overload, and the loss of spousal connection (Tweedy, 2008). Studies have found that depression as a result of caregiver burden is reported most commonly amongst wives of dementia patients, whose mental condition is progressively aggravated depending on the severity of their partner's disease (Tweedy, 2008). Interestingly however, not all aspects of the caregiving experience are negative, in fact many spousal caregivers report positive features regarding their caregiving role including, fulfillment, companionship, and the feeling that they are improving the lives of their loved ones (Tweedy, 2008). These positive associations can be particularly devastating to relinquish following the death of a spouse, something that can be acutely difficult for female caregivers (Tweedy, 2008). The study went on to describe an interesting gender difference in caregiver depression post-death of their spouse, surviving males were less mentally affected, quicker to find new companions, and enjoyed freedom following the caregiving role (Tweedy, 2008). Conversely, wives of the deceased care recipients encountered intense feelings of loneliness, role-loss, and were less inclined to meet new people, also frequently reporting higher levels of depression (Tweedy, 2008).

Preventing and regulating caregiver burden is a realistic goal given the general understanding of informal care demands. Offering support to informal caregivers of dementia patients has proven to be an effective means of opening up communication between caregivers and social, or healthcare staff (Van Mierlo, 2012). Sadly, current research predicts that social support services will not be able to expand to meet the demands of the growing population of informal caregivers in the coming years (Van Mierlo, 2012). Overburden and depression are often linked to lack of formal support, education, social interaction, and health check-ups for dementia caregivers, who will suffer immensely due to the anticipated deficit in resources (Van Mierlo, 2012). Extramural nursing support has been reported to benefit caregivers directly by offering respite, and relief, as well as assistance with the more clinical aspects of providing care (Rosness, 2011). There is a direct positive correlation between hours spent giving care, and the increase of caregiving burden; the size and support of the family caregiving network can greatly affect the degree of exhaustion, or depression experienced by the direct caregiver (Khalaila, 2011).

Support groups have been reported to improve overall psychological and emotional well-being of caregivers when offered on a consistent basis, they can also promote socialization, and education about effective coping strategies (Chien, 2011). Immediate psychological intervention following the death of a spouse should be offered to caregivers of both sex, although males may only require this service during the grieving period, females may benefit from regular counseling to overcome the death of the loved one (Tweedy, 2008).

Losing a spouse to the effects of Alzheimer's disease can devastate a marriage, however, women have been reported to feel a sense of fulfillment, and duty as they take on a wider set of roles on behalf of the couple (Neundorfer, 2006). The same report explained the increase in female spousal caregiving depression to be attributed to the sentimental aspects of caring for a loved one, and the sense of responsibility toward their spouse (Neundorfer, 2006). Traditionally, women are understood to be the familial caretakers, whose role definition includes a moral accountability to nurture family members, and offer unconditional support (Losada, 2010). Because of these enduring social expectations, many women are subject to guilt, and negative self-esteem, which in turn affect coping styles, and increase the risk of succumbing to anxiety or depression (Losada, 2010). In a study of gender responses to familial dementia care, it was found that women were more likely to use escape-avoidance, and wishful thinking coping methods, compared to their male counterparts under the same levels of stress, who were able to employ more productive coping strategies (Papastavrou, 2011). It could be argued that the statistics related to the higher number of spousal caregiver depression reported in females, is related to the higher number of females taking on informal caregiving roles, close to 80% (Chien, 2011). Although that may be the case, it should be considered that depressive symptomology is experienced quite differently between genders (Chien, 2011), this is made clear based on the research following caregiver mental health, post the loss of their spouse (Tweedy, 2008). It could also be reasoned that wives report greater levels of depression after the death of the care recipient because they offered more hands-on care, and performed more sensitive tasks, that drew them closer to their spouse during the caregiving period (Tweedy, 2008).

The recent world healthcare report issued on the global state of Alzheimer's disease, estimated that approximately 35.6 million people are affected by dementia, a number predicted to double every 20 years moving forward (Van Mierlo, 2012). The number of informal caregivers will continue to rise, and with that so will the physical, and psychosocial sequelae related to full-time care provision (Van Mierlo, 2012). Studies have shown that females, specifically wives and daughters, most commonly assume the role of caregiver when a family member is diagnosed with dementia (Van Mierlo, 2012). The average Canadian caregiver is an older adult who will require support to continue living independently, and needs services that relieve the burden of caring for someone with high care demands (Alberts, 2011). Research has shown that regardless of the caregiving situation, females are at greater risk of suffering from depression while caring for a spouse with dementia. It is a national, social, and governmental responsibility to address the needs of the informal caregiver, and to prevent the onset of mental illness related to caregiver burden. The laws of physics prevent an object from being able to hold more than its physical limits, the balloon continues to stretch as the population continues to grow, age, and decline; but yet the social support system remains static. It isn't a question of whether or not the balloon will burst; it is just a matter of when.

References

- Alberts, N.M., Hadjistavropoulos, H.D., Pugh, N.E., & Jones, S.L. (2011). Dementia anxiety among older adultcaregivers: an exploratory study of older adult caregivers in Canada. International Psychogeriatrics, 23(6), 880- 886.
- Chien, L., Chu, H., Guo, J., Liao, Y., Chang, L., Chen, C., & Chou, K. (2011). Caregiver support groups in patients withdementia: a meta-analysis. Int J Geriatr Psychiatry, 26, 1089-1098.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2007). Coping strategies, anxiety and depression in caregivers ofpeople with Alzheimer's disease. Int J Geriatr Psychiatry, 23, 929-936.
- Garcia-Alberca, J., Cruz, B., Lara, J.P., Garrido, V., Lara, A., & Gris, E. (2012). Anxiety and depression are associatedwith coping strategies in caregivers of Alzheimer's disease patients: results from the MA'LAGA-AD study. International Psychogeriatrics, 24(8), 1325-1334.
- Joling, K.J., Smit, F., van Marwijk, H.M., van der Horst, H., Scheltens, P., Schulz, R., & van Hout, H.P. (2012).Identifying target groups for the prevention of depression among caregivers of dementia patients. InternationalPsychogeriatrics, 24(2), 298-306.
- Khalaila, R., & Litwin, H. (2011). Does filial piety decrease depression among family caregivers? Aging & MentalHealth, 6, 679-686.
- Losada, A., Marquez-Gonza, M., Penacoba, C., & Romero-Moreno, R. (2010). Development and validation of theCaregiver Guilt Questionnaire. International Psychogeriatrics, 22(4), 650-660.
- Neundorfer, M.M., McClendon, M.J., Smyth, K.A., Strauss, M.E., & McCallum, T.J. (2006). Does depression prior tocaregiving increase vulnerability to depressive symptoms among caregivers of persons with Alzheimer's disease? Aging & Mental Health, 10(6), 606-615.
- Ornstein, K., & Gaugler, J.E. (2012). The problem with "problem behaviours": a systematic review of the associationbetween individual patient behavioral and psychological symptoms and caregiver depression and burden withinthe dementia patient-caregiver dyad. International Psychogeriatrics, 24(10), 1536-1552.
- Papastavrou, E., Tsangari, H., Karayiannis, G., Papacostas, S., Efstatithiou, G., & Sourtzi,P. (2011). Caring and coping:The dementia caregivers. Aging & Mental Health, 15(6), 702-711.
- Romero-Moreno, R., Gonzalez, M.M., Mausbach, B.T., & Losada, A. (2012). Variables modulating depression indementia caregivers: a longitudinal study. International Psychogeriatrics, 24(8), 1316-1324.
- Rosness, T., Mjørud, M.J., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onsetdementia. Aging & Mental Health, 15(3), 299-306.

Tweedy, M.P., Charles, M.S., & Guarnaccia, A. (2008). Change in depression of spousal caregivers of dementia patients following patient's death. *Omega*, 56(3), 217-228.

Van Mierlo, L.D., Meiland, F.J., Van der Roest, H.G., & Droege, R. (2012). Personalised caregiver support: effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *Int J Geriatr Psychiatry*, 27, 1-14.

Watson, L.C., Lewis, C.L., Moore, C.G., & Jeste, D.V. (2011). Perceptions of depression among dementia caregivers: findings from the CATIE-AD trial. *Int J Geriatric Psychiatry*, 26, 397-402.