

Depressive symptomatology in care-givers of patients with Alzheimer's disease

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Abstract:

Background: The stress and strain of being an Alzheimer's caregiver can cause physical and mental problems. Nearly half of all Alzheimer's caregivers report that they have suffered from depression at some point, according to the Alzheimer's Association. The objective of this study was to identify depressive symptoms in caregivers of patients with Alzheimer's disease.

Method: A descriptive study was carried out in the Department of psychiatry, Pakistan Institute of Medical Sciences (PIMS), Islamabad from May 2010 to September 2010. Thirty caregivers participated in the study. Informed written consent was obtained. The Beck Depressive Inventory (BDI) was used.

Results: 57 % of caregivers met criteria for depression. The females scored more on the depressive scale compared to males (Female = 73 %, Male = 40 %).

Conclusion: Female caregivers are more prone to depression. Caring for the carer is as important as caring for the individual with Alzheimer's disease.

Key Words: Depressive symptomatology, Care-givers, Alzheimer's

Introduction

Alzheimer's disease is the most common type of dementia. Alzheimer's disease causes changes in mood and personality (All-on-Depression-Help.com, 2009). Stress, anger, guilt and grief related to care giving can lead to depression. Caregivers can experience depression at any point in the disease process.

Caregiver distress is typically operationalized as caregiver depression or caregiver burden. Caregiver depression is a mood disturbance resulting from the stress of providing care (Fortinsky et al., 2002; Harris et al., 2001), which may be manifested as feelings of loneliness, isolation, fearfulness, and being easily bothered. Caregiver burden is considered "a multidimensional bio-psychosocial reaction resulting from an imbalance of care demands

relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (Given et al., 2001, p. 5). Together, caregiver burden and depression may be considered as a general distress response for caregivers. Although there is a great deal of research on correlates of distress for caregivers who are at various points in the care trajectory, little work has been done to assess the impact of providing end-of-life care on the distress of family caregivers of patients with Alzheimer's disease (Given et al., 2004). This study focused on how Alzheimer disease affects caregiver's mental health and its association with depressive symptoms.

Method

A descriptive study was carried out in the Department of psychiatry, Pakistan Institute of Medical Sciences (PIMS), Islamabad from May 2010 to September 2010. Fifteen male and fifteen female caregivers participated in the study. Informed written consent was obtained. The Beck Depressive Inventory (BDI) was used.

The data collection questionnaire had demographic information including gender of caregiver, educational status, number of family members, socio-economic status, and caregiver's relationship with patient and duration of illness.

A standardized scale of depression, the Beck depression inventory (BDI), was used for the assessment of depressive symptoms in care givers.

The statistical package for social sciences (SPSS) was used for data analyses.

Results

Most of the caregivers (51.6%) had more than five family members. The monthly income in the majority (54.8%) of the families was above 10,000 Pakistani rupees. The majority of the care givers (64.5%) are non-spouses. In most (58.1%) the duration of illness was greater than 12 months.

Results of the BDI indicate that the majority of the care givers are depressed due to the illness of their loved ones and their care giving roles and responsibilities (Table 1). It was also found that females are more depressed than males.

Table 1 - K10 and K6 scores by subject group

Carers	Depressed	Not depressed
Male	06 (40%)	09
Female	11 (73%)	04
Total	17 (56%)	13

Discussion

The study shows that depression is common in caregivers of patients with Alzheimer's disease.

The family members of patients with Alzheimer experience distress due to care giving roles. This distress has been shown to continue over time and may be exacerbated by changes in the patient's condition. The emotional impact of providing care is linked to caregiver negotiation of the care giving role, as caregivers may be unfamiliar with the care they must provide and may not be aware of or able to utilize available resources (Given and Given, 1992; Oberst et al., 1989).

The distress resulting from assuming the role of caregiver can be manifested as anxiety, depression, helplessness, burden, and fear (Nijboer et al., 2001; Weitzner et al., 1997; Northouse et al., 1995; Siegel et al., 1991; Blank et al., 1989) and is often related to providing direct care, performing complex medical procedures, coping with disruptions in daily routine, and negotiating the

need to provide emotional support to the patient and to other family members. Specifically, caregivers may experience distress from assuming the responsibility for communicating with healthcare professionals, managing symptoms, administering medication, performing medical/nursing treatment and handling patient behavioral problems and emotional reactions (Kurtz et al., 2002; Weitzner et al., 2000; Sarna and McCorkle, 1996; Schumacher, 1996; Schumacher et al., 1995; Kurtz et al., 1995; Laizner et al., 1993; Given and Given, 1991). Caregiver distress may stem from the reprioritization or relinquishment of responsibilities related to childcare and employment, the prioritization of home-care demands, and the negotiation and renegotiation of factors related to familial and generational relationships (Lyons et al., 1999; Weitzner et al., 1999; Sales, 1991). Consistently reported predictors for caregiver distress include caregiver gender (Northouse et al., 2000), level of personal and social support, patient functional status (Stommel et al., 2002; Williamson et al., 1998),

and patient symptom status (Kozachik et al., 2001; Nijboer et al., 2001; Nijboer et al., 2000; Song et al., 1997; Foxall and Gaston - Johannson, 1996; Kurtz et al., 1995; Schultz et al., 1995; Clipp and George, 1993; Given et al., 1993; Schumacher et al., 1993). In general, female caregivers 12 and caregivers with lower levels of personal and social support (Williamson et al., 1998) experience higher levels of distress.

Caregiver distress resulting from the patient's functional status involves the caregiver's level of assistance with activities of daily living (ADL): eating, dressing, bathing; and instrumental activities of daily living (IADL; household tasks, shopping, and transportation). Decreases in the patient's functional status increase the amount of tasks with which the patient requires assistance. Caregivers who must assist with multiple tasks, or with tasks they find difficult or unappealing (such as performing medical procedures at home or toileting) may have higher levels of distress (Kurtz et al., 2002; Given and Given, 1992). Research has shown that providing assistance with both ADLs such as bathing and toileting (Vitaliano et al., 1991), as well as IADLs such as errands or transportation (Gonzalez-Salvador et al., 1999) can increase caregiver distress. The patient's symptom status (including number, type, and severity of symptoms) can also affect caregiver distress (Given et al., 2001). As patients' symptom distress increases and results in depressive symptoms and deteriorations in quality of life for the patient (Sarna, 1993, 1998; Sarna and Brecht, 1997), functional limitations may increase and caregiver responsibilities to help manage symptoms and assist with functional limitations may increase. Patient symptom status requires caregiver assistance not only with recognizing emerging and changing patient symptoms related to the disease and its treatment, but also with the management of those symptoms (Kozachik et al., 2001; Nijboer et al., 1998; Williamson et al., 1998). For the patient with advanced disease, family assistance with symptoms may increase as the patient's disease progresses and the patient's health declines. In addition, caregivers have varying emotional reactions to patient symptoms, which can cause distress as the patient's health declines (Toseland et al., 1995; Carey et al., 1991).

Conclusion

The impact of caring for a relative with Alzheimer's brings the risks of mental ill health to the carer in the form of emotional stress, depressive symptoms or clinical depression. Being a caregiver is a complex role with many responsibilities. Female gender was a risk factor for caregiver depression. Caring for the carer is as important as caring for the individual with Alzheimer's disease for a successful outcome in difficult circumstances.

References

- All-on-Depression-Help.com (2009). Definition of Depression (online). Available at <http://www.all-on-depression-help.com/definition-of-depression.html>
- Blank J.J., Clark L., Longman A.J. and Atwood J.R.. (1989). Perceived home care needs of cancer patients and their caregivers. *Cancer Nursing*, 12(2): 78-84.
- Carey P., Oberst M., Mc Cubbin M. and Hughes S. (1991). Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum*, 18: 1341-1348.
- Clipp E. and George L. (1993). Dementia and cancer: A comparison of spouse caregivers. *Gerontologist*, 33: 534-541.
- Fortinsky R.H., Kercher K. and Burant C.J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging and Mental Health*, 6(2): 153-60.
- Foxall M. and Gaston-Johannson F. (1996). Burden and health outcomes of family caregivers of hospitalized bone marrow transplant patients. *Journal of Advanced Nursing*, 24(5): 915-923.
- Given B. and Given C. (1991). Family caregiving for the elderly. *Annual Review of Nursing Research*, 9: 77-101.
- Given B. and Given C. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Women's Association*, 47(5): 201-212.
- Given B., Wyatt G., Given C., Gift A., Sherwood P., De Voss D., and Rahbar M. (2004). Burden and Depression among Caregivers of Patients with Cancer at the End-of-life. *Oncology Nursing Forum*, 31(6): 1105-1117.
- Given C., Stommel M., Given B., Osuch J., Kurtz M. and Kurtz J. (1993). The influence of cancer patients, symptoms, and functional states on patients, depression, and family caregivers' reaction and depression. *Health Psychology*, 12: 277-285.
- Given C.W., Given B., Azzouz F., Kozachik S. and Stommel M. (2001). Predictors of pain and fatigue in the year following diagnosis among elderly cancer patients.

- Journal of Pain and Symptom Management*, 21(6): 456-66.
- Gonzalez-Salvador M., Arango C., Lyketos C. and Barba A. (1999). The stress and psychological morbidity of the Alzheimer patient and caregiver. *International Journal of Geriatric Psychiatry*, 14(9): 701-710.
- Harris J.K., Godfrey H.P., Partridge F.M. and Knight R.G. (2001) Caregiver depression following traumatic brain injury (TBI): a consequence of adverse effects on family members? *Brain Injury*, 15(3): 223-38.
- Kozachik S., Given C., Given B., Pierce S., Azzouz F., Rawl S., et al. (2001). Improving depressive symptoms among caregivers of patients with cancer: Results of a randomized clinical trial. *Oncology Nursing Forum*, 28(7): 1149-1157.
- Kurtz M., Kurtz J., Given C. and Given B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states, and depression-A longitudinal view. *Social Science and Medicine*, 40: 837-846.
- Kurtz M., Kurtz J., Stommel M., Given C.W. and Given B. (2002). Predictors of depressive symptomatology of geriatric patients with lung cancer – a longitudinal analysis. *Psycho-Oncology*, 11: 12-22.
- Laizner A., Yost L., Barg F. and McCorkle R. (1993). Needs of family caregivers of persons with cancer: A review. *Seminars in Oncology Nursing*, 9: 114-120.
- Lyons K., Zarit S., Sayers A. and Whitlatch C. (2002). Caregiving as dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology: Psychological Sciences*, 57B(3): 195-204.
- Nijboer A., Schultz R., Matthews K., Scheler M., Ormel J. and Lindenberg S. (1998). Spousal caregivers' activity restriction and depression: A model for changes over time. *Social Science Medicine*, 47: 119-136.
- Nijboer C., Tempelaar R., Triemstra M., van den Bos G.A. and Sanderman R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer*, 91(5): 1029-39.
- Nijboer C., Triemstra M., Tempelaar R., Mulder M., Sanderman R. and van den Bos G. (2000). Patterns of caregiver experiences among partners of cancer patients. *The Gerontologist*, 40(6): 738-746.
- Northouse L., Dorris G. and Charron-Moore C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41(1): 69-76.
- Northouse L., Mood D., Templin T., Mellon S. and George T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science and Medicine*, 50: 271-284.
- Oberst M.T., Thomas S.E., Gass K.A. and Ward S.E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12(4): 209-15.
- Sales E. (1991). Psychological impact of the phase of cancer on the family: An updated review. *Journal of Psychological Oncology*, 9(4): 1-18.
- Sales E., Schulz R. and Beigel D. (1992). Predictors of strain in families of cancer patients: A review of the literature. *Journal of Psychosocial Oncology*, 10(2): 1-26.
- Sarna L. (1993). Correlates of symptom distress in women with lung cancer. *Cancer Practice*, 1: 21-28.
- Sarna L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum*, 25(6): 1041-1048.
- Sarna L. and Brecht M. (1997). Dimensions of symptom distress in women with advanced lung cancer: A factor analysis. *Heart and Lung*, 26(1): 22-30.
- Sarna L. and McCorkle R. (1996). Burden of care and lung cancer. *Cancer Practice*, 4: 245-251.
- Schultz R., O'Brien A. and Borhwala J. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence correlates causes. *The Gerontologist*, 35: 771-791.
- Schulz R. and Williamson G.A. 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging*, 6(4): 569-578.
- Schumacher K. (1996). Reconceptualizing family caregiving: Family-based illness care during chemotherapy. *Research in Nursing and Health*, 19(4): 261-271.
- Schumacher K., Dodd M. and Paul S. (1993). The stress process in family caregivers of persons receiving chemotherapy. *Research in Nursing and Health*, 16(6): 395-404.
- Siegel K., Raveis V., Mor V. and Houts P. (1991). The relationship of spousal caregiver burden to patient disease and treatment-related conditions. *Annals of Oncology*, 2(7): 511-516.
- Song L., Biegel D. and Mulligan S. (1997). Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community Mental Health Journal*, 33: 269-286.
- Stommel M., Given B. and Given C.W. (2002). Depression and functional status as predictors of death among cancer patients. *Cancer*, 29(10): 2719-2727.
- Stommel M., Given B., Given C. and Collins C. (1995). The impact of frequency of care activities on the division of labor between primary caregivers and other care providers. *Research on Aging*, 17(4): 412-433.
- Toseland R., Blanchard C. and McCallion P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine*, 40(4): 517-528.
- Vitaliano P., Russo J., Young H., Teri L. and Maiuro R. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and Aging*, 6(3): 392-402.
- Weitzner M., Haley W. and Chen H. (2000). The family caregiver of the older cancer patient. *Hematology/Oncology Clinics of North America*, 14: 269-281.
- Weitzner M., McMillan S. and Jacobson P. (1999). Family caregiver quality of life: Differences between curative

- and palliative cancer treatment settings. *Journal of Pain and Symptom Management*, 17: 418-428.
- Weitzner M., Moody L. and McMillan S. (1997). Symptom management issues in hospice care. *American Journal of Hospital Palliative Care*, 14(4): 190-195.
- Williamson G., Shaffer D. and Schulz R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology*, 17: 152-162.