

# A Swift Travel to Stormy Shore: Burden and Distress Experience by Caregivers Availing Neuro-rehabilitation Services

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## Abstract

**Background:** Persons with neurological conditions predominantly receive their care from informal caregivers in India. The day-to-day caring of these persons requires tireless effort, energy, and empathy, and can often impact the quality of life of caregivers. In this study, we assess the impact of caregiving on the quality of life of informal caregivers. **Materials and Methods:** Fifty caregivers of patients with neuro-rehabilitation needs admitted in the neuro-rehabilitation ward of our hospital were recruited for this study. A descriptive research design, burden assessment schedule, and a self-reporting questionnaire were used to assess the distress level. The data collected were analyzed using descriptive, parametric, and nonparametric statistics. **Results:** Of the 50 caregivers recruited, 32 were female and 28 were male. The caregivers in our cohort were predominantly over 40 years of age. Thirty caregivers were from nuclear family and 36 families had below poverty line card. Majority of the caregivers reported physical and mental health burden due to their caregiving role. This was followed by need for external support to facilitate their caregiving role. Overall, the burden perceived by the caregivers ranged from moderate to severe. **Conclusion:** The caregivers come from diverse backgrounds, but nonetheless, they experienced significant physical and emotional burden while caring for the ill person at home. Providing adequate training and socioeconomic support to the caregivers may be helpful in reducing their burden.

**Keywords:** Burden, caregiver, disability, neuro-rehabilitation

## INTRODUCTION

Caring is a fundamental challenge in the treatment for persons with neurological illness/disability requiring neuro-rehabilitation services. The onset of a chronic illness in any family is often and understandably a time of turmoil.<sup>[1]</sup> Most families are ill-prepared to deal with the initial onset of neurological/neurosurgical illness in their family member. Nevertheless, individuals with neurological conditions living with their families in the community receive more physical, medical, psychological, and social care from their family members.<sup>[2]</sup> Caring for persons with neurological disorders requires tireless effort, energy, and empathy, and indisputably, all these can greatly affect the daily lives of a caregiver.<sup>[3]</sup> There are also physical, social, emotional, and financial impacts of caregiving on the families.<sup>[4]</sup> Hence, a significant number of caregivers do experience distress and burden of caring.<sup>[3,4]</sup>

Approximately 28.8 million adults in the United States are family caregivers, a number that is expected to increase to 37 million by the year 2050.<sup>[5]</sup> This dramatic rise in the number of family members providing care at home has sparked much

interest among the researchers to study on the emotional and physical health of family caregivers. Research, which is often guided by a stress and coping conceptual model, has detailed negative emotional consequences of providing care such as stress, depression, burden, and anxiety.<sup>[6]</sup> However, work in family caregiving has also shown that providing care can have negative physical consequences for the caregiver, such as altered immune function, hypertension, morbidity, and poor overall physical health.<sup>[7]</sup> Investigations in the area of bio-behavioral and mind-body interactions outside the field of caregiving have shown that emotional and physical health are often interrelated as the body responds to a stressful event and that behavioral responses to stress may attenuate alterations in the physical health.<sup>[8]</sup> A subset of caregivers are reported to suffer from negative psycho-behavioral responses such as depressive

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symptoms, anxiety, difficulty in sleeping, and negative biologic responses such as altered immune function.<sup>[9-11]</sup> The caregivers undergo physical and mental exhaustion, loss of privacy, and loss of social activity and also experience the financial burden of caring. Hence, the caregivers are at a greater risk for negative outcomes including developing depressive symptoms.<sup>[12]</sup>

It is unfortunate that the experiences of the families caring for persons with different types of neurological illness have not been adequately studied. Yet, there is a limited holistic understanding, of both the difficult roles they play and the circumstances under which they care for persons with neurological illness. Further, the emotional and practical challenges faced by the caregivers through the different phases of the illness are not well-documented. This understanding is vital for planning interventions to maintain or improve caregiver health, promote high-quality care in caregivers, and prevent caregiver burnout.

## MATERIALS AND METHODS

The study aims at understanding the profile of the caregivers and distress levels and burden experiences by the caregivers while providing care during the inpatient stay. Descriptive research design was used for this study. All the caregivers of neurological and neuro-rehabilitation needs admitted in the neuro-rehabilitation ward in the National Institute of Mental Health and Neurosciences, Bengaluru, were included in this study. The institute has neuro-rehabilitation ward, which provides continuous care. On an average, 200 patients are admitted to neuro-rehabilitation ward every year. For the current study, primary caregivers of persons with neurological illness requiring rehabilitation services were recruited from June 2016 to June 2017. Child caregivers and caregivers reported to have mental illness were excluded from the study. The research study was reviewed and approved by the Institute Ethics Committee. The psychiatric social workers while providing psychosocial care collected data on caregivers' burden, distress levels, and coping patterns for all patients admitted in the neuro-rehabilitation ward. These data were used as baseline data before initiating interventions to test the efficacy of their intervention.

### Measures

A semi-structured questionnaire to collect sociodemographic details such as age, education, socioeconomic status, domicile, type of family, and relationship of caregiver to the patients was used apart from collecting background details.

### Burden assessment schedule

The burden assessment schedule by Sell *et al.*<sup>[13]</sup> was used. The scale has 40 items. Each item is rated on a 3-point scale (not at all, to some extent, and very much). The items of the schedule are categorized under five factors, i.e., impact well-being, marital relationship, appreciation for caring, impact on relationships with others, and perceived severity of disease. The scale measures are proven to have good inter-rater reliability and criterion validity.

### Self-reporting questionnaire (World Health Organization-SR20, 1994)

This is a 20-item subset of the self-reporting questionnaire (SRQ) (World Health Organization-SR20, 1994)<sup>[14]</sup> developed by the World Health Organization for screening the presence of mental disorder in patients contacting primary health-care settings. The complete SRQ consists of 25 questions, which have to be answered by “yes” or “no.” Of these 25 questions, 20 are related to neurotic symptoms, 4 to psychotic symptoms, and 1 to convulsions. The SRQ-20 consists of the neurotic items only. These reflect depressive symptoms, anxiety, and psychosomatic complaints and have been found to detect probable cases of common mental disorder with reasonable accuracy.

Sample pilot interviews were conducted to train the psychiatric social workers with the interview schedule. Finally, the psychiatric social workers administered the interview schedule after obtaining written consent from the caregivers. The data were coded and entered in the Statistical Package for the Social Sciences (SPSS) (IBM, NIMHANS, Bangalore), and descriptive statistics and parametric statistical analysis were adopted for the analysis.

## RESULTS

Fifty persons with neurological illness were admitted in the neuro-rehabilitation ward for a period of 6 months. The clinical profile of the person with neurological illness included Guillain-Barré syndrome (22%), myelopathy (6%), stroke (8%), transverse myelitis (4%), traumatic brain injury (8%), spinal cord injury (10%), postinfectious myelitis (2%), paraplegia (4%), and other neurological conditions (36%).

### Sociodemographic details

Table 1 shows that in this study, the total sample was composed of 50 caregivers. Among these, 32 were female and 28 were male. While 8% of the caregivers were in the age group of 20–30 years, 26% were in the age group of 31–40 years (26.0%), and 66% were over 40 years of age. Thirty caregivers (60%) were coming from nuclear family and 36 families (72.0%) were having below poverty line card. Most often, it was the mother (25; 50.0%) who was staying with the patient in the ward and happened to be the main caregiver. The educational background of the caregiver was up to primary school level. These caregivers were taking care of the patient all through the illness at home and in the hospital. The highest duration of hospitalization was 2–6 months (44%).

### Scores of burden assessment schedule (BAS)

Table 2 explains the burden experiences by the family, having persons with neurological disability. Most of the family members reported that physical and mental health ( $17.58 \pm 6.15$ ) was affected due to the patient's illness. This was followed by impact on external support ( $13.24 \pm 5.17$ ) and taking responsibility ( $15.28 \pm 8.03$ ). Overall, the burden was reported to be moderate to severe by family members.

## Psychological distress (self-reporting questionnaire) 20-item analysis

Table 3 shows the item-wise analysis of psychological distress of the caregivers. The results show that 44% of respondents reported frequent headache, poor appetite (54%), had sleep disturbances (50%), easily frightened (44%), suffered with handshake (36%), felt nervous, tense or worried during

hospitalization (76%), poor digestion (42%), suffered with troubled thinking (44%), felt unhappy (86%), cried more than usual (46%), could not enjoy daily activities (74%), and felt difficulty in decision-making (38%). In addition, caregivers daily work suffered (98%), were unable to meet the daily demands (70%), lost interest in everything (60%), felt worthlessness (12%), felt ending life (12%), experienced difficulty in maintaining time (52%), felt uncomfortable in the stomach (32%), and felt easily tired (52%).

**Table 1: Sociodemographic details**

|                  | Frequency (%) |
|------------------|---------------|
| Gender           |               |
| Male             | 18 (36)       |
| Female           | 32 (64)       |
| Age group        |               |
| 20-30            | 4 (8.0)       |
| 31-40            | 13 (26.0)     |
| 40 and above     | 33 (66.0)     |
| Domicile         |               |
| Rural            | 31 (62.0)     |
| Urban            | 19 (38.0)     |
| Type of family   |               |
| Nuclear family   | 30 (60.0)     |
| Joint family     | 20 (40.0)     |
| Economic status  |               |
| BPL              | 36 (72.0)     |
| APL              | 14 (28.0)     |
| Caregiver        |               |
| Mother           | 25 (50.0)     |
| Father           | 9 (18.0)      |
| Relatives        | 7 (14.0)      |
| Others           | 9 (18.0)      |
| Education status |               |
| Illiterate       | 2 (4.0)       |
| Primary          | 11 (22.0)     |
| Secondary        | 17 (34.0)     |
| Graduation       | 18 (36.0)     |
| Postgraduate     | 2 (4.0)       |
| Hospitalization  |               |
| Up to 1 month    | 10 (20.0)     |
| 2-6 month        | 22 (44.0)     |
| 7 months-1 year  | 8 (16.0)      |
| Above 1 year     | 10 (20.0)     |

BPL: Below poverty line, APL: Above poverty line

## DISCUSSION

All caregivers in our study cohort were close family members (parents, spouses, siblings, and their children). Majority of the caregivers were in the age group of 40 years and above, which suggests that the responsibility of looking after the person with neurological/neurosurgical illness requiring rehabilitation services lies on the older family member as they are at home and have the time to take the responsibility of caring. This also suggests that in India, the cultural factors such as strong family ties, culture, values, and environment have extensively contributed to reducing the burden of patient care on the state. In India, people with chronic illness are always accompanied by the family member/s as compared to other western countries, where caregivers are not necessarily family members.<sup>[15,16]</sup>

Women provide the majority of informal care to the patient while in the hospital. Specifically daughters and daughters-in-law provide care not only to the patient with neurological illness requiring rehabilitation needs but also to the parents and their parents-in-law. It was also noted that more number of spouses (husband/wives) provided care to their spouse in need. In our study cohort, we observed that greater burden was associated with caring male patients with neurological illness,<sup>[17,18]</sup> younger patients,<sup>[18,19]</sup> and patients with poorer levels of functioning.<sup>[20,21]</sup> We also observed that the burden experienced by the caregivers received comparatively less attention. Our observations are consistent with other studies reporting, women being larger part of caregiving responsibilities,<sup>[22-25]</sup> and younger and educated caregivers experiencing greater burden.<sup>[26]</sup> The study also revealed that 36% of the caregivers were males (husbands, fathers, and sons)

**Table 2: The scores of burden assessment schedule results**

| Variables                  | n  | Minimum | Maximum | Mean ± SD       |
|----------------------------|----|---------|---------|-----------------|
| Spouse related             | 50 | 5.00    | 14.00   | 8.1000±1.65677  |
| Physical and mental health | 50 | 11.00   | 47.00   | 17.5800±6.15477 |
| External support           | 50 | 6.00    | 43.00   | 13.2400±5.17277 |
| Caregivers' routine        | 50 | 3.00    | 24.00   | 7.3200±2.78069  |
| Support of patient         | 50 | 1.00    | 3.00    | 2.1200±0.55842  |
| Taking responsibility      | 50 | 9.00    | 44.00   | 15.2800±8.03066 |
| Other relationship         | 50 | 4.00    | 37.00   | 7.0000±5.11500  |
| Patient behavior           | 50 | 6.00    | 17.00   | 10.0200±1.88971 |
| Caregiver strategy         | 50 | 3.00    | 36.00   | 5.4400±4.44999  |

SD: Standard deviation

**Table 3: Psychological distress (self-reporting questionnaire) 20-item analysis**

| Variable                                 | Yes (%)   |
|------------------------------------------|-----------|
| Headache                                 | 22 (44.0) |
| Poor appetite                            | 27 (54.0) |
| Sleep badly                              | 25 (50.0) |
| Frightened easily                        | 22 (44.0) |
| Tremors/handshake                        | 18 (36.0) |
| Nervous/tense/worried                    | 38 (76.0) |
| Poor digestion                           | 21 (42.0) |
| Trouble thinking clearly                 | 22 (44.0) |
| Feel unhappy                             | 43 (86.0) |
| Cry more than usual                      | 23 (46.0) |
| Difficult to enjoy your daily activities | 37 (74.0) |
| Difficult to make decisions              | 19 (38.0) |
| Daily work suffering                     | 49 (98.0) |
| Unable to play usual part in life        | 35 (70.0) |
| Lost interest in things                  | 30 (60.0) |
| Feeling as worthless person              | 6 (12.0)  |
| Ending your life been on your mind       | 6 (12.0)  |
| Feel tired all the time                  | 26 (52.0) |
| Uncomfortable in stomach                 | 16 (32.0) |
| Easily tired                             | 26 (52.0) |

who took the responsibility of caring their ill family members. Men do provided care for their female ill family member with the help of the extended families, however this was not shared or spoken to others and they often did not participate in the caregivers meeting. Health-care provider, care manager, friends, companion, and surrogate decision-maker are also reported as advocators of caregiving.<sup>[27,28]</sup>

Family caregivers provide extraordinary uncompensated care involving significant amounts of time and energy for months or years and were required to perform tasks that were often physically, emotionally, socially, or financially demanding. They are constantly challenged to solve problems and make decisions as care needs changed, yet they felt untrained and unprepared as they continued to struggle to adjust to new roles and responsibilities.<sup>[1,29-32]</sup> Due to extensive focus and commitment to the patients, their own needs were often neglected. The caregivers' need for quality information and training are ever emerging, as they are not always known at the time of a clinic visit. Physicians are frequently unable to address caregiver questions, a situation which is further compounded by time constraints and cultural barriers. Spouse caregivers often experience greater difficulty as they have to balance multiple roles (raising children and financial burden). This is particularly so when the illness strikes the primary wage earner.<sup>[33,34]</sup> Lower educational level of the patient contributed to greater caregiver burden. Lower literacy level among these patients resulted in their getting poorly paid menial jobs. This is a group of caregivers from a predominantly lower socioeconomic background, and financial difficulties are a major concern for them. Our observations indicated that patients with low education levels

will benefit from psychosocial rehabilitation programs that emphasize the acquisition of work-related skills and income generation.

Caregivers often need to take up new tasks for which they are not adequately trained. It is not surprising that their physical and emotional needs go unnoticed as and when they compensate between time, jobs, money, energy, and social and family roles.<sup>[35,36]</sup> Family caregivers often reported feeling overwhelmed and isolated in balancing additional responsibilities. Hence, family caregivers may benefit by an educational plan that includes helping them to develop the skills they need to better communicate their own problems (anxiety, shock, disbelief, denial, and frustration) and concerns while effectively meeting their responsibilities.<sup>[29,37]</sup> The long duration of hospitalization together with need for multitasking is often not anticipated by the family caregivers; hence, this unprepared situation together with lack of professional support adds to the burden faced by the family caregivers. This burden can be in the form of severe emotional distresses, significant fatigue, sleep impairment, and difficulty maintaining focus and energy levels. Compared to noncaregivers, caregivers often experience psychological, behavioral, and physiological effects that can contribute to impaired immune system function and coronary heart disease and in some cases early death.<sup>[30-32,38-40]</sup> The caregivers are also likely to postpone their own health-care needs. As a result, caregivers experience layer upon layer of stress, as the burden of caring (often exclusively) for their sick loved ones, separated from their own support systems, while balancing other life responsibilities, threatens to overwhelm them.<sup>[41]</sup>

## CONCLUSION

In this study, we observed that caregivers undergo extensive distress and experience burden while caring person with neurological and neurosurgical illness. Our observations are in concurrence to several other studies evaluating impact on caregivers while caring for patients with other chronic illness (such as cancer and Alzheimer's disease).<sup>[35,36,42-45]</sup> The study did address a clinically important topic that has rarely been explored in the research. The current study has some limitations. The sample was selected in a nonrandom sampling taking all the beneficiaries of the inpatient ward. Some of the findings of caregiving giving experience may be confound by the differences seen in the sociocultural background of the sampling region. The duration of illness and the clinical status also determine the caregiving experiences. It included a relatively small number of caregivers when compared to vast prevalence of neurological illness. Only the primary caregiver was interviewed in this study, despite the likelihood of other caregivers in the family; hence, interviewing multiple caregivers and comparative analysis would have add value for the present study. Hence, generalizing the observations from this study should consider these limitations.

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## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

- Janardhana N, Raghunandan S, Naidu DM, Saraswathi L, Seshan V. Care giving of people with severe mental illness: An Indian experience. *Indian J Psychol Med* 2015;37:184-94.
- George LK, Gwyther LP. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist* 1986;26:253-9.
- Roland KP, Jenkins ME, Johnson AM. An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's disease. *Mov Disord* 2010;25:189-93.
- Nirmala BP, Janardhana N. Profile of patients availing neurological rehabilitation services in super specialty tertiary care hospital. *Indian J Neurosci* 2017;3:134-8.
- Spillman BC, Black KJ. Staying the course: Trends in family caregiving. AARP, Public Policy Institute; California; 2005.
- Lazarus RS, Folkman S. Stress, Appraisal, and Coping. Springer Publishing Company; New York, USA; 1984.
- Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler IC, *et al*. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosom Med* 2002;64:418-35.
- Cohen S, Doyle WJ, Skoner DP. Psychological stress, cytokine production, and severity of upper respiratory illness. *Psychosom Med* 1999;61:175-80.
- Pinquant M, Sørensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychol Aging* 2003;18:250-67.
- Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S, *et al*. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292:961-7.
- Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129:946-72.
- Sherwood PR, Given BA, Given CW, Schiffman RF, Murman DL, Lovely M, *et al*. Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health* 2006;29:105-20.
- Sell H, Thara R, Padmavati R, Kumar S. Burden Assessment Schedule. New Delhi: WHO Regional Health Office for South East Asia; 1998.
- World Health Organization. A User's Guide to the Self Reporting Questionnaire (SRQ). Geneva: World Health Organization; 1994. p. 1-84.
- Leff J. Working with the families of schizophrenic patients. *The British Journal of Psychiatry* 1994;164 supplementary (23):71-6.
- Thara R, Padmavati R, Kumar S, Srinivasan L. Instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry* 1998;40:21-9.
- Gautam S, Nijhawan M. Burden on families of schizophrenic and chronic lung disease patients. *Indian J Psychiatry* 1984;26:156-9.
- Martyns-Yellowe IS. The burden of schizophrenia on the family. A study from Nigeria. *Br J Psychiatry* 1992;161:779-82.
- Roychaudhuri J, Mondal D, Boral A, Bhattacharya D. Family burden among long term psychiatric patients. *Indian J Psychiatry* 1995;37:81-5.
- Salleh MR. The burden of care of schizophrenia in Malay families. *Acta Psychiatr Scand* 1994;89:180-5.
- Winefield HR, Harvey EJ. Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophr Bull* 1993;19:619-25.
- Jenkins JH, Schumacher JG. Family burden of schizophrenia and depressive illness. Specifying the effects of ethnicity, gender and social ecology. *Br J Psychiatry* 1999;174:31-8.
- American Association of Retired Persons, National Alliance for Caregiving. Family Caregiving in the U.S: Findings from a National Survey. Bethesda, MD: National Alliance for Caregiving; 1997.
- Family Caregiver Alliance. Family Caregiving: State of the Art, Future Trends. Report from a National Conference. San Francisco: Family Caregiver Alliance; 2007.
- Kreisman DE, Joy VD. Family response to the mental illness of a relative: A review of 1974 the literature. *Schizophrenia Bull* 1974;10:34-57.
- Gopinath PS, Chaturvedi SK. Distressing behaviour of schizophrenics at home. *Acta Psychiatr Scand* 1992;86:185-8.
- Janardhana N, Shravya R, Naidu DM, Saraswathi L, Seshan V. Caregivers in Community Mental Health. Bangalore: Basic Needs India; 2008.
- Amirkhanyan AA, Wolf DA. Caregiver stress and noncaregiver stress: Exploring the pathways of psychiatric morbidity. *Gerontologist* 2003;43:817-27.
- Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro Oncol* 2008;10:61-72.
- Janardhana N, Naidu D. Inclusion of people with mental illness in community based rehabilitation: Need of the day. *Int J Psychosoc Rehabil* 2012;16:15-45.
- Janardhana N, Shravya R, Naidu D, Saraswathi L, Seshan V. Giving care to men and women with mental illness. *Indian J Gender Stud* 2011;18:405-24.
- Janardhana N, Naidu D, Seshan V. Un-sung samaritans in the lives of people with mental illness: An Indian experience. *Indian J Soc Work* 2017;75:7-32.
- Mannion E. Resilience and burden in spouses of people with mental illness. *Psychiatr Rehabil J* 1996;20:13-23.
- Noh S, Avison W. Spouses of discharged psychiatric patients: Factors associated with their experience of burden. *J Marriage Fam* 1988;50:377-89.
- Cohen S, Tyrrell DA, Smith AP. Psychological stress and susceptibility to the common cold. *N Engl J Med* 1991;325:606-12.
- Glaser R, Kiecolt-Glaser JK. Stress-induced immune dysfunction: Implications for health. *Nat Rev Immunol* 2005;5:243-51.
- Mathis M. Personal needs of family members of critically ill patients with and without acute brain injury. *J Neurosurg Nurs* 1984;16:36-44.
- Gouin JP, Hantsoo L, Kiecolt-Glaser JK. Immune dysregulation and chronic stress among older adults: A review. *Neuroimmunomodulation* 2008;15:251-9.
- Lee S, Colditz GA, Berkman LF, Kawachi I. Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *Am J Prev Med* 2003;24:113-9.
- Janardhana N, Shravya R, Naidu DM, Hampanna H. Availability and accessibility of treatment for persons with mental illness through community mental health programme. *Disabil CBR Inclusive Dev* 2011;22:124-33.
- Beattie S, Lebel S. The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: A comprehensive literature review. *Psychooncology* 2011;20:1137-50.
- Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2010;19:1013-25.
- Williams LA. Whatever it takes: Informal caregiving dynamics in blood and marrow transplantation. *Oncol Nurs Forum* 2007;34:379-87.
- Palos GR, Mendoza TR, Liao KP, Anderson KO, Garcia-Gonzalez A, Hahn K, *et al*. Caregiver symptom burden: The risk of caring for an underserved patient with advanced cancer. *Cancer* 2011;117:1070-9.
- Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA Cancer J Clin* 2010;60:317-39.