



Impacts of chronic illness on families: Experiences of Iranian family of patients with Multiple Sclerosis: A Qualitative Study

Hossein Ebrahimi¹, Hadi Hasankhani², Hossein Namdar³, Esmail Khodadadi^{4*} and Marjaneh Fooladi⁵

¹PhD in Nursing, Associate Professor, and Dean of Psychiatric Nursing department, Faculty of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

²PhD in Nursing, Associate Professor, Dean of Qualitative studies centre, Tabriz University of Medical Sciences, Tabriz, Iran

³PhD in Nursing, Assistant Professor, and Dean of Research department, Faculty of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

⁴PhD in Nursing, Iranian Social Security Organization, Iran

⁵Doctor of Philosophy in Nursing, University of Texas at El Paso, College of Health Sciences, School of Nursing, Campbell, El Paso, USA

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ABSTRACT

Family members are often the primary healthcare providers and support for patients with a chronic disease such as Multiple Sclerosis (MS). Families endure and encounter long term difficulties when caring for a person suffering from MS. This study was conducted to explain the family experiences with multiple sclerosis and their problem and concerns. In a qualitative research, based on conventional content analysis, 18 family caregivers of patients with MS were selected by using purposive sampling method. Data were collected through semi-structured and in-depth interviews conducted at the Multiple Sclerosis Society and hospitals of Tabriz in Iran from May to December of 2015. Data were analyzed according to qualitative content analysis by using the MAXQDA.10 software. Interviews identified three main categories regarding family caregiver experiences with MS: 1) disease onset crisis, 2) disease burden, and 3) living in the shadow of death. The results showed that family caregivers of MS patients face numerous problems and they are at risk for depression and a lower quality of life due to disease burden. Also the results revealed the main concerns of families are financial problems and fear of paralysis and patient be crippled. Healthcare providers can use these results to better support and care for patients and their family members in order to improve their quality of life and reduce disease complications.

Keyword: Multiple Sclerosis; Family Caregivers; Chronic illness; Disease Burden; Qualitative Research.

Corresponding author: Esmail Khodadadi

e-mail: esmailkhodadadi11@gmail.com

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INTRODUCTION

Chronic disease is known as a long term and incurable health impairment without a definitive treatment, requiring lifelong support and care[1]. Anyone at any age could be affected by a chronic disease with a significant impact on the family members and community. A patient with chronic disease will ultimately change the family life style with some disharmony and imbalance[2, 3]. Moreover, managing a chronic disease creates challenges for the whole family as the primary source of patient care, financial and emotional supports and direct involvement with the healthcare services to obtain the necessary treatments[4]. As the disease progresses, patient's capability for self-care decreases and family members have to assume more responsibility to care for the patient[2].

Besides physical exhaustion, caring for chronic diseases has psychosocial issues for patients and their family, which originates from the course and nature of disease process. As

the patient's condition worsen the psychological stress and tensions in the family are increased[4, 5]. In fact, every aspect of a chronic disease brings role changes within the family by assuming responsibilities to care for the patient, while patient's disturbed mental image and low self-confidence creates uncertainty for an unpredictable future associated with feelings of distress, anxiety, stress, hate, and helplessness. The way a family reacts to a chronic disease differs based on age, growth and developmental stage of patient, power and strength of family adaptation skills, and life cycle stage of the family[6].

One of the main family challenges is caregiving for a patient with progressive disease as Multiple Sclerosis (MS)[7]. It is known that MS is an autoimmune disease of central nervous system with neural inflammation, demyelization and losing axon of neurons features, often diagnosed in 20 to 40 years old and 2-3 times more prevalent in women[8]. According to the MS International Federation, there are about 2.3 million people in the world with MS[9]. The reports show that there are nearly 400 thousand patients with MS in United States[10]. According to Iran Neurology Society, figures for people with MS have increased from 51.9 in 2009 to 73 in 100,000 people in 2011[11]. No valid statistics of MS prevalence is available in Iran, though it was estimated to be around 60 to 70 thousands of cases[12].

Long term caregiving to chronically ill patients especially MS, has been associated with stress related physical and mental fatigue and caring responsibility for a young lovely with MS is intensified with unpredictable episodes, incurability, and debilitating neural symptoms[13, 14].

The MS diagnosis of a family member, has led to caregivers' experience of emotional distress due to constant caregiving responsibilities including chronic sadness for managing patient's daily life with unpredictable episodes of role modifications[14]. On the other hand, patients, their spouses and family members face numerous challenges such as losing a job, reduced income, changes in social status, and caregiver exhaustion[15]. Other studies have reported the effects of MS on economic setbacks and overall family welfare and suggested mental relaxation for family members as they learn to adapt to the disease progress, financial loss due to unemployment, and meeting the needs for additional expenses related to transportation and medical devices for patient mobility[16, 17]. Economic impacts originate from patient's inability to work, hospitalization, and medical device for daily activities and costly medications for the disease management[18-20]. Issues related to the patient with MS are compounded with excessive burden on the family members and community at large, who play an essential part in providing effective healthcare services based on their needs[21].

After a period of time, most family caregivers experience a sense of helplessness, tension, and their daily challenges drive them to negative reactions such as depression, loneliness, fear, anger, frustration, and anxiety[22].

In recent decades, the numbers of families caring for chronically ill patients have rapidly increased and most studies have focused more on the disease management and less on the family dynamics and their experiences[3]. The many of family caregivers often have been described as "hidden patients" and they keep silence and hide their burden by facing the challenges at their own physical and mental expense[10].

In Iran, the major problem for MS patients is the unknown state of the disease and most people do not what is MS, why there is no cure, and how it should be managed[18]. Addressing The Iranian knowledge deficit in this context is this study's main goal to highlight, recognize and explain the family experiences of MS patients and problems they face in Iran.

MATERIALS AND METHODS

For this qualitative study, a conventional content analysis approach[23] and purposive sampling method were applied. Primary codes and theoretical sampling were used for coding and finding categories. Sampling continued until obtain data saturation was reached for a group of 18 family caregivers of MS patients (14 females and 4 males). Participants were closed relatives of the MS patients such as husband, wife and parents. As shown in Table (1), the Mean duration of caregiving history was 3.5 years, with an age range of 25-54 years (Mean age=40.2 years). The inclusion criteria for participant selection were; acceptance to take part in the study, at least six months of caregiving experience, and closely related to the patient. Setting for data collection took place over an eight months period at the Multiple Sclerosis Society, Internal and Neurology wards in hospitals of Tabriz, Iran from May to December of 2015.

First data were collected through unstructured in-depth interviews with family caregivers using general questions about their experiences while living with person with MS and continued toward semi-structured questions such as "what were your concerns about the MS condition?" or "what

kind of caregiving problems did you have with MS?" Data saturation was achieved when no new information was gained from the participants. Interviews lasted between 45 and 60 minutes.

Data Analysis

As stated below, a six-step conventional content analysis method was used to analyze data.

1. Transcribing data by reading and re-reading documents to find the perceived initial ideas
2. Creating the original codes, verbatim and line by line
3. Searching for themes by compiling codes into potential themes
4. Reviewing themes, and relating themes with each other, with extracted codes and with the entire data set
5. Defining and naming themes after ongoing analysis, refining themes, creating apparent definitions and naming each theme.
6. Producing a report after final analysis, moving between transcripts and themes, selecting vivid stories for each theme, and generating the final report[23].

The MAXQDA software 10.0 (2010) was used to organize and analyze data[24]. To ensure rigor, researchers discussed and debated the findings as a group to reach consensus. The primary analysis and results were presented to the participants to verify accuracy and validate congruency of the codes with their experiences. Credibility of data was improved through long term engagement with the subject. To increase dependability, at beginning of study researchers had partial review of literature to reduce researchers' bias in data gathering and analysis processes. Confirmability was achieved by careful data recording, reporting steps, and decision making to provide a path for further research. Selection of a diverse group of participants helped amplify transferability[25].

This study was approved by the Regional Ethics Committee for Medical Research at Tabriz University of Medical Sciences, in addition to an official agreement from Multiple Sclerosis Society and hospital managers to approach and recruit family caregivers of MS patients. An approved written informed consent form, outlining the study goals and objectives, voluntary participation, and participant anonymity was obtained.

RESULTS

Content analysis of participant interviews provided 645 primary codes. Researchers classified and categorized coded data according to their similarities and differences and later condensed to find the main conceptual categories and themes with subthemes. Participant interviews identified three main themes regarding family caregiver experiences with MS as 1) "disease onset crisis" with four subthemes; 2) "disease burden" with seven subthemes; and 3) "living in the shadow of death" with three subthemes.

Disease onset crisis

Confirmed diagnosis of MS brought patients and family members face-to-face with a bitter truth as they felt shock and helplessness. Family reactions were different in each situation and mostly had fear and worries for the future. They were in shock and disbelief, when for the first time figured MS became a reality and showed extreme reactions to an unpleasant experience. At first they felt shock and later denial by not accepting the news and asking others "is it true?" Some would seek other physician's opinion thinking there was an error in their primary diagnosis.

Table 1: -The demographic characteristics of study participants

Participant no.	Age(yea)	Gender	Type of Relation	Caregiving history(year)
P1	27	Female	Wife	3
P2	44	Male	Husband	4
P3	32	Female	Wife	2
P4	54	Male	Husband	7
P5	35	Female	Wife	4
P6	29	Female	Wife	3
P7	48	Female	Mother	4
P8	36	Female	Wife	3
P9	48	Female	Mother	2
P10	50	Male	Husband	6
P11	30	Female	Wife	2
P12	47	Female	Mother	4
P13	49	Female	Mother	3
P14	38	Female	Wife	2
P15	25	Female	daughter	4
P16	46	Male	Husband	3
P17	38	Female	Wife	4
P18	48	Female	Mother	3

Confusion

Participants revealed that, after being aware of diagnosis, they did not know what to do. They were confused due to unfamiliarity with the disease state and inability to solve the problem. They were concerned about the negative social perceptions of MS and tried to hide it. *"When I found that my husband is suffering from MS, my life was ruined...I was confused and did not know what to do and who to reach for help...In confusion I walked aimlessly...Did not want anyone to know... could not find a solution and my mind stopped working"*(P3).

Disease related tension

Experience of family caregivers showed that confirmed diagnosis of MS was the pivotal moment for family experience of mental anguish, fear and concerns for the MS patient's future as an incurable disease, which worsens over time and requires long term care. *"When I realized that my daughter has been caught with MS, I felt helpless and anxious. I cried all the time and felt a heavy burden by knowing that MS is not curable and we have to care for her for a long time. We were concerned about our daughter's future. We were scared"* (P12).

Distress

Family awareness of the disease process increased stress and mental pressure as parents felt helpless with the anticipation of losing a child. *"We've heard that this disease is not curable and may progress and worsen...and the thought of losing him one day, was difficult to imagine, miss him one day, we looked at his childhood pictures and cried, we could not believe that there was no solution and we could not change the situation"* (P18).

Disease burden

Diagnosis of MS brought significant challenges upon the family caregivers who felt responsible to provide care under extreme pressure. Moreover, MS as a chronic and incurable disease required costly medications and mobilizing equipment, which were hard to find. This theme generated 7

subthemes, which included finances problems; medical treatment problems; patient's physical and mental conditions; caregiver exhaustion; knowledge deficit about the disease; family issues; and lack of support.

Finance problems

The high cost of medication was a disease burden on the family and sometimes they were unable to pay for it due to

the disease related unemployment and lack of medical insurance for disability pension. *"When my husband became ill with MS, he could not work anymore and lost his job...After that, we encountered many problems...We could not even buy his drugs and had to borrow money from friends and relatives. Sometimes I had to work cleaning houses to pay our expenses"* (P6).

Medical treatment problems

Participants explained that most of the prescribed medications were foreign made, costly and hard to find. Consequently, many families could not find or afford purchasing the drugs or substitute with cheaper brands with less efficiency. Meanwhile, substandard skill among the healthcare providers, lack of medical and laboratory equipment for accurate clinical diagnosis in some regions were among the disease burdens for caregivers. *"We had a prescription for Avonex, imported from America and hard to find due to sanctions at \$400.00 monthly and had to purchase Sevone with less potency"*(P16).

Patient's physical and mental state

Patients with MS experienced various physical and mental complications as they become more aware of their illness. They exhibit stress and anxiety for the incurability of their disease. Moreover, physical symptoms such as blurred vision and muscle stiffness with limited mobility create difficulties with daily activities and cause depression and hopelessness. Family caregivers feel sad and try to calm and comfort the patients. *"My daughter rarely goes out and doesn't want her friends to see her in this condition. She is very unhappy and depressed and sometime cries quietly worrying about lack of recovery. She asks me frequently whether she would feel healthy again and I try to calm her down... In this situation I feel really hopeless and helpless"* (P13).

Caregiver exhaustion

Caregiving for a patient with MS is overwhelming and exhausting work and requires skills, patience, and caregiving experience. Caring for a patient with chronic and incurable disease is a long term endeavor and gradual worsening with slow to no improvement is discouraging for family caregivers who feel isolated without support from other relatives. The intensity of commitment to care may seem in vain and hopeless to some, but not to the exhausted caregiver. *"It has been some years since my wife has been home bound under my care and I am trying to be patient and calm under so much pressure...but, I feel really exhausted. Thinking of what people may say, I am not willing to leave him and I feel I am ill as well"*(P4).

Table 2:- The process of obtaining main categories and sub-categories

Them	Main categories	Subcategories
Illness effects On Family	Disease onset crisis	Confusion
		Disease related tension
		Distress
	Disease burden	Finance problems
		Treatment problems
		Patient's physical and mental state
		Caregiver exhaustion
		Knowledge deficit
		Family issues
	Living in the shadow of death	Lack of support
		Disease progress and disabilities
		Fear of patient's death
		Waiting for patient's death

Knowledge deficit

Family caregivers and MS patients were unaware of the disease, its chronic and progressive nature requiring long term care. The socioeconomic aspects, psychological demands, unavailability of medication and medical devices were extremely difficult and unknown to families. Patients and caregivers suffered with recurrence episodes of the disease and lost faith in everything. "When my wife's MS diagnosis was confirmed, I did not know what MS was and have never heard it...At first I thought it was something contagious and worried about that...but when her legs began to get stiff, I thought she was paralyzed...and did not know how to take care of her" (P10).

Family issues

Family dynamic was changed for most participants and their lives were significantly affected by the news of MS disease with discussions about sharing caregiving responsibilities, taking turns, as well as family discourse leading to divorce. Moreover, among families who managed to remain together and manage the problems, spouse's experienced impotence. "Some families could hide their child's disease, but among the married couples few would accept living with a partner who suffered from MS and finally are separated from each other." (P9).

Lack of support

Families experienced disease related loss of employment, high cost of medical care and mental anguish for lack of support from insurance and governmental agencies. There was financial burden on top of social and emotional abandonment for most families. Even relatives distanced themselves and unwilling to communicate with the family caregivers or MS patients. "I wish people knew the difficulties and pressure we are facing...may be then, they would show empathy and more support. Government should provide a monthly payment for these families to reduce their pains and suffering" (P15).

Living in the shadow of death

The thought of losing someone in the family to the MS disease has a lasting emotional effect on the whole family and among the participants in this study fear of death from a progressive and incurable disease was obvious. Family caregivers learned to gradually accept the bitter truth and surrender to the MS disease final outcome. The progressive crippling effects of MS on the patient and the family brought everyone to face the fear and accept death. Most families described their experiences as bitter and overwhelming.

Disease progress and disabilities

The worsening state of MS and progressive symptoms such as paralysis of extremities, inability to move, urinary incontinence and lack of defecation control made morbidity and mortality of MS evident to families. Immobility of patient led to develop of bedsores because the elderly caregivers could not move the patient and made it even more difficult for everyone in the family. "When disease progressed, we noticed gradual disabilities and paralysis...death was inevitable and as a family we had to face our fears and recognized that there was no miracle. It was a difficult time...without mobility... bedsores developed...and with loss of control for urination and defecation...we did not know what else to do in this situation" (P11).

Fear of patient's death

As the disease stages advanced, family caregivers and the patient lost hope for a miracle and began to accept that death could occur at any time. Families experienced helplessness, especially for a young patient facing early death in a horrible way. "I have heard that this disease was incurable and death is a torturous process...and now I can see paralysis of my daughter legs, immobility...and tolerating this situation is really difficult for me. I may face my child death at any time...and when I think about future, I see myself alone and helpless...it is really a bad feeling" (P7).

Waiting for patient's death

The waiting period for such a heartbreaking event was difficult. Imagining the patient's death and life after that was tough and frustrating, especially when disease progress was slow and deteriorations were unbearable with lingering concept of death as a major stressor. Families suffered for their inability to prevent the disease progress and felt helpless. "My husband is in bed, he cannot move, he is suffering from blurred vision... doctors have no hope for improvement. I cannot leave him in fear of something happening to him in my absence. Sometimes I have nightmares and wake up in fear of living my life with uncertainties...I worry about the future" (P14).

DISCUSSION

This study was intended to describe the experiences of family caregivers of MS patients in Iran and similar to other results, we found that families faced many problems and obstacles to receive support[26, 27]. Families faced physical and mental issues and their quality of life deteriorated with exhaustive suffering[5, 28]. In fact, World Health Organization (WHO) has emphasized the need for relief services to help families of patients with chronic diseases and providing professional mental and emotional support for long term care at home[29].

Studies on families of MS patients have shown that confirmed diagnosis of MS provokes various emotional reactions such as shock and disbelief, especially when everyone involved has heard what MS is, what can happen to the patient, and how to care for a patient with MS at home[4]. Families struggle with confusion when they discover there is no hope for recovery and experience hopelessness. In fact, some people are stressed by hearing the word "MS" as a life threatening condition. Selye theory (1960) refers to stress and tension as the outcome of any demand on body's physical and mental abilities, when a person's resources are inadequate to solve the crisis[30]. According to Lazarus Folkman's stress theory (1984), tension is a complex process of a person's response to stress and emotional pressures[31]. Other studies have shown that families with stress and tension due to onset of patient's illness are susceptible to emotional breakdown with anger and depression[5, 32, 33].

In this study we found that family caregivers for MS patients with a pending morbidity and mortality state, experience financial burden and lack of support from government and healthcare system. These problems brought family discourse, marital problems and divorce in some cases. Although family caregivers were not willing to live with someone who suffered from a chronic disease, their marital commitment led them to continued care, which is a testament to the Iranian culture of "until death do us apart". Other studies indicated that family caregivers of chronic illnesses experienced various mental issues such as depression and hopelessness[4, 6], in addition to fatigue and exhaustion for providing long term care without hope for recovery. Caregiver exhaustion was noted as a negative effect on both the caregiver and the patient [2, 10, 14].

In this study, the major problems and concerns for family caregivers were the financial setbacks and lack of public support. High cost of medications, unavailable drugs and medical devices, loss of employment due to MS diagnosis, and no government support made it difficult to care for the patient and increased stress for family members who couldn't solve the problem. This situation may be led to stress, role captivity, and even the cessation of caregiving[34]. The studies in other parts of the world have had similar reports regarding the care of chronic and disabling diseases and financial burdens[17, 19, 20].

Another concern of patient's families was the fear of death as MS disease progressed. Families were aware that MS was incurable and gradually worsened. They feared death with every new symptom and were strongly distressed and worried. Debilitating condition made families feel uneasy for unintentional wait for death of a loved one. They experienced an endless wait which severely affected their mental health. Similar to other studies, loss of a loved one in such a condition was stressful and unpleasant[35-37].

CONCLUSION

Results of this study showed that family caregivers of MS patients face numerous problems and are at risk for physical and mental breakdown under severe pressure. Participant experiences showed that financial problems and disease progress were the major concerns. A clear and realistic understanding of MS as a disease can reduce pressure on the family and improve the patient care. Governmental support is crucial to help the families and enhance public awareness regarding MS disease as a chronic and debilitating condition. Healthcare providers can use these results to better support and care for patients and their family members in order to improve their quality of life and reduce disease

complications.

CONFLICTING INTEREST

No conflict of interest has been confirmed by the authors. This study was funded by the Tabriz University of Medical Sciences. "I had full access to all of the data in this study and I take complete responsibility for the integrity of the data and the accuracy of the data analysis."

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REFERENCES

1. Thompson J. How chronic illness affects family relationship and the individual [tesis]. Wisconsin: University of Wisconsin-Stout. 2009.
2. Arnett PA. Caregiver burden in multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2007;78(10):1041.
3. Glozman JM. Quality of life of caregivers. *Neuropsychol Rev* 2004;14(4):183-96.
4. Dobbie M, Mellor D. Chronic illness and its impact: Considerations for psychologists. *Psychology, health & medicine* 2008;13(5):583-90.
5. Ellenwood AE, Jenkins JE. Unbalancing the effects of chronic illness: Non-traditional family therapy assessment and intervention approach. *The American Journal of Family Therapy* 2007;35(3):265-77.
6. Lawrence E. The impact of chronic illness on the family. *IG Living*. 2012.
7. Murray JT. Multiple Sclerosis: Etiology, Diagnosis, and New Treatment Strategies. *Ann Intern Med* 2005;142(9):804-.
8. MacAllister W, Belman A, Milazzo M, Weisbrot D, Christodoulou C, Scherl W, et al. Cognitive functioning in children and adolescents with multiple sclerosis. *Neurology* 2005;64(8):1422-5.
9. MS International Federation: Epidemiology of MS. Available from: <http://www.msif.org/research/epidemiology-of-ms/>. 2015. Buhse M. Assessment of caregiver burden in families of persons with multiple sclerosis. *J Neurosci Nurs* 2008;40(1):25-31.
10. Ghafari S, Khoshknab MF, Norouzi K, Mohamadi E. Spousal Support as Experienced by People With Multiple Sclerosis: A Qualitative Study. *J Neurosci Nurs* 2014;46(5):E15-E24.
11. Nabavi S. 12th International Congress of Multiple Sclerosis. Tehran 2015. Available from: <http://www.ghatreh.com/news/nn27862825>.
12. Fooladi MM. When Extreme Stress Reveals Multiple Sclerosis: A Case Report. *International Journal of Community Based Nursing and Midwifery* 2013;1(1):69-75.
13. Pakenham KI. Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health & Medicine* 2001;6(1):13-27.
14. Ehrensperger M, Grether A, Romer G, Berres M, Monsch A, Kappos L, et al. Neuropsychological dysfunction, depression, physical disability, and coping processes in families with a parent affected by multiple sclerosis. *Mult Scler* 2008;14(8):1106-12.
15. Bowen C, MacLehose A, Beaumont J. Advanced multiple sclerosis and the psychosocial impact on families. *Psychology and Health* 2011;26(1):113-27.

16. De Judicibus MA, McCabe MP. The impact of the financial costs of multiple sclerosis on quality of life. *Int j behav med* 2007;14(1):3-11.
17. Abolhassani S, Yazdannik A, Taleghani F, Zamani A. Expectations of Multiple Sclerosis Patients and Their Families: A Qualitative Study in Iran. *Iranian Red Crescent Med J* 2015;17(2):1-7.
18. De Judicibus MA, McCabe MP. Economic deprivation and its effects on subjective wellbeing in families of people with multiple sclerosis. *J Ment Health* 2005;14(1):49-59.
19. Jennum P, Wanscher B, Frederiksen J, Kjellberg J. The socioeconomic consequences of multiple sclerosis: a controlled national study. *Eur Neuropsychopharmacol* 2012;22(1):36-43.
20. Ytterberg C, Johansson S, Gottberg K, Holmqvist LW, von Koch L. Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study. *BMC Neurol* 2008;8(1):36.
21. Kalb R. The emotional and psychological impact of multiple sclerosis relapses. *J Neurol Sci* 2007;256:S29-S33.
22. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105-12. PMID: 14769454.
23. Godau R. Qualitative data analysis software: MAXqda and MAXdictio. *Qualitative Research Journal* 2004;4(1):66.
24. Streubert HJ, Carpenter DR. Qualitative research in nursing: Advancing the humanistic imperative. 5 ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins; 2011.
25. Canam C, Acorn S. Quality of life for family caregivers of people with chronic health problems. *Rehabil Nurs* 1999;24(5):192-200.
26. Thielemann PA, Conner NE. Social support as a mediator of depression in caregivers of patients with end-stage disease. *Journal of Hospice & Palliative Nursing* 2009;11(2):82-90.
27. Bookwala J, Yee JL, Schulz R. Caregiving and detrimental mental and physical health outcomes. Physical illness and depression in older adults: A handbook of theory, research, and practice. 2000;93-131.
28. Hudson PL, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *Journal of palliative medicine* 2004;7(1):19-25.
29. Rice VH. Handbook of stress, coping, and health: Implications for nursing research, theory, and practice: Sage; 2011.
30. Lazarus R, Folkman S. Stress, Appraisal, and Coping: Springer Publishing Company; 1984.
31. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res in Nurs and Health* 1992;15(4):271-83.
32. Yoon S-J, Kim J-S, Jung J-G, Kim S-S, Kim S. Modifiable factors associated with caregiver burden among family caregivers of terminally ill Korean cancer patients. *Support Care Cancer* 2014;22(5):1243-50.
33. Lyons JG, Cauley JA, Fredman L. The Effect of Transitions in Caregiving Status and Intensity on Perceived Stress Among 992 Female Caregivers and Noncaregivers. *Journals of Gerontology: Medical Sciences* 2015:1-6.
34. Li LW. From caregiving to bereavement: trajectories of depressive symptoms among wife and daughter caregivers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 2005;60(4):P190-P8.
35. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300(14):1665-73.
36. Dumont I, Dumont S, Mongeau S. End-of-life care and the grieving process: family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qual Health Res* 2008;18(8):1049-61.