



**ORIGINAL ARTICLE**

**OPEN ACCESS**

## **Experiences of Family Caregivers of patients with Multiple Sclerosis**

**Abbas Firoozi Manesh<sup>\*1</sup>, Heidar Ali Abedi<sup>2</sup>**

<sup>1</sup>Graduate student, Nursing Education of Internal Surgery, Management Center, Accident and emergency medicine, University of Medical Sciences of Zahedan

<sup>2</sup>Associate Professor, Islamic Azad University, Khorasgan Branch, Iran

### **ABSTRACT**

*Multiple sclerosis is chronic, progressive and debilitating. Care of these patients, it saps energy and cause despair and desperation family, frustration, depression, and risk of erosion and psychosomatic disorders in family members, especially parents and husband patient. The aim of this study was to describe experiences of family caregivers of patients with multiple sclerosis in 2013 that live in Zahedan city. This study is qualitative content analysis was performed in public hospitals in Zahedan. Unstructured data through interviews with 6 of caregivers of patients with MS who were selected by purposive sampling was conducted. Validity and reliability of data and return results to participants to confirm their findings and analysis team were confirmed. The numbers of participants in this study were six patients with an average age of 43.66 years old. 9 basic groups of data analysis include grief reactions, needs, fragmentation, and career, emotional and financial burden of family relationships and social disruption, stress, exhaustion, isolation, vulnerability against each following result was several stories high. Most of these consequences for patient physically, mentally and socially to them, especially when patient relapses dependence on caregivers have more, some degree of anxiety, depression and have isolationism. Thus eliminating need to identify problems and their needs is essential.*

**Keywords:** family caregivers, caregivers' experience, multiple sclerosis

Received 11.04.2015

Revised 02.06.2015

Accepted 11.06. 2015

### **INTRODUCTION**

Multiple Sclerosis is chronic disease, pre-process, debilitating inflammation and destruction of myelin of central nervous system is usually in young adults [1][2][3] and occurs between ages of 20 to 40 years[4]. The number of patients with multiple sclerosis in world is estimated at 2.5 million [5] that have spread. MS in women is almost twice that of men [6]. The incidence and prevalence of MS in Sistan and Baluchistan respectively is 2.67 and 13.96 per 100,000 populations [7]. This disease is second leading cause of neurological disability in young labor force counts [5].

Its incidence in young people would increase social and economic problems for patient, family and society [8]. On other hand, due to chronic nature of disease, as well as its economic activity, MS is a costly disease [5]. These patients are unable in finding way to solve problems and achieve an approach to improve quality of life and health [4]. Studies have shown that often, patients, changes in work and social activities of daily experience and to cause it to lose his family's financial resources are depleted and thereby causing economic problems in family [9].

According critical role of family caregivers in field of rehabilitation of patients with mental and physical disabilities are able to help patients enhance their abilities constant pressure of patient care and curative effects on quality of life of individuals and families[2]. Caring also saps energy and cause despair and desperation of family, frustration, depression, and risk of erosion and psychosomatic disorders in family members, especially parents and wife is sick [10].

Gibbins believe the most important factors of stress in caregivers, including coping, communication, power, role playing, professional, role ambiguity and conflict, problems related to limitations and expectations are unrealistic [2]. Due to important role of family care in each community's healthcare system, expert attention to issues related to care of health and wellbeing non-formal, increasing [11].

So researcher, considering that academic research has not been done in this area, by using family experiences consequences of disease in these patients, treatment and support of national and social

research to describe experiences of family caregivers of patients with multiple sclerosis in 2013 was living in Zahedan city.

## METHOD

This study is qualitative study by using qualitative content analysis to discover and understand experiences of caregivers of patients with multiple sclerosis in families in Zahedan city from February to March of 2013 which was performed in public hospitals in Zahedan. The study population consists of family caregivers of patients with MS in Zahedan city.

After approval and licensing and receiving code of research ethics committee of Islamic Azad University of Khorasgan Branch, researchers presented in environment study after expressing purposes of recording and notifying participants of interviews, it was observed that inclusion criteria were invited to participate in study.

Inclusion criteria included: 1. Patients who develop their families in multiple sclerosis is confirmed by a neurologist. 2. be able to attend interview and transfer their knowledge and experiences. 3. Willingness to participate in study and interviews motivation and cooperation are necessary. 4. Already to be patient in one place. To determine volume of sample code, rewritten text of interview and initial codes were extracted. After coding each interview with results, next participants were chosen and sampling process was continued until data saturation and repetition of code. In general, families with 6 tons of unstructured interviews and recording statements of participants were from tape recorder. 30 to 60 minutes for each interview, participants were examined on basis of patience and tolerance. To protect your information, interviews with consent of all participants in digital recording, and then after a few times listening interviewed by researcher, was fully written on paper. Moral vision of informed consent, participants completed and signed by researcher and participant. Interview with a general question like when you first heard patient is diagnosed with multiple sclerosis what happened was next question is designed on basis responses.

The study analyzed data from first interview and interviews conducted in parallel (simultaneous analysis) was performed. The interviews were rewriting word. After that, several times listened to tapes of interviews and interviews were read several times to realize a general understanding of obtained data. Then, based on seven Klaizery, descriptions of participants to understand and feel they are being studied by researchers after reviewing material and then extracted sentences in relation to phenomenon under study was organized in groups and clusters. All opinions derived by combining a comprehensive description of details of phenomenon under study were obtained. The reliability of results, comprehensive descriptions of phenomenon were returned to participants. Validity and reliability of data and return results to participants to confirm their findings and analysis team were confirmed.

## Findings

Numbers of participants in this study were 6 of caregivers and families living with MS in Zahedan, with an average age of 43.66 years. Of these, 3 patients were wife, 2 mothers and 1 brother of patient. In total participants were 3 males and 3 females.

The data analysis resulted in extraction of essential 9Grvh that each has had a few categories below (Table 1).

Table (1) main themes derived from second to fourth stage of analysis Klaizery's codes

Categories	Sub-Categories
Grief Reactions	Denial - anger - Depression - Fears
Needs	Need to know - need support
Disruption of career	Ineffective job performance - a lack of job protection
Emotional and financial burden	And provision of drug therapy problems - inability to provide for cost of living
Disruption of family and social relationships	Lack of understanding - emotions - devastating disease
exposure to tension	Disrupted family relationships - the transformation of social relations
Exhaustion	Trying to fit - harmful compensatory mechanism
Isolation	Physical exhaustion - mental exhaustion
resistance against vulnerability	Rejection - despair - alone

**A- Grief reaction:** according to disease in family is tragic accident; Family members, from moment of diagnosis until full acceptance of disease process as a reaction to bereavement. So that one participant stated, "...

We had to go to Mashhad and

And set up MS diagnosis. At first we were shocked and scared that I could not admit that we were did not believe that my daughter was paralyzed s why I took her to a doctor here in Zahedan, who confirmed that we could not believe and we thought they are wrong..."

**B. Needs:** After disease, patient's family is faced with a series of requirements that meet these needs in accordance with established disease and solve many of their problems. Participant No. 3 states that "...When I saw that problems of past and not present situation and reaction I saw that He was very angry and was severe. Of course, we are passive stance we took.Two members of paralysis and blindness had lost her place for me in my research question and more and greater awareness of disease and it was found that more I work with him..."

**C. Job Disruption:** Since my illness. MS can cause physical and psychological problems for patient and his or her family and problems caused by hypothyroidism and subsequent lack of support from people we work two sub-themes of formation of disruptive employment and participant No. 5 states that "...I work a shift at bakery is just too good to not be able to do same to her why problem. I do not work in bakery. For living expenses and medications to help them, sometimes I have trouble being reached..."

**D. Financial and Emotional Burden:** financial and emotional burden caused by disease include provision of drug therapy problems - inability to meet the cost of living - a lack of understanding - emotions - is devastating disease that form sub-concepts of it and one participant stated, "... I just did not have money to buy drugs. I do not think that drugs and medications borrowed so much I went and got it. Poor wife eats very sad. They give so much money that he does not want to go through..."

**E. Disruption of family and social relationships:** Disease is caused by impact on family and social relationships within family and community ties are cluttering. Participant No. 1 states that, "... Little by little, I realized that emotional feelings of first few days I felt a duty to help my wife but after that it works like a normal person do I deal with it, sometimes nerves and nerves got to corrupt her as my wife and I cannot bear pain..."

**E. Exposure to tension:** Since people have different behaviors in face of stress and some are trying to combat problem and some have become inefficient adaptation; so trying to ineffective coping, stress themes have formed. In relation to adaptation, Participant No. 4 states:"... His morale is good. He do his own duties and pay attention to health. But we will help him and behaves as we think he does not need to us..." and ineffective compliance, participant number 3 says: "... The harsh confrontations wife had an adverse effect on children and on my mood. I was so annoyed that he was addicted slip this shortcoming is due to come. A person was forced to divorce one to indifference. For my addiction to resort to comrades to compensate for this deficiency was emotional..."

**F. Burnout:** patient care often leads to mental and physical exhaustion of workers that make up two sub-themes. So that one participant stated, "... When I'm alone I cannot do work to get it to kids. Even things up a few days cleaning house look random choice I am always bored and tired ..."

G isolation, loneliness caregivers in caring for patient, rejection by family and friends, and despair of treatment, has formed theme of isolation Participant No. 2 states that "... God, I do these days I cannot get him to talk to my daughter one that can beat me. It's nice to have shit, I cannot go to work, who has a present situation cannot get married until you go backed had a listen to disease do not look same. Neither have we hoped he does not able to get married, and formation alive. "

**G- Resistance against Vulnerability:** and finally, in spite of all that adversity, caregivers and patients are mainly measures to resist vulnerabilities. Participant No.1 states expressed

"The Haj said good word to me, he said; do not worry that maybe God loves you and your wife that give opportunity to care you and to disease due to sit close to God. It was really time we go we both disconsolate over prayer and cry during prayer".

## DISCUSSION

The aim of this study was to describe experiences of family caregivers of patients with multiple sclerosis in 2013 live in Zahedan city. The nature of experiences can be expressed as follows: Disease and stress in family leads to anxiety, fear, and some degree of anxiety and depression for patients and families that in early stages of family's reaction to stress is denial and shock. However, during time of anger and depression can happen to people. In these steps are as people sometimes called grief reactions are rapid traverse and sometimes because of occurrence of mishaps and other long-term stress can be entered. MS patients have problems with family caregivers, and identify ways to overcome these challenges take place.

Chabaei's [12] study suggested that, denying his reaction supporting cast and strategy that ignoring reality and severity of disease to someone helps, before it was considered primary protective responses which only temporarily suppress anxiety, so then deal on offer is not enough. Recently, majority of experts agree that dispute shall be treated from different perspectives and specific performance shall be in addition to all of cases evaluated.

Since onset of illness in family, families are faced with new requirements such as need for awareness and support needs. Results of this study by relying on previous studies showing that meet these needs by offering a better quality of care and patient care and caregiver satisfaction.

Results Zeynali and colleagues [13] found that family support and provide training and information to parents makes them feel in control and more power over their situations.

The findings of Buchanan et al [14] found that informal caregivers wide range of services to people with MS, including personal care, housekeeping, mobility and leisure activities offer. Care would be reduced with pressure of care, quality of life. More access to formal support services helps reduce burden of care.

Since MS is due to physical problems that are causing problems for patient, and consequently family business. These works by reducing quality of life of additional economic burden on families are created. The research of Neiestani Sharifi et al [9] showed that there is significant relationship between self-esteem and employment status, meaning that workers had higher self-esteem which this finding is consistent with results of Fraser. In this regard Masoudi et al [15] concluded that there is no significant relationship between self-esteem and employment status. In this connection, studies have shown that employment status as agent of social and mental health and self-esteem desired effect of increase.

After economic problems from changes in work procedures and lack of basic needs of patient and family to cope with family stress, and family MS patients with new challenges to face financial and emotional burden.

The findings of Ghanati et al [16] showed that cost of MS is disease with considerable financial burden on individuals and state and society. Research of Tarlow and colleagues [17] suggested that loss of jobs and work from physical effects of disease eventually leads to inability to pay one's life. On other hand high cost of treatment, additional economic burden imposed on family.

Financial difficulties and lack of funding for mental imbalance and create negative consequences on family life caused patients. These factors combine to make the family and social relationships are faced with more stress on interconnection. Disrupted family relationships and transformation of social relations provides basis for development of variety of emotional and social problems and issues such as suicide and divorce. Research findings of Sadr Arham al [18] showed that majority of MS patients with moderate social impact of disease activity and sexual activities are considered moderate to high.

On basis of patients with MS, disease affects their social and sexual activity was significantly higher than that of males. Perhaps this difference of opinion can be based on vulnerability and sensitivity, more women than men, especially in our society, among others.

Care of patients with MS, caregivers suffered physical and mental exhaustion is caused by physical problems such as back pain and leg care that the incidence of mental health problems such as depression and isolation among these problems. Results of Mayumi and colleagues [19] showed that problems in care of caregivers were significantly associated with poorer mental health. It is likely that caregivers may suffer from anxiety and depression. Increase difficulty of care and increase time it takes to care was associated with an increase in severity of depression.

Since persistence of problems created for diseases such as lack of basic needs, financial and family problems, to make them part of family leads to rejection and disappointment in community; so families in this situation would be marginalized. Khaje et al.'s findings [20] showed that compared between two groups was statistically significant based on despair of publication was obtained. Using multivariate analysis and logistic regression model showed frustration can increase chance of suicide by ratio of 1.19. The mood of patients with suicide hopelessness scores than control group had attempted suicide

Finally, in spite of all that adversity, caregivers and patients are mainly measures to resist vulnerabilities. Measures such as those associated with peer and religious appeals of positive efforts that have formed theme of resistance to vulnerabilities. Haejung [21] supports role of religion in increased pressure adjustment, mental health care and family care. The results of Ashtari and colleagues [1] found that participation in peer groups; improve physical health status at end of intervention.

## CONCLUSION

Experiences expressed by caregivers of family members of patients with MS, it follows that the most of these consequences for patient physically, mentally and socially to them, especially when patient relapses dependence caregivers some degree of anxiety, depression and isolationism have therefore concluded that reduction in patient care, providing jobs and living expenses in addition to disturbance of group was,

subsequently, also causing disruption of family and social relationships. Thus eliminating need to identify problems and their needs is essential.

## REFERENCES

1. Ashtari, F, Shaygannejad,V; Heidari, F.; Akbari,M.(2011) Estimating the relative prevalence of multiple sclerosis in Isfahan. *Journal of Isfahan Medical School*, in Twenty-Nine, Number 138: 561-555.
2. Masoudi, R.,Alhani F.(2010). The effect of family-centered empowerment model on knowledge, attitudes and practices of caregivers of patients with multiple sclerosis. *Journal of Agricultural Science*, Volume 17, No. 2: 97-87
3. Ghasemi,A., Shaygannejad,V.(2011). Comparative study of the efficacy and Swiss Ball Exercises to Improve Balance Frankel and depression in people with MS. *Research in Rehabilitation Sciences*, Vol. 7, No. 3: 283-278.
4. Hares Abadi, M., Karimi,M., Foroghi pour M.(2010). Quality of life in patients with multiple sclerosis in hospitals Ghaem. *Mashhad University of Medical Sciences Journal*, Volume 2, Number 4: 12-7.
5. Bahraini S., A. Naji, Mannani R, Bekhradi. (2011). Effect of aromatherapy massage on fatigue in women with multiple sclerosis. *Journal of Sabzevar University of Medical Sciences*, Volume 18, No. 3: 178-172.
6. Alipour, A.,Sahraian,S., Haji Aghababaei,M.(2011).The relationship between perceived social support and hardness mental health and disability in patients with Multiple Sclerosis. *Research in social psychology*, Volume 1, Number 3: 133-1110.
7. Raghibi, M., Khosravi,M.(2013). Comparison of cognitive function in patients with multiple sclerosis. *Journal of Information Sciences*, Volume 14, No. 2: 48-45.
8. Asadai Zaker M., Magdi,N., Atapour, M., Latif, M.,Babadi,M.(2010). The effect of exercise on walking speed, fatigue and quality of life in patients with multiple sclerosis. *Journal of Medicine*, Volume 9, No. 2: 198-190.
9. Sadat,J., Alimohammadi, N., Alamdari,A.(2011). Phenomenological study of family and social relationships of patients with multiple sclerosis. *Journal of Mazandaran University of Medical Sciences*, 21: 252-244.
10. Shamsaie,F.; Mohamad Khan, S., Vanaki,Z.(2010). Family care needs of patients with bipolar disorder. *Journal of Hamadan University of Medical Sciences and Health Services*, Volume Issue 3: 63-57.
11. Bambara JK, Owsley C, Wadley V, Martin R, Porter C, Dreer LE. Family caregiver social problem-solving abilities Mexican-American families. *Aging Ment Health*. 2009; 13 (1): 84-91.
12. Chabaei, Martha and Molnar, P.(2010). *Textbook of medical psychology of health, illness and care*, translation by Azari:Danesh Publication
13. Zeynali,J., Mirhaqjo N., Mirzaei,M.; Alhani, F.(2012). The effect of family-centered care to meet the need for information on the parents of hospitalized children. *Holistic Nursing*, Vol 22, No 67: 37-30.
14. Buchanan RJ, Radin D, Huang CH, Zhu L. 2010. Caregiver perceptions associated with risk of nursing home admission for people with multiple sclerosis. *Disability and Health Journal* 3: 117 – 124.
15. Masoudi, R.,Soleimani M.(2012). Family-centered empowerment model effects on self-esteem and perceived satisfaction Multiple Sclerosis patient care. *Koomesh*, Volume 14, No. 2: 248-240.
16. Ghanati, H., Daghighi Asl,A.(2011). Assess the economic costs of MS drugs and economic feasibility of insurance policies for the disease agents. *Health Management*, 14 (45): 55-47.
17. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D.(2004) Positive aspects of caregiving: contributions of the reach project to the development of new measures for Alzheimer's care- giving. *Research on Aging*.26 (4): 429-53
18. Sadr Arhami,N.; Atarod,S.,Amanat,S.(2008).Attitudes of patients with multiple sclerosis, the disease impact on their social and sexual activity. *Behavioral Sciences*, Vol. 6, No. 2: 88-79.
19. Mayumi M, Reiko N,Yoko K.(2008).Nurses perception of their relational behavior with family members of hospitalized patients: survey of nurses who work at national hospital organizations in Tohoku district. *Journal of the Faculty of Nursing*.8;pp: 1-12.
20. Khaje,N., Behrouzian, F., Ghanavati,F(2009). Evaluation of the relationship between hopelessness and suicide in patients with mood disorders. *Journal of Medicine*, Volume 8, Number 4: 413- 408.
21. Haejung L. 2010. Appraisals, Burnout and Outcomes in Informal Caregiving. *Asian Nursing Research*, Vol 4, No 1: 32 – 44.

## CITATION OF THIS ARTICLE

Abbas Firoozi M, Heidar Ali A. Experiences of Family Caregivers of patients with Multiple Sclerosis. *Bull. Env. Pharmacol. Life Sci.*, Vol 4 [8] July 2015:137-141