



SOCIO-ECONOMIC IMPACT ON THE STATUS OF MULTIPLE SCLEROSIS PATIENTS IN SAUDI ARABIA

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ABSTRACT

Multiple Sclerosis (MS) is a demyelinating patchy disease affecting the nerve fiber in the central nerves system, resulting in a range of signs and symptoms, including physical, mental, and sometimes psychiatric problems. Unlike other disease the MS was found to have a real impact on the quality of life, the social functioning and the degrading towards family commitment. In many studies The socio-economic factors were found connected to the psychological and social status of the patients. The **aim** of this study is to investigate the impact of these two domains on the female Saudi MS patients. The study used a carefully designed questionnaire which was tested for reliability and validity. A ninety four female (94) MS patients were surveyed and data were tested using SPSS package and ANOVA test was applied to statistically handle the result. The Social factors showed the lack of awareness of the most challenging problem. However the social factors that impact on the MS patient were (loss of confidence), (difficult of join social events) which almost represented in 40% of the study population. The identified economic factors as a real challenge were the (lack of role and regulation that manage the financial rights for the patient). The factor that mostly impact on the patients was the lack of (financial support to maintain reasonable life of the patients). **Conclusion:** the social factors showed reasonable effect on most of the patient this is indicate the well connected families and the integrated social support provided to the patient. The economic domain was found a triggering factors to most of the psychological deterioration of the patient and may play a role to raise the corisole hormone level in many cases.

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INTRODUCTION

LITERATURE REVIEW

Multiple sclerosis (MS) is a demyelinating disease in which the insulating covers of nerve trunk and cells in the brain and spinal cord are damaged. This damage disrupts the abilities of many parts of the nervous system to communicate functions, resulting in a range of signs and symptoms, including physical, mental, and sometimes psychological problems.¹ A widely-accepted model considers MS to be an autoimmune chronic inflammation, mediated by T-cells and macrophages infiltrating the CNS

There is no known cure for multiple sclerosis.¹ Treatments however try to reduce relapse frequencies and reduce the effect as well as improve function after an attack.⁸ Medications used to treat MS, while modestly effective, can have side effects and be poorly tolerated. MS imposes a significant socio-economic cost on women, this is also impacted on the family and community and because women with MS are less likely to

commit to a full-time job or suffer from forms of presenteeism and absenteeism consequently affect the relation with employer and will be reflected on her financial income.³

While the impact of the disease has been examined in considerable detail,^{3,7} and there is a recognition that patients with MS experience changes to their physical, mental and emotional health and subsequently to their lives due to symptoms and disabilities related the disease, there has been little targeted research on whether the disease has a differential impact on women.

Direct costs: The direct costs of MS on patients and society have been investigated in detail. These direct costs encompass all resources used to diagnose, treat and assist patients with MS in daily life. Several examples include medical costs to pay for diagnostics, medication, inpatient and outpatient care, nursing care, specialty care and rehabilitation services. Many researchers have also examined direct nonmedical costs such as formal and informal care to help with daily activities, home and car modifications, mobility devices and other resources.³ Indirect costs: There is also literature on indirect costs of MS,

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or those that occur outside of the healthcare system and accumulate throughout an MS patient's care.⁴ Indirect costs include work and earnings losses (both due to increased morbidity and early mortality) and the cost of the indirect impact of MS on family and friends. A significant amount of research documents the impact of MS on labor force participation in terms of absenteeism, presenteeism, potential job changes and early retirement. An MS patient also often has family or friends who act as informal caregivers and decrease their labour force participation as well. Intangible costs: The literature documents pain, psychological suffering and decreased quality of life both for the patient and for their dependents. Although these costs are more difficult to quantify, they have a substantial impact on the patient and in aggregate on social status, society at large.³

It is likely that the psychological correlates with Social-Economic Status (SES) itself and might promote MS incidence. Individuals of low SES experience higher levels of psychological distress.⁷ This however leads to measureable differences in physiological indicators of stress, such as elevations in the stress hormone Cortisol^{7,8} Cortisol and other stress-related hormones such as Catecholamines are branded to have significant effects on the immune system. One such effect is that Cortisol causes a shift in the T helper cell population away from Th1 cells, important in cell-mediated immunity, and towards Th2 cells, drivers of humoral immunity^{7,11}

Stress, Depression related immune changes are often posited as explanations of the harmful effects of low SES on health, An association between acute stressors and increased MS relapse rate has been reported in two meta-analyses.¹² However, a protective effect of chronic stress in humans has not previously been considered. Two studies have looked at the relationship between stressful events in childhood and MS risk, hypothesizing that they would be harmful.^{13,14} There was insufficient evidence of an effect for most events, with some having wide confidence intervals ranging from a 3-fold reduced risk to a 2-fold higher risk.

From the above it is clear that the SES is initiating cascade of events that cause or aggravate the MS. It is likely correlates with the deterioration of QoL and may be triggering a psychological events, therefore the present study **aimed** to investigate factors with the Socio-Economic aspect that induced or aggravate the MS. The study will try to identify the hard social and economic aspects facing Saudi MS patients, and the consequences impact of these factors.

MATERIALS METHOD

This is a prospective cross sectional study ,uses several questionnaires to survey the multi-dimensional aspects related to socio-economic impact on the MS status and the blood Cortisol level on Saudi female patients. The study distribute the questionnaires to the patient after they receive a detailed information about the study. The ethical consent form was obtained from each individual. All questionnaires were anonymous, and confidentiality of information was ensured. Instructions to complete the questionnaire and confidentiality issues were explained on the cover page of each questionnaire. This study was approved by the Institutional Review Board. The survey uses closed answer questions and focuses on the current socio-economic problems of the patients. Study community: is the patients referred, diagnosed and treated in Prince Sultan medical military City, which received

almost 492 patients. The sample size was calculated and identified to be 100 patients. Inclusion criterion: 1: female 2:referred and treated in PSMCC, 3: complete all diagnosis and identified as MS patient.

The questionnaires were distributed to them and collected after completion, the researchers have no influence on the distribution and collection. The survey was designed and examined for validity and reliability, and considered valid and reliable by external experts. The blood cortisol levels was reviewed for all patients immediately following the relapsed event at the clinical visit. Data then were interred to SPSS package and statistically examined by ANOVA test. The frequency and percentage were addressed for all variables. Mean and Standard Deviation were also obtained.

RESULT

Data on socioeconomic problems were obtained from 94 female patients. Total mean age for the entire group of patients was 32.7 ±10.3 years (age range 16-55 years). Most of the patients were single (49%), almost 90% live with their family, and 50% of the patients are working. About 40% has enough monthly income.

The most important problem the MS patients facing is the high cost of the medicine and the cost of the care they usually need. Almost 50% of the study population was suffering from this increased cost. This coincident with the reduced income or lose the job of some patients which is expressed in 20% of the study community.

From the classified data to study the social difficulties that usually face the MS patients, it was found that the lack of awareness about the disease and the social event directed to the MS patients were the most highlighted problems among the study community. The failure of the patient to engage into the social role or commit to certain degree of social responsibilities was recognized in almost 40% of the sample. Some other aspects were highlighted in the table1 below.

Table 1 seven social aspects were studied and carefully analyzed, the data showed huge shortages in the awareness of the community about the disease, consequently there is a lack of social events directed to MS patient. The other social factors were found reasonably impact or has less impact on MS patients. Table 1 below representing the actual result.

Social Problems	Agree	To Some Extent	Don't Agree	Mean	SD	Degree Of Use
Lack Of Awareness	R 67 % 71.3	17 18.1	10 10.6	2.61	0.68	Agree
Lack Of Social Events	R 65 % 69.1	14 14.9	15 16	2.53	0.76	Agree
Hard To Do Certain Social Role	R 38 % 40.4	30 31.9	26 27.7	2.13	0.82	To Some Extent
Hard To Tell Spouse Or groom About the incidence of MS	R 30 % 31.9	22 23.4	42 44.7	1.87	0.87	To Some Extent
Prefer Isolation	R 29 % 30.9	24 25.5	41 43.6	1.87	0.86	To Some Extent
Family Ignorance	R 23 % 24.5	21 22.3	50 53.2	1.71	0.84	To Some Extent
Social Ignorance	R 17 % 18.1	16 17	61 64.9	1.53	0.79	Don't Agree
Grand Average of Mean				2.04		To some extent

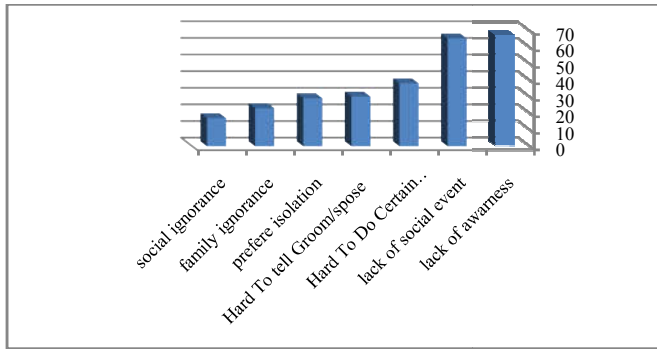


Fig 1 the patient feedback on the main social problems. The figure reflect the response of all the seven variables.

Table 2 the effect of social factors were classified into eight factors. The representation was closed to each other in the (Agree, and not agree) level of effect. There is little increase in the effect of confidence and difficulty to join social events. However the majority of the answer indicate a less effect of social factor on the patient.

Social Problem Impact on MS Patients	Agree	To some extent	Not agree	Mean	SD	Degree of use
Loss of confidence	R 37 % 39.4	R 25 % 26.6	R 32 % 34	2.05	0.86	Agree
Difficult of join social events	R 35 % 37.2	R 29 % 30.9	R 30 % 31.9	2.05	0.83	Agree
Need support of the surroundings	R 33 % 35.1	R 31 % 33	R 30 % 31.9	2.03	0.82	Agree
Dissatisfaction community response	R 33 % 35.1	R 27 % 28.7	R 34 % 36.2	1.99	0.85	Not agree
Marriage life difficulties	R 30 % 31.9	R 18 % 19.1	R 46 % 48.9	1.83	0.89	Not agree
Coping difficulties with community	R 26 % 27.7	R 22 % 23.4	R 46 % 48.9	1.79	0.85	Do not agree
Fear of telling about her condition	R 25 % 26.6	R 21 % 22.3	R 48 % 51.1	1.76	0.85	Do not agree
Increase family conflict	R 24 % 25.5	R 18 % 19.1	R 52 % 55.3	1.7	0.85	Do not agree
Average of mean				1.9		Not agree

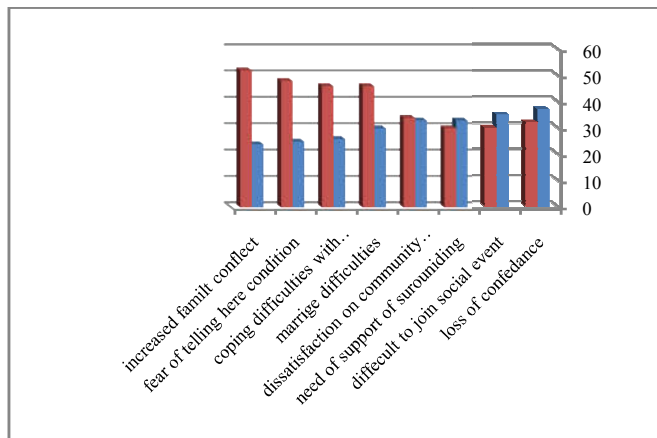


Fig 2 the table below representing the effect of social factors. It is relatively close with indication of less effect on the MS patients. Blue bars indicate the agree and red bars refer to the not agree.

The economic domain was classified into 7 main problems, the most challenging are the lack of role and regulations to support the work related issues (sick leaves, short working hours, absenteeism and work environment modification), as well as the financial compensation policies similar to the other special needs or disabled clients. Almost 70% of the study population is facing a real haling. The need of house made and driver come as second chilling. Many other were highlighted in sequence of importance as addressed in table 3 below.

Table 3 The economic problems addressed in Seven main challenges' arranged from the most important to the lees importance as per the percentage of the answers of the study population.

Economic Problems On MS Patients	Agree	To Some Extent	Not Agree	Mean	SD	Degree Of Use
Lack Of Role And Regulation	R 67 % 71.3	R 11 % 11.7	R 16 % 17	2.54	0.77	Agree
Need House Made	R 59 % 62.8	R 16 % 17	R 19 % 20.2	2.43	0.81	Agree
Need Driver	R 54 % 57.4	R 17 % 18.1	R 23 % 24.5	2.33	0.85	Agree
Increase Of Personal Needs	R 44 % 46.8	R 18 % 19.1	R 32 % 34	2.13	0.89	Agree
Rejection Of Certain Jobs	R 39 % 41.5	R 12 % 12.8	R 43 % 45.7	1.96	0.94	Not Agree
Cannot Pay For Medication	R 24 % 25.5	R 28 % 29.8	R 42 % 44.7	1.81	0.82	Not Agree
Not Declare My Condition When Apply For Job	R 27 % 28.7	R 16 % 17	R 51 % 54.3	1.74	0.88	Not Agree
Grand total of mean				2.13		To Some Extent

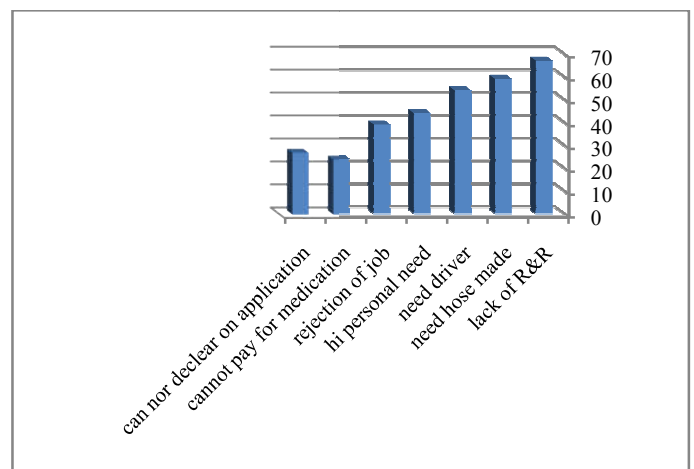


Fig 3 Represent the patients perception on the economic factors.

In the economic domain there are several points that should be considered of high importance. The most chilling is the lack of legislations that support the work related issues. Almost 71% have expressed their suffer from the lack of role and regulation related to MS patient in the work. Another aspects were highlighted in the patient feedback of about 60% which is the need of hose made and driver. Almost 40% of the patient cannot accept any job, particularly jobs of long hours or committed to physical effort.

Table 4 the below table represent the impact of economic domain on the MS patients. It is divided into seven factors. The overall result indicate a serious effect on most of the patients particularly the first three factors. However the 4th factor was almost equal effect. The last three were less effect in most of the patients. The Cortisol hormone blood work was retrospectively reviewed and found little high in the patient with sever financial problems consistent but not significant.

Effect Of Economic Problems On MS Patients		Agree	To Some Extent	Nor Agree	Mean	SD	Degree Of Use
No Financial Support As Other Disabled	R	69	14	11	2.62	0.69	Agree
	%	73.4	14.9	11.7			
Must Work To Gain Income	R	44	16	34	2.11	0.91	Agree
	%	46.8	17	36.2			
Always Think Of How To Financially Survive	R	38	22	34	2.04	0.88	Agree
	%	40.4	23.4	36.2			
My Expenses Increased	R	39	15	40	1.99	0.92	Agree
	%	41.5	16	42.6			
Worry About Economic Survival	R	36	19	39	1.97	0.9	Not Agree
	%	38.3	20.2	41.5			
Hi-Cost Of PT	R	30	14	50	1.79	0.9	Not Agree
	%	31.9	14.9	53.2			
Cannot Get Important Needs	R	23	24	47	1.74	0.83	Not Agree
	%	24.5	25.5	50			
General Average of Mean					2.04		Agree

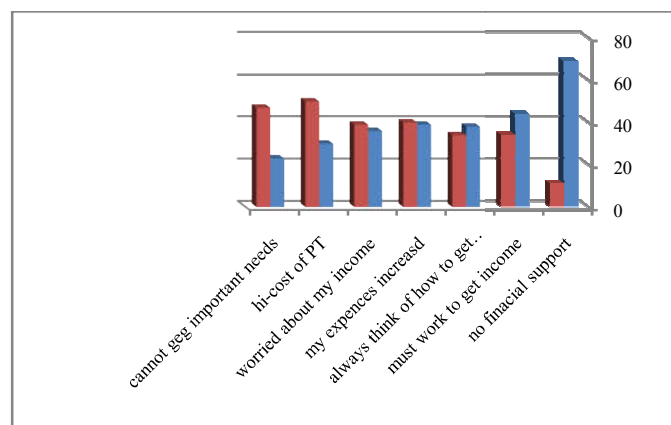


Fig 4 this represent the agree, not agree response for the impact of Economic Domain. Is clear the variance in the first Factor which indicate the serious problem of lack financial support.

DISCUSSION

In this study we used specially designed questionnaire which was tested on Validity and reliability by independent experts. It takes a little time to be filled up and most of the participants find it easy to be filled. The variables in the social and economic domains were selected and defined to answer the real problems and the true impact on patients. This has been trailed before proceeds to the study.

Several studies have confirmed the obvious deterioration of quality of life of MS patient compared with healthy normals also MS was reported to worsen with poor quality of life compared with other diseases, e.g. Diabetes, congestive heart failure and hypertension.¹⁵ Multiple Sclerosis affect the patient in many aspects apart from the main physical illness. The predominant were the psychological status, pain ,social and community isolation.¹⁶

It is obvious that the community is lack the awareness about the MS, consequently the social and the economic impact were directly proportionate with this. The very devastating is the lack of appreciation of the severity of disease effect and the

patient direct physical capacity and the predominantly ADL. Almost 30% of the study sample expressed the difficulties of coping with the family need. Similar percentage were expressed this preference to isolate themselves from others even their closed family or friends.

The social status of MS patients were found connected to the depression, stress as well as other illness which consequently affect the work performance and converted to a psychological status which directly impacted on the family, social functioning. The depression may be corresponding to the pathology changes in the CNS particularly the left fronto-parital lobes.¹⁷

In this study almost 50% of the patients reported moderate to severe depression which correlate with deterioration of patient quality of life. However this study tried to breakdown the social, economic effect into many factors and study each of them through the survey with closed answers of agree, to some extent, and disagree. The result of almost 70% of the study population has reported the lack of awareness about MS and lack of social event for MS patient and families. This reflects The overall effect of social factors was seen limited compared with same factors in the western countries. This may be explained by the fact that almost 90% of the patient are living with their family in a very connected community which in a way or another will provide a reasonable level of support.

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There is a lack of policies to legalized the financial compensation and regulate sick leave, absenteeism and the work duration and the work environment adjustment. Almost 71% were agreed on its importance. Another highly recognized needs are the house made and driver recorded a 63% and 57% respectively. This goes in line with the finding of Hussein A. Algahtani *et al.*¹⁸

The real impact of economic factors on MS patient were assessed and The economic impact is a broad concept that is affected by multiple parameters which immediately reflected on the patient's health status. E.g. Lack financial support compared to other disease or disabilities. Patients must work to secure regular monthly income, a consistent thinking was observed in patient feedback about the financial future. There is an increased in the expenses, and there is a continuous worry about getting the important needs. Collectively these have been recognized as factors associated with poor quality of life in a regression process.¹⁹

The lack of governmental financial support was found a major contributor of economic crisis of 73% of the study population. This is also considered the trigger of most of psychological declining of most of the patients. The level Cortisol hormone in the blood in acute financial crisis was found little high in most of the patients. There is a strong desire of almost 50% of the population to find a job and secure a regular monthly income.

CONCLUSION

Social factors were found less impacted on the Saudi MS patients due to the close connected family and the continuous support they received by their family. Economic factors was found impacted on most of the patients. Cortisol Hormone was found little elevated in patient who suffer critical economic crisis. There may be a relation on the psychological problem such as depression and stress with cortisol hormone and the financial problems. Economic factors are likely to have the stronger effect on most of the patients and may trigger many dark side events on MS patients.

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