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### RESEARCH ARTICLE

#### THE STUDY OF COMMUNITY AWARENESS ABOUT MULTIPLESCLEROSIS.

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##### Key words:-

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system;Knowledge.

#### Abstract

**Objectives:-** Multiple sclerosis (MS) is a chronic inflammatory autoimmune disease, in which the ability of the nervous system to communicate is disturbed. The aim is to describe the awareness and knowledge of the community about types, symptoms & signs of MS.

**Methods:-** A Cross sectional community base study included over three hundred visitors of Granada Center, Panorama Mall, Alqasr Mall and Hayat Mall in Riyadh, Saudi Arabia in 2014. The study population was selected by random sampling, and the Data collection tool was a self-administered questionnaire that contained personal information and measurement of community awareness. After gathering the information; clearance, coding, entry and analysis was done.

**Results:-** 46% of the sample are within the age between 20-30 years old and two third of them are females. 40% have heard about MS, half of them have an average knowledge about it, and know the correct cause. Around 80% of the sample did not attend any awareness campaign, and 50% mentioned that combination method (TV, radio, campaigns) is the best way for awareness. 96% want to know more about MS and 79% preferred to get the awareness from doctors.

**Conclusion:-** The majority of people have limited knowledge about what is MS disease, and they did not attend or see MS awareness campaigns. Almost all people in this study have the desire to know more about MS and they prefer television awareness campaigns and doctors as a source of information.

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#### Introduction:-

Multiple sclerosis is a chronic inflammatory autoimmune disease in which the myelin sheath is affected in the brain and spinal cord. This damage disturbs the ability of the nervous system to communicate, resulting in a wide range of signs and symptoms.

Exactly what causes the immune system to act this way is unclear, but scientists believe that a combination of several factors may be involved. These factors include gender (more common in females than males by 2:1 ratio), genetics, ethnic backgrounds, geography and age.<sup>1</sup>

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It affects 2.5 million people worldwide. It is the most common disabling neurological disease of young adults, appearing mostly at 20 to 40 years old. However, it can also affect children and older people. It also occurs in various regions of the world and in different proportions. It usually occurs in cold more than tropical regions.<sup>2</sup> Although it is a common neurological disease, few people know about it.

The exact cause of MS is unknown but it is considered as an autoimmune disease that affects multiple sections of the brain and spinal cord and this disease has 3 main features:

Destruction of myelin, a fatty insulation covering the nerve fibers, is the main characteristic of MS. The end results of this process "demyelination" are multiple patches of hard, scarred tissue called plaques or lesions. Sclerosis comes from the Greek word skleros, which means hard. Damage of axons; the fibers that carry electric impulses away from a nerve cell, is also a major factor in the permanent disability that occurs with MS. As well as inflammation that is caused by permeability of blood brain barrier to T cell which attacks myelin.<sup>3</sup>

The signs and symptoms of MS can be mild or severe, ranging from disturbance of sensation in the limbs to paralysis and loss of muscle control, vision and balance.

#### **Objectives:-**

To assess the awareness and knowledge of the community about types, signs and symptoms of MS.

#### **Literature review:-**

In a research studying the relation between MS and environmental factors, gender and ethnicity, prevalence of MS; indicates that the rate of the disease has increased steadily during the twentieth century. As with most autoimmune disorders, twice as many women are affected by MS as men. MS is more common in colder climates. People of Northern European descent appear to be at the highest risk for the disease, regardless of where they live. Native American of North and South America, as well as Asian American population, have relatively low rate of MS.<sup>2</sup>

A study done by the Division of Neurology, King Khalid University Hospital, Riyadh, Saudi Arabia. Showed that there are indications of increasing incidence of MS in Saudi Arabia. The symptomatology and site of lesions are similar to that seen in the West, but the course and evolution might be different. The main course was remissions and relapses but without transformation to chronic progressive disease, and the main disability was partial or complete bilateral visual loss.<sup>1</sup>

A study about the relationship of UV exposure to prevalence of MS in England concluded that the regression of MS against UVB intensity for all seasons, while the interaction between IM and UVB seasonal rose.<sup>4</sup>

A study about the relationship of ultraviolet B radiation (UVB) and Epstein-Barr virus (EBV) exposure in explaining the period prevalence of multiple sclerosis (MS) in England, concluded that UVB exposure and IM together can explain a substantial proportion of the variance of MS. The effect of UVB on generating vitamin D seems the most likely candidate for explaining its relationship with MS.

A study about the prevalence of MS in Qatar showed that a positive family history was found in MS patients and Qatar is now a medium-to-high risk area for MS.<sup>5</sup>

Imaging research from Western University (London, Canada) by Ravi Menon, PhD, of the Robarts Research Institute. They found iron deposits in deep gray matter, suggesting that the accumulation occurs very early in the disease course. The scientists found iron deposits in the clinically isolated syndrome (CIS) group were well above the amounts found in the control group. The MRIs also revealed for the first time, subtle damage to the brain's white matter even at this early stage.<sup>6</sup>

The Global Advisory Committee on Vaccine Safety (GACVS) has concluded that there is no association between administration of the hepatitis B vaccine and MS. By 2001, more than 700 cases of central demyelinating diseases with a close match to the natural epidemiologic distribution of MS had been reported to the French authorities, the majority were adult females. No cases were reported among children less than 25 months despite vaccination of 1.8 million babies. The analysis of data from spontaneous reports and results of epidemiological studies do not support a

causal relationship between MS and hepatitis B vaccination. The most likely explanation is a coincidental association.<sup>7</sup>

A study was done about the relationship between headaches and MS concluded that MS patients had tension headaches or vascular headaches of the migraine type; there was no distinctive "MS headache". Headaches did not correlate with any clinical features of MS. The study concludes that an association between headaches and MS may exist.<sup>8</sup>

A study about the high and low risk profile for the development of MS within 10 years after optic neuritis showed that the 10-year risk of MS following an initial episode of acute optic neuritis is significantly higher if there is a single brain MRI lesion; higher numbers of lesions do not appreciably increase that risk. However, even when brain lesions are seen on MRI, more than 40% of the patients will not develop clinical MS after 10 years. In the absence of MRI lesions, certain demographic and clinical features seem to predict a very low likelihood of developing MS. This natural history information is a critical input for estimating a patient's 10-year MS risk and for weighing the benefit of initiating prophylactic treatment at the time of optic neuritis or other initial demyelinating events in the central nervous system.<sup>9</sup>

A study conducted in Norway determined the relationship between tobacco smoking and the risk of developing MS in a general population of 22,312 individuals. A total of 87 individuals reported having developed MS. The study concluded that the risk of MS was higher among smokers than among never-smokers.<sup>10</sup>

Studies in Canada have provided strong evidence that environmental factors act at a population level to influence the unusual geographical distribution of MS. However, the available data accommodate more than one type of environmental effect. Migration studies show that changes to early environment can greatly affect risk, and there are recent indications that risk can be altered in situ. The rising incidence rates of MS in Canada implied by longitudinal increases in sex ratio place this effect in temporal context and narrow the candidates for mediating the effect of environment. Similarly, geographical patterns in Australia imply that modifiable environmental factors hold the key to prevent 80% of cases. Genetic epidemiology provides overwhelming evidence that genetic background has an important complementary role. If genetic factors are held constant, the environment sets the disease threshold. Although these could be independent additive risk factors, it seems more likely that susceptibility is mediated by direct interactions between the environment and genes.<sup>11</sup>

## Methodology:-

We searched the following databases from three hundred and nineteen visitors and workers of the malls, both males and females. The study areas were Granada Center, Panorama Mall, Alqasr Mall and Hayat Mall in Riyadh, Saudi Arabia. The Study design is Cross sectional community based study. The study population was selected by simple random sampling. Data collection tool was a self-administered questionnaire, which contains questions measuring community awareness. After gathering the information; clearance, coding, entry and analysis was done. On Ethical considerations, a verbal consent was obtained from all participants, and all participants answered anonymously.

## Results:-

### Showing research results and discussing them

#### Table 1:-

#### First: Demographic data and characteristics

#### Distribution of the research sample according to the demographic data.

**Table 1:-** shows that (46.1 %) of the sample are within 20-30 years old, (66.5%) are females, the majority are married (48.6%), (83%) finished high school, and (42.6%) are in good financial condition.

Age	Frequency	Percent
< 20	74	23.2
20-29	147	<b>46.1</b>
30-39	56	17.6
>40	42	13.2
Gender		
Male	107	33.5
female	212	<b>66.5</b>

<b>Marital status</b>		
<b>married</b>	155	<b>48.6</b>
<b>single</b>	149	46.7
<b>divorced</b>	10	3.1
<b>widowed</b>	5	1.6
<b>Level of education</b>		
<b>Didn't finish</b>	5	1.6
<b>Primary school</b>	7	2.2
<b>secondary school</b>	39	12.2
<b>High school</b>	264	<b>82.8</b>
<b>College graduate and Postgraduate</b>	4	1.3
<b>Financial condition</b>		
<b>Excellent</b>	101	31.7
<b>Good</b>	136	<b>42.6</b>
<b>Average</b>	78	24.5
<b>Weak</b>	4	1.3

**Table 2:-** Second: The results on the extent of the knowledge about multiple.

<b>knowledge about MS</b>	<b>Frequency</b>	<b>Percent</b>
Yes	125	39.2
No	194	<b>60.8</b>
<b>Level of knowledge</b>		
low	46	36.8
Average	62	<b>49.6</b>
Good	17	13.6
<b>Knowledge about the Cause of illness</b>		
<b>Genetic</b>	38	<b>30.4</b>
<b>Viral</b>	20	<b>16.0</b>
<b>Radiation</b>	21	16.8
<b>Knowledge about the types of MS</b>		
Yes	45	36.0
No	10	8.0
<b>Don't know</b>	70	<b>56.0</b>
<b>Knowledge about signs and symptoms</b>		
<b>Good</b>	17	<b>13.6</b>
Average	43	34.4
Weak	38	30.4
<b>Don't know</b>	27	21.6
<b>Knowledge of how to deal with MS</b>		
Yes	22	<b>17.6</b>
No	103	82.4
<b>Knowledge of ways to prevent MS</b>		
Yes	29	<b>23.2</b>
No	23	18.4
<b>Don't know</b>	73	58.4
<b>knowledge of the outcome of MS</b>		
Yes	21	16.8
No	53	<b>42.4</b>
<b>Don't know</b>	51	40.8
<b>Knowledge of cure from MS</b>		
Yes	29	<b>23.2</b>
No	40	32.0
<b>Don't know</b>	56	44.8

Table (2) shows that (60%) have never heard of MS and (50%) have an average knowledge about it. (46%) Mentioned the correct answer that MS is because of genetics and viral cause, and about one third (36%) of the sample know the correct answer of the types of the disease, (13.6%) have a good knowledge about the signs and symptoms of MS, and only (17%) of the sample knows how to deal with MS. 23% Mentioned that MS can be prevented, and only (23%) mentioned that MS can be cured (42%) of the sample did not know if MS is fatal or not.

**Table 3:-** Third: The extent of awareness of study population regarding multiple sclerosis.

<b>Attended awareness campaigns about MS</b>	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	21	16.8
<b>No</b>	104	<b>83.2</b>
<b>Best way to raise awareness about MS</b>		
<b>Television</b>	30	24.0
<b>Radio</b>	3	2.4
<b>Campaigns</b>	28	22.4
<b>All of the above</b>	61	<b>48.8</b>
<b>Other</b>	3	2.4
<b>Source of awareness</b>		
<b>Doctor</b>	98	<b>78.4</b>
<b>Nurse</b>	5	4.0
<b>Patient</b>	22	17.6
<b>Desire to know more about MS</b>		
<b>Yes</b>	120	<b>96.0</b>
<b>No</b>	5	4.0

Table (3) shows that (83.2%) of the sample did not attend any awareness campaign, and (49%) mentioned that combination method (TV, radio, campaigns) is the best way for awareness although only (2%) mention radio. (96%) Wants to know more about MS and (79%) preferred the doctors as source of awareness.

### **Discussion:-**

In this study of public awareness regarding MS, the majority has no knowledge about the disease; this is a clear evidence of low awareness in the community. Where the majority emphasized that they did not attend any awareness campaigns about MS.

The majority of the sample has a good knowledge about the causes of the disease, as they mentioned the correct answer which is genetic and viral. Genetic cause of MS is supported by a study in Qatar that showed a positive family history in MS patients, and by another study in the United States showed that almost all patients with MS have a viral antigen.<sup>5,12</sup>

This study also suggests that the majority of the sample has no knowledge about MS types. But one third of the sample know that there are types of MS which is correct as there are four types of the Disease according to a study was done about MS types (All About MS) in America, 2002.<sup>13</sup>

The study also indicates that the majority of the sample has low knowledge of how to deal with MS patients. A survey of MS perceived cognitive problems and compensatory strategy use in Canada, showed that there was a high prevalence of spontaneous utilization of strategies to deal with cognitive difficulties. The most common strategy was the use of an external memory aid (e.g., note pad). This low knowledge might be due to the low awareness in signs, symptoms and causes of the disease.<sup>14</sup>

One third of the study's target population has medium level knowledge about the signs and symptoms of MS. A study in the United States about the worst symptoms, showed that it mostly was fatigue then pain and the least being dizziness. Another study said that the signs and symptoms range from those that command the immediate attention of patient and doctor to those that escape the attention of patient and family over the course of a lifetime.<sup>15,16</sup>

The majority of study population chose the correct answer that MS cannot be cured, this agrees with what Dr. Gray said "Unfortunately, there are currently no effective disease modifying therapies that people with progressive MS can take to slow, stop or reverse accumulation of disability". Disease modifying drugs (DMDs) in the form of tablets or injections can be used to reduce frequency and severity of symptoms for people with MS relapses. So far, most MS DMDs must be injected or administered intravenously. The newest drug, Gilenya (fingolimod), approved by the FDA in 2010, is the first disease-modifying MS drug that can be taken orally.<sup>17,18</sup>

About a quarter of the population chose the correct answer that MS can be prevented, when a geographical pattern in Australia implies that modifiable environmental factors hold the key to prevent 80% of cases.<sup>11</sup>

In the study almost half of the sample did not know the answer that MS is rarely fatal.<sup>19</sup>

The majority of the sample supports that TV is the best way to raise awareness about MS and clearly about any other medical issue. This finding supports the result of a study that was done about (Mass media and smoking cessation) which concluded that media awareness campaigns and programs produced a change in the awareness.<sup>20</sup>

This study result showed that the majority of people trust counseling a doctor about any information they need in regard to MS or other medical issues. This result supports the one of a study titled (Exploration of the relationship between continuity, trust in regular doctors and patient satisfaction with consultations with family doctors) that concluded that the majority of people consult their doctors about any health issue, with the trust being the strongest influence.<sup>21</sup>

### **Conclusion:-**

In regard to measuring knowledge of people about MS it was found that the majority of people have no idea about what is MS disease, and the level of knowledge in general was average. Specifying the knowledge about the cause of multiple sclerosis, the majority of people think it is genetic in nature. Regarding the knowledge if MS has types or not, the greatest proportion of people agrees that MS has different types. As to having information about dealing with MS patients, the majority was found to lack any knowledge about this aspect. Coming to the sign and symptoms of MS and the extent of people's knowledge about them, the majority of people were average. Regarding the cure and the prevention approach of MS, the majority of people do not know if it is curable or preventable. Asking about the knowledge of whether MS is fatal or not, the greatest number of people answered with no.

In respect to the awareness of people about MS, the majority of people mentioned that they did not attend or see MS awareness campaigns. The majority of people prefer television awareness campaigns and doctors as a source of information.

Finally, almost all people in this study have the desire to know more about MS.

### **Recommendations:-**

1. According to the discussion, we recommend increasing awareness media campaigns regarding MS, recruiting in it some of the specialized doctors.
2. Increase the public awareness by activating the awareness programs using different methods, such as social media, TV, published brochures, and newspapers.
3. Increase the number of researches about MS around the world.
4. Develop support groups for MS patients, so they can benefit from each other's experiences.

### **Acknowledgment:-**

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## Questioners

## Awareness of People Regarding Multiple Sclerosis

- 1- Name (optional):
- 2- Age:
- 3- Gender:  
Female Male
- 4- Marital status:  
Married Single Divorced
- 5- Education Level:  
Elementary Intermediate Secondary Academic Postgraduate
- 6- Financial status:  
Very good Good Medium Bad
- 7- Have you heard about multiple sclerosis:  
Yes No
- 8- What is the level of your knowledge about the disease:  
High Medium Low
- 9- Do you think the cause of the disease is:  
Radiological Viral Bacterial Hereditary Other
- 10- Do you know the types of this disease:  
Yes No
- 11- What is the level of your knowledge about signs and symptoms of this disease:  
High Medium Low
- 12- Do you know someone who has this disease:  
Yes No
- 13- Do you know how to deal with this disease:  
Yes No
- 14- Do you think that there is protection from this disease:  
Yes No
- 15- Do you think that this disease is curable:  
Yes No
- 16- Do you consider multiple sclerosis lethal:  
Yes No
- 17- Have you ever watched awareness campaigns about the disease:  
Yes No
- 18- What do you prefer to be a raising awareness of the disease:  
TV Radio Campaigns
- 19- From whom do you prefer to be raising awareness:  
Patient Nurse Doctor
- 20- Would you like to know more about the disease after this survey:  
Yes No