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Information Needs for People with MS A study of the Information Needs of MS Patients in the Gulf Region

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Introduction:

Multiple Sclerosis (MS) is a neurological chronic disease with unpredictable course. Although it was first identified in the 1860s, the cause of MS remains in dispute and a cure is elusive. MS, characterized with attacks and remissions, damages the insulation or myelin sheath that surrounds the nerve fibers in the central nervous system (the brain and the spinal cord). When the sheath is destroyed, hardened plaques of varying sizes form and cause a slowing or complete obstruction of the nerve impulses, something that might eventually lead to partial or complete disability. MS strikes women more than men (ratio is around 2:1) and affects adults between 20-40. Although no exact figures are available. MS affects approximately 250-300,000 in the Unites States alone and about 85,000 in the UK. In spite of the fact that MS is predominant among white women living in colder climates, typically the States and Europe, it became more common in other parts of the world in recent years including the Middle East.

Patients and Information Needs:

There have been very few studies about the information needs for patients. Most of these studies have focused on patients information needs from the perspective of physicians and clinicians, as well as patients information seeking behavior when communicating with doctors.

One of the most recent studies to tackle these issues is the one undertaken by Tang and others (Tang, 2004). The authors examined patients' information needs from the perspective of clinicians, educational software vendors, and patients. The study points out that among the changes in health care is the recognition of patients' role in their health management. Among the many changes occurring in healthcare is an increasing recognition of the patients' role in their health management. As the notion of shared decision-making between the patient and the provider gains acceptance, the need to understand patients' information needs becomes essential. It was clear

that the patients who participated in the survey seek more information about their health and that the information should be tailored to their specific clinical condition.

In another study focusing on doctors patients communication, Daltroy reports that patients desire more information than they receive (Daltroy, 1993). Furthermore, the literature reports that the patients need for information is generally underestimated by physicians. (Beisecker, 1990) and that shared decision-making has been linked to improved outcomes.

MS Patients and Information Seeking behavior:

Information plays a vital role for people with MS. The nature of the disease the long lasting symptoms and the effects it has on the patients make it essential to keep the patients informed in order to help them overcome some of the suffering they go through.

Woolin points out that newly diagnosed MS patients need “ *accurate, timely, relevant information to take control of their health and life style decisions. Lack of this knowledge further handicaps patients.* ” (Woolin, 2000)

The information needs concept could be defined by as follows:

- Data, information and knowledge that helps the MS patients cope with situations and can lead to more effective management of the condition and improved quality of life.
- Information needs are associated with immediate as well as long-term situations, for example: diagnosis; the onset of a new symptom; the need to acquire a mobility aid or a state benefit; dealing with incontinence or maintaining a positive state of mind.
- Information needs include both stated needs and those which may not be stated or are unrecognized by the individual.

People with MS need to make long term information-based decisions about their illness. When people are affected by a chronic disease they seek information to fill gaps in their knowledge or understanding, to solve a problem or make informed decisions. Dervin states that “ *people seek information when they realize that there are gaps in their knowledge which prevent them from making sense of the situation* ” (Dervin, 1983)

Crisp points out that patients information seeking behaviors represent an attempt to maintain some control over their lives, which is vital for people with long term disability or illness. According to Baker (Baker, 1995) information seeking occurs when a particular situation arises, prompting them to recall what they know about a subject. When the retrieved information is not adequate for handling the new situation, a gap is identified and the person finds some way of increasing her/his knowledge in order to bridge the gap (Crisp, 1992).

However, studies about MS have shown that in addition to having various information needs, MS patients might as well have conflicting information seeking behaviors. Baker (Baker, 1995) states that each person's response is likely to be either information-seeking or information-blocking. The variation in information-blocking behaviors may be from fear of the unknown, fear of discovering distressing information, or it might be from fear of frightening oneself. Gulick (Gulick, 1994) reveals that once many patients realized there was no known cause or cure for MS, they believed that more information could do little to alter their situation. As the condition progresses, however, they developed new informational needs in response to either to new symptoms or to progressive deterioration of current ones.

Categorization of Information related to MS:

In an attempt to categorize information related to MS, Hepworth suggested two information categories : 'information about MS' and 'information that helps the person with MS interact with the world around them'. (Hepworth, 2002)

These two categories were further divided as follows:

1) Information about MS:

- MS, a general explanation
- MS research trials
- drug treatments
- symptoms
- prognosis
- treatment and management of symptoms
- physiotherapy
- complementary therapy
- nutritional advice
- health and fitness
- emotional changes

2) Information that helps the person with MS interact with the world around Them.:

- service providers (health service, social service, benefits agency, voluntary organizations)
- support groups
- aids and appliances
- facilities for the disabled
- MS and work and the issues associated with giving up work
- communicating about MS with family, friends, colleagues and the public
- leisure activities including, when necessary, provision for the disabled

Previous Research:

The literature dealing with information needs of patients with MS is rather scarce. As Hepworth notes earlier research tends to be general and does not attempt to comprehensively identify and categorize the information needs of MS

patients.(Hepworth, 2002) Almost all the previous research has dealt with information needs of MS patients in the United States and the UK. No research has been conducted to investigate those needs in the Arab world in general or the Arabian Gulf region in particular.

Although there are a common ground as regards wit information needs for all MS patients, however, the cultural, social as well as informational factors should be taken into consideration when considering those needs.

In 1987 Matson and Brooks studied patients with MS in the United States to determine how they had adjusted to the condition since diagnosis. They concluded that most adjustment takes place in the first ten years after diagnosis. Based on their findings they proposed a four-stage model of adjustment to MS, in which information plays a role. Stage 1 (denial stage) which newly diagnosed patients enter immediately. Here they sought information through different medical channels in an attempt to dispute the diagnosis. When people acknowledge the possibility of having MS they enter stage 2 (resistance stage) where they anxiously sought information about the condition and a cure. Patients also turned to others with the same condition and participated in groups or classes to garner any information that might be helpful. Stage 3 involved telling other people about MS (telling stage) . Stage 4 (acceptance stage) began when a person had fully accepted the condition. (Brooks, 1987)

Matson and Brooks stated that information given by the consultant was seen as inadequate, perhaps because patients desired life-encompassing direction, which might be beyond the knowledge of the individual consultant. Most PWMS wanted practical information that would help them live with their condition. To find this information they used a variety of sources, with varying degrees of success.

Stewart and Sullivan, found that information seeking activity starts in the pre-diagnosis period and continues until a diagnosis of MS is confirmed. They also found that, because symptoms could be fleeting and might vary from one exacerbation (attack) to another, people engaged in physician shopping' until they found a doctor who could diagnose their condition. People also sought information from popular literature and medical texts, as well as from health professionals, family and friends.(Stewart, 1982)

Brooks and Matson noted that in the post-diagnostic period, people with MS wanted practical information to help them live with their condition and sought information from other people with MS. . (Brooks, 1987)

In 1996, Robinson, Hunter and Neilson conducted a qualitative study of the needs of patients with MS in the UK. Part of this study concerned information. They found that appropriate information was hard to find and use and that it was not available when and where they were needed. Examples of the information needs that were identified included:

- Information on the condition itself

- Symptoms and managing symptoms
- Current research
- Benefits and entitlements
- Transport for the disabled
- Medical and complementary therapies
- Social and support groups
- Employment and statutory rights advice
- Home adaptations and aids (Robinson, 1996)

Baker undertook a study of people who had recently undergone a severe exacerbation of MS. This study involved a questionnaire survey of 260 women. The results helped to identify categories of information need. Categories of information need included:

- Physiological (general information about MS, nutritional literature, fatigue, bowel and bladder disturbances etc.);
- Psychological (dealing with a hidden disability, emotional behavior, spiritual material etc.);
- Social (education, support for family members, branches for women etc.);
- Economic (insurance, employer relations etc.). (Baker, 1997)

Baker revealed gaps in people's knowledge about physical symptoms MS patients were experiencing, emotions they felt, and drugs that could be used. Various sources of and barriers to obtaining information were identified. The results also suggested that health professionals needed to be aware of the continuing need for relevant, current and specific information to help PWMS retain their independence and to enable them to make informed decisions.

In another study Baker (Baker, 1994) also found that people tended to fall into the category of either 'monitors' or 'blunters', that is, people 'either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety'.

In a recent review of health care preferences of people with MS in the UK, Somerset (Somerset, 2000) found that three quarters of the people surveyed reported lacking advice about at least one MS related issue and 17% lacked advice in five areas. The most frequently consulted health professional was the GP followed by the hospital consultant. The professional that most people said they would have liked to see, however, was a MS specialist nurse. The study concluded that people with MS displayed a wide variation in their unmet needs, and that information about MS management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be components of high quality care.

A very comprehensive study investigating the information needs of MS patients in the UK was undertaken by Hepworth and others. (Hepworth, 2002). More than 2000

patients were surveyed. The study revealed various information needs for people with MS, it has also made recommendations as concerning targeted information provision, the character of information provision as well as the contents of information provided. The results of this study helped to identify categories of information needed and contributed to the questionnaire design in the current study.

The literature does, therefore, provide some insight into the information needs of MS patients, their information seeking behavior and information provision. The needs can be seen to be broad and patients might not be successful in satisfying them.

Woolin suggests that the literature about MS stated that not only do patients have various information needs, but each person's response is likely to be either information-seeking or information-blocking. (Woolin, 2000)

Aim And Purpose:

This study aims at investigating information needs of MS patients in the Gulf region as represented by sample in the State of Qatar where social cultural as well as medical circumstances are very similar.

The purpose of this study was to answer the following questions:

- What are the information needs of MS patients in the Gulf region ?
- What are the main sources of information about MS ?
- What information needs are considered more important than others ?
- what are the information that are considered difficult to get ?
- How do MS patients like to get this information ?
- What are the problems associated with getting information related to MS ?
- How is the internet used as a source of information about MS ?

Methodology:

A quantitative method was used for the purpose of this study. A survey instrument was developed in the form of a questionnaire . The questionnaire included closed ended type questions aiming at gathering information regarding the following aspects:

- Personal data (gender- age - job condition)
- History of diagnosis (source – type of information offered at time of diagnosis – information liked to be offered)
- Level of difficulty as regards to acquiring information
- Importance of various types of information
- Preferred sources of information
- The use of the internet as a source of information

In addition to the closed ended questions covering with the aspects mentioned above, an open ended type question was introduced giving the respondents a chance to express their opinion freely as well as making recommendations and suggestions. (An example of the questionnaire is attached as Appendix 1)

Distribution of questionnaire:

A total of 30 questionnaires were distributed among a purposive non-random sample of MS patients in Hamad Medical Corporation , the official government hospital in the city of Doha the capital of Qatar, which is the only MS therapy center in the country.

The response rate to the questionnaire was relatively high , 20 questionnaires were returned representing a rate of 66%.

Discussion:

In the following paragraphs an analysis of the questionnaire results will be provided. This analysis covers the main aspects covered by the questionnaire as indicated earlier in the study.

- **Gender, Age Group and Diagnosis**

Table (1) Gender, age groups and diagnosis

Personal Data		Gender		Total	%
		F	M		
Number of respondents		16	4	20	100
Age Group					
10-19		4	0	4	20
20-29		0	0	0	0
30-39		7	2	9	45
40-49		5	2	7	35
50+		0	0	0	0
year of first symptoms	1996	3	0	3	15
	1997	0	1	1	5
	1998	1	1	2	10
	1999	0	0	0	0
	2000	6	2	8	40

	2001	2	0	2	10
	2003	4	0	4	20
	2004	0	0	0	0
year of diagnosis	1996	0	0	0	0
	1997	2	0	2	10
	1998	1	2	3	15
	1999	0	0	0	0
	2000	0	0	0	0
	2001	4	2	6	30
	2003	4	0	4	20
	2004	4	0	4	20
Full time employment		12	2	14	70
Effect of MS on employment status		0	0	0	0

As shown in table (1) the respondents comprised 16 females and 4 males, a figure that was anticipated considering the ratio between MS female and male patients. As regards to age groups, patients between 30-39 years of age represented 45% of the respondents followed by people between 40-49 years of age constituting 35%. The majority (55%) of all respondents have been diagnosed with MS at least 4 years ago, it also matches up with the fact that MS targets people between 20-40 years of age.

Asked about the date of first symptoms of MS as well as the year in which they were diagnosed, respondents' answers varied as shown in table (1). It was indicated that 60% of the respondents had their first symptoms between 1990-2001. The attempt to correlate the year of having first symptoms and the date of diagnosis showed that the vast majority of correspondents indicated that there was a time gap between the two. Needless to say, there was a considerable lack of information about their condition as diagnosis was not made until a later stage. There were only two cases, however, that were diagnosed at in the same year in which they had their first symptoms.

Concerning the affect of MS on their employment status, all of the respondents indicated that it didn't affect their jobs up till now. However, it should be noted here that 30% of the respondents are unemployed.

▪ **Diagnosis source and types of information offered at time of diagnosis:**

Table (2) sources of information at diagnosis

Sources of Diagnosis	Gender		Total	%
	F	M		
Neurology Consultant	7	1	8	40
Hospital Doctor	8	4	12	60
Medical Center Doctor	0	0	0	0
Other	0	0	20	0

Asked about who did they rely on in making the first diagnosis, 12 patients reported that they were diagnosed by a hospital doctor while 8 patients only were diagnosed by the neurology consultant. This is a common practice as patients do not normally seek the advice of the neurologist unless they were referred to by a GP.

▪ **Nature of Information provided at time of Diagnosis:**

One of the crucial aspects included in the questionnaire is the type of information offered to the patients at the time of the diagnosis. It was apparent that responses varied according to many factors i.e. when the diagnosis took place ? and who made it ? Respondents who were diagnosed by the consultant neurologist received more information than those diagnosed by general practitioner or any other doctor. This is not uncommon considering the background and expertise usually available to the neurologist.

Table (3) Categories of information provided

Information Provided	Gender		Total	%
	F	M		
Possible MS symptoms	16	4	20	100
Disease course	7	1	8	40
Diet	6	2	8	40
Available treatment	9	3	12	60
Benefits and entitlements	4	0	4	20
Insurance	0	0	0	0
Exercise	6	2	8	40
Psychological symptoms	7	1	8	40
Information for family members	3	1	4	20
Societies and support groups	0	0	0	0

As illustrated in Table 3, there was a consensus (100%) , however, among the respondents that they were offered information regarding possible MS symptoms that lie ahead. The second category of information related to the available treatment as was reported by 60%of respondents. This kind of information is not uncommon with a patient who is encountered with a chronic disease and has a lot of anxiety as regards to the expected symptoms of such a disease as well as the possible treatment. 40% indicated that they were offered information associated with the course of the disease, diet, exercise and physiological symptoms of MS, these have scored 40% of the total each. The lowest ranked type of information was related to information given to family members and the benefits for patients. This could be attributed to some cultural factors which do not pay much attention to spreading the information to those surrounding the patient. The lowest rank is associated to information

related to societies and support group, and indication of the noticeable lack of such societies in the developing countries in general and the Arab world in particular.

▪ **Information liked to be offered at the time of Diagnosis:**

Concerning the information liked to be offered at the time of diagnosis from the patients perspective, apart from their opinion about information regarding support groups and family members, there was no noticeable variations in results (table 4) as compared to the information provision at the time of diagnosis. MS symptoms and the course of the disease ranked first with 100% each, followed by information about societies and support groups. Information to family members with 95%, 65% of respondents indicated that they would have liked information linked to diet and psychological symptoms. Little interest has been shown in information associated to benefits, entitlement and insurance. This can attributed to the fact that all Qatari patients are treated and given medications free of charge.

Table (4) Information liked to be offered

Information Provided	Total	%
Possible MS symptoms	20	100
Disease course	20	100
Diet	13	65
Available treatment	20	100
Benefits and entitlements	9	45
Insurance	8	40
Exercise	11	55
Psychological symptoms	12	60
Information for family members	13	65
Societies and support groups	19	95

▪ **Sources of Information :**

Table (5) Information liked to be offered

Information Provided	Total	%
Neurology consultant	20	100
Neurology nurse	0	0
GP	0	0
Private Doctor	0	0
Family	0	0
Friends	0	0
Pharmacist	0	0
Other MS patients	8	40

Library	0	0
Internet	4	20

Table (5) shows the all respondents identified neurology consultants as their primary source of information about MS. Chronic diseases such as MS needs constant and regular interactions between patients and their neurologists. The second source of information identified by 40% of respondents was other MS patients indicating the confidence the patients have in their peers. From a patient's perspective, other patients are excellent source of information given the fact that they have been through very similar disease course, something that MS patients in particular find very hard to explain to the others. Information about symptoms and treatment represent the most required by MS patients from their peers. The third source of information was the internet, however it didn't represent more than 20% of the respondents. Other possible sources of information such as private doctors, friends pharmacists and family did not seem to play a vital role in this regard.

- **Level of Difficulty in Acquiring Information about Various MS Aspects:**

Table (6) Level of Difficulty in Acquiring Information

Information	Very Difficult	Difficult	Slightly Difficult	Not at all Difficult	Not Important
Treatment methods	0	7	0	13	0
Drug treatment	0	0	5	15	0
Expenses & Insurance	12	0	8	0	0
Research trials	8	8	0	4	0
Psychological affects	8	0	8	4	0
General information about the condition	7	0	6	7	0
Chronic symptoms	0	8	12	0	0
Temporary symptoms	0	9	7	0	4
Copying with MS	0	8	12	0	0
Information for family	0	8	4	8	0
Exercise	4	4	8	0	4
Diet and nutrition	4	4	8	0	4
Aids	3	5	4	4	4
Professional Associations	9	4	4	3	0
MS effect on employment	0	4	4	4	8

Asked about the most difficult information to get, patients indicated that information regarding new research trials for MS medication as well as professional associations are equally difficult to find. Since research trials are normally reported by physicians and/or drug manufacturers, either in scientific journals or on MS related sites on the Internet; and given the fact that a large proportion of the respondents do not refer to

these journals or the internet as a primary source of information, it is quite comprehensible why this information is difficult to obtain.. As regards to information about professional associations, it has to be noted that the number of such associations in the Arab world is almost zero. Information about insurance and expenses are very rare for the very same reason mentioned earlier. About 80% of the respondents suggested that information associated with chronic, temporary and psychological symptoms of the disease is hard to find. Naturally, that will be affected by their information seeking behavior as well as their sources of information. Most of the respondents who talk to other MS patients have a better chance to obtain this particular piece of information than those who do not. Information about exercise, diet followed by the affect that MS has on job status are reported to be the least difficult information to locate.

- **The Most Important types of information as perceived by respondents:**

Table (7) The Most Important types of information

Information	Not important	Slightly importance	Important	Very important
Treatment methods	0	0	3	17
Drug treatment	0	0	8	12
Expenses & Insurance	2	2	8	8
Research trials	0	0	4	16
Psychological affects	0	0	12	8
General information about the condition	0	0	12	8
Chronic symptoms	0	0	13	7
Temporary symptoms	0	0	12	8
Copying with MS	0	0	20	0
Information for family	0	0	18	2
Exercise	8	12	0	0
Diet and nutrition	0	12	0	8
Aids	0	4	16	0
Professional Associations	0	4	8	8
Support groups	0	2	10	8
MS effect on employment	10	4	6	0

Respondents were asked to determine how different information categories related to MS are important to them. There was an agreement among a large portion of the patients that most of these categories are important. Treatment methods, drugs, research trials, general information about the disease and chronic and temporary symptoms have gained the highest percentage among the others, each scored 100% when considering the two responses (important and very important) together. When asked about the importance of information about exercise and nutrition, respondents indicated that it is of a little importance. It is worth mentioning in this context that

this opinion reflects a wide spread culture in the region that any disease is treated solely by drugs, nutrition, diet and exercise are not normally play a vital role in treatment, although these are very crucial in the treatment of MS in particular.

The least important information, as indicated by the respondents, was that related to the impact of MS on employment. This could be attributed to the fact that most of patients affected by MS are females. In Arab societies women are not so much concerned with employment as ,generally, they are not the main supporters of the family.

- **The preferred method/source of delivering information related to the condition itself i.e. Symptoms, Treatment- MS course- Coping with MS- Nutrition- Exercise- Physiological impact.**

Table (8) The Preferred Method of Delivering Information (Condition itself)

Information	Preference		
	Most preferred	Preferred	Not Preferred
Direct contact (face to face)	14	6	0
Telephone	0	12	8
Books	6	0	14
Medical pamphlets	8	8	4
Magazines	8	8	4
Video tapes	0	12	8
Audio tapes	0	12	8
CDs	0	4	16
E-mail	5	8	7
Internet	12	8	0

Respondents were asked about their preferred method to deliver information from their own perspective. They were first questioned about information sources linked to MS itself as a condition and related aspects such as treatment, symptoms and nutrition. Face to face is seen by the vast majority as the most preferred way in delivering information about MS. It is assumed that face to face here is doctor/patient communication, where patients would pose many questions regarding their condition. It has been noticed, however, that this method is preferred by those patients who are newly diagnosed , 60% of the newly diagnosed patients do prefer verbal communication with doctors in an attempt to overcome the anxiety common in the early stages of the disease.

The internet is considered a very important source of information as indicated by the respondents. 60% of the patients consider the internet their favorite source on MS information while 40% consider it important but with a lesser degree. This finding

doesn't mean that all respondents do use the internet , this issue will be discussed when analyzing the use of the internet as source of information about MS.

In addition, as shown in table (8) MS patients don't tend to rely on printed material such as books and magazines, underestimating the role of libraries and information centers in this regard. This applies to audio-visual resources as well. However, patients showed some interest in medical pamphlets as preferred source of information. It should be noted that these pamphlets normally come with drugs and they are smaller in size compared to other printed materials.

- **The preferred method/source of delivering information related to some other MS aspects i.e. Insurance – Research trials- Associations- Support groups- Medical aids- Employment)**

**Table (9)The Preferred Method of Delivering Information
(Other MS aspects)**

Information	Preference		
	Most preferred	Preferred	Not Preferred
Direct contact (face to face)	18	2	0
Telephone	0	17	3
Books	3	15	2
Medical pamphlets	8	8	4
Magazines	7	6	7
Video tapes	0	8	12
Audio tapes	0	6	14
CDs	0	0	20
E-mail	0	6	14
Internet	12	0	8

The second category of information patients were asked about was information linked to MS related aspects such as research trials, support groups and medical aids. When comparing these results shown in table (9) with those in table (8) it is obvious that face to face contact remains the most preferred method for delivering information to MS patients. However, books appeared to play a more essential role as a source of information. This could be attributed to the nature of information required in this context.

- **Frequency of information seeking :**

Table (10) Frequency of Information Seeking

Frequency	Respondents	%
1-3 months	16	80
4-6 months	2	10
More than 6 months	2	10

Table (10) shows the frequency of information seeking for the respondents. It was apparent that the vast majority 80% of the respondents do search for information at least once every 3 months. Very few respondents, 20% seek information less frequent. It is worth mentioning in this context that these results tone with the fact most of the respondents have been diagnosed in the last 4 years, something that dictates information seeking on regular basis in attempt to acquire the necessary information to cope with the condition.

- **Use of the Internet as an information source**

Respondents were requested to indicate whether they use the internet as a source of information about MS. 75% of the respondents did use the internet.

- **Web sites visited by respondents using the Internet**

Table (11) Web pages visited by MS Patients

Website	Number of Respondents
MS condition	15
Drug manufacturers	8
Associations & Societies	0
Patients	1
Others	0

When asked to specify the most visited web sites, 75% of the respondents reported that they visited sites dealing with MS and related topics, while 40% indicated that they checked sites linked with drug manufacturers, these sites not only give information about the effectiveness of a given drug or instructions to use it, but also the provide information about trials for new drugs by the same manufacturer as well as some useful information for MS patients. Not a single respondent indicated that he/she has visited sites related to associations and societies which are dedicated to MS. The lack of information about these societies as well as the noticeable shortage of these societies in the region contribute to a large extent to this result. All MS associations and societies do exist either in the US or Europe, up till now there is no Arab association to cater for the needs of MS patients in the Arab world.

It should be noted in this context that these associations provide valuable information for MS patients. In addition to offering information about MS, its symptoms and available treatment, they usually provide information about current

research, publications, useful information to family members and most of these sites have chat rooms for MS where they can discuss issues of common interest.

- **Value of information found on the Internet**

70% of internet users found the information provided by these sites very useful, while 30% described it as useful.

- **Obstacles of Internet use:**

Table (12) Obstacles of Using the Internet

Obstacle	Number of Respondents
Lack of computer skills	2
Language (English) barrier	16
Absence of Arab websites	15
Others	1

Table (12) shows than main obstacles of using the internet identified by respondent. It is evident from the results shown that there are 2 main obstacles that are very closely related, the lack of English language skills(80%) and the absence of any Arabic sites dealing with MS on the internet (75%). Unless physicians and health care agencies and support groups begin to initiate MS Arab web sites this issue will remain unresolved.

General Findings:

- This study aimed at exploring information needs of MS patients in the gulf region as represented by a sample of patients in the State of Qatar.
- A questionnaire was developed as the main tool for this study. The questionnaire was distributed to 30 MS patients, 20 responses were received.
- The main results emerged from this study could be summarized as follows:

- The respondents comprised 14 females and 6 males. . As regards to age groups, patients between 30-39 years of age represented 45% of the respondents followed by people between 40-49 years of age constituting 35%
- It was indicated that 60% of the respondents had their first symptoms between 1990-200, 12 patients reported that they were diagnosed by a hospital doctor while 8 patients only were diagnosed by the neurology consultant
- Concerning the affect of MS on their employment status, all of the respondents indicated that it didn't affect their jobs
- There was a consensus among the respondents that they were offered information regarding possible MS symptoms that lie ahead. The second category of information related to the available treatment.
- Concerning the information liked to be offered at the time of diagnosis MS symptoms and the course of the disease ranked first , followed by information about societies and support groups. Information to family members, diet and psychological symptoms. Ranked third. Little interest has been shown in information associated to benefits
- All respondents identified neurology consultants as their primary source of information about MS. The second source of information identified by respondents was other MS patients. The third source of information was the internet
- Regarding the most difficult information to get, patients indicated that information related to new research trials for MS medication as well as professional associations are difficult to find.
- There was an agreement among a large portion of the patients that treatment methods, drugs, research trials, general information about the disease and chronic and temporary symptoms are the most important information.
- The preferred method to deliver information about MS from the respondents own perspective was face to face.
- The majority , 80%, of the respondents do search for information at least once every 3 months. Very few respondents, 20% seek information less frequent
- Concerning the use of the internet as an information source about MS, 75% of the respondents did use the internet. 75% of the respondents reported that they visited sites dealing with MS and related topics, while 40% indicated that they checked sites linked with drug manufacturers

○ There are 2 main obstacles that are very closely related, the lack of English language skills(80%) and the absence of any Arabic sites dealing with MS on the internet (75%)

Recommendations:

- Since information about MS is very important not only to patients but to all those involved with MS, it is recommended that information about MS should be available to various categories : patients, service providers, family members as well as the general public in the Gulf region.
- Arab physicians should be well aware of the information needed by MS patients, especially at the time of diagnosis. Also, a clear distinction should be made between this immediate needs at time of diagnosis and long term ones.
- Information related to MS and all related aspects should be provided to patients. The most important information categories are: dealing with MS, drugs and treatment, physical and psychological symptoms, MS research trials, support groups. More effort, however, should be spent to provide more information about diet and nutrition as well as exercise.
- There is an urgent need to establish professional associations on national level in Qatar as well as on regional level in the Gulf to serve MS patients. These associations would play a vital role in the provision of MS related information, they would also facilitate access to other MS patients who have many things in common. MS society in the United States and the MS trust in the UK are good examples to follow.
- Information provision to MS patients should cater for different and individual needs of those patients. It is evident that each MS patient has a different need for information based on his/her condition, duration of having MS, age group, level of disability. Information provision should also cater for cultural as well as social characteristics of the Arabian society.
- Information about MS should be provided in an effective way of communication considering the patient condition and the type of information offered. More emphasis, however, should be put on face-to-face communication.
- Libraries, especially academic, as well as other information centers should take the necessary steps towards the provision of information services to chronic diseases patients in general and MS patients in particular
- Ms Arabic web sites are urgently needed. It was evident that the vast majority of the patients did not use the internet due to the noticeable lack of these sites on the internet as well as their lack of knowledge of the English language which doesn't allow them to benefit the sites available in foreign languages.

The recommended sites will offer an excellent information source about MS especially for the younger age groups of patients who tend to rely on the internet as their main source of information at the present.

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