THE RELATIONSHIP OF SOCIAL SUPPORT AND THE ROLE OF PHYSICAL ACTIVITY IN REDUCING FATIGUE AMONG PATIENTS WITH MULTIPLE SCLEROSIS

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ABSTRACT:

The aim of this study was to identify the relationship of social support and the role of physical activity in reducing fatigue among patients with multiple sclerosis in Jordan. A descriptive quantitative design was used in this study. A total of (N=80) patients with multiple sclerosis were randomly selected by using convenience sampling from the Health Insurance Center in the capital Amman, Jordan. Two questionnaires were used in this study; the first questionnaire was designed by the researchers to assess the social support which consisted of 28 questions distributed into 3 subscales (family, friends and medical). The second questionnaire was the Modified Fatigue Impact Scale (MFIS) and consisted of 21 questions distributed into 3 subscales (physical, cognitive, and psychosocial). Results revealed that the mean score of the total fatigue was 72.51 ± 25.971 among patients with multiple sclerosis and the mean score of social support among patients with multiple sclerosis was 91.91± 22.567. In addition, there was a significant difference in scores between participants and non-participants in physical activities p=.000. There was no correlation between the fatigue and social support among multiple sclerosis patients p= 0.206. The researchers recommend patients with multiple sclerosis to perform physical activities to decrease the severity of fatigue. Moreover, the researchers recommend the need to increase the awareness about fatigue associated with multiple sclerosis among family members and friends of the patient with multiple sclerosis with the importance of ideal use of social support.

Key words: Social Support, Physical Activity, Multiple Sclerosis, Fatigue.

I. INTRODUCTION:

Multiple sclerosis (MS) is a chronic disease that affects the central nervous system and removes the melanin layer, and there are an estimated 2.5 million people worldwide with MS (Multiple Sclerosis Trust., 2018). MS affects individuals aged between 20 and 40 years, and it prevalence among females are higher than males (Pugliatti et al., 2006). The average time of death is around 30 years from the onset of symptoms of the disease, and represents a decrease from 5-10 years of life expectancy (Bromnum-Hansen et al., 2004). Approximately 85% of patients suffer from relapse and remission of the disease, which is the “relapsing-remitting MS (RRMS) stage”, which is characterized by the unexpected onset of neurological symptoms that affect the patient’s physical, sensory and visual motors (Confavreux & Vukusic., 2006).

MS is an unexpected pathway with symptoms that include impaired cognition, mood, impaired and loss of vision, bladder and bowel incontinence, and the disease is characterized by the highest prevalence of psychiatric disorders and symptoms (Chwastiak & Ehde., 2007). It is one of the main causes of various disabilities during youth (Compston & Coles., 2008; Guzik & Kwolek., 2015). Multi-focal cerebral damage is characterized by a variety of symptoms, such as partial paralysis, imbalance, sensory deficiencies, mental disorders, and excessive...
Fatigue (F) (Garczyńska, 2016). F associated with MS is one of the most common symptoms for patients and one of the most disruptive symptoms (Kraft et al., 1986). More than 90% of people with MS suffer from F, and they consider it one of the most annoying symptoms (Lauren & Krupp, 2010). A study showed that the F associated with MS is the main reason that prevents patients from participating in various activities, which leads to a decrease in their quality of life (Nery, 2016).

F is a feeling of severe physical and mental tiredness which negatively affects patients' daily practice and ability to cope with other symptoms of MS (Lauren & Krupp, 2010). There are primary factors for the F associated with MS, which is associated with damage to the central nervous system in patients. Secondary factors are associated with sleep disorders, pain, psychological factors and medication (Bakshi, 2003). Therefore, a distinction must be made between the two types of F associated with MS in order to take the appropriate treatment. There is peripheral F equivalent to muscle F as a result of physical exertion and relieved by rest, and central F accompanied by difficulty paying attention and concentration (Shah, 2009).

Having MS during youth makes acceptance of the chronic disease difficult and makes psychological and social adaptation to the disease a particular problem, especially in the early years after diagnosis (Rainone et al., 2017; Strober, 2018). This disease has various consequences that negatively affect patients' personal and social lives (Jahanbakhsh et al., 2013). It has also been shown that the F associated with MS causes profound disturbances in the social and functional life of patients (Hemmett et al., 2004). F interferes with patients' daily activities, social roles and causes MS to worsen or other symptoms appear (Matuska et al., 2007). One of the most important psychological and social variables to predict F in adult patients is Social Support (SS) (Belza et al., 1993).

SS refers to the perceived availability of resources, provided by the individual's social networks such as families, spouses, and friends. It has a significant role in mitigating the negative effects of stressful conditions (Cohen & Wills, 1985). Therefore, SS is an important factor to be taken into account in assessing the health of MS patients (Mohr & Genain, 2004; Schwartz & Frohner, 2005). SS has been seen as a coping strategy when individuals suffer from distress (Latkin & Knowlton, 2015). Studies showed that SS is an important positive factor for health related to the quality of life of patients with MS and also works to reduce their symptoms of depression (Costa et al., 2012; Costa et al., 2011).

One of the non-pharmacological treatment methods that attracted attention to enhance the physical and mental well-being of patients with MS is the practice of Physical Activities (PA's) (McDonald et al., 2001). Individualized and supervised program can improve their fitness and adjustable disabilities, and it is an effective and safe way to rehabilitate patients with MS (Halabchi et al., 2017). MS patients often reduce their activities due to their fear of worsening symptoms (Dalgas et al., 2008). This leads to increase F, disability, lack of fitness, muscle weakness, gait abnormalities, and a decrease in their quality of life (Pilutti et al., 2014). However, PA's have been described as a treatment option for MS patients; especially for patients who do not adhere to the recommended exercise regimes. Therefore, it is very important to design effective individual PA's to increase their tendency to exercise and commitment to obtain beneficial positive effects (Cramer et al., 2014; Halabchi et al., 2017).

Regular PA's is essential for patients with MS as an important part of their treatment and lifestyle, as it achieves the physical and mental health of patients, reduces the risk of chronic diseases, increases the chance of survival and improves their quality of life over the coming years (Sutherland & Andersen, 2001; Atashzade et al., 2003). It was also found that PA's in particular have an important role for patients with MS, as it relieves their F (Giunti et al., 2018; Castro-Sánchez et al., 2012; Stroud & Minahan, 2009). Practicing PA's strengthens patients' muscles and improves their physical fitness, which helps them to perform their various activities and better meet their needs by relieving exerted effort (Motl & Pilutti, 2012). There are some concerns among patients with MS about the effect of PA's on exacerbating their F, but the existing evidence supports the fact that the practice of PA's regularly have a role in a slight decrease in F, but it is important for patients (Andreasen et al., 2011; Pilutti et al., 2013). Therefore, PA's can be considered a safe and effective method as an important option during planning treatment of F in patients with MS and should be encouraged (Motl, 2014).

MS has many social, psychological and physical consequences (Costa et al., 2012). The physical restrictions and psychological changes resulting from MS reduce the social relationships of patients. The loss of SS and the decrease in the practice of PA's lead to more psychological complications; the most important of which is the symptom of F (Aghaei et al., 2016; Stroud & Minahan, 2009; Halabchi et al., 2017; Pilutti et al., 2014). Nearly 80% of patients reported that they suffer from F that negatively affects their daily activities and they have lost

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their jobs because of it, which in turn led to reduce the ability of patients to perform their individual and social tasks, work, activity and maintain a normal life (Pappalardo et al., 2004). In addition, 71% of patients reported that they had more sick leaves than usual, 28% of patients were forced to quit, and 75% of patients had to change jobs due to F (Zifko., 2004).

As a result, the search process has extended to many health conditions for patients with MS. In the field of SS, studies have shown that SS has a role in improving several aspects among patients with MS; the most important of which is reducing their F, adapting to the disease and staying healthy. (Chronister et al., 2008; Pakenham ., 2007; Schwartz & Frohner ., 2005; Costa et al., 2012; Aghaei et al., 2016). In the field of PA’s, a decrease in PA’s is associated with poor mental health (Shor & Shalev., 2016). Despite the doctors’ report for patients with MS to engage in PA’s as usual, it is the ideal solution for the patient not to move from one condition to a worse condition and to reach the best stage of his activity (Halabchi et al., 2017). However, it was found that patients with MS are less active. Some of them reported that there are different obstacles to participate in PA’s, some of them lacked awareness about the benefits of PA’s and some of them reduced PA’s as a fear of exacerbating symptoms, the most important of which is F (Motl et al., 2005; Halabchi et al., 2017; Nery., 2016; Stroud et al., 2009).

Despite all the limitations, the practice of PA’s have beneficial effects among patients with MS and is one of the most important strategies that must be followed to treat F, moreover, no side effects were observed on patients (Gallien et al., 2007; Brown & Kraft., 2005; Motle., 2014; Stroud & Minahan., 2009). Despite the increased number of patients with MS, the negative effects of F associated with the disease on their lives (Aghaei et al., 2016), and the lack of local studies that target the symptom of F associated with MS. Therefore, this study aimed to identify the relationship of SS and the role of PA’s in reducing F among patients with MS in Jordan.

II. MATERIAL AND METHODS:

A descriptive quantitative design was used in this study. A total of (N=80) patients with MS were randomly selected by using convenience sampling from the Health Insurance Center in the capital Amman, Jordan.

Two questionnaires were used in this study. The first questionnaire was designed by the researchers to assess the SS which consisted of 28 questions distributed into 3 subscales (family, friends and medical). To ensure validity of this tool, it was judged and reviewed by a (N=10) of academic professors specialist in the subject of study. Cronbach's alpha was used to estimate the reliability of the sample of study. The Cronbach’s alpha for the Arabic Social Support Scale was (0.846). A pilot study was conducted on (N=10) patients with MS to ensure content validity.

The second questionnaire was the Modified Fatigue Impact Scale (MFIS), it was used to measure the effect of F on MS from National Multiple Sclerosis Society which consisted of 21 questions distributed into 3 subscales (physical, cognitive, and psychosocial).

III. RESULTS:

A total of (N=80) patients with MS participated in the study. All the participants were categorized under the first stage of MS the Relapsing-Remitting Multiple Sclerosis (RRMS) stage. There were 60 females and 20 males in this study. A total of 25 patients with MS participated one hour per day in PA’s. Out of the 60 females only 18 participated in PA’s. In addition, 7 out of 20 males participated in PA’s. Moreover, the mean score of the total F was 72.51± 25.971 among patients with MS. The lowest mean score of the F scale was the “psychosocial” subscale 7.13±2.753. It is present in table (1).

<table>
<thead>
<tr>
<th>Subscales/ Scale</th>
<th>N</th>
<th>M±SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>80</td>
<td>30.44±11.753</td>
</tr>
<tr>
<td>Cognitive</td>
<td>80</td>
<td>34.95±12.081</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>80</td>
<td>7.13±2.753</td>
</tr>
</tbody>
</table>
The mean score of SS among patients with MS was 91.91±22.567. The lowest mean score of the SS scale was the “friends” subscale 25.84±9.505. It is present in table (2).

Table (2): The Number of participants, Mean and Standard deviation for the SS scale.

<table>
<thead>
<tr>
<th>Subscales/ Scale</th>
<th>N</th>
<th>M±SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>80</td>
<td>31.88±6.347</td>
</tr>
<tr>
<td>Friends</td>
<td>80</td>
<td>25.84±9.505</td>
</tr>
<tr>
<td>Medical</td>
<td>80</td>
<td>34.19±6.715</td>
</tr>
<tr>
<td>Total Social Support (SS)</td>
<td>80</td>
<td>91.91±22.567</td>
</tr>
</tbody>
</table>

In addition, independent t-test was conducted to compare the total F score for participants in PA’s and non-participants in PA’s. There was a significant difference in scores between participants and non-participants in PA’s p=.000. It is present in table (3).

Table (3): Independent t-test for the F according to PA’s variable for MS patients.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Group</th>
<th>N</th>
<th>M±SD</th>
<th>df</th>
<th>t</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (F)</td>
<td>Participants in physical</td>
<td>25</td>
<td>37.52±11.233</td>
<td>78</td>
<td>19.914</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>activities (PA’s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-participants in physical</td>
<td>55</td>
<td>88.42±10.300</td>
<td>78</td>
<td>19.914</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>activities (PA’s)</td>
<td></td>
<td></td>
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</tbody>
</table>

The relationship between F and SS was investigated using Pearson correlation coefficient. There was no correlation between the F and SS among MS patients, N=80, r 0.143= and p=0.206. It is presented in table (4).

Table (4): Pearson correlation coefficient between F and SS among MS patients.

<table>
<thead>
<tr>
<th>Fatigue (F)</th>
<th>Social Support (SS)</th>
<th>N</th>
<th>r</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>80</td>
<td>0.143</td>
<td>0.206</td>
</tr>
</tbody>
</table>

Note. N= Number of participants; M= Mean, SD= Standard Deviation, df= degree of freedom, t= t-value, Sig (2-tailed) = level of statistically significance at the level of (α ≤ 0.05).

IV. DISCUSSION:

The result of this study agreed with several studies, which indicated that patients with MS suffer from SS (Stroud & Minahan., 2009; Pariser et al., 2006; Pilutti et al., 2013; Cramer et al., 2014; Shah., 2009). The researchers explain the result of the study through their review of the theoretical literature, that F is an unclear pathological
symptom, one of the most common pathological symptoms among patients with MS and has a negative impact on the physical, psychological and social aspects of the patient.

F associated with MS is a subjective feeling of diminished physical and mental abilities that is observed by the patient and caregivers and affects daily activities or the tasks the patient wants to do (MSCFCPG., 1998). It has been indicated that the F associated with MS can be chronic and non-chronic (Lauren & Krupp., 2010). However, the cause of F associated with MS is not yet known, and it has been reported that it is one of the most common and disturbing symptoms among patients with MS (Petajan& White., 1999; Pariser et al., 2006; Turpin et al., 2007).

Any defect in the physical or mental health of the individual is associated with the possibility of a decrease in the exercise of PA’s. (Smith et al., 2015). The lack of PA’s among patients with MS lead to increase F, lack of physical fitness, gait abnormalities, and muscle weakness (Gallien et al., 2007; Pilutti et al., 2014; Stroud & Minahan, 2009). Accordingly, the result of this study agreed with several studies that showed the role of PA’s in reducing F among patients with MS (Andreasen et al., 2011; Pilutti et al., 2013; Stroud & Minahan., 2009).

The researchers explained this result that the practice of various PA’s in proportion to the patient, his preferences and abilities is one of the most important treatment methods for F among patients with MS. Therefore, practicing PA’s works on developing the fitness of MS patients which delays the appearance of their F. About 40% of patients with MS suffer from functional impairment resulting from F (Murray., 1985). Although the therapeutic possibilities of F associated with MS are few, treatment through PA’s has the ability to have a positive effect on F associated with MS (Andreasen et al., 2011). The practice of PA’s in general does not pose any danger to patients with MS and requires individual training; as the benefits of these activities depend on the F associated with sclerosis and on the patient's own physical capabilities (Mäurer et al., 2018).

Patients with MS can through their PA’s reduce their F, overcome walking difficulties and strengthen their limbs, thus significantly reduce the severity of F after performing PA’s (Giesser et al., 2007). Aerobic physical exercises can improve aerobic fitness and reduce F among patients with MS affected by mild to moderate disability. It is also possible for patients with MS to exercise resistance exercises which showed its effectiveness in relieving F (Halabchi et al., 2017). Water exercises have also proven to be effective in relieving F and have been considered as a means of rehabilitating patients with MS (Kargarfard et al., 2012). Yoga has also been considered as one of the possible complementary treatments among patients with MS as it improves their F (Velikonja et al., 2010). Patients with MS have to practice various PA’s as it is an effective way to improve physiological functions and muscle strength. This leads to relieve the energy expended in daily activities which reduces their sense of F (Motl&Pilutti., 2012).

The result of this study showed that there is no correlation between SS and relieving F among patients with MS. While another study showed a correlation between the F associated with MS and SS (Aghaei et al., 2016). The researchers attribute the result to the lack of sufficient awareness about F among parents and friends of patients with MS and how to provide them with appropriate support. MS is not associated with building new relationships for patients, but patients often feel embarrassed in public or anxious due to the negative effects of the disease on their personal and practical lives (Buchanan et al., 2010).

MS patients reported in a study that their symptoms were often overemphasized or ignored making them feel more ill as if they were alone (Grytten&Måseide., 2006). F reaches 90% among patients with MS and negatively affects their activities and interactions with family and friends (Shah., 2009). However, social dimensions such as personal relationships may have a positive role in adapting to MS disease (Thomas et al., 2006). SS varies in different countries, cultures and individual perceptions (Freitas et al., 2017). A study showed that women with MS or fibromyalgia face uncertainty and inadequate treatment from doctors, family, and friends (Phillips et al., 2010). While another study showed that satisfaction with SS and social participation have positive effects on pathological symptoms in women with fibromyalgia syndrome (Okifuji et al., 2000).

Concerning the F associated with MS, a study showed the importance of SS in monitoring the level of F for patients and its beneficial effects for the rehabilitation of patients (Aghaei et al., 2016). SS is a resource for overcoming chronic diseases and has been reported to be one of the most important factors in promoting health (Shin et al., 2008). SS directly enhances the immune system by enhancing self-confidence and positive feelings which leads to improvement of disease symptoms. In addition, supportive behaviors from others may help increase the patient's healthy behavior (Ghasemi& Nazari., 2011; Fakhri et al., 2012). The family and friends of
MS patients have a role in helping patients by providing information on the most effective strategies for coping. These strategies promote and encourage positive health behaviors and reduce the patient's nervous reactions (Levine & Targ., 2002). The specialists and health care providers of patients with MS should provide SS programs to the family and friends of MS patients to rehabilitate patients with MS (Aghaei et al., 2016).

V. CONCLUSION:
Patients with MS suffer from F. Moreover, participating in PA’s have a positive effect on decreasing F level among patients with MS. In addition, there was no correlation between the F level and SS among patients with MS.

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REFERENCES:


