FATIGUE AND HEALTH-RELATED QUALITY OF LIFE IN MULTIPLE SCLEROSIS

(Corresponding author)

Professor Ekhlas Al-Gamal BSc, MSc, PhD, RN Professor, Psychiatric and Mental Health Nursing School of Nursing The University of Jordan Amman Jordan P.Box 11942 e.algamal@ju.edu.jo https://orcid.org/0000-0003-1248-6266

Focused in mental health nursing, Professor Ekhlas supports efforts in the field of mental health and quality of life among patients with chronic illnesses in Arabic countries and internationally.

Saba Yaseen Hyarat

Registered Nurse London Health Sciences Centre University Hospital, London, Ontario Canada Saba.Hyarat@ihsc.on.ca

Saba Hyarat, a Ph.D. student at Western University, holds a BSc in Nursing and a Master's in Palliative Nursing. She has diverse clinical experience and publications in leading nursing journals.

Latifa Al Jaried

Teaching Assistant College of Nursing King Saud bin Abdulaziz University for Health Sciences Al Ahsa Kingdom of Saudi Arabia aljariedlatifa@Hotmail.com

Latifa is a PhD student at Queen's University Belfast, holds a BSc (Nursing) and an MSc (Mental Health Nursing). She is part of the Northern Ireland Pregnancy Loss Research Network

Ellaine Rama

Lecturer College of Nursing King Saud bin Abdulaziz University for Health Sciences Riyadh Kingdom of Saudi Arabia ramae@ksau-hs.edu.sa Ellaine Dela Rama serves as a Lecturer at the College of Nursing, KSAU-HS in Riyadh, KSA. She is involved in clinical training and conducts applied research for undergraduate students.

Professor Muayyad Ahmad RN, PhD

Professor, Clinical Nursing Department School of Nursing The University of Jordan Amman Jordan mma4@ju.edu.jo https://orcid.org/0000-0002-4388-8332

Muayyad Ahmad is a professor at the University of Jordan, Clinical Nursing Department. With over 150 publications, he has supervised 30 graduate theses and received numerous national and international awards.

Professor Tony Long BSc, MA, PhD, RN Emeritus Professor of Child & Family Health University of Salford SALFORD UK t.long2@salford.ac.uk https://orcid.org/0000-0003-2726-8798

Research Professor 2006-2022. Now Trustee and Director at the Birtenshaw Group (education and care services for children with SEND), and Board member of the All-Ireland Paediatric Academic Health Science Centre.

No conflict of interest has been declared by the authors.

Acknowledgment We would like to thank all Saudi participants who participated in this study.

STATEMENT OF ETHICAL RESEARCH

Ethical approval was obtained from the research unit at the College of Nursing, Al Ahsa; and King Abdullah International Medical Research Center (KIMARC) – approval number RA19/002/A. Signed consent was secured from all participants.

ABSTRACT

BACKGROUND: Multiple sclerosis is a debilitating, chronic neurological disease with diverse symptoms. Fatigue is a major aspect of this, impacting negatively on physical functioning, productivity, general wellbeing and health-related quality of life.

AIM: To expose the relationship between fatigue and health-related quality of life in this clinical population in Saudi Arabia, supporting the development of comprehensive nursing management regimes.

METHODS: Patients were recruited from out-patient clinics in three Saudi Arabian cities (130 women, 71 men) for a correlational, cross-sectional study. SF-36 Health Survey and Fatigue Severity Scale were used, together with demographic variables. Descriptive analysis, correlation and t-test were applied within IBM Statistics v22.

RESULTS: Mean total Fatigue Severity Scale score was 5.59 (SD 1.18). Mean total Quality of Life score was 43.69 (SD 25.97). Fatigue was the major manifestation of the disease impacting negatively on patients' quality of life.

CONCLUSION: The findings linked fatigue to lower quality of life, but also addressed the specific national demographic: an unusual pattern of significantly increasing prevalence, especially among females and young, well-educated populations. Screening this population routinely for fatigue is vital to optimize assessment, care, and review of the effectiveness of nursing interventions, ultimately promoting productivity, and enhancing health-related quality of life.

Keywords: Fatigue; Health-related quality of life; Multiple Sclerosis; Saudi Arabia

BACKGROUND Multiple Sclerosis

The incidence of people living with a chronic disease increases persistently as a consequence of improved living conditions; more effective prevention of other diseases, notably infectious diseases; enhanced medical technological; and general increase in longevity (Bratas et al, 2012). One of these chronic diseases is multiple sclerosis (MS); the most common disabling disease of young adulthood (Kołtuniuk et al, 2021). Multiple sclerosis is an immune-mediated disorder (Latimer-Cheung et al, 2013) resulting from an inflammatory demyelinating process in the central nervous system. In its classical form, periodic attacks are followed by either partial or complete reduction of symptoms that cause physiological, psychological, cognitive and socioeconomic problems (Aghaei et al, 2016; Compston and Coles, 2008).

Multiple sclerosis presents clinically through diverse symptoms including severe fatigue, vertigo, ataxia, spasticity, muscular weakness and visual impairment (Compston and Coles, 2008), as well as loss of sight, speech impairment, cognitive impairment, neurologic disability, and paralysis. Research in Saudi Arabia has shown significant correlation between fatigue and both anxiety and depression in those with MS (AlSaeed et al, 2022). Independence and mobility are impaired, and there may be difficulties in relationships or sexual intimacy. There is international evidence from Iran (Aghaei et al, 2016), Australia (Carey et al, 2016), and Poland (Kołtuniuk et al, 2021) that all these problems impair normal functioning, resulting in consequent disruption of learning, role function, family functioning, friendships and activities of daily living. Khatri et al (2020) in Saudi Arabia found social anxiety and obsessive-compulsive disorder to be problematic for MS patients, and that this tendency was aggravated by increasing disability. Turkish researchers noted that reduced activity together with increased anxiety prompted by the COVID-19 pandemic exerted negative impact on both physical and psychological aspects of life (Özkeskin et al, 2021). Such challenges impact on physical functioning, productivity, general wellbeing and health-related guality of life (HRQoL).

Medical and social management for Saudi patients was challenging, particularly since quality of life was seen to deteriorate with ongoing progression of the disease (Algahtani et al, 2017). This frequently promotes a high burden on health care (Latimer-Cheung et al, 2013). A study in the USA to assess depressive symptoms and social support found that women experienced more social support than did men, and depressive symptoms were reduced significantly in the presence of social support (Jensen et al, 2014). A more recent study of the association between level of depression and perceived social support in patients with MS in Saudi Arabia (Hyarat et al, 2018) showed no statistical difference between males and females (t(138) = -1.85, p=0.06). In France, Gay et al (2017) found anxiety to be a factor increasing vulnerability to depression, though gender was only "modestly involved"; while another French study identified social support as a buffering agent for stress and anxiety in those with MS (Henry et al, 2019). Tan-Kristanto et al (2015) showed resilience, avoidance, and emotion-focussed coping to relate strongly to levels of depression and anxiety in newly diagnosed patients in Australia.

The importance of the phase of MS in such studies is emphasized by a Saudi study which found 70% of MS patients to be within normal parameters for depression and 57% for anxiety - but these were all in the ambulatory phase (AlSaeed et al 2022). Indeed, a systematic review by Fisher et al (2020) concluded that anxiety, depression, negative mood, emotional distress and trauma symptoms were all common in MS, but the evidence base for the cause or process of such emotional and psychological turmoil remained unconvincing. However, findings from a recently introduced national initiative to map data nationally about the disease in the Kingdom of Saudi Arabia uncovered an unusual pattern of increasing prevalence particularly in young (<40 years), educated women (AlJumah et al 2020). Greater understanding of the problem of missing data and under-reporting was also a feature of this work.

Fatigue

From Iranian research, the most predominant and incapacitating symptom of MS is fatigue (Aghaei et al, 2016). Although fatigue is a common symptom among healthy individuals, it is markedly pronounced and enduring in those diagnosed with MS. Research in the USA (Cella et al, 2007) and Spain (Gil-Gonzalez et al, 2020) has found the disease to be characterised by an irresistible, overpowering, devastating, and constant sense of tiredness that reduces physical functioning and the maintenance of activities of daily living;. Torchio et al (2022) established that the severity of fatigue correlated significantly with reduced moderate to vigorous activity in an Italian population commencing a rehabilitation regime. Reduced physical activity, often associated with disordered gait and balance, exerted a negative impact on mental health.

Plow et al (2012) found that 75–90% of those suffering MS reported fatigue, and 60% considered this to be the most exhausting symptom. A comprehensive review of documented interventions to manage fatigue in MS patients found fatigue to be a disabling symptom in almost 80% of respondents (Khan et al, 2014). Fatigue of moderate intensity was found in 45.16% (n=28) of Polish patients with the relapsing-remitting subtype of MS (Halicka et al, 2017). AlSaeed et al (2022) reported a similar figure in Saudi patients, and these individuals were more likely to suffer anxiety and depression concomitantly.

Earlier research in Canada (Sayao et al, 2011) and Poland (Papuć & Stelmasiak, 2012) noted the impact on quality of life to be more pernicious. Up to 60% of those affected consider this to be the most distressing and negatively impactful symptom. Reduced physical activity is reflected in depressed mood, impaired social interactions, and reduced recreational activities, resulting in reduced health-related quality of life in Turkish (Basak et al, 2015) and Polish (Kołtuniuk et al, 2021) populations, and this was also found in a systematic review by Guerra (2013;). Experiences of increased cognitive impairment and reduction in participatory roles such as relationships and social interactions, together with decline in general health, increased disability, impaired activities of daily living (including the parenting role), and ascending burden of health care in MS, as detailed above, have all been correlated specifically with fatigue in Australia (Khan et al, 2014) and the USA (Haynes-Lawrence and West, 2018). Henry et

al (2019) highlighted the direct impact of anxiety on depression and fatigue in French MS sufferers.

Health-related Quality of Life

Ninety-three Norwegian patients with MS were studied for HRQoL by Klevan et al (2014). Participants showed significantly lower HRQoL in physical health and mental health domains than the control group of those without MS with mean 57.3 compared to 84.5 (physical health) and 66.4 compared to 79.2 (mental health). The presence of both motor and non-motor symptoms contributed to the reduced HRQoL of MS patients. In Mexico, Hernández-Ledesma et al (2018) found significant impact of depression and anxiety on quality of life, but physical, social and psychological factors were involved. Effective positive coping strategies, social support, and better physical health linked to better quality of life.

The Relationship between Fatigue and Health-Related Quality of Life

A study of 108 Spanish patients with MS concluded that those with physical manifestation of the disease as expressed in higher levels of fatigue exhibited worse cognitive performance. This, in turn, exerted negative impact on HRQoL (Fernández-Muñoz et al, 2015). Similarly, a Lithuanian study relating physical disability and depression to physical quality of life in 137 patients with relapsing-remitting MS established a close relationship between worse physical disability (and associated depression) and poorer quality of life. Fatigue was experienced more frequently in these patients (Leonavicius, 2014).

Fatigue in patients ranges from 75% to 90%. Fatigue is reported by approximately half of sufferers in Canada (Forwell et al, 2008) and Slovakia (Jakubíková and Klímová, 2010) to exert the greatest burden. In the United Kingdom it occurs almost 1.8 times more commonly in women than in men, and most commonly in young adults from 20 to 40 years, with a maximum reported onset of 33 years (Naci et al, 2010). This makes it the most common cause of progressive disability among young adults in the USA (Ascherio et al, 2010). Fatigue in MS is classified as primary fatigue, caused by disease process itself; or secondary fatique which may be triggered by infection. Both impact negatively on cognitive, physical, and social aspects of life (Akkus and Akdemir, 2012).

PROBLEM STATEMENT

The incidence of MS in Saudi Arabia has been estimated to be 25/100,000, though statistical evidence is somewhat lacking (Alamri and Al-Busaidi, 2016; Heydarpour et al, 2015; Al Jumah et al, 2012). More recent data shows that there has been a significant increase in prevalence, especially so for the indigenous population (61.95/100,000), and with a predominance among females, younger adults and those who are well-educated (AlJumah et al, 2020). Previous studies have focussed on fatigue (for example, Kos et al, (2008) in Belgium) or HRQoL in MS. However, the association between fatigue and HRQoL among Saudi patients with MS has been largely neglected. This study was designed to address this gap in the knowledge base. The outcomes add to nurses' and other health professionals' understanding of the nature of the relationship between fatigue and HRQoL in MS in order to guide assessment, care, and review of the effectiveness of nursing interventions. The findings should support the development of

comprehensive nursing management regimes to address the identified problems in this patient population.

STUDY DESIGN

An observational, descriptive, correlational, cross-sectional study design with selfreported questionnaires was adopted to analyse authentic conditions without any form of manipulation. Detailed descriptions of observed phenomena and an evaluation of the correlation between fatigue and HRQoL were facilitated, offering significant insights into the inherent connections within the specific context (Farid & Alam, 2023). This cautious, exploratory approach was warranted given the current state of knowledge about the diagnostic group and the specific clinical variables. The outcomes will inform further studies into the effectiveness of nursing interventions.

Aim of the study

The aim of this study was to explore the relationship between fatigue and HRQoL in patients with MS in Saudi Arabia in order to guide development of effective nursing intervention strategies.

Conceptual framework

The Health Belief Model (HBM) guided the study by examining individuals' perceptions of fatigue severity in MS and their beliefs about coping strategies. It considers how these factors affect health-related behaviours and, in turn, people's quality of life in general. This model aids in understanding the psychological mechanisms that contribute to the relationship between fatigue and HRQoL in individuals with MS, providing insights for interventions and support strategies. Researchers may be able to learn more about how MS patients perceive fatigue and how this affects their HRQoL if they use the HBM as a guide for their research (Habibi et al, 2021). With the use of this data, interventions may be created that assist MS patients in controlling their fatigue and enhancing their quality of life.

Specific Objectives

1 To determine level of fatigue and HRQoL among Saudi patients with MS

2 To assess the relationship between HRQoL and fatigue in Saudi patients with MS

3 To examine the relationships between fatigue, HRQoL, and selected demographic variables

4 To examine the differences in fatigue and HRQoL between males and females with MS

Setting

Data were collected from patients diagnosed with MS, determined by medical records, attending out-patient clinics in three Saudi cities to assure the demographic variability across different cities.

Study Subjects

A convenience sampling technique was used. The inclusion criteria were: (1) patients with MS, (2) ability to speak Arabic, and (3) competent to consent to participation in the study. Patients currently receiving professional treatment for serious cognitive or mental

disorder such as late-stage dementia which could make understanding of the study purpose or ability to complete the instruments doubtful were excluded. Otherwise, the researchers were determined to minimize exclusion.

Sample size

G*Power (Faul et al., 2009) was used to determine the appropriate sample size. The researcher used paired t-test, and determined a medium effect size of 0.50, significance level of α =0.05 which is acceptable to control the risk for making a Type 1 error, and power of 80% to reduce the risk of a Type II error (Munro, 2005). Subsequently, the minimum required sample size was 128 participants (64 males and 64 females). However, to overcome the problems of attrition and incomplete questionnaires, a final sample was 201 patients.

Ethical Approval and Data Collection:

Ethical approval was obtained from the research unit at the College of Nursing, Al Ahsa; and King Abdullah International Medical Research Center (KIMARC). The targeted hospitals were contacted for approval, and for the head of the unit to be assigned as liaison to facilitate approach to patients during visits to the outpatient clinics. Eligible patients were identified by the in-charge nurse. Participants were assured of their right to confidentiality. Participants' anonymity was also assured in the study, and participants were allocated an identification code. Signed consent forms were collected. Participants were assured of the ability to discontinue the study without having to provide a reason. Support through referral to a psychologist was available should they become distressed. All data were held in a password–protected workplace computer. Completed questionnaires were stored securely in a locked filing cabinet in a locked room with access restricted to the principle researcher.

Research assistants introduced the study, and distributed the invitation letter during outpatient appointment clinics. The demographic survey was distributed at this point. Patients with MS who expressed interest in participation were asked each item of the questionnaire by the researchers who recorded the responses. Completing the survey took, on average, approximately 20 minutes.

Instruments

Demographic variables included age, gender, marital status, health insurance, occupation, educational level, years of diagnosis, medical treatment, type of medication, periods of relapse during last year, hospitalization episodes during last year, and other concurrent disease.

Translated Arabic versions of two instruments were adopted. The SF-36 Health Survey was used to measure HRQoL. This consists of 36 items. Two components which include eight dimensions address varied aspects of HRQoL. The physical component summary (PCS) has four scales, with a further four representing the mental component summary (MCS). Alterations in health status during the previous 12 months are covered by an additional single question. Scores from every item in the two components are coded and transformed into a scale of 0 (poor health) to 100 (optimal health). Better health is

represented by higher scores. Good internal consistency reliability was reported (Vickrey et al, 1992).

The Fatigue Severity Scale (FSS) is a self-report scale in the form of a 9-item questionnaire investigating how fatigue interferes with specified activities (Krupp, 1989). It has internal consistency reliability (Cronbach's alpha) 0.84. The internal consistency of the Arabic version was also 0.84. Moreover, good construct validity using factor analysis was reported (AI-Sobayel et al, 2017).

Data analysis

IBM Statistics version 22 was used for data entry and analysis. Statistical significance was set at p<.05. Descriptive statistics, suitable to the level of measurement, were utilized to describe and summarized all demographic variables (age, family income and number of years since diagnosis variables), the items of the questionnaires and the degree of fatigue and HRQoL. Mean, median, standard deviation, and range statistics were employed to describe these continuous variables. Frequency and percentage statistics were used to describe nominal variables; gender, religion, marital status, employment status, weekly activity variables.

Inferential statistics including correlation measures (Pearson) was used to examine the relationship between HRQoL mean score, subscales and fatigue mean score and some selected demographics (age, family income variables, and number of years since diagnosis). Pearson correlation is used when the level of measurement for variables is continuous and the assumptions of normality and linearity are met (Garson, 2012). Differences between men and women on the total fatigue scale score and HRQoL score were examined by t-test. To compare the differences between two groups on a continuous variable, the independent sample t-test is used when the assumption of normality is satisfied and a sufficient sample size is available (Warner, 2013).

RESULTS

Characteristics of study participants

Of the 201 Saudi participants, 71 (35.3%) were male and 130 (64.7%) female, reflecting the recently identified gender distribution of those with MS. Their mean age was 35.32 years (SD=10.14) with a range from 18 to 60 years. This also supports the newly-recognised pattern of younger adult patients (<40 years). The frequency distribution of marital status, level of activity, and employment status in the sample is displayed in Table 1. The mean of family monthly income for all patients was SR4258 with a range from SR1500 to SR45000. The mean family income among male patients was SR5201 with a range from SR5000 to SR45000, and the mean family income among female patients was SR3746 ranging from SR1500 to SR32000. The mean family monthly income for all patients who worked full time was SR 8473 with a range of SR7500 to SR45000. For patients who worked part time, the mean of family monthly income was SR 1924 ranging from SR7000 to SR19000. Patients who were not working or were unemployed had a mean family monthly income of SR3396 with a range of SR32000. All of the patients were Muslims. The average number of years since diagnosis was 6.16 years (SD=4.21).

Degrees of fatigue

Table 2 details the mean scores and standard deviation of each item of the Fatigue Severity Scale. The mean total score was 5.59 (SD=1.18). The highest mean score was item 7 "Fatigue interferes with carrying out certain duties and responsibilities", while the lowest mean scores were for item 2 "Exercise brings on my fatigue" and item 9 "Fatigue interferes with my work family or social life".

HRQoL

The mean total score was 43.69 (SD=25.97). The "Physical functioning" quality of life subscale was the highest-scoring domain with a mean of 65.69, while the "Energy/fatigue" quality of life subscale was the lowest-scoring. See Table 3.

Relationship between HRQoL and fatigue scores

Pearson correlation was used to examine the relationship between HRQoL mean score, subscales and fatigue mean score. The result revealed there was a significant negative relationship between total QoL mean score, QoL subscales and fatigue score. This indicated that the patients with high level of fatigue experienced lower quality of life. See Table 4.

Relationship between HRQoL, fatigue and selected demographics

Correlational analysis was performed to examine the association between patients' characteristics and both HRQoL and fatigue. There was a significant negative relationship between age and all total HRQoL mean score and subscale scores. This indicated the older the patient the poorer their HRQoL. Moreover, the result revealed that there was a significant positive relationship between fatigue and age. This explained that the older the patients, the more fatigue would be experienced.

There was a positive significant relationship between the total HRQoL mean score and all HRQoL subscales and level of income. This indicated that patients with a high level of income experienced better HRQoL than those with a lower level of income. However, there was a negative relationship between level of income and fatigue. This indicated that patients with lower income experienced more fatigue.

A negative relationship was established between total HRQoL and all subscales and the number of years since diagnosis. This indicated that a greater length of time since diagnosis linked to lower quality of life compared to newly diagnosed patients. Furthermore, there was a significant positive relationship between number of years since diagnosis and level of fatigue.

Gender differences

A two-tailed t-test was used to examine the effect of gender on total scales and subscale scores. There were statistical differences between male and female patients and total score of HRQoL (t(199)=2.99, p=0.003) and Role functioning/physical (t(199)=2.31, p=0.022), Role functioning/emotional (t(199)=3.28, p=0.001), Energy/fatigue (t(199)=2.06, p=0.041), Emotional well-being (t(199)=3.11, p=0.002), Social functioning

(t(199)=2.11, p=0.036), Pain (t(199)=2.59, p=0.010), and General health (t(199)=2.11, p=0.036). This indicates that women reported poorer quality of life than men.

DISCUSSION

MS is a progressive disease encompassing a multitude of symptoms which exert significant impact on HRQoL. The disease should not be dealt with as a physiological problem alone, as patients suffer psychological burdens, too. As the disease progresses, decline in HRQoL is to be expected, but this can be ameliorated through cognisance of the complex causes. Given the generally younger age of those with MS in Saudi Arabia, together with the predominance of the relapsing remitting type, an emphasis on early intervention for problems is vital to ensure continued economic productivity and ability to undertake socially and culturally determined family caring roles.

Patients with MS identified fatigue as a major negative impact on multiple aspects of life. It was identified as the most disabling of all symptoms. This is congruent with a study by Khan et al (2014) which identified fatigue as one of the most common restricting symptoms of MS. The link between fatigue and impaired HRQoL was substantial. This resonates with the findings of Fernadez-Munoz et al (2015) in which MS patients showed significantly lower HRQoL than those without the disease, with fatigue as the primary cause. Other studies adopting self-reported measures also found fatigue to be a disabling symptom that prevents completion of activities of daily living and impairs cognitive thinking, resulting in poorer HRQoL (Klevan et al, 2014). Increasing age, lower income, and increasing length of time since diagnosis all were linked to more intense fatigue and diminished HRQoL.

While studies in Europe, the USA, and Australia have highlighted varied factors that impact on HRQoL for those with MS, some including fatigue, it is vital to include the cultural and societal context as well as the specific demographic of the country and its regions when considering such correlations in Saudi Arabia. The population of patients in Saudi Arabia is more likely to be younger, better educated and reasonably affluent, so other factors must exert more impact to stimulate fatigue. Gender appears to be a major factor, but deeper insight into this is needed. A wider issue of gender-based expectations and restrictions in Saudi society seems likely to be the active factor. This could be related more to work or to caring for children or other family members, especially given the greater prevalence of MS in women and the gender-identified cultural expectations of Saudi society.

Vision 2030 (Kingdom of Saudi Arabia, 2016), a major initiative of economic, cultural and societal diversification launched in 2016, includes significant steps to improve women's active participation in work, education and business. This has already demonstrated notable changes, with steadily increasing rates of female activity in the labour market, (Riyadh Behavioural Insights Center, 2022). The changes in female engagement go beyond work and employment: from participation in sport, to investment in the stock market, and education at all levels (General Authority for Statistics, 2023). Given the age and gender profiles of those with MS in Saudi Arabia, the impact of fatigue on participating in this progress may be complex. Currently, the greatest advances in female inclusion

across the board, including employment, are seen in younger women, but the statistics may hide a sub-population of women with MS who are unable to sustain regular, full-time work regimes due to fatigue. Part-time work opportunities are available, however, and being supported to access these could exert positive impact on mental health for women with MS.

In addition to assessment of mobility and physical impairment, range of movement, the proper use and effectiveness of walking aids, and review of medication adherence, nursing intervention for this population needs to include routine screening for fatigue. Psychological factors of perceived loss of control and hopelessness should also be reviewed, offering the opportunity for patients to explore and express explicitly their thoughts, perceptions and frustration. Self-help interventions of regular aerobic exercise to reduce symptoms of fatigue (in this population, gradually becoming more available as women-only exercise groups gain societal acceptance), together with range of motion exercises to improve mobility should be incorporated into the plan. Other basic, well-established lifestyle interventions of a healthy diet, sufficient sleep, and mindfulness would be expected to feature in a nursing plan linked to a multi-disciplinary approach. Similarly, referral to self-help groups in person or online may be possible and culturally acceptable for women to boost mood and feelings of regaining control. Public health nurses might play a role in the development and support of such groups. The impact of peer-to-peer support can be especially significant in many debilitating conditions.

Dissemination of such improvements in nursing care should be pursued through the development of comprehensive national nursing management regimes to address the identified problems in this patient population. This strategy could include continuous education programmes addressing screening and interventions. Further research should be conducted to examine the impact of such an initiative and developing trends in symptomology in the clinical population. Wider dissemination is contemplated of awareness particularly of how to identify these nuances in patient populations and the impact of societal and cultural norms.

CONCLUSION

Successful management of MS symptoms, especially fatigue, to facilitate enhanced quality of life and return to fuller engagement in work and other societal activities requires cultural awareness and understanding of the demographics of specific populations. Fatigue was found to be a major determinant of impaired quality of life for those with MS in Saudi Arabia, affecting particularly women in younger age groups. National initiatives offer the opportunity for nurses to promote simple interventions for individuals and groups of women to overcome the limitations prompted by the medical condition, reasserting self-control, managing the impact of fatigue, and re-engaging in the world of employment, continuing education, and productivity.

KEY POINTS

- Cultural and demographic awareness of the population is essential to expose nuanced aspects in the needs of clinical groups that are susceptible to nursing intervention both directly (behavioural change) and indirectly (perhaps through support of self-help women-only peer groups).
- 2) The range and relative rapidity of change in Saudi Arabia (though in a mediumterm project) serves as a reminder to nurses of the need for preparedness for equally timely responses both to patients' changing needs and to the opportunities offered to intervene in different ways and with a wider group of professionals and organisations.
- 3) In the celebration of notable progress in promoting engagement by women in varied aspects of society through the Vision 2030 initiative, it is vital that Saudi authorities pay attention to those who could inadvertently be left behind through debilitating conditions. Reasonable adjustments to expectations of working hours and other workplace challenges (for example, to reduce the impact of fatigue) could ameliorate negative experiences.
- 4) While this study has uncovered new understanding of the problems considered to be most debilitating by those with MS, the impact of suggested complex interventions will require investigation of multiple variables through empirical studies. Both small scale, in-depth narrative studies of perceived impact and population-based studies of large-scale impact are indicated.

REFERENCES

Aghaei N, Karbandi S, Gorji M, et al (2016) Social support in relation to fatigue symptoms among patients with multiple sclerosis. *Indian Journal of Palliative Care* 22(2):163-7. doi: 10.4103/0973-1075.179610

Alamri Y and Al-Busaidi IS (2016). Multiple sclerosis in Saudi Arabia: Anxiety, depression and suicidality. *Psychiatry Research* 238: 24. doi: 10.1016/j.psychres.2016.02.009

Algahtani HA, Shirah BH, Alzahrani FA, et al (2017) Quality of life among multiple sclerosis patients in Saudi Arabia. *Neurosciences (Riyadh)* 22(4):261-266. doi: 10.17712/nsj.2017.4.20170273

Al Jumah M, Al Balwi M, Hussein M, et al (2012) Association of SNPs rs6498169 and rs10984447 with multiple sclerosis in Saudi patients: a model of the usefulness of familial aggregates in identifying genetic linkage in a multifactorial disease. *Multiple Sclerosis Journal* 18: 1395–1400

AlJumah M, Bunyan R, Al Otaibi H, et al (2020) Rising prevalence of multiple sclerosis in Saudi Arabia, a descriptive study. *BMC Neurology* 20: 49. doi: 10.1186/s12883-020-1629-3

AlSaeed S, Aljouee T, Alkhawajah N, et al (2022) Fatigue, depression, and anxiety among ambulating multiple sclerosis patients. *Frontiers in Immunology* 13: 844461. doi: 10.3389/fimmu.2022.844461

Al-Sobayel H, Al-Hugail H, AlSaif R, et al (2017) Validation of an Arabic version of Fatigue Severity Scale. *Saudi Medical Journal* 37:(1) 73-78. doi: 10.15537/smj.2016.1.13055

Akkus Y and Akdemir N (2012) Improving the quality of life for multiple sclerosis patients using the nurse-based home visiting model. *Scandinavian Journal of Caring Sciences* 26: 295–303. doi: 10.1111/j.1471-6712.2011.00933.x

Ascherio A, Munger KL, Simon KC (2010) Vitamin D and multiple sclerosis. *Lancet Neurology* 9(6): 599–612. doi: 10.1016/S1474-4422(10)70086-7

Basak T, Unver V, Demirkaya S. (2015) Activities of daily living and self-care agency in patients with multiple sclerosis for the first 10 years. *Rehabilitation Nursing* 40(1): 60–65. doi: 10.1002/rnj.153

Bratås O, Espnes GA, Rannestad T, et al (2012) Relapse of health related quality of life and psychological health in patients with chronic obstructive pulmonary disease 6 months after rehabilitation. *Scandinavian Journal of Caring Sciences* 26: 219–227. doi: 10.1111/j.1471-6712.2011.00921.x

Carey TA, Schouten K, Wakerman J, et al (2016) Improving the quality of life of palliative and chronic disease patients and carers in remote Australia with the establishment of a day respite facility. *BMC Palliative Care* 15(1): 62. doi: 10.1186/s12904-016-0136-1

Cella D, Yount S, Rothrock N, et al (2007) The Patient-Reported Outcomes Measurement Information System (PROMIS): Progress of an NIH roadmap cooperative group during its first two years. *Medical Care* 45: S3–S11. doi:10.1097/01.mlr.0000258615.42478.55

Compston A and Coles A (2008) Multiple sclerosis. *Lancet* 372(9648): 1502–17. doi: 10.1016/S0140-6736(08)61620-7

Farid S, Alam M F (2023) Interrelationship of teachers' written feedback & students' achievements in English at secondary school level. *Journal of Social Research Development* 4(1): 146-153. doi: 10.53664/JSRD/04-01-2023-13-146-153

Faul F. Erdfelder E, Buchner A, Lang A G (2009) Statistical power analyses using G^{*} Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods* 41(4), 1149-1160. doi: 10.3758/BRM.41.4.1149

Fernández-Muñoz JJ, et al (2015) Disability, quality of life, personality, cognitive and psychological variables associated with fatigue in patients with multiple sclerosis. *Acta Neurologica Scandinavica* 132(2): 118-124. doi: 10.1111/ane.12370

Fisher PL, Salmon P, Heffer-Rahn P, et al (2020) Predictors of emotional distress in people with multiple sclerosis: A systematic review of prospective studies. *Journal of Affective Disorders* 276: 752-764. doi: 10.1016/j.jad.2020.07.073

Forwell SJ, Brunham S, Tremlett H, et al (2008) Primary and nonprimary fatigue in multiple sclerosis. *International Journal of MS Care* 10: 14–20. doi: 10.7224/1537-2073-10.1.14

Garson G D (2012) Testing statistical assumptions. Asheboro, NC: Statistical Associates Publishing.

Gay M-C, Bungener C, Thomas S, et al (2017) Anxiety, emotional processing and depression in people with multiple sclerosis. *BMC Neurology* 17(1): 43. doi: 10.1186/s12883-017-0803-8.

General Authority for Statistics (2023) GASTAT Issues Saudi Women's Report 2022. <u>https://www.stats.gov.sa/en/news/472</u>

Gil-Gonzalez I, Martin-Rodriguez A, Conrad R, et al (2020) Quality of life in adults with multiple sclerosis: a systematic review. *BMJ Open* 10 (11): e041249. doi: 10.1136/bmjopen-2020-041249

Guerra S (2013) Management of psychosocial adjustment among people with multiple sclerosis: a critical analysis. *British Journal of Neuroscience Nursing* 9(2): 89-92. doi: 10.12968/BJNN.2013.9.2.89

Habibi H, Sedighi B, Jahani Y, Hasani M, Iranpour A (2021) Self-care practices and related factors in patients with multiple sclerosis (MS) based on the health belief model. *Journal of Caring Sciences* 10(2), 77. doi: 10.34172/jcs.2021.015

Halicka D, Tarasiuk J, Szczepański M, et al (2017) Zespół zmęczenia, depresja oraz jakość życia u pacjentów ze stwardnieniem rozsianym. *Pielęgniarstwo Neurologiczne i Neurochirurgiczne* 6(2). doi: 10.15225/PNN.2017.6.2.5

Haynes-Lawrence D and West AR (2018) Managing fatigue in parents with multiple sclerosis. *Journal of Child and Family Studies* 27(5): 1640-1649. doi: 10.1007/s10826-017-1007-y

Henry A, Tourbah A, Camus G, et al (2019) Anxiety and depression in patients with multiple sclerosis: The mediating effects of perceived social support. *Multiple Sclerosis and Related Disorders* 27:46-51. doi: 10.1016/j.msard.2018.09.039

Hernández-Ledesma AL, Rodríguez-Méndez AJ, Gallardo-Vidal LS, et al (2018) Coping strategies and quality of life in Mexican multiple sclerosis patients: Physical, psychological and social factors relationship. *Multiple Sclerosis and Related Disorders* 25: 122-127. doi: 10.1016/j.msard.2018.06.001

Heydarpour P, Khoshkish S, Abtahi S, et al (2015) Multiple sclerosis epidemiology in Middle East and North Africa: a systematic review and meta-analysis. *Neuroepidemiology.* 44: 232–244. doi: 10.1159/000431042

Hyarat S, Al Gamal E, Rama E (2018) Depression and perceived social support among Saudi patients with multiple sclerosis. *Perspectives in Psychiatric Care* 54(3): 428-435. doi: 10.1111/ppc.12293

lasiukiavichene L and Vasiliauskas D (2006) Chronic fatigue syndrome in cardiology neurohumoral changes. *Kardiologiia* 46, 58–64. (in Russian)

Jakubíková H and Klímová E. (2010) Paliatívna liečba a starostlivosť o chorých so sclerosis multiplex. *Paliatívna Medicína a Liečba Bolesti* 3(1): 12–14. (in Slovak)

Jensen MP, Smith AE, Bombardier CH, et al (2014) Social support, depression, and physical disability: age and diagnostic group effects. *Disability and Health Journal* 7(2): 164-172. doi: 10.1016/j.dhjo.2013.11.001

Johansson S, Ytterberg C, Gottberg K, et al (2009) Use of health services in people with multiple sclerosis with and without fatigue. *Multiple Sclerosis* 15(1): 88–95. doi: 10.1177/1352458508095730

Khan F, Amatya B, Galea M (2014) Management of fatigue in persons with multiple sclerosis. *Frontiers in Neurology* 5: 177. doi: 10.3389%2Ffneur.2014.00177

Khatri IA, Aliwair S, Alammar H, et al (2021) Social anxiety and obsessive-compulsive disorder are common among persons with multiple sclerosis at King Abdulaziz Medical City, Riyadh. *Cureus* 13(2):e13619. doi: 10.7759/cureus.13619

Kingdom of Saudi Arabia (2016) Saudi Vision 2023 https://www.vision2030.gov.sa/en

Klevan G, Jacobsen CO, Aarseth JH, et al (2014) Health related quality of life in patients recently diagnosed with multiple sclerosis. *Acta Neurologica Scandinavica* 129(1): 21-26. doi: 10.1111/ane.12142

Kołtuniuk A, Kazimierska-Zajac M, Cisek K et al (2021) The role of stress perception and coping with stress and the quality of life among multiple sclerosis patients. *Psychology Research and Behavior Management* 14: 805-815. doi: 10.2147/PRBM.S310664

Kos D, Kerckhofs E, Nagels G, et al (2008) Origin of fatigue in multiple sclerosis: review of the literature. *Neurorehabilitation and Neural Repair* 22(1): 91–100. doi: 10.1177/1545968306298934

Krupp LB, LaRocca NG, Muir-Nash J, et al (1989) The Fatigue Severity Scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology* 46(10): 1121–1123. doi: 10.1001/archneur.1989.00520460115022

Latimer-Cheung AE, Pilutti LA, Hicks AL, et al (2013) Effects of exercise training on fitness, mobility, fatigue, and health-related quality of life among adults with multiple sclerosis: a systematic review to inform guideline development. *Archives of Physical Medicine and Rehabilitation* 94(9): 1800-1828. doi: 10.1016/j.apmr.2013.04.020

Leonavicius R (2016) Among multiple sclerosis and fatigue. *Neurology, Psychiatry and Brain Research* 22(3-4): 141-145. doi: 10.1016/j.npbr.2016.08.002

Naci H, Fleurence R, Birt J, et al (2010) Economic burden of multiple sclerosis: a systematic review of literature. *Pharmacoeconomics* 28(5): 363–79. doi: 10.2165/11532230-00000000-00000

Ormel J, Lindenberg S, Steverink N, et al (1997) Quality of life and social production functions: a framework for understanding health effects. *Social Science and Medicine* 45(7), 1051–1063. doi: 10.1016/s0277-9536(97)00032-4

Özkeskin M, Özden F, Karaman B, et al (2021) The comparison of fatigue, sleep quality, physical activity, quality of life, and psychological status in multiple sclerosis patients with or without COVID-19. *Multiple Sclerosis and Related Disorders* 55: 103180. doi: 10.1016/j.msard.2021.103180

Papuć E and Stelmasiak Z (2012) Factors predicting quality of life in a group of Polish subjects with multiple sclerosis: Accounting for functional state, socio-demographic and clinical factors. *Clinical Neurology and Neurosurgery* 114(4), 341–346. doi: 10.1016/j.clineuro.2011.11.012

Plow M, Finlayson M, Motl RW, et al (2012) Randomized controlled trial of a teleconference fatigue management plus physical activity intervention in adults with multiple sclerosis: Rationale and research protocol. *BMC Neurology* 12: 122. doi: 10.1186/1471-2377-12-122

Riyadh Behavioural Insights Center (2022) Achieving gender equality at work in Saudi Arabia.

https://www.hrsd.gov.sa/sites/default/files/2024-

03/20220520_RBIC%20-%20KSA%20gender%20norms%20and%20BI%20report_3.pd

Sayao AL, Bueno AM, Devonshire V, et al (2011) The psychosocial and cognitive impact of longstanding 'benign' multiple sclerosis. *Multiple Sclerosis Journal* 17(11): 1375–1383. doi:10.1177/1352458511410343

Schwid SR, Covington M, Segal BM, et al (2002) Fatigue in multiple sclerosis: current understanding and future directions. *Journal of Rehabilitation Research and Development* 39(2): 211–224.

Tan-Kristanto S and Kiropoulos LA (2015) Resilience, self-efficacy, coping styles and depressive and anxiety symptoms in those newly diagnosed with multiple sclerosis. *Psychology*, *Health & Medicine* 20(6): 635-45. doi: 10.1080/13548506.2014.999810

Torchio A, Fusari G, Perini G, et al (2022) Objective and subjective measures of daily physical activity in persons with multiple sclerosis beginning a rehabilitation regime: A cross-sectional study. *Multiple Sclerosis and Related Disorders* 68: 104394. doi: 10.1016/j.msard.2022.104394

Vickrey BG, Hays RD, Harooni R, et al (1995) A health-related quality of life measure for multiple sclerosis. *Quality Life Research* 4(3): 187-206. doi: 10.1007/BF02260859

Ware JE and Sherbourne CD (1992) The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 30(6): 473–483. doi: 10.1097/00005650-199206000-00002

Warner R (2013) Applied statistics from bivariate through multivariate techniques. (2nd Ed) Sage Publications, London.

Whitmarch ET (2003) Homeopathy in multiple sclerosis. *Complementary Therapies in Nursing & Midwifery* 9(1): 5–9. doi: 10.1016/S1353-6117(02)00105-1

Characteristics	Number (%)	
Marital status		
Single	89 (44.3%)	
Married	99 (49.3%)	
Divorced	7 (3.5%)	
Widow	6 (3%)	
Engaged in activity		
Yes	56 (27.9%)	
Νο	149 (72.1%)	
Employment status		
Full time	42 (20.9%)	
Part time	31 (15.4%)	
Unemployed	128 (63.7%)	

Table 1. Frequency distribution of marital status, engagement in activity and employment status

Table 2. Mean scores of Fatigue items scale

Item	Item	Mean (SD)
number		
1	My motivation is lower when I am fatigued	5.70 (1.40)
2	Exercise brings on my fatigue	5.47 (1.48)
3	I am easily fatigued	5.61 (1.34)
4	Fatigue interferes with my physical functioning	5.65 (1.26)
5	Fatigue causes frequent problems for me	5.50 (1.52)
6	My fatigue prevent sustained physical functioning	5.51(1.55)
7	Fatigue interferes with carrying out certain	5.73(1.39)
	duties and responsibilities	
8	Fatigue is among my most disabling symptoms	5.68 (1.40)
9	Fatigue interferes with my work family or	5.47 (1.67)
	social life	

Table 3. Mean scores for HRQoL domains

HRQoL Domains	Mean (SD)
Physical Functioning	65.69 (32.39)
Role functioning/physical	44.77 (41.80)
Role functioning/emotional	42.78 (44.64)
Energy/fatigue	30.87 (21.47)
Emotional well-being	43.36 (23.86)
Social functioning	47.13 (27.60)
Pain	39.21 (26.81)
General health	35.69 (23.57)
Total QOL	43.69 (25.97)

Table 4. Relationship between HRQoL and fatigue scores

HRQoL Domains	Fatigue	
Physical Functioning	-0.552**	
Role functioning/physical	-0.586**	
Role functioning/emotional	-0.579**	
Energy/fatigue	-0.632**	
Emotional well-being	-0.527**	
Social functioning	-0.633**	
Pain	-0.636**	
General health	-0.613**	
Total QOL	-0.685**	

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).