

DETAILED REPORT

# MULTIPLE SCLEROSIS AWARENESS BASELINE SURVEY IN THE UNITED ARAB EMIRATES

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## FOREWORD

As we navigate the complexities of healthcare, it is imperative that we shine a light on conditions that often exist in the shadows of misunderstanding and misconception. Multiple Sclerosis (MS) is a condition that highlights the resilience of the human spirit in the face of adversity.

It is a great honor to present the findings of the MS Awareness Baseline Survey in the United Arab Emirates (UAE). This comprehensive study, conducted under the auspices of the National Multiple Sclerosis Society (NMSS), sheds light on the landscape of MS awareness, perception, and support systems within our nation. As the Vice Chair of the National Multiple Sclerosis Society, Director General of the Emirates Drug Establishment, and Executive Director of the Abu Dhabi Bone Marrow Transplant Program at the Abu Dhabi Stem Cells Center (ADSCC), I am deeply committed to advancing the cause of health awareness and particularly Multiple Sclerosis awareness and support for people living with Multiple Sclerosis (PwMS). This commitment is rooted in a profound understanding of the challenges they face and a deep belief in the transformative power of knowledge, empathy, and collaboration.

The findings presented in this report serve as a call to action for policymakers, healthcare professionals, advocacy organizations, and the wider community. They underscore the urgent need for raising the level of awareness of Multiple Sclerosis as a chronic disease, to dismantle the barriers that hinder the well-being of PwMS.

Together, let us harness the power of knowledge, compassion, and solidarity to transform the lives of people living with Multiple Sclerosis in the UAE and beyond.

With sincere regards,

HE Dr. Fatima Al Kaabi Vice Chair of the National Multiple Sclerosis Society, Director General of the Emirates Drug Establishment, and Executive Director of the Abu Dhabi Bone Marrow Transplant Program at the Abu Dhabi Stem Cells Center (ADSCC).

## ABBREVIATIONS

CNS	Central Nervous System
HCP	Health Care Professional
MS	Multiple Sclerosis
PwMS	People Living with MS

## ABOUT

### THE NATIONAL MS SOCIETY (NMSS)

The National Multiple Sclerosis Society (NMSS), which operates under the Ministry of Community Development in the UAE, is dedicated to bettering the lives of people with Multiple Sclerosis and their communities through education, advocacy, and contributing to global research for a cure.

The National Multiple Sclerosis Society strives to raise awareness of Multiple Sclerosis, establish a comprehensive support system for the Multiple Sclerosis community in the UAE, and provide resources to those impacted by the condition.



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# EXECUTIVE SUMMARY

## BACKGROUND

Multiple Sclerosis (MS) affects an estimated 2.9 million people worldwide, and in the region, the burden has been significantly rising over the past decade. In the UAE, the total prevalence of MS was estimated in 2011 and 2016 to be 18-19 per 100,000 people. Despite the increasing prevalence of MS in the UAE, public awareness of the condition remains low, leading to widespread misconceptions that can have serious consequences for people living with MS (PwMS) and impede timely diagnosis.

## METHODOLOGY

A cross-sectional, population-based, face-to-face survey was conducted of 1054 adults  $\geq 18$  years of age, including Emiratis and expats. The survey assessed public awareness of MS, perceived symptoms, preferred health information sources, and the perceived challenges that impact PwMS.

## RESULTS

Approximately 70% of respondents have either never heard of or heard of MS but are unfamiliar with any other information about it. Only 31% of respondents expressed that they have basic to good knowledge. Within this group, although there is a general understanding of physical symptoms such as walking difficulties, knowledge of MS symptoms was poor where only the seen symptoms such as walking difficulties were mentioned.

About half of these individuals were unaware of invisible symptoms such as fatigue, pain, and cognitive problems. The most crucial needs identified were affordable and accessible medication and support from employers or assistance finding employment.

Common misconceptions included that MS is a condition that prevails among older people, that it equally affects men and women, that it is contagious, and that PwMS should not exercise.

## CONCLUSIONS

The public understanding of MS remains low, leading to significant knowledge gaps regarding symptoms and misconceptions about the condition. This lack of awareness can hinder early diagnosis and appropriate treatment, contribute to stigma, and impact the level of support received from friends and family of PwMS.

Raising public awareness through social media, educational programs, and clear communication strategies is crucial. Additionally, policy changes that address medication access and employment opportunities for people living with MS are essential in supporting their well-being.

# Introduction

Multiple sclerosis (MS) is a chronic, neuroinflammatory autoimmune condition affecting the central nervous system (CNS) characterized by demyelination of the myelin sheath, a protective layer surrounding nerve fibers and causing damage to the nerve fibers. This leads to the dysregulation of the immune system, causing it to mistakenly attack healthy tissues in the CNS.

This damage can be irreversible and causes People living with MS (PwMS) to experience a diverse range of symptoms, including visual disturbances, motor impairments, and disruptions in various bodily functions. MS symptoms can immensely affect daily life activities.

## 2.9M

Individuals worldwide are affected by MS.

## 64 / 100K

Emiratis in Abu Dhabi are diagnosed with MS.

## 2-3<sup>x</sup>

MS affects women two to three times more frequently than men.

Despite affecting an estimated 2.9 million individuals globally, currently, there is no cure for MS (MS Atlas, 2023). MS typically develops in young adults between the ages of 20 and 40. This can significantly impact individuals as they navigate important life stages like starting families or building careers. It is important to note that women are diagnosed with MS two to three times more frequently than men.

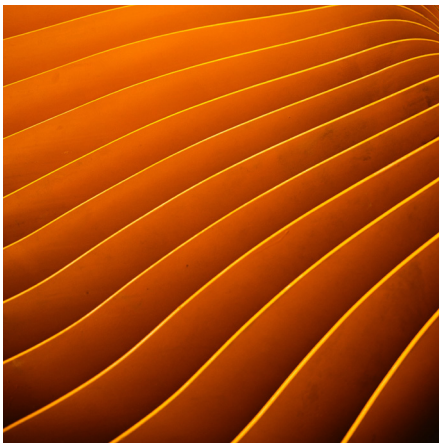
The UAE is witnessing a concerning rise in MS. The total prevalence of MS cases in the UAE was estimated in 2011 and 2016 to be 18-19 per 100,000 (Sheiss et al., 2016; Inshasi et al., 2011).

Approximately 64 per 100,000 Emiratis in Abu Dhabi are diagnosed with MS (Schiess et al., 2016); this is twice the global estimate of 30 per 100,000 (MS Atlas, 2023). While this figure is lower among expats, this should not automatically be interpreted as a lower burden of the condition, as expats often face difficulties accessing diagnostics due to limited health insurance, and they may even leave the country for treatment due to accessibility concerns and high healthcare costs (Schiess et al., 2016).

Lack of condition awareness can delay individuals from recognizing symptoms and seeking timely diagnosis (Solomon et al., 2023). This can hinder their ability to access early treatment and potentially worsen the progression and prognosis of the condition.

In the region and the UAE, there is a significant lack of data on the true burden of MS (Alroughani & Al Jumah, 2014; Inshasi & Thakre, 2011). This results in a lack of understanding of the challenges faced by PwMS and healthcare providers, making it hard to effectively allocate resources for MS (Aderinto et al., 2023). Furthermore, PwMS often struggle to find clear and up-to-date information about their condition, which can be confusing and stressful, making it hard to manage their illness (Hosseini et al., 2022; Mehr & Zimmerman, 2015). The lack of public awareness was considered a challenge for PwMS in the UAE as it often impacted the support received from family and friends (Kasie S., 2021).

These challenges can significantly impact the well-being of individuals with MS, highlighting the need for improved awareness, earlier diagnosis, and access to credible information.



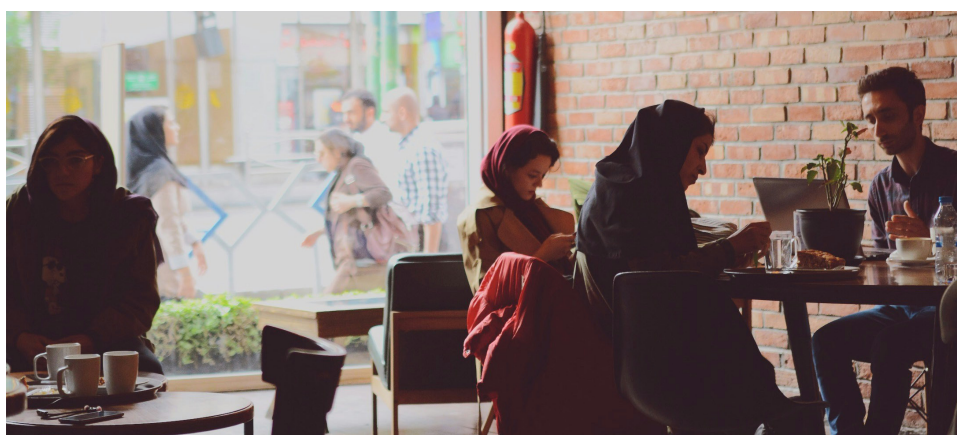
## WHY IS THIS STUDY IMPORTANT?

Public understanding of MS, including knowledge, attitudes, and perceptions, plays a crucial role in various aspects of the condition. Improved public understanding of MS symptoms can empower individuals to seek medical advice earlier, potentially leading to faster diagnosis and timely treatment (US National MS Society, 2024). It could help in addressing misconceptions and promoting accurate information that can reduce the stigma associated with MS.

When the public understands the challenges individuals face with MS, it can foster empathy and a sense of compassion (National MS Society, 2024). This can translate into improved support systems from families, friends, colleagues, and the wider communities, leading to better overall well-being for individuals with MS.

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**This study aimed to gain a comprehensive understanding of the UAE's general population by assessing their knowledge and perspectives on MS, including its symptoms and the perceived challenges faced by PwMS.**



## WHAT THIS STUDY ADDS

This study contributes to the field by exploring nationwide perceptions of MS across the UAE. It captures the perspectives of Emiratis, Arab expats, and non-Arab expats residing across all emirates, including Abu Dhabi, Dubai, Sharjah, and the Northern Emirates.

This comprehensive approach ensures that the study reflects the diverse population of the UAE, unlike other studies in the region that often focus solely on the national population despite significant expat communities (Asmri et al., 2020). Additionally, the study explores the perceived challenges that PwMS experience, which provides valuable insights for program design, policy adjustments, and future research considerations.



# Study design and methodology

This cross-sectional descriptive study was conducted across UAE between 30th July 2023 to 4th September 2023.

# 1,054

Participants recruited for the study.



## 01. SAMPLE

A total of 1,054 participants were recruited to ensure a representative sample of the target population across key demographic characteristics, including gender and age. Additionally, to gain deeper insights into the Emirati population, the sample included a higher proportion of Emirati nationals compared to their overall population percentage in the UAE.

## 02. DATA COLLECTION

The participants were interviewed randomly. Data was collected using a validated questionnaire. The questionnaire contained 11 items and was divided into 3 sections:

- A) Sociodemographic characteristics, including age in years, gender, education level, employment, and marital status.
- B) Knowledge of MS and sources of information on MS.
- C) MS knowledge and perception among personal acquaintances of PwMS.

## 03. DATA ANALYSIS AND ETHICAL CONSENT

The data analysis was conducted using a 95% confidence level with a 5% margin of error; all  $p$  values  $< 0.05$  were considered statistically significant, allowing for generalization of the findings to the wider population with a high degree of certainty. Furthermore, the study adhered to ethical research principles, including informed consent, confidentiality, and anonymity.

# Results

# DEMOGRAPHIC CHARACTERISTICS

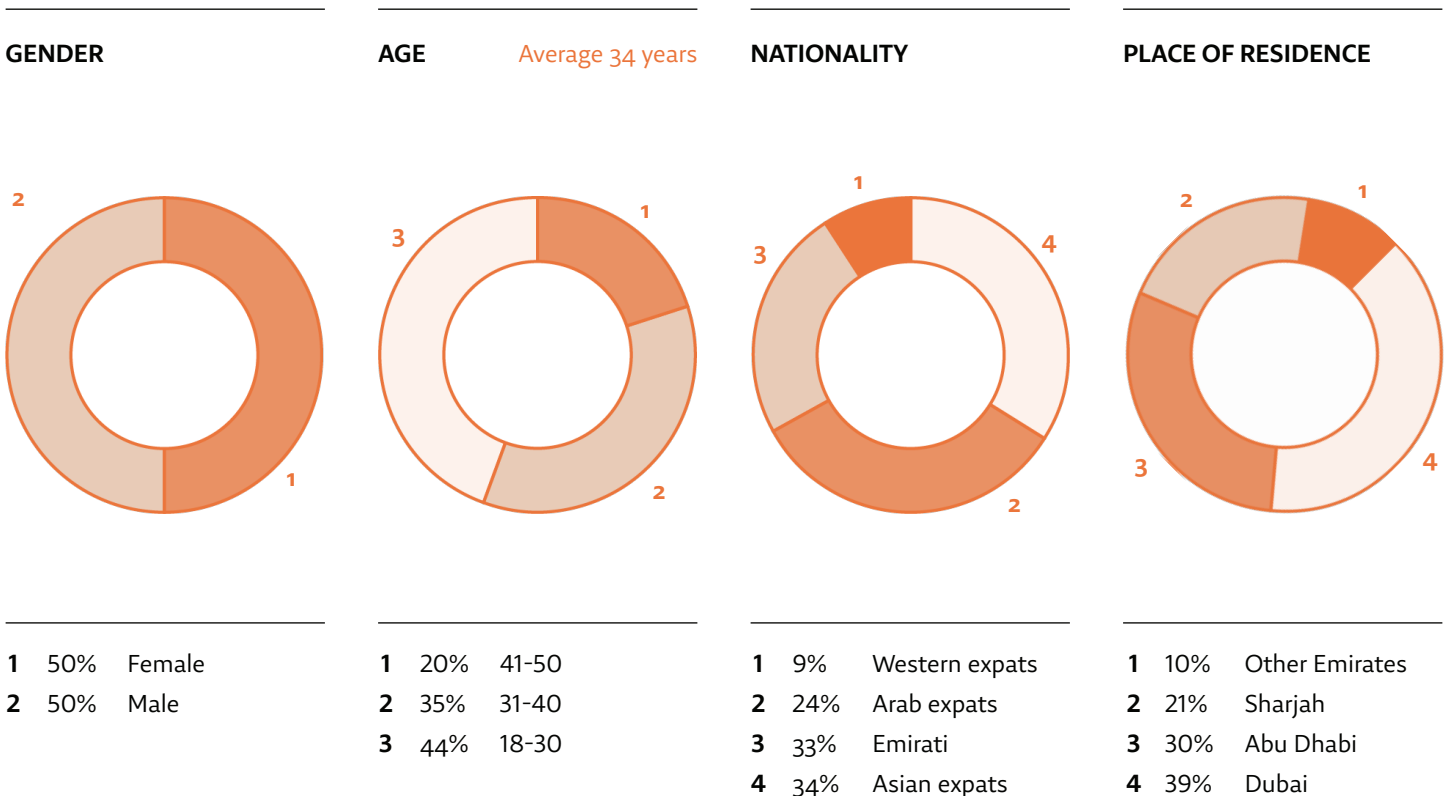
## 31-44

Most common age group of the participants.

A total of 1,054 participants answered the questionnaire. The most common age group of the participants was in the age range of 31-44 years. This study included representation across all seven emirates, representing 34% Asian expats, 33% Emiratis, 24% Arab expats, and 9% Western expats, as shown in Figure 1.

Overall, a significant proportion of participants (60%) had formal education and were employed. 90% held private insurance and had an average monthly household income above AED 12,000.

**FIG 1. SAMPLE CHARACTERISTIC OF THE MS AWARENESS BASELINE SURVEY IN THE UAE**



# OVERALL AWARENESS

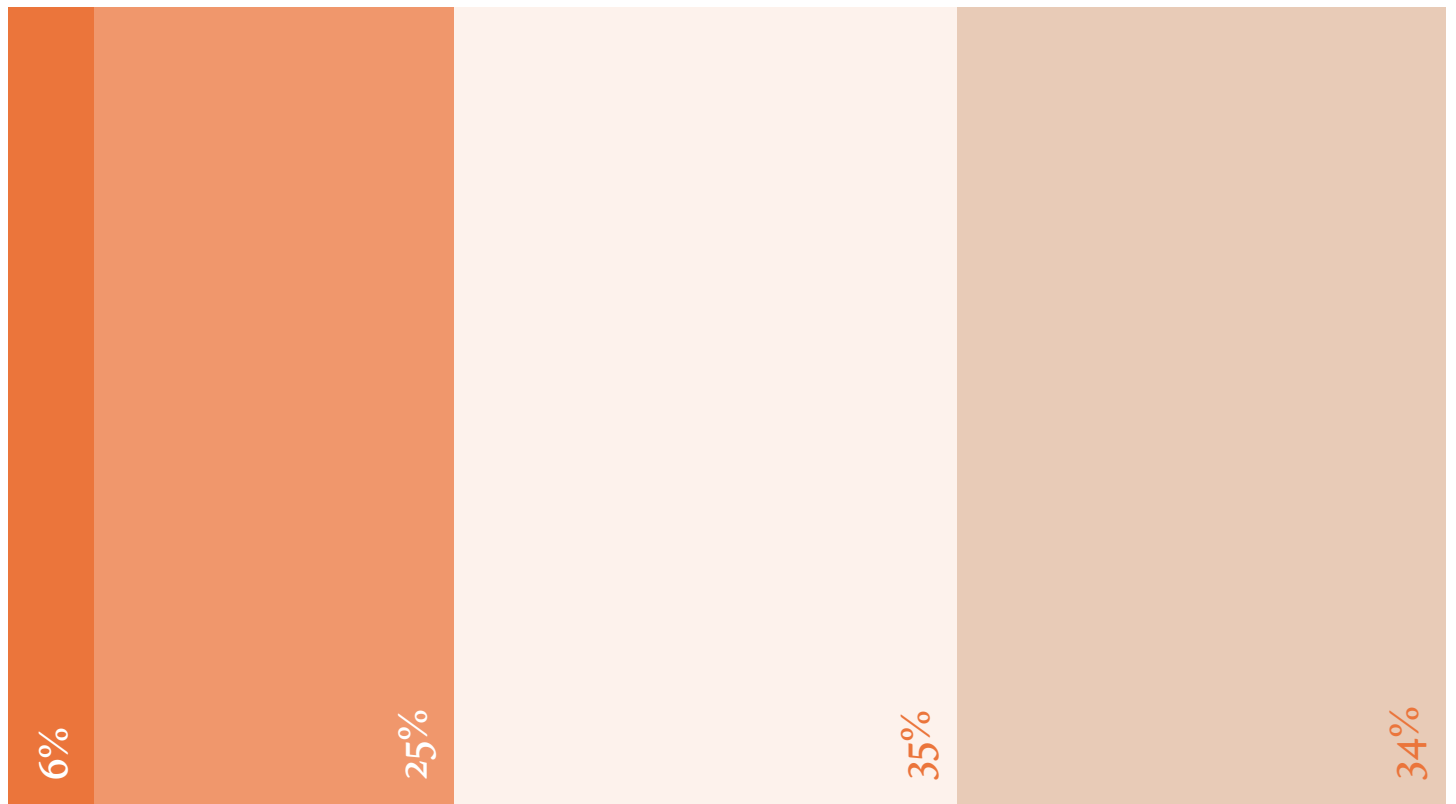
## 31%

Respondents stated to have basic to good awareness about MS.

### LOW AWARENESS OF MS IN THE UAE

Only 31% of those interviewed had basic to good awareness of MS. Approximately 70% of respondents have either never heard of MS or have heard of it but are not familiar with any information about the condition, as shown below in Figure 2. Of these, two-thirds consider it highly important to learn about MS.

FIG 2. AWARENESS OF MS AMONG THE POPULATION INTERVIEWED



### LEGEND

● Heard of this condition and have good knowledge on this condition.

● Heard of this condition and know some basic knowledge on this condition.

● Heard of this condition but not familiar with any further knowledge on this condition.

● Never heard of this condition.

**Healthcare providers play a pivotal role in MS awareness;** individuals first learned about it from healthcare professionals (HCPs) such as doctors or nurses.

**Social media plays a significant role in MS health information-seeking behavior,** with Instagram emerging as the most popular platform, especially among Emiratis in Abu Dhabi (around 50%). Television remained another important information source for many (around 44%).



**44%**

Of people get their information from watching television.



# Awareness among respondents with basic to good knowledge of MS.

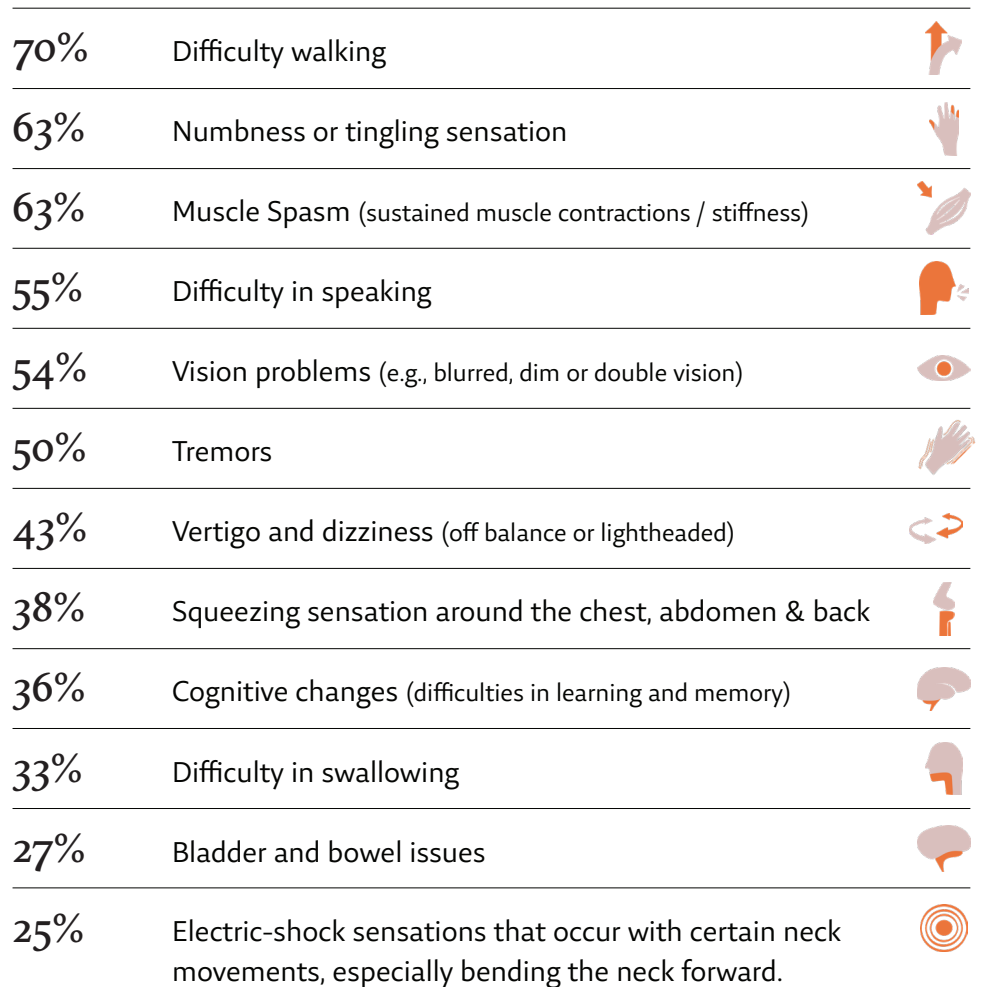
## KNOWLEDGE ABOUT COMMON MS SYMPTOMS

Limited identification of the MS symptoms was evident among those reporting knowledge of MS. While those who claim to have basic knowledge of MS were aware of a few general symptoms, they often only recognized physical ones such as trouble walking, numbness, and muscle spasms, as shown in Figure 3.

Nearly two-thirds were aware of walking and movement difficulties for most PwMS but were not aware of other hallmark symptoms of MS, such as fatigue, brain fog, and pain. This can leave PwMS feeling unheard and unseen.

FIG 3. COMMON SYMPTOMS AMONG THE MS AWARE GROUP

N: 322



50%



Nearly half believe exercise is harmful for PwMS.

40%



2 out of 5 think MS affects both men and women equally.

33.3%



1 out of 3 believe MS is contagious.

20%



Around 1 in 5 think MS only affects older adults.

## Perceptions of the challenges faced by PwMS

Survey participants primarily identified mobility limitations as the most significant challenges associated with MS. Approximately 66% reported that maintaining balance and walking were the most frequently mentioned difficulties. Pain and discomfort were reported by around half of the participants, and a significantly lower proportion (only 47%) recognized social interaction challenges as a symptom of MS. Notably, even fewer participants (around 40%) identified cognitive issues like memory, concentration, and speech difficulties.

These findings highlight the need for increased awareness of the wide range of symptoms associated with MS, including those that may not be readily apparent.



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Despite having knowledge about MS, misconceptions remain widespread. It was noted that misconceptions were more common among the non-Arab expat group, where 70% of non-Arab expats thought that MS is contagious.

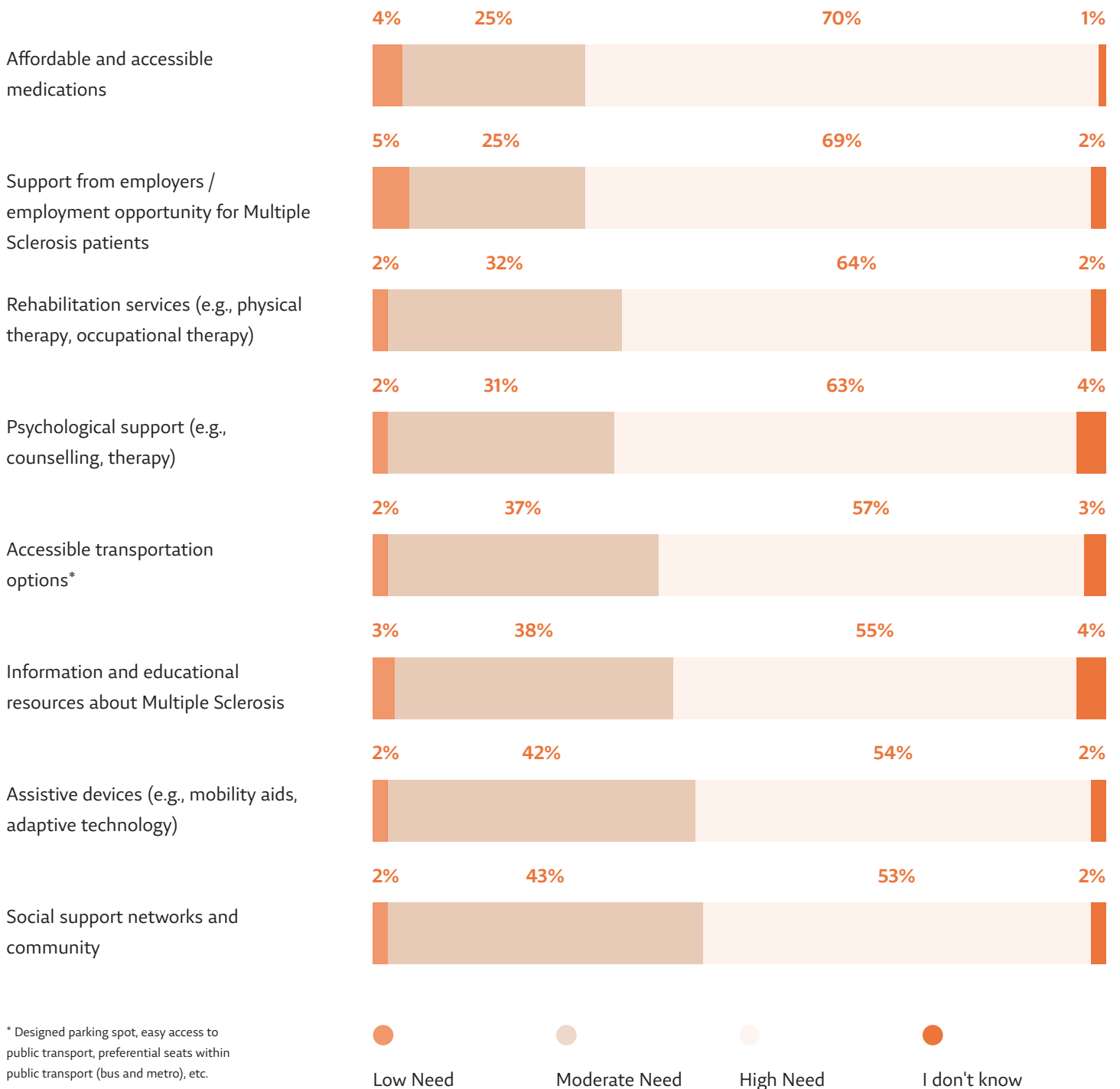


## PERCEPTION ON THE LEVEL OF NEED TO SUPPORT PWMS

While several areas were identified as important for supporting PwMS, as determined in Figure 4 below, the study found that respondents overwhelmingly felt the most crucial needs were affordable and accessible medication and support from employers or assistance finding employment.

**FIG 4. PERCEPTION ABOUT VARIOUS CHALLENGES ASSOCIATED WITH MS AND ITS IMPACT ON PATIENT'S DAILY LIFE**

N: 322



## FINDINGS

# 69%

Believe that support to find and maintain employment is highly needed.

**Access to treatment and medication for PwMS is a major concern, especially for Arab expats and local Emiratis.** Over 70% of people surveyed emphasized that PwMS have a high need for affordable and accessible medication.

**Support to find and maintain employment is highly needed,** as identified by respondents (69%) 82% of Arab expats and 77% of Emiratis felt that PwMS often don't have the right support for employment opportunities or the adaptable environment that could let them carry on their jobs.

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**These findings likely reflect the significant financial burden MS can place on PwMS and the need for better support systems to help them manage both their health and livelihood.**



**Arab expats reported that they felt PwMS face particular challenges in accessing rehabilitation services,** where around 78% and 75% of Arab expats reported that PwMS are in high need of psychological and rehabilitation services, respectively.

**Respondents believed that PwMS in the UAE face challenges in accessing assistive technologies, home adjustments, and mobility tools** despite having the potential to improve independence and quality of life significantly. This was particularly strong among individuals with moderate household incomes and 60% of those with private insurance, highlighting potential financial and insurance-related barriers that may limit access to these essential tools.

**Practical support, including transportation services and information provision, was highlighted** as a significant area of need. Over 50% of respondents emphasized the importance of accessible transportation options and access to relevant information and education for PwMS.

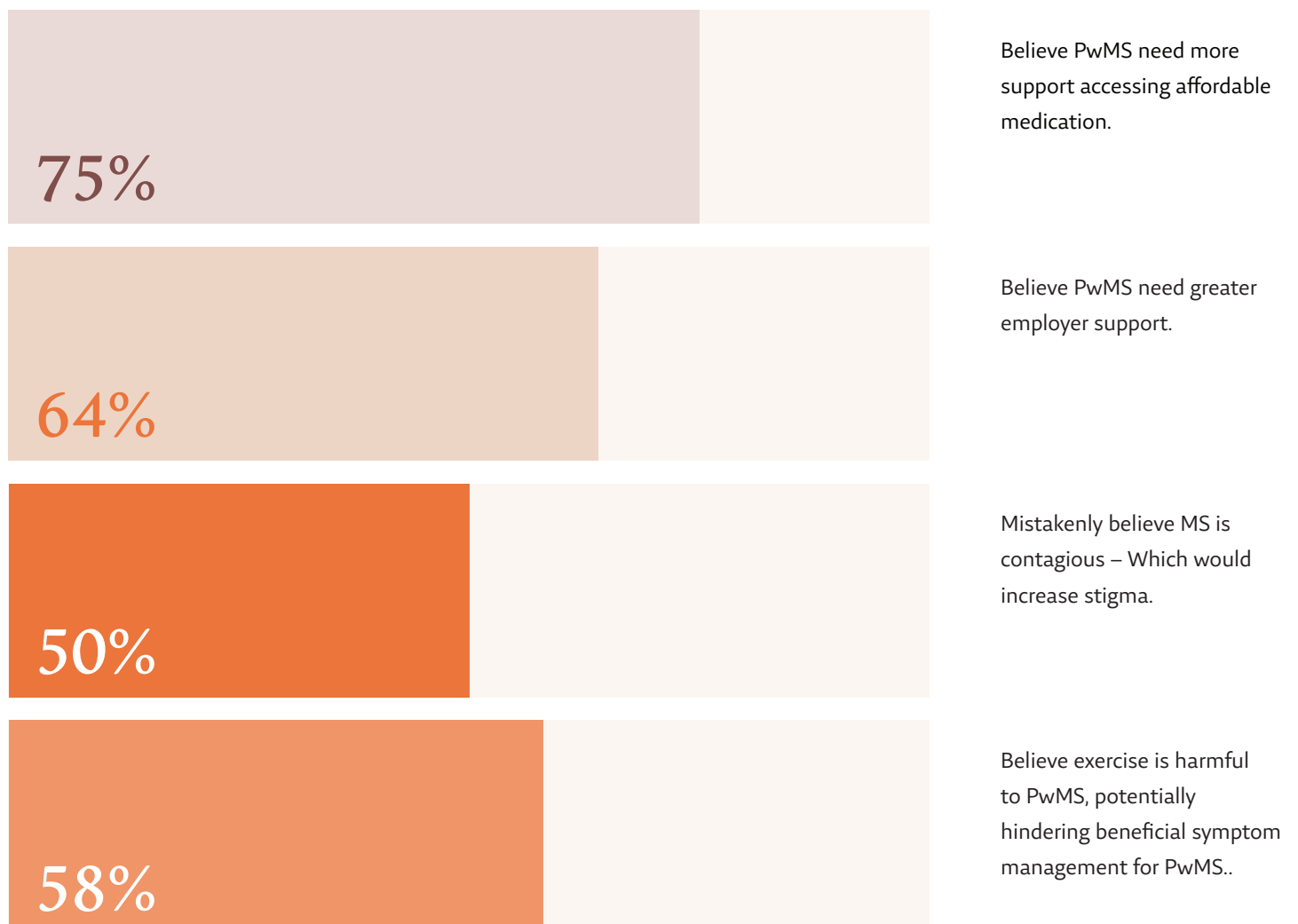
The results underpin the significant efforts the UAE has made to provide social network support for PwMS, as evidenced by the lower percentage of the general population feeling this is a required need.

However, 60% of Arab expats still believe that additional social support structures are crucial for PwMS. This reflects the importance of social support for PwMS as the condition could be daunting, and having social support can ease their lives.

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## AWARENESS OF PERSONAL ACQUAINTANCES OF PWMS.

Acquaintances express concerns regarding PwMS's challenges in accessing affordable medication and finding and maintaining employment. Despite close relationships with people with PwMS, acquaintances may still hold misconceptions about the condition.



# MS Myths debunked: What you really need to know.

## **MS IS NOT CONTAGIOUS**

This means you cannot catch it from someone else through contact or interaction. It is an autoimmune condition where the body's immune system mistakenly attacks healthy tissues (MS Atlas, 2023).

While the exact cause of MS remains unknown, research suggests a combination of genetic and environmental factors may contribute to the condition. Some people may have a higher risk due to their genes or certain environmental exposures, but this does not guarantee they will develop MS (Olsson et al., 2016).

## **PWMS CAN EXERCISE BUT WITH NECESSARY PRECAUTIONS.**

There is no reason individuals with multiple sclerosis cannot exercise; in some cases, stretching can help reduce muscle spasms and improve mood (MS Society, 2024b). Heat often worsens symptoms, so overheating during exercise should be avoided (MS Society, 2024c).

## **MS IS TWICE AS LIKELY TO DEVELOP IN WOMEN COMPARED TO MEN.**

Multiple sclerosis, like most autoimmune disorders, is much more common in women than men at a ratio of about 2:1 (MS Atlas, 2023).

## **MS IS A CONDITION THAT AFFECTS YOUNG ADULTS.**

Most people with MS experience their first symptoms between the ages of 20 - 40 (MS Atlas, 2023). In the UAE, MS often strikes young people with an average onset of around 26 years old (Ahmed M, 2019), which is lower than the global average of 32 years (MS Atlas, 2023).

# RECOMMENDATIONS

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## FOR THE PUBLIC

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|-----------|--|
| <b>01</b> | Learn about the symptoms of MS.  |
| <b>02</b> | Help to dispel myths and stereotypes by sharing accurate information from reputable sources.   |
| <b>03</b> | Be mindful that PwMS can experience mobility issues. Advocate for accessible spaces and transportation options.                            |
| <b>04</b> | Be patient, supportive, and understanding of the experiences of PwMS, especially as some of their struggles are often hard to communicate. |
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## FOR CLOSE ACQUAINTANCES, FAMILIES, CAREGIVERS

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|-----------|--|
| <b>01</b> | Access to accurate information about MS is essential to offer the best support and avoid unintentionally causing harm. |
| <b>02</b> | Understand the symptoms of MS to be better equipped to provide support.  |
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## FOR HEALTHCARE PROVIDERS

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|-----------|--|
| <b>01</b> | Ensure that accurate and timely information about the condition is communicated.   |
| <b>02</b> | Collaborate with the MS care team and ensure collaboration for a holistic approach to patient care. This collaborative approach should consider all professionals, including rehabilitative, occupational, and emotional care professionals. |
| <b>03</b> | Understand the challenges, concerns, and needs of PwMS living with MS; you can better empathize and communicate effectively.   |
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# RECOMMENDATIONS

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## FOR RESEARCHERS

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**01** Research to understand the specific barriers hindering access to crucial support services, medication, assistive technologies, and employment opportunities for PwMS.

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**02** Develop culturally sensitive solutions to explore unique challenges faced by different demographic groups, such as Arab expat communities, in accessing necessary support for MS management and to address different misconceptions among various demographics.

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## FOR MS SOCIETIES

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**01** Ensure continued advocacy to raise awareness of credible information about MS.

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**02** Continue to engage PwMS in social circles and support groups and ensure that PwMS with different backgrounds, such as expats, are represented in the circles.

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