Original Article

Do people with multiple sclerosis in Saudi Arabia want to know their prognosis? A cross-sectional nationwide study

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ABSTRACT

الأهداف: التحقق مما إذا كان الأشخاص المصابون بالتصلب المتعدد (pwMS) في المملكة العربية السعودية يرغبون في مناقشة تشخيصهم طويل الأمد (LTP) والعوامل المؤثرة على هذا القرار باستخدام استبيان عبر الإنترنت.

المنهجية: في هذه الدراسة المقطعية، قمنا بتوزيع استبيان عبر الإنترنت من ديسمبر 2022م إلى يوليو 2023م في جميع أنحاء المملكة العربية السعودية لتحديد اهتمام الأشخاص المصابين بالتصلب المتعدد (pwMS) بمناقشة تشخيصهم طويل الأمد. شمل المشاركون مرضى تزيد أعمارهم عن 18 عامًا، من أي جنس، قمنا بتشخيص إصابتهم بالتصلب المتعدد. تم استخدام أسلوب أخذ العينات غير الاحتمالية الملائمة، مع إرسال الاستبيانات من خلال منظمات وقنوات التصلب المتعدد.

النتائج: أفاد ما يقرب من ثلثي (66–68%) من 375 مشاركًا بأن تشخيصهم طويل الأمد لم تتم مناقشته أبدًا أثناء مواعيد طبيب الأعصاب وأعربوا عن عدم تأكدهم بشأن ذلك. بالإضافة إلى ذلك، لاحظ 23.5% وجود تناقضات في المعلومات التي قدمها أطباء أعصاب مختلفون. أعرب معظمهم (81.6%) عن رغبتهم في وجود أداة تشخيصية عند التشخيص. في هذه الدراسة، ارتبطت رغبة مرضى التصلب المتعدد في التعرف على أداة لتقييم التشخيص طويل الأمد ارتباطًا وثيقًا بالعمر، والمستوى التعليمي ($p<0.001$)، والجنس ($p=0.02$). أبدت نسبة أعلى من النساء (65.7%) اهتمامًا بمعرفة هذه الأداة مقارنةً بالرجال (34.3%).

الخلاصة: في حين أن أكثر من نصف مرضى التصلب المتعدد (pwMS) مهتمون بتشخيصهم، إلا أن حوالي ثلثهم فقط يُجرون مناقشات مثالية حول العلاج طويل الأمد مع أطباء الأعصاب. يرغب الكثيرون في الحصول على معلومات حول أدوات التشخيص. هناك حاجة إلى مزيد من البحث لتقييم معرفة المرضى بتشخيصهم وتحسين التواصل مع الأطباء.

Objectives: To investigate whether Persons with MS (pwMS) in Saudi Arabia want to discuss their long-term prognosis (LTP) and the factors influencing this decision using a self-administered online questionnaire.

Methods: In this cross-sectional study, an online questionnaire was distributed from December 2022 to July 2023 across Saudi Arabia to determine pwMS interest in discussing their LTP. Participants included patients over 18 years, of any gender, diagnosed with MS. A nonprobability convenience sampling technique was used, with questionnaires sent through MS organizations and channels.

Results: Almost two-thirds (66–68%) of the 375 respondents reported that their LTP had never been discussed during neurologist appointments and expressed uncertainty about it. Additionally, 23.5% noted discrepancies in information provided by different neurologists. Most (81.6%) expressed a desire for a prognostic tool at diagnosis. In this study, MS patients' desire to learn about a tool for assessing long-term prognosis was significantly associated with age, education level ($p<0.001$), and gender ($p=0.02$). A higher percentage of women (65.7%) showed interest in learning about the tool compared to men (34.3%).

Conclusion: While more than half of pwMS are curious about their prognosis, only about one-third have optimal discussions about LTP with neurologists. Many desire information on prognostic tools. Further research is needed to assess patients' knowledge of their prognosis and improve communication with physicians.

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An autoimmune neurological condition of the central nervous system (CNS), multiple sclerosis (MS) can worsen over time. The prevalence of MS is rising globally, in part because of increased incidence and in part because of earlier diagnosis and longer survival times. In young people, multiple sclerosis is a more frequent source of neurological symptoms.[1,2] Although the precise process of MS development is unclear, some people think it is brought on by an autoimmune attack on the central nervous system's white matter, carried out by T-cell activation. There is also growing evidence that B cells and the innate immune system play a significant part in this attack. The complex interaction between hereditary and environmental factors is thought to be the origin of an autoimmune reaction.

The myelin sheath, an insulating coating that envelops neurones to enhance action potential conduction, can become destroyed, leading to demyelination. This is the main pathogenic feature of multiple sclerosis. But demyelination by itself cannot explain the deficiencies and impairments seen in people with MS (pwMS). Axonal injury, not demyelination, is the primary cause of clinical deficits in multiple sclerosis, according to a recent study, and myelin degradation alone is not enough to produce the whole spectrum of symptoms.[3]

The main diagnostic method for multiple sclerosis is clinical suspicion. To satisfy these requirements, clinical and imaging evidence must be used to demonstrate dissemination throughout time and space. The criteria make it clear that there should be no other explanation for a patient's presentation.[4]

In 2014, the MS phenotypic group's recommendations were presented after reviewing the clinical presentation, course, and progression of the disease. Clinically isolated syndrome, relapsing-remitting MS (RRMS), primary progressive MS (PPMS), and secondary progressive MS (SPMS)[5] are among the current phenotypes of MS. Determining the prognosis of multiple sclerosis is challenging, because its usual course is unpredictable. The clinical course of pwMS determines the prognosis, which is bad and unknown for progressive phenotypes and favorable but uncertain for relapsing-remitting phenotypes.[6]

Communication between doctors and patients is made ambiguous and difficult by differences in the prognosis of diseases. Clinical guidelines like the National Institute of Clinical Excellence[7] emphasize the value of open, sincere communication and providing pwMS with information. There are, however, no guidelines for communicating a patient's prognosis or the uncertainty around the course of their illness.

Physicians communicate in a broad variety of ways. Before determining whether, when, and how to provide expectations and prognostications in an individualized manner, each doctor tries to make a clinical judgment based on their own experience with patients. This is the reason for this diversity. The PwMS reacts differentially to uncertainty and prognostic information. Therefore, doctors should carefully consider if, how, and when to inform patients about their prognosis.[8]

Only a small percentage of pwMS receive proper counseling, according to research, and their reactions to prognostic information vary.[9] Although 76% of patients in UK research said they would rather talk about their long-term prognosis, Argentina also showed comparable preferences.[10,11] There is a knowledge gap on the demands and desires of pwMS about their prognosis, nevertheless, no research has been conducted in Saudi Arabia that addresses this topic. Using a self-administered online questionnaire, this study seeks to determine whether pwMS in Saudi Arabia want to talk about their long-term prognosis (LTP) and the factors impacting this desire. The results will fill important research gaps by demonstrating the level of patient interest in LTP conversations and their desire for prognostic tools.

The results of the study show that while over half of the participants were interested in learning more about their LTP, only about one-third of them had a productive conversation regarding LTP with their treating neurologists during follow-up appointments. A lot of patients want to know about the prognostic tools that are available

Methods. In order to ascertain whether pwMS in Saudi Arabia were interested in discussing their LTP, assess patients' attitudes towards prognosis forecasting tools, and investigate whether clinical and demographic factors are linked to and predict LTP, a self-administered online questionnaire was distributed as part of this cross-sectional study.

A comprehensive assessment of the literature was carried out to find previous studies that were relevant to the prognosis of MS and the communication preferences of patients. Specific keywords, such as "multiple sclerosis prognosis," "patient preferences," "prognostic information," and "communication in MS," were used to search databases like PubMed,

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Google Scholar, and Scopus. In order to guarantee relevance and recentness, the search was restricted to English-language publications from 2010 to 2024.

To find more pertinent material, the reference lists of important research were also examined. Empirical research, reviews, and guidelines that addressed prognostic communication and patient involvement in MS care were the main emphasis of the inclusion criteria. In the end, this thorough search approach produced a variety of research that filled in knowledge gaps in the literature, especially in the Saudi Arabian setting, and contributed to the current understanding of patient attitudes towards prognostic conversations.

Raosoft was used to calculate the sample size, with a 5% margin of error, 95% was used as the confidence interval. There were roughly 14,500 patients in the population, and 50% of them responded; 375 people made up the total sample size. The non-probability convenience sampling technique served as the foundation for the study, in which patients with an MS diagnosis received online questionnaires through MS organizations and outlets.

All Saudi Arabian MS patients over the age of 18 who were male or female were included in this study. Following the completion of informed consent, participants were requested to complete an electronic questionnaire that they may complete on their own. There were two sections in the questionnaire. Sociodemographic information, the number of years since MS diagnosis, the number of years since MS symptoms began, and the type of MS (RRMS, SPMS, PPMS) were all included in the first section. Seventeen MS questionnaire items (PIMS study, MS patients' attitudes towards prognosis communication, and their understanding of the condition) in the second portion dealt with prognosis.[11]

Two bilingual translators who speak Arabic as their first language translated the questionnaire from English into Arabic. The questionnaire was modified during a pilot test. Patients whose surveys were not completed

Table 1 - Socio-demographic characteristics of the sample (n=375).

Variables	Number	Percent
Age		
Mean	33.99	
SD	8.87	
20 or less	14	3.7
21– 30	128	34.1
31 – 40	162	43.2
41 – 50	52	13.9
51 and up	19	5.1
Gender		
Male	137	36.5
Female	238	63.5
Education		
Primary or Secondary	55	14.7
Occupational/diploma University	43	11.5
University or postgraduate	268	71.5
Other	9	2.4
Marital Status		
Married	214	57.1
Not married	161	42.9
Nationality		
Saudi	351	93.6
Non-Saudi	24	6.4
Region		
Central Region	166	44.3
Eastern Region	62	16.5
Western Region	88	23.5
Southern region	38	10.1
Northern region	21	5.6
Occupation		
Employed/self-employed (full or part-time)	178	47.5
Not working due to sickness or disability	69	18.4
Retired	24	6.4
Other	104	27.7

Table 2 - MS History among the Subjects in the Sample (n=375).

Variables	Number	Percent
MS type		
RRMS	269	71.7
SPMS	49	13.1
PPMS	57	15.2
Duration since diagnosis (in years)		
Mean	8.59	
SD	6.50	
5 or less	147	39.2
6-10	105	28.0
11-20	107	28.5
21 and up	16	4.3
Duration since the onset of symptoms (in years)		
Mean	9.61	
SD	6.62	
5 or less	112	29.9
6-10	120	32.0
11-20	122	32.5
21 and up	21	5.6

MS - Multiple Sclerosis, RRMS - Relapsing Remitting MS, SPMS - Secondary Progressive MS, PPMS - Primary progressive MS

were not included. Three qualified specialists created the questionnaire and double-checked its content validity. They evaluated the items for completeness, relevance, content coverage, and question clarity (content validity). The necessary adjustments were made.

Statistical Package for Social Sciences version 25 was used to enter and code the data for analysis. Descriptive statistics are used to display data like percentages and frequencies. Both ordinal and nominal variables are shown as percentages and numbers. Means and standard deviations are used to display interval and ratio variables. The association between certain demographic factors and patients' wish to be informed about the LTP estimation tool was evaluated using the chi-square test. The mean period of diagnosis, duration of symptom onset, and patients' desire to be told about the LTP estimation technique were compared using an independent sample t-test. A significance threshold of $p<0.05$ was established.

The study followed the Helsinki Declaration's guidelines for medical research involving human beings in order to maintain ethical compliance. Participants were made aware of the goal of the study, and patient confidentiality was guaranteed. The study was approved by the King Abdullah International Research Centre (approval number IRB/2328/22). To ensure anonymity, codes were allocated to the questionnaires, and each questionnaire's results were kept private to safeguard the privacy of the participants.

Results. The purpose of the cross-sectional study design was to determine whether MS patients were interested in talking about their long-term prognosis. In order to determine if clinical and demographic characteristics are linked to and predict long-term prognosis communication preference, it is necessary to assess patients' views towards prognosis forecasting methods. To determine if Saudi Arabian MS patients would like to talk about their long-term prognosis and the reasons influencing their choice, a self-administered online questionnaire was utilized.

The sample's sociodemographic features are displayed in **Table 1**. The sample's average age was 33.99 (±8.87 years old). Only 3.7% of the sample were under the age of 20 years, whereas over one-third (43.2%) were between the ages of 31 and 40 years. Men made up more than one-third (36.5%) of the sample, while women made up almost two-thirds (63.5%). In terms of education, nearly three-quarters (71.5%) of the sample finished their undergraduate or graduate studies. Married people made up more than half of the sample (57.1%). Ninety-four percent of the sample were Saudi nationals. Central region accounted for 43% of the total. Nearly half of the sample (47.5%) were employed or self-employed.

The sample's MS history is displayed in in **Table 2**. In terms of MS type, RRMS type was present in more than two thirds (71.7%). However, just 13.1% had SPMS. 39.2%, or more than one-third, had a diagnosis within five years. The diagnosis took an average of 8.59 (±6.50 years). In terms of how long symptoms started to appear, the average was 9.61 (±6.62 years). Nearly the same proportion of the participants in the study

Table 3 - Frequency distribution of MS long-term prognosis as reported by the subjects in the sample (N= 375).

Variables	Number	Percent
"During your consultation with your Neurologist, has your long-term prognosis ever been addressed?"		
No	256	(68.3)
Yes	119	(31.7)
"During your appointments, who introduced you the discussion of long-term prognosis?"		
The patient	43	(11.5)
Neurologist	86	(22.9)
Multiple Sclerosis specialist nurse	5	(1.3
GP	5	(1.3)
Other health care professional	5	(1.3
Family member or friend	7	(1.9)
Don't know / can't remember	11	(2.9)
Nobody	256	(70.5)
"Which healthcare professionals gave you different messages when your long-term prognosis was addressed?"		
Different neurologists gave different messages.	88	(23.5)
Different GPs gave different messages.	31	(8.3)
Nobody	256	(68.3)
"Do you well-understand your long-term prognosis?"		
I have no idea at all	248	(66.1)
I have a very rough idea (give or take 20 years)	48	(12.8)
I have a rough idea (give or take 10 years)	39	(10.4)
I have an accurate idea (give or take 5 years)	15	(4.0)
I have a very accurate idea (give or take 2 years)	25	(6.7)
"At the moment, please rate how eager you are to identify your long-term prognosis."		
A lot	231	(61.6)
A little	41	(10.9)
I do not want to know	70	(18.7)
Not sure	33	(8.8)
"The moment your diagnosis was provided, please rate how eager you are to identify your long-term prognosis."		
A lot	225	(60.0)
A little	59	(15.7)
I would not have wanted to know	58	(15.5)
Not sure	33	(8.8)
"In the years to come, please rate how eager you are to identify your long-term prognosis."		
A lot	224	(59.7)
A little	52	(13.9)
I would not have wanted to know	58	(15.5)
Not sure	41	(10.9)
Approximately how often you contemplate about your long-term prognosis?		
Daily	108	(28.8)
Weekly	69	(18.4)
Monthly	54	(14.4)
Once a year	22	(5.9)
Rarely	89	(23.7)
Never	33	(8.8)
"By the following people, have you ever addressed your long-term prognosis with them?"		
Partner or spouse	74	(19.7)
Parents	53	(5.3)
Children	16	(4.3)
Other family members	67	(17.9)
Friends	88	(23.5)
Colleagues at work	10	(2.7)
Employer	9	(2.4)
No-one	210	(56.0)
"Does it will influence your current decision if you will learn an accurate long-term prognosis?"		
Treatment	249	(66.4)
Relationships	117	(31.2)
Family planning (i.e. if and when to have children)	86	(22.9)
Job matters	202	(53.9)
Financial planning	162	(43.2)
Drawing up a will	61	(16.3)
End-of-life decisions (e.g. instructions about medical interventions if you became very ill or disabled)	148	(39.5)

reported experiencing symptoms between the ages of 6 and 10 or 11 and 20 years prior (32% and 32.5%, in that order).

The frequency distribution of MS long-term prognosis as stated by the sample's participants is displayed in **Table 3**. Over two-thirds of the participants

Table 4 - MS oatients' attitudes towards prognosis forecasting tools (N=375).

Variables	Number	Percent
"Do you want to be notified about the availability of this tool during your medical appointment if this tool is successfully created?"		
Yes	321	85.6
No	54	14.4
"What is the timeline you prefer to avail the prognosis tool?"		
At diagnosis	306	81.60
A few weeks or months after diagnosis	52	13.87
When you need to make a treatment decision	115	30.67
When you need to make a life decision	103	27.47
At other times	9	2.40
Never	34	9.07
"Learning your long-term prognosis by using this tool, which of the following setup would you agree?"		
I use the software myself, on my own	131	34.9
Use the software myself, accompanied by a significant other)	98	26.1
With a neurologist, unaccompanied by a significant other	159	42.4
With a neurologist and accompanied by a significant other	116	30.9
With an MS specialist nurse, unaccompanied by a significant other	51	13.6
With an MS specialist nurse and accompanied by a significant other	44	11.3
Never	34	9.1
"The following long-term prognosis can be measured by the tool. At the moment, which of these you most want to know?"		
Whether / when you will need a stick	167	44.5
Whether / when you will need a wheelchair	187	49.9
Whether / when your MS will convert to the secondary progressive	259	69.1
Life expectancy	181	48.3
"Should we announce publicly the availability of the tool, such as on the web?"		
1=Yes	156	41.6
0=No	85	22.7
2=Not sure	134	35.7

in the study (68.3%) stated that they had never been told about their long-term prognosis when they saw a neurologist. The long-term prognosis was discussed by the neurologist in 22.9% of the participants. 23.5% of the sample's participants said that different neurologists conveyed different meanings. About two-thirds of the sample's participants (66.1%) said they were unsure of their long-term prognosis.

Over half of the sample participants (61.6%) stated that they are currently interested in learning their long-term prognosis. Approximately two-thirds (66.4%) wanted to know their long-term prognosis because it will influence their health decisions, 53.9% so they can make decisions about their jobs, and 43.3% so they may draft their will. Because the individuals may choose more than one response, the percentages in this variable are not exclusive.

The attitudes of MS patients regarding prognosis forecasting techniques are displayed in **Table 4**. Most of the participants (85.5%) said they prefer to be notified when the tool is available during a clinic visit. Additionally, most (81.6%) said they would prefer to receive the predictive tool at the time of diagnosis.

Table 5 illustrates the relationship between certain demographic factors and the patient's desire to learn about instruments for predicting long-term prognosis. The age and education level of MS patients were statistically significantly correlated with their desire to learn about a tool for assessing long-term prognosis (p<0.001).

Additionally, the desire to learn about instruments was statistically significantly associated with gender (p=0.02). A higher percentage of women (65.7%) expressed interest in being informed about the instrument compared to 34.3% of men.

The mean time between diagnosis and symptom onset, as well as the patient's wish to learn about methods for predicting long-term prognosis, are compared in **Table 6**. The mean length of the illness, the mean onset of its symptoms, and their wish to learn about a tool for predicting long-term prognosis did not differ statistically significantly (p=0.360 and p=0.239, respectively).

Data analysis. The statistical software tool SPSS version 25 was used to code the data for entry and analysis. Frequencies and percentages were used to display the data using descriptive statistics. Both ordinal and nominal variables were displayed as percentages and integers.

Table 5 - Relationship between the MS patient's desire to be informed about tools for estimating long term prognosis and selected demographic variables.

Variables	If the development of this tool were to succeed, would you like to be informed of this tool's availability during a clinic appointment?		Chi Square	*P*-value
	No (n=54)	Yes (n=321)		
	Number (%)	Number (%)		
Age				
20 or less	0 (0.0)	14 (4.4)		
20–30	13 (24.1)	115 (35.8)	22.05	<0.001
31–40	20 (37.0)	142 (44.2)		
41–50	18 (33.3)	34 (10.6)		
51 and up	3 (5.6)	16 (5.0)		
Gender			4.934	0.020
Male	27 (50.0%)	110 (34.3)		
Female	27 (50.0%)	211 (65.7)		
Education			2.843	0.416
Primary or Secondary	10 (18.5)	45 (14.0)		
Occupational/diploma	9(16.7)	34 (10.6)		
University or postgraduate	34 (63.0)	234 (72.9)		
Other	1 (1.9)	8 (2.5)		

Table 6 - Comparison of the mean duration of diagnosis and duration of symptoms onset and the patient's desire to be informed about tools for estimating long term prognosis.

Variables	If the development of this tool were to succeed, would you like to be informed of this tool's availability during a clinic appointment?				F	P
	No		Yes			
	Mean	SD	Mean	SD		
Duration since diagnosis (in years)	11.31	6.86	8.13	6.33	0.839	0.360
Duration since the onset of symptoms	12.11	7.12	9.19	6.45	1.389	0.239

The means and standard deviations of interval and ratio variables were displayed. The association between the patient's wish to learn about methods for predicting long-term prognosis and certain demographic factors was evaluated using the chi-square test. The mean time since diagnosis and the time since symptoms began, as well as the patient's want to be informed about methods for predicting long-term prognosis, were compared using an independent sample T-test. The level of significance was established at $p<0.05$.

Discussion. Given the wide range in how the disease progresses, prognostic counseling for MS is difficult. For patients and neurologists, who are in charge of creating a treatment plan for the illness in its early stages, this poses a problem.[12] To optimize the balance between therapeutic benefits and potential hazards, treatment planning is insufficient if individual prognostic risks are not taken into account.[12,13] Thus, it is essential to comprehend the prognostic aspects of pwMS. The current study offers fresh perspectives on the LTP preferences and experiences of pwMS in Saudi Arabia.

According to the results of the study, 68.3% of the subjects never discussed LTP with their neurologists at their planned visits. Dennison et al found that 51.3% of participants in the UK did not discuss their LTP with their neurologists, which is in line with our findings. Nonetheless, research conducted in Argentina found that a comparatively smaller percentage of individuals (21.5%) had never spoken to their neurologists about LTP 15.

According to the majority of study participants (66.1%), they do not fully comprehend LTP. 50% and 54.2% of participants in the cross-sectional research carried out in Argentina and the UK, respectively, lacked clarification regarding LTP.[14] Few participants talked to their neurologists about their prognosis outcomes, which may account for the dearth of information on LTP. Additionally, pwMS knowledge of disease processes, therapies, and prognostic variables is below ideal, according to previous Saudi studies.[15] Since the emphasis is on communicating the diagnosis to

patients, there aren't many studies on communication and information preferences surrounding LTP in MS.[16]

According to our results, the majority of participants (66.4%) were eager to find out what their LTP was Similar findings were seen in a UK study where the majority of participants said that LTP knowledge would assist them in making decisions, mostly about treatment (71.2%), end-of-life care (78.3%), and money (77.8%).[11] A German study revealed similar findings: 66% of pwMS wanted the end-of-life issues to be discussed during their neurology sessions, and 76% of them thought it was important to talk about the disease's development.[17]

Several variables contribute to pwMS's desire for a better prognosis. Being aware of the prognosis can enable people to take an active role in choosing their course of therapy. Additionally, individuals can behave appropriately by understanding the possible path of their illness. Furthermore, patients who are aware of their prognosis are better able to plan for the future on both a personal and professional level and establish reasonable expectations. According to earlier research, neurologists do not provide pwMS with enough LTP information when they diagnose them with.[8] Giving pwMS prognostic information necessitates a balanced strategy. As a result, Saudi Arabian professionals ought to receive training on how to discuss patients' long-term health concerns.

When choosing a treatment plan for pwMS, it is critical to take individual prognostic factors into account. Individual risks can be estimated using tools like the Evidence-Based Decision Support Tool in Multiple Sclerosis and online analytical processing, which are based on searches in sub databases that include matching individuals.[18] A prognosis tool should be offered, according to 81.6% of participants in the current study, and 85.5% of participants said they would prefer to be informed about the tool's availability during a clinical consultation.

These results are comparable to those of national cross-sectional studies carried out in Argentina and the United Kingdom. According to this research, the majority of participants (98.9% and 94.3%, respectively) expressed interest in using the tool for their individual LTP estimates.[12] Since participants were not shown any such tool throughout the survey, the question about using the tool for LTP was purely hypothetical. Such surveys will be necessary for future studies on these instruments.

According to a prior study,[19] the LTP tool should be beneficial at various moments in time and aid in decision-making. According to the current survey, 61.6% of individuals said they were very interested in learning about their LTP at that particular moment. Our results are comparable to those of a UK study where 68.5% of participants were asked about their LTP at diagnosis, 76.0% during the survey, and 79.3% after the fact.[11]

There were multiple restrictions on this study. Since this study was cross-sectional, we were unable to assess changes over time in order to determine the underlying causes. Another significant drawback of this study in comparison to a study carried out in the UK was its small sample size.[11] Only 375 of the 14,500 patients took the survey. The reason for this poor reaction could be that patients were either uninterested in this issue or reluctant to discuss their LTP because of stress or fear.

Given that the patients who answered this survey are interested in learning more about their LTP, bias may be present. Additionally, mood problems such anxiety, depression, and cognitive impairment were not assessed in this study. To our knowledge, this study represent an initial report into preferences of Saudi Arabian multiple sclerosis patients regarding information and communication about LTP. Overall, the results of our study show interest in LTP. As a result, healthcare providers ought to communicate with pwMS about LTP more effectively.

To sum up, this study evaluated pwMS's present understanding of the illness and investigated their interest in their LTP. Only around one-third of the individuals had an ideal conversation with their treating neurologists at follow-up visits, even though over half of them expressed interest in learning more about their LTP. Many of the participants also said that they would like to know more about the prognostic tools that are currently available. To evaluate the current patient data on their prognosis and communication deficiencies with their doctors, more research should be carried out both domestically and internationally.

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