Original article

# Do people with multiple sclerosis want to discuss their long-term prognosis? A nationwide study in Argentina

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## ARTICLE INFO

## ABSTRACT

*Background:* Demographics, clinical and imaging prognostic factors have been reported in large series of people with multiple sclerosis (PwMS). However, personalized long-term prognosis (LTP) is varied and uncertain in each particular case. Currently, there is limited evidence on how PwMS feel about prognosis communication and their coping strategies. Therefore, we aimed to assess the prognosis communication experiences and preferences of PwMS. In addition, we investigated whether demographic, clinical and neuropsychological factors are associated with prognosis information preferences.
*Methods:* A cross-sectional online survey that included 301 PwMS from Argentina was carried out. Data on self-administered surveys including prognosis in MS questionnaire (*PIMS* study, evaluating prognosis communication experiences, attitudes and preferences), MS impact scale (*MSIS-29*), Brief Coping Orientation to Problems Experienced (*COPE-28*) inventory, Fatigue Severity Scale and Expanded Disability Status Scale (*EDSS*) were evaluated. A logistic regression model was performed.
*Results:* 21.5% of responders never had discussed LTP with their neurologist and 47.1% lacked clarity about their LTP. PwMS had similar preference for LTP information at diagnosis, survey (current) or in the future (72.4%, 71.7%, 73.4%, respectively). Most participants (94.3%) wanted to be informed about LTP tool availability, and 61.7% wanted to know more about conversion to SPMS. Older age ($p = 0.03$) and lower fatigue ($p = 0.04$), and COPE denial ($p < 0.01$), humour ($p = 0.03$), self-blame ($p < 0.01$) and venting ($p = 0.02$) were associated with lower LTP information preference. Trends were observed for higher MS duration ($p = 0.06$), physical ($p = 0.07$) and psychological ($p = 0.08$) impact. Fatigue and COPE denial were predictors of higher LTP information preference in a multivariate model.
*Conclusion:* PwMS from Argentina want more discussion and clarification about their LTP. Several physical and neuropsychological factors predict LTP information preference.

## 1. Introduction

Multiple sclerosis (MS) is a chronic neurodegenerative and in-flammatory disease of the central nervous system (CNS) (Reich et al., 2018), which mainly presents during the ages of 18–50 years. MS is the most frequent cause of non-traumatic neurological disability in young adults with a universal increase in incidence and prevalence over time in several countries worldwide, including the Argentinean population (Koch-Henriksen and Sørensen, 2010; Cristiano and Rojas, 2017; Negrotto and Correale, 2018). Approximately 80–85% of people with MS (PwMS) experience a relapsing-remitting (RRMS) course and around 10–15% of PwMS have a progressive decline in disability at disease onset, termed primary progressive MS (PPMS), or after some time of RRMS, termed secondary progressive MS (SPMS) (Lublin and Reingold, 1996; Lublin et al., 2014). In most PwMS, axon loss leads to the development of persistent neurological deficit over time, with potential impact over many years of life with respect to health, productivity and quality of life (QoL) (Reich et al., 2018). Different demographic and environmental features, clinical characteristics, biomarkers and imaging prognostic factors have been reported in large

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series of PwMS (Rotstein and Montalban, 2019). However, personalized long-term prognosis (LTP) is varied and uncertain in each particular case (Galea et al., 2013). Prognostication is useful for shared decision-making regarding selection of disease-modifying therapies (DMTs), helping to inform the joint decision of clinicians and patients (Rotstein and Montalban, 2019; Dennison et al., 2018). Nevertheless, there is limited evidence regarding the level of understanding that PwMS have about their LTP and how they feel about LTP communication and their coping strategies. A United Kingdom (UK) qualitative study reported that PwMS have revealed experiences of limited prognosis communication with healthcare professionals and they are often ambivalent about the prospect of receiving more detailed and personalized prognosis information; and consider it may be emotionally deleterious and of limited usefulness (Dennison et al., 2016). However, a subsequent quantitative nationwide UK study revealed that half of PwMS had never discussed LTP with healthcare professionals, and three-quarter of them had strong preferences for receiving LTP information, suggesting bias in the preceding study (Dennison et al., 2018). When PwMS from Germany were asked about their opinion of an online analytical processing tool to help prognostication, this was found to be of modest interest and relevance, though this study was focused around the tool, and its utility in short-term prognostication (Heesen et al., 2013). In another German study of LTP, roughly half the participants found doctors' communication about disease progression inadequate, and the majority wanted to more discussion (Buecken et al., 2012). In this line, different social support, socio-economic status, access to DMTs, geography, and socio-cultural factors could influence patient preferences (Rotstein and Montalban, 2019). Therefore, we aimed to assess the LTP communication experiences and preferences of PwMS from Argentina, who would be expected to present differences compared with people from the above-mentioned regions. In addition, we investigated whether demographic, clinical and neuropsychological factors are associated with LTP information preferences.

## 2. Methods

A nationwide cross-sectional study from 19 out of 23 Argentinean provinces was carried out between February and April 2019. An anonymous, voluntary, self-administered web-based survey was administered by the coordinating center of the study (Hospital Alemán de Buenos Aires) in collaboration with the University of Southampton, UK (I.G), using the Prognosis in MS (PIMS) questionnaire, originally designed to investigate the prognosis communication experiences, attitudes and preferences of PwMS (Dennison et al., 2018).

People diagnosed with MS according to the 2017 McDonald criteria (Thompson et al., 2018), who were under follow-up of some of the co-authors (E.C.C, P.A.L, J.P.P, R.A, S.T and V.T), were invited to participate in the survey. In addition, PwMS recruited from the local Asociación de Lucha Contra la Esclerosis Múltiple (ALCEM) database were also invited to answer the survey via an email that explained the investigation and linked to the survey website. All PwMS under follow-up by the co-authors were also ALCEM members. Therefore, all ALCEM members ($n = 2051$) were invited to participate and 301 completed surveys were identified.

## 3. Data collection

Age at survey, MS duration, gender, MS course (RRMS, PPMS, or SPMS), MS relapses in the last 6 months, education level, current employment and use of MS medications were evaluated. To investigate how much PwMS want to know about their LTP, the PIMS questionnaire was administered, as previously used in a UK nationwide study (Dennison et al., 2018). This questionnaire, which included 17 questions about LTP communication experiences, attitudes and preferences, was designed and used in PwMS from the UK with a high level

of comprehensibility and acceptability (Dennison et al., 2018). Fatigue was assessed using the Fatigue Severity Score (FSS), a self-administered questionnaire including 9 items. Scores for each item can range from 1 (without fatigue) to 7 (highest fatigue level). Responders with scores ≥45 were diagnosed as having significant fatigue (Krupp et al., 1989). The MS impact scale (MSIS-29) is a 29-item self-report measuring the physical (20-items) and psychological (9-items) impact of MS on day-to-day life in the preceding two weeks from the patient's perspective (Hobart et al., 2001). Scores for each item can range from 1 (not at all) to 5 (extremely). Each of the two sub-scales are scored by summing the responses across items, physical impact scoring between 0 and 100 and psychological impact between 0 and 45, with a higher score reflecting a greater degree of disability (Hobart et al., 2001; Riazi et al., 2002). Coping refers to a variety of cognitive and behavioural strategies individuals use to manage responses to stress (Folkman and Moskowitz, 2004), including problem-focused and emotion-focused strategies (Folkman and Lazarus, 1980). The Brief Coping Orientation to Problems Experienced (*COPE-28*) inventory (Carver, 1997) measures 14 different coping strategies across thought or action that people may adopt under stress or in difficult situations: active coping, planning, acceptance, denial, use of instrumental support, use of emotional support, humour, substance use, behavioural disengagement, self-distraction, positive reframing, self-blame, religion, and venting. For each item, respondents indicate whether they have used the coping response on a four-point Likert scale ($0 = I$ have not been doing this at all, $1 = I$ have been doing this a little bit, $2 = I$ have been doing this a medium amount, $3 = I$ have been doing this a lot). In addition, we used the abbreviated Miller Behavioural Style Scale, during which PwMS were presented with fictitious threatening situations to determine their coping personality (see supplementary data) (Steptoe, 1989; Dennison et al., 2018). Visual analogue scales (0–10) were also used to evaluate perceptions of (i) severity of MS and (ii) seriousness of wheelchair-dependency (Boeije and Janssens, 2004). Lastly, disability was evaluated by self-reported Expanded Disability Status Scale (EDSS) (Collins et al., 2016; Kobelt et al., 2017). Patients-reported EDSS ranges from 0 (without disability) to 9 (confined to bed) and correlates highly (95% of feasibility and reliability) with a clinician-scored EDSS, as previously informed (Collins et al., 2016; Kobelt et al., 2017).

This study was approved by the Independent Ethics Committee of the "Hospital Alemán de Buenos Aires". All the participants signed an electronic informed consent form before data collection.

## 4. Statistical analysis

Data analysis was conducted using SPSS Statistics v22. Results are presented as percentages, mean ± SD, and median values. The Kolmogorov-Smirnov test was used to assess the normal distribution of variables. Continuous data were evaluated using T or Mann-Whitney U tests and $\chi^2$ or Fisher exact tests were performed to compare categorical data between groups, as appropriate. Current LTP information preference was dichotomized as follows: higher (want to know a lot, want to know a little) and lower (unsure, don't want to know). We applied multivariate logistic regression analysis to assess the impact of potential variables (demographic, clinical and psychological features) associated with a higher LTP information preference. All variables were included in multivariate regression if univariate analysis showed at least a trend ($p < 0.20$) towards association with current LTP information preference. For all the analyses, the significance level was established as $p < 0.05$.

## 5. Results

The survey was sent to 2051 PwMS (with one reminder after 2 weeks) and 301 of them completed the survey (14.6% response rate). General characteristics of the studied Argentinean cohort are summarized in Table 1. Most responders were female (71.4%), were of the

**Table 1**
General characteristics of the studied Argentinean cohort.

| General characteristics | |
| --- | --- |
| N (simple size) | 301 |
| Mean age at survey y, ( ± SD) | 39.9 ( ± 11.04) |
| Female No (%) | 215 (71.4) |
| MS duration, y mean ± SD (range) | 7.8 ± 7.2 (1–45) |
| **MS course No (%)** | |
| RRMS | 269 (89.3) |
| PPMS | 17 (5.6) |
| SPMS | 15 (4.9) |
| EDSS, mean ( ± SD) at survey | 2.3 ( ± 2.1) |
| **Last relapse No (%)** | |
| < 6 months | 56 (18.6) |
| **Live No (%)** | |
| Alone | 42 (13.9) |
| Spouse or partner | 256 (85.02) |
| Other | 3 (1) |
| **Education No (%)** | |
| Primary school | 44 (14.6) |
| High school | 80 (26.5) |
| Tertiary education | 76 (25.2) |
| University | 101 (33.5) |
| **Employment No (%)** | |
| Employed (full-time) | 110 (36.5) |
| Employed (part-time) | 44 (14.6) |
| Unemployed | 28 (9.3) |
| Self-employed | 37 (12.2) |
| Housewife | 25 (8.3) |
| Retired | 12 (3.9) |
| Retired by MS | 24 (7.9) |
| Currently studying | 21 (6.9) |
| **Fatigue severity scale** | |
| ≥ 45 No (%) | 131 (43.5) |
| Mean ( ± SD) | 38.2 ( ± 20) |
| **MSIS-29 score** | |
| Physical impact mean ( ± SD) | 46.4 ( ± 21.6) |
| Physiological impact mean ( ± SD) | 23.6 ( ± 10.2) |
| **Use of medications No (%)** | |
| Injectables | 83 (27.5) |
| IFN, Pegylated IFN, GA | |
| Oral | 138 (45.8) |
| Fingolimod, Teriflunomide, Dimethyl fumarate | |
| Intravenous | 37 (12.9) |
| Natalizumab, Alemtuzumab, Ocrelizumab | |
| None | 43 (14.2) |

**Table 2**
Long-term prognosis communication experiences and preferences.

| Prognosis communication experiences and preferences | | |
| --- | --- | --- |
| Survey Item | Answer options | N (%) |
| Discussion of LTP during neurology appointments | Yes | 236 (78.4%) |
| | No | 65 (21.5%) |
| Who started LTP discussion[a,b] | Patient | 115 (48.7%) |
| | Neurologist | 136 (57.2%) |
| | Nurse | 5 (2.1%) |
| | General physician | 7 (2.9%) |
| | Other healthcare professional | 11 (4.6%) |
| | Family member/friend | 18 (7.6%) |
| | Do not know/cannot remember | 22 (9.3%) |
| LTP message consistency[a] | Similar | 214 (71.1%) |
| | Different | 38 (12.6%) |
| | Did not talk with health professionals | 49 (16.2%) |
| Source of LTP message inconsistency[a,b,c] | Neurologists | 53 (63.8%) |
| | General physicians | 12 (14.4%) |
| | Different healthcare professionals | 18 (21.6%) |
| Clarity about LTP | No idea | 142 (47.1%) |
| | Very rough idea | 68 (22.5%) |
| | Rough idea | 46 (15.2%) |
| | Accurate idea | 26 (8.6%) |
| | Very accurate idea | 19 (6.3%) |
| Frequency of thinking about prognosis | Daily | 91 (30.2%) |
| | Weekly | 50 (16.6%) |
| | Monthly | 41 (13.6%) |
| | Once a year | 18 (5.9%) |
| | Rarely | 84 (27.9%) |
| | Never | 17 (5.6%) |
| Who is LTP discussed with (non-healthcare professionals)[b] | Partner or spouse | 107 (35.5%) |
| | Parents | 49 (16.2%) |
| | Children | 6 (1.9%) |
| | Other family members | 1 (0.3%) |
| | Friends | 28 (9.3%) |
| | Colleagues at work | 7 (2.3%) |
| | Employer | 1 (0.3%) |
| | No-one | 102 (33.8%) |
| Preference for LTP information: current [301] | Want to know a lot | 216 (71.7%) |
| | Want to know a little | 30 (9.9%) |
| | Not sure | 40 (13.2%) |
| | Do not want to know | 15 (4.9%) |
| Preference for LTP information: in future [301] | Want to know a lot | 221 (73.4%) |
| | Want to know a little | 29 (9.6%) |
| | Not sure | 35 (11.6%) |
| | Do not want to know | 16 (5.3%) |
| Preference for LTP information: at diagnosis [301] | Want to know a lot | 218 (72.4%) |
| | Want to know a little | 35 (11.6%) |
| | Not sure | 37 (12.2%) |
| | Do not want to know | 11 (3.6%) |
| Understanding LTP is useful for decisions about[b] [433 responses from 301 patients] | Treatment | 131 (43.5%) |
| | Relationships | 58 (19.2%) |
| | Family planning | 80 (26.5%) |
| | Job matters | 60 (19.9%) |
| | Financial planning | 52 (17.2%) |
| | Drawing up a will | 8 (2.6%) |
| | End of life medical decisions | 44 (14.6%) |
| Want to be informed about LTP tool availability [301] | Yes | 284 (94.3%) |
| | No | 17 (5.6%) |
| Acceptable timings of LTP tool use[b] [357 responses from 301 patients] | At diagnosis | 133 (44.1%) |
| | Weeks/months post-diagnosis | 40 (13.2%) |
| | At time of treatment decision | 94 (31.2%) |
| | At time of life decision | 52 (17.2%) |
| | Other times | 12 (3.9%) |
| | Never | 14 (4.6%) |

*(continued on next page)*

RRMS sub-type (89.3%) and had a mean EDSS of 2.3 ( ± 2.1), MS duration of 7.8 years (range: 1–45 years) and a mean age at survey of 39.9 years.

As shown in Table 2, 21.5% of responders had never discussed LTP with their neurologist, and when LTP was discussed during the neurology interview, the subject was brought up by the patients in 48.7% of the cases and by the neurologists in 57.2% of them. Interestingly, 47.1% ($n = 141$) of PwMS lacked clarity about their LTP (100 out of 141 [70.9%] of these had discussions about LTP), but 30.2% and 16.6% of responders thought about their LTP daily and weekly, respectively. In addition, PwMS from Argentina felt that the information communicated was inconsistent among different healthcare professionals, with the most commonly identified source of inconsistency being among different neurologists (63.8%) or different healthcare professionals (21.6%). PwMS had similar preference for LTP information at diagnosis, survey (current) or in the future (72.4%, 71.7%, 73.4%, respectively). Most responders (94.3%) wanted to be informed about LTP tool availability, and 61.7% (166 out of 269) of RRMS patients wanted to know more about conversion to SPMS.

As shown in Table 3, older age ($p = 0.03$), lower Fatigue Severity Score ($p = 0.01$), and lower levels of coping strategies on COPE denial ($p < 0.01$), humour ($p = 0.03$), self-blame ($p < 0.01$) and venting ($p = 0.02$) were associated with lower LTP information preference. In addition, statistical trends suggesting a lower LTP information

**Table 2** (*continued*)

Prognosis communication experiences and preferences

| Survey Item | Answer options | N (%) |
|---|---|---|
| Acceptable settings for LTP tool use[b,d] [411 responses from 301 patients] | Independently, alone | 102 (33.8%) |
| | Independently, with F/FM[e] | 83 (27.5%) |
| | With neurologist | 88 (29.2%) |
| | With neurologist and F/FM | 125 (41.5%) |
| | With MS nurse | 5 (1.6%) |
| | With MS nurse and F/FM | 8 (2.6%) |
| Desirable prognostic estimates[b,d] [475 responses from 301 patients] | If/when need stick | 82 (27.2%) |
| | If/when need wheelchair | 87 (28.9%) |
| | If/when convert to SPMS[f] | 156 (57.9%) |
| | Life expectancy | 150 (49.8%) |
| Endorsement of public availability of LTP tool e.g. on web | Yes | 170 (36.6%) |
| | No | 40 (27.0%) |
| | Not sure | 83 (36.4%) |

[a] Question applicable only to participants who answered "yes" to discussion of LTP.

[b] Response option was "Tick all that apply" therefore% will not add up to 100 and there may be different n responders for each response option.

[c] Question applicable only to participants who answered "different" to LTP message consistency.

[d] Applicable only to participants who did not answer "never" to acceptable timings of tool use.

[e]F/FM = friend or family member.

[e] F/FM = friend or family member..

[f] Response option applicable only to participants with RRMS.

**Table 3**

Comparison of demographics and clinical features among lower and higher current LTP information preference groups.

| Current LTP information preference (Dichotomized: Lower/Higher) Potential variables associated with current LTP information preference | Lower (N = 55) | Higher (N = 246) | P-value (effect size) |
|---|---|---|---|
| Age at survey | 42.16 ± 1.754 | 39.47 ± 0.6711 | **0.03 (r = 0.008)** |
| Female | 35 (63.4) | 180 (73.1) | 0.21 |
| MS duration | 9.182 ± 1.123 | 7.557 ± 0.4413 | **0.06 (r = 0.007)** |
| Education (University or not) | 20 (36.3) | 104 (42.2) | 0.51 |
| Employment (Yes or not) | 35 (63.6) | 156 (63.4) | 0.90 |
| EDSS | 2.045 ± 0.2759 | 2.427 ± 0.1363 | 0.71 (r = 0.004) |
| MS course (RR or progressive form) | 8 (14.5) | 24 (9.7) | 0.42 |
| **COPE-28 (scores between 0–3)** | | | |
| COPE active | 4.109 ± 0.2388 | 4.386 ± 0.1040 | 0.26 (r = 0.004) |
| COPE planning | 3.145 ± 0.2824 | 3.654 ± 0.1160 | 0.06 (r = 0.01) |
| COPE acceptance | 4.927 ± 0.1738 | 4.720 ± 0.09250 | 0.32 (r = 0.003) |
| COPE denial | 0.5273 ± 0.1718 | 1.285 ± 0.1114 | **0.002 (r = 0.02)** |
| COPE instrumental support | 3.255 ± 0.2096 | 3.325 ± 0.09708 | 0.75 (r = 0.0003) |
| COPE emotional support | 2.927 ± 0.2781 | 3.041 ± 0.1186 | 0.68 (r = 0.0005) |
| COPE humour | 2.527 ± 0.2841 | 3.199 ± 0.1360 | **0.03 (r = 0.01)** |
| COPE substance use | 0.4182 ± 0.1341 | 0.5203 ± 0.07829 | 0.56 (r = 0.001) |
| COPE behavioural disengagement | 0.9273 ± 0.2024 | 0.9675 ± 0.09088 | 0.85 (r = 0.0001) |
| COPE distraction | 3.564 ± 0.2768 | 3.415 ± 0.1178 | 0.59 (r = 0.0009) |
| COPE positive reframing | 3.891 ± 0.2402 | 3.736 ± 0.1139 | 0.56 (r = 0.001) |
| COPE self-blame | 1.564 ± 0.2152 | 2.276 ± 0.1186 | **0.008 (r = 0.02)** |
| COPE religion | 2.364 ± 0.2997 | 2.154 ± 0.1400 | 0.52 (r = 0.001) |
| COPE venting | 1.891 ± 0.2227 | 2.488 ± 0.1130 | **0.02 (r = 0.01)** |
| **Fatigue severity scale** | | | |
| Total score | 32.20 ± 2.634 | 39.56 ± 1.270 | **(r = 0.02)** |
| Fatigue | 30 (30.9) | 114 (46.4) | **0.04** |
| **MSIS-29** | | | |
| Physical impact | 41.73 ± 2.544 | 47.52 ± 1.413 | 0.07 (r = 0.01) |
| Psychological impact | 21.45 ± 1.280 | 24.09 ± 0.6511 | 0.08 (r = 0.01) |
| Perception of severity of MS (range 1–10) | 6.491 ± 0.3732 | 6.415 ± 0.1614 | 0.84 (r = 0.0001) |
| Perception of severity of MS ** (higher or not) | 34 (61.8) | 168 (68.2) | 0.44 |
| Perception of severity of wheelchair (range 1–10) | 8.200 ± 0.2824 | 8.081 ± 0.1670 | 0.75 (r = 0.003) |
| Perception of severity of wheelchair**(higher or not) | 46 (83.6) | 202 (82.1) | 0.94 |

Definition of LTP with patients: Long-term prognosis (LTP) is an estimate of how you will probably be throughout your lifetime as a result of MS.

Current LTP information preference was dichotomized as follows: higher (want to know a lot, want to know a little) and lower (unsure, don't want to know).

** Variable was dichotomized as follows: low-medium perceived severity and higher perceived severity (cut-off used was 6 or higher).

preference were observed in PwMS with higher MS duration ($p = 0.06$), and lower physical ($p = 0.07$) and psychological ($p = 0.08$) impact. There were no statistical differences when we compared lower vs. higher LTP information preference (attitudes towards LTP) as regards gender, MS duration, education level, employment status, EDSS score, and MS course. In addition, there were no statistical differences when we evaluated perceptions of severity of MS and seriousness of wheelchair-dependency. As shown in Table 4, univariate analysis showed that age, gender, MS duration, education level, employment status, EDSS score, and MS course were not associated with LTP information preference. However, higher levels of fatigue and COPE denial were predictors of higher LTP information preference in a multivariate model.

## 6. Discussion

This study is unique since it assesses the experience of PwMS from Argentina regarding LTP communication and preferences, and we find a strikingly similar situation to that in the UK and Germany, suggesting that the issue has worldwide significance.

The study of prognostic factors in MS is evolving, based on prospective longitudinal cohort studies (Tintore et al., 2015; Rotstein and Montalban, 2019). However, studies on LTP information preferences and communication in PwMS are limited, since the focus tends to be on conveying the diagnosis to the patients (Elian and Dean, 1985; Solari et al., 2014; Solari et al., 2007). In addition, LTP is a sensitive theme during a medical appointment, and may be difficult to bring up in discussion between the clinician and patient. Our study showed that nearly one-quarter of responders had never discussed LTP with their neurologist, in comparison with 53.1% in the UK (Dennison et al., 2018). Despite this, 50% of Argentinian PwMS lacked clarity about

**Table 4**

Results of logistic regression (multivariate) analysis including potential variables associated with current LTP information preference.

| Current LTP information preference (Dichotomized: Lower/Higher) Potential variables associated with higher current LTP information preference | Univariate model OR (95% Cl) | P-value | Multivariate model* OR (95% CI) | P-value |
| --- | --- | --- | --- | --- |
| Age at survey | 0.97 (0.95–1.04) | 0.10 | | |
| Gender (F or M) | 0.64 (0.34–1.18) | 0.15 | | |
| MS duration | 0.97 (0.93–1.00) | 0.13 | | |
| Education (University or not) | 1.28 (0.70–2.34) | 0.42 | | |
| Employment (Yes or not) | 0.99 (0.53–1.81) | 0.97 | | |
| EDSS | 1.09 (0.94–1.26) | 0.22 | | |
| MS course (RR or progressive form) | 1.63 (0.26–1.50) | 0.30 | | |
| **COPE-28** | | | 1.35 (1.01–1.80) | **0.03** |
| COPE active | 1.10 (0.92–1.30) | 0.26 | | |
| COPE planning | 1.15 (0.98–1.34) | 0.07 | | |
| COPE acceptance | 0.89 (0.71–1.11) | 0.32 | | |
| COPE denial | 1.45 (1.12–1.87) | **0.004** | | |
| COPE instrumental support | 1.03 (0.85–1.24) | 0.75 | | |
| COPE emotional support | 1.03 (0.88–1.20) | 0.68 | | |
| COPE humour | 1.15 (1.00–1.33) | **0.03** | | |
| COPE substance use | 1.08 (0.82–1.41) | 0.56 | | |
| COPE behavioural disengagement | 1.02 (0.82–1.25) | 0.85 | | |
| COPE distraction | 0.95 (0.81–1.12) | 0.59 | | |
| COPE positive reframing | 0.95 (0.80–1.12) | 0.55 | | |
| COPE self-blame | 1.26 (1.05–1.50) | **0.01** | | |
| COPE religion | 0.95 (0.84–1.09) | 0.52 | | |
| COPE venting | 1.22 (1.02–1.45) | **0.02** | | |
| **Fatigue severity scale** | | | | |
| Total score | 1.01 (1.0–1.03) | **0.01** | 1.02 (1.00–1.05) | **0.03** |
| **MSIS-29** | | | | |
| Physical impact | 1.01 (0.99–1.02) | 0.07 | | |
| Psychological impact | 1.02 (0.99–1.05) | 0.08 | | |
| Perception of severity of MS** | 1.33 (0.72–2.44) | 0.35 | | |
| Perception of severity of wheelchair** | 0.89 (0.40–1.96) | 0.78 | | |

Definition of LTP with patients: Long-term prognosis (LTP) is an estimate of how you will probably be throughout your lifetime as a result of MS.

* Variables were included in multivariate regression if univariate analysis $p < 0.20$.

** Variable was dichotomized to low-medium perceived severity and higher perceived severity (cut-off used was 6 or higher).

their LTP, similar to numbers (54.2%) in the UK (Dennison et al., 2018). This might imply that even though a greater proportion of PwMS receive some amount of information in Argentina, this does not suffice. LTP is of relevance for Argentinian PwMS as almost 50% of them thought about it at least once a week, even when one-third of patients do not discuss the subject with anybody. The fact that relevance and active discussion of LTP seem to be independent from each other, suggests that complex psychological factors are at play. This may explain why several coping strategies were associated with LTP information preference in our data (Tables 3 and 4). We presumed that different coping strategies might be related to different levels of LTP information preferences and found that those participants with lower levels of denial, humour, self-blame and venting coping profiles showed statistically significant lower levels of LTP information preferences. On the other hand, PwMS with higher scores on fatigue showed higher level of LTP information preference. These findings imply that different personality traits and severity of symptoms play an important role in molding LTP information preferences.

We observed that 61.7% of PwMS (relapsing course) from Argentina wanted to know more about conversion to SPMS. Similar results were observed in a cohort from Germany (Buecken et al., 2012), where 76% of PwMS considered it important to discuss progression and 66% wanted end-of-life problems addressed in the medical appointment. However, satisfaction with the degree of communication on these themes was poor in those population (Buecken et al., 2012). Thus, it appears that clinicians need to be further trained to communicate about these difficult long-term issues.

When asked about the proper timing for LTP information, almost three-quarters of PwMS considered the time of the diagnosis, the current moment and the future as possible options in similar proportions: 72.4%, 71.7% and 73.4% respectively. That LTP was not discussed in many cases could be due to several reasons, as follows: simply not being

aware of the desire of PwMS to discuss this issue, the lack of precise prediction models for long-term prognostication in MS, a lack of time during medical appointments, the assumption that PwMS already had such a discussion with another clinician, or a lack of clinician training (Dennison et al., 2016; Heesen et al., 2013; Buecken et al., 2012; Janssen et al., 2011; Reimke et al., 2011).

The idea of a tool that might provide individualized LTP estimates was demonstrated to be of interest to the vast majority of study participants (94.3%). Only prototypes of such tools exist and the PwMS in our study were not shown any such tool, so this was a hypothetical question. However, it is important to know, to help inform the need for future research into such tools. A LTP tool was perceived to be useful at various time-points and helpful for decision-making, similar to other studies (Dennison et al., 2018, 2016; Heesen et al., 2013). Similar proportions of PwMS in this cohort as in the UK, about one-third, considered that this tool could be used in different settings: alone, with friends or family member, or with their neurologist. Interestingly, 41.5% thought that the best setting to use this tool was with the neurologist and friends or family members. This suggests concerns about accessing and interpreting important and emotive information without the input of a healthcare professional and the support of their loved ones. This aligns with qualitative findings where PwMS emphasized the simultaneous need for expertise and emotional support when receiving prognosis predictions (Dennison et al., 2016).

Several limitations of this study should be mentioned. Firstly, this was a cross-sectional study and changes over time to explore causality could not be evaluated. Secondly, we used a self-reported EDSS, although there is growing evidence that patient-reported outcomes are valid (Collins et al., 2016; Kobelt et al., 2017). Thirdly, this was a study with relatively small population size compared with other cohorts from Europe. Fourthly, we had a relatively lower response rate, since only around 15% ($n = 301$) of PwMS invited to participate answered the

survey. One possible explanation is related to survey deployment method: it cannot be known with certainty how many patients received the invitation as it was an online survey sent by email through a patient association (ALCEM members). Another possible reason is that PwMS might be reluctant to talk about LTP, either because of lack of interest or due to anxiety or stress related to this theme. Hence, PwMS who answered this questionnaire might have been biased towards wanting to know more about their LTP. Fourthly, we did not evaluate cognitive impairment and other mood disorders such as anxiety and depression. Despite these limitations, we consider that this is a valuable first study into LTP communication and information preferences amongst Latin American PwMS.

## 7. Conclusions

There is an apparent unmet need amongst Argentinian PwMS to discuss LTP, which is strikingly similar to the UK and Germany. Many think of their LTP at least on a weekly basis, and those who have received information find it inconsistent among health care professionals or other sources. A great majority of responders were interested in being informed about the availability of a LTP tool to help the discussion. Such a tool may convey to PwMS the reasons for information consistency by appreciation of confidence intervals. Also, its use could function as a trigger for LTP discussion.

As in other countries, a small proportion of patients do not want to know about their LTP. It is probably unlikely to be able to predict which patient does or does not want to receive this information. One possible strategy could be asking individual PwMS at the time of diagnosis and on a regular basis about their LTP communication preferences, in case they change their opinion, and proceed accordingly.

Further research is needed into the preferences of PwMS on LTP communication and the best strategies to deploy in clinical practice, to ensure the patient´s emotional wellbeing and optimize their coping abilities.

## Declaration of Competing Interest

None of the authors has any financial conflict of interest relating to this manuscript.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.msard.2019.101445.

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