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Web-based family-reported outcomes to assess family functioning in multiple sclerosis: an Italian multicenter digital survey

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ABSTRACT

Background and Objectives: Multiple sclerosis (MS) affects not only individuals but also family dynamics. Scalable, digitally delivered assessments may support routine screening of psychosocial and relational needs across the household. This study aimed to investigate perceived family functioning in families living with MS, using a web-based, multi-informant approach, focusing on relationship quality and psychosocial factors.

Methods: This Italian multicenter, cross-sectional study recruited families with a member diagnosed with MS. Participants included individuals with MS (PwMS), partners, adolescent children, and other adult relatives. Families without self-reported chronic illness were included as a comparison group. Participants completed anonymous, validated online questionnaires. Standardized instruments included: Hospital Anxiety and Depression Scale (HADS), Family Assessment Measure-III (FAM-III), Multidimensional Scale of Perceived Social Support (MSPSS), Toronto Alexithymia Scale (TAS-20), Dyadic Adjustment Scale (DAS), and Inventory of Parent and Peer Attachment (IPPA).

Results: The final sample consisted of 50 families: 50 PwMS (mean age: 42.6 ± 11.4 years), 34 partners (mean age: 45.2 ± 10.6 years), 25 adolescent children (mean age: 16.2 ± 3.6 years), 25 adult relatives (mean age: 47.2 ± 17.7 years). Compared with controls, PwMS reported lower anxiety (median HADS-A: 6.5 vs. 9; $p = 0.002$), higher dyadic adjustment (median DAS: 109.5 vs. 104.5; $p = 0.024$) and greater perceived support from significant others (median MSPSS: 27 vs. 24; $p = 0.047$). Adolescent children showed stronger attachment to parents (IPPA total mother: 94 vs. 83; father: 92.5 vs. 76.5; both $p < 0.001$) and peers (IPPA total peers: 98 vs. 90; $p = 0.016$). In PwMS, higher disability correlated with more severe depressive symptoms ($\rho = 0.55$, $p < 0.001$) and poorer family functioning ($\rho = 0.37$, $p = 0.009$).

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Discussion: A web-based, standardized, multi-informant assessment can capture family functioning and key psychosocial correlates in MS, supporting the design of digitally enabled screening pathways to identify families who may benefit from early psychological or relational interventions.

1. Introduction

Multiple sclerosis (MS) is the leading cause of chronic neurological disability in young adults in developed countries, typically beginning between ages 20 and 40. It is a chronic, progressive disease leading to a gradual accumulation of physical and cognitive impairments, ultimately resulting in serious disability over time [1]. Among these symptoms, psychiatric disorders may affect up to 95% of people with MS (PwMS), with approximately half reporting high levels of anxiety and depression [2–4].

Beyond the individual, the psychosocial burden of MS frequently extends to the family unit [5–7]. Families of PwMS face substantial challenges, including strain on marital relationships and difficulties in parent–child bonding. MS can deeply affect intimacy and partnership stability, with a considerable proportion of relationships deteriorating over time [8]. Various factors, including individual characteristics (e.g., alexithymia, perceived social support) and clinical features (e.g., depression, apathy), can influence family functioning in the context of MS. Understanding the complex interplay between MS, family dynamics, and these associated factors is essential to provide comprehensive care and support strategies for PwMS and their families.

From a clinical and informatics perspective, multi-informant family-reported outcomes may provide added value over patient-only assessments by capturing psychosocial and relational needs that are distributed across the household and may otherwise remain under-recognized. A digitally delivered, web-based approach may enable scalable, standardized, and low-burden data collection in routine care, supporting the early identification of families requiring tailored psychological support and contributing to the implementation of family-centered digital care pathways in MS [9,10].

This study investigates the effect of MS on family dynamics by assessing the subjective perspectives of each family member (i.e., individuals with MS, their partners, adolescent children, or other relatives) on overall family functioning, with a specific focus on the quality of marital and parental relationships considered as separate dimensions. The study also examines whether alexithymic traits, psychological distress (e.g., anxiety and depressive symptoms), and perceived social support are associated with the quality of family relationships.

2. Methods

2.1. Study design and data collection

This Italian multicenter, cross-sectional study was conducted between July 5, 2020, and June 5, 2023, across five sites: the University of Turin, the University of Campania “Luigi Vanvitelli” (Naples), the University of Naples “Federico II”, the University of Genoa, and the University of Rome “Tor Vergata”. The study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [11].

Participants were consecutively recruited through neurologists at the participating centers during outpatient visits and invited to complete a set of self-administered questionnaires via a General Data Protection Regulation (GDPR)-compliant online platform, developed with funding from the University of Turin. The platform was hosted on SMsocialnetwork, a completely independent server dedicated to PwMS and managed by University of Campania “Luigi Vanvitelli”. The platform was designed to ensure complete anonymity, using each PwMS’s mobile phone number as a non-identifying code for the individual and their family unit. The system was linked to a secure external server to ensure that all collected data remained separate from any personal identifiers. The platform allowed final submission only after completion of all mandatory fields; therefore, only complete questionnaires entered the dataset. Potential duplicate entries were checked using the unique family access code and participant role. Records were reviewed prior to final analytic selection to identify clearly inconsistent or invalid entries.

Neurologists submitted mobile numbers of eligible patients to the online platform, which then generated unique access codes. A dedicated SMS gateway was used to send login credentials to participants, allowing them to access the platform and complete the questionnaires anonymously.

The study was conducted in accordance with the guidelines of the Declaration of Helsinki involving human participants and the patient’s informed consent was obtained at the outset of the survey. The Ethical Committee of AOU San Luigi Gonzaga approved the study (protocol number 10899).

2.2. Study population and Eligibility criteria

The study enrolled both nuclear and single-parent families, including diverse parental configurations (e.g., single parents, mother and father, mother and mother, father and father) and adolescent children. A comparison group of families without self-reported chronic illness (controls) was also recruited from the general community and through social networks. For comparative analyses, controls were matched 1:1 to PwMS or family-member subgroups by age and sex, depending on the analysis performed.

Exclusion criteria were defined separately for each family member category:

People with MS:

- Age < 18 years
- Low educational level (<5 years) or inadequate knowledge of the Italian language
- History of neurological disorders other than MS
- History of psychiatric disorders
- Severe motor or visual impairments limiting ability to complete questionnaires
- Absence of a matched family member who completed the survey

Partners of people with MS:

- Age < 18 years
- Low educational level (<5 years) or inadequate knowledge of the Italian language
- History of neurological disorders
- History of psychiatric disorders
- Absence of a matched PwMS who completed the survey

Adolescent children:

- Age < 12 years
- Low educational level (<5 years) or inadequate knowledge of the Italian language
- History of neurological disorders
- History of psychiatric disorders
- Absence of a matched PwMS who completed the survey

Control group:

- Any member reporting a chronic medical condition
- Absence of a matched family member who completed the survey

2.3. Sociodemographic, clinical, and psychometric variables

Study covariates included sociodemographic information such as year of birth, sex, relationship to the PwMS (for non-PwMS), geographical area of residence, level of education, current occupation, marital status, religious belief (believer vs. non-believer), information related to children, and data on psychotherapy. For analytical purposes, family members aged >20 years who were not partners were grouped as "other adult relatives"; this subgroup consisted of 14 parents, 10 siblings, and 1 other relative. This grouping was used to distinguish adult non-partner relatives from partners and adolescent children, and was based on the limited size of the parent and sibling subgroups, which precluded meaningful role-specific analyses.

Clinical characteristics of PwMS included disability level, assessed using the Patient Determined Disease Steps (PDDS), a validated patient-reported measure that correlates with the Expanded Disability Status Scale (EDSS), the most widely used measure of disability in multiple sclerosis, with particular relevance to ambulatory function [12].

To comprehensively assess psychological well-being, interpersonal dynamics, and perceived family functioning, participants also completed a structured set of standardized questionnaires. All questionnaires had been previously validated in Italian, including for online administration, and were delivered through the digital study platform [13]. All participants completed a core set of questionnaires, while additional measures were administered based on their role within the family.

All family members completed the Family Assessment Measure III – Brief Version (FAM-III) to evaluate overall family functioning, the Hospital Anxiety and Depression Scale (HADS) to assess symptoms of anxiety and depression, the Multidimensional Scale of Perceived Social Support (MSPSS) to measure perceived emotional and practical support from family, friends, and significant others, and the Toronto Alexithymia Scale – 20 items (TAS-20), which evaluates difficulties in identifying and describing emotions as well as externally oriented thinking.

Patients and partners additionally completed the Dyadic Adjustment Scale (DAS), which evaluates the quality of romantic relationships across satisfaction, consensus, cohesion, and affectional expression.

Finally, adolescent children completed the Inventory of Parent and Peer Attachment (IPPA) to assess emotional bonds with parents and peers.

Further details on the form (Italian original version and English translated version) and all measurement tools are provided in **Supplementary Materials**.

2.4. Statistical analysis

A priori power analysis was performed using GPower 3.1 to determine the minimum sample size required to detect a large effect (Cohen's $f = 0.5$) with $\alpha = 0.05$ and power = 0.80 in a one-way ANOVA comparing three family member roles (PwMS, partners, adolescents). Based on these assumptions, a total of 125 participants (approximately 42 per group) would be sufficient to detect large differences in perceived family functioning or psychological outcomes. This effect size was deemed appropriate considering the nature of the constructs (e.g., depressive symptoms, family functioning) and the magnitude of between-group differences observed in previous literature and our preliminary data.

Study variables were described as mean (standard deviation), median (interquartile range), or number (percentage), as appropriate. Comparisons between the total sample of patients with MS and a selected subgroup were performed using Mann–Whitney U tests for continuous variables and chi-square tests (or Fisher's exact test, when appropriate) for categorical variables. Wilcoxon signed-rank tests were applied to compare paired groups: PwMS and partners, PwMS and younger (≤20 years) or older (>20 years) family members, PwMS and matched controls, and family members and matched controls. In families with multiple participating family members in the same category, average values were calculated for comparison. Spearman correlation coefficients were computed to assess the relationship between disability level (PDDS) and psychosocial measures within PwMS and their matched family members. Statistical significance was defined as $p < 0.05$. Analyses were conducted using Stata version 18.0.

3. Results

A total of 302 complete questionnaires were collected, including 185 from PwMS, 45 from partners, and 72 from other family members. After exclusion of duplicate and ineligible entries, 281 valid individual submissions remained, corresponding to 193 family units identified through unique family access codes/mobile numbers; at this stage, a family unit could also be represented by a single respondent. In line with the study aim of analyzing matched family-level multi-informant data, only family units in which both the PwMS and at least one family member completed the questionnaires were retained for the final analysis. This resulted in a final analytic sample of 50 family units, corresponding to 134 individual respondents.

The selection process is illustrated in Fig. 1.

The final dataset included a total of 50 PwMS (age, 42.6 ± 11.40 years; females, 68.0%), 34 partners (age, 45.2 ± 10.60 years; females, 44.1%), and 50 other family members, comprising 25 adolescent children (mean age: 16.2 ± 3.6 years; females: 40.0%) and 25 family members over the age of 20 (mean age: 47.2 ± 17.7 years; females: 64.0%), including 14 parents, 10 siblings, and 1 other relative. Comparisons between the total PwMS sample (n = 166) and the selected subgroup (n = 50) showed no differences in sociodemographic or clinical characteristics, except for higher dyadic adjustment (DAS Tot; $p = 0.043$) and a tendency toward lower perceived family dysfunction in the subgroup (FAM-III Tot; $p = 0.072$).

Tables 1 and 2 present an overview of the sociodemographic and clinical characteristics of the total population and the selected subgroup of PwMS, along with the results of their comparison. A descriptive comparison of included and excluded respondents across all respondent groups is provided in **Supplementary Table 1**.

When comparing PwMS with their family members across psychological and relational dimensions, no differences were found between PwMS and their partners in any of the assessed scales, including HADS, FAM-III, MSPSS, TAS, and DAS. Conversely, when compared to their adolescent children, PwMS reported higher levels of depressive symptoms (median: 7 [IQR: 4–9] vs. 2 [IQR: 1–5]; $p = 0.022$), as visually depicted in Fig. 1 **of Supplementary Materials**. No other differences were observed across the remaining scales, although a tendency toward higher anxiety levels in PwMS compared to their adolescent children was noted (median: 8 [IQR: 4–11] vs. 4 [IQR: 1–8]; $p = 0.087$). No differences were found between PwMS and other adult family members (>20 years) in any of the measures. Full results are reported in Table 2 **of Supplementary Materials**.

When compared with controls, PwMS reported lower levels of anxiety (HADS-A: median 6.5 [IQR: 4–9] vs. 9 [IQR: 7–10]; $p = 0.002$), and higher scores on dyadic functioning, including total DAS (median: 109.5 [IQR: 104.5–114] vs. 104.5 [IQR: 88–113]; $p = 0.024$), dyadic consensus (median: 55 [IQR: 51–58] vs. 50 [IQR: 41–56]; $p = 0.018$), and expression (median: 10 [IQR: 9–11] vs. 9 [IQR: 7–11]; $p = 0.049$). PwMS also showed higher perceived support from significant others (MSPSS–Significant Other: median 27 [IQR: 23–28] vs. 24 [IQR: 21–28]; $p = 0.047$). No differences were observed for HADS-D, FAM-III, total MSPSS, or TAS.

When comparing with controls, adult family members (>20 years) reported higher levels of dyadic functioning, as indicated by higher total

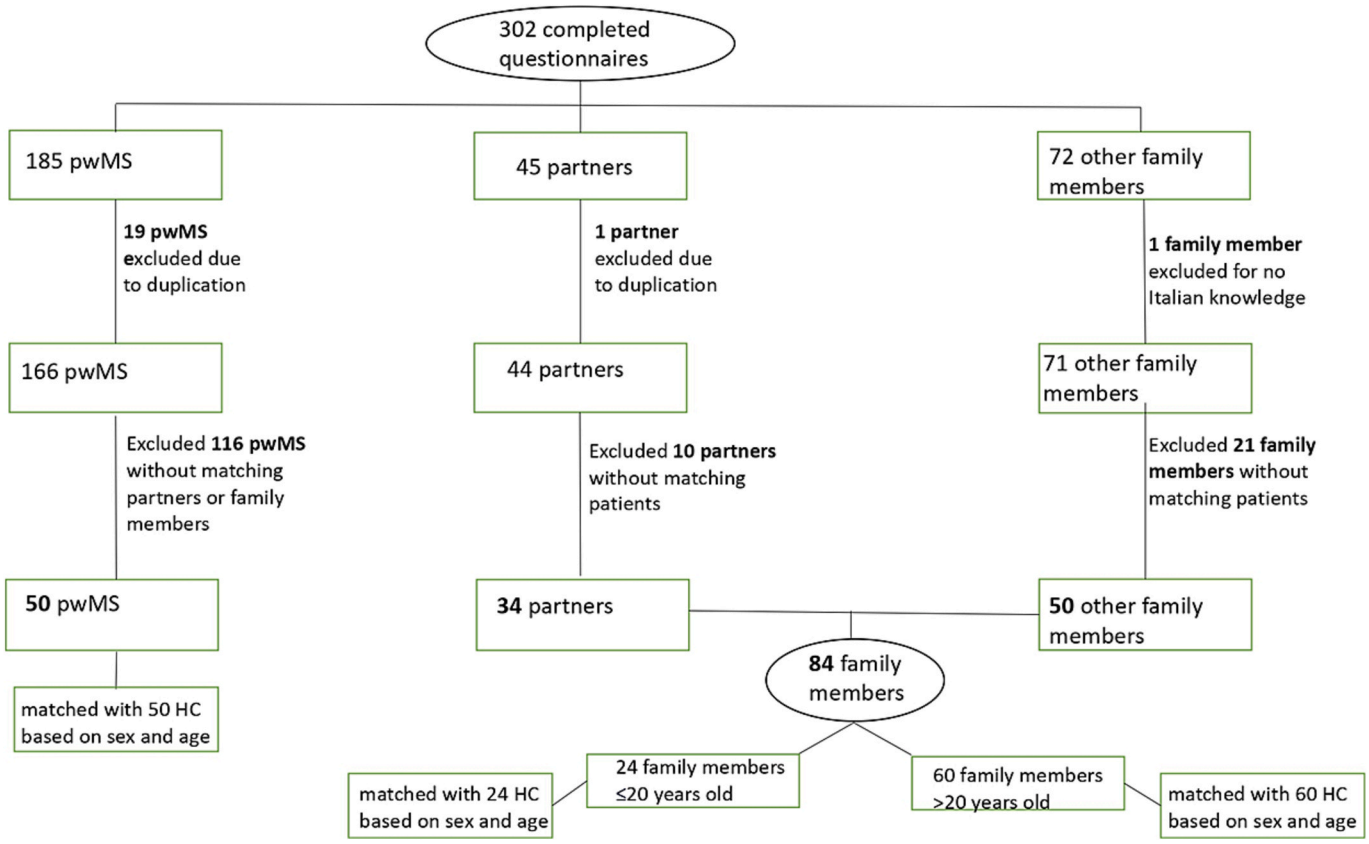

Fig. 1. Flowchart of the participant selection process according to inclusion and exclusion criteria. Out of 302 completed questionnaires (185 from PwMS, 45 from partners and 72 from other family members), 21 participants were excluded due to duplication or insufficient knowledge of Italian. Among the remaining 281, only those belonging to family units in which both the PwMS and at least one family completed the questionnaires were included. This resulted in 50 PwMS, 34 partners, and 50 other family members, for a total of 84 matched family members. Participants were subsequently matched with comparison group based on sex and age. *PwMS*, people with multiple sclerosis; *HC*, healthy controls.

DAS scores (median: 110 [IQR: 104–115] vs. 96.5 [IQR: 86.5–112]; $p = 0.039$) and dyadic consensus (median 56.5 [IQR: 53–60.5] vs. 44.5 [IQR: 38–56.5]; $p = 0.005$). They also reported greater perceived support from significant others (MSPSS–Significant Other: median 26.5 [IQR: 23–28] vs. 24 [IQR: 20–26.5]; $p = 0.044$). No differences were observed in HADS scores, FAM-III, total MSPSS, TAS, or other dyadic subscales.

When compared to controls, younger family members (≤20 years) reported stronger relational bonds across multiple dimensions of the IPPA. Specifically, they showed higher total scores for relationships with both mother (median: 94 [IQR: 85–103] vs. 83 [IQR: 77–86]; $p = 0.001$) and father (median: 92.5 [IQR: 85–102] vs. 76.5 [IQR: 72–82]; $p = 0.001$), with differences in the subscales of security, trust, and disaffection (all $p < 0.05$). Similarly, peer relationships were rated more positively among family members, with higher total scores (median: 98 [IQR: 89–108] vs. 90 [IQR: 81–96]; $p = 0.016$) and lower disaffection (median 26 [IQR: 25–31] vs. 16 [IQR: 12–20];$p < 0.001$). No differences were found for communication or trust in peer relationships.

The comparisons between PwMS, family members, and their matched controls are reported in detail in Tables 3–5.

Finally, in PwMS, higher PDDS scores were correlated with greater depressive symptoms (HADS-D: $\rho = 0.55$; $p < 0.001$) and poorer family functioning (FAM-III: $\rho = 0.37$; $p = 0.009$). Anxiety levels showed a weaker correlation with PDDS scores (HADS-A: $\rho = 0.26$; $p = 0.069$). No correlations emerged between PDDS and psychosocial outcomes in partners, younger family members (≤20 years), or adult family members (>20 years). All correlation results are reported in Table 3 **of Supplementary Materials**.

4. Discussion

This study aimed to explore the psychosocial functioning of family units living alongside MS, focusing on the emotional, relational, and support dynamics among patients and their close family members. Prior research has highlighted how MS can deeply affect family dynamics, leading to difficulties in marital relationships, disruptions in parent–child bonds, and elevated psychological stress within the household [8,14]. These dynamics may compromise both individual well-being and overall family functioning.

Firstly, a notable finding in our study was the lower level of anxiety reported by PwMS compared with controls, together with stronger dyadic functioning and greater perceived support from significant others. One possible interpretation is that these findings reflect adaptive coping processes that may develop over time in the context of chronic illness, including greater reliance on emotional regulation and interpersonal support, as highlighted in previous research [15–19]. However, this interpretation should be considered with caution. Alternative explanations are also plausible, including selection bias, whereby families with better relational functioning may have been more likely to participate and complete the full multi-informant assessment, as well as response tendencies toward presenting the family unit as stable or resilient. In addition, people with MS are often active users of digital and web-based health environments, which may have facilitated participation independently of disability level [20,21]. Although the survey was anonymous, a social desirability component cannot be excluded. In addition, the web-based format may have favored participation by individuals and families with digital confidence, practical resources, or greater engagement with care, potentially contributing to a more

Table 1
Sociodemographic and clinical characteristics of the total PwMS population, the selected subgroup with complete family participation, and family members.

	PwMS (whole population) (No = 166)	PwMS (selected subgroup) (No = 50)	p	Partner (No = 34)	Children (No = 25)	Other family members (No = 25)
Relationship with PwMS, No (%)						
Father/Mother		–		–	–	14 (56.0%)
Brother/Sister		–		–	–	10 (40.0%)
Other		–		–	–	1 (4.0%)
Age, y, mean (SD)	41.6 (12.13)	42.6 (11.4)	0.599	45.2 (10.6)	16.2 (3.6)	47.2 (17.7)
Women, No (%)	117 (70%)	34 (68.0%)	0.737	15 (44.1%)	10 (40%)	16 (64%)
Geographic area, No (%)						
Southern Italy	91 (55.5%)	21 (42.9%)		12 (35.3%)	3 (13.6%)	18 (72%)
Central Italy	26 (15.9%)	14 (28.6%)	0.111	13 (38.2%)	14 (54.6%)	1 (4.0%)
Northern Italy	47 (28.7%)	14 (28.6%)		9 (26.5%)	8 (31.8%)	6 (24.0%)
Occupation, No (%)						
Student	16 (10%)	5 (10.0%)		0 (0.0%)	24 (96.0%)	5 (20.0%)
Employed	93 (56%)	30 (60.0%)	0.979	24 (70.6%)	1 (4.0%)	13 (52.0%)
Unemployed	13 (8%)	3 (6.0%)		3 (8.8%)	0 (0.0%)	2 (8.0%)
Retired	13 (8%)	4 (8.0%)		3 (8.8%)	0 (0.0%)	1 (4.0%)
Homemaker	31 (19%)	8 (16.0%)		4 (11.8%)	0 (0.0%)	4 (16.0%)
Education level, No (%)						
No Education	0 (0.0%)	0 (0.0%)		0 (0.0%)	0 (0.0%)	0 (0.0%)
Elementary School	0 (0.0%)	0 (0.0%)		0 (0.0%)	1(4.0%)	0 (0.0%)
Middle School	1 (0.6%)	1 (2.0%)		0 (0.0%)	3(12.0%)	2 (8.0%)
High School Diploma	29 (17.5%)	6 (12.0%)		5 (14.7%)	17(68.0%)	6 (24.0%)
University Degree	119 (71.7%)	36 (72.0%)	0.817	22 (64.6%)	4 (16.0%)	16 (64.0%)
Postgraduate specialization	9 (5.4%)	3 (6.0%)		2 (5.9%)	0 (0.0%)	0 (0.0%)
Missing	8 (4.8%)	4 (8.0%)		5 (14.7%)	0 (0.0%)	1 (4.0%)
Education, y, No (%)						
<5	0 (0%)	0 (0.0%)		0 (0.0%)	0 (0.0%)	0 (0.0%)
5	2 (1%)	1 (2.0%)	0.599	0 (0.0%)	1 (4.0%)	0 (0.0%)
8	20 (12%)	3 (6.0%)		3 (8.8%)	10 (40.0%)	7 (28.0%)
12–13	56 (34%)	16 (32.0%)		11 (32.3%)	8 (32.0%)	5 (20.0%)
>13	88 (53%)	30 (60.0%)		20 (58.8%)	6 (24.0%)	13 (52.0%)
Marital status, No (%)						
Single	21 (12.7%)	8 (16.0%)		2 (5.9%)	20 (80.0%)	4 (16.0%)
Cohabiting	13 (7.8%)	5 (10.0%)		5 (14.7%)	0 (0.0%)	0 (0.0%)
Married	97 (58.4%)	30 (60.0%)	0.749	27 (79.4%)	0 (0.0%)	14 (56.0%)
Separated	11 (6.6%)	2 (4.0%)		0 (0.0%)	0 (0.0%)	0 (0.0%)
Divorced	6 (3.6%)	0 (0.0%)		0 (0.0%)	0 (0.0%)	1 (4.0%)
Widowed	0 (0%)	0 (0.0%)		0 (0.0%)	0 (0.0%)	3 (12.0%)
Missing	18(10.8%)	5 (10.0%)		0 (0.0%)	5 (20.0%)	3 (12.0%)
Children, No (%)						
No	64 (38.6%)	21 (42.0%)		13 (38.2%)	–	–
Yes	100 (60.2%)	28 (56.0%)	0.878	20 (58.8%)	–	–
Missing	2 (1.2%)	1 (2.0%)		1 (2.9%)	–	–
Number of children, No (%)					–	–
1	48 (48%)	11 (39.3%)		6 (30.0%)	–	–
2	41 (41%)	12 (42.9%)	0.422	11 (55.0%)	–	–
3	11 (11%)	5 (17.9%)		3 (15.0%)	–	–
Desire for more children, No (%)	76 (46%)	22 (44.0%)	0.824	11 (32.4%)		
Parenthood renunciation associated with MS, No (%)						
No	34 (58.6%)	9 (56.3%)		6 (54.6%)	–	–
Yes	24 (41.4%)	7 (43.8%)		5(45.5%)	–	–
			0.865			
Past psychotherapy, No (%)	59 (36%)	21 (42.0%)	0.407	4 (11.8%)	2 (8.0%)	4 (16.0%)
Ongoing psychotherapy, No (%)	17 (10%)	5 (10.0%)	0.961	0(0.0%)	2 (8.0%)	1 (4.0%)
Religious belief, No (%)	35 (21%)	15 (30.0%)	0.190	6 (17.7%)	9 (36.0%)	7 (28.0%)
PDDS, median (IQR)	1(0; 3)	1 (0; 3)	0.815	––	––	––

The table reports characteristics of the total sample of people with multiple sclerosis (PwMS), the subgroup of 50 PwMS with matched family data, and their respective partners, children, and other family members. Continuous variables are expressed as mean (standard deviation) or median (interquartile range); categorical variables are shown as number (percentage). Between-group comparisons are presented for the total sample and the subgroup. Bold values indicate statistical significance.
PwMS, people with Multiple Sclerosis; *No,* Number; *p,* p-value; *y,* years; *SD*, standard deviation; *IQR*, interquartile range; *PDDS*, Patient-Determined Disease Steps.

favorable psychosocial profile in the final sample.

Beyond the association with reduced anxiety, these relational aspects may have contributed to the psychosocial profile of PwMS compared with controls. These findings may suggest that, rather than being negatively affected by the presence of the disease, the quality of romantic relationships in some PwMS may be relatively preserved, rather than uniformly compromised by the presence of the disease. This observation may appear to contrast with earlier reports describing greater relationship strain or reduced quality of life among couples dealing with MS, particularly in the presence of progressive disease or higher levels of disability [22,23]. However, it may reflect a different point along the trajectory of the illness, in which the influence of MS on couple dynamics is still limited, and relational resources are more readily preserved. In this regard, the specific characteristics of our sample, relatively young individuals with low disability levels, may explain this divergence. Indeed, previous research has shown that, in the absence of substantial disability, couples living with MS may report preserved emotional bonds, particularly when engaging in shared

Table 2
Psychosocial measures of the total PwMS population, the selected subgroup with complete family participation, and family members.

	PwMS (whole population) (No = 166)	PwMS (selected subgroup) (No = 50)	p	Partner (No = 34)	Children (No = 25)	Other family members (No = 25)
HADS – Anxiety, median (IQR)	7(4; 11)	6.5 (4; 9)	0.269	6.5 (4; 12)	4(1;8)	4(2;9)
HADS – Depression, median (IQR)	6(3; 9)	5 (3; 8)	0.513	5 (1; 8)	2(1;5)	3(1;8)
FAMIII, median (IQR)	13 (8; 17)	10 (7; 15)	0.072	9.5 (6–15)	13(9;17)	10(8;14)
MSPSS, median (IQR)	70 (62; 79)	72 (64; 80)	0.484	73 (62; 80)	71(64;77)	72(69;80)
TAS, median (IQR)	59 (50; 69)	57.5 (49; 65)	0.477	55.5 (49; 65)	55(49;58)	61(51;70)
DAS, median (IQR)	104 (96; 113)	109.5 (104.5; 114)	**0.044**	110 (104; 115)	–	–

The table reports characteristics of the total sample of people with multiple sclerosis (PwMS), the subgroup of 50 PwMS with complete family data, and their respective partners, children, and other family members. Continuous variables are expressed as mean (standard deviation) or median (interquartile range); categorical variables are shown as number (percentage). Between-group comparisons are presented for the total sample and the subgroup. Bold values indicate statistical significance.
PwMS, people with Multiple Sclerosis; *No,* Number; *p,* p-value; *y,* years; *SD*, standard deviation; *IQR*, interquartile range; *HADS*, Hospital Anxiety and Depression Scale; *FAMIII*, Family Assessment Measure III – Brief Version; *MSPSS*, Multidimensional Scale of Perceived Social Support; *TAS*, Toronto Alexithymia Scale – 20 items; *DAS*, Dyadic Adjustment Scale.

Table 3
Comparison of psychosocial variables between PwMS and matched controls.

Psychosocial variables, median (IQR)	PwMS (No = 50)	Controls (No = 50)	p
HADS – Anxiety	6.5 (4;9)	9 (7;10)	**0.002**
HADS – Depression	5 (3;8)	5 (3;7)	0.574
FAMIII	10 (7;15)	11 (9;19)	0.220
MSPSS	72 (64;80)	69 (61;75)	0.098
Significant other	27 (23; 28)	24 (21; 28)	**0.047**
Family	25 (21; 28)	24 (22; 26)	0.358
Friends	22 (18; 26)	21 (17; 24)	0.061
TAS	57.5 (49;65)	60.5 (50;66)	0.699
Describe emotions	14 (11; 17)	15 (12; 17)	0.308
Identify emotions	17 (11; 22)	18 (12; 23)	0.457
Externally oriented thinking	27 (24; 29)	26 (23; 28)	0.328
DAS	109.5 (104.5;114)	104.5 (88;113)	**0.024**
Dyadic consensus	55 (51; 58)	50 (41; 56)	**0.018**
Dyadic satisfaction	29 (27; 30)	28 (25; 30)	0.153
Dyadic cohesion	16 (13; 18)	15 (13; 17)	0.581
Expression	10 (9; 11)	9 (7; 11)	**0.049**

PwMS and controls were matched 1:1 by sex and age. Comparisons were performed using the Wilcoxon signed-rank test. Continuous variables are expressed as median (interquartile range). Bold values indicate statistical significance.
PwMS, people with multiple sclerosis; *No,* Number; *p,* p-value; *IQR*, interquartile range; *HADS*, Hospital Anxiety and Depression Scale; *FAMIII*, Family Assessment Measure III – Brief Version; *MSPSS*, Multidimensional Scale of Perceived Social Support; *TAS*, Toronto Alexithymia Scale – 20 items; *DAS*, Dyadic Adjustment Scale.

Table 4
Comparison of psychosocial variables between adult family members (>20 years) and matched controls.

Psychosocial variables, median (IQR)	Family members > 20 (No = 60)	Controls (No = 60)	p
HADS – Anxiety	6 (3.5;12)	8 (7;10)	0.132
HADS – Depression	5 (2;8)	5 (3;7)	0.889
FAMIII	10 (7;15)	11.5 (8;20)	0.054
MSPSS	73 (62;79)	67 (58;73)	0.068
Significant other	26.5 (23;28)	24 (20;26.5)	**0.044**
Family	26.5 (21.5;28)	24 (20.5;26)	0.186
Friends	20.5 (19;25)	20 (16;23.5)	0.128
TAS	57 (49;65.5)	59 (50;65.5)	0.950
Describe emotions	14 (11;17)	15 (12;17)	0.647
Identify emotions	15 (11;21)	17.5 (11;22)	0.391
Externally oriented thinking	28 (25;30.5)	26 (24;29)	0.077
DAS	110 (104;115)	96.5 (86.5;112)	**0.039**
Dyadic consensus	56.5 (53;60.5)	44.5 (38;56.5)	**0.005**
Dyadic satisfaction	28 (26;29)	28 (25.5;30)	0.963
Dyadic cohesion	14 (12.5;18)	15 (13.5;17.5)	0.560
Expression	10 (8;11)	8 (7;10)	0.132

Family members aged > 20 years were matched 1:1 with controls based on sex and age. Comparisons were performed using the Wilcoxon signed-rank test. Continuous variables are expressed as median (interquartile range). Bold values indicate statistical significance.
No, Number; *p,* p-value; *IQR*, interquartile range; *HADS*, Hospital Anxiety and Depression Scale; *FAMIII*, Family Assessment Measure III – Brief Version; *MSPSS*, Multidimensional Scale of Perceived Social Support; *TAS*, Toronto Alexithymia Scale – 20 items; *DAS*, Dyadic Adjustment Scale.

lifestyle modifications, that promote communication and togetherness [22]. In our study, this pattern was also observed among partners, who reported higher dyadic adjustment compared to matched controls, supporting a reciprocal perception of relational closeness. This hypothesis is further supported by our findings, which showed that higher disability levels were linked to greater depressive symptoms and poorer family functioning in PwMS. This result suggests that marked impairment in broader emotional and relational functioning may not yet be evident in this selected low-disability subgroup. In this context, when physical functioning is preserved and emotional closeness is present, couples living with MS rely on shared goals and mutual adaptation to support relationship quality. Psychological support, particularly when focused on enhancing communication and reinforcing existing relational resources, may help maintain relationship quality over time, potentially preserving it even as the disease progresses. Overall, these findings should be interpreted as evidence of preserved relational resources within this selected, low-disability sample, rather than as definitive evidence of true resilience. Larger, longitudinal, and more representative studies are needed to clarify whether these relational patterns remain stable over time and reflect adaptive processes beyond possible selection-related effects. Moreover, in the absence of more detailed clinical information, such as disease duration, disease subtype, treatment status, and recent clinical progression, the interpretation of this association should remain cautious.

The psychosocial experience of adolescents living with a parent affected by MS remains largely unexplored in the literature. Compared to controls, they reported significantly stronger attachment across multiple IPPA subscales, particularly in the domains of trust, security, and reduced disaffection toward both parents and peers. Different interpretations may account for this observation. First, the experience of navigating a chronic illness within the household may foster greater emotional closeness and solidarity, reinforcing family cohesion [24]. Second, growing up in a context that involves confronting vulnerability, and uncertainty may promote earlier emotional maturation, enhancing sensitivity and relational attunement [25,26]. Finally, it is possible that attachment is intensified by a latent fear of potential health deterioration in the affected parent, resulting in a heightened drive to maintain proximity and connection. [25].

The study has several limitations. First, although 302 complete

Table 5
Comparison of attachment dimensions between younger family members (≤20 years) and matched controls.

Psychosocial variables, median (IQR)	Family members < 20 (No = 24)	Controls (No = 24)	p
IPPA, Total Mother	94 (85;103)	83 (77;86)	**0.001**
Security	32 (28;35)	19 (14;24)	**<0.001**
Trust	41 (37;44)	38 (33;41)	**0.022**
Communication	33 (27;36)	32 (27;36)	0.681
Disaffection	21 (16;23)	14 (9;16)	**<0.001**
IPPA, Total Father	92.5 (85;102)	76.5 (72;82)	**0.001**
Security	34 (32;37)	19 (15;25)	**<0.001**
Trust	43 (37;46)	37 (32;38)	**0.021**
Communication	28.5 (26;35)	27 (24;32)	0.648
Disaffection	22.5 (19;24)	12.5 (10;16)	**<0.001**
IPPA, Total Peers	98 (89;108)	90 (81;96)	**0.016**
Security	31 (28;35)	18 (13;21)	**<0.001**
Trust	43 (38;46)	42 (39;46)	0.761
Communication	29 (27;34)	33 (27;37)	0.338
Disaffection	26 (25;31)	16 (12;20)	**<0.001**

Younger family members (≤20 years) were matched 1:1 with controls based on sex and age. Comparisons were performed using the Wilcoxon signed-rank test. Continuous variables are expressed as median (interquartile range). Bold values indicate statistical significance.
No, Number; *p,* p-value; *IQR*, interquartile range; *IPPA*, Inventory of Parent and Peer Attachment.

questionnaires were collected, the final analytic dataset comprised 50 family units corresponding to 134 individual respondents, because the analyses required matched multi-informant participation at the family-unit level. This may have introduced selective participation, potentially favoring families more able or willing to complete a coordinated multi-informant assessment. This interpretation is consistent with the higher dyadic adjustment observed in the selected PwMS subgroup compared with the broader PwMS sample. In addition, the web-based, asynchronous design and the number of psychometric instruments administered may have influenced completion, particularly among non-patient relatives, and may also have introduced some degree of digital literacy bias. At the same time, the digital format was central to the study rationale, as it enabled scalable family-level data collection beyond the clinic setting. Importantly, this limited adherence may not indicate a lack of involvement in the patient's life, but rather a perceived lack of relevance or necessity in taking part in a structured psychological evaluation. In well-functioning relationships, partners may perceive their support as already evident and not requiring formal validation, as also suggested by previous research [27]. This, combined with the emotional and practical burden often experienced by partners, who frequently act as primary caregivers, may have reduced their willingness or availability to engage in research participation [28–30]. Moreover, the clinical characterization of PwMS was intentionally focused on disability level, assessed through the PDDS. More detailed clinical variables, such as disease duration, disease subtype, treatment status, and clinical progression as well as relational variables, were not collected. While these data could have added depth to the interpretation of relational outcomes, they were deliberately omitted to preserve participant privacy and reduce respondent burden [31]. This may limit the interpretation of the association between disability, depressive symptoms, and family functioning, as higher disability scores may also reflect longer disease exposure, progressive disease course, recent clinical worsening, treatment-related burden, or different stages of psychological adaptation. Future studies should integrate family-reported outcomes with more detailed clinical data to clarify how disease trajectory and treatment-related factors interact with psychosocial burden and relational functioning in MS families. Further, the "other adult relatives" category included parents, siblings, and one other relative. Although these relatives may differ in their emotional roles and caregiving expectations, the limited subgroup sizes did not allow reliable role-specific analyses. Accordingly, results for this category should be interpreted as referring to adult non-partner relatives as a whole, rather than to parents or siblings separately. Finally, the comparison group was recruited from the general community and social networks and matched by age and sex, but was not formally matched for socioeconomic or family-context variables. Future studies should consider strategies to improve engagement and completion, such as shorter assessment pathways, stepwise questionnaire delivery, automated reminders, and greater clinician facilitation during recruitment and follow-up.

5. Conclusion

This study highlights the importance of exploring psychosocial dynamics within families living with MS, offering novel insights into both couple and parent–child relationships. Our findings suggest that, in this selected sample characterized by low disability and emotional closeness, relational bonds appeared to be relatively preserved, both in romantic partnerships and in adolescents' attachment to parents and peers. These findings support the value of offering psychological support early in the disease course, when relational resources may still be present and can be strengthened through targeted interventions. These preliminary findings require confirmation in larger, longitudinal cohorts to clarify whether such relational patterns persist over time, reflect true adaptive processes, and evolve with disease progression, while also identifying protective factors that may help sustain emotional well-being and guide the development of targeted psychosocial interventions.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Marinella Clerico reports financial support was provided by Merck. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijmedinf.2026.106534.

Data availability

The data that support the findings of this study are available from the corresponding author, [SB], upon reasonable request.

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