

Dyadic Coping of NMOSD and MOGAD patients and their partners: a sociological and psychological examination of strategies (CoMMOnsense-Study)

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ABSTRACT

Background Neuromyelitis optica spectrum disorders (NMOSD) and myelin oligodendrocyte glycoprotein antibody-associated diseases (MOGAD) impose psychological burdens on patients. Chronic illnesses create challenges for both patients and their partners, who also play a crucial role in managing disease-related stress. Despite its relevance, little is known about the role of dyadic coping (DC) in these conditions. This study investigates DC in NMOSD and MOGAD, aiming to provide clinical recommendations.

Methods The CoMMOnsense-Study is a cross-sectional, prospective study of 59 NMOSD and 50 MOGAD patients and their respective partners, recruited from 15 centres of the German Neuromyelitis Optica Study Group registry. Participants completed self-report questionnaires on DC, depression, anxiety and quality of relationship. Correlation analyses were performed to compare findings based on antibody status. Subsequently, multivariate regression analyses were conducted to identify relevant predictors of DC.

Results Patients with NMOSD and MOGAD demonstrated higher levels of depressive symptoms (NMOSD: $p=0.007$; MOGAD: $p=0.023$) and stress communication scores (NMOSD: $p=0.022$; MOGAD: $p=0.013$) than their partners. Negative coping was low across all subgroups (Stanine 1). Despite high DC and relationship quality, discrepancies were observed in the coping perceptions between partners.

Conclusions Coping is highly shared within partnerships affected by NMOSD and MOGAD, while discrepancies in coping perceptions and protective buffering suggest the presence of unfavourable coping mechanisms. Reducing protective buffering and illness-related distortions shows potential areas for enhancing DC.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Previous research provides only limited insight into dyadic coping (DC) among patients with neuromyelitis optica spectrum disorders (NMOSD) and no information on myelin oligodendrocyte glycoprotein antibody-associated diseases (MOGAD). Few studies with small sample sizes, primarily focusing on caregivers other than partners, suggest that maladaptive coping strategies are commonly used in the context of NMOSD.

WHAT THIS STUDY ADDS

⇒ The CoMMOnsense-Study represents the largest investigation of NMOSD and MOGAD partnerships, revealing that DC is extensively shared, with both high relationship quality and partners reporting fewer depressive symptoms than patients do. No specific coping strategies were identified as particularly distinct, except for low levels of negative coping, suggesting the presence of protective buffering. Despite their different pathophysiological characteristics, NMOSD and MOGAD patients and their partners exhibit comparable coping mechanisms and psychosocial dynamics.

INTRODUCTION

Neuromyelitis optica spectrum disorders (NMOSD) and myelin oligodendrocyte glycoprotein antibody-associated diseases (MOGAD) are rare, chronic neuroinflammatory diseases, affecting optic nerves and the central nervous system.¹ Living with NMOSD

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Given the high level of DC in NMOSD and MOGAD, it should be reinforced and optimised in clinical practice. We recommend involving partners in medical appointments and self-help groups. To explicitly address this topic in the clinic, a screening tool should be developed to assess discrepancies in coping perceptions and protective buffering, identifying couples at risk for maladaptive coping mechanisms. Couple-based therapy could then be considered to improve DC for these couples.

or MOGAD imposes a substantial physical and emotional burden on patients, who often experience depression and a reduced quality of life.^{2 3} For patients suffering from chronic illnesses who are involved in dyadic relationships, it is well established that their partners also experience stress.^{4 5} At the same time, partners are essential for providing support to patients.^{5 6}

Bodenmann's concept of dyadic coping (DC) is crucial for understanding how couples manage stress together, viewing it as an interpersonal phenomenon where the couple copes through support and communication.⁷ Coping strategies vary depending on the specific physical, cognitive and social challenges associated with different illnesses, but little is known about how patients with NMOSD and MOGAD cope with their condition.⁴ Understanding coping strategies is essential as they are modifiable and represent a potential clinical target to support patients.⁸

The importance of DC is evidenced by research in several medical fields such as oncology, neurology and transplantation.⁴ A study on breast cancer has demonstrated that DC is essential in helping couples manage the stress associated with the disease, with mutual support improving both patients' quality of life and adherence to treatment.⁹ Additionally, Kayser *et al* emphasised the interpersonal aspect of cancer coping, suggesting that viewing cancer as a 'we-disease' rather than an individual illness can significantly improve coping outcomes.¹⁰ In the context of multiple sclerosis (MS), Pakenham *et al* found that couples who collaborate in managing symptoms, such as fatigue and mobility issues, experience better emotional functioning.¹¹ For NMOSD, few studies with small sample sizes have primarily focused on qualitative rather than quantitative aspects, addressing caregivers in general, the majority of whom were not partners.^{12 13} Esiason *et al* identified overcontrolled and avoidant coping behaviours, including emotional suppression and cognitive fusion.¹² These were accompanied by mistrust in healthcare providers and a tendency to internalise distress, hindering help-seeking.¹² Liao *et al* reported frequent misperception of relapse risk—either underestimation or overestimation—and treatment non-adherence.¹³ These studies provide evidence that the coping strategies employed in the context of NMOSD are largely ineffective, and that partners experience significant distress due to the illness, highlighting the need for

a more comprehensive analysis.^{12 14 15} In NMOSD, the few available studies have focused on individual coping, while partners or caregivers have primarily been examined in relation to other psychosocial burdens rather than coping itself (online supplemental eTable 1). There is currently no published study on coping strategies and the situation of partners in MOGAD patients. Based on previous findings, we hypothesised that (1) patients with NMOSD would show limited use of effective coping strategies (e.g., low supportive and high negative DC) and (2) partners of NMOSD patients would exhibit elevated psychological burden (depression, anxiety, reduced relationship quality), similar to patients.

The CoMMOnsense-Study presented here is the first to investigate DC in NMOSD and MOGAD, and seeks to identify the predominant coping strategies used, examine the dynamics of DC within partnerships and determine which patterns positively or negatively affect mental health and relationship quality. By elucidating these associations, the study aims to lay the groundwork for enhancing disease coping and to integrate these findings into clinical practice to reduce illness-related distress.

METHODS

Participants

As a part of a prospective cross-sectional, multicentre study, a cohort consisting of 109 patients and their partners was recruited from 15 centres of the German Neuro-myelitis Optica Study Group registry (NEMOS) between March 2022 and April 2024.

Inclusion criteria comprised patients of legal age with a diagnosis of NMOSD or MOGAD.^{16 17} The couples must have been in a relationship for a minimum duration of 1 year. The exclusion criterion was severe cognitive deficits. The study received approval from the Ethics Committee of Hannover Medical School (Approval No. 10140-2022). All participants provided written informed consent prior to their enrolment. Patients and their partners independently completed standardised questionnaires, either via online surveys or paper-based forms.

Dyadic Coping

The Dyadic Coping Inventory (DCI), a 37-item questionnaire, was used to assess coping behaviours, common DC and satisfaction with DC.¹⁸ Dyads rated their responses on a 5-point Likert scale from 1 (very rarely) to 5 (very often). The DCI is structured into five subscales. Stress communication aims to gain attention for requesting support from the partner, as reflected in items such as: 'I let my partner know that I appreciate his/her practical support, advice or help'. Supportive DC alleviates stress through listening, while delegated DC reduces stress by assigning tasks to the partner. Negative DC involves dysfunctional responses like hostility and criticism. Common DC involves shared, coordinated responses to stress, where both partners actively engage in problem-solving together, as illustrated by the item: 'We engage in a serious discussion about

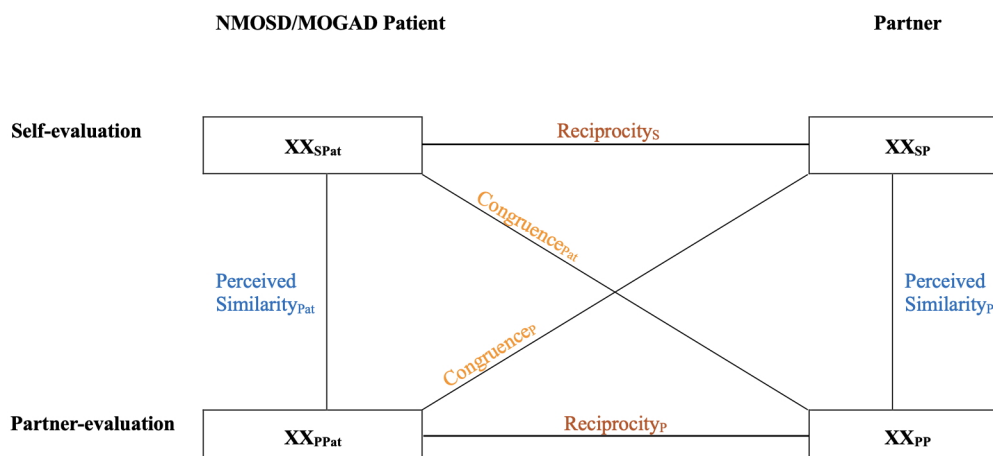


Figure 1 Discrepancy indices of the Dyadic Coping Inventory (DCI). XX represents items (stress communication, supportive, delegated and negative dyadic coping (DC)). S, self-evaluation (own DC, own supportive coping). P=partner-evaluation (supportive DC of the partner). Pat=NMOSD or MOGAD patient. P=partner of patient. Modified from Bodenmann¹⁸, with permission. MOGAD, myelin oligodendrocyte glycoprotein antibody-associated diseases; NMOSD, neuromyelitis optica spectrum disorders.

the problem and think through what has to be done’.⁸ Beyond the five subscales, composite scales can be calculated, such as total positive and negative DC. The total score ranges from 35 to 175, with the following cut-off values: <111 (below average), 111–145 (normal) and >145 (above average).¹⁸ The total DC score reflects the extent to which stress is managed within the partnership, but does not provide information about the coping strategies employed or their effectiveness. It reflects the extent to which partners jointly manage stress, with higher scores indicating more frequent use of DC. DCI subscales are described in online supplemental eTable 2. Stanines, a scoring system dividing data into nine intervals, were used to compare the DCI with population norms.

The DCI also allows the calculation of three discrepancy indices (figure 1), integrating both the patient’s and partner’s perspectives to analyse their agreement and discrepancies of coping perceptions. The reciprocity index measures the similarity of behaviours within the same subscale. The perceived similarity index assesses how each partner perceives their own contributions to DC in relation to those of their partner. The congruence index shows the degree of concordance between both partners’ DC evaluations. While higher values on the reciprocity index indicate greater agreement, higher values on the congruence and perceived similarity indices correspond to less alignment.¹⁸ Cronbach’s alpha for all participants in the current sample is 0.93.

Relationship quality

The German version of the Quality of Marriage Index was used to measure relationship quality.¹⁹ The questionnaire is applicable to all forms of partnerships, regardless of whether the individuals are married or not. It consists of six items, five of which use a 7-point Likert scale response. The sixth item is rated on a 10-point scale (1=very unhappy to 10=perfectly happy) to assess overall relationship quality. The total score varies between 6

and 45. Scores below 34 indicate an unhappy relationship. Cronbach’s alpha for all participants in the current sample is 0.96.

Depression

The German version of the 9-item depression scale of the Patient Health Questionnaire (PHQ-9) was used to measure symptoms of depression.²⁰ Response options range from ‘not at all’ to ‘nearly every day’, with corresponding scores of 0 to 3. Total scores range from 0 to 27, with severity levels classified as none (0–4), mild (5–9), moderate (10–14), moderately severe (15–19) and severe (20–27). Cronbach’s alpha for all participants in the current sample is 0.84.

Anxiety

The Generalised Anxiety Disorder scale (GAD-7) was used to measure anxiety symptoms.²¹ Participants rate the frequency of statements on a scale from 0 (‘not at all’) to 3 (‘nearly every day’). The total score ranges from 0 to 21, with four severity categories: minimal (0–4), mild (5–9), moderate (10–14) and serious (14–20). Cronbach’s alpha for all participants in the current sample is 0.85.

Statistical analysis

IBM SPSS Statistics 29.0 was used to perform statistical analysis. Participants’ sociodemographic data are reported using descriptive statistics. Significance level was determined at $p \leq 0.05$. The data were tested for normal distribution, but did not meet these criteria. Differences between groups were evaluated by using the Kruskal-Wallis test. The Wilcoxon test was used to assess median differences between self- and partner-evaluation. The relationships between total DC scores, discrepancy indices, depression, anxiety and relationship quality in both patients and their partners were analysed using Spearman’s rank correlation coefficient. Due to the insufficient sample size of couples with male patients, the couple-based analysis was limited

Table 1 Patient characteristics

	All patients	NMOSD*	MOGAD	P value	Test statistic	Effect size
N (%)	109 (100)	59 (54.1)	50 (45.9)			
Demographic characteristics						
Age median (IQR), years	48 (38–62)	55 (42–64)	41 (37–54)	0.001	Z=−3.25	r=0.31
Range of age, years	19–82	22–82	19–78			
Female sex, n (%)	75 (68.8)	46 (78.0)	29 (58.0)	0.025	χ^2 (1)=5.03	Cramér's V=0.22
Clinical characteristics						
Disease duration, median (IQR), years	6 (3–10)	8.5 (5–12)	4 (1–6)	<0.001	Z=−4.43	r=0.42
Range of disease duration, years	0.2–34	0.2–34	0.4–14			
EDSS, median (IQR)	2.5 (1.5–3.5)	3 (2–4)	1.5 (1–2.5)			
Range of EDSS	0–7	0–7	0–6	<0.001	Z=−4.28	r=0.41
Relationship characteristics						
Relationship length, median (IQR), years	19 (10–33)	24 (13–40)	15.5 (10–25.5)	0.011	Z=−2.53	r=0.24
Range of relationship length, years	1.5–56	3.5–56	1.5–50			
Partner age, median, years	48 (38–61)	55 (42–67)	39 (36–56)	<0.001		
Range of partner age, years	19–76	26–76	19–76		Z=−3.59	r=0.34

Significant differences in bold.

*Includes aquaporin-4 (AQP4)-IgG positive (n=48) and AQP4-IgG negative (n=11) patients.

EDSS, Expanded Disability Status Scale; IQR, Interquartile range; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated diseases; NMOSD, neuromyelitis optica spectrum disorders; r, rank-biserial correlation (effect size for Mann-Whitney U test); V, Cramér's V (measure of association for categorical variables); Z, Z-score (Mann-Whitney U test); χ^2 , Chi-square test.

to couples with female patients. For the comparison of total DC, discrepancy indices, depression, anxiety and relationship quality with population means, the respective publications that examined the general population using the corresponding questionnaires were used.^{18 22–25}

Multivariate regression analyses were performed to identify predictors of variations in total DC, common DC and individual stress communication, with a focus on understanding the factors influencing differences observed in both diseases, MOGAD and NMOSD. Furthermore, multicollinearity was assessed to ensure the validity of the regression models.

RESULTS

Patient characteristics

Data from n=109 patients were analysed, including n=59 (54.1%) with NMOSD and n=50 (45.9%) with MOGAD (table 1). The median age of NMOSD patients was 55 years (range: 22–82), while MOGAD patients exhibited a younger median age of 41 years (range: 19–78, p=0.001). Correspondingly, partners of NMOSD patients were older than those of MOGAD patients (p<0.001). A higher proportion of female patients was found in the NMOSD group (78%) compared with the MOGAD group (58%; p=0.025). NMOSD patients had a longer median disease duration of 8.5 years (IQR=5–12) compared with 4 years (IQR=1–6) in the MOGAD group (p<0.001). Disability levels were higher in the NMOSD group (NMOSD: EDSS (Expanded Disability Status Scale) median (Md)=3, range: 0–7; MOGAD: EDSS Md=1.5, p<0.001). Regarding relationship characteristics, NMOSD patients had longer relationships, with a median duration of 24 years (IQR=13–40, range: 3.5–56) compared with 15.5

years (IQR=10–25.5, range: 1.5–50) in MOGAD patients (p=0.011).

Comparison of DC, depression, anxiety and relationship quality in NMOSD and MOGAD patients versus population averages

Patients with NMOSD and MOGAD exhibit more depressive and anxiety symptoms compared with population norms (p<0.05) (table 2). For partners of both groups, depressive and anxiety symptoms were higher than population averages but lower than the patients' scores (partners vs population norms for depression and anxiety p<0.05; partners vs patients for depression p=0.007, anxiety p=0.065). Regarding relationship quality, NMOSD patients mean scores were similar to the general population and their partners (NMOSD patients: M (mean)=38.0, SD=9.1; partners: M=38.7, SD=6.5). The relationship quality reported by MOGAD patients (M=40.2, SD=6.8) and their partners (M=40.6, SD=3.9) was descriptively higher than the population average (M=38.7, SD=6.9), although this difference was not statistically significant (p>0.1). Concerning total DC, NMOSD and MOGAD patients scored higher compared with the population average (NMOSD patients: M=126.4, SD=20.1; MOGAD patients: M=127.9, SD=16.6; population averages: M=115.4, SD=13.8; p<0.05). DCI-subscores for NMOSD and MOGAD dyads exhibited average values compared with the general population (Stanine 4–6 for stress communication, supportive coping, delegated coping). Their own negative coping scores were clearly below the population average for all subgroups (Stanine 1).

Table 2 Comparison of dyadic coping, depression, anxiety and relationship quality in NMOSD and MOGAD patients and their partners versus population averages

	NMOSD patient female (n=46)		NMOSD partner male (n=46)	
	Mean (SD)	Population mean (SD)	Mean (SD)	Population mean (SD)
Depression	7.3 (4.4)	3.1 (3.5)	4.9 (3.9)	2.7 (3.5)
Anxiety	5.3 (3.7)	3.2 (3.5)	4.1 (3.6)	2.7 (3.2)
Relationship quality	38 (9.1)	38.65 (6.91)	38.7 (6.5)	39.49 (5.81)
Total DC	126.4 (20.1)	115.39 (13.83)	125.8 (15.8)	114.26 (12.04)
Congruence index	15.3 (5.7)	10.30 (4.52)	15.9 (4.7)	11.30 (4.56)
Perceived similarity index	14.0 (5.4)	9.62 (5.34)	13.7 (4.7)	9.46 (4.72)
	Self-evaluation		Partner-evaluation	
Reciprocity index	10.7 (5.2)	11.30 (4.69)	14.0 (7.2)	11.64 (5.08)
	Stanine		Stanine	
Own stress communication	13.4 (3.2)	5	12.0 (2.5)	5
Own supportive coping	19.5 (3.8)	5	18.9 (3.0)	5
Own delegated coping	7.3 (1.5)	5	7.6 (1.4)	5
Own negative coping	7.2 (2.6)	1	7.0 (2.5)	1
	MOGAD patient female (n=29)		MOGAD partner male (n=29)	
	Mean (SD)	Population mean (SD)	Mean (SD)	Population mean (SD)
Depression	7.7 (5.4)	3.1 (3.5)	4.7 (3.5)	2.7 (3.5)
Anxiety	6.1 (4.6)	3.2 (3.5)	4.4 (3.7)	2.7 (3.2)
Relationship quality	40.2 (6.8)	38.65 (6.91)	40.6 (3.9)	39.49 (5.81)
Total DC	127.9 (16.6)	115.39 (13.83)	126.0 (13.0)	114.26 (12.04)
Congruence index	13.1 (3.6)	10.30 (4.52)	16.1 (6.5)	11.30 (4.56)
Perceived similarity index	13.6 (5.6)	9.62 (5.34)	15.4 (5.7)	9.46 (4.72)
	Self-evaluation		Partner-evaluation	
Reciprocity index	12.5 (6.0)	11.30 (4.69)	14.2 (7.2)	11.64 (5.08)
	Stanine		Stanine	
Own stress communication	14.0 (2.9)	6	11.7 (3.8)	4
Own supportive coping	19.7 (2.5)	6	19.0 (2.7)	6
Own delegated coping	7.2 (1.4)	6	7.6 (1.5)	5
Own negative coping	7.3 (2.6)	1	8.3 (2.5)	1

DC: cut-off <111 DC below the average, 111–145 average DC, >145 DC above the average.

QMI: this scale ranges from 6 to 45, cut-off <34 low partnership quality, >34 high partnership quality.

PHQ: this depression scale ranges from 0 to 27. Scores of 5, 10, 15 and 20 represent mild, moderate, moderately severe and severe depression, respectively.

GAD: this anxiety scale ranges from 0 to 21. Scores of 5, 10 and 15 indicate mild, moderate and severe anxiety, respectively.

Stanine reference group of the validation sample of Bodenmann¹⁸: men/women from 41 years to 50 years and >50 years, 1=far below average, 2–3=below average, 4–6=average, 7–8=above average, 9=far above average. Population means reference group from the validation sample of Gmelch and Bodenmann²² for total DC and indices. Population means: PHQ from Kocalevent *et al*²³; GAD-7 from Löwe *et al*²⁴; QMI from Zimmermann *et al*.²⁵

DC, dyadic coping; GAD, Generalised Anxiety Disorder; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated diseases; NMOSD, neuromyelitis optica spectrum disorders; PHQ, Patient Health Questionnaire; QMI, Quality of Marriage Index; SD, standard deviation.

In terms of discrepancy indices, NMOSD patients and partners exhibited higher scores than the population average on both the congruence and the perceived similarity indices (congruence index: $M=15.3$, $SD=5.7$, $p<0.001$, perceived similarity index: $M=14.0$, $SD=5.4$, $p<0.001$). The reciprocity index in NMOSD dyads showed a trend towards being slightly below the

population average for self-evaluation, while partner-evaluation was higher than the population mean (NMOSD: reciprocity index self-evaluation: $M=10.7$, $SD=5.2$, $p=0.28$; partner-evaluation: $M=14.0$, $SD=7.2$, $p<0.001$). MOGAD patients and partners exhibited a comparable trend (MOGAD patients: congruence index— $M=13.1$, $SD=3.6$, $p<0.001$, perceived similarity

index— $M=13.6$, $SD=5.6$, $p<0.001$; partners: congruence index— $M=16.1$, $SD=6.5$, $p<0.001$, perceived similarity index— $M=15.4$, $SD=5.7$, $p<0.001$), including the reciprocity index (MOGAD: reciprocity index self-evaluation: $M=12.5$, $SD=6.0$, $p=0.059$, partner-evaluation: $M=14.2$, $SD=7.2$, $p<0.001$).

Differences in DC, relationship quality, depression and anxiety within couples

In NMOSD dyads, patients exhibited higher scores than partners in both own stress communication (NMOSD patients: $Md=13.5$, $IQR=11-16$, partners: $Md=12$, $IQR=10-14$, $p=0.022$) and depressive symptoms (NMOSD patients: $Md=7$, $IQR=4-10$, partners: median=4, $IQR=2-7$, $p=0.007$) (table 3). Furthermore, the reciprocity index was lower for self-evaluation ($Md=10.5$, $IQR=7-14$) compared with partner-evaluation ($Md=13.5$, $IQR=10-17$, $p=0.013$), indicating greater congruence in the partner's evaluation of DC than in the evaluation of one's own coping behaviour. In MOGAD dyads, patients also exhibited higher scores than partners in their own stress communication (MOGAD patients: $Md=15$, $IQR=12-17$, partners: $Md=11$, $IQR=9-15$, $p=0.013$) and more depressive symptoms (NMOSD patients: $Md=7$, $IQR=4-11$, partners: $Md=4$, $IQR=2-6$, $p=0.023$).

Comparison of DC between NMOSD and MOGAD

Differences were found in own stress communication, where female MOGAD patients scored the highest ($Md=15$, $p=0.028$), and in common DC, where male NMOSD patients achieved the highest scores ($Md=18$, $p=0.044$) (table 4). No further significant differences were observed between the two diseases.

Correlation analysis between DC, relationship quality, depression and anxiety within the couples

Key findings include positive correlations between patients' and partners' DC (NMOSD: $\rho=0.535$, $p<0.01$; MOGAD: $\rho=0.657$, $p<0.01$) and relationship quality in both groups (online supplemental eTable 3). In NMOSD couples, patients' DC correlated positively with relationship quality ($\rho=0.706$, $p<0.01$) and negatively with depression ($\rho=-0.382$, $p<0.01$) and anxiety ($\rho=-0.500$, $p<0.01$). MOGAD couples showed similar correlations, with DC positively linked to relationship quality ($\rho=0.478$, $p<0.01$) and negatively to anxiety ($\rho=-0.106$, $p<0.05$). Perceived similarity was positively associated with relationship quality and DC in both groups. Notably, NMOSD couples exhibited more highly significant correlations ($p<0.01$).

Regression analysis of DC

Our multivariate regression analyses examined the total DC and DCI subscales that differed between NMOSD and MOGAD to identify predictive factors. Based on correlation analysis (online supplemental eTable 3) and significant demographic and clinical differences (table 1), we selected variables for regression (online supplemental eTable 4). For total DC, univariate analysis showed significant negative associations with anxiety

($\rho=-0.255$, $p=0.007$) and a strong positive association with relationship quality ($\rho=0.586$, $p<0.001$). In multivariate analysis, relationship quality remained a strong positive predictor ($\beta=1.563$, $p<0.001$), while relationship duration had a negative association ($\beta=-0.396$, $p=0.020$). The model explained 46.7% of the variance ($r^2=0.467$). For common DC, univariate analysis revealed negative associations with depression ($\rho=-0.221$, $p=0.021$) and anxiety ($\rho=-0.268$, $p=0.005$), and a strong positive association with relationship quality ($\rho=0.529$, $p<0.001$). In multivariate analysis, relationship quality remained a significant predictor ($\beta=0.314$, $p<0.001$), with age positively associated ($\beta=0.089$, $p=0.041$) and relationship duration negatively associated ($\beta=-0.092$, $p=0.032$). This model explained 36.8% of the variance ($r^2=0.368$). For multivariate analysis of the own stress communication, only relationship quality remained a predictor ($\beta=0.098$, $p=0.021$). The model explained 22.7% of the variance ($r^2=0.227$). Multicollinearity was not an issue in any model, as tolerance and VIF values were within acceptable thresholds, confirming the validity of the regression results.

Coping strategies associated with different levels of depression and anxiety within NMOSD and MOGAD patients

No significant differences in coping strategies were found in relation to depression severity. For anxiety severity, significant associations were observed for own negative coping ($p=0.05$, $H(3)=7.76$, $\epsilon^2=0.04$) and total negative discrepancy coping ($p=0.03$, $H(3)=9.20$, $\epsilon^2=0.06$) (online supplemental eTable 6).

Regression analysis of EDSS

EDSS was used as the dependent variable in a multivariate regression model including total dyadic coping (DC), anxiety, depression, age and diagnosis as independent predictors. Depression ($\beta=0.14$, $p=0.005$) and diagnosis ($\beta=-1.13$, $p<0.001$) emerged as significant predictors, whereas age, anxiety and total DC were not significantly associated with EDSS. The model explained 28.2% of the variance ($R^2=0.282$). Tolerance and VIF values indicated no issues of multicollinearity (online supplemental eTable 7).

DISCUSSION

The CoMMOnsense-Study represents the largest cohort in the field of partnerships and rare autoimmune diseases, offering a comprehensive analysis of DC mechanisms in patients with NMOSD and MOGAD. Within this cohort, NMOSD patients are, on average, older, more severely affected and with a higher proportion of females compared with those with MOGAD, ensuring that our patient population reflects typical characteristics of these diseases.¹

Patients and partners report their relationship quality comparable to or even higher than that of the general population, as well as a high total DC. This association is known from the literature regarding both the

Table 3 Differences in dyadic coping, relationship quality, depression and anxiety within NMOSD and MOGAD couples

	NMOSD patient female (n=46)				NMOSD partner male (n=46)			
	Range	Median	IQR		Median	IQR	P value	r
Own stress communication	4-20	13.5	11-16		12	10-14	0.022	-2.29
Own supportive coping	5-25	20	17-22		19	17-21	0.264	-1.12
Own delegated coping	2-10	7	6-8		8	7-8	0.225	-1.21
Own negative coping	4-20	6	5-9		6.5	5-8	0.906	-0.12
Common DC	5-25	15	12-18		16	12-19	0.508	-0.66
Total negative DC	8-40	13.5	10-18		14	10-17	0.781	-0.28
Total positive DC	19-95	68	58-79		68	60-74	0.722	-0.36
Total DC	35-175	127	109-143		125	113-138	0.851	-0.19
Relationship quality	6-45	41.5	35-44		41	35-43	0.518	-0.65
Depression	0-27	7	4-10		4	2-7	0.007	-2.71
Anxiety	0-21	4	3-7		3	1-6	0.065	-1.85
Congruence index	0-120	14.5	12-18		15	12-19	0.418	-0.81
Perceived similarity index	0-120	14	10-19		13	10-17	0.625	-0.49
		Self-evaluation			Partner-evaluation			
Reciprocity index	0-120	10.5	7-14		13.5	10-17	0.013	-2.48
		MOGAD patient female (n=29)			MOGAD partner male (n=29)			
	Range	Median	IQR		Median	IQR	P value	r
Own stress communication	4-20	15	12-17		11	9-15	0.013	-2.50
Own supportive coping	5-25	19	18-21		19	17-22	0.372	-0.89
Own delegated coping	2-10	7	6-8		8	6-8	0.358	-0.92
Own negative coping	4-20	7	5-10		8	7-10	0.199	-1.28
Common DC	5-25	17	15-20		17	15-19	0.628	-0.49
Total negative DC	8-40	15	12-18		16	13-19	0.289	-1.10
Total positive DC	19-95	67	61-77		70	64-74	0.858	-0.18
Total DC	35-175	127	117-141		126	120-135	0.686	-0.41
Relationship quality	6-45	43	39-44		42	38-44	0.551	-0.60
Depression	0-27	7	4-11		4	2-6	0.023	-2.27
Anxiety	0-21	5	2-9		3	2-8	0.146	-1.46
Congruence index	0-120	13	10-16		15	11-21	0.103	-1.63
Perceived similarity index	0-120	12	10-16		15	12-20	0.147	-1.45
		Self-evaluation			Partner-evaluation			

Continued

Table 3	Continued	NMOSD patient female (n=46)					NMOSD partner male (n=46)				
		0–120	12	9–17	14	9–20	0.334	–0.97	0.13		
		Reciprocity index									
		DC: cut-off <111 DC below the average, 111–145 average DC, >145 DC above the average.									
		QMI: this scale ranges from 6 to 45, cut-off <34 low partnership quality, >34 high partnership quality.									
		PHQ: this depression scale ranges from 0 to 27. Scores of 5, 10, 15 and 20 represent mild, moderate, moderately severe and severe depression, respectively.									
		GAD: this anxiety scale ranges from 0 to 21. Scores of 5, 10 and 15 indicate mild, moderate and severe anxiety, respectively.									
		Significant differences in bold.									
		DC, dyadic coping; GAD, Generalised Anxiety Disorder; IQR, Interquartile range; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated diseases; NMOSD, neuromyelitis optica spectrum disorders; PHQ, Patient Health Questionnaire; QMI, Quality of Marriage Index; r, rank-biserial correlation (effect size for Mann-Whitney U test); Z, Z-score (Mann-Whitney U test).									

establishment of DCI and the majority of diseases studied in the context of DC.^{26 27} These findings also align with a study on NMOSD by Esiason *et al*, which observed that the relationship within the dyad was strengthened by the disease, while relationships with others were negatively affected.¹² This could be attributed to the rarity of the diseases. The hypothesis arises that rare diseases, due to their unfamiliarity, may not be fully understood outside the dyadic relationship. When patients and partners collaborate to understand the disease, they share a unique experience, which may foster an emotional bond.^{28–30} Whether the rarity of the diseases is the driving factor behind this dynamic needs to be investigated in a longitudinal, comparative cohort study involving autoimmune diseases of higher prevalence (eg, MS or rheumatoid arthritis). If such a link is confirmed, the partner may emerge as an even more crucial resource in the context of rare diseases than previously recognised. In the analysis of coping strategies, study participants report an average application of coping strategies, with the exception of negative DC, which is particularly low (Stanine 1), not in line with our first hypothesis. In the first approximation, this may appear favourable, as low negative coping is generally associated with positive outcome parameters such as higher adherence to treatment.⁸ However, this finding shows parallels to oncology, where such extensively low values of negative coping are interpreted as protective buffering and are therefore negatively associated with psychosocial outcomes.³¹ A direct cohort comparison with oncology patients would be beneficial to further explore this interpretation.

In the inter-partner analysis, similarities between NMOSD and MOGAD patient groups emerged. Patients reported higher levels of depressive symptoms and more own stress communication compared with their partners. Increased depression and anxiety have already been reported in both conditions.^{2 3} It is noteworthy that depressive symptoms are more prevalent among patients than partners, although this is not universally observed across all diseases. For instance, in certain oncology conditions, partners of patients may report similarly high levels of depressive symptoms.^{32 33} The fact that DC and relationship quality are reported to be high among partners who use similar coping strategies as patients but are significantly less depressed suggests that partners are a valuable resource in supporting patients. Nevertheless, when compared with the general population, partners of both disease groups show elevated levels of depression and anxiety symptoms (table 2). Our second hypothesis is partly supported, as partners show elevated psychological burden, but less so than patients. This underlines the emotional burden of partners, reinforcing the need for targeted support to maintain the well-being of both members of the dyad.

The interpretation of discrepancy indices remains a relevant challenge in current research, at the same time showing potential for a better understanding of a dyadic interplay. To the best of our knowledge, the

Table 4 Subgroup comparison by antibody status

	NMOSD patient female Median (IQR)	NMOSD patient male Median (IQR)	MOGAD patient female Median (IQR)	MOGAD patient male Median (IQR)	P value	H(3)	ϵ^2
Depression	7 (4–10)	5 (3–8)	7 (4–11)	6 (2–12)	0.73	1.29	0
Anxiety	4 (3–7)	5 (2–7)	5 (2–9)	6 (3–9)	0.72	1.33	0
Relationship quality	41.5 (35–44)	44 (42–45)	43 (39–44)	41 (33–45)	0.27	3.94	0.01
Own stress communication	13.5 (11–16)	13 (12–15)	15 (12–17)	11 (9–14)	0.028	9.14	0.06
Own supportive coping	20 (17–22)	19 (18–21)	19 (18–21)	18 (16–19)	0.1	6.21	0.03
Own delegated coping	7 (6–8)	7 (6–8)	7 (6–8)	7 (7–8)	0.93	0.43	0
Own negative coping	6 (5–9)	7 (5–9)	7 (5–10)	7 (5–11)	0.95	0.38	0
Common DC	15 (12–18)	18 (15–21)	17 (15–20)	16 (13–19)	0.044	8.12	0.05
Total own DC	57 (50–64)	57 (53–59)	57 (54–64)	52 (47–58)	0.12	6.10	0.03
Total partner's DC	54 (47–62)	58 (54–64)	53 (51–59)	51 (47–58)	0.19	4.78	0.02
Total negative DC	13.5 (10–18)	12 (11–16)	15 (12–18)	13 (12–23)	0.79	1.03	0
Total positive DC	68 (58–79)	75 (66–82)	67 (61–77)	65 (56–69)	0.12	6.12	0.03
Total DC	127 (109–143)	136 (120–142)	127 (117–141)	118 (107–131)	0.18	4.89	0.02

DC: cut-off <111 DC below the average, 111–145 average DC, >145 DC above the average.

QMI: this scale ranges from 6 to 45, cut-off <34 low partnership quality, >34 high partnership quality.

PHQ: this depression scale ranges from 0 to 27. Scores of 5, 10, 15 and 20 represent mild, moderate, moderately severe and severe depression, respectively.

GAD: this anxiety scale ranges from 0 to 21. Scores of 5, 10 and 15 indicate mild, moderate and severe anxiety, respectively.

H(df) refers to the H-value of the Kruskal-Wallis test, where df represents the degrees of freedom.

Significant differences in bold.

DC, dyadic coping; GAD, Generalised Anxiety Disorder; IQR, Interquartile range; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated diseases; NMOSD, neuromyelitis optica spectrum disorders; PHQ, Patient Health Questionnaire; QMI, Quality of Marriage Index; ϵ^2 , epsilon squared.

discrepancy indices, initially established by Gmelch and Bodenmann,²² have been applied in six studies involving different diseases (online supplemental eTable 5).^{22 34–38} Accordingly, there is still a lack of clarity regarding cut-off values and comparability. When compared with a study examining these indices in healthy couples, our patient population shows higher discrepancies among all indices (table 2). This finding underscores that the illness distorts the perception of coping efforts within the dyad. The reciprocity index in NMOSD dyads is significantly higher in their assessment of the partner's coping efforts compared with their own self-assessment. Such discrepancies in the perception of coping strategies have been linked to feelings of guilt in oncology and transplantation contexts.^{34 36} These findings point to the impact of illness on the subjective evaluation of coping within the analysed dyads, as well as the potential psychological consequences of such perceptual discrepancies, despite the limitations described here.

Our regression analysis revealed that, in addition to relationship quality, age and relationship duration were significant predictors of DC (online supplemental eTable 4). These findings suggest that the few differences observed in coping strategies between NMOSD and MOGAD patients are attributable to age and relationship

duration rather than to the diseases themselves. Although increasingly recognised as distinct in terms of pathophysiology and treatment,¹ these two conditions share notable similarities in psychological factors and coping. We propose that coping concerns may be addressed together in strategies to optimise DC.

Our study's strength lies in its sufficiently large patient sample, which is particularly notable for NMOSD and MOGAD due to the rarity of these conditions and the unique focus on a couple study design—factors that typically result in smaller sample sizes. However, several limitations must be considered. The partner analysis was restricted to female patient/male partner couples due to limited numbers of the reverse constellation, which may introduce a gender bias. Additionally, reliance on self-reported data may result in bias, as participants could provide socially desirable responses. Moreover, a selection bias cannot be ruled out, as couples with stronger relationships may have been more likely to participate. While the use of discrepancy indices is innovative, they are still in the early stages of development, limiting their reliability and validity. The exploratory nature of our analyses, including multiple testing and the related potential for type I error, should be taken into account when interpreting the findings.

Given that DC is high and positively associated with relationship quality, we propose increasing the involvement of the partner in the clinical context to strengthen this resource. The parameters identified in our study that could promote negative coping, such as discrepancies in coping perception and protective buffering, should be validated. It is essential to examine the circumstances triggering these phenomena.

CONCLUSION

NMOSD and MOGAD are comparable in terms of disease burden, both showing high levels of DC, strong relationship quality and fewer depressive symptoms in partners compared with patients. Thus, coping within the partnership emerges as an important resource. A closer analysis of coping mechanisms suggests protective buffering and discrepancies in coping perception. The reduction of these phenomena presents opportunities to optimise coping strategies. To translate these findings into clinical practice, we recommend involving partners in medical consultations and self-help groups. Furthermore, a screening tool should be developed to identify discrepancies in coping perception and protective buffering, enabling identification of couples at risk for maladaptive coping. For these couples, couple-based therapy could be introduced to improve DC and foster the partnership.

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