The relationship between illness coherence and well-being among persons with multiple sclerosis and their caregivers: A multicenter study

M. Bassi[1], M. Falautano[2], S. Cilia[3], B. Goretti[4], M. Grobberio[5], M. Pattini[6], E. Pietrolongo[7], R.G. Viterbo[8], M.P. Amato[4], M. Benin[5], A. Lugaresi[7], E, Minacapelli[2], E. Montanari[6], F. Patti[3], M. Trojano[8], A. Delle Fave[9] on behalf of the Care System Group*

[1]Department of Biomedical and Clinical Sciences L. Sacco - University of Milan, Via G.B. Grassi 74, 20157 Milano, marta.bassi@unimi.it; [2] Neurological Department - San Raffaele Hospital – Milano; [3]Department GF Ingrassia - Neuroscience section - University of Catania - Catania; [4]Department of NEUROFARBA - University of Florence; [5]Lab of Clinical Neuropsychology - Hospital S. Anna of Como; [6]Multiple Sclerosis Centre - Neurology Unit - Hospital of Vaio – Fidenza; [7]Department of Neurosciences, Imaging and Clinical Science - University G. d'Annunzio – Chieti; [8]Department of Basic Medical Sciences, Neurosciences and Sense Organs - University of Bari; [9]Department of Pathophysiology and Transplantation - University of Milano.

Objectives

According to the salutogenic approach, making sense of disease represents a crucial psychological resource in facilitating illness adjustment of patients and their caregivers. Illness coherence implies comprehending and accepting the disease as part of life, and it is related to positive outcomes such as positive mental health, healthy lifestyles, adaptive coping. In multiple sclerosis (MS), unknown etiology and unpredictable progress may hamper patients' and caregivers' formation of a coherent picture of MS, negatively affecting their well-being.

→ **The present study aimed to jointly investigate perceived illness coherence among persons with MS (PwMS) and their caregivers, and its relation to well-being.**

Participants

Written informed consent was collected for all participants. In addition:

PwMS' inclusion criteria:
- Age: ≥ 18
- Clinically-definite MS diagnosis (McDonald's revised criteria)
- At least 3 years from diagnosis
- Having a caregiver

PwMS' exclusion criteria:
- Neurological disorders other than MS
- Psychiatric disorders
- Severe physical impairment (EDSS ≥ 8)
- Being in the active phase of the disease
- Severe cognitive impairment (below the cut-off point of Token Test or Raven Matrices; equivalent score = 0-1)

No specific criteria were set for caregivers.

Data analyses

• Paired t-tests and Pearson's correlations were calculated to compare illness coherence between patients and caregivers.
• Hierarchical linear regressions examined the contribution of illness coherence to participants' well-being. In step 1 we introduced the predictors PwMS' and caregivers' illness coherence simultaneously; in step 2 we added the interaction between them (moderation effect). Simple slopes were then calculated for significant interactions, and then plotted and tested for significance both for high and for low beliefs values (± 1 SD).

Methods

This study involved PwMS and their caregivers from 7 MS centers in Northern, Central and Southern Italy. Each center recruited participants following common criteria and procedures.
• Persons with MS were contacted by researchers. After participation consent, they were asked to identify their primary caregiver. Next, a neuro-psychologist performed a cognitive evaluation to assess PwMS' comprehension and logical abilities.
• If no severe cognitive impairment was detected, the patient and his/her caregiver were enrolled, and the research questionnaires were administered.
• Individual briefings were scheduled to present the questionnaires and to make sure that participants' doubts and questions were cleared. Option was given to complete the battery in situ (85.9% PwMS and 80.3% caregivers) or at home.

Materials

1) The **Revised Illness Perception Questionnaire** (IPQ-R) [1] measuring the dimensions: illness identity (18 symptoms on a yes/no answering format), illness causes (18 items on scales ranging from 1 "strongly disagree" to 5 "strongly agree"), and opinions about MS (38 items on 1-7 scales), including Timeline acute/chronic, Timeline cyclical, Consequences, Personal control, Treatment control, Emotional representations, and **Illness coherence**. IPQ-R was developed to assess patients' perception of their illness, so an alternative version was devised for caregivers. Items administered to PwMS were phrased referring to *my illness* as in the standard IPQ-R version; while items administered to caregivers were phrased referring to *this illness* (i.e. MS) as suggested in [2].
2) **Psychological Well-being Scales** (PWBS) [3] tapping with three items each the dimensions of **psychological well-being**: environmental mastery, autonomy, purpose in life, personal growth, self-acceptance and positive relations. Ratings range from 1 "strongly disagree" to 6 "strongly agree". Items were aggregated into one factor, with higher scores referring to higher psychological well-being [4].
3) The **Satisfaction with Life Scale** (SWLS) [5] asking participants to report how much they agreed (from 1 "strongly disagree" to 7 "strongly agree") on five statements assessing their level of overall **life satisfaction**. A higher total score indicated higher satisfaction.
4) The **Positive Affect and Negative Affect Schedule** (PANAS) [6] in which 10 items measure positive affect (PA) and 10 measure negative affect (NA). Item scales range from 1 (very slightly or not at all) to 5 (extremely). The difference between PA and NA ratings was calculated to obtain the **hedonic balance** score.

PwMS' clinical information was gathered on MS type, age of onset, disease duration and current level of impairment/disability measured with Expanded Disability Status Scale (EDSS; ranging from 0 "normal examination" to 10 "death from MS") [7]. All participants reported on their age, gender, education, civil status, and employment.

RESULTS

Findings showed that PwMS and caregivers reported similar average levels of MS coherence. In addition, significant positive correlations were detected between PwMS' and caregivers' coherence scores. Analyses further revealed that PwMS' coherence was positively related to their own psychological well-being, life satisfaction and hedonic balance, and that caregivers' coherence was positively related to their own psychological well-being. PwMS' coherence also had a positive cross-influence on caregivers' hedonic balance. Interaction effects were observed between PwMS' and caregivers' coherence on PwMS' psychological well-being and hedonic balance. Specifically, when both PwMS and caregivers perceived low illness coherence, PwMS reported lower scores in both well-being measures. By contrast, when a mismatch between caregivers' low and PwMS' high coherence was detected, PwMS reported higher scores of psychological well-being and hedonic balance.

Demographic and clinical characteristics	Persons with MS (N = 71)		Caregivers* (N = 71)	
	N (%)	M (SD)	N (%)	M (SD)
Age		40 (10)		46.6 (11.7)
Gender				
Women	48 (67.6)		42 (59.2)	
Men	23 (32.4)		29 (40.8)	
Education[a]				
High school or less	56 (78.9)		60 (84.5)	
University	15 (21.1)		11 (15.5)	
Employment status				
Employed	40 (58.8)[b]		51 (71.8)	
Unemployed	28 (41.2)		20 (28.2)	
Civil status				
Married/cohabiting	46 (64.8)		57 (80.3)	
Single/divorced/widowed	25 (35.2)		14 (19.7)	
MS type				
Relapsing-remitting	44 (62)			
Primary progressive	8 (11.3)			
Secondary progressive	19 (26.7)			
Disease duration (in years)		10.4 (6.7)		
Disability level (EDSS)		4.1 (2)		
% mild (0 to 3.0)	27 (38.0)			
% moderate (3.5 to 6.0)	31 (43.7)			
% severe (>6.5)	13 (18.3)			
DMT	55 (77.5)			
Immune modulators	25 (45.5)			
Immune suppressants	30 (54.5)			
Caregiving years				8.8 (5.9)

Note: *caregivers were primarily PwMS' partners (59.2%), followed by mothers (23.9%), children and siblings (5.6% respectively), friends (2.8%), one father (1.4%), and one professional caregiver (1.4%).
[a]For education, "high school or less" included elementary school, middle school, or high school. [b]Three PwMS did not report their employment status. Of those who were unemployed, 16 (64%) received a disability pension.

Descriptives, correlations and paired t-tests

	Persons with MS (N = 71)			Caregivers (N = 71)			t-values	Pearson correlations
	M	SD	Range	M	SD	Range		
Illness coherence	3.33	.77	1-5	3.23	.80	1-5	.74	.27*
Psychological well-being	4.27	.68	2-6	4.10	.66	2-6		
Satisfaction with life	3.82	1.57	1-7	4.07	1.48	2-7		
Hedonic balance (PA-NA)	.86	1.30	-2.7-3.4	.88	1.19	-2.0-3.3		
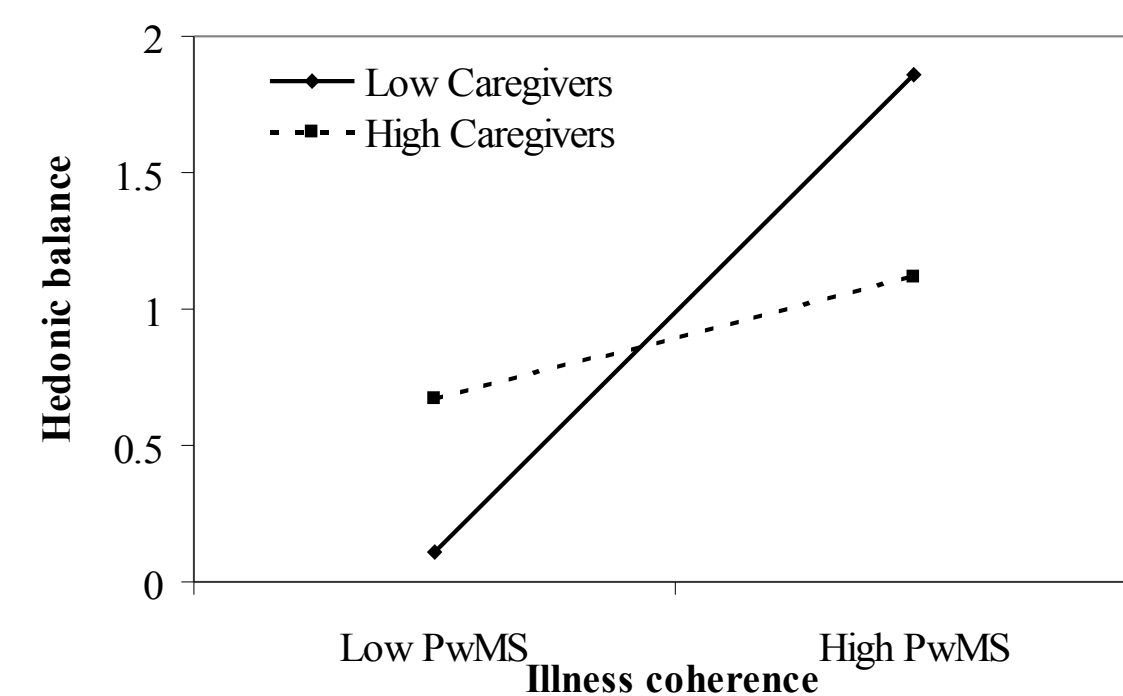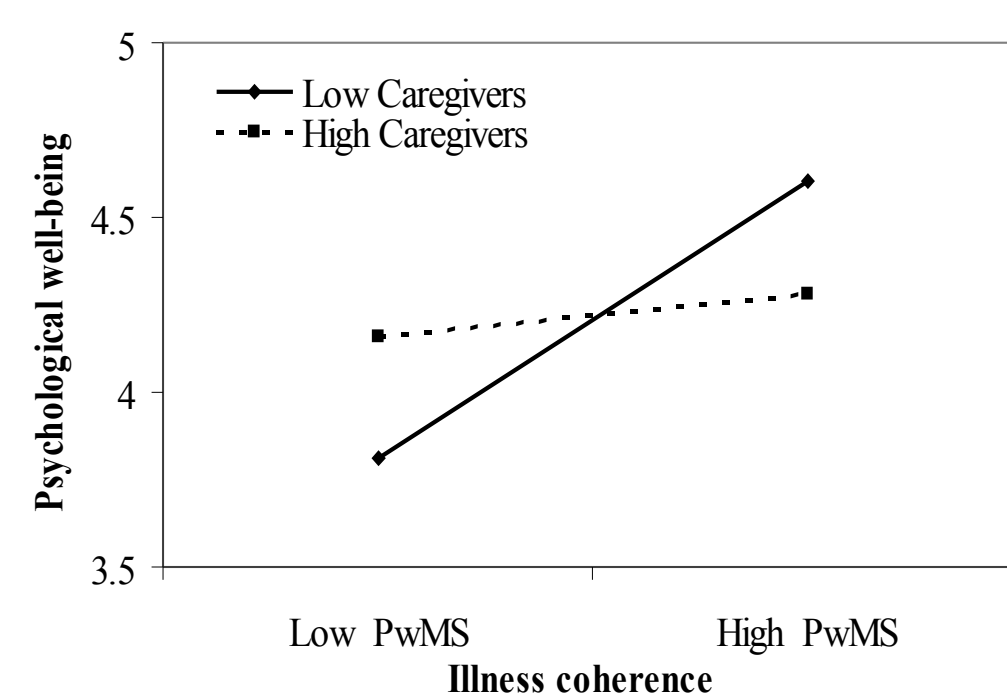
Note. caregivers' illness coherence was used as moderator for simple slope analyses of PwMS' well-being. Concerning the relationship between PwMS' coherence and psychological well-being, only the simple slope for caregivers' low illness coherence was significant ($t (69) = 3.68$, $p < .001$). Concerning the relationship between PwMS' coherence and hedonic balance, only the simple slope for caregivers' low illness coherence was significant ($t (69) = 4.36$, $p < .001$).

Multiple linear regression analyses predicting PwMS' and caregivers' well-being from PwMS' and caregivers' illness coherence (Step 2)

	Illness coherence	
	PwMS β	C β
Psychological well-being		
Persons with MS (PwMS)	.34**	.14
Caregivers (C)	.01	.44***
PwMS x C	-.25*	-.10
R^2	.19	.29
F	5.26**	8.89***
Satisfaction with life		
Persons with MS (PwMS)	.43***	.22
Caregivers (C)	.07	.16
PwMS x C	-.06	-.02
R^2	.22	.09
F	6.11**	2.28
Hedonic balance		
Persons with MS (PwMS)	.42***	.33**
Caregivers (C)	-.04	.18
PwMS x C	-.26*	-.17
R^2	.25	.22
F	7.31***	6.27**

* $p < .05$; ** $p < .01$; *** $p < .001$

Conclusions

PwMS and caregivers co-construct the meaning they attribute to MS which can affect their well-being in complex ways. For both patients and caregivers, higher illness coherence was associated with higher well-being levels. A compensation mechanism was also observed through which PwMS' more coherent view mitigated the effect of caregivers' less coherent representation, thus enhancing PwMS' well-being. Findings suggest that providing PwMS and caregivers with better understanding of their mutual illness beliefs may represent a powerful tool to enhance well-being and illness adjustment.

References
[1] Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, & Buick D. The Revised Illness Perception Questionnaire (IPQ-R). Psychol and Health 2002;17:1-16.
[2] Figueiras MJ, & Alves NC). Lay perceptions of serious illnesses: An adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for healthy people. Psychol and Health 2007;22:143-158.
[3] Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. J Pers Soc Psychol 1989;57:1069-1081.
[4] Ryff CD and Keyes CLM. The structure of psychological well-being revisited. J Pers Soc Psychol 1995;69:719–727.
[5] Diener E, Emmons R, Larsen RJ, Griffin S. The satisfaction with life scale. J Pers Assess 1985;49:71–75.
[6] Watson D, Clark LA and Tellegen A. Development and validation of brief measures of positive and negative affect: The PANAS scale. J Pers Soc Psychol 1988;54:1063-1070.
[7] Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an Expanded Disability Status Scale (EDSS). Neurology 1983;33:144-152.

* **The Care System Group:** Marta Bassi[1], Monica Falautano[2], Beatrice Allegri[6], Miriam Benin[5], Francesca Cenci[4], Sabina Cilia[3], Emanuele D'Amico[3], Giovanna De Luca[7], Benedetta Goretti[4], Angelica Guareschi[6], Monica Grobberio[5], Bahia Hakiki[4], Pietro Iaffaldano[8], Carmela Leone[3], Salvatore Lo Fermo[3], Letizia Manneschi[4], Eleonora Minacapelli[2], Marianna Pattini[6], Ilaria Pesci[6], Erika Pietrolongo[7], Emilio Portaccio[4], Raffaela Sartori[6], Daniela Travaglini[6], Samuela Turati[5], Manuela Valsecchi[5], Rosa Gemma Viterbo[8], Maria Pia Amato[4], Giancarlo Comi[2], Mauro Comola[2], Franco Di Palma5, Alessandra Lugaresi[7], Vittorio Martinelli[2], Nerina Mascoli[5], Enrico Montanari[6], Francesco Patti[3], Monica Rezzonico[5], Maria Trojano[8], Antonella Delle Fave[9].