

# Illness Perception and Well-Being Among Persons with Multiple Sclerosis and Their Caregivers

Marta Bassi<sup>1</sup> · Monica Falautano<sup>2</sup> · Sabina Cilia<sup>3</sup> · Benedetta Goretti<sup>4</sup> ·  
Monica Grobberio<sup>5</sup> · Marianna Pattini<sup>6</sup> · Erika Pietrolongo<sup>7</sup> · Rosa Gemma Viterbo<sup>8</sup> ·  
Maria Pia Amato<sup>4</sup> · Miriam Benin<sup>5</sup> · Alessandra Lugaresi<sup>7</sup> · Eleonora Minacapelli<sup>2</sup> ·  
Enrico Montanari<sup>6</sup> · Francesco Patti<sup>3</sup> · Maria Trojano<sup>8</sup> · Antonella Delle Fave<sup>9</sup>

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**Abstract** This study jointly examined illness beliefs held by persons with multiple sclerosis (PwMS) and caregivers in relation to well-being. A group of 68 PwMS and their caregivers completed the Revised Illness Perception Questionnaire, Psychological Well-being Scales, Satisfaction with Life Scale and Positive Affect and Negative Affect Schedule. Findings revealed that PwMS' well-being was primarily predicted by their own illness beliefs, and that also caregivers' well-being was primarily predicted by their own beliefs. Across the two groups, well-being was positively associated with their belief that they understood the disease, and inversely associated with their representations of negative emotions. In addition, among PwMS, well-being was inversely associated with the number of

symptoms they specifically attributed to their illness, while among caregivers, well-being was positively associated with beliefs that treatment could control the disease. Based on the study findings, psychoeducational and cognitive-behavioral strategies are suggested to promote well-being among PwMS and caregivers.

**Keywords** Multiple sclerosis · Illness perceptions · Psychological well-being · Satisfaction with life · Hedonic balance

## Introduction

Multiple sclerosis (MS) is a neurodegenerative disease affecting over 2.3 million people worldwide (National MS Society, 2014). MS is characterized by irreversible damage to the myelin sheath of neurons in the central nervous system, resulting in a wide range of symptoms such as muscle spasticity, tremor, ataxia, visual deficits, fatigue, bladder, bowel and sexual dysfunctions, as well as cognitive alterations in attention, memory, executive functions, and verbal fluency. Persons with MS (PwMS) may also develop depression symptoms and, occasionally, psychiatric disorders. Disease manifestations, progression and severity are largely unpredictable and subject to individual variation. MS can take several clinical courses, with new symptoms either arising in isolated attacks (relapsing forms) or building up over time (progressive forms). What is more, to date no clear cause of MS has been identified, and no cure is yet available.

As a result, MS has a significant impact on the lives of both affected persons and their caregivers (Dennison, Moss-Morris, & Chalder, 2009; Pakenham, 2007). Increasing physical disability poses limitations to PwMS'

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✉ Marta Bassi  
marta.bassi@unimi.it

<sup>1</sup> Department of Biomedical and Clinical Sciences L. Sacco, University of Milano, Via G.B. Grassi 74, 20157 Milan, Italy

<sup>2</sup> Neurological Department, Hospital San Raffaele, Milan, Italy

<sup>3</sup> Multiple Sclerosis Center, University Polyclinic Hospital G. Rodolico, Catania, Italy

<sup>4</sup> Department of NEUROFARBA, Section Neurosciences, University of Florence, Florence, Italy

<sup>5</sup> Department of Neurology, S. Anna Hospital, Como, Italy

<sup>6</sup> Multiple Sclerosis Center – UOC Neurology Unit, Hospital of Vaio-Fidenza, Fidenza, Italy

<sup>7</sup> Department of Neuroscience, Imaging and Clinical Sciences, University “G. d’Annunzio”, Chieti, Italy

<sup>8</sup> Department of Basic Medical Sciences, Neurosciences and Sense Organs, University of Bari, Bari, Italy

<sup>9</sup> Department of Pathophysiology and Transplantation, University of Milano, Milan, Italy

daily living (e.g., household tasks, personal care), productive life (e.g., employment), and social activities. As for caregivers, primarily family members (who may be patients' parents, partner, children, or siblings), changes in personal and social life include caregiving tasks encompassing household keeping, mobility assistance, nursing care (e.g., distribution of medicines/injections), as well as relational and emotional support. Greater assistance is then needed as care recipients' level of disability increases.

A number of studies showed that the above changes in PwMS' and caregivers' lives have profound psychological implications (Dennison et al., 2009; Forbes, While, & Mathes, 2007; Giordano et al., 2012). In particular, compared to the healthy population matched by age and gender, both PwMS and caregivers report higher depression and anxiety, as well as lower health-related quality of life (HRQOL; Schipper, Clinch, & Olweny, 1996), defined as the degree to which the medical condition affects various life areas including general health, social functioning, bodily pain, vitality, role limitations due to physical conditions, and mental health (Patti et al., 2007).

While these studies provided important information on participants' living conditions and psychological distress, some shortcomings can be detected. First, PwMS and caregivers were investigated separately, whereas in reality patients and caregivers (especially family members) constantly interact. Besides sharing relational ties, they can mutually influence their belief systems, disease conceptualization, and coping strategies (Leventhal, Brissette, & Leventhal, 2003). Second, psychological investigation in MS has primarily neglected that there is more to well-being than the reduction of negative emotional symptoms of anxiety and depression, and that disease can also have positive implications for individuals (Bassi et al., 2014). In light of these shortcomings, the present study adopted a family-related theoretical approach, considering PwMS and caregivers both as distinct and as interacting individuals (Feetham, 1991). Within this theoretical framework, we aimed to investigate participants' well-being and its possible predictors in terms of illness beliefs.

### Well-Being and MS

Over the last two decades, researchers have been increasingly involved in the study of well-being (Lopez & Snyder, 2011). While health research has traditionally equated well-being with absence or reduction of mental disorders and negative mood, researchers working in a positive psychology framework have explored new definitions of well-being, with the aim of catalyzing a change in focus from the sole preoccupation with repairing the worst things in life to also building positive qualities (Seligman & Csikszentmihalyi, 2000). In particular, two lines of

research were developed: hedonism and eudaimonism, both rooted in ancient Greek philosophical frameworks (Ryan & Deci, 2001). The first one, dating back to Aristippus, equates well-being with pleasant feelings, comfort, enjoyment and contentment with one's life. The second one refers to Aristotle's concept of "eudaimon" (good spirit), according to which individuals should pursue their true virtuous nature in life. Accordingly, eudaimonic well-being is equated with optimal human functioning, meaning-making and the ability to fulfill one's potential and to pursue complex goals. The main hedonic concepts are life satisfaction and hedonic balance, i.e. prevalence of positive over negative affect (Diener, 2009). Among the eudaimonic constructs, psychological well-being (Ryff, 1989) comprises self-acceptance, positive relations, environmental mastery, purpose in life, autonomy and personal growth. Hedonic and eudaimonic dimensions are complementary aspects which need to be assessed jointly in order to acquire a comprehensive picture of individuals' well-being condition (Delle Fave, Brdar, Freire, Vella-Brodrick, & Wissing, 2011). Moreover, the identification of different hedonic and eudaimonic dimensions supports the distinction of well-being from reduction or absence of mental illness. Even if well-being and mental illness are correlated, they are not opposite poles of a single continuum (Westerhof & Keyes, 2010), so that presence of well-being is not equivalent to absence of mental illness, and absence of well-being is not equivalent to presence of mental illness.

Research on well-being in MS recently started to burgeon (Dennison et al., 2009). Adjusting for age and gender, caregivers' levels of life satisfaction were shown to be comparable to normative data, whereas PwMS reported being more dissatisfied with their lives (Bassi et al., 2014; Ryan et al., 2007; Sherman et al., 2007). However, after controlling for demographic differences in gender and education between PwMS and caregivers, matching values of both hedonic and psychological well-being were observed (Bassi et al., 2014). These findings suggest that well-being can coexist with illness conditions, and the identification of the factors affecting it can help devise strategies to promote well-being among PwMS and their caregivers.

### Illness Beliefs and Psychosocial Functioning

Within health research great attention has been devoted to illness perceptions, i.e. people's cognitive and emotional representations of an illness (Benyamini, 2011). According to the common-sense model (Leventhal et al., 2003), when facing a health threat, individuals pose themselves a number of queries in the attempt to understand it. Questions concern illness identity, causes, consequences,

timeline, controllability, coherence, and emotional response. The way individuals answer these questions, their personal evaluations, can influence their bio-psycho-social adjustment, both directly and indirectly via coping strategies. Research on chronic diseases has shown that illness perceptions directly affect anxiety, depression, as well as psychosocial functioning among both patients and caregivers (Heijmans, de Ridder, & Bensing, 1999; Kaptein et al., 2006; Weinman, Heijmans, & Figueiras, 2003). In particular, among patients: illness identity (e.g., the number of symptoms an individual believes are linked to a specific illness); and emotional representations (e.g., the degree to which an individual links negative emotions to a specific illness) proved to be positive predictors of psychological distress related to that illness. In contrast: illness coherence (e.g., the degree to which an individual feels she understands a specific illness); personal control (e.g., the extent to which she believes she can take action to control the illness); and treatment control (e.g., the extent to which she believes treatment can control a specific illness) all showed negative correlation with distress (Kaptein et al., 2006; Sawicki, Sellers, & Robinson, 2011). Moreover, illness beliefs can have far-reaching effects on long-term outcomes such as patients' adherence to medication (Jessop & Rutter, 2003) and caregivers' coping strategies (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

Researchers also examined jointly patients' and caregivers' illness beliefs, assuming their combined influence on adjustment. In particular, attention was paid to the degree of congruence (similarity vs. dissimilarity) between patients' and caregivers' representations, and its effect on outcomes such as recovery from myocardial infarction (Figueiras & Weinman, 2003) and response to chronic diseases (Heijmans et al., 1999; Karademas, Zarogiannos, & Karamvakalis, 2010; Olsen, Berg, & Wiebe, 2008). Overall, findings revealed that patients and caregivers prominently reported similar beliefs. When differences were identified, caregivers reported more pessimistic views about, for example, illness identity, chronicity, consequences, and emotional representations (Benyamini, Medalion & Garfinkel, 2007; Heijmans et al., 1999; Olsen et al., 2008), and more optimistic perceptions of personal control (Karademas et al., 2010). Findings also revealed that congruent positive perceptions were associated with better adjustment, while congruent negative perceptions were associated with poorer adjustment. Mixed results were obtained for conflicting views, that is, when patients held negative illness views and caregivers held positive views, or vice versa, caregivers held negative views and patients held positive views. In some studies, belief dissimilarities were associated with poor outcomes (Heijmans et al., 1999; Olsen et al., 2008). In other studies (Figueiras & Weinman, 2003; Karademas et al., 2010), only small

outcome differences were detected between patient-caregiver dyads with similar positive perceptions and those with conflicting views. This finding suggested that at least one member of the dyad should hold a positive illness perception in order to improve adjustment to illness.

Research concerning MS perceptions is still in its infancy (Dennison et al., 2009). The few studies conducted with PwMS showed that strong illness identity, perception of a chronic timeline and severe consequences, attribution to psychological causes, low illness coherence and low personal control were associated with higher anxiety and depression levels (Jopson & Moss-Morris, 2003). Stronger illness identity was also predictive of lower HRQOL levels (Spain, Tubridy, Kilpatrick, Adams, & Holmes, 2007). To the best of our knowledge, only one study investigated the relationship between PwMS' and caregivers' illness beliefs and a well-being indicator. Specifically, that study focused on adversarial growth, i.e., the positive transformations in beliefs and behavior derived from a highly stressful adverse event such as illness (Ackroyd et al., 2011). Findings showed that adversarial growth positively correlated with personal control, illness identity and cyclical timeline among patients, and with emotional representations among caregivers. Conflicting views about illness consequences positively predicted growth among caregivers, but not among PwMS.

## The Present Study

As shown above, little information is currently available on PwMS' and caregivers' well-being and on its relation to their illness belief systems. We thus conducted a study among Italian PwMS and their caregiving family members, investigating their illness perceptions, satisfaction with life, hedonic balance, and psychological well-being. Notably, contrary to most reported studies, we did not select a priori spousal caregivers, but relied on PwMS' personal judgment for the identification of their primary caregiving person.

Specifically, our study aimed to investigate: (1) the similarities and differences between PwMS' and caregivers' illness perceptions; (2) the relationship between illness beliefs and well-being in the two groups; and (3) the cross-correlations between PwMS' and caregivers' beliefs and their respective levels of well-being. Bearing in mind that illness beliefs are shaped by both individuals' experiences and disease characteristics, research findings described in the previous section helped us formulate the study hypotheses. Particularly, we hypothesized to detect similarities between PwMS' and caregivers' illness perceptions: These would primarily concern disease chronicity, as progressive physical disability is commonly experienced in MS; and treatment control, since drug regimens are available and commonly administered by

both patients and caregivers. At the same time, we also expected to identify conflicting views, according to which caregivers would report more pessimistic views about illness identity and emotional representations, as well as more optimistic views about personal control.

Concerning illness beliefs and well-being, we assumed that, among both PwMS and caregivers, negative perceptions (particularly, strong illness identity and increased emotional response) could correlate negatively with well-being dimensions. Moreover, we expected illness coherence and treatment control to be positively associated with well-being.

We finally took into consideration cross-influences between PwMS' and caregivers' illness beliefs and well-being. Researchers have measured belief congruence by creating discrete groups in which patients' and caregivers' ratings were both high, both low or discrepant based on their median scores (Figueiras & Weinman, 2003; Karademas et al., 2010), or by calculating mean differences between patient and caregiver (Ackroyd et al., 2011; Heijmans et al., 1999; Olsen et al., 2008). These researchers have acknowledged methodological limitations in these approaches. In the present study, we thus adopted the approach proposed by Benyamini et al. (2007), in which both individual perceptions and their interactions were taken into account. This allowed us to explore the congruence patterns of PwMS' and caregivers' belief ratings (both positive, both negative, or conflicting) over and above individual beliefs, and to appraise their association with well-being. In line with the literature (Heijmans et al., 1999; Figueiras & Weinman, 2003; Karademas et al., 2010; Olsen et al., 2008), for both PwMS and caregivers, we expected similar positive illness beliefs to be associated with higher well-being, and similar negative beliefs to be associated with lower well-being. In addition, when conflicting views were identified, that is, when patients held negative illness views and caregivers held positive views, or when caregivers held negative views and patients held positive views, we expected that the presence of at least one positive perception in the patient-caregiver pair could be associated with higher well-being.

## Methods

### Sampling and Procedure

This study involved PwMS and their caregivers from seven MS centers in Northern, Central and Southern Italy. Each center recruited 10 PwMS and 10 caregivers, following common criteria and procedures. From the clinical point of view, PwMS were enrolled if they met McDonald's revised

diagnostic criteria for at least 3 years. These criteria are the gold standard in MS diagnosis: They are based on magnetic resonance imaging for demonstration of dissemination in space and time of central nervous system lesions (Polman et al., 2011), and for exclusion of other neurological diseases with similar characteristics. Other PwMS' inclusion criteria were being at least 18 years of age, and having a caregiver.

Moreover, since PwMS can develop mental and cognitive impairments which can interfere with their ability to understand and fill in self-report questionnaires, we added psychiatric disorders and severe cognitive impairment to the exclusion criteria. Information about possible psychiatric disorders was taken from patients' clinical history record drawn up by a neurologist. Patients were eligible for the study if their clinical record made no mention of the presence of a psychiatric disorder. Cognitive functioning was evaluated with Token Test and Raven Matrices (De Renzi & Vignolo, 1962; Raven, 1962). The former assesses language comprehension, while the latter measures logical abilities and nonverbal reasoning. These widely-used measures were chosen as they were shown to provide more sensitive assessment than general tests such as the Mini-Mental State Examination or the Montreal Cognitive Assessment, which are usually administered to persons with dementia (Beatty & Goodkin, 1990). Based on standard scoring procedures, we excluded PwMS who reported at least one pathological score on the Token Test or Raven Matrices, namely, a score below the cut-off point at the 16th percentile, corresponding to standardized age- and education-equivalent scores of 0 or 1 (Capitani & Laiconica, 1997; De Renzi & Vignolo, 1962; Raven, 1962).

Finally, two more exclusion criteria were introduced in order to exempt from the study PwMS who were currently experiencing extreme, debilitating symptoms associated with illness progression. The first criterion was being in the active phase of disease, namely, experiencing a clinical exacerbation which, together with required cortisone treatment, could temporarily affect patients' performance. The second criterion was severe physical impairment (EDSS  $\geq$ 8), accounting for PwMS' restriction to bed and progressive inability to communicate, eat, and take care of themselves.

Psychologists and neurologists working together in each center consulted medical records, in order to identify eligible PwMS who met preliminary clinical inclusion and exclusion criteria as assessed in their last medical evaluation. These potential participants were contacted during check-ups or by phone. Upon participation agreement, they were asked to identify their primary caregiver, by answering the following question: "Under disease conditions, each of us can generally count on other people who

offer us material help and psychological support. Can you identify in your current life a particular person who performs these roles?”. If the answer was “yes,” PwMS were further asked to report the kind of relationship they had with this person (partner, mother, father, friend, other relative, or other person), and to inquire about his/her participation in the study.

PwMS’ cognitive screening was then scheduled and performed by a psychologist. If no severe cognitive impairment was detected, the patient and his/her caregiver were enrolled, and the research questionnaires were administered. On the same day of the cognitive assessment (for the patient), or on a day agreed upon with the researcher (for the caregiver alone, or for the patient and his/her caregiver), participants who wished to fill out the questionnaires at the center (85.3 % of patients and 79.4 % of caregivers) were given access to a private room, either alone or together, in the presence of the researcher. The researcher provided the guidelines for filling out the questionnaires, cleared questions and doubts, and made sure that, if together, communication between patient and caregiver did not occur during the administration. As for those participants who wished to fill out the questionnaires at home (14.7 % of patients and 20.6 % of caregivers), the researcher at the center gave to each of them personally the questionnaire battery, explained guidelines, and cleared questions and doubts. Both orally and through written instructions, participants were reminded of the value of their personal opinion, and were asked to fill out the questionnaires on their own, with no help from family members, relatives or friends. They were further provided with the researcher’s telephone number in case of need, and were asked to hand in the questionnaires at the center after one week/ten days. Written informed consent was obtained from participants. The study protocol was approved by all local ethical committees.

## Participants

Altogether we contacted 80 PwMS. Four of them declined participation and five did not meet inclusion criteria because of severe cognitive impairment. One caregiver declined participation, leading to the exclusion of the corresponding PwMS. Additionally, one PwMS and his/her caregiver were recruited based on voluntary request. The sample thus comprised 71 PwMS and 71 caregivers. Most caregivers (95.8 %) were family members, whereas two were friends and one was a professional caregiver. Since our research focused on family members, the formal caregiver and friends were not considered in present analyses. Consequently, the final sample included 136 participants: 68 PwMS and 68 caregivers.

## Instruments

### *Personal Data*

Neurologists provided patients’ clinical information taken from the last available evaluation concerning MS type, disease duration, disease-modifying treatment (immune modulators or immune suppressors), and current level of impairment measured with the Expanded Disability Status Scale (EDSS; Kurtzke, 1983). An EDSS score is attributed by the neurologist, after clinical examination of the patient. It ranges from 0 = “normal examination” to 10 = “death from MS,” and includes the assessment of limb movement and coordination, sensation, bowel and bladder function, and visual function.

All participants provided information on demographic variables such as age, gender, education, marital status, and employment. They also specified whether they suffered from diseases other than MS, and whether they were taking treatment for them. In addition, caregivers were asked to report on the duration of their caregiving task (in years), and to indicate how much help they gave to the PwMS. For the latter purpose, they were administered the Caregiving Tasks in MS Scale (CTiMSS; Pakenham, 2007). This questionnaire comprises 24 items assessing the amount of help caregivers provide in terms of Activities of Daily Living care, instrumental care, psycho-emotional care, and social-practical care (e.g., transportation, feeding, managing mood swings/moodiness, providing companionship). Ratings were: 0 = “no help;” 1 = “little help;” 2 = “moderate help;” 3 = “quite a lot of help;” and 4 = “lots of help.” According to Pakenham (2007), items were aggregated into one factor, with a total score calculated by averaging the 24 items that comprise the scale. Higher scores indicated higher amount of provided help. For the present dataset, Cronbach alpha for the CTiMSS was 0.93.

### *Illness Beliefs*

Participants’ illness perceptions about MS were measured with the Revised Illness Perception Questionnaire (IPQ-R; Giardini, Majani, Pierobon, Gremigni, & Catapano, 2007; Moss-Morris et al., 2002). IPQ-R was originally developed to assess patients’ opinions about their illness, and so it was necessary to devise an alternative version for caregivers who do not have MS. Instructions for PwMS asked them to express their personal views about their illness; instructions for caregivers asked them to express their personal views about multiple sclerosis. Consequently, items administered to PwMS were phrased referring to “my illness” or “this illness” as in the standard IPQ-R version (Moss-Morris et al., 2002); while items administered to caregivers were

phrased referring to “this illness,” as suggested in the IPQ-R version for healthy people (Figueiras & Alves, 2007). The questionnaire comprised three parts. The first part evaluated *Illness identity* using a list of 18 symptoms. Of these, 14 were taken from the IPQ-R (e.g., nausea, sore throat). As suggested by Moss-Morris et al. (2002, p. 13), and based on the MS literature (Bianconi, Poggioli, Merelli, Razzaboni & Comelli, 2006; Jopson & Moss-Morris, 2003), four additional MS symptoms were added: speech distortion, bladder problems, clumsiness, and numbness. For each of these 18 symptoms, PwMS were first asked to report in a yes/no format whether they had experienced it since their illness. Then, using the same yes/no format, they were asked to indicate whether they believed that those symptoms were related to their illness. This second illness-related symptoms rating represents the illness identity subscale (Moss-Morris et al., 2002, p. 4). Accordingly, caregivers were asked to report for the same list of symptoms whether they believed each one of them to be related to MS. Based on Kaptein et al. (2006), the illness identity score was generated by dividing the total “yes” answers for each symptom item by the total number of symptoms ( $N = 18$ ), with higher scores indicating a stronger belief that those symptoms were related to MS.

The second part of the questionnaire included 38 scaled items ranging from 1 = “strongly disagree” to 5 = “strongly agree.” The items were grouped into seven subscales and measured participants’ opinions about MS. For each subscale, a total score was calculated by averaging the number of items in each subscale. Range of possible scores was 1–5. Two typical items are presented below for each of the seven subscales. Each IPQ-R item is shown first in the format for PwMS, and then in the revised format used for caregivers. Thirteen items are reverse-scored, and these are identified below with an asterisk (\*).

Two timeline subscales evaluated participants’ perceived illness course over time. One referred to the perception of MS as short versus long lasting (6 items; *Timeline acute/chronic*). For PwMS, two typical items for that subscale were: “\*This illness will pass quickly” and “My illness is likely to be permanent rather than temporary.” For caregivers, the corresponding revised items were: “\*This illness passes quickly” and “This illness is likely to be permanent rather than temporary.” The other Timeline subscale assessed the extent to which the disease waxes and wanes in episodes (4 items; *Timeline cyclical*). For PwMS, two typical items for that subscale were: “The symptoms of my illness change a great deal from day to day” and “My illness is very unpredictable.” For caregivers, the corresponding revised items were: “The symptoms of this illness change a great deal from day to day” and “This illness is very unpredictable.” For both

PwMS and caregivers, higher scores indicated that participants held a more chronic and cyclical view of the illness. The subscale *Consequences* (6 items) appraised the impact of disease on patients’ life, with higher scores indicating perception of more severe consequences. For PwMS, two typical items for that subscale were: “My illness is a serious condition” and “My illness has serious financial consequences.” For caregivers, the corresponding revised items were: “This illness is a serious condition” and “This illness has serious financial consequences.” Two subscales about *Personal control* (6 items) and *Treatment control* (5 items) measured the beliefs that something could be done at the personal or treatment level to improve health status or at least prevent its deterioration. For PwMS, typical items for the Personal control subscale were: “\*My actions will have no affect on the course of my illness” and “The course of my illness depends on me.” For caregivers, the corresponding revised items were: “\*The PwMS’ actions will have no affect on the course of this illness” and “The course of this illness depends on the PwMS.” For the Treatment control subscale, typical items for PwMS were: “\*There is nothing which can help my condition” and “\*There is little that can be done to improve my illness.” For caregivers, the corresponding revised items were: “\*There is nothing which can help this condition” and “\*There is little that can be done to improve this condition.” Higher scores referred to higher control beliefs. The subscale *Illness coherence* (5 items) assessed participants’ understanding of the illness, whether it made any sense to them and they held a clear picture of it; while the subscale *Emotional representations* (6 items) explored the emotional impact of MS on their lives (e.g., anxiety, anger, fear). For PwMS, typical items for the Illness coherence subscale were: “\*My illness is a mystery to me” and “\*My illness doesn’t make any sense to me.” For caregivers, the corresponding revised items were: “\*This illness is a mystery to me” and “\*This illness doesn’t make any sense to me.” For the Emotional representations subscale, typical items for PwMS were: “\*My illness does not worry me” and “My illness makes me feel angry.” For caregivers, the corresponding revised items were: “\*This illness does not worry me” and “This illness makes me feel angry.” Higher scores respectively indicated higher coherence and a more negative emotional response.

The third part of the questionnaire consisted of 18 scaled items assessing perception of the illness *Causes*, ranging from 1 = “strongly disagree” to 5 = “strongly agree.” According to the categorization proposed by Moss-Morris et al. (2002), these causes refer to psychological attributions (e.g., stress and worry), risk factors (e.g., smoking), immunity (e.g., altered immunity), and accident or chance (e.g., chance and bad luck).

### Well-Being Measures

Eudaimonic well-being was measured through the 18-item version of the Psychological Well-being Scales (PWBS; Ruini, Ottolini, Ravanelli, Ryff, & Fava, 2003; Ryff, 1989) which tap the dimensions of environmental mastery, autonomy, purpose in life, personal growth, self-acceptance, and positive relations. Sample items are: “I am quite good at managing the many responsibilities of my daily life” (Environmental mastery); “I have confidence in my opinions, even if they are contrary to the general consensus” (Autonomy); “Some people wander aimlessly through life, but I am not one of them” (Purpose in life); “I think it is important to have new experiences that challenge how you think about yourself and the world” (Personal growth); “I like most aspects of my personality” (Self-acceptance); “People would describe me as a giving person, willing to share my time with others” (Positive relations). Ratings range from 1 = “strongly disagree” to 6 = “strongly agree.” In line with previous studies (Abbot et al., 2006), items were aggregated into one factor with a total score calculated by averaging the 18 items that comprise the scale. Higher scores referred to higher psychological well-being.

Concerning hedonic well-being, the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985; Goldwurm, Baruffi, & Colombo, 2004) evaluated participants’ level of agreement (from 1 = “strongly disagree” to 7 = “strongly agree”) on five statements concerning life satisfaction. Sample items are: “The conditions of my life are excellent”; “In most ways my life is close to my ideal”; and “So far I have gotten the important things I want in life.” A total score was calculated by averaging the five items, with higher values indicating higher satisfaction. Hedonic balance was evaluated with the Positive Affect and Negative Affect Schedule (PANAS; Terracciano, McCrae, & Costa, 2003; Watson, Clark, & Tellegen, 1988), which assesses the perceived intensity of 10 positive emotions (e.g., interested, alert) and 10 negative ones (e.g., distressed, irritable) with scores ranging from 1 = “very slightly or not at all” to 5 = “extremely.” Participants were given the following instructions: “This scale consists of a number of words that describe different feelings and emotions. Please, read each item and then mark the appropriate answer which best corresponds to how you have felt over the last two weeks.” Hedonic balance was calculated as the difference between mean PA and NA ratings, with positive scores referring to prevalence of PA over NA.

### Data Analysis

Separately for PwMS and caregivers, mean scores were calculated for all well-being measures and eight

dimensions of illness beliefs, with the exclusion of illness causes. Since MS etiology is still unknown, illness causes raise complex issues going beyond the aims of this study and deserving separate analysis. Descriptive statistics and internal reliabilities for each scale were calculated, as reported in Table 2. For patients, Cronbach alphas for all questionnaires were essentially in line with both English and Italian validation studies. Concerning caregivers, low reliability indices (<0.50) were observed for illness consequences and timeline-cyclical. Thus, as in Olsen et al. (2008), these two dimensions were removed from subsequent analyses.

In order to detect similarities and differences between PwMS’ and caregivers’ illness beliefs, we performed paired *t* tests and between-group Pearson correlations on mean scores of IPQ-R dimensions. Next, we addressed the association of illness beliefs with psychological well-being, satisfaction with life, and hedonic balance, both separately for each group and jointly.

As a preliminary step, Pearson correlations between all study measures were computed separately for each group: illness beliefs, well-being measures, demographic variables (age, gender, education, employment and civil status), and medical conditions (disease other than MS). For patients, we also calculated correlations with clinical variables (MS type, disease duration, disability level) and, for caregivers, with caregiving years and amount of help.

Correlations between illness beliefs and well-being measures were examined to assess their degree of association in each group. Then, in line with Benyamini et al. (2007), we performed a series of hierarchical multiple regression analyses, separately for each illness perception in each group, to address the joint contribution of PwMS’ and caregivers’ illness representations to their respective well-being levels. In PwMS’ regressions, outcome variables were their measures of psychological well-being, satisfaction with life, and hedonic balance. Possible significant relationships of demographic and clinical variables with well-being outcomes were controlled for in step 1. We then added the predictor PwMS’ illness representation in step 2, and the corresponding caregivers’ illness representation in step 3. The interaction between PwMS’ and caregivers’ illness representations (moderation effect) was introduced in step 4. In order to reduce multicollinearity (Aiken & West, 1991), participants’ beliefs were centered at their mean values prior to creating the product term. The caregivers’ belief was used as moderator, thus allowing us to detect changes in the relationship between patients’ belief and well-being at different levels of caregivers’ belief. To interpret moderation effects more closely, simple slopes were calculated and tested for significance through *t* tests (Aiken & West, 1991), for both high and low belief values ( $\pm 1$  SD).

In caregivers' regressions, outcome variables were their measures of psychological well-being, satisfaction with life, and hedonic balance. We introduced in step 1 possible demographic or medical variables that correlated with their well-being outcome measures, in order to control for their effect. In step 2, we then added the predictor caregivers' illness representation, and in step 3 the corresponding PwMS' illness representation. In step 4, we added the interaction term using the PwMS' belief as moderator. Simple slopes were then calculated and tested for significance.

## Results

PwMS' and caregivers' demographic and clinical information is presented in Table 1. The majority of participants were women, in their 40s, with an elementary, middle or high school degree, employed, and married. Significant differences were detected for age,  $t(134) = 3.49, p < .001$ , and civil status ( $\chi^2 = 5.65, p < .05$ ), with caregivers being older and more frequently in a relationship than PwMS.

PwMS had been diagnosed with MS for more than 10 years on average; they prominently had relapsing-remitting MS, received disease modifying treatment, and suffered from mild to moderate disability. Caregivers were primarily PwMS' partners (61.8 %), followed by mothers (25.0 %), children (5.9 %), siblings (5.9 %), and one father (1.5 %). On average, they provided little to moderate help ( $M = 1.7$ ), and mean caregiving duration was 8.9 years ( $N = 66$ ; range 1–22). In addition, a modest percentage of PwMS and caregivers suffered from diseases other than MS (primarily hypothyroidism and hypertension among PwMS, and hypertension and diabetes among caregivers). Half of those PwMS with other diseases and 77.8 % of caregivers with other diseases were receiving appropriate treatment for their conditions.

### Comparing Illness Beliefs Among PwMS and Caregivers

Table 2 illustrates participants' illness belief mean scores, as well as paired  $t$  test comparisons and Pearson correlations between PwMS' and caregivers' ratings. Participants in the two groups held similar views about MS chronic timeline, treatment control, and illness coherence. As for differences, PwMS reported significantly fewer MS-related symptoms, less negative emotional reactions, and lower personal control than caregivers.

Correlation analyses showed that PwMS' and caregivers' perceptions mostly concurred even when they were dissimilar. Significant positive correlations highlighted a parallel increase of both PwMS' and caregivers' scores for

most variables (illness identity, treatment control, coherence, and emotional representations). By contrast, the two groups' perceptions of chronic timeline and personal control were unrelated.

### Correlations Among Study Variables

Pearson correlations among all study measures are shown in Table 3, for PwMS below the diagonal, and for caregivers above the diagonal. Concerning well-being, in both groups, there were significant positive correlations among psychological well-being (PWBS), satisfaction with life (SWLS), and hedonic balance (PANAS). In addition, significant correlations were observed between well-being measures and some demographic variables. Specifically, PwMS with a university degree reported higher psychological well-being, satisfaction with life, and hedonic balance than PwMS with lower educational level. Employed PwMS reported higher satisfaction with life and hedonic balance than unemployed PwMS; PwMS having a partner were more satisfied with their lives than PwMS without a partner; and older PwMS reported lower psychological well-being than younger PwMS. Among caregivers, women reported lower ratings of all the three measures of well-being than men; and older participants were less satisfied with their lives than younger participants.

Among PwMS' illness beliefs, significant positive correlations were detected between treatment control and personal control, and between emotional representations and illness identity. In addition, significant negative correlations were obtained between treatment control and chronic timeline, as well as between emotional representations and illness coherence. At the demographic level, there were also significant positive correlations of PwMS' illness coherence with educational level and employment status. Specifically, PwMS with a university degree perceived higher illness coherence than PwMS with a lower education level; and employed PwMS perceived higher coherence than unemployed PwMS. At the clinical level, patients with relapsing-remitting MS reported higher personal control and treatment control than patients with a progressive MS form; PwMS with a higher disability level perceived less treatment control than PwMS with a lower disability level.

Among caregivers' illness beliefs, significant positive correlations were highlighted between treatment control and personal control, and between illness coherence and personal and treatment control. Furthermore, emotional representations correlated negatively with personal control, treatment control, and illness coherence; and treatment control correlated negatively with illness identity. At the demographic level, older caregivers assigned lower chronicity and lower coherence to MS than younger



**Table 1** Demographic and clinical characteristics of the participants

	Persons with MS ( <i>N</i> = 68)		Caregivers ( <i>N</i> = 68)	
	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )
Age		39.6 (10.0)		46.0 (11.4)
Gender				
Women	45 (66.2)		39 (57.4)	
Men	23 (33.8)		29 (42.6)	
Education <sup>a</sup>				
High school or less	54 (79.4)		57 (83.8)	
University	14 (20.6)		11 (16.2)	
Employment status				
Employed	40 (61.5) <sup>b</sup>		49 (72.1)	
Unemployed	25 (38.5)		19 (27.9)	
Civil status				
Married/cohabiting	45 (66.2)		57 (83.8)	
Single/divorced/widowed	23 (33.8)		11 (16.2)	
MS type				
Relapsing-remitting	43 (63.2)			
Primary progressive	8 (11.8)			
Secondary progressive	17 (25.0)			
Disease duration (in years)		10.0 (6.4)		
Disability level (EDSS)		4.0 (1.9)		
% mild (0–3.0) <sup>c</sup>	27 (39.7)			
% moderate (3.5–6.0)	30 (44.1)			
% severe (>6.5)	11 (16.2)			
DMT	54 (79.4)			
Immune modulators	25 (46.3)			
Immune suppressants	29 (53.7)			
Other disease <sup>d</sup>	12 (18.2 %)		18 (26.5 %)	
Treatment for other disease	6 (50 %)		14 (77.8 %)	
Caregiving years				8.9 (5.9)
Caregiving help (CTiMSS)				1.7 (.80)

*DMT* disease modifying treatment

<sup>a</sup> For education, “high school or less” included elementary school, middle school, or high school

<sup>b</sup> Three PwMS did not report their employment status. Of those who were unemployed, 16 (64 %) received a disability pension

<sup>c</sup> Disability ranges were taken from Provinciali, Ceravolo, Bartolini, Logullo, & Danni (1999)

<sup>d</sup> Two PwMS did not report whether they suffered from other concomitant disease. No caregivers suffered from MS

caregivers, and they also reported more negative emotional representations. Women reported lower illness coherence and more negative emotional representations than men.

**Illness Beliefs and Well-Being Among PwMS and Caregivers**

Table 3 further illustrates the relationship between illness representations and well-being among PwMS and caregivers. The high correlations between psychological well-being (PWBS), satisfaction with life (SWLS) and hedonic

balance (PANAS) resulted in parallel patterns of significant correlations between illness representations and well-being measures, both among PwMS and among caregivers, thus providing built-in replications of results. Specifically, among PwMS, stronger illness identity, i.e., more symptoms linked to MS, and more negative emotional representations were related to lower psychological well-being, reduced satisfaction with life and lower hedonic balance. By contrast, there was a significant positive correlation between illness coherence, i.e., beliefs that one understands the illness, and the three measures of well-being.

**Table 2** Descriptive statistics, paired *t* test and correlation analyses between PwMS' and caregivers' illness beliefs and between their well-being measures

	Persons with MS ( <i>N</i> = 68)				Caregivers ( <i>N</i> = 68)				<i>t</i> value	Pearson correlations
	<i>M</i>	<i>SD</i>	Range	Cronbach's $\alpha$	<i>M</i>	<i>SD</i>	Range	Cronbach's $\alpha$		
Illness beliefs (IPQ-R)										
Identity	0.54	0.21	0.06–0.83	0.82	0.64	0.15	0.22–0.89	0.73	-4.24***	0.47***
Timeline—acute/ chronic	4.30	0.69	1–5	0.75	4.45	0.56	3–5	0.69	-1.61	0.14
Consequences	3.61	0.76	1–5	0.65	3.96	0.54	2–5	0.34	–	–
Personal control	3.03	0.65	1–5	0.58	3.29	0.63	2–5	0.65	-2.70**	0.22
Treatment control	3.37	0.72	1–5	0.70	3.50	0.75	1–5	0.77	-1.59	0.55***
Illness coherence	3.32	0.77	1–5	0.65	3.25	0.81	1–5	0.73	0.66	0.25*
Timeline—cyclical	3.46	0.85	1–5	0.71	3.65	0.67	2–5	0.47	–	–
Emotional representations	3.19	1.04	1–5	0.89	3.65	0.92	1–5	0.85	-3.14**	0.25*
Psychological well-being (PWBS)	4.17	0.69	2–6	0.76	4.11	0.67	2–6	0.73	0.56	0.25*
Satisfaction with life (SWLS)	3.84	1.58	1–7	0.92	4.04	1.46	2–7	0.90	-0.95	0.37**
Hedonic balance (PANAS) <sup>a</sup>	0.79	1.28	-2.7 to 3.4	(PA = 0.89; NA = 0.93)	0.83	1.18	-2.0 to 3.3	(PA = 0.85; NA = 0.92)	-0.24	0.35**

Scores for all variables were obtained by calculating the average score on all items within each scale. Paired *t* tests and Pearson correlations between PwMS' and caregivers' consequences and timeline-cyclical were not calculated due to the low reliability indices reported by caregivers  
\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> Hedonic balance was calculated as the difference between mean positive affect and mean negative affect (PA–NA)

Among caregivers, more negative emotional representations were significantly related to lower psychological well-being, lower satisfaction with life and lower hedonic balance. In contrast, a significant positive correlation was detected between illness coherence and the three measures of well-being. Moreover, higher treatment control was associated with higher psychological well-being and hedonic balance.

### Cross-Influences Between Illness Beliefs and Well-Being Among PwMS and Caregivers

Hierarchical multiple regressions were next performed to investigate the joint effect of PwMS' and caregivers' illness beliefs on their respective levels of well-being. For PwMS, those demographic variables which uniquely correlated with each well-being measure were introduced in step 1: namely, age and education for psychological well-being (PWBS); education, employment status and civil status for satisfaction with life (SWLS); and education and employment status for hedonic balance (PANAS). Then, each dimension of PwMS' illness beliefs was introduced in step 2, and each corresponding dimension of caregivers' illness beliefs was introduced in step 3. Finally, the interaction term was inserted in step 4. For caregivers, step 1 control variables were gender for psychological well-being

(PWBS) and hedonic balance (PANAS), and age and gender for satisfaction with life (SWLS). Each dimension of caregivers' illness beliefs was then introduced in step 2, the corresponding dimension of PwMS' beliefs in step 3, and the interaction term in step 4. Our sample size was adequate for analysis, as an absolute minimum of 10 participants per predictor variable is deemed appropriate in regressions with five to six predictors (Harris, 1985). Findings from step 1 to step 3 are illustrated in the following tables. Step 4 data will be described separately, after the main findings, because the great majority of the tests for interaction/moderation were non-significant, and results should be considered with caution.

In Table 4, we report analyses with PwMS' and caregivers' psychological well-being (PWBS) as an outcome variable. After controlling for demographic variables, PwMS' illness identity, illness coherence and emotional representations made unique contributions to PwMS' psychological well-being, respectively accounting for 6, 7, and 14 % of the model variances. Specifically, psychological well-being was positively related to illness coherence, and negatively related to illness identity and emotional representations. Among caregivers, psychological well-being was positively related to treatment control, which accounted for 18 % of the model variance. It was also positively related to illness coherence (19 % of the

**Table 3** Correlations between demographic and clinical variables, illness representations, and well-being measures: Scores for the PwMS group are reported below the diagonal; scores for the caregiver group are reported above the diagonal

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)	(19)	(20)
(1) Age	–	.05	–.29*	.00	.22	.13	–	–	–	.10	–.04	–.18	–.26*	–.17	–.08	–.41**	.33**	–.23	–.30*	–.20
(2) Gender <sup>a</sup>	–.03	–	.06	–.48***	–.22	–.02	–	–	–	–.01	.03	.20	–.01	–.06	–.3	–.26*	.27*	–.40**	–.29*	–.29*
(3) Education <sup>b</sup>	–.10	.06	–	.10	–.24*	–.08	–	–	–	–.08	–.10	.05	.01	.19	.21	.15	–.23	.16	.12	.11
(4) Employment status <sup>c</sup>	–.04	.08	.26*	–	.08	.08	–	–	–	–.00	.13	–.00	.18	–.08	–.04	–.04	.07	.13	.19	.06
(5) Civil status <sup>d</sup>	.51***	.01	–.02	.04	–	.17	–	–	–	.06	.02	–.11	–.17	.15	.07	–.09	–.03	.08	.14	–.05
(6) Other disease <sup>e</sup>	.15	.08	–.04	.05	.25*	–	–	–	–	.07	.11	.16	–.12	–.11	–.10	.00	.01	.09	–.01	.03
(7) MS type <sup>f</sup>	–.45***	.23	.09	.09	–.09	–.05	–	–	–	–	–	–	–	–	–	–	–	–	–	–
(8) Disease duration	.39**	–.06	.12	–.05	.27*	–.14	–.36**	–	–	–	–	–	–	–	–	–	–	–	–	–
(9) Disability level (EDSS)	.30*	–.15	–.03	–.21	.10	–.05	–.59***	.53***	–	–	–	–	–	–	–	–	–	–	–	–
(10) Caregiving years	–	–	–	–	–	–	–	–	–	.16	.02	.21	–.15	–.15	–.24	–.15	.14	–.17	.00	.08
(11) Caregiving help (CTIMSS)	–	–	–	–	–	–	–	–	–	–	.11	.03	–.15	–.20	–.20	–.21	.11	–.15	.08	–.04
(12) Identity	–.01	–.08	–.07	–.18	–.09	.13	.11	–.15	–.01	–	–	–	.02	–.19	–.26*	–.03	.04	–.13	.04	–.20
(13) Timeline—acute/chronic control	.14	–.01	–.06	.05	.18	.08	–.21	.20	.21	–	–	.09	–	–.09	–.18	.14	.19	.00	–.01	.03
(14) Personal control	–.19	.20	.05	.16	.08	.13	.27*	–.10	–.21	–	–	.19	–.20	–	.52***	.45***	–.30*	.22	.11	.15
(15) Treatment control	–.20	.24	.19	.15	.04	–.02	.38**	–.08	–.34***	–	–	–.01	–.36**	.52***	–	.40**	–.39**	.44***	.21	.41**
(16) Illness coherence	–.03	.04	.29*	.29*	.16	.15	.10	.06	–.18	–	–	–.10	–.11	.20	.19	–	–.50***	.53***	.25*	.35**
(17) Emotional representations	.02	.24	–.20	–.23	–.20	–.06	–.05	–.07	.10	–	–	.25*	.10	–.07	–.20	–.50***	–	–.36**	–.33**	–.39**
(18) Psychological well-being	–.25*	.05	.43***	.18	.11	.07	.10	.03	–.06	–	–	–.27*	.00	.18	.13	.37**	–.45***	–	.65***	.66***
(19) Satisfaction with life	–.12	–.14	.28*	.32*	.26*	.14	.05	.03	–.15	–	–	–.32**	–.09	.07	.16	.46***	–.45***	.68***	–	.54***
(20) Hedonic balance	–.13	–.13	.34**	.27*	.17	.01	.07	.12	–.02	–	–	–.27*	.00	.17	.22	.44***	–.62***	.69***	.61***	–

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

<sup>a</sup> Women were coded as 1 and men as 0

<sup>b</sup> For education, university degree was coded as 1 and “high school or less” as 0

<sup>c</sup> Employed participants were coded as 1 and unemployed participants as 0

<sup>d</sup> Participants having a partner were coded as 1 and participants not having a partner were coded as 0

<sup>e</sup> Participants suffering from a disease other than MS were coded as 1 and those not suffering from a disease other than MS were coded as 0

<sup>f</sup> Participants with relapsing-remitting MS were coded as 1 and participants with progressive MS forms as 0

**Table 4** Hierarchical multiple regression analyses predicting PwMS' and caregivers' psychological well-being (PWBS) from PwMS' and caregivers' illness beliefs

Psychological well-being (PWBS)	Identity			Timeline acute/chronic			Personal control		
	$\Delta R^2$	$\beta$	$\Delta F$	$\Delta R^2$	$\beta$	$\Delta F$	$\Delta R^2$	$\beta$	$\Delta F$
<i>Persons with MS</i>									
Step 1	0.23		9.50***	0.23		9.50***	0.23		9.50***
Control variables									
PwMS age		−0.21			−0.21			−0.21	
PwMS education <sup>a</sup>		0.41***			0.41***			0.41***	
Step 2	0.06		5.47*	0.00		2.81	0.02		1.23
PwMS score on IPQ–R subscale		−0.25*			0.06			0.12	
Step 3	0.00		0.08	0.02		1.50	0.02		2.01
Caregiver score on IPQ-R subscale		−0.03			0.14			0.16	
Total R <sup>2</sup>	0.29		6.37***	0.25		5.18**	0.27		5.66**
<i>Caregivers</i>									
Step 1	0.16		12.89**	0.16		12.89**	0.16		12.89**
Control variables									
Caregiver gender <sup>b</sup>		−0.40**			−0.40**			−0.40**	
Step 2	0.00		0.19	0.00		0.00	0.04		2.98
Caregiver score on IPQ-R subscale		−0.05			0.00			0.19	
Step 3	0.01		0.31	0.02		1.81	0.03		2.39
PwMS score on IPQ-R subscale		−0.07			0.15			0.18	
Total R <sup>2</sup>	0.17		4.36**	0.18		4.89**	0.23		6.33**
Psychological well-being (PWBS)	Treatment control			Illness coherence			Emotional representations		
	$\Delta R^2$	$\beta$	$\Delta F$	$\Delta R^2$	$\beta$	$\Delta F$	$\Delta R^2$	$\beta$	$\Delta F$
<i>Persons with MS</i>									
Step 1	0.23		9.50***	0.23		9.50***	0.23		9.50***
Control variables									
PwMS age		−0.21			−0.21			−0.21	
PwMS education <sup>a</sup>		0.41***			0.41***			0.41***	
Step 2	0.00		0.02	0.07		5.93*	0.14		14.16***
PwMS score on IPQ–R subscale		0.02			0.27*			−0.38***	
Step 3	0.00		0.12	0.00		0.33	0.00		0.01
Caregiver score on IPQ-R subscale		0.05			0.06			−0.01	
Total R <sup>2</sup>	0.23		4.65**	0.30		6.61***	0.37		9.11***
<i>Caregivers</i>									
Step 1	0.16		12.89**	0.16		12.89**	0.16		12.89**
Control variables									
Caregiver gender <sup>b</sup>		−0.40**			−0.40**			−0.40**	
Step 2	0.18		17.89***	0.19		19.08***	0.07		5.62*
Caregiver score on IPQ-R subscale		0.43***			0.45***			−0.27*	
Step 3	0.00		0.04	0.02		2.17	0.03		2.82
PwMS score on IPQ-R subscale		−0.03			0.15			−0.19	
Total R <sup>2</sup>	0.34		11.20***	0.37		12.77***	0.26		7.59***

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$ <sup>a</sup> For education, university degree was coded as 1 and “high school or less” as 0<sup>b</sup> Women were coded as 1 and men as 0

variance), while being negatively related to emotional representations (7 % of the variance). No cross-group contributions of caregivers' beliefs to PwMS' psychological well-being and no cross-group contributions of PwMS' beliefs to caregivers' psychological well-being were detected.

Table 5 illustrates regression analyses for participants' satisfaction with life (SWLS). After controlling for demographic variables, significant direct contributions of illness beliefs to life satisfaction were obtained only among PwMS. In particular, PwMS' life satisfaction was negatively related to PwMS' illness identity and emotional representations, which respectively accounted for 7 and 12 % of the model variances. In addition, illness coherence positively contributed to PwMS' life satisfaction, accounting for 10 % of the model variance. No cross-group contributions of caregivers' beliefs to PwMS' life satisfaction and no cross-group contributions of PwMS' beliefs to caregivers' life satisfaction were detected.

Finally, Table 6 presents regression analyses for participants' hedonic balance (PANAS). After controlling for demographic variables, PwMS' illness coherence made a significant positive contribution to PwMS' hedonic balance, accounting for 11 % of the model variance; while PwMS' emotional representations were negatively related to PwMS' hedonic balance, explaining 26 % of the model variance. Concerning caregivers, unique positive contributions of their beliefs about treatment control and illness coherence on their hedonic balance were highlighted, respectively accounting for 16 and 8 % of the model variances. By contrast, caregivers' emotional representations provided a negative contribution to their hedonic balance, explaining 10 % of the model variance. In addition, some unique cross-group contributions were detected. Specifically, caregivers' hedonic balance was positively related to PwMS' illness coherence (9 % of the variance) and negatively to PwMS' emotional representations (8 % of the variance).

As noted earlier, Tables 4, 5, and 6 reported only the first three steps of the 36 hierarchical regression analyses that were performed. Besides the first-order effects reported in these Tables, a fourth step was added to each regression analysis to search for possible combined effects of PwMS' and caregivers' illness beliefs on their respective dimensions of well-being. In fact, only three models out of 36 (8 %) indicated possible evidence of interaction effects. Considering the low number of significant interactions, these results must be considered exploratory, and should be taken with caution. However, we present them because they are in line with previous findings concerning other illnesses, as described in the introduction (Heijmans et al., 1999; Figueiras & Weinman, 2003; Karademas et al., 2010; Olsen et al., 2008).

Among PwMS, a significant interaction effect was obtained for illness coherence on hedonic balance ( $\beta = -0.27$ ,  $p < .05$ ;  $\Delta R^2 = 0.06$ ). Simple slope analyses showed that only the slope for caregivers' low coherence was significant,  $t(63) = 3.75$ ,  $p < .001$ . Specifically, when both PwMS and caregivers perceived low coherence, PwMS reported lower hedonic balance. By contrast, when coherence was low among caregivers and high among PwMS, PwMS' hedonic balance was higher.

Among caregivers, another significant interaction effect was observed for illness identity on satisfaction with life ( $\beta = -0.36$ ,  $p < .01$ ,  $\Delta R^2 = 0.11$ ). Only the simple slope for PwMS' low scores in illness identity was significant,  $t(62) = 2.21$ ,  $p < .05$ . When both caregivers and PwMS perceived low identity, caregivers also reported lower life satisfaction. By contrast, the discrepancy between PwMS' low and caregivers' high identity was associated with higher life satisfaction among caregivers. A significant interaction effect was also observed for personal control on satisfaction with life ( $\beta = -0.23$ ,  $p < .05$ ;  $\Delta R^2 = 0.05$ ), however, simple slope analyses yielded no significant results.

## Discussion

The present study targeted the joint analysis of illness beliefs and well-being among PwMS and their caregivers. Innovative contributions were (a) the assessment of well-being not through indicators of psychological distress, but through positive dimensions such as satisfaction with life, hedonic balance and psychological well-being; (b) the adoption of a family-related approach in the investigation of the cross-effects between patients' and caregivers' perceptions in responding to illness; and (c) the inclusion of those specific family caregivers who were directly identified by PwMS. Findings allowed us to address our research aims, and to bring forward suggestions for intervention.

### The Views About MS

In line with our hypothesis, PwMS and caregivers were shown to construct similar MS representations concerning chronic timeline, treatment control, and also illness coherence. At the same time, some dissimilarities were observed, as in studies on other chronic diseases (Heijmans et al., 1999; Karademas et al., 2010; Olsen et al., 2008). Compared to PwMS, caregivers held more pessimistic views about MS identity and emotional representations, and a more optimistic perception of personal control. As suggested by Heijmans et al. (1999), caregivers' worry for the patients' conditions and coping resources could lead them to exaggerate illness severity. However, their

**Table 5** Hierarchical multiple regression analyses predicting PwMS' and caregivers' satisfaction with life (SWLS) from PwMS' and caregivers' illness beliefs

Satisfaction with life (SWLS)	Identity			Timeline acute/chronic			Personal control		
	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F
<i>Persons with MS</i>									
Step 1	0.23		6.03**	0.23		6.03**	0.23		6.03**
Control variables									
PwMS education <sup>a</sup>		0.24*			0.24*			0.24*	
PwMS employment status <sup>b</sup>		0.24*			0.24*			0.24*	
PwMS civil status <sup>c</sup>		0.28*			0.28*			0.28*	
Step 2	0.07		5.80*	0.02		1.89	0.00		0.06
PwMS score on IPQ-R subscale		-0.27*			-0.16			-0.03	
Step 3	0.04		3.52	0.02		1.46	0.01		0.70
Caregiver score on IPQ-R subscale		0.24			0.14			0.10	
Total R <sup>2</sup>	0.34		5.98***	0.27		4.37***	0.24		3.70**
<i>Caregivers</i>									
Step 1	0.16		6.34**	0.16		6.34**	0.16		6.34**
Control variables									
Caregiver age		-0.29*			-0.29*			-0.29*	
Caregiver gender <sup>d</sup>		-0.27*			-0.27*			-0.27*	
Step 2	0.00		0.17	0.01		0.62	0.00		0.20
Caregiver score on IPQ-R subscale		0.05			-0.09			0.05	
Step 3	0.01		0.30	0.04		3.15	0.02		1.14
PwMS score on IPQ-R subscale		-0.07			0.20			0.13	
Total R <sup>2</sup>	0.17		3.21*	0.21		4.20**	0.18		3.47*
Satisfaction with life (SWLS)	Treatment control			Illness coherence			Emotional representations		
	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F
<i>Persons with MS</i>									
Step 1	0.23		6.03**	0.23		6.03**	0.23		6.03**
Control variables									
PwMS education <sup>a</sup>		0.24*			0.24*			0.24*	
PwMS employment status <sup>b</sup>		0.24*			0.24*			0.24*	
PwMS civil status <sup>c</sup>		0.28*			0.28*			0.28*	
Step 2	0.00		0.16	0.10		8.86**	0.12		11.23**
PwMS score on IPQ-R subscale		0.05			0.35**			-0.37**	
Step 3	0.02		1.26	0.00		0.03	0.00		0.09
Caregiver score on IPQ-R subscale		0.15			0.02			-0.04	
Total R <sup>2</sup>	0.25		3.87**	0.33		5.77***	0.35		6.39***
<i>Caregivers</i>									
Step 1	0.16		6.34**	0.16		6.34**	0.16		6.34**
Control variables									
Caregiver age		-0.29*			-0.29*			-0.29*	
Caregiver gender <sup>d</sup>		-0.27*			-0.27*			-0.27*	
Step 2	0.03		2.44	0.01		0.41	0.03		2.43
Caregiver score on IPQ-R subscale		0.18			0.08			-0.19	
Step 3	0.00		0.01	0.03		2.19	0.03		2.68
PwMS score on IPQ-R subscale		-0.01			0.18			-0.19	
Total R <sup>2</sup>	0.19		3.79**	0.20		3.85**	0.22		4.62**

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$ <sup>a</sup> For education, university degree was coded as 1 and "high school or less" as 0<sup>b</sup> Employed participants were coded as 1 and unemployed participants as 0<sup>c</sup> Participants having a partner were coded as 1 and participants not having a partner were coded as 0<sup>d</sup> Women were coded as 1 and men as 0

**Table 6** Hierarchical multiple regression analyses predicting PwMS’ and caregivers’ hedonic balance (PANAS) from PwMS’ and caregivers’ illness beliefs

Hedonic balance (PANAS)	Identity			Timeline acute/chronic			Personal control		
	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F
<i>Persons with MS</i>									
Step 1	0.14		5.17**	0.14		5.17**	0.14		5.17**
Control variables									
PwMS education <sup>a</sup>		0.27*			0.27*			0.27*	
PwMS employment status <sup>b</sup>		0.20			0.20			0.20	
Step 2	0.04		3.00	0.01		0.18	0.03		2.18
PwMS score on IPQ-R subscale		-0.20			0.05			0.17	
Step 3	0.01		0.49	0.00		0.09	0.01		0.37
Caregiver score on IPQ-R subscale		-0.10			0.04			0.07	
Total R <sup>2</sup>	0.19		3.51*	0.15		2.58*	0.18		3.24*
<i>Caregivers</i>									
Step 1	0.08		6.04*	0.08		6.04	0.08		6.04*
Control variables									
Caregiver gender <sup>c</sup>		-0.29*			-0.29*			-0.29*	
Step 2	0.02		1.62	0.00		0.04	0.02		1.26
Caregiver score on IPQ-R subscale		-0.15			0.02			0.13	
Step 3	0.01		0.52	0.00		0.02	0.01		0.91
PwMS score on IPQ-R subscale		-0.10			-0.02			0.12	
Total R <sup>2</sup>	0.11		2.73*	0.08		1.97	0.11		2.74*
Hedonic balance (PANAS)	Treatment control			Illness coherence			Emotional representations		
	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F	$\Delta R^2$	$\beta$	F
<i>Persons with MS</i>									
Step 1	0.14		5.17**	0.14		5.17**	0.14		5.17**
Control variables									
PwMS education <sup>a</sup>		0.27*			0.27*			0.27*	
PwMS employment status <sup>b</sup>		0.20			0.20			0.20	
Step 2	0.01		0.82	0.11		8.93***	0.26		26.64***
PwMS score on IPQ-R subscale		0.11			0.36**			-0.53***	
Step 3	0.00		0.02	0.00		0.06	0.00		0.23
Caregiver score on IPQ-R subscale		0.02			0.03			0.05	
Total R <sup>2</sup>	0.15		2.75*	0.25		5.08**	0.40		10.24***
<i>Caregivers</i>									
Step 1	0.08		6.04*	0.08		6.04*	0.08		6.04*
Control variables									
Caregiver gender <sup>c</sup>		-0.29*			-0.29*			-0.29*	
Step 2	0.16		13.86***	0.08		6.16*	0.10		8.15**
Caregiver score on IPQ-R subscale		0.40***			0.29*			-0.33**	
Step 3	0.00		0.12	0.09		8.08*	0.08		6.50*
PwMS score on IPQ-R subscale		-0.05			0.32**			-0.29*	
Total R <sup>2</sup>	0.24		6.97***	0.25		7.38***	0.26		7.54***

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

<sup>a</sup> For education, university degree was coded as 1 and “high school or less” as 0

<sup>b</sup> Employed participants were coded as 1 and unemployed participants as 0

<sup>c</sup> Women were coded as 1 and men as 0

tendency to impute more symptoms to MS and to assign patients more personal control could be due to an actor-observer attribution bias, as suggested by Benyamini et al. (2007). Overall, caregivers' representations could be aimed at reducing the uncertainty of an unpredictable disease such as MS. As for PwMS, a less severe and deterministic view of disease may help them withstand the burden of their chronic condition. The two interpretations are not necessarily mutually exclusive and further investigation is needed in order to understand the psychological mechanisms underlying the formation of illness beliefs.

### Personal Illness Beliefs and Well-Being

Findings further showed that PwMS' and caregivers' illness beliefs were related to both eudaimonic and hedonic well-being components. Not only were well-being measures highly correlated, they also showed highly similar correlational patterns with illness beliefs, both among PwMS and among caregivers, thus giving strong support to these findings. In line with our hypotheses, for both groups, more negative emotional representations were associated with lower psychological well-being, life satisfaction, and hedonic balance. This result complements previous research showing that depression, anger, and anxiety make a relevant negative contribution to HRQOL among PwMS and their caregivers (Benito-Leon, Labiano-Fontcuberta, Mitchell, Moreno-Garcia, & Martinez-Martin, 2014; Giordano et al., 2012; Patti et al., 2003, 2007). Most importantly, for both groups, a positive correlation was revealed between illness coherence and the three well-being dimensions. According to the salutogenesis model (Antonovsky, 1987), coherence represents an important resource for improving resilience to stressful events, and specifically facilitating disease adjustment and well-being (Eriksson & Lindström, 2006). Our findings supported this interpretation: Making sense of a disease such as MS, accepting its unknown etiology, highly mutable symptoms, and unpredictable course make up a global orientation or attitude that is positively related to both PwMS' and caregivers' well-being.

Contrary to our hypotheses, interesting group-specific patterns were also detected, reflecting the different perspectives of patients and caregivers in organizing a mental representation of the disease. For PwMS, but not for caregivers, stronger illness identity was associated with lower eudaimonic and hedonic well-being. This is consistent with previous studies in which PwMS' identity beliefs were associated negatively to psychosocial functioning and positively to mental and physical fatigue (Jopson & Morris, 2003). Since MS symptoms are largely unpredictable, widely vary across individuals and worsen according to disease progression, it is easy to understand how patients

may misattribute to MS unrelated symptoms such as sore throat, and how this could impact their well-being. By contrast, as a novel finding, only among caregivers was treatment control associated with higher psychological well-being and hedonic balance. This suggests that, even if MS is not curable, confidence about treatment effectiveness in controlling disease progression or symptoms can offer caregivers a valuable source of control, with positive consequences on their well-being.

### The Complex Pattern of Individual and Mutual Influences on Well-Being

Our final analyses examined the influences of PwMS' and caregivers' illness beliefs on their respective well-being, controlling for demographic variables. In line with previous studies (Benyamini et al., 2007), findings revealed that PwMS' well-being was primarily predicted by their own beliefs, and the same was true of caregivers. In particular, among PwMS, results confirmed the negative predictive role of emotional representations and the positive predictive role of illness coherence on the three measures of well-being, as well as the negative effect of illness identity on psychological well-being and life satisfaction. Likewise, among caregivers, results supported the positive influence of treatment control and illness coherence on psychological well-being and hedonic balance, as well as the independent negative effect of emotional representations on those same outcome variables.

Concerning cross-group associations, only a few significant effects were observed regarding caregivers' well-being. Specifically, caregivers' hedonic balance decreased as PwMS reported more negative emotional representations, and increased when PwMS perceived higher illness coherence.

Finally, concerning congruence between PwMS' and caregivers' beliefs, only three significant interactions were detected in the high number of regression analyses, making it difficult to discern whether these interactions were due to chance. Nonetheless, simple slope analyses seemed consistent with other findings (Figueiras & Weinman, 2003; Karademas et al., 2010), according to which holding similar negative illness perceptions could be associated with poorer well-being, while sharing positive perceptions could be associated with higher well-being. In addition, as in Figueiras and Weinman (2003), and Karademas et al. (2010), in the case of conflicting perceptions, findings seemed to hint that the presence of at least one positive perception in the patient-caregiver pair could be associated with higher well-being. However, more studies in the MS domain are needed to lend support to these tentative results about illness beliefs interactions.



## Implications for Intervention

Information gathered in this study entails relevant implications for intervention. As general considerations, findings suggest that practitioners working in the field of MS should broaden their focus of action, aiming at both distress reduction and well-being promotion. Contrary to common lay beliefs, individuals can find benefits in disease and construct a meaningful and rewarding life, which can counteract disease burden (Lopez & Snyder, 2011). In the same vein, intervention could greatly benefit from both reducing negative illness perceptions and improving positive perceptions. Moreover, practitioners should consider that PwMS and their caregivers co-construct their subjective views about MS, while also building their own independent opinion. According to a family-related approach, both individual and PwMS-caregiver intervention should be considered in order to bring about more effective outcomes. Involving both PwMS and caregivers in intervention programs is particularly important because, in Italy and in other western countries, the recent economic crisis has led to a worrying reduction in caregiving services provided by the national health system, such that families primarily have to count on their own resources and strengths to deal with disease.

In line with studies in positive and health psychology (Benyamini, 2011; Fava & Tomba, 2009), psycho-educational programs and cognitive-behavioral therapy could be particularly useful in MS intervention, by both providing factual information about disease characteristics and progression, and promoting cognitive restructuring, through the reappraisal of negative thoughts and the strengthening of positive beliefs. Particularly, intervention offered to PwMS could comprise management of negative beliefs about illness identity: Regular update of information on MS status and symptoms, and holistic care including psychological support could help contain their negative effects (Golla, Galushko, Pfaff, & Voltz, 2012). As for caregivers, intervention could include strengthening their beliefs about treatment control. MS treatment implies that caregivers provide help to PwMS in taking drugs and attending therapies at the hospital, as well as active administration of medicaments or procedures (e.g., catheter use). Supporting caregivers in the psychological adjustment to their role and helping them to acquire dexterity with devices could be valuable intervention strategies.

Other critical areas of intervention highlighted in this study concern emotional representations and illness coherence of both PwMS and caregivers. Practitioners could work with participants to promote awareness, processing and expression of negative emotions associated with disease and caregiving burden (Stanton et al., 2000). Bringing to surface anger, depression, as well as worry or

fear can help come to terms with them and possibly reduce their intensity. At the same time, identification of positive emotions associated with occasions such as receiving good news about treatment effectiveness could help reframe disease in a less negative light (Fava & Tomba, 2009). As for efforts targeting promotion of illness coherence, research suggests working not only on disease comprehensibility, but also on disease meaningfulness and manageability, as crucial resources in an incurable and unpredictable condition such as MS (Antonovsky, 1987; Eriksson & Lindström, 2006). Useful strategies comprise discussing the meaning of disease within a more general life perspective, understanding the gains it could bring, (e.g., in terms of tighter social relations, personal growth, or transcendental needs), and fostering beliefs in personal coping abilities.

Finally, intervention targeting PwMS and caregivers should encourage mutual understanding. Discussing openly each other's views, understanding which aspects of illness are more important and why, adopting mutual role-taking, and comprehending, accepting or embracing each other's emotions can help solve misunderstandings and recriminations, and tighten relational bonds (Manne et al., 2006).

## Study Limitations

In spite of its original contributions, this study presented some limitations. Concerning data collection, we did not take into account newly diagnosed persons who potentially did not require caregiving help, as well as extreme conditions of clinical exacerbation or severe disability. Thus, present findings cannot be generalized to the entire populations of individuals facing MS. In addition, we did not collect detailed information on the amount of time and on the quality of interactions between PwMS and caregivers, besides self-reported caregivers' burden. Concerning analyses, we did not take into consideration participants' beliefs about illness causes. This choice was in line with previous studies which analyzed causes separately from other illness belief dimensions (Hoth, Wamboldt, Bowler, Make, & Holm, 2011), as they raise specific issues about individuals' perceived locus of control and sense of agency. In addition, due to low reliability values of illness consequences and timeline-cyclical among caregivers, these two variables were not taken into account in our analyses. This datum is in contrast with studies on other illnesses for which measures of these beliefs were psychometrically reliable (Benyamini et al., 2007; Figueiras & Weinman, 2003; Olsen et al., 2008). However, since to the best of our knowledge, no previous studies assessed caregivers' beliefs through IPQ-R in MS research, it was difficult to interpret the low alpha scores obtained for these variables. Researchers should investigate more deeply

caregivers' understanding of these dimensions and possibly devise a specific version of IPQ-R that could be profitably administered in MS research. Finally, our research design was cross-sectional. Based on the common-sense model (Leventhal et al., 2003) and previous research findings (Benyamini, 2011), we assumed that illness beliefs can influence well-being outcomes. However, we cannot rule out that well-being levels can affect illness belief patterns. For instance, higher levels of well-being could promote perceived illness coherence and personal control while buffering the emotional burden associated with disease. Only longitudinal studies could help ascertain the direction of causality.

### Future Research Directions and Conclusions

Overall, our study contributed to open up new areas of investigation in MS research focusing on presence of well-being and not just absence or reduction of psychological distress. It showed that PwMS' and their caregivers' illness beliefs correlate with well-being measures in various complex ways, providing clinical practice and intervention with insight into fruitful strategies that individuals can adopt to respond to illness. In light of the study limitations, a number of interesting questions are still pending and in need of future investigation. More exploration is required to enhance our understanding on the formation of illness beliefs in newly diagnosed individuals and in individuals for whom taking on the role of caregivers is a novel experience. The same applies for severe cases in which PwMS are constrained to bed and caregivers are involved in more physically demanding caring tasks. While in our study PwMS' disability ratings and caregivers' burden did not affect participants' well-being levels, they could have a negative impact on well-being indicators when conditions worsen.

Future research should also investigate other aspects of illness beliefs, such as causes. Since MS etiology is yet to be fully understood, delving deep into patients' and caregivers' causal attributions may shed light on the process of disease acceptance. It may also shed light on the potential role of personal and treatment control related not to MS per se but to the individual and environmental resources that can be mobilized to cope with disease. Attention should also be devoted to illness consequences, which were found to be relevant in other disease domains, and cyclical timeline which may be significant in case of a relapsing-remitting disease progression.

As a concluding consideration, we hope that current findings may inspire future research on other diseases as to the usefulness of accompanying investigation on patients' and caregivers' psychological distress with examination of

their well-being. A shift in perspective can contribute to a more comprehensive view on how individuals globally respond to illness and on what personal and social resources are available to promote their well-being.

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