



# Relapsing-remitting multiple sclerosis: an interpretative phenomenological analysis of dyadic dynamics.

Emilie Wawrziczny, Aubane Corrairie, Pascal Antoine

## ► To cite this version:

Emilie Wawrziczny, Aubane Corrairie, Pascal Antoine. Relapsing-remitting multiple sclerosis: an interpretative phenomenological analysis of dyadic dynamics.. Disability and Rehabilitation, 2019, Disability and Rehabilitation, 43 (1), pp.76-84. 10.1080/09638288.2019.1617794 . hal-03101311

**HAL Id: hal-03101311**

**<https://hal.univ-lille.fr/hal-03101311>**

Submitted on 21 Mar 2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

# Relapsing-remitting multiple sclerosis: an interpretative phenomenological analysis of dyadic dynamics

Emilie Wawrziczny, Aubane Corrairie & Pascal Antoine

## Abstract

**Background:** Multiple sclerosis, a chronic degenerative disease, impacts persons with the disease and their caregivers, usually the spouse. Few studies have considered the dyadic adjustment to the disease, and even fewer have considered the type of multiple sclerosis. This study aimed to explore the experiences and strategies of couples in which one spouse had relapsing-remitting multiple sclerosis using dyadic interpretative phenomenological analysis.

**Methods:** Six couples agreed to participate in the study. Semi-structured interviews were conducted with both spouses together to observe their interactions.

**Results:** Three higher-order themes emerged from the analyses. First, "each is stuck in its own bubble " represents a situation in which each spouse fights on his or her own side to avoid the disease or to avoid the suffering associated with it. Second, "the breakdown of communication" highlights disconnected emotional communication that protects each person but weakens the couple. Third, "the alienated couple" indicates that the two spouses are both emotionally distant and physically united, which prevents them from talking about difficult things.

**Conclusion:** These results demonstrate the importance of supporting the couple before avoidance strategies for fighting the disease are put in place and become entrenched.

**Keywords:** multiple sclerosis; couple; qualitative study; adjustment; avoidance; strategies; communication

Multiple sclerosis (MS) is a chronic inflammatory autoimmune disease of the central nervous system. There are 4 forms of MS based on the progression of the disease, the most common of which is the relapse-remitting form (affecting approximately 85% of patients) [1].

Persons with MS are usually 20 to 45 years of age when the first signs of the disease appear and are hence in the most active years of their life (e.g., leisure, children, job) [1,2]. Persons with MS exhibit cognitive impairments [3–5] and mood disorders and often feel very tired. They also exhibit physical impairments, such as muscle weakness, loss of bladder and bowel control, sexual dysfunction, or speech impediments [6]. The progression of MS is highly variable and unstable [1,2], which necessitates constant adjustments and restrictions in terms of everyday activities and social relationships [7,8]. These restrictions are also linked to the financial situation of the household, which is often compromised due to the loss of employment of persons with MS and the cost of their care [7,9]. The disorder impacts their physical and mental well-being, their quality of life, and their professional and social engagements [2,10]. At present, there is no curative treatment [2], and persons with MS can only receive treatments aimed at reducing the progression of the disease and improving their quality of life [1].

The impairments are often disabling and render persons with MS increasingly dependent on family members, most often the spouse [9]. The spouse often provides a large part of daily assistance, which leads to changes in all areas of life (e.g., strain, disturbed sleep, disrupted routine, financial problems, sexual and relationship problems, loss of family support, giving up full-time employment, restrictions on social life), particularly when he or she experiences insufficient support [9,11]. In previous research conducted among spouse caregivers of persons with MS, a lack of recognition from other family members was reported [12], and social and institutional resources are often limited due to the low prevalence of the disease [9,13]. Spouse caregivers experience a sense of loss in regard to the activities the couple previously performed together and can no longer do, and they worry about the future [14]. They feel that they are

losing control of their couple life (e.g., communication, activities, projects, intimacy, organization of daily life, roles) [15]. They also feel helpless watching the condition of the person with MS deteriorate while not always knowing how to help [16].

The negative consequences of MS have been extensively explored. However, the recent literature has investigated positive aspects of the caregiving experience and resources to attain well-being under unfavorable and irreversible conditions [17]. Persons with MS and their caregivers have reported well-being in relevant life domains, such as family and close relationships [17] and the marital relationship satisfaction is positively related to social support, love and communication [18,19]. Moreover, spouse caregivers' encouragement of person with MS well behaviors are associated with lower distress, and higher levels of independence in families are associated with better functioning in persons with MS [20]. Finally, caregivers experience an increase in their sense of personal growth due to the adversity that they face [21], the need to take care of their health by changing their lifestyle [16], and a focus on what is important in life and new priorities [16].

While the impact of the disease on each of the two spouses has been documented extensively [2,9,22–26], some studies have aimed to emphasize the experience as a couple but have ultimately studied the experience of each individual more than the process of dyadic adjustment [27–34]. Indeed, these studies have shown that high levels of anxiety and distress are felt by the two spouses, particularly shortly after the diagnosis [28]. The level of satisfaction with the relationship decreases over time for both spouses [29], and the priorities and projects of the couple are disrupted by the arrival of the disease, necessitating a recalibration of the values held in common throughout its progression [30]. Because they may have very little information regarding the progression of MS, the two spouses may feel uncertain and require health professionals to adapt to the information and to learn to cope with the physical and mental demands of the disease [31]. Spouse caregivers dedicate themselves to the person with MS to

the point of feeling a strong sense of guilt when they believe they have not adequately catered to the person's needs [27]. However, it is more an issue for them to manage the emotional reactions of the person with MS than this daily management [34]. Caregivers also state that they maintain their involvement out of loyalty, to uphold their marriage vows, or to avoid institutionalization. Finally, both spouses express mutual admiration: persons with MS admire their spouses for the help they receive, and spouse caregivers are admiring and rewarding to persons with MS who manage their disease [33]. The two spouses avoid dwelling on the worst scenarios and the potential impacts of the disease, and they retain a substantial degree of hope, which is essential for the survival of the couple and to avoid individual emotional collapse [33].

To cope with these stressful changes, both spouses implement coping strategies that play a substantial role in adaptation [35]. The literature on adjustment in MS and other chronic diseases, such as dementia, has shown that to maintain control of the situation and emotions, to minimize their problems and to maintain their self-esteem and lifestyle, both spouses devise individual and dyadic adaptation strategies [7,35–38], such as normalizing, fighting, denial, avoidance, non-anticipation of the future, hope or wishful thinking, seeking social support, positive re-appraisal, cognitive reframing, and planning. Spouse caregivers also use rigid control behavior to protect their spouses, which creates long-term tensions between the two spouses [39].

Finally, previous studies about the MS experience are mainly based on input from only the spouse caregiver, only the person with MS, or couples interviewed separately [27–34]. Interviews with both spouses present would clearly deepen our understanding of this issue by allowing us to capture their interactions and shared experiences. This approach entails studying the functioning of couples and understanding how the couple as a unit provides meaning to their experience. This type of interview can demonstrate how each spouse validates, corrects, and modifies what the other one says, revealing a discourse that develops slowly but steadily, with

the two spouses making a case for or debating their opinions [40]. Furthermore, despite the different profiles of the disease, previous studies have not distinguished between the types of MS in their analyses. Starks et al. [41] highlighted two types of functioning in couples confronted with MS. "Synchronized" couples were preferentially associated with relapsing-remitting MS (RRMS) and "desynchronized" couples were preferentially associated with progressive MS, but these profiles are not exclusive. Therefore, to better understand the implications depending on the type of MS, there appears to be considerable relevance in evaluating couples' experiences by focusing on each type of MS.

The objective of this study was to understand how couples experience the disease and the impact of the disease on the couple's relational dynamics and to provide evidence of individual and dyadic adjustment strategies for coping with the disease. To achieve this, both spouses were interviewed together, and the focus was placed on "couple" dyads in which one of the spouses had received a diagnosis of RRMS, the more common form of MS.

## **Method**

### ***Participants***

The participants were recruited through the hospitals of Valenciennes and Arras in northern France. The inclusion criteria were as follows: heterosexual couples in which one member of each couple had received a diagnosis of RRMS and the two spouses resided together.

The interviews were analyzed using the IPA analysis method developed by Smith et al. [42]. The numbers recommended in the literature for this method range from a single case study [43] to approximately 20 participants. A small number allows researchers to master the entire

corpus to develop a global vision and ensure its homogeneity [44]. We therefore chose a sample of dyads that deal with the RRMS to ensure the homogeneity of the sample [33].

### ***Procedure***

Couples who met the inclusion criteria were selected by the staff of the hospitals above from their active clinical queues. They were contacted by phone by the interviewer (AC), a psychologist trained in interviewing and qualitative analysis, to explain the objectives of the study and request their participation. Among the 11 couples who met the inclusion criteria mentioned above and who were called by the interviewer, 6 agreed to participate in the study.

The interviews took place at the couples' homes. Each of the 12 participants was provided an information letter and an oral explanation of the details regarding the study. If they still agreed to participate in the study, they provided a signed consent form. The couples were assured that their information would be kept confidential and that their identities would not be revealed in published reports. The couples were administered a semi-structured interview by following the interview grid shown in Table 1. The interviews were recorded with a voice recorder and transcribed in full, and pseudonyms were used to designate the participants. The same initial was given both partners within a couple (for example: couple A: Aline for the person with RRMS and Alain for the spouse caregiver) (Table 2).

-----[Insert Table 1 about here]-----

### ***Data Analysis***

The aim of this study was to report the experiences of couples in which one of the spouses had received a diagnosis of RRMS and to synthesize the series of case analyses that constitute the sample to obtain a contextualized model. Therefore, the interview data were analyzed qualitatively using interpretative phenomenological analysis (IPA;[42]). IPA is well suited to

an investigation with this aim because it captures the subjective meanings and experiences associated with a given phenomenon [45]. It is a dynamic process that involves double hermeneutics by combining an empathic and questioning hermeneutic. This approach is based on the subjective accounts of individuals rather than on an objective description of the facts. In addition, the researcher is directly involved. This approach attempts to access the singular universe of the participants, and this access is both based on and limited by the researcher's own conceptions [46]. The analytical narrative constituted is at the junction of the reflexive processes of the participants and researchers. The IPA approach allowed us to explore the experience of the participants, the meaning that they assigned to their experience, and the underlying psychological mechanisms [42]. The sequences of interactions were used to identify points of agreement and disagreement and communication strategies. We focused on the expressions and vocabulary used, emotions associated with the situations, and disagreements expressed directly or indirectly. The dyadic analysis allowed us to highlight the common and discordant items for the couple.

In keeping with the recommendations of Wawrziczny et al. [39], to increase the validity of our study, two researchers (AC and EW) analyzed, annotated, and interpreted each interview (first individually and then jointly). Based on these six analyses, the researchers then created a list of all of the salient phenomena.

## **Results**

Table 2 shows that 5 spouse caregivers were male and 3 were female. The mean age of the spouse caregivers was 38.5 years [range: 28-50], and the mean age of the persons with RRMS was 39.17 years [range: 29-50]. Each interview lasted 1 hour and 15 minutes on average. The



average length of time since diagnosis was 8 years [range: 3-14]. The average length of the relationship was 17.17 years [range: 11-25].

-----[Insert Table 2 about here]-----

The analyses permit the observation of different levels of impairment perceived by the couple. At the time of the interview, couple E described flare-ups that did not entail consequences that the couple deemed particularly disabling. Couple D had just experienced their first disabling flare-up. The other couples (couples A, B, C, and F) had already experienced several pronounced flare-ups with perceived disabling consequences that significantly limited the activities and the autonomy of the persons with MS.

The data were grouped into three higher-order themes: “each is stuck in its own bubble”, “the breakdown of communication”, and “the alienated couple” (Table 3). Each theme is described and illustrated with examples from the dyadic interviews. After each quote, we have added the pseudonym of the person speaking and (P) if the person speaking was the person with RRMS or (C) if the speaker was the spouse caregiver.

-----[Insert Table 3 about here]-----

### ***Each is stuck in its own bubble***

As the disease progresses, the couple’s life gradually becomes more concentrated on the disease, and each spouse fights individually against the difficulties caused by the disease.

*A focus on the disease.* With the arrival of the disease and its progression, Alain explained, “The couple’s lives are dictated by the disease and the decisions as you cannot do certain things [...]”.

The four couples (A, B, C, and F) who described the most disabling consequences stated that activities, decisions, arrangements, and organization were increasingly shaped by the schedule

of the treatments or the physical options for the person with RRMS. Bernard explained, “For the couple, it takes up a lot of time: between taking care of the kids, driving them to school, taking care of everything on top of the disease, whereby you need to pay attention to what she need to eat, blend food, etc....”. Even separately from the flare-ups, a level of vigilance developed that was linked to fear of placing the person with RRMS in danger or anticipation of the next flare-up.

We had helpers come to provide her personal daily care. Despite having no relapses, she’s still disabled by the after-effects. (Bernard, C)

The less tired I am, the better it will be for me. (Brigitte, P)

So they come to help her with her personal care, even though we leave her to do some things so that she still keeps a minimum of independence but there are many things that we’ll anticipate even if she’s capable because the more she gets tired, the more likely it is that it will go wrong... we’re always afraid of a relapse. (Bernard, C).

This gravitation around the disease steadily reduced spontaneity and the wishes of the couple and maintained a continuous state of alert in both spouses.

*Individual management of the disease.* Each spouse has his or her own way of focusing on the disease depending on their respective difficulties. The person with RRMS must progressively manage physical limitations that make him or her feel worthless. Faced with a threat to their integrity and sense of identity, persons with RRMS implement coping strategies to address this threat and avoid collapse. Etienne, who suffered from minimal consequences, held the disease and concern for the future at bay through action, minimization, and normalization. When the flare-ups became more intense, the disease could no longer be ignored. Denise explained, "The last flare-up, which was really quite disabling, I needed to know what was happening to me, and that is how this starts for all of us". As explained by Cathy, the more disabled individuals managed their feelings of worthlessness and uselessness by focusing on managing the

symptoms to maintain maximum autonomy and scheduling everyday tasks (Aline, Brigitte, Cathy, and Francine):

I don't know how to manage anymore. I don't know how to drive, which means that I always need someone. For example, he (Claude) is working this afternoon, which means that I need someone to go fetch the little one from school... I need someone to wash my children, to feed them. It's really this loss of independence that gets to me. I'm always telling him: I'm useless. Sometimes he tells me to go sit down, he'll tidy up or do the laundry... But then what do I do? Do I just watch him? I'd like to do things but I can't anymore, it's really hard. (Cathy, P)

So, sit down. (Claude, C)

That's not my nature, I'm not a woman who doesn't care. (Cathy, P)

You know you've got to become one. (Claude, C)

It's like the cleaning ladies, they tell me they're here to help me. It's hard, I'm young and I look like a 90-year-old granny. (Cathy, P)

Meanwhile, the spouse caregiver is mainly focused on managing everyday tasks and new responsibilities, which depend on the level of impairment. While Emilie needed to manage the consequence of Etienne's forced efforts to remain active, four spouse caregivers (Alain, Bernard, Claude, and Fabien) stated that all of their time was usurped by the tasks that arose due to the loss of autonomy of the person with RRMS, obligating them to fulfill their multiple roles as caregiver, worker, and spouse as well as possible. Alain explained this pressure meant that "even when things are bad...when she can't, everything needs to go ahead, needs to work out...". Fabien had to be present for quite a few things and do everything that Francine can no longer do.

Some time to swallow the pill but then I had to get right back on track because I had my job, my kid, my wife to take care of, because at the beginning it was getting her out of bed, washing her, dressing her, cutting up her meat because she couldn't do anything anymore. It was doing the apartment, and I'm also a fireman. I quickly moved on in order to do everything... I'm not saying that it's okay but... (Claude, C)

But we live differently now, we adapt. (Cathy, P)

We do and that's all, we adapt and we find solutions. (Claude, C)

Persons with RRMS and their spouse caregiver each struggle with the difficulties caused by the disease in their own way, leading to a withdrawal that is not without consequences for the couple's relationship.

### ***The breakdown in communication***

This withdrawal caused a breakdown between the two spouses. This breakdown could be seen in different communication processes in the interactions, such as negation of the other's experiences, difficulty establishing a dialogue, and the use of an external outlet.

*Negation of what the other experiences.* An initial pattern of interaction was the negation of the other's experiences. It manifested in one of two forms: either one of the spouses explicitly expressed their difficulties and the other negated these by trivializing them, downplaying them with humor, cancelling in the form of resignation, or engaging in a positive re-evaluation (as in the example of Fabien and Francine below), or one of the spouses remained positive and avoided dwelling on the difficulties linked with the disease while the other tried to address their difficulties and the sacrifices that arose with the disease by assuaging the emotional impacts through humor or downplaying them (as in the example of Bernard and Brigitte below).

You have to take care of everything, the laundry, the cleaning, etc....I do it willingly even though, sometimes, I get a bit fed up of it. It's OK; I get over it, and then I do what needs doing, no problem.  
(Fabien, C)

He does it really well! It's not something everybody could do. (Francine, P)

For six months, it was a long time, I was in complete denial. You just want to deny having this disease. I needed time to accept it, but now that's it, it's there and I accept it. As my neurosurgeon told me, you won't die of multiple sclerosis nowadays with all the treatments that are available. (Aline, P)

Now she (Aline) can make my life miserable (laughs). (Alain, C)

This negation of the experience of the other spouse provides a glimpse of the difficulty of listening to the suffering of the other spouse or expressing one's own distress.

*A dialogue of the deaf.* The two spouses did not listen to each other, and they engaged in a monologue of struggling that gave rise to a standoff (as in the example of Etienne and Emilie or Alain and Aline below).

I had more of an understanding of the disease because I've cared for people with multiple sclerosis, so I know a bit about where it could go if it really turns out like that. That's what was the hardest to accept, but at the very beginning, it was the fear of telling myself, "One day he won't be able to get up" or they'll call to tell me that something has happened to him. Not anymore; now it's part of everyday life. (Emilie, C)

We try not to think about what could be the consequences in 5, 10, 15 years, of no longer being able to walk ... If I worry about it now.... (Etienne, P)

At the very beginning, it was this blur. (Emilie, C)

Like everyone, you have to get organized. There's no other solution. It's not by feeling sorry for yourself that it's going to get better. (Alain, C)

Because I think, in the end, there's always something more serious than us. (Aline, P)

It's not cancer. It's just an education in our daily lives. We're going to evolve with the disease so every time you have to either get used to it or change the way you live or maybe one day sell the house. If you feel sorry for yourself, then the disease takes over your morale and the body fights differently when you are not feeling 100% mentally. (Alain, C)

This pattern of interactions permits each spouse to handle his or her own anxiety by closing in on the other's speech.

*An external outlet.* For all of the interviewed couples, communicating emotions with each other was difficult. Bernard, Claude (below) and Emilie sometimes had the need to confide in someone, and they sought someone outside their respective couple relationships. Emilie explained, “I talk about it with my family instead, my sister who is a nurse, but otherwise no. In the beginning, it was talked about because it was new, but afterward, no....”.

We talk about more things. You more, because inevitably you can do less so you confide more in me but I don't confide more in you than before. (Claude, C)

You don't talk to me, but then I'm the one who's sick so you can't confide in me about my illness, but you talk a lot with T. (Cathy, P)

This strategy allowed spouse caregivers to benefit from a way to freely express themselves and release internal emotional tensions.

*Avoiding suffering.* Different reasons were provided by the two spouses to explain this breakdown in communication: the pace imposed by the disease left little place for reflection or the expression of the emotions that they experienced (Alain), they did not wish to make the disease visible (Etienne), or they wanted to avoid conflict (Emilie).

Everything is contained because we can't either.... maybe it's a lack, that there's no place to let something get away. We've always had to deal with another problem. (Alain, C)

Although these processes of communication had the short-term objective of attenuating the emotional consequences of the disease, in the medium and long term, they led to weakening the couple.

### ***The alienated couple***

This communication breakdown is the cause of an emotional distance between the two weakened spouses, who nevertheless remain physically in the daily life and management of the disease.

*The person with RRMS capitulates, the spouse caregiver is close to the breaking point.* As the disease progresses, persons with RRMS increasingly depend on their spouse caregivers. The spouse caregivers handle the treatments, the appointments, the children, and the daily chores, particularly when there are flare-ups and during the recovery time from flare-ups. Cathy and Francine expressed total surrender to their spouse caregivers, whom they described as indispensable to their survival.

For me, he's everything. I confide in him; he's my confidant, my husband, my helper, my walking stick. He's everything. In fact, when he's not here, I can't do anything. If he's not here, I can't live anymore. Even to go outside, to walk because I lean on him; everything here, I can do practically nothing. It's him who does it, the children, he's the one who does it, the shopping, he does it. If I didn't have him, I wouldn't be alive. (Cathy, P)

And me, what would I do without you? (Claude, C)

You'd take a breather! (Cathy, P)

David, who was facing the first disabling flare-up, still expressed optimism and positivity and encouraged and valued Denise (see below). Alain, Bernard, and Fabien felt anger, sadness, or a desire to leave, which were feelings laden with blame that they did not allow themselves to express because they perceive the persons with RRMS too dependent and emotionally fragile. Claude stated that it was impossible to express his feelings to his spouse, who was already very vulnerable with dark thoughts sometimes.

For a start, you can walk, you've got your two legs. There are some who are in a wheelchair. There are some who've got nothing left. (David, C)

Yes, but it may just be a matter of time. (Denise, P)

But we're going to hold on, we're going to get by. You have to be strong in life. That's what I always tell her. (David, C)

Strong, I am strong. I'm the strongest. (Denise, P)

I don't know how you do it because three months in the hospital plus the ongoing rehabilitation as well as the heavy treatment you had [...] honestly, she was great. (David, C)

The spouse caregivers prevented themselves from expressing their feelings and their exhaustion to protect the persons with RRMS, who were perceived as vulnerable and totally dependent on them.

*A two-fold alienation.* This lack of externalization and the increase of tasks and responsibilities can sometimes cause an accumulation that leads spouse caregivers to near burnout and contributes to the emotional gap between the two spouses. In particular Bernard and Claude talked about changes in the character (irritability, pessimism, emotionality) of Brigitte and Claude that they had a difficult time withstanding, Fabien evoked conflicts by minimizing them, and Alain spoke of an emotional breakdown with Aline perhaps related to a lack of consideration.

We don't look at each other anymore! (Laughs). We're used to it now. We tolerate each other. (Alain, C)

I can handle it, I don't like to pity people, I never pity people, and I know that it bothers some people, but

I don't like people to complain to me because I don't like to be moaned at and I don't complain. (Aline, P)

So she doesn't pity her husband, I've also got serious back problems. (Alain, C)

Yes, well... (Aline, P)

So we don't complain to each other. (Alain, C)

While an emotional gap may develop between the two spouses that can threaten the relationship, physically, four of the couples (A, B, C, and F) described themselves as being very close, almost fused together. This fusion can be explained, first, by the increase of the level of



dependence of the person with RRMS, Cathy explained that the disease brought them together, that they were united and that it was even worse since the arrival of the disease. Second, there may be a severing of social connections. The couple closes in on itself.

We're completely alone, there's only the couple. Even with the children, if there's a problem at school, there's no one, it's just us. (Bernard, C)

So inevitably, if we don't get along with each other, who are we going to get along with, we have nobody. (Brigitte, P)

Nevertheless, for Bernard, the future of the couple's relationship was conditioned by the mutual engagement of both spouses in the fight against the disease. If Brigitte gave up fighting, Bernard would give up the couple. No place is left for the expression of suffering and complaints, which reinforces the emotional gap. Brigitte was thus limited in her expression of her feelings because she feared overloading Bernard, who threatened divorce.

I wasn't well because I was told the names of some quite serious illnesses that ended in death and I said to myself if I have a little bit of both, I'm going to die, I'm not going to die... it was a mental prison but I didn't complain all the time either. (Brigitte, P)

Still you talked about it a lot. (Bernard, C)

There were times when I was listless because I was fed up and you were there to cheer me up. (Brigitte, P)

For me, she was always strong and at first I started....not to feel sorry for her but to be there to listen to her, to be a shoulder to cry on when she needed to, I let her cry, to let it out... (Bernard, B)

But I wasn't always like that... (Brigitte, P)

No, exactly, you weren't like that all the time because at one point it's true that it got on my nerves a bit and after a while I was hard on her so that she would fight. So she had to take some responsibility. I wouldn't have been able to put up with it if she was always in tears; she had to fight as well. If I'd seen that she wasn't going to fight, I would have given up. (Bernard, C)

These are reasons that keep both spouses physically together although they may be emotionally distant.

*Hope for a possible upside.* Couples A, B, and C indicated that there was hope for a possible upside by renewing their conjugal commitment, living vicariously through their children, or the discovery of a miracle treatment that can reconstitute the myelin around the nerves.

Our dream, both as a couple and as parents, the ideal in our minds, is that our children will succeed where we haven't been able to persist. (Brigitte, P)

Where we couldn't persist because of the disability. (Bernard, C)

This strategy allows them to project themselves into a more positive future.

## **Discussion**

While there are different forms of MS with their own particular modes of progression, previous studies focusing on the experiences of couples, spouse caregivers or persons with MS have not differentiated them. Moreover, couples' adjustment to the disease has rarely been studied, although understanding of this adjustment is a clinical issue for health professionals to provide support and relevant interventions [27]. The original objective of this study was to specifically explore the interactions and modes of adjustment of couples in which one of the spouses had been diagnosed with RRMS. This approach is particularly important for responding appropriately to the couples' needs and difficulties for this type of MS.

The analyses permit the observation of different strategies for individual and dyadic adjustment depending on the level of impairment perceived by the couple.

### ***Individually fighting the disease***

The first important result of this study showed that each spouse withdrew into himself or herself and fought the disease individually. The strategies implemented targeted either the distance from the disease or the distance from suffering depending on the level of impairment perceived by the spouses.

When couples experienced flare-ups that did not entail consequences that the spouses deemed to be particularly disabling, the two spouses fought the disease and kept it at a distance to make it as unobtrusive as possible and to continue to live a “normal” life. They retained their roles and activities as long as possible because flare-ups do not lead to disabling consequences in the early stages [41]. Persons with RRMS thus sense a pressing need to maximize their use of time when they are not having a flare-up [33]. They push themselves to the point that their spouse caregivers must intervene by telling them to slow down, which is often a source of conflict [34]. Meanwhile, the spouse caregivers encourage independence and the retention of abilities [47]. The spouses manage each other by talking about the disease as little as possible to avoid making it too present. For the couples who have already experienced one or several pronounced flare-ups with perceived disabling consequences, the disease can no longer be kept at a distance and is a source of distress for both spouses that they seek to avoid. Each spouse, on his or her own side, implements avoidance strategies to minimize the influence of the disease on their lives [33] and to fight the suffering caused by it. They seek to maintain their spouse’s self-worth [34] and to avoid facing the future [33] and letting the disease get the upper hand [34]. Márquez-González et al. [48] showed that the inability to accept is associated with avoidance adjustment strategies that generally prove to be ineffective for managing situations of assistance and lead to an increase in the level of distress. Therefore, even if these strategies prove to be effective in the short term, in the long term, they risk undermining the couple’s relationship.

### ***Emotional distance and physical closeness***

The second important result of this study was that while the struggle in which each spouse engaged individually had a protective function, it also created a certain emotional distance between them. The withdrawal caused by this absorption in the management of the disease made each spouse less sensitive, receptive, and available to meet the emotional needs of the other. The two spouses each struggled with the disease in their own way, giving the impression that each was in an anti-depressive bubble to prevent them from collapsing. Therefore, they could not provide satisfactory emotional support for each other [8]. While silence represented this cognitive unavailability to the other, it was also partly intended to protect the individual. The spouse caregiver coped with difficult feelings and decisions (such as the question of separation) and did not discuss them with the person with RRMS. Meanwhile, the person with RRMS feared that the spouse would leave but did not express this [47]. The two spouses maintained silence to avoid disturbing the relationship.

While this silence created an emotional distance that could eventually permanently estrange them, it was compensated by a physical closeness that brought the spouses together. The couple perceived themselves as a unit, particularly when emotional stability was in jeopardy [33]. This very strong link was supported by the increasingly pronounced physical dependency of the person with RRMS, their social isolation and their commitment to the fight. Persons with RRMS progressively left things up to their spouses, who became essential to their survival [33]. At this point, it became impossible for the spouse caregiver to express distress and to think or talk about a possible separation. This thinking was guiltily and quickly ousted because it would give rise to a sense of giving up on the person with RRMS and inflicting a double sentence: being ill and having to manage the disease alone, especially since the social network became more limited. Nevertheless, one of the spouse caregivers expressed that maintaining the relationship is only possible if both spouses are united around a common fight.

The disease is perceived as a "common enemy", an external target against which they both commit themselves to fight, even though it manifests itself in person with RRMS's incarnation. To fight is not to complain, to complain is to give up, and to give up is to put the couple at risk. There is a prohibition on verbalizing their feelings, which reinforces the emotional gap between them. If they needed to, they used a nonjudgmental listener to allow them to express themselves [47]. This strategy reinforced the lack of communication between the two spouses.

### **Clinical implications**

In light of the results of this study, individual and dyadic support should be provided as early as possible to facilitate better acceptance of the disease and to promote communication between the two spouses.

Intervention centered on the development of skills for persons with RRMS would permit the optimization of their participation, empowerment, and independence. Indeed, many of the points of contention discussed by the participants focused on the person with RRMS's level of independence, her/his sense of devaluation and the frustration of both spouses because things are not as they "should" be. For example, participation-based therapy, which has been proposed for children with physical disabilities [49], could be adapted for persons with RRMS in collaboration with their spouse caregivers.

Intervention centered on acceptance would allow each of the spouses to experience psychological events (thoughts, feelings, and memories) without seeking to avoid them or letting them influence their behavior [50]. Indeed, strategies of acceptance are associated with a better quality of life, a greater sense of well-being [50], a lower level of distress, a higher level of satisfaction, and better health [51]. Pakenham and Samios [52] showed the role of full awareness and acceptance in the individual and dyadic adjustment of couples facing MS.

Furthermore, Nordin and Rorsman [53] reported promising effects of a program centered on acceptance that limited strategies of avoidance.

Moreover, the implementation of dyadic support would allow the two spouses to maintain emotional communication to preserve their relationship as a couple. Couples with a high-quality relationship are better able to cope with stress caused by disease [54], particularly when each spouse expresses the need to receive emotional support from the other [8]. Programs carried out in relation to other chronic diseases have shown a degree of efficacy by enabling couples to communicate better, explore the relationship problems caused by the disease, better understand each other, respond to fears regarding the future and give some thought to the progression of the disease [55].

### **Limitations of the study**

Several limitations of our study should be noted. We did not have access to information about participants' EDSS to properly characterize our sample but it did not impair our interpretations since the IPA analysis method focuses on the subjective experiences of the participants. It was by analyzing the interviews that we identified different experiences based on the perceived level of disability. Moreover, we were less interested in the actual severity than in the experience of both spouses and the level of impairments experienced and perceived by participants. The interviews were conducted with both spouses together, which allowed us to access their interaction but may hinder access to more honest and intimate information for fear of hurting and offending the other. The combination of two investigation methods, individual and dyadic interviews, might be the best approach in future research [39]. This study mainly considered the experience of couples facing RRMS. The literature has shown that the primary progressive forms have a more negative impact and that the two spouses are less complementary in regard to managing difficult situations [2,41,56]. Conducting a similar study among couples in which

one individual has a progressive form of MS would be especially important considering the additional challenges. Furthermore, the results of this study describe the experiences reported by 6 couples with different levels of perceived impairment, which allowed us to make assumptions about what happens when the severity increases. This could be examined more closely in the context of a longitudinal study. Lastly, studies show gender differences in the understanding of the caregiver role and in the expression of feelings [47]. Our sample was mainly composed of women with RRMS. A larger sample with more men with RRMS would allow identification of gender-specific aspects.

## **Conclusion**

In this study, we explored the interactions and adjustment modes of couples facing RRMS. This study highlights an essential point: the importance of accounting for the experience of the couple when designing interventions for support. Indeed, the severity of the disease, the unpredictability of its progression, and the lack of treatment affect both persons with the disease and their spouse caregivers [8]. When the two spouses avoid facing the disease and communicating their feelings, these strategies, in the long term, become a source of emotional estrangement. This is why it is essential to support the couple as early as possible before avoidance strategies become entrenched to reduce the risk of jeopardizing the couple relationship by proposing different support axes. Intervention centered on the development of skills for persons with RRMS would contribute to optimizing their self-esteem and empowerment. Furthermore, interventions focused on acceptance could be provided to promote openness to experiencing the present and to help the spouses develop the ability to deal with negative internal events. Finally, dyadic interventions could promote better communication between the two spouses and decrease conflict [55].

**Declaration of conflicting interests**

The authors declare that there is no conflict of interest.



## References

1. Goldenberg MM. Multiple Sclerosis Review. *Pharm Ther.* 2012;37:175–184.
2. Benito-León J, Morales JM, Rivera-Navarro J, Mitchell AJ. A review about the impact of multiple sclerosis on health-related quality of life. *Disabil Rehabil.* 2003;25:1291–1303.
3. Barak Y, Achiron A. Effect of Interferon-beta-1b on Cognitive Functions in Multiple Sclerosis. *Eur Neurol.* 2002;47:11–14.
4. Benedict RHB, Wahlig E, Bakshi R, Fishman I, Munschauer F, Zivadinov R, Weinstock-Guttman B. Predicting quality of life in multiple sclerosis: accounting for physical disability, fatigue, cognition, mood disorder, personality, and behavior change. *J Neurol Sci.* 2005;231:29–34.
5. Hakim EA, Bakheit AMO, Bryant TN, Roberts MWH, McIntosh-Michaelis SA, Spackman AJ, Martin JP, McLellan DL. The social impact of multiple sclerosis - a study of 305 patients and their relatives. *Disabil Rehabil.* 2000;22:288–293.
6. Schapiro RT. Managing the Symptoms of Multiple Sclerosis. *Handb Mult Scler.* 2006
7. Dennison L, Moss-Morris R, Chalder T. A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clin Psychol Rev.* 2009;29:141–153.
8. Kleiboer AM, Kuijer RG, Hox JJ, Schreurs KMG, Bensing JM. Receiving and providing support in couples dealing with multiple sclerosis: A diary study using an equity perspective. *Pers Relatsh.* 2006;13:485–501.
9. Corry M, While A. The needs of carers of people with multiple sclerosis: a literature review. *Scand J Caring Sci.* 2009;23:569–588.
10. Mikula P, Nagyova I, Krokavcova M, Vitkova M, Rosenberger J, Szilasiova J, Gdovinova Z, Groothoff JW, Dijk JP van. Coping and its importance for quality of life in patients with multiple sclerosis. *Disabil Rehabil.* 2014;36:732–736.
11. McKeown LP, Porter-Armstrong AP, Baxter GD. The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. *Clin Rehabil.* 2003;17:234–248.
12. Hughes N, Locock L, Ziebland S. Personal identity and the role of ‘carer’ among relatives and friends of people with multiple sclerosis. *Soc Sci Med.* 2013;96:78–85.
13. Bowen C, MacLehose A, Beaumont JG. Advanced multiple sclerosis and the psychosocial impact on families. *Psychol Health.* 2011;26:113–127.
14. Rollero C. The Experience of Men Caring for a Partner With Multiple Sclerosis. *J Nurs Scholarsh.* 48:482–489.
15. Bogosian A, Moss-Morris R, Yardley L, Dennison L. Experiences of partners of people in the early stages of multiple sclerosis. *Mult Scler J.* 2009;15:876–884.
16. Neate SL, Taylor KL, Jelinek GA, De Livera AM, Brown CR, Weiland TJ. Psychological Shift in Partners of People with Multiple Sclerosis Who Undertake Lifestyle Modification: An Interpretive Phenomenological Study. *Front Psychol.* 2018;9:15.

17. Delle Fave A, Bassi M, Allegri B, Cilia S, Falautano M, Goretti B, Grobberio M, Minacapelli E, Pattini M, Pietrolongo E, et al. Beyond Disease: Happiness, Goals, and Meanings among Persons with Multiple Sclerosis and Their Caregivers. *Front Psychol*. 2017;8:2216.
18. O'Connor EJ, McCabe MP, Firth L. The impact of neurological illness on marital relationships. *J Sex Marital Ther*. 2008;34:115–132.
19. Perrone KM, Gordon PA, Tschopp MK. Caregiver Marital Satisfaction when a Spouse has Multiple Sclerosis. *J Appl Rehabil Couns*. 2006;37:26–32.
20. Schwartz L, Kraft GH. The role of spouse responses to disability and family environment in multiple sclerosis. *Am J Phys Med Rehabil*. 1999;78:525–532.
21. Ackroyd K, Fortune DG, Price S, Howell S, Sharrack B, Isaac CL. Adversarial Growth in Patients with Multiple Sclerosis and their Partners: Relationships with Illness Perceptions, Disability and Distress. *J Clin Psychol Med Settings*. 2011;18:372–379.
22. O'Connor AB, Schwid SR, Herrmann DN, Markman JD, Dworkin RH. Pain associated with multiple sclerosis: Systematic review and proposed classification. *PAIN®*. 2008;137:96–111.
23. Boeschoten RE, Braamse AMJ, Beekman ATF, Cuijpers P, van Oppen P, Dekker J, Uitdehaag BMJ. Prevalence of depression and anxiety in Multiple Sclerosis: A systematic review and meta-analysis. *J Neurol Sci*. 2017;372:331–341.
24. Arnett PA, Barwick FH, Beeney JE. Depression in multiple sclerosis: Review and theoretical proposal. *J Int Neuropsychol Soc*. 2008;14:691–724.
25. Topcu G, Buchanan H, Aubeeluck A, Garip G. Caregiving in multiple sclerosis and quality of life: A meta-synthesis of qualitative research. *Psychol Health*. 2016;31:693–710.
26. Opara J, Broła W. Quality of Life and Burden in caregivers of Multiple Sclerosis patients. *Physiother Health Act*. 2018;25:9–16.
27. Esmail S, Huang J, Lee I, Maruska T. Couple's Experiences When Men are Diagnosed with Multiple Sclerosis in the Context of Their Sexual Relationship. *Sex Disabil*. 2010;28:15–27.
28. Janssens ACJW, Doorn PA van, Boer JB de, Meché FGA van der, Passchier J, Hintzen RQ. Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurol Scand*. 108:389–395.
29. Samios C, Pakenham KI, O'Brien J. A Dyadic and Longitudinal Investigation of Adjustment in Couples Coping with Multiple Sclerosis. *Ann Behav Med*. 2015;49:74–83.
30. Pakenham DK. The nature of benefit finding in multiple sclerosis (MS). *Psychol Health Med*. 2007;12:190–196.
31. Boland P, Levack WM, Hudson S, Bell E. A qualitative exploration of barriers and facilitators to coping experienced by couples when one has multiple sclerosis. *Int J Ther Rehabil*. 2018;25:240–246.
32. Boeije HR, Duijnste MSH, Grypdonck MHF. Continuation of caregiving among partners who give total care to spouses with multiple sclerosis. *Health Soc Care Community*. 2003;11:242–252.
33. Boland P, Levack WMM, Hudson S, Bell EM. Coping with multiple sclerosis as a couple: 'peaks and troughs' – an interpretative phenomenological exploration. *Disabil Rehabil*. 2012;34:1367–1375.

34. Esmail S, Munro B, Gibson N. Couple's Experience with Multiple Sclerosis in the Context of their Sexual Relationship. *Sex Disabil.* 2007;25:163–177.
35. Mohr DC, Cox D. Multiple sclerosis: Empirical literature for the clinical health psychologist. *J Clin Psychol.* 2001;57:479–499.
36. Molyneaux VJ, Butchard S, Simpson J, Murray C. The co-construction of couplehood in dementia. *Dementia.* 2012;11:483–502.
37. Wawrziczny E, Pasquier F, Ducharme F, Kergoat M-J, Antoine P. Do spouse caregivers of persons with early- and late-onset dementia cope differently? A comparative study. *Arch Gerontol Geriatr.* 2017;69:162–168.
38. Robinson L, PhD LC, Evans K. Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging Ment Health.* 2005;9:337–347.
39. Wawrziczny E, Antoine P, Ducharme F, Kergoat M-J, Pasquier F. Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia.* 2016;15:1082–1099.
40. Eisikovits Z, Koren C. Approaches to and outcomes of dyadic interview analysis. *Qual Health Res.* 2010;20:1642–1655.
41. Starks H, Morris MA, Yorkston KM, Gray RF, Johnson KL. Being in- or out-of-sync: Couples' adaptation to change in multiple sclerosis. *Disabil Rehabil.* 2010;32:196–206.
42. Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: Theory, method, research. London: Sage; 2009.
43. Robson FM. 'Yes!—A Chance to Tell My Side of the Story': A Case Study of a Male Partner of a Woman Undergoing Termination of Pregnancy for Foetal Abnormality. *J Health Psychol.* 2002;7:183–193.
44. Antoine P, Smith JA. Saisir l'expérience : présentation de l'analyse phénoménologique interprétative comme méthodologie qualitative en psychologie. *Psychol Fr.* 2017;62:373–385.
45. Eatough V, Smith JA. Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology.* 2008; 179: p 194.
46. Smith JA, Jarman M, Osborn M. Doing Interpretative Phenomenological Analysis. In: *Qualitative Health Psychology: Theories and Methods.* London: SAGE Publications Ltd; 1999. pp 218–240.
47. Courts NF, Newton AN, McNeal LJ. Husbands and wives living with multiple sclerosis. *J Neurosci Nurs J Am Assoc Neurosci Nurses.* 2005;37:20–27.
48. Márquez-González M, Romero-Moreno R, Losada A. Caregiving issues in a therapeutic context: new insights from the Acceptance and Commitment Therapy approach. In: Pachana N, Laidlaw K, Knight B, editors. *Casebook of clinical geropsychology.* Oxford University Press; 2010. pp 33–53.
49. Palisano RJ, Chiarello LA, King GA, Novak I, Stoner T, Fiss A. Participation-based therapy for children with physical disabilities. *Disabil Rehabil.* 2012;34:1041–1052.
50. Butler J, Ciarrochi J. Psychological acceptance and quality of life in the elderly. *Qual Life Res.* 2007;16:607–615.

51. Pakenham KI, Fleming M. Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychol Health*. 2011;26:1292–1309.
52. Pakenham KI, Samios C. Couples coping with multiple sclerosis: a dyadic perspective on the roles of mindfulness and acceptance. *J Behav Med*. 2013;36:389–400.
53. Nordin L, Rorsman I. Cognitive behavioural therapy in multiple sclerosis: a randomized controlled pilot study of acceptance and commitment therapy. *J Rehabil Med*. 2012;44:87–90.
54. McPheters JK, Sandberg JG. The relationship among couple relationship quality, physical functioning, and depression in multiple sclerosis patients and partners. *Fam Syst Health J Collab Fam Healthc*. 2010;28:48–68.
55. Whitlatch CJ, Judge K, Zarit SH, Femia E. Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*. 2006;46:688–694.
56. Jones KH, Ford DV, Jones PA, John A, Middleton RM, Lockhart-Jones H, Peng J, Osborne LA, Noble JG. How People with Multiple Sclerosis Rate Their Quality of Life: An EQ-5D Survey via the UK MS Register. *PLOS ONE*. 2013;8:e65640.

**Table 1. Interview grid**

1. What can you tell me about the disease?
  - >How did it start?
  - >How did you experience the diagnosis?
  - >How do you manage the disease in daily life?
2. Can you tell me about your couple relationship?
  - >Can you explain to me how you met?
  - >How has your couple relationship evolved over the years?
  - >What are the major events that have marked your couple life?
3. What has changed in your couple relationship since the onset of the disease?
4. What difficulties have you encountered?
5. How did you manage to adapt to everyday life?
6. Can you tell me about the medical support you received?
7. Can you tell me about the social support you received?
8. How do you see the future?

**Table 2. Characteristics of the couples**

Couples	Pseudonym		Age		Gender		Number of children	Length of the relationship	Time since diagnosis
	Person with RRMS	Spouse Caregiver	Person with RRMS	Spouse Caregiver	Person with RRMS	Spouse Caregiver			
Couple A	Aline	Alain	33	34	F	M	4	16 years	12 years
Couple B	Brigitte	Bernard	50	47	F	M	2	16 years	4 years
Couple C	Cathy	Claude	31	32	F	M	2	14 years	6 years
Couple D	Denise	David	29	28	F	M	0	11 years	10 years
Couple E	Etienne	Emilie	45	40	M	F	4	21 years	3 years
Couple F	Francine	Fabien	47	50	F	M	0	25 years	14 years

F: Female; M: Male; person with RRMS: person with relapsing-remitting multiple sclerosis

Table 3. Summary of themes.

Overarching themes	<i>Each is stuck in its own bubble</i>	<i>The breakdown in communication</i>	<i>The alienated couple</i>
Sub-themes	<ul style="list-style-type: none"> <li>•A focus on the disease</li> <li>•Individual management of the disease</li> </ul>	<ul style="list-style-type: none"> <li>•Negation of what the other experiences</li> <li>•A dialogue of the deaf</li> <li>•An external outlet</li> <li>•Avoiding suffering</li> </ul>	<ul style="list-style-type: none"> <li>•The person with RRMS capitulates; the spouse caregiver is close to the breaking point</li> <li>•A two-fold alienation</li> <li>• Hope for a possible upside</li> </ul>