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The experience of men caring for a partner with multiple sclerosis

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CLINICAL SCHOLARSHIP

The Experience of Men Caring for a Partner With Multiple Sclerosis

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Key words

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Abstract

Purpose: The aim of this study was exploring the experience of male caregivers living with a partner with multiple sclerosis (MS).

Design and Methods: A qualitative study was conducted following a grounded theory approach. Twenty-four men—husbands or partners of a woman diagnosed with MS—were interviewed in-depth. A thematic analysis was carried out and involved line-by-line coding with codes deriving from narratives.

Findings: Five major themes emerged: caregiving as a full-time job; changes in the couple; the importance of social support and social life; gender specificities; and fear of the future.

Conclusions: Results highlight the complexity of issues surrounding this specific form of caregiving. Social expectations referring to the marital relationship and to gender norms play a central role.

Clinical Relevance: Findings can help in developing ad hoc interventions to support male spousal caregivers to care for their partners.

Multiple sclerosis (MS) is a progressive neurodegenerative disorder of the central nervous system affecting more than 2.1 million people around the world (Buchanan & Huang, 2012). It is at least two to three times more common in women than in men, and most people are diagnosed between the ages of 20 and 50 years (Starks, Morris, Yorkston, Gray, & Johnson, 2010). MS is considered a polysymptomatic disease, whose progress, severity, and specific symptoms vary from time to time and from person to person. It is characterized by episodes of neurological symptoms that are often followed by fixed neurological deficits. Such deficits may involve motor and sensory functions (e.g., muscle weakness, paraesthesia, fatigue), cognitive functions (e.g., memory, attention, verbal fluency), and behavioral functions (e.g., anxiety, depression, emotional lability).

Because of their clinical condition, people with MS often experience limitations in their ability to do everyday tasks and thus require demanding support from others. Their need for personal assistance increases as the disease progresses and disability becomes more severe and permanent (Kouzoupis, Paparrigopoulos, Soldatos, &

Papadimitriou, 2010). More than 50% of people with MS require some form of assistance with daily activities, most of which is offered by informal caregivers (Buchanan, Radin, & Huang, 2010).

An informal caregiver has been defined as an unpaid person providing needed care to a friend or a family member who cannot manage everyday living without help or support because of sickness or disability (Giovannetti, Cerniauskaite, Leonardi, Sattin, & Covelli, 2014). Informal caregivers provide several services to people with MS, including personal care, homemaking, mobility, emotional support, and leisure activities (Buchanan & Huang, 2012). Although psychological research on MS has focused primarily on patients, there is increasing literature on caregivers and caregiving burden (Corry & While, 2009; Kleiboer, et al., 2007; Kouzoupis et al., 2010; Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014). Literature highlights that caregivers report more stress symptoms than the general population. They also experience a decrease in their physical health, psychological well-being, and social life (Corry & While, 2009; McKeown, Porter-Armstrong,

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2
3 & Baxter, 2003). Frequently, caregiving has an adverse
4 effect on their work activity and financial situation
5 (Opara, Jaracz, & Broła, 2012). Studies have also shown
6 that caregivers perceive an inner conflict between desir-
7 ing independence in their role as carer and wanting
8 others to offer them assistance, although in general they
Q3 report receiving little social support (McKeown, Porter-
10 Armstrong, & Baxter, 2004). Additionally, the specific
11 characteristics of MS, such as the unpredictability of its
12 course and the lack of specific treatment, seem to increase
13 caregiver burden (Corry & While, 2009). Recent studies
14 demonstrate that cognitive impairment in patients signif-
15 icantly affects health-related quality of life of caregivers
16 (Labiano-Fontcuberta et al., 2014). The decreased cogni-
17 tive function associated with MS is often more difficult
18 to cope with than the physical deficits. The caregiver
19 not only has to provide augmented surveillance, but also
20 experiences the loss of the individual he or she once
Q4 knew (Starks et al., 2010).

22 Despite this abundance of negative consequences of
23 the caregiving role, caregivers can also report positive
24 emotions related to assisting a person with MS, such as
25 satisfaction, pride, and gratification (Opara et al., 2012).
26 The identification of benefits in such difficult situations
27 can help the caregiver cope with adversity (Pakenham,
28 2007). Some caregivers gain personal reward from their
29 caring, and those who experience personal growth in pro-
30 viding assistance are exposed to less burden (Buchanan
31 & Huang, 2012; Corry & While, 2009). A greater ef-
32 fort assisting the person with MS increases the feeling
33 of caregiver accomplishment, especially for low-educated
34 caregivers (Buchanan & Huang, 2012). Other benefits of
35 caregiving include increased feelings of closeness, recog-
36 nition of inner strengths and abilities, and reprioritizing
37 life goals (Starks et al., 2010).

40 Gender and Caregiving

42 Several factors influence the experience of caregiving,
43 the most significant being gender (Li, Mak, & Loke,
44 2013). Researchers who have analyzed gender differ-
45 ences in caregiving found that women not only provide
46 a greater amount of care, but also show higher levels of
47 burden and depression and lower levels of well-being
48 and physical health than men (Akplnar, Küçükgülçü,
49 & Yener, 2011; del-Pino-Casado, Frías-Osuna, &
50 Palomino-Moral, 2011; del-Pino-Casado, Frías-Osuna,
51 Palomino-Moral, & Ramón Martínez-Riera, 2012;
52 Vitaliano, Zhang, & Scanlan, 2003). Consistently, recent
53 literature reviews on spousal caring experience for
54 cancer patients found that women report more distress
55 and lower mental health and life satisfaction than men

(Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne,
2008; Li et al., 2013). These gender differences seem
to be exclusively attributable to caregiving activities
and could indicate a diverse appraisal of the caregiv-
ing situation in men and women, which is culturally
rooted (del-Pino-Casado et al., 2012). Indeed, due to
the traditional societal norms concerning gender roles
(Eagly & Karau, 2002; Rollero, 2013), women are more
likely to be regarded as caregivers and assume more
over-responsibility and self-sacrifice than men for the
care of other family members (Hsiao, 2010; Rollero,
Gattino, & De Piccoli, 2014).

Although the factors discussed in the preceding text
suggest that caregiving is affected by gender, little work
concerning MS has been devoted to this area (Lopez,
Copp, & Molassiotis, 2012). The very few studies on
gender differences in caregiving reported that men and
women differ in how they protect themselves and
their lives. Women are more likely to feel guilty if
they set limits to preserve their own lives, while men
tend to clearly establish such protections (Boeije & Van
Dooorne-Huiskes, 2003). Moreover, husbands and wives
of people with MS experience different coping strate-
gies. Women tend to help their partner to maintain his
independence and role, whereas men tend to express
anger and to become protectors of their wives (Courts,
Newton, & McNeal, 2005). However, as a consequence
of the traditional societal norms about gender behaviors
and of the prevalence of women as caregivers, the expe-
riences of men are notably overlooked (Denby, Brinson,
Cross, & Bowmer, 2014).

It is clear that important gaps remain in our under-
standing of caregivers' experience, particularly those of
male caregivers (Lopez et al., 2012). The present research
is aimed at illuminating such experiences. Specifically,
the purpose of this qualitative study is to provide insight
into the meaning of the experience of male caregivers liv-
ing with and providing care for a partner with MS.

Method

Participants and Procedure

Participants were recruited through the Italian sections
of the Multiple Sclerosis International Federation. They
were identified using purposive sampling techniques. By
snowballing through contacts between the Federation
and people diagnosed with MS, the author identified po-
tential participants and invited them to take part in the
research. To be included in the study, participants needed
to be the husband or partner of a woman diagnosed with
MS and the woman he assisted should have been diag-
nosed for at least 1 year. On the basis of previous research

2
3 (Boland, Levack, Hudson, & Bell, 2012; McKeown et al.,
4 2004), this last criterion was formulated to exclude sub-
5 jects new to the role of caregiving.

6 Ethical approval for this study was obtained from the
7 author's University's Research Ethical Committee. The
8 author provided the Ethical Committee with a detailed
9 description of the study, the list of the primary inter-
10 view questions, and a copy of the consent form for par-
11 ticipants. When the ethical approval was obtained, the
12 author contacted the Italian sections of the Multiple Scle-
13 rosis International Federation to gain access to potential
14 participants. Consenting caregivers were informed about
15 the study, and written informed consent was obtained.
16 Participants were assured that they could discontinue the
17 study at any time. They were told that to protect confi-
18 dentiality all information provided by them would be
19 de-identified.

20 A grounded theory approach was selected as a general
21 framework (Corbin & Strauss, 2008; Glaser & Strauss,
22 1967). Following Charmaz's constructivistic perspective
23 (Charmaz, 2006), theoretical sampling was applied to
24 elaborate and refine categories founding a theory. Con-
25 sistentlly, caregivers were involved in this study until a re-
26 peated pattern of conceptual and theoretical dimensions
27 emerged and their experience was fully described.

28 A total of 24 male caregivers participated in the study.
29 None of those contacted refused to participate. All par-
30 ticipants were Italian (Caucasian) and 37 to 68 years of
31 age (mean age 52 years). Twenty were spouses and the
32 remaining were partners or fiancés. All participants lived
33 in the same house with their wives or partners. Most of
34 the participants had completed high school ($n = 14$) or
35 college ($n = 2$), whereas the others had lower levels of
36 education. Eight participants were retired, one was given
37 time off, one was working part time, and the remaining
38 14 were employed full time.

40 Data Collection

41 Data were collected using face-to-face in-depth inter-
42 views. The interviews were conducted by one female psy-
43 chologist with experience in qualitative research. All in-
44 terviews took place in the patients' homes but separately
45 from the patients. They were carried out between June
46 and September 2015 in the caregivers' native language.
47 Citations reported here were translated into English.

48 Each interview began with brief sociodemographic
49 questions. Caregivers were then asked, "Could you please
50 describe your experience after the diagnosis?" During the
51 interview the researcher used additional prompts to en-
52 courage the in-depth description of the lived experience,
53 such as questions that sought greater detail on topics al-
54 ready spoken about or questions aimed at exploring what
55

Table 1. Primary Interview Questions

| |
|---|
| Could you please describe your experience after the diagnosis? |
| What are the main challenges you encountered? |
| What impact did the diagnosis have on your everyday life? |
| What impact did the diagnosis have on your social life, your family and friends? |
| Could you describe what your intimate relationship was like before the diagnosis? |
| How did your relationship change after the diagnosis? |
| What do you support your caregiving work on? |
| What are the main problems you have to cope with now? |
| What do you think about the future? |

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impact the diagnosis may have had on their life and their family (**Table 1**). Interviews lasted between 35 min and 1 hr and 45 min, with an average length of 55 min. The interviews were audiotaped and subsequently transcribed verbatim for analysis.

Data Analysis

Since a grounded theory approach was chosen as the framework for this research, interviews and data analysis were conducted simultaneously. After 21 interviews were completed, no new topics emerged and saturation was obtained for the main themes identified. Such saturation was confirmed with three subsequent interviews, and thus no more participants were contacted (Guest, Bunce, & Johnson, 2006).

A thematic analysis was carried out without a predetermined coding scheme. Analysis was inductive and involved line-by-line coding with codes deriving from narratives. A three-step coding procedure was used (Corbin & Strauss, 2008; Giovannetti et al., 2014). In step 1, the words used by caregivers were considered and used for generation of meanings and indications for further data collection. In step 2, data were aggregated to identify the emerging codes and categories. In step 3, theoretical coding was applied to explore relationships between categories. All interviews were double coded and the coders (the psychologist who conducted the interviews and a researcher in psychology) met to discuss codes and their definitions. Discrepancies were resolved through discussion until agreement was reached.

Results

Figure 1 shows a graphic representation of the key themes and subthemes that emerged during the interviews: caregiving as a full-time job; changes in the couple; social support and social life; gender specificities; and fear of the future.

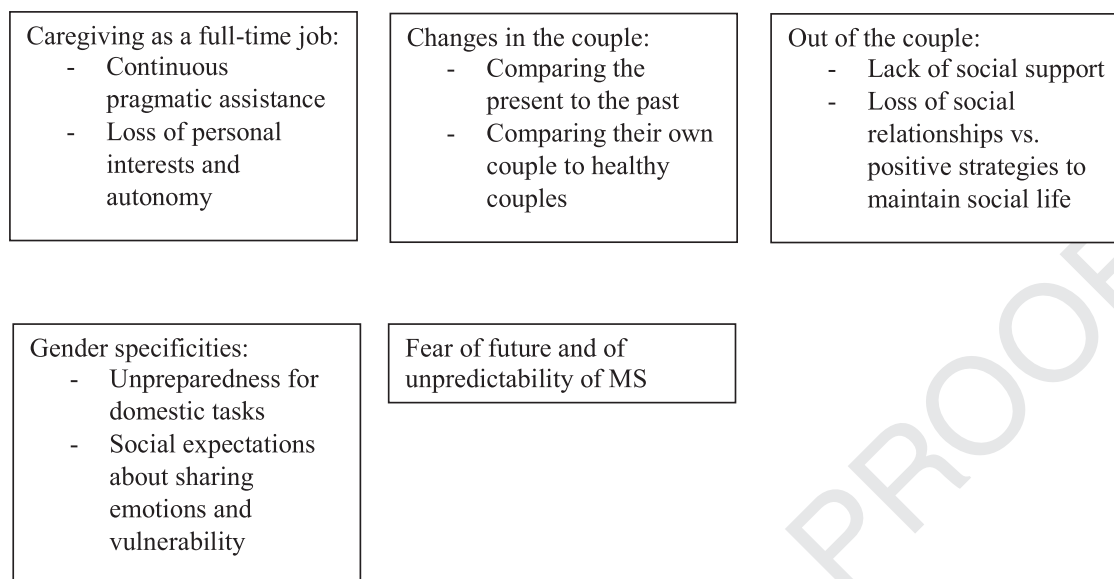


Figure 1. Key themes and subthemes emerged during the interviews.

Caregiving as a Full-Time Job: Continuous Assistance and the Loss of Autonomy

After the diagnosis, the caregiver's role became a new role and in most cases the predominant one. As his partner got worse, caregiving came to be the focus of his life. This implied two different outcomes: continuous pragmatic assistance and heavy physical workload, and the loss of personal interests and autonomy.

Most men indicated that they cared for their partner night and day: "I think this is a full-time job ... maybe more ... even at night I do not feel completely relaxed: when she can't sleep and gets up, I get up too" (P 17). "I know she prefers not being alone, so I try to be present every moment I don't have to work" (P 3). Assistance is physically demanding, especially for those who are older: "I have to move her, to wash her, to do domestic tasks: it is a hard work. My backache is permanent by now" (P 5).

When caregiving played this all-consuming role, partners experienced the loss of autonomy:

Everything has changed. My life has become totally different ... but little by little: sometimes I feel a bit like a prisoner ... I would need someone to come here to take care of her just for a couple of hours, just to go for a walk alone. (P 12)

Consistently, some caregivers reported difficulties in enjoying relaxation and restorative activities: "Sometimes one would need more freedom: I would like to go away knowing that she's all right. For example, last year I never

went skiing because leaving her and organizing assistance would have been too complicated" (P 21).

Changes in the Couple: "Our Love Is Different"

Another core issue of the caregivers' experience pertains to the changes affecting the couple. Such changes are reported mainly with two terms of comparison: the past of the couple and the everyday life of the other "healthy" couples. Almost all participants reported relevant changes within the couple after the diagnosis, with different degrees and intensity: "Our love is completely different now, it is more care-based ... or maybe only care-based" (P 11). "Our relationship has changed: she has become more a patient than a partner" (P 21).

As the dimension of care became predominant, the partner suffered an absence of sexual life: "For us sex was really important, but now, you know, we can't have sex because she becomes too tired after that" (P 8).

Other caregivers emphasized that they were not prepared for their partner's cognitive impairment and to its consequences in their relationship:

The most important things have changed in our couple. I was quite prepared to see her in a wheelchair, but I was not prepared at all about cognitive deficiency, I was not prepared to the fact that we cannot talk each other as we did before. (P 5)

Moreover, a number of partners referred to social expectations concerning their care roles within the couple:

You're expected to do it: you're her husband. (P 2)

I know one man whose wife had MS and got divorced, and I understand him: it's hard to live with it. But I've heard very blaming comments toward him, because he was her husband and should have been with her in sickness and in health. (P 21)

For some couples social expectations were interconnected with comparisons with healthy couples:

My parents are very sad because they have no grandbabies. They are always talking about their friends who spend their time with grandsons and granddaughters. I know, it can be hard to accept, but they don't do any effort to hide their sorrow, even when my wife is present. (P 19)

Making comparisons with healthy couples resulted in grieving for what might have been had MS not become center to their lives:

I have to admit that sometimes I'd like to be as the couples you see all around. We are young, as they are, but we are different, even if I try to let her do anything she would like to. We are different from other couples. (P 16)

We got married after her diagnosis. We wanted to fight against this damned disease, but during these years quite often I have wondered whether ... well, what would have happened if she would have been healthy? If we would have been as the other normal and healthy couples? (P 12)

Out of the Couple: Social Support and Social Life

Most partners discussed the lack of constant social support. A common experience was strong support from people just after diagnosis, but an increased feeling of loneliness as this support was withdrawn over time:

At the beginning relatives and friends were all supportive sympathetic. However, once we came back home we were alone and I felt the complete responsibility ... I was alone with my hard caregiving work. (P 21)

When people know that your wife is ill they offer their help and support. But my experience taught me that probably they offer their help because they feel they have to but this does not mean that you can actually rely on them. Indeed, now just me and her parents are taking care of her. (P 19)

The friends and neighbors have been good at the beginning, but there's a limit to what they can do. (P 5)

Another relevant issue for participants concerns social life. Two different positions emerge. First, the accounts from the interviews showed the progressive limitation of social contacts, mainly due to the lack of social support described in the preceding section and to practical difficulties:

In the end you lose your friends. Before, we still went out sometimes, but since she is in a wheelchair it is actually impossible. She has also difficulties in eating, and going out for dinner is not funny at all. ... (P 13)

When you organize something to do, they don't think about all the problems we can deal with: architectural barriers, schedules, her tiredness. ... People don't understand. People can't understand. (P 22)

However, on the other hand, a number of partners (along with patients) tried to adopt positive coping strategies in order to maintain a pleasing social life:

In the first year after the diagnosis, she was a bit depressed and didn't want to see anyone. Now it's better ... we are going out again, we even organize dinners at home with other patients. (P 12)

We try to live as normally as we can. We go out, even to have a pizza: you just have to cut it in small pieces. Her mother does not agree, but I always tell her that we don't have to care about her mother's opinion, we have to care about her life and her pleasure, if it's possible. (P 19)

Gender Specificities: "I Feel Like a Housewife and I Have to Be Strong"

Caregivers often mentioned traditional gender roles that specify which behaviors are expected by an individual on the basis of his or her sexual identity. Since domestic tasks and caregiving are usually associated with female roles, most men mentioned being unprepared to take on "female" work:

Since her illness, I have started doing domestic tasks ... it's a very different side of myself ... I feel like a housewife sometimes! (P 17)

I have to do the domestic jobs. I had to learn many things, as before she did almost everything at home. I had to become cook, gardener, cleaner ... (P 5)

Besides the unpreparedness for traditional female tasks, social expectations concerning gender specificities also affected the emotional dimension of caregivers' experiences. They found it difficult to express their

emotions and concerns to other people and tried not to look too vulnerable:

I see women who are married to a man with MS who create groups. They support each other. They chat about their everyday challenges. For men I think it's a bit different. We are not used to sharing with others our emotions and our difficulties. (P 12)

You know, men are supposed to care for. If I look weak and vulnerable, how can she rely on me? (P 20)

I am a man. I am her man. I have to be strong. It doesn't matter how I really feel. I have to keep her spirits up. (P 11)

Fear of Uncertainty: The Future

The unpredictability of MS and the related fear of the unknown were also reported. Caregivers were particularly worried about the uncertainty of the illness's course and the lack of information concerning specific trajectories and treatments. They felt uncomfortable and powerlessness in the face of such unpredictability:

When I notice things getting worse, I start thinking what is going to happen and I get a little bit nervous. (P 19)

I try to take it day by day, but this illness is so unpredictable that I can't ... horrible thoughts about the future come to my mind ... I know it's progressive. (P 20)

I would like to know what to expect ... someone who tells me: "Ok, this is what it's gonna be" ... it will help me in feeling a sort of control of the situation. (P 5)

The long-lasting course of MS had often discouraged both caregivers and patients: "At the beginning we were more optimistic about new drugs and treatments. We fought. Now we just fear the future" (P 17).

Other partners used active coping strategies in order to prevent future troubles:

I always think about [the] future, about what I can do. In this period, I am planning to buy another home, on the ground floor, so that she will be able to move freely and easily even if she will be in a wheelchair. (P 7)

When I think about the future, I think "if something happens to me, what will become of her without me?" I am getting old. For this reason, I have written anything she needs and I have shared this document

with friends and relatives. I say to myself: "You have to be ready." (P 9)

Discussion

The literature about caregiving presents a lack of knowledge about experiences of male caregivers because females have been thrust more often into the caregiver role (Hsiao, 2010). The in-depth examination of interviews employed in this study has enabled an exploration of men's experiences caring for a partner with MS. Taken together, the findings of this study highlight the complexity of issues surrounding this form of caregiving.

As a consequence of becoming a caregiver, men felt that their everyday lives were progressively disrupted, with several repercussions. All participants experienced caregiving as demanding, as a "full time job" where no break is allowed. Consistently, as previous studies showed (Covelli et al., 2014), caregivers expressed a need for leisure time for themselves, which is often missing, due to their responsibility in caregiving. The uncertainty of the disease appeared to be another relevant source of stress: the unpredictable relapses, disease progression, or even the everyday functional capacity of the patient may account for the overwhelming feelings of responsibility (McKeown et al., 2004).

After the onset, significant changes affect marital intimacy. When one partner is diagnosed with such a chronic illness, the ill partner becomes more dependent on the healthy partner, not only for assistance, but also for emotional support (Kleiboer et al., 2007). Indeed, in our study caregivers seemed to take it upon themselves to protect their partners throughout the illness, providing both emotional and pragmatic support. This is in line with previous research on male caregivers of women with breast cancer (Lopez et al., 2012). At the same time, our participants reported low marital satisfaction due to the shift to a care-based relationship (Starks et al., 2010). Partners felt obligated to stay together due to beliefs that they must remain true to their marriage vows. Social expectations play a relevant role in this process, as they make caregivers sensitive to duties and responsibility that are socially rooted, such as not leaving the partner, being strong and supportive, and avoiding any form of burden.

Social and cultural expectations refer not only to the marital relationship, but also to specific gender roles. Most male caregivers have assumed a role they were not familiar with. Spending time taking over the patient's personal care and household tasks is often understood as female gendered and can foster feelings of discomfort and strain. Gender expectations also significantly affect the emotional level. Caregivers revealed the need to

show and share their emotions, such as fear for the future, sadness, discomfort, worries, and everyday difficulties. However, expressing emotions and showing vulnerability can be seen as not appropriate for the male gender. This represents a relevant impasse and can contribute to caregivers' burdens. As reported earlier in this article, the scarce research on caregiving from a gender perspective has demonstrated that women show lower levels of well-being than men (del-Pino-Casado et al., 2012; Vitaliano et al., 2003). This may be due to the fact that women provide a greater amount of care than their male counterparts. However, the present study suggests that such gender differences may also be related to different ways of showing weaknesses and sharing emotions and difficulties, which are socially and culturally rooted.

Regarding the identification of positive aspects of the experience of caregiving, in our study, participants expressed few positive benefits from the caregiving experience, whereas other studies found greater benefits. Differently from other studies (Buchanan & Huang, 2012; Corry & While, 2009; Opara et al., 2012; Pakenham, 2007), caregivers reported neither positive emotions related to assisting a person with MS nor the impression of personal growth. The most positive aspects of their experience seem to be related to preserving the status quo. They felt proud and satisfied when they were able to help their partner maintain her everyday life and social relationships.

In sum, the theory that seems to emerge involves both the pragmatic and the emotional level. At the pragmatic level, it posits a significant relationship between the demanding characteristics of caregiving (i.e., the continuous pragmatic assistance) and the loss of personal autonomy. At the emotional level, three aspects are assumed to decrease caregivers' well-being: comparing the present to the past (or their own to those of healthy couples), the perception of lack of social support, and the fear of the future.

The data from this study can provide useful considerations for healthcare professionals working with people with MS and especially with their male caregivers. Indeed, health [professionals should be sensitive to the impact caregiving has on the emotional health of caregivers and understanding the psychosocial dimensions of caregiving in case of MS is necessary to alleviate family burden. In this perspective, the present findings can help nurses in developing interventions to support male spousal caregivers to care for their partners. One of the most pressing aspects to be considered is the necessity to deconstruct social expectations, in order to give men the chance to share their emotions and to show their vulnerability. Interventions aimed at developing positive emotion-focused strategies could be particularly helpful

to this aim. Moreover, nurses who are aware of these social expectations can take them into consideration when assessing the needs and concerns of people with MS and their caregivers.

Some limitations of this study need to be taken into account and considered as recommendations for future research. One of the most significant issues pertains to the importance of the cultural context. All caregivers recruited for this study came from Italy, which is one of the less egalitarian European countries according to the Gender Empowerment Measure index (i.e., a rank of 21 among 91 world nations; United Nations Development Programme, 2007). Since expectations concerning gender roles appear to be particularly relevant, generalizing our results to other cultural contexts requires caution. Rather, future research should investigate the replicability of these findings in different countries. Another limitation was that this study did not address the experiences of men who were no longer able to provide care to their partner, and as such it does not shed light on the possible sources of burn-out and breakdown. Further research is needed to examine these processes.

Despite these limitations, it is hoped that the present results can contribute to a better understanding of the experience of male caregivers, leading to a more sensitive approach to support them and to a better management of welfare services devoted to the care of patients with MS.

Acknowledgment

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Clinical Resources

- Family Caregiver Alliance: <https://www.caregiver.org/>
- International Organization of Multiple Sclerosis Nurses: <http://www.iomsn.org/>
- Multiple Sclerosis International Federation: <http://www.msif.org/>
- Multiple Sclerosis Italian Association: <http://www.aism.it/home.aspx>

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Author Queries

- Q1:** Au: Please confirm that given names (red) and surnames/family names (green) have been identified correctly.
- Q2:** Au: Please supply the Key words for your article.
- Q3:** Au: “to receive low social support” was changed to “receiving little social support.” Please verify that your meaning has been preserved.
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