



Body image in multiple sclerosis patients: a descriptive review

Marcella Di Cara¹ · Viviana Lo Buono¹ · Francesco Corallo¹ · Cecilia Cannistraci¹ · Carmela Rifici¹ · Edoardo Sessa¹ ·
Giangaetano D'Aleo¹ · Placido Bramanti¹ · Silvia Marino^{1,2}

Received: 7 November 2018 / Accepted: 12 January 2019 / Published online: 22 January 2019
© Fondazione Società Italiana di Neurologia 2019

Abstract

Objective Multiple sclerosis is a neurological disorder—may in some patients have impact on body image; this could contribute to neurological disability, psychological distress, and can reduce quality of life. This review has been conducted on studies investigating the representation of body image.

Method We have researched PubMed and Web of Science databases and included screening references for studies and review articles about this topic. From the initial 316 publications, we included only 9 studies that met the search criteria.

Result and conclusion The results showed that this construct has been little emphasized over time and has a significant impact on the patient.

Keywords Body image · Multiple sclerosis · Body esteem · Sexual disorder

Introduction

Body image is a multidimensional construct characterized by perceptions and assessments of individual about own physical appearance [1]. Schilder defines the body image as “the picture of our own body which we form in our mind, that is to say the way in which the body appears to ourselves” [2]. Slade describes this topic as the subjective representation that each person has of their body [3]. The representation of the body image, which everyone has of them self, is fundamental for awareness, development, and maintenance of individual psychological identity [4].

The body image can be divided into three components [5]:

- The real body, which allows an objective vision of one’s own body
- The ideal body, which focuses on what we want our body to be

- The body’s mental representation, which examines the body from a perceptual, cognitive, and effective point of view [6, 7]

Body image disorder is defined as an alteration of the way in which the subject lives own body [8], characterized by an exaggerated relationship between external appearance and perceived self-esteem [9].

A disorder of body image can lead to the development of anxiety, depression, social inadequacy, and sexual dysfunction. The sense of belonging of the body depends on afferent sensations regarding our own body [10], but also on sensory inputs and cognitive representation we have of body [11].

The representation of body image is based on the multisensory integration of body signals [12]. Specific multisensory brain areas appear intrinsically linked with the immune system, and studies indicate that immune-mediated diseases such as multiple sclerosis (MS) could compromise multisensory integration, potentially interfering the representation of the body image [13].

Furthermore, it would appear that these areas may also influence the possible development of body self-consciousness disorders (BSC). Considering the high incidence of sensory-motor disorders, pain, and cognitive disorders following MS in the study by Nava et al. [14], the BSC was investigated through the use of the rubber hand illusion paradigm.

✉ Marcella Di Cara
mdi.cara@libero.it

¹ IRCCS Centro Neurolesi “Bonino Pulejo”, S.S. 113 Via Palermo, C.da Casazza, 98124 Messina, Italy

² Department of Biomedical and Dental Sciences and Morphological and Functional Imaging, University of Messina, Via Consolare Valeria, Messina, Italy

Patients with MS may have disorder in representation of body image, which contributes to neurological disability, psychological distress, and reduces quality of life [15]. The incidence of body image alteration reported by MS patients is not yet clear [16], and it is not yet known whether this pathological process is associated with the disease [17].

In addition, it has been shown that increased dissatisfaction with body image affects personal value and sense of self, leading to lower self-esteem and high depression and more frequent sexual dysfunction. In fact, a positive correlation between body image and sexual satisfaction was found [18].

This descriptive review focused on studies that investigated the representation of body image in patients with MS and examined all evaluation methods used for this purpose.

Method

Search strategy

A descriptive review was conducted on the measures of body image used by the MS patients. Studies were identified by searching on PubMed (1987, year of the first-related published article, 2017) and Web of Science databases (2000–2014). The search combined the following terms: “body image AND body esteem AND multiple sclerosis AND sexual disorder” (“body image” [MeSH Terms] OR (“body” [All Fields] AND “image” [All Fields]) OR “body image” [All Fields]) AND (“human body” [MeSH Terms] OR (“human” [All Fields] AND “body” [All Fields]) OR “human body” [All Fields] OR “body” [All Fields]) AND esteem [All Fields]) AND (“multiple sclerosis” [MeSH Terms] OR (“multiple” [All Fields] AND “sclerosis” [All Fields]) OR “multiple sclerosis” [All Fields]) AND (“sexual behavior” [MeSH Terms] OR (“sexual” [All Fields] AND “behavior” [All Fields]) OR “sexual behavior” [All Fields] OR “sexual” [All Fields]) AND (“disease” [MeSH Terms] OR “disease” [All Fields] OR “disorder” [All Fields])).

The search terms were identified as title and abstract (Fig. 1). We have selected only English texts and all articles were evaluated based on title, abstract, and text after duplicates had been removed. Studies that examined the concept of body image in patients diagnosed with MS were included after they fulfilled the following criteria:

- Publication of peer-reviewed research
- The sample population included patients with MS; data that compared MS patient performance and health controls (HC) or other diseases

Result

Of the 316 studies identified, only 9 studies have met the inclusion criteria. All studies have expected the association between body image representation and multiple sclerosis, focusing on concepts such as self-esteem and sexual disorders.

For the purposes of this review, we have divided the studies according to the construct examined and the tools used. In particular, we have identified different measures to evaluate: the representation of the body image; the body image as a predictor of sexual disorders; the self-esteem linked to your body; and the support received and perceived.

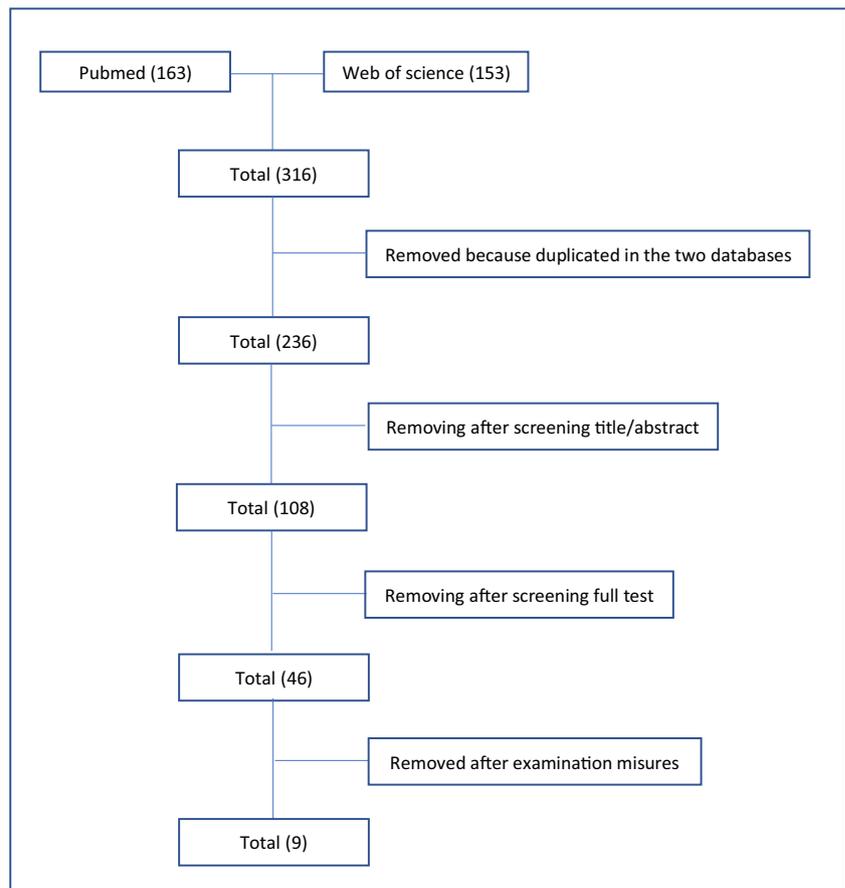
Measure body representation in patients with multiple sclerosis

Many data in the literature have focused on cognitive and physical disability resulting from MS. However, only very few studies have investigated the representation of body image and related constructs in these patients.

Measure body image

Samonds et al. [19] conducted a longitudinal study of 20 male patients with MS to examine the relationship between body image and the severity of a physical disability. The satisfaction or dissatisfaction with their body was assessed by two scales, the Body Cathexis Scale (BC) and Self-Cathexis Scale (SC). Kurzke’s Status Disability Scale was used to rate the physical disability of the subject. The results showed that subjects with greater disability have higher scores on the BC and SC scale. The disease duration and the slow progression of disability give to the individual more time to adjust, realize potential and have greater satisfaction in them self.

A similar study, with 40 MS patients, has examined different aspects of body image disturbances considering the disability status as well as depressive symptoms [17]. The body image was analyzed using the questionnaire on assessment of one’s body and the questionnaire on body image. The first questionnaire investigates the body concepts of psychosomatic patients. It consists of 52 items divided into 4 factors: attractiveness, accentuation of external appearance, worry about possible physical deficits, and sexual problems. The second questionnaire assesses body image disorders through the concept of “body.” The latter comprises 20 items divided into two factors, including negative body judgment and vitality. The Beck Depression Inventory-II (BDI-II) was used to assess the presence of mood changes on the depressive side. Medical parameters such as the state of global disability were also evaluated.

Fig. 1 Search and selection of eligible articles

Patients with MS, in comparison to HC, described negative feelings about their body, showing greater insecurities and concerns about possible physical problems.

These patients also described sexual problems in a more significantly way than healthy controls, which involved sexual dissatisfaction. These problems were particularly evident in male patients. Moreover, there was a significant correlation between BDI-II scores and almost all body image parameters (worse mood, worse body image).

Kindrat et al. [20] investigated how females perceive their body image with MS and examine a potential relationship between body image and depression. A sample of 30 females completed a demographic questionnaire, the Body Image Ideals Questionnaire (BIQ) and the Beck Depression Inventory-Short Form (BDI-SF). The data suggested that the body image perceived by these females is good; however, a significant correlation between it and depression was found. This correlation is consistent with the literature, which shows that fatigue, indecision, social retreat, and body image are highly interconnected [21].

Nava et al. [14] used the illusion of a rubber hand to evaluate changes in body image of 26 patients with a relapsing-remitting type of MS. The result of this study showed that only the component of autolocalization of body consciousness is altered in subjects with MS, while the subjective sensation,

i.e., the sense of body property, is maintained. The autolocalization component is based on multisensory interactions and allows to melt the real hand and rubber together. This difficulty in MS patients may result from an alteration of the multisensory component because of damaged myelin. The illusion of the rubber hand has often been evaluated in patients with stroke, showing the presence of stronger illusory effects. This is probably because the more focal lesion may promote a brain reorganization that leads to an abnormality of multisensory inputs influencing body representation. On the contrary, degenerative lesions of the white matter mainly interrupt the transmission and interaction of sensory-motor signals necessary to locate the body in space. It should be noted, however, that the patients evaluated by Nava's study did not have severe motor disabilities, unlike the stroke patients tested in previous studies. This underlines the important role of movement in the development and maintenance of a coherent sense of bodily property.

Body image was also studied through sexual dysfunction (SD), which is a common symptom often present in patients with MS.

Kolzet et al. [22] assessed the correlates of sexual dysfunction related to altered body image, considering as variables the sociodemographic data, mental health, time spent in the diagnosis, and the state of self-reported disability. Four thousand

two-hundred and sixty-seven people completed the questionnaires for all variables of interest. The sum of the physical and mental component (PCS/MCS) of the short form (SF)-12 version 2 questionnaire was used to assess the quality of life of patients. Another tool used in this study is a 9-point self-assessment scale for the severity of disability, the Patient Determined Disease Steps (PDDS). Finally, The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19) was administered. In this questionnaire, the seventh item “feeling my body is less attractive” was used to measure body image in relation to sexual dysfunction.

The results showed statistically significant correlations between SD and body image, related to age, employment, gender, mental health, and global disability. Mental health, age, time spent in diagnosis, and overall disability were found to be predictive factors influencing body image related SD. In particular, in this study, mental health emerged as the most important predictor. The psychological effects of this loss can negatively affect the sexual activity or patient satisfaction and need to be addressed in treatment to improve health and quality of life.

Another study [23] evaluated sexual functions related to body image in patients with Huntington’s disease and 27 patients with MS. The standardized questionnaires included the PFB, a questionnaire for the evaluation of marital relationships; the FBK, a questionnaire for the perception of one’s own body image; German version of the Relationship Assessment Scale (ZIP) for the measurement of relational satisfaction; Tu`bingen Scales for Sexual Therapy (TSST), which includes items for different aspects of the sexual experience. The results of the semistructured interview showed that only 38% of patients with MS experienced higher levels of sexual function, and only 57% felt physically satisfied. As regards the perception of their body image, MS patients showed higher levels of insecurity. They also showed more problems in marital relationships and indicated that partners were less willing to meet their wishes. In general, patients with MS showed higher levels of sexual dysfunction, with less desire and initiative, showing less perception of their body image.

Sexual dysfunction in MS patients was influenced by three factors in this study: (a) neurological changes in sexual responses and stimuli; (b) physical changes that affected sexual responses; (c) psychological, emotional, social, and cultural aspects that negatively impact sexuality by changing the perception of the body image.

With reference to the body image, it is also very important that the construct of the esteem of their body plays an important role in people with physical disabilities.

Shirvani et al. [24] examined the relationship between body esteem, self-esteem, and the social support perceived in 395 patients with MS. A body estimation questionnaire, which contains 13 general sentences, using on a five-point scale. Appropriate body esteem is determined by total score of body esteem and total mean body esteem score. Total scores rang 13–65 in which closer scores to 65 reveal higher body esteem.

The spouse used a Nordhouse questionnaire, in which five sections were provided, to evaluate the support received by patients. In addition, the Rosenberg self-esteem questionnaire was used. This last contains ten general phrases to be answered on a 4-point Likert scale. The results showed that body estimation in patients with MS is appropriate, with an inverse association between body estimation and age. Furthermore, an association between body esteem, self-esteem and the perception of social support has been found.

Wilski et al. [25] evaluated whether specific sociodemographic, clinical, and sociopsychological factors are related to body esteem in 185 females with MS. The tools used were body estimate scale (BES); the Rosenberg self-esteem scale (RSES); the multiple sclerosis impact scale (MSIS-29); the perception questionnaire (B-IPQ); the actual support scale received (part of the Berlin social support scale); and the extended disability scale (ED). Results showed a positive correlation between body estimate and general self-esteem that was analyzed and found. Two sociodemographic variables (age, occupation status); two clinical variables (physical condition, subgroups of disability EDSS⁺); and ten sociopsychological variables (psychological condition, support received, disease consequences, timing, personal control, treatment control, identity of disease, disease concern, disease understanding, and emotional representation of disease) were found to be significantly related to body estimate scores.

A good psychological condition is undoubtedly associated with a more positive self-image, both in healthy people and in people with different disabilities [26].

In another study [27], self-esteem and body esteem were examined to clarify the possible psychological disability and the relationship with self-esteem, physical, and sexual attractiveness on a group with RR MS. Data was examined by comparing the BES and the Eysenck Self-Esteem (ESES) scale with age and sex. The results showed a significant decrease in the estimation of their physical condition for both sexes. This is probably related to the physical disability in MS patients. On the contrary, sexual attractiveness was not perceived as reduced, which contradicts the initial assumption that patients with MS refuse to engage in sexual activity if they felt unattractive and repugnant. Psychological compensation, through denial or reaction mechanisms, can play a role in this population to cope with the disease. Indeed, it may be assumed that disability is the main factor that contributes to lowering the levels of esteem for one’s body.

Discussion

MS is a chronic demyelinating autoimmune disorder affecting the central nervous system and damage the myelin sheaths around nerves, leading to inflammation, myelin loss, and axonal destruction [28]. It is estimated that MS affects 2.5

million people worldwide, and it is the most common cause of neurological disability among young people aged between 20 and 50 years [29]. Moreover, MS is associated with a greater loss of quality of life compared with other neurological diseases [30].

Patients with MS are a heterogeneous group and the disease differs in duration of symptoms, physical disability, and site of injury [31]. MS is often characterized by cerebral atrophy and lesions can be present in both gray and white matter. In addition, there are numerous changes in brain activity and connectivity [32]. Several studies [33] have shown that white or gray matter damage correlates with a worsening of motor performance (particularly locomotion; [34]), and the interruption of critical white matter tracts can lead to reduced functional connectivity between cortico-cortical and cortico-subcortical cognitive processing regions, resulting in impairment of specific cognitive domains [35]. Such deficits, together with the presence of possible sexual dysfunction, pain, and depression [36], may adversely affect the structure of the body image [37], which includes satisfaction with appearance, concern for one's own body and the social well-being [38].

In particular, it would appear that immune-mediated demyelination, stopping the exchange of information within multisensory brain areas, and between these areas and the body, can alter the representation of the body image, influencing the self-localization component and leaving the sense of body property unchanged. The latter requires additional top-down processes, which seem more resistant to multifocal damage caused by MS. In fact, degenerative lesions of MS caused by white matter mainly interrupt the transmission and interaction of sensorimotor signals necessary to represent the body image.

However, it is necessary considerer that the construct examined, in according to the literature, is also associated with body esteem and social support in MS patients, indicating that this is an important factor that should be considered during interventions to increase body esteem. The studies also showed that younger and more employed women are represented with higher levels of overall body esteem than older and unemployed patients.

We have seen how the construct of body image is closely linked to identity, self-esteem, attractiveness, sexual functioning, and social relations.

It has been observed that in the case of disabilities, as in the case of multiple sclerosis, it is difficult to adapt the right concept of body image because the individual may have preconceived ideas of future disabilities that may occur. It has been shown that due to disability, changes in physical appearance can significantly have an impact on mental representation of body image [39].

In addition, body image has also been assessed in relation to sexual dysfunction, showing how the gender most affected is the female gender, where there is a greater chance of

suffering from depression and a lower perception of self-esteem due to dissatisfaction with one's body image [40].

Sexual functioning and body image are important aspects of psychosocial functioning and can have a significant impact on quality of life, depression, anxiety, and stress.

Even patients with mild and not strongly depressed disabilities can have body image problems (which mainly concern their body esteem, sexuality, and fear of physical deficit). The body is considered one of the main parts of its identity. In fact, people's opinion on their body image is the result of a perception of their "I"; and when they are not satisfied with their body, their general evaluation also changes [41]. In particular, it is possible to hypothesize that since it is primarily a subjective experience and therefore a dimension of mental representation; this may tend to change into degenerative pathologies that may lead to disability. Most body image research overlooks the psychological importance of these assessments, assessing only the physical attributes [42]. These problems should be better addressed through appropriate psychological interviews, encouraging the patient to accept support. Although psychological treatment can lead to several quality of life benefits, only a small number of MS patients consult a psychologist [5]; Praise, 2010).

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was not necessary because the present study consist of a literature revision.

Abbreviations MS, multiple sclerosis; HC, health controls; BC, Body Cathexis Scale; SC, Self-Cathexis Scale; BDI-II, Beck Depression Inventory-II; BIQ, Body Image Ideals Questionnaire; BDI-SF, Beck Depression Inventory-Short Form; SD, sexual dysfunction; PCS/MCS of the SF-12, Physical/Mental Component Summary of the Short Form-12; PDDS, Patient Determined Disease Steps; MSISQ-19, The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19; ZIP, German version of the Relationship Assessment Scale; TSST, Tübingen Scales for Sexual Therapy; BES, body estimate scale; RSES, Rosenberg self-esteem scale; MSIS-29, multiple sclerosis impact scale; B-IPQ, perception questionnaire; ED, extended disability scale; ESES, Eysenck Self-Esteem

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

References

1. Cash TF, Pruzinsky T (2004) *Body image: a handbook of theory, research, and clinical practice*. Guilford, New York
2. Schilder P (2013) *The image and appearance of the human body*, vol. 163. Routledge
3. Slade PD (1994) What is body image? *Behav Res Ther* 32(5):497–502

4. Tsakiris M (2010) My body in the brain: a neurocognitive model of body-ownership. *Neuropsychologia* 48(3):703–712
5. Price B (1990) A model for body-image care. *J Adv Nurs* 15(5):585–593
6. Posavac SS, Posavac HD (2002) Predictors of women's concern with body weight: the roles of perceived self-media ideal discrepancies and self-esteem. *Eat Disord* 10(2):153–160
7. Strauss RS (1999) Self-reported weight status and dieting in a cross-sectional sample of young adolescents: National Health and Nutrition Examination Survey III. *Arch Pediatr Adolesc Med* 153(7):741–747
8. Connors J, Casey P (2006) Sex, body-esteem and self-esteem. *Psychol Rep* 98(3):699–704
9. Lewis JS, Kersten P, McCabe CS, McPherson KM, Blake DR (2007) Body perception disturbance: a contribution to pain in complex regional pain syndrome (CRPS). *Pain* 133(1–3):111–119
10. Tsakiris M, Hesse MD, Boy C, Haggard P, Fink GR (2007) Neural signatures of body ownership: a sensory network for bodily self-consciousness. *Cereb Cortex* 17(10):2235–2244
11. Tsakiris M, Haggard P (2005) The rubber hand illusion revisited: visuotactile integration and self-attribution. *J Exp Psychol Hum Percept Perform* 31(1):80–91
12. Serino A, Alsmith A, Costantini M, Mandrigin A, Tajadura-Jimenez A, Lopez C (2013) Bodily ownership and self-location: components of bodily self-consciousness. *Conscious Cogn* 22(4):1239–1252
13. Costantini M (2014) Body perception, awareness, and illusions. *Wiley Interdiscip Rev Cogn Sci* 5(5):551–560
14. Nava E, Mattioli F, Gamberini C, Stampatori C, Bellomi F, Turati C, Bolognini N (2018) Altered bodily self-consciousness in multiple sclerosis. *J Neuropsychol* 12(3):463–470
15. Chiaravalloti ND, DeLuca J (2008) Cognitive impairment in multiple sclerosis. *Lancet Neurol* 7(12):1139–1151
16. Moseley GL, Flor H (2012) Targeting cortical representations in the treatment of chronic pain: a review. *Neurorehabil Neural Repair* 26(6):646–652
17. Pfaffenberger N, Gutweniger S, Kopp M, Seeber B, Stürz K, Berger T, Günther V (2011) Impaired body image in patients with multiple sclerosis. *Acta Neurol Scand* 124(3):165–170
18. Cash TF, Santos MT, Williams EF (2005) Coping with body-image threats and challenges: validation of the body image coping strategies inventory. *J Psychosom Res* 58:191–199
19. Samonds RJ, Cammermeyer M (1989) Perceptions of body image in subjects with multiple sclerosis: a pilot study. *J Neurosci Nurs* 21(3):190–194
20. Kindrat S (2007) The relationship between body image and depression in women diagnosed with relapsing remitting multiple sclerosis. *Can J Neurosci Nurs* 29(1):8–13
21. Minden SL, Orav J, Reich P (1987) Depression in multiple sclerosis. *Gen Hosp Psychiatry* 9(6):426–434
22. Kolzet J, Quinn H, Zemon V, Tyry T, Marrie RA, Foley FW, Flood S (2015) Predictors of body image related sexual dysfunction in men and women with multiple sclerosis. *Sex Disabil* 33(1):63–73
23. Reininghaus E, Reininghaus B, Fitz W, Hecht K, Bonelli RM (2012) Sexual behaviour, body image, and partnership in chronic illness: a comparison of Huntington's disease and multiple sclerosis. *J Nerv Ment Dis* 200(8):716–720
24. Shirvani M, Ali Sheikhi R, Heidari M, Ghodusi M (2016) The relation between body esteem with self esteem and perceived social support in multiple sclerosis patients—assessment. *NJIRM* 7(1)
25. Wilski M, Tasiemski T, Dąbrowski A (2016) Body esteem among women with multiple sclerosis and its relationship with demographic, clinical and socio-psychological factors. *Int J Behav Med* 23(3):340–347
26. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Cash SM, Kaiser J (1995) Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. *Rehabil Psychol* 40(2):95–110
27. Barak Y, Lampl Y, Sarova-Pinchas I, Achiron A (1999) Self and body esteem perception in multiple sclerosis. *Behav Neurol* 11(3):159–161
28. Koutsouraki E, Costa V, Baloyannis S (2010) Epidemiology of multiple sclerosis in Europe: a review. *Int Rev Psychiatry* 22(1):2–13
29. Higuera L, Carlin CS, Anderson S (2016) Adherence to disease-modifying therapies for multiple sclerosis. *J Manag Care Spec Pharm* 22(12):1394–1401
30. Sharac J, McCrone P, Sabes-Figuera R (2010) Pharmacoeconomic considerations in the treatment of multiple sclerosis. *Drugs* 70(13):1677–1691
31. Rahn K, Slusher B, Kaplin A (2012) Cognitive impairment in multiple sclerosis: a forgotten disability remembered. In: *Cerebrum: the Dana forum on brain science*, vol. 2012. Dana Foundation
32. Tomassini V, Matthews PM, Thompson AJ, Fuglø D, Geurts JJ, Johansen-Berg H, Palace J (2012) Neuroplasticity and functional recovery in multiple sclerosis. *Nat Rev Neurol* 8(11):635
33. Dineen RA, Vilisaar J, Hlinka J, Bradshaw CM, Morgan PS, Constantinescu CS, Auer DP (2009) Disconnection as a mechanism for cognitive dysfunction in multiple sclerosis. *Brain* 132(1):239–249
34. Peterson DS, Fling BW (2017) How changes in brain activity and connectivity are associated with motor performance in people with MS. *NeuroImage*
35. Guimarães J, Sá MJ (2012) Cognitive dysfunction in multiple sclerosis. *Front Neurol* 3:74
36. Mohr DC, Cox D (2001) Multiple sclerosis: empirical literature for the clinical health psychologist. *J Clin Psychol* 57(4):479–499
37. Gutweniger S, Kopp M, Mur E, Günther V (1999) Body image of women with rheumatoid arthritis. *Clin Exp Rheumatol* 17:413–418
38. Thompson JK (2004) The (mis) measurement of body image: ten strategies to improve assessment for applied and research purposes. *Body Image* 1(1):7–14
39. Rumsey N, Clarke A, Musa M (2002) Altered body image: the psychosocial needs of patients. *Br J Community Nurs* 7(11):563–566
40. Leopold JS (2003) The direct and indirect effect of body image on sexual satisfaction
41. Farnam A, Marashi F, Sana'nama M (2017) The relationship of body image with emotion regulation, stress, and aggression and their comparison between males and females with multiple sclerosis. *Jundishapur J Chronic Dis Care* 6(3)
42. Cash TF, Pruzinsky TE (1990) *Body images: development, deviance, and change*. Guilford, New York