Body Image in active and sedentary people with multiple sclerosis

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ABSTRACT

Objective: The aim of this research was to evaluate perceptive and attitudinal aspects of body image among people with multiple sclerosis, and the differences between these variables among active and sedentary people. **Method:** This study was descriptive, exploratory, and cross-sectional. The sample was composed of 26 volunteers, with Expanded Disability Status Scale (EDSS) up to 6. Software for Perceptual Assessment, *Adaptive Probit Estimation*, Appreciation Scale of Own Body, Symptom scale, and a demographic questionnaire were the scales used to collect data. Nominal data were submitted to a descriptive analysis and interval data were submitted to inferential analysis. **Results:** The main results indicate accuracy in body perception, with high sensitivity to body change - the active people being the more sensitive. Also, 73% were dissatisfied with their appearance and tingling pain was the most frequent complaint. There was no association between dissatisfaction with body parts and painful body parts, and the reasons for their being dissatisfied were mostly esthetic. **Conclusion:** We concluded that regular physical activity seems to contribute to enhancing body perception, but not body satisfaction. In its turn, pain was established as a real fact - however, apart from physical appearance, indicating for health professionals who work with this clinical group that appearance and body function are distinct elements of body identity, and both have an impact on the subject relationship with its body.

Keywords: body image, multiple sclerosis, pain

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INTRODUCTION

Multiple sclerosis (MS) is a chronic disease of unknown origin, more frequent in women, with its usual onset in early adulthood. There are multiple lesions in time and space characterized by areas of inflammation, demyelination, and formation of glial scars (multiple sclerosis) in the white substance of the central nervous system (CNS). The clinical manifestations are related to the CNS areas involved. Among the symptoms observed in MS are the sensory and motor deficiencies, fatigue, depression, eye disturbances, impaired vision, cerebellar dysfunctions (ataxia, tremors, and dysarthria), and vesical, intestinal, and sexual dysfunctions.[1]

Although there is currently no cure for the disease, medication can favorably alter the natural history of the disease. A multidisciplinary approach is also fundamental to guarantee good quality of life to those afflicted by MS. In this context, the impact of physical activity on the health of this population has been much studied, and the results from research represents a coherent guiding basis for the proposals of new interventions and conduct modifications related to practicing exercises.[2,3]

The bibliographical review made by Furtado & Tavares[4] gathered evidence that favors the practice of physical activity for people with multiple sclerosis, with light to moderate degrees of impairment. The programs developed have included muscle strengthening exercises, aerobic exercises, activities in water, and yoga. Exercising has brought a positive outcome in functional aspects, in the execution of daily life activities, in the reduction of fatigue, and in the quality of life of the participants. Group training promotes social interaction among the participants and reduces depression. The exercises are shown as safe however, it is important to adopt basic care and adaptations coherent with the individual needs of each patient. Thus, excessive increases in the body temperature must be avoided, and the functional affliction of each patient must be well known by the instructor.

Body image encompasses all the forms by which a person experiences and conceptualizes his or her own body. It is connected to an integrated cerebral organization, influenced by sensory factors, a development process, and psychodynamic aspects. But it is not only a cerebral organization in operation. Though dependent on a circumscribed organic structure, body image can be understood as a singular phenomenon, structured in the context of the body experience of every human being, in a universe of inter-relations between Body Images. Body image includes conscious and unconscious aspects that are inter-related and interact with the external world every moment, giving body image a variable and dynamic character. From this perspective, the varied aspects - social, physiological, psychological, and environmental - connect in an integrated form in experiences of perception of our body as a whole that is, it forms our body image.[5-7]

As pointed out by Cash,[8] function and appearance mold our lives. This is because these two aspects deeply affect the way others react to our body, how we interact with our social world and how we, as individuals, perceive and relate with our own body. The body image of people with deficiencies is modeled by perceptions that emerge from a special context.

Body image modifications that occur after a cerebral lesion are derived from it, but also from the perceptual experiences stemming from the dysfunction. And these experiences are dependent on the body's reaction that is trying to preserve its identity. This body reaction is different for each person, and it is related to personal history and to the circumstances of the trauma. It can be modified by current body experiences, which have different meaning for each person. The multiple loss in functional systems, alterations in appearance, and the unpredictability of the disease flair-ups modify the body experiences of people afflicted by Multiple Sclerosis. In the development process of body image, this population faces a double challenge in their daily lives: to recover functions - when possible - and to accept losses - when inevitable.[7,9,10]

For the professional who works with body movements, it is important to have consistent knowledge of the impact that his or her proposals for physical activity would have on the body experience of each patient and to have the resources available to allow them to evaluate this question coherently.[4]

Body image is the representation of body identity. Body experiences are fundamental in the development of body identity, and the practice of physical activities can be someone's source of meaningful body experiences. The objective of this study was to evaluate the body image in its perceptual and attitudinal dimensions in people from the *Grupo de Esclerose Múltipla de Campinas - GEMC* (Multiple Sclerosis Group of Campinas), and to compare the data obtained from those subjects who practiced physical exercises regularly with the data from subjects who did not practice physical exercise regularly.

METHOD

This transversal research of a descriptive and exploratory nature was initiated with the approval of the Research Ethics Committee from the *Universidade Estadual de Campinas - Unicamp* (Campinas State University - Unicamp) (Opinion 642/2005).

Sample

All the GEMC members were invited to participate in this study either through emails or during monthly GEMC meetings, and those who showed an interest in the research were contacted again by telephone. Currently, there are 210 people with Multiple Sclerosis associated with the GEMC, with an average of 50 people participating in the monthly meetings. Twenty-six (26) people volunteered to come to the Body Image Laboratory at the Physical Education College from Unicamp for the data collection.

The average age of the sample was 46.65 ± 10.52 years, the average weight was 71.53 ± 16.41 kg, and the average height was 1.67 ± 0.09 meters. The average value of body mass index (BMI) was 25.22 ± 4.55 kg/m^2, with 57.7% of the sample being eutrophic. The diagnosis of multiple sclerosis had been given, on average, 7.84 ± 5.89 years before, and the average value for EDSS (Expanded Disability Status Scale) was of 3.23 ± 1.7, with 53.8% of the sample of the EDSS range between 0 and 3 points. Half of the sample was retired or on work leave, while the remaining participants were active in the work market. As for physical activity, 46.2% of the sample exercised regularly. Of the total, only 5 volunteers were male.

Instruments

Software for perceptual assessment (SPA):[11] software developed by the Body Image Laboratory (PEC/UNICAMP). The software has been validated with males and females between 18 and 59 years old, from the most varied levels of education and clinical conditions, including eating disturbances. For this study we used the second part of the test, where the satisfaction with the body is verified, given by the distance between the size/shape of the body that the subject has and the size/shape of the body the subject would like to have. The SAP

adjustments were made following the instruction: "adjust your image on the screen so that your body becomes the way you would like it to be". For the operation of this instrument, a digital video camera was used that captured the images and transmitted them to a digital projector that projected them full size on a white screen.

Adaptive probit estimation:[12] this instrument, created under a psychophysical approach to perception, allows one to identify two components of perception separately, deploying them in measurements: the point of subjective equality (PSE), which refers to the non-sensory component, and the differential threshold (DT), which refers to the sensory component. Using a picture taken with a digital camera of the whole body of each volunteer, 5 sets of 40 pictures were shown for adjustments. Following the instructions of the author, the PSE is the independent measurement of the estimation of the body size, while the DT is the measurement of sensitivity in detecting alterations in the body size. At the end of the test we asked if any specific area of the body had been chosen to guide the choices of images.

Body Appreciation Scale and Symptoms Scale:[13] this consists of a before and a after silhouette of the body, with female and male versions. In the appreciation scale, the subjects must mark on the silhouette the points of their body that they do not appreciate and describe the reason for the dislike. In the symptoms scale, the subjects must mark where they feel pain and then describe this pain.

Demographic questionnaire: in a questionnaire prepared especially for this study, the volunteers filled in their data on age, gender, occupation, time of diagnosis, and habits in the practice of physical activity. In this instrument the EDSS scores were registered, along with weight and height after the clinical evaluation.

Procedures

Individual appointments were made with the subjects for the collection of data. After their signing of the Free and Informed Consent Form, the volunteers were taken to the projection room, where the body satisfaction test was given. In another room, the volunteer took the perception test. Afterwards, under the guidance of researchers, they filled in the appreciation and symptoms scales. The last stage was the filling in of the demographic questionnaire and the clinical evaluation. The total collection time varied from 50 to 90 minutes.

Data analysis

Before the data analysis, we evaluated the occurrence of lost data, atypical to the data distribution, applying the Shapiro-Wilks normality test. In addition to these descriptive tests, we used the Spearman correlation test for the non-parametric data and the Pearson test for the parametric data. We also used the Mann-Whitney variability tests for the non-parametric tests, and the *Student-t* test for the parametric data in the statistical analysis. For all the tests the confidence interval of 95% was adopted. Version 14 of the SPSS software was used.

RESULTS

Perception of the Body

The results indicate that the sample had the average value of estimating the size of the body - determined by the PSE - of -0.04% ± 7.27%. This allows us to affirm that the sample has a very accurate perception of their body size, with a negligible tendency to underestimate their size. Table 1 shows the results for the PSE between those who practice physical activities regularly and those who do not.

There was no significant difference between those who practiced physical activities regularly and those who did not in the perception of body size (U = 66.00, N_1 = 12, N_2 = 14, p = 0.374).

As for sensitivity in detecting alterations in their body size, given by the DT, only an alteration of 2.90% ± 3.41% was necessary to occur in the image for the participants to notice, which indicates that the volunteers were very sensitive to alterations in their body (Table 1).

The Mann-Whitney test indicated that the difference between the two groups in their capacity to discriminate alterations in their Image is not significant (U = 51.50, N_1 = 12, N_2 = 14, p = 0.09).

The literature points out that sensory and non-sensory perceptions are independent of each other, which is why the researcher must expect the absence of any correlation between them. Actually, this was confirmed in our data (rho = 0.089, N = 26, p = 0.69) and no other significant correlation was found among the components of the body perception - PSE and DT - and the other variables analyzed: their age, BMI, EDSS, time of diagnosis, and body dissatisfaction. The body region most commonly chosen to guide the adjustment of the tests was the hip area, chosen by 60.8% (n = 16).

Body Satisfaction: the whole body

The measurement of dissatisfaction with the body was given by the percentage difference between the size/shape of the body the subject has and the size/shape of the body the subject would like to have. The data obtained in the SPA indicated an average dissatisfaction in the sample of -10.30% ± 1.40%, indicating that on average, the sample subjects wished to be smaller and thinner. Examining the cases, it was confirmed that none of the volunteers was satisfied: 21 (76.9%) of the volunteers wished to be thinner, and 5 (23.1%) of them wished to be fatter (or stronger, as worded by the males).

The t test indicates no significant difference between those who practiced physical activities and those who did not in regards to satisfaction with their bodies (t = 0.275, df = 24, p = 0.394). The dissatisfaction with the body correlated negatively with the BMI (rho = -0.395, N = 26, p = 0.04).

Body Satisfaction: parts of the body

Through the body appreciation scale, it was possible to localize the areas of dissatisfaction and the reasons for their deprecation. The participants could choose up to 4 parts of their bodies and relate them with the silhouette. For this, in this item, there is the largest number of answers from subjects. The least appreciated parts of the body were the waist (including the parts participants called belly and abdomen), with 32.2% of the answers, and the hip and legs with 10.2% of the answers each (Table 2).

For each part of the body, the subject was asked to give one or more reasons for his or her dissatisfaction. The reasons are centered on esthetic problems. Excess fat, disproportionate size (too small or large), flac-

Table 1. Perception: average values and standard deviation of PSE and DT

	Average PSE	SD	Average DT	SD
Practiced Physical Activity regularly (n = 12)	0.19	4.74	1.63	0.70
Did not practice Physical Activity regularly (n = 14)	-0.24	9.08	3.99	4.38
Total sample (n = 26)	-0.04	7.27	2.90	3.41

cidity, deformities, and scars explain 90% of the reasons for their unhappiness with some part of their bodies. Only 5% of the answers related to loss of function - motor or sensory (Table 3).

We analyzed the association made by the volunteers between the part of the body they chose to make the percentual adjustment on and a specific area of dissatisfaction with the body. We expected a great conjunction of data, for the investment that is usually made when one part of the body is not "perfect". In this way, we pay more attention and alterations to those regions are more easily detected. Indeed, in 46.5% of the sample (n = 12), the part of the body the subjects were not happy with coincided with the body region used to guide the perception test, and for 15.4% of the sample (n = 4) two parts of the body coincided with it.

Pain

On the symptoms scale the participants described the places in which they felt pain and described it. More than one region of the body could be chosen. The head, the lumbar vertebrae, and the legs were the 3 areas most affected by pain, representing a total of 35.7% of the answers (Table 4).

Paresthesia is the most recurrent description of pain, in a total of 24.6% of the pain descriptions. Pains that cannot be described (19.3%), intense and constant pains (10.5%), burning/numbness (10.5%), pains like needles (10.5%), and pains related to posture (10.5%) were also mentioned.

When we cross-reference the data from the areas chosen to guide the perception test and the areas referred to as painful, we see that 73.1% (n = 19) of the sample did not establish one or more painful parts of the body as a central area of attention in the perception test, while 23.1% (n = 6) chose an area of the body in which they felt pain as referential for the adjustments, and only 3.8% (n = 1) established two areas of the body in which they felt pain as referential. Among those who practiced physical activities, 9 did not establish any association between the pain and the perception adjustment, and 3 chose one painful body part as referential. No significant difference was found between the groups regarding this association of the body area chosen to guide the adjustment of the perception test and that in which the subject feels pain ($U = 79.5$, $N_1 = 12$, $N_2 = 14$, $p = 0.82$).

After that, we cross-referenced the data from the figure scale on satisfaction with body areas with areas where the subject feels pain. Most of the sample, 76.9% (n = 20) did not associate areas of dissatisfaction with the body with painful areas of the body (Table 5).

For the two volunteers in which two areas of pain coincided with parts of the body they did not like, the reasons for this dislike were related to functional questions: loss of sensitivity and impaired motor function, despite also being related to esthetic reasons - fat, flaccid - as motive for not liking the other parts of the body not related to pain. No significant difference was found between those who practiced physical activities and those who did not, as for this association of painful parts of the body and dissatisfaction with specific areas of the body ($U = 66.00$, $N_1 = 12$, $N_2 = 14$, $p = 0.37$).

Table 2. Body areas of dissatisfaction

Areas of Dissatisfaction	Frequency	Percentage
Head (including eyes, mouth, nose, ears)	1	1.7
Thorax (chest)	1	1.7
Hair	1	1.7
Hands	1	1.7
Lumbar vertebrae	1	1.7
Neck	1	1.7
Buttocks	2	3.4
Back	2	3.4
None/nothing	2	3.4
Skin	2	3.4
Arms	4	6.9
Feet	4	6.9
Breasts	5	8.6
Hips	6	10.3
Legs (thighs)	6	10.3
Waist (belly, abdomen)	19	32.8
Total	58	100.0

Table 3. Reasons for dissatisfaction with parts of the body

Motives	Frequency	Percentage
It has lost part of its sensitivity	1	1.7
It is too thin, not enough flesh	1	1.7
It is ugly	2	3.3
It has lost part of its motor function	2	3.3
It has scars, marks, or spots	5	8.3
It has deformities (crooked, has callouses)	7	11.7
It is flaccid	8	13.3
It has the wrong size (bigger/smaller than it should be)	10	16.7
It is too fat, it has too much fat	24	40.0
Total	60	100.0

DISCUSSION

This study aimed to identify body image features - in terms of general subjective satisfaction and in the emotional dimension, operating through questions related to pain - among people with multiple sclerosis, seeking also to verify any differences between those who practiced physical activities and those who did not.

As for body perception, on average the subjects of the sample judged their body size accurately. The low values of PSE are lower than those of clinical samples of people with food disturbances and also lower than samples of healthy people.[14,15] In relation to the sensory component of perception, the sampled subjects proved to be quite sensitive to alterations in their body, requiring little alteration in the original image to detect changes. It is noteworthy that the scores from those who do not practice any regular physical activity are higher and significantly different from

Table 4. Parts of the body with pain

Areas of Pain	Frequency	Percentage
Thorax (chest)	1	1.7
Hips	1	1.7
Breasts	1	1.7
Muscles	1	1.7
Intestines	1	1.7
Pelvis	1	1.7
Trigeminal nerve	1	1.7
Thoracic curve	1	1.7
Scapula	1	1.7
Groin	1	1.7
Waist (belly, abdomen)	2	3.4
None/nothing	2	3.4
Cervical vertebrae	2	3.4
Shoulders	3	5.1
Knees	3	5.1
Arms	4	6.8
Back	4	6.8
Hands	4	6.8
Feet	4	6.8
Head (including eyes, mouth, nose, ears)	6	10.2
Lumbar vertebrae	6	10.2
Legs (thighs)	9	15.3
Total	59	100.0

Table 5. Satisfaction and pain in parts of the body

	Frequency	Percentage
There is no association of pain and dissatisfaction area	20	76.9%
One of the areas of dissatisfaction coincides with a painful area	2	7.7%
Two of the areas of dissatisfaction coincide with a painful area	2	7.7%
No correlation between pain and dissatisfaction in any specific region of the body	2	7.7%

the scores of those who are regularly active, which allows us to speculate that the regular practice of physical activity is contributing to improve sensitivity in relation to body changes, for the group that is active could notice even minimal body changes.

As for satisfaction with their bodies, the sample reflects what is seen in the literature, especially among women: a search for thinness. Schwartz & Brownell[16] affirm that young women are consistently more dissatisfied with their bodies than men and that, for overweight women, this risk is even greater. For Striegel-Moore & Franko[17] the expression "normative discontentment" directly describes the situation in which most of the female population is found - experiencing negative feelings about their bodies. Among the 5 subjects whose dissatisfaction with the body occurs for their being smaller/thinner than they really wanted to be, 4 are men. In relation to this, it is known that the ideal male body is not unidirectional to thinness like the ideal female body. The ideal male body is big and muscular, especially the upper part of the body - with wide shoulders and big arms and a low percentage of fat.[18-23]

Congruent with the measurement of dissatisfaction with the whole body, the body parts considered far from ideal - thighs and hips, are considered by the literature as areas related to adipose tissue.[24] Under the dissatisfaction with these specific body parts, the concern with body fat and the search for being thinner is re-confirmed. This statement can be corroborated by the third source of information given by the sample, while declaring that esthetic reasons - those related to size and excess weight - are the most recurrent reasons for dissatisfaction with parts of the body. Regular physical activity does not appear to be a source of compensation for this dissatisfaction with the body, since there were no differences between active and sedentary people.

Pain is established as a real fact, although independent from physical appearance. The sample subjects make no connection between the painful body parts and the parts that provoke dissatisfaction, and consider even less the painful parts as a reference to adjust their body perception. We can infer that function and appearance in the sample operate in parallel and in a relatively independent manner, indicating also that in the clinical handling of these patients, these two components of body identity must be worked.

The limitations of this work regard the sample size, the non-random sampling, and the fact that the data refers to a specific support group - the GEMC. Thus, the data must not be generalized. Future studies must investigate other aspects of body image - body anxiety, drive for muscularity, drive for thinness, appreciation of the body - that our study showed as significant for this group.

CONCLUSIONS

We are aware of and point out that this data must not be generalized; however, considering the absence of research of this kind, we find that the study contributes to a greater understanding of the body identity aspects of people with multiple sclerosis, serving also as an alert so that the questions related to appearance and esthetics be considered in the approach to this population by health professionals in the rehabilitation process, for these issues also have an impact on the identity of the subject.

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