

The effect of illness perception on physical health-related quality of life promotion in multiple sclerosis (MS) patients attending peer support groups

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ABSTRACT

Illness perception influences patients' decision to adopt effective behavior and achieve positive results such as adapting with the disease and improving functionality, and the interventions that increase illness perception can promote health. This study aimed to investigate the effect of illness perception on the physical health-related quality of life of MS patients attending peer support groups. This study with a quasi-experimental before-and-after design included 33 MS patients in three groups: male-only(n=10), female-only(n=11) and one with both males and females (mixed, n=12) that selected by convenience sampling. Participants were required to attend 8 weekly sessions comprising 2 hours each. Instruments used to assess physical health related quality of life and illness perception were the physical health section of "Multiple Sclerosis Quality of Life Inventory (MSQLI)" and "Revised Illness Perception Questionnaire(IPQ-R)" respectively, which were completed by participants before and after attending the group sessions. The results showed that although illness perception of MS patients attending peer support groups did not show a significant increase, physical health significantly improved(p=0.001). Attending peer support group increased illness perception in the mixed group(p=0.01) and elevated physical health in men only and mixed group (p=0.03 for the mixed group and p=0.04 for men only group). Regression analysis showed a significant relationship between MS and physical health with efficacy of 0.54(p<0.001). The results showed that increased illness perception in MS patients improves their physical health. Therefore, we can improve MS patients' physical health-related quality of life through peer support groups and hence promote patients' quality of life.

Keywords: Multiple Sclerosis; Illness Perception; Physical Health-Related Quality of Life; Peer Support Group

INTRODUCTION

Symptoms of MS are unpleasant and disabling and often unpredictable. Symptoms often vary between individuals and their presentation may change over time[1]. In addition, treatment protocols may be problematic, resulting in adverse drug effects and increased physical disability[2]. Considering this, it is clear that improving patients' health, in particular their physical health, is essential.

Illness perception influences patients' decision to adopt effective behavior and achieve positive results such as adapting with the disease and improving functionality, and the interventions that increase illness perception can promote health[2].

Peer support groups have been shown to play a role in health promotion [3]. Peers can reach out to one another, which may allow individuals to cope better with the stress caused by the disease. Furthermore, peer support groups enable knowledge sharing, skill learning and an increased understanding of the disease, all of which may lead to health promotion[4]. Peer support groups often provide very effective communication style for people with problems in life. Groups enable people with the same experience to communicate with one another, share experiences, exchange information about coping and provide opportunities for self-transcendence[5,6].

Although many studies have been conducted on improving patients' awareness of and attitude toward MS in Iran, no studies were

found to focus on the effect of illness perception on physical health-related quality of life through peer support group. Also in Iran, no peer support groups for individuals suffering chronic diseases including MS currently exist. Similarly, there is a paucity of research investigating the effectiveness of peer support groups in MS. Considering this, the current study aimed to investigate the effect of illness perception on the physical health-related quality of life of MS patients attending peer support groups.

MATERIAL AND METHODS

This quasi-experimental intervention study employed a before-and-after design to determine the effect of self-transcendence and peer support groups on physical health related quality of life in MS patients. This study was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences in Tehran, Iran.

Convenience sampling was used for this study. The samples were selected according to the tendency of Tehran MS Association's patients in taking part in the peer support group in 2010 and also their physical condition and ability of speaking. The participants were divided into 3 groups: male-only group, female-only group and one involving both males and females (mixed group), and the effect of cultural differences on the groups were determined. Based on participants' wishes, participants themselves selected their preferred group. It was anticipated that this would allow participants to feel comfortable talking about the topics of interest. Research suggests the optimal group size for health studies is between 8 and 12 participants[3], and as such, each group had 12 participants, which also allowed compensation for possible attrition. Three participants did not attend all sessions due to their clinical condition. The rest of the 33 participants attended all sessions (n=10 in the male-only group, n=11 in the female-only group and n=12 the mixed group).

In cooperation with the MS society of Tehran, the schedule of sessions was developed and provided to the participants during the first session. All participants were provided with transport to enable them to attend the sessions. On the first day of the study, the objectives, data collection methods and regulations of the study were explained to participants and informed

written consent was obtained for all participants. Group meetings were scheduled for 8 weeks[7-9], for 2 hours per week at the MS Society of Tehran central office. If participants were absent, the topics and discussions were explained to participants on the phone by researcher or peers. Being absent for more than two times excluded the participant from the study. During the meetings, participants' feedback regarding the dynamics of the group was evaluated using direct questioning and observation of participant behaviour. The meetings were modified according to this feedback.

The topics focused on during each session were include introduction to the disease and its perception, learning its physical symptoms and their effect on each other, the way to adapt with physical changes and its problems using peers' experiences.

The research instruments used in the study include the following: Revised Illness Perception Questionnaire (IPQ-R): This tool was designed by Moss-Morris et al. (2001). It has 75 statements with scores of 38 to 201, where higher score shows subject's better illness perception. This questionnaire has seven components: identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical, and emotional representations. Moss-Morris et al. reported Cronbach's Alpha Coefficient of 0.79 to 0.89 for this tool[10]. In the present study, a few statements were added, and scoring method of some components was modified with permission from designers and was renamed to MS patients' illness perception questionnaire. In the present study, reliability of the tool was 0.80 for both Cronbach's Alpha Coefficient and Spearman coefficient.

Physical health-related quality of life: The Multiple Sclerosis Quality of Life Inventory(MSQLI) was designed by Paul et al in 1997, sponsored by the Consortium of Multiple Sclerosis Centres and Health Services Research Subcommittee in the United States. The MSQLI contains 138 statements in 10 sections providing a quality of life measure that is both generic and MS-specific. In this study we used the following subscale: the physical section of Multiple Sclerosis Quality of Life Inventory consists of aspects the sections Physical Components Summary Scale (PCS) of Health Status Questionnaire (SF36) plus

Modified Fatigue Impact Scale (MFIS), Pain Effects Scale (PES, Sexual Satisfaction Scale (SSS), Bladder Control Scale (BLCS), Bowel Control Scale (BWCS) and Impact of Visual impairment Scale (IVIS). Physical health has 78 statements with a score of 6–287. Higher scores implied higher physical health. The designers of the tool validated parts of MSQLI and found Cronbach’s Alphas between 0.78 and 0.95[11]. In the present study, Cronbach’s Alpha was 0.91 and Spearman Coefficient was 0.93.

All instruments were used with permission and were translated and adapted to Iranian culture according to guidelines of the World Health Organization. The translation was performed as follows: forward translation to Persian, expert panel to identify and resolve the inadequate expressions/concepts of the translation tool to Persian, back-translation to English by a native speaker of English, pre-testing and cognitive interviewing with patients. All steps were documented and the final version was sent to the designers[12].

The instruments for collecting data were completed by participants before the intervention and one week after it. In the present study, descriptive and inferential statistical methods were used including Wilcoxon and Kruskal–Wallis tests, as well as regression, in order to determine the effect of the variables on physical health quality of life before and after the intervention.

RESULTS

The mean age of the participants was 39.51 ± 11.7 years. Most participants (42.4%) were married, 30.3% were single and %27.3 were divorced or widowed. A total of 45.5% participants had secondary school degree, 42.4% had completed college education and 12.1% had primary school degree. Most participants (57.6%) were unemployed whereas 42.4% were employed. A majority of the participants (60.6%) exercised irregularly, 12.1% exercised regularly and 27.3% did not exercise. Most participants (51.5%) took immunomodular medication for MS whereas 48.5% did not take any medication. None of the participants had a family history of MS. The mean duration of the disease was 14.5 ± 7.5 years and the mean age at onset of the disease was 27.15 ± 15.7 years of age.

Comparing mean scores of physical health-related quality of life showed meaningful difference before and after attending peer support group(p=0.001). Although the mean score of the patients’ illness perception increased, it was not significant. Table-1 shows mean scores of illness perception and physical health-related quality of life of MS patients. The increase in mean score of illness perception in the mixed group was significantly different before and after attending the peer support group (p=0.01), table 2.

Table 1. The comparison of mean scores of illness perception and physical health related quality of life of MS patients before and after attending a peer support groups in 2010

Time of the test Mean scores of	Before intervention Mean (SD)	After intervention Mean (SD)	Comparison of mean scores (Wilcoxon’s test)
Illness perception	129.30(7.8)	133.30(15.7)	Z=1.404 P=0.160
Physical health-related quality of life	151.84 (33.3)	171.58 (37.5)	Z=3.440 P=0.001

Table 2. The comparison of mean scores of illness perception in MS patients before and after intervention based on peer support groups in 2010

Time of the test Peer support group	Before intervention Mean (SD)	After intervention Mean (SD)	Comparison intergroup scores (Wilcoxon’s test)
Women only N=11	133.18(4.6)	134.81(15.4)	Z=4.89 P=0.62
Men only N=10	127(8)	124(14.3)	Z=0.357 P=0.72
Mixed N=12	127.66(9.1)	139.25(14.8)	Z=2.364 P=0.01
Comparison difference of mean scores before and after intervention between groups (Kruskal–Wallis tests)	X ² = 4.127 P=0.12		

The comparison of mean physical health-related quality of life scores before and after attending the peer support group program is presented by group in Table-3, showing that the before and after comparison is significant in the male-only and mixed groups (intergroup comparison) (male only: $p=0.047$, mixed: $p=0.034$). The comparison of scores between groups before and after intervention does not show a

significant difference, and physical health-related quality of life improved in a similar manner.

Regression analysis showed that Physical health may predict illness perception, as indicated by a correlation coefficient $0.54(p<0.001)$. Figure1 demonstrates the relationship between the two variables.

Table 3. The comparison of mean physical health-related quality of life scores of MS patients before and after intervention based on a peer support group in 2010

Time of the test	Before intervention mean (SD)	After intervention Mean (SD)	Comparison intergroup scores (Wilcoxon's test)
Peer support group			
Women only N=11	149.67 (29.1)	172.54 (40.6)	Z=1.778 P=0.075
Men only N=10	130.63 (14.8)	150.30 (38.4)	Z=1.988 P=0/047
Mixed group N=12	171.51(37.9)	188.42(25.4)	Z=2.120 P=0.034
Comparison difference of mean scores before and after intervention between groups (Kruskal-Wallis tests)	X ² = 0.618 P=0.73		

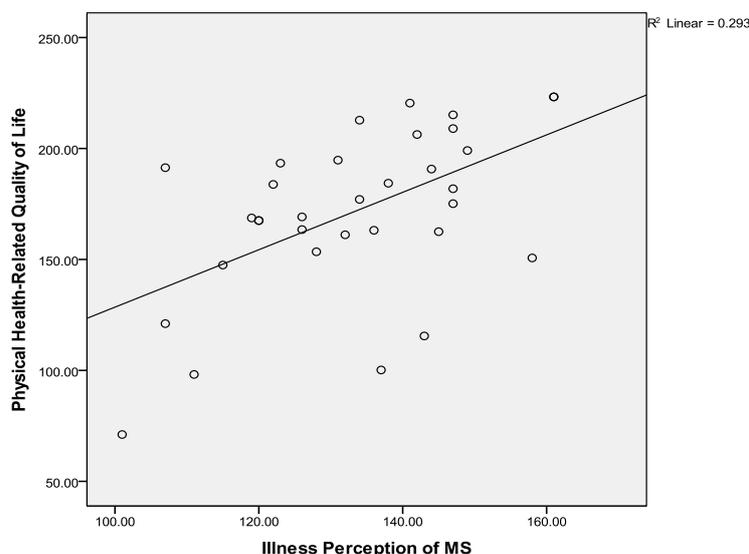


Figure 1. Predicting the trend of physical health-related quality of life based on self-transcendence in MS patients attending a peer support group program in 2010

Among underlying variables (age, gender, marital status, education, employment, immunomodular medication intake, exercise, duration of the disease and age at onset of the disease), only education was found significantly related with MS perception using regression model(coefficient of education=14.53 , $p=0.045$). According to the regression

coefficient, higher education level corresponded with better understanding of MS by 14.5 units.

DISCUSSION

The comparison of mean physical health-related quality of life scores showed a significant difference after attending the peer support group program. Comparison of mean physical health-related quality of life scores

before and after intervention in the men only and mixed groups showed a significant difference, which is in line with findings of similar studies[4,13]. However, Mohr et al(2005) did not find a significant difference in physical health scores[14]. Promotion of physical health-related quality of life following the peer support group program shows the positive effect of this group and the importance of establishing such groups so members can feel they belong to a community. This enables patients to feel comfortable sharing their problems with their peers, as well as reflecting on their successful and unsuccessful experiences. Sharing of positive experiences within the group provides an opportunity to examine the experience and its effect, which may not be found in any published books about the MS. These experiences help patients learn how to reduce their problems and increase their capabilities.

Mean score of illness perception in patients attending peer support group increased. However, it was not statistically significant. Illness perception increased in women only group and mixed group, but decreased in men only group. Matti et al. 2010 showed that training MS patients can improve their perception of the signs and optic nerve inflammation symptoms[15]. Bell et al. (2010) showed that attending peer support group can increase cancer patients' awareness of the disease[16]. Further, Divett et al. (2010) reported that members of lung cancer peer support group are willing to know more about their disease[17]. Van-Ittersum et al. (2011) showed the effect of educational interventions on patients' improved illness perception in fibromyalgia[18].

The present study showed that attending peer support group did not have much effect on illness perception. MS is still an unknown disease for experts and patients. The unpleasant and unpredictable signs, treatment costs, and medication adverse effects are difficult especially for young patients. They always look for ways to treat themselves. The researcher met patients who studied the latest scientific articles. One of the first questions that patients ask is 'Do you know what the latest treatment is?' This has caused patients' illness perception change every day.

Using regression analysis, we found that patients with higher education had a better

perception of multiple sclerosis. The reason might be that people with higher education trust only reliable scientific sources and they seldom trust non-scientific sources. They learn about MS using the latest technology. On the other hand, those without higher education are not aware of scientific studies, and do not know how to validate what they read or hear. That is how they are sometimes cheated by charlatans who claim to cure them completely through different domestic and foreign media. Therefore, it is essential that officials, specialists and therapists inform patients of the cutting edge treatments so that they are not deceived by charlatans.

In the present study, we found that higher illness perception causes higher physical health status. This finding corresponds with those of Spain et al. in 2007[19]. Since physical health status in MS causes the patients to worry of an uncertain future, this finding proves that increased knowledge of MS and how to control and treat it, can help the patient adapt with the disease. Therefore, patient's perception of MS can help patients design and implement health programs to modify their behavior. Also, peer support group is cost effectiveness because it has less cost than MS symptoms due to lack of awareness of illness.

Using an open question at the end of the questionnaire, participants were asked to provide their opinion regarding attending the peer support group program. All participants reported that it had reduced their physical and mental problems significantly. Most of the participants in all three groups complained of not being understood by family, friends and society because of the adverse effects of the disease. They considered it a limitation for themselves, and this was discussed and solutions were suggested in the peer support group.

Examining the dynamics of the groups showed that the women only and the mixed groups were more dynamic and meetings were held without researchers' help, while for the men only group, researchers' efforts were necessary to maintain the schedule of meetings, and participants needed prompting to discuss the topics. This might be explained by gender differences, with women being more extroverted and expressing their problems more freely than men. It appeared that in the mixed group, the gender differences and the need to

emphasize them made the group dynamic. Therefore, it seems that mixed groups can improve group dynamics even in Iran, where women might not normally feel comfortable in mixed groups. It might explain the reason behind increased illness perception in MS patients of the mixed group.

The present study had some limitations. The lack of a control group was a limitation. This was because patients already had strong relationship with the MS society and were recruited through the society's channels. Another limitation was that participants chose which group to attend, which may influence the results. Importantly however, the similar results in all groups indicate a minimal effect of this limitation. Importantly, the instruments contained a large number of statements, often too many for MS patients to complete in a single session without tiring. To solve this problem, the researcher asked the participants to take the questionnaire home and complete it at their convenience. Although filling out questionnaires at home reduces the reliability of the answers, the researcher was obliged to do this for participants' comfort. One of the strengths of this study was that the instruments were translated and culturally adapted.

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CONCLUSION

Social support and social networks create a feeling of belonging and thus may help sufferers of MS adapt better to life events, and decrease the influence of MS on physical and mental health. The findings of this study suggest it would be beneficial to develop nursing interventions for MS patients based on social support and self-transcendence.

The results of the study may be useful for educating all groups of medical science students and also for the clinical management of MS. This study is a first step toward understanding factors that predict physical health-related quality of life in MS patients. MS therapists may also be able to use illness perception and processes to design interventions to improve the physical health-related quality of life of MS patients.

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