Promotion of Self-Transcendence in a Multiple Sclerosis Peer Support Groups

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Abstract

Background: Self-transcendence can organize the challenges of multiple sclerosis patients to achieve and maintain a constant state of well-being and sense of integrity in the disease process. As a research based on self-transcendence didn't done in Iran, the present study was conducted to evaluate the effectiveness of peer groups on promoting self-transcendence level in multiple sclerosis (MS) patients.

Materials and Methods: This study is a before and after quasi-experimental study that was conducted on 33 patients with confirmed MS participated in three peer support groups: 10 men in male group, 11 women in female group and 12 men and women in mixed group. Eight weekly sessions and each session was 2 hours were held. Data collection tool was Self-Transcendence Scale (STS) with 15 item and Cronbach's coefficient was 0.68 that after modifying, it increased to 0.81. Patients completed self administered questionnaires pre- and post of sessions.

Results: Results showed that peer support groups promote the self-transcendence (p=0.001) with increases in mean self-transcendence scores in all 3 groups (men group: 0.006, women group 0.005 and mixed group: 0.003). Comparing scores before and after intervention demonstrated that self-transcendence increased equally in all groups.

Conclusion: The results showed an improving in self-transcendence in peer support group participants at the end of the intervention. The results can be used in areas of nursing education and management. It is proposed that the self-transcendence assessment to be done in other chronic disease in order to evaluate its efficiency.

Introduction

Self-transcendence refers to intangible and invisible conceptual realities [1]. Self-transcendence, according to Reed, is purported to be an evolutionary characteristic that increases an individual’s awareness of their surroundings and provides them with a deeper insight into their lives [2]. Self-transcendence is understood to contribute to building self-esteem and identity [1]. Reed’s Self-Transcendence theory was initially applied in the area of elderly mental health [1, 3]. In the past 2 decades, the term self-transcendence has been widely applied to all life stages, from adolescence to adulthood and old age, and in all cultures including those of American and Asian [2]. The concept of self-transcendence includes extending a person’s boundaries in several dimensions: (A) inwardly, through introspection, self-acceptance, establishing meaning and building purpose; (B) outwardly, through considering others’ welfare and focusing on relationships with others and the environment; (C) temporally, by understanding that the past and future positively affects the present; and (D) transpersonally, through which self-transcendence is achieved at a higher and greater level [1, 2]. Self-transcendence thus aims to extend an individual’s boundaries and to enhance awareness of boundaries beyond oneself. It also addresses internal attitudes and behaviours, relationships with others and oneself, external views and behaviours, feelings of being accepted, having a meaningful life, and living in the present time. Self-transcendence as a developmental talent (perhaps as a survival mechanism) can result from an individual’s experiences of health and disease [2]. Self-transcendence is critical in the personal evolution of self-acceptance, communication with others and the integration of the past and future with the present. When humans transcend limitations, they may consequently feel released from physical or temporal boundaries [4]. In Reed’s opinion, self-transcendence can be obtained via helping others [5] and is developed through processes such as sharing wisdom with others, changing behaviours when one is old or ill, accepting death as a part of life and discovering spiritual concepts [2]. It is thought that nursing interventions can facilitate self-transcendence and achieve the highest level of health by enabling an individual to better mobilize both their own internal resources and the support of others [1]. Chronic diseases even when not life threatening cause patients’ families concern about the future, patients’ current condition and possibility of death. It can be claimed that self-transcendence assists patients facing challenges in maintaining a constant state of well-being and a sense of integrity through the course of the disease [2]. How can self-transcendence improve? Interpersonal approaches using face-to-face contact as
well as the telephone and internet can facilitate self-transcendence, since they focus on the individual’s relationships with others. Peer counselling, informal networks and formal support groups are among the interpersonal approaches that may be provided by nurses for their patients [2]. Peer support groups are usually one of the most effective methods of communication for people experiencing difficult clinical conditions. Groups gather individuals with similar experiences together and facilitate self-transcendence through communication, sharing of experiences, transferring information about adaptive methods and by providing them an opportunity to help one another [2, 6, 7]. A few studies have investigated the impact of nursing interventions on the improvement of self-transcendence. Studies showed that self-transcendence increased in patients with breast cancer [8] and prostate cancer [9] who attending in support groups. Research regarding to relationship between self-transcendence and nursing students’ attitudes towards taking care of older people showed that also self-transcendence has increased before and after creative bonding intervention but it was not significant [10, 11]. Studies also showed that self-transcendence significantly increases self-care and daily activities in chronic diseases [12-14], resilience and purpose in life [15], quality of life in serious diseases [16], and liver transplant patients [17]. In Iran no research has explored the influence of nursing or any other health interventions on self-transcendence. Importantly, there are no documents indicating that peer support groups are being established in Iran. There are currently only self-help groups for drug addicted individuals, who are active all over the country, and their establishment permission is issued by the State Welfare Organization [18]. Considering this, there is a great need to establish peer support groups in Iran, particularly for patients with chronic diseases. Patients suffering from multiple sclerosis (MS) in particular require such groups. MS is a chronic disease that mostly affects young adults, family dynamism, the roles of family members and their lifestyle [19]. It also reduces patients’ abilities to conduct their daily lives in a practical manner [20]. Considering the existing controversies regarding the quality and quantity of nursing interventions and their impact on self-transcendence, as well as the lack of research on self-transcendence in Iran, the present investigation seeks to examine the influence of peer groups on improving self-transcendence in MS patients.

Materials and Methods

This quasi-experimental intervention study employed a before-and-after design to determine the effect of peer support groups on self-transcendence in MS patients. The study was conducted in MS association of Tehran in 2010 and was approved by the Ethics Committee of the Shahid Beheshti University of Medical Sciences in Tehran, Iran. Convenience sampling was used for this study. Patients belonging to the Tehran MS Association were selected according to their desire to take part in the peer support group, as well as their physical condition and ability to speak. To clarify ideological and cultural differences that may affect a group, 3 groups were formed: women, men and mixed (men and women). Based on participants’ wishes, participants selected their preferred group. It was anticipated that this would allow participants to feel comfortable talking about the topics of interest. The most appropriate group size for assessing post-intervention changes is between 8 and 12 participants [21]. Therefore, 12 people were selected for each group. It was thus hoped that there would remain at least 10 individuals in each group if some decided to withdraw from the study. Three participants did not attend all sessions because of their clinical condition and 33 (10 in the men’s group, 11 in the women’s group and 12 in the mixed group) attended all sessions. In cooperation with the Tehran MS Association, the schedule of sessions was developed and provided to the participants during the first session. All participants were provided with transport facilities 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, 22, 23] for 2 hours per week at the central office of the Tehran MS Association.

If participants were absent from a session, the topics and discussions were explained to participants on the telephone by a researcher or peers. Being absent for more than 2 sessions was a criterion for exclusion from the study. During meetings, participants’ feedback regarding the dynamics of the group was evaluated using direct questioning and observation of participant behaviour. Future meetings were modified according to this feedback. Topics to be discussed were determined based on Reed’s Self-Transcendence Scale (STS). According to Reed, the items in STS can be used to develop support groups, education and spiritual discussions in the target group [1].

Topics discussed in this study included adapting to changes associated with MS and its problems, adapting to the current condition, establishing new meaning in life, developing a positive attitude, taking advantage of the experiences and opinions of others and communicating with families and other society members.

Reed’s STS was completed by the participants in the first group meeting and also 1 week after the last session (within 9 weeks). STS consists of 15 items, with the possible total score ranging from 15 to 60 and higher scores indicating a higher level of self-transcendence. Since this tool has not previously been translated into Persian, translation and inter-cultural adaptation was performed to adapt this tool for appropriate use in the Iranian culture. The process was performed as follows:

First, translation permission of the tool was gained from its designer (Reed) via e-mail. Then, according to WHO guidelines [24], the following steps were taken to translate the tool:

1- The tool was translated into Persian by researchers who were familiar with English.

2- Using experts’ views, accuracy of the translation was determined by 10 members of the Nursing Scientific Archive of SID
Board familiar with both Persian and English, and their opinions were taken to further refine the tool.

3- Pre-test and Cognitive interview: The tool was conceptually investigated by 10 male and female MS patients at different ages with education ranging from high school diploma to university degree. Their viewpoints were used in further refining the tool.

4- Back translation: The tool was back translated into English by a native English speaker who was familiar with translating the tool, to ensure the original meaning was maintained in the translated version.

5- Reliability: To investigate internal correlation, the tool was distributed among 20 patients. The Cronbach’s alpha coefficient was 0.68. It was found that 2 items on the tool-item 13 (‘When I need help, I allow others to help me’) and 15 (‘I do not think much about thing I have lost’) decreased Cronbach’s alpha coefficient. After removing these 2 items, Cronbach’s alpha coefficient increased to 0.81. However, these 2 items were considered important by the Committee of Nursing and Midwifery of Shahid Beheshti University and Dr. Reed (the tool designer) and therefore were retained. The reason for the relative unreliability of these items was thought to be because some participants attended classes held at the Tehran MS Association and were trained not to reflect significantly on past events. It thus may be probable that they gave negative answers to these 2 items while other study participants did not do so. In previous studies, the Cronbach’s alpha coefficient was 0.72 to 0.93 [1, 2]. To test its reliability, the tool was given to 10 patients. The Spearman coefficient for the retest was 0.93 indicating high reliability.

6- Registration: All steps of the translation process were documented, including the original questionnaire, a summary of the specialists’ opinions, the retransmission of the questionnaire to English, problems encountered during the process of refining and testing the tool and the final questionnaire. All documents were sent to the tool’s designer, with the Persian version approved for use by Dr. Pamela J. Reed. In this study the quantitative methods of data analysis were as follows.

For the translation and inter-cultural adaptation of tools, Cronbach’s alpha and Spearman correlation coefficient were used to determine the tool’s reliability. In the semi-empirical section of the study examining self-transcendence before and after intervention, different methods were utilized. This included descriptive and inferential statistical methods including Wilcoxon and Kruskal-Wallis tests to compare the mean self-transcendence scores within groups and among groups, respectively. Regression was used to predict the variables contributing to changes in self-transcendence before and after intervention.

Results

The mean age of the 33 patients was 39.51±11.7 years that mean age in female group was 42.36±9.08, male group 45.9±9.7 and mixed group 34.2±7.1 years. The mean age at onset of the disease was 27.15 ±15.7 years of age. The mean duration of the disease was 14.5±7.5 years. The majority of patients (42.4%) were married, 45.5% were high school graduates, with most (57.6%) being unemployed. Regarding exercise, 60.6% patients exercised irregularly, 12.1% exercised regularly, whilst 27.3% did not exercise at all. Information about the contextual variables is presented for each group in table 1. Mean self-transcendence score in all patients was 53.21±6.2 after intervention. The comparison of mean scores between the 3 distinct peer groups, presented in Table 2, shows that the mean self-transcendence scores within each group increased after participating in the peer group program. This difference is significant (women: p(0.005, men: p(0.008 and mixed: p(0.003). There was no significant difference in the scores between the groups before or after the intervention, which indicates that the change in self-transcendence scores because of the intervention was of a similar magnitude in each group.

| Table 1. Information of the contextual variables of MS patients of Tehran MS association participating in peer support groups according to the groups in 2010 |
|-----------------|----------------|----------------|
| Marital status: | Research Samples | Men Group N(%) | Women Group N(%) |
| Single          | 10 (30.3)       | 2 (20)         | 0               |
| Married         | 14 (42.4)       | 6 (60)         | 8 (72.7)        |
| Divorced        | 9 (27.3)        | 2 (22.2)       | 3 (33.3)        |
| Education:      |                |                |                |
| Primary school  | 4 (12.1)        | 1 (10)         | 3 (27.3)        |
| Secondary school| 15 (45.5)       | 3 (30)         | 6 (54.5)        |
| University      | 14 (42.4)       | 6 (60)         | 2 (18.2)        |
| Employment status: |            |                |                |
| Unemployed      | 19 (57.6)       | 4 (40)         | 6 (54.5)        |
| Works for an employer | 21.2 | 2 (16.7)       | 2 (18.2)        |
| Self-employed   | 7 (21.2)        | 3 (30)         | 3 (27.3)        |
| Exercise: N(%)  |                |                |                |
| Yes / regularly | 4 (21.1)        | 0              | 1 (9.1)         |
| Yes / irregularly| 20 (60.6)      | 8 (80)         | 4 (36.4)        |
| NO              | 9 (27.3)        | 2 (20)         | 6 (54.5)        |
| Total           | 33 (100)        | 10(100)        | 1(100)          |
Mean scores of self-transcendence before and after the formation of peer support groups in table 3 shows that the change in the mean of self-transcendence scores because of the intervention was the same. Regression analysis demonstrated that contextual variables (age, sex, marital status, educational level, employment status, using Imenomedullar, exercise, disease duration and age at disease onset) do not play a specific role in predicting the differences of self-transcendence before or after intervention.

**Discussion**

The results showed that taking part in peer support group significantly increased mean self-transcendence scores in MS patients and that this change was similar among the 3 groups. Although few available studies have been carried out investigating self-transcendence and Reed’s opinion, the results of this study are consistent with those of previous studies by Coward and Chin-A-Loy and Fernsler [8, 9]. The study of Chen and Walsh examined the contribution of increased self-transcendence and positive attitude in nursing students in the United States towards the care provided to the elderly; in this study, self-transcendence improved after intervention but not significantly [10]. Also, in Lamet et al. research, in which creative bonding intervention was used to improve the nursing students’ attitudes towards taking care of the elderly, no significant difference was observed in the self-transcendence of students before and after intervention [11]. The discussed differences and similarities in findings can be related to the target group of Reed’s theory. The target group, according to Reed’s theory, includes individuals in whom critical conditions have conferred an increased vulnerability to death. While nursing students take care of the elderly, they may not be an appropriate target group as they are not actually suffering from the disease; this could be the cause of insignificant changes in their self-transcendence. Overall, the results of this study in MS patients support Reed’s theory. On the other hand studies that showed positive relationship between self-transcendence and improving self care and quality of life with our study emphasis that the input of nursing intervention which can improve self-transcendence, is improve in patient’s quality of life.

Participation in peer group increase in self-transcendence in the present study may reflect participation in social activities where they can share both problems and solutions. Activities performed in the peer group allowed participants to extend their personal boundaries through self-reflection, accepting the present situation, forming relationships with others, feeling concerned and responsibility towards others, incorporating others’ experience and having hope for future improvements. Post-intervention levels of self-transcendence in the 3 groups in this study (women 55.72±3.74, men 48.80±8.39, mixed 45.58±4.03) were compared with those in the studies performed by Reed, Upchurch and Lamet et al. Scores in these studies were similar to the findings of the current study at 49.50 and 50, respectively [11, 13, 25]. It is thus suggested that the results of this study support Reed’s idea that each individual has a capacity to develop their self-transcendence. These studies have demonstrated the positive impact of peer support groups in patients undergoing allogeneic hematopoietic stem cell transplantation [26], improved mental health, sense of self-efficacy and expectancy in patients with chronic diseases [27-30], and improved understanding displayed by the patients’ caregivers [31-33]. The improvement in self-transcendence scores after intervention was equal in all 3 groups, which indicates that participant self-selection of their group, did not have any impact on the results. Self-selection was implemented following Forsite’s findings, which suggest that groups are more efficient when their members are self-selected [34]. Some participants of Coward’s study were also placed in support groups according to their interests [8]. An open question was asked at the end of the questionnaire regarding participants’ views on taking part in the peer group program. All participants indicated that attending the peer support group program had immensely helped them in terms of resolving problems associated with their disease. In all 3 groups, most participants generally complained about not being understood by their families, society and their friends, and regarded this as a limitation.

| Table 2. Comparing of mean scores of self-transcendence in MS patients before and after intervention based on peer support groups in 2010 |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Before intervention        | After intervention          | p-Value                     |
|                            | Mean±SD                    | Mean±SD                    |                            |
| Women only                 | 47.09±8.06                 | 55.72±3.74                 | 0.005                      |
| Men only                   | 39.09±8.96                 | 48.80±8.39                 | 0.008                      |
| Mixed                      | 46.16±6.54                 | 54.58±4.03                 | 0.003                      |

| Table 3. Comparing mean scores of self-transcendence before and after the participation in peer support groups of Tehran MS Association patients |
|-----------------------------|-----------------------------|-----------------------------|
| Difference between two peer support groups | Difference before intervention | Difference after intervention |
| Women-men groups            | 12.91                       | 13.92                       | 1±10.9                     | 0.66                       |
| Women-mixed groups          | 9.91                        | 10.42                       | 0.5±9.5                    | 0.89                       |
| Men-mixed groups            | 3                           | 3.5                         | 0.5±10.4                   | 0.82                       |

Comparison of mean scores of self-transcendence in MS patients before and after intervention based on peer support groups in 2010: The results showed that taking part in peer support group significantly increased mean self-transcendence scores in MS patients and that this change was similar among the 3 groups. Although few available studies have been carried out investigating self-transcendence and Reed’s opinion, the results of this study are consistent with those of previous studies by Coward and Chin-A-Loy and Fernsler [8, 9]. The study of Chen and Walsh examined the contribution of increased self-transcendence and positive attitude in nursing students in the United States towards the care provided to the elderly; in this study, self-transcendence improved after intervention but not significantly [10]. Also, in Lamet et al. research, in which creative bonding intervention was used to improve the nursing students’ attitudes towards taking care of the elderly, no significant difference was observed in the self-transcendence of students before and after intervention [11]. The discussed differences and similarities in findings can be related to the target group of Reed’s theory. The target group, according to Reed’s theory, includes individuals in whom critical conditions have conferred an increased vulnerability to death. While nursing students take care of the elderly, they may not be an appropriate target group as they are not actually suffering from the disease; this could be the cause of insignificant changes in their self-transcendence. Overall, the results of this study in MS patients support Reed’s theory. On the other hand studies that showed positive relationship between self-transcendence and improving self care and quality of life with our study emphasis that the input of nursing intervention which can improve self-transcendence, is improve in patient’s quality of life. Participation in peer group increase in self-transcendence in the present study may reflect participation in social activities where they can share both problems and solutions. Activities performed in the peer group allowed participants to extend their personal boundaries through self-reflection, accepting the present situation, forming relationships with others, feeling concerned and responsibility towards others, incorporating others’ experience and having hope for future improvements. Post-intervention levels of self-transcendence in the 3 groups in this study (women 55.72±3.74, men 48.80±8.39, mixed 45.58±4.03) were compared with those in the studies performed by Reed, Upchurch and Lamet et al. Scores in these studies were similar to the findings of the current study at 49.50 and 50, respectively [11, 13, 25]. It is thus suggested that the results of this study support Reed’s idea that each individual has a capacity to develop their self-transcendence. These studies have demonstrated the positive impact of peer support groups in patients undergoing allogeneic hematopoietic stem cell transplantation [26], improved mental health, sense of self-efficacy and expectancy in patients with chronic diseases [27-30], and improved understanding displayed by the patients’ caregivers [31-33]. The improvement in self-transcendence scores after intervention was equal in all 3 groups, which indicates that participant self-selection of their group, did not have any impact on the results. Self-selection was implemented following Forsite’s findings, which suggest that groups are more efficient when their members are self-selected [34]. Some participants of Coward’s study were also placed in support groups according to their interests [8]. An open question was asked at the end of the questionnaire regarding participants’ views on taking part in the peer group program. All participants indicated that attending the peer support group program had immensely helped them in terms of resolving problems associated with their disease. In all 3 groups, most participants generally complained about not being understood by their families, society and their friends, and regarded this as a limitation.
Promotion of Self-Transcendence in patients with MS

Jadid-Milani M et al.

in their lives. Through group discussions and participation of some families in some sessions, practical solutions of these problems were sought. In the present study, the women and mixed groups were more dynamic in the absence of the researcher, while participants in the men group took part in discussions only after much prompting of the researchers. This may be due to differences between genders, with women being more extroverted than men and more comfortable with sharing their problems [34]. In the mixed group, the differences between genders made the group dynamic. The results of this study confirm the influence of the peer group on self-transcendence in patients with MS. The findings of this study can be applied to nursing education and management; however, their practicality depends on the support of managers. The translated STS can be utilized by other researchers, and the results of this study may be useful for designing the curriculum of nursing courses. The findings can also be utilized by nursing professors to enable nursing of patients with MS or other chronic conditions by focusing on self-transcendence. Formation of peer support groups for MS and other chronic diseases by healthcare nurses should be encouraged as it can positively influence patients’ self-transcendence. Also, the formation of support groups can provide patients’ families with a better understanding of the disease and the patients’ conditions. This would likely lead to the reduction of problems experienced by the patients and their caregivers. This study did not have a control group, and this was the main limitation of the study. However, use of a control group was not possible because the members of the Tehran MS Association already had developed good relationships with one another and this could not be replicated in a control sample. One of the positive aspects of the study was the development of a translated and culturally adapted version of the STS. This contribution reflects the richness of the study.

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Authors’ Contributions
All authors had equal role in design, work, statistical analysis and manuscript writing.

Conflict of Interest
The authors declare no conflict of interest.

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