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EVIDENCE BASED CARE

Effect of a Self-Management Empowerment Program on Anger and Social Isolation of Mothers of Children with Cerebral Palsy: A Randomized Controlled Clinical Trial

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Abstract

Background: Cerebral palsy (CP) is the most common chronic motor disability, which can have negative impacts on social behavior of mothers as the primary caregivers.

Aim: To investigate the effect of an intervention program based on the self-management empowerment model on the anger and social isolation of mothers with CP children.

Method: This randomized controlled clinical trial was performed on 72 mothers of CP in Bushehr and Shiraz, Iran, 2015. We employed Buss-Perry Aggression Questionnaire and the UCLA Loneliness Scale for data collection. The intervention group received self-management empowerment in five steps and two face-to-face sessions and was followed up regularly for 1.5 months. Thereafter, anger and social isolation of both groups were reexamined. Data analysis was performed using the Chi-square test, independent t-test, paired t-test, and Mann-Whitney test in SPSS, version 18.

Results: The mean ages of the intervention and control groups were respectively 28.1 ± 6.09 and 28.1 ± 5.8 years, which independent t-test showed to be homogenous ($P=0.31$). Before the intervention, there was no significant difference between the two groups in terms of aggression ($P=0.58$) and loneliness scores ($P=0.93$); however, after the intervention, independent t-test reflected significant inter-group differences in terms of both scores ($P<0.001$).

Implications for Practice: The designed empowerment program could reduce the anger of mothers of CP children and serve as a framework for empowering these mothers in healthcare and rehabilitation centers. The efficacy of the program in alleviating the social isolation of these mothers requires further research.

Keywords: Anger, Cerebral palsy, Empowerment, Mothers, Social isolation

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Introduction

Children are among the most important targets of healthcare programs, and their conditions and diseases can pose a heavy burden on healthcare systems (1). Today, the significant association of chronic illnesses with major mental and physical health complications is a widely accepted fact (2). The most common chronic motor disability in children is cerebral palsy (CP). CP is caused by non-progressive disturbance in developing brain, which may occur before, during, or after birth (3). CP encompasses a wide range of conditions including motor function disorders (4) and cognitive, perceptual, sensory, and behavioral impairments (5). According to the majority of reports, the prevalence of CP is between 2 and 2.5 per 1,000 live births (6). In Iran, the prevalence of CP is currently 2.6 per 1,000 live births (7). At present, no intervention can successfully repair the injuries to the brain areas that control muscles and movement (8). As a result, a child with CP often needs extensive special and long-term care, which is why families of CP children have below normal physical and mental health.

In most cases, mother is constantly engaged with the affairs of children with CP, and the child's health greatly affects her well-being. Feelings like guilt, fault, failure, and deprivation due to the child's abnormality and fear of the future can cause withdrawal and disinterest in social engagement and create an environment of anger, sadness, and grief (9, 10). Anger is a psychological state that plays a decisive role in individual and social life. As such, anger can become the underlying cause of a wide range of disorders, hence arising other negative mental states like the feeling of loneliness, isolation, helplessness, and tension (10). Social isolation is a condition in which a person or group of people, because of their perception of self and the environment or their individual and social motivations, choose to disconnect from the environment and continue their life as an isolated individual or group.

People afflicted with social anxiety and isolation are afraid of social encounters and avoid such situations as they deem themselves vulnerable to negative evaluation by others (11). In a study conducted in 2013 on the parents of mentally disabled children in Khorramabad, Iran, it was found that although all these parents had psychosocial problems, mothers, because of their multiple roles in the family, had more problems than fathers. More than half of the parents surveyed in that study stated that their social relations with their families and neighbors have faded (12). Further attention to the knowledge of the mothers with special needs children regarding the child's condition and the ways of acquiring support from others can improve their ability to manage the situation (13).

A meta-analysis study on the effects of psychological interventions on the mental health of the families with mentally disabled children reported that although these interventions have an impact on the mental health of these families, they need to be integrated with supportive interventions (14).

In a study conducted in 2010 in Melbourne, Australia, on the impact of caring for a CP child on the life of the main caregiver (usually the mother), it was reported that this task is significantly challenging for the caregivers and can compromise their mental and social health (15). Another study carried out in 2015 in Queensland, Australia, found that acceptance and commitment therapy-integrated parenting interventions can promote the quality of life of CP children (16). Several studies conducted in Iran emphasize on the importance of directing extra attention to the mothers of CP children as the persons whose health plays a pivotal role in maintaining the health and development of the child, as well as other family members (17).

A study performed by Alaei on the experiences of parents of CP children demonstrated a generally elevated level of anger and reduced level of social relationship (isolation) in these parents (18). In a study conducted by Zandvanian (2012) in Yazd, Iran, anger management training of mothers with disabled children showed a significant effect on their mental health, but it could not alleviate their social functioning impairment (19). Efficacy of stress coping skills training in increasing the resilience of mothers with disabled children was proved by Almasi, who recommended further attention to the needs of families with disabled children, especially mothers who play the primary role in caring for these patients (20).

Nurses, as integral members of health teams, should be able to understand the emotional and psychological responses of parents to the disease and provide suitable education in relation to the disease and its outcomes in order to help them discover the inherent capabilities necessary for

coping with the problems and acquire a good understanding of their new roles under the new condition (21). Empowerment in the form of education through skills training and knowledge improvement can contribute to self-care and quality of life (22). For empowerment to be effective, nurses should be well aware of the sources of power and sense of empowerment in people (23). Empowerment as a nursing intervention can be devised and implemented based on diverse models. One of the recent varieties of empowerment model is the self-management empowerment model proposed by Ravanipour et al. (2008), which is the result of a study based on the grounded theory on the concept of power and consists of seven concepts including change awareness, independence, role functioning, adaptability, perceived satisfaction, sense of control, and self-management ability (24).

This model has been used in several studies to, for example, empower grandmothers with the ultimate objective of empowering their primipara daughters with hospitalized neonates. In this regard, this model was shown to lower depression score and improve the role realization of these primiparae (25). This model was also applied to empower adolescents and youths with major thalassemia, where it managed to enhance their quality of life (26).

Given the chronic nature of CP and its impact on the mother as the primary caregiver, the self-management empowerment model can serve as a suitable framework for educational interventions aimed at controlling the psychosocial outcomes of this condition (27). Such interventions can assist the mother to discover the resources available within her and the society and how to make full use of all these resources to manage the challenging task of caring for her CP child with lower degrees of anger and social isolation (24). In view of the above, and considering the fact that the studies in this field are mostly focused on the care and rehabilitation of disabled children while rarely addressing the health of mothers, especially their anger and social isolation, we attempted to investigate the effect of an intervention devised based on the self-management empowerment model on the anger and social isolation of mothers with CP children.

Methods

This randomized controlled clinical trial investigated the effect of an intervention devised based on the self-management empowerment model on the anger and social isolation of mothers of children with CP in the cities of Shiraz and Bushehr, in southern Iran, in 2015. The study population comprised of mothers with CP children who had a medical record at Bushehr Welfare Center, Shiraz Welfare Center, or Baharan Health Center in Shiraz and were regularly visiting the respective center. The inclusion criteria were mothers aged 20-45 years with a child aged 2-10 years diagnosed with moderate or severe CP by a pediatric neurologist. The exclusion criteria were any chronic physical and mental disabilities in the mother that impeded her participation, her inability to visit the center to receive the intervention, and inability to complete the questionnaire.

After consultation with a panel of experts, the authors used the sample size formula for comparison of two means with the test power of 80% and the confidence interval of 0.95 and computed the standard sample size to be 36 per group (72 in total). The subjects were selected through convenience sampling and randomly assigned to the intervention and control groups by the use of Excel. The sampling duration was six months. The data were collected using a demographic information form, Buss-Perry Aggression Questionnaire, and the UCLA Loneliness Scale.

Buss-Perry Aggression Questionnaire (BP-AQ) consists of 29 items that measure four aspects of anger and aggression. The total score of aggression is the sum of scores of all the items. In a study conducted by Samani on 492 female and male 18-22 years old students of Shiraz University and Shiraz University of Medical Sciences, the validity of BP-AQ was confirmed and its test-retest reliability was reported to be 0.78 (28).

Social isolation was measured using UCLA Loneliness Scale, which consists of 20 items rated on a 4-point Likert scale and measuring the person's subjective feelings of loneliness and social isolation in three dimensions of relationship with family, relationship with friends, and relationship with neighbors. The Cronbach's alpha coefficient of this scale for the populations of adults, students, and teachers ranged from 0.89 to 0.94. In a study performed by Yaghoubi Doust

on 384 high school students, validity of this scale was verified and its reliability was reported to be 0.88 (11).

Our study was performed in three stages. In the first stage (pre-intervention assessment), the subjects in the intervention and control groups attended separately held meetings, where they were briefed about the research objectives, and then asked to complete research instruments, that is, the demographics form, BP-AQ, and UCLA Loneliness Scale (in each session, completion of questionnaires took about 45 to 60 minutes).

In the second stage, the intervention was implemented through two 2-hour sessions using an educational program designed in five main steps to ensure the uniformity of the intervention received by the participants. This program was designed based on the self-management empowerment model, which consists of seven concepts including change awareness, independence, role functioning, adaptability, perceived satisfaction, sense of control, and self-management ability (24). The content validity of this educational program was evaluated and verified by two professors with expertise in the subject in addition to the supervising and advising professors.

The ethical propriety of the program and research in general was approved by the Ethics Committee of the university. The program was focused on the concepts of empowerment of mothers with CP children, with an emphasis on the methods to address and control anger and improve social relationships, and was designed to assist the researcher in correct and uniform implementation of the intervention for all the subjects in the intervention group. The intervention consisted of the following steps:

Step 1: evaluation of mother's self-awareness about changes and recognition of one's performance level and expectations. In this step, individual interviews were conducted using a series of evaluation forms previously prepared based on the self-management empowerment model (each subject was given a sheet, in which all the stages of the intervention were jointly registered by the subject and the researcher). The aim of these interviews was to examine the person's knowledge and awareness about the changes in her psychological, spiritual, and social capacities, range of activities and roles she plays, her functional and mental independence, her adaptation to the condition, and then her abilities and skills and available support sources and their limitations in each of these domains. The subjects were also encouraged to express their expectations from a desirable life. Then, the problems of the person in each of the mentioned domains were identified. For example, when a mother stated that "I don't know if I can cope with the fact that I will see my child in this condition through her life or my life?", the researcher interpreted this as the mother's deficiency of knowledge and awareness about the changes occurred in her life because of having a disabled child and how to manage it. When another mother stated that "I used to go to all sorts of festivities, events, parties, I was free to do as I like, but now, because of my child's illness, I've lost many of my contacts, I'm always home and feel empty", the researcher interpreted this as maladaptation to the change in the role, subjective misconception about motherhood, and the state of isolation. When another mother stated that: "I often treat my husband and other children with a sense of aggression and hostility, sometimes I start to break things around the house", the researcher registered this as unchecked and rising feeling of anger and hostility in the mother.

Step 2: Goal setting

The desired goals were determined with the help of mothers based on the assessment and the scope of their problems in the first stage. For example, one goal was to improve the person's understanding regarding her performance level and changes in her mental capacities, her caregiving capability, and her ability to identify and utilize support sources and adapt to her child's illness.

Step 3: Planning

Based on the goals set in the second stage and the solutions suggested by the subject, a plan was devised in accordance with the domains of the self-management empowerment model. It should be noted that these three steps were carried out in two 45-60 minutes sessions per individual.

Step 4: Adjusting the physical, psychosocial, and social structure

Based on the patient condition and the goals set in the previous steps, the empowerment strategies for self-management and adaptation were introduced. For instance, the mothers were educated about how to discover and utilize social support sources or gain better insight into their child's condition, they were also provided with some strategies to control anger and overcome social isolation. The subjects were followed up for 1.5 months after the intervention. They were asked to contact the researcher in case of any ambiguities or inquiries. During this time, the researcher contacted every subject on a regular schedule in accordance with the goals specified in the needs assessment form and the prescribed strategies, in order to check the validity of the process and performance of the subjects. The subjects were also provided with a booklet containing information about CP and some instructions on how to manage anger and avoid social isolation.

Step 5: Evaluation

This part of the program involved systematic evaluation of the covered subjects at each training session and later by regular telephone calls during the test period to check the conformity of the process with the goals and plan of the intervention.

In the third stage of the study (post-intervention assessment at the end of 1.5 month test period), the subjects were asked to refill the aggression and loneliness scales. Thus, the alterations in the aggression and social isolation of the mothers with CP children with and without the intervention were measured.

In compliance with the codes of research ethics, the project outlines were first reviewed and approved by the Research Department of Bushehr University of Medical Sciences (BPUMS). Prior to participation, the subjects were briefed about the research objectives and general concepts, intervention requirements, the self-management empowerment model, the voluntary nature of participation, and the confidentiality of disclosed information. Then, they were asked to fill out the informed consent forms.

The data were analyzed using descriptive statistics (frequency, mean, and standard deviation) in SPSS, version 18. The Kolmogorov-Smirnov test was run to verify the normality of the data, the Chi-square test was performed to study the qualitative (ordinal) demographic variables by group, and the Mann-Whitney test was utilized to compare non-normally distributed quantitative variables between the two groups. In all the analyses, the significance threshold was set at 0.05.

Results

The mean age of the mothers was 28.1 ± 6.09 years in the intervention group and 28.1 ± 5.8 years in the control group ($P > 0.31$). The mean ages of the CP children were 4.4 ± 2.2 and 4.6 ± 2.2 years in the intervention and control groups, respectively ($P > 0.64$). According to the independent t-test, there was no significant difference between the two groups in terms of the mean age of the mothers or children. Table 1 presents the descriptive statistics (frequency and percentage) of the demographic characteristics of the mothers with CP children. As observed in this table, according to the Chi-square test, there was no significant difference between the groups in terms of demographic characteristics ($P > 0.05$).

As exhibited in Table 2, the mean aggression scores in the intervention and control groups before the intervention were respectively 90.6 ± 22.04 and 88 ± 6.6 , and reached to 68.6 ± 14.5 and 90.2 ± 14.6 after the intervention. According to the independent t-test, before the intervention, the difference between the mean aggression score of the two groups was not significant ($t(70) = 0.5$; $P > 0.58$), but after the intervention, this difference became significant ($t(63.3) = -6.6$; $P < 0.001$).

The mean loneliness scores in the intervention and control groups at the pre-intervention stage were respectively 2.4 ± 0.5 and 2.4 ± 0.5 , and reached to 2.5 ± 0.2 and 2.8 ± 0.2 after the intervention. The independent t-test demonstrated that the difference between the mean loneliness scores of the two groups before the intervention was not significant ($t(70) = -0.08$; $P > 0.93$), but became significant after the intervention ($t(70) = -3.8$; $P < 0.001$). However, the independent t-test reflected no significant difference between the two groups in terms of change in the mean loneliness scores ($t(70) = -1.3$; $P > 0.16$).

Table 1. Demographic characteristics of the mothers with cerebral palsy children in the intervention and control groups

Variable		Group		P-value (Chi-square test)
		Control n = 36 Frequency (Percentage)	Intervention n = 36 Frequency (Percentage)	
Marital status	Married	34 (94.4)	33 (91.7)	0.08
	Separated	0 (0)	3 (8.3)	
	Divorced	2 (5.6)	0 (0)	
Family size	1-3	17 (47.2)	16 (44.4)	0.20
	3-6	19 (52.8)	17 (47.2)	
	> 6	0 (0)	3 (8.3)	
Birth order of the disabled child	First-born	25 (69.4)	21 (60)	0.09
	Second-born	6 (16.7)	11 (31.4)	
	Third-born	5 (13.9)	1 (2.9)	
	Fourth-born and higher	0 (0)	2 (5.7)	
Number of children with cerebral palsy	1	33 (94.3)	31 (91.7)	0.66
	>1	2 (5.7)	3 (8.3)	
History of attending therapy and counseling classes	Yes	27 (75)	31 (86.1)	0.37
	No	9 (25)	5 (13.9)	
Father's occupation	Self-employed	22 (62.9)	24 (66.7)	0.80
	Employee	9 (25.7)	7 (19.4)	
	Other	4 (11.4)	5 (13.9)	
Mother's occupation	Self-employed	1 (2.8)	2 (5.6)	0.49
	Employee	0 (0)	1 (2.8)	
	Other (homemaker)	35 (97.2)	33 (91.7)	
Father's education	Less than high school diploma	19 (54.3)	14 (38.9)	0.29
	High school diploma	13 (37.1)	20 (55.6)	
	College education	3 (8.6)	2 (5.6)	
Mother's education	Less than high school diploma	17 (47.2)	9 (25)	0.13
	High school diploma	17 (47.2)	25 (69.4)	
	College education	2 (5.6)	2 (5.6)	

Table 2. Comparison of the mean aggression and loneliness scores of the mothers with cerebral palsy children before and after the intervention

		Group		P-value (inter-group comparison)
		Intervention	Control	
Mean aggression score	Pre-intervention	90.6±22.04	88.0±19.6	0.58*
	Post-intervention	68.7±14.5	90.2±14.6	0.001*
	P-value (intra-group comparison)	0.001**	0.26**	0.001*
Mean loneliness score	Pre-intervention	2.4±0.5	2.4±0.5	0.93*
	Post-intervention	2.5±0.2	2.8±0.2	0.001*
	P-value (intra-group comparison)	0.24**	0.007**	0.16*

* Independent-samples t-test; ** Paired t-test

Discussion

The purpose of this study was to investigate the effect of an intervention devised based on the self-management empowerment model on the anger and social isolation of mothers with CP children. According to the results, implementation of the empowerment program significantly reduced the aggression scores. More specifically, the intervention led to a significant difference between the intervention and control groups in terms of change in the mean aggression scores, which implies the significant effect of the intervention in alleviating the anger of mothers in the intervention group. It should be borne in mind that most of the mothers participating in this study were from moderate, low, even very low-income families. In addition, some mothers confessed that under the heavy burden of

caring for their CP children in addition to the usual stresses of the low-income families, they resort to physical punishment to discipline their healthy children and sometimes even the disabled child.

The literature contains no similar study on the effect of the self-management empowerment model on anger or social isolation of mothers with CP children, but several studies were conducted on the effect of the empowerment model on various aspects of the patient's life. Various studies on this issue have shown that increased inclination to express anger is correlated with factors such as health problems, cultural problems, social isolation, and depression among others. Although parents' anger is widely known to have substantial detrimental effects on children, many families still abuse their children with physical and mental problems (29).

The findings of the present study are consistent with the argument that families with limited relationship with the external environment are likely to show violence against their children, and that in the absence of interrelationship between parents and children and between family and the environment, there is a higher likelihood of violence. This is also consistent with the findings of William et al. (30), who reported that the extent of anger in mothers is associated with their social isolation, and both factors are effective in the quality of life of CP children.

Although the change in social isolation of mothers after intervention was insignificant, comparison of the post-intervention mean loneliness scores of the control and intervention groups showed a statistically significant difference, implying the possible effect of the empowerment intervention on social isolation.

In the study conducted by Zandvavian et al. (2012) in Yazd, Iran, anger management training of mothers with disabled children showed a significant effect on their mental health, but did not alleviate their social functioning impairment. Those authors attributed the latter result to the shortness of follow-up period and argued that perhaps more time is needed for training to exert a significant impact on the social functioning of subjects (19). In our interviews, mothers suggested that since the birth of the disabled child, they have had very poor and limited relations with others and sometimes even lacked a close friend or family member to talk to and share their problems with. Accordingly, to explain the insignificant change in the mean loneliness scores despite the significant intergroup differences of the post-intervention loneliness scores, it can be argued that although the empowerment intervention has provided mothers with some strategies to reduce their isolation and improve their relations (depending on their personal conditions), this is a long-term process that is hinged upon many structural factors beyond the scope of the family environment, as well as the culture, beliefs, and conditions at home. Thus, perhaps a longer follow up period and giving mothers more time to practice their education and training could have resulted in a significant change in mean scores of the subjects in the intervention group.

Our results concerning the isolation and social exclusion of mothers with CP children are consistent with the reports of Vauth et al. (31), Sayles et al. (32), and Dehnavi et al. (33), all believing that having a special-needs child is associated with parents' inclination to hide the child and feelings of anxiety, discrimination, and unworthiness, which in turn have a negative impact on the sense of self-efficacy and power, hence reduced quality of life. In another study, parents of the schoolchildren with asthma were inclined to better adapt to the chronic conditions of their child by identifying and utilizing social support sources such as relatives, neighbors, and teachers (34).

Extensive studies have confirmed the relationship of parental patterns with the quality of life of CP children, which emphasizes on the need for interventions with a focus on parental lifestyle patterns (35); although it should not be forgotten that the quality of life of CP children is a function of fairly complex interactions between the disease-specific factors and the family context on a broader level (5). As mentioned, most of the participants in our study were from low and even very low-income families. The majority of our subjects had elementary education and were mostly homemakers. In addition, the families of these mothers had very little to no external financial support. Overall, only a few mothers were well educated or employed. The reason for choosing moderate to severe CP patients was that mothers of these patients can be expected to have a substantially more noticeable levels of anger and social isolation than mothers of children with mild CP. Thus, to reduce the bias in selection, the study was limited to the mothers of children with moderate to severe CP. A similar consideration was made when choosing the age group of children, because within a short time after diagnosis, the mother is likely to still be in a state of shock and disbelief; on the other hand, mothers with older CP children are likely to cope with the child's disease in their own way. Thus, children's

age was limited to the range of 2 to 10 years to avoid the mentioned interferences. Following this logic, demographic factors may influence mother's performance, but no statistically significant difference was noted between the intervention and control groups in this regard. Likewise, in the study conducted by Mahmoudi et al. on the effect of a self-care program on the quality of life of chronic patients (36), demographic data did not show any significant impact on the effect of the self-care program. Nevertheless, in the study of Arab et al. (37) on the psychosocial problems of children with thalassemia and their siblings, education of the mothers and occupation of the parents were reported to be significantly effective.

Implications for Practice

In view of our findings and the dominant Iranian culture of anger mismanagement, development of a comprehensive empowerment plan including anger management concepts could improve the efficacy of nursing interventions for mothers with CP children. As regards the social isolation of the mothers with CP children and their families in general, although a significant difference was found between the final loneliness score of the two groups, the intervention failed to make a noticeable improvement in isolation after 1.5 months. Moreover, considering the cross-sectional nature of this study and the lack of control over the recent events in the lives of the participants, further studies with a longitudinal design and larger sample sizes are highly recommended. Lastly, since this study was conducted on mothers and children of a certain age group, generalization of the results to other age groups requires further research.

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Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this article.

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