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A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial

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ABSTRACT

Background: Mothers of moderately to severely affected children with cerebral palsy (CP) have to spend a long time to take care of their children. This time-consuming responsibility affects their physical and psychosocial health. Therefore, mothers as caregivers are required to receive special training to take care of their children.

Aims: The aim of this study was to evaluate the effectiveness of a developed web-based intervention for daily care training of children with CP on their mothers' quality of life (QOL), anxiety, depression, stress, and their musculoskeletal pain.

Methods and procedures: This study was a single blind randomized controlled trial. 91 mothers of children with CP with Gross Motor Function Classification System (GMFCS) levels III, IV, and V, who aged from 4 to 12 years were assigned to the intervention and control groups using block randomization. Mothers in the control group received their routine face to face occupational therapy intervention and mothers in the intervention group received 12 weeks web-based intervention. QOL, depression, anxiety, stress, and pain were measured before and after the intervention in both groups.

Outcomes and results: The results of analysis of covariance showed that after controlling the mean score of pretest of pain, the mean score of post-tests in the intervention and control groups was significantly different ($P < 0.05$). The mean scores of physical health and total QOL scores of post-tests in the intervention group were significantly higher than the control group with controlling pretest scores.

Conclusions and implications: Designed web-based intervention affects the caregivers' QOL and pain significantly. This intervention can be used to provide daily care training for mothers of children with CP.

What this paper adds?

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- A web-based intervention can be used to provide daily care training for mothers of children with cerebral palsy.
- Quality of life of mothers of children with cerebral palsy was improved through the web-based intervention.
- Mothers' musculoskeletal pain was reduced through the web-based intervention.

1. Introduction

Cerebral palsy (CP) describes a group of permanent and non-progressive disorders of the movement and posture, causing activity limitation, in the developing fetal or infant brain (Rosenbaum et al., 2007). Moderately to severely affected children with CP are more dependent to their mothers as main caregivers in performing their activities of daily living for their whole life (Razavi, Rassafiani, Sarfaraz, Malekpour, & Salehi, 2013). As a result, mothers have to spend a long time for taking care (e.g., to feed, bathe, and clothe) of these children (Rassafiani & Sahaf, 2011; Stillerova, Liddle, Gustafsson, Lamont, & Silburn, 2016). Taking care of these children is time-consuming and is a source of stress for their mothers (Rassafiani, Kahjoogh, Hosseini, & Sahaf, 2012). In addition, it affects physical and social welfare, freedom and independence, comfort, and financial stability of the whole family (Davis et al., 2010; Jalili, Godarzi et al., 2013). It has been well established that 24-h care of a child with CP who has special needs for transportation, eating, bathing, dressing, sleeping, and toileting have a significant negative impact on the physical and mental health of his/her mother (Al-Gamal & Long, 2012; Altindag et al., 2007; Brehaut et al., 2004; Mobarak, Khan, Munir, Zaman, & McConachie, 2000; Yilmaz, Erkin, & Nalbant, 2013). Mothers of children with CP require special training to either reduce or prevent this negative impact (Razavi et al., 2013).

There are several methods to train such mothers including face to face, workshops, booklets, and videos (McConachie et al., 2000). Basically, child handling interventions focusing on physical aspects of caring. The subjects provided in handling interventions consisted of feeding, bathing, toileting, carrying, dressing, movement principle and sleep. The effectiveness of mothers' training through these methods have been well investigated and their results demonstrated positive influences on mothers' knowledge, as well as reducing their stress, and improving their quality of life (QOL) (Allah, El Awady, & Hameed, 2012; Ghorbanpoor et al., 2014; Hettiarachchi & Kitnasamy, 2013; Jalili, Rassafiani, Dalvand, Haghgoo, & Farzi, 2013; Nobakht & Rassafiani, 2016). However, there is little evidence about the effectiveness of telehealth model, which uses electronic information and telecommunication technologies, to provide health-related services for mothers of children with CP (Cason, 2012; Nobakht, Rassafiani, Hosseini, & Ahmadi, 2017).

Chi and Demiris (2015), in a systematic review conducted on telehealth services for caregivers in general (mothers were considered as caregivers), found out that caregivers had significant improvements in the outcomes of interventions such as anxiety, depression, stress, and QOL (Chi & Demiris, 2015). One of the common forms of providing services in telehealth model is web-based intervention ((AOTA), American Occupational Therapy Association (2013)). Chiu and Eysenbach (2011) in a study conducted on caregivers theorized three main factors influencing the use of internet-based health service: a) caregiver needs (personal capacity, available social support, and care giving belief); b) information communication technology factors (accessibility barriers and perceived efforts to use the technology); and c) the style of using the technology (preference for using email or the customized website). They showed that new caregivers employed interactive intervention such as using email while more experienced caregivers used more reflective learning such as information on website (Chiu & Eysenbach, 2011). Therefore, it appears that a web-based intervention for experienced caregivers compared with less experienced caregivers of children with CP is more appropriate.

Rehabilitation is a long-term and continuous process, which sometimes leads to the disruption of a mother's job, daily routines, and the role of the family members. It appears that limited numbers of experts in remote areas reduce training accessibilities. Then web-based interventions provide more accessibility to services for children who live in remote areas. Also in some special circumstances such as widespread of covid-19, web-based intervention is one of the possible way to support these children and their families. It seems that clients' satisfaction of telerehabilitation is high in various areas such as saving their time and low cost of services (Cason, 2014; Kairy, Lehoux, Vincent, & Visintin, 2009). However, there is no evidence to show whether this type of training can be effective if it is used for training of mothers of children with CP. Furthermore, if it is effective, which aspects of their health and how are they affected? Therefore, the primary purpose of this study was to evaluate firstly the efficacy of a developed and evaluated web-based intervention for daily care training of children with CP on the mother's Quality of Life (QOL). The secondary purposes of this study were to evaluate the efficacy of the intervention on mother's anxiety, depression, stress, and their musculoskeletal pain.

2. Methods

In order to achieve the aim of this study, a randomized controlled trial was designed.

2.1. Participants

A single blind randomized controlled trial was designed and conducted. Mothers of children with CP were included in this study if their children had Gross Motor Function Classification System (GMFCS) levels III, IV, and V, and aged between 4 to 12 years. If the participants had two or more children with disabilities, or previously received face to face caring training they were excluded from this study.

To determine a difference of at least 10 score in the mean of QOL between the intervention and control groups with a power of 0.80 and a significance level of $P < 0.05$, 45 participants in each study group were needed (Jalili, Rassafiani et al., 2013). Participants were recruited from 14 occupational therapy clinics in Tehran, Karaj, and Shiraz, (three main cities of Iran).

2.2. Procedure

First, mothers of children with CP received some information about the study from the assessor. Informed consent was obtained from mothers who were eligible to be included. Then they were requested to complete a demographic questionnaire, and perform QOL, depression, anxiety and stress, and pain measurements. Then, they were assigned to the groups using block randomization that was prepared by an expert in this field. Obtained sequentially block randomization was written on envelopes and mothers picked up one by chance, by which they were assigned to the intervention or control group accordingly. Both the outcome assessors and data analyzer were blind in this study. After that, mothers in the intervention group received the study website address and a sitemap. They were requested to visit the page and register to the website. After registering to the website and the confirmation by the site admin, the mothers entered to their own page and determined their educational priorities. Then, they received nine educational topics weekly. Also, they received an SMS reminder weekly to download their educational priorities. During 12-week intervention, they had access to an expert to ask any question. Mothers in the control group received their routine face to face occupational therapy intervention. Approval was obtained from the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences IR.USWR.REC.1394.111. The protocol of the study was registered at the Iranian Registry of Clinical Trials (ID: NCT02545179).

2.3. Intervention

Both groups continued each treatment they received and additionally the intervention group received web-based intervention. Recruitment of the participants started between October and December 2016; and follow-up was between January 2016 to March 2017. The web-based intervention was developed and evaluated by applying the steps of the CeHRes road map (van Gemert-Pijnen et al., 2011) with some modification. As typical web-based interventions, our web-based intervention was developed to be used by caregivers once a week, lasts for 12 weeks and includes interaction with the system, an occupational therapist, and peers on the web. To help all participants with different level of experience, we provided interaction through email with an expert occupational therapist. Then, our web-based intervention for caregiver training included nine general topics that were received by caregivers weekly for the first 9 weeks. These topics consisted of feeding, bathing, toileting, carrying, dressing, movement principle, sleep, and play, as well as, caregiver self-care. The participants had three further weeks to interact with an expert who was a PhD holder in occupational therapy with more than 25 years working experience in the field of children with CP regarding any questions arise. When they accomplished the final priorities and submit questions on their own web-page then they received responses by the expert. The web-based intervention had the possibility that the caregivers could determine their educational priorities. Also, the users could share their experiences with other users and could ask questions from an expert (<http://www.cpcare.ir>). The website has various capabilities including registering caregivers of children with CP and to confirm registration with an SMS (Nobakht, Rassafiani, & Hosseini, 2018).

2.4. Measurements

Three outcome measures were employed for this study including SF-36, Depression Anxiety and Stress Scales (DASS-21), and visual analog scale (VAS).

3. QOL

SF-36 is a general QOL instrument, translated to different languages with high validity and reliability (Bullinger, 1995; Razavi & Gandek, 1998). It measures eight concepts: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and perceived mental health. Each concept is directly transformed into a 0–100 scale. Lower score indicates less QOL and higher score indicates higher QOL (Ware & Sherbourne, 1992). The Persian version of SF-36 has acceptable validity and reliability. Reliability of the Persian version of SF-36 was estimated using the internal consistency that showed all eight scales met the minimum reliability standard. The Cronbach's α coefficients was from 0.77 to 0.90. Convergent validity showed correlations ranging from 0.58 to 0.95 (Montazeri, Goshtasebi, Vahdaninia, & Gandek, 2005).

4. Depression, anxiety and stress

DASS-21 is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety, and stress. Evidence supports the validity of DASS-21 as a routine clinical outcome measure and it was translated to variety of languages (Ng et al., 2007). Validity of the Persian version of DASS-21 was measured using factor analysis and criterion validity. The reliability of that scale was assessed through its internal consistency. In general, the validity and reliability coefficients were very satisfactory and were significant at $P < 0.001$. Correlation between depression subscale and the Beck depression inventory scale was 0.77, anxiety subscale with Zung anxiety inventory was 0.67, and the stress subscale and perceived stress inventory was 0.49 (Sahebi, Asghari, & Salari, 2005).

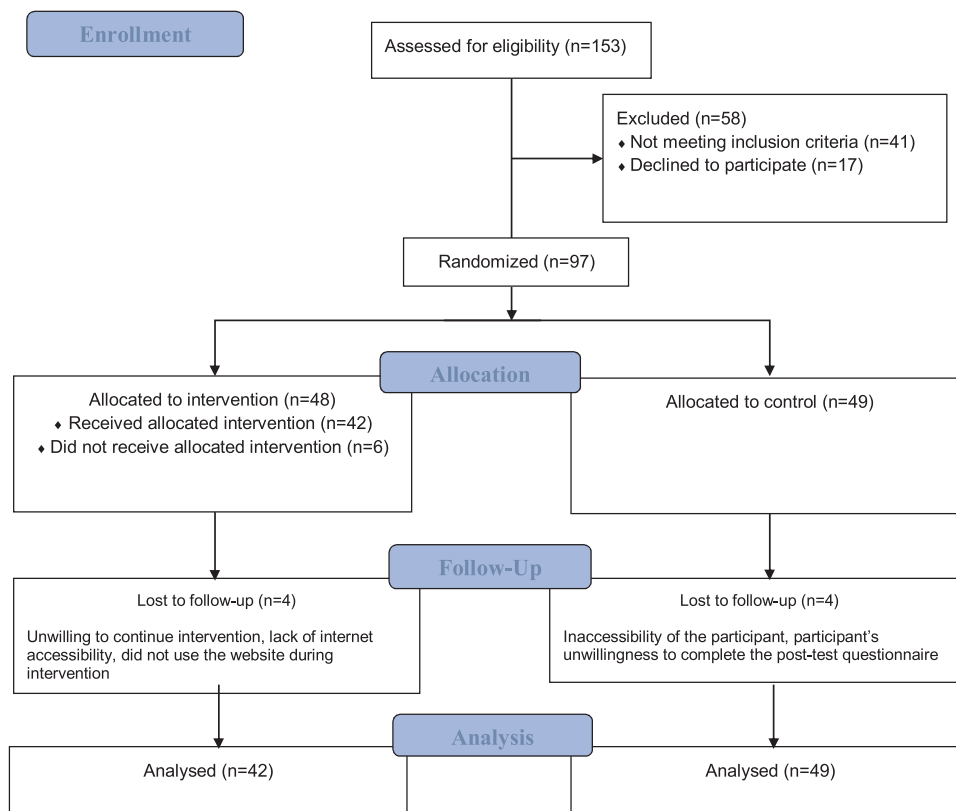


Fig. 1. CONSORT flow diagram of the study.

5. Pain

Visual analog scale (VAS) is a simple method for evaluating variations in pain intensity. It is often used in various studies. Participants were encouraged to indicate the intensity of the pain by marking a 100-mm line for each body part in whole body including head and neck, trunk, and upper and lower extremities according to the DeLoach, Higgins, Caplan, and Stiff (1998).

5.1. Data analysis

The data were checked for normality using Kolmogorov–Smirnov test (K–S test). Analysis of covariance (ANCOVA) was used to evaluate between-group differences in each at post-test controlling for pre-test scores. All analyses were performed using SPSS software version 20.

6. Results

97 participants were randomly assigned to the intervention and control groups. Of them, 42 were in intervention group, 49 were in the control group, and six did not receive allocated intervention due to family problem (1) and unknown reasons (5). Eight participants lost to follow up (4 in each group). Therefore, an intention-to-treat analysis was used by imputing their pretest outcome scores for their post-test outcome score (Fig. 1).

Caregivers had a mean age of 33.62 years (SD = 5.76). 35.2 % had university education, and 91.2 % were housewives. Their children had a mean age of 82.65 months (SD = 29.87) and 62.6 % of them were male (Table 1).

No statistically significant differences were found in caregivers' age and educational level between the intervention and control groups. Also, there were no significant differences in the age, sex, and GMFCS level of the children under their care between the two groups ($P > 0.05$) (Table 1).

The results of ANCOVA showed that the mean score of pretest of physical health and total score of QOL and pain had significant effect on mean score of post-tests. The mean scores of physical health and total QOL scores of post-tests in the intervention group were significantly higher than the control group with controlling pretest scores. After controlling the mean score of pretest of physical health and total score of QOL and pain, the mean score of post-tests in the intervention and control groups was significantly different ($P < 0.05$) (Table 2).

To further understand pain in which body parts was influenced by the intervention, two further analysis were used. An

Table 1
Baseline characteristics of the participants Characteristics of Participants.

Variable	Description	Intervention group	Control group	Statistics	P value
Caregivers' age (year)	Mean (SD)	34.17(5.89)	33.16(5.67)	0.825-t =	0.412
Caregivers' education	< diploma	11(26.2)	21(42.9)	3.287	0.349
	diploma	13(31)	14(28.6)		
	Associate and bachelor	16(38.1)	13(26.5)		
	Master and PhD	2(4.8)	1(2)		
Caregivers' job	Housewife	39(92.9)	44(89.8)		
	Part-time	2(4.8)	3(6.1)		
	Full-time	1(2.4)	2(4.1)		
Child age (month)	Mean (SD)	86.78(29.58)	79/12(29.97)	1.418-z =	0.156
Child sex	female	15(35.7)	19(38.8)	0.091	0.763
	male	27(64.3)	30(61.2)		
GMFCS level	Level 3	11(26.2)	19(38.8)	1.753	0.416
	Level 4	21(50)	19(38.8)		
	Level 5	10(23.8)	11(22.4)		

Table 2
Descriptive statistics for pretest and post-test outcome measures and ANCOVA results.

		Intervention group (N = 49)	Control group (N = 42)	F	P	Eta
SF36						
Physical health	pretest	57.87(19.61)	55.17(19.47)	4.89	0.030	0.05
	posttest	58.24(19.97)	48.73(22.23)			
Mental health	pretest	51.97(16.37)	48.16(17.98)	1.97	0.163	0.02
	posttest	55.34(17.38)	47.96(21.83)			
Total score	pretest	55.51(15.94)	52.42(16.30)	4.39	0.039	0.048
	posttest	57.07(17.01)	48.45(20.23)			
DASS-21						
Depression	pretest	11.90(8.79)	13.96(9.35)	2.59	0.111	0.03
	posttest	11(8.44)	14.77(10.16)			
Anxiety	pretest	10.28(7.97)	11.47(8.76)	0.94	0.335	0.01
	posttest	10.09(7.49)	12.33(10.43)			
Stress	pretest	17.24(8.53)	19.06(9.76)	1.76	0.188	0.02
	posttest	16.52(8.53)	19.59(9.37)			
VAS						
	pretest	242.12(199.58)	274.90(224.56)	8.53	0.004	0.09
	posttest	199.93(183.95)	329.98(264.86)			

Analysis of covariance with post-tests scores as the dependent variable, group as the independent variable, and pretest scores as covariates.

exploratory factor analysis was initially carried out to identify related components. To conduct this, a principle component analysis was done using SPSS (KMO = 0.715, P value for Bartlett's test = 0.000). At this point three factors (components) were discovered. Questions related to the severity of pain in the area of neck and shoulder were placed in factor 1, elbow, wrists and fingers, low back, and knee were placed in factor 2, and upper part of the spine, pelvis and thigh, and ankle and toes were placed in factor 3. Also, a reliability test was run on each new factor. Cronbach's Alpha for factors 1, 2, and 3 were 0.590, 0.742, and 0.701, respectively. Then, ANCOVA was performed to evaluate between-group differences in each factor. The results demonstrated that there are significant differences between two groups in these three factors and pain in intervention group was reduced (Table 3).

7. Discussion

Since late 20th century, there is evidence demonstrating the influence of daily care training for mothers of children with CP on their QOL and health. In this era, also, the provision of clinic-based services was changed into family-based services (McConachie et al., 2000). With the advances in communication technology, health-related services were possible while the client was at a point away from the therapist. These kinds of services and interventions are still under development and evaluation. There is lack of evidence in providing remote services to increase the capacity of mothers of children with CP. Therefore, according to the best of our knowledge it appears that this study is the first study to examine the effectiveness of web-based training for mothers of children with CP. The effectiveness of web-based training on QOL, depression, anxiety, stress, and pain of mothers of children with CP were

Table 3

Descriptive statistics for pretest and post-test of three factors of pain and ANCOVA results.

		Intervention group (N = 49)	Control group (N = 42)	F	P	Eta
Factor 1	Pretest	54.43(57.32)	47.53(48.94)	7.74	0.032	0.051
	Posttest	46.42(59.69)	65.53(64.02)			
Factor 2	Pretest	126.93(110.19)	130.73(95.69)	9.34	0.003	0.096
	Posttest	105.45(97.04)	153.51(101.22)			
Factor 3	Pretest	36.21(56.47)	64.79(77.22)	4.34	0.04	0.047
	Posttest	32.67(41.60)	71.18(80.71)			

Analysis of covariance with post-tests scores as the dependent variable, group as the independent variable, and pretest scores as covariates.

investigated in this study.

Mean scores of QOL in the intervention and control groups were compared using covariance analysis. The mean scores of physical health and total QOL scores of post-tests in the intervention group were significantly higher than the control group with controlling pretest scores. [Chi and Demiris \(2015\)](#) systematically reviewed the provision of remote health care to support caregivers in their study. Only 12 % of the studies with entry criteria examined the effects of these kinds of interventions on the QOL of the caregiver. In this review, about 50 % of the studies with entry criteria were in the field of caregivers of children. Although there was no specific evidence of effectiveness of service provision for caregivers of children with CP and the number of studies was limited, they reported significant differences in intervention group compared with control group, which is in agreement with our study.

In our study, there were no significant differences in the mean score of post-test of depression, anxiety, and stress in the intervention group in comparison with the control group by covariance analysis with controlling pretest scores. There is no similar research on mothers of children with CP. However, the effectiveness of web-based interventions on other groups and conditions showed mixed results. For example, [Hadjiconstantinou et al. \(2016\)](#), in a systematic review with meta-analysis examined the emotional effects of web-based interventions for people with type 2 diabetes and reported that although a number of studies had shown significant effects on participants' depression and distress, this was not approved by the results of meta-analysis ([Hadjiconstantinou et al., 2016](#)). [Davies and their colleagues](#), in a systematic review with meta-analysis assessed the effects of web-based interventions on the improvement of depression, anxiety, and stress in postgraduate students reported that there was significant improvement in intervention group compared with the control group that received no intervention. While there was no significant improvement in intervention group compared with the control group receiving placebo or other interventions ([Davies, Morriss, & Glazebrook, 2014](#)). In the review of [Chi and Demiris](#), about 50 % of the studies with entry criteria examined the effects of these kinds of interventions on reducing depression, anxiety, and stress. In most of these studies, depression, anxiety, and stress were significantly decreased ([Chi & Demiris, 2015](#)). There was no specific evidence of effectiveness of service provision for mothers or caregivers of children with CP in the study of [Chi and Demiris](#). The present study is the first study on mothers of children. As mentioned before, significant effects have been reported in some studies. This might be due to using video conference along with web-based intervention. Therefore, adding video conference may increase the effectiveness of these types of interventions on mothers' mental health.

The results of this study also demonstrated that the mean scores of musculoskeletal pain of post-tests in the control group were significantly higher than the intervention group with controlling pretest scores. After performing factor analysis and finding new components, correlation between knees, low back and upper limbs, and neck and shoulder were discovered. After controlling the mean score of pretest of these three factors, the mean score of post-tests in the intervention and control groups was significantly different and the most effect was on the pain of the lower back, knee, elbow, wrists, and fingers. There was promising evidence in terms of pain reduction by web-based interventions. However, more well designed studies are needed to strengthen the evidence concerning the impact of web-based interventions on mothers' pain ([Johari, Rassafiani, Dalvand, Ahmadi Kahjoogh, & Daemi, 2016](#)).

7.1. Limitations

In the present study, it was not possible to take into account the level of caregivers' experiences. Therefore, it is suggested to pay attention to the duration of mothers' experiences in future studies. [Chiu and Eysenbach](#) in a qualitative study identified effective factors in the use of internet-based services. These factors included mothers' needs, factors relating to communication technology, and information use style. This study noted that the experience of mothers affected the style of using that information ([Chiu & Eysenbach, 2011](#)). Another limitation to this study was to consider the Iranian culture within which, most of caregivers of children with CP were mothers. Therefore, training was provided to mothers as the main caregiver. So, it is suggested that future studies be designed for fathers and other family members of children with CP who are responsible for caring these children. Also, in the present study, it was not possible to record the amount of time mothers spent on the website. In other words, downloading information could have taken more time and did not give us accurate information. Therefore, we suggested providing this possibility in the future studies to determine the frequency of using the website.

7.2. Conclusion

Designed web-based intervention can be used to provide daily care training for mothers of children with CP. Given that the intervention provided was entirely web-based and that there was no need for travel, pay, spending time, and continuing communication between the website's supervisor and the mothers, such interventions would be cost-effective.

CRedit authorship contribution statement

Z. Nobakht: Data curation, Writing - original draft. **M. Rassafiani:** Conceptualization, Methodology, Supervision. **S.A. Hosseini:** Supervision, Writing - review & editing. **S. Hosseinzadeh:** Data curation, Writing - review & editing.

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