

Effect of education “Self-Management 5-A's program” on the quality of life mothers of children with cerebral Palsy

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ABSTRACT

Introduction: Cerebral palsy is the most common chronic motor disability in children that have a negative effect on the quality of life mothers. This study is aimed to determine the effect of education “Self-Management 5-A's program” on the quality of life mothers of children with cerebral palsy.

Materials & Methods: In this quasi-experimental study conducted in 2015-2016, 47 mothers of children with cerebral palsy from 4 to 12 years old living in Kurdistan province were selected using census sampling method and after the intervention due to the loss of the samples, 23 mothers remained in the intervention group and 16 in the control group. To collect the data related to mother and child, the demographic information questionnaire and the short form 36 Health Questionnaire which has the good reliability and validity were completed by mothers before and after learning "self-management five A's program", and data were analyzed using SPSS version 22.

Findings: The mean age of mothers in this study was 33.5 and the average age of children was 6.2 years. At pre intervention the mean quality of life mothers in intervention group was 38/92 and control group was, 37/63 and no significant differences between two groups ($P = 0.705$). But after intervention the mean quality of life mothers 39/25 was control group and in intervention group was, 50/48 and the study was significant ($P = 0.000$).

Conclusion: The quality of life mothers of children with cerebral palsy is at a low level And training " five - A self-management program " based on the needs of mothers due to child -care facilities and to improve the health of mothers were looking for .

KEY WORDS: Cerebral Palsy, Self-Management 5-A's Program, Quality Of Life, Family Caregivers.

1. INTRODUCTION

Cerebral palsy is the most common chronic mobile disability and neurological complication among the kids which is caused by any injury caused to the brain during development, before and after birth. This disease is usually accompanied by sensory, cognitive, communicative, behavioral and epileptic and muscular-skeletal problems which will limit and decrease the participation of individual in social activities (Dickinson, 2007). Of every 303 kids in the US, one is suffering from cerebral palsy. This value has been reported to be 2.06 out of one thousand in Iran (Sajedi, 2015; 2011).

Considering the importance of this issue, conducting appropriate interventions to increase the level so satisfaction or enhance the life quality of baby sitters can be a really useful measure for both kids and the baby sitters. If caring for these kids utilizes appropriate methods, this process will be facilitated (Hung, 2010; Sajedi, 2015).

Ab appropriate solution to this situation is utilization of appropriate and correct methods of care giving. This method helps enhance the interactions between mother and kid and the interaction between parents. On the other hand, the house environment will turn into a warm family place where parents would be responsible for carrying out caring activities and the house will be a safe, sound, and quiet environment. The parents will be able to teach different activities to their kids in the form of various games and they will have more time to take care of their kids at home (Bilde, 2011; Joghataei, 2002; Khanjani, 2010; Jahangiri, 2016). Teaching “5A self-management program” is an evidence-based program which includes a large range of behavioral changes in different health conditions and situations in the primary care of a chronic disease (Sawicki, 1999; Rahimi, 2014).

This program consists of 5 sections beginning with measurement of the behavioral level, believes and motivations of patients. The initial examination or patient's history will be recorded in this section. The second section includes guiding and informing the patient on personal sanity where the individual is informed of dangerous damages caused as a result of unhealthy behaviors. The third section includes the real selection of concrete goals and measurement and prediction of obstacles. The fourth section is where practical and educational plans in line with the goals defined are developed. The last section is a follow up and adjustment of plans using telephone follow-up and in house visits (Dalvand, 2012).

Considering the importance of this issue and keeping in mind the few number of researches conducted with the goal of evaluating the consequences of in-house educational-therapeutic interventions on kid and family and significant advantages of in-house caring (Ahmadi, 2015), the present research seeks to determine the effect of teaching “5A self-management program” on the life quality of mothers with kids suffering from cerebral palsy.

2. MATERIALS AND METHODOLOGY

This research is a semi-empirical study conducted in Kurdistan province based on the influence of teaching “5A self-management program” on the life quality of mothers with kids suffering from cerebral palsy in 2005-06. The families were included in the research based on a census approach. The samples included 27 families from Sanandaj for the test group and 20 families for control group. The inclusion criteria: the families residing in Kurdistan province and two cities of Sanandaj and Saghez, with both parents (nuclear families), physically healthy mothers with one kid suffering from cerebral palsy aging 4 to 12, no participation in similar researches, no disability among other family members, keeping the disabled kid at home.

This research studied the life quality of mothers. The closer the average score was to 0, the lower the quality of life was. A closer average score to 100 indicated a more favorable life quality (34 - 35).

The intervention used in this research was education of a package developed in accordance with the requirements of mothers and based upon “5A self-management program”. This program consists of 5 steps and the corresponding educational package is designed based upon these steps. Having studied the questionnaires in the pre-intervention phase and through interviewing mothers, the necessary researches to specify the demands and requirements were carried out. In the second phase or guidance, only the intervention group was present and mothers were informed of the possible dangers of care-giving. In the third phase or agreement phase, researchers focused on the behavioral goals in order to determine the goals. In the fourth phase, educational classes were held for mothers of the intervention group in seven sessions in welfare organization. As for those mothers who could not attend these classes for any reason, the researchers went to their houses and provided them with educational packages. One session of class consisted of meeting with fathers in order to make them aware of the health status of their wives and enhance their participation in caregiving process. In fifth phase, in-house meetings and telephone follow up sessions were held to guide the intervention program and answer any possible questions.

3. RESULTS

Having reduced the data, 39 mothers and kids suffering from cerebral palsy took part. The results pointed to no significant difference between the two groups in terms of demographic data concerning the kid, mother, and family. An analysis of the main results showed that physical health as one of the sub-scales in control group before and after intervention ($P = 0.030$) and in intervention group before and after intervention ($P < 0.001$) exhibited a significant difference. In other words, the educational intervention has been able to cause a statistically significant difference between the two groups in terms of the average physical health sub-scale of life quality (table 1).

Table.1. Comparing the average physical health sub-scale of life quality before and after intervention in both groups

Phase Group	Before	After	T statistics	P-value Paired t
	Mean (SD)	Mean (SD)		
Intervention	39.81 (9.31)	46.79 (6.97)	-5.219	0.000
Control	39.49 (8.65)	41.88 (8.45)	-2.397	0.030
T statistics	-0.108	-1.983		
Independent t P-values	0.915	0.055		

According to the results, the average mental health subscale in the control group showed no statistically significant difference before and after intervention ($P = 0.084$). The average mental health sub-scale indicates a statistically significant difference before and after the intervention ($P < 0.001$). In other words, this educational intervention has been able to cause a statistically significant difference in mental health sub-scale in both groups, but no significant difference has been caused in control group (table.2).

Another part of the table makes a comparison between the average mental health sub-scale of life quality before intervention and after intervention in both groups. According to the results of statistical test, no statistically significant difference is observed between the two groups in terms of the average mental health sub-scale of life quality before intervention ($P = 0.440$) (table.2).

In other words, we can conclude that this intervention has not been able to create a statistically significant difference between the two groups before and after intervention.

Table.2. Comparing the average physical health sub-scale of life quality before and after intervention in both groups

Phase Group	Before	After	T statistics	P-value Paired t
	Mean (SD)	Mean (SD)		
Intervention	13.35 (10.47)	45.76 (7.20)	-8.710	0.000
Control	37.86 (11.10)	41.12 (12.23)	-1.848	0/084
T statistics	0.781	-1.812		
Independent t P-values	0.440	0.078		

According to the results of these tests, the total life quality score before intervention in both groups shows no statistically significant difference ($P = 0.705$). In other words, although the total life-quality score before

intervention in the intervention group is more than control group, this difference is by no means statistically significant. As it is shown in the above table, a statistically significant difference is observed between the two groups in post-intervention total score of life quality ($P < 0.001$). In other words, the educational intervention has been able to cause a statistically significant difference in the total score of life quality in both groups (table 3).

Table.3. Comparing the total score of life quality before and after intervention in both groups

Indicator Phase/group		Number	Average life quality	SD	Levene's variance equality test		Independent T equality test		
					F statistics	P- Value	T statistics	Freedom degree	P- value
Before intervention	Intervention	23	38.92	10.90	0.415	0.523	-0.382	37	0.705
	Control	16	37.63	9.65					
After intervention	Intervention	23	50.48	7.89	2.816	0.102	-3.931	37	0.000
	Control	16	39.25	9.92					

DISCUSSION

In this research, the mothers of those kids suffering from cerebral epilepsy played the main role in taking care of them (Masoumi, 2016). Their experience while taking care of their children pointed to the fact that looking after kids affects their life quality.

Concerning the life quality, the life quality level of mothers before the intervention was low. According to Davis et al (Davis, 2010), looking after kids with cerebral palsy influences their physical welfare, emotional and mental welfare, self-confidence, freedom and welfare of family and most parents suppose themselves without any support. This will have a negative influence on life quality indicators. In an analysis of the parents' experience in looking after kids suffering from cerebral palsy, Alaiee (2015) demonstrated the results of three levels of life (with difficulty, ambiguous, support needed) and suggested interventions to support the parents looking after kids and utilization of certain strategies to reduce physical and mental pressure and to enrich the information concerning child's disability.

In the research conducted by Ahmadizadeh (2013), in order to compare the life quality of mothers with kids suffering from cerebral palsy based upon the walking ability of kids, a significant difference was observed in the total score of life quality and aspects of social performance, physical performance and general health. As for those mothers with kids unable to walk, the life quality and its sub-scales were significantly less and role disruption due to physical health was less influenced (Ahmadi, 2015). This issue is indicative of the fact that despite physical pain and performance problems, mothers still show a high degree of self-devotion and are prone to better performing their maternal role. This will further weaken their physical performance and increase their pain and lower their life quality. They would need appropriate and timely intervention suitable for their needs (Khayatzadeh, 2009; Jalili, 2013).

In the research conducted by Khanjani (2010), it turned out that although rehabilitation can enhance the motion and movement of kids suffering from cerebral palsy, it has no influence on the health state and life of the mothers. Further to paying attention to the demands of the kid, certain interventions will be required to increase the life quality of mothers and it is necessary to develop a health-based supporting plan to enable mothers to manage their needs and those of their kids (Khanjani, 2010). "5A self-management program" is one of such methods.

In the current research and after carrying out "5A self-management program", the life quality of mothers in intervention group enhanced. In the research conducted by Kafami (Kafami, 2012; Taheri, 2016), the self-management program helped increase the life quality of those suffering from chronic disorder. In the research conducted by Ahmadi (2015), self-management program had an effective role on the scale of energy and fatigue which is in line with the results of our research.

Concerning the results of these researches and the results achieved in this study, teaching "5A self-management program" which is a new self-management program for those suffering from chronic disorder and utilization of the educational package developed through this program helps increase the life quality of mothers with kids suffering from cerebral palsy.

The short time span (7 sessions to teach the training package) was an important limitation in this research as many of the educational materials and problem solving techniques required rehearsal and repetition. What's more, absence of a professional treatment staff beside the nurses while presenting healthcare trainings was another limitation as existence of several specialties next to one another helps better understand the concepts and learners will gain a deeper understanding of issues at hand.

4. CONCLUSION

According to the results, it turned out the most mothers with kids suffering from cerebral palsy have a low level of life quality and suffered from health problems which influenced self-caring and looking after kids. Thus, it is necessary to develop appropriate plans to enhance life quality.

Teaching "5A self-management program" is a positive measure which helps enhance mothers' ability to manage their child's problems and provide them with better and less costly care in line with therapeutic and rehabilitator plans which help enhance the life quality of mothers.

It is therefore recommended to train mothers so that they can provide the appropriate care to enhance the health condition of those looking after kids with cerebral palsy and facilitate looking after them.

5. ACKNOWLEDGEMENT

This research is an extract from the M.S thesis of Taban Nemati advised by Dalvand in Nursing Department of Tehran University of Welfare and Rehabilitation. The author wishes to thank all the participants and those dear parents who helped us carry out this project.

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