

The Effectiveness of Life Skills Training on Quality of Life in Mothers of Children with Down syndrome

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Objectives: This study aimed to examine the effectiveness of life skills training on quality of life in mothers of children with Down syndrome.

Methods: This research was done as a semi-experimental with pre-post test and with control group. Statistical population included all children with down syndrome, age from 2 months to 8 years, and their mothers who referred to Iran's down syndrome society. Thirty six children were randomly chosen and equally assigned to two groups: experimental and control group. The data were collected by using the demographic questionnaire and the short form of the World Health Organization Quality of Life. Experimental group was trained for life skills in 12 sessions, each session 60 minutes. Data were analyzed using SPSS-16 software and multivariate analysis of covariance test.

Results: The results indicate that the mean score of quality of life in the experimental group was significantly higher than the control group after intervention.

Discussion: According to the results, life skills training increased the quality of life in mothers of children with Down syndrome. Therefore the life skill training can be applied in mental health services for improving the quality of life in mothers of children with Down syndrome.

Keywords: life skills, quality of life, mothers, children with Down syndrome

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Introduction

One of the most stressful experiences for any family is handling a child with a disability or chronic illness (1). The parents of a disabled child experience complicated and different feelings (2) Birth of a disabled neonate usually comes as a shock to the family at first. It sometimes leads to feelings of guilt, grief and desperation and parents experience mental distress (3) This changes the status of the family as a social unit in many ways (4) The mother is the first person who can directly communicate with the child. Faced with her disabled child, the mother's natural function will be undermined due to the special circumstances including stereotypes, language difficulties, struggling and lack of self-care skills and mobility problems (5). According to the fundamental role of the mother in raising, and stabilizing the

family, giving support to the parents of disabled children, will noticeably reduce their mental problems such as depression, stress and anger (6).

Down syndrome is the most common genetic cause of mental retardation (7,8) The incidence of this syndrome is one per 800 - 900 live births (9), and is considered as one of the most common congenital abnormalities with varying degrees of mental retardation from moderate to severe (10,11). Although the number of problems in children with Down syndrome compared with other disabilities is less, children with Down syndrome compared to normal children are faced with more difficulties (12,13) These children may have adaptive behavior, social development, memory, language, and emotional problems (14). Due to the problems such as accepting having a child with disabilities, care-related

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fatigue, leisure time problems, financial problems, health issues, education and rehabilitation, mothers of children with Down syndrome are under mental pressure, stress and anxiety and they feel more impotent towards their children (15). These daily challenges and pressures of raising a disabled child may have a negative impact on the quality of life in mothers (16). Several studies showed that the quality of life in mothers with disabled children is lower than the quality of life in mothers with normal children (17,18). According to the World Health Organization definition, the quality of life includes a person's perception of their position in life and in the structure of cultural-value system which they live in. Quality of life is a broad concept that includes concepts such as individual physical health, psychological state, level of independence, social relationships or communicating with outstanding environmental aspects. Environmental factors not only affect the individual's participation in society, but also have impact on quality of life; this is far more important in individuals with disability rather than the normal population (19). Quality of life is related to disease and conditions that endanger the health and on the other hand, having a disabled child in a family can be a challenging and unpleasant event causing physical and psychological stress in the family, especially the mother (20).

Recent studies showed that supporting the families of exceptional children or children with disabilities, has vital importance, as studies showed that supporting and training these families have positive impact on the family and children (21). Life skills' training is one of the most effective methods in approaches to meet the challenges of life (22). Life skills include psycho-social abilities to have an effective and adaptive behavior that enables individuals to deal more effectively with the needs and challenges of daily life (23). Bahrami (2) showed that life skills training has positive effects on mental health of mothers with exceptional children. Mc Carthy (24) investigated the impact of life skills training on parental stress and family functioning of families with a disabled child; the results showed that parents were well adapted to the levels of parental stress, family and marital relations. Wigrosski's (25) study showed that life skills training can help increase family stress management skills of the participants. Barlow and colleagues (26) showed that life skills training, health interventions and lifestyle are the effective approaches to improve the supervision, health care,

children's mental-social issues and depressed mood. Lam et al (27) in a study; the effectiveness of the life skills training on the parents of young children to deal properly with disabled children showed that their children's difficulties were reduced in comparison with the parents who were not trained.

According to the high prevalence of Down syndrome and their disabilities, and long-term effects on family, especially mother as the main child caregiver, this study was carried out to determine the effectiveness of life skills training on quality of life in mothers of children with Down syndrome.

Methods

This research was done in a semi-experimental study design with the pre-post test and control group. The participants consisted of all mothers with children with Down syndrome age from 6 months to 8 years old who referred to Down Syndrome Society of Iran in 2013. Participants were randomly chosen. To determine the sample size previous studies were used with the confidence interval of 95%. The sample size was 36 children who met inclusion criteria and were randomly assigned to two groups: experimental (18) and control (18).

After obtaining the permission from the University of Welfare and Rehabilitation Sciences, the researcher was introduced to the Down Syndrome Society of Iran in Tehran. The aims of this study and the methodology were explained to the officials of the society. Informed consent obtained from the mothers. Ethical considerations were performed. The measurements were demographic questionnaire and World Health Organization quality of life (short form) questionnaire (QOL-Brief). The QOL questionnaire is translated into 40 languages and has been standardized. The questionnaire consisted of 26 questions. The first two questions are about the overall quality of life and public health. The questionnaire examined four domains of quality of life including physical and psychological health, social relationships and environmental health. The scores of the four domains range from 0 to 20 that a higher score indicates a better quality of life. The item has a minimum score of "one" and a maximum score of "five". Internal consistency was 77% and 73% for the patient group and the control group respectively using Cronbach's alpha for the 4 domains (17). This questionnaire has been standardized in Iran. Its reliability with the index of cluster correlation was 77%, 77%, 75% and 84% for physical health, psychological health, social relationships and

environmental health respectively (28). The quality of life questionnaire was implemented as the pre-test. Then, the experimental group received life skills training in 12 sessions (2 sessions per week, each 60 minute) while the control group did not receive any training.

Klinke (29) and World Health Organization (23) life skills training program were used. The content of training sessions as follows: session 1: greeting and introducing the members; introducing life skills training program, explain the rules of training sessions, the time of classes and take the pre-test. Session 2: stress, coping skills and effective factors to deal with stress were described. Session 3: different types of emotions and their impact on social relationships and some strategies to control unpleasant feelings were expressed. Session 4: mothers were acquainted with problem solving. Session 5: The importance of decision making skills to achieve a goal as well as various ways of decision making was taught. Session 6: self-awareness components, factors influencing the growth and barriers to the growth of self-awareness were described. Session 7: empathy skills, necessary condition were expressed for sympathy. Session 8:

the importance of effective communication in human flourishing, the barriers of communication. Session 9 interpersonal skills and the importance of it in mental health, social interaction skills were learned. Mothers got to know conflict of personal life in the tenth session. Session 11 creative thinking and the difference of material thinking and thinking was explained. Session 12: the training topics were summarized, and the post-test was performed. The pre-test and post-test were also taken from mothers in the control group without any intervention. Data were analyzed using SPSS-16 software and multivariate analysis of covariance test.

Results

Thirty-six mothers participated in this study. The mean and standard deviation of mothers' and children ages were (36/36± 6/73) and (5±1/3) respectively. 66/65% of mothers were high school graduates or less and 33/35% had a University degree. 75% of mothers were housewives and 25% were employed. Table (1) shows the descriptive parameters of data in the pre-test and post-test, in 2 groups.

Table 1. Quality of life scores in pre-test and post-test, in two groups.

groups	variable	Pre-test			Post test	
		SD	M	SD	M	
Experimental (N=18)	Physical health	3.47	20.94	3.56	25.66	
	Psychological	3.16	17.39	3.20	21.83	
	Social relationships	1.41	9.11	1.82	12.16	
	Environment	3.76	17.94	5.51	24.22	
	Quality of life	10.17	65.39	10.17	83.89	
Control (N=18)	Physical health	2.43	18.44	2.36	18.22	
	Psychological	2.11	14.61	2.03	15.39	
	Social relationships	1.97	7.00	2.03	7.17	
	Environment	2.43	15.44	2.46	15.94	
	Quality of life	6.48	55.50	5.84	56.72	

As it is seen, the mean scores of the quality of life domains in post-test increased in experimental group, after intervention in comparison to pre-test. This change is not observed in the control group.

Multivariate analysis of covariance was used to assess the effectiveness of life skills training on quality of life in mothers of children with Down syndrome (Table 2).

Table 2. The overall results of the multivariate analysis of covariance

Type of test	quantity	Df Hypothetical	Df Error	f	p
Pillai's Trace	0.73	4	27	18/28	0.00
Wilks' Lamda	0.27	4	27	18/28	0.00
Hotelling's Trace	2.70	4	27	18/28	0.00
Roy's Largest Root	2.70	4	27	18/28	0.00

The meaningful indicators of multivariate test, i.e Wilks's Lambda , Hotelling's Trace, Roy's Largest Root and Pillai's Trace (F=18.283, p < 0.0005)

confirmed this significant difference at least in one component of quality of life test . Hence each of these components was examined (Table 3).

Table 3. Comparison of the effects of pretest posttest control group

Sources changes	Value	Df	F	P Value	Multiplier effect	Statistical power
Experimental	Physical health	1	14.99	0.001	0.33	0.96
	Psychological	1	17.61	0.00	0.37	0.98
	Social relationships	1	2.01	0.16	0.06	0.28
	Environment	1	12.87	0.001	0.30	
control	Physical health	1	33.37	0.00	0.53	0.93
	Psychological	1	30.62	0.00	0.50	1.00
	Social relationships	1	29.44	0.00	0.49	1.00
	Environment	1	13.75	0.00	0.38	0.99
	Quality of life	1	70.51	0.00	0.70	0.99
Error		30				
total		36				1.00

Discussion

The results obtained from the comparison of the pre-test and post-test of physical health, psychological health, social relationships and environmental health in both of the groups suggests that after life skills training, the scores of the physical health, mental health, social relationships and environmental health of the mothers in the experimental group were significantly increased in comparison to control group ($P < 0.0005$). This showed that life skills training is effective in the quality of life in mothers of children with Down syndrome, so life skills training can increase individuals' awareness about their capabilities and it enables individuals to use their abilities for solving problems and improving the aspects of life.

Since life skills training sessions were in group form, it can have a positive effect on reducing stress. Gathering people in a group cases individual feels others also have similar problems. It can reduce stress and minimize the negative mood, thus the acceptance of reality and dealing with it can be increased. Life skills training makes individuals get to know more their strengths and weaknesses and have a better self- recognition. This awareness helps the individual solves problems. Berg, et al (30) concluded that most problems have essentially a social and interpersonal nature. When people are in a group counseling session, they will be able to replicate the characteristics of other members of the group, they can and achieve a true understanding of their problems by observing others' behavior (31) The results of this research is also consistent with these studies (2,25,31-35). Rach et al (36) found that parents of children with Down syndrome have more severe stress and depression rather than parents of normal children and as the child grows, mother's level of satisfaction with life will decrease. Higher life skills training provide mental, social and physical health in individuals, and in contrast, lower life skills training causes psychological harm and

inappropriate behaviors of individuals (37). Many researchers believed that coping skills such as problem solving, foresight and reasonable and accurate evaluation helps people deal with problems successfully. Unfortunately, many people have not acquired the necessary skills to cope with daily problems of life, so it is vulnerable for them to face everyday problems. Many mental-emotional problems have socio-psychological roots and if people have such capabilities, they are able to be in a desirable mood (38). Barlow et al. also stated that life skills training leads to actual knowledge and individuals' perception of their capabilities. It allows compatibility with a wide variety of environments and it helps individuals face everyday situations in ways that is acceptable to the family and society (26). According to the study it concludes that life skills training make individuals prepared to deal with problems and it leads to more resistant personality, increasing insight into the life and events, increasing life management skills and better interaction with the environment and people. As a result, individuals try to deal with the inevitable problems with comprehensive knowledge, so the basis for improving the quality of life is provided. Raising parents' awareness about stress, anxiety, facilitating access to the appropriate information and recommending treatment is not only useful for the parents but also can lead to a trustful relationship between parents and child, and thus increases the quality of life (39). The implementation of such psychological interventions can prevent the occurrence of mental health problems due to unfortunate circumstances and play an important role for coping. Life skills include a set of abilities that increase effective and positive behaviors and adaptation. Life skills training can be applied by experts as an educational approach to improve the quality of life in mothers and create a space for mothers of children with Down syndrome to help mental health services.

This study has also some limitations; since the sample size was small, generalizability of the results should be done with caution. Other limitations were the lack of availability of fathers to participate in the intervention program, follow-up test had not been performed and thus we could not determine the persistent of life skills training effects.

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