



The Influence of Acceptance and Commitment Therapy on Perceived Social Support, Hope Level, and Caregiving Burden of Mothers with Down Syndrome Children

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Abstract

Background: Children with Down syndrome (DS) can pose many problems and challenges for parents and caregivers. Therefore, seeking and implementing specific treatment options can improve the psychological parameters of parents.

Objectives: The main aim of this study was effectiveness evaluation of acceptance and commitment therapy (ACT) on perceived social support, life expectancy and caregiver burnout of mothers with DS children.

Methods: For this study, 30 mothers with DS children were selected by the random simple sampling method and divided into two intervention groups (15 mothers) and control groups (15 mothers). For the intervention group, the ACT method was implemented during eight weekly sessions, while for the control group no intervention method was implemented. Next, the subjects were questioned at three different stages: Before the ACT, immediately after the ACT, and one month after the ACT. SPSS-Ver.22 software was used for analyzing of obtained data.

Results: The results indicated that for the control mothers, the average score of the three main study variables among the three main phases of the study (pre-evaluation, post-evaluation, and follow-up) did not have a considerable difference, while for the control mothers some considerable differences were observed ($P < 0.001$). Based on the results obtained, in the post-evaluation and follow-up phases, the mean score of the "perceived social support" and "hope level" variables in the ACT mothers was considerably higher than that of the control mothers ($P < 0.001$), while for the "caregiving burden" variable it was considerably lower ($P < 0.001$).

Conclusions: It can be concluded that ACT has a positive and considerable effect on improving the psychological parameters of mothers of DS children. Therefore, it is suggested that this therapeutic method be used in clinical interventions and psychological counseling for caregivers of DS children, especially their mothers.

Keywords: Down Syndrome, Children, Mothers, Caregivers, Psychological Parameters, Acceptance and Commitment Therapy

1. Background

Children with Down syndrome (DS) are a large group of children with special needs who have distinct clinical features (1, 2). The DS is the most common chromosomal genetic cause of intellectual disability in children. The severity of the disease varies among individuals, in addition to intellectual disability, can cause developmental delays in various human body parts. Also, DS can commonly cause other diseases, especially heart and gastrointestinal diseases (3). The incidence of

DS in the United States America (USA) is estimated to be 14.47 per 1000 live births, or about 6000 children per year (4). The worldwide incidence of this disorder is 1 in 700 - 800 live births, although this figure has increased in recent years (5, 6). Children with DS are considered to be children with special needs and require more care than healthy children because DS children are usually at risk for physical, mental, behavioral, and emotional illnesses (7-9).

The birth of a child with DS creates various problems for parents and other family members. These problems

usually start with a shock in the early stages. Sometimes it is accompanied by feelings of sadness, grief and helplessness for the parents. The birth of a child with a disability, such as DS, can cause psychological distress to the point of suicide in the parents (10). On the other hand, the obligations of the parents and their daily responsibilities in life are affected by the problems of their child with a disability and lead to a change in the role or duties of the parents. This situation causes stress, anxiety and depression in the parents (11-14). In general, it can be said that the parents of children with DS, due to the widespread and more permanent symptoms of this disorder, are often continuously involved in caring for these children throughout their lives (15). Therefore, family members, especially parents, experience many stresses throughout their lives that may affect their mental and physical health (16). Among parents of DS children, mothers are under the greatest psychological pressure. Because, due to their personality structure, mothers feel more responsible and sometimes feel guilty. In addition, mothers are more likely than fathers to communicate with neighbors, relatives, and others and are exposed to explaining the DS child's condition (17).

Given the low life expectancy of mothers of DS children and the need for perceived social support in them, it is necessary to provide a supportive intervention aimed at increasing the sense of control over caregiving tasks, reducing psychological distress, and managing stressful situations. Acceptance and commitment therapy (ACT) seems to be helpful in this regard, as the goal of ACT is to create a rich and meaningful life in a situation where the individual accepts the unwanted suffering that exists in it (18, 19). The ACT is a cognitive-behavioral psychotherapy method that focuses on acceptance and commitment to life values. Rather than trying to eliminate or control painful thoughts and feelings, this therapy helps individuals to accept them and at the same time move towards important goals and values in their lives (19-21).

2. Objectives

The main aim of this study was effectiveness evaluation of ACT on perceived social support, life expectancy and caregiver burnout of mothers with DS children.

3. Methods

To conduct the present study, first, the characteristics and addresses of mothers with DS children were identified by accessing the DS children's file in Qaemshahr city, Iran. The sample size was calculated

based on a statistical power of 0.8 and an effect size of 0.3 using G*Power software, equivalent to 30 people, which were selected by simple random sampling. The selection criteria for mothers to participate in the present study included being under 60 years of age, having no history of personality disorder, not having participated in the ACT course in the last two years, not being the head of the family, and being willing to participate in the study. Subsequently, 15 of them were classified as the intervention mothers and the other 15 as the control mothers. The ACT intervention was held for the Intervention mothers during eight one-and-a-half hour sessions (during 8 consecutive weeks), while no intervention was performed for the control mothers.

Data collection tools included the Multidimensional Perceived Social Support Questionnaire (MSPSS), Adult Hope Scale (AHS), and Caregiver Burden Scale (CBS). The validity and reliability of the Persian version of the MSPSS in Babaieamiri research (22), AHS in the study of Kermani et al. (23) and CBS has been found appropriate and confirmed by findings of Qorbani et al. study (24).

For both study groups, pre-evaluation, post-evaluation and follow-up stages were conducted by distributing the above-mentioned questionnaires. Pre-evaluation, post-evaluation and follow-up stages were conducted at different times, respectively, including "before implementing the ACT intervention", "immediately after implementing the ACT" and "one month after implementing the ACT". Finally, SPSS-Ver.22 software was used for analyzing of obtained data.

4. Results

Based on the findings presented in Table 1, the frequency of the age range of 25 - 46 and 60 - 46 years for the ACT mothers was 7 (46.7%) and 8 (53.3%) and for the control mothers, it was 5 (33.3%) and 10 (66.7%), respectively. For the ACT mothers, 6 (40%) and 9 (60%) were employed and unemployed, respectively; while for the control mothers, these values were 5 (33.3%) and 10 (66.7%). In terms of educational level, for the ACT mothers, 3 (20%) had a sub-diploma and diploma and 12 (80%) had a Bachelor's degree and above, while for the control mothers, these values were 6 (40%) and 9 (60%), respectively. In addition, the study findings showed that for the control mothers, the mean score of the three main study variables among the three main phases of the study (pre-evaluation, post-evaluation, and follow-up) did not have a considerable difference, while for the control mothers some considerable differences were observed ($P < 0.001$, Tables 2 to 5). Based on the results obtained, in the post-evaluation and follow-up phases, the mean score of the "perceived social support" and

Table 1. The Age, Occupation, and Educational Characteristics of the Mothers Evaluated in the Present Study^a

Variables	Test Group (ACT)	Control Group	P
Age (y)			0.887
25 - 45	7 (46.7)	5 (33.3)	
46 - 60	8 (53.3)	10 (66.7)	
Job			0.912
Employed	6 (40)	5 (33.3)	
Unemployed	9 (60)	10 (66.7)	
Educational level			0.695
Less than a BSc	3 (20)	6 (40)	
BSc and above	12 (80)	9 (60)	

Abbreviations: ACT, acceptance and commitment therapy; BSc, bachelor of science.

^a Values are expressed as No. (%).

"hope level" variables in the intervention mothers was considerably higher than that of the control mothers ($P < 0.001$), while for the "caregiving burden" variable it was considerably lower ($P < 0.001$, Tables 2 to 5).

5. Discussion

The findings of the present study showed that the ACT intervention method can be considerably effective in increasing perceived social support and hope level and reducing caregiving burden in mothers with DS children. In explaining the results, it can be said that ACT is a mindfulness-based and behavior change treatment approach that emphasizes accepting internal experiences, clarifying values, and committing to actions based on them. This treatment helps individuals to accept negative emotions rather than avoid them and move towards their meaningful goals. Previous research has shown that ACT can play an effective role in improving mental health, reducing anxiety and stress, and increasing psychological flexibility (25). In particular, this treatment has been effective in improving the quality of life (QoF) of people with chronic stress, including parents of children with special needs (26). The ACT has six basic processes, including acceptance, cognitive decoupling, mindfulness, self-context, value clarification, and committed action. These processes help individuals focus on performing adaptive behaviors that are consistent with their values instead of engaging in negative thoughts (27). One of the important features of ACT is its ability to reduce experiential avoidance, which helps people accept unpleasant emotions and actively face life challenges instead of running away from them (8-10).

Similar to this research, various other research have been done previously, the findings of which are

consistent with the results of the present study. Hayes et al. showed that ACT can effectively increase social support and hope in individuals (25), and the results of the present study also confirmed the high effectiveness of ACT in improving the aforementioned indicators. In addition, a study by Arch and Craske showed that ACT plays an important role in improving emotional regulation and reducing stress, which is consistent with the findings of the present study (28). In another study conducted by Aghababae and Alipour, the effectiveness of ACT focusing on compassion on emotional processing and self-care in adolescent girls with premenstrual syndrome was examined, and the results indicated an improvement in emotional processing and self-care, which could be related to increased hope (29). Also, in a study by Shavaran and Dehghani Champiri investigated the effectiveness of ACT on perceived social support and life expectancy in caregivers of patients with amyotrophic lateral sclerosis (ALS), and the results showed that this treatment increased perceived social support (30). Saeedifard et al. indicated that ACT-based group therapy increased the resilience of mothers of children with intellectual disabilities, which can lead to a decrease in caregiver distress (31). Carvalho et al. compared the influence of ACT and compassion-focused therapy (CFT) for people with chronic illnesses; the results indicated that both interventions were effective in reducing psychological stress, improving QoF, and increasing emotional regulation. However, ACT had a greater effect on acceptance of the illness, while CFT considerably improved self-compassion and reduced feelings of shame (32). Nikonezhad et al. compared the effectiveness of ACT and CFT in controlling emotions in women with multiple sclerosis (MS) (33). The results show that both methods are effective in reducing anger, depression, and anxiety and increasing positive affect,

Table 2. The Social Support Category in the Acceptance and Commitment Therapy and Control Mothers in Different Study Phases ^a

Variables	Pre-evaluation	Post-evaluation	Follow-up
Friends			
ACT	6.57 ± 1.78	15.30 ± 6.14	15.38 ± 2.07
Control	6.41 ± 1.98	6.55 ± 1.75	6.62 ± 1.74
Family			
ACT	7.81 ± 1.84	14.83 ± 3.25	14.93 ± 3.33
Control	7.49 ± 1.80	7.59 ± 1.76	7.65 ± 1.61
Others			
ACT	6.34 ± 1.01	13.62 ± 2.49	13.77 ± 2.03
Control	6.20 ± 0.85	6.52 ± 1.41	6.59 ± 1.65
Perceived social support			
ACT	20.72 ± 2.57	43.75 ± 9.57	44.08 ± 4.87
Control	20.10 ± 2.17	20.66 ± 3.26	20.86 ± 2.56

Abbreviation: ACT, acceptance and commitment therapy.

^a Values are expressed as mean ± standard deviation (SD).

Table 3. The Hope Category in the Acceptance and Commitment Therapy and Control Mothers in Different Study Phases ^a

Dependent Variables	Pre-evaluation	Post-evaluation	Follow-up
Agency thinking			
ACT	7.59 ± 0.73	12.13 ± 1.56	12.19 ± 1.59
Control	7.57 ± 0.85	7.55 ± 0.81	7.52 ± 0.77
Pathways thinking			
ACT	7.78 ± 0.48	14.25 ± 2.05	14.36 ± 1.91
Control	7.79 ± 0.50	7.82 ± 0.67	7.89 ± 0.50
Hope level			
ACT	15.37 ± 0.92	26.38 ± 2.31	26.55 ± 2.24
Control	15.37 ± 0.94	15.37 ± 1.01	15.42 ± 0.98

Abbreviation: ACT, acceptance and commitment therapy.

^a Values are expressed as mean ± standard deviation (SD).

but CFT has provided better results in reducing anxiety and increasing self-compassion, while ACT has helped improve acceptance of the situation and commitment to personal goals. The researchers of the aforementioned studies suggested that the choice of treatment should be based on the individual needs of each patient (33). In another study by Mousavi et al. compared the effectiveness of ACT, FCT, and ACT enriched with CFT (ACT+CFT) on social adjustment in women with depression and marital conflict. They showed that all three methods are effective, but "ACT+CFT" had a greater effect on improving social adjustment and reducing marital conflict. The researchers of the aforementioned study emphasized that the combination of compassion and acceptance elements can help increase the effectiveness of the treatment (34).

In line with the finding of this investigation, in a study done by Ne'matpour et al., they observed a considerable effect of ACT on the perceived social support of mothers with children with autism (35). In addition, Kashfi et al. also showed a positive and considerable effect of ACT on life expectancy and decision-making ability of addicts (36). In another study by Fadae et al., they evaluated ACT as effective on the happiness and psychological adjustment of parents of mentally retarded children, and its findings showed that the hopefulness of students with substance-dependent parents was considerably increased under the influence of acceptance and commitment-based education (37). In the study by Rostami et al., ACT and coping strategies were considerably effective in reducing anxiety and hopelessness in mothers of autistic children (38). Also, Poddar et al. examined the

Table 4. The Category of Caregiving Distress in the Acceptance and Commitment Therapy and Control Mothers in Different Study Phases ^a

Dependent variables	Pre-evaluation	Post-evaluation	Follow-up
General distress			
ACT	16.08 ± 1.99	13.18 ± 1.93	13.07 ± 2.10
Control	16.09 ± 1.58	16.05 ± 1.61	16.02 ± 1.64
Loneliness			
ACT	10.29 ± 1.42	6.57 ± 1.60	6.55 ± 1.81
Control	10.29 ± 1.50	10.21 ± 1.48	10.08 ± 1.44
Hopelessness			
ACT	14.58 ± 3.29	11.15 ± 3.20	11.06 ± 3.08
Control	14.60 ± 2.15	14.38 ± 2.40	14.25 ± 2.48
Emotional involvement			
ACT	9.58 ± 2.04	6.20 ± 1.44	6.11 ± 1.25
Control	9.59 ± 1.31	9.49 ± 1.36	9.45 ± 1.50
Environment			
ACT	9.96 ± 2.45	6.79 ± 1.78	6.69 ± 1.66
Control	9.98 ± 1.57	9.86 ± 1.77	9.76 ± 1.81
Caregiving suffering			
ACT	60.47 ± 10.49	43.90 ± 6.76	43.48 ± 6.37
Control	60.56 ± 6.37	59.98 ± 7.70	59.55 ± 7.76

Abbreviation: ACT, acceptance and commitment therapy.

^a Values are expressed as mean ± standard deviation (SD).

Table 5. The Comparison of Average Score of the Perceived Social Support, Hope Level, and Caregiving Suffering in Different Study Phases for the Acceptance and Commitment Therapy Group

Dependent Factors	Study Groups		P
Perceived social support	Pre-evaluation	Post-evaluation	< 0.001
	Pre-evaluation	Follow-up	< 0.001
	Post-evaluation	Follow-up	0.999
Hope level	Pre-evaluation	Post-evaluation	< 0.001
	Pre-evaluation	Follow-up	< 0.001
	Post-evaluation	Follow-up	0.999
Caregiving suffering	Pre-evaluation	Post-evaluation	< 0.001
	Pre-evaluation	Follow-up	< 0.001
	Post-evaluation	Follow-up	0.999

considerable effects of this treatment method among parents of children and adolescents with autism, and the results indicated positive effects of this treatment on anxiety, depression, psychological flexibility, and QoF (39). Maughan et al. (2024) also found positive effects of this treatment on improving depression in mothers of autistic children (40). Positive effects were also observed in the study by Marino et al. following the use of this treatment in considerably improvements in psychological flexibility, state of awareness, personal values in daily life, and stress of mothers of autistic children, and parents' understanding of the destructive behaviors of the autistic child (41). The results of this

research and the results of other similar studies indicate a positive and considerable effect of ACT on increasing social support, increasing hope, and reducing the suffering of caring for mothers of children with illnesses or special needs.

5.1. Conclusions

Based on the results obtained in the present study, it can be concluded that the intervention method of ACT can be very effective in increasing perceived social support and hope level and reducing caregiving burden in mothers of DS children. The findings indicate a

positive and considerable effect of ACT on improving the QoF and psychological parameters of mothers of DS children. Therefore, it is suggested that this therapeutic method be used in clinical interventions and psychological counseling to improve the QoF of caregivers of DS children, especially their mothers.

5.2. Limitations

One of the limitations of this research was that its results were only related to mothers of DS children and these findings may not be generalizable to mothers of other children with health and physical problems. In addition, the use of self-reporting by mothers and the use of limited tools to collect information were other limitations of this study that may cause bias. It is suggested that future research should include mothers of other children with physical and mental problems and use alternative tools such as interviews to increase the generalizability of the findings.

Footnotes

Authors' Contribution: H. D. K.: Participation in study design, data collection, and data analysis; S. H.: Participation in study design, writing and revision of original and revised manuscript; K. A. N. B.: Participation in study design, supervision, investigation, methodology, project administration, and data curation.

Conflict of Interests Statement: The authors declare no conflict of interest.

Data Availability: The dataset presented in the study is available on request from the corresponding author during submission or after publication.

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