

Effect of Therapeutic Recreation on Mothers Having Children with Autism Spectrum Disorders

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Abstract

Introduction: Families having children with autism spectrum disorder (ASD) were the most negatively affected group in terms of depression, anxiety, somatic complaints, burnout and quality of life (QoL). It is known that Therapeutic Recreation Programs have positive effects on depression symptoms and quality of life of individuals. Therefore, the aim of this study was to investigate the effect of a one-week therapeutic recreation program on the symptoms of depression and QoL of mothers who have children with ASD.

Method: Fifteen mothers volunteered in this quantitative research, which was performed as a single-group pre-test and post-test experimental design. ASD diagnosed by medical professionals and classified as having moderate or severe ASD according to the Gilliam Autism Rating Scale-2-Turkish Version (GARS-2-TV). Data was collected via Quality-of-Life Questionnaire-Parent Edition and Beck Depression Inventory before and after the therapeutic recreation camp at a mountain camping center in 2020.

Results: Wilcoxon Signed Ranks Test results revealed that the therapeutic recreation program had a positive effect on the levels of depression and ASD related QoL but did not have a significant effect on the general QoL of mothers.

Conclusion: It can be argued that even a one-week therapeutic recreation program provides a significant improvement in the QoL of mothers and, consequently, a decline in their symptoms of depression.

Keywords: autism spectrum disorder, depression, mothers, quality of life, therapeutic recreation.

Introduction

Recreation has been described as the experience and activities that someone choose and pursue in one's leisure time (Austin, 2004). These activities of an individual's own choice have soothing

and regenerative effects which create motivation for the work they need to perform outside of leisure time.

Recreational activities performed by individuals with physical or mental health problems are called recreation therapy or therapeutic recreation. Therapeutic recreation helps people with physical or mental health problems to improve their quality of life (QoL) by reducing the effects of health problems (Hutchinson & Lauckner, 2020). In the case of a disease or disability, recreation may slow down or even stop the progression of diseases, provide supportive contributions to the treatment and increase the QoL of the individual and therefore is recalled as recreation therapy or therapeutic recreation (Sylvester, 2013). Not only disease and disability, but also social and psychological discomfort of the individual is within the scope of the therapeutic recreation (Williams and Bond, 2002). Therapeutic recreation has significant contributions in reducing physical and mental health problems such as depression and anxiety, thus, it improves well-being (Carruthers & Hood, 2007; Sylvester, 2013; Vella et al., 2013)

Several studies have focused on the evaluation of QoL of individuals with disabilities so far, however, their family members' QoL have not been included in these studies and recently begun to attract attention. QoL of the family is defined as not only fulfilling the needs of individuals in the family, but also sharing life as a family and achieving meaningful goals together (Park et al., 2002) The relationships with children and each other, significantly affects family functioning, communication and life habits of family members (Rettig & Leichtentritt, 1999). This relationship is the main element that differs in families with children with disabilities and therefore may affect the QoL of the whole family members at different levels depending on the direction of the relationship (Bertelli et al., 2011).

In the last decade, rates of ASD diagnoses have been rising rapidly all over the world (Elsabbagh et al., 2012). ASD is a neurodevelopmental disorder which is characterized primarily by limited social communication deficiencies that start in early childhood and progress with restricted and repetitive patterns of behavior and interests. There are usually no obvious physical markers of ASD, while it is lifelong and extremely disruptive with increased probability of strained social encounters (Farrugia, 2009). The characteristic features of ASD may negatively affect the QoL of both the individual and family members due to the psychological stress in everyday life. Families having children with ASD face many problems such as stress, heavy care burden of the children with ASD, and problem behavior of their child like bouts of anger, destructive routine behavior, difficulties in social skills, and often being refused to be teased with rejection (Gurbuz-Ozgur et al., 2017). The inability to act independently in life and the intense anxiety of the future as a result of the need for one-to-one assistance are among the important factors effecting the QoL (Chiri & Warfield, 2012). Experience of stress and depression and lower overall family functioning in the family depends on the severity of child's ASD (Benjak, 2011; Hayes & Watson, 2013; Khanna et al. 2011). The psychological problems of parents who have children with ASD are the most intense among the parents having children with other types of neurodevelopmental disabilities (Chiri & Warfield, 2012; Dabrowska & Pisula, 2010; Estes et al. 2009; Sikora et al. 2013). Moreover, Weiss (2002) stated that families having children with ASD were the most negatively affected group in terms of depression, anxiety, somatic complaints and burnout.

Krausz and Meszaros (2005) stated that having a child with ASD has a negative effect on mother's QoL, since the caregiver demands has been taken on by women as a result of cultural expectations (Hastings et al., 2003; Lai & Oei, 2014). Thus, mothers are faring worse on a

variety of outcomes such as stress (Dabrowska & Pisula, 2010) and depression (Hastings et al., 2005) and anxiety (Hastings, 2003). The higher stress level and burnout of parents having children with ASD shows an increased need for a social support (Lai & Oei, 2014; Sikora et al., 2013). No previous research specifically addresses how perceived support as physical exercise based therapeutic recreation would affect the symptoms of depression and QoL of mothers.

The results from this study will help to determine whether physical exercise based recreational therapy program significantly (1) improve the mental health of mothers having children with an ASD, and (2) increase their perceived QoL.

Method

The effect of a Therapeutic Recreation Program (TRP) on the symptoms of depression and levels of QoL of mothers having children with ASD was determined with a single group pre and posttest experimental design. The study was conducted with the approval of National Institutional Review Board. Pretest was performed before the recreation camp, whereas the posttest was performed at the last day of the camp.

Participants

A series of activities (such as academic, social, educational, and behavioral) have been carried out with special education experts from the Provincial Directorate of National Education, faculty members from the Faculty of Sports Sciences of University in provincial and volunteer students, and individuals with ASD for about 2 years and their families. A total of 30 mothers who participated in these activities were invited to our study. The criteria sampling method was used to select participants who are mothers of children with ASD. The inclusion criteria of the study was (a) being healthy and volunteering to participate in the study, (b) having only one child with ASD at school age (at least 7 years old and younger than 18 years), (c) having a child with ASD diagnosed by medical professionals and classified as having moderate or severe ASD according to the Gilliam Autism Rating Scale-2-Turkish Version (GARS-2-TV). GARS-2-TV was applied to all children prior to the study by a specialist having a practitioner certificate in order to verify the ASD levels of children. GARS-2-TV is a rating scale used for the evaluation of individuals' behaviors specific to autistic disorder and is also quite powerful in detecting the psychometric properties of individuals with ASD (Diken et al., 2012). Fifteen mothers met these criteria and volunteered to the study by signing the written informed consent. Demographic data of the participants are presented in Table 1.

Table 1

Descriptive characteristics of the mothers having children with ASD

<i>Variables</i>	$\bar{x}\pm SD$	<i>f</i>	<i>%</i>
<i>Children</i>			
Age	11.7±2.7		
7-12		10	66.7
13-18		5	33.3
Gender			
Girl		2	13.3
Boy		13	86.7
Level of ASD			
Intermediate		7	46.7
Heavy		8	53.3

<i>Total</i>		15	
<i>Mothers</i>			
Age		39.9±5.96	
Level of education			
Primary school		10	66.7
High school		3	20.0
Undergraduate		2	13.3
Income			
Low		3	20.0
Moderate		8	53.3
High		4	26.7
<i>Total</i>		15	

Note: \bar{x} =Mean, SD=standard deviation

Experimental Design and Camp Program

The study was performed at a mountain camping center in 2020. Fifteen mothers and their children with ASD and 15 sports science students were transferred to the camping center by bus and were introduced to the 5 camp leaders who are specialized for physical education training for individuals with special needs. Ice breaker activities were performed at their arrival and camp program was shared with the team. Pre-test evaluation was performed by two special education specialists at the first day of the camp. During the camp, mothers and their children joined the gamified physical exercise sessions together every morning for 7 days. Breakfast, lunch and dinner were held together with families and trainers. On the afternoon, children performed art activities such as painting, listening or performing music, whereas mothers joined recreational activities such as outdoor games, walking in nature, creative drama, and winter sled for 3 hours individually or as group for 7 days. Mothers joined with their children to an hour dancing session after every dinner. At the end of the camping program, post-test evaluation was performed by the same specialists at the same day (Table 2). Activities have been chosen according to improve the relationship between the mother and the child with ASD and to establish healthy communication (Solish et al., 2010).

Table 2

Experimental design of the study and weekly camp program

Timeline (days)	Phase	Content
Pre-camp period	Preparation	-Determination of ASD level in children by GARS-2-TV - Selection of Participants - Obtaining written consent forms - Collecting Personal Information Forms
Day 1	Adaptation Phase	Transfer to the camping center by bus (6.30 pm) - Ice breaker activities - Sharing the camp program with families and team
Day 2	Pre-test Assessment	1) QoLA 2) BDI 3) Observation
Days 3-9	Therapeutic Recreation	Group activity (Mother and child paired activities)

Camp	- 10.30 am – 12.00 am; physical exercise workout; low intensity a) Warm-up: 10 min, b) Main session A: 45 min (Fitness), and c) Main session B: 25 min gamified exercises Cool down: 10 min - 12.00 am – 1.00 am; Free Time - 1.00 am – 1.30 pm; Lunch
	Individual activity (Mother and child activities separately) - 1.30 pm – 5.00 pm; Recreational activity sessions a) Mothers; outdoor games, walking in nature, creative drama, storytelling, and b) Children; creative art activities, painting, listening to music, playing an instrument, drama, educational games, outdoor activities. - 5.00 pm – 5.30 pm; a) Free Time for mothers and children, and b) Daily Evaluation Meeting for the team - 5.30 pm – 6.00 pm; Dinner - 6.00 pm – 6.30 pm; Free time - 6.30 pm – 7.30 pm; Dance workout - 7.30 pm – 8.00 pm; Communication session and relaxation - 8.00 pm – 9.00 pm; Rest
Day 10	Post-test Assessment 1) QoLA 2) BDI 3) Observation
Day 11	Closure City tour and transfer to hometown

Data Collection Tools

Personal information form including questions for descriptive statistics, Quality of Life in Autism Questionnaire-Parent Version (QoLA) and Beck Depression Inventory (BDI) were used as data collection tools in pre-and post-test assessment.

Quality of Life in Autism Questionnaire-Parent Version (QoLA)

QoLA was developed by Eapen et al. (2014) and adapted to Turkish by Gurbuz-Ozgun et al. (2017). QoLA consists of two sub-scales, Part A and B. QoLA-Part A includes 28 questions that measure how parents perceive their overall QoL. Each question is scored with a five-point likert-type scale from one (none) to five (too much). The higher the score received from QoLA-Part A, the higher parents' quality of life is. The QoLA-Part B consists of 20 questions that evaluates parents' perception of their child's ASD related behaviors. QoLA-Part B test scoring is based on a five-point likert-type scale ranging from "it was not a problem for me" scored as "1" to "it was too much problem for me" scored as "5". Higher scores at QoLA-Part B indicate lower quality of life for parents. Both Part A and Part B of the Turkish adaptation of QoLA measure

have high internal consistency with alpha coefficients ranging from .92 to .94 (Gurbuz-Ozgun et al., 2017).

Beck Depression Inventory (BDI)

BDI was initially developed by Beck (1967). BDI contains 21 items that assess cognitive, behavioral, affective, and somatic components of depression symptoms. It consists of 21 multiple choice self-report items, which has four levels sorted by symptom intensity. Each item is scored on a scale of 0 to 3. The total lowest score that can be obtained from the scale is 0, and the highest total score is 63. If the total score is between 0-9, it is evaluated as minimal depression, between 10-16 as mild depression, between 17-29 as moderate depression and between 30-63 as severe depression. BDI has high internal consistency with alpha coefficients ranging from .73 to .92 at the original form (Beck et al., 1988) and alpha coefficient of .80 at the Turkish adaptation form (Hisli, 1989).

Statistical Analysis

Statistical analysis was performed with IBM (SPSS ver. 25.0, Armonk, NY: USA) statistical package program. Normality of data was tested by Shaphiro-Wilk's test. Wilcoxon Signed Ranks Test was used to determine the effect of gamified physical exercise a) on the mental health and b) QoL of mothers having children with ASD. Significance level was set as $p < .05$.

Results

Descriptive statistics of mothers before the recreational camp showed that 6.7% of mothers has severe, 73.3 % has moderate, 6.7% has mild and 13.3% has minimal symptoms of depression. The program applied on the camp reduced the depression level of mothers significantly such that severe symptoms of depression disappeared totally among mothers, whereas moderate, minimal and mild symptoms of depression were observed as 80%, 13.3% and 6.7% respectively (Table 3). After the TRP, QoLA-Part B scores significantly increased whereas QoLA-Part A scores improved only slightly (Table 4).

Table 3

Symptoms of depression, BDI and QoL scores of mothers

	Pre-test		Post-test	
	<i>f</i>	%	<i>f</i>	%
<i>Symptoms of Depression</i>				
Severe	1	6.7	0	80
Modarate	11	73.3	1	6.7
Mild	1	6.7	2	13.3
Minimal	2	13.3	12	0
	$\bar{x} \pm SD$ (Min-Max)		$\bar{x} \pm SD$ (Min-Max)	
BDI	18.47±6.59 (4-31)		7.29±4.49 (0-18)	
QoLA-PartA	87.9±9.99 (64-99)		89.73±11.49 (69-111)	
QoLA-PartB	56.0±4.04 (30-80)		48.8±15.13 (24-77)	

Note: \bar{x} =Mean, SD=standard deviation

Table 4

Effect of the TRP on the Depression and QoLA of mothers

	<i>N</i>	<i>Mean Rank</i>	<i>Sum of Ranks</i>	<i>z</i>	<i>p</i>
<i>BDI</i>					
Negative Ranks	0	.00	.00		
Positive Ranks	12	6.50	78.00		
Equal	3			-3.276	.001*
<i>Total</i>	15				
<i>QoLA-Part A</i>					
Negative Ranks	5	8.50	42.50		
Positive Ranks	10	7.75	77.50		
Equal	0			-.995	.320
<i>Total</i>	15				
<i>QoLA-Part B</i>					
Negative Ranks	2	9.25	18.50		
Positive Ranks	12	7.21	86.50		
Equal	1	0	0	-2.135	.033*
<i>Total</i>	15				

Note: * $p < .05$, statistically significant difference

According to the Wilcoxon Signed Ranks test, the TRP caused a statistically significant decrease ($Z = -3.28$; $p = .001$) in depression symptoms of participant mothers. Not only depression, but also QoLA-Part B of mothers ($Z = -2.14$; $p = .03$) improved significantly after the recreational camp program, whereas QoLA-Part A did not show any statistically significant improvement (Table 4).

Statistical analysis showed that there was a significantly moderate negative correlation between BDI and QoLA-Part B ($r = -.06$; $p = .03$), whereas BDI and QoLA-Part A ($r = .09$; $p = .75$) did not show any statistically significant correlation after the therapeutic recreational camp.

Discussion

This study investigated the effect of a one-week TRP on the symptoms of depression and QoL of mothers who have children with ASD. As a result, comparison of pre-post TR camp BDI scores indicated a positive improvement in mothers mental health. Mild to minimal symptoms of depression was observed in mothers who had severe or moderate level depression pre-TR camp. Moreover, QoLA-Part B scores dropped indicating an improvement in the ASD related QoL of mothers, whereas QoLA-Part A scores remained the same after the TR camp. In the light of these findings, it can be argued that TRP have a positive effect on mental health of mothers having children with ASD, by decreasing depression symptoms and increasing QoL within a week.

In the present study, depression symptoms of mothers decreased significantly after the TRP that was mostly based on physical activities. These findings are parallel to literature which shows that physical exercise-based recreative activities contribute to psychological well-being in mothers of children with physical, mental, and emotional disabilities (Columna et al., 2011). Physical activity and exercise decrease clinical depression and is an excellent tool for the treatment of physical and mental health problems (Dinas et al., 2011; Knapen et al., 2015; Patten et al., 2009; Peluso & Andrade, 2005; Strasser & Schobersberger, 2010). An overall

improvement was observed for all mothers, such that none of them have shown severe depression symptoms after the TRP. Present findings are supported by literature where recreational activities; especially physical exercise is a fundamental component in therapeutic recreation (Bedimo-Rung et al., 2005; Godbey et al., 2005). Maughan and Ellis (1991) described therapeutic recreation as a basic practice to reduce an individual's symptoms of depression.

Participation of families in the physical activity based recreational intervention programs might have increased the communication and teamwork within the family, thus TRP becomes a support factor in balancing the burden on the mother as stated in previous studies (Townsend & Puymbroeck, 2017). Studies that focus on stress factors in families having children with ASD indicated that their needs for individual psychological counseling are accompanied by limitations in social life participation and intra-family imbalances. As the mothers of children with ASD also have a high tendency for depression (Khanna et al., 2011), a more holistic content with a mental health component could be created to increase the positive effect of physical exercise. TRP in the present study did not have direct mental health related content, thus it might be insufficient to diminish the symptoms of depression and create an overall decline for mothers' intense stress within one-week.

The present study showed an improvement in terms of not only depression, but also in mothers' ASD related QoLA levels (QoLA-Part B). Previous research has shown the importance of social support received by parents of children with neurodevelopmental disorders which has positive effects on their quality of life (Marsack & Samuel, 2017). The improvement of QoL of mothers were parallel to the findings of Columna et al. (2015) who stated an improvement in QoL of individuals with vision impairments and their families as a result of increased socialization and decreased independency problems after physical activity-based therapeutic recreation activities. Literature shows that the depression levels of mothers having children with ASD and the severity of behavioral difficulties of their children are also proportional to their social support needs and physical health (Ingersoll et al., 2011; Jose et al., 2017; Zablotzky et al. 2013). Therefore, taken all of these together, it can be argued that the decrease in depressive symptoms might have an effect on ASD related QoL (Jones et al., 2017; Kouros et al., 2020).

Although mothers ASD related quality of life (QoLA-PartB) improved after the camp, the duration of the TR camp may not be sufficient to have a positive effect on their overall quality of life (QoLA-PartA). Several studies have shown improvement in QoL of families having children with physical and mental disabilities following a 6 months family support program including recreational activities (Sung & Park, 2012). These contradictory results might be explained by the duration of the TRP because frequency and duration of recreational activities affect its contributions to the individual (Russel, 1987; Russel, 1990). Stress levels of parents having children with ASD is reported to be higher compared to those who have children with typically developing children (Baker-Ericzen et al., 2005). Moreover, ASD has a greater negative impact on parental quality of life compared to both typically developing individuals (Allik et al. 2006; Gurbuz-Ozgur et al., 2017), and also other disability groups including Attention Deficit Hyperactivity Disorder (Brown et al., 2006; Lee et al., 2008). Therefore, a one-week camp might be not sufficient to increase parents' overall quality of life and it can be argued that TRP for families with children having ASD should be longer than one week and repeated several times for a longer duration than 6 months. A more intensive TR program that is spread through a longer period of time could further improve the overall quality of life of the mothers in the present study (Stuart & McGrew, 2009; Wang et al., 2018). Though, the type and intensity of

exercise might also play a key role for the benefit of mothers; therefore, physical activity level and health status of families should be taken in to consideration while planning the physical activities during the TRP (Fletcher et al., 2013).

Although BDI and QoLA-Part A did not show any correlation, QoLA-Part B and BDI were negatively correlated in the present study (Bayat, 2007; Piovesan et al., 2015; Zablotzky et al., 2013). Tekinarslan (2013) also found a negative relationship between the depression and QoL levels of the mothers of individuals with ASD, Cerebral Palsy and Down Syndrome. These findings were supported by several studies that depression negatively affect the QoL of families having children with disabilities (Bumin et al., 2008; Favero-Nunes & Santos, 2010). On the other hand, physical exercise-based therapeutic recreation activities affect some psychological parameters such as stress, depression, and burnout, depending on the frequency, duration, and participation rate of TRP the continuation of sustainable activities (Patten et al., 2013).

Besides the valuable findings of the present study, there are some limitations that need to be noted. First of all, there are some uncontrolled variables, which might influence the results of the present study such as environmental change, and support of trainers in the TR camp. These limitations can be overcome with an additional control group of mothers having children with ASD who do not join the activities in the same camp. Also, the sample size could have been more. Another limitation is that the depression symptoms of mothers was only measured by the BDI, and no review of the medical records of the mothers or was performed. Also considering whether they get outside mental health support would improve our findings.

As a conclusion, it can be suggested for future research that;

1. Therapeutic recreation programs should be developed for families of individuals with ASD that includes all family members.
2. Follow-up studies should be performed after the TRP to examine the sustainability of the effect.
3. The duration and frequency of the TRP should be altered according to the subjects with different backgrounds and needs.
4. Studies should be performed with different parameters (burnout, stress levels, perceptions of social support, etc.) to obtain data for inclusion TRP.
5. Psychosocial and psychoeducational components might be added to TRP.
6. Projects for individuals with ASD and their families should be increased in number and offered to the city/district local administrations.

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