

ORIGINAL ARTICLE

The Recreational Physical Activity from the Perspective of Mothers of Children with Autism Spectrum Disorder

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ABSTRACT

Objective: In this research, we aim to investigate the evaluation of the Recreational Physical Activity Program participated by the children with Autism Spectrum Disorder from the perspective of mothers in Konya.

Methods: For this aim, we conducted face to face interviews with 10 mothers and then a focus group with the same mothers to discuss our results. The data is analysed by using MAXQDA 2018 program.

Results: It was emerged 'life with Autism Spectrum Disorder through the eyes of mothers' and 'factors affecting mothers' evaluations of the program' as the main themes.

Conclusion: Our results show that mothers perceive their life as a difficult and empowering struggle and mothers evaluated the program positively based on the impact of the program on the skill development of their children, the role of the trainer and the limited leisure activities of their children. Mother's views of challenges and solutions mainly signify the need for increasing the number and accessibility of these centers and for designing programs both for children and for mothers.

Keywords: Autism Spectrum Disorder, Recreation Therapy, Physical Activity, Mothers

INTRODUCTION

Autism spectrum disorder (ASD) is a neuro-developmental disorder observed in 1 out of 160 children¹. It is characterized by difficulty in social communication and interaction, limited / recurring behaviours, excessive interest in some areas, delay in language development, and insistence on order and routines².

Recreational physical activities positively contribute to the physical, psycho-social and cognitive development of the children with ASD^{3, 4, 5}. For such positive effects to emerge, these children should participate in such programs regularly.

In this study, considering thinking of parents in general and mothers in particular and in line with the literature which emphasizes the need for conducting research on the positive experiences of mothers of children with ASD^{6, 7}, it is aimed to evaluate the Recreational Physical Activity Program in which children with ASD participated from the perspective of mothers in Konya. The research, based on the literature emphasizing the need for 'implementing evidence-based practices with interdisciplinary teams'⁸.

It is conducted the research with mothers in the only centre in Konya which provides rehabilitation, therapy, and activities to individuals with ASD. It is aimed to explain how and in what ways the recreational physical activity program strengthened the individuals with ASD directly and mothers indirectly. Finally, the study may contribute to local and international disability research and practice by showing the advantages and deficiencies in the implementation of such programs.

METHODOLOGY

Study Design: The study was designed considering the phenomenological paradigm, which seeks an answer to the questions like 'What is the meaning, structure and essence of experienced phenomena for a particular person(s)?' to reveal the perspectives of the participants in detail⁹. It was

utilized both descriptive and interpretative approaches of phenomenology.

Participants: The participants were selected using the purposeful sampling method from among the mothers who came to the centre, whose child completed the program, and who volunteered to participate in our research. The mothers (n = 10) who took their children to the centre were the primary sources of information. The socio-demographic characteristics of the participants are given in Table 1. Since all the participants were women, married, and unemployed, their gender, marital and working status were excluded from the table.

Setting: The study was carried out with the mothers of ten children with ASD in a centre providing education to individuals with ASD in Konya. The program is carried out by two specialists with five years of experience in sports activities with children with ASD. They have first level swimming and gymnastics coaching certificate and two hours of in-service training every week. The Program, conducted on one-to-one basis, consists of 16 sessions, eight sessions of swimming and eight sessions of sports, and lasts for approximately two months.

Data Collection Procedure: The data were collected between June-July 2018, using the semi-structured in-depth interview form. The form was prepared through the literature review on the experiences of the mothers of children with ASD and the effects of recreational physical activities on children with ASD^{10, 11, 12}.

The data was collected through face-to-face interview and a focus group interview, which aimed to discuss the results of the study with the participants. In this study, note taking was used. In order not to miss any information, one of the researchers was the facilitator of the interview and the others were the note takers.

Data Analysis: The data were analyzed with the MAXQDA 2018 Program. We followed the procedures of 'transcribing the data, coding the underlying ideas in the data, grouping similar kinds of information together in categories, and relating different themes to one another'¹³.

Trustworthiness: To ensure trustworthiness, we used Creswell and Miller (2000)'s eight strategy (prolonged engagement in the field, triangulation, rich-thick description, member checking, disconfirming evidence, peer debriefing, researcher reflexivity and external audits¹⁴. For a study should satisfy at least two of the strategies to ensure validity.

We tried to satisfy the criteria of prolonged engagement in the field with the presence of one of the researchers throughout the program. To ensure rich-thick description, we used direct quotations from the participants in the findings section. For member checking, we summarized the general points of the participants at the end of each interview. Furthermore, we conducted a focus group interview with the same mothers to verify our general results and to ask whether they want to add any information. Triangulation was ensured with a multi-disciplinary research team. No disconfirming evidence was found. Although we received expert opinion from service provider of the centre and two academicians working on autism for the questions, we did not have any peer debriefing for the general results of the study. We also did not apply any external audits throughout the research process. For the researcher reflexivity, we introduced ourselves in the introduction part of the study and wrote our related deficiencies to the limitations section.

Research Ethics: The study was approved by the Ethics Committee of our university and official permission was obtained from the centre. The purpose of the study was explained to the mothers and they were informed about their right to withdraw from the interview any time. Signed informed consents were secured from all participants. To protect the privacy of the participants, the names were kept confidential; pseudonyms were used.

RESULTS

The first theme of the study is "life with ASD through the eyes of the mothers", created to understand the participants' evaluations of the program and to explain the experience of women. This theme is followed by the second theme, "factors affecting mothers' evaluations of the program". The figure given at the end demonstrates the themes and the sub-themes.

Life with Autism Spectrum Disorder through the Eyes of the Mothers: Metaphors for Autism Spectrum Disorder and Family Relations: This theme, which aims to describe the family life of the participants and their perceptions and experiences of ASD, focuses on the metaphors used by the mothers for ASD, the care role of mothers, the relationship of fathers and siblings with children with ASD, and social exclusion.

Mothers describe autism as a struggle shaped by difficulties:

It is a desperate struggle that begins with diagnosis. You even have to think of what will happen when you die and you have nobody to help' (Rezzan).

'Sometimes I think that I am digging a well with a needle' (Hayriye).

'I used to get angry easily, but since my child entered my life, I've become more mature and patient' (Nazlı).

'I became more patient, empathetic, and compassionate. I realized my own strengths' (Mine).

'I spend all my time with my daughter. I have no time for myself. My husband is at home only in the evenings, so he doesn't realize most things' (Hayriye).

'Financially there is a father, but not spiritually' (Nazlı).

'The younger brother is jealous and sometimes wants his brother to fall and die so that we can get rid of this situation' (Nazlı).

'Other kids can do anything. He compares his brother with other children' (Rukiye).

'My older son was shocked at first because he had a brother who could not speak. Now, he has a warm and normal relationship with his brother since he has started to speak' (Safiye).

'He gets on well with his brothers since he started to speak' (Nazlı).

'When we go somewhere, different looks and words of people hurt a lot. But we got used to it' (Aykan).

'Our society is so inconsiderate' (Ayşe).

Factors Affecting Mothers' Evaluations of the Program: The changes mothers observe in their children, the way their children spent their leisure time outside this activity, the facilitating role of the trainer, the difficulties experienced during the program, and their suggestions regarding these difficulties are the main factors affecting mothers' program evaluations.

Observations Regarding the Change in Children as a result of the Recreational Physical Activity Program

The mothers stated that the program had positive effects on both themselves and their children:

'It makes me happy to see that my child is progressing' (Ayşe).

'There is a noticeable change after we started the training here' (Aykan).

'My son feels so good here' (Rukiye).

'His attention has improved compared to the past' (Safiye).

'His attention, memory power and focus improved; his interests expanded; his interest in mind games increased; we realized that he has visual memory and an ear for music' (Mine).

'He did not use to even step on the bicycle pedal, but now he can ride a bicycle' (Rabia).

'We had a balance problem while walking, he couldn't climb and run, but now he can do these' (Mine).

'Aggression subsided and movements increased, which is good for us because he was a very sedentary child. Now, he started to climb up and down the couches' (Rukiye).

'When he got angry, he used to slam the doors and windows. This is now over' (Mine).

'He didn't have any sleep patterns. I don't know if it's because of sports, but he sleeps very well now' (Safiye).

'There were foods he didn't consume like cheese and olives, but now he eats them. Hopefully, he will also start eating fruits now' (Mine).

'He used to love loneliness, but now he plays with his friends and addresses his friends with their names. I couldn't get on public transport with my child before, but now we ride comfortably. He does not find strangers odd; he is friendlier with them' (Mine).

Table 1. The Socio-Demographic Characteristics of the Participants

	Mother's age	Perception of income	Educational status	Children's age (years)	Children's gender
Ayşe	33	High	University	6	Male
Mine	42	High	University	6	Male
Safiye	33	Middle	University	8	Female
Aykan	29	High	Secondary	8	Female
Nazlı	32	Middle	Secondary	4	Male
Rezzan	13	Middle	Primary	8	Male
Zeynep	41	Middle	Primary	3	Male
Hayriye	40	Middle	Secondary	8	Female
Rabia	31	Middle	University	6	Male
Rukiye	30	Middle	Secondary	3	Male

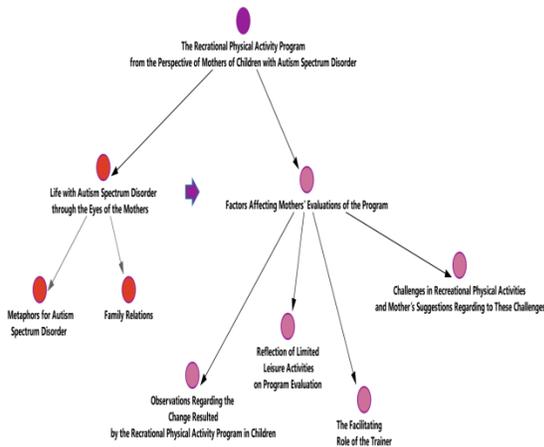


Figure 1. Themes and Subthemes

'When we go to the park or crowded places, nobody realizes that he is a special child as he can adapt to any environment' (Aykan).

Reflection of Limited Leisure Activities on Program Evaluation

Mothers' narratives show that before attending the program, the children spent their free time mostly at home on activities with low social connection. The mothers exemplified their children's limited free time activities and their favorite activities as follows:

'Watching TV, playing with the tablet computer, running' (Hayriye).

'She likes listening to music, going to the market, and playing in parks' (Rukiye).

'He saw the pool here for the first time. Although he likes water, he was nervous. He wanted to escape in the first days of the lessons. Now he got used to the pool; he is very happy and wants to come here' (Rezzan).

The Facilitating Role of the Trainer

The facilitating role of the trainer led to positive evaluations of the program. The participants emphasized that at the beginning of the program, they wanted to be with their children during the training as they believed their children would have difficulties in the adaptation process of the education; however, as they trusted the trainer, they stopped doing so:

'At first, I was curious about what the training included. I wanted to see my child's response to the education and his relationship with the teacher" (Mine).

'I was watching the training sessions at first, but now I do not. It makes me feel good that teachers care about the kids and they give information after the training' (Zeynep).

'We were out of the daily routines. They were shouting and nervous when they saw this place. However, the attitudes of the trainers and their relation with the children solved this problem' (Zeynep).

Challenges in Recreational Physical Activities and Mother's Suggestions Regarding These Challenges

Although the mothers are highly satisfied with the program, they also pointed out some problems such as the distance of the centre. They suggested that transportation problem can be solved with a shuttle service, the variety and frequency of the programs could be increased.

'Such activities should be a lifestyle for these children. It takes a long time for our children to improve and to teach something very simple' (Nazlı).

'Sports activities with increased duration and frequency will make a great contribution to our children. I wish my son could participate in such activities every day of the week' (Rabia).

'I am aware that physical activity will be good for my child, but the number of centres offering this opportunity is limited. It is really difficult for us to come here. I live 40 km away from the centre and I have no car' (Rukiye).

'There is only one centre in Konya where there are sports activities. This place is far away from my house (30 km)' (Mine).

'The program is good, but a playground can also be designed for children' (Safiye).

'I want activities such as music, drama, and playground and game time. Children need an area to spend time having fun because they don't like to wait doing nothing' (Mine).

DISCUSSION

This study investigated mothers' evaluations of the recreational physical activity program offered to children with ASD. The findings suggest that mothers perceive life with ASD as a struggle; however, they turned this process into an empowerment process for themselves and their children. It was revealed that the program had an impact on the skill development of the children with ASD. Moreover, the findings point to the importance of education centers for the execution of such structured practices and of the accessibility of these centers. Within the scope of the study, two themes, life with ASD through the eyes of mothers and factors affecting mothers' evaluations of the program, were discussed.

Life with Autism Spectrum Disorder through the Eyes of Mothers: The mothers' perception of living with a child with ASD as a challenging process and their metaphors coincide with those in the literature^{15, 16}. ASD is a process that empowers mothers and teaches them to be patient^{7, 17}. Although they experience the difficulties of ASD, they develop coping mechanisms, get stronger, and face this struggle with their children⁶.

In parallel with the literature, our findings show that ASD has an impact on family life, including the roles and responsibilities of parents and siblings^{18, 19}. While mothers bear the responsibilities of life with ASD, fathers continue their business lives (20). Siblings can show negative

attitudes such as not accepting the situation or jealousy as well as positive attitudes such as taking care of the sibling and assuming responsibility in the family^{21, 22}.

Families may also experience social exclusion. Mothers can be influenced by the attitudes and behaviors of individuals in their social environment and may avoid social life²³. Research findings show that mothers with a child with ASD experience social exclusion; however, they cope with this situation by establishing relationships with individuals who accept their children and themselves as they are.

Factors Affecting Mothers' Evaluations of the Program: Our findings show that both the mothers and the children were satisfied with the program.

The mothers stated that they observed the positive effects of this program on their children's skills, namely on cognitive skills, including attention and focus; on motor skills including fine and gross motor skills, balance skills and muscle coordination; on social skills as their children's interaction with other children improved; on behavioral skills as their children have started to exhibit fewer aggressive and disruptive behaviors; on nutrition and sleep habits; and on mobility and activity. Thus, it can be said that physical activity is an effective intervention and evidence-based practice for multiple behavioral results^{24, 3}.

Another factor that is thought to be effective in mothers' positive feedback is that such a program created diversification of activities. When structured and a variety of recreational activities are designed for these children, positive effects on socialization may be observed, and as access to such programs increases, the development of children is fostered.

The facilitating role of the trainers is also found to be effective in the program evaluation of the participants. The participants stated that at the beginning of the program they wanted to be with their children in activities such as swimming; however, these difficulties were overcome with the trust relationship established with the trainers. Experienced trainers are effective in overcoming the difficulties experienced in the initial phase of the activities and helping children get used to the program²⁵.

The mothers listed some challenges while evaluating the program. First, education centers should be accessible to children with ASD and families with low socio-economic status. Although the benefits of physical activity for these children are clearly evident, families may face difficulties in accessing sports and recreational activities²⁶. The fact that there is only one education center in Konya and it is difficult to access this center constitutes an obstacle for families to benefit from the services provided by the center. As seen in the literature, children living in rural areas cannot benefit from some services as they live far away from the centers providing recreational activity programs²⁷. Therefore, the development of ASD services in remote and rural areas should be supported through community collaboration²⁸.

The results of our study are limited with the perceptions of the mothers.

CONCLUSION

Life with autism is a struggle, and mothers are the strong agents of this process. According to the mothers in our study, the recreational physical activity program had

positive effects on their children's cognitive, motor and psychosocial skills. It is recommended to conduct prospective and follow-up studies to evaluate the effects of the program on children with ASD and on all family members.

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