

THE IMPORTANCE OF SELF-CARE SKILLS DEVELOPMENT FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDER FROM THE PARENTS' PERSPECTIVE

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ABSTRACT

This research aims to explore the awareness of parents of children with autistic spectrum disorder about rehabilitation services developing self-care skills. A quantitative research method was used in this work, which allows to form knowledge based on precise logic, mathematical-statistical calculations. The study included an online and paper-based questionnaire survey where 35 parents of children with autistic spectrum disorder have participated. The use of the quantitative method for data collection and analysis made it possible to rigorously adhere to the aim and the objectives of the study as well as to obtain objective results, test the accuracy of the hypothesis, and establish causation.

The summary of the results showed that the majority of parents of children with autistic spectrum disorder (81.8%) have a clear idea of the services aimed at improving self-care activities and realize the importance of performing them independently. For 6.7% of parents, it was important that their children can perform self-care activities independently, but they did not take steps in that direction, and only 26.7% wanted to seek professional help. However, as parents of children with autistic spectrum disorder, select rehabilitation services for enhancing their children's skills, being aware of appropriate services, and suitable intervention approaches were considered to be important points for approving children's future independent life.

Keywords: Autistic spectrum disorder, self-care, occupational therapy, occupational therapy service, independency, rehabilitation.

INTRODUCTION

Autism is characterized as a complex developmental disorder that is distinguished by the peculiar manifestations of the child's behavioral-emotional spheres, communication limitations, problems in language skills, difficulties in games, and social interaction. It is considered a spectrum disorder, as the abilities of children with autism may vary greatly from one child to another (Koenig & Rudney, 2010). These children, adolescents, and adults often have difficulty in adjusting to social relationships and interpersonal relationships because they perceive the environment completely differently. They can have limited interests, ability to initiate and perform daily activities, often have difficulty in engaging in self-care, games, and learning processes effectively (Taylor & Mailick, 2014). However, it should be noted that every individual with autism is unique.

Due to complex developmental dysfunction, individuals with autism very often have difficulty in realizing the roles they are expected to accomplish in their life and they can display behaviors that can hinder their participation in daily life. Being the mother of a child with autistic spectrum disorder and facing the difficulties of performing self-care activities in everyday life it became clear that over-care and continuously doing self-care instead of a child may reduce the development of the child's abilities and independence. It has been approved that early intervention and many educational and rehabilitation services that children with autism are intended to develop their skills and abilities for overcoming difficulties in daily life. Particularly, the primary aim of occupational therapy practice ensures that individuals with autism can take part in daily situations by minimizing the difficulties in the daily activities they experience at home, school, or in the community (Christiansen, Baum, & Haugen, 2005). Occupational therapists believe that the use of client-centered and holistic therapeutic interventions can facilitate children's participation in meaningful and purposeful activities. Also, they can provide a considerable advantage in dealing with the problems individuals with autism, and their families face in daily life, to accomplish the aims that they have during the day (Novak & Honan, 2019).

For this reason, this study aims to explore the awareness of parents of children with autistic spectrum disorder about self-care services provided for their children, as well as to understand how they perceive the role of occupational therapy for developing necessary skills and abilities to perform self-care activities to be as independent as it is possible. Therefore, the research question has the following formulation: Are the parents of children with autistic spectrum disorder aware and informed about the services that are aimed at developing skills to perform self-care activities?

LITERATURE REVIEW

According to the literature, Autism Spectrum Disorder (ASD) is the most common developmental disability and neurological disorder affecting people across their lifespan (APA, 1994). ASD is considered a developmental disability, which is defined by behavioral characteristics, and the primary features of ASD are described as problems in language skills, games, and social interaction (Cebula, 2011). Since ASD is a unique form of psychological developmental disorder, it is accompanied by the disturbance of various mental functions' development, with unique emotional-behavioral, verbal, and sometimes intellectual disorders (Nikolskaya & Vedenina, 2014). Symptoms begin in early childhood and in addition to the primary features, individuals with autism generally have sensory processing and sensory integration dysfunction, which affect adaptive behavior and involvement in daily activities.

According to the 10th International Classification of Diseases (ICD-10), autism is defined under the broader category of pervasive developmental disorders (PDD) and are defined as a group of neurodevelopmental disorders characterized by qualitative deficits in reciprocal social interactions, qualitative deficits in communication, and presence of restricted, stereotypic, and repetitive behavioral interests and activities (WHO, 1992).

Since autism has a wide range of severity and symptoms which are different from one person to another, the abilities and needs of people with autism always vary and can evolve.

ASD is a lifelong condition with varying degrees of severity and prognosis. It presents differently in every individual, impacting all aspects of an individual's development and occupational performance, including their

ability to perform activities of self-care, daily living, and to participate in productive work (education for children), leisure and recreation activities, as well as overall, their ability to communicate and participate socially (Bumin, Huri, Salar, & Kayihan, 2015). Some people with ASD can live independently, others have severe disabilities and require life-long care and support. Autism often has an impact on education and employment opportunities. In addition, the demands on families, providing care, and support can be significant. Societal attitudes and the level of support, care provided by families and specialists are important factors determining the quality of life of people with autism (Rodger & Umaibalan, 2011).

Due to the peculiarities of ASD, the development of self-care activity performance skills of children can be very slow, and in some cases, these skills may be completely absent, due to the specifics of the disease (Reinhard, Given, Petlick & Bemis, 2008). For people with autism, learning life skills is essential to increase independence at home, at school, in the community. By introducing these skills at an early age, step by step people with autism gain the tools that will allow him or her to increase self-esteem and lead to more happiness in all areas of life.

As these skills are learned over time, beginning from home at a very young age and developing further throughout adolescence and adulthood, it leads to the fact that without proper help, the child becomes more dependent and has less participation in daily life. According to the definition of “participation”, it is defined as involving oneself in a life situation (WHO, 2001), is considered one of the important outcomes of rehabilitation interventions (Coster & Khetani, 2008), and a critical indicator of the quality of life. Individuals with ASD generally have the risk of limited engagement in activities and have weaker daily life skills when compared with individuals with other developmental disorders or with typical development. The engagement of individuals with the autistic spectrum disorder in daily living activities may be affected by core characteristics specific to autism as well as sensory processes (Kientz & Dunn, 1997). Depending on the level of developmental disorder, children may have some difficulties at different phases of life. However, they are all able to learn to master self-care activities (dressing, brushing their teeth, eating on their own, crossing the road safely,

etc.), though for someone it happens quite quickly, and for the others - gradually (Gal, Meir & Katz, 2013).

According to Merluzzi et al., self-care can include maintaining one's health and well-being, actively seeking support, and maintaining some activity apart from the caregiving situation (Merluzzi, Philip, Vachon, & Heitzmann, 2011). Self-care skills, which include feeding, toileting, dressing, bathing, and grooming, are classified as Activities of Daily Living (ADL's) because they are a critical part of a child's overall health and participation every day. In order to participate in self-care, a child must have component skills within a variety of performance areas, and delays in any of these areas can make seemingly simple tasks feel nearly impossible. These activities are "fundamental for living in a social world as they enable basic survival and wellbeing" (AOTA, 2008). Usually, children and young people learn to perform ADL activities with socially appropriate ways to be engaged in education in the family and society, game playing, leisure, social participation, and work occupations (LeVesser & Berg, 2011).

It is important to mention, that learning life skills are very important for children with ASD, whether at home, at school, in the community, it increases self-confidence and independence. Early intervention for the development of these skills gives children with autism the tools they need to increase their self-esteem and develop feelings of happiness in larger areas of life (Tanner, Hand, O'Toole & Lane, 2015). According to the International Classification of Functioning (ICF), a person's "activity and participation" is the performance of a task or action by an individual, it covers the complete range of domains denoting aspects of functioning from both an individual and a societal perspective (WHO, 2001). Out of these domains, special attention is paid to self-care, which includes the following activities:

- Washing oneself
- Caring for body parts
- Toileting
- Dressing
- Eating
- Drinking
- Looking after one's health

Developing self-care activities' performance skills are important for a child's development as they require functional skills to plan and sequence the tasks, and physically control motor skills. However, studies have shown that individuals with ASD are less likely to participate in daily life, and will have self-care activities' performance skills than people with other developmental disabilities (Roger & Umaybayla, 2011).

Because children, adolescents, and adults with ASD often have difficulty in adapting, developing interpersonal relationships, learning new skills, and difficulties in living independently, therefore the role of multidisciplinary intervention is considered to be significant to advance their lives and participation in daily routines.

It should be noted that occupational therapy offers a way of intervention that restores the meaningful activities and working capacity of people with physical and mental disabilities (Tomchek & Koenig, 2016). Occupational therapists believe that participation is supported or constrained by the physical, emotional, or cognitive abilities of the person, the characteristics of the activity, the physical, cultural, social, behavioral, and legal environment. For this reason, occupational therapy focuses on increasing the competence of individuals by organizing the person, activity, environment, or all of these to increase social participation.

Occupational therapists bring a unique and comprehensive perspective in the treatment of a person with ASD. They are highly educated and experienced to evaluate and provide intervention, both direct treatment, and consultation to families, educators, and caregivers, in the areas of physical, sensory processing, and social-emotional health in all environments of the person with an ASD (Kuhaneck & Watling, 2014). Occupational therapists know that involvement as a participant in self-care and daily living activities, productive engagement and participation in social and communication-oriented events, leisure and play activities affect the development and live performance of every person with an autism spectrum disorder, which will markedly differ in the individual (Case-Smith & Arbesman, 2008).

It is noteworthy that family members play a key role in the development of these children's skills and self-care activities, so the role of the parents/caregiver in choosing a child rehabilitation intervention is

considered an important factor and only productive cooperation can bring positive results. Since family support and time management are very important in building skills and making intervention smoother occupational therapists will try to understand and assess the daily life of the family and the tasks that children have to perform (Lord, Rutter, DiLavore, Risi, Gotham & Bishop, 2012). Parents need to maintain a balance in developing self-care activities, performance skills in a child with ASD; they need to help them when they really need it, but not doing instead of them. Taking into consideration the importance of the involvement of the family in the development of self-care activities and skills, the aim of the research is to explore the awareness of parents of children with autistic spectrum disorder, rehabilitation services developing self-care skills.

METHODOLOGY

The quantitative research method has been used in the work, which allows to form knowledge based on precise logic, mathematical-statistical calculations. The procedure for applying the method is clearly stated. The quantitative method used for data collection and analysis in this work made it possible to be objective, to acquire accurate knowledge of social reality. In the framework of the research, a survey was conducted for data collection and analysis (Yadov, 2007).

The research was conducted to find out the level of awareness of parents about self-care services and their general perceptions of them. Through the survey, parents will be able to find out which self-care activities are currently performed by them, or by their children. In addition, parents' perception and knowledge will be exposed regarding the services and intervention approaches that are aimed at developing self-care activities, performance skills for children with autism.

Participants

In total 35 parents of children with autistic spectrum disorder have participated in the current survey that aimed at exploring the awareness of parents about the services helping children and their families to develop self-care activities' performance skills. Participants were informed that the survey was anonymous and before the study, the agreement from the participants for taking part in this survey was gained. To ensure an adequate level of

confidentiality for both the participants and the survey data they have been informed that the collected data would be used only in a generalized form. The survey was conducted while using an online and hard copy questionnaire, where parents had an opportunity to answer the questions and give their opinion about the suitable subject. The study involved different age groups of children with ASD, including parents of children from ages 4 to 17.

Data collection

A questionnaire was developed and used to collect the survey data using the modern Google Forms e-survey tool, as well as the documented survey of the same questionnaire. Formulated questions allowed obtaining demographic data and to study the parents' perception and understanding about the importance of developing self-care skills for children with ASP as well as their considerations about the rehabilitation services in that field. The questionnaire was posted on the online platform and Facebook domain within 5 months, also some participants were handed over the hard copies.

Data analysis

The analysis of the survey data was carried out according to a quantitative methodology, as a result of which the answers of the 35 parents who took part in the survey were generalized and presented in the form of numerical patterns. The open-ended questions, which included the respondents' personal opinions and awareness in particular about the self-care services, were coded according to the relevant categories, grouped, and presented in numerical percentage (Yadov, 2007).

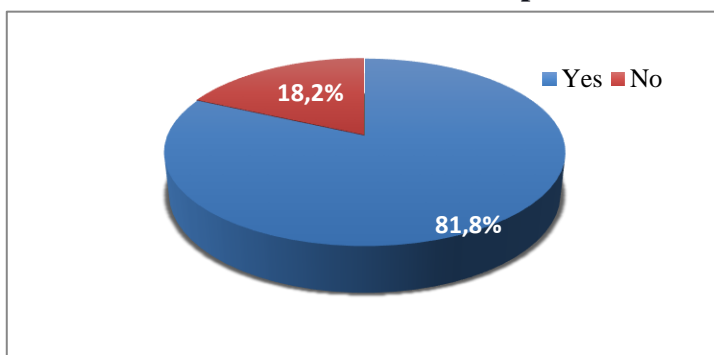
RESULTS AND DISCUSSION

As a result of data analyses, it was possible to study the awareness of parents of children with ASD on self-care skills, their opinion, and perceptions of professional approaches and used methods as well as current rehabilitation services that were focused on the development of those skills. Concluding the data provided by parents became clear that the majority of children with ASD were involved in various rehabilitation services, in particular, speech therapy (78.8%), special education (90.9%), psychological (81, 8%) services. Rehabilitation services such as occupational therapy and art therapy received accordingly 24.2% and 30.3% of responders. Only two parents have mentioned that their children have not got any services yet.

It is well known that children with ASD experience many challenges in their lives and generally have the risk of limited engagement in different activities. Occupational therapy interventions, which are designed according to standardized assessment tests, questionnaires, skilled observations, provide a considerable advantage in dealing with the problems children with autism and their families face in daily life (Miller-Kuhaneck, 2004). In Armenia, the need for occupational therapy is very high but, many parents are not aware of these services and provided possibilities. The study has shown that about 24.2% of children with autism receive occupational therapy intervention only in the capital city.

Data analysis of the survey has shown that 81.8% of parents were aware of the services and the main approaches that are directed to develop and improve self-care skills. Though they were aware of occupational therapy, some of the parents presented the main principles and functions of occupational therapy service in a completely different way - for example, brain development work or the provision of special knowledge. 18.2% of respondents were not aware of the services provided in the area of this profession and believed that self-care activities and skills could be developed by the other MDT members such as by a special educator or a social educator (Figure 1).

Figure 1.
Awareness about the functions of self-care improvement services.

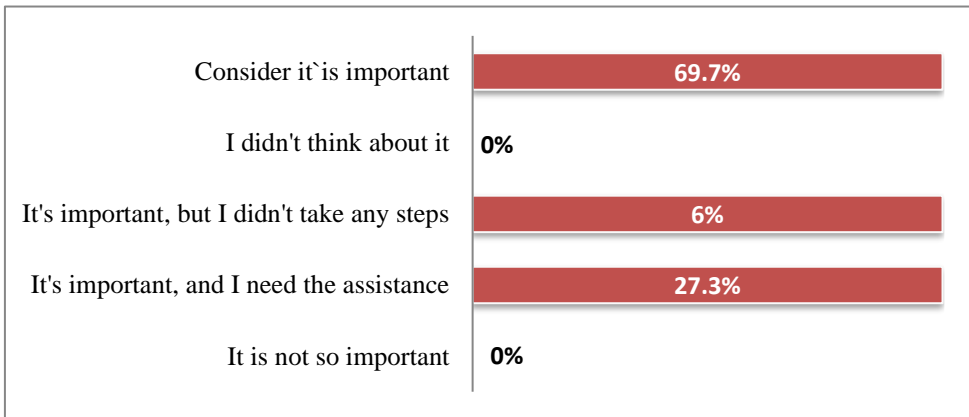


the To question of the importance of self-care activities, the summary of the parents' answers suggested that in their opinion, growing up a child with autism is a unique challenge for them, and to perform any activity independently was perceived

as a victory. According to the data, about 69.7% of the parents considered the independent performance of their children's self-care activities were very important, the 27.3% were willing to seek help to overcome these skills through reciprocal cooperation, and only 6.1% considered that important but did not take steps for overcoming that problems (Figure 2).

Figure 2.

Parents' perception about the importance of performing self-care activities.



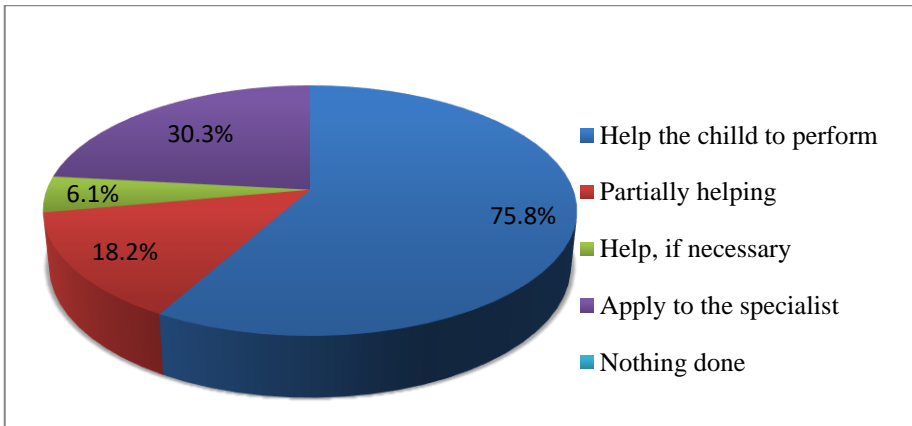
Numerous studies have shown that parental involvement in improving self-care activities advanced the generalization of skills and increased the outcomes of intervention received by the child (Rogers & Dawson, 2010). The integration of all aspects of a child's life increases the chances of having more successful outcomes. It is known that the family environment has a great influence on a person's learning, so children perceive and accept the norms of social cohesion through their parents. However, the over-care provided by the parents also raises many problems. The parent by helping the child to perform daily activities prevents the dangers and does not allow them to overcome the difficulties of developing those skills on their own (Polatajko & Cantin, 2010). While exploring to what extent parents interfere in the child's daily activities, 45.5% of them said that they usually help the child with daily activities, about 45.5% have mentioned that they help only if there was a need, 9, 1% tried not to intervene, and only 6.1% did instead of children justifying that they were not able to perform any actions.

As it is well known, the development of a lifelong daily routine for a child with autism is a priority and necessary point for their development (Bagatell, Cram, Alvarez & Loehle, 2014). Daily routine should have a certain sequence and repetition of the activities, so at that time, the child's anxiety will gradually decrease and daily arrangements can help to organize his behavior. Taking into consideration this fact during this study parents were asked about the daily routine of their children, and 36.4% of the surveyed parents had established a routine for their children, 33.3% were still unable to organize the child's daily life, and 30.3% of the respondents find it difficult for children to adapt to the changes, but parents realize the need of special work to organize and establish a daily routine for children.

Exploring how and what steps did the parents take to overcome the difficulties in performing daily activities 30.3% of the respondents have mentioned that they apply to a specialist, but did not specify that professional assistance was convenient for the case. 75.8%, unfortunately, have mentioned that they help the child to perform these activities, reducing the existing difficulties, and 18.2% partially help the child to perform daily tasks, only if necessary, 6.1% of the respondents refrained from answering. According to the results of the research, it can be assumed that parents perceive the importance to apply to the specialist to get assistance and help in the development of self-care skills, but they were not aware of what specialists and professional assistance can be relevant for that (Figure 3).

Figure 3.

The means and ways of parents' overcoming the problems of performing daily activities.



As Occupational therapy has its permanent place and role in rehabilitation services the awareness of occupational therapy profession and service was explored among the parents. Accordingly, 65.6% of the participants were aware of the special role of Occupational therapy service and intervention possibilities that were aimed at raising the independence of person in life, but despite that, they have considered other specialists of the multidisciplinary team who were responsible for self-service activities development. Other 34.4% of the participants were not aware of the Occupational therapy profession at all.

In general, to grow up a child with ASD is a unique challenge for parents, and when the child is doing something on his own it is already considered a victory. Mothers of children with autism have higher levels of stress due to their child's low level of independence, behavioral problems, and physical development, so for them, it is very important to be able to orient themselves in choosing specific support and services. Parents mainly focus on getting support from a multidisciplinary team, giving importance to speech development and other directions while providing over-care instead of the child; for many of the parental care prevents the opportunity to develop independence in their children. It is important to highlight that self-care is an important element in everyone's daily life. Taking time to maintain a healthy balance in life is a key factor in overall health (Dabrowska & Pisula, 2010). For parents with an ASD child, is even more important, than for the others. Since children with ASD can perform self-care independently or with less support this will allow parents to take time for themselves, other family members and will have positive benefits.

Thus, the study revealed the level of awareness of parents of children with ASD about the importance of performing self-care activities, as well as the role and importance of rehabilitation intervention in this area. In particular, the survey revealed the awareness of parents about the occupational therapy profession and general perceptions of occupational therapy intervention that strive for collaborative service delivery to meet the diverse challenges experienced by the individual with ASD across the lifespan. It is noteworthy that family members play a key role in developing the skills and self-care activities of children with autism, as well as while applying for professional assistance. Accordingly, the role of the caregiver in choosing children's rehabilitation services is an important issue in enabling them to become and act as more independent members of society.

CONCLUSION

This study outlined that the majority of parents having children with ASD were not aware of occupational therapy and the intervention approaches that can be beneficial for their children to become more independent in daily situations. They used to apply to a different specialist to overcome “main” difficulties and help children to do self-care as a parental responsibility. This study has shown that self-care may be important for parents however, some obstacles may prevent them from making self-care a priority. But at the same time, occupational therapists can help parents improve their physical, emotional, spiritual, or social wellbeing. “Whether helping parents find coping mechanisms that fit their family lifestyle, creating a weekly routine that schedules ‘spouse time or ‘alone-time while meeting their child’s needs, or searching for local parental support groups,” occupational therapists can help parents find balance in their life (Razon, 2019).

As a person's self-care skills are assessed in everyday life, the parent's knowledge about the abilities of the child allows them to find out what the child is doing best, what he or she is just beginning to master, what he or she is unable to do, and so on. Parents will succeed in overcoming the problems if they choose the right, directed and relevant professional intervention.

Occupational therapists may refer to different approaches to improve the performance of activities of the daily routine of children with autism while establishing and maintaining performance, as well as activity adaptations or

compensatory methods (Miller-Kuhaneck, 2004; Shepherd, 2005). Also within the frame of occupational therapy intervention parents can receive family training on how to build daily routine and facilitate the participation of children in selected self-care activities besides teaching the most needed skills for that (Bagatell, Cram, Alvarez & Loehle, 2014; Kuhaneck & Glennon, 2001).

During the research, it became clear that the most common areas reported by families were limited independence in dressing, eating routines, limited independence and discomfort in many hygiene tasks, obvious difficulty in toilet training, limited engagement in chores, and continuous intense supervision to provide safety. Though 69.7% of the parents considered the independent performance of their children's self-care activities to be very important, they have almost no idea about the treatment and services necessary for the development of self-care activities. Parents give huge importance to the development of skills that are needed for performing daily activities, but mainly use the support of other specialists rather than occupational therapy.

However, occupational therapy may combine a variety of strategies which include modification of task or task method, use of assistive technology, or modification of the environment to help the child better perform daily tasks and achieve a higher level of independence in completing self-care activities (Polatajko & Cantin, 2010). Occupational therapists work as part of a team collaborate with parents, teachers, and other professionals. Therefore, occupational therapy as the rehabilitation and client-centered profession is considered to be extremely important for children with ASD to help them to facilitate the individual's maximum independence and participation in meaningful activities (Case-Smith & Arbesman, 2008). Since the stress on families with ASD children is quite considerable. It is very important to raise parents' awareness of finding appropriate and valuable self-care interventions and rehabilitation services which can be essential for children and families as it will increase the children's participation in daily activities and enhance their independent living prospects.

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