

THE CHALLENGES OF OCCUPATIONAL THERAPY INTERVENTION IN SUPPORTING ADOLESCENTS WITH AUTISM TO ACCOMPLISH SELF-CARE ACTIVITIES

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ABSTRACT

Objective: The study aimed to explore occupational therapy intervention approaches to strengthen and enhance the self-care skills of adolescents with autism.

Method: This research used qualitative methodology and in total five occupational therapists working in rehabilitation centers were involved in expert interviews. The thematic analysis method was applied for data analysis and main categories were developed to describe occupational therapy intervention approaches used in enhancing the self-care performance of adolescents with autism (Guest, MacQueen, and Namey, 2012).

Conclusion: Four themes were developed to describe the main difficulties of adolescents with autism in performing self-care activities: **person-based difficulties in performing self-care activities; challenges in providing external assistance to carry out self-care.** As well as effective occupational therapy support was formed to strengthen their active participation in self-care: **execution of interventions based on adolescents' active involvement; a combination of occupational therapy specified approaches** (using visual-verbal cues, chaining teaching, and time visualization).

Keywords: autism, adolescents with autism, occupation therapy intervention, participation, self-care activity.

INTRODUCTION

Doing activities of daily living (ADL) such as personal hygiene, toileting, dressing, eating, and cleaning the house was essential for all human beings, and especially for adolescents with autism the mastery of these skills was directly related to the opportunities to live independently, being involved in the community, moreover, it allowed being independent (Butterworth et al., 2013). It was well known, that occupational therapy being a healthcare profession involved the use of assessment and intervention to develop, recover, or maintain the meaningful activities or occupations of individuals, groups, or communities including self-care activities (Law, Steinweinder, and Leclair, 1998). Occupational therapy intervention for adolescents with autism might determine the client's self-esteem and motivation to take part in areas of occupation and use united treatment activities that tap into an individual's preferences and interests (Little et al., 2014). Little was known about occupational therapy intervention methods and approaches used with adolescents with autism in Armenia that enhance their independent participation in daily occupations and facilitate the performance of self-care activities. For this reason, this qualitative research is directed to determine the challenges of occupational therapy intervention in supporting adolescents with autism to accomplish their self-care activities.

LITERATURE REVIEW

Autism spectrum disorder (ASD) is a common neuro-developmental disorder characterized by pervasive difficulties since early childhood across reciprocal social communication and a restricted repertoire of activities and interests (American Psychiatric Association, 2013). The symptoms of ASD manifest themselves in the form of defects in communication and social interactions and in addition, children and adolescents with autism experience serious problems with sensory processing, perceptual and cognitive skills, and language which can affect their occupational performance in self-care, productivity and play areas (Seltzer et al., 2003; Diagnostic and Statistical Manual of Mental Disorders 5th Edition, 2013).

As children with autism become adolescents and young adults, they may have difficulties developing and maintaining friendships, communicating with peers, or understanding what behaviors were expected in school or on the job. Also, they could have insufficient participation in their self-care activities due to anxiety, depression, or attention-deficit/hyperactivity disorder, which occur more often in people with autism than in people without it (Shepherd, 2005). Because of this, adolescents with autism became dependent on their surrounding people like parents, care providers, and others and therefore, their limited occupational performance leads to limited participation (Dewinter et al, 2013). And according to the International Classification Model of Function Disability and Health, participation is the involvement of the individual in life situations and is one of the important components of function and health (ICF, 2001).

According to the World Health Organization (WHO, 2018), adolescence age may begin in the second decade of life, which assumed a transition period from childhood to youth. To the other authors, that phase is defined as a period of adolescence that includes a variable period of 10-24 years (Sawyer et al., 2012). At these age adolescents used to actively engage in different activities of daily life and usually perform self-care activities independently. As a rule, independently performing self-care activities can increase the life quality of adolescents with autism and decrease their dependence on others (Wertalik, and Kubina, 2018). Given the significant differences in performing self-care activities independently, adolescents with autism may experience problems in achieving skill proficiency and mastery to perform daily activities (Little et al., 2014).

In the American Journal of Respiratory Medicine (2006), self-care was defined as the ability to take care of oneself, to take care of one's own needs, to ensure one's independent existence, and to be physically independent. All of these were considered manageable needs while outside help may be a little and less than once a day. Learning to perform activities of daily living, like dressing, self-feeding, and toileting, is considered to be crucial to a person's independence and ability to take part in the larger world (Hampshire, Butera and Bellini, 2016). Due to autism adolescents have interaction and communication disorders, attention deficit, emotional disturbances, and limited, stereotyped repetitive behaviors experiencing difficulties to master their daily living skills or abilities, and performance of such tasks can be especially challenging for them (American Psychiatric Association, 2013; Gillham et al., 2000). Therefore, daily activities are considered to be the main tasks that must be performed every day to assure individual development, health and well-being (Stephen et al., 2007).

As every person with autism used to be very different, accordingly the life skills and the pace that were taught also used to vary from person to person. For people with autism, learning life skills could be essential to increase independence at home, at school and in the community. By introducing these skills at an early age and building block by block, people with autism gain the tools that would allow them to increase self-esteem and lead to more happiness in all areas of life (Jasmin et al., 2009).

To this end, occupational therapy intervention played a primary role in working with adolescents with autism while maximizing their ultimate functional independence and quality of life by facilitating the development of daily living skills (McPartland, Law, and Dawson, 2015). In general, occupational therapy interventions aimed to help individuals with deficits or disabilities in various areas become as self-sufficient as possible in their daily lives (AOTA, 2014).

In the evaluation and treatment of individuals with autism, occupational therapy professionals tend to address activities of daily living, adaptive behavior, rest and sleep, employment/pre-employment, and social participation (Hooper, and Wood, 2014). Additionally, the evaluation and treatment process of individuals with autism includes context (conditions within and surrounding the

client) and the environment (external physical and social conditions), activity demands (tools, space, action and performance skills needed) and finally client factors (underlying beliefs, abilities and values) (AOTA, 2014). The specific intervention techniques used in occupational therapy with individuals with autism include; establishing new functional skills, modifying activity demands, creating healthy lifestyles, maintaining existing performance, and preventing future difficulties for clients at risk (Dunn, 2007). Such an intervention is aimed at restoring and enhancing a person's independence and self-satisfaction, as well as the quality of life (Law, Steinweinder, and Leclair, 1998).

Therefore, little was known about occupational therapy intervention methods and approaches used with adolescents with autism in Armenia. One of the hallmark features of adolescents with autism considered their tendency towards strong preferences and focused interest. For this reason, occupational therapy intervention might determine the client's self-esteem and motivation to take part in areas of occupation and use united treatment activities that tap into an individual's preferences and interests (Hyman, Levy, Myers, and AAP Council on Children with Disabilities, 2020). Given the fact that research on the challenges of organizing self-care for adolescents with autism in Armenia was very limited, the need for conducting qualitative research on the challenges of self-care and household activities for adolescents with autism became very urgent.

Thus, the study aimed to explore occupational therapy intervention approaches to strengthen and enhance the self-care skills of adolescents with autism.

Based on the purpose of the study, the research question was formulated as follows: How have difficulties of self-care activities of adolescents with autism overcome during occupational therapy intervention?

METHODOLOGY

Qualitative research was conducted for this study to explore the main methods and approaches used during occupational therapy intervention to overcome the difficulties of self-care activities for adolescents with autism. The perception and professional experience of 5 occupational therapists' were examined using an expert method that allowed the understanding of the interpretation of the situation from the perspective of the respondents (Marshall, and Rossman, 2006). The analysis of the research data was carried out according to the method of thematic analysis (Guest, MacQueen, and Namey, 2012).

Participants

The participants of the study were 5 occupational therapists who worked in various rehabilitation centers and provided professional assistance to improve the self-care skills of adolescents with autism in Armenia. The selection of research participants was made according to the following criteria:

- Having professional education (occupational therapy education).
- Three and more years of work experience.

To ensure the ethical considerations of the research, participants were provided with an information-consent form and gave their signed agreement to provide relevant information. The purpose of the research was stated in the questionnaire, and it was mentioned that provided information would be anonymous, and the results would be presented in generalized form.

Data collection

An expert method was used for data collection since it was a special method necessary to obtain needed "expert knowledge" for the current study (Meuser, and Nagel, 2002). Under these method experts considered to be:

- People who have professional /field/ scientific knowledge or technical knowledge.
- All individuals involved in their life experience in terms of the event being explored.

An individual expert survey guide was made and used that was similar to an in-depth survey guide, but questions were more complex and assorted and specified according to the research question (Marczyk, DeMatteo, and Festinger, 2010).

Data analysis

The analysis of the research data was carried out according to the thematic analysis method which was one of the most common forms of analysis in qualitative research and emphasized the identification, analysis, and interpretation of topics within qualitative data (Braun, and Clarke, 2006). With the use of thematic analysis, it was possible to focus on the perception and professional experience of occupational therapists working with adolescents with autism and to outline the main approaches and used intervention methods for overcoming difficulties in performing self-care activities (Daly, Kellehear, and Gliksman, 1997). With the use of the thematic analysis method, the content analysis was done to explore the explicit and implicit meanings of the data. This process involves identifying topics "through careful reading and re-reading of the data" (Rice, and Ezzy, 1999).

FINDINGS

As a result of data analyses, the challenges of occupational therapy intervention in supporting adolescents with autism to accomplish self-care had been declared and effective occupational therapy intervention methods were outlined. Concluding the data provided by the experts, it became clear that adolescents with autism were still faced with serious difficulties in performing their self-care activities; moreover, it was even observed limitation of doing these activities independently. These self-care activities included dressing, brushing teeth, bathing, personal hygiene (cutting nails, combing, washing, grooming the body), toileting, eating, and so on. Increasing adolescents' participation in self-care activities helped them to develop independent living skills, which were essential to the transition from

adolescence to adult age. The main difficulties in self-care activities for adolescents with autism and the specific focus of occupational therapy intervention to overcoming them included the following four characteristics and sub-characteristics:

1. Person-based difficulties in performing self-care activities

- 1.1 Limited skills in activity performance
- 1.2 Exposure to social-psychological problems
- 1.3 Having overweight

2. Challenges in providing external assistance to carry out self-care

- 2.1 Over-care/under-care- caregivers' biased attitude
- 2.2 Being manipulated by the adolescents

3. Execution of interventions based on adolescents' active involvement

- 3.1 Emphasizing personal abilities and desires
- 3.2 Significance of an early intervention

4. Combination of occupational therapy specified approaches

- 4.1 Activity modification approach
- 4.2 Importance to maintain the correct and constant sequence of the activity
- 4.3 Application of differentiated approaches in occupational therapy intervention (using visual-verbal cues, chaining teaching, and time visualization).

1. Person-based difficulties in performing self-care activities

The summary of the study results has shown that adolescents with autism had difficulties in performing self-care activities that were mainly based on not well-developed personal abilities and skills at a young age. In particular, these include:

1.1 Limited skills in activity performance

All the participants of the study noted that potential activity-based skills hadn't been developed during childhood for adolescents with autism. In particular, not developed mental, physical, and sensory integration skills limited and caused serious barriers to achieving independence in performing self-care activities. Especially each activity of everyday life required a person to show physical and mental ability like pushing buttons, to perform object manipulation skills; therefore, the development of these skills determined the independence of the person and the quality of life. The study participants had highlighted also sensory integration issues that made barriers and limited adolescents' participation in self-care. The participants emphasized that adolescents with autism needed sensory integration, and particularly they mentioned: “...adolescents with autism everyday face barriers when it comes to brushing their teeth because almost everyone is hypersensitive to smells and tastes.”

1.2 Exposure to social-psychological problems

According to the participants, the most common barriers to performing self-care activities considered the behavioral, social and psychological problems which made it difficult for adolescents with autism to perform self-care. The participants paid special attention to social and psychological problems, and they mentioned the necessity to make adolescents with autism realize the importance of self-care activities. Particularly, they had mentioned: *"...as occupational therapists, when we work with adolescents with autism, we aim to bring them to a level of self-awareness that self-care is very important to them."*

The participants especially emphasized the fact that adolescents had a hardened character, which led to the obstacles in participating to accomplish self-care activities. In general, they had mentioned: *"...they already have a hardened character at a young age, therefore it's very difficult to change the way they used to perform the activity."* All participants noted that adolescents with autism had undesirable behavioral manifestations, which were considered a kind of barrier to performing self-care at that age.

1.3 Having overweight

Having overweight can affect both an individual's health and physical activity. Adolescents with autism were more likely to be overweight since they avoided exercise, led sedentary lifestyles, and had a food addiction. Thus, study participants declared that being overweight could be a problem and limit adolescents' participation in self-care activities: *"...when an adolescent with autism is overweight, he has trouble in dressing/undressing, as can't bend down, can't lift up."*

2. Challenges in providing external assistance to carry out self-care

Data analysis of the study had allowed proving that adolescents with autism were faced with several challenges in performing self-care activities. These problems were due to the position and attitude of caregivers, particularly:

2.1 Over-care/under-care- caregivers' biased attitude

All the participants of the study mentioned that the given support to adolescents with autism should be moderate which would allow them to realize their own needs, and would allow growth and development. They had especially underlined the attitude of caregivers (over-care/under-care) as a major barrier to achieving independence in self-care. The participants emphasized that over-care doubled the work of the specialist, and maybe led to aimless work and waste of time. Particularly, they had noted *"...if instead of the adolescents the activity is performed by the caregiver, then the question occurs, is it worth spending so much time on developing and strengthening self-care skills? "*

Participants also identified the biased attitude of the caregivers, which also made a barrier and restricted the adolescents' participation in self-care activities. Particularly, they had mentioned: *"... they*

don't believe in their child's power, that he/she can do. They think that if he/she hasn't been able to learn that skill or activity in childhood, he/she certainly won't be able to learn in adult age."

2.2 Being manipulated by the adolescents

The analysis of the research data revealed that the manipulation of caregivers by adolescents with autism was a serious obstacle to not using the knowledge that was gained for executing self-care activities. The respondents stated that during supporting adolescents to perform self-care activities the caregivers had been manipulated which also limited adolescents' participation in self-care activities.

3. Execution of interventions based on adolescents' active involvement

Data analysis proved that active participation of adolescents with autism in self-care activities helped them more effectively develop independent living skills. However, being passively involved in daily activities did not allow achieving the desired result. All participants had stated that an occupational therapy intervention conducted with the active involvement of adolescents, considered being an important indicator of participation in self-care actions and an effective way for overcoming difficulties. The participants had declared the importance of depth assessment of adolescents' abilities and desires, which should be emphasized during the intervention. Moreover, they had also mentioned the importance of organizing an early intervention, since it had been considered to be the best way of preventing further difficulties and challenges.

3.1 Emphasizing personal abilities and desires

Since participants had stated occupational therapy to be a "client-centered" profession, they had especially noted the importance of identifying client's wishes and needs, while mentioning: *"... being occupational therapists, we have to be client-centered. It is very essential to take into account the client's opinion, needs and desires."* Moreover, the participants mentioned the value of taking into consideration the client's abilities, noting that: *"...Occupational therapy intervention goals should be based on the client's abilities. We have to determine how independent will they be?"*

Participants also identified the importance of increasing the active participation of adolescents with autism in their self-care activities. Furthermore, they mentioned that active participation contributed to achieving the desired result, as well as helping them to develop independent living skills. They mentioned the necessity of identifying the client's motivation during organizing occupational therapy intervention. According to their opinion, both internal and external factors motivated adolescents with autism to perform self-care activities. Hence, a successful work process was due to the discovery of motivation: *"... A therapist must be very attentive for being able to determine the motivation of adolescents with autism; this is the quickest way to achieve success".*

3.2 Significance of an early intervention

According to the study participants' point of view the adolescents' challenges in performing self-care activities, mainly due to lack of early intervention, had a fundamental influence on the further development of their abilities, independence, and quality of life. Moreover, study participants emphasized that adolescents with autism who had received an early intervention had a positive outcome: *"... There are some adolescents with autism who have been attending a rehabilitation center since childhood, and lots of problems in self-care activities have been overcome and observed at an earlier age."*

4. Combination of occupational therapy specified approaches

Study participants had affirmed that the combination of a variety of occupational therapy approaches promoted the involvement of adolescents with autism in self-care activities; as well it promoted the development of necessary skills. In particular, these include:

4.1 Activity modification approach

All the participants had underlined that the use of occupational therapy approaches during intervention focused on modifying the way of accomplishing the activity that brought the desired result in daily life. Particularly, these included the following: to start the task from the simpler step to the more difficult, to divide the task into subtasks, which allowed adolescents with autism to feel more self-confident. Furthermore, study participants recognized these approaches to help support adolescents to continue their involvement in self-care activities and feel positive about the activity. That was very essential to conduct occupational therapy intervention based on these approaches: *"...once adolescents with autism experience success in performing the task correctly, they will have a positive feeling. So we start from the simpler tasks, then step by step making it more difficult."*

The importance of dividing the task into subtasks also had been pointed out by the participants, as some activities had multi-steps which could cause stress for adolescents with autism. *"...it is very important helping them to learn how to perform self-care activities in small steps. This will keep adolescents with autism away from stressful situations. For example, how to hold trousers, socks, etc."* Also, numerous achievements had been recorded as a result of using activity modification approaches: *"...If an adolescent with autism can do self-care activities differently, he/she should do it in a way they like, but on his/her own or independently. Working in this way we have recorded many positive results."*

4.2 Importance to maintain the correct and constant sequence of the activity

A summary of the research data showed that adolescents with autism had difficulty maintaining the correct sequence of activities. Therefore, the participants declared the necessity to train activity learning without changing any step. Also following the correct and constant sequence of the activities helped them to achieve independence in performing self-care: *"... While training an activity, we have to teach and keep the correct sequence, in a ritualistic way, without making any changes."*

4.3 Application of differentiated approaches in occupational therapy intervention (using visual-verbal cues, chaining teaching, and time visualization).

Results of data analyses proved that the application of differentiated occupational therapy approaches in self-care activities helped adolescents with autism to develop the necessary skills for performing activities independently. In particular, these included: visual and verbal cues; visualization of time and chaining strategy. Respondents had underlined that adolescents with autism needed visual and verbal guidance, since it gave them a feeling of safety, as well as helped to easily orientate or perform self-care activities. In occupational therapy intervention the use of visual and verbal cues seemed to be an essential support for them: *"... If adolescents with autism know what to do and what to expect, they can orientate more simply, and also easily perform all required activities. Before starting any activity I speak, I always say what we should do."* In addition, the participants pointed out that the use of cards in the therapy process helped to reduce unwanted behavior. Having the opportunity to predict the beginning and the end of the activity was a very important strategy for enhancing participation in self-care. That prevented chaotic situations and led to reducing undesired behavior. *"...It is very necessary for adolescents with autism to see the beginning and the end of the activity, that help them not to fall into the chaos, and reduce showing not appropriate behavior."* The participants of the survey also underlined the importance of time visualization, while working with adolescents with autism. They mentioned that time visualization, and an alert about the end of time also avoided the possibility of showing unwanted behavior. Particularly, they had mentioned: *"...I work with timers. Adolescents with autism need to see the beginning and the end of the activity, for not having unwanted behavior."*

One of the most common differentiated approaches in occupational therapy intervention for mastering self-care activities had considered to be the use of a chaining strategy, which had been noted by the participants. According to the participants, forward chaining and backward chaining training methods helped to master multi-step tasks gradually - step by step, until all the steps were mastered. The participants emphasized that the chaining training method was mostly used in ADL training.

DISCUSSION

The following study aimed to explore the challenges of self-care activities of adolescents with autism and to identify the most effective approaches to overcome these difficulties during occupational therapy interventions. The study identified four main themes: **person-based difficulties in performing self-care activities; challenges in providing external assistance to carry out self-care; execution of interventions based on adolescents' active involvement, and combination of occupational therapy-specified approaches.**

The current study supported the knowledge that doing ADL such as personal hygiene, toileting, dressing, eating, and cleaning the house was essential for all human existence, especially for adolescents with autism, as these skills are directly related to living independently, being involved in the community, moreover it had given adolescents with autism an opportunity to be independent (Helt et al., 2008). This study once again proved the idea that adolescents with autism still faced serious difficulties in performing activities of self-care, which was mainly due to the lack of person-based abilities and skills developed at early ages. Several studies had also shown that the behavioral, social-psychological problems of adults with autism, as well as manifestations of complex character and the need for sensory integration, limited their participation in self-care activities (Lecavalier, 2006).

The findings demonstrated that adolescents with autism tended to be overweight, which hindered their participation in self-care activities as well. Previous studies had also shown that people with autism were more likely to be overweight, from 10% to 31.8% (Whitely et al., 2004; Phillips et al., 2014).

The findings of this study allowed underline the important role of the given external support. From this point of view, if caregivers were overprotective, that hurt adolescent and limited their ability to active participation in self-care activities. Previous studies had also stated that lack of parental knowledge of these issues put the development of self-care skills at risk, and parents could not promote the development of self-care skills at an early age, could be unaware of their children's capabilities, moreover could show overprotection (Bagarollo, and Panhoca, 2010; Serra, 2010). However, the findings of the current study proved that the active involvement of adolescents with autism in self-care activities allowed them to achieve independence in their environment. From this point of view, performing self-care activities every day related to the person's preservation of independence, mobility, and communication, and was aimed at stimulating their independent participation in daily occupations (Law, 2002).

This study again stressed the importance and essential role of **early intervention** for adolescents with autism to be able to accomplish self-care activities independently based on their wishes and needs. Previous research had also proved the fundamental necessity of early intervention for further development of skills, independence, and quality of life of adolescents with autism (Rogers, and Lewis, 1989; Reichow, and Wolery, 2009).

The findings of the study had found that **a combination of occupational therapy-specified approaches** had a positive impact on the development of self-care skills for adolescents with autism, and doing things on their own it promoted the development of self-confidence and independence. Several studies had also approved that combined approaches and chain training were the most commonly used differentiated approaches to modifying self-care activities (Kazdin, 1994). The use of

occupational therapy-specified approaches had allowed for enhancing the participation of adolescents with autism in self-care activities and while achieving even small success they used to feel more confident, not gave up, and showed a willingness to accomplish the next task. It had been proven that a combination of occupational therapy approaches such as visual and verbal guidance as well as time visualization helped to make daily life predictable, making it easier to learn about self-care (Van, Kraus, Karpman et al., 2010).

The summary of current study findings showed that adolescents with autism used to overcome difficulties and barriers in performing self-care activities due to not developing the necessary skills and abilities at an early age. But not only personal skills should be taken into account at this age also the provision of external assistance played an important role in enhancing the participation of adolescents with autism in self-care activities. Therefore, a combination of occupational therapy-specified approaches helped adolescents with autism to develop the necessary skills for independent participation and accomplishment of self-care activities.

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