OCCUPATIONAL THERAPY APPROACHES TO OVERCOME PLAY ACTIVITY PROBLEMS OF CHILDREN WITH RETT SYNDROME

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ABSTRACT

The goal of the research was to study the occupational therapy features of organizing play activities for children with Rett Syndrome. Qualitative research method was used for current research work and, a semi-structured interview was conducted with three occupational therapists working with children with Rett Syndrome (RS) who had three and more years working experience. Conducted semi-structured interview revealed and described the specifics of treatment approaches from their own professional perspective. As a result, it was studied what kind of play activities occupational therapists implement in their work with children with RS. The analysis of the research data was conducted based on the descriptive method.

Results: The results of the study showed that occupational therapists widely use various play methods and activities in their work with children with autism spectrum disorders, aimed at developing the child's motor, cognitive, and social abilities. Play activities contributed to the development of children's independence, concentration, interaction with the environment and participation in everyday life activities. At the same time, some difficulties have also been recorded, related to the child's motor limitations, short-term attention span and low level of play initiative. The study highlighted the role of occupational therapy in the process of organizing play activities for children with RS and emphasized the need for targeted, individual interventions. The results of the study further could contribute to the effective organization of occupational therapy treatment and improve children's quality of life.

Keywords: *Rett Syndrome, occupational therapy, play, occupational therapy intervention, play activity, participation, and quality of life.*

INTRODUCTION

It was well known that play activities were crucial for a child's holistic development and was the main mean of communication, mastering skills, and self-expression (Astik, & McDonald, 2016; Harvard, & Lindel, 2020). However, for children with various developmental disorders, especially girls with RS,

being involved in play activities may be accompanied by a number of complications such as physical, sensory, and communication difficulties.

Since RS considered to be a neurological genetic disorder which occurred mainly among girls it was characterized by the loss of skills acquired after a period of normal development and motor limitations, impaired hand function, lack of or limited speech, and sensory perception difficulties were often observed. All of these factors hindered child's participation in play activities, which were important for child's socialization, learning, and the development of emotional stability.

In this context, occupational therapy played a key role which aimed at promoting the child's practical skills, taking into account her/his individual needs, physical and sensory capabilities. Occupational therapy intervention approaches aimed to ensure the child's maximum participation in play and everyday activities by creating an appropriate environment, using adaptive devices and applying individual approaches (Sansom, & Krishnan, 2017; Stahlhut, 2018).

The current study highlighted the peculiarities of the play activities for children with developmental disabilities, the existing difficulties, and the possibilities of overcoming them through occupational therapy interventions. **Therefore, the aim of this study was to explore occupational therapy intervantion approaches for overcoming play activity problems of children with Rett Syndrome.**

LITERATURE REVIEW

According to the definitions included in the literature, Rett Syndrome (RS) is a rare, severe neurodevelopmental disorder characterized by developmental disorders, comorbidities, and abnormal behaviors, such as hand stereotypies and emotional features. It predominantly affectes girls and may occur, on average, in one in every 10,000–15,000 female births (Neul et al., 2022).

Scientific research in the health sector distinguished that RS is progressing by four-stage course. Developmental delay begin in early childhood, and there was usually a period of stunted head growth. Affected girls usually has normal development for the first 6–18 months, although subtle symptoms such as muscle hypotonia and slow head growth are presented at an earlier age but are not seen. Symptoms may not be apparent initially, but may become apparent during the first two clinical stages. Common symptoms include severe cognitive impairment, loss of goal-directed manual skills, and the development of stereotyped hand movements such as repetitive hand clenching (Hagberg et al., 1983). Motor dysfunction of children with RS include gait disturbances, muscle rigidity, and scoliosis. Loss of acquired motor skills such as walking is a hallmark of the disorder. Some studies have documented age-related decline in motor skills among children with RS (Marschik et al., 2013).

The play activities of children with RS often differ from those of children at other levels of normal development. Thus, play is the main activity of a child and develop the child's mind, increases intuition, helped to quickly orientate, and positively influenced on memory. It stimulated the child's development in the areas of social and spiritual development as well (Shah et al., 2017; Odom et al., 2010). Childhood considered to be the period when the child gradually discovers the environment and various authors, discussing play activities from a number of perspectives, unanimously noted that play activities were a unique and integral part of the human cultural system (Lucas, 2018).

As it was know, children typically developed social skills through play activities, but children with RS often had difficulties with both recognition and communication (Sigafoos et al., 2023) which made their social interaction with other people difficult. Therefore, for them, play can be used as a social and educational tool to better understand the child's inner world. They may be socially isolated or uncoordinated, which interfered with social play as well. Special programs have been developed for these children, including visual and highly sensory games that can contribute to their development. Using play activities during occupational therapy intervention are of great importance, since play is not only an effective tool for children, but also an important means of discovery, learning, socialization and self-expression (Case-Smith, 2015; Vignoli et al., 2019). Since play activities have an important therapeutic role for overcoming various issues it focused not only on physical, but also on social and psychological aspects of development. During occupational therapy intervention play can be used in the process of child development and disease treatment (Moser, 2017; Long, & Case-Smith, 2014).

Occupational therapy using individual goal setting and enriched environment for creating the conditions to reduce the functional deficit due to RS (Downs et al., 2018). Interventions may include: cognitive engagement, sensory stimulation, social stimulation, timing of activities and gross motor practice and exercise (Carter, 2010). The work of an occupational therapist begins with observation of the child in his/her natural environment, during which the specialist assesses movements, the child's response to external stimuli, the ability to functional use of hands, the degree of participation in play activities, and non-verbal communication methods. This observation allows to identify the child's behavioral patterns and understand how sensory and motor disorders affect the performance of his daily activities (Percy, 2016). Other study highlighted that there is a need for early and regular intervention, preventive management and an individualized approach at every age with RS (Anderson et al., 2014; Halbach et al., 2008).

Recent studies have shown that play can help children develop motor skills (Harvard, & Lindel, 2020; McAmis et al., 2017). Thus, occupational therapists often use methods that establish harmony between movement, play, and the body to improve coordination, and variety of play-based approaches to create practical environments that support integrated rehabilitation work across different disciplines (psychotherapy, physical therapy (Adams, 2019). The occupational therapist makes play the main means of development of the child, adapting it to his/her motor abilities, level of participation and sensory responses. Meaningfully selected game activities allowed the child to move, explore, communicate and express himself in comfortable way (Brunetti, & Lumsden, 2020; Carter et al., 2010).

Occupational therapy interventions may increase participation for children with RS since, occupational therapists use occupation as the primary therapeutic agent as well as a goal of intervention (Fisher, 2013). The opportunity to take part in activities differs due to age, interests, motivation, earlier experiences, support and network, aids, financial situation, place of residence, health care, school or daily work resources (Andrews, Falkmer, & Girdler, 2015). Collaboration with parents, teachers, and other members of the multidisciplinary team is also an important part of the occupational therapist's work, as family support increases the effectiveness of interventions and ensures more sustainable development (Urbanowicz, 2016; Retzlaff, 2007).

Scientific studies show that RS is not degenerative in nature, and with appropriate interventions, it is possible to maintain and develop a child's motor, practical, cognitive, and communication skills, as explained in a multidisciplinary study published by Cass (2003) and co-authors. According to the above, **the aim of this study was to explore occupational therapy intervantion approaches for overcoming play activity problems of children with Rett Syndrome.**

METHODOLOGY

A qualitative research methodology was used for this study, which allows for an in-depth study of the participants' subjective perceptions, practical experience, and professional approaches. Within the framework of the study, a semi-structured interview was used with three occupational therapists to identify the occupational therapy features of organizing and developing play activities for children with RS based on their professional experience. The semi-structured interview was conducted to identify and describe the features of their work activities from their own professional perspective. The descriptive method of data analysis was used to analyze the research data, as it allows us to identify the point of view or perception of the sample group on a given phenomenon, in particular, to describe what kind of play activities occupational therapists implement in their work with children with RS (Nayar, Stanley, 2015).

RESEARCH PARTICIPANTS

Semi-structured interview method was used with three qualified occupational therapists having at least three years of experience working with children with RS. Participants were selected through purposive sampling based on their professional experience and relevance to the topic (Adeoye, 2023).

DATA COLLECTION AND ANALYSIS

The main data collection tool was the semi-structured interview that was often used in qualitative research to obtain detailed information especially when a little was known about the topic being studied (Whiting, 2008). Conducted data collection method allowed to explore and discover the characteristics of children with RS and used assessment methods based on their work experience. Data collection was directed also for specifying the forms and effectiveness of occupational therapy intervention, as well as highlighting the difficulties and challenges encountered during collaborating with families.

The analysis of the research data was carried out by descriptive analysis method that aimed at to provide a clear picture of the problem under study while capturing the nuances and complexities inherent in the data (Ghorbani, & Matourypour, 2020). Applied descriptive analysis helped to summarize and define main areas of play activity problems that children with RS and their families meet. For research data analysis all interviews were recorded and transcribed ensuring the integrity of the content. The data was read multiple times to be familiar with the responses and after the main characteristics and patterns were identified based on the participants' responses. This approach allowed to identify the main recurring ideas, trends and significant differences in the experiences of specialists. All interviews conducted were

recorded and a detailed analysis was performed. The next step was to organize responses into meaningful categories using a coding framework. And after all data was categorized, the summary of key themes was developed without over-interpreting the content (Kim et al., 2017).

RESULTS

As a result of the analysis, several main directions were identified that characterize the effectiveness and existing difficulties during organizing occupational therapy intervention for play activities for children with RS. As a result of the analysis of interviews and observations collected during the research, it became clear that the organization of play activities for children with RS had a number of features that require a professional, flexible and individualized approach.

According to the occupational therapists' data analysis it was possible to declare that play-based interventions for children with RS cannot be implemented through general programs, as each child's motor, communication, and sensory capabilities were significantly different. Since each child's abilities could be in a different level of development such as motor limitations, communication difficulties, and sensory characteristics, that had to be taken into account when organizing play. According to the experts, the main difficulties related to: impaired eye-eye and eye-hand coordination, short-term attention span, inability to initiate and complete play activities, and difficulty participating in cooperative games.

Data analysis had shown that in addition repetitive and atypical hand-to-hand and hand-to-mouth movements interfered with the purposeful use of hands during play activities. All these stated the importance for developing an individual play program for each child, based on his or her preserved capabilities and abilities. All participants emphasized that sensory games play an important role in promoting play activity for children with RS. The most targeted games were those that included tactile stimulation (toys with different surfaces), motor stimulation (light rocking, rolling, swinging), olfactory and visual stimulation (safe materials with scents, bright colors).

According to the research participants during provided treatment sensory integration mainly used to reduce stereotypic movements of childnre, overcome their tactile hypersensitivity and develop a conscious perception of the hands for organizing further play activities using various sensory balls, kinetic sand, soft and rough touch surfaces and so on. The inclusion of **sensory integration approaches,** structured and socially interactive games, as well as a purposefully selected environment and safe toys significantly increased a child's engagement and reduce stereotypical behavior.

These works were connected to play in such a way that the child learns not only to "feel" the material, but also to use it in a playful way: to fill, squeeze, build, move. As a result, play becomes more purposeful, not just a series of stereotypical movements.

The research participants emphasized the importance **of developing social interaction in a play environment**, especially for communication and building relationships with peers and family members. It was noted that the effective duration of play for children with ADHD is a maximum of 20-30 minutes, since this duration is appropriate for a child to maintain maximum attention and engagement but with the support of another person. According to the data analysis it was possible to state that mentioned **during for games and organization of play activities should be well structured** so the child could

respond to the actions of an adult, take turns (e.g., "take turns rolling a ball") or maintain simple social rules during play (waiting, responding to name). As a result, it was observed that appropriately organized play interventions contribute to a small but steady increase in a child's communication initiative.

Research participants also emphasized that the purposeful selection of toys and the organization of the environment had great impact on the effectiveness of play. Occupational therapists who participated in the study noted that the following were most appropriate for children with RS:

1. toys made of ecologically friendly and safe materials,
2. toys with sound signals,
3. games with bright colors and simple structures.

This considered to be important since children with RS often put things in their mouths, and the toy needs to be completely safe. The sound and bright colors helped to focus attention and maintain interest.

The results of the study showed that **explanatory work with parents significantly increased the effectiveness of play activities at home**. While summarizing the research data the following important steps were outlined that occupational therapists usually offer to parents:

1. Creating a suitable play environment for the child: a bright room, an adapted table and chair.
2. Not placing multiple toys in front of the child at the same time so that he/she can focus on one specific game.
3. During play, giving clear and concise instructions and wait until the child tries to follow them.
4. Regularly implementing small sensory integration exercises as part of the play process.

According to the specialists above mentioned approaches contributed to the fact that the child with RS began to perceive play not only as a field of repetitive movements, but as a meaningful and enjoyable activity.

Research data analysis revealed that effective organization of play activities for children with RS could be possible only when it was based on an individualized approach, applied sensory integration, stimulation of social interaction, and a properly selected environment. The combination of these conditions promoted the child's active participation in play activities, contributing to reduce stereotyped movements, and gradually developing functional play skills.

The following recommendations were developed based on the research results:

1. Developing individual play programs for a child with RS based on the results of his/her motor, sensory, and communication skills and abilities.

2. Systematically applying sensory integration approaches to be sure that sensory integration exercises are linked to the play for reducing stereotyped movements and increasing attention focus.

3. Using structured and short game sessions – Organizing the game duration within 20–30 minutes, maintaining structural clarity and a simple sequence.

4. Promoting social interaction - Structure games to include turn-taking, response to an adult, and simple social rules, promoting the development of communicative initiative.

5. Adapting the environment – Creating a safe, bright, and overstimulation-free environment by reducing the number of unnecessary toys and ensuring focused attention.

6. Parental education and involvement – Organizing parental consultations and practical training to ensure the generalization of play skills at home.

7. Conducting multidisciplinary collaboration – Implementing the play-based intervention using the principle of teamwork, including a speech therapist, psychologist, physiotherapist, and educator.

DISCUSSION

The findings from this study highlight the features of organizing play activities for children with RS during occupational therapy treatment. This study provides concise overview of organization play activities that requires a high level of flexibility, creativity, and a use of sensory approach.

The research data also underscores the implications of rehabilitative intervention during play activities for children with RS through which it is possible to develop self-expression, motor and social interaction skills. Some challenges have also been noted, particularly children's mobility limitations, communication barriers, and varying degrees of family involvement. However, experts have found ways to overcome these barriers by linking sensory integration approaches during play activities, and giving simple structured tasks.

The results of the study showed that play-based interventions cannot be implemented **with general programs, since physical,** communication, and sensory capabilities of each child differ significantly from each other. According to sensory integration theory, interventions should build on existing sensory and motor foundations rather than deficits, which contributes to increasing the child's self-confidence and play motivation (Ayres, 1979; May-Benson, & Koomar, 2010*).* This conclusion coincides with the fundamental approaches of pediatric occupational therapy, according to which activity-based interventions should correspond to the individual functional profile of the child (Eklund et al., 2017). Christiansen and Townsend (2010) emphasize that "one-size-fits-all" approach to occupational therapy is inconsistent with the nature of activity-based interventions. Generic programs fail to address the frequency of stereotyped movements, limitations in purposeful hand use, and sensory hypersensitivity or hyposensitivity that children with RS exhibit.

The main difficulties, such as difficulty initiating and completing play activities, limitations in participating in cooperative games, and the presence of atypical movements, are due to the neurodevelopmental characteristics of RS. Literature review shows that such behavioral manifestations can hinder the formation of functional play if the intervention is not structured on a purposeful and gradual basis (Sansom & Krishnan, 2017).

The analysis of the results demonstrates that an effective play intervention should be based on an individual play program based on the child's existing capabilities. An individual play program is viewed as a structured form of intervention that takes into account the child's existing abilities, interests, and opportunities for participation. This approach is consistent with the provisions of Gary Kielhofner's Model of Human Activity (MOHO), according to which activity is effective when it is appropriate to the person's abilities, environmental conditions, and activity requirements (Kielhofner, 2008).

Reviewed literature stated that controlled multisensory environment, incorporating clinical knowledge in the field of RS and suggesting this approach as an appropriate intervention method for this

population (Lotan, 2006). During the study, special importance was given to sensory games, which, according to experts, are a key factor in promoting play activity in children with RS. The effectiveness of sensory stimulations and approaches used during play is also confirmed by modern research, which emphasizes the role of sensory play in the development of functional skills (Bundy et al., 2020). Also occupational therapy interventions may include: cognitive engagement; sensory stimulation; social stimulation; timing of activities and gross motor practice and exercise (Hammell, 2014).

Data analysis confirmed the importance of **social interaction development which** is an important platform for the formation of social skills, including turn-taking, responding to adult actions, and following simple social rules. This approach is consistent with the theory of sociocultural development, according to which play is a primary means of social interaction and development, where, with the support of an adult or peer, the child can act in his "zone of proximal development" (Vygotsky, 1978; Boonen, 2020). For children with RS social interaction often does not develop spontaneously, but targeted by play interventions and promote even minimal but sustained communication initiatives, are basis for emotional safety and participation (Rose et al., 2019).

Research findings highlight the importance of explanatory work with parents. Active parental involvement promotes the generalization of play skills in the home environment and increases the sustainability of interventions (King et al., 2018). There is a need for early and regular intervention, preventive management and an individualized approach at every age for children with RS (Anderson et al., 2014). Parents and all professionals supporting individuals with RS also need support to be able to cope (Lamb et al., 2016; Retzlaff, 2007).

In general, the discussion of the results of this study and their literary justification allow us to conclude that the effective organization of play activities of children with developmental disabilities is possible only when it is based on an individual approach, play programs built on preserved abilities, sensory integration, stimulation of social interaction, and a correctly selected environment. The combination of these factors contributes to the child's active participation in play, reduction of stereotypical behavior, and gradual development of functional play skills.

Occupational therapy interventions may increase participation for the RS individuals, since occupational therapists use occupation as the primary therapeutic agent as well as a goal of intervention (Fabio et al., 2020). The opportunity to take part in play activities differs for children with RS due to a range of reasons that are not solely related to the degree of severity (dyspraxia, latency, limited communication skills, seizures, stereotypies) and many other reasons that can include; age, interests, motivation, earlier experiences, support and network, aids, financial situation, place of residence, health care, school or daily work resources (Fabio et al., 2020).

SUMMARY

This research aim was to study of occupational therapy approaches for overcoming play activity problems of children with Rett Syndrome. Literature analysis has shown that RS is a neurological genetic disorder accompanied by motor, communication, and sensory difficulties that directly affect play

participation. At the same time, scientific studies have shown that with appropriate interventions, it is possible to maintain and develop a child's functional abilities.

The research was conducted using a qualitative methodology, using semi-structured interviews with three experienced occupational therapists. Descriptive data analysis allowed to identify the main directions and professional challenges in organizing play activities.

The results of this study allowed to conclude that the organization of play activities for children with RS was one of the key components of occupational therapy intervention and requires a highly individualized approach. The results showed that effective play intervention was based on individualized programs, including sensory integration approached, promoting social interaction, and proper organization of the environment. The importance of active parental involvement was also noted. Overall, the work emphasizes that play was one of the most important factors in the development of children with autism spectrum disorders and can serve as an effective rehabilitation tool, that was organized in a professional, scientifically, and individualized manner.

It was confirmed that general and unadapted programs did not provide sufficient effectiveness, since each child with RS had a unique motor, communicative, and sensory profile. The basis of effective play intervention should be the identification of the child's preserved abilities and an individual play program built on them.

Thus, it can be concluded that effective organization of play activities for children with Rett syndrome is possible only when it is based on:

1. on individual assessment,
2. on the activation of preserved abilities,
3. on the application of sensory integration approaches,
4. on promoting social interaction,
5. on the purposeful organization of the environment.

Research shows that the development of play activities for children with RS requires structured, sensory-rich, flexible approaches, since play not only contributed to the overall development of the child, but also provided an opportunity to create a bond between the specialist and the child.

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