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Influence of the functional intervention on the development of essential social skills in children with life-limiting conditions

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Life-limiting conditions often cause children to be overlooked as participants in everyday activities. For parents child development should lead to independence in daily living activity. For parents of children who are disabled, independence is a step to a better quality of a child's life. The aim of the study was to examine the effectiveness of functional intervention of self-service activities in children with life-limiting conditions at the age of 3–6 years of life. 32 children aged 3–6 years ($N = 32$, girls and boys) were followed for two years. The Progress Assessment Chart of Personal and Social Development (PPAC) H.C Gunzburg according to Witkowski inventory was used to assess. After two years of functional intervention, statistically significant improvement in everyday activities was observed in examining group. The control group showed less progress than the study group, even though the children in the control group were older. Functional intervention allows for effective work with a patient with life-limited conditions. Better progress was observed in the younger group, subjected to therapy for the existence of developmental potential occurring in children with limitations in intellectual development.

Keywords Developmental delay, Childhood, Early intervention, Qualitative data, Family support, Life-limiting conditions

Life-limited conditions are described as irreversible but non-progressive conditions causing severe disability such as severe cerebral palsy, and multiple disabilities, such as following brain or spinal cord injury connected with intellectual disability. Intellectual disability¹ combined with behavioral disorders occurs in 2 to 3% of the world's population. Profound intellectual disability occurs in 6 out of 1000 people^{2,3}. Among this group, there is a percentage of people with profound disability who are diagnosed with an additional disease entity. Part of those numbers are children. Among children aged 0–6 years, the observation and diagnosis of intellectual disability are difficult due to the critical time for the development of social skills, which physiologically occurs in the first 3 years of life². During this period, environmental conditions play a crucial role in a child's development. They influence the formation of relationships, a sense of security, and consequently, the achievement of developmental milestones at the appropriate time^{4–6}. Enabling children with life-limiting conditions to utilize the skills they develop in practice is essential for their consolidation⁵. In his work, Tottenham discusses the impact of institutionalization on children in their early years on the abnormalities observed in emotional relationships, attachment, and motor skills⁵. The emotional bond between a child and a caregiver in care facilities is often characterized by uncertainty. This emotional disorganization can lead to a disorder in psychomotor development, resulting in a slowdown in the acquisition of new skills^{4–8}. Advanced care planning is crucial for parents. The opportunity to develop independence in their children is essential for maintaining a good quality of life, especially in life-limiting conditions^{9,10}. Children with intellectual disabilities achieve social skills much slower than their healthy peers, which leads to secondary exclusion from their peer groups. Irregularities are described as behavior that is inappropriate to the situation and harms the person or the environment¹¹. For this reason, supporting development through therapeutic activities may lead to a reduction delay in the development phases of social skills appropriate to the patient's age^{2,12–14}. Activation of a pediatric patient leads to the promotion of desired behaviors and the inclusion of patients in everyday activities. This makes everyday functioning easier for families and enables caregivers/parents to lead a regular life, return to work, and leisure, reducing the social costs of maintaining a disabled person and preventing exclusion from society^{2,15}. Lack

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of physical activity guidelines for children with life-limiting conditions is still the most commonly reported barrier to providing functional intervention¹². Among already known and described therapeutic methods and techniques, many different approaches are used, depending on the patient's capabilities and caregivers' expectations. Building the therapeutic process is based on gradually developing abilities and skills in accordance with developmental norms^{11,16,17}. Coordinated support in daily activities and social skills is crucial for child development^{18–20}. The implementation of therapeutic interventions described in the literature as a guiding takes place over a long period count in years²¹. Therapeutic procedures in case of intellectual disability should be conducted continuously and maintained in the home environment to obtain the best and long-lasting effects. Basic abilities in daily functions such as independent eating, using the toilet, dressing, and undressing are crucial for a more comfortable family life. In the case of people with intellectual disabilities, it is possible to develop everyday activities adequate to the skills of a child at the age of 3^{3,22,23}. Self-service opportunities provide the opportunity to participate in learning, playing, and leisure in a way that is natural and acceptable to the external environment, without causing exclusion from the environment. People with disabilities but with social skills are well-suited for the community they live in^{11,13,21}. Socially accepted behaviors let children participate in the peer's life²¹. The social aspects of life, such as communication with the environment, manual skills, and maintaining proper contact with the people living around, are just as important as the ability to carry out everyday life tasks²⁴. Participation of children with disabilities in everyday life is an element widely described by the authors. Parents' expectations and expectations concerning the environment are assessed²⁵. Therapy conducted at the session is difficult to separate from everyday life. For children, continuous participation in social life is constant training in everyday activities. Activities performed by a child are permanent work leading to independence²⁶. A change in the perception of a disabled person by the closest environment and entering the relationship with the dependents instead of subjective treatment is the key to the development of social competencies²⁷.

The aim of the study was to examine the effectiveness of functional intervention of self-service activities in children with life-limiting conditions at the age of 3–6 years of life.

Materials and methods

Study group

A total of 32 children with life-limiting conditions were examined with PPAC inventory. Children were divided into two groups each 16 children at an average age of 3.58 years. The characteristics of the study groups are presented in Table 1. Since birth, the children have been living in two long-term facilities in Eastern Europe. In Eastern Europe, the requirements imposed by the Ministry of Health and the National Health Fund specified in separate provisions that regulate the way that long-term care and nursing homes are managed. The difference between the centers was based on the approach to the therapy which was conducted among children. In the first center - in the study group, functional intervention was used. In the second center from which the control group was selected, functional intervention was not applied. Functional intervention involves performing the same activities several times throughout the day. Organizing activities into a structured scheme allows for better consolidation over time. In both study groups, general rehabilitation therapy was conducted regardless of the research program.

The research was conducted in accordance with the Declaration of Helsinki. The authors obtained informed consent from all participants and/or their legal guardians to participate in the study, informed consent from a parent and/or legal guardian was taken. Each participant could withdraw from the study at any stage of the project. The study was conducted in accordance with relevant guidelines and regulations with the consent and under the supervision of the Senate Bioethics Committee of Wroclaw University of Health and Sport Science No. 04/11/2011. The trials are registered with the New Zealand Clinical Trials Registry No. ACTRN 12,622,000,417,785, the first data registered :11/03/2022.

The children resided in two long-term care and nursing homes that were managed in accordance with the requirements set by the Ministry of Health. These requirements are outlined in specific regulations that govern the number and types of staff employed at long-term care and nursing homes. The nursing home provided round-the-clock care and conducted general developmental activities, either individually or in groups, based on each child's condition. The study required that the children have a psychological diagnosis of profound intellectual disability and infantile paralysis and that they did not have any other coexisting diseases that could affect their socio-motor development. All the children had been at the center since birth, with an average stay of 3.58 years, and they were not influenced by the family environment.

	Group 1		Group 2		U MW test's
	Mean	SD	Mean	SD	p
Age (years)	3.22	0.89	3.94	1.29	0,0595
	n	%	n	%	χ ²
Sex					
Girls (n)	11	68.8	5	31.2	0,690
Boys (n)	5	31.2	11	68.8	

Table 1. Characteristics of the study group. *p ≤ 0,05,

Research method

The skill level was assessed twice before and after the two-year treatment program by the same examiner. Both the first and second examinations were performed using the PPAC inventory by H.C. Gunzburg, modified by Witkowski. The social competencies were assessed using the PPAC inventory by H.C. Gunzburg, modified by Witkowski²⁸, which is applied to evaluate the progress of social development of persons with intellectual disabilities. It is a circle chart that illustrates the four areas of social functioning: self-help (feeding, mobility, personal hygiene and bathing, dressing), communication (initiated and received), socialization, and occupations (manual skills, dexterity). The complete inventory consists of 130 tasks that determine the social capabilities of a child up to 3 years of age who is developing properly. In the case of individuals with severe intellectual disabilities, the inventory can be used to evaluate children as old as 13 or 14. The tasks included in the PPAC inventory are based on normal developmental milestones established by the creators of developmental psychology²⁶. The PPAC inventory was the most suitable tool for evaluating the observed groups. The evaluation was centered on the progression of skills in the individuals being assessed over time, without taking into account the average values for the populations being assessed using the PPAC inventory.

Therapeutic model

The therapeutic model was based on the principle of everyday repetition and schematization of tasks related to self-service. In the children in the study group, daily independence training was used through activation and participation in everyday activities such as self-help (feeding, mobility, personal hygiene and bathing, dressing), communication (initiated and received), socialization, and occupations (manual skills, dexterity), covering 130 tasks included in PPAC inventory. Assisted therapy was used by guiding the therapist's hand movements supported by a verbal command. As the skills in a given activity were acquired, the therapist left the children free to perform it independently. Everyday therapy was conducted by an eight-person team trained in functional intervention. One assisted therapist was assigned to each child, and his recommendations were also used by other therapists and caregivers. In this way, schematization and repetition of the activities performed were achieved.

Statistical analysis

The distribution of quantitative variables was verified with the Shapiro-Wilk test. The study groups were characterized by calculating mean values, standard deviations, and counts. The significance of differences between groups was checked using the Student's *t* test for independent samples or the χ^2 test. Due to the non-normal distribution of quantitative variables and the ordinal nature of the remaining variables, the median was used as a measure of central tendency, and the interquartile range (IQR) as a measure of dispersion. The significance of differences between two groups of subjects and between two observations was verified using the Kruskal-Wallis analysis of variance and, when necessary, the Dunn-Bonferroni post hoc test. To determine the effect size of differences between study groups and measurements, the adjusted Cohen's *d* test was used for continuous and ordinal variables. The interaction effect size was calculated by Eta squared (η^2) and then transformed to Cohen's *d* (Lenhard & Lenhard, 2016). Cohen's *d*-test values ≥ 0.8 indicated a large effect, ≥ 0.5 a moderate effect, ≥ 0.2 a weak effect, < 0.02 no effect (Cohen, 1988). The progress that the children achieved as a result of the therapy was calculated. Progress was calculated as the difference between the results of observations 2 and 1 of each of the analyzed skills. The Mann-Whitney *U* test was used to check the significance of differences between groups 1 and 2. Spearman's *R* coefficient was used to check the covariation of age and the effects of therapeutic activities.

Calculations were performed in the Statistica 13.3 program and statistical calculators http://www.psychometrika.de/effect_size (access date March 8, 2023).

The significance level was $p < 0.05$.

Results

The level of children's social and functional maturity was assessed twice: before and after two years of functional intervention. The study showed no significant differences between the two groups in any of the domains assessed. The second observation, however, shows significantly higher values obtained in the assessment of group 1. No significant differences were confirmed only for children's mobility. In both groups examined in observation 2, an increase in the value of each assessed competence was demonstrated. However, only in group 1 was the statistical significance of the observed changes confirmed (Tables 2 and 3).

To assess the effectiveness of the therapeutic activities, for each assessed variable, progress was calculated for each child, defined as the difference between the values achieved in studies 2 and 1. The average values in both study groups, for each assessed competence, confirm the significantly greater progress observed in children from group 1. The significant nature of this relationship is confirmed by high values of Cohen's *d* coefficient, indicating a large effect size (Table 4).

Children from groups 1 and 2 did not differ significantly in terms of age. It was checked whether the age of children had an impact on the effectiveness of activities. For this purpose, the values of Spearman's correlation coefficient between age and progress (the difference observed between the 2nd and 1st examination) were calculated. No significant correlations were confirmed in group 1. However, in group 2, a significant, positive, and high covariation between age and progress was demonstrated for most competencies. Apart from hygiene, the remaining *R* values were in the range of 0.62–0.70. This means that the older the child was, the higher the effect of the activities carried out. Cohen's *d* coefficient was used to check the significance of differences between the correlation coefficients obtained in both groups. The obtained values confirmed the large effect (Table 5).

Variable	Grupa 1				Grupa 2				ANOVA Kruskala Walisa <i>p</i>	Cohen's <i>d</i>
	Badanie 1		Badanie 2		Badanie 1		Badanie 2			
	Median	IQR	Median	IQR	Median	IQR	Median	IQR		
Feeding	6.00	4.50	13.00	1.50	4.00	2.00	4.00	8.00	<0.0001*	1.91
Mobility	5.50	6.50	9.50	7.00	2.50	4.00	3.50	10.00	0.0094	0.81
Hygiene and bathing	0.00	0.00	2.00	1.50	0.00	0.00	0.00	0.50	<0.0001*	1.98
Dressing up	1.50	1.00	5.00	1.50	1.00	2.50	3.00	4.00	<0.0001*	1.62
Communication initiated	5.00	3.00	11.00	13.00	2.50	1.50	3.50	2.50	0.0005	1.13
Communication received	6.50	2.50	14.00	5.00	4.00	4.50	7.00	7.50	<0.0001*	1.23
Socialization	7.00	1.50	18.50	3.50	4.50	3.50	6.00	9.50	<0.0001*	1.58
Manual skills	5.00	3.00	13.00	6.00	4.00	6.00	6.00	6.50	0.0002	1.22
Skill	4.50	1.50	8.50	6.50	2.00	4.00	3.00	7.00	<0.0001*	1.53

Table 2. Level of social and functional maturity estimated in both study groups before and after therapy. * $p < 0.05$

	Group 1	Group 2	Test 1	Test 2
Post hoc	Test 1 vs. 2	Test 1 vs. 2	Group 1 vs. Group 2	Group 1 vs. Group 2
Feeding	0.0063*	1.0000	0.2833	0.0002*
Mobility	0.6453	1.0000	0.6268	0.1171
Hygiene and bathing	0.0001*	1.0000	1.0000	0.0060*
Dressing up	0.0001*	1.0000	1.0000	0.0060*
Communication initiated	0.3063	1.0000	0.2802	0.0128*
Communication received	0.0023*	0.7303	0.5740	0.0015*
Socialization	0.0025*	1.0000	1.0000	0.0023*
Manual skills	0.0083*	1.0000	1.0000	0.0272*
Skill	0.0478*	1.0000	0.2589	0.0009*

Table 3. Significance of differences in the level of maturity of children between groups 1 and 2 and observations before and after therapy. * $p < 0.05$

Differences: test 2-test 1	Ggroup 1				Group 2				U MW test <i>p</i>	Cohen's <i>d</i>
	Mean	SD	Median	IQR	Mean	SD	Median	IQR		
Feeding	4.94	3.04	5.50	4.50	1.75	2.86	0.00	3.50	0.0029*	1.25
Mobility	2.50	2.22	3.00	4.00	1.69	2.57	0.00	3.00	0.2427	0.43
Hygiene and bathing	2.25	2.14	2.00	1.50	0.19	0.54	0.00	0.00	0.0002*	1.79
Dressing up	3.25	0.86	3.00	1.00	0.81	1.33	0.00	2.00	0.0001*	1.94
Communication initiated	5.94	4.86	5.00	7.50	0.88	1.63	0.00	2.00	0.0007*	1.50
Communication received	6.69	2.57	6.50	5.00	2.63	3.36	1.00	5.00	0.0020*	1.32
Socialization	9.81	2.76	10.00	4.00	2.56	4.29	0.00	3.00	0.0001*	1.90
Manual skills	5.50	3.29	6.00	4.00	1.88	2.53	0.00	3.50	0.0023*	1.29
Skill	4.94	2.98	4.50	4.50	1.31	2.47	0.00	2.50	0.0009*	1.46
Average difference	5.09	1.40	5.06	1.39	1.52	2.08	0.33	2.72	0.0001*	2.03

Table 4. Level of changes observed in both study groups. * $p < 0.05$

Discussion

Life-limiting conditions as severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury include developmental delay in childhood as common phenomenon^{2,29,30}. Functional intervention conducted in the case of children with intellectual disabilities allows them to develop functional skills needed and accepted in society^{13,16}. Social skills adequate for a 3-year-old child are related to the development of fine motor skills. They include self-care skills such as: eating, toileting, dressing and undressing, simple communication, and locomotion³¹. Research conducted in Eastern European institutions confirms the limited self-determination and self-service capabilities of institutionalized individuals, consistent with the initial findings of our own research³⁰. Lack of engaging children can result in a subsequent limitation of their functional abilities³². Abbot observed the correlation between the home environment and the functional development of children with

Variable vs. age	Group 1	Group 2	d Cohen
	R Spearman	R Spearman	
Feeding	-0.21	0.70*	1.08
Mobility	-0.13	0.70*	0.981
Hygiene and bathing	0.07	0.35	0.295
Dressing up	-0.10	0.62*	0.825
Communication initiated	0.19	0.63*	0.549
Communication received	0.28	0.78*	0.758
Socialization	-0.01	0.67*	0.821
Manual skills	0.32	0.69*	0.516
Skill	0.10	0.62*	0.625
Average progress	0.01	0.79*	0.838

Table 5. Covariation of the mean difference of individual skills and the age of the respondents. *R statistically significant ($p < 0.05$)

intellectual disabilities³³. The environment in which children are raised from birth forms the basis for their emotional, social, and motor development. The opportunities provided by the environment play a crucial role in developing social skills, which is reflected in one's accomplishments. A sense of security is essential for the holistic development of the child. An environment that supports regular practice of acquired skills helps to reinforce and strengthen them³⁴. Therapeutic work involving the patient in everyday activities is described in the literature as facilitating the pediatric patient's ability to participate in everyday activities, play, and rest. This is the effect expected by parents of disabled children^{31,32,35}. In own work, observations concerned the possibility of developing self-service activities, which are considered critical for functioning in society. Research has shown that by using coordinated multi-level treatment, progress can be made in the self-care activities expected by parents^{11,15,21}. Early multidisciplinary therapeutic intervention leads to activation of the musculoskeletal system and simultaneous stimulation of cognitive functions^{19,36–39}. Upper limb function is essential for achieving independence in activities of daily living during growth^{40–42}. Research led by Veldman et al. (2019) confirms the positive impact of the development of motor functions in the upper limbs on the development of cognitive functions⁴², which is consistent with own research. Including children in every day activities by all the people taking care of them allowed for the development of self-service skills based on manual functions. Abbot and Bartlet (1999) in their research observe that activities supported and promoted by parents are achieved and used by children faster, which is also confirmed by own research³³. Cintas (1989) also analyzes the impact of the home environment on the development of skills in early life and proves the possibility of environmental influence as a modifier of socially acceptable behavior for a given region of the world^{14,43}. Own research confirms the possibility of modifying behavior through organized multi-level therapeutic activities.

Conclusion

The developmental progress was achieved in all areas of social development, irrespective of the children's age. Therefore, the progress is not spontaneous or related to the child's growth and maturation – it consists of the skills acquired as a result of the therapy program. The statistical analysis of the data about the second group did show progress in the activities evaluated with the PPAC inventory, but it was markedly lower and linked to the age of the examined children. Consequently, slow and steady development of skills can be observed. It proves the existence of developmental potential in intellectually disabled children.

The topic of children with life-limited conditions is not widely described in the literature. Observations and analyses are an important point of therapy and allow for the identification of the problem and the dissemination of knowledge.

Data availability

Data availability. The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request. E-mail: agnieszka.ptak@awf.wroc.pl.

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Author contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [A.P.], [M.S.] and [E.D-W.]. The first draft of the manuscript was written by [A.P.] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Declarations

Competing interests

The authors declare no competing interests.

Additional information

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