

Effect on Quality of Life in Children and Adolescents with Disabilities after a Functional Intensive Therapy Approach

Buse Busra Sanli^{1*}, YJM Janssen Potten², Ingrid Meeuwssen³, Marcel Coenen³, Lidia Caponi³, Ruud Roijen³, Lizette Teeuwen³, Gina van den Berge³, Coen de Haan³, Catherine Steinbusch³, Boukje Knops³, Cis Knols³, Stefan Knoops³, Giovanni Paloni⁴ and Eugene AA Rameckers^{2,3,5,6}

¹Faculty of Physical Therapy and Rehabilitation, Hacettepe University, Turkey

²Adelante Center of Expertise in Rehabilitation and Audiology, Valkenburg and Hoensbroek, The Netherlands

³Adelante Pediatric Rehabilitation Functional Intensive Therapy Team

⁴Master student, FHML, Maastricht University, the Netherlands

⁵Department of Rehabilitation Medicine, School for Public Health and Primary Care (CAPHRI), Maastricht University, The Netherlands

⁶Rehabilitation Science, Department pediatric rehabilitation, Hasselt University, Belgium



Corresponding author: Buse Busra SANLI, Faculty of Physical Therapy and Rehabilitation, Hacettepe University, Turkey

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Abbreviations: QOL: Quality of Life; H-CIMT: Hybrid-Constrained Induced Movement Therapy; CIMT: Constrained Induced Movement Therapy; BIMT: Bimanual Intensive Movement Therapy; HABIT-ILE: Hand and Arm Bimanual Intensive Therapy Including Lower Extremity; FITCARE4U: Functional Intensive treatment; COPM: Canadian Occupational Performance Measure; SD: Standard Deviation

ABSTRACT

The aim of this study was to determine whether a functional intensive therapy approach can successfully improve the quality of life and ability to perform self-care in children and adolescents with disabilities. Thirty-one children (mean age: 14.13 years, standard deviation: 2.306 years) with disabilities including, but not limited to cerebral palsy, spina bifida, and muscular dystrophy, participated in intensive therapy, which was planned to last fifteen consecutive days. All participants received therapy six hours every day and also participated in home activities and physical and recreational group activities. The primary outcomes included proxy and self-report measurements using KIDSCREEN-52, and the secondary outcomes were determined using the Canadian Occupational Performance Measure (COPM). All assessments were completed by participants and their caregivers both before the intervention and again three months after its completion. Before the intensive therapy, all thirty-one caregivers completed the assessment. After three months, the KIDSCREEN domains of physical well-being (proxy and self-reports; $p=0.01$) and school environment (self-report; $p=0.006$) had increased significantly, and COPM domains showed a statistically significant increase for all participants ($p=0.000$). Based on the results from the KIDSCREEN and COPM assessments, all participants demonstrated improvements after three months. Therefore, the intensive therapy approach may be an appropriate intervention to improve the quality of life and levels of self-care of children and adolescents with disabilities. However, as there are many aspects that affect QOL, it may be beneficial to include a control group in a future study.

Keywords: Intensive Therapy; Adolescents with Disabilities; Quality of Life; Self-Care

Introduction

Quality of life (QOL) is a complex, multidimensional, comprehensive concept that includes social, physical, functional,

and mental health [1-3]. In children with disability, QOL has been shown to be diminished, compared to that of their healthy peers [4-

6], though recently, there has been an increased awareness of the importance of treatment applications to increase QOL in children with disability [7]. There are many factors that affect QOL, such as level of functioning, participation, and psychosocial factors. Conditions that prevent mobility and participation in activities, such as cerebral palsy, spina bifida, and developmental delays, have the same impact on QOL as psychosocial effects [8-10]. Furthermore, motor skills, mental health, and mobility skills contribute to daily and recreational activities, showing a strong correlation to the physical well-being domain of QOL [11]. Thus, in order to improve the QOL and functioning levels of children with disability, goal-oriented rehabilitation approaches should be used [12-14].

Hybrid-Constrained Induced Movement Therapy (H-CIMT) [15], Constrained Induced Movement Therapy (CIMT) [16], Bimanual Intensive Movement Therapy (BIMT) [17], Hand and Arm Bimanual Intensive Therapy Including Lower Extremity (HABIT-ILE) [18], and Functional Intensive treatment (FitCare4U) [19] have all been proven to be effective intensive treatment methods for children with cerebral palsy. All these treatment options are based on motor learning and known to be effective on the level of activity rather than body structure and function domains of the International Classification of Functioning [20]. FitCare4U, an intensive therapy treatment for children and adolescents with disability, focuses on stimulating motor learning and neuroplasticity through intensive training of self-care and mobility to contribute to improved activity and participation. We hypothesized that this treatment method could contribute to improving participants' QOL and increasing their performance of the goals. Evaluations performed after the intensive treatment of upper extremities showed that the physical well-being domain of QOL in these children had improved [16].

Materials and Methods

Participants

Inclusion criteria were as follows: children and adolescents aged 12 to 18 years with any motor disability who have the abilities to stand or perform a standing transfer with or without support and to follow instructions. The FitCare4U program was applied and the outcome measures were used as in a usual care, after participants and parents signed informed consents.

Procedures

Intervention and assessments were part of the regular functional intensive treatment program in Adelante Centre of Pediatric Rehabilitation in the Netherlands. All participants and parent signed informed consents to use the outcome anonymous. The participants were assessed two weeks before start of the treatment - goals and quality of life-, directly after finishing the program- goals- and three months after the program had ended - goals and quality of life. All participants and their parents completed KIDSCREEN questionnaires to evaluate the participants' QOL

[21], with scoring done separately for parents' and participants' responses. At the same time, participants' goals were determined by occupational therapists using the Canadian Occupational Performance Measure (COPM) [22]. Final COPM elements were set as participants' personal goals and became the starting point for the intervention.

Intervention

The FitCare4U approach is aimed to improve functionality and independency in self-care and mobility. The intervention is goal- and needs based and included motor learning, active participation, and training in context. The participants were individually coached by members of a multidisciplinary team of pediatric physical and occupational therapists, sport teachers, nurses, social workers, psychologists and physicians. Each participant had one personal coach. All activities were performed in real-life context when possible. For example, sports activities were performed in the official sport accommodations. The program was planned to last 15 consecutive days in order to improve individuals' home participation, community participation, and peer relationships. Each day, six hours of therapy were practiced, so participants received a total of 90 hours of therapy. The participants stayed overnight during the whole intervention, attending schools in the mornings, while FitCare4U was performed in the afternoons and evenings.

Individual goals were practiced in 90-minute individual goal-oriented training sessions, and goals were likewise considered and worked toward throughout each day in all relevant situations. Relevant goals were in the domain of daily activities, such as transfers, mobility, and independently sitting up, preparing sandwiches, dressing, and showering. On the weekends, activities started immediately after breakfast. The rest of the program consisted of physical and recreational group activities to improve participants' activity levels. After dinner, home based play and game activities were done. Participants were encouraged to perform at their maximum capacity during all activities; this included sitting on unsupported chairs even between activities and at break times, and walking tools were used minimally. They also actively participated in self-care activities, such as preparing food, using cutlery, cleaning and setting the dining table, and washing dishes. These activities were integrated into this program for daily skills training during activity-based therapy in the afternoon [19].

Outcome Measures

The primary outcomes in FitCare4U related to QOL were measured using KIDSCREEN-52, which was developed for children and adolescents by the European Commission and is applicable to children and adolescents between the ages of 8 and 18. The dimensions of KIDSCREEN-52 include 52 items and 10 domains: physical well-being (5 items), psychological well-being (6 items), moods and emotions (7 items), self-perception (5 items), autonomy

(5 items), parent relationships and home life (6 items), financial resources (3 items), social support and peer (6 items), school environment (6 items), and social acceptance/bullying (3 items). The psychometric properties of the KIDSCREEN were good, with Cronbach's alpha (the internal consistency) ranges from 0.77 to 0.89. The intraclass correlation coefficients (ICC) ranged from 0.56 to 0.77. The KIDSCREEN scores were calculated for each of the ten domains and transformed into T-values, with a mean of 50 and standard deviation of 10. Higher scores indicated better health as related to QOL and well-being [21,23]. Proxy reports of the KIDSCREEN assessment were completed by all parents, and self-reporting was completed by participants who did not have intellectual disability.

The Canadian Occupational Performance Measure (COPM) was used to measure secondary outcomes by first determining individual intervention goals for each participant, then stating changes in participants' self-perceptions of the performance of their needs and their satisfaction. The COPM includes a 20 - 30 minutes interview about the children's daily routines. Participants or their parents identified problems that the children experience in performing daily living activities. The performance (ICC = 0.73) and satisfaction (ICC = 0.83) domains of the COPM have good reliability and validity [24]. Each activity was rated on a scale from 1 to 10, with 1 meaning participants are not able to do something at all and 10 meaning they are able to do something extremely well, for perceived performance capacity and performance satisfaction. An improvement of two or more points has clinical significance. Participants collaborated with their families and occupational therapists to determine and prioritize participants' goals [22].

Analyses

Statistical analysis was performed using SPSS Statistics 21.0 (SPSS Inc., Chicago, IL, USA). Descriptive data have been presented as mean, standard deviation (SD), minimum, and maximum values. In the evaluation of the data, the normal distribution of the variables was examined by visual (histogram and probability graphs) and analytical methods (Kolmogorov-Smirnov / Shapiro-Wilk tests). In the analysis of the data, no normal distribution was shown; non-parametric statistics were used to detect the effects of the treatment. The Wilcoxon signed-rank test was used to detect the treatment effects based on the KIDSCREEN and COPM subtests. Spearman's rank-order test was used to determine correlations between the KIDSCREEN subtests of self and proxy report measures; the significance level was at $p < 0.05$.

Table 2: Statistical analysis of KIDSCREEN between before intervention and after 3 months.

Domains	Before Intervention		Follow-up Assessment		p values
	Mean (SD)	Min - Max Values (Median)	Mean (SD)	Min - Max Values (Median)	
Physical Well-Being, <i>self report</i> (n=22)	47.083 (9.682)	32.69 - 73.20 (47.082)	50.596 (11.227)	34.65 - 73.20 (49.627)	0.159
Psychological Well-Being, <i>self report</i> (n=22)	55.711 (8.847)	39.91 - 68.49 (54.495)	56.629 (8.630)	39.91 - 68.49 (57.603)	0.266

Results

Thirty-one children between the ages of 12 and 18 participated in a FitCare4U intervention, and there were no adverse events. Before the camp, thirty-one caregivers completed proxy reports using KIDSCREEN and COPM assessments; nine out of thirty-one adolescent participants were unable to self-report using KIDSCREEN due to their intellectual impairment. Participants' mean ages were 14.13 ± 2.306 years.

Primary Outcomes

KIDSCREEN-52 was used to determine participants' QOL. This questionnaire was completed as a proxy-report and self-report twice: before the intervention and three months after its completion. The physical well-being domain of the proxy report increased significantly after the intervention ($p = 0.01$). The financial resources domain had the most missing data at the three-month follow-up assessment; only twenty-one out of thirty-one parents completed this domain (Tables 1 & 2). Statistically significant increases were also observed in the school environment domain of the self-report follow-up assessment ($p = 0.006$), with the bullying domain showing a similarly significant increase ($p = 0.07$). The proxy reports showed a significant increase in the domain of physical well-being ($p = 0.01$), but there were no significant differences in the other domains (Table 2). The correlation between self and proxy reported changes before and after the camp was examined; it was found that there was no statistically significant relationship between self and proxy reports (Table 3).

Table 1: Characteristics of Participants.

Demographic Characteristics	Number (%)
Gender	
Female	14 (45.2)
Male	17 (54.8)
Condition	
Bilateral CP	14 (45.2)
Unilateral CP	4 (12.9)
Dyskinetic CP	3 (9.7)
Hereditary Spastic CP	3 (9.7)
Spina Bifida	4 (12.9)
Muscular Dystrophy	1 (3.2)
Hemispherectomy	1 (3.2)
Achondroplasia	1 (3.2)

Mood and Emotions, <i>self report</i> (n=22)	50.173 (11.411)	33.58 - 70.91 (47.151)	53.484 (12.403)	31.42 - 70.91 (52.682)	0.098
Self Perception, <i>self report</i> (n=21)	53.799 (11.554)	37.85 - 69.78 (52.186)	57.493 (11.206)	39.21 - 69.78 (57.7491)	0.308
Autonomy, <i>self report</i> (n=22)	53.475 (9.034)	35.61 - 68.75 (53.219)	55.687 (8.629)	43.59 - 68.75 (53.219)	0.449
Parent Relation Home Life, <i>self report</i> (n=22)	57.123 (8.821)	39.69 - 65.87 (58.528)	58.916 (7.388)	45.72 - 65.87 (58.528)	0.344
Financial Resources, <i>self report</i> (n=18)	53.434 (10.328)	23.24 - 62.86 (56.347)	52.602 (11.758)	23.24 - 62.86 (52.413)	0.552
Peers-Social Support, <i>self report</i> (n=21)	53.953 (10.797)	35.44 - 71.46 (54.933)	56.581 (10.992)	36.81 - 71.46 (58.136)	0.338
School Environment, <i>self report</i> (n=21)	52.249 (9.585)	35.35 - 73.80 (52.226)	59.703 (7.211)	48.61 - 73.80 (58.875)	0.006**
Bullying, <i>self report</i> (n=22)	46.203 (11.100)	29.13 - 58.85 (48.071)	51.235 (9.988)	33.13 - 58.85 (58.847)	0.07
KIDSCREEN Proxy Report (n)					
Physical Well-Being, <i>proxy report</i> (n=26)	38.328 (6.972)	26.30 - 52.68 (38.784)	43.159 (6.237)	34.77 - 55.89 (41.084)	0.01**
Psychological Well-Being, <i>proxy report</i> (n=25)	50.378 (10.579)	26.28 - 69.88 (48.870)	52.058 (10.388)	26.28 - 69.88 (52.120)	0.338
Mood and Emotions, <i>proxy report</i> (n=26)	46.763 (12.050)	28.43 - 70.82 (46.123)	47.709 (11.420)	20.72 - 70.82 (49.928)	0.587
Self Perception, <i>proxy report</i> (n=26)	48.444 (9.409)	32.73 - 70.98 (44.246)	50.771 (8.179)	37.33 - 70.98 (50.686)	0.108
Autonomy, <i>proxy report</i> (n=26)	49.594 (8.365)	33.58 - 67.95 (48.216)	48.094 (7.227)	33.58 - 67.95 (48.216)	0.951
Parent Relation Home Life, <i>proxy report</i> (n=26)	55.406 (8.443)	36.17 - 69.22 (55.129)	55.019 (8.296)	40.20 - 69.22 (55.129)	0.781
Financial Resources, <i>proxy report</i> (n=20)	54.654 (15.002)	23.96 - 65.02 (65.021)	53.185 (15.130)	23.96 - 65.02 (59.329)	0.682
Peers-Social Support, <i>proxy report</i> (n=24)	41.544 (15.300)	8.28 - 73.08 (42.458)	42.472 (14.103)	8.28 - 73.08 (40.518)	0.56
School Environment, <i>proxy report</i> (n=25)	57.498 (10.271)	30.95 - 72.50 (59.597)	58.387 (9.240)	41.28 - 72.50 (57.008)	0.876
Bullying, <i>proxy report</i> (n=25)	45.231 (14.128)	18.25 - 58.83 (50.555)	48.206 (13.413)	14.74 - 58.83 (50.555)	0.235

** p ≤ 0.01

Min: minimum values of KIDSCREEN domains; max: maximum values of KIDSCREEN domains.

Table 3: Correlation analysis between before and 3 months later assessments of self and proxy report of quality of life.

Differences Analysis between Self - Proxy		
KIDSCREEN DOMAINS	Correlations	Significance
Physical Well-Being	r= - 0.02	p= 0.935
Psychological Well-Being	r= 0.173	p= 0.47
Mood and Emotions	r= - 0.275	p= 0.241
Self Perception	r= 0.401	p= 0.08
Autonomy	r= - 0.178	p= 0.453
Parent Relation Home Life	r= - 0.285	p= 0.223
Financial Resources	r= 0.390	p= 0.151
Peers-Social Support	r= 0.132	p=0.580
School Environment	r= 0.181	p= 0.457
Bullying	r= - 0.087	p= 0.723

Secondary Outcomes

Satisfaction and performance domains of COPM showed

statistically significant increase after treatment for all participants (p=0.000; p=0.000) (Table 4).

Table 4: Statistical analysis of COPM between before intervention and after 3 months.

COPM	N (Before/Follow-up)	Before Intervention		Follow-up Assessment		p values
		Mean (SD)	Min - Max Values (Median)	Mean (SD)	Min - Max Values (Median)	
Performance	30/29	3.233 (1.101)	1.00 - 5.59 (3.00)	6.810 (1.109)	4.70 - 8.70 (7.00)	0.0000 (*)
Satisfaction	30/29	3.457 (1.217)	1.00 - 6.00 (3.10)	6.997 (1.095)	4.70 - 8.80 (7.3)	0.0000 (*)

(*) $p \leq 0.001$

Min: minimum values of COPM domains; max: maximum values of COPM domains.

Discussion

This study aimed to explore whether the QOL of children and adolescents with disabilities would improve after a functional intensive therapy program. It was found that most relevant outcomes from the KIDSCREEN assessment, including the domains of school environment (self-report) and physical well-being (proxy-report), increased. In addition, reported levels of performance and satisfaction, as assessed by the COPM, improved after the participants underwent the intensive therapy. As it is known, there is a strong correlation between the areas of functionality and physical well-being. Sakzewski, et al. found that intensive therapy had positive effects on the physical well-being domain in both proxy and self-reports [16]. Similarly, FitCare4U had positive effects on the physical well-being domain. An increase in physical well-being was expected because of the physical approach of Fitcare4U, which includes intensive outdoor activities, sports, and stimulation of active sitting, standing and mobility, as well as the intense practicing of self-care activity goals. These results were shown in the proxy report but not in the self-report, in agreement with the lack of correlation between the two reports.

Furthermore, the participants reported a significant increase in the school environment domain, indicating an improved quality of relationships between peers at school. In terms of child QOL, there is no definite conclusion about whether there exists a correlation between a caregiver/parent report and child report [25,26]. After the intervention, no statistically significant correlation was found between the increases in self and proxy reports of KIDSCREEN scores. This could have been caused in part by unequal sample sizes for self and proxy reports. Furthermore, QOL has a subjective construct, so different results might be obtained according to different perspectives; the QOL questionnaire scores of the parents and children reports were evaluated separately perspective in order to assess the QOL of the children with disability [25,27]. It has been shown that, three months after FitCare4U treatment, the satisfaction and performance areas of the COPM had significantly increased, indicating a transfer of the learned goals into daily life at home.

FitCare4U has a similar intensity and identical motor-learning concepts to other intensive treatment approaches, such as CIMT, BMT, and HABIT-ILE [15-17,28], most of which showed similar

results on the COPM. A limitation of the present study is that due to the three months period after the program many other aspects may affect participants' QOL. To identify impacts of FitCare4U more specifically, a control group should be included in a future study. As a result, it was concluded that FitCare4U increased relevant domains of QOL and occupational performance of all disabled participants. Overall, it was concluded that FitCare4U increased relevant domains of QOL and occupational performance of the participants. The current study showed that participants had improved QOL and goal performances after undergoing FitCare4U therapy, therefore this treatment may be an appropriate intervention to improve the QOL of children and adolescents with disabilities.

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Conflict of Interest

The authors declare no conflict of interest.

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