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

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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

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**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

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**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-
The participants were assessed two weeks before the start of the program- goals and three months after the program had ended. The participants were assessed two weeks before the start of the program, and parents signed informed consents to use the outcome anonymous. All participants and parents signed informed consents. Outcome measures were used as in a usual care, after participants to follow instructions. The FitCare4U program was applied and the participants were observed to stand or perform a standing transfer with or without support and to walk independently on unsupported chairs even between activities and at break times, and to walk unsupported even in the afternoons and evenings.

**Intervention**

The FitCare4U approach is aimed to improve functionality and independency in self-care and mobility. The intervention is 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.

**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.

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)    |

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

| Domains                          | Before Intervention | Follow-up Assessment | p values |
|----------------------------------|---------------------|----------------------|----------|
| KIDSCREEN Self Report (n)        |                     |                      |          |
| Mean (SD)                        | 47.083 (9.682)      | 50.596 (11.227)     | 0.159    |
| Physical Well-Being. self report (n=22) | 32.69 - 73.20 (47.082) | 34.65 - 73.20 (49.627) | 0.159    |
| Psychological Well-Being. self report (n=22) | 39.91 - 68.49 (54.495) | 39.91 - 68.49 (57.603) | 0.266    |
Mood and Emotions, self report (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, self report (n=21)  
53.799 (11.554)  
37.85 - 69.78 (52.186)  
56.587 (8.629)  
35.61 - 68.75 (53.219)  
0.308

Parent Relation Home Life, self report (n=22)  
57.123 (8.821)  
39.69 - 65.87 (58.528)  
59.703 (7.211)  
45.39 - 68.75 (58.847)  
0.006*

Financial Resources, self report (n=18)  
53.475 (9.034)  
35.61 - 68.75 (53.219)  
55.687 (8.629)  
43.59 - 68.75 (52.682)  
0.449

Peers-Social Support, self report (n=22)  
53.475 (9.034)  
35.61 - 68.75 (53.219)  
55.687 (8.629)  
43.59 - 68.75 (52.682)  
0.449

School Environment, self report (n=21)  
52.249 (9.585)  
35.35 - 73.80 (52.226)  
59.703 (7.211)  
45.72 - 73.80 (58.875)  
0.006*

Financial Resources, self report (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, self report (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, self report (n=21)  
52.249 (9.585)  
35.35 - 73.80 (52.226)  
59.703 (7.211)  
45.72 - 73.80 (58.875)  
0.006*

Physical Well-Being, proxy report (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, proxy report (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, proxy report (n=26)  
46.763 (12.050)  
28.43 - 70.82 (46.123)  
47.709 (11.421)  
20.72 - 70.82 (49.928)  
0.587

Self Perception, proxy report (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, proxy report (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, proxy report (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, proxy report (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, proxy report (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, proxy report (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, proxy report (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.

| 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)            | (Med)                |          |
| 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 ≤ 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 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, BIMT, 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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