

Relationship Between Functional Level and Quality of Life in Children With Spina Bifida

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Abstract

Background: This study examined the relationship between functional level and quality of life in children with spina bifida (SB).

Methods: The study includes 44 children with SB (20 females and 24 males) of average age 9.18 ± 2.39 years. A independence measurement (WeeFIM) developed for children was used to evaluate functional level, and the Health Questionnaire Parent Form (CHQ-PF50) was used to evaluate health-related quality of life (HRQoL) of children whose demographic information, affection levels and the use of assistive devices.

Results: Regional involvement among children in the study was 2.3% thoracic, 27.3% thoracolumbar, 38.6% lumbar, 27.3% lumbosacral, and 4.5% sacral. While 56.8% use an assistive device in daily activities, 43.2% do not use any device. Statistical analysis, showed a positive relationship between WeeFIM and role/social limitation parameter of the CHQ ($r=0.316$, $p=0.037$). No relationship was found between WeeFIM and global behaviour, parental impact-time, general behavior, bodily pain/discomfort, mental health, family activities, self-esteem, family cohesion, parental impact-emotional parameters ($p>0.05$).

Conclusion: Physical disorder among children with SB can cause role restriction in everyday activities, and thus can affect quality of life. The rehabilitation practices to be made for having children to gain maximum independence will improve quality of life.

Keywords: Quality of life; Questionnaire

Introduction

Spina bifida (SB) is a complex congenital disorder that represents a broad spectrum of neural tube defects, including spina bifida aperta and spina bifida occulta [1]. The incidence varies in different parts of the world, but is generally 0.4-1.0 per 1000 live births in the USA, and a higher incidence is found in Northern Europe [2]. The incidence of SB live births is estimated at 3% in Turkey [3]. SB has a multi-systemic impact on the physical, neurocognitive, psychological and social functioning of affected individuals [4].

Children with SB have a wide range of functional impairments depending on the type of malformation, its location on the spine and the co-morbidity of brain injuries and orthopedic deformities [5]. Several studies found a relationship between level of lesion and independence in everyday activities of children and young adults with spina bifida [1,6-8]. Higher levels of independence in everyday activities, were reported in children and adults with meningocele than in patients with myelomeningocele [9]. In patients with spina bifida, the main clinical problems are difficulty or an inability to stand, walk, and voluntarily bladder control and bowel functions [10]. Obviously, these neurologic deficits can greatly impair patients' quality of life [11,12]. For this group, being independent in everyday activities is an important prerequisite for independent living and social participation [13].

This study planned to examine the relationship between functional level and health-related quality of life in children with SB.

Materials and Methods

The study included 44 children with SB, 20 females (45.5%) and 24 males (54.5%). The study inclusion criterion was myelomeningocele, whereas any other genetic/neurologic diseases were exclusion criteria. The children were selected from children that are attending rehabilitation centers (from the Western Black Sea Region in Turkey). The children were selected from them. The ones chosen whose's family

accepted to attend to the study. Also, some of the children that were quitted from the study, because it was hard to make evaluation, even measuring height. The method and aim of the study was explained to parents, and they provided written consent to their child's participation in the study. The study was approved by the Ethics Committee of Clinical Research at Abant İzzet Baysal University (Ref. no. 2009/33).

Sociodemographic data comprised the age, gender, weight, co-operation (communication ability), level of spinal cord lesion and ambulatory status of each child. WeeFIM was used to evaluate functional independence level in daily life, and The Health Questionnaire Parent Form-50 item (CHQ-PF50) was used to evaluate quality of life [14,15]. The questionnaire filled out in clinics by the same physical therapist, asked children's caregivers. They were mostly their mothers (Mostly means that a few of the children's caregivers were their sister, or their grandmother).

Ambulatory status in patients with SB was classified into four levels: [1] independent ambulation with no assistive devices; [2] walking full-time using an assistive devices; [3] walking with an assistive device at home but using a wheelchair in the community; and [4] uses a wheelchair full-time [16].

The functional independence status of children in everyday life was observed using the Turkish version of (WeeFIM). The scale includes 18

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items covering six areas: self-care (eating, grooming, bathing, dressing upper body, dressing lower body, toileting); sphincter control (bladder management, bowel management); transfer (chair/bed/wheelchair transfer, toilet transfer, tub/shower transfer); locomotion (crawling/walking/wheelchair, stair-climbing); communication (comprehension, expression); and social cognition (social interaction, problem-solving, memory). A 7-level ordinal rating system ranging from 7 (complete independence) to 1 (total assistance) is used to score performance in each item. Each measurement item of the subsets is scored on a scale of 1–7, where 1 represents total assistance and 7 indicates complete independence. The minimum total score is 18 (total dependence in all skills) and the maximum score is 126 (complete independence in all skills) [14]. The WeeFIM was performed via direct observation by one physiotherapist and through interviews with the caregiver, who was the child’s mother in most cases.

The Health Questionnaire Parent Form-50 item (CHQ-PF50) was used to determine the HRQoL of children. CHQ-PF50 evaluates the HRQoL of children via the responses of family members. The questionnaire includes 50 questions and 14 subsections, comprising: global health (GGH), physical functioning (PF), role/social limitations–emotional/behavioral (REB), role/social limitations–physical (RP), bodily pain/discomfort (BP), general behavior (BE), global behavior (GBE), mental health (MH), self-esteem (SE), general health perceptions (GH), parental impact-time (PT), parental impact–emotional (PE), family activities (FA), family cohesion (FC), change in health (CH). The maximum score for each section is 100. The caregivers (generally mothers) were asked to complete the questionnaire [15].

Statistical analysis

SPSS (version 18) was used for statistical analyses. The findings are presented as descriptive statistics: number, percentage frequencies, Mean ± standard deviation (Mean ± SD). The relationship between the parameters was determined via Spearman correlation coefficient. Simple linear regression analysis was conducted for interaction level of parameters showing a relationship. Total WeeFIM score was added to Regression analyze. The level of statistical significance was $p < 0.05$.

Results

The average age of children included in the study was 9.18 ± 2.39 years. None of the children has mental retardation and all of them have co-operation. The socio-demographic characteristics of the children are shown in table 1.

The minimum, maximum, and average WeeFIM and CHQ values in children are shown in table 2.

Correlation analysis showed a negative relationship between age and SE ($r = -0.343$, $p = 0.023$) and FC ($r = -0.420$, $p = 0.005$) values. A negative relationship was found between ambulation level and WeeFIM total value ($r = -0.358$, $p = 0.017$), ambulation level and PT ($r = -0.305$, $p = 0.044$), and REB ($r = -0.332$, $p = 0.028$) parameters. No relationship was found between ambulation level and the scores for GGH, GBE, PF, RP, BP, BE, MH, FA, SE, FC, GH, or PE ($p > 0.05$). A positive relationship was found between WeeFIM total value and GGH ($r = 0.402$, $p = 0.007$), PF ($r = 0.557$, $p = 0.000$), REB ($r = 0.316$, $p = 0.037$), RP ($r = 0.393$, $p = 0.008$) and GH ($r = 0.310$, $p = 0.04$) values of CHQ, but no relationship was found with GBE, PT, BE, BP, MH, FA, SE, FC or PE ($p > 0.05$) (Table 3 included as supplementary).

Regression analysis, revealed that functional independence affected GGH and PF QoL parameters ($p < 0.05$) but did not affect REB, RP and GH in children’s everyday activities ($p > 0.05$) (Table 4).

Discussion

The results showed a relationship between ambulation, functional independence level and quality of life in children with SB.

In recent years, several studies have investigated the QoL of children with SB [3,6,17]. These studies have highlighted the negative impact of mobility limitation, urinary incontinence and level of the lesion on

| | Mean ± SD [Median (Min-Max)] |
|-------------------------------------|-------------------------------|
| Age (years) | 9.18 ± 2.39 [8.5 (6-15)] |
| Height (cm) | 113.70 ± 18.17 [115 (81-165)] |
| Weight (kg) | 28.34 ± 13.77 [25 (12-64)] |
| Sex | n (%) |
| Female | 20 (45.5) |
| Male | 24 (54.5) |
| Lesion level | n (%) |
| Toracal | 1 (2.3) |
| Toracolumbal | 12 (27.3) |
| Lumbal | 17 (38.6) |
| Lumbosacral | 12 (27.3) |
| Sacral | 2 (4.5) |
| Ambulation status | n (%) |
| 1 | 3 (6.8) |
| 2 | 4 (9.1) |
| 3 | 34 (77.3) |
| 4 | 3 (6.8) |
| Use of shunt | n (%) |
| Yes | 30 (68.2) |
| No | 14 (31.8) |
| Use of assistive devices | n (%) |
| Yes | 25 (56.8) |
| No | 19 (43.2) |
| Cooperation (communication ability) | |
| Yes | 100 (100) |
| No | 0 |

Table 1: Socio-demographic datas of the subjects.

| WeeFIM | (Min-Max) | Mean ± SD |
|--|------------------|---------------|
| Self care | 25.5 (8-42) | 24.97 ± 7.29 |
| Sphincter control | 2 (2-14) | 3.93 ± 3.66 |
| Transfer | 8.5 (3-21) | 9.93 ± 5.83 |
| Locomotion | 7.5 (2-14) | 7.84 ± 3.49 |
| Communication | 14 (8-14) | 13.79 ± 1 |
| Social cognition | 21 (12-21) | 20.29 ± 1.77 |
| Total WeeFIM | 82 (47-116) | 81 ± 17.26 |
| CHQ | | |
| Global health | 60(0-85) | 50.77 ± 19.83 |
| Global behavior | 72.5(0-100) | 70.11 ± 25.89 |
| Parental impact-time | 66.67(0-100) | 56.36 ± 29.79 |
| Physical functioning | 11.11(0-100) | 19.31 ± 23.06 |
| Role/social limitations-emotional/behavioral | 38.88(0-144) | 47.97 ± 40.01 |
| Role/social limitations-physical | 33.33(0-100) | 41.51 ± 37.69 |
| Bodily pain/discomfort | 65(0-100) | 64.54 ± 25.83 |
| General behavior | 76.67(33.33-110) | 75.81 ± 17.56 |
| Mental health | 65(20-100) | 62.38 ± 17.86 |
| Family activities | 66.67(8.33-100) | 63.06 ± 22.74 |
| Self-esteem | 70.83(25-100) | 70.39 ± 17.46 |
| Family cohesion | 60(30-100) | 68.06 ± 22.90 |
| General health perceptions | 51.67(12.5-85) | 51.40 ± 16.59 |
| Parental impact-emotional | 75(12.5-100) | 75.96 ± 72.58 |

Table 2: Mean ± standard deviation (Mean ± SD), Median values of the WeeFIM ve CHQ.

| | Beta | t | p |
|--|--------|--------|-------|
| Global health | 0.317 | 1.964 | 0.05 |
| Physical functioning | 0.400 | 2.562 | 0.015 |
| Role/social limitations-emotional/behavioral | -0.167 | -0.863 | 0.393 |
| Role/social limitations-physical | 0.210 | 1.052 | 0.300 |
| General health perceptions | 0.053 | 0.347 | 0.731 |

(Independent variable: WeeFIM total score, $F=4.615$, $R^2=0.378$)

Table 4: Regression analysis.

QoL. A study by Bier et al. [18] concluded that 'maximizing functional independence should be a priority in improving HRQoL in individuals with myelomeningocele'. Padua et al. [11] found there was not a linear correlation between disability and quality of life in individuals with SB. The same study also found that individuals with lower disability needed more physiological support, than individuals with higher disability. They concluded that the function of the lower limb muscles, especially the proximal muscles are strongly related to greater disability and more severe impairment of the physical aspects of quality of life. Similarly, it was reported that mobility difficulties, insufficiency in self-care activities, cognitive disorders, and bladder-bowel problems negatively affected activity and participation and thus led to reduced life satisfaction and QoL advancing age among adolescents and adults with SB [6,10,19-21].

The present study found a negative relationship between ambulation level (which was one of the factors determining disability severity in children with SB) and WeeFIM, and between ambulation level and, physical function and role/social limitation-emotional behavior QoL parameters. Very few children in the study walked independently, and ambulation combined with wheelchair use was more common. Ambulatory status among children with SB can affect everyday independence, and therefore levels of physical independence, physical activity and social participation. Independent mobility is extremely important in everyday function and the child's quality of life [1]. Therefore, it should be remembered that, in the rehabilitation of children with SB, activities that support and increase ambulation level by using assistive devices from the early stages are important factors in improving quality of life. No relationship was found between ambulation level and other QoL parameters. This might be because quality of life among children with SB is affected by many other factors (lesion level, mental status, shunt usage, etc.) apart from ambulation. As this is not main aim of our study, there were not asked questions about caregivers and their socioeconomic status. But it is known that socio-cultural status effects chronic disabled children's quality of life [22]. A negative relationship was found between age and self-esteem, and family cohesion, in common with findings in the literature. Accordingly, activities to encourage early functional independence of children with SB will increase self-confidence, and family affection will decrease due to greater intra- and extra-societal participation of a child independent of the family [23,24]. This is also an important factor in improving the quality of life of both the individual and family.

In the WeeFIM evaluations, the lowest average point score was under sphincter control, whereas the highest score was for communication and social cognition. The results support those reported in the literature [11,25]. A positive correlation was found between functional independence of children in daily life and parameters of global health, physical function, role/social limitations-emotional/behavioral, role/social limitations-physical and general health perceptions. Moreover, the regression analysis showed that global health and physical function were affected by functional independence, whereas this was not the case for role/social limitations-emotional/behavioral, role/social limitations-physical and general

health perceptions. In children with SB, functional independence can affect physical function, participation and activity levels, but it is not a factor on its own. Other health problems that may be seen with SB and secondary situations can also affect quality of life. In addition to this parallel to Padua et al. [6]. we think that bladder-bowel problems in children effects activity and participation negatively, in his way causes low quality of life. Physiotherapy and rehabilitation programs should aim to achieve maximum everyday independence for children with SB. This will increase physical activity level and social participation, improve feelings of self-perception, and accordingly improve their quality of life. At the same time, we think that, methods of minimizing bladder and bowel problems in children with SB is really important for their quality of life.

In our study there is used CHQ parent form, because there is no specific form for measuring quality of life in children with SB. Our results express children's quality of life at parents' perspective. This can be effected children's quality of life results. The reason using parent form is, CHQ child form can be used for the children who is older than 10. Parent form is suitable for the children between 5-18. Also we think that filling a questionnaire can be difficult for the children. There are needed studies evaluating children's own quality of life with specific scales enhanced at this field. Further studies can be made in that point of view.

Although the literature includes studies on the relationship between functional status and QoL among of adults and adolescents, there are few studies involving children with SB. The greatest limitation of the present study was the small sample size. It is very important to conduct further studies with larger patient groups in order to identify factors that might improve quality of life and rehabilitation for children with SB.

Conclusion

In this study it is found that there is a relationship between functional status and quality of life in children with SB. In children with SB, activity social participation is effected because of physical problems, bladder and bowel problems and this concludes with lower quality of life. The rehabilitation programmes for continence and physical problems for children with SB is really important for improving quality of life. Further studies are needed about this subject.

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