

# Comparative parenting stress measures between segmental and community-based rehabilitation services in parents of children and adolescents with intellectual and developmental disabilities (IDD): A cross-sectional survey

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## Abstract.

**BACKGROUND:** There is a dearth of information on the effects of different types (Segmental rehabilitation service (SRS) vs Community-based rehabilitation service (CRS)) on the parenting stress and family quality of life in parents of children who have individuals with intellectual and developmental disabilities (IDD).

**OBJECTIVE:** This paper is to compare the effects of SRS and CRS on parenting stress and family quality of life in parents of individuals with IDD.

**METHODS:** A cross-sectional design was used to examine parenting stress and family quality life in cohorts of 120 fathers and mothers of children with IDD who had received either SRS or CRS participated in the survey. The outcome measures included the modified Parenting Stress Index (PSI) and the modified Beach Center Family Quality of Life Scale (mBCFQLS). The Mann-Whitney *U* test was performed at  $P < 0.05$ .

**RESULTS:** A significant difference was observed in social stress in PSI between the SRS and CRS groups ( $P = 0.03$ ). The child rearing, emotional well-being, and physical and material well-being variables in mBCFQLS were different between the SRS and CRS groups ( $P < 0.05$ ), indicating superior benefits from CRS than SRS.

**CONCLUSIONS:** These findings provide important information and about parenting stress and family quality of life in children with IDD, for developing effective rehabilitation programs and services for these parents.

Keywords: Parenting stress, community-based rehabilitation, quality of life, children with disabilities, developmental disabilities

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## 1. Introduction

Parenting stress is a paramount issue for developmental health and social wellness in children with disability across their life span. Parenting stress includes financial stress, psychological stress, social stress, physical stress, and educational stress. A recent survey investigated parenting stress in parents of 818 children aged 8 to 12 years and demonstrated that parents of children with limited communication abilities, cognitive impairment, or pain, were at great risk of stress [1]. Goudie and colleagues examined the parenting stress in children with intellectual and developmental disabilities (IDD) was double when their caregivers had high levels of financial stress, and almost three and half times higher in caregivers with high levels of financial stress. The children's stress was further compounded by very high levels of psychological stress, higher than in typical developing children [2–5]. To mitigate such parenting stress associated with financial stress, psychological stress, social stress, physical stress, and educational stress, a segmental rehabilitation service (SRS) has been conventionally accepted as a mainstream health-care model in South Korea. The conventional SRS model tends to emphasize functional and structural impairments and activity limitation domains in individuals with IDD, rather than addressing the entire international classification of function (ICF) spectrum including the participation domain. Hence, based on the ICF conceptual framework, we have developed a community-based rehabilitation service (CRS) model that embraces functional and structural impairments and activity limitations, as well as the participation domain to effectively manage the special needs of individuals with IDD. However, the therapeutic benefits of such a model have never been ascertained. Hence, the aim of the present study was to compare the differential effects of SRS and CRS on financial stress, psychological stress, social stress, physical stress, and educational stress in the parents of children and adolescents with IDD. We hypothesized that CRS would produce a greater reduction in parenting stress and a greater increase in family quality of life than SRS because CRS might provide community-based rehabilitation care for body function and structure impairments and activity limitation as well as social participation for children and adolescents with multiple disabilities.

## 2. Methods

### 2.1. Participants

The current study used a cross-sectional design to analyze parenting stress and family quality of life in cohorts of 120 fathers and mothers of children with IDD who had received either SRS or CRS participated in the survey. One hundred and fifty parents of children and adolescents with IDD (aged 1 to 24 years) were initially recruited from a city community from October 15–31, 2019 in South Korea. Among them, 120 parents participated in the study. All the participants provided their informed consent. The study protocol was approved by the Human Ethic and Subject Review Board (IRB: 1041849-201810-SB-098-01). Inclusion criteria included the following: 1) children and adolescents aged from 1 to 24 years old with IDD, 2) parents and caregivers of children and adolescents with IDD; and 3) community-dwelling participants. Children and adolescents with IDD who required hospitalization and institutional or residential care were excluded.

### 2.2. Survey procedure

Parenting stress was assessed using the modified Parenting Stress Index (mPSI). The index consists of

Table 1  
Parenting stress and family quality of life

Parenting stress	CRS	SRS	<i>P</i> -value	CRS 95% CI		SRS 95% CI	
Financial stress	3.17 ± 0.91	3.43 ± 0.85	0.18	2.94	3.40	3.20	3.65
Psychological stress	3.33 ± 0.68	3.49 ± 0.72	0.30	3.15	3.50	3.30	3.68
Social stress	3.16 ± 0.71	3.49 ± 0.82	0.03*	2.99	3.37	3.28	3.71
Physical stress	2.72 ± 0.87	2.92 ± 0.96	0.41	2.59	2.95	2.67	3.17
Educational stress	3.52 ± 0.55	3.67 ± 0.61	0.20	3.39	3.68	3.52	3.83
Family quality of life							
Family interaction	3.81 ± 0.61	3.56 ± 0.70	0.09	3.63	3.96	3.38	3.74
Child rearing	3.69 ± 0.53	3.38 ± 0.60	0.01*	3.52	3.82	3.22	3.53
Emotional well-being	3.41 ± 0.63	3.09 ± 0.69	0.02*	3.24	3.58	2.91	3.27
Physical and material well-being	3.80 ± 0.65	3.47 ± 0.75	0.01*	3.63	3.97	3.28	3.66
Support related to disability	3.34 ± 0.71	3.14 ± 0.65	0.25	3.13	3.51	2.97	3.31

SRS, segmental rehabilitation service; CRS, community-based rehabilitation service; CI, confidence interval.

\*Mann-Whitney test was significant at  $P < 0.05$ .

five factors: financial stress, psychological stress, social stress, physical stress, and educational stress – stresses that parents who raise disabled children face in their daily lives. mPSI has a total of 25 parenting stress measures, each measured on a five-point Likert scale (1 to 5 points) in which the higher the score, the higher the level of parenting stress [6]. Quality of life was determined using the modified Beach Center Family Quality of Life Scale (mBCFQLS). A total of 24 family quality of life measures were evaluated using a five-point Likert scale (1 to 5 points) in which the higher the score, the higher the level of the family's quality of life [7]. The reliability and validity are well established [8].

### 2.3. Data analysis

The statistical results were expressed as means and standard deviations. All the variables were analyzed using the Mann-Whitney U test to determine the correlation between the parenting stress of parents with children and adolescents with multiple disabilities and the family's quality of life between the CRS and SRS groups using the SPSS for Windows (version 25.0, SPSS, Chicago, IL, USA) at  $P < 0.05$ .

## 3. Results

### 3.1. Parenting stress

The Mann-Whitney U test showed a significant difference in social stress between the CRS and SRS groups ( $P = 0.03$ ); however, other financial stress, psychological stress, physical stress and educational stress variables did not differ between the groups (Table 1).

### 3.2. Family quality of life

The Mann-Whitney U test revealed significant differences in child rearing, emotional well-being, and physical and material well-being variables between the CRS and SRS groups ( $P < 0.05$ ). However, family interaction and support related to the disability variable did not differ between the groups (Table 2).

## 4. Discussion

The present prospective investigation was the first community-based rehabilitation service survey to

compare the segmental rehabilitation service model and community-based rehabilitation service model on parenting stress and quality of life. As anticipated, the survey demonstrated that the CRS model produced a greater reduction in social stress than the SRS model, and improved the quality of life in family interaction, child rearing, emotional well-being, and in areas of physical and material well-being.

The CRS model showed a greater reduction (5%) only in the social stress element when compared with the SRS model. This finding was consistent with previous evidence of increased social stress in parents of children with CP [8]. Social stress was primarily derived from the fact that the parents were unable to participate in social interaction due to their children's physical and cognitive disability. Similarly, Wang et al. investigated the associations between parenting stress, social support, and family quality of life in parents of children with CP as well as the moderating effect of social support on the relationship between parenting stress and family quality of life. As a result, parenting stress was negatively correlated with total social support and quality of life in parents of children with CP due to their multiple disabilities [9]. The social stress of these parents may be associated with a lack of community-based care and assistance in the "conventional" segmental rehabilitation service model. Interestingly, other physical, psychological, financial, and educational stress factors were not different between the CRS model and SRS model. Family quality of life analyses demonstrated superior qualities in child rearing, emotional well-being, and physical and material well-being elements in the CRS model when compared with the SRS model. Certainly, this result supports previous research that the quality of life associated with child rearing, emotional well-being, and physical and material well-being elements, was better in the CRS model than SRS model. This finding was consistent with previous evidence that reported that the higher the parenting stress levels, the lower the family's quality of life associated with child rearing in parents of disabled children [10]. Rolle and colleagues suggest that emotional well-being is an important element that mediates the relationship between parenting stress and adjustment in a family's quality of life [11]. In conclusion, the present survey's findings demonstrated that the CRS model was more conducive for parents of children and adolescents with IDD to mitigate their stress and to improve family quality of life than the SRS model.

### **Conflict of interest**

The authors declare that this manuscript has been submitted solely to this journal and has not been published or submitted elsewhere.

### **Funding**

The present study was supported by the Korea Health Industry Development Institute grant funding (grant no. 2019-51-0468).

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