

Social support perceived by parents of children with intellectual disability in Tamilnadu

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Abstract

Aims: The study analyzed the social support available of the parents of children with intellectual disability. This study used a descriptive approach with a cross-sectional approach. This study aimed to identify and explore social support in parents with intellectual disabilities children in Cuddalore district, Tamilnadu.

Methods: The samples studied were 81 parents as a primary caregiver and lived with intellectual disabilities children, taken by purposive sampling. Social support was measured using a Social Support Questionnaire that had been modified and developed using Sarafino theory with alpha Cronbach values of 0.728. The questionnaire includes the domain of emotional support, instrumental support, informational support, and award/assessment support. **Results:** The data indicated that parents mostly have social support in high categories (70.4%). Among them; that majority (93.8%) of the respondents received support from a spouse (husband/ wife); 71.6 per cent of respondents received support from parents (grandparents of intellectual disabilities children). Then 67.9 per cent of parents perceived support from friends (fellow parents of children with intellectual disability). **Conclusion:** It can be concluded that the present study exhibited that the parents of children perceived social support from spouses, family, friends, peer groups and other health workers. Parents need more support for access to health information, praise or appreciation from those around them and professionals. **Suggestion:** So, the study suggested that the general public also should need to support to the parents of children with disability.

Keywords: Intellectual Disabled Children, Parents, Social Support

Introduction

Disability in children is a condition that includes physical, mental, intellectual, or sensory limitations over a long period of time, which will cause delays in children's participation in society¹. At present, the prevalence of disability in children is increasing. Indonesia is the 8th largest country that

has children with disabilities. Intellectual disability in children is ranked second from overall disability that occurs in children in Indonesia for about 30,460 number of cases³. West Java Province is in the highest position with intellectual disabilities children, which has 13,173 children and Bandung is the town that has 1,077 children with intellectual disability⁴, almost reaches 10% of the total population of intellectual disabilities children in West Java.

Social support is broad term encompassing a variety of constructs, including support perceptions (perceived support) and receipt of supportive behaviours (received support). The recent studies report no difference between mothers and father's in terms of their social isolation (Beck man, 1991). Evidence exists that in some instances families of children without disabilities may have larger and less dense social networks than families of children who are disabled (Fredrich & Fredrich, 1981); Kazak & Wilcox 1984), both attributes indicative of less adequate support. Mothers of children with disability have the higher the perception of economic situation and income adequacy, parenting social support, and religious practices, and the lower the symptoms of depression and found that minority mothers showed the higher the religious coping, the lower the symptoms of depression. Some studies found that the presence of social support significantly predicts the individual's ability to cope with stress and it was knowing that they are valued by others is an important psychological factor in helping them to forget the negative aspects of their lives, and thinking more positively about their environment. It also found that social support not only helps improve a person's well-being, it affects the immune system as well. Thus, it also a major factor in preventing negative symptoms such as depression and anxiety from developing (Corey 2005). Stress has been shown to relate to positive and negative parenting behaviors (Abidin, 1995), and high levels of stress are correlated with a perception of low levels of social support. No studies have examined the relationships between hope and optimism and stress as these relate to parenting behaviors, and no studies have examined social support in relation to hope, optimism and stress among parents of children with mental retardation (Kashdan et al., 2002).

Material and Methods

This study used a descriptive approach with a cross-sectional approach. This study aimed to identify and explore social support in parents with intellectual disabilities children in Cuddalore district, Tamilnadu. The samples studied were 81 parents as a primary caregiver and lived with intellectual disabilities children, taken by purposive sampling. Social support was

measured using a Social Support Questionnaire that had been modified and developed using Sarafino theory with alpha Cronbach values of 0.728. The questionnaire includes the domain of emotional support, instrumental support, informational support, and award/assessment support. Each statement item was measured on a 1-4 scale. The method of categorizing uses the cut-off point, with a low support category if the total score was ≤ 50 , and high category if the total scores between 51-80. Data collection was carried out for 2 months (January-March 2019). The collected data was then analyzed using univariate analysis.

Aims

1. To study the socio demographic profile of parents of the children with intellectual disability
2. To examine the social support available of the parents of children with intellectual disability

Criteria for Sample Selection

Inclusion criteria

Parents of children with only intellectual disability

Parents of children with intellectual disability those who can understand either Tamil or English language.

Exclusion criteria:

Parents of mild, moderate, sever, profound level children

Parents of children from 5 years to 25 years

Analysis

Table 1: The Characteristics of Respondents

| Characteristics | Frequency (f) | Percentage (%) |
|-------------------|---------------|----------------|
| Age of Parents | | |
| 26-35 | 8 | 9.9 |
| 36-45 | 36 | 44.4 |
| 46-55 | 29 | 35.8 |
| 56-65 | 8 | 9.9 |
| Gender of Parents | | |
| Men | 20 | 24.7 |
| Women | 61 | 75.3 |
| Characteristics | | |

| | | |
|--|----|------|
| Working | 19 | 23.5 |
| Not Working | 62 | 76.5 |
| Family Income | | |
| Above or equal to the minimum wage | 57 | 70.4 |
| Above or equal to the minimum wage | 24 | 29.6 |
| Marital Status | | |
| Married | 77 | 95.1 |
| Not Married or divorced | 4 | 4.9 |
| Age of Children | | |
| 5-12 | 29 | 35.8 |
| 13-16 | 31 | 38.3 |
| 17-25 | 21 | 25.9 |
| Children Status | | |
| Biological | 79 | 97.5 |
| Not Biological | 2 | 2.5 |
| Gender of Children | | |
| Male | 43 | 53.1 |
| Female | 38 | 46.9 |
| Level of Intellectual disability of Children | | |
| Mild | 45 | 55.6 |
| Moderate | 32 | 39.5 |
| Severe | 2 | 2.5 |
| Profound | 2 | 2.5 |

Regarding the characteristics of respondents, it was found that the age of parents who have children with intellectual disabilities was dominated by 36-45 years old (44.4%), 95.1% were married, mostly was mothers (75.3%) and were not working (housewife) (76.5%). Most family income was below the minimum wage (70.4%), and the last education taken was high school (67.9%). The age of children mostly was in the teenage years (13-16 years) (38.3%) the child status were biological children (97.5%), more than half of children were male (53.1%), and the intellectual disability categories were mild (55.6%).

Table 2: Parent's Social Support Sources

| Source of Social Support | Frequency (f) | Percentage (%) |
|---|---------------|----------------|
| Spouse | | |
| Yes | 76 | 93.8 |
| No | 5 | 6.2 |
| Parents (Grandfather/ mother) | | |
| Yes | 58 | 71.6 |
| No | 23 | 28.4 |
| Friends (fellow parents of intellectual disabilities children/peer group) | | |
| Yes | 55 | 67.9 |
| No | 26 | 32.1 |
| Others: -Professional Staff | 9 | 11.1 |
| Siblings (Family) | 14 | 17.3 |
| Neighbour | 2 | 2.5 |
| Community | 4 | 4.9 |

The above table shows that majority (93.8%) of the respondents received support from a spouse (husband/ wife); 71.6 per cent of respondents received support from parents (grandparents of intellectual disabilities children). Then 67.9 per cent of parents perceived support from friends (fellow parents of children with intellectual disability). Parents also mentioned several other sources of support such as professionals, relatives, neighbors, social media and the community.

Table 3: Social Supports Received by Parents

| Social Support | Frequency (f) | Percentage (%) |
|----------------|---------------|----------------|
| Low | 24 | 29.6 |
| High | 57 | 70.4 |

Table 3 indicates that parents mostly have social support in high categories (70.4%), whereas parents who have low social support were 29.6%. Based on the social support domain, it was found that instrumental support

was the highest domain (84%) and award/assessment support became the lowest domain (60.5%) that received by parents (table 4).

Table 4: Social Support Domains Received by Parents of Children with Intellectual Disabilities

| Social Support Domain | Categories | | | |
|--------------------------|------------|------|------|------|
| | Low | | High | |
| | f | % | f | % |
| Emotional Support | 25 | 30.9 | 56 | 69.1 |
| Instrumental Support | 13 | 16.0 | 68 | 84.0 |
| Informational Support | 31 | 38.3 | 50 | 61.7 |
| Award/Assessment Support | 32 | 39.5 | 49 | 60.5 |

The table shows the social support domain regarding the high category; 84 per cent of the respondents perceived instrumental support, 69.1 per cent perceived emotional support, 61.7 per cent perceived informational support and 60.5 per cent perceived award/assessment support. Besides social support domain regarding the low category; 39.5 per cent perceived award/assessment support, 38.3 per cent perceived informational support, 30.9 per cent emotional support and 16 per cent perceived instrumental support.

Recommendations

Recommendations arising from this study include the exploration of the role of environmental factors in the participation of children with intellectual disabilities in other countries. Specifically, further research is recommended on the effects that social support interventions have on the participation of children who are typically developing and those with disabilities.

Conclusion

In most of the previous studies highlighted that lack of support for parents with intellectual disabilities children can be a negative experience for parents and children with intellectual disabilities. Parents with limited support tend to have negative effects, such as emotional and behavioral problems as an anxious response in providing care for children with intellectual disability. But the present study exhibited that the parents of children perceived social support from spouses, family, friends, peer groups and other health workers.

Parents need support for access to health information, praise or appreciation from those around them and professionals. Appreciation support is very important to increase parental self-efficacy in parenting intellectually disabled children.

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