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Well siblings psycho-social behaviour and disability: A study on perception, attitude and social support for well sibling of disabled children

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Abstract

Well siblings of disabled children from both urban and rural areas of Gadag and Dharwad taluk of Northern Karnataka were selected for the study. A total of 86 well siblings were the population for the study. Sibling and Parent Perception Questionnaire (SPQ; Carpenter and Sahler, 1991), Siblings Attitudes toward Disability Questionnaire (SADQ; De Caroli and Sagone, 2008), Child and Adolescent Social Support Scale (CASSS; Malecki and Demaray, 2004) and Socio-economic status by Aggarwal *et al.* (2005) was used to assess the well siblings perceptions, attitude and social support. Results revealed that in rural and urban area well siblings with lower perception majority were in abnormal level of psycho-social behaviour. Well siblings with lower perception with low mean scores on psycho-social behaviour. Well siblings with lower attitude majority of them were in abnormal level of psycho-social behaviour. In both rural and urban area well siblings with lower social support were in abnormal level followed by borderline of psycho-social behaviour. Social support showed significant association with psycho-social behaviour of well siblings in both rural and urban area.

Keywords: Sibling relationship, perception of well siblings, attitude of well siblings, social support for well siblings

Introduction

Sibling relationships are emotionally charged, and defined by strong, uninhibited emotions of a positive, negative and sometime ambivalent quality. Sibling relationships are often characterized by intimacy as youngsters spend large amount of time together.

Living with a sibling with a psychological or behavioral disorder can ultimately be educating and gratifying or confusing and stressful. Children must adjust to the sibling, which can necessitate a considerable amount of family attention, time, money and emotional support. Both positive and negative experience has been noted in relationship where one sibling has some type of psychological or behavior difficulty.

Healthy siblings of disable children face multiple challenges, such as exposure to the physical and emotional pain of their brothers or sisters disability, fear, parental distress, and extended separation from the disable child and the parents because of hospitalization.

Having a brother or sister with a chronic illness or developmental disability (CI/DD) is a risk factor for sibling adjustment problems (Sharpe & Rossiter, 2002) ^[1]. The issues surrounding sibling relationships change over time as children develop and the family responds to illness related and other life experiences (Bluebond-Langner, 1996) ^[2]

The presence of a retarded child can be a stress source for family and affects deeply on sibling's relationships. The

situation of retarded child requires the most money, attention and support of the family. Presence of brother or sister with disability can have a profound impact on siblings by creating a source of tension in family. In well siblings of these children, self-esteem and confidence is low. In these families, well siblings have been described as a forgotten people whom their duty is care and maintenance of their disabled siblings.

Materials and Methods

Population of the study was well siblings of disabled children selected from urban and rural areas of Dharwad and Gadag Talukas of Karnataka. The sample of the study was well siblings of disabled children aged between 5-18 years. The sample comprised of 45 well siblings from the rural area and 41 well siblings from urban areas of Gadag and Dharwad talukas. A total of 86 well siblings were selected as the study samples.

The special schools situated in the urban localities of Dharwad and Gadag taluka were surveyed. The Principal of the school were approached to get permission and information about the well siblings of disabled children. These children were contacted through home visits. Parents and siblings were briefed about the research work and rapport was developed. These were considering as the urban samples.

For rural samples, two villages from each talukas were

randomly selected. Aganwadi teachers were contacted to get the information about the children with disability. Home visits were made to obtain related information from their well siblings and parents.

The Demographic information about the child's age, gender, ordinal position, number of sibling, sibling spacing, sibling constellation, parent's age were collected using self structured general information schedule.

Sibling and Parent Perception Questionnaire (SPQ; Carpenter and Sahler, 1991) [3].

The Sibling Perception Questionnaire (SPQ) measures the impact an illness of a child has on a sibling's interpersonal relations in the family, communication, intrapersonal perceptions and fear of the illness. Questionnaire includes 23 items with 4 subscales, "interpersonal difficulties", "intrapersonal difficulties", "open communication" and "fear of the disease". The measure of responses is of ordinal and verbal nature with five-point Likert response format (never, a little, sometimes, a lot, always). Scores for these items were summed to create a Negative Impact Composite Scale. The Negative Impact Composite Scale was used in subsequent analyses, with higher scores reflecting a greater impact of illness (range 1-5) except for communication subscale.

A parent version of the SPQ was developed with adding 17 extra items to the originally developed SPQ.

Sibling perception	Scores
Lower perception	23-28
Moderate perception	39-77
Higher perception	78-115

Siblings Attitudes toward Disability Questionnaire (SADQ: De Caroli and Sagone, 2008) [4].

This tool consisted of 37 items scored on five Likert scale questions used to investigate siblings' social attitudes toward brothers or sisters with disability; the participants were asked to express their degree of agreement with proposed statements in 7- points (ranging from 1=*totally disagree* to 7=*totally agree*). The obtained total scores were categorized as follows:

Sibling Attitude	Scores
Lower attitude	37-86
Medium attitude	87-172
Higher attitude	173-259

Child and Adolescent Social Support Scale (CASSS: Malecki and Demaray, 2004) [8]

The CASSS is a 40-item measure designed to assess multi-faceted social support i.e., support from parents, teachers, classmates, close friends, and people in the school for children and adolescents. Scale items are categorized in four groups (emotional, informational, appraisal, and instrumental) for each factor (parents, teachers, classmates, close friends, and other people in school). Respondents are asked to rate the amount of support they receive for each of 12 specific social support items for each source defined above on a six-point Likert scale (1 =never to 6 = always). They also indicate how important they perceive each support action to be on a three-point Likert scale (1 = not very important to 3 = very important). Separate social support (i.e., how often) and importance scores are calculated for each source of support.

Table 1: Social support scores

Frequency rating of the social support			Importance rating of social support		
Factors	For each item	For total scale	Factors	For each item	For total scale
Parents	12-72	60-360	Parents	12-36	60-180
Teachers	12-72		Teachers	12-36	
Classmates	12-72		Classmates	12-36	
Close friends	12-72		Close friends	12-36	
Other people in school	12-72		Other people in school	12-36	

Socio-economic status by Aggarwal et al. (2005) [1].

It consists of 22 statements which assess parents' education, occupation, location, type of family, number of children, possessions of agricultural land, domestic animals, and social status of the family. The scores are given for different dimensions and added to obtain total score. It can be classified as:

Table 2: SES Classification

Sl. No	SES Classification	Total score
1	Upper higher	>76
2	High	61-75
3	Upper middle	46-60
4	Lower middle	31-45
5	Poor middle	16-30
6	Very poor	<15

Chi-square test of association was employed to know the association of child perception, attitude and social support. T-test also used to know the difference between child perception, attitude and social support.

Results

Association and comparison between perception of disabled child's disability and psycho-social behaviour among rural and urban well siblings

In rural area, majority of well siblings who showed lower perception were in abnormal level (81.80%) followed by 15.20 percent were in borderline and 3.00 percent of them were in normal level of psychosocial behaviour. Similarly in the higher perception category also majority of well siblings were in abnormal level (62.50%), followed by 25.00 percent were in borderline and 12.5 percent were in normal level psycho-social behaviour of well siblings. Chi-square analysis showed significant association between psycho-social behaviour of well siblings and perception on sibling disability.

In urban area, well siblings with lower perception, majority of them were (73.3%) in abnormal level, 23.3 percent were in borderline and only 3.3 percent were in normal level. But for well siblings with higher perception majority were in abnormal level (85.70%) and none were in normal level of

psycho-social behaviour. Chi-square analysis showed significant association between psycho-social behaviour of well siblings and perception on sibling disability.

Mean comparison also showed sibling significant difference between the mean scores of psycho-social behaviour of well siblings in rural area. Mean scores of well siblings having lower perception were slightly higher (20.20) than with higher perception (18.73). For the urban area mean comparison showed non-significant difference.

Well siblings with lower perception majority of them were in low level of psycho-social behaviour. Well siblings with higher perception majority of them were in medium level followed by low level of psycho-social behaviour. Similar results were reported by Taylor *et al.* (2001)^[10] well siblings

as having significantly more negative attitude and perception about the disorder. The level of agreement on sibling attitudes and perception was significantly negatively associated with psychopathology on two of the strength and difficulty subscales (emotional symptoms, hyperactivity-inattention) and the strength and difficulty total difficulties scores. Similarly Hadjikakou (2010)^[6] hearing siblings seem to be worried about their brother's or sister's future, and so they do not feel any rejection toward their deaf and hard of hearing siblings, nor do they have any feeling of bearing a burden. Hearing siblings also reported that both their parents and peers react positively to the deaf and hard of hearing child.

Table 3: Association between perception of disabled child's disability and psycho-social behaviour among rural and urban well sibling

Psycho-social behavior (N=86)	Rural(n=45)		Modified χ^2	Urban(n=41)		Modified χ^2
	Perception of sibling disability			Perception of sibling disability		
	Lower perception	Higher perception		Lower perception	Higher perception	
Normal	1(3.00)	1(12.50)	7.25*	1(3.30)	-	6.03*
Borderline	5(15.20)	4(25.00)		7(23.30)	2(14.30)	
Abnormal	27(81.80)	7(62.50)		22(73.30)	9(85.70)	
Total	33(100)	12(100)		30(100)	11(100)	

Figure in parentheses indicates percentage

*Significant at 0.05 level

Table 4: Comparison of mean scores of psycho-social behaviour of well sibling by perception of disabled child's disability
N=86

Locality	Perception of sibling disability	Psycho-social behavior	
		Mean \pm SD	t-value
Rural(n=45)	Lower perception	18.73 \pm 2.04	3.05**
	Higher perception	20.20 \pm 3.68	
Urban(n=41)	Lower perception	17.95 \pm 2.75	1.15 ^{NS}
	Higher perception	19.66 \pm 1.93	

**Significant at 0.01 level

Ns-Non-significant

Association and comparison of attitude towards disabled sibling and psycho-social behaviour among rural and urban well siblings

Results on attitude towards disabled sibling were presented in the table 5 and 6. Well siblings with lower attitude towards disabled sibling majority were in the abnormal level (72.20%) followed by 22.20 percent were in borderline and 5.60 percent were in normal level of psycho-social behaviour. When well siblings with higher attitude, 87.50 percent were in abnormal level and 12.50 percent were in borderline of psycho-social behaviour.

In urban area, well siblings with lower attitude, majority of them were in abnormal level (66.70%) followed by 20.60 percent were in borderline and 2.90 percent were in normal level of psycho-social behaviour. Well siblings with higher

attitude, 66.70 percent were in abnormal level and 33.20 percent were in borderline.

Chi-square analysis showed non-significant association between attitude towards disabled sibling and psycho-social behaviour among rural and urban well siblings. On comparison t-test also revealed the non-significant difference in attitude towards disabled and psycho-social behaviour well siblings.

Association and comparison of social support and psycho-social behaviour among rural and urban well siblings

Results on the association and comparison of social support and psycho-social behaviour among rural and urban well siblings were presented in table 7 and 8.

Table 5: Association between attitude towards disabled sibling and psycho-social behaviour among rural and urban well sibling

Psycho-social behavior (N=86)	Rural(n=45)		Modified χ^2	Urban(n=41)		Modified χ^2
	Attitude towards disabled sibling			Attitude towards disabled sibling		
	Lower attitude	Higher attitude		Lower attitude	Higher attitude	
Normal	2(5.60)	-	1.29 ^{NS}	1(2.90)	-	2.63 ^{NS}
Borderline	8(22.20)	1(12.50)		7(20.60)	2(33.30)	
Abnormal	26(72.20)	8(87.50)		26(76.50)	5(66.70)	
Total	36(100)	9(100)		34(100)	7(100)	

Figure in parentheses indicates percentage

Ns-Non-significant

Table 6: Comparison of mean scores of psycho-social behaviour of well sibling by attitude towards disabled child
N=86

Locality	Attitude towards disabled sibling	Psycho-social behavior	
		Mean ±SD	t-value
Rural(n=45)	Lower attitude	18.81 ±2.45	0.12 ^{NS}
	Higher attitude	19.44 ±3.39	
Urban(n=41)	Lower attitude	19.57 ±1.28	0.21 ^{NS}
	Higher attitude	20.75 ±2.83	

NS-Non-significant

Table 7: Association between social support and psycho-social behaviour among rural and urban well sibling

Psycho-social behavior(N=86)	Rural(n=45)		Modified χ^2	Urban(n=41)		Modified χ^2
	Social support			Social support		
	Lower support	Higher support		Lower support	Higher support	
Normal	2(8.00)	3(15.00)	6.42*	1(4.50)	3(15.80)	5.73*
Borderline	6(24.00)	17(85.00)		6(27.30)	16(84.20)	
Abnormal	17(68.00)	-		15(68.20)	-	
Total	25(100)	20(100)		22(100)	19(100)	

Figure in parentheses indicates percentage

*Significant at 0.05 level

Table 8: Comparison of mean scores of psycho-social behaviour of well sibling by social support
N=86

Locality	Social support	Psycho-social behavior	
		Mean ±SD	t-value
Rural(n=45)	Lower support	17.90 ±2.77	0.36 ^{NS}
	Higher support	19.80 ±3.26	
Urban(n=41)	Lower support	18.33 ±2.67	0.57 ^{NS}
	Higher support	19.78 ±2.25	

Ns-Non-significant

In rural area, well siblings with lower support, 68.00 percent of them were in abnormal level followed by 24.00 percent of them were in borderline and 8.00 percent of them were in normal level of psycho-social behaviour. Well siblings with higher social support majority of them were in borderline (85.00%) followed by 15.00 percent were in normal level of psycho-social behaviour.

Well siblings in urban area in the lower support category majority were in abnormal level (68.20%), 27.30 percent were in borderline and 4.50 percent were in normal level. Well siblings with higher social support 84.20 percent were in borderline and 15.80 percent were in normal level.

Chi-square analysis showed significant association between social support and psycho-social behaviour of well siblings in both rural and urban area. On comparison of mean scores t-test showed non-significant association between social support and psycho-social behaviour of well siblings in both rural and urban area.

Well siblings with higher social support were in borderline and normal level of psycho-social behaviour of well siblings. Well siblings with higher social support were with higher mean scores. The results are in line with study conducted by Gousmett (2006) [5] Families who receive higher levels of support have more positive perceptions of the family environment, and families who have more support and more positive views of the environment have fewer concerns on the resources and stress scale. These results are in line with study by Lukens *et al.* (2002) [7] examined the perceive services and support for the siblings of those with severe mental illness. The respondents expressed consistent concern about obtaining more and better services for their ill siblings. Participants also

expressed confusion about the role of confidentiality in provider communications with family members.

Conclusions

- Well siblings perception about disabled sibling disability found to have significant association with the psycho-social behaviour of well siblings in both rural and urban area. Well siblings with lower perception majority of them were in low level of psycho-social behaviour. Well siblings with higher perception majority of them were in medium level followed by low level of psycho-social behaviour.
- In both rural and urban area social support showed significant association with the psycho-social behaviour of well siblings. Well siblings with higher social support were in borderline and normal level of psycho-social behaviour of well siblings. Well siblings with higher social support were with higher mean scores.

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