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Health promotion practices and coping behaviors among caregivers of children suffering from thalassemia major

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ABSTRACT

Introduction: According to the Global Health Organisation thalassemia is the most prevalent genetic disorder which immensely affect the life of about 100,000 infants in over 60 countries. In India, thalassemia major is also the most prevalent genetic disorder. As indicated by the national statistics report, 22,000 patients of thalassemia major exist in our country. Thalassemia major is a chronic disease which has a long treatment regimen thus putting the affected children and their caregivers through a variety of challenges both physically and mentally.

Objective: To assess the health promotion practices and coping behaviors among parents/caregivers of children suffering from Thalassemia Major.

Materials and Methods: A descriptive study was conducted in the thalassemia clinic, APC, PGIMER, Chandigarh. Data was collected from 70 parents of thalassemic children with age group of 4 to 17 years on Socio Demographic Profile, clinical profile, Coping Health Inventory of Parents (CHIP) and Health Promotion Practices (HPP).

Results: The study showed that 51.9% caregivers of thalassemic children reported that they considered the items enlisted in CHIP to be moderately helpful, 45.2% reported them to be extremely helpful while according to 2.9% of the subjects, they were minimally helpful. All the subjects were in the “always” level of the HPP i.e. caregivers were following health promotion practices. This study also revealed that majority of parents (61%) did not receive any genetic counselling during their first pregnancy.

Conclusion: The study concluded the association between major study variables like Health Promotion practices (HPP) and Coping Health Inventory Of Parents (CHIP) analysed by Pearson correlation. The results revealed that there was low positive correlation between HPP and CHIP i.e. +0.078.

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1. Introduction

Thalassemia can be described as a group of genetic disorders which are characterized by defective hemoglobin production. It is a common genetic disorder and has more prevalence in India, the Mediterranean region, West Africa and South- East Asia. Patients with thalassemia have defects

in the production of either alpha or beta globulin chain of hemoglobin which cause the deficiency of one of these chains while the other chain keeps accumulating within the RBC precursors. This accumulation of unpaired chains and excessive RBC breakdown result in anemia.

Worldwide, for every 10,000 children born, up to 4.4% children are affected by thalassemia. In India, it varies between 1-17% with the average being 3.2%. This implies that, on an average, 1 in 25 Indians carry thalassemia.

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Distribution of genetic thalassemia is not the same in all parts of India. The prevalence of this disorder has been found to be very high among certain ethnic communities such as Punjabis (Banushalis, Kutchis), Sindhis, Gujarat (Lohans, Mahars), Neo Buddhists, Maharashtra (Kolis and Agris) and Karnataka (Gowdas, Lingayats) etc.¹

Among the parents, the stress of having a child with such chronic disorder and treatment take a huge toll on the mental state. Since it is a life-threatening condition which leads to the fear and anxiety in care givers related to the good prognosis. Hope for good prognosis keep them in a state of apprehension, helplessness and frustration including consumption of great deal of time and income in the treatment as well as care of these children. In addition to it, disease process can also lead to adverse effects on the relationship among the family members. Health promotion practices are also used by the parents of thalassemic children in order to promote and maintain the health of their children. For good health promotion practices, parents or caregivers try their best to maintain equilibrium in environmental factors, biological and social factors.² This study will help us to know about practices that are more commonly followed and will also help the parents to figure out what practices currently they are following and what other practices they can adopt. Even, additional focus is to identify coping strategies used by the caregivers with thalassemic children.

2. Material and Methods

This was a cross-sectional study conducted on caregivers of children suffering from thalassemia major. A total sample of 70 caregivers of thalassemic children in the age group of 20-60 years that were available during 10 days data collection period in the month of March 2021 in Advanced Pediatric Centre in PGIMER, Chandigarh. The sample for the research study included the caregivers of children who were suffering from thalassemia major excluding the caregivers of the children who were suffering from other disorders.

Ethical approval was obtained from Ethics Committee, National Institute of Nursing Education, PGIMER, Chandigarh. Further, permission was obtained from Head of the Department, Advanced Pediatric Centre, PGIMER to conduct the study. Participant Information Sheet explaining the purpose of the study was handed over to the caregivers of the thalassemic children. Informed written consent was also taken from the caregivers of thalassemic children. Before the administration of questionnaire a brief interactive session was conducted explaining the purposes of the study and thereby encouraging honest answers from the respondents. Researchers emphasized about the confidentiality of the data provided.

Tools used in study were (1) Socio-demographic profile of the caregivers of thalassemic children, (2) clinical

profile of the child included age, sex, education, height, weight, BMI, type of diagnosis, year of diagnosis, start of treatment, transfusion year, chelation therapy, use of other therapies, family history of thalassemia major, any genetic counseling received, number of sibling with thalassemia major, status of sibling with thalassemia, (3) Coping Health Inventory for Parents (CHIP) developed by McCubin, Nevin R and Caubie (1996) was used to assess coping behavior of caregivers during care of thalassemic child which has three domains a) Maintaining family integration, cooperation and an optimistic definition of the situation b) Maintaining self- support, self- esteem and psychological stability c) Understanding the medical situation through communication with other caregivers and consultation with medical staff, (4) self developed tool to assess Health Promotion Practices provided by caregivers to their thalassemic children which included personal hygiene, nutrition, elimination, physical activities, psychological and emotional aspects, social aspect, spiritual aspect, socio-economic aspect, body image concerns and treatment adherence.

Tools used in the study were valid and reliable. Data was collected through interview method telephonically from 38 subjects and face to face from 32 subjects.

Data was analysed by using descriptive and inferential statistics in SPSS 26.0,

3. Results

Table 1 depicts the socio demographic data of the caregivers of children suffering from Thalassemia Major. Majority 47.1% of caregivers were the mothers of the children. Most of the caregivers 45.7% lie in the age group of 41-50 years. In terms of educational status, half 50% of the caregivers were having educational qualification as graduate or post graduate. In regards to occupation, majority 48.6% caregivers were unemployed. Out of all respondents, majority 71.4% were dwelling in urban setting. Majority 68.6% of caregivers lived in nuclear families. Mean of per capita income was 9261.2 ± 12492.6 with range from Rs. 1428.57-1,00,000.

Table 2 depicts the clinical profile of children suffering from Thalassemia. Mean age of children was 13.01 ± 3.48 with range from 4-17 years. Majority 65.7% of these children were in the age group of 13-17 years. Majority 71.4% of children were males. In terms of educational status, majority 64.3% of children were pursuing secondary education. Mean weight of children was 35.196 ± 11.47 with range from 12-66 kg. Mean height was 1.36 ± 0.219 with range 0.90-1.90 metres. Mean years of diagnosis was 8.828 ± 5.917 with range from 1 month to 2.5 years. 62.9% were diagnosed with disease when they were <1 year of age. Mean start of treatment was 8.414 ± 4.786 with range from 1 month to 2 years. More than half 55.7% of children started their treatment when they were <1 year of

Table 1: Sociodemographic profile of caregivers N=70

S. No.	Variables	n(%)
	Relation with child	
1.	Mother	33(47.1)
	Father	26(37.1)
	Grandparents/siblings	6(8.6)
	Friends/relatives	5(7.1)
	Age	
2.	20-30	8(11.4)
	31-40	25(35.7)
	41-50	32(45.7)
	51-60	3(4.3)
	>60	2(2.9)
	Mean \pm SD = 40.73 \pm 8.59 Range = 23-74	
	Gender	
3.	Male	32(45.7)
	Female	38(54.3)
	Education	
4.	Illiterate	1(1.4)
	Primary school certificate	5(7.1)
	Middle school	9(12.9)
	High school	18(25.7)
	Diploma	1(1.4)
	Graduate or post graduate	35(50.0)
	Professional degree	1(1.4)
	Occupation	
5.	Unemployed	34(48.6)
	Unskilled worker	4(5.7)
	Semi- skilled	4(5.7)
	Skilled	12(17.1)
	Clerical/ shop-owner/farmer	5(7.1)
	Semi professional	2(2.9)
	Professional (white collar)	9(12.9)
	Domiciliary background	
6.	Rural	20(28.6)
	Urban	50(71.4)
	Religion	
7.	Hindu	58(82.9)
	Sikh	11(15.7)
	Muslim	1(1.4)
	Other religion	0(0)
	Type of family	
8.	Nuclear	48(68.6)
	Joint	22(31.4)
	No. of family members	
9.	1-4	33(47.1)
	5-8	31(44.3)
	9-12	4(5.7)
	13-16	2(2.9)
	Mean \pm SD = 5.24 \pm 2.1 Range = 3-14	
	Family income	
10.	2391-7101	2(2.9)
	7102-11836	5(7.1)
	11837-17755	11(15.7)
	17756-23673	10(14.3)
	23674-47347	23(32.9)
more than 47348	19(27.1)	
	Mean \pm SD = 46457 \pm 82915.47 Range = 10000-7,00,000	
	Monthly per capita income	
11.	7533 and above	30(42.9)
	3766-7532	26(37.1)
	2260-3765	5(7.1)
	1130-2259	7(10.0)
1129 and below	2(2.9)	
	Mean \pm SD = 9261.2 \pm 12492.6 Range = 1428.57-1,00,000	

age. All 100% thalassemic children had family history of thalassemia major. Majority 87.1% parents of thalassemic children had not received any genetic counseling. Mean of number of sibling with thalassemia 0.142 ± 0.826 with range from 0-1. In siblings with thalassemia 5.7% were live, 5.7% were dead, 7.1% were under treatment.

Table 3a Maintaining family integration, cooperation, and an optimistic definition of the situation. 44.3% caregivers found it moderately helpful that their children will get better. Believing that their child is getting best medical care, about 62.9 % of the caregivers found it to be extremely helpful. About 47.1% of caregivers responded as extremely helpful for talking with other parents with same type of situation and learning about their experiences. 45.7% of caregivers responded that reading about the medical problem which concern them is extremely helpful. Talking with the doctor about their concerns and about the condition of children, has been admitted as extremely helpful by 62.9% of caregivers.

Table 3 b: depicts the responses of caregivers in CHIP for sub-items: Maintaining social support, self esteem and psychological stability. Trying to maintain family stability, has been found to be moderately helpful by 67.1% of the caregivers. About 47.1% of caregivers responded as extremely helpful to have their children with medical condition seen at the hospital on a regular basis.

Table c: depicts the responses of caregivers in CHIP for sub- items like understanding the medical situation through communication with other parents and consultation with medical staff. Taking good care of medical equipment at home has been responded to be extremely helpful by 42.9% of caregivers.

Table 4 depicts the health promotion practices among caregivers of thalassemic children. 57 % caregivers ensure that their child uses soft bristles brush for brushing his / her teeth. 43% of caregivers avoid giving iron rich diet to their child, 37% caregivers give vitamin C rich fruits and supplements to their child, 32% of caregivers maintain record of food intake of the child and 42% of the caregivers give folic acid rich food to their child. 50% caregivers ensure that their child wears proper protective footwear while going outside. 32% caregivers routinely get their child's bone density checkup and 37% caregiver routinely check for any bone deformity in their child. Regarding treatment adherence, 66% caregivers ensure their child takes medicine daily, 64% caregivers maintain proper record of their child medication, 66% caregivers take their child to hospital for regular checkup and follow-up, 67% of caregivers maintain all health records of their child, while 63% caregivers take their child for their regular complete blood count checkup.

Table 5 depicts the correlation between health promotion practices and coping health inventory for parents. The association between study variables (HPP and CHIP) was statistically assessed by Pearson correlation (r-value).

The results revealed that there is low positive correlation between HPP and CHIP, i.e. the r-value between HPP and CHIP was +0.078.

4. Discussion

The current study was conducted to assess the Health Promotion Practices and Coping Behaviours among caregivers of children suffering from thalassemia major registered in APC, PGIMER, Chandigarh during 2021. The study included 70 participants, the caregivers of children suffering from thalassemia major. This study assessed the coping behaviours related to disease condition and health promotion practices by caregivers to thalassemic children. In the present study it was found that 87.1% of parents of thalassemic children did not receive genetic counselling and only 12.9% received genetic counselling.

The present study was supported by a similar study conducted by Manjoor and Zakar in 2019 to evaluate the socio demographic factors which affects parental knowledge about availability of thalassemia major screening services in Lahore. Results of this research shows that the parents of thalassemic children had enough knowledge about the disease condition and its screening services. It was found that about 91% parents had knowledge about screening services to be done before and throughout the pregnancy and 89% knew about genetic screening to be done before marriage.³ Study done by Biswas et al also found that 52.4% of study subjects had heard about premarital counselling and 50.9% about antenatal screening.⁴

The results of present study was similar to a study conducted Rao et al in 2004 for evaluation of psychopathology of parents having children with chronic illness and coping mechanisms used by them. They interviewed 30 parents of thalassemic children using semi structured proforma and rated SCL-90-R and mechanisms of coping scales. The results of this study showed that high general distress among parents and high scores on SCL-90-R. In the present study CHIP was used to view the coping methods of caregivers in maintaining social aid, self-regard and psychological stability. It was found that trusting that all will work out has been agreed to moderately helpful by 48.6% of caregivers and believing in God has been responded as extremely helpful by 65.7% of caregivers.²

The present study was supported by a similar study conducted by Dadipoor et al in 2015 to assess the psychological health and coping strategies of parents of thalassemic children in Bandar Abbas using a general health survey by Goldberg and Williams along with the survey of coping methods. The results revealed that the 87% parents trust in God that their problems would be solved, 53% would visit mosques and holy shrines to get mental and spiritual relief and 50.7% make harder attempts to overcome problems.⁵

Table 2: Clinical Profile of Thalassemic Children N= 70

S.No.	Variables		n (%)
1.	Age		
	4-7 Years	Mean \pm SD = 13.01 \pm 3.48	7 (10)
	8-12 Years	Range = 4-17	17 (24.3)
	13-17 Years		46 (65.7)
2.	Sex		
	Male		50 (71.4)
	Female		20 (28.6)
	Education		
	Kindergarten/Anganwadi		4 (5.7)
	Primary		21 (30)
	Secondary		45 (64.3)
4.	Weight (kg)		
	10-25	Mean \pm SD = 35.196 \pm 11.47	12 (17.1)
	26-40	Range = 12-66	36 (51.4)
	41-55		16 (22.9)
	56-70		6 (8.6)
5.	Height(m)		
	0.9-1.10	Mean \pm SD = 1.36 \pm 0.219	12 (17.1)
	1.11-1.30	Range = 0.90-1.90m	8 (11.4)
	1.31-1.50		32 (45.7)
	1.51-1.70		18 (25.7)
6.	BMI (kg/m²)		
	<14.2, <5th percentile, underweight)	Mean \pm SD = 18.6 \pm 3.82	2 (2.9)
	14.2-19.4, 5th – 85th percentile, healthy weight	Range = 9.42-32.5	51 (72.9)
	19.4-22.2, 85th -95th percentile, overweight		7 (10.0)
	>22.2, >95th percentile		10 (14.3)
7.	Thalassemia type		
	Beta		70 (100)
8.	Year of diagnosis		
	< 4 months	Mean \pm SD= 8.828 \pm 5.917	11 (15.7)
	< 6 months	Range = 1month -2.5years	7 (10.0)
	<1 year		44 (62.9)
	1-3 years		8 (11.4)
9.	Start of treatment		
	<4 months	Mean \pm SD= 8.414 \pm 4.786	13 (18.6)
	<6 months	Range=1month -2years	9 (12.9)
	<1 year		39 (55.7)
	1-3 years		9 (12.9)
10.	Transfusion since (years)		
	<4 months	Mean \pm SD= 8.771 \pm 4.537	10 (14.3)
	<6 months	Range= 1month - 2years	9 (12.9)
	<1 year		40 (57.1)
	1-3 years		11 (15.7)

In this study, in terms of health promotion practices among caregivers with thalassemic children, it was found that most (95.7%) caregivers always encouraged their child to wash his/her hands before and after meals. In terms of social aspects 80% parents allowed their child to play with other children, 80% allowed their child to participate in group activities and 77.1% helped child in socialising with relatives.

The present study is supported by a similar study conducted by Hatami and Motamed in 2014 to explore life satisfaction in children and adolescents with beta thalassaemia major in southwest Iran. The multi-dimensional student life satisfaction scale was used to measure the participant's quality of life in five domains. The results of this study showed that the total score of five domains i.e. "school, friends, living environment, family and self" were comparatively higher in thalassemic patients than in healthy

Table 2:

11	Chelation therapy started since	Mean \pm SD= 2.992 \pm 1.472 Range= 0.5-4	9 (12.9)
	0.5 – 1.5 years		37 (52.9)
	1.5– 3 years		8 (11.4)
	3 – 4.5 years		16 (22.9)
12	Use of other therapies		2 (2.9)
	Yes		68 (97.1)
13	Family history of thalassemia major / minor		70 (100)
	Yes (minor)		
14	Any genetic counselling received by parents		9 (12.9)
	Yes		61 (87.1)
15	No	Mean \pm SD = 1.114 \pm 0.826 Range= 0-3	16 (22.9)
	No. of siblings		35 (50.0)
	0		13 (18.6)
	1		6 (8.6)
16	>2	Mean \pm SD= 0.142 \pm 0.352 Range= 0-1	61 (87.1)
	No. of siblings with thalassemia (if any)		9 (12.9)
	0		
17	1		4 (5.7)
	Status of sibling with thalassemia		4 (5.7)
	Live		5 (7.1)
	Dead		55 (78.6)
	Under treatment		
	Others(No ailment)		

Table 3: Coping health inventory for parents

3(a): Maintaining family integration, cooperation, and an optimistic definition of the situation N=70.

S. No	Items	Extremely helpful (3)	Moderately helpful (2)	Minimally helpful (1)	Not helpful (0)
1.	Believing that my child(ren) will get better.	29(41.4)	31(44.3)	10(14.2)	–
3.	Doing things with my children	29(41.4)	39(55.7)	2(2.9)	–
6.	Building a closure relationship with my spouse.	27(38.6)	33(47.1)	5(7.1)	5(7.5)
8.	Doing things with my family relatives.	18(25.7)	35(50)	16(22.9)	1(1.4)
11.	Believing that my child is getting the best medical care possible.	44(62.9)	23(32.9)	2(2.9)	1(1.4)
13.	Doing things together as a family (involving all members of the family)	27(38.6)	34(48.6)	9(12.9)	–
23.	Eating	14(20)	25(35.7)	26(37.1)	5(7.5)
26.	Purchasing gifts for myself and /are other family members	15(21.4)	29(41.4)	22(31.4)	4(5.7)
28.	Working, outside employment	7(10)	29(41.4)	25(35.7)	9(12.9)
31.	Talking to someone (not professional counselor/ doctor) about how I felt.	16(22.9)	35(50)	15(21.4)	4(5.7)
36.	Building close relationship with people.	14(20)	39(55.7)	13(18.6)	4(5.7)
38.	Talking with other parents in the same type of situation and learning about their experiences.	33(47.1)	31(44.3)	4(5.7)	2(2.9)
41.	Reading more about the medical problem which concerns me.	32(45.7)	25(35.7)	8(11.4)	5(7.1)
43.	Being sure prescribed medical treatment for child (ren) are carried out at home on a daily bases.	39(55.7)	27(38.6)	4(5.7)	–
44.	Talking with other individuals/parents in my same situation.	36(51.4)	29(49.4)	3(4.2)	2(2.9)
45.	Talking with the doctor about my concerns about my child (ren) with the medical condition.	44(62.9)	24(34.3)	2(2.9)	–

3(b): Maintaining social support, self-esteem and psychological stability N=70

S.No.	Variables	Extremely helpful (3)	Moderately helpful (2)	Minimally helpful (1)	Not helpful (0)
2.	Investing myself in my children	31(44.3)	34(48.6)	5(7.1)	–
4.	Believing that things are always workout.	24(34.3)	34(48.6)	12(17.1)	–
7.	Taking over personal feeling and concerns with spouse.	26(37.9)	38(54.3)	3(4.3)	3(4.3)
9.	Believing in God.	46(65.7)	20(28.6)	4(5.7)	–
12.	Trying to maintain family stability.	19(27.1)	47(67.1)	4(5.7)	–
14.	Trusting my spouse (or former spouse) to help support me and my child (ren).	32(45.7)	29(41.4)	3(4.3)	6(8.6)
17.	Having my child with the medical condition seen at clinic/hospital on a regular basis.	33(47.1)	34(48.6)	2(2.9)	1(1.4)
19.	Encouraging child (ren) with medical condition to be more independent.	34(38.6)	32(45.)	3(4.3)	1(1.4)
22.	Getting away by myself.	8(11.4)	36(51.2)	20(28.6)	6(8.6)
24.	Sleeping.	9(12.9)	30(42.9)	28(40.0)	3(4.3)
27.	Concentrating on hobbies (art, music, jogging).	12(17.1)	27(38.6)	22(31.4)	9(12.9)
29.	Becoming more self-reliant and independent.	15(21.4)	43(61.4)	11(15.7)	1(1.4)
32.	Engaging in relationship and friendship which help me to feel important and Appreciated.	10(13.3)	41(58.6)	16(22.9)	3(4.3)
33.	Entertaining friends in our home.	8(11.4)	32(45.7)	18(25.7)	12(17.1)
34.	Investing time and energy in my job.	13(18.6)	32(45.7)	19(27.1)	6(8.6)
37.	Developing myself as a person.	13(18.6)	39(59.7)	15(21.4)	3(4.3)
39.	Talking with other parents in the same type of situation and learning about their experiences.	28(40)	31(44.3)	9(12.9)	2(2.9)
42.	Explaining our family situation to friends and neighbors so they will understand.	18(25.7)	35(50)	11(15.7)	6(8.6)

3(c): Understanding the medical situation through communication with other parents and consultation with medical staff. N=70

S. No.	Variables	Extremely helpful (3)	Moderately helpful (2)	Minimally helpful (1)	Not helpful (0)
5.	Telling myself that I have many things I should be thankful for.	28(40)	39(55.7)	3(4.3)	–
10.	Taking good care of all the medical equipment at home.	30(42.9)	35(50)	5(7.1)	–
15.	Showing that I am strong.	24(34.3)	38(54.2)	8(11.4)	–
20.	Involvement in social activities (parties, etc.) With friends.	16(22.9)	34(48.6)	17(24.2)	2(2.9)
25.	Allowing myself to get angry.	11(15.7)	25(35.7)	29(41.4)	5(7.1)
30.	Keeping myself in shape and well groomed.	12(17.1)	35(50)	19(27.1)	5(7.1)
35.	Going out with my spouse on a regular basis.	13(18.6)	32(45.7)	18(25.7)	7(10)
40.	Reading more about how other persons in my situation handle things.	25(35.7)	30(42.9)	13(18.6)	2(2.9)

children and their parents.⁶

Karmansaravi F et al. (2018) conducted a study on parents with thalassemic children to investigate about their coping behavior. It concluded that the most prevalent coping behavior used by mother and father include “I read more about the medical problems that worry me and turn to god” and “I show that I am strong”.⁷

The current study concluded that the most expressed coping behavior used by caregivers was “Talking with the doctor about my concerns, about my child(ren) with the medical condition” and “believing that my child is getting the best medical care possible”.

The above studies supported the present study findings. The current study concluded that all the caregivers do follow the health promotion practices and also showed that they have different coping strategies to combat their stress and anxiety regarding the treatment process.

5. Conclusion

The study findings concluded that learning package can be effective to guide parents/caregivers about the good health promotion practices and positive coping behaviours among caregivers of children suffering from thalassemia major.

Table 4: Health Promotion Practices among parents with thalassaemic children N=70

S.No.	Variables	Always (3)	Sometimes (2)	Never (1)
I.	Personal hygiene			
1.	I ensure that my child uses soft bristles toothbrush for brushing his/her teeth.	57(81.4)	10(14.3)	3(4.3)
2.	I encourage my child to wash his/her hands before and after meals.	67(95.7)	3(4.3)	–
II.	Nutrition			
1.	I avoid giving iron rich diet to my child	23(32.9)	43(61.4)	4(5.7)
2.	I give vit. C rich fruits and supplements to my child	37(52.9)	33(47.1)	–
4.	I maintain record of fluid intake of my child.	32(45.7)	30(42.9)	8(11.4)
5.	I give folic acid rich food to my child.	42(60)	28(40)	–
III.	Elimination			
1.	I monitor and maintain record of my child's urine output.	37(52.9)	19(27.1)	14(20)
2.	I check the elimination pattern of child.	28(40)	30(42.9)	12(17.1)
3.	I check the color and consistency of stool of my child.	19(27.1)	32(45.7)	19(27.1)
IV.	Physical activities			
1.	I allow my child to do self-care activities.	59(84.3)	11(15.7)	–
2.	I make sure that my child wears proper protective footwear while going out.	50(71.4)	18(25.7)	2(2.9)
3.	I help my child to do exercise.	33(47.1)	29(41.4)	8(11.4)
4.	I discourage my child to play outdoor games.	22(31.4)	19(27.1)	29(41.4)
V.	Psychological and emotional aspects.			
1.	I ask my child to share his/her problems with parents /teachers.	58(82.9)	11(15.7)	1(1.4)
2.	I motivate my child to share his/her fear with parents.	58(82.9)	11(15.7)	1(1.4)
3.	I explore my child's feelings about disturbed body image.	33(47.1)	29(41.4)	8(11.4)
4.	I ask my child to share doubts about her/his life expectancy.	42(60)	19(27.1)	9(12.9)
5.	I appreciate my child on completion of his/her own work.	59(84.2)	8(11.4)	3(4.3)
VI.	Social aspects			
1.	I allow my child to play with other children.	56(80)	13(18.6)	1(1.4)
2.	I allow my child to participate in group activities.	56(80)	14(20)	–
3.	I help my child in socializing with relatives.	54(77.1)	16(22.9)	–
4.	I motivate my child to maintain good relations with friends and teachers.	62(88.6)	8(11.4)	–
VII.	Religious aspects			
1.	I encourage my child to go temple.	38(54.3)	32(45.7)	–
2.	I encourage my child to worship/pray.	43(61.4)	27(38.6)	–
3.	I encourage my child to do meditation/relaxation therapy	23(32.9)	27(38.6)	20(28.6)
VIII.	Body image concerns			
1.	I explore my child's worries about weight loss/gain due to diseases condition.	46(65.7)	21(30)	3(4.3)
2.	I explore my child for disturbed body image concern.	33(47.1)	30(42.9)	7(10)
3.	I routinely get my child's bone density checked.	32(45.7)	19(27.1)	19(27.1)
4.	I routinely check for any bone deformity in child.	37(52.9)	13(18.6)	20(28.6)
IX.	Treatment adherence			
1.	I ensure my child takes medicine daily.	66(94.3)	4(5.7)	–
2.	I maintain proper record of my child's medication.	64(91.4)	6(8.6)	–
3.	I take my child to hospital for regular checkup and follow up.	66(94.3)	4(5.7)	–
4.	I keep and maintain all health records of the child.	67(95.7)	2(2.9)	1(1.4)
5.	I take my child for regular complete blood count checkup.	63(90)	5(7.1)	2(2.9)
6.	I periodically take my child for dental checkup.	27(38.6)	20(28.6)	23(32.9)
7.	I take my child for 6 monthly checkup for growth and development.	60(85.7)	9(12.9)	1(1.4)
8.	I take my child for annual endocrine and cardiac function checkup.	29(41.4)	21(30)	20(28.6)

Table 5: Correlation between health promotion practices and Coping health inventory for parents.

Pearson Correlation		HPP	CHIP
CHIP	Pearson correlation	0.078	
	Sig. (2-tailed)	0.263	—
	N	70	
HPP	Pearson correlation		0.078
	Sig. (2-tailed)	—	0.263

The findings of the study revealed that all the subjects had their total HPP score in the range of 75-111 and there is low positive correlation between HPP and CHIP.

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7. Conflict of Interest

The authors declare that there are no conflicts of interest in this paper.

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