

Predictors of Caregiver's Burden: Interplay of Physical and Emotional Health and Perceived Hope in Children with Thalassemia and Hemophilia

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Physical and emotional health problems and hope in children with thalassemia and hemophilia are very important to study as they are linked with primary caregiver's burden. The aim of the present study was twofold; 1) to investigate the physical and emotional health problems that can affect the hope in children with thalassemia and hemophilia. 2) to examine predictors of the caregiver's burden. The sample was comprised of 100 children (50 children with thalassemia and 50 children with hemophilia) and 100 caregivers (i.e., one caregiver with each child, n=100). The sample was selected through purposive sampling technique. The participants between 8-16 years were taken from private and public blood transfusion cells of Lahore. Three tools besides demographic information sheet were used to collect data. The participant's hope was screened by using Children's Hope Scale (Snyder, 1997), the Pediatric Symptom Checklist (Jellinek & Murphy, 2003) and Zarit Burden Interview (Zarit, 1983). The results showed that male children had more physical and emotional health problems than female children. However, they were more hopeful than female children. Female caregivers experienced more burden than male caregivers. There was a negative relationship between physical and emotional health problems and hope of children. Furthermore, male gender, first birth order, physical and emotional health problems, hope of the children, young age and gender of the caregivers being female were the significant predictors of caregiver's burden.

Keywords: hope, health, children, caregiver, thalassemia, hemophilia, caregiver's burden.

Thalassemia and hemophilia are life-long crippling genetic disorders; both need frequent blood or blood product transfusions. These disorders lead to premature deaths due to complication of disease and transfusion. In Pakistan, 50,000 to 100,000 patients are suffering from thalassemia and every year 5,000 babies are born with thalassemia. In Pakistan, 5 out of 100 people are patients of thalassemia and around 8 million populations is thalassemia carrier. World Health Organization, (1998) has estimated that 2 million Americans are carrier of thalassemia. Rachmilewitz and Rund (2005) found that the number of new cases has been progressively decreased in developed parts such as United States and Europe.

In Pakistan, National Institute of Blood Diseases (NIBD) revealed the astonishing fact in 2010 that there are 17000 people suffering from Hemophilia. Bolton-Maggs (2013) explained hemophilia as a dangerous blood disease and a hereditary genetic ailment. In America, approximately 2 percent of the population suffers from hemophilia. Hemophilia is more common in men as compared to women.

Thalassemia is among the most common genetic blood disorders worldwide (Arana, Caro, Eleftheriou, Green, Huybrechts, Waitn & Ward, 2002). Thalassemia is a group of inherited disorders. It is considered as quantitative disease of hemoglobin. Children with thalassemia face a major problem, i.e., a deficiency of red cells in blood. A patient becomes pallor, feels weak and tired. Thalassemia ranges from mild to life threatening. Angastiniotis and Modell (1998) found that thalassemia has extended through immigration from their residency areas of Asia, Africa, etc. Asian, African and American with family history of Thalassemia are at high risk of having thalassemia

A group of psychologist associated thalassemia and its treatment with physical and psychosocial aspect (Chatterjee & Roy, 2007). Indaratna, Nuchprayoon, Riewpaiboon, Thavorncharoensap, Torcharus and Ubol (2010) found that a significant negative impact of thalassemia had observed in areas of physical and psychosocial functioning. An appropriate therapy of thalassemia includes a regular monthly blood transfusion. However, patients will inevitably confront with several side effects particularly iron overload in body critical organs and tissues including heart, ductless glands and liver (Azarkeivan, Faranoosh, Mehran, Nejad & Vosoogh, 2008).

Children with thalassemia face many emotional challenges (Chaturvedi, Girimaji & Shaligram, 2007b). Mood swings quite abruptly in children with thalassemia is very natural and a major challenge. They may feel confidence in the future in one day of a week but after that day they may feel nervous, restless and hopeless. Feeling good gives them power to lead a normal life. On the other hand, feeling hopeless undermines their willpower to fight with the disease. Children with thalassemia have to deal with emotions such as fear of needles, pain and anger. Borgna-Pignatti, Marsella and Pepe (2010) analyzed 2000 study and reported that male children with thalassemia had more behavioral, health and emotional problems.

Hemophilia is the rare disorder of blood. In hemophilia, blood clotting is not proper. According to Keyle (2007) patients with hemophilia have low or sometimes lack important proteins for clotting of blood. Severity of hemophilia may depend on the amount of excessive bleeding. Sometimes, a scratch can cause threaten to life of patient with hemophilia. Berntorp, Giangrande, Gringeri, Kroner, Ludlam, Royal, Schramm and Szucs (2002) investigated that patients with hemophilia scored lower on bodily pain and reported good health whereas patients with thalassemia scored higher on physical and social functioning, etc.

Hemophilia causes stress in children. This stress can affect family members as well as the person with hemophilia. Cottrell, Evans and

Shiach (2008) noted in a study that boys with haemophilia had more emotional, behavioral and family troubles when compared to the group of same age and healthy school peers. Isolation or other emotional problems can accompany hemophilia. Bussing and Johnson (1992) spotlighted that some features of personality, coping strategies, relative working, education functioning, habitat remedies, psychological factors involved in bleeding had an effect on psychosocial problems of children with hemophilia. The risk factors of hemophilia are having a family member with hemophilia, family history and male gender. Although the condition is a lifelong, it is important to minimize negative physical and psychological effects. Patients with hemophilia and thalassemia lose their will power, healthy aptitude towards life due to their illness. (Bussing & Johnson, 1992).

Hope in children with thalassemia and hemophilia may be a predictor of good health. Hope is interconnected with better outcomes in physical health and psychological well-being. Doering, Dracup, Evangelista, Kobashigawa and Vassilakis (2003) addressed that hope is an independent predictor of mood states and quality of life of a patient. Hope is a key factor to improve one's physical and mental health. Doering et al. (2003) found that it is considered that people with low hope are more prone to have depression symptoms whereas people with high hope can easily adapt in any situation or can easily develop one's physical and psychological comfort.

Theorist of child development viewed that parents' behavior and motivation plays a key role in progress of hope in their offspring (Erikson, 1998). According to Snyder and Lopez (2014) there are three interrelated elements in this model: these are goals, agency, and pathways. These three elements can not alone define hope. Pathways thinking and agency thinking both can be added or related in a positive manner. Snyder (1994) addressed that children reported that their parents even assisted them with tactics to reach their goals and educated them to think of hurdles as challenges in achieving their goals.

Martin and Westburg (2003) were influenced by children's goal-directed thinking. They identified links between emotional adjustment and hope in children having persistent illness in a study. Kliever and Lewis (1996) communicated that high level of hope in children with sickle cell disease predicted an increased use of coping strategies. It was also found that higher hope children reported less anxiety and positive outcomes.

Caregiver burden means physical, psychological and financial burden that a person (usually a member of family) may experience in caring a person with some illness. In caregiver burden, an individual can experience burden or stress when caring a person with persistent disease. Tull (2008) explained that individual become stressful due to financial loss, fear of losing a loved one or feel incapable to deal with daily problems adequately.

According to Social exchange theory, burden is the main outcome or element in care receiver and caregiver's relationship (Call, Finch, Huck & Kane, 1999). They found that there were many factors which affected the burden of caregivers. Role relationships of dyads like adult children, joint family, living arrangements, care provision timing, etc were the important factors in caregiver's burden. Similarly, Aydinok, Bukusoglu, Erermis, Solak and Yilmaz (2004) pointed out the children with thalassemia major and their families especially mothers had psychosocial problems. The burden of primary caregivers is associated with feelings of loneliness or isolation. Primary caregivers can also have trouble in accepting support from relatives but they perceive lack of support. Depression in primary caregivers is high and they also experience higher degrees of burden.

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Objectives

The objectives of the present research were to explore the physical and emotional health problems of children with thalassemia and hemophilia and to investigate the element of hope regarding gender. Furthermore, another objective was to examine the predictors of burden in primary caregiver regarding gender.

Hypotheses

Male children with thalassemia and hemophilia have more physical and emotional health problems than female children with thalassemia and hemophilia.

Male children with thalassemia and hemophilia have better hope than female children with thalassemia and hemophilia.

Female caregivers report more burden as compared to male caregivers.

There is a negative correlation between physical and emotional health problems and hope of children with thalassemia and hemophilia.

Physical and emotional health problems of children, hope in children and characteristics of children and caregiver's predict the caregiver's burden.

Method

Sample

The sample comprised of 100 children (50 children with thalassemia and 50 children with hemophilia) and 100 caregivers (i.e., one caregiver each child, n=100). The sample was selected through non-probability purposive sampling technique. Only those children were recruited in the study that were between the ages of 8 to 16 years. Both girls and boys were included. Children seeking treatment from blood transfusion cell were included. This research did not include the secondary caregiver. It was assured that the children having any other blood diseases were excluded. Those children were excluded who have general medical conditions and other medical diseases.

Variables

Health of Children with Thalassemia and Hemophilia

Emotional and physical health goes together in children with thalassemia and hemophilia. According to Jellinek and Murphy (1998) emotional and physical health refers to overall health, how one's think, feel, manage emotions and use coping strategies to events and face challenges in the area of daily life, i.e., home, school, friends, activities, etc.

Hope in Children with Thalassemia and Hemophilia Hope is defined by Danovsky et al. (1997) as a cognitive set. Hope has two components i.e., the pathways component and the agency component. It involves the self-perceptions which produce ways to desired goals and motivation which in turn is used to reach toward those goals. The view that children can initiate or sustain a specific action to obtain desired goal reveals by "agency thoughts" of children whereas "pathways thoughts" of the children reveal that they have the capability to generate routes to desired goals. Hope is

reflected by the combination of agency thoughts and pathways thoughts toward goals (Snyder, 1997).

Table 1

Demographic Characteristics of the Study Sample (N=200)

Variables	n	M	SD
Child Age (8-16)		12.51	2.82
8-10 years	32		
11-13 years	23		
14-16 years	45		
Child Gender			
Male	50		
Female	50		
Type of Disease			
Thalassemia	50		
Hemophilia	50		
Birth Order			
1	26		
2	31		
3	20		
4	8		
5	8		
7	4		
8	3		
Single Born			
Yes	22		
No	78		
Age of caregiver		41.24	4.88
32-41	52		
42-51	48		
Gender of caregiver			
Male	25		
Female	75		
Primary Caregiver's Education in years		5.72	4.86
0	34		
5	13		
10	24		
14	4		
Primary Caregiver's Profession			
Working	26		
Non- working	74		
Marital Status			
Single	17		
Married	83		
Relation of caregiver with child			
Mother	66		
Father	25		
Any other	9		

Caregiver's Burden In caring a child with thalassemia or hemophilia, extra burden will be experienced by caregiver in terms of physical, emotional and financial. Caregiver's burden is "level of burden (i.e., emotional, physical health, social, and financial) a

caregiver feels when caring of person with chronic illness" (Bach-Peterson Reeve & Zarit, 1980).

Instruments

Demographic information sheet It was used to obtain information related to demographic variables. It was prepared by the researcher, keeping in mind the variables of the research to be explored. In the demographic information sheet, the questions asked were related to age, gender, education, family income, year of onset of disease, any other disease, years of treatment, birth order, single born and siblings having similar disease. Number of caregivers was probed. Age, gender, education, profession and marital status of primary caregiver's were also asked.

Pediatric Symptoms Checklist (PSC) Physical and emotional symptoms are assessed by translated version of Pediatric Symptom Checklist by Jellinek and Murphy (2003). It comprises of 35 items assessing the physical and emotional symptoms in children. These items have to be reported by the caregivers. Responses are rated as never=0, sometimes=1 and often=2 respectively. The scale's concurrent validity was .79 - .92. A test-retest reliability of .84 - .91 was obtained.

Children Hope Scale (CHS) Hope in children is measured with translated version of CHS. CHS is developed by Snyder et al. (2007). CHS consists of 6-item self-report questionnaire. The three items (item number: 1, 3, 5) tell agency whereas the three items (item number: 2, 4, 6) tell pathways. Responses are rated on 6-point Likert scale, i.e., 1 means none and 6 mean all the time. The original analysis of content validity conducted by the authors of CHS resulted in agency and pathways correlated factors was $r = 0.61$. The Pearson's Correlation for test-retest reliability was .73 and the Cronbach's alpha for internal consistency was .77.

Zarit Burden Interview (ZBI) The burden of primary caregiver is measured by translated version of The ZBI. It was developed by Zarit (1983). It has 22 items. It is scored on a 5 point Likert scale. It ranges from never to nearly always. The range of response was 0 to 4. The scale has good "construct validity". The scale has a high reliability i.e. 0.89 and the test-retest reliability of scale was 0.71.

Procedure

The objectives of the study were informed to all participants and informed consent was acquired. After informed consent. Data was collected ensuring confidentiality. The instruments were administered in such an order as structured interview schedule, Pediatric Symptom Checklist (Jellinek & Murphy, 2003), Children's Hope Scale (Snyder et al. 1997) and the Zarit Burden Interview (Zarit, 1983). First, the participants and their caregivers were asked about demographic variables. The questions of CHS were asked to the children with thalassemia and hemophilia. Then PSC and ZBI questionnaires were completed by the caregivers because the caregivers know their children condition better than anybody else.

Results

Present study used two phases for analyzing the data. In the first phase, t-test was run to determine group differences between health and hope of children with thalassemia and hemophilia and burdens of caregivers, furthermore, correlation was also employed. In the

second phase, multiple regression was employed for analyzing the predictors of caregiver's burden.

Table 2 revealed that male children with thalassemia and hemophilia scored ($M = 63.98$, $SD = 2.97$) significantly higher on Physical and emotional symptoms (as measured by PSC through caregivers) than female children with thalassemia and hemophilia ($M = 54.04$, $SD = 4.77$). The difference was significant, $t(98) = 12.50$, $p < 0.01$. The same trend was observed in the hope of children regarding gender. Male children with thalassemia and hemophilia scored ($M = 28.62$, $SD = 0.83$), which was significantly higher than female children with thalassemia and hemophilia ($M = 10.40$, $SD = 1.23$). The difference was significant, $t(98) = 86.87$, $p < 0.01$.

Table 2
T-Test Comparing Gender Differences in PSC and CHS

Variables	Male Child		Female Child		<i>df</i>	<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
PSC	63.98	2.97	54.04	4.77	98	12.50	.000*
CHS	28.62	0.83	10.40	1.23	98	86.87	.000*

Note: * $p < 0.01$

Table 3
T-Test Comparing Gender Difference of Caregiver on ZBI

Variables	Male Child		Female Child		<i>df</i>	<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
ZBI	43.56	1.87	51.80	5.47	98	-7.37	.000*

Note: * $p < 0.01$

Table 4
Pearson's Correlation between PSC and CHS

Variable	<i>M</i>	<i>SD</i>	CHS
PSC	59.01	6.31	-.64**

Note: ** $p < 0.01$

Table 5

Multiple Regression for Predicting Caregiver's Burden (Resulting Variable: Caregiver's Burden)

Variable	Step 1			Step 2			Step 3			Step 4		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
Physical and Emotional health	.63	.07	.66*									
Hope for Children				-.37	.09	-.37*						
Age							-.06	.08	-.03			
Gender							-12.63	.79	-1.60*			
Education (In years)							.14	.08	.86			
Single Born							.01	.59	.00			
Birth Order							-.35	.16	-.10**			
Any other disease							-.27	.79	-.01			
Age of caregiver										-.17	.06	-.14*
Gender of caregiver										1.69	.72	.12**
Marital status of caregiver										-.03	.67	-.00
Caregiver's education										.05	.05	.04
Caregiver's profession										.31	.53	.02
Relation of caregiver with children										1.04	.47	.11*
R ²	.44			.52			.89			.90		
ΔR^2	.44			.08			.37			.02		

Note: * $p < 0.01$; ** $p < 0.05$

Table 3 findings showed that female caregiver's burden was significantly higher ($M = 51.80$, $SD = 5.47$) as compared to male caregiver's burden ($M = 43.56$, $SD = 1.87$) on ZBI. A significant difference revealed as, $t(98) = -7.37$, $p < 0.01$.

From the table 4, results revealed significant negative relationship between physical and emotional health problems and hope of children with thalassemia and hemophilia (i.e., $r = -.64$, $p < 0.01$) which further showed that children who have less physical and emotional problems are more hopeful.

Multiple regression analysis was carried out for predicting caregiver's burden. Physical and emotional health problems of the children were entered in step 1 for the purpose of predicting caregiver burden and the model was significant ($\beta = 0.66$, $p < .01$). The 44% of variation in caregiver's burden showed that there will be increase in caregiver's burden when physical and emotional health problems of the children will increase. Hope of the children was entered in step 2 to predict caregiver burden and this model was significant ($\beta = -0.37$, $p < .01$). Furthermore, the model indicated 52% of variation in caregiver's burden showing that the burden in caregivers will increase when the children show less hope.

Characteristics of the children were entered in step 3 for predicting caregiver burden and this model was significant; ($F(8, 91) = 87.23$, $p < .01$). In step 3, some variables were considered as insignificant except gender being Male and first born in birth order. The gender and birth order of the children showed 89% of variation. Moreover, gender of children being male was proved to be more significant ($\beta = -1.06$, $p < .01$) as compared to be born first in birth order ($\beta = -.10$, $p < .05$). Caregiver's characteristics were entered in step 4. The model showed 90% of variation in caregiver's burden indicating that caregiver's characteristics are significant predictors of caregiver burden, as compared to the rest of the variables in other models. Significant caregivers' characteristics as predictors include young age of the caregiver ($\beta = -.14$, $p < .01$). Gender of the caregiver being female ($\beta = .02$, $p < .05$) and relation of caregiver with child as mother ($\beta = .11$, $p < .01$).

Discussion

Results of the present study showed some interesting findings. This study showed that male children with thalassemia and hemophilia have more physical and emotional problems than female children. In this context, the main reason is the cultural difference. In Pakistani culture, the problems of males are more highlighted than females. Moreover, parents give more attention to physical and emotional health problems of their male or single born child. Birth order of male child is also considered of prime importance in Pakistani culture. It is important to keep in mind the fact that "Male dominating society prevails in Pakistan" where male is considered to be the head of family and is fully authorized to take any kind of decision. Some researchers of the existing literature have also agreed that male children with thalassemia and hemophilia have more physical and emotional health problems as compared to female (Brown and Lambert, 1999). Male children with thalassemia and other hemoglobinopathies also tended to have more behavioral, general health, and emotional problems (Borgna-Pignatti, Marsella, & Pepe, 2010).

On the contrary, some evidence showed that in Asian culture the greater prevalence of physical and emotional health problems were observed in girls with thalassemia but they received less medical attention and care at home due to sociocultural factors (Chaturvedi, Girimaji & Shaligram, 2007b). Furthermore, Borgna-Pignatti, Marsella and Pepe (2010) highlighted that female patients with thalassemia enjoy a longer survival as compared to male patients. Another study showed that parents pay more attention to problems of male as compared to female children with thalassemia (Salahuddin & Zaman, 2006).

The pattern of the observed findings supported the research hypothesis of the current study that male children have better hope as compared to female children. The main reason of better hope in male children is that in Pakistani culture, parents pay more attention to their male children. On the contrary, evidence from the existing literature showed that female adolescents are more hopeful than male adolescents with cancer (Hendricks-Ferguson, 2006). It was also identified that girls reported high spiritual well-being than boys. However, Snyder (2002) found out that there was no significant gender difference in hope among normal children of same age.

One of the important reasons behind the researchers' interest in examining caregiver's burden is that it has a major effect on the physical and emotional health problems as well as on the hope of children. The present study provided evidence that female caregivers have more burdens as compared to male caregivers. Furthermore, some researchers believed that females experience more physical and psychological burden than males. Women caregivers have higher rates of psychiatric problems because of their poor quality of life. Also, they have to run their homes with caregiving role (Chaturvedi, Girimaji & Shaligram, 2007a).

In addition, physical and emotional health problems of children were expected to negatively correlate with the hope of children with thalassemia and hemophilia. Hope theorist believes that higher hope often results in good health (i.e. less physical and emotional problems). Doering et al. (2003) believed that people with less hope are more likely to suffer from depression as compared to people with high hope.

Notably, the study supported the notion that caregiver burden was better predicted by a combination of different variables like physical and emotional health problems, hope, gender of the child

being male, first birth order of children, caregiver's young age and being female. A relationship between children's physical and emotional health problems, hope, gender and age of caregivers mediates by caregiver's burden. Gonyea, Hooyman and Montgomery (1985) found that the caregivers' characteristics were found to be the best predictor of subjective burden in caregiving experience of cancer patients. The present study gave an interesting indigenous finding that the caregiver's characteristics are the strongest predictor of caregiver's burden. A younger caregiver and a female caregiver will report more burden as compare to and aged and male caregiver. Ohaeri and Shokunbi (2002) reported that a young mother as caregiver will experience more burden for a child having Thalassemia or Hemophilia than anyone else. These findings are consistent with the present research as well. These findings shed important light on importance of caregivers' characteristics with reference to caregivers' burden.

Limitations

Some of the possible shortcomings of the present study are explained below:

- It was hard to generalize the findings of the present study as the sample size of patients with thalassemia and hemophilia and their caregivers was small.
- Thalassemia and hemophilia are critical diseases because of which data collection was proved to be very difficult for the researchers. Children and their caregivers refused to participate in the study because they faced many problems in the process of blood transfusion (i.e., fear of injection/needle, a clot in blood or in plasma bag directly effect the hope of children and pose burden on the caregivers).
- Caregivers refused to participate in the study because of the exertion and unavailability of resources (i.e., blood or plasma bag are not available on time)

Suggestions

Following are some of the recommendations of the study:

- Government should provide economical, free and accessible treatment of these diseases and should spend more funds so that caregivers of children with thalassemia and hemophilia may be relieved to some extent from monetary burden.
- In our country, new cases of thalassemia and hemophilia should be prevented through media (newspaper, television, radio etc.).
- Health education programs for public awareness should also be managed so that public awareness can be spread about the complications and preventions of thalassemia and hemophilia.
- Blood transfusion cells should be increased in both urban and rural areas so that patients with thalassemia and hemophilia may get blood or plasma bags easily.
- Public seminars and conferences should be arranged to prompt management of thalassemia and hemophilia and how to live with these diseases.
- More factors are needed to be explored regarding caregiver's burden e.g. financial constraints, family system and home environment etc.
- Social welfare programs should be arranged for the relief of psychosocial burden and to improve quality of life of patients as well as of caregivers.

Conclusion

The present research showed that male children have more physical and emotional health problems than female children. Male children were more hopeful than female children. The results found that there was a negative relationship between physical and emotional health problems and hope of children with thalassemia and hemophilia. Female caregivers experienced more burden than male caregivers. It is concluded that the gender, physical and emotional health problems, hope of the children and young age of the caregivers are the significant predictors of caregiver's burden.

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