

Influence of Parental Guilt, Expressed Emotion, Self-transcendence and Mental health on Resilience among Parents of Children with Thalassemia

Ms. Angela Jean Mary^{1*}, Ms. Lidia Fernandez²

ABSTRACT

Families of children with chronic illness experience persistent stress, fatigue and burnout. Facing diagnosis, frequent visits to the hospital and the unpredictability of most chronic illness diagnosed in childhood tends to take a toll on the emotional health of parents, a consequence that is minimally documented. The present study aims to understand the component of guilt, expressed emotion, ability to transcend one's emotional and physical space and mental health on the resilience of parents of children with thalassemia. The study was exploratory in nature and correlational in its method. A total of 40 parents (mothers, fathers or both) participated in the study from JSS hospital, Mysore. The results of the study showed parental guilt, expressed emotion, self-transcendence (STS), mental health and resilience at varying levels in parents. Pearson's chi-squared test showed no significant association between parental guilt, expressed emotion, self-transcendence and mental health, individually, with resilience. However, low self-hate appeared to be associated with low levels of self-transcendence and significantly greater percent of parents with low STS were found having high expressed emotion. Spearman's rank correlation showed significant association, i.e., omnipotent guilt was noted to be positively correlated with self-transcendence and poor mental health. Similarly, self-hate was also positively correlated with self-transcendence ability. Emotional over-involvement (EOI) was negatively correlated with resilience, and EOI along with omnipotent guilt were positively correlated with poor mental health.

Keywords: *Thalassemia, Parents, Guilt, Expressed Emotion, Self-transcendence, Mental Health, Resilience*

Parenting has been a part of human evolution since the very beginning, although the many facets of it has gradually changed and come into the glare of publicity very recently. Psychological, emotional and psychosocial development of the child has primarily been associated to appropriate parenting; regrettably, minimal focus has been placed on the physical, emotional and social fatigue that parents undergo at different stages of parenting that is unpleasant for both the parents and the child (Chau & Giallo, 2014). It often goes unaccounted and unaccredited as well.

¹HOD & Asst. Professor, Department of Humanities, St. Claret College, Bengaluru Karnataka, India

²Asst. Professor, PG Psychology, St. Claret College, Bengaluru Karnataka, India

*Corresponding Author

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Parenting a child with a diagnosis of a chronic illness is bound to be quite different from parenting a child whose health is not marked by uncertainty. The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHD, 2021) defines chronic illness an illness that is long term and either is not curable or leaves behind residual features that result in limitation in daily living and requires special attention. In the pediatric population, the prevalence of chronic illness varies from common asthma and diabetes to cystic fibrosis and thalassemia (Tanja Pate, 2016). Many people believe that raising a child with chronic illness strains the parent-child relationship because: a) child-rearing responsibilities are increased for parents of chronically ill children in comparison to healthy children; b) parents may feel overwhelmed and incompetent to meet the demands; c) financial stressors may exacerbate parental stress; and d) parents may feel resentment toward the child for not meeting their expectations (Pinquart, 2013; Teubert & Pinquart, 2013).

Thalassemia (named after the Greek word for sea, 'thalassa'; the condition was initially documented in populations living near the Mediterranean Sea) is a group of inherited autosomal recessive hematologic disorders that induce hemolytic anemia. As a result, the synthesis of globin chains, which are essential for the formation of haemoglobin, the protein that carries oxygenated blood, is reduced or nonexistent. Thalassemia is a collection of illnesses ranging from barely noticeable blood abnormalities to severe or deadly anemia. Approximately 5% of the world's population possesses a globin variation, only 1.7 percent of the population has alpha or beta thalassemia phenotype. Thalassemia affects both men and women equally and occurs in around 4.4 of every 10,000 live births. The symptoms manifest themselves in this scenario when the infant is six months old (Muncie & Campbell, 2009). Anemia, jaundice, growth retardation, facial bone abnormalities, an enlarged spleen, and a heightened susceptibility to infections are all clinical indications of thalassemia.

The complication and the chronicity that the diagnosis of thalassemia brings out is both stressful and demanding on the parents physical, emotional and psychological well-being. Though the stressors experienced are plenty and multiple at different points of the time, they can broadly be categorized into: a) at the time of diagnosis, b) during developmental transitions, c) ongoing healthcare of the child and d) as and when the child experiences exacerbation of the illness. Long periods of stress in parents can lead to the development of depressive symptoms as well certain health conditions. The concept of guilt is as old as human and yet the disclosure of it, even in today's time, marked as it is by human and technological advancement, is still met with eyes downcast and humiliation. The concept of guilt was included in the study primarily to explore and understand if parents experienced feelings of guilt given that a disease like thalassemia is inherited in nature and the possibility of prevention was always present. The burden carried by parents is both visible and invisible, the invisible burden being feelings of internalized guilt, worry and fear which often go unnoticed in periods of exacerbation of the illness (Senger et al., 2015).

Preserving a reasonable emotional balance is one of the core components of adjusting to a chronic illness and it bears its association with low levels of expressed emotions (Morris, 2013). For family carers taking care of either a child or adult, expressed emotions can evoke feelings of immense guilt and shame (Patterson, 2013). Considering that the family plays a vital role reducing the psychosocial stressor for the child with thalassemia, it is also a place from which expressed emotions emerge, both beneficial and non-beneficial to the child.

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Self-transcendence, the ability to de-center oneself by connecting to oneself, nature and expand boundaries is noted to be strongly tied with resilience, especially in the caregiving population. Parents of children with chronic illness are often overwhelmed by a sense of limitedness, however, studies have also shown that re-evaluation of one's spiritual beliefs which forms a component of self-transcendence increases psychological well-being (Soell, 2011).

The present study seeks to understand the influence of parental guilt, expressed emotions, self-transcendence and mental on resilience of parent of children with thalassemia. Guilt with its intricate components hasn't been studied in detail especially in this context and population of caregivers. The current study attempts to understand the subtle interplay, if any, between guilt and expressed emotion, while also incorporating concepts of self-transcendence and resilience in a chronic illness condition.

METHODOLOGY

The present study seeks to explore whether or not factors such as parental guilt, expressed emotion, the quality of self-transcendence and overall mental health have an impact on the resilience among parents of children with thalassemia. Furthermore, this study also looks at the interrelationship between the above-mentioned factors/variables as well as the extent of their interrelationship. The sample size of the current study was 40 and consisted of parents (mothers, fathers, or both) who visited the pediatric wing of JSS Hospital, Mysore for their child's blood transfusion. The undertaken study was exploratory in nature and correlational in its method. The protocol of the study was submitted and approved from the Institutional Ethics Committee of JSS Academy of Higher Research & Education, Mysore. Written consent forms were obtained from the participants, the study was explained as well confidentiality of information was assured.

Parents belonging to the age-group of 31-35 years dominated the sample with a base level educational qualification of SSLC. Males (fathers) were more in number than females (mothers) and the mainstream of the sample consisted of parents who were married and staying in nuclear families. 62.5% of the parents were employed while 55% of them belonged to the lower socio-economic background.

Instruments

- **General Health Questionnaire-28 (GHQ-28):** The questionnaire consists of 28 items which assess four domains namely somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. It uses Likert scoring method of 0-1-2-3. The cut-off score for the tool is 23, i.e., scores below 23 indicate no distress while scores above 23 indicate distress.
- **Interpersonal Guilt Rating Scale-15 Self report (IGRS-15s):** consists of 15 items and is a self-report rating scale which assesses interpersonal guilt according to Control-Mastery theory (Gazzillo, 2016 & Silberschatz, 2005). IGRS-15s differentiates between Survivor guilt, Omnipotent guilt (includes separation guilt) and Self-hate. Each item is assessed on a 5-point rating scale ranging from 1 (totally uncharacteristic) to 5 (completely characteristic). There is no overall score, however, the three components are scored and interpreted separately. For survivor guilt, the cut-off score is 2.28 and score above and below it indicated high and low survivor guilt, respectively. Similarly, the cut-off for omnipotent guilt is 2.53 and self-hate is 1.64.

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- **Family Questionnaire (FQ):** Family questionnaire (FQ) developed by Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K., (2002) is an instrument that assesses EE and shows 74% agreement with the Camberwell Family Interview (CFI). It consists of 20 items with responses ranging from very rarely to very often. Scoring involves a cut of point of 23 (below 23 is low; above 23 is high) for the CC scale and for the EOI scale, the cut-off point yielding maximum accuracy was 27.
- **Self-transcendence scale (STS):** Scoring involves a cut of point of 23 (below 23 is low; above 23 is high) for the CC scale and for the EOI scale, the cut-off point yielding maximum accuracy was 27.
- **Brief Resilience Scale (BRS):** Developed by Smith et al. (2008), consists of 6 items that use a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Items 1, 3 and 5 are positively worded and items 2, 4 and 6 are negatively worded. The BRS is scored by reverse scoring items 2, 4 and 6 and taking an average of the total score. The total ranges from 1 to 5 with higher scores indicating higher resilience.

Statistical tools

Descriptive statistics such as mean, standard deviation and percentage were used to demographic variables. Individually, frequency of each variable was noted. Owing to the clinical sample, test of normality was done to determine whether the data were normally distributed or not. Since, the data was not normally distributed, Pearson’s chi-squared test was employed to evaluate the association among variables. Furthermore, Spearman rank correlation was also used to measure the degree of association between the variables of the study.

RESULTS

Mental health of parents of children with thalassemia was assessed using GHQ-28. It was noted that equal percentage of parents showed both not being distress and feelings distressed while taking care of their children with thalassemia.

Among parents of children with thalassemia, omnipotent guilt (OmG) was noted to be high while self-hate (SH) was noted to be low. High level of expressed emotion (92.5%) was shown by the parents as compared to other variables under study. Low level of self-transcendence and medium level of resilience was observed in parents of children with thalassemia.

Table 1: Shows the mean and standard deviation (SD) all the variables

Variables	Parental guilt			EE		MH	STS	RES
	SG	OmG	SH	CC	EOI			
Mean	2.6	3.4	1.3	16.7	29.8	25.7	2.3	3.0
S.D	6.5	.66	.53	4.8	4.2	9.9	.511	.60

SG: survivor guilt

SH: self-hate

OmG: omnipotent guilt

CC: critical comments

EOI: emotional over-involvement

The above table represents the mean and standard deviation of both the independent and dependent variables. Among the components of parental guilt, the typical score obtained on SG is 2.6, OmG is 3.4 and SH is 1.3. Additionally, the representative score for CC and EOI are 16.7 and 29.8 respectively. Relatively, scores of CC (SD = 4.8) are spread out when

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compared to EOI (SD = 4.2). The characteristic score on General Health Questionnaire-28 which was used to assess mental well-being is 25.7 indicating distress. Similarly, mean scores of STS and RES indicate low and moderate level respectively.

No significant associations between the following variables were noted:

- a) Survivor guilt with expressed emotion, self-transcendence, mental health and resilience ($p > .05$).
- b) Omnipotent guilt with expressed emotion, self-transcendence, mental health and resilience ($p > .05$).
- c) Self-transcendence with mental health and resilience ($p > .05$).
- d) Resilience and mental health ($p > .05$).
- e) Person's Chi squared test showed no statistically significant association between the three components of guilt and RES, expressed emotion and resilience, self-transcendence and resilience and, mental health and resilience.

Table 2: Association of Self-hate (SH) with Expressed emotion (EE), Self-transcendence (STS), Mental health (MH) and Resilience (RES)

Variables		Self-hate		χ^2	p	F
		Low N (%)	High N (%)			
EE	Low	1 (3.7)	0 (0)	4.76	.092	
	Med	0 (0)	2 (15.4)			
	High	26 (96.3)	11 (84.6)			
STS	Low	23 (85.2)	7 (53.8)	4.59	.050	
	Med	4 (14.8)	6 (46.2)			
MH	ND	16 (80)	4 (20)	2.84	.091	
	D	11 (55)	9 (45)			
RES	Low	4 (14.8)	3 (23.1)	.55	.75	
	Med	17 (63)	8 (61.5)			
	High	6 (22.2)	2 (15.4)			

$p < .05$

ND: not distress; D: distress; F: Fisher's exact test

Chi-square results were significant for associations between self-hate and self-transcendence ($p < .05$), i.e., parents of children with thalassemia who expressed a lower degree of self-hate towards themselves are more likely to experience high degree of self-transcendental ability.

Table 3: Association of Expressed emotion (EE) with Self-transcendence (STS), Mental health (MH) and Resilience (RES)

Variables		Expressed emotion			χ^2	p	F
		Low N (%)	Med N (%)	High N (%)			
STS	Low	0 (0)	0 (0)	30 (81.1)	9.73	.008	
	Med	1 (100)	2 (100)	7 (18.9)			
MH	ND	1 (5.0)	2 (10)	17 (85)	3.24	.198	
	D	0 (0)	0 (0)	20 (100)			
RES	Low	0 (0)	0 (0)	1 (18.9)	5.26	.26	

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Med	0 (0)	2 (100)	23 (62.2)
High	1 (100)	0 (0)	7 (18.9)

$P < .05$

ND: not distress; D: distress; F: Fisher's exact test

The above table shows significant association between EE and STS ($p < .05$) which leads to an understanding that parents of children with thalassemia who are emotionally over-involved with their children are likely to experience low levels of self-transcendental abilities.

Table 4: Spearman rank correlation showing the degree of association among variables (SG: survivor guilt, OmG: omnipotent guilt, SH: self-hate; EE: expressed emotion; STS: self-transcendence; MH: mental health; RES: resilience)

Variable	M	SD	1	2	3	4	5	6	7	8
1 PG-SG	2.6	6.5	x			.22	.20	.14	-.07	.19
2 PG-OmG	3.4	.66		x		.25	.05	.32*	-.20	.32*
3 PG-SH	1.3	.53			x	.20	.19	.33*	-.16	.25
4 CC	16.7	4.8	.22	.25	.20	x		.21	-.13	.23
5 EOI	29.8	4.2	.20	.05	.19		x	-.23	-.42**	.58**
6 STS	2.3	.51	.14	.32*	.33*	.211	-.2	x	.09	-.24
7 RES	3.0	.60	-.07	-.20	-.16	-.13	-.42**	.09	x	-.21
8 MH	25.7	9.9	.19	.32*	.25	.23	.58**	-.24	-.21	x

*. Correlation significant at .05 level

**. Correlation significant at .01 level

As presented in the table above, omnipotent guilt is positively correlated with self-transcendence ($r_s = .32$, $p = .038$, $N = 40$) and poor mental health ($r_s = .32$, $p = .040$, $N = 40$) i.e., an increase or decrease in omnipotent guilt leads to an increase or decrease in self-transcendence ability and mental well-being respectively on this sample of parents of children with thalassemia. Similarly, self-hate is also positively correlated with self-transcendence ability.

Correlation between emotional over-involvement (EOI) and resilience showed a negative association ($r_s = -.42$, $p = .007$, $N = 40$), i.e., as EOI decreases, there is an increase in the resilience of parents of children with thalassemia and vice-versa. The construct of EOI ($r_s = .58$, $p = .000$, $N = 40$) and omnipotent guilt are positively correlated to poor mental health condition ($r_s = .32$, $p = .040$, $N = 40$).

DISCUSSION

Preliminary analysis of the data included the frequencies of certain demographic factors (Fig. 1) which showed that majority of the parents of children with thalassemia belonged to the age range of 31-35 years with the highest qualification noted be SSLC. 95% of the parents were married and 72.5% were living in a nuclear family set-up. 55% of the parents belonged to the lower socio-economic strata and 62% were employed.

Descriptive statistics (percentage) showed omnipotent guilt was noted to be high for parents of children with thalassemia while self-hate was lowest. Regarding mental health, around 50% of parents were noted to be positive for mental health condition while the rest of the 50% reported no distress. Low level of STS and medium level of resilience were also noted in the sample.

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Varying levels of parental guilt, EE, STS, MH and RES were seen in parents of children with thalassemia. Pearson's chi-squared test showed no significant association between parental guilt, expressed emotion, self-transcendence and mental health, individually, with resilience. However, low self-hate appeared to be associated with low STS and significantly greater percent of parents with low STS were found having high EE.

Spearman's rank correlation showed significant association, i.e., omnipotent guilt was noted to be positively correlated with self-transcendence and poor mental health. Similarly, self-hate was also positively correlated with self-transcendence ability. Emotional over-involvement (EOI) was negatively correlated with resilience, and EOI along with omnipotent guilt were positively correlated with poor mental health.

Implication

The present study has made an attempt to study the influence of parental guilt, expressed emotion, self-transcendence and mental health on resilience of parents of children with thalassemia. It also sought to assess the relationship, if any, between the variables. To the best of our knowledge, no previous study, especially in the Indian context has been done whereby the above-mentioned constructs have been taken jointly. Hence, there were a few surprising findings with respect to the inconsistency of the current study's results when compared to previous studies. One of them being the association of self-transcendence with both self-hate and omnipotent guilt, and positive correlation between emotional over-involvement and mental health. This particular association is vital in approaching parents of children with thalassemia as it indicates a sense of unrest within the individual that is leading to both de-valuing oneself in the process of providing care as well as engaging in emotions that do more harm than good. The additional stress brought about by this is implicit and can hamper an individual's (parents) coping styles, and which can be addressed as a part of a holistic approach when treating a child with thalassemia. Additionally, emotional over-involvement in parents of children with thalassemia needs to be addressed for possible future repercussions in the child's emotional well-being.

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Conflict of Interest

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