



The Role of Perceived Stress in Families of Patients with Hemophilia in Prediction of Cognitive Failures and Mental Health of Patients with Hemophilia

Fatemeh Makki,^{1,*} and Zahra Nikmanesh¹

¹Department of Psychology, Faculty of Psychology and Educational Sciences, University of Sistan & Baluchestan, Zahedan, Iran

*Corresponding author: Fatemeh Makki, MA of General Psychology, Department of Psychology, Faculty of Psychology and Educational Sciences, University of Sistan & Baluchestan, Zahedan, Iran. E-mail: fatemeh_makki@yahoo.com

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Abstract

Background: Haemophilia (hemophilia) is a chronic and inherited genetic disorder that can cause physical and mental problems, as well as harm the individual and social life of families. The present paper aimed to survey the role of perceived stress in families of patients with hemophilia and its role in the prediction of cognitive failures and mental health in patients with hemophilia.

Methods: The present paper was a descriptive - correlational study. The population of the study comprised 370 patients with hemophilia and one of their companions in 2017. Using convenience sampling, 188 patients were chosen by the use of Morgan's formula. Data were gathered using cognitive failures, mental health, and perceived stress questionnaires. The data were analyzed in SPSS - 16 using Pearson correlation and Stepwise Regression.

Results: The results showed a significant positive correlation between cognitive failure of patients with hemophilia and negative perception of stress in families of patients with hemophilia ($r = 0.195$, $P = 0.05$). There was also a significant negative correlation between the mental health of patients with hemophilia and negative perception of stress in the families ($r = 1.060$, $P < 0.05$). Regarding the results of the regression analysis, negative perception of stress predicted 3.8% of changes in cognitive failure and 2.6% of changes in the mental health of patients with hemophilia.

Conclusions: The findings showed that negative perception of stress in patients with hemophilia and their families could predict cognitive failure and mental health of these patients. Therefore, it is necessary to provide more access to strong social support networks and provide parents and patients with essential information about hemophilia, in addition to current hemophilia treatments.

Keywords: Hemophilia (Haemophilia), Stress, Cognition, Mental Health, Family

1. Background

The general term clotting factor impairment refers to a wide range of medical problems associated with blood clotting disorder. Mostly, these are inherited genetic disorders that impair the body's ability to make blood clots, including hemophilia A, hemophilia B, Von Willebrand Disorder, and Rare Bleeding Disorders. Hemophilia is a sexually transmitted disease that happens due to a gene mutation; hemophilia A occurs due to not enough clotting factor VIII and hemophilia B occurs due to not enough clotting factor IX (1). Hemophilia A affects about 1 in 5000 - 10000 while hemophilia B affects about 1 in 40000 males at birth (2). The difference between hemophilia A and B is not clinically determinable (3). For many patients with hemophilia, the stages of development and adoles-

cence are hard to manage. At this stage, the patients with hemophilia need others, especially the family, due to the illness and special care requirements (4). Family as a fundamental support system is essential and its role could not be ignored (5). Over the past two decades, the number of families caring for patients with chronic diseases has grown (6). A family member's disease can affect all family members. As a result, diseases may pose bad psychological effects on families and affect their mental health, in addition to mental and physical limitations and problems to the patients (7). Since hereditary factors are responsible for hemophilia, child's parents feel a kind of guilt and this causes stress in the family.

Perceived stress is the response of the body to a change that requires adaptation or physical, mental, and emotional response (8). Akbari dehkordi et al. (2011) found that

one of the causes of stress in the family is the birth of the sick child. Parental stress can lead to poor performance of the family system and, in general, improper parenting (9). The results of a study showed that having a sick child has a significant relationship with family performance and families with sick children are more exposed to stress than other families are (10). Stress not only affects the families but also makes the sick person more vulnerable to various conditions and diseases (11). Vulnerable people to stress or discomfort show distress and difficulty in performing their duties (12, 13). Many studies have shown that cognitive failure or cognitive vulnerability is highly associated with personality traits, depression, anxiety, and stress (11).

Cognitive failure (cognitive vulnerability) is an individual's failure to complete tasks that they are naturally able to complete. This concept refers to the fact that a person normally has the ability to do the job, but interfering with another task or a disrupting agent causes the person to act awkwardly and with difficulty (11). Cognitive failure is an influential variable in causing mental disorders in people (14), and due to the interference with daily activities, it can cause serious damage (15). Brantley & Joens (1989) showed that individuals, who assessed mild and moderate stressors as highly stressful, were more vulnerable to them, and they had little ability to deal with them (16). Garber & Hilsman (1992) expressed that when individuals face stressful situations, their negative cognitive style increases the tendency of vulnerability to stress and decreases self-efficacy (17). As families' stress affects cognitive failure, it also affects patients' mental health.

Mental health has different dimensions. The World Health Organization (WHO) defines mental health as a level of physical and psychological well-being or an absence of mental illness. The WHO further states that the well-being of an individual is encompassed in the realization of their abilities, coping with normal stresses of life, productive work, and contribution to their community (18). Ha et al. (2011) reported that when parents with a disabled child receive more family support, the negative effects of children's disability on their mental health reduce (19). The findings of the Kwan study (2004) in Germany showed that social support and family performance are effective in the mental health of patients (20). The results of Jewell et al. (2009) showed that family's psychological education in controlling stress and concern is effective in improving mental health (21). Fristad (2003) believed that family's psychological education could increase the mental health endurance in patients (22). Moreover, the results of Pahlavanzadeh et al. (2009) and Lotfi Kashani et al. (2006) studies showed that psychological education of families increases the general health and decreases the anxiety of affected children (23, 24).

Since the patients with hemophilia are predominantly part of the young population of the country, the role of the family is very important in caring for them (25). In addition, given that the family core (father and mother) is often responsible for meeting daily needs of the patient, the above-mentioned factors lead to increased mental stress and tension in the family (26). Therefore, it is necessary to develop health and social policies in order to properly plan for the prevention, diagnosis, and treatment of the problems in the various areas of the life of these patients and provide necessary services and support; regardless of considering all aspects of the disease, especially the mental health, we cannot provide peace for these patients and their families (27). The lack of research on the role of perceived stress in the families of patients with hemophilia in predicting cognitive failure and mental health in patients with hemophilia indicates the necessity and importance of the implementation of this research.

2. Objectives

Since a few studies have been conducted to determine the role of perceived stress in families of patients with hemophilia in predicting cognitive failure and mental health of patients with hemophilia, the aim of this study was to determine the role of perceived stress in the families of patients with hemophilia in predicting cognitive failure and mental health of patients.

3. Methods

3.1. Research and Patient Environment

This was a descriptive-correlational study. The statistical population of the study consisted of 370 patients with hemophilia along with one of their family members who cared for them and referred to the Afzalipour Hospital in Kerman during the period from September to March 2017. Data collection from the population was done through convenience sampling. The sample size was calculated using Cochran's formula based on the parameters $d = 0.05$, $z = 1.96$, $q = 0.5$, $p = 0.5$, and $N = 370$, giving the sample size of 188. Finally, 171 completed questionnaires were processed. Inclusion criteria for patients with hemophilia and families included lack of psychiatric problems such as depression, psychosis, and dissociative disorders (according to the patient's case), willingness to participate in the study, the ability to answer questions verbally or in writing, and patient awareness of their illness. Exclusion criteria included an unwillingness to participate in the research and returning an incomplete questionnaire.

3.2. Questionnaire

The demographic questionnaire, Cognitive Failures Questionnaire, General Health Questionnaire, and Perceived Stress Scale were used to collect data.

Demographic questionnaire created by the researcher included age, gender, marital status, education, and occupation.

Cognitive Failures Questionnaire (CFQ) was created by Broadbent in 1982. This scale has 25 items and 4 subscales in the areas of distraction, memory, blunders, and not remembering the names. The subject responds to these items on a five - point scale (very low to very high). In Wallace's survey, the Cronbach's Alpha coefficient of this questionnaire was 0.96 and its coefficient of validity was 0.51 (28). In another study, Abolghasemi and Kiamerti reported the Cronbach's alpha coefficient for the whole scale as 0.84 and for the subscales as 0.79, 0.64, 0.66, and 0.62, respectively (29). In the current study, the Cronbach's alpha coefficient of the questionnaire was 0.84.

General Health Questionnaire (GHQ) was created by Goldberg & Hiller in 1970. The questionnaire includes four scales of seven questions including physical symptoms, anxiety and sleep disorders, social dysfunction, and severe depression. A Likert scoring system ("more than usual" to "much less than usual") was used to answer the questions of this questionnaire. In a survey, Goldberg reported the validity of this questionnaire as 0.95 and presented an alpha coefficient of 0.93 (30). In Iran, the reliability of this questionnaire was also reported in Ansari et al. study as 0.84 (31). In the current study, the Cronbach's alpha coefficient of the questionnaire was 0.76.

Perceived Stress Scale (PSS) has three versions with 4, 10, and 14 items. In this research, the one with 14 items was used. In a study by Ghorbani et al., Cronbach's alpha was calculated to be 0.81 in an Iranian sample (32). In addition, the construct validity of this scale was confirmed by Safaei and Shokri (2015), and the values of internal consistency coefficients for negative perception of stress, positive perception of stress, and the total score of perceived stress were 0.80, 0.60, and 0.76, respectively (33). The scoring of this questionnaire is based on a 5 - point Likert scale (none to very much). In the current study, the Cronbach's alpha coefficient of the questionnaire was 0.72.

3.3. Data Collection Method

The questionnaires were given to 188 patients with hemophilia and their families who were willing to participate, randomly selected in the period from September to March 2017. They were asked to fill out the questionnaires if they wished to help us with the research and to answer

the questions accurately and honestly without mentioning the names only by writing gender and age, and we assured them about the confidentiality of the information.

3.4. Ethical Considerations

After receiving the code 24134 and coordinating with the officials of Afzalipour Hospital in Kerman, the qualified patients with hemophilia and their families signed an informed consent form. Subsequently, the questionnaires were distributed to the patients and families. An additional explanation was provided whenever a question appeared obscure. It should be noted that this explanation was provided to avoid any ambiguity or bias. The information of the participants was undetectable and only one code was assigned to each subject.

3.5. Statistical Analysis Method

Descriptive statistics (mean and standard deviation) and inferential statistics (Pearson correlation coefficient and regression analysis) were used in SPSS - 16 to analyze the data.

4. Results

Demographic data showed that the age range of patients with hemophilia in the study group was between 20 and 56 years, and the mean age was 29.65. The age range of their families was between 20 and 60 and their average age was 43.71.

Table 1 presents the demographic characteristics of patients with hemophilia and their families. Among the patients with hemophilia, there were 120 males (70.2%), 51 females (29.8%), 90 single (52.6), and 75 married (43.9%). In addition, 70 family members of the patients with hemophilia were males (40.9%), 101 females (59.1%), and 133 were married (77.8%).

Table 2 shows the descriptive statistics of the research variables. The results of the Kolmogorov - Smirnov test showed that the significance level of the normalization test is more than 0.05. Therefore, the assumption of normal distribution of the data was met and the use of Pearson correlation coefficient and stepwise regression was allowable (Table 3).

Does perceived stress in families of patients with hemophilia have a predictive role in the cognitive failure of patients with hemophilia?

According to Table 4, there was a positive significant relationship between the patient's cognitive failure and the underlying component of the negative perception of stress in families of patients with hemophilia ($P < 0.05$). The results of stepwise regression were used to examine

Table 1. The Demographic Characteristics of Patients with Hemophilia and Their Families

Variable	Frequency (Percentage)
Patient's sex	
Female	51 (29.8)
Male	120 (70.2)
Patient's marital status	
Single	90 (52.6)
Married	75 (43.9)
Divorced	3 (1.8)
Widowed	3 (1.8)
Family member's sex	
Female	101 (59.1)
Male	70 (40.9)
Family member's marital status	
Single	15 (8.8)
Married	133 (77.8)
Divorced	7 (4.1)
Widowed	16 (9.4)

Table 2. The Descriptive Statistics of the Research Variables

Variables	Mean ± Standard Deviation	Number
Perceived stress	34.94 ± 40.06	171
Cognitive failure	55.63 ± 12.97	171
Mental health	42.61 ± 9.87	171

Table 3. Kolmogorov - Smirnov Test for Normal Distribution Survey

Variables	Mean ± Standard Deviation	Kolmogorov - Smirnov Z	P Value
Perceived stress	34.94 ± 40.06	1.250	0.088
Cognitive failure	55.63 ± 12.97	1.232	0.096
Mental health	42.61 ± 9.87	1.076	0.197

the predictive role of cognitive failure in perceived stress; thus, the sub - component “negative perception of stress” was put into the regression (Table 5). The correlation coefficient of this variable with cognitive failure was 0.195 and this variable was able to predict 3.8% of changes in the cognitive failure of patients with hemophilia.

Does perceived stress in families of patients with hemophilia have a predictive role in the mental health of patients with hemophilia?

According to Table 6, there was a significant inverse relationship between the mental health of patients with hemophilia and the subcomponent “negative perception of stress” in families of patients ($P < 0.05$). Using the re-

Table 4. Pearson Correlation Test Results for Examination of the Relationship between Cognitive Failure and Perceived Stress Subscales^a

Variables	Cognitive Failure	Positive Perception of Stress	Negative Perception of Stress
Cognitive failure	1		
Positive perception of stress	-0.139	1	
Negative perception of stress	0.195 [*]	0.696 ^{**}	1

^a $P < 0.05$.

sults of stepwise regression analysis for the examination of the predictive role of the mental health variable in perceived stress, the sub - component “negative perception of stress” was put into the regression (Table 7). The correlation coefficient of this variable with mental health was -0.160, and this variable could predict 2.6% of changes in the mental health of patients with hemophilia.

5. Discussion

The results of correlation analysis showed that negative perception of stress by the family of patients affects the cognitive failure (cognitive vulnerability) of patients with hemophilia. According to the results, it was found that as the families’ stress increases, the cognitive failure of patients also rises. Few studies have been conducted to examine the effect of stress on cognitive failure in patients with hemophilia. Most research on cognitive failure has emphasized the role of a specific type of coping strategies in the vulnerability of individuals to disorders and diseases. In a study, Brantley & Jones (1989) showed that those who assessed the severity of mild stressors as very high were more vulnerable to the stressors and had little ability to deal with them. In their view, it is expected that such people would be more likely to experience negative emotional states than those who assess the minor and mild stressors as less stressful. They also found that these people often use emotional coping strategies because of their vulnerability to stress and focus coping strategies on problem - solving (16). Garber and Hilsman (1992) examined the relationship between cognitive vulnerability and coping strategies within the context of the cognitive - talent - stress model. In the framework of this model, they assumed that children formed a negative cognitive style based on the example of other people and their experiences with uncontrollable stressful events in their lives. When they are faced with life - threatening events, their negative cognitive style increases their susceptibility to stress and self - efficacy, which in

Table 5. Stepwise Regression Results for Examination of the Predictive Role of Perceived Stress Dimensions in Cognitive Failure

Step	Component	R	R ²	F	β	B	T	Significance Level
First step	Negative perception of stress	0.195	0.038	6.686	0.195	0.524	2.586	0.011

Table 6. The Pearson Correlation Test Used to Examine the Relationship between Mental Health and Perceived Stress Subscales^a

Variables	Mental Health	Positive Perception of Stress	Negative Perception of Stress
Mental health	1		
Positive perception of stress	0.07	1	
Negative perception of stress	-0.160 [*]	0.696 ^{**}	1

^aP < 0.05

turn leads to negative coping strategies (17). In studies on the effects of environmental noise and congestion, it has been found that people, especially those who are vulnerable to stress or discomfort, are apparently affected by undesirable and inappropriate stressors. They adopt weak coping strategies for dealing with stressful situations and show distress and difficulty in performing their duties (12, 13). Cohen, Glass, and Philip (1978) assumed that the reason may be often due to little control over the environment that these people experience, and therefore in dealing with stress, they experience high levels of stress and counter-emotional coping strategies (13). In various studies, sound evidence suggests that cognitive failure may have devastating effects on the use of specific strategies to cope with stressful situations. It is concluded that people with high cognitive failure are vulnerable to stress because self-healing does not adequately address their coping strategies. On the other hand, inefficient strategies tend to be more prone to cognitive failures, but people with appropriate metacognition apply strategies to regulate their emotions and self-awareness that lessens stress, and creates positive excitement and mental health, resulting in a person experiencing fewer cognitive failures (34).

The results of the relationship between the perceived stress of the families of patients with hemophilia and the mental health of these patients showed a reverse and significant relationship; in other words, the higher the stress of families, the lower the mental health of patients. There are few studies about the effect of family stress on the mental health of patients with hemophilia. In a research, Kwan (2004) examined the effect of social support and family functioning on the mental health of thalassemia patients in Germany and found that social support and family func-

tioning were effective in the mental health of patients. He believes that the family can be considered as the most important social institution affecting behavior and personality. Social function and social support in families can have many effects on people's mental disorders or mental health (20). The results of Jewell et al. (2009) study showed that family's psychological education is effective in controlling stress and worries and improving the mental, social, and functional health of schizophrenic patients and their families (21). Fristad (2003) believed that psychological training of the family could increase the survival rate of patients. In addition, lack of agreement, coordination, and cooperation in the families or caretakers of the affected person increases the level of behavioral problems, reduces the quality of family functioning, and leads to lower levels of family-related problem solving and lack of parent-child efficiency. By increasing coordination and collaboration in the family, it is anticipated that stress in the home environment can be reduced, leading to the reduction of symptoms in the person and the increase of mental health in the patient (22). Pahlavanzadeh, Navidian, and Yazdani (2009) concluded that the family education program was effective in reducing depression, anxiety, and stress in family caregivers of mental patients, and this could potentially improve the quality of life and mental health of patients and caretakers (23). Lotfi Kashani, Sharifi, and Seifi (2006) concluded that psychological education of the family could increase the general health and reduce the anxiety among families of children with schizophrenia (24).

Among the limitations of the present study was the reluctance of some patients due to their poor physical and mental condition, and low literacy or illiteracy of some people (solved by reading a questionnaire to them).

It is proposed to conduct a similar study in other diseases. Workshops should be held focusing on the recognition and awareness of patients with hemophilia and their families. Educational brochures should be prepared by practitioners and cultural, educational, and therapeutic authorities to raise the awareness of patients and their families about hemophilia. Due to cognitive failures in diseases, it is suggested in subsequent studies examining the degree of cognitive failure in other diseases in a comparative way to obtain results useful in psychological therapies.

Table 7. Stepwise Regression Results to Examine the Predictive Role of Perceived Stress in Mental Health

Step	Component	R	R ²	F	β	B	T	Significance Level
First step	Negative perception of stress	0.160	0.026	4.425	-0.160	-0.327	-2.104	0.037

5.1. Conclusion

In general, the findings of this study indicated the effect of stress in the families of patients with hemophilia on the mental health and cognitive failure of patients. Because these patients are faced with many challenges that are critical to respond, the role of their families in providing a variety of social protection is very important. Therefore, it is essential to have more people with strong social support networks in addition to the current hemophilia care. Considering the important role of nurses in care and treatment, they are expected to provide parents and patients with essential information about the disease while familiarizing them with family adaptation methods. It is also recommended to provide parents and patients with periodic monitoring of the condition and psychological and social counseling to promote the mental health in this group.

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