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Original Article

Investigating the Relationship Between Coping Strategies and Quality of Life Among the Principal Caregivers of Children With Hemophilia

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Abstract

Background and Aim: Hemophilia is among the most prevalent and the most serious coagulation disorders which causes different problems for both the afflicted children and their families. This study was undertaken to investigate the relationship between coping strategies and quality of life (QOL)among the principal caregivers of children with hemophilia.

Methods: This correlational study was conducted in 2014. All 50 principal caregivers of the children who suffered from hemophilia were recruited through the census method from the Hemophilia Care Center of Valiasr (PBUH) hospital, Birjand, Iran. The data collection tools were a questionnaire for the demographic characteristics of the caregivers as well as the children's age, the Anisi's 12-item QOL questionnaire, and the Calsbeek 21-item Coping Inventory for Stressful Situations (CISS). The SPSS software (v. 16.0) was employed for data analysis. The data were analyzed through conducting the Mann-Whitney U, the Kruskal-Wallis, and the Spearman correlation tests as well as the stepwise multiple regression analysis at a significance level of less than 0.05.

Results: The QOL total score was inversely correlated with emotion-oriented and avoidance-oriented coping strategies ($P<0.05$). Moreover, the mean score of male caregivers' QOL was significantly higher than female caregivers'. In addition, the mean score of problem-based coping strategies among the caregivers who aged 40 or younger was significantly higher than those caregivers older than 40 ($P<0.04$). However, the relationship of coping strategies and QOL with the other demographic characteristics was not statistically significant.

Conclusion: Individuals' QOL can be improved by educational programs and workshops for revising and improving their coping strategies.

Keywords: Hemophilia, Principal caregivers, Coping strategies, Quality of life.

Introduction

Hemophilia is among the most prevalent and the most serious coagulation disorders which is associated with delayed bleedings, particularly with deep and intra-articular bleedings. Patients with hemophilia are at risk for intra-articular (particularly knee, ankle, and elbow joints), intraperitoneal, intracranial, and postoperative bleedings, pain, bruising (1), hepatitis, acquired immunodeficiency syndrome, anxiety, and depression (2). These complications cause children with hemophilia to have a difficult life which is fraught with fatigue, weakness, and suffering and prevent them from experiencing life in the same way as healthy people do (3).

Parents of children who have hemophilia experience great emotional distress due to the likelihood of bleeding, concerns over injuries, or the necessity to supervise their children during physical and recreational activities. Moreover, they may feel guilty because hemophilia is a hereditary disease (4). Besides the afflicted children and their family members, children's principal caregivers may also be affected by the problems and the difficulties of hemophilia. Principal caregivers are greatly involved in care giving and helping children and families cope with their chronic conditions (5) and hence, they experience burnout and great stress. Such stress and suffering reduce their quality of life (QOL) (6). Davis et al also reported that endangered physical and psychosocial well-being, the lack of appropriate recreational activities, time shortage, and

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financial strains negatively affect the QOL of the principal care givers of patients with chronic conditions (7).

Concerning the problems and the difficulties which hemophilia causes for children, families, and caregivers, and the negative effects of the disease on their QOL, coping is an important aspect of hemophilia management. Coping with hemophilia and its problems necessitates considerable coping skills and attempts (8).

Coping strategies include the appropriate and the consistent use of coping mechanisms as well as the ability to manage the activities and the problems of daily life in order to cope with internal and external stressors (9). They are classified into problem-oriented, emotion-oriented, and avoidance-oriented strategies. Problem-oriented coping includes the strategies which an individual uses to reduce or eliminate stressors. Emotion-oriented coping encompasses the strategies through which an individual focuses on one's self and attempts to reduce his/her own negative emotions. Avoidance-oriented coping necessitates the use of cognitive activities and modifications to avoid stressful conditions or events (10).

Effective coping strategies help reduce individuals' reactions to high levels of stress and mitigate the destructive effects of stress. It is noteworthy that stress and even its severity are not inherently bad; rather, the important matter is the quality of an individual's coping with stress. Accordingly, strategies which an individual uses for coping are parts of his/her vulnerability profile. Inappropriate stress management strategies and policies can aggravate problems while effective strategies can lead to positive consequences (11).

Yazdi et al found that the family members of the patients who suffer from thalassemia used different strategies for coping with the socioeconomic and the psychological problems of having a sick child (12). However, there is limited information on the strategies which caregivers of children with hemophilia use for coping with their problems. Children who suffer from chronic conditions such as hemophilia need long-term care and treatment services. The cores of families (i.e. parents) usually accept the responsibility of fulfilling the needs of sick children. The disease of a child causes psychological strain and stress for families. This study was undertaken to investigate the relationship between coping strategies and QOL among the principal caregivers of children with hemophilia.

Methods

This correlational study was conducted in 2014 in Valiasr (PBUH) hospital, Birjand, Iran. All 50 principal caregivers of the children who suffered from hemophilia were recruited through the census method. The inclusion criteria were having a less than 18-year child with hemophilia and referring to the Hemophilia Care Center of Valiasr (PBUH) hospital, Birjand, Iran. Principal caregivers included family members who had accepted the primary responsibility of providing care to children at their own homes.

Data collection was performed through using a questionnaire for the demographic characteristics of caregivers as well as for children's age, the Anisi's QOL questionnaire, and the Calsbeek Coping Inventory for Stressful Situations (CISS).

1. QOL questionnaire: The 13-item QOL questionnaire (SF-12) was developed by Anisi in 2012 for assessing QOL. This questionnaire includes twelve items in 8 domains: general health perceptions (1 question), physical functioning (2 questions), physical health (2 questions), emotional problems (2 questions), bodily pain (1 question), social functioning (2 questions), vitality (1 question), and mental health (2 questions). These questions are scored either dichotomously (Yes/No) or on a Likert-type scale. The total score of the SF-12 is 0–100. The score 0 reflects poorest possible QOL while the score 100 shows highest possible QOL. The content validity of this questionnaire was assessed and approved by Habibi et al (13). They also recruited 10 people to complete the questionnaire twice with a 1-week interval in between and reported a test-retest correlation coefficient of 0.90 (13). In the present study, the Cronbach alpha of the questionnaire was 0.89.

2. The CISS: The sort-form CISS was developed by Calsbeek et al. It contains 21 items in three domains of problem-oriented, emotion-oriented, and avoidance-oriented coping strategies. The number of items in each domain is seven. The items are scored on a 5-point Liker scale from 1 (Never) to 5 (Very much), resulting in a total domain score of 7–35. The results of the confirmatory factor analysis performed by Calsbeek et al confirmed a three-factor structure for the CISS and its construct validity. Bayazi et al (10) reported that the Cronbach alpha values of the problem-oriented, emotion-oriented, and avoidance-oriented domains of the CISS were respectively 0.70, 0.71, and 0.72.

After obtaining the necessary approvals and permissions from a university-affiliated Institutional Review Board and the administrators of the study setting, we referred to the setting for data collection. The participants were provided primarily with information about the researchers and the aim of the research. Caregivers who were intended to participate in the study were included and asked to complete the study questionnaires. Their questions were answered before and during data collection. One participant was excluded due to filling out the questionnaires incompletely and therefore, the final data analysis was performed on the data retrieved from 49 caregivers.

We used the SPSS software (v. 16.0) for data analysis. The data were described by using the table of absolute and relative frequencies. The Kolmogorov-Smirnov test was conducted for assessing the normality of the study variables. As the distribution of the variables significantly differed from the normal distribution, the Mann-Whitney U and the Kruskal-Wallis tests were conducted to compare means across the participants' demographic characteristics. Moreover, the Spearman correlation

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test and the stepwise multiple regression analysis were employed to examine the correlation of QOL with coping strategies. The level of significance was set at 0.05.

Results

From a total of 49 participating caregivers, 35 ones were male and fourteen ones were female. Most of the participants were older than 40 (55.1%), were unemployed (46.9%) and illiterate (42.9%), and lived in rural areas (53.1%). Most of the participating children (53.1%) were also more than twelve years (Table 1). The results of the Spearman correlation test illustrated that caregivers' emotion-oriented and avoidance-oriented coping strategies were inversely correlated with their QOL ($P<0.05$). Moreover, there was a positive correlation between problem-oriented coping strategies and the vitality and the mental health domains of QOL ($P<0.05$). In addition, the score of the emotion-oriented strategies was inversely correlated with the general health perceptions, physical functioning, emotional problems, bodily pain, social functioning, vitality, and mental health domains of QOL ($P<0.05$). Finally, there was an inverse correlation between avoidance-oriented strategies and the physical functioning, physical health, emotional problems, and social functioning domains of QOL ($P<0.05$; Table 2). Stepwise multiple regression analysis was performed in order to determine the percentage of the variance of QOL which could be explained by coping strategies. Accordingly, coping strategies and QOL were considered respectively as independent and dependent variables in the regression model. The results revealed that emotion-oriented and problem-oriented coping strategies explained about 46% of the QOL variable. The variable of avoidance-oriented strategies was excluded from the regression model (Table 3).

The mean of total QOL score among the caregivers of the children who were 12 years or younger was not significantly different from that of the caregivers of children who were older than twelve. Moreover, the mean score of problem-based coping strategies among the caregivers who were 40 or younger was significantly higher than those older than 40. Male caregivers also had significantly better QOL, compared with female ones ($P=0.04$). However, the relationship of coping strategies and QOL with the other demographic characteristics was not statistically significant (Table 4).

Table 1. Children and Their Principal Caregivers' Demographic Characteristics

Variable		No.	%
Caregivers' gender	Male	35	71.4
	Female	14	28.6
Caregivers' age	40 years and younger	22	44.9
	Older than 40 years	27	55.1
Caregivers' employment	White-collar worker	9	18.4
	Self-employed	9	18.4
	Unemployed	23	46.9
	Housewife	8	16.3
Caregivers' educational status	Illiterate	21	42.9
	Primary and junior high school	11	22.4
	Diploma and bachelor's	17	34.7
Caregivers' place of residence	Urban areas	23	43.9
	Rural areas	26	53.1
Children's age	Twelve years or younger	23	46.9
	Older than 12 years	26	53.1

Discussion

The study findings revealed a positive relationship between problem-oriented coping strategies and the vitality and the mental health domains of QOL. Moreover, the mean score of emotion-oriented coping strategies was significantly correlated with the total QOL and all its domains except for the physical health domain. The score of avoidance-oriented strategies was also inversely correlated with the total QOL and the physical functioning, physical health, emotional problems, and social functioning domains of QOL ($P<0.05$).

Momeni and Shahbazi Rad (14) also reported that students' QOL was positively correlated with their problem-oriented strategies and negatively correlated with their emotion-oriented coping strategies. In addition, Kheir-Abadi et al (15) and Marsac et al (16) found a significant correlation between coping strategies and QOL. All these findings are consistent with our findings, though the populations of these studies were different from our study population, confirming the relationship of coping strategies with QOL.

Table 2. The Correlation of QOL With Coping Strategies

Coping Strategies	General Health Perceptions	Physical Functioning	Physical Health	Emotional Problems	Bodily Pain	Social Functioning	Vitality	Mental Health	Total QOL
Problem-oriented	r=0.16	r=-0.21	r=-0.10	r=-0.12	r=0.02	r=-0.11	r=0.20	r=0.38	r=-0.02
	$P=0.28$	$P=0.14$	$P=0.51$	$P=0.42$	$P=0.91$	$P=0.45$	$P=0.04$	$P=0.007$	$P=0.91$
Emotion-oriented	r=-0.45	r=-0.64	r=-0.26	r=-0.53	r=-0.36	r=-0.57	r=-0.50	r=-0.58	r=-0.63
	$P=0.001$	$P<0.001$	$P=0.07$	$P<0.001$	$P=0.01$	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$
Avoidance-oriented	r=-0.15	r=-0.67	r=-0.36	r=-0.40	r=-0.21	r=-0.57	r=0.03	r=0.11	r=-0.44
	$P=0.29$	$P<0.001$	$P=0.01$	$P=0.004$	$P=0.16$	$P<0.001$	$P=0.85$	$P=0.45$	$P=0.002$

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Table 3. The Regression Coefficients Regarding the Role of Coping Strategies in QOL

Predictors	Unstandardized Coefficients		Standardized Coefficients	Correlation Coefficient	Determinant Coefficient	T	*P* Value
	B	Standard Error	β				
Emotion-oriented	-4.18	0.67	-0.71	0.63	0.40	6.22	<0.001
Problem-oriented	-2.02	0.94	-0.25	0.68	0.46	2.14	0.04

Table 4. Comparing the Means of Coping Strategies and QOL Based on Caregivers' Demographic Characteristics

Variable	Problem-oriented Mean±SD	Emotion-oriented Mean±SD	Avoidance-oriented Mean±SD	Total QOL Mean±SD
Gender				
Male	27.80 ± 2.51	18.29 ± 3.24	14.11 ± 6.22	76.31 ± 20.88
Female	28.64 ± 2.73	18.79 ± 4.51	۱۳/۰۵۷±۳/۸۸	65.63 ± 20.42
P value (the Mann-Whitney U test)	0.17	0.65	0.67	0.04
Age				
40 years or younger	28.81 ± 2.65	18.23 ± 3.49	13.86 ± 5.73	74.62 ± 18.38
Older than 40 years	27.41 ± 2.37	18.59 ± 3.75	14.03 ± 5.63	72.14 ± 23.37
P value (the Mann-Whitney U test)	0.04	0.89	0.89	0.78
Educational status				
Illiterate	27.14 ± 2.56	18.47 ± 3.11	13.52 ± 4.51	72.62 ± 21.39
Primary and junior high school	29.18 ± 2.86	19.27 ± 7.47	17 ± 9.14	72.34 ± 20.44
Diploma and Bachelor's	28.41 ± 2.12	17.82 ± 3.68	12.52 ± 2.85	74.63 ± 19.61
P value (the Kruskal-Wallis test)	0.11	0.57	0.52	0.95
Place of residence				
Urban areas	28.81 ± 2.65	18.23 ± 3.49	13.86 ± 5.73	74.62 ± 18.38
Rural areas	27.41 ± 2.37	18.59 ± 3.75	14.03 ± 5.63	72.14 ± 23.37
P value (the Mann-Whitney U test)	0.79	0.59	0.51	0.66

Raina et al (17) noted that the degree of damage to the QOL of the family members and the principal caregivers of sick children depends on different factors such as environmental factors, socioeconomic status, social support, parents and children's characteristics, and their coping strategies. However, Maleki et al (18) and Momeni et al (cited in Momeni and Shahbazi) (14) found no significant correlation between coping strategies and QOL. The findings of these studies conflict with our findings.

Considering both conflicting and the consistent findings, the findings of this study can be justified by using the Lazarus and Folkman's model. According to Lazarus and Folkman, while using problem-oriented strategies, an individual assesses the existing problem and finds its solutions. The outputs of this process are stress relief, psychological satisfaction, and improved QOL. Stress relief in turn helps the individual use his/her own cognitive abilities effectively to manage the problem which finally results in greater psychological security and satisfaction and higher QOL.

Denial and passivity are the characteristics of people who use ineffective emotion-oriented coping strategies (19). Denying the immediate stressful situation causes isolation and avoidance from that situation and hence, prevents the afflicted individual from attempting to resolve the underlying problems. Therefore, the problem persists, brings the individual with dissatisfaction, and reduces his/her QOL. Accordingly, finding the source of stress and using effective strategies for managing it have received considerable attention during the recent years. It has been shown that using effective coping strategies has a critical role in alleviating stress and improving QOL (20).

After receiving a diagnosis of a chronic condition, the family members of the afflicted patient attempt to cope with their immediate situation. Most families successfully cope with their children's chronic conditions. However, some families may be unable to cope with chronic conditions due to the limited access to accurate information and strong support.

Regarding the substantial advances in medical sciences and subsequent decreased mortality rate and increased life expectancy, QOL has become an important indicator of healthcare services (21). QOL is correlated with diseases and conditions which endanger health. The parents and the caregivers of sick children are constantly exposed to different stressors which put them under great strain (22), restrict their normal development, and require them

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to recourse to ineffective coping strategies. Accordingly, they develop marital, occupational, and parental problems which finally can cause negative consequences for their sick children.

The findings of the present study showed a non-significant difference between the caregivers of children who were twelve-year old or younger and the caregivers of children who were older than twelve regarding the mean score of QOL. However, the mean score of problem-oriented coping strategies of those caregivers who aged 40 or younger was significantly higher than caregivers older than 40 ($P=0.04$). Moreover, male caregivers acquired a significantly higher QOL score than female caregivers. Nevertheless, coping strategies and QOL were not significantly associated with other demographic characteristics.

Saadatjoo et al (23) conducted a study on patients with type II diabetes mellitus and found that the QOL of male patients and patients who held diploma and associate degrees was respectively better than female patients and patients with other degrees. Furthermore, they found an inverse correlation between QOL and age ($P<0.001$).

Other studies also reported a higher QOL among men compared with women. For instance, Sajjadi et al (24) noted that the mothers of sick children experience considerable physical and psychological problems which in turn, reduce their QOL. Ben-Zur et al (25) also reported a positive correlation between QOL and educational status. In other words, they found that QOL is improved as educational status enhances. Nonetheless, Khatibi-Aghda (26) reported that QOL was not significantly correlated with educational status. These findings show that in difficult situations such as caring for sick children who suffer from serious diseases, variables such as gender, age, and educational status cannot be significant predictors of QOL.

Conclusion

Regarding the significant effects of coping strategies on the QOL of families of children who suffer from hemophilia, these strategies can be employed for improving their QOL. Moreover, their QOL can be improved by implementing educational programs and workshops for revising and improving their coping strategies.

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