

The Relationship between Perceived Life Changes and Mental Health in Family Caregivers of Patients with Heart Failure who Referred to Rajaei Cardiovascular Medical and Research Center, Tehran

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Received: 10 March 2015 Revised: 5 August 2015 Accepted: 20 August 2015

ABSTRACT

Background: Caring for a patient with heart failure can be a challenging and stressful situation. However, researchers have paid less attention to caregiving outcomes in heart failure caregivers. This study was conducted to investigate the relationship between perceived life changes and mental health of family caregivers of heart failure patients.

Methods: Through a correlational design, a convenience sample of 90 Iranian family caregivers of patients with heart failure was selected. Data were collected using demographic-clinical characteristics form, Bakas Caregiving Outcomes Scale and General Health Questionnaire-28. Data were analyzed in SPSS using independent t-test, one-way ANOVA, Pearson correlation coefficients, and multiple regression analysis.

Results: Half of the caregivers reported that their lives had changed for the worse and nearly three fourths were suspected cases of mental disorders. There was a strong negative correlation between perceived life changes and mental health ($r=-0.607$, $P<0.001$). This finding remained consistent ($B=-0.522$, $P<0.001$) even when potential confounding factors including caregiver's age ($B=-0.222$, $P=0.016$), caregiver's marital status ($B=-6.085$, $P=0.025$), and patient's age ($B=-0.153$, $P=0.030$) were controlled. Being younger, unmarried caregiver and caring of younger patients were identified as other correlated factors of poor caregivers' mental health.

Conclusion: The strong negative correlation between perceived life changes and mental health in caregivers of patients with heart failure suggests that the heart failure caregivers with poor mental health may benefit from nursing interventions that improve appropriate coping with life changes related to caregiving.

KEYWORDS: Family; Caregiver; Heart failure; Mental health

Please cite this article as: Negarandeh R, Delkhosh M, Janani L, Samiei N, Ghasemi E. The Relationship between Perceived Life Changes and Mental Health in Family Caregivers of Patients with Heart Failure who Referred to Rajaei Cardiovascular Medical and Research Center, Tehran. *IJCBNM*. 2015;3(4):283-291.

INTRODUCTION

Heart Failure (HF) is an emerging epidemic issue¹ with high rate of prevalence, readmission, mortality and millions of dollars of health care costs. Recent statistics show an estimation of 26 million people afflicted with HF in the world, resulting in more than 1 million hospitalizations annually in both the United States and Europe.² In Iran, it has been estimated that 3337 per 100000 people suffer from Heart Failure.³

HF is a chronic disease which leads to progressive disability^{4,5} and has a higher prevalence among the diseases of the elderly.⁶ Therefore, many family members are serving as caregivers for these patients and the figures will continue to increase.⁷ There is growing evidence that family support for HF patients is associated with better outcomes of the disease such as improving overall patient's quality of life and medical management,⁸ medication adherence⁹⁻¹¹ and self-care¹² and reduce the risk of hospital readmission;⁹ also, it has been emphasized to pay more attention to a family-centered approach for managing the disease.¹³

In Iranian culture, humanity and strong family attaches make people feel more committed to relatives, particularly when a family member experiences an illness, and in this situation, they more concerned.¹⁴ Accordingly, giving care for HF patients is a challenging and stressful duty for family caregivers, and nurses as professional care givers should support them. It is believed that supporting family caregivers is one of the most cost-effective long-term care investments to provide ongoing quality care for HF patients.⁷ This issue is considerable especially for nurses who have a key role in health outcomes promotion among HF patients and caregivers by the means of improving the wellbeing of caregivers.⁷

The family caregivers of HF patients are dealing with a wide range of challenges related to providing care. Molloy et al. mentioned several caregiving demands in congestive heart failure such as limitations in physical activity, fluctuating symptoms,

complex medical and self-care regimen, CHF-related depression, frequent hospitalizations, caregiver-restricted social life, disturbed sleep patterns, changes in sexual activity and worry associated with an Implantable Cardioverter Defibrillator or other technological medical device.¹⁵ For dealing with these challenges, caregivers have to change their daily lives. Bakas et al. reported that in many HF caregivers, life had been changed for the worse as a result of providing care.¹⁶ These caregivers might have less time for activities with friends or ignore fulfillment of their own life expectations.¹⁷

Also it has been reported that compared to the general population, HF family caregivers had lower ratings of life satisfaction.¹⁷ Many studies suggested that providing care for HF patients often burdens psychological demands on caregivers^{15,17-19} so that three out of 10 caregivers experience stress related to caregiving and 53% suffer from social isolation.²⁰ Saunders reported that caregiving burdens were significantly related to depressive symptoms among HF caregivers.¹⁹ Moreover, the association between caregiving with distress, anxiety and depression has been reported in large prospective longitudinal population studies.²¹

It seems that perceived life changes may be associated with status of mental health in HF family caregivers. Peyrovi et al. found that as the caregivers of patients with stroke perceived care-related life changes for the worst, the feeling of depression increased.²² Bakas et al reported that negative HF caregiver perceptions of outcomes were correlated strongly with poorer perceived mental health.¹⁶ Due to the importance of the issue and the limited studies in this area, this study was conducted to examine the correlation between perceived care-related life changes and mental health among Iranian HF caregivers.

MATERIALS AND METHODS

This was a correlational study conducted during October and December in 2012. The study

population consisted of the family caregivers of patients with HF who referred to inpatient wards of Shahid Rajaei Cardiovascular, Medical and Research Center of Iran University of Medical Sciences in Tehran, the capital of Iran. Family members who were the main caregivers, were aged ≥ 18 , had provided care at least for six months and did not suffer from any known mental disorders or drug abuse were included in the study. Moreover, the patients must have been diagnosed HF with "The New York Heart Association (NIHA) functional classes of III (Marked limitation of physical activity, comfortable at rest, with activity less than ordinary causing fatigue, palpitation, or dyspnea) or IV (Unable to carry out any physical activity without discomfort, symptoms of cardiac insufficiency at rest; and If any physical activity is undertaken, discomfort is increased)".²³ The study did not include caregivers of patients with cancer, stroke, dementia, or those receiving dialysis. The sample size was calculated considering a correlation coefficient of 0.3, a confidence interval of 0.95, and a power of 0.80. A sample of 90 caregivers was recruited using the convenience sampling method in the study.

Data were gathered using three questionnaires that were filled out by face to face interview. The demographic-clinical characteristics form included questions regarding the caregivers (age, gender, marital status, educational degree, economic status, job status, relationship to patient, duration of caregiving) and the patients (age, gender, educational degree, the percentage of ejection fraction (EF), duration of HF disease, history of non-cardiac diseases). The clinical information of the patients was derived from their medical records to ensure data validity.

Bakas Caregiving Outcomes Scale (BCOS) was used to measure the caregiver's perceptions of their life changes resulting in caregiving. It is a 15 item questionnaire rated on a 7-point scale ranging from -3 (changed for the worst) to +3 (changed for the best), and a score of 0 indicating no change. In order to obtain positive numbers, the -3 to +3 ratings were recoded to 1 to 7.²⁴ Possible range of

total BCOS score was between 15 and 105. Several studies have supported the reliability of the revised 15-item BCOS.^{16,17} Peyrovi et al. translated the scale into the Persian language for the first time. They confirmed validity and also the reliability with correlation coefficient of 0.80.²² In the present study, internal consistency was confirmed using Cronbach alpha coefficient ($\alpha=0.91$).

General Health Questionnaire (GHQ-28) was administered to assess the caregivers' perceptions of their mental health. This questionnaire was developed by Goldberg and Hillier in 1979 and measures the current mental health. It consists of 28 items scored as a 4-item Likert scale from 0 to 3. The possible total score ranges from 0 to 84 with lower scores indicating better mental health. Noorbala et al. validated GHQ-28 in Tehran, the capital of Iran, and reported the cut-off point of 23 for this questionnaire. So, individuals with score 23 or lower are recognized as healthy and people with scores higher than 24 are suspected cases of mental disorder.²⁵ A review of the previous studies in different parts of the world shows the high validity and reliability of the questionnaire.²⁶⁻²⁸ In the present study, the Cronbach alpha coefficient of 0.92 confirmed the internal consistency.

The study was approved by Tehran University of Medical Sciences Ethics Committee. The purposes and methods of the study were explained for all participants. They were assured that participation in the study was voluntary, and it would not affect the care that their patients received. Other ethical subjects of interest included confidentiality of the data and anonymity of the participants. Finally, informed consent was signed by all caregivers who agreed to participate in the study.

The Statistical Package for Social Sciences (SPSS), version 16.0, (SPSS Inc., Chicago, IL, USA) was used for statistical analysis. Descriptive statistics (frequency, mean and standard deviation) were carried out to describe demographic data. Statistical tests (The independent samples t-test, one-way ANOVA, Pearson correlation test and multiple

linear regression) were used for data analyses. A p value of less than 0.05 was considered significant for all statistical tests.

RESULTS

The mean age of the caregivers was (M: 43.67, SD: 12.88) with a range of 18-78 years. The mean duration of caregiving was (M: 27.83, SD: 31.21) ranging from 6-120 months. 32.2% of HF patients were in the age group 70 years or older with a mean age of (M: 60.28, SD: 16.88) and range of 18-88 years. The duration

of HF was less than 5 years in 51.1% of the patients (M: 6.23, SD: 5.63) in range of 1-25. Other personal and clinical characteristics of caregivers and HF patients are presented in Tables 1 and 2, respectively.

The caregivers' score of the perceived life changes was obtained (M: 49.02, SD=17.22) with a range of 21 to 104. Half of the caregivers (n=45) reported that their lives had changed for the worse; 27.8% (n=25) had no life changes, and 22.2% of them (n=20) perceived life changes for the better. With respect to the mental health of the caregivers, the GHQ-28

Table 1: Frequency distribution of demographic-clinical characteristics and their relationships with BCOS and GHQ-28 scores of the HF caregivers (n=90)

Variable	n	Percentage	BCOS (Pv*)	GHQ-28 (Pv*)
Age (M: 43.67, SD:12.88; range:18-78)			r=-0.105**	r=-0.202**
<30 years	12	13.3	P=0.323	P=0.056
30-40	24	26.7		
40-50	21	23.3		
50-60	22	24.4		
≥60	11	12.2		
Sex			t=2.505	t=1.18
Female	73	81.1	P=0.014	P=0.238
Male	17	18.9		
Marital status			t=2.007	t=0.536
Unmarried	24	26.7	P=0.054	P=0.593
Married	66	73.3		
Educational level			F=4.138	F=1.232
Less than high school	8	8.9	P=0.019	P=0.297
High school	37	41.1		
Higher education	45	50		
Economic status			F=2.85	F=0.783
Poor	26	28.9	P=0.06	P=0.46
Average	56	62.2		
Good	8	8.9		
Job status			t=1.577	t=0.337
Unemployed	65	72.2	P=0.118	P=0.737
Employee	25	27.8		
Relationship to patient			F=1.899	F=1.931
Spouse	28	31.1	P=0.136	P=0.131
Adult child	41	45.6		
Parent	7	7.8		
Other	14	15.6		
Duration of caregiving (M: 7.83,SD: 31.21; range: 6-120)			F=0.083	F=1.823
>10 (months)	25	27.8	P=0.92	P=0.168
10-20	26	28.9		
≥20	39	43.3		

Note: HF: Heart Failure; M: Mean; SD: Standard Deviation; * P values lower than 0.05 are considered as significant; **Pearson Correlation Coefficient

Table 2: Frequency distribution of demographic-clinical characteristics and their relationships with BCOS and GHQ-28 scores of HF patients (n 90)

Variable	n	Percentage	BCOS (Pv*)	GHQ-28 (Pv*)
Age (M: 60.28, SD:16.88; range:18-88)			r=0.268**	r= -0.343**
<40 years	12	13.3	P=0.011	P=0.001
40-50	8	8.9		
50-60	22	24.4		
60-70	19	21.1		
≥70	29	32.2		
Sex			t=2.395	t=0.848
Female	54	60	P=0.019	P=0.399
Male	36	40		
Educational level			F=3.691	F=1.776
Less than high school	39	43.3	P=0.029	P=0.175
High school	33	36.7		
Higher education	18	20		
EF (%) (M:20.61, SD: 7.06; range:10-35)			r=-0.035**	r=-0.096**
10	26	28.9	P=0.742	P=0.366
15	56	62.2		
20	8	8.9		
25	15	16.7		
30	11	12.2		
35	6	6.7		
Duration of HF (M: 6.23, SD: 5.63; range: 1-25)			F=0.535	F=0.288
>5 (years)	46	51.1	P=0.587	P=0.751
5-10	23	25.6		
≥10	21	23.3		
History of non-cardiac diseases			t=0.336	t=0.290
Yes	53	58.9	P=0.737	P=0.772
No	37	41.1		

Note. EF: Ejection Fraction; *P values lower than 0.05 are considered as significant;**Pearson Correlation Coefficient

total score was (M: 33.06, SD: 14.34) with a range of 9-72, and 74.4% were suspected cases of mental disorders, that has been reported in our previous publication.²⁹

According to the results of independent samples t-test, there were significant relationships between BCOS score with caregiver's sex (t=2.505, P=0.014) and patient's sex (t=2.395, P=0.019), so that male caregivers had higher BCOS scores than female caregivers. Moreover, the caregivers who provided care for female patients obtained higher BCOS scores. Also, One-way ANOVA results showed a significant difference between caregivers' GHQ-28 score with caregiver's educational level (F=4.138, P=0.019), and patient's educational level (F=3.691, P=0.029). Post hoc analyses using the Scheffé post hoc criterion for significance indicated that the caregivers

with higher education level had higher BCOS scores, and the caregivers who provided care for HF patients with higher education level obtained lower BCOS scores. Patient's age was correlated with BCOS score (r=0.268, P=0.011) and GHQ-28 score (r=-0.343, P=0.001). There was no significant relationship between caregivers' BCOS or GHQ-28 score with other demographic-clinical variables of caregivers and HF patients (Tables 1 and 2).

According to Pearson correlation coefficient test, there was a strongly negative correlation between perceived life changes (BCOS) and mental health (GHQ-28) among the caregivers (r=-0.607, P<0.001). In other words, as the score of perceived life changes decreased (or changed for the worse), caregivers were more at risk of mental health problems. For controlling of potential confounding factors,

variables were entered into regression analysis based on their importance or p values less than 0.3 (including caregiver’s perceived life changes, age, gender, marital status, duration of caregiving and the patient’s age, EF and duration of HF disease, as the independent variables, with the GHQ-28, as the dependent variable). And so, the strong negative correlation between BCOS and GHQ-28 scores remained consistent (B=-0.522, P<0.001) even when potential confounding factors (caregiver’s age (B=-0.222, P=0.016); caregiver’s marital status (B=-6.085, P=0.025); and patient’s age (B=-0.153, P=0.030)) were controlled. Being younger, unmarried caregiver and caring of younger patients were identified as other factors correlating with poor caregivers’ mental health (Table 3).

DISCUSSION

In this study, half of the caregivers perceived life changes related to the caregiving as negative. During responsibility for caregiving of HF patients, caregivers are dealing with a number of challenging situations.³⁰ They have to spend a substantial amount of time and so many aspects of their personal life can be influenced. It has been reported that many caregivers of patients with HF reported that their lives had changed for the worse as a result of providing care.¹⁶ Aldred et al. indicated that HF affected all aspects of the patients’ and caregivers’ lives.³¹ Because of caregivers’ focus on performing care for their HF patients, they often become overwhelmed and neglect their health, leading to the potential for “burnout”. So it is important to identify caregiving problems before HF caregivers reach “burnout” to provide optimal quality of care to

patients and prevent poor outcomes of family members.³²

Based on the results of the hypothesis test, there was a strongly negative correlation between HF caregivers’ perceived life changes and mental health; as the perceived life changes for the worst, caregivers were more at risk of mental health problems. This finding is similar to the result of Bakas et al.’s study which indicated that caregivers’ negative perceptions of how their lives have changed since providing care for a family member were associated strongly with perceptions of poorer mental health.¹⁶ Also, it could be compared with the findings of the study conducted by Peyrovi et al., in which as the caregivers of patients with stroke perceived care-related life changes for the worst, the feeling of depression increased.²² Perceiving life changes for the worst and burden of caregiving role can disrupt the individual’s comfort and potentially impact several aspects of health. Life events such as major change in health of a family member create changes in the family caregiver’ life pattern and require modifying lifestyle. Individual’s reaction to any change that requires an adjustment or response may be viewed as stress. Experiencing a high level of stressful life changes, individuals become susceptible to psychological illness.³³

To balance caregiving tasks with daily activity related to working, family and leisure, caregivers usually have difficulty paying attention to the positive aspects of caregiving and so perceive more negative responses, and they may become increasingly more distressed if they perceive inability to be engaged in their valued activities and interests,³⁴ Saunders showed that there were moderate to large,

Table 3: Adjusted correlation between BCOS and GHQ-28 scores by controlling potential confounding factors* (n=90)

Model	B	SE	Standardized Coefficient (β)	t	P**
Caregiver’s Perceived life changes (BCOS)	-0.522	0.069	-0.627	-7.61	<0.001
Caregiver’s age	-0.222	0.09	-0.20	-2.463	0.016
Caregiver’s marital status	-6.08	2.667	-0.189	-2.282	0.025
Patient’s age	-0.153	0.069	-0.18	-2.207	0.030

*Results from a multiple regression analysis; **P values lower than 0.05 are considered as significant

positive relationships between caregiver's depressive symptoms and caregiving burden in the domains of family, finance, schedule, and health.¹⁹ Moreover, it has been reported that burden and distress were associated with caregiving tasks and perceived difficulty in caregiving activity of caregivers of patients with HF.³⁵ In the current study, the perceived life changes remained strongly correlated with mental health after controlling potential confounding factors including caregivers' age, caregiver's marital status and patient's age. So, this finding suggests that caregivers with poor mental health may benefit from interventions that improve appropriate coping with life changes related to care giving.

In this study, younger age, unmarried caregiver and caring of younger patients were identified as other correlating factors of poor mental health among HF caregivers. It may well be that younger patients and caregivers are most distressed. Younger patients and caregivers may have difficulty accepting the seriousness of the illness, but may cope with problems and adapt to it in older ages. Similarly, previous studies reported that younger caregivers had more difficulty than older caregivers did in providing care.^{16,36} Bakas et al. reported that younger HF caregivers perceived their tasks to be more difficult and their mental health to be worse than older caregivers.¹⁶ Also, social support provided to informal caregivers has been identified to predict better outcomes for caregivers.¹⁵ It has been mentioned that the relationship between the family members and participating in the patient care improves the caregivers' mental status and eliminates the sense of isolation and depression.³⁷ Probably, in our study the married caregivers had received more support from their family members and, compared with caregivers who were unmarried, reported lower GHQ-28 scores.

Recruiting study participants from a large referral hospital was the strength of this study. Furthermore, the authors conducted a very robust statistical analysis in an effort to control for potential confounders. However,

this study had limitations; one limitation of this study was that it relied on self-reported data, which may be subject to social-response bias. A further limitation concerns the sampling method. In theory, the ability to generalize the findings of the study to the population depends on the use of random samples. Convenience samples are, however, commonly used by researchers in a clinical context because they are feasible.

CONCLUSION

This study highlights the negative outcomes of caregiving to family members with HF. Therefore, it can be argued that caregivers are hidden patients themselves. Considering that family caregivers are often marginalized by health care professionals, nurses will be needed to support both patients and family caregivers.

Based on the findings of this study, nurses as formal and professional caregivers of patients should pay attention to family caregivers. Up to now, few studies have been done about caregivers' perceived life changes, mental health and their relationships. Therefore, the results of this study can be used as body of knowledge in this regard. With respect to the fact that the mental health was poorer when these caregivers perceived life changes for the worse or negative as a result of providing care, decreasing any negative aspects of caregiving and supporting them in play a very important role and is recommended to be a priority. Also, attention should be paid to assessing the mental health of HF caregivers who are younger, unmarried and provide care for younger patients. Because caregivers who have high levels of stress may be less able to accomplish their caregiving role, identifying those at risk could potentially impact the patients' outcomes.

ACKNOWLEDGMENT

This study was conducted by Nursing and Midwifery Care Research Center, Tehran University of Medical Sciences; Grant no.

90-03-99-15183. The authors acknowledge Tehran University of Medical Sciences for the financial support. They thank all personnel and family caregivers who cooperated with the study in Shahid Rajaei Cardiovascular, Medical & Research Center.

Conflict of Interest: None declared.

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