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Mental health in family caregivers of patients with heart failure

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ABSTRACT

Background & Aim: Family caregivers of patients with heart failure (HF) deal with a wide range of problems related to caregiving that influence their mental health. The aim of this study was to investigate the mental health status of the family caregivers of patients with HF.

Methods & Materials: In this descriptive cross-sectional study, 90 family caregivers of patients with HF, who referred Shahid Rajaei Cardiovascular Center, were selected through convenience sampling method. The data were collected using General Health Questionnaire (GHQ-28) for measuring mental health and were also analyzed by SPSS 16, and then processed using descriptive statistics, independent t-test, one-way ANOVA and Pearson correlation test.

Results: The mean score of GHQ-28 was 33.06 ± 14.34 (range: 9–72). The majority of caregivers (74.4%) were suspected cases of mental health disorders. Regarding to instrument subscales, the prevalence of caregivers' problems were 65.6% in somatic symptoms, 82.2% in anxiety/insomnia, 83.3% in social dysfunction, and 25.6% in depression. The total GHQ-28 score of the caregivers gradually decreased with increasing patient's age as in the minimum age group of the patients (aged 40 years and lower), the highest mean score of GHQ-28 was observed ($P < 0.05$).

Conclusion: A considerable proportion of family caregivers of patients with HF were suspected cases of mental health disorders. A routine assessment of mental health in this group of caregivers should be considered to identify those at risk. Also, clinical team should design and implement effective programs aimed at improving the mental health, especially in caregiver who provide care for younger patients.

Introduction

Caregiving is considered as an important phenomenon in today's society due to the increased prevalence of chronic diseases and elderly population in the world (1). Heart failure (HF) is one of the diseases which demands high care and long-term dependence of patients (2). It

is reported that HF causes more than 4 million outpatient visits, 1 million hospitalizations, and 300,000 deaths every year in the United States (3). In 18 provinces of Iran, it has been estimated that 3337/100,000 people suffer from HF (4). Also, 25% of patients hospitalized in heart wards have been affected by this disease (5). Failure to control and manage the disease may result in increased use of healthcare services and costs, aggravating disease symptoms, and in some cases, patient's death. In addition, it generally imposes a heavy burden on healthcare and treatment systems (6). Regarding the debilitating

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nature of the disease, the progressive loss of function, poor mental health of the patients, and higher prevalence of the disease in the elderly, the patients required the support of their caregivers (7). Caregiving refers to mental and/or physical support given to a patient with HF that is provided by a family member (8). Existing evidences accentuate the fact that maintaining the health and improving the quality of life of the patients with HF and their adherence to the treatment regimen depend on their caregiver's health (8-10). Saunders' literature review indicates the need for more studies on the health of the HF patients' caregivers with attention to a family-centered approach and also necessitate for considering it as a standard of care in HF (7). Therefore, besides the positive effects and advantages of supporting patients by caregivers, the effect of caring on the caregivers should not be ignored (2). Family caregivers of patients with HF face a wide range of problems and numerous symptoms of the disease, behaviors, and limitations of the patient caused by the disease including limitations in physical activities, diet, and the self-care programs of the patient (2). In addition, they may be exposed to the clinical crises of the patient leading to stress and anxiety (11). A combination of these factors has a strong potential impact on caregivers' health (2). It is estimated that 3 out of 10 caregivers experience stress associated with the burden of caregiving and 53% suffer from social isolation (1). Emotional distress is been observed in spouses of the patients with HF (12). It also has been reported that HF equally influences mental health of the patients and their spouses (7). Therefore, healthcare providers must consider the family caregiver besides the patient and pay attention to the ability of the caregiver to support the patient (8).

Based on the existing evidences in Iran, most studies have been carried out on the caregivers of patients with Alzheimer (13-15), stroke (16), cancer (17), or psychiatric disorders (18-20). While the caregivers of patients with HF has received less attention despite the increasing prevalence of HF, high care demands, especially for the moderate and severe types of the disease, and also the significance of consequences and costs related to the mental health of this group of caregivers.

Knowledge in this area can help to design clinical trials and care programs in order to promote caregivers' mental health and quality of life. It must be noticed that in Iranian culture humanity and strong family attaches make Iranians feel more committed to relatives, particularly when a member experiences an illness (21). So, considering the significance and lack of studies on the mental health condition of caregivers of patients with HF in Iran, the present study was conducted to determine the mental health and its related factors in caregivers of patients with HF.

Methods

The study population of this analytical descriptive cross-sectional study consisted of all the main caregivers who were first degree relatives of patients with HF hospitalized in Rajaei Cardiovascular, Medical and Research Center of Tehran University of Medical Sciences in Iran. As inclusion criteria, the caregivers aged at least 18 and, according to the patients, provided care as the main caregiver for at least 6 months. Furthermore, they did not suffer from known mental disorders or drug abuse. HF with functional class (FC) III (marked limitation of physical activity, comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea) or IV (unable to carry out any physical activity without discomfort, symptoms of cardiac insufficiency at rest; if any physical activity is undertaken, discomfort is increased) (22) was diagnosed by a physician. The study did not include caregivers of patients with cancer, stroke, dementia, or those receiving dialysis. Using convenience sampling, 90 caregivers were selected as the study population. After receiving the approval of the Ethics Committee and required authorizations, researchers attended different wards of Shahid Rajaei Cardiovascular Center and described the study objectives and obtained written consent from the individuals qualified for the study. Then, they provided the caregivers with clear explanation on how to complete the questionnaire and collected the data.

The data collection tools included a questionnaire on the demographic characteristics of the caregivers and the patients and also 28-item

General Health Questionnaire (GHQ-28) used to investigate the mental health of the caregivers. Demographic characteristics included information related to the caregivers (age, sex, marital status, education level, income status, job status, kinship of the caregiver and patient, duration of caregiving, providing care alone or with the help of other family members) and the patients' information (age, sex, education level, the percentage of ejection fraction (EF), and history of non-cardiac diseases). The clinical information of the patients was derived from their medical records to ensure data validity. The major measurement tool in this study was the GHQ-28 which is a measure of current mental health and Goldberg and Hillier developed it in 1979. The questionnaire consists of four subscales, each with seven items. The questions of each subscale are written in order as questions 1–7, 8–14, 15–21, and 22–28 and are related to “somatic symptoms”, “anxiety/insomnia”, “social dysfunction”, and “depression” subscale, respectively. Questions are 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, and reported the cut-off point of 23. So, individuals with score 23 or less than it are recognized as healthy and people with scores higher than 24 are suspected cases of mental disorder. Moreover, in each subscale, people with the score equal to or <6 were considered healthy. A review of the previous studies in different parts of the world shows the high validity and reliability of the test (23). In Iran, several studies confirm the validity and reliability of GHQ-28 (13, 23-25). In the present study, to test the reliability the internal consistency of the questionnaire was measured using Cronbach's alpha coefficient. The alpha for the whole sample was found to be 0.92 that indicated the acceptable reliability of the instrument. The collected data were analyzed SPSS 16.0 statistical package (Spss Inc, Chicago, IL, USA) descriptive and inferential statistical methods (independent t-test, one-way ANOVA, and Pearson correlation test).

Results

Based on the results, the mean age of the

studied caregivers was 43.67 ± 12.88 years (range: 18–78 years). Most of the caregivers were female (81.1%), 73.3% of them were married, and half of them had diploma or higher degrees. The economic status of 62.2% of the caregivers was average; most of them were unemployed (72.2%) and 45.6% of them were patients' children. Half of the caregivers took care of the patient alone while the other half used the help of other family members. In 43.3% of the caregivers, duration of caregiving was equal to or >20 months with a mean and standard deviation of 27.83 ± 31.21 , ranging from 6 to 120 months. With respect to the demographics of the patients, 32.2% of them were in the age group 70 years or over with a mean age of 60.28 ± 16.88 years (range: 18–88 years). About 60% of the patients were female and most of them were illiterate (43.3%). EF in 27.8% of the patients was 20% with a mean and standard deviation of 20.61 ± 7.06 , ranging from 10 to 35. The duration of HF was <5 years in 51.1% of the patients, with a mean and standard deviation of 6.23 ± 5.63 (range: 1–25). More than half of the patients (58.9%) had non-cardiac disease.

With respect to the mental health of the caregivers, the mean and standard deviation of the GHQ-28 total score were 33.06 ± 14.34 (range: 9–72), and most of the caregivers (74.4%) were suspected cases of mental disorder. In subscales of the instrument, mean and standard deviation of the somatic symptoms (8.80 ± 4.73 ; range: 1–21), anxiety/insomnia (10.52 ± 4.59 ; range: 0–21), social dysfunction (8.98 ± 2.98 ; range: 3–17), and depression (4.75 ± 5.15 ; range: 0–20). Other details have been reported in table 1.

One-way ANOVA results showed significant difference between the caregivers' mean score of GHQ-28 total score based on the patients' age ($P = 0.032$). Analysis of the linear trend in this regard indicated a significant linear trend as the caregivers of the patients younger than 40 years showed the highest mean score of GHQ-28; that is, this group of caregivers had the most mental health problems. The GHQ-28 score of the caregivers gradually decreased with patient's age as in the maximum age group of the patients (aged 70 years and over), the lowest mean score

of mental health was observed ($P < 0.05$). The correlation between patients' EF and caregivers' mental health using Pearson correlation coefficient was not statistically significant ($r = -0.096$,

$P = 0.366$). Furthermore, no significant relationship between caregivers' mental health and other demographic variables of caregivers and patients was observed (Tables 2 and 3).

Table 1. Distribution of the GHQ-28 subscales and total scale scores

| Mental health state | Suspected cases | | Healthy | |
|---------------------------|-----------------|------|---------|------|
| | N | % | N | % |
| Somatic symptoms | 59 | 65.6 | 31 | 34.4 |
| Anxiety/insomnia disorder | 74 | 82.2 | 16 | 17.8 |
| Social dysfunction | 75 | 83.3 | 15 | 16.7 |
| depression | 23 | 25.6 | 67 | 74.4 |
| GHQ-28 total scale | 67 | 74.4 | 23 | 25.6 |

GHQ: General Health Questionnaire

Table 2. Comparison of mean \pm standard deviations of GHQ-28 total score based on caregivers' characteristics

| Variable | Mean \pm SD | P-value |
|---------------------------------------|-------------------|-----------|
| Age (year) | | |
| < 30 | 39.66 \pm 16.31 | P = 0.328 |
| 30–40 | 34.62 \pm 14.7 | |
| 40–50 | 32.80 \pm 15.08 | |
| 50–60 | 29.54 \pm 12.43 | |
| ≤ 60 | 30.00 \pm 12.82 | |
| Sex | | |
| Female | 33.93 \pm 14.52 | P = 0.238 |
| Male | 29.35 \pm 13.27 | |
| Marital status | | |
| Unmarried | 34.41 \pm 15.88 | P = 0.593 |
| Married | 32.57 \pm 13.83 | |
| Educational status | | |
| Illiterate | 39.00 \pm 21.26 | P = 0.297 |
| Middle school | 34.18 \pm 13.67 | |
| High school and higher | 31.08 \pm 13.4 | |
| Income | | |
| Poor | 36.03 \pm 17.61 | P = 0.46 |
| Average | 31.82 \pm 13.02 | |
| Good | 32.12 \pm 11.24 | |
| Job status | | |
| Unemployed | 33.38 \pm 14.23 | P = 0.737 |
| Employee | 32.24 \pm 14.88 | |
| Kinship with the patient | | |
| Spouse | 31.25 \pm 14.42 | P = 0.131 |
| Child | 34.46 \pm 15.26 | |
| Parent | 42.42 \pm 10.90 | |
| Others | 27.92 \pm 10.74 | |
| Providing care | | |
| Lonely | 33.88 \pm 14.02 | P = 0.589 |
| With the help of other family members | 32.24 \pm 14.76 | |
| Duration of caregiving | | |
| < 10 | 29.96 \pm 12.11 | P = 0.168 |
| 10–20 | 37.30 \pm 15.67 | |
| ≤ 20 | 32.23 \pm 14.42 | |

GHQ: General Health Questionnaire

Table 3. Comparison of mean \pm standard deviations of GHQ-28 total scale based on patients' characteristics

| Variable | Mean \pm SD | P-value |
|------------------------|-------------------|------------|
| Age (year) | | |
| < 40 | 42.58 \pm 8.76 | P = 0.032* |
| 40–50 | 40.50 \pm 16.43 | |
| 50–60 | 32.13 \pm 14.99 | |
| 60–70 | 31.42 \pm 12.95 | |
| \leq 70 | 28.86 \pm 14.28 | |
| Sex | | |
| Female | 32.01 \pm 13.17 | P = 0.399 |
| Male | 34.63 \pm 15.99 | |
| Educational status | | |
| Illiterate | 30.23 \pm 14.75 | P = 0.175 |
| Middle school | 33.90 \pm 15.03 | |
| High school and higher | 37.66 \pm 11.07 | |
| Duration of HF | | |
| < 5 | 16.66 \pm 2.45 | P = 0.751 |
| 5–10 | 12.70 \pm 2.65 | |
| \leq 10 | 31.14 \pm 10.34 | |
| Co-morbidity | | |
| Yes | 32.69 \pm 14.08 | P = 0.772 |
| No | 33.59 \pm 14.87 | |

*Analysis of the linear trend indicated a significant linear trend as the caregivers of the patients younger than 40 years showed the highest mean score of GHQ-28 ($P < 0.05$). GHQ: General Health Questionnaire; HF: Heart failure

Discussion

Considering the results of the study, almost three-fourth of the caregivers (74.4%) had unfavorable mental health, that is, were suspected cases of mental disorder. Compared to the results of other studies on mental health of general populations, this result showed higher prevalence of mental health problems in the studied caregivers. So that in study of Noorbala et al. in people aged 15 and over in Tehran, 34.2% of the individuals were suspected of having mental disorder (37.9% of women and 28.6% of men) (23). Moreover, based on the results of Qorbani et al. 38.5% of the women had not a favorable mental health condition (26). The caregivers often forget themselves and do not care about their health problems. As a result of the caregiving, they may be exposed to many health problems and diseases (27). Providing care to the patients with HF is accompanied by fear, limitation, and mental distress not only for the patients but also for their caregivers (9). Some studies have shown significant distress in caregivers who were HF patients' spouses (12). Furthermore, quoting from Martensson et al., Saunders reported that the mental quality of life in patients

with HF and their spouses did not differ significantly, that is, the HF influenced the mental well-being of the patients and their spouses equally (7). In the present study, only one-fourth of the caregivers had favorable mental health, which is comparable to the findings of a study performed by Bastani et al. who using GHQ-28 reported that only 24% of the female caregivers of patients with Alzheimer's disease had favorable general health (13). The similarity of the results indicates that like the caregivers of patients with Alzheimer's disease, the caregivers of patients with HF are also exposed to health problems and therefore should receive the attention of researchers and care providers more than ever.

Based on the mean scores of the subscales of GHQ-28, the studied caregivers suffered from anxiety and insomnia, social dysfunction, and somatic symptoms. In a study by Qorbani et al. on mental health of women in Qazvin (26), the mean scores of all domains of GHQ-28 were less than our results. In a study by Luttik et al., the perceived general health as a dimension of quality of life in the spouses of the patients with HF was reported to be less than that of healthy people (12). Providing long-term care causes health problems in different physical, mental,

social, and spiritual areas for caregivers (1). In the present study, the subscale of anxiety/insomnia had the highest mean score. The high level of anxiety in caregivers may be associated with their concerns for the future, adjustment with the existing condition, fear of loss and being alone, responsibility toward children and unfamiliar duties at home (28). Furthermore, according to the existing evidence, sleep disorders are a more prevalent and complicated phenomenon in caregivers than in the general population. The factors causing sleep disorders in caregivers might include changes in the place of sleeping and nighttime behaviors of patients with HF, the pressure of caregiving, depression, and health problems (1). In a study performed by Castro et al. on the comparison of sleep patterns of female caregivers and non-caregivers, despite the fact that the polysomnography results did not show any significant difference in the sleep patterns between the two groups, the caregivers perceived more sleep disturbances than non-caregivers (29). Although the present study did not examine the patients' clinical manifestations but regarding to the percentage of EF and also patients' FC III or IV, it can be argued that these patients have a broad spectrum of problems and symptoms of the disease and therefore they had suffer from anxiety/insomnia, social dysfunction and somatic symptoms in the process of managing different aspects of the disease in addition to dealing with other responsibilities. According to Grov et al., the level of anxiety in caregivers of patients with cancer was higher than that of norm data while the level of depression in the caregivers did not differ significantly from norm data. Moreover, the mean score of the mental health and social functioning (as domains of SF-36) of the caregivers was less than norm (28). In the present study, caregivers obtained the lowest score in the depression scale; that is, the caregivers had fewer problems with depression than with other dimensions of mental health. Similarly, in a study by Schwarz and Elman the caregivers of patients with HF had low levels of depression symptoms (mean score of 11.4 ± 8.8 , range: 3–46) and only 21% of the caregivers suffered from depression symptoms (30).

Comparison of GHQ-28 total scores of the

studied caregivers in different age groups of patients showed that with the increase in the patients' age, the caregivers obtained lower scores, that is, mental health problems decreased with the increase in the patients' age. Families expect an elderly to be sick. However, they hardly accept the sickness of a young family member with a progressive chronic disease such as HF. In other words, a caregiver's adjustment with the sickness of a young relative is much more complicated. Therefore, the impact of a younger person's disease on the caregiver's mental health is expected to be more than that of an elderly patient. Furthermore, acceptance of the disease for a young patient is much more difficult than for an older patient and consequently, younger patients need more support from their caregivers in order to adjust with HF, which is accompanied by a broad spectrum of symptoms and physical restrictions. In this respect, in comparison with the caregivers of the elderly patients who accept their condition more easily, the caregivers of younger patients are expected to be more influenced by the outcomes of caregiving and are exposed to more mental health problems.

This study is a primary investigation to estimate mental health status among caregivers of patients with HF, therefore it is recommended to conduct further studies to compare mental health status in caregivers of these patients and other chronic diseases. Also, further similar studies with larger sample sizes are suggested in order to examine the exact factors affecting the caregivers' mental health. In this study, the samples were collected only from one medical center; however, considering the fact that Shahid Rajaei Cardiovascular Center is a major referral cardiovascular hospital in Iran, it can be said that sample of present study may be representative. However, similar multi-center studies on caregivers of patients with other chronic diseases are suggested in order to compare the mental health of different groups of caregivers.

Based on the results of the present study, it can be concluded that the studied caregivers are among the groups exposed to the risk of mental disorders and therefore their mental health requires attention. The problem is even more serious in younger patients' caregivers. Considering

the fact that maintaining the health and promoting the quality of life of the patients with HF and their adherence to the treatment regimen depend on their caregivers' health, it is suggested that healthcare providers and treatment services to the patients with HF deliver services to these caregivers and take action toward identifying the caregivers exposed to the risks of mental disorders and refer them to available resources of support. Designing supporting interventional programs are also suggested for stress management, development of effective coping strategies and consequently, promotion of the caregivers' mental health by taking into account the dimensions related to the caregivers' mental health.

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