

The impact of family functioning and expressed emotion on caregiver burden

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ABSTRACT

Objectives. Expressed emotion and family functioning have been reported as negative impacts of the caregiver burden, mostly in mental disorders. There are limited data available to explain how these factors affect caregiver burden particularly for those caring for rehabilitation patients. In this study, the relationship of family functioning and expressed emotion with the caregiver burden was examined. **Methods.** A total of 103 caregivers with a mean age of 43.1 ± 13.8 years were participated in the study. The caregivers' demographic data, psychiatric symptomatology, subjective burden, expressed emotion, and family functioning were assessed using structured and semi-structured scales. **Results.** Expressed emotion level ($R^2=0.361$, $p<0.001$), family functioning ($R^2=0.275$, $p=0.003$) and caregiver gender ($R^2=0.361$, $p=0.004$) were determined as significant contributory factors with the subjective burden. **Conclusion.** Psychological intervention programs focused on both expressed emotion and communication skills in family should be developed to reduce the caregiver burden.

Eur Res J 2017;3(1):55-61

Keywords: Caregiver burden; expressed emotion; family functioning

Introduction

According to World Health Organization, disability is a general term for impairments, activity limitations and participation restrictions, and refers to the negative aspects of the interaction between an individual and that individual's contextual factors. Whether temporary or permanent, almost everyone may experience a disability during his or her lifetime. More than one billion people worldwide have a disability in various forms and degree, and of these,

nearly 200 million have severe functional difficulties [1].

Chronic diseases such as cardiovascular diseases (stroke and heart disease), mental illness, cancer, and respiratory diseases are the most common health conditions causing disability. It is expected that their prevalence rates will rise because of the ageing population, changing lifestyles related to tobacco, alcohol, diet, and physical activity [1-3]. Injuries such

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Received: May 30, 2016; Accepted: November 15, 2016; Published Online: December 3, 2016

as traffic accidents, occupational injuries, and violence are also recognized as contributors to disability. Traffic accidents, violence, and conflict have been reported to account for approximately 1.5% of all years lived with disability [2].

Due to changing global healthcare systems, hospital stays have become shorter, and physicians and nurses are in short supply, which has resulted in community-based care [3, 4]. Support and care at home for disabled people is provided by family members [5]. Many non-disabled family members take responsibility for supporting and caring for their relatives with disabilities as informal caregivers [6]. Caregiving is a labor-intensive occupation and requires direct support of the caregiver in various activities such as assisting daily activities, administering medications, providing transportation, preparing meals, managing finances, advocating for health care and providing emotional support for the patient [7]. Research on informal caregivers indicates that some of these caregivers experience an intense emotional and physical burden [8]. This burden may negatively affect both the caregivers' health and quality of life, which may result in mental health disorders.

Several family-related factors including family functioning and expressed emotion have the potential of negative physical and psychological impact on caregivers, which may lead to psychopathology in the caregiver [9]. Emotional over-involvement and having a critical or hostile attitude are considered to be the core components of the emotion construct and an index of the emotional climate between the patient and the caregiver [10].

There is an interaction between family members with disabilities and the qualities and functioning of the family. Transactional patterns among the subsystems are suggested to be important in understanding individual behavior and coping capacities [11]. It has been reported that poorer family functioning is associated with higher rates of caregiver burden [12].

The physical burden can be treated in a classical medical way, but emotional problems are generally intrinsic in nature. This means they are not easily diagnosed and may cause more pathological experiences as a consequence. In this study, it was aimed to address the relationship of family functioning and expressed emotion with the caregiver burden in a population of caregivers of rehabilitation patients. Furthermore, the impact of the caregiver burden on

psychiatric symptomatology and quality of life (QoL) was investigated.

Methods

Participants

Participants were recruited consecutively from a rehabilitation center between October 2012 and May 2013. A total of 125 family caregivers, older than 18 years, Turkish speaking, literate, and with no psychotic spectrum disorder were informed about the study. Informed consent was obtained from 122 caregivers were recruited and 113 completed the study (5 were discharged before completion of the study, 4 were lost to follow-up). Ethics Committee approved this study, which complied with all ethical requirements.

Procedure and Instruments

The demographic data of caregivers and patients were collected from the caregivers and medical records of the patients using a data collection form. The current and past medical histories of both caregivers and patients were also recorded on this form. The functional independence measure scores of the patients were calculated to measure the patients' current functional status severity, where higher scores indicate a greater level of independence [13]. Caregivers were asked how much time they spent caregiving and a measure of caregiving occupation rate was calculated by dividing the expressed amount of time by the total time of disability of their patient. The Zarit burden interview was used to assess the subjective burden of caregivers. It is a self-administered questionnaire containing 22 items including physical and psychological health, social participation, finances, and relationship with the patient. The participants rated each item on a 5-point Likert scale. Higher scores indicate a greater burden; 0-20 points: little or no burden, 21-40 points: mild to moderate burden, 41-60 points: moderate to severe burden, and 61-88 points: severe burden [14]. The Turkish version of the Zarit burden interview was used [15, 16].

Family functioning was assessed using the McMaster family assessment device. This has 60 items and seven subscales including problem solving, communication, family roles, emotional involvement, behavior control, emotional reactions, and general functioning. The participants rated each item on a 4-

point Likert scale. Higher scores indicate healthier family functioning [17]. The validated Turkish version of the original scale was used [18].

The expressed emotion scale was used to assess the caregivers' expressed emotion levels. It is a self-administered, 41 item true-false scale. In this study, the scale developed by Berksun [19] was used because of its simplicity and high reliability for the Turkish population [20].

The psychiatric evaluation of caregivers was performed in two steps. First, caregivers were interviewed for their possible psychiatric comorbidities with the help of the Structured Clinical Interview for DSM-IV (SCID-I) form, which was administered by the research psychiatrist [21]. Second, symptoms of anxiety and depression were evaluated using the Hamilton anxiety (HAM-A) and Hamilton depression scales (HAM-D). A research psychologist who was blind to the caregivers' diagnosis administered both the HAM-A and HAM-D to the participants.

The evaluation was completed in four sessions: acquiring demographic data, self-reporting scale administration, psychometric evaluation, and psychiatric evaluation sessions.

Statistical Analysis

Statistical analyses were performed using a commercially available statistical software package (SPSS for Windows, Version 16.0. Chicago, SPSS Ltd., 2007). Descriptive features were described as mean \pm standard deviation. Correlation coefficients and their significance were analyzed using the Pearson test. Possible factors identified in correlation analyses were further entered into the logistic regression analysis to determine independent predictors of the caregiver burden. Hosmer-Lemeshow goodness of fit statistics was used to assess the model fit. A 5% type-I error level was used ($p < 0.05$) to infer statistical significance.

Results

Demographic Features of Participants

A total of 113 caregivers completed the study. The mean age of the participants was 43.1 ± 13.8 years and 72.6% were female. The caregivers were mostly the mother (25.7%), spouse (20.4%) or daughter (16.8%) of the patient. Most caregivers had primary school education (38.9%) and were unemployed (73.5%).

The mean caregiving duration was 19.9 ± 35.3 months and caregiving occupation rate was found to be 86.9 ± 27.9 .

The mean age of the dependents of the caregivers was 40.8 ± 21.3 years, and 62.8% were male. The primary diagnosis of the patients fell into four major diagnostic groups; cerebrovascular accident (46%), spinal cord injury (23%), traumatic brain injury (46%) and cerebral palsy (11.5%). The overall functional severity of the patients was assessed using functional independence measure and the mean score was 69.4 ± 23.1 .

Family Functioning and Expressed Emotion

The expressed emotion level was assessed with the expressed emotion scale and revealed that the level experienced by the caregivers was 20.8 ± 4.2 . Family functioning was assessed with family assessment device in seven subcategories and presented in Table 1.

Subjective Burden

The caregiver's subjective burden was evaluated with Zarit burden interview and the mean level was found to be 35.7 ± 14.9 . Correlations between demographic factors, family functioning and expressed emotion levels with the subjective burden were examined. A correlation was determined between caregiver gender, occupation, number of hospitalizations, location of caregiving, caregiving occupation rate, expressed emotion level and family assessment device subcategories of communication, affective involvement, behavior control and general functioning. Expressed emotion level ($R^2 = 0.361$, $p < 0.001$), family assessment device general functioning ($R^2 = 0.275$, $p = 0.003$) and caregiver gender ($R^2 = 0.361$, $p = 0.004$) were determined to have a positive correlation with the subjective burden. Regression analysis showed expressed emotion, caregiver occupation, family assessment device communication subscale and caregiving occupation rate to be the most contributory factors to the subjective burden (Table 1).

Caregivers' Psychological Profile

A research psychiatrist who was blinded to the mental history interviewed the caregivers with the help of SCID-I and diagnosed co-morbid psychopathology using DSM-IV-TR diagnostic criteria. Twenty-five (22.1%) caregivers reported that they had a psychiatric diagnosis before they began caregiving. The

Table 1. Correlations of selected demographic factors, subjective burden, expressed emotion and family functioning domains on caregivers' anxiety and depression symptomology parameters

	ZCBI	HAM-A	HAM-D
Caregiver gender	.271**	.379**	.372**
Caregiver occupation	-.244**	-.252**	-.271**
Hospitalizations	.190*	.370**	.363**
Hospitalization site	.233*	.278**	.338**
COR	.269**	.237*	.222*
Expressed emotion	.361**	.287**	.208*
FAD problem solving	0.137	0.183	0.113
FAD communication	.229*	.331**	.264**
FAD roles	0.13	.196*	0.115
FAD affective responsiveness	0.144	.201*	0.112
FAD affective involvement	.213*	0.121	0.038
FAD behavior control	.194*	.252**	0.139
FAD general functioning	.275**	.365**	.219*
ZBI	1	.500**	.592**

ZBI=Zarit burden interview, HAM-A=Hamilton anxiety scale, HAM-D=Hamilton depression scale, FAD=family assessment device, COR=caregiving occupation rate, * Correlation is significant at the 0.05 level (2-tailed), ** Correlation is significant at the 0.01 level (2-tailed).

prevalence rates of reported previous psychiatric disorders were 15%, 4.4%, 3.5% for anxiety disorder, depressive disorder, and panic disorder, respectively. The diagnostic interview according to SCID-I revealed that 51.8% of the caregivers had at least one psychiatric disorder. The most common psychiatric disorders were anxiety disorder (n=20), obsessive-compulsive disorder (n=18), post-traumatic stress disorder (n=15), panic disorder (n=12), and depressive disorder (n=6), respectively.

The psychometric scores of the caregivers were 9.94 ± 7.68 and 7.58 ± 5.82 for HAM-A, and HAM-D, respectively. The correlation between the caregiver burden and psychometric symptomatology and calculated correlation coefficient was 0.500 for HAM-A, and 0.592 for HAM-D ($p < 0.001$).

Discussion

Providing care for a disabled family member at an out-of-hospital setting is being promoted by current healthcare policies. Family members are the most common source of care provider (informal caregivers) for the disabled. Female family members are more often engaged as informal caregivers, which may be a result of their social role to nurture [22]. Furthermore, our sample showed that caregivers are mostly under-educated and unemployed. An investigation into the

relationship between gender, education, occupational status, and acting as a caregiver may provide more information on the causality of being an informal caregiver.

The expressed emotion effect on the caregiver burden has been investigated mostly in mental and behavioral disorder studies [23]. The current study is one of the few studies investigating the expressed emotion effect on the caregiver burden and, as a consequence, psychiatric symptomatology and quality of life. Expressed emotion is the most contributory factor among family functioning and other demographic factors.

The impact of the emotional environment between patient and caregiver, which is reflected by expressed emotion, may vary depending upon the nature of the disorder [23]. However, no such variance was found regarding the patient diagnosis and severity of the disease. This finding suggests that expressed emotion is more likely to be related to the caregiver's personal traits. The findings of this current study support the evidence that high- and low- expressed emotion relatives may differ in the beliefs they hold about problems associated with the patient's illness [24].

The characteristic style of high-expressed emotion family members is that they are prone to be intolerant of their dependent's problems, intrusive, and use inappropriate strategies to deal with difficulties [25]. Greenley [26] reported that high expressed emotion is

associated with family members being more fearful and anxious. It has been suggested that relatives high in emotional over-involvement would be especially unlikely to blame patients for their disturbed behavior, instead viewing the patient as an unfortunate victim of a severe illness [27]. Also, emotionally over-involved relatives have made sense of the illness in terms of factors that are outside the patient's control. Therefore, high emotional over-involvement relatives attempt to ameliorate events by using themselves as a buffer between the patient and the outside world and, through their self-sacrifice and intrusive behavior, try to control events and people [28].

Published expressed emotion studies support the importance of family intervention programs for relatives of patients with schizophrenia. Relapse rates for patients with schizophrenia in high expressed emotion families was reported to be significantly reduced when family treatments are focused on reducing some aspects of high-expressed emotion behavior [29].

Several studies investigating the family functioning effect on the caregiver burden have reported that poor family functioning is related to higher levels of caregiver burden, particularly disturbances in roles and communication [12]. Communication is the exchange of information within the family. The finding of the current study of disturbances in communication among family members is correlated to previously published studies and adds new information on how family functioning may influence the caregiver burden in correlation with expressed emotion.

Associations between high expressed emotion and some chronic medical conditions have been reported [30], although to the best of our knowledge no data are available about caregivers of rehabilitation patients.

There are a limited number of studies using clinical psychiatric evaluation including diagnostic interviews, the caregiver burden has been proposed as a risk factor increasing the prevalence of psychiatric disorders along with psychiatric symptomatology [31]. In the current study, it was determined from the diagnostic interview that nearly half of the caregivers had at least one psychiatric disorder, and 12.6% had more than one psychiatric disorder. Post-traumatic stress disorder was the most remarkable diagnosis with a substantial prevalence rate of 13.4% among caregivers. In a recent meta-analysis, symptom prevalence rates of post-traumatic stress disorder were

reported as 21% (13%-56%) and 35% in relatives of children and adult patients, respectively [32]. Prevalence rates of post-traumatic stress disorder have been reported as 7.7% and 40% in different populations [33, 34]. Variance in reported rates may be due to the study settings or study designs that use self-reporting psychometric tests, which could be limited in the ability to differentiate psychiatric diagnoses.

Although it was not the aim of this study to determine the impact of demographic factors on the subjective burden, the results showed that the caregiver occupation and caregiving occupation rate have a substantial impact on the subjective burden. This finding suggests that the caregiver's participation in activities other than caregiving may help to reduce the caregiver burden.

Several interventional programs have been developed to reduce the caregiver burden and increase quality of life in different populations. However, the effectiveness of these programs has been found to be beyond the expectations [35].

The Limitations of the Study

Even our study expands the knowledge for the contributory factors associated with caregiver burden of the rehabilitation patients by utilizing clinician administered psychometric tests. But contradictory, we couldn't assess the contributing personality factors associated with the caregiver burden and expressed emotion levels. Association of personality types with caregiver burden needs to be addressed in further studies.

The factors, which may be associated with expressed emotion and family functioning domains such as personality traits of the caregiver or the caregiver's past experiences including having been cared for at some time in their life, were not examined in this study. These limitations may lead further studies to help understand the contributory factors to expressed emotion and family functioning. Thus, more specific interventional programs for caregivers could be developed.

Conclusions

In an era of out-of-hospital care, these findings suggest that interventions focusing on reducing the caregiver's emotional over-involvement or critical/hostile manner to improve family functioning

should be incorporated into family education programs aimed at reducing the caregiver burden. Such a reduction in caregiver burden may decrease psychiatric symptomatology and improve quality of life for caregivers.

Conflict of interest

The authors disclosed no conflict of interest during the preparation or publication of this manuscript.

Financing

The authors disclosed that they did not receive any grant during conduction or writing of this study.

Acknowledgement

The study was presented as an oral presentation at 30th Pacific Rim International Conference on Disability and Diversity, Honolulu, Hawaii, USA on May 19 & 20, 2014.

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