

Burden Experienced by Family Caregivers of Patients with Mental Disorders

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Family caregivers are regarded as backbones of the health care system. This descriptive-analytic research was carried out on a randomized sample of 125 family caregiver in Zahedan Mental Health Center. The data was collected using the Zarit Burden Inventory (ZBI; Zarit, Todd, & Zarit, 1986). 73.6% of family caregivers in this study experienced a moderate to severe level of burden. The study concludes that, professional interventions should be offered especially to those caregivers of patients with mental disorders who experienced moderate to severe level of burden.

Keywords: burden; caregiver; mental disorders.

Over the past two decades, the deinstitutionalization movement has shifted the primary locus of care from psychiatric hospitals to community mental health centers. However, the funds for professional community resources have been limited and families of the seriously mentally ill have been asked to take increasing responsibility for practical help and emotional support for patients living in the community (Gutierrez, Urizar, & Kavanagh, 2005). In Iran, this process has been particularly rapid. It has been estimated that approximately 50% of patients with schizophrenia discharged from psychiatric hospitals return to live with family members.

The burden on people caring for a family member with mental illness is considerable. The families must sometimes cope with the stress of the patient's disruptive symptoms, changes in household routines, strained social relations within the family, loss of social support, diminishing opportunities for leisure, and deteriorating finances. Furthermore, family members often have mixed feelings such as sorrow, worry, anger, guilt, and shame. All these burdens severely tax the family member's coping and adjustment abilities and

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the strain frequently results in anxiety, guilt, and depression (Stengard, 2002).

In the family that one of the members gets hurt, personal needs may be changed into increasing needs to the family time and sources (Loukissa, 1995) and may have terrible effects on the family (Stengard, 2002). Family members, spouses and partners, and friends of patients are obviously impacted by a patient's illness. While these important persons spend far more time with patients than either physicians or the mental health professionals who provide care, family members are frequently, albeit unintentionally, left out as important players in the care and management of persons who are chronically ill. Such a patient puts all other members in a sorrowful condition (Milanifar, 2004). When a person gets a serious mental or physical illness, other members of the family show different reactions. The signs and symptoms of these reactions are differentially manifested in behaviors of each member. These signs include: emotional disturbance, confusion, anger, helplessness, impatience, crying, stupor and eating and sleep disturbance (Asadollahi & Abbasalizadeh, 1998; Sullivan, 2002). Caregiver burden is a three-dimensional concept. It reflects the impact of care giving on interpersonal relationships, expression of caregiver anxiety, and the personal impact of the caregiver role (Browing & Schwirian, 1994). Jenkins and Schumacher (1999) state that caregiver burden is mostly assessed in three domains:

1. The patients' behavioral problems (e.g. irritability, violence, and unpredictability).
2. Patients' social role dysfunction at work and at home.
3. Adverse effects on others (e.g. the impact of the illness on others work and leisure time).

A study on sixty family caregivers was conducted by Karanci in 2004. In this study, the most frequently reported difficulties were family conflicts and disruptions of family life (57%), subjective burden (48%) and financial costs due to the patient (27%). Another study was done by Ostwald in 1997. In this study, caregiver exhaustion was found to be predicted by three factors: lack of personal time, employment in a job outside the home, and frequent behavioral problems in the care recipient. The findings showed that 56.4% of them suffered from psychological burden.

Family caregivers suffer a high burden because of exposure to dangers and illness (Maurine & Barmann, 1990) and members of the psychiatric team can help these vulnerable people by playing the role of a teacher and providing psychological and emotional cares

(Doornbos, 1997). Family therapy can help the relatives of the patient to change their attitude toward the disorder and behaviors and this can reduce the stress and burden experienced by caregivers (Watson, Modeste, Catolico, et al., 1998). The ways in which families deal with the process of the illness has been reported to vary significantly among ethnic groups, SES categories, gender, position of family members, and the stage of the illness. Most studies of family burden in mental disorders have taken place in developed countries. There are an increasing number of young caregivers in Iran. However, little research has been devoted to the identification and understanding of this phenomenon among Iranians.

Method

Sample

This is a descriptive- analytic study which was done on 125 family caregivers that their relative patients referred to the only Mental Health Center and Hospital in Sistan (Iran) and Balochistan (Pakistan).

Instrument

The data was collected through interviews in the form of a questionnaire by the researcher. The questionnaire was developed based on Zarit Burden Inventory (ZBI) and was translated and modified based on Iranian cultural standards. Its reliability was calculated by test-retest method ($r = .94$).

The ZBI is a widely used 22-item assessment tool for measuring caregiver's perceived burden of providing family care. It asks family caregivers about areas that may cause stress and strain such as physical, psychological, economic, and relational problems. Items are answered on a five-point scale ranging from 0 = *Never* to 4 = *Always*. Scores are added to give the total score which ranges from 0 to 88, with higher scores implying greater perceived caregiver burden. Zarit, Todd, and Zarit (1986) originally proposed severe burden at scores in the range of 61 to 88, moderate to severe burden at 41 to 60, mild to moderate burden at 21 to 40, and little or no burden at less than 21. The psychometric properties of the ZBI include an acceptable inter-item reliability and convergent validity, indicated by a Cronbach's alpha of .79 and a correlation coefficient of .71 between caregiver's global evaluation and ZBI scores. A test-retest reliability of .71 and internal consistency (Cronbach's alpha = .91) also have been reported

(Lopelowicz, Zarate, Smith, Mintz, & Liberman, 2003; Smith & Schwirian, 1998; Zarit, Todd, & Zarit, 1986).

Procedure

The sample was selected using simple sampling method and then were studied. The sampling criteria specified that no patient with organic problems and addiction was selected. It was made sure that data was collected from patients having had the illness for at least 6 months. A caregiver is one who is a member of the family and has the most frequent contact with the patients, helps to supports the patient financially, has most frequently been collateral in the patients' treatment and with the age of at least 15 years who was able to make a good communication.

Results

The findings about personal characteristics of family caregivers showed that the average age was 38.38 years ($SD = 12.8$) and 28.8% of caregivers were patients' parents, 20.8% spouses, 16% children, 34.4% were siblings. 80% of them were married, and 50.4% were housewives. The results about patients revealed that the average age of them was 35.52 years ($SD = 12.6$), and most of them (66.4%) were males. Table 1 summarizes additional socio-demographic data from patients and caregivers.

The findings also showed that 18.4% of patients had had the illness for two years or less time, 30.4% between two to six years, and 51.2% had been ill for 6 years and more, 47.2% could do their daily activities independently, 43.2% needed help, and 9.6% were completely dependent on their caregivers.

With regard to the main purpose of the study, the results showed that 26.4% of caregivers suffered from a mild level of burden, 60.8% had moderate burden and 12.8% had high burdens. With regard to the age of the patients and caregiver burden, the results showed that caregivers of 20 year-old patients or younger had no high level burdens. 44.2% of caregivers of 21-35year-old patients were suffering from moderate burden, 12.3% were suffering from a severe level of burden. Caregivers of 36 year-old patients or higher 68.2% had moderate burden and 18.2 % of them experienced high burdens.

Table 1

Clinical and Socio-Demographic Characteristics of Patients and their Caregivers (N=125)

| | Patients (n = 125) | | Caregivers (n = 125) | |
|--------------------------------|------------------------|------|--------------------------|------|
| | <i>f</i> | % | <i>f</i> | % |
| <i>Gender</i> | | | | |
| Male | 83 | 66.4 | 59 | 47.2 |
| Female | 42 | 33.6 | 66 | 52.8 |
| <i>Age</i> | | | | |
| < 20 years | 4 | 3.2 | 16 | 12.8 |
| 21-35 years | 74 | 59.2 | 65 | 52.0 |
| > 36 years | 47 | 37.6 | 44 | 35.2 |
| <i>Civil Status</i> | | | | |
| Married | 58 | 46.4 | 100 | 80 |
| Single | 55 | 44 | 15 | 12 |
| Widow- Divorced | 12 | 9.6 | 10 | 8 |
| <i>Educational Background</i> | | | | |
| No studies/illiterate | 56 | 44.8 | 67 | 53.6 |
| primary education | 33 | 26.4 | 27 | 21.6 |
| Higher education or more | 36 | 28.8 | 31 | 24.8 |
| <i>Occupational Status</i> | | | | |
| Housekeeper | 37 | 29.6 | 63 | 50.4 |
| Employee | 10 | 8 | 11 | 8.8 |
| Unemployed | 41 | 32.8 | 8 | 6.4 |
| Farmer & Rancher | 25 | 20 | 12 | 9.6 |
| Business & other jobs | 12 | 9.6 | 31 | 24.8 |
| <i>Diagnosis (of patients)</i> | | | | |
| Schizophrenia & Psychotics | 65 | 52 | - | - |
| Mood Disorders | 54 | 43.2 | - | - |
| Other Mental Disorders | 6 | 4.8 | - | - |

Those with high level burdens were mostly females (75%). The mean burden for single caregivers was the least (38) and for married caregivers (43.7) and those who had got divorced had the highest burdens (45.3). The average burden of caregivers of patients with

schizophrenia and other psychotic disorders was (42.30) which was more than caregivers of patients with mood disorders (40.62).

Caregivers of patients whose illness duration lasted 2 years or less showed an average burden of 41.86, ranging from 38.97 with 2-to-6 year illness duration to 42.65 with longer illness duration. Caregivers of completely dependent patients showed the highest burdens (57.83). Caregivers of patients who needed help experienced the burden of 39 and caregivers of independent patients experienced the burden of 40.32. 75% of caregivers who suffered from high burden were family caregivers of male patients. The burden experienced by caregivers of male patients was reported to be 49.02 which were more than the burden experienced by caregivers of female patients (38.15).

Table 2

One Way Analysis of Variance of Caregivers' Burden & the Rate of Daily Activities of the Patients (N=125)

| Source | SS | df | MS | F | Eta | Power |
|--------|--------|-----|-------|--------|-----|-------|
| Group | 46.22 | 2 | 23.11 | 15.10* | .39 | .72 |
| Error | 186.70 | 122 | 1.53 | | | |
| Total | 232.92 | 124 | | | | |

df = 124; * $p < .05$

Based on the results of variance analysis (one-way ANOVA) represented in Table 2, the average of caregivers' burden has a relationship with the rate of daily activities done by the patients. Post hoc analysis showed that there is a significant difference between the mean of the burden experienced by caregivers of totally dependent patients and the mean of the burden experienced by caregivers of independent patients ($t = 11.95$, $p < .05$) and between the mean of the burden experienced by caregivers of totally dependent patients and caregivers of patients who need help ($t = 5.6$, $p < .05$).

The findings showed that the older the patients were, the more the level of the moderate and severe burdens in caregivers. The results of the chi-square test showed that this relation is meaningful ($\chi^2 = 9.59$, $p < .05$). This relation can be explained in the way that the long duration of the illness and chronic disorders and subsequently higher age can increase burdens in caregivers. The findings also

showed that taking care of male patients causes more burdens in family caregivers. The results of chi-square test revealed that this relation is statistically meaningful ($\chi^2=5.90$, $p<.05$). Kaplan argues that male patients experienced deterioration and regressions of the illness more than women (Asadollahi & Abbasalizadeh, 1998). For this reason, taking care of male patients is more stressful to caregivers because of the patients' psychosocial and moral problems.

Discussion

The results showed that most caregivers were housewives. In Iranian culture, it is women's or girls', who are unemployed or drop out school, responsibility to look after children, patients, and elderly and disabled people in the family and it is a part of their household chores. Westerns studies also showed that women and girls are usually the main caregivers at home and most of them are women with the age of lower than 60 years and for elderly mostly their wives or daughters are primary caregivers (Lopelowicz et al., 2003; Smith & Schwirian, 1998). It is assumed that most of caregivers were married who have a more economic safety and showed a sense of responsibility more than single caregivers. With regard to the main goal of the study, it can be said that most of family caregivers suffer from moderate to high burdens (73.6%) and only 26.4% showed a mild level burden. Jenkins and Schumacher (1999) argue that burdens experienced by the relatives of mentally ill patients are considerable. The results of the study by Perlic, Clarkin, Sirey, et al., (1999) revealed that there is moderate to high burden caused by the signs and symptoms of the illness in 91%, caused by dysfunction in 75% and caused by the adverse effects on others' lives in 82% of the family caregivers. Fadden, Bebbington, and Kuipers (1987) carried out a research on burdens experienced by caregivers of schizophrenia patients. They found that 55% to 76% of these caregivers experienced burdens (Perlic, Clarkin, Sirey, et al.). Therefore, the average mean of the burdens experienced by family caregivers in Iran is not very different from other countries. Apart from where the research is carried out, all findings show that a mentally ill person can impose a considerable burden on other members of the family especially on family caregivers (Maurine & Barmann, 1990).

Most of caregivers experiencing high level of burden were females and the findings showed that the average burdens experienced by women (43.47, $SD=17.4$) was more than those of men (39.06, $SD=14.84$). However, considering the results of the statistical *t*-test showed that the difference is not meaningful. Studies support sex differences in the level

of burden experienced by the caregivers, that is, females usually get more stressed than males and females experience more burden because they are mainly the primary caregivers and on the other hand, having children, social status of women and special stresses of women bear more burden on them (Maurine & Barmann, 1990). Married caregivers get more burden than single ones. Baker (1997) believes that ordinary life activities, job, and various functions (to be the wife, parent, etc.) increase these burdens.

With regard to the duration of the illness and the times of hospitalization, the findings showed that caregivers of patients with a longer duration of illness and more times frequent times of hospitalization experienced more burdens than others. However, this difference was not statistically meaningful based on the results of chi-square test. Studies show that the duration of care giving has an impact on the experienced (Baker, 1997). When someone confronts tensions for a long time to adapt to new situations, he/she consumes a lot of energy, so the stored energy may not be sufficient for his /her needs and he/she is very probable to get a mental imbalance (Stengard, 2002). Therefore, chronic and recurrent illnesses and frequent hospitalization can harass the family and caregivers.

The findings by other researchers also confirm that there is an adverse correlation between the ability of patients to do their daily activities and their self-care and the level of the burden experienced by the caregivers, that is, the less the patients are able to look after themselves, the more their caregivers experience burdens (Baker, 1997). Many of the problems and struggles between patients and their families is caused by patients' disability to do their daily activities (Asadollahi & Abbasalizadeh, 1998). The findings of one-way ANOVA showed that there was not a meaningful correlation between the kind of the mental disorders and the level of the burdens experienced by caregivers. However, the average level of the burdens experienced by caregivers of patients with schizophrenia and other psychotic disorders (42.30) was more than that of caregivers for patients with mood disorders and other psychiatric disorders (40.40). The reason may be the lower dysfunction and more regression in the patients with schizophrenia. The study by Perlic, Clarkin, Sirey, et al. revealed that if factors related to demographic characteristics and socio-economic class are controlled, a meaningful difference cannot be found in the level of the burden experienced by caregivers in the two main groups of the mental disorders (psychotic disorders and mood disorders). The level of anxiety of caregivers is correlated with the symptom and signs of the disorder and kind of the behavioral disturbances more than the kind of psychiatric diagnosis.

We can generally conclude that anxiety and different emotional, psychological, social and economic pressures on the members of the family and especially on the main family caregiver is certain. So, these burdens can reduce the quality of care giving and can also endanger the mental and physical health of the caregiver. Therefore, to reduce the rate of such burdens, some interventions including home visit, education, family therapy and group therapy seem necessary to be applied so that the quality of care giving gets better and the physical and mental health of care givers as hidden patients improves.

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