

Burden and coping strategies in caregivers of schizophrenic patients

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Abstract: Care of schizophrenic patients is an enduring stress and leads to considerable amount of burden among caregivers. Little is known about the ways in which families cope while caring for a relative with schizophrenia in developing countries. The aim of the present study was to explore burden and coping strategies in caregivers of schizophrenic patients and identify the relationship between burden and coping strategies among them. Caregivers were assessed by utilizing caregiver burden self report and ways of coping questionnaires. A descriptive correlational design was used for the study. The sample comprised of 100 caregivers of schizophrenic patients from psychiatric inpatient and the outpatient clinic of Neuropsychiatry Department at Assiut University Hospital. The result revealed that level of burden reported by caregivers of schizophrenic patients was high. The most coping strategies used by caregivers of schizophrenic patients were self controlling, positive reappraisal and escape-avoidance. Burden was negatively and non significantly correlated with confrontive coping, distancing, seeking social support and positive reappraisal coping strategies. However, it was positively and non significantly correlated with self controlling, accepting responsibility, escape- avoidance and planful problem solving. Sociodemographic variables were not associated significantly with burden and coping strategies. It is concluded that: Caregivers experienced high level of burden. Burden was none significantly correlated with coping strategies. Recommendation: Psycho educational program is needed to assist caregivers cope successfully with burden resulting from the care of schizophrenic patients.

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Key words: schizophrenia; caregivers; Sociodemographic.

1. Introduction:

Caregiver burden refers to the negative feelings and subsequent strain experienced as a result of caring for a chronically sick person (Natalie et al., 2003).

Schizophrenia is a severe mental illness, which is stressful not only for the patients, but also for family members. Numerous studies have demonstrated that family caregivers of persons with severe mental illness suffer from significant stress, experience moderately high levels of burden and often receive inadequate assistance from mental health professionals (Saunders, 2003). In the same respect, Seltzer et al., 1997 stated that-care for severely mentally ill individuals, particularly in the community, may carry a heavy burden, more so than care of other disabled individuals such as mentally retarded people. Such burden manifests in reduced caregiver well being (Jungbauer & Angermeyer, 2002). Hence caregiver burden, particularly that of closely involved family members such as parents, is important as an outcome measure in mental health care, so as to assess and reduce it for the well- being of both caregivers and mentally ill. Indeed, the measurement of caregiver burden has been shown to enhance worker and administrator awareness of the need to reduce such

burden in the health care field in general (Guberman et al, 2003).

Similarly, Gutierrez-Maldonado et al., 2005 and Bandeira et al., 2006 stated that de-institutionalization of psychiatric patients has led to a greater emphasis on family management in the community and family members are often overwhelmed by the demands that caring for a patient with schizophrenia involves. Most studies of family burden in schizophrenia have taken place in developed countries. However, they examined family burden and its correlates in a regional area of a medium income country in South America and they found that the average levels of burden were very high, particularly for mothers, carers with less education, carers of younger patients and carers of patients with more hospitalizations in the previous 3 years. Also, Shibre et al., 2003 postulated that, studies have consistently shown that both the subjective and objective dimensions of burden among family members of schizophrenia patients and other psychiatric disorders are prevalent. However, as most of these reports were from western societies, we lack information on the subject in developing countries.

Scazufca and Kuipers, 1999 concluded that ways of coping are influenced by relatives' perceptions of the situation with patients.

Avoidance strategies seem to be less effective in regulating the distress of caregivers than problem-focused strategies. On the other hand, Johnson in 2000 found passive coping styles associated with a high level of burden, and problem solving coping styles related to lower levels of burden in caregivers. The results of Lakiska, et al., 2000 showed that caregivers used emotional and practical strategies to cope with participant's negative symptoms and difficult behaviors and experienced more worries about these problems.

Significance of study:

Magliano et al., in 2000 stated that only few data are available on how family burden in schizophrenia changes over time. In addition, no study has explored how such factors as coping styles and social support influence burden over time. Similarly, Chandrasekaran et al., in 2000 stated that, little is known about the ways in which families cope while caring for a relative with schizophrenia in developing countries. Perhaps if professional nurses and other health team members explored how much caregivers of schizophrenic patients burdened and how they cope with this burden, this could be a useful way of generating information that can guide management strategies.

Aim of the study:

1. To explore burden and coping strategies in caregivers of schizophrenic patients.
2. To identify the relationship between burden and coping strategies in caregivers of schizophrenic patients.

2. Subjects and Methods

Research Design: A descriptive correlational design was used on the study.

Setting: This study was conducted at the in-patient unit of Psychiatry and the outpatient clinic of Neuropsychiatry at Assiut University Hospital.

Subjects: The subjects of this study consisted of 100 caregivers of schizophrenic patients from psychiatric inpatient unit and the outpatient clinic of Neuropsychiatry at Assiut University Hospital.

Tools of the study:

1. Caregiver burden self report questionnaire:

It will be used to assess caregiver burden. It was developed by Rudnick and Otsma representatives in 2003. The questions are conceptualized as belonging either to practical burden or to emotional burden, according to an established framework of practical vs. emotional needs, as utilized in health care in general and in mental health care in particular. The final form of the questionnaire consists of 27 items, of

which the first 12 address practical burden, the next 13 address emotional burden, and the last 2 address total burden and burden in the last month relative to the last year. All questions are rated on a 4-point ordinal scale, ranging from 1 (no) to 4 (very much).

2. Ways of coping questionnaire (revised form):

It will be used to assess caregivers coping strategies. It was developed by Folkman et al in 1986. It consists of 66 items. These items are classified into 8 coping subscales as the following: Confrontive coping, distancing, self-controlling, seeking social support, accept responsibility, escape-avoidance, planful problem-solving and positive reappraisal. The subjects responds on a 4-point Likert scale (0 = does not apply and/or not used; 3 = used a great deal).

The previous questionnaires were translated into Arabic language to suit caregivers' culture and revised by the researchers to ensure that they give the same meaning of the original ones.

Statistical measures:

The following statistical measures were used:

- a) Descriptive measures included: count, percentage, arithmetic mean and standard deviation.
- b) Statistical tests included: Unpaired T-test, used to compare two independent means. One way analysis of variance (ANOVA) test used to compare means of more than two groups. Pearson correlation coefficient (r) was used to study correlation between quantitative variables. The level of significance selected for this study was p equal to, or less than 0.05.

3. Results

Table (1) shows socio-demographic characteristics of the caregivers of schizophrenic patients. The mean age of the studied caregivers was 33.6 ± 11.6 (17 – 60 years), 25.0% of them were males and 75.0% of were females, 59.0% were from rural areas. 50.0% were single and 35.0% and were married. 62.0% of them were illiterate- read & write. In relation to consanguinity, it was noticed that 77.0% were from first degree relatives. In addition, it was found that 67.0% were housewives.

Distribution of the means and standard deviations of burden questionnaire scores among caregivers of schizophrenic patients was illustrated in table (2). It was found that the mean score of burden of being busy to care for their mentally ill family members was 3.66 ± 0.77 followed by burden of being sad and worried related to their mentally ill family members mean \pm SD was 3.54 ± 0.92 and then burden of investing time, physical effort in caring for their mentally ill family members and spending money on them mean \pm SD was $(3.49 \pm$

0.86, 3.47 ± 0.89 and 3.35 ± 0.89) respectively. In addition, the total mean score of burden among them was 77.16 ± 15.91 and this indicates that they were suffering from high level of burden.

Table (3) reveals the total mean scores of each subscale (factor) of coping strategies among caregivers of schizophrenic patients. It was found that, the mean \pm SD of self controlling as coping strategies was 10.01 ± 3.39 followed by positive reappraisal and escape-avoidance; the mean \pm SD was 9.29 ± 3.96 and 9.22 ± 3.10 respectively.

The relation between socio- demographic characteristics and burden among caregivers of schizophrenic patients revealed no statistical significant association (Table 4).

Concerning the relation between socio demographic characteristics and coping strategies among caregivers of schizophrenic patients, it was found that, the mean score of coping strategies was slightly higher among younger age groups, male, divorced/ widow, educated caregivers and those of urban areas. There were no statistical significant association between socio- demographic characteristics and coping strategies among

caregivers of schizophrenic patients as shown in table (5).

Table (6) illustrates the relation between burden and coping strategies among caregivers of schizophrenic patients. It was found that burden was negatively and non significantly correlated with confrontive coping, distancing, seeking social support and positive reappraisal coping strategies ($r = -0.126, -0.066, -0.013$ and -0.190 with p -value = $0.211, 0.517, 0.897,$ and 0.059) respectively. However, it was positively and non significantly correlated with self controlling, accepting responsibility, escape- avoidance and Planful problem solving ($r = 0.158, 0.129, 0.087$ and 0.010 with p - value= $0.116, 0.201, 0.391$ and 0.924) respectively.

Figures 1& 2 demonstrate correlation between age and self controlling as well as escape-avoidance as coping strategies. It is clear from these figures that the age was negatively and significantly correlated with both self controlling ($r = -0.276$ at $P = 0.006^*$) and escape- avoidance ($r = -0.233$ at $P = 0.020^*$). This indicates that the older caregivers use minimum self controlling and avoidance coping strategies.

Table (1): Distribution of sociodemographic data of the caregivers of schizophrenic patients

Variables	No. (n= 100)	%
Age:		
< 30 years	47	47.0
\geq 30 years	53	53.0
Mean \pm S D (Range)	33.6 ± 11.6 (17 – 60)	
Sex:		
Males	25	25.0
Females	75	75.0
Residence:		
Urban	41	41.0
Rural	59	59.0
Marital status:		
Single	50	50.0
Married	35	35.0
Divorced/ widow	15	15.0
Education:		
Illiterate/ read & write	62	62.0
Basic education	10	10.0
Secondary education	25	25.0
University	3	3.0
Consanguinity:		
First degree	77	77.0
Second degree	8	8.0
Others	15	15.0
Work:		
Housewife	67	67.0
Employed	5	5.0
Farmer	4	4.0
Others	4	4.0
Unemployed	20	20.0

Table (2): Distribution of the means and standard deviations of burden questionnaire scores among caregivers of schizophrenic patients

Variable items	Mean \pm SD
I invest time in my mentally ill family member (MIFM)*	3.49 \pm 0.86
I spend money on my MIFM	3.35 \pm 0.89
I invest physical effort in caring for my MIFM	3.47 \pm 0.89
I am busy caring for my MIFM	3.66 \pm 0.77
I am ill due to caring for my MIFM	2.86 \pm 1.32
I am in danger due to caring for my MIFM	2.30 \pm 1.34
I lack privacy due to caring for my MIFM	2.83 \pm 1.26
I lose work time due to caring for my MIFM	3.01 \pm 0.85
My leisure activities are reduced due to caring for my MIFM	3.07 \pm 1.06
I lack rest due to caring for my MIFM	3.24 \pm 1.08
I lack company due to caring for my MIFM	2.98 \pm 1.16
My plans are inhibited due to caring for my MIFM	2.87 \pm 1.19
I lack assistance in caring for my MIFM	2.97 \pm 1.13
I cannot share with others my concerns regarding my MIFM	2.70 \pm 1.19
I am angry about the care of my MIFM	1.53 \pm 0.95
I am desperate, related to my MIFM	1.81 \pm 1.10
I am ashamed, related to my MIFM	2.51 \pm 1.37
I am sad, related to my MIFM	3.54 \pm 0.92
I am worried, related to my MIFM	3.54 \pm 0.92
I am humiliated, related to my MIFM	2.76 \pm 1.35
I am exhausted, related to my MIFM	3.03 \pm 1.25
I am frightened, related to my MIFM	3.12 \pm 1.18
I feel guilty, related to my MIFM	1.66 \pm 1.07
I feel exploited, related to the care of my MIFM	1.40 \pm 0.90
I feel misunderstood, related to my MIFM	3.04 \pm 1.08
I generally suffer from burden, related to my MIFM	3.18 \pm 1.11
I suffered such burden the last month relative to the last year	3.24 \pm 1.14
Total mean score of burden scale (total score= 108)	77.16 \pm 15.91

* MIFM: Mentally Ill Family Member

Table (3): The total means scores of each subscale (factor) of coping strategies among caregivers of schizophrenic patients

Factors of coping strategies	Score	Mean \pm SD	Range
Confrontive coping	18	6.29 \pm 2.40	1 – 13
Distancing	18	7.54 \pm 2.98	2 – 16
Self controlling	21	10.01 \pm 3.39	3 – 17
Seeking social support	18	6.11 \pm 3.48	0 – 14
Accepting responsibility	12	3.59 \pm 1.69	0 – 10
Escape- Avoidance	24	9.22 \pm 3.10	0 – 16
Planful problem solving	18	5.14 \pm 2.87	0 – 13
Positive reappraisal	21	9.29 \pm 3.96	1 – 21

Table (4): The relation between socio- demographic characteristics and burden among caregivers of schizophrenic patients

	Mean \pm SD	Range	P-value
Age: (years)			
< 30 years	79.5 \pm 15.2	41 – 100	0.161
\geq 30 years	75.1 \pm 16.4	33 – 97	
Sex:			
Male	77.4 \pm 16.6	37 – 98	0.931
Female	77.1 \pm 15.8	33 – 100	
Marital status:^o			
Single	79.4 \pm 15.1	41 – 98	0.380
Married	75.3 \pm 17.0	33 – 100	
Divorced/ widow	74.3 \pm 16.0	48 – 94	
Education:			
Illiterate/ read & write	76.8 \pm 16.7	33 – 100	0.778
Educated	77.7 \pm 14.7	37 – 98	
Residence:			
Urban	79.0 \pm 14.7	37 – 97	0.325
Rural	75.8 \pm 16.7	33 – 100	

Unpaired T-test

^oANOVA**Table (5): Relation between socio- demographic characteristics and coping strategies among caregivers of schizophrenic patients**

	Mean \pm SD	Range	P-value
Age: (years)			
< 30 years	58.3 \pm 12.0	32 – 93	0.386
\geq 30 years	56.2 \pm 12.0	24 – 81	
Sex:			
Male	58.3 \pm 10.5	37 – 80	0.602
Female	56.8 \pm 12.5	24 – 93	
Marital status:^o			
Single	58.2 \pm 11.7	32 – 93	0.272
Married	54.7 \pm 12.2	24 – 85	
Divorced/ widow	59.8 \pm 11.9	44 – 81	
Education:			
Illiterate/ read & write	56.8 \pm 11.8	24 – 85	0.685
Educated	57.8 \pm 12.4	32 – 93	
Residence:			
Urban	58.8 \pm 11.8	37 – 93	0.263
Rural	56.1 \pm 12.0	24 – 85	

Unpaired T-test

^oANOVA

Table (6): Correlation between burden and coping strategies

Coping strategies	Burden score
Confrontive coping	r= -0.126
	P= 0.211
Distancing	r= -0.066
	P= 0.517
Self controlling	r= 0.158
	P= 0.116
Seeking social support	r= -0.013
	P= 0.897
Accepting responsibility	r= 0.129
	P= 0.201
Escape- avoidance	r= 0.087
	P= 0.391
Planful problem solving	r= 0.010
	P= 0.924
Positive reappraisal	r= -0.190
	P= 0.059

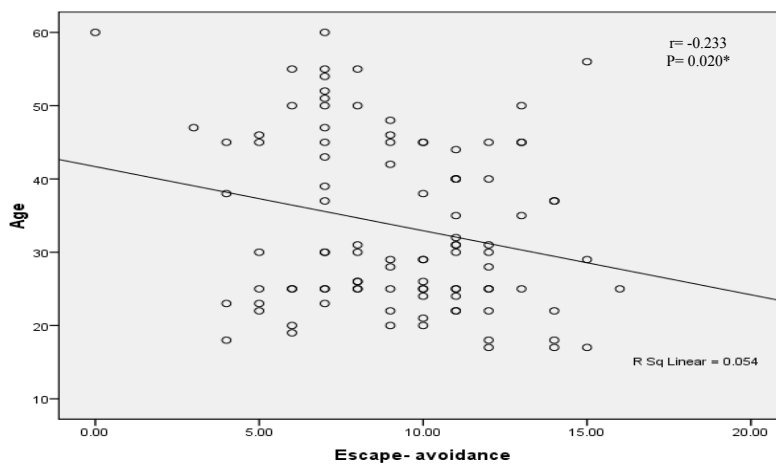
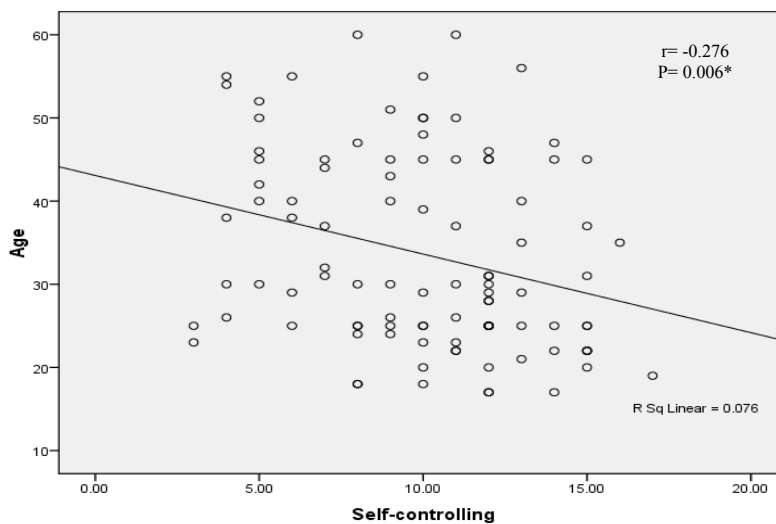


Fig. (2): Correlation between age and escape- avoidance

4. Discussion

Various study results showed that caregiver caring for patients with schizophrenia experience burden (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Roick, et al. 2007; Grandon, et al, 2008; Shu-Ying, et al, 2008). The current study showed that the general burden reported by caregivers of schizophrenic patients was high. The highest scores of burden were related to being busy to care for their mentally ill family members, being sad and worry, investing time, physical effort in caring for their mentally ill family members and spending money on them respectively. This could be attributed to the characteristics of the sample as the majority of them were females who are responsible for household duties and more than half of them were illiterate.

This finding is partially supported by Yusuf (2010) who reported that a high level of caregiver burden was found in 47.3% respondents and Rudnick (2004) who found that the general burden reported by the family members of schizophrenic was moderate and reported that the highest burden was related to worry, which is particularly understandable if satisfactory services are not provided, and the second highest burden was related to financial costs, which again is understandable if sufficient public resources are not in place. The same author stated that practical and emotional burden were not clearly distinguished among our subjects, perhaps because each type of burden may feed into the other (e.g., financial costs may augment worry, and worry, which is stressful, may augment physical illness).

Similarly, the majority of studies on burden of caregivers of patients having schizophrenia conducted so far report significant burden of caregivers with over 90% of families, experiencing moderate to severe burden. (Provencher, 1996, Unal et al., 2004; & Magliano et al., 2005). The burden of carers of schizophrenia is large and multifaceted. Headmost, there are the direct costs of providing care for individuals with schizophrenia. The indirect costs encompass the loss of productivity through impairments, disability as well as some legal problems including violence. The burden was present in areas like finance, routine activities, family leisure and interaction. Similarly the study of Sreeja et al., 2009 revealed that , thirty-eight out of sixty caregivers have reported 'Moderate burden' and 22 out of 60 have reported 'Severe burden'. Caregivers of both groups have burden predominantly in the same areas; i.e. patient care, finance, physical and emotional burden, family relations and occupation respectively. Furthermore, the study of (Kumar & Raguram (2009) showed that caregivers of schizophrenic patients in experienced moderate level of burden. The higher mean score was recorded for

physical and mental health followed by external support, caregivers' routine, taking responsibility, patient behavior, support of patient and other relations respectively. In the same study, caregiver, also reported greater use of emotion focused copings strategies as acceptance, denial religious. Similar findings reported by Chandrasekaran et al., 2002.

Caregivers used a wide variety of coping strategies, both problem and emotion-focused. In the current study, the most coping strategies used by caregivers of schizophrenic patients were self controlling, positive reappraisal and escape-avoidance. This finding is not supported by Chakrabarti & Gill (2002) found that problem-focused coping strategies were more common in caregivers of bipolar patients and emotion-focused strategies in caregivers of schizophrenic patients. Similarly, Chandrasekaran et al., 2002 reported that an emotion-focused coping strategy was found to be more commonly employed by the relatives, than other strategies. In contrast, Sczufca & Kuipers (1999) found that Problem-focused coping was the strategy used more often at inclusion than at follow-up.

In this respect, Rammohan et al., 2002 reported that parent caregivers were found to use denial as a coping strategy more than spouses. Spouses used more of negative distraction strategies when compared to the parent group. Negative distraction strategies such as use of alcohol and drugs are reported more often in males. A predominance of male caregivers in the spouse group could have influenced the scores on this subscale. The results suggest that male caregivers need to be specifically targeted in intervention programs to teach them more adaptive ways of handling stress.

Although the present study demonstrated that the mean score of burden was higher among younger age groups, male, single, illiterate caregivers and those of urban areas, there were no statistical significant association between these socio-demographic characteristics and burden among caregivers of schizophrenic patients.

The study of Juvang et al, (2007) is not in agreement with the current study findings as they investigated the relationship between demographic characteristics of caregiver's burden when providing care for a member with schizophrenia in China and the finding showed that the age of caregiver was positively correlated to burden of caregiver. When caregiver becomes older, they are worried about who will take care of their ill family member in the future. Older caregiver also cannot provide care well to the ill member. In addition, younger age of caregiver which has to provide caring for ill member, result in increasing sense of life is worth living (Fujino & Okamura, 2009).

Also, the findings of Juvang, et al., (2007) showed that the education level has negative correlation with caregiver's burden. It was assumed that higher the level of education, higher the salary will be. High salary would decrease financial problem related to providing care for ill family member. Level of education of the caregiver also tends to have more knowledge to deal with the stressful event. Therefore caregiver's education level influences burden of the caregiver.

In general, the current study revealed that there were no statistical significant associations between socio- demographic characteristics and coping strategies among caregivers of schizophrenic patients as shown in table (5). However, the age was negatively and significantly correlated with both self controlling and escape- avoidance as demonstrated in figures 1& 2. In contrast, Kumar et al., (2010) reported that female spouses were found high on emotion focused - religion/faith coping mechanisms. In this coping mechanism one visits places of worship, go on a pilgrimage, participates in religious groups, pray to God, perform special 'puja'. This is partially supported by Miller (2002) who reported that women are more religious than men to the extent that being irreligious constitutes risk-taking behavior. The differential use of high religious coping by female spouses is obviously because of their high religiosity. In female spouses, problem solving coping mechanism is negatively associated with spousal burden, (Beta: -.268; t-value=2.236, p=.029). Problem focused coping is considered the best. It points out to the ways of solving the problem and minimizes negative emotional consequences. In this approach an individual typically review the problems several times to enhance understanding, come up with a variety of probable solutions, works harder to manage the situation, analyze the problem bit by bit and seek assistance from others .

The results of the present study revealed that burden was negatively and non significantly correlated with confrontive coping, distancing, seeking social support and positive reappraisal coping strategies. However, it was positively and non significantly correlated with self controlling, accepting responsibility, escape- avoidance and planful problem solving. This could be interpreted by that, using confrontive coping, distancing, seeking social support and positive reappraisal coping strategies lead to decrease of the level of stress of mentally ill patients and consequently diminish the level of burden. In contrast, the use of self controlling, accepting responsibility, escape-avoidance and planful problem solving increase stress level and consequently the level of burden increase.

This result is partially supported by (Scazufca and Kuipers, 1999) who noticed that avoidance coping is strongly associated with burden, distress and high expressed emotion. Avoidance strategies appear to be less effective in regulating the distress of care-givers of schizophrenic patients than problem-focused strategies. Rammohan, et al., 2002 found that caregivers who used denial as a coping strategy experienced greater burden. Similarly, it was reported that the use of avoidance and denial coping methods results in greater burden and distress. (Hinrichsen & Lieberman, 1999, Scazufca & Kuipers,1999).

In this respect, Rauktis et al., 1995 found that negative social interactions were more important predictors of burden than social interaction. On the other hand, a reduction of family burden was found over time among relatives who adopted less emotion-focused coping strategies (Magliano et al., 2000). Moreover, Solomon and Draine (1995) found that perceptions of self- efficacy, mastery and satisfaction with coping responses were predictors of lower levels of burden. In contrast, Hobbs (1997) found no significant relationship between coping and burden in care giving mothers of adult schizophrenics.

Recommendation: Psycho educational program is needed to assist caregivers cope successfully with burden resulting from the care of schizophrenic patients.

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