

Comparison of Dependence in Daily Life Activities, Quality of Life and Caregivers' Expressed Emotions in Schizophrenic Patients with and without Relapse

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ABSTRACT: Schizophrenia is a chronic, relapsing disease, characterized by adverse set of signs and symptoms that strongly affect the patient functional behaviors, quality of life, and quality of caregivers emotional responses. The aim of this study was to explore the differences between dependence in activities of daily life, quality of life (QOL), and expressed emotion (EE) in schizophrenic patients with and without relapse. A retrospective case-control design was utilized in this study. It included 120 schizophrenic patients and their caregivers divided into two groups. The group with relapse consisted of 60 schizophrenic patients with history of recent relapses and their caregivers and the group without relapse included 60 patients. The tools used for data collection were interview questionnaire sheet, QOL scale for patients, and Camberwell family interview for caregivers. The results revealed that there were statistically significant differences between the two groups of caregivers under study regarding their expressed emotions, relapse group had more problems related to work than non relapse, more relapse patients had low QOL, compared to group without relapse. Also, the QOL scores had a negative statistically significant correlation with the number of relapses. It is concluded that patients group with relapse have more dependence in activities of daily life, lower QOL, and their caregivers have higher expressed emotions. Thus, it is necessary to train caregivers of schizophrenic patients regarding expressed emotions and how to control them for the safe of better prognosis and lower susceptibility to relapse among their patients.

INTRODUCTION

Schizophrenic disorders are characterized in consciousness and intellectual capacity general by fundamental and characteristic are usually maintained although certain distortion of thinking perception, and affects cognitive deficits may evolve in the course that are inappropriate or blunted Clear of time. The most important psycho-

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pathological phenomena include thought echo, thought insertion or withdrawal, thought broadcasting, delusional perception and delusions of control, influence of passivity, hallucinatory voices, and negative symptoms.⁽¹⁾ The clinical course following a first psychotic episode often fluctuates with periods of psychotic remissions, as well as psychotic exacerbations and relapses, and the degree of work and social impairment is highly variable among patients.⁽²⁾

Relapse is a deterioration or recurrence of positive rather than negative features. It appears to impair the course of the disease. Impairment is often longer than expected for those patients who discontinue antipsychotic medication; they then relapse to their pre-discontinuation clinical state of function.⁽³⁾ Psychosocial factors mean psychological development in, and interaction with a social environment. Psychosocial factors include

quality of life, stigma, expressed emotions (EE), psychological effects, depression, self-esteem, relationships, role change and impact on careers, identity and sense of self, disability, functionality and lifestyle changes.⁽⁴⁾

Quality of life (QOL) is known to be indicative of the level of social functioning in mental health persons. It can be defined as an overall sense of wellbeing, which is comprised of both objective and subjective evaluations of physical, material, social and emotional wellbeing, together with personal development and purposeful activity.⁽⁵⁾ Patients with schizophrenic symptoms and poor personal and social functioning have a far-reaching impact on their own quality of life, while the nature of schizophrenia and its early onset often impoverish the lives and lifestyles of those who care for them.⁽⁶⁾

EE as a concept reflects the

emotional atmosphere of home environment. The three attitudes pertaining to expressed emotion are known as hostile, critical comments, and emotional over-involvement. The attitudes of the relatives determine the direction of the illness after treatment. Relatives' negative comments and non-verbal actions with a patient are stressful on the recovery of this patient.⁽⁷⁾

If has been demonstrated that relapse could be expected in 70% of patients after the first schizophrenic episode; in parallel 70% of patients show an incomplete remission of the disorder after the first episode.⁽⁴⁾ The risk for a relapse after a schizophrenic episode remains increased throughout patient's lifetime. Moreover, the risk of chronicity increases with every relapse of the patient.⁽³⁾ Meanwhile, most of the nurses in outpatient clinics have negative attitudes towards caring for patients with schizophrenia. Their roles

are limited only to administration of medications, and are not concerned with patients' needs. This would increase the chances of relapse among these patients. Many psychosocial factors such as EE, and worsened quality of life are influencing relapse among patients with schizophrenia.⁽⁴⁾ Hence, relapse prevention is a primary focus in the treatment of schizophrenia. Therefore, it is deemed necessary to conduct this study to assess the influence of the psychosocial factors on relapse among non-hospitalized patients with schizophrenia.

MATERIAL AND METHODS:

- Assess dependence in activities of daily life, QOL, and EE among schizophrenic patients with and without relapse
- Explore the differences between dependence in activities of daily life, QOL, and EE in schizophrenic patients with and without relapse

- Explore the association between quality of life and expressed emotions and disease and relapse characteristics

The study was undertaken in the psychiatric outpatient department at El-Abbassia Governmental Hospital for Mental Health with the following.

Objectives

A retrospective case-control design was utilized in this study to compare schizophrenic patients with relapse and those without relapse.

Sampling

Subjects consisted of 120 schizophrenic patients and their caregivers. They were divided into two groups. The group with relapse consisted of 60 schizophrenic patients with history of recent relapses and their caregivers. The inclusion criteria for patients were the age (20-50 years) and being diagnosed of, having schizophrenia according to Diagnostic Statistical Manual

Fourth Edition (DSM-IV) criteria with at least two episodes of relapses. Caregiver's selection criteria were being adult (18 years or older), and permanently living in the same dwelling with the patients. The group without relapse included 60 patients with the same criteria as the group with relapse, except for the absence of any relapses during the preceding year. Their caregivers were selected with the same inclusion criteria as those of the group with relapse. Patients in the two groups were matched for the duration of the disease

The sample size was estimated to detect any difference between the rate of expressed emotions present in the non-relapsers with a rate of ($p_1=35\%$) and the expected rate among relapsers ($p_2=60\%$) with a 95% level of confidence (α error = 5%), and a study power of 80% (β error=20%).⁽⁸⁾ Using the equation for the difference between two proportions.⁽⁹⁾ The estimated sample size turned to be 60

subjects per group.

Data collection tools

Interview questionnaire: This was designed by the researcher and included three sections. The first was for the socio-demographic data of both patient and caregivers as age, gender, school grade, and residence, education, job, family size, and family income. The second section was for medical history of the patient such as duration of illness, age at onset of the disease, number of hospital admission, treatment modality, and details of relapses. The third section involved caregiver's viewpoint about patient's degree of dependence in various activities of daily life as personal hygiene, dressing, eating and drinking, shopping, financial, and social affairs. It was categorized into completely self-dependent, partially-dependent, and completely-dependent.

Camberwell Family Interview: This tool was originally used to obtain detailed

information about "Expressed Emotion" from caregivers of patients in response to patients' illness.⁽¹⁰⁾ and the formal version of the tool was developed.⁽¹²⁾ The Arabic version used in the present study was previously developed.⁽¹¹⁾ It consisted of the following categories and components:

a) psychiatric symptoms of schizophrenic patients as reported by caregivers. This category has the following 4 subcategories with a total items of 56: Loss of control over behavior (6 items), Patient's feeling of sadness and depression (7 items), Relating with others (4 items), Patient's social behavior (4 items), and Patient's physical disorders (9 items);

b) disturbed patient's daily program: includes Work (3 items), Recreation (3 items), Domestic duties (4 items);

c) Inadequate family management of patients' illness: includes family reaction to patient's behavior (7 items) , and action taken by family (9 items);

Items were scored 0, 1, 2, and 3 for the responses never, rarely, usually, and always, respectively. The scores of the items were summed-up and the total divided by the number of the items, giving a mean score. These scores were converted into a percent score. The expressed emotions were considered high if the percent score was 50% or more, and low if less than 50%.

Lehman Quality of Life Interview: The scale was developed⁽¹³⁾ and modified according to Ghaith 2005⁽¹⁴⁾. It was used to assess the life circumstances of persons with severe and persistent mental illness in terms of what they actually do and experience "objective quality of life" and their feelings about this experience "subjective quality of life or life satisfaction." It consisted of 49 items divided into six subscales: performance at work (7 items), activities of daily living (7 items), social relations (13 items),

personal hygiene (5 items), interest in surrounding events (7 items), and interest in recreational activities (10 items). Responses were checked on a 4-point Likert Scale: always, usually, rarely, and never. A higher score means better QOL.

Items were scored 0, 1, 2, and 3 for the responses never, rarely, usually, and always respectively. The scores were reversed for negative items. For each domain of factors, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score. The QOL was considered high if the percent score was 50% or more, and low if less than 50%.

Pilot study

A pilot study was carried out on twelve patients (6 with relapse and 6 without relapse) and their caregivers to test the feasibility of the study and the clarity of the tools. The pilot study also helped to know

the time needed for filling the forms.

Fieldwork

The actual fieldwork started after an approval was obtained to conduct the study from the directors of El-Abassia Governmental Hospital for Mental Health to facilitate data collection. Once permission was granted to proceed in the study, the researcher contacted each patient and his/her caregiver individually. At the same time, the purpose and nature of the study were explained.

A semi-structured interview with each patient and his/her caregiver, the questionnaires were read, explained and the choices were recorded by the researcher. Each patient was interviewed individually for about 60 minutes twice weekly. For more validation of information, the interview was done in the presence of the psychiatrist. Also, patient's file was used to help in completion of needed information. Data collection was

completed over a six-month period, from May to October 2009.

Administrative design and ethical considerations

Official letters to conduct the study were addressed from the Faculty of nursing to the directors of El-Abassia Governmental Hospital for Mental Health. Participants were informed about the purpose of the study and voluntary participation and confidentiality were ensured. They were also informed about their rights to refuse or accept to participate.

RESULTS

Table 1 shows that both groups had a mean age around 34 years, with a majority of males. More than half of the patients in both groups had basic to secondary education, were working, and were single or divorced. The majority were residing in urban areas.

Table 2 indicates that, the monthly

income was higher among caregivers of the group with relapse ($p=0.04$). It is also noticed that the mean age and the percentages of illiterates of caregivers of the group without relapse were higher than among the group with relapse.

Table 3 shows that two thirds of the group with relapse had three or more relapses in total, and 1-2 relapses during the last year, the majority were gradually deteriorated and the current attack was severe.

As table 4 demonstrates, statistically significant differences was revealed between the group with relapse and group without relapse regarding "patient dependence in the activities of daily life". Also more patients in the relapse group had significant partial or total independence in all activities, except personal hygiene and clothing did not reach statistical significance.

Table 5 points to statistically significant

differences between the two groups of caregivers regarding their expressed emotions. As regards disease symptoms, the group with relapse had more inability to control behavior ($p=0.006$), relating with others ($p=0.02$), and physical disorders ($p= 0.002$). As regards disturbed patient daily schedule, the group with relapse had more problems related to work ($p=0.03$). Also in family response, they had more causes of patient complaints ($p=0.01$). In total, 88.3% the caregivers of the group with relapse had expressed emotions, compared to 68.3% of those in group without relapse ($p=0.008$).

Concerning Quality of life, Table 6 indicates statistically differences between the group with relapse and group without relapse regarding work ($p=0.02$). In total, the group with relapse had low QOL (41.7%), compared to group without relapse (30.0%), however the difference was not statistically significant ($p=0.18$).

Table 7 points to statistically significant correlation between expressed emotion and the number of hospitalizations and the time since last hospitalization among the group with relapse. This was positive ($r=0.241$) for the first, negative ($r=0.325$) for the last. Also, the QOL scores had a negative statistically significant correlation with the number of relapses($r=0.0338$).

DISCUSSION

The current study demonstrated that the highest percentage of the group with relapse and group without relapse had age between 30 and 50 years (Table 1). This is in line with previous literature which indicated that schizophrenia typically begins in late adolescence or early adulthood. On the same line, many studies revealed that the onset of psychotic symptoms is usually during adolescence or early adulthood.⁽¹⁵⁾ However, the initial decade of illness is generally marked by repeated episodes of

psychosis with partial and variable degrees and duration of inter-episode remission with occurrence of disability with each episode of illness.⁽¹⁶⁾

According to the present study, more patients in the group with relapse were partially or totally significantly dependent, compared to those in the group without relapse (Table 4). This may be due to that schizophrenia cause marked change in patient's behavior, which makes them socially isolated, neglecting of their personal hygiene, verbally abusive and threatening to cause harm to self and others. These deviated behavioral symptoms are often observed during relapse or a prodroma to relapse. This is consistent with another study which added that such patients fail to adhere to regular time schedules, are generally uncooperative, verbally abusive, and making unreasonable demands. Thus, relapsed patients had more severe

deterioration at work, along with the deterioration of the ability to concentrate, this would increase their dependence on others in their activities of daily living.⁽³⁾

Concerning caregivers expressed emotions, the present study indicated that the majority of caregivers of the group with relapse had high level of expressed emotions, which was significantly higher, compared to those of the group without relapse (Table 5). This finding is quite expected since high expressed emotions reflect lack of coping and negative attitude of caregivers towards patients, which would increase their susceptibility to relapse. It also implies that caregivers could not take the proper action in case of symptoms increase as seeking professional help, but instead may go to "sheikh" or traditional healers and thus increase the relapse rate among schizophrenic patients. Also their avoidance of social interaction could pose

a burden and stress to caregivers who always blame patient as they had a significant role in their problem. This would result in disturbed relationship with the patient and increased vulnerability to relapse⁽³⁾

The finding of the present study revealed that there were statistical significant positive correlations between number of hospitalization and caregivers' expressed emotion. This relationship between number of hospitalization and increased expressed emotion could be reciprocal. Thus, increased expressed emotions could lead to more relapses, with associated more frequent hospital admission. On the other hand, the repeated hospitalizations could increase the burden on family caregivers, and could be reflected in higher expressed emotions among them. In agreement with this, the studies revealed that the direct effects of hospitalization and the resulting

psychosocial consequences place a huge burden on caregivers and relatives and may lead to difficulties in their relationship with the patient.⁽¹⁷⁾

As for the time since last hospitalization, the present study demonstrated a statistically significant negative correlation between this time since last hospitalization and caregivers' expressed emotions (Table 7). This could be explained by the association between the length of time since last hospitalization and the remission of symptoms. Schizophrenic patients who are stable and controlled do not actually need frequent hospitalizations, and thus take longer times of quiescence between the hospitalization episodes. This period of quiescence is certainly associated with lower burden on caregivers, and thus could decrease their expressed emotions. In agreement with this, the studies reported that patients with schizophrenia

who experience repeated relapse typically characterized by exacerbation of psychosis and re-hospitalization can have significant impairment of their psychological functioning, including poor social interaction, particularly difficulty maintaining relationships with family and friends, or functioning in the workplace.⁽¹⁸⁾ All these would lead to higher expressed emotions among their caregivers.

The present study has also demonstrated that the group with relapse had significantly lower QOL scores concerning work and daily activities, compared to the group without relapse. Moreover, a statistically significant negative correlations was revealed between the total number of relapse episode, and the number of relapses in the last year and QOL scores (Table 7) ,this means that the repeated frequent relapses have a negative impact on patient QOL. These findings agreed with, another study which found that there was a statistically significant positive

correlation between fewer number of episodes and high scores of quality of life.⁽¹⁹⁾

The current study indicated that the length of time since last relapse was positively correlated with the QOL score which indicates that a shorter time since last relapse is associated with lower QOL score. This is quite plausible since relapse is associated with exacerbation of psychotic symptoms, which may require hospitalization and affect most of the patient's life aspects. This finding is consistent with another study which highlighted that relapses in schizophrenia predict poor prognosis, bring about deterioration in social, occupational, and financial status and increase the burden of care on the family, i.e. negatively affect patient's QOL(3).

CONCLUSION AND RECOMMENDATIONS

In conclusion, the comparison of the Group with relapse and group without

relapse revealed that group with relapse have more dependence in activities of daily life, lower QOL, and their caregivers have higher expressed emotions which was positively related to the number of hospitalizations.

In view of these findings, it is recommended to train caregivers of schizophrenic patient regarding expressed emotions and how to control them for the safe of better prognosis and lower susceptibility to relapse among their patients. Thus, this needs efforts from the psychiatric nurse who should be able to counsel schizophrenic patient's family caregivers, and would necessitate training programs for nurses to master the counseling skills. The long-term effects of counseling family caregivers regarding expressed emotions on the occurrence of relapse could be then investigated in future research.

Table 1. Socio-demographic characteristics of patients with and without relapse

Socio-demographic characteristics	patients group				X ² Test	p-value
	With relapse (n=60)		Without relapse (n=60)			
	No.	%	No.	%		
Age (years):						
<30	18	30.0	20	33.3	0.15	0.69
30+	42	70.0	40	66.7		
Range	20.0-50.0		20.0-49.0			
Mean±SD	34.1±8.1		34.7±8.7			
Sex:						
Male	44	73.3	39	65.0	0.98	0.32
Female	16	26.7	21	35.0		
Education:						
Illiterate	17	28.3	17	28.3	0.00	1.00
Basic/secondary	34	56.7	34	56.7		
University	9	15.0	9	15.0		
Marital status:						
Married	23	38.3	18	30.0	0.93	0.34
Single/divorced	37	61.7	42	70.0		
Residence:						
Urban	46	76.7	53	88.3	2.83	0.09
Rural	14	23.3	7	11.7		
Job status:						
Not working	25	41.7	26	43.3	0.03	0.85
Working	35	58.3	34	56.7		

Table 2. Socio-demographic characteristics of caregivers of patients with and without relapse

Socio-demographic characteristics	Caregivers of patients group				X ² Test	p-value
	With relapse (n=60)		Without relapse (n=60)			
	No.	%	No.	%		
Age (years):						
<30	23	38.3	15	25.0	2.46	0.12
30+	37	61.7	45	75.0		
Range	18-79		18-80			
Mean±SD	46.0±15.0		47.9±13.0			
Sex:						
Male	30	50.0	26	43.3	0.54	0.46
Female	30	50.0	34	56.7		
Education:						
Illiterate	25	41.7	35	58.3	3.84	0.15
Basic/secondary	28	46.7	18	30.0		
University	7	11.7	7	11.7		
Marital status:						
Married	53	88.3	47	78.3	2.16	0.14
Single/divorced	7	11.7	13	21.7		
Have children:						
No	2	3.7	4	7.3	0.67	0.71
1-2	17	31.5	17	30.9		
3+	35	64.8	34	61.8		
Residence:						
Urban	47	78.3	51	85.0	0.89	0.35
Rural	13	21.7	9	15.0		
Job status:						
Not working	32	53.3	25	41.7	1.64	0.20
Working	28	46.7	35	58.3		
Monthly income (LE):						
<500	20	33.3	31	51.7	4.13	0.04*
500+	40	66.7	29	48.3		
Family size:						
<4	14	23.3	21	35.0	1.98	0.16
4+	46	76.7	39	65.0		
Crowding index:						
≤1	16	26.7	18	30.0	0.16	0.69
>1	44	73.3	42	70.0		

* Statistically significant at $p < 0.05$

Table 3. Details of relapses among patients group with relapse

Details of relapses	NO	%
Number of total relapses:		
1-2	20	33.3
3+	40	66.7
Range	1-25	
Mean±SD	5.3±5.3	
Number of relapses in the last year:		
1-2	41	68.3
3+	19	31.7
Range	0-3	
Mean±SD	1.2±0.9	
Deterioration:		
Sudden	9	15.0
Gradual	51	85.0
Current attack:		
Severe	40	66.7
Moderate	18	30.0
Mild	2	3.3

Table 4. Dependence in activities of daily life among schizophrenic patients with and without relapse

Dependence in daily life activities	patients group				X ² Test	p-value
	With relapse (n=60)		Without relapse (n=60)			
	No.	%	No.	%		
Personal hygiene:						
Independent	46	76.7	53	88.3	2.83	0.09
Partial/total dependent	14	23.3	7	11.7		
Clothing:						
Independent	26	76.7	53	88.3	2.83	0.09
Partial/total dependent	14	23.3	7	11.7		
Eating and drinking:						
Independent	53	88.3	60	100.0	Fisher	0.01*
Partial/total dependent	7	11.7	0	0.0		
Shopping:						
Independent	20	33.3	35	58.3	7.55	0.006*
Partial/total dependent	40	66.7	25	41.7		
Finances:						
Independent	13	21.7	19	31.7	1.53	0.22
Partial/total dependent	47	78.3	41	68.3		
Social affairs:						
Independent	20	33.3	31	51.7	4.13	0.04*
Partial/total dependent	40	66.7	29	48.3		

* Statistically significant at $p < 0.05$

Table 5. Expressed emotions as reported by caregivers of schizophrenic patients with and without relapse

EE domains	patients group				X ² Test	p-value
	With relapse (n=60)		Without relapse (n=60)			
	No.	%	No.	%		
Disease symptoms:						
Inability to control behavior	56	93.3	45	75.0	7.57	0.006*
Feeling depressed/sad	40	66.7	36	60.0	0.57	0.45
Relating with others	54	90.0	44	73.3	5.57	0.02*
Patient social behavior	54	90.0	47	78.3	3.06	0.08
Physical disorders	48	80.0	32	53.3	9.60	0.002*
Total	53	88.3	41	68.3	7.07	0.008*
Disturbed patient daily program:						
Work	48	80.0	37	61.7	4.88	0.03*
Recreation	35	58.3	27	45.0	2.14	0.14
Domestic work	43	71.7	38	63.3	0.95	0.33
Total	43	71.7	31	51.7	5.08	0.02*
Inadequate family management of patients' illness:						
Family reaction to patient's behavior	28	46.7	27	45.0	0.03	0.85
Action taken by family	48	80.0	39	65.0	3.39	0.07
Causes of patient complaints	53	88.3	42	70.0	6.11	0.01*
Family related causes	55	91.7	50	83.3	1.90	0.17
Total expressed emotions:						
High (50%+)	53	88.3	41	68.3		
Low (<50%)	7	11.7	19	31.7	7.07	0.008*

* Statistically significant at $p < 0.05$

Table 6. Quality of life of schizophrenic patients with and without relapse

Quality of life (QOL)	patients group				X ² Test	p-value
	With relapse (n=60)		Without relapse (n=60)			
	No.	%	No.	%		
Work:						
High (= ≥50%)	20	33.3	33	55.0	5.71	0.02*
Low (<50%)	40	66.7	27	45.0		
Daily life activities:						
High (= ≥50%)	38	63.3	49	81.7	5.06	0.02*
Low (<50%)	22	36.7	11	18.3		
Social relations:						
High (= ≥50%)	50	83.3	56	93.3	2.91	0.09
Low (<50%)	10	16.7	4	6.7		
Personal hygiene:						
High (= ≥50%)	37	61.7	44	73.3	1.86	0.17
Low (<50%)	23	38.3	16	26.7		
Interest in outside events:						
High (≥50%)	26	43.3	25	41.7	0.03	0.85
Low (<50%)	34	56.7	35	58.3		
Interest in recreational activities:						
High (= ≥50%)	44	73.3	44	73.3	0.00	1.00
Low (<50%)	16	26.7	16	26.7		
Total QOL:						
High(= ≥50%)	35	58.3	42	70.0	1.78	0.18
Low (<50%)	25	41.7	18	30.0		

* Statistically significant at $p < 0.05$

Table 7. Correlations between expressed emotions and QOL scores and disease and relapse characteristics

Disease and relapse characteristics	Pearson correlation coefficient	
	Expressed emotions	QOL
Disease characteristics		
Duration of illness	0.010	-0.103
Age at onset	-0.179	0.141
Number of hospitalizations	0.241*	-0.206
Time since last hospitalization	-0.325**	0.202
Hospital stay	0.066	-0.045
Relapse characteristics		
Total number of relapses	0.244	-0.338**
No. of relapses in last year	0.206	-0.289*
Time since last relapse	-0.188	0.302*
Longest hospital stay	0.152	-0.119

* Statistically significant at $p < 0.05$

** Statistically significant at $p < 0.01$

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