



Differences by Retrospective Illness Course on Burden, Expressed Emotion, Psychological Distress and Quality of Life in Relatives of Mexican Outpatients with Psychosis: A Cross-Sectional Study

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Abstract

Patients' illness might also affect their relatives' psychological state. The present cross-sectional study aimed at assessing the levels of burden, expressed emotion, psychological distress and quality of life in a sample of relatives of Mexican outpatients with psychosis and the possible effect of illness course assessed retrospectively. Sample included 65 participants: 73.8% female; mean age of 48.7 years. Relatives self-responded the following scales: the Caregiver Burden Interview, the Family Questionnaire, the WHOQOL-BREF and the GHQ-28. Mean scores were compared by groups according to the retrospective illness course of patients (diagnosis, residual symptoms, relapses) with one tailed Mann-Whitney tests. Levels of burden, expressed emotion, psychological distress, and poor quality of life were low, significantly related and particularly influenced by patient residual symptoms. It is important to involve relatives not only as care providers but also as individuals whose psychological well-being is at risk, particularly when their ill relative present residual symptoms.

Keywords

Burden, Expressed emotion, Psychological distress, Quality of Life, Psychosis, Illness course

Introduction

The availability and the efficacy of treatments for psychosis have evolved improving illness outcome and prognosis. As patients need less often to be institutionalized, the role of families as providers of informal care has increased. Initially, attention was paid to family environment as a significant factor in the onset and course of psychosis [1] leading to the development of several psychosocial interventions centered on the family unit to prevent relapses and clinical exacerbations [2,3]. Nevertheless, it must be acknowledged the caregivers' need for support as they might also be affected by their relatives' illness, experiencing

worry, shame, stigma, guilt and even depression [4-7]. Both, as an influence on patients and as individuals at risk of distress, caregiving relatives are of interest to research and clinical practice [8-11] and concepts such as burden of care, expressed emotion, psychological distress and quality of life have become usual outcome measures when assessing this population.

Burden involves feelings of emotional overwhelming, physical discomfort, social life restrictions, and financial struggles [12,13], and also subtle but distressing notions such as embarrassment, stigma and self-blame [14]. Relatives of patients with psychosis are likely

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to suffer burden, increasing their risk of mental disorders [15,16]. Expressed emotion (EE) refers to critical, hostile or emotionally overinvolved attitudes and interactions of family members towards a relative with a disorder or impairment. Criticism, hostility, emotional over-involvement, warmth and positive remarks are its five original components. The first three have been most widely used to rate EE in families [17,18], and in some studies hostility and criticism have been considered as one single component [19]. Evidence supports that patients interacting with family members with high EE are at high risk for relapse [18,20]; nevertheless, a causal relationship should not be assumed, but rather an influence in both directions [21]. Relatives of patients with psychosis are also likely to experience psychological distress (PD), characterized by symptoms of depression and anxiety that might be tied in with somatic symptoms [22-25]. Furthermore, research has also found that the Quality of life (QoL) of people providing care to a relative with psychosis tends to diminish [26]. Health care literature abounds with articles reporting on these relative outcome measures and their association with various socio-demographic, clinical and psychological factors; yet, the possible differences by illness course in patients are to be explored.

Although severe, the course following a first episode of psychosis is rather heterogeneous and outcomes may vary from full recovery to a deteriorating chronic course [27-40]. It has been observed that between two and five years after the first episode, psychotic disorders seem to plateau and follow a more stable course [41], so that a fair prediction of course can be made by year three [42]. Regarding diagnosis, research has found schizophrenia to have a poorer global outcome when compared with other types of psychoses [43,44]. Although psychotic disorders share some key features (e.g. delusions, hallucinations, disorganized thinking, odd behavior, negative symptoms), by definition a clinical diagnosis of schizophrenia reflects a more severe condition in comparison to other psychoses (i.e. esquizofreniform, esquizoafectivo, delusional, brief, others) [36]. For instance, schizophrenia implies that two or more key symptoms are continuously present for at least one month and that disturbance of daily functioning is significant and persistent for at least 6 months [36]. The presence of residual symptoms is another given criterion for illness course [45,46]. Residual symptoms are the signs of the disorder

manifested by: (i) only negative symptoms or (ii) 2 or more characteristic symptoms (delusions, hallucinations, unorganized and incoherent speech, grossly unorganized or catatonic behavior, and negative symptoms) present in an attenuated manner (sub-threshold) (e.g., strange thoughts or beliefs or highly unusual perceptive experiences) [36]. Although usually not very intense, the persistence of residual symptoms might disrupt the patient's functioning and causing him distress and diminishing his quality of life [47,48]. A relapse (a later psychotic episode) is defined as "the incidence of any major modification belonging to the psychological clinical picture, which causes the patient to be referred to a psychiatric center, to increase the dosage of the antipsychotic medication, or to be admitted to hospital" [49]. A relapse could have occurred as a change from (1) a state of complete reestablishment (absence of psychotic symptoms) to the reappearance of psychotic symptoms, or (2) a state of partial reestablishment (stable state of persistent symptoms) up to a clear worsening of the psychotic symptoms [45,49]. A relapsing course can be considered a negative outcome given that not only might lead to functional deterioration and diminished stability in employment and relationships [50] but also give the individual a sense of frustration and hopelessness when facing illness.

Although noble and morally satisfying, caregiving compares to a chronic stress experience featuring physical and psychological strain over extended periods of time, high levels of unpredictability and uncontrollability and requiring constant vigilance [51]. Research and clinical services due attention to those who provide informal care to patients on daily bases, not only because they can influence the patient but also because such responsibility exposes them to distress, increasing their vulnerability to physical and/or mental illness. Improving caregivers' well-being would increase the quality of caregiving, improving treatment efficacy and patient rehabilitation. Available literature shows no previous research that had assessed burden, EE, PD and QoL in a single study, neither that had explored the possible effect of the course followed by psychosis (diagnosis, residual symptoms, and relapses). Research has found that patients' poor outcome (e.g. poor functioning and high symptom severity) significantly relates to increased burden, EE, psychological distress, and poorer quality of life in their relatives [14,21,52,53]. Thus,

considering the three above mentioned criteria for illness course, a less favorable psychological outcome would be expected in the relatives of those patients with a disfavorable course that is, diagnosed with schizophrenia, who still have residual symptoms and/or who have relapsed. In Mexico, limited research has been undertaken regarding relatives' psychological state when providing care for a family member with psychosis. Therefore, this study aimed at assessing the levels of burden, EE, PD and QoL in a sample of relatives of Mexican outpatients with psychosis and exploring how they can be affected by illness course.

Method

■ Participants

This cross sectional study was performed at the only public psychiatric hospital located in the city of Merida, Mexico. Protocol design, consent forms and measures were approved by the Hospital's Research and Ethics Committees and conformed to the provisions of the Declaration of Helsinki [54]. First, patients were selected according to the following inclusion criteria: (1) a primary diagnosis of schizophrenia or other related disorder [36], (2) at least 3 years since the first episode of psychosis had occurred, (3) age at onset 16-45 years, and (4) inhabitant of Merida. Exclusion criteria were: (1) psychosis of affective, organic or toxic type, (2) evident intellectual disorder, and (3) inadequate contact information. According to the information recorded in clinical files, 158 cases met the criteria; yet, only 103 could be contacted (3 had passed away and 55 had moved away or were temporarily out of the city. Final sample included 65 patient/relative dyads who agreed to be interviewed, signing informed consent with no economic compensation involved. The primary caregiver was the relative identified by patient as the one s/he relies on for all issues related to the disorder (e.g. appointments, treatment, coping), providing most of the needed support, caring and company.

■ Measures

Burden was measured with the Zarit Caregiver Burden Interview [55]. The scale includes 22 items addressing how relatives feel about the daily experience of taking care of a close one: interactions, physical and psychological well-being, finances, social life and expectations. Although it was originally designed for caregivers

of people with dementia, its use has been satisfactorily extended to primary caregivers of patients with psychosis [56-58]. EE was measured with the Family Questionnaire [19], an instrument specially designed for relatives of patients with schizophrenia. It includes 20 items addressing the relatives' level of intrusiveness, emotional response, attitude toward the illness, level of tolerance and expectations. It yields one global and two subscale scores: criticism and emotional over-involvement. PD was measured with the General Health Questionnaire (GHQ-28). Its 28 items are distributed in 4 subscales: somatic symptoms, anxiety and insomnia, social dysfunction, and depression. The scale has been used in relatives of patients with schizophrenia or other psychiatric disorders to detect cases of at-risk mental states [22,23,25]. QoL was measured with the World Health Organization Quality of Life Questionnaire, abbreviated version (WHOQOL-BREF) [59]. This 26-item was designed by the World Health Organization [60] to assess QoL cross-culturally. The first and second items question about overall QoL and general health, respectively, and are scored individually. The remaining 24 items are distributed in four domains: physical health, psychological well-being, social relationships and satisfaction with the conditions of the immediate environment. This instrument is widely used in diverse populations, including relatives of patients with schizophrenia [60,61]. All scales were presented in Likert format (scores from 1 to 4) and self-responded by relatives. High scores in burden, EE and PD and low scores in QoL represent a negative psychological state.

Clinical records and interviews [62] with patients were used to establish the course of illness at the time of assessment and to categorize it according to three criteria: a) relapses (i.e. exacerbation of psychotic symptoms requiring hospitalization and/or increase in medication [45] in the time period from the first episode to participation in the study), b) residual symptoms (only negative symptoms or two or more positive symptoms present in an attenuated form [36], and c) primary clinical diagnosis [36,62].

■ Statistical analysis

Data were analyzed with the SPSS v.20 software. Descriptive statistics (means, standard deviations) were generated for all scales. Kolmogorov-Smirnov tests revealed that data in groups were not normally distributed ($p \leq 0.05$); thus, non-parametric tests were performed. Sequentially,

one tailed Mann-Whitney tests explored differences between groups defined by the three retrospective illness course criteria. Tests were performed with global scores summing all the corresponding items for Burden (22 items), Expressed emotion (20 items), Psychological distress (28 items), and Quality of life (26 items). Effect sizes (r) were estimated as a reference; nevertheless, given that data were not normally distributed, interpretation is limited. Two-way Anova tests explored possible interactive effects between criteria pairs.

Results

Patients' mean age was 36.2 (SD=9.8) years and mean age at onset of psychosis was 29.3 years (SD=9.7). Retrospective illness course time ranged from 3 to 14 years, with a mean of 6.9 (SD=2.1). Clinical diagnosis included 44 cases of schizophrenia (16 paranoid, 3 disorganized, 1 catatonic, 24 residual) and 21 cases of other psychoses (9 esquizoafectivo, 7 delusional, 2 esquizofreniform, 2 brief, 1 not otherwise specified). In the group of patients with schizophrenia with residual symptoms 19 had experienced at least one relapse while 5 had only one single episode. In the group of patients with schizophrenia with no residual symptoms 14 had experienced at least one relapse while 6 had only one single episode. In the group of patients with other psychoses with residual symptoms 5 had experienced at least one relapse while 6 had only one single episode. In the group of patients with other psychoses with no residual symptoms 3 had experienced at least one relapse while 7 had only one single episode. At the time of assessment none of the patients reported to have any other medical condition requiring specialized treatment.

Sample included 30 (46.2%) parents, 17 (26.2%) spouses, 7 (10.8%) siblings, 6 (9.2%) offspring and 5 (7.7%) other relatives (grandmother, aunt, nephew, mother-in-law and sister-in-law). All relatives have contact with the patient at least once a week and 58 (89.2%) live with him/her. Most relatives (73.8%) were female; mean age was 48.7 years (SD=16.5, from 16 to 85), with no significant differences by sex ($t_{(63)} = -1.10$). Forty (61.5%) had secondary or lower educational level (up to 9th grade). Sex, age, and educational level of relatives were not significantly related to any of the outcome measures.

Individual item and mean scale scores could range from 1 to 4, being considering the value

of 2.5 as the mid-point. Thus, as the mean scores for burden, EE, and PD were below 2.5 and for QoL above 2.5, it could be assumed that relatives reported a fairly positive psychological state. Descriptive data is presented in **Table 1**.

Analyzing how burden, EE, PD and QoL could be affected by retrospective illness course it was found that relatives of patients with schizophrenia in comparison to relatives of patients with other type of psychosis had similar outcomes. When considering relapses, relatives of patients who have not relapsed reported significantly higher levels of depression (GHQ-28); yet, the effect size was very small ($r=-0.06$). The residual symptom criterion stands out when comparing relatives according to the patient's retrospective illness course. Relatives of patients with residual symptoms scored significantly higher in burden and EE, with medium effect sizes ($r \geq 0.30$). They also scored higher in some dimensions of PD and lower in some aspects of QoL; yet, effect sizes were small (**Table 2**). No significant interaction effects between illness course criteria were found for any of the outcome variables.

Discussion

This study aimed at assessing the levels of burden, EE, PD and QoL in a sample of understudied relatives, that is, relatives of Mexican outpatients with psychosis. Overall, participants reported a positive psychological state, with low levels of burden, EE, PD and good levels of QoL. This might well, at first, call into question the validity of the results; however, other arguments must be considered. The expression and levels of PD may vary by ethnicity; if the individual's behavior and functioning is distant from cultural norms and values endorsed by culture, family member may find more difficult to interact with the patient and being less critical [63]. Previous studies in families of Mexican origin (in the United States) have shown that they are less critical and have a better acceptance of psychosis [64,65]. Moreover, it must be considered that in Latin American cultures people are more likely to receive support from their immediate communities, and that might moderate the impact that illness can have on relatives [66]. Nevertheless, it should also been taken into account that this study included relatives of patients with a chronic course but also of patients with a more favorable course and that might have biased the overall result.

Another aim was to explore the possible effect of retrospective illness course in relative

Table 1: Descriptive Statistics for Outcome Variables (N=65).

Variable	Scale	Number of Items	Mean (SD)	Range
Burden	Caregiver Burden Interview	22	1.8 (0.4)	1.1 – 3.0
Expressed emotion (EE)	Family Questionnaire	20	1.9 (0.5)	1.2 – 3.0
Criticism		10	1.8 (0.6)	1.0 – 3.5
Overinvolvement		10	2.1 (0.5)	1.3 – 3.8
Psychological distress (PD)	GHQ-28	28	1.6 (0.5)	1.0 – 3.2
Somatic symptoms		7	1.7 (0.7)	1.0 – 3.7
Anxiety / Insomnia		7	1.6 (0.7)	1.0 – 3.9
Social dysfunction		7	1.2 (0.6)	1.0 – 3.6
Depression		7	1.2 (0.6)	1.0 – 3.7
Quality of life (QoL)	WHOQOL-BREF	26	3.3 (0.5)	2.1 – 4.0
General quality of life		1	3.3 (0.6)	2.0 – 4.0
General health		1	3.3 (0.9)	1.0 – 4.0
Physical		7	3.4 (0.5)	1.7 – 4.0
Psychological		6	3.4 (0.6)	1.7 – 4.0
Social		3	3.4 (0.7)	1.0 – 4.0
Environmental		8	3.2 (0.6)	1.4 – 4.1

Table 2: Differences in Burden, Expressed Emotion, Psychological Distress and Quality of Life According to Illness Course Criteria (N=65).

	Diagnosis		U	z	p	r
	Schizophrenia n=44	Other psychoses n=21				
	Median	Median				
Burden	1.72	1.55	396.500	-.920	0.18	0.12
Expressed emotion	1.88	1.85	430.500	-.442	0.33	0.07
Psychological distress	1.43	1.39	457.500	-.063	0.48	0.00
Quality of life	3.36	3.46	448.500	-.189	0.43	-0.03
	Residual Symptoms					
	Present n=35	Absent n=30	U	z	p	r
	Median	Median				
Burden	1.81	1.50	329.500	-2.574	0.01	0.30
Expressed emotion	2.10	1.60	249.500	-3.629	0.00	0.41
Psychological distress	1.57	1.29	367.500	-2.075	0.02	0.08
Quality of life	3.24	3.62	334.500	-2.507	0.01	-0.27
	Relapses					
	Any relapse n=41	Single episode n=24	U	z	p	r
	Median	Median				
Burden	1.72	1.66	417.000	-1.020	0.15	0.13
Expressed emotion	1.95	1.80	455.500	-.497	0.31	0.05
Psychological distress	1.39	1.50	459.500	-.442	0.33	-0.09
Quality of life	3.38	3.45	446.000	-.625	0.27	-0.02

Tests were performed with single global scores for Burden, Expressed emotion, Psychological distress, and Quality of life.

U: Mann-Whitney test statistic. z: associated z-score. p: level of significance. r: effect size.

One-tailed significant results ($p \leq 0.05$) in bold.

outcome. Overall, higher levels of burden, EE, PD and lower QoL were found in relatives of patients who have a diagnosis of schizophrenia, have residual symptoms or have experienced any relapse; probably because these patterns

of retrospective illness course indicate a more severe disorder. However, it was the presence of residual symptoms, rather than the occurrence of any relapse or a diagnosed schizophrenia, the retrospective illness course criterion clearly

making a significant difference. Psychotic episodes are characterized by dramatic changes on the individual's behavior and cognitions; yet, once acute symptoms have remitted, stable periods follow. Nevertheless, in some cases, residual symptoms (i.e. attenuated positive symptoms and/or negative symptoms) might persist and prevent the individual's functional recovery. This situation might cause stress to caregivers as they worry about their ill relative and his future, wondering about his ability to establish interpersonal relationships and function independently in everyday life [67-69]. Patient residual symptoms might hinder his/her total reintegration to daily tasks and responsibilities (e.g. formal employment), affecting the socio-economic status of the family. Moreover, residual symptoms in psychosis, compared to onset/relapse symptoms, are rather mild and relatives might misinterpret them as unwillingness of patient to get involved in common social, family and working activities. These dynamics might overload the other members of the family and indirectly increase burden, EE, PD and diminish QoL. Efforts have been made to interpret the experience of caregiving and its outcome under the light of theoretical models, some considering stress-coping and cognitive appraisals [70,71]; however further research to test hypotheses on more than a single outcome variable according to these models has yet to be done. At present, the impact of psychosis on family life and the importance of the family's collaboration to properly address the disorder are undeniable. Family members of patients with psychosis must face possible crisis situations and live with a person suffering from a disorder which may become chronic and require prolonged treatments, even for life. Relatives often contribute to the patient's care and find themselves in need of education, guidance, and support, as well as training to optimize their caretaking role and to protect/improve their own well-being. Accordingly, current international guidelines encourage psycho-educational programs to provide families with information regarding the disorder and training of skills for better coping. Yet, it is recommended to transmit information gradually depending on the needs and uncertainties of the patient and his/her family and the phase of the disorder the patient is in. Findings from the present study not only provide evidence of the effect of illness course on the psychological state of relatives but also identify the presence of residual symptoms

(in patients) as a particular condition affecting their overall well-being. Including four of the most relevant outcome measures in the study of relatives of patients with a mental disorder offers a clear picture of the negative effect of an illness course characterized by residual symptoms. Therefore, design and implementation of psycho-educational programs for this population should focus on the understanding and managing of residual symptomatology.

Limitations

Some limitations of the study must be observed. Although simplifying the course of psychosis into two categories has been useful for research purposes [45,46,49,72], its heterogeneity and complexity is undeniable. Given the limited number of participants, it was not possible to perform finer analyses with groups formed considering simultaneously the three criterion (e.g. relatives of patients with schizophrenia, a relapsing course and residual symptoms) that would allow us to understand more clearly the effect of the patient clinical status on the relative. Expanding the inclusion criteria to include relatives of patients with other types of psychoses or with other mental disorders would also enrich future studies. Furthermore, the measurement of a more ample number of potential patient and caregiver socio-demographic and clinical factors, related with both exposure and outcome and that may function as confounders, must be considered. This would allow a finer multivariable analysis considering possible confounding bias and would enhance the interpretation of results.

Conclusions

Notwithstanding its limitations, the present study provides evidence that, even though burden, EE, PD and poor QoL reported by relatives of patients with psychosis in Mexico are rather low, they are particularly influenced by patient residual symptoms. As most patients are now at home and under the care of their families it is important to involve relatives not only as care providers but also as individuals whose psychological well-being is at risk. Assessing the psychological state of relatives and exploring new factors of influence would provide the necessary information to identify those in risk so that targeted early interventions can be designed and provided.

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