

Experience of Caregiving in Schizophrenia: preliminary results

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INTRODUCTION

In the late 90's, the *Experience of Caregiving* (EC) (11), conceptualized from the theoretical model *stress-appraisal-coping* (Lazarus and Folkman, 1984), addressed important limitations in the research of *Family Burden*.

The EC assumes an important role in the understanding of the experience of schizophrenia, by focusing on the idiosyncratic assessment that the informal carer makes of his experience, capturing the positive and the negatives aspects of caregiving. In Portugal, little research has been carried out in this area, although the trans-cultural studies of the BIOMED I program, led by L. Magliano (5a, 5b, 6, 7) and focused on *family burden* (coping, social network and psychoeducational interventions), which cover five European countries, including Portugal, deserve special mention.

In this study, we intend to assess the importance of the perceptions of difficulties, satisfaction and coping in the determination of the EC, more positive or negative, of the informal carer of patients with schizophrenia.

A deeper understanding of the EC will enable a richer analysis for research in this area and, consequently, a more effective clinical practice.

OBJECTIVES and CONCEPTUAL HYPOTHESIS

Objectives

- Characterize the EC
- Characterize the frequency of symptoms and behaviours and respective degrees of concern and coping, perceived by the carers
- Determine the existence of psychopathology in carers
- Characterize the difficulties and degrees of disturbance, possible sources and degrees of satisfaction and coping strategies and degrees of effectiveness, perceived by the carers
- Understand the relationship between the different variables mentioned in the point above
- Understand the importance of the perceptions mentioned above in the prediction of the EC

Hypothesis

The Experience of Caregiving is determined by the perception of difficulties, of sources of satisfaction and of coping

METHOD

Sample 50 carers

Inclusion/exclusion criteria of patient with schizophrenia: diagnosis of schizophrenia at least 1 year (excluded affective psychoses); age above 17 years; not institutionalized

Inclusion/exclusion criteria of carer: relative and/or another informal carer (relative or not) that live/deal (frequent contact – week-end and holidays) with the patient with schizophrenia; age above 17 years; not involved in caregiving to other(s) person(s) with mental or physical illness

Measures

Patient and informal carer questionnaires

Experience of Caregiving Inventory (Szmukler et al., 1996; Portuguese translation: Gonçalves Pereira, 2005)

Family Questionnaire (Quinn et al. 2003; Portuguese translation: Luísa Campos, 2005) *Carer's Assessment of Satisfactions Index*; *Carer's Assessment of Managing Index*; *Carer's Assessment of Difficulties Index* (Nolan et al., 1996; Portuguese translation: Luísa Brito and João Barreto, 2000)

Brief Symptom Inventory (Derogatis, 1993; Version: MC Canavaro, 1995)

Procedures

Application of self-report measures to a set of informal carers of patients with schizophrenia (in small groups), between May of 2005 e March of 2006

CONCLUSION

- All the patients have diagnosed schizophrenia and almost half are integrated in occupation centres or are in professional rehabilitation.
- Predominant dyad "mother-son", majority of primary carers, with a good level of education, some ties with family associations and with no psychopathology.
- Symmetrical distribution of positive and negative ECI.
- Low perception of illness, good level of sources of satisfaction and predominant use of problem-focused coping strategies.
- Positive EC correlated with the perception of effective use of problem-focused cognitive coping strategy – Managing meanings/Perceptions - and with the perception of Intrapersonal satisfactions as a result of caregiving.
- Negative EC, carer does not perceive sources of satisfaction, but difficulties, and uses, predominantly, the emotion-focused coping strategy – Managing stress.
- These data could be important to develop more effective interventions, reducing negative experiences and promoting the positive experiences of caregiving, through the modification of the assessments and the development of coping skills (3,11), which should be more effective, that consequently, will improve the psychological health of the carers.
- Based on all of this, we understand that the EC is a valid concept (3, 4, 11) and more appropriate for the development of works on caregiving to patients with schizophrenia.

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Carers and Family associations/institutions
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RESULTS

1. DESCRIPTION OF CARERS AND PATIENTS WITH SCHIZOPHRENIA

Table 1. Characteristics of carers and patients with schizophrenia

Carers	Patients
Sex 80% female Age median (P10-P90) 57 (39-71)	Sex 82% male Age median (P10-P90) 38 (24-45)
Civil Status 52% married/cohabiting Number of children 66% ≥ 2 children	Civil Status 87% single Number of children 91% without children
Education level 2% illiterate 20% 1 st cycle 22% 2 nd cycle 18% secondary 36% baccalaureate/graduate/master	Education level 2% 1 st cycle 38% 2 nd cycle 38% secondary 22% university freq./baccalaureate/graduate
Occupation 47% at home/unemployed/retired 33% employed Number of people who live in household 96% ≥ 2 people	Occupation 86% at home/unemployed/retired 14% employed Where With who they live 87% family environment Years of illness 83% ≥ 5 years
Age of diagnostic contact with the patient 88% daily Relationship with patient 64% mother 14% father 4% spouse 12% sibling 2% child 4% other relative/friend	Age of diagnostic contact with the patient 20 (17-31) Current patient support 92% psychiatric 65% psychological 20% social 43% group 68% social-occupational forum 22% socio-professional rehabilitation

Table 2. Questionnaire - other questions

Question	Answers (%)
Do you consider yourself the primary carer of the patient?	96% yes
Do you consider that the patient has professional support?	78% yes
Do you consider that the patient has family support?	88% yes
Has the patient already had behaviour problems that were treated by the justice system, court or police?	72% no
Do you feel to have knowledge about the illness?	67% some / 10% a lot
Do you feel to have control over the patient?	46% some / 22% a lot
Because of the problem of the patient, are you followed professionally?	74% no

Source of data collection

90% family associations
4% private doctor's office
Place of residence
14% north
54% center/south

Carers are almost all female and consider themselves primary carers.

The majority are mothers, married/cohabiting, with secondary education or above, living at home, living with the patient with schizophrenia and/or in daily contact, consider they have some or a lot of knowledge about the illness and control over the patient, and they are not followed professionally because of the problem of the patient.

A large majority considers that the patient has family and professional support and that he/she never had more serious behaviour problems.

They don't have psychopathology with clinical evidence evaluated by the BSI.

Patients with schizophrenia are almost all male, single, unemployed, without children, living with their family, have 5 years or more of illness, have secondary education or above and are followed psychiatrically.

It's worth pointing out that 42% of the patients are in a socio-occupational forum or in socio-professional rehabilitation.

Present sample was collected almost entirely in family associations, and is symmetrically distributed between the north and center/south of the country.

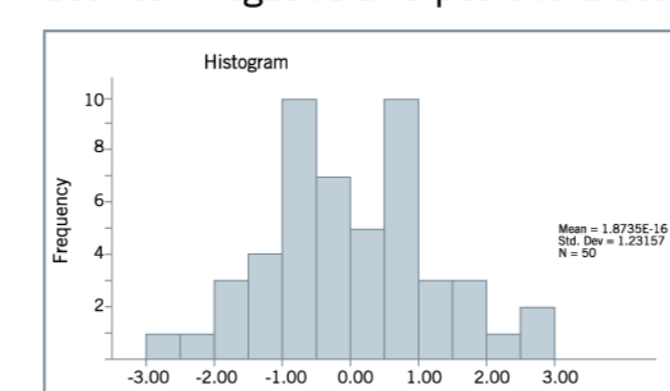
2. ANALYSIS OF THE EXPERIENCE OF CAREGIVING

2.1 Experience of Caregiving (Experience of Caregiving Inventory - ECI)

Table 3. Sub-scores and global scores of negative and positive ECI

Negative ECI Scales	Total average (sd)
Difficult behaviours	16.5 (7.5)
Negative symptoms	13.0 (6.0)
Stigma	4.9 (4.2)
Problems with services	13.9 (8.9)
Effect on family	10.4 (6.2)
Need to backup	13.4 (4.8)
Dependency	11.7 (4.8)
Loss	11.7 (5.2)
Global Negative ECI (0-208)	95.5 (35.9)
Positive ECI Scales	Total average (sd)
Positive personal experiences	17.8 (7.1)
Good aspects of relationship	14.3 (6.4)
Global Positive ECI (0-56)	32.2 (10.1)

Figure 1. Distribution of values of the difference between negative and positive Z scores of the ECI



Picture 1. Correlation of negative and positive Z scores of the ECI

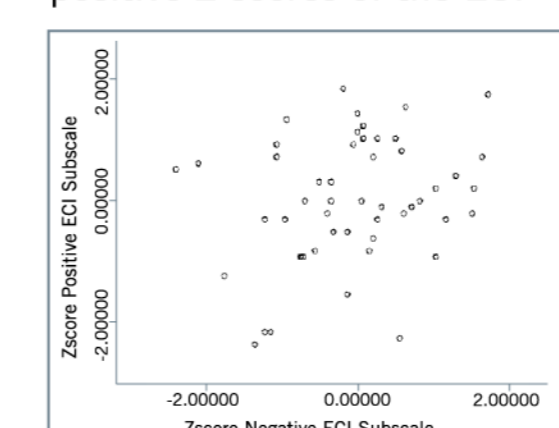


Table 4. Comparison of average negative and positive Z scores of the ECI

Average	SD	Paired Differences		t	df	Sig. (2-tailed)
		Mean	Std. Error			
Z score: Negative ECI						
Z score: Positive ECI						
Z score: Difference						

Z score: Negative ECI
Z score: Positive ECI
Z score: Difference

* Paired Samples Test

Observed symmetrical distribution of Z scores of the ECI.

No significant correlation between the negative and positive dimensions of the ECI.

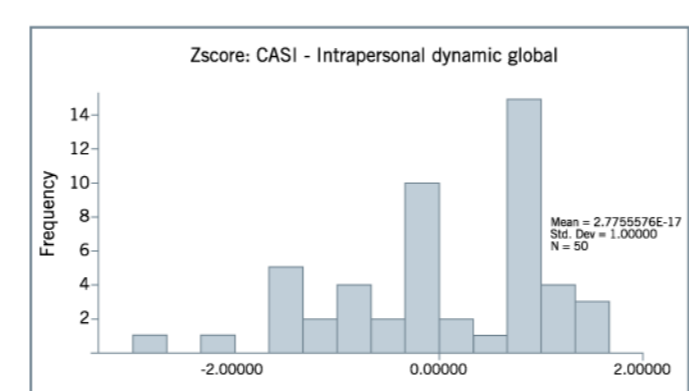
No significant differences between positive and negative Z scores.

Possibly the averages of the negative ECI and the positive ECI are similar.

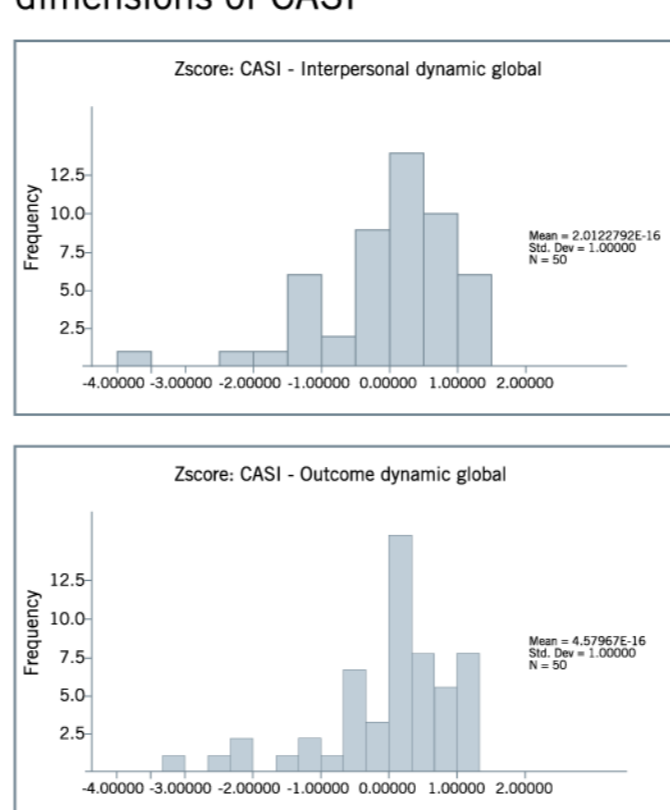
2.3 Perception of difficulties, of sources of satisfaction and of coping (Carer's Assessment of Difficulties Index - CADI; Carer's Assessment of Satisfactions Index - CASI; Carer's Assessment of Managing Index - CAMI)

Table 6. Sub-scores of CASI (perception of possible sources and degrees of satisfaction)

Sub-scales	Total average (sd)
Satisfactions derived from interpersonal dynamic (0-27)	19.6 (5.3)
Satisfactions derived from intrapersonal dynamic (0-42)	27.9 (10.4)
Satisfactions derived from outcome dynamic (0-21)	14.9 (4.7)



Figures 2, 3 and 4. Distributions of relative frequencies of the different dimensions of CASI



Results of the three dimensions of CASI show that carers perceived a positive level of sources and degrees of satisfaction.

Based on the distributions of Z scores, it can be observed that the predominantly positive perceptions can be found in the dimensions of satisfaction derived from interpersonal dynamic and from outcome dynamic.

2.2 Perception of frequency of symptoms, concern and ability to cope (Family Questionnaire - FQ)

Table 5. Sub-scores and scores of FQ

Scales	Total frequency average (sd)	Total concern average (sd)	Total coping average (sd)	Total constructed score average (sd)
Negative symptoms	18.3 (4.7)	16.5 (7.1)	15.3 (6.9)	48.8 (19.9)
Antisocial behaviours	15.1 (3.6)	10.5 (6.5)	9.8 (7.3)	33.7 (17.2)
Intrapersonal problems	17.0 (5.0)	13.0 (7.4)	12.5 (7.8)	39.5 (19.8)
Affective symptoms	14.1 (3.4)	11.2 (5.5)	11.0 (5.5)	34.6 (14.4)
Psychotic symptoms	12.4 (3.7)	9.4 (5.5)	9.5 (5.9)	29.3 (14.9)
Scores	76.6 (15.0)	57.4 (26.5)	54.8 (27.9)	185.1 (67.9)
	(44-132)	(44-132)	(44-132)	(132-396)

Low perception of the frequency of symptoms and behaviours of schizophrenic illness, and an even lower evaluation of their relative degree of concern.

The carers of this sample have a good perception about the resolution of the concern above.

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