

FAMILY BURDEN AND SOCIAL SUPPORT IN MENTAL ILLNESS

Researchers:

Dr. Josy K. Thomas, MSW, MPhil, PhD

FaPMI (Families where a Parent has a Mental Illness) Coordinator
Mental Health Services, South West Healthcare
Warrnambool, VIC, Australia

&

Dr. Melissa Petrakis, PhD

Prof Rosemary Sheehan, PhD

Department of Social Work, Monash University, Melbourne



Introduction

- Deinstitutionalisation movement in the 1960s and 70s
- Moving mental patients out of the institutions into the community resulted in the families of those patients becoming the 'institution of choice' (Parker, 1993).
- Caregiver burden in mental illness - almost 80% of caregivers experience burden in the caregiving role (Magliano, 2005).
- Family members - parents, spouses, siblings, and children.
- Caregivers may feel stressed, anxious and low, and in the long run there may occur burnout and emotional exhaustion (Kate et al., 2013).



Concept of Family Burden

- The term 'family burden', 'burden of care' or 'caregiver burden' in mental illness - extent of suffering experienced by the family of a psychiatric patient (Pai & Kapur, 1981).
- Platt (1985) - "the difficulties and problems suffered by the patient's household and his/her significant others".
- The existence of burden - the breakdown of reciprocal arrangements that people maintain in their relationships so that some persons have to do more than their fair share (Fadden et al., 1987).
- Schene (1990) dealt with 'objective' and 'subjective' dimensions of family burden to develop an integrative framework for research.
- 'objective burden' - specific effects of the illness on the household
- 'subjective burden' - the distress experienced by the family members with regard to these factors.



Concept of Social Support

- 'Social support' - perceived by the recipient of that activity as esteem enhancing or stress related interpersonal aid or emotional support, cognitive restructuring or instrumental aid.
- Cobb (1976) - social support as 'information leading the individual to believe that he or she is loved, cared for, and is esteemed, and that he or she belongs to a system of mutual obligations and expectations'.
- Lin et al. (1979) - social support of an individual as 'a function of his/her ties to other individuals, groups or to the society at large'.
- Hatfield & Lefley (1993) - social support as 'the extent to which a family's social needs, such as affection, belonging, confidence, encouragement, friendship, esteem, respect, validation, and identity are met through relationships with other people.



Literature Review

- Initially researchers focus on caregiver burden
- Studies assessing social support gaining attention due to its effectiveness on promoting psychological well-being.
- It reduces or buffers the adverse psychological impacts or exposure to stressful life-events and ongoing life strains.
- Reviewed 50 years of research (1960s to 2010s) - screened over 450 studies worldwide.
- Agreement in the literature that burden exists.
- Last three decades - families of individuals affected with mental illness received more research attention
- Focus on caregiver characteristics - relationship to the patient and gender, family education and support, and the importance of family needs assessment.



Rationale of the study

- In India, more than 90% of patients with severe mental illness live with their families (Thara et al., 1994; Chadda, 2001).
- Mental health interventions in India are still predominantly institution-based.
- Once a patient is discharged from hospital - responsibility of the family to care for the patient in the community.
- The families left on their own to shoulder this burden
- Limited resources available from both government and non-government organisations.
- The caregivers feel isolated from the society, due to restriction of their social and leisure activities, and social discrimination and stigma attached to the mental illnesses.



- Only limited number of studies dealt with various aspects of social support and its relationship with patient functioning and burden of care (Kohn-Wood and Wilson, 2005; Chiou et al., 2009; Hsiao, 2010; Moller-Leimkuhler and Wiesheu, 2012; Ae-Ngibise et al., 2015).
- Studies in India (Ali and Bhatti, 1988; Aggarwal et al., 2011; Kate et al., 2013; Jagannathan et al., 2014) focused on burden of care in schizophrenia.
- No systematic study conducted in India on examining the relationships among severity of mental illness, burden of care and social support (patient's as well as caregiver's
- Hence the present study was conceived and carried out.



Aims of the Study

- To assess patients' global functioning and social support perceived by them, and family burden and social support perceived by the caregivers.
- To examine associations among these key variables, and clinical and socio-economic factors.
- To compare these parameters across different groups



Methodology

- **Research Design:** Quantitative Descriptive study
- **Study Setting:** Institute of Mental Health (IMH), Hyderabad, India
- **Ethical considerations:** Study subjects provided informed verbal consent
- **Sampling Method:** Non-probability sampling, sample was drawn purposively and consecutively meeting certain inclusion and exclusion criteria:

Inclusion Criteria

- Patients with a diagnosis of either schizophrenia or mood disorder (major mental illnesses)
- Patients of either gender in the age range of 18 - 60 years
- Patients with minimum of two years illness duration
- A key relative (caregiver) above 18 years staying with the patient at least for 3 previous years, prior to the assessment

Exclusion Criteria

- Patients with any chronic physical illness, organic problems, intellectual disability and substance dependence
- Families where another family member had a mental or chronic physical illness



Study Instruments

- The data were gathered through interview method.
- The instruments used for data collection:
 - Socio-demographic and clinical proforma.
 - Global Assessment of Functioning (GAF) Scale from DSM-IV to assess patients' severity of illness. (10 point scale)
 - Social Support Questionnaire (SSQ) developed by Nehra & Kulhara (1987) to measure patient's perceived support (18 items)
 - Social Support Network Inventory (SSNI) developed by Flaherty et al. (1983) to measure caregiver's perceived support. (11 questions, 5 supports, 11x5 matrix, 55 responses)
 - Family Burden Interview Schedule developed by Pai & Kapur (1981) to assess the family burden experienced by caregivers. (24 items)



Procedure of the Study

- 120 patients and 120 caregivers each were recruited for the study (total $120+120=240$)
- The sample was drawn on an in-patient basis.
- A key relative (caregiver) chosen while staying or visiting the patient at the hospital.
- Socio-demographic and clinical details gathered from the key relative/hospital files.
- Global functioning of patients assessed by the treating psychiatrist.
- Patients were administered Social Support Questionnaire.
- Key relatives were administered Social Support Network Inventory and Family Burden Interview Schedule.



Statistical Analysis

- 8 samples were excluded due to incomplete/missing data - final sample is 224 (112 patients + 112 relatives)
- Data entry and in Ms office excel
- Data management and analysis in SPSS (version 23)
- Normality tests used - Kolmogorov-Smirnov and Shapiro-Wilk
- Statistical tests used- both parametric and non-parametric depending on the distribution of data
- Tests included χ^2 test, Karl Pearson's correlation, Spearman's correlation co-efficient, Independent Samples ' t ' test and Mann-Whitney u -test'

Study Findings

1. Socio-demographic Details of Patients

Variable	N=112 (%)	Variable	N=112 (%)
Age (in years)		Occupation	
18-25 (Youth)	38 (33.9)	Unemployed	74 (66.1)
26-35 (Young Adults)	42 (37.6)	Elementary occupations	27 (24.0)
36-50 (Middle Adults)	24 (21.4)	Skilled occupations	11 (9.8)
51-65 (Late Adults)	8 (7.1)		
Gender		Monthly Income (in Indian rupees)	
Male	52 (46.4)	No income	74 (66.1)
Female	60 (53.6)	Up to 2000	25 (22.3)
		2001-5000	8 (7.1)
Marital Status		Above 5000	5 (4.5)
Unmarried	47(42.0)		
Married	55 (49.1)	Place of Residence	
Others	10 (8.9)	Rural	76 (67.9)
		Urban	36 (32.1)
Education		Religion	
Illiterate	29 (25.9)	Hindu	99 (88.4)
Primary school	29 (25.9)	Muslim	11 (9.8)
High School	33 (29.5)	Christian	2 (1.8)
Higher secondary	9 (8.0)		
Graduate & above	12 (10.7)		

2. Clinical Details of Patients

Variable	N=112 (%)
Diagnosis	
Schizophrenia	54 (48)
Mood Disorders	58 (52)
Age at Onset of Illness (in years)	
Below 18	18 (16.1)
18-25	34 (30.3)
26-35	45 (40.2)
Above 35	15 (13.4)
Duration of Illness (in years)	
2-5	83 (74.1)
6-10	21 (18.8)
Above 10	8 (7.1)
Family History of Psychiatric Illness	
Yes	44 (39.3)
No	68 (60.7)
History of Substance Abuse	
Yes	19 (17.0)
No	93 (83.0)

3. Socio-demographic Details of Relatives

Variable	N=112 (%)	Variable	N=112 (%)
Relationship with Patient		Occupation	
Parent	65 (58.0)	Unemployed	30 (26.7)
Spouse	34 (30.3)	Elementary occupation	69 (61.6)
Sibling	7 (6.3)	Skilled occupation	13 (11.7)
Child	6 (5.4)		
Gender		Type of Family	
Male	59 (52.7)	Nuclear	66 (58.9)
Female	53 (47.3)	Joint	46 (41.1)
Age (in years)		Size of Family	
18-25 (Youth)	7 (6.3)	Below 5	36 (32.1)
26-35 (Young Adults)	18 (16.1)	5-8	67 (59.8)
36-50 (Middle Adults)	41 (36.6)	Above 8	9 (8.1)
51-68 (Late Adults)	46 (41)		
Marital Status		Monthly Family Income (in Rupees)	
Unmarried	5 (4.5)	Below 3000	17 (15.2)
Married	101 (90.1)	3000-5000	75 (67.0)
Others	6 (5.4)	Above 5000	20 (17.8)
Education		Role of Relative in the family	
Illiterate	58 (51.8)	Guardian	53 (47.3)
Primary school	24 (21.4)	Supplementer	53 (47.3)
High school	13 (11.6)	Others	6 (5.4)
Secondary school & above	17 (15.2)		

4. Assessment of Patients' Functioning, Family Burden and Social Support

Variable	Schizophrenia N=54 (%)	Mood Disorder N=58 (%)	Significance
Global Assessment of Functioning			
Mean	30.93	46.72	p<0.0001
SD	7.338	10.985	
Patients' Perceived Social Support			
Mean	34.96	40.21	P<0.0001
SD	3.464	5.071	
Global Family Burden			
Mean	25.15	21.02	P<0.0001
SD	2.851	4.439	
Relatives' Perceived Social Support			
Mean	87.81	88.91	NS
SD	6.168	7.603	

Severity of Illness and Subjective Family Burden

Variable	Schizophrenia N=54 (%)	Mood Disorder N=58 (%)	Significance
Patient's Severity of Illness			
Severe	44 (81.5)	7 (12.1)	P<0.001
Moderate	10 (18.5)	49 (84.5)	
Mild	0	2 (3.4)	
Subjective Family Burden			
Severe burden	52 (96.3)	29 (50.0)	P<0.001
Moderate burden	2 (3.7)	29 (50.0)	
No burden	0	0	



5. Associations among Patients' Global Functioning, Social Support and Family Burden

Association	Level of Significance		
	Schizophrenia (N=54)	Mood Disorder (N=58)	Overall (N=112)
Patients' Global Functioning vs Patients' Perceived Social Support	NS	p<0.01 Direct	p<0.01 Direct
Patients' Global Functioning vs Global Family Burden	NS	p<0.05 Inverse	p<0.01 Inverse
Global Family Burden vs Subjective Burden	p<0.01 Direct	p<0.01 Direct	p<0.01 Direct
Patients' Perceived Social Support vs Global Family Burden	p<0.05 Inverse	NS	p<0.01 Inverse
Relatives' Perceived Social Support vs Global Family Burden	NS	NS	NS
Patients' Perceived Social Support vs Relatives' Perceived Social Support	NS	NS	NS

Conclusion & Implications of the Study

- Families of patients affected with schizophrenia experienced significantly higher burden as compared to families of patients with mood disorder.
- The global functioning of patients with schizophrenia and the social support perceived by them was lower than the patients with mood disorder.
- Social support perceived by the caregivers was lower and similar in both diagnostic groups.
- Clinical management of patients with severe mental illness needs to be combined with addition of family interventions such as education about the illness, assessment of family's needs, strengths, and weaknesses, training in problem-solving skills, and improving communication skills.



- Need to design interventions that help caregivers to effectively cope with burden to prevent ensuing psychological morbidity in themselves.
- Establishing and strengthening the family's social network will be a useful strategy to alleviate their burden.
- Awareness programs to be undertaken in the society to reduce stigma in society about mental illness.
- This can address social isolation of family and caregivers, which in turn, can enhance social support of both patients and caregivers.
- Research and policy should consider measures to maintain and strengthen extended family network ties in developing countries like India.



Thank you

