ORIGINAL RESEARCH PAPER

Psychosocial Needs of the Families with a Person with First Episode Psychosis

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ABSTRACT

Background: The people who experience psychotic symptoms first time can be frightening for them and their close family members. It is crucial to provide family support and care to persons with first episode psychosis. **Aim:** To assess the needs of family members presenting to a tertiary care centre. **Methods:** Cross-sectional outpatient based study design was adapted to collect data from the family members of persons with first episode psychosis presented to a tertiary care centre. Total 60 family members were randomly selected for the study and assessed for the burden, attitude, ways of coping and quality of life. **Results:** Study results indicate the high burden; it has noted that high negative expressed emotions among family members. Negative coping styles were also found and the family members and having a poor quality of life. **Conclusion:** First episode of psychosis can traumatizing to the patients and their family members. Family members can experience the burden of caregiving including financial burden, can have faulty ways of coping and negative expressed emotions towards their own wards having psychosis which can lead to poor treatment outcome. Findings indicated that need to provide psychosocial intervention for family members of persons with first episode psychosis.

Keyword: Family, psychosocial intervention, needs, first episode psychosis, expressed emotions, burden

INTRODUCTION

The experience of psychotic symptoms can be frightening to people who have such symptoms, and to the people who are close to their lives. It may be traumatic to experience to see that one beloved family member declined in functioning, lose orientation and touch with his or her surroundings. This will be upsetting and provoke anxiety about the normal behaviour of the affected person. Moreover having once loved or one close family member with mental illness can have a devastating effect on one's identity and self-esteem. An individual who presents at a clinical setting with psychosis and who has never previously presented at a clinical setting with psychosis is identified as experiencing their 'first-episode psychosis'.[1]

The first episode of psychosis usually occurs in late adolescence to early adulthood.[2-3] The few years following the emergence of symptoms are considered to be a "critical period" involving the greatest clinical deterioration determining the future course and prognosis of the illness and offering a window for ensuring optimal support and treatment.[4,5] Delays in accessing treatment after the onset of psychosis have a median of 8-11 months with longer duration being associated with poorer outcome.[4-7] Moreover, service users with the first episode of psychosis report high levels of trauma, commonly present with self-harm, social and vocational difficulties.[8-10] Diagnostic uncertainty can often follow the first episode and long-term outcomes are unclear.[11] An increased number of episodes or relapses during the early stages of psychosis is associated with poorer clinical and recovery outcomes.[12-14]

Access the Article Online	
DOI: 10.29120/IJPSW.2019.v10.i1.138	**Quick Response Code**
Website: www.pswjournal.org	

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How to Cite the Article:
Kapse PP, Kiran M. Psychosocial needs of the families with a person with first episode psychosis. Indian Journal of Psychiatric Social Work 2019:10(1):56-61.

Family support is relevant for persons with mental illness particularly for the persons with early psychosis as the onset of illness is often at the time when many of them are young.[15-17] Evidence confirms that family support can be linked to significantly lower the rates of relapse and re-hospitalization, improved mortality and treatment engagement.[18-20] Crucially, the manner in which family members respond to the condition has considerable influence on illness course. High levels of critical comments, hostility and emotional over-involvement of family members are associated with poorer treatment outcomes including more frequent relapse and hospitalization in people with longstanding psychosis and relatives reporting higher burden of care and less adaptive coping strategies.[21-25] So, the present study was intended to identify the psychosocial intervention needs in the areas of family burden expressed emotion, coping and quality of life of family members presented with a relative with first episode psychosis.

METHODS AND MATERIALS

This was a cross-sectional hospital-based study. Participants were selected from the out-patients department of Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi, India a tertiary care hospital for mental illness. The Department Research Committee has provided permission for the study. Informed consent was obtained from the patients before recruitment in the study. Total of 60 participants between 21-35 years of age presented with first episode psychosis (as operationally defined, an individual who presents at a clinical setting with psychosis and who has never previously presented at a clinical setting with psychosis is identified as experiencing their 'first-episode psychosis')[1] at the out-patients department was randomly selected for the study. Those who were having any co-morbid psychiatric disorder or severe physical illness were excluded.

Those primary caregivers (family members) of persons with first-episode psychosis who were staying with them since last one year and expected to continue staying with them during the study period; aged above 21 years and able to read and write Hindi, or English language. Family members with history or presence of any psychiatric illness or severe physical illness were excluded and also having a psychiatric illness in more than one family member.

Tools Used

Socio-demographic Datasheet: A semi-structured data sheet was specially designed to collect the socio-demographic details of the patients and family members.

Attitude Questionnaire: Attitude questionnaire is a measurement of expressed emotion of the key-relatives towards their wards. This questionnaire consists of 30 questions relating to a number of critical comments, hostility, dissatisfaction, warmth and emotional over involvement by a key relative towards the patient.[26]

Family Burden Interview Schedule: This instrument consists of seven domains and one extra category to account for any other burden on the family about which they were not asked. The authors have included 24 items in the instrument and also another two mutually exclusive additional questions in the schedule. The schedule has to be filled and burdens rated by skilled raters on a three-point scale of severe burden-2, moderate burden-1 and no burden-0. Each item clearly shows the intent behind it.[27]

Ways of Coping Questionnaire: This test was developed by Folkman and Lazarus. The ways of the coping questionnaire are designed to identify the thoughts and actions an individual has used to cope with a specific stressful encounter. It measures coping processes, not coping disposition or styles.[28]

WHO Quality of Life BREF: It encompasses 26 items, which measure the six domains: physical health, psychological health, social relationships, and environment. The items are based on 5 points Likert Scale. The higher the score, the higher is the quality of life.[29]

RESULTS

Socio-demographic Details

Table 1 shows the socio-demographic details of participant's family members. Mean age of the family members 35.75 years. Male family members were 49(81.7%) and female 11(18.3%). Regarding education 22(36.7%) studied up to primary followed by secondary 21(35.0%), higher secondary and graduation by 7(11.7%) each and only 3(5%) studied up to post-graduation or other professional courses. By occupation 18(30%) was a farmer, 18(30%) were a small business, 6(10.0%) each were professional/Govt. employee and homemaker, 12(20%) had other occupation. Regarding marital status 11(18.3%) never married and 49(81.7%) married.

Table 1 Socio-demographic details of caregivers

Variables	**Category**	**Mean±SD/ N (%)**
Age		35.75±11.69
Gender	Male	49(81.7)
	Female	11(18.3)
Education	Primary	22(36.7)
	Secondary	21(35.0)
	H. Secondary	7(11.7)
	Graduation	7(11.7)
	PG/Professional	3(5)
Occupation	Farmer/Agri.	18(30.0)
	Small Business	18(30.0)
	Professional/ Govt. employee	6(10.0)
	Homemaker	6(10.0)
	Other	12(20.0)
Marital Status	Never Married	11(18.3)
	Married	49(81.7)

Table 2 shows the socio-demographic details of persons with first episode psychosis. Mean age of the patients was 27.76(8.08) years. Male participants were 35(58.3%) and female 25 (41.7%). Regarding education 16 (26.7%) studied up to primary, secondary 28(46.7.0%), Higher secondary 8(13.3%), graduation by 7(11.7%) and only 1(1.7%) studied up to a postgraduate degree or other professional courses. By occupation 10(16.7%) were farmers, 5(8.3%) were small business people, 6(10.0%) each were professional/Govt. employee and homemaker, 12(20%) had other occupation. Regarding marital status, 26 (43.3%) of them were never married, 31 (51.7%) married and 3(5%) widow/widower. Regarding domicile 36(60.0%) of them were rural, 16(26.7%) semi-urban, 8(13.3%) of them were from an urban background. By religion 37(61.7%) belonged to Hindu religion, 12(20%) Islam, 10 (16.7%) Sarna and 1(1.7%) Christian.

Table 2 Socio-demographic details of the PWFEP

Variables	**Category**	**Mean±SD/ N(%)**
Age		27.76±8.08
Gender	Male	35(58.3)
	Female	25(41.7)
Education	Primary	16(26.7)
	Secondary	28(46.7)
	H. Secondary	8(13.30)
	Graduation	7(11.70)
	Post- Graduation	1(1.70)
Occupation	Farmer	10(16.7)
	Small Business	5(8.30)
	Professional/ Govt. Service	3(5.00)
	Homemaker	19(31.7)
	Unemployed	23(38.30)
Family Type	Nuclear	35(58.30)
	Joint	22(36.70)
	Extended	3(5)
Marital Status	Never Married	26(43.30)
	Married	31(51.70)
	Widow/ Widower	3(5.00)
Domicile	Rural	36(60.00)
	Semi-urban	16(26.70)
	Urban	8(13.30)
Religion	Hindu	37(61.70)
	Islam	12(20.00)
	Sarna	10(16.70)
	Christian	1(1.70)

Table 3 Family burden of caregivers

Domain	**Mean±SD**
Financial Burden	7.28±2.76
Disruption of routine	4.36±2.31
Disruption of Leisure time	3.25±2.01
Disruption of family interaction	4.85±2.16
Physical Health	2.01±1.01
Mental Health	1.86±0.98

Table 3 displays the score in various domains of the family burden interview schedule. The financial burden had 7.28±2.76, disruption of family routine had 4.36±2.31, disruption of leisure time 3.25±2.01, disruption of family interaction 4.85±2.16, physical health 2.01±1.01 and mental health had 1.86±0.98. This indicates that family members had moderate to severe level of burden of caregiving to persons with first episode psychosis.

Table 4 Expressed emotions of caregivers

Domains	**Mean±SD**
Critical Comments	6.45±1.66
Hostility	8.1±2.30
Dissatisfaction	7.7±1.67
Emotional Over Involvement	8.83±2.29
Warmth	6.66±1.79

Table 4 shows the expressed emotions among the family members. Negative expressed emotions i.e. critical comments mean score 6.45±1.66 indicates a high level of critical comments by the family members, regarding hostility, mean score 8.1±2.30 indicates high hostility. Regarding dissatisfaction, 7.71±1.67 indicates high dissatisfaction among family members and emotional over-involvement 8.83±2.29 and positive expressed emotion (warmth) mean 6.66±1.79 this shows that family members had a high score on negative expressed emotions domains.

Table 5 ways of coping in caregivers

Domains	**Mean±SD**
Confrontive Coping	8.98±2.93
Distancing	8.45±3.50
Self-controlling	11.76±3.67
Seeking Social Support	9.33±2.44
Accepting Responsibility	5.65±2.77
Escape-Avoidance	12.15±4.00
Planful Problem-solving	8.73±3.03
Positive Reappraisal	10.35±3.94

Table 5 shows the ways of coping with family members. Regarding confrontive coping 8.98(±2.93)mean score, distancing 8.45±3.50, self-controlling 11.76±0.47, seeking social support 9.33±2.44, accepting responsibility 5.65±2.72, escape-avoidance 12.15±4.00, planful problem-solving 8.73±3.03 and positive reappraisal mean 10.35±3.94. Mean score indicates that positive ways of coping planful problem-solving, positive reappraisal, seeking social support, accepting responsibility had minimal adoption however negative ways of coping was highly adopted by the participants.

Table 6 shows the various domains of quality of life. Mean score for physical quality of life is 9.81±2.70, psychological quality of life 8.28±2.84, regarding social relationship quality of life 4.35±1.88 and environmental quality of life mean score indicates 11.21±4.51 which correspond as low quality of life among the family members.

Table 6 Quality of life of family members

QOL **Domains**	**Mean + SD**
Physical	9.81±2.70
Psychological	8.28±2.84
Social Relationship	4.35±1.88
Environmental	11.21±4.51

DISCUSSION

Family members of persons with psychosis have a crucial role in seeking professional care. [17,30] Several studies have also shown that family members often feel despair, fears and concerns regarding professional support. Results of the study show that family member having the burden in various domains, another study has also shown a higher burden among family members.[31]

The study also revealed that participant's family members had a high score on the negative expressed emotions corresponding with another study.[32]

In the present study, confrontive coping, distancing, self-controlling escape-avoidance and negative styles of coping were being used largely by the family members. This is in line with other studies indicating the high negative coping adopted in the careers of persons with first episode psychosis.[33-35] In the present study, family members were having a lower quality of life. The several studies report poor quality of life family members of a person with mental illness.[36-37]

Overall study results reveal the immediate and urgent need for psychosocial intervention for the family members presented with the first episode psychosis patients. Since the nature of the illness is acute and many times family members do not know what is happening with patients. How to handle the patients in the illness situation especially in an acute episode with aggression or violence. Hence it is imperative that the current clinical management should include the outpatients' based psychosocial intervention models to address the high burden, expressed emotions and negative coping and low quality of life among the family members. So, the family members accompanying the patients can also seek help in dealing with these needs aroused from the caregiving to persons with first episode psychosis.

CONCLUSION

The study results revealed family members presented at tertiary care centre with persons with first episode psychosis can have various psychosocial intervention needs. Caring for persons with psychosis can be distressing and need professional help to deal with the burden, expressed emotions, negative coping and poor quality of life.

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Source of Funding: The paper is a part of the Ph.D. thesis work carried out by the first author under the guidance of the second author during the period 2009 to 2013 at the department of psychiatric social work RINPANS, Ranchi. During the study period, the first author received a scholarship from the Institute

Conflict of interest: None

Ethical Clearance: Taken