CHAPTER II

REVIEW OF LITERATURE

Literature Review and Theoretical Perspective

This section reviews literature pertaining to family caregivers’ experiences of caring for their PWCMI and the multi-dimensional concept of burden. A comprehensive literature review was conducted to examine the current state of knowledge regarding the burden of family caregivers. It consists of research studies on psychosocial aspects of burden on caring of persons with chronic mental illness, family distress and its impact on emotional distress or emotional well-being of family caregivers, conducted both in India and elsewhere. Perhaps the most significant discovery of this section is the absence of a body of current Indian research addressing the gender differences in care-giving roles, psychosocial issues and needs of kinsman relationship of FCGs, the consequences of globalization and place of residence and intervention model that is culturally appropriate and brief which address the needs of both FCG’s and their PWCMI, using Social Work Methodologies and Burden of FCGs of in-patient PWCMI. This fact, in itself highlights the need for this study.

Maurin and Boyd (1990) noted that research findings about burden should be interpreted with some caution because many studies did not employ a theoretical framework. They wrote, “Without a theoretical framework, the designation of burden as a dependent or independent variable is an arbitrary one” (p. 102). The lack of an adequate theoretical framework leads to inconsistent use of theoretical and operational definitions and reliability and validity flaws in the measurement of burden. Furthermore, as developed, this theoretical approach is incomplete in addressing the range of care-giving experience—in particular, the possible benefits and positive relationships between the family caregiver and the ill relative. Instead, the single negative perspective is taken toward the experience of caring for a person with mental illness. Research suggests that there are both gratifications and rewards in care-giving (Greenberg, Greenley & Benedict, 1994). These are overlooked in the current theoretical approaches. Szmukler et al. (1996) noted the problems of operationalizing the concept of caregiver burden as a distinct burden. They debated
whether objective burden is a normal disruption in the caregiver’s usual life in terms of its effects on work or social life. They argued that some burdensome activities, such as household routines, are the same as those that occur when other families experience any normal life change. Therefore, caregivers might experience burden regardless of the presence or absence of an ill family member. Similarly, Gubman and Tessler (1987) and Pickett, Vraniak, Cook, and Cohler (1993) argued that the experience of caring for a relative with a mental illness might be considered a normal stress leading to enhanced growth. Therefore, the critical question is, How can we confidently assume that the burden is attributable to the mental illness of a family member?

In recent years, research on family care-giving has gone beyond the purely descriptive to investigate the physical and psychological consequences of care-giving (George & gwyther, 1986). Research on families caring for persons with mental illness has been largely limited to studies describing the nature and predictors of caregiver burden. In the West, studies have found that burden of family caregivers of the chronic mentally ill does impact their financial, physical, emotional, and psychological health, (Hirst, 2005). However, in India, this has not received due attention and very few studies (Mridula & Prabhu, 2008) have attempted to determine the relationship between burden of family caregivers, family distress and emotional distress.

**Indian Studies on Family Burden, Distress and Emotional Well-being**

In the West, studies have found that burden of family caregivers of the chronic mentally ill does impact their financial, physical, emotional and psychological health, (Hirst, 2005). However, in India, this is not received due attention and very few studies (Mridula & Prabhu, 2008) have attempted to determine the relationship between burden of family caregivers, family distress and emotional distress.

Studies on burden of family caregivers, family distress and emotional distress in India have been conducted since the past few decades. Early studies indicated that the mentally ill persons were perceived as a financial liability and as a source of disturbance to family life (Sathyavathi & Golam, 1976). Kulhara and Wig (1978) found that female patients were able to function adequately in their role as
housewives but that the illness was more disabling for young patients, as it affected their education.

Burden was perceived by family members mainly in the areas of finance, interpersonal relationships and physical and mental health of the caregivers (Muralidhar & Shariff, 1981). In a study by Giel et al (1983) as part of the WHO Collaborative Study on Strategies for Extending Mental Health Care, 259 families from four developing countries (Colombia, Sudan, India and the Philippines), were evaluated with regard to the social burden faced due to the mental illness of a family member. It was found that psychosis caused more economic burden and social burden was found to be greater in urban than in rural areas.

The studies in this section of the review have been categorized under five subheadings:-

- Studies related to prevalence of schizophrenia
- Gender differences in family care giving of PWCMI
- Burden of Caring:
  - Family Distress
  - Emotional Distress
- Intervention studies

Studies related to prevalence of schizophrenia

Recent systematic reviews have encouraged the psychiatric research community to re-evaluate the contours of schizophrenia epidemiology. Studies that report the prevalence of schizophrenia are important to estimate the proportion of population affected with chronic schizophrenia. The prevalence proportion can provide insights into the incidence rates and also to estimate the burden of disorder. Understanding the prevalence of schizophrenia has important implications for both health service planning and risk factor epidemiology. Systematic reviews need to cover four key epidemiologic indicators in order to promote understanding of the dynamics of a disorder in a population: incidence, prevalence, remission/recovery, and mortality. Incidence and prevalence express disease frequencies in different ways. Incidence counts the number of new cases per given population per year.
Over the last decade, there has also been a growing appreciation that reviews should be based on data as complete and as free of bias as possible. The need for systematic reviews with respect to the incidence and prevalence of schizophrenia was recognized by Jablensky (1997): “Ideally, a meta-analysis involving a standardized recalculation of the rates from many previous studies should generate a distribution allowing one to estimate with some probability the extent to which populations differ”. Before we can attempt to build realistic models of the dynamics of schizophrenia in the population, the various epidemiologic estimates need to be collated systematically.

Jablensky (1997) reports that since Kraepelin delineated dementia praecox as a disease entity construct, epidemiological studies conducted since the beginning of the century have produced remarkably consistent estimates of its prevalence, incidence and lifetime risk across various populations and geographic areas. A similar pattern emerged from the WHO ten-country study on first-contact incidence of schizophrenia; studies were found to overlap extensively, indicating continuity over time. However, the findings of a similar incidence of schizophrenia in diverse populations and across time periods are unusual for a multi-factorial disease and are compatible with at least two alternative interpretations that have different implications for the search for genetic and environmental causes of the disorder.

Saha et al., (2005) in a meta-analytical study of 1,721 prevalence estimates from 46 countries, based on an estimated 154,140 potentially prevalent cases. Results show that about seven to eight individuals out of 1,000 were affected by schizophrenia and found point and lifetime prevalence rates of 4.6 and 4 per thousand respectively. Out of 1,000 people 4.6 had the disease at a specific time point and 3.3 had the disease within a surveillance period of one to 12 months. The life time prevalence was 4.0 per 1,000 and the lifetime morbid risk was 7.2 per 1000, which did not differ considerably from previous estimates. The study found that the prevalence of schizophrenia was the same in males and females and in urban and rural sites. When sites were grouped by economic status, prevalence estimates from “least developed” countries were significantly lower than those from both “emerging” and “developed” sites (p = 0.04) and was higher in migrant population as compared to native-born individuals. Studies that scored higher on a quality score had significantly higher prevalence estimates (p = 0.02).
Indian Epidemiological Estimation

Following the path-breaking effort by Dube (1970’s) in Agra, the majority of the classical Indian psychiatric epidemiological studies in the past 4 decades (Nandi et al, 1980; Padmavati et al, 1985; Rajkumar et al, 1993; Wig et al., 1995; Kulhara, 1993; The Census India, 2001 and the NSSO, 2002), focussed on general psychiatric morbidity in small-to-medium population. The population samples were more often convenient samples. Chandrashekar and Issac (1999) reviewing these studies reveal the wide variation in prevalence rates, ranging from 10 -370/1000 population in different parts of the country.

Venkataswamy Reddy and Chandrashekar (1998) conducted a meta-analysis of 13 psychiatric epidemiological studies consisting of 33572 persons in 6550 families which yielded an estimate prevalence rate of 58.2 per thousand populations. A prevalence of 2.7 for schizophrenia was found. Authors concluded that in the selected studies no significant difference of prevalence w.r.t. sex and locality could be found. Ganguli (2000) reviewed major epidemiological studies in the last four decades and found a national prevalence rate of 2.5 per 1000. He also concluded that schizophrenia is the only disorder whose prevalence is consistent across cultures and over time. The paucity of incidence studies in India could be due to the absence of demarcated catchment areas for health service delivery and lack of case registers and costs involved in conducting community surveys.

In India, a community based cross-sectional study was done to assess prevalence and pattern of mental disability. One thousand subjects were randomly selected from four villages in Karnataka. Disability was assessed by Indian disability evaluation and Assessment Scale (IDEAS). The prevalence of mental disability was found to be 2.3%. The prevalence was higher among females (3.1%) than among males (1.5%). The prevalence was higher among elderly (3%) and illiterates (34%). There was a negative correlation between literacy and prevalence of mental disability.

A population based cross-sectional study was conducted in India to estimate the prevalence of mental disorders by sex, religion and area, using Rapid Psychiatric Examination Schedule. Stratified random sampling method was used to select 4,022 persons (49% males and 51% females) from both urban and rural areas. Prevalence of mental disorders was 60.2/1000 and was more among males (85.7/1000) than
females (35.6/1000) (p<0.001). A predominant disororder was schizophrenia psychosis (14.2/1000). Prevalence of mental disorders was 1.6 times higher among Christians as compared to Hindus. Prevalence rates was similar in both urban and rural areas.

Limitation of epidemiological studies:

Most of the epidemiological studies done in India use poor sensitive screening instruments, single informant and systematic underreporting have added to the discrepancy in the prevalence rate. Researchers have focused on broad non-specific, non-modifiable risk factors, such as age, gender and social class. Future research focused on the general population, longitudinal (prospective), multi-centre, co-morbid studies, assessment of disability, functioning, family burden and quality of life studies involving a clinical service providing approach, is required (Math, Chandrashekar, Bhugra, 2007). The paucity of incidence studies in India could be due to the absence of demarcated catchment areas for health service delivery and lack of case registers and costs involved in conducting community surveys, (Rangaswamy Thara and Sujit John ). Multi-centric, well-coordinated studies using modern instruments are needed to arrive at a consensual figure about prevalence and incidence of schizophrenia with need to work on associated epidemiological variables. There is a need to create nationwide case registers, improve research facilities and creation of better psychiatric centres for more meaningful research into this area (Avasthi & Singh, 2004).

These discrepancies are not specific to Indian studies but are also seen in international studies like the Epidemiological Catchment Area Program and the National Co morbidity Survey (Regier, Kaelber, Rae, et al., 1998; & Murphy, Monson, Laird, Sobol, Leighton, 2000). This discrepancy will impact planning, funding and health care delivery. Providing accurate data about the prevalence of mental disorders in the community would help to justify the allocation of scarce resources and planning of health services

Gender differences in care- giving

Today the trend worldwide shows that more caregivers are male. Despite this fact, the vast majority of research on care- giving has centred on the experience of the female caregivers. Currently there is a dearth of research about male caregivers, including the ways in which they are similar to and different from their female peers.
Little is known about men’s care-giving experiences, physical and mental health status, or their interaction with professional health care providers. Moreover, the literature on male caregivers focuses primarily on caregiver burden, failing to identify the distress they face and its impact on their emotional well-being and evidence-based interventions for improving caregiver quality of life.

Schneider, Steele, Cadell and Hemsworth (2010) studied the gender differences in 273 parents caring for children with life-timing illness in Canada. Results showed that there was a significant difference in gender in terms of their burden. Women had higher score in care-giving, depression and burden compared with men. It can be explained by social gender role and hormones. Related to social role, women were predominant in care-giving, spending more time in care-giving than men. In terms of hormonal causes, oxytocin contributed to distress and women’s’ need to nurture. When caring for patient with schizophrenia, women experienced distress, her oxytocin level and nurture need increases, but at the same time she had to pay more attention to the patient. Therefore women felt more burden than men.

Fujino and Okamura (2009) identified factors affecting the sense of burden felt by family members caring for patients with mental illness at home in Japan. The cross-sectional method used a questionnaire to 30 patients and 30 family caregivers. A multiple regression analysis with sense of burden as the dependent variable, showed a significant correlation in the univariate analysis as the independent variables. The results of the study revealed that patients' satisfaction with daily life and ability to perform tasks had a strong impact on the sense of burden felt by the caregivers. These results suggest that providing support that enhances the quality of life of the patients with mental illness may indirectly help reduce the sense of burden felt by family members caring for them.

Sugiura, Ito, Kutsumi, and Mikami (2009) examined gender differences in spousal caregivers and their relationship to care experiences, social demographics, and caregivers' depression, in Japan. Responses from 308 spouses (56.2% wives, 43.8% husbands from a stratified random sample of 2,020 users of public long-term care insurance, were analyzed. Variables relating to care experiences, social demographics, and caregivers' depression were compared by conducting simultaneous
analyses of multiple populations. The findings indicated that wives caring for husbands had higher depression scores than husbands caring for wives. Wives tended to adopt "emotional support seeking" and "willing commitment" as coping strategies for their care giving experience. Husband caregivers used more home-care services; however, increased service use had no effect on husbands' depression. The availability of secondary caregivers reduced depression for caregivers, regardless of gender. The effects on depression differed related to the caregiver's gender. Husbands relied more on family or home-care services when caring for their wives, whereas wives provided higher levels of care, positively accepted their role, and did not seek to share care giving, but sought emotional support.

Wilms, Mory and Angermeyer (2004) studied the illness related costs for spouses of patients suffering from a mental illness, in Germany, using repeated measures. 117 spouses of patients suffering from schizophrenia, depression or anxiety disorders, filled in a standardized questionnaire about illness related expenses and financial losses over a period of 12 months. The results revealed that 90% of the spouses reported direct cash expenditures on behalf of the patients' illness. On average, these costs amounted to yearly expenditures of euro 1146 (range: euro 0 - 11910). Costs did not differ significantly across types of illness and income was not found to be a significant covariate. Spouses reported substantial direct cash expenditures on behalf of the patients' illness. Since expenditures varied to a large extent over the three points of measurement, repeated measurement designs seem to be a prerequisite for a reliable assessment of illness-associated costs. Living with a mentally ill partner is associated with an increased risk of developing a burden-related psychiatric illness for spouses which could lead to double costs and double decreases in income, which needs to be taken into consideration when planning changes in health policy.

Yee and Schulz (2000) reviewed empirical research on Gender differences in psychiatric morbidity among family caregivers to find out whether there was (a) greater psychiatric morbidity among female than male caregivers (b) excess psychiatric morbidity among female caregivers attributable to care giving, and (c) factors in the care giving situation that contributed to the excess psychiatric morbidity among female caregivers. The findings indicated that women caregivers reported more psychiatric symptoms than male caregivers did. Comparisons with non-care
giving community samples suggested that female caregivers experienced excess psychiatric morbidity attributable to care-giving. Using a stress process model as an organizing framework, the study demonstrated that at all stages of the stress process; women were at greater risk for psychiatric morbidity than men.

**Indian Studies**

Trivedi, Gupta and Agarwal (1978) examined the patterns of marital interaction in male neurotic patients. The sample consisted of 30 patients and 30 controls that were assessed on assertiveness and affection. It was observed that the patient group had a greater tendency towards segregated marriages, compared to cooperative marriages in the non-psychotic control group. The patients also showed significantly more assertiveness and less affection in their marital interaction.

Kar and Verma (1978) studied the disturbed sexual life of 72 married male patients with that of 80 married men who were either close relatives and/or friends of the patients. The sample for both groups hailed from the same socio-economic background. Sexual relations were found to be unpleasant in 63.4% of the patients as compared to only 2.5% of the control group. The importance of loss of semen was ascribed by 45 patients, which resulted in their mental breakdown, as the reasons for unpleasant marital sexual relationship. Many of the patients ascribed it as unethical practices according to their religious concepts. Twenty seven percent of patients complained of hostility, resentment and suspiciousness of wife, and an equal number expressed disgust in marital sexual relationship as a cause for unpleasantness. Twenty two percent of the patients complained of lack of opportunities and social inhibition for contact with wife due to increasing age of children. 7% reported refusal of wives to share the same bed, as a cause for unpleasantness.

Tripathi, Agarwal and Gupta (1981) examined 50 female neurotic patients from outpatient clinic and their husbands were evaluated for psychological disturbances and to find out its relationship with the nature, severity and duration of psychotic illness in the wives. Personality characteristics and neurotic symptoms of the spouses were assessed on Eysench Personality Inventory and Middlesex Hospital Questionnaire. Of the sample of 50 couples, 30 husbands were found to be psychiatrically ill. The husbands who had neurotic predispositions were more likely to adopt neurotic patterns of behaviour when confronted with stressful situations.
The husbands with a diagnosis of neurosis, scored higher on N-Scale of EPI and lower score on E-Scale of EPI in comparison to healthy husbands. Their illness did not seem to be related with the duration of marriage, severity and nature of wives illness.

Mayamma and Sathyavathy (1985) examined marital disharmony in terms of disturbed communication in patients with neurosis and their spouses as compared with normal couples. It was hypothesized that there would be significant differences between patients with neurosis and the normal group and between spouses of patients with neurosis and spouse of the normal group with regard to communication. An experimental consisted of 30 patients with Neuroses diagnosed in accordance with ICD – 10 and their spouses were selected from NIMHANS and 30 non-subjects and their spouses were also screened. Marital Communication Inventory and The Personal Report of Spouses Communication Apprehension, was administered individually. Findings showed that patients with neuroses and their spouses reported significantly poorer communication in their marriages as compared to normal couples. They felt that they did not understand each other, had arguments over money, were unable to discuss problems together in a calm manner, felt that they were not offered co-operation, encouragement and emotional support in their respective duties.

Vijayalakshmi and Ramana (1987) studied the role disturbances in families of mentally ill patients. Due to the patients’ illness and inability to perform their respective roles in the family, they found that spouses often took over the breadwinner’s role while other family members, especially the children, took over the index patient’s responsibilities.

Pramod (1994) studied the adjustment patterns of spouses of the mentally ill. They examined the reported inconsistency in the relationship of gender differences; wives employment and marital duration with adjustment in marriage. The sample comprised of 80 married couples in the age range of 25 to 45 years. The results suggested that marital duration was significantly correlated with one’s adjustment in marriage.

Shankar et al., (1996) studied 30 married patients of both sexes, who were living with their spouses, to assess the gender differences in disabilities of the persons
with schizophrenia. The psychiatric disabilities define role expectations and consequently role performance. The study focuses on the differences in disability in married patients, as marital status is an important determinant of role expectation. The findings of the study indicated that women were more disabled than men on many of the evaluation parameters were (P<0.05). There was also a strong correlation between negative symptoms and disability variables in both sexes. While the correlation between PSE syndromes and disability variables was seen in the care of males, the relationship was not seen in females. Stepwise regression also revealed that negative symptoms predominated among the factors associated with global disability in both sexes. This corroborates research findings that women are more disabled than men, in India.

Kumar and Mohanty (2007) investigated the effects of socio-demographic variables on spousal burden of care in patients with schizophrenia. 70 spouses (35 male and 35 female), of chronic schizophrenic patients were drawn from outpatient services. The duration of spousal exposure was determined on the basis of the onset and their stay with the patients. The demographic and clinical characteristics of the patients and spouses were recorded and were individually administered the Burden Assessment Schedule (Thara, Padmavati, Kumar & Srinivasan, 1998). Significantly, greater burden was experienced in all areas in spouses who were female and duration of contact with the patient. The patient’s unpredictable behaviour and disturbances at home caused marked burden in female spouses, who felt that they had done more than enough to improve the situation and sought temporary separation. The family type significantly affected spousal burden in spouse related, external support and caregivers’ strategy. The joint family system was found to contribute significantly to the burden. Nuclear family system caused more burdens in the areas of external support and caregivers’ strategy.

Thara, Kamath and Kumar (1997) interviewed caregivers of 75 women attending mental health facilities in Chennai, in an attempt to understand their perceptions, attitudes and concerns about the future of their married wards. Burden on the family was assessed using the Burden Assessment Schedule developed by them. Most families expressed intense distress and were especially concerned about the long-term future and security of these women. Care of the children of these
women was an additional problem. This was more so, as they had no financial support from their husbands.

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**Burden of Caring**

Hadryś, Adamowski and Kiejna (2010) studied 141 eligible subjects, to find out if diagnosis of mental disorders in Polish families was a predictor of caregiver’s burden. The Brief Psychiatric Rating Scale, Manchester Short Assessment of Quality of Life, Groningen Social Disability Schedule and Client's Socio-demographic and Clinical History Inventory tools were used. The caregivers completed the Involvement Evaluation Questionnaire (IEQ). Subjects were grouped according to ICD-10 diagnoses: schizophrenia (n = 55), depression (n = 61), and anxiety and personality disorders (n = 25). Highly aggressive, suicidal and somatically unstable patients were excluded along with patients below 18 and over 65 years. Statistics included multiple regression analysis, ANOVA, Kruskal-Wallis and chi-square tests. The results indicated that diagnostic groups differed with respect to socio-demographics, psychopathology and quality of life, but not with respect to mean level of social functioning. Despite between-group differences, the caregiver’s burden did not differ according to the diagnostic group. Of the four dimensions of burden,
"worrying" and "urging" scored the highest. Majority of caregivers worried about their relative's general health (82%), future (74%) and financial status (66%). Caregivers' characteristics and not patients' explained the largest proportion of the family burden variance (almost 23% for IEQ Tension). Higher burden seemed to be associated with the carer's age, being a parent and number of hours spent weekly on caring for the ill relative. Lower burden was associated with the carers' subjective feelings of being able to cope with problems and to pursue their own activities. Longer history of patient's illness led to higher IEQ Tension.

Wong, Davidson, McGlashan, Gerson, Malaspina, and Corcoran (2008) examined the extent of burden reported by families of patients during a putative prodromal period and in the after-math of psychosis onset. 23 family members of patients with emerging or early psychosis participated in the exploratory study, using the Family Experiences Interview Schedule to assess both objective and subjective burden. Objective burden is comprised of increased resource demands and disruption of routine. Subjective burden includes worry, anger/displeasure and resentment at objective burden. Family burden was comparable for the clinical high-risk and recent-onset psychosis patients. Worry was as high for more chronic patients. By contrast, there was a relative absence of displeasure/anger. Family members endorsed assisting patients in activities of daily living, although not ‘minding’ doing so and reported little need to supervise or control patients’ behaviour.

Juvang, Lambert, and Lambert (2007) investigated the relationship between demographic characteristics of caregiver and family caregiver’s burden when providing care for a member with schizophrenia in China. Purposive sampling technique was used to recruit 96 subjects from 3 hospitals. Findings showed that the age of caregiver was positively correlated to burden of caregiver. Older caregivers worried more about who would take care of their ill family member in the future. The education level had negative correlation with caregiver’s burden. It was assumed that higher the level of education, higher the salary will be. High salary would decrease financial problem related to providing care for ill family member. Educational level of the caregivers resulted in more knowledge to deal with stressful events. Therefore caregiver’s education level influences burden of the caregiver.
Lambert and Lambert (2007) studied the predictors of family caregivers' burden and quality of life of family members with schizophrenia in the People's Republic of China. The study examined: (i) the level of family caregivers' burden and QOL; (ii) its relationships with demographic characteristics of family caregivers and (iii) the best predictors of family caregivers' burden and QOL. The findings suggest that family caregivers suffer a high level of burden when caring for a family member with schizophrenia. Significant correlations among the variables family caregivers' burden was their level of education, while the best predictors of family caregivers' QOL were physical health and household income.

Chien, Chan and Morrissey (2007) in a cross-sectional descriptive study examined the level of perceived burden of 203 Chinese families caregivers of relatives with schizophrenia in the community and tested its associations with their demographic characteristics, social and family factors and health conditions, from three regional psychiatric outpatient clinics in Hong Kong. Measures included a set of well-validated questionnaires, consisting of the Chinese version of four instruments - Family Burden Interview Schedule, Family Assessment Device, Six-item Social Support Questionnaire and MOS 36-Item Short Form Health Survey and a socio-demographic data sheet. This was. The results indicated that families who perceived a higher level of caregiver burden were those who lived in a family with poorer functioning, worse health status and less satisfaction of social support. The caregivers' burden score was positively correlated with their age; conversely, it was negatively correlated with their monthly household income and number of family members living with patient. Social support was the best predictor of caregiver burden and helping families to maintain and enhance a supportive social network, with interventions may represent a useful means to reduce family burden in schizophrenia.

Krautgartner, Unger, Göessler, Rittmannsberger, Simhandl, Grill, Stelzig-Schöler, Doby and Wancata (2007) investigated the burden of minor relatives of schizophrenia patients and of the need for support for the relatives. The study conducted in Germany with a sample of 135 relatives of patients with schizophrenia or schizoaffective disorders were assessed using the "Involvement Evaluation Questionnaire" and the "Carers' Needs Assessment for Schizophrenia". 24.4% of the total sample (N=33) had minor (i.e. below 18 years) siblings (N=18) or children (N=15). If the patient had minor siblings, almost the half of the adult relatives
reported moderate or severe problems. However, among those patients who had to take care for minor children, only a fifth reported moderate or severe problems. Offspring is under the age of 16 years frequently reported behavioural disturbances, reduced appetite and other consequences of the disease. These results indicated that in minor relatives frequently reported marked burden.

Schmid, Schielein, Spiess and Cording (2006) studied the burden of siblings of inpatients with schizophrenia, using narrative interviews with 37 siblings of schizophrenia patients, in Germany. The global statements were analysed using a summarizing content analysis and categories were quantitatively analysed to assess their relative importance. 492 individual statements of the siblings revealed 26 global types of statements, were assigned to five categories: 1. "Burden due to daily contact with the sibling" (36.2 %). 2. "Burden due to respect of healthy sibling's privacy" (26.8 %). 3. "Burden due to contact with the family" (15.7 %). 4. "Burden with respect to the contact with institutions and professionals" (14.2 %) and 5. "burden with respect to the siblings' own social contacts (friends/public)" (7.1 %). Three types of burden were reported by the healthy siblings: "Handling the symptoms of illness" (100 %), "Emotional burden due to the illness of the sibling" (100 %) and "Uncertainty in judging what amount of stress the schizophrenia patient can cope with" (81.1 %).

Margareta Ostman (2005) investigated the different aspects of family burden, need for support and participation in care situations with carers who lived with and apart from their patients. A sample of 162 relatives (73 relatives of committed patients and 89 relatives of voluntarily admitted patients) answered a semi-structured questionnaire concerning their situation as a relative of a severely mentally ill person. Results indicated that there was an increased experience of family burden in several aspects due to the relative and patient living together. However, relatives who lived with the patient were less likely to believe that the patient would be better off dead, experienced more participation in the patient’s treatment and more often viewed the psychiatric services as being of good quality than those relatives who did not live with the patient. The findings of the study are that persons with severe mental illness who are admitted to inpatient units are in need of different aspects of intensive psychiatric care. Some of these needs are supplied by relatives in everyday life, often without any support. In providing for the needs of relatives, in relieving their burden,
the psychiatric services needs to implement different methods according to whether
the relatives live with or apart from the patient

Lauber, Eichenberger, Luginbühl, Keller and Rössler (2003) assessed the
relationship between caregiver burden and behavioural disturbances of patients with
exacerbating schizophrenia in Switzerland. Sixty-four relatives of schizophrenic
patients were assessed by a semi-structured "Interview for Measuring the Burden on
the Family". Subscales and total scales of burden were calculated. Predictors were
identified by regression analyses. The most important predictor of burden was burden
in the relationship between caregiver and the affected representing the changes in the
relationship occurring in acute illness. Threats, nuisances, time spent with the
affected, and burden due to restricted social life and leisure activities were additional
predictors of burden, but not aggression or substance abuse. Two weeks prior to the
last hospitalization was considered as being the most burdensome period for relatives.
Eighty-five percent of the cases could be correctly assigned.

Jungbauer, Mory and Angermeyer (2002) compared the perception of
financial burden in parents and spouses of schizophrenic patients, in Germany. Using
a qualitative-interpretative technique, 42 In-depth-interviews with parents and
spouses of schizophrenic patients were analyzed. Results revealed that when talking
about their living situation, caregivers tended to keep away from the topic of financial
charges; played down objective financial disadvantages or didn't assess them as
burdensome. However, considerable financial burdens were reported by parents of
young patients who were living with their parents' household and by spouses in
families with very low income. Financial burdens were usually superimposed by
other problems of the caregivers, such as dealing with acute episodes and sorrow
about the future. Both material and immaterial costs of caregivers should be
considered when taking health policy decisions.

Ostman and Hansson (2002) investigated the prevalence and needs for
support, of minor children and spouses in families with a severely mentally ill
member. A multi-centre study on the quality of the mental health services in Sweden
during 1986, 1991 and 1997 was conducted. The sample consisted of relatives of
compulsorily and voluntarily admitted inpatients to acute psychiatric wards. A semi-
structured questionnaire assessed burden, needs for support and participation in care
and items of under-aged children and spouses. The investigations over the years showed that the same proportions of patients were admitted to hospitals who were also parents to minor children and a decreasing proportion of patients who had the custody of their children. Female patients were more often a parent and had the custody of the children. The results suggested that the majority of the children with needs for support caused by their parent's illness were met in only half of the cases. The healthy spouses in families with minor children often had to give up their own occupation and to a higher extent experienced own needs for care and support from psychiatric services as compared to spouses without minor children. Authors recommend an urgent need for psychiatric services to initiate parental issues in programmes for treatment and rehabilitation to ensure specific needs of minor children are met.

Solomon & Draine (1995) opine that the best set of predictors of burden, identified by stepwise linear regression, was young patient age, awareness of patient's suicidal ideation, and family resources.

Lefley (1996) identified three types of burdens faced by family caregivers. These burdens are also echoed by related studies. Objective Burden is the daily problems, coping and challenges that accompany mental illness (financial burden, time and effort in care giving, disruption of daily routine and social life) Subjective Burden consists of the emotional consequences of the illness for other family members, (feelings of loss, shame, worry, anger and hopelessness towards the client with mental illness) and Burden in management of problem behaviour of clients with mental illness (assault, mood swings, unpredictability, negative symptoms).

Indian Studies on Burden

Gautam & Nijhawan (1984) compared the burden on families of schizophrenic patients with chronic lung disease. The sample was randomly selected with 25 relatives in each group, using a structured interview schedule. Caregivers of patients with schizophrenia reported greater burden, financially, on family leisure, family routine, family interaction and mental health of other family members. The financial burden was higher when the male member had the illness.

Mubarak and Bhatti (1988) compared the burden experienced by families of chronic schizophrenic patients living in urban and rural areas. They found that both
urban and rural families reported equal degree of burden. They found no relationship between family burden and social support system. Bharat (1991) reviewed 48 studies on family structure and problems faced. A majority of the psychiatric patients came from nuclear families and suggested that family interaction patterns, rather than family structure should be studied in detail.

Chatterjee, Rao, Murthy (1988) studied the burden of care in families of the psychiatrically ill. They found that urban families reported significantly higher levels of burden, especially in the areas of routine family activities and interactions. Burden was significantly associated with extent of disability in the patients. The authors concluded that family members had greater tolerance because of lowered expectations, mutual sharing and acceptance and attribution of external causes.

Ranganathan, Nirmala and Padankatti (1991) carried out an exploratory study to understand the problems of the mentally ill and their family members. A sample of 280 patients, a majority of whom were male, and their caregivers were assessed. Almost two-thirds were unmarried. The main problems for relatives were disruptive behaviour of the patient, non-contribution to family income, problems with personal care and embarrassing behaviour.

Nautiyal (1993) studied 80 caregivers of patients attending the inpatient and outpatient departments of a mental hospital to assess their orientation to mental illness and burden. The severities of symptoms were also rated. The results indicated that the symptoms severity did not correlate with orientation to mental illness or with perceived burden. Negative orientation towards outcome of mental illness was associated with greater perceived objective burden. Among the different categories of burden, financial difficulties were rated as most burdensome.

Moily et al., (1997) studied the burden of care of families of persons with schizophrenia from a rural background. Pai and Kapur interviewed 30 families using the Family Burden Schedule (FBS, 1981). The results showed that the majority of the patients were female (55%), illiterate and unemployed. The major areas of burden were financial, followed by disruption in family routine, disturbance in family interaction, disruption of leisure activities and adverse effects on mental and physical health of the caregivers.
Heru (2000) studied the concept of family conflict and family intimacy with regard to the degree of burden or reward experienced. The authors suggested that the family system, as the context within which the patient exists, be seen as the mediating environment for care giving burden and reward.

Chakrabarti, Raj, Kulhara, Avasthi and Verma (1995) compared the extent and pattern of family burden in 60 patients with schizophrenia and affective disorder. Both groups were similar with regard to socio-demographic variables, duration of illness and degree of dysfunction in the patients. The results indicated that both groups experienced high levels of burden, which was felt mainly in the areas of family routine, family leisure and family interaction and finances.

Roychoudhari, Boral, Mondal and Bhattacharya (1995), carried out a similar study comparing 30 families of patients with schizophrenia and 24 families of persons with affective disorder on burden and well-being. Burden was found to be greater in families of persons with schizophrenia, patients who were younger in age and were male. Despite high levels of burden, caregivers experienced subjective well-being scores in the normal range, indicating that they possessed considerable coping resources or resilience.

Sushma, Mishra, Kumar and Paul (2003) studied the association among burden, coping strategies and expressed emotions of 30 relatives of persons with first episode psychosis. The caregivers of patients aged between 18 to 55 years, were in daily contact with the patient at least for two years and who were supportive both financially and emotionally. The patients were rated on the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962) for psychopathology. The caregivers were administered the General Health Questionnaire (GHQ-5) (Shamsunder et al, 1986) and the Burden Assessment Schedule (BAS) (Thara et al, 1998), the Attitude Questionnaire (Sethi et al, 1985) and the COPE Scale (Craver et al, 1989) to find out the effects of patients illness on their health and the burden experienced. Significant differences were found in the expressed emotions, use of emotional coping strategies and psychopathology in the high and low burden groups. The caregivers who were experiencing high burden also had high expressed emotions
and made greater use of emotional coping strategies. Family burden was found to increase with psychopathology.

Creado, Parkar and Kamath (2006) evaluated the level of functioning of 100 patients with chronic schizophrenia to the burden and coping of their primary caregivers. The patients attending a psychiatric outpatient department were assessed on the General Assessment of Functioning (GAF) Scale and the caregivers were administered the Burden Assessment Schedule (BAS) and Mechanisms of Coping (MOC) Scale. Fatalism and problem solving were the two most common patterns of coping. It was found that problem focused or problem solving and expressive-action decreased the burden of caregiver, while emotion-focused coping or fatalism and passivity increased it. As the level of functioning of the patient decreased, the significance with which the coping mechanisms influenced the burden, increased. The use of problem-solving coping by caregivers showed a significant correlation with higher level of functioning in patients.

The studies reviewed in this subsection indicate that empirical work on burden has been carried out for about five decades. Despite the diverse methodologies used, it is evident that family members experience considerable amount of burden in their role as caregivers for the relatives with schizophrenia. It is also a role that they largely carry out unsupported, as the mental health infrastructure is often inadequate.

**Distress experienced by Family Members**

Researchers have acknowledged that caregivers of persons with schizophrenia experience considerable distress in addition to burden, as a result of the care-giving role. The concepts of burden and distress have been differentiated in terms of distress being applied to a more general living situation, while burden is specific to care-giving (St-Onge & Lavoie, 1997). Caregivers also experience a range of emotions ranging from anger and frustration to grief and hopelessness.

Birchwood and Smith (1984) surveyed the behaviour of schizophrenic patients that caused the most distress to their families. Two thirds of the families experienced some behavioral disturbances and 15% reported severe disturbance. A minority of the families reported that offensive behaviour, rudeness and violence caused most distress. Behaviours that caused severe distress were those directed at
the carers or were the product of active psychoses. Families were more resigned to chronic negative symptoms.

Potasznik and Nelson (1984) examined the relationship between burden, level of distress and social support in 56 parents of persons with schizophrenia. They found that 82% of the sample reported that the stress was chronic and that small dense support networks and satisfaction with support was linked to lower level of burden and distress. Gender differences in the level of distress experienced by caregivers were highlighted in a study on parents of persons with chronic mental illness by Cook (1988). Mothers reported significantly higher levels of anxiety, fear, depression and emotional drain.

Miller, Dworkin, Ward and Barone (1990) found that families of persons with mental illness (schizophrenia and BPAD), undergo grief reactions similar to that of bereavement. They found they found that delayed grief reaction was also present, as majority of the patients in their sample had been ill for over 2 years. There was no single patient or family demographic factor that predicted the occurrence of grief in these families.

Tausig (1992) investigated 83 caregivers of persons with chronic mental illness to examine the relationship between social support and levels of caregiver distress. Almost 23% of caregivers reported very sparse social networks while one third reported dense networks. High density of social networks and high proportion of kin in the network were inversely related to distress experienced, as well as use of formal services by caregivers.

Oldridge and Hughes (1992) assessed the level of distress and burden in 25 primary caregivers of patients with chronic schizophrenia on the GHQ-28 and the Hospital Anxiety and Depression Scale (HADS). Burden was also assessed using the Social Behaviour Assessment Schedule. They found that 36% of the carers qualified for caseness on the GHQ and the HADS. Greater distress was associated with negative symptoms in patients, Objective burden was significantly correlated with the anxiety and insomnia subscale of the GHQ, while subjective burden was correlated with the GHQ screening score, the anxiety and insomnia subscale score and the depression score of the HADS.
Rauktis, Koeske & Tereshko, (1995) studied the negative social interactions, distress, and depression among those caring for a seriously and persistently mentally ill relative. 106 family members were investigated for positive and negative social interactions and its effect on mental health. Results from mixed-model (hierarchical and stepwise) multiple regression analyses controlling caregiver age, socioeconomic status, care giving demand, and severity of patient symptoms, showed negative social interaction accounted for significant portion of variance in the caregivers' feelings of distress and depression. Moderated multiple regression analyses showed that under conditions of high negative interaction, the relationship between demand and distress intensified.

satisfaction with services provided by mental health professionals. interviewed a sample of 121 caregivers of persons with schizophrenia on areas of burden, distress and satisfaction with services provided by mental health professionals. Majority of the care givers were women (69%), and were middle aged. The areas where burden was perceived the most were leisure activities, social relationships and relationships with the family. Parents reported that patient related stress accounted for 51% of the stress they faced. Spouse caregivers reported more burden than other groups. Caregivers expressed the need for early treatment, rehabilitation services and counselling supports for themselves.

Salleh (1994) examined 210 caregivers of persons with a psychiatric disorder to assess burden and distress in caregivers. The results indicated that 50% of the caregivers had neurotic depression and reported subjective burden and distress. Burden was related to the patient’s symptoms such as violent behaviour, hostility and acting out. There was greater tolerance of negative symptoms.

Winefield and Harvey (1996) described the psychological state and experienced needs of 134 family members caring for a person with schizophrenia. Psychological distress was high as compared with test norms and the level of behavioural disturbances in the sufferer was found to contribute to distress after controlling for age, sex and social supports. Results showed that family members needed attention, information and support. Burden in the sense of interference in their daily lives was most marked for those caregivers who were in high contact with the patients. Socially disruptive and antisocial behaviour by persons with
schizophrenia, added significantly to the distress and burden. Greater distress was reported in caring for female patients than male patients.

Bibou et al., 1997, interviewed two groups of 31 caregivers of individuals with chronic schizophrenia diagnosed over two years and 21 diagnosed less than 2 years, both groups reported distress. Deficits in social role performance on the part of the relative was the source of family burden.

Rauktis, Koeske and Tereshko (1997) examined the contributions of positive and negative support to stress experienced by 106 carers of persons with mental illness. Approximately 75% of the samples were parents and 86% were female. Respondents reported receiving a fair amount of emotional support and a lesser amount of practical help and support. They also reported low to moderate levels of distress and depression. A multiple regression analysis where caregiver age, socioeconomic status, caregiving demand and severity of symptoms were controlled showed that negative social interaction accounted for a significant proportion of the variance in caregiver distress. Caregivers from higher socioeconomic class experienced lower levels of distress.

Boye, Bentsen, Ulstein, Notland, Lersbryggen, Lingjaerde and Malt (2001) explored the relationship between relatives’ distress and patients’ symptoms and behaviour. The sample consisted of 50 relatives who were in close contact with 36 patients with schizophrenia. Relatives reported distress was related to patients’ problematic behaviour, especially anxious & depressed behaviour.

Struening et al (2001) studied 461 caregivers of persons with schizophrenia and bipolar affective disorder. They assessed beliefs regarding the extent to which caregivers felt that most people devalue patients and their families. They found that 70% of the caregivers felt that people, in general, devalued patients and 43% felt that families were also devalued. The stigma perceived by patients as well as their families, was an added source of distress to the caregivers.

Martens and Addington (2001) studied if a measure of care giving would be a stronger predictor of the psychological well-being of families who have a member with schizophrenia than a measure of burden. Forty-one family members of 30 individuals with schizophrenia were rated on a measure of burden, experience of care giving, and duration of the illness to determine the best predictor of psychological
well-being. Regression analyses indicated that the strongest predictor of psychological well-being was the negative scale of the Experience of Care giving Inventory (ECI). There was also a significant relationship between poor psychological well-being and short duration of illness. Conclusions: The findings indicated that family members are significantly distressed as a result of having a family member with schizophrenia.

Ukpong (2006) examined the demographic factors and clinical correlates of burden and distress in relatives of service users experiencing schizophrenia, in Nigeria. This cross-sectional study used the Carer Burden Index and the 30-item General Health Questionnaire to assess burden and distress in relatives, and the Brief Psychiatric Rating Scale and the Scale for Assessment of Negative Symptoms, to rate the positive and negative symptoms of schizophrenia, respectively. High levels of emotional distress and burden were observed in the caregivers and they were significantly associated with some demographic variables. They were also significantly associated with positive and negative symptoms of schizophrenia. Because Nigerian families continue to play a primary care-giving role for their relatives experiencing schizophrenia, there is a need to focus on specific interventions that will reduce their high levels of distress and burden.

**Indian Studies on Distress**

Vergheese (1984) studied 60 patients with a diagnosis of schizophrenia and affective disorder, using the Family Evaluation Form (Spitzer, Endicott and Gibbon, 1971). His study concluded that families of patients with mania perceived the most severe burden. They also had the most disruptive psychopathology. Burden was perceived specifically with regard to subjective distress, household functioning and financial problems. Family distress, social isolation and community problems were significantly and positively correlated with objective burden. Burden was least perceived in families of depressed patients. The study also highlighted a significant, positive correlation between the distress experienced by the families and the severity of illness of the patients.

Gopinath and Chathurvedi (1992), studied the Distressing behaviour of schizophrenic patients that family members found difficult to cope which increased burden of care. They interviewed 62 relatives of schizophrenic patients using the
Scale for Assessment of Family Distress by regarding the behaviour of the patient that was perceived to be distressful. Most of the relatives were male (61%) and married. Behaviour related to activity and self-care was perceived to be most distressful, and not aggressive or psychotic behaviour. Younger relatives and those with more education more often reported distress. The most common behavioural disturbances were not doing any work (64%), not doing household chores (56%), poor personal hygiene (53%) and slowness (53%). Lack of self-care and slowness was perceived as more distressful in female patients. Educated caregivers reported greater distress. Caregivers of older patients reported distress. Negative symptoms in patients were associated with greater distress in caregivers. Their findings are at variance with Gibbons, Horn, Powell and Bibbons, (1994), who reported aggression and active symptomatology to be most distressing.

Thara, Kamath and Kumar, (2001) interviewed caregivers of 75 women attending mental health facilities in Chennai, in an attempt to understand their perceptions, attitudes and concerns about the future of their married wards. Burden on the family was assessed using the Burden Assessment Schedule developed by them. Most families expressed intense distress and were especially concerned about the long-term future and security of these women. Care of the children of these women was an additional problem. This was more so, as they had no financial support from their husbands.

Research on burden and distress carried out in the Indian context indicates similar trends to empirical work in the West. Patient demographic variables like age, gender and education are correlated with burden, as are illness related variables such as duration and severity. Financial difficulties and disruption of family routine are the areas where burden is felt most. The research carried out in this area indicates that a significant proportion of caregivers experience high levels of distress, poor quality of life and many they are at risk for a psychiatric or physical disorder.

III Distress experienced by Family Members Chang, Chiou and Chen (2009) explored the important influence of mental health of family caregivers and burden on their physical health. 388 caregivers who were 18 years or older and spent time taking care of an ill family member were administered the 12-item Chinese Health Questionnaire (CHQ-12), burden was measured using a modified scale for
caregiver's burden, Self-perceived health (SPH), illness symptoms and the number of diagnosed chronic diseases assessed health status. Factors such as age, education level, caring hours per day, and emotional, functional, and physical support systems used by caregivers were controlled. A high number of hours per day of care giving were associated with low emotional support and SPH, poor mental health and high burden. Higher emotional support was associated with better mental health and fewer illness symptoms. Higher physical support was associated with poorer mental health, higher burden, a greater number of illness symptoms and chronic diseases, and a lower SPH score. Hours per day of care giving and use of emotional, functional, and physical support were associated with mental health, and the hours per day of care giving and use of physical support were predictors of burden. Mental health and burden were significantly associated with caregivers' health problems simultaneously.

Yusuf and Nuhu (2009) studied the factors associated with emotional distress among caregivers of patients with schizophrenia in Nigeria. Samples of 129 caregivers of patients with schizophrenia were enrolled from the outpatient clinic of Katsina State Psychiatric Hospital. The data from the Socio-demographic data collecting sheet and Hospital Anxiety and Depression Scale were analyzed and statistical significance was set at 5% level of probability. The caregivers consisted of 87 (67.4%) females and 42 (32.6%) males. The mean age of the subjects was 45.07 +/- 8.91 years. Siblings constituted majority of the caregivers. Emotional distress was found in 79.84% of the caregivers (95% CI 72.82-86.86). Factors associated with emotional distress in the caregivers were family size, education, financial support, patient gender and relationship with the patient.

Friedrich, Lively and Rubenstein (2008) surveyed data from a national study of 746 respondents with regard to the importance of mental health services and coping strategies of siblings with schizophrenia. The authors developed and used the Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIIISS), a closed-ended questionnaire that included questions about coping strategies and mental health services. The findings revealed that the siblings identified services for their ill sibling, including symptom control, adequate housing, and long-term planning, as more important than direct services for themselves. The top-ranked coping strategies were education about schizophrenia, a supportive family, and seeing the ill sibling suffer less because symptoms were controlled. Understanding that
families were not to blame for schizophrenia was the most helpful coping strategy for nearly three-fourths of siblings. Siblings had little contact with providers in the past; yet the majority of siblings wanted providers to be available to answer questions and clarify their role in future care. At the time of the study, respondents provided social support and helped with crises, but few coordinated the total care. The siblings also identified multiple ways that providers can support and assist them in coping with the impact of schizophrenia, i.e. education and support.

Hou, Ke CL, Su YC, Lung FW and Huang (2008) explored the burden of primary family caregivers of schizophrenia patients in Taiwan. 126 pairs of patients and their primary family caregivers were recruited from the day care and acute wards of two teaching general hospitals. Data was collected on caregiver burden and the caregivers' health condition using Demographic sheet Brief Psychiatric Rating Scale (BPRS), Caregiver Burden Inventory-Brief Version and the Chinese Health Questionnaire (CHQ). One-way analysis of variance and Pearson correlation were used to analyze the relationship between demographic factors and caregiver burden. Multiple regressions were used to analyze predictors of burden of caregivers. Statistical significance in this study was defined as P ≤ 0.05. The results revealed that caregiver burden scores (25.9 +/- 10.7; range, 3-61) indicated a moderate burden level. Among the five dimensions of burden, caregiver anxiety (2.13 +/- 0.86) was the highest, followed by dependency of the patient (1.85 +/- 1.02), feeling shame and guilt (1.56 +/- 1.02), and family interference (1.43 +/- 0.83). The burden level of stigmata (1.32 +/- 1.24) was the lowest. The first three rankings of burden were 'I worry about his/her safety when he/she is alone' (2.26 +/- 1.15), 'I worry that she/he will become sick at any time' (2.23 +/- 1.10), and 'I feel he/she depends on me very much' (2.02 +/- 1.29). Patient satisfaction with medical staff support (P = 0.00), CHQ scores of the caregivers (P = 0.00), and the BPRS scores of the patients (P = 0.01) were significantly associated with the caregiver burden scores. The authors found that the physical and mental health condition of the primary family caregiver of schizophrenia patients were the most important factor determining the caregiver burden level.

Chien, Chan and Morrissey (2007) examined the level of perceived burden of families caring for a relative with schizophrenia and to test its associations with their demographic characteristics, social and family factors and health condition. A cross-
sectional descriptive study, recruited 203 family caregivers from three regional psychiatric outpatient clinics. A set of well-validated questionnaires, consisting of the Chinese version of four instruments - Family Burden Interview Schedule, Family Assessment Device, Six-item Social Support Questionnaire and MOS 36-Item Short Form Health Survey and a socio-demographic data sheet were used. Statistical analyses to test the differences in mean burden scores between subgroups, the inter-relationships among the mean scores of the scales and socio-demographic variables and the predictors of family burden. Families who perceived a higher level of caregiver burden were those who lived in a family with poorer functioning, worse health status and less satisfaction of social support. The caregivers' burden score was positively correlated with their age; conversely, it was negatively correlated with their monthly household income and number of family members living with patient. Social support was the best predictor of caregiver burden.

Yen and Lundeen (2006) studied the association between (a) meaning of care-giving, perceived social support and level of depression of caregivers during the transition phase, immediately following a family members' discharge from the hospital to the community; (b) determinants and meaning of care-giving, perceived social support and level of depression and (c) meaning of care-giving, perceived social support and level of depression. The sample consisted of 55 caregivers of schizophrenic patients from a private hospital in Taipei, Taiwan. The results revealed that certain characteristics of caregivers were found to be associated with lower levels of depression, meaning of care-giving and perceived social support. Perceived social support was shown to be a mediator between the meaning of care-giving and caregivers' level of depression. The authors found that despite the small sample size, the findings could serve as a reference for mental health professionals working with patients and caregivers.

Foster, O'Brien and McAllister (2004) reviewed the risk and protective factors that may impact on the psychosocial health of children of parents with a mental illness, in Australia. However many children identified as vulnerable to experiencing a variety of psychosocial effects arising from the impact of parental mental illness, did not experience difficulties as a result of their parent's mental illness and were able to thrive despite what may be an adverse situation. Recent government initiatives have led to greater awareness and recognition of the needs of children whose parents
have a mental illness, and key principles and actions have been developed to assist health services to adequately care for them.

Yee and Schulz (2000) reviewed and synthesized the empirical research on caregiver gender and psychiatric morbidity, with the aim of answering three questions: (a) if there was greater psychiatric morbidity in female than male caregivers, (b) is the excess psychiatric morbidity among female caregivers attributable to care-giving, and (c) what factors in the care-giving situation contribute to the excess psychiatric morbidity among female caregivers? In almost all studies reviewed, women caregivers reported more psychiatric symptoms than men caregivers. Comparisons with non-care-giving community samples suggest that female caregivers experience excess psychiatric morbidity attributable to care-giving. Using a stress process model as an organizing framework, the study demonstrated that at all stages of the stress process; women are at greater risk for psychiatric morbidity than men. Directions for future research and implications for interventions and public policy are discussed.

Pereira and de Almeida (1999) studied the repercussions of mental disease on family members of psychotic patients diagnosed with schizophrenia, chronic psychosis or affective disorder. The descriptive, cross-sectional study of 80 primary caregivers were evaluated with Involvement Evaluation Questionnaire (IEQ), General Health Questionnaire (GHQ) and a semi-structured interview schedule Levels of caregiver burden and psychological distress, objective and subjective burden correlation were evaluated and a preliminary analysis conducted on. The extent of burden was found to be significant being (e.g. tension, worrying or financial burden). Forty-one percent of caregivers experienced minor psychiatric morbidity. Measures of objective and subjective burden were moderately correlated. The same applied to magnitude of associations between each of them and distress parameters. Higher levels of burden were found in groups of caregivers to more severely ill or disabled patients, while diagnosis was not important for this purpose.

Dyck, Short and Vitaliano (1999) tested predictive models of schizophrenia caregiver burden and infectious illness episodes for 70 caregivers who had regular contact with their mentally ill family members. The Health Review, were administered to family members who were assessed in three stages. i) by a nurse
interviewer, blind to patient's symptoms, caregiver burden, and psychosocial status, ii) a second nurse blind to caregiver health status and patient symptoms, assessed caregiver resources (e.g., active coping and social support), vulnerabilities (e.g., anger expression and passive coping) and burden and iii) independent patient raters, blind to caregiver health and psychosocial status, assessed caregiver stressors. The Brief Psychiatric Rating Scale and the Modified Scale for the Assessment of Negative Symptoms assessed the severity of positive (e.g., hallucinations and delusions) and negative (e.g., anhedonia and a sociality). Predictive models, including measures of stressors, resources, and vulnerability factors for caregiver burden and for presence of infectious illness, were highly significant, accounting for 40% and 29% of the variance, respectively. The specific measures that predicted burden and infectious illness differed. Greater burden was predicted by more severe patient negative symptoms (stressor), greater anger control and blame self-coping (vulnerability), and decreased tangible social support (resource). Presence of infectious illness episodes was predicted by more severe patient positive symptoms (stressor) and less satisfaction with social support while controlling for the frequency of reporting on the Health Review. When scores from the Brief Psychiatric Rating Scale (stressors) were categorized into quartiles, it was found that the frequency of infectious illness in the highest quartile was four times that in the lowest quartile. Other results indicated that even though burden was not associated with infectious illness, it was associated with "continuing health problems," perceived stress, and depression.

Vaddadi, Soosai, Gillear and Adlard (1997) assessed the prevalence of physical abuse and burden experienced by 101 relatives of persons with a psychiatric disorder admitted to an in-patient facility. A semi-structured interview format was used to record burden and specific incidents of abuse, the General Health Questionnaire (GHQ-18) was used to record caregiver distress and the Brief Psychiatric Rating Scale was used to evaluate patient symptomatology. Burden was positively correlated with abuse, and 79% of caregivers scored above the cut off on the GHQ. Verbal abuse, threats and temper outbursts were reported by half the sample and 32% reported being physically abused on more than one occasion. Abuse was associated with younger age of the patient, drug misuse and poor pre-morbid relationship between the caregiver and the patient.

Indian studies on emotional distress of FCGs
Mahendru (1996) examined the occurrence and pattern of psychiatric morbidity in spouses of patients with schizophrenia. They were compared with 20 spouses of normal group, and were matched for age and socioeconomic status. The Middlesex Hospital Questionnaire was used to screen caregivers for the presence of a psychiatric disorder. The results indicated that 40% of the spouses in the patient group had a neurotic illness as compared to none the normal group.

Mahendru, Singh & Sachan (1997) in a comparative study of spouses of patients with schizophrenia and normal control, reported that in addition to experiencing high degrees of psychiatric morbidity, spouses of person’s with schizophrenia reported more time sharing and less participation in social activities than spouses in the normal group.

Sushma, Mishra, Kumar & Paul (2003) studied the association among burden, coping strategies and expressed emotions of 30 relatives of persons with first episode psychosis. The caregivers of patients aged between 18 to 55 years, were in daily contact with the patient at least for two years and who were supportive both financially and emotionally. The patients were rated on the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962) for psychopathology. The caregivers were administered the General Health Questionnaire (GHQ-5) (Shamsunder et al, 1986) and the Burden Assessment Schedule (BAS) (Thara et al,1998), the Attitude Questionnaire (Sethi et al, 1985) and the COPE Scale (Craver et al, 1989) to find out the effects of patients illness on their health and the burden experienced. Significant differences were found in the expressed emotions, use of emotional coping strategies and psychopathology in the high and low burden groups. The caregivers who were experiencing high burden also had high expressed emotions and made greater use of emotional coping strategies. Family burden was found to increase with psychopathology.

Marimuthu, Prashanth, John & Russell (2000), studied the psychiatric morbidity in caregivers of persons with mental illness. Samples of 103 caregivers were screened on the General Health Questionnaire -30 and corroborated the psychiatric diagnosis on the Brief Psychiatric Rating Scale. The results indicated that 30% of the caregivers met the criteria for psychiatric morbidity. Of these 53% were females and 40% belonged to the lower socioeconomic status. Socioeconomic status,
stigma and low educational level of the caregiver were correlates of psychiatric morbidity.

**INTERVENTION STUDIES**

A physician Henry Richardson (1948) described the role of family care in the recovery from physical and mental health problems. His landmark book titled "Patients have families" was read by a group of psychiatrists and social anthropologists at the Palo Alto Research Institute in California. This later became the basis of the systemic approach to family interventions. Parsons (1951) provided an impetus by providing a conceptual framework for social scientists who were concerned with the mentally disordered patients and their families.

The de-institutionalization movement in the late 1950’s – early ‘60s, was the single most important reform of the 20\(^{th}\) century, it led to the development of family interventions for person with CMI:

1. Family caregivers began to play an increasingly important role in care-giving of their ill members who lived at home
2. Popular theories about the role of the family in causing schizophrenia (eg. The Double- Bind hypothesis, marital skew and Schism, schizophrenogenic mothers etc.) which predominated from the 1920’s through the 1950’s, were not supported by empirical studies of family processes, as increasing evidence pointed to the role of biological factors in the aetiology of chronic mental illness.
3. Families began to speak openly about the burden and challenges associated with caring for their ill member and the mistreatment they often received at the hands of professionals, which led to advocacy organizations such as the National Alliance for the Mentally Ill (NAMI).
4. Important, accumulated evidence suggested that high levels of stress within the family contributed to an increased risk of relapse for clients recently discharged from the psychiatric hospital.

The convergence of these factors by the late 1970s and early 1980s encouraged the development of different treatment models for families of persons with CMI. Some of these treatment programs are educational and supportive in nature; others are cognitive-behavioural, while still others are based on modified
family systems approaches. In addition to differences in theoretical orientation, family intervention models also vary in their locus of treatment (clinic or home-based), format (single-family vs. multiple-family groups) and duration of treatment (time-limited vs. time-unlimited)

Family-based intervention programmes constitute one of the most important advances in the treatment of schizophrenia over the last four decades. Of all the psychosocial interventions found to be useful in schizophrenia, family treatment is the most extensively studied intervention. The evidence favouring other positive outcomes such as a decrement in symptoms, reduction of caregiver burden, improvements in caregiver-coping and cost-effectiveness was, however, either minimal or inconsistent.

A growing body of research evidence has confirmed the efficacy of family-interventions as adjuncts to antipsychotics for the treatment of schizophrenia. Much of the recent evidence for such interventions derives from Asian, principally Chinese, studies. These trials have shown that relatively simple forms of family-interventions have wide ranging benefits and can be implemented successfully in routine clinical settings. With the accumulation of this evidence in their favour, family-interventions for schizophrenia in Asia are poised to take the next critical step, that of wider implementation and improved accessibility for potential users. However, several issues merit consideration. Family-interventions need to be based on a culturally-informed theory, which incorporates cultural variables of relevance in these countries. While the ideal format for conducting family-interventions is still to be determined, it is quite evident that for such interventions to be useful they need to be simple, inexpensive, needs-based, and tailored to suit the socio-cultural realities of mental health systems in Asian countries. The evidence also suggests that delivery by non-specialist personnel is the best way to ensure that such services reach those who stand to benefit most from these treatments. However, there are several existing challenges to the process of dissemination of family-interventions. The major challenges include the achievement of a critical mass of trained professionals capable of delivering these interventions and finding innovative solutions to make family-interventions more acceptable to families.
Xia, Merinder, Belgamwar (2011) assessed the effects of psycho educational interventions compared with standard levels of knowledge provision involving a total of 5142 participants from 44 trials conducted between 1988 and 2009 (median study duration was 12 weeks). This review compares the efficacy of psycho education added to standard care as a means of helping severely mentally ill people with that of standard care alone. The evidence shows a significant reduction of relapse or readmission rates. The findings showed that psycho education has a positive effect on a person’s wellbeing and promotes better social function.

Chien and Norman (2009) assessed the effectiveness of mutual support groups for family caregivers of people with schizophrenia and other psychotic disorders. A systematic review of the research literature based on the procedures suggested by the National Health Service Centre for Reviews and Dissemination (2001) Report Number 4 in the UK [National Health Service Centre for Reviews and Dissemination, 2001. A combined free-text and thesaurus approach was used to search relevant research studies within electronic databases, including Medline, Embase, CINAHL, OVID full-text, PsycINFO, the Cochrane Library, the British Nursing Index, the NHS National Research register, and System for Info on Grey literature for the period 1980-2007. Reference lists of all retrieved literature were searched to identify studies that may have been missed. Twenty-five research studies were selected for inclusion in the analysis on the basis that they were either family led or professional-facilitated support group programmes for family caregivers of people with schizophrenia or other psychotic disorders. The review identified that most studies on this group programme used qualitative, exploratory cross-sectional surveys and quasi-experimental study designs (n=19); six were experimental studies or randomised controlled trials. There were only a few small-scale, single-centre controlled trials with the findings supporting the significant positive effects of mutual support groups on families' and patients' psychosocial well-being. A number of non-experimental studies conducted in Western countries reported benefits of group participation up to 1 year, such as increased knowledge about the illness, reduced burden and distress, and enhanced coping ability and social support. However, many of these studies lacked rigorous control and did not use standardised and valid instruments as outcome measures or schedule follow-up to examine the long-term effects of support groups on families and/or patients.
Glynn, Cohen, Dixon and Niv (2006) examined the potential impact of the recovery movement on family interventions for schizophrenia: opportunities and obstacles. The authors found that there were many types of family interventions have been found to be effective in reducing exacerbations in schizophrenia; some also improve consumer social functioning and reduce family burden. Regardless of their origins, these interventions share a number of common features, such as showing empathy for all participants, providing knowledge about the illness, assuming a non-pathologizing stance, and teaching communication and problem-solving skills. Importantly, these family interventions have many characteristics that are consistent with the growing recovery movement in mental health in that they are community-based, emphasize achieving personally relevant goals, work on instilling hope, and focus on improving natural supports. Nevertheless, these interventions are generally reflective of older models of serious and persisting psychiatric illnesses that are grounded in a "patient being treated for a chronic illness" rather than a "consumer assuming as much responsibility as possible for his/her recovery" stance. These interventions could be made more consistent with recovery principles by (1) expanding the definition of family to include marital, parenting, and sibling relationships, (2) identifying better ways to match consumers with treatments, (3) broadening the research focus to include systems change that promotes making family members a part of the treatment team (with the consumer's consent), and (4) overcoming implementation obstacles that preclude access to effective family interventions for most consumers and their relatives.

Wai-Tong Chien and Sally Chan (2004) in a One-Year Follow-up of a Multiple-Family-Group Intervention for Chinese Families of Patients with Schizophrenia, tested the effectiveness of a mutual support multiple-family-group intervention for schizophrenia in terms of improvements in patients' psychosocial functioning, use of mental health services, and rehospitalisation compared with a psycho education intervention and standard care. The controlled trial was conducted on a sample of 96 Chinese families caring for a relative with schizophrenia in Hong Kong. Families were randomly assigned to one of three groups: mutual support (N=32), psycho education (N=33), and standard care (N=31). The interventions were delivered at two psychiatric outpatient clinics over a six-month period. The mutual support and psycho education interventions consisted of 12 group sessions every two
weeks, each lasting about two hours. The mutual support group was a peer-led group designed to provide information, emotional support, and coping skills for care-giving in stages. The psycho education group was a professional-led group designed to educate families about the biological basis of schizophrenia and treatment and to improve illness management and coping skills. The standard care group and the other two groups received routine psychiatric outpatient care during the intervention. Data analyses of multiple outcomes over one-year follow-up were conducted on an intention-to-treat basis. The findings indicated that the Multivariate analyses of variance showed that the mutual support intervention was associated with consistently greater improvements in patients' functioning and re-hospitalization and stable use of mental health services over the follow-up period compared with the other two interventions. The study provides evidence that mutual support groups can be an effective family intervention for Chinese persons with mental illness in terms of improving patients' functioning and hospitalization without increasing their use of mental health services.

Magliano, Marasco, Fiorillo, Malangone, Guarneri and Maj (2002) explored (a) burden related to care giving and support received from professionals and social network in relatives of patients with schizophrenia in Northern, Central and Southern Italy; and (b) to test whether a higher level of family burden is associated with a lower level of professional and social network support. Seven hundred and nine patients with schizophrenia and their key-relatives were consecutively recruited in 30 Italian mental health departments. Data were collected on: (a) patients' clinical status and levels of disability; (b) relatives' burden, social and professional support; (c) interventions received by patients and their families. Family burden was found lower in Northern Italy. However, after controlling for psychosocial interventions, differences in family burden among the three geographical areas disappeared. Family burden was associated with patients' levels of disability and manic/hostility symptoms, and with professional and social network support received by the family.

Pitschel-Walz, Leucht, Bäuml, Kissling and Engel (2001) meta-analytically examined twenty-five intervention studies regarding the effect of Family Interventions on Relapse and Rehospitalisation in Schizophrenia and their inclusion in treatment. The studies investigated family intervention programs to educate relatives and help them cope better with the patient’s illness. The main study criterion
was the patient’s relapse rate, measured by a significant worsening of symptoms or rehospitalisation in the first years after hospitalization. The main result of the meta-analysis was relapse rate could be reduced by 20 percent if relatives of schizophrenia patients were included in the treatment. Family interventions that continued for longer than 3 months, was found to be more effective. The different types of comprehensive family interventions were found to have similar results. The bifocal approach, offering psychosocial support to relatives and schizophrenia patients in addition to medical treatment, was found to be superior to the medication-only standard treatment. The effects of family interventions and comprehensive patient interventions were comparable. However, combination did not yield significantly better results than did a treatment approach, which focused on either the patient or the family, indicating that psycho educational interventions are essential to schizophrenia treatment.

Bentsen (2003) investigated the efficacy of psycho educational family intervention by reducing stress levels in families in order to improve outcome, in Norway. Systematic reviews and search in databases (until February 2002, "Family" and "Schizophrenia") were used to find randomized controlled studies of effect. Seven studies of short-term family treatment were found, 15 studies of long-term treatment comparing it to individual therapy, and seven studies comparing family treatment modalities. Long-term family intervention reduces the risk of psychotic relapse to about the half within the first two years. These methods also shorten hospital stays, improve compliance with medication, patients' social functioning and relatives' well-being, and they seem to be cost-effective. Single and group family therapies including patients are equally efficacious. Relatives' groups do not seem to improve outcome. Several factors, such as expressed emotion and duration of illness, modify the effects and should be taken into account.

Bustillo, Lauriello, William, Horan and Keith (2001) sought to update the randomized controlled trial literature of psychosocial treatments for schizophrenia. Computerized literature searches were conducted to identify randomized controlled trials of various psychosocial interventions, with emphasis on studies published since a previous review of psychosocial treatments for schizophrenia in 1996. Family therapy and assertive community treatment were found to have clear effects on the prevention of psychotic relapse and rehospitalisation. However, these treatments had
no consistent effects on other outcome measures (e.g., pervasive positive and negative symptoms, overall social functioning and ability to obtain competitive employment). Social skills training improves social skills but has no clear effects on relapse prevention, psychopathology, or employment status. Supportive employment programs that use the place-and-train vocational model have important effects on obtaining competitive employment. Some studies have shown improvements in delusions and hallucinations following cognitive behavior therapy. Preliminary research indicates that personal therapy may improve social functioning. The authors were of the view that relatively simple, long-term psycho educational family therapy should be available to the majority of persons suffering from schizophrenia. Assertive community training programs ought to be offered to patients with frequent relapses and hospitalizations, especially if they have limited family support. Patients with schizophrenia can clearly improve their social competence with social skills training, which may translate into a more adaptive functioning in the community. For patients interested in working, rapid placement with ongoing support offers the best opportunity for maintaining a regular job in the community. Cognitive behavior therapy may benefit the large number of patients who continue to experience disabling psychotic symptoms despite optimal pharmacological treatment.

Amenson and Liberman (2001) studied the effect of Dissemination of educational classes for families of adults with schizophrenia. They noted that despite the well-documented efficacy of psycho educational and behavioural approaches in family interventions for persons with serious mental illness (1) clinicians have rarely included these methods in their professional repertoires (2) Journal publications, books, continuing education courses, and advocacy by the National Alliance for the Mentally Ill and its local affiliates had induced few professionals to provide family psycho education. Mental health professionals adopted new services, because the authority structure and contingencies of reinforcement that impinged on their daily activities are altered in a direction favouring change. Therefore, administrative influence must be brought to bear to mandate the inclusion of family psycho-education in the spectrum of services provided by a clinic, mental health centre, community support program, hospital, or independent provider (3). The consequences of clinicians' services must differentially reward the use of these methods of involving families in services for the seriously mentally ill (4). Differential rewards
could come from performance standards and evaluations, performance-based pay, third-party payments, positive feedback from clients and families, public recognition, and increased self-efficacy. Use of in-service training or workshops to persuade clinicians to adopt innovations such as family psycho education and family management techniques has a chequered and unremarkable track record. For example, brief training has failed completely in efforts to bring about adoption of family interventions. On the other hand, more extended efforts to train staff, including organizational consultation, have been more successful (5). In one study, two days of staff training produced no change, whereas intensive training over several months resulted in the implementation of new family programs at the majority of study sites (6). Staff who had received extensive training but did not adopt the interventions rated family interventions as less consistent with their professional philosophy and agency norms and identified more obstacles to intervention, notably intense work pressure, uncertainty about financing the intervention, agency bureaucracy, lack of leadership, scepticism about the interventions, problems with confidentiality, and inability to provide services in the evenings or on weekends (7).

Dixon (1999) identified critical issues and challenges in the provision of services to families of persons with schizophrenia and other serious and persistent mental illnesses, from both a literature review and a summary of pertinent data from the Schizophrenia Patient Outcomes Research Team (PORT). The recommendations specify that families should be given education and support. One of the PORT treatment recommendations states that "Patients who have on-going contact with their families should be offered a family psychosocial intervention which spans at least nine months and which provides combinations of: Education about the illness; Family support; Crisis intervention; and, Problem solving skills training". The PORT treatment recommendations are based on well designed and rigorous research on family psycho education programs that demonstrate reduced relapse rates and improved patient and family well-being for persons whose families receive psycho education. While family psycho education programs have been the subject of extensive treatment trials, family members and family organizations have endorsed a variety of other models of services such as family education and consultation models. These models have not been as rigorously researched as family psycho education. Control groups are generally lacking. No consistent findings have been reported,
although isolated studies have found increased knowledge, self-efficacy and greater satisfaction with treatment among families who have participated in family education programs. Remarkably little is known about the extent to which families actually receive appropriate services. However, PORT data from administrative claims and client interviews suggest that family services are minimal. Further, previous research has consistently revealed that families have high levels of dissatisfaction with mental health services.

Penn and Mueser (1996) reviewed controlled treatment outcome research evidence supporting psychosocial treatment for schizophrenia, by summarizing literature on social skills training, family interventions, cognitive rehabilitation and coping with residual positive symptoms. Different models of family therapy were contrasted and current literature on cognitive rehabilitation and coping with residual positive symptoms were examined. Social skills training was found to produce improvement on specific behavioural measures, although changes in symptoms and community functioning were less pronounced. Family interventions (i.e., family psychoeducation and behavioural family therapy) are highly effective for reducing families' expressed emotion and improving patients' relapse rates and outcomes. Furthermore, family interventions are also associated with reduced family burden. Cognitive rehabilitation and training in coping with positive symptoms appear to be promising interventions, but more controlled, group trials are needed before definite conclusions can be drawn. The efficacy of a variety of different family intervention models, as well as social skills training, is supported by a large body of research. Future work needs to address improving delivery of existing psychosocial interventions, integrating these interventions with other psychosocial approaches (e.g., vocational rehabilitation and case management), identifying which patients will benefit from which treatments, isolating the "active" ingredients of family interventions (i.e., psycho education versus behavioural intervention), and identifying the amount of treatment (e.g., number of sessions) needed before treatment response is expected.

INDIAN STUDIES ON FAMILY INTERVENTION PROGRAMMES

Family Intervention Programme for the chronic mentally ill in India have to be culturally sensitive and flexible (Kapur, 1982). Most Western approaches are labour intensive as well as time consuming, and present practical difficulties in the
Indian context, due to lack of trained personnel. Shankar (2002) recommended that certain issues be incorporated when designing intervention Programme for family. These include providing information that is compatible with the educational background of the caregiver, enhancement of medication compliance, helping caregivers identify practical strategies to normalize the patients functioning, developing realistic expectations regarding outcome of the illness and improving wage-earning skills through income generation strategies.

One of the first community studies in a developing country was carried out at Chandigarh, India, under the leadership of N. Wig. This study focussed on 'attempts to meet the needs of a group of chronic schizophrenics in the community. The setting was the Modocate Clinic and the team consisted of a psychiatric nurse, one psychiatric social worker, and two psychiatrists. In this study, 30 of the persons suffering from chronic schizophrenia attending the special clinic were evaluated in detail for their symptoms and social functioning. Further efforts were made to provide required help to the ill individuals and the families. Interventions consisted of regular home visits, family counselling, marital counselling, contact with social welfare agencies and providing an understanding about the illness. All the families were visited at home periodically. These home visits became a source of support to the family. The visits were utilised to share the caring skills with the family members.

**Indian Studies**

Rukadikar and Rukadikar (1976) started a weekly group meeting for relatives of patients at the Wanless Hospital, conducted by a psychiatric social worker. The main aim of the meetings were to dispel misconceptions and superstitions about mental illness, to clarify doubts of relatives, to demystify mental disorders and to reduce the stigma attached to mental disorders and their treatment. Findings revealed that lack of information regarding the illness was a barrier in their helping the patient to get well, confusion regarding their role in the treatment programme and doubts, misconceptions and superstitions about mental illness were very common even among the educated people.

Suman, Baldev, Murthy and Wig (1980) studied 30 patients with chronic schizophrenia and their families were evaluated. The intervention consisted of home visits, family counselling, marital counselling, contact with social welfare agencies
and education about the illness. Caregivers demonstrated enhanced understanding of the patient and illness and more regularity in follow up.

Pai and Kapur (1982; 1983) compared two groups of 27 patients each, who were undergoing two treatment modalities (hospital admission and home treatment by a psychiatric nurse) were compared on outcomes of symptoms, social dysfunction and burden. Results indicated that the group who received home treatment had a better outcome at the end of six months in terms of improvement of symptoms, better social functioning and reduced burden. Pai, Kapur and Roberts (1983) carried out a follow up study of this group. It was observed that the group who received home treatment continued to have better clinical status, though the difference between the two groups in terms of social functioning and burden was no longer present.

Verghese (1988) reported that family participation in all aspects of the treatment led to an improvement in attitudes towards the mentally ill family member.

Shankar and Kamath (1991) elicited the needs of 40 primary caregivers who sought the services of an urban rehabilitation centre. They found that the families showed little interest in seeking information about the illness, but were willing to listen to advice that would be beneficial to the patient. Of these families only 30% wanted emotional support from mental health professionals. The majority chose to discuss problems with other family members and friends and received adequate support from these sources. Shankar and Kamat (1991)

Sovani (1993) conducted a one-day psycho education programme for 49 caregivers of persons with schizophrenia. All caregivers were from an urban background. The topics covered were information on schizophrenia, nature of the illness, relapse and management of illness. Delivery of intervention was by trained mental health professionals. The duration of illness in the patients ranged from three to 5 years. Of the caregivers who attended, 75% reported that they benefited from the programme.

Chandra, Verghese, Anantharaman and Channabasavanna (1994) conducted a longitudinal study of 30 families of patients with chronic schizophrenia, referred over a 3-year period. The duration of the illness in patients was greater than 2 years. Psycho-education alone failed to decrease distress. Depression was reported by 20% of family members and 50% reported adjustment problems. A high level of
communication deviance and problems with affective expression were found. The authors recommend the need to go beyond psycho education for such families and the use of other intervention strategies to cater to specific needs of caregivers.

Sarkar, Nagpal, Apte and Anand (1997) examined therapeutic processes in a group intervention format for families of persons with schizophrenia. They conducted 12 group sessions for 8 – 10 families. They used a focus group interview technique to find out areas of distress. They found that the therapeutic processes deemed helpful were intra-group interaction, sharing of emotions and psycho education about the illness.

Prafulla, Murthy, Ramaprasad (2010). Assessed Family Burden and Rehabilitation Need of beneficiaries of a Rural Mental health camp in south India. Assessing the rehabilitation needs and the burden of care faced by the families is an important component constituent of planning effective mental health services. Using the Interview Schedule for the Assessment of Family Burden and Rehabilitation Needs Assessment Schedule, 50 care givers were interviewed. The results indicated mild to moderate objective burden experienced by the families. All respondents had some need or the other pertaining to the rehabilitation of the ill family member.

Ismail Shihabuddeen and Gopinath, (2005) assessed the perceived benefits and difficulties of group meetings among caregivers of persons with schizophrenia and bipolar mood disorders, and to evaluate the utilization pattern of general hospital psychiatric unit (GHPU) services by caregivers who regularly attend such group meetings. Conducting regular group meetings for a homogeneous population at a GHPU is feasible and beneficial.

Pillai, Sahu, Matthew, Hazra, Chandran & Ram (2010) studied the rehabilitation needs of persons with major mental illness in India. Mental health care services are shifting its focus from inpatient to community care. Community based psychosocial rehabilitation programmes are widely advocated to provide comprehensive care to persons with mental illness. Psychosocial interventions suiting the needs of persons with mental illness would be more viable and sustainable in terms of recovery and socio-occupational functioning and integration in the community. This outpatient based study conducted in the North-East Region of India,
at Central Institute of Psychiatry, Ranchi attempted to assess and compare the subjective rehabilitation needs of persons with Schizophrenia and Bipolar Affective Disorders. 120 persons with Schizophrenia and Bipolar Affective Disorders (60 from each category) were sampled and studied using Rehabilitation Needs Assessment Schedule (Nagaswami et al., 1985). Results indicate that both the studied groups exhibited multiple needs, thereby emphasizing the role of multifaceted, comprehensive after-care packages, involving concerted efforts of several mental health facilities.

Hegde, Rao and Raguram (2007) aimed to develop a treatment program for schizophrenia, which integrated cognitive retraining with family intervention, and to test its clinical effectiveness. The sample consisted of three outpatients diagnosed as having schizophrenia and their caregivers. Cognitive retraining for the patients targeted the functions of attention, information processing, executive functions, learning & memory, comprehension & production of emotions. Family intervention consisted of psycho education, improving communication and problem-solving skills, lowering expressed emotions and modifying expectations. The treatment lasted 6 weeks, with cognitive retraining being given every day and family intervention in bi-weekly sessions. The patients were evaluated on a battery of neuropsychology tests and Global Assessment of functioning scale and the caregivers on the General Health Questionnaire, and Burden Assessment schedule at pre intervention, post intervention and at two-month follow-up. Following intervention the cognitive and global functioning of the patients improved. The psychological distress and subjective burden of the caregivers decreased. Two patients sustained the gains on neuropsychological functions and global functioning at the follow up. At the end of three months all the three patients were in fulltime gainful employment. The integrated psychological intervention has shown promise and merits further evaluation of its efficacy.

Stanley & Shwetha, (2006) compared a pre and post intervention analysis to determine the extent of change in psychiatric symptomatology in schizophrenic patients attending a community based rehabilitation programme and the family burden and perceived quality of life of their caregivers. An integrated intervention package comprising of pharmacotherapy, psychosocial therapies and spiritual therapy was provided to the patients and their caregivers. Instruments to assess the psychiatric
status of the patients as well as family burden and quality of life of their caregivers were administered. Results indicated significant reduction in patient symptomatology as well as caregiver burden and enhanced QOL of the caregivers following intervention. A significant negative correlation between the family burden and QOL scores of the caregivers was obtained. It is suggested on the basis of this study that spiritual therapy specific to the religious orientation of patients combined with pharmacotherapy and other psychosocial therapies may enhance the effectiveness of intervention in schizophrenia.

Despite the strong evidence for the efficacy of family-interventions for schizophrenia, the implementation and dissemination of these treatments has been hindered by complex organisational and attitudinal difficulties, even in countries with well-developed mental health services (Barrowclough, 2003; Murray & Dixon, 2004). Therefore, this is expected to be an even greater challenge in Asian countries, with their resource limitations and a variety of other social, economic and cultural problems (de Jesus, Razzouk, Thara, Eaton, Thornicroft, 2009). However, some encouragement can be derived from the fact that many of the Asian trials have been carried out in clinical environments more representative of usual care, both in urban and rural areas (Yip, 2005). Moreover, they have employed relatively simple formats of family-interventions, have often relied on non-specialist professionals for service-delivery and have turned out to be cost-effective in many instances (Kulhara, Chakrabarti, Avasthi, Sharma, Sharma, 2009). Some studies have used structured assessments of burden, while others have relied on a more descriptive and narrative approach. A combination of both methods would be more useful in providing accurate and in depth information on degree of burden and also which aspects of care giving are most burdensome for the caregiver. Majority of the studies on burden have used the Family Burden Schedule (Pai and Kapur, 1981) to assess burden. However, there has been a recent shift to the use of other instruments, such as the Burden Assessment Schedule which assess both objective and subjective burden in greater detail.